Chapter One – Introduction

Introduction

A person born with an intellectual disability eighty years ago in the United States of America (USA) would not be expected to live past their second decade (Carter & Jancar, 1983). However, in developed countries all around the world, people with intellectual disabilities are now living longer than at any time in recorded history (Bigby et al, 2008; Bittles et al, 2002; Buys et al, 2008; Hogg, Moss & Cooke, 1988; Patja et al, 2000; Yang, Rasmussen & Friedman, 2002). While this improvement is a very desirable outcome, it is resulting in a new crisis within disability support organisations and the wider community that remains unresolved: How are a substantial number of people with an intellectual disability going to be supported as they start experiencing age-related problems?

This chapter is designed to introduce the reader to the current study of direct care support workers and their needs as they support people with an intellectual disability through the varying stages of the ageing process. The chapter provides a brief background and overview of the need for the current research. The theoretical framework underpinning the project is described. The significance of the present study to the quality of service provided to individuals with an intellectual disability, the training of the staff who assist this group of people, and the government policy and practice of the disability and aged care sectors is critiqued. The methodology that the study used is presented, and a key assumption underpinning the research is identified and discussed. The key terms are defined and the organisation of various chapters of the thesis is outlined.

1.1 Background to the Study

In recent years, a combination of factors including improved care, new technologies and the recognition of the right for people with a disability to receive appropriate medical attention and personal care has seen the life expectancy of a person with an intellectual disability increase dramatically (Haveman et al, 2009; Jenkins, 2005a, 2005b; World Health Organization, 2000). The expansion of neonatal knowledge and care has resulted in many individuals surviving childhood illness and disease that would have proven fatal in previous generations (Ory, Abeles & Lipman, 1992). The combination of improved medical diagnosis and care management has now resulted in a situation where individuals are able to live into adulthood and beyond, even with severe disabilities (Crewe, 1990).

The progress in health and allied care meant that by 1993 a person with a mild intellectual disability in the USA had a life expectancy of seventy years (Strauss & Eyman, 1996). Another American study estimated the difference in lifespan between the standard population and a person with a mild intellectual disability to be only 2 percent (Janicki et al, 1999). If people who have a specific genetic disability, such as Down Syndrome, as well as those individuals with complex and severe associated disabilities, are removed from the total figures, the life expectancy of an Australian with an intellectual disability now approximates that of the mainstream (Australian Institute of Health and Welfare, 2000).

For people with Down Syndrome, the increase in life expectancy in the past one hundred years has been remarkable. Both Australian and overseas studies have shown that, at the start of the 20th Century, a person with Down Syndrome had a life expectancy of approximately ten years. By the 21st Century, it had increased to nearly sixty (Carmeli et al, 2004; Glasson et al, 2002). While the increasing life expectancy of people with intellectual disabilities has been recognised within the research literature over the past decade, a significant problem is emerging in delivery of services to this cohort of people.

A general report on disability services across Australia commissioned by the Commonwealth of Australia (2009b, p. 4) described the disability system as "broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need". When a specific focus is placed upon the emerging issue of ageing and intellectual disability, it is apparent that government departments responsible either directly for the provision of ageing and disability services, or indirectly through allocating funding of other organisations to provide these support programs have not successfully developed comprehensive policies and work procedures. Likewise, relevant models of practice have not been consistently or widely implemented across Australia (Bigby, 2008a; Kunkel & Applebaum, 1992).

While issues associated with ageing and intellectual disability have been clearly identified since the 1990s, the current population of Australian people with intellectual disabilities is the first that has lived in large numbers into chronological old age and can now reasonably expect to outlive their parents (Buys et al, 2008). The importance of this issue has also only recently been formally recognised on the international front with the 2006 Graz Declaration on Disability and Ageing. This document, which was originally commissioned by the Austrian European Union Presidency, was designed to provide a focus and emphasis upon the needs of older people with disabilities (Weber & Wolfmayr, 2006).

The provision of many disability services in Australia occurs through funding by the various state governments to provide a variety of accommodation and day support programs for people with intellectual disabilities (e.g. Department of Ageing, Disability and Home Care, 2008a). However, the changing needs and requirements associated with ageing are currently not appropriately recognised within these funding frameworks (Bigby, 2008a). A major problem facing many disability service providers relates to the fact that there is no state government mechanism to ensure additional funding to support people with an intellectual disability as they grow older. A person with a mild intellectual disability may have only required occasional support to retain his/her independence within the local community and, as such, will have only received a minimal level of funding. However, as they get older and their support needs increase, there is no easy process for these changing needs to be funded appropriately (NSW Ombudsman, 2009).

Many community based supported accommodation services established within the 1980s and 1990s were setup under a ‘block’ funding model. This system was one in which the accommodation provider was granted a sum of money designated to serve a set number of residents (Edmundson et al, 2005). This system is in contrast to the predominant current delivery structure in which money is allocated to an individual rather than an organisation. The issue facing many providers now is that the block funding money, which was determined on the basis of a person's individual need decades ago, is now inadequate to meet the changing requirements of these ageing residents. While the grant may have received an annual indexation, this figure has not corresponded to the Consumer Price Index (CPI) and there is currently no facility to increase the base block funding amount to cope with the needs of individuals as they age.

Within Australia there are no consistently applied inter-governmental policy guidelines, either internally within the states' varying departments or externally between the state and federal levels, specifically for people with an intellectual disability who are ageing (Bigby & Pierce, 2008). The consequence of this policy void is that many services that support people with intellectual disabilities have been forced to individually determine the best methods to resolve the problem (Courtenay, Jokinen & Strydom, 2010). This situation has led to a wide range of different approaches to address the issue and considerable gaps within the support framework.

1.2 Research Aims and Objectives

Demographic research, such as the 2003 *Survey of Disability, Ageing and Carers,* indicates that the rates of disability are not evenly distributed across Australia. Rural and remote areas, including the Western and North Coast regions of New South Wales (NSW), are reported as having a higher prevalence of disability than metropolitan locations (Australian Bureau of Statistics, 2003). Recent studies, such as that by Dowse, McDermott and Watson (2009), have noted concerns that rural people ageing with a disability may experience problems not similarly evident in their metropolitan counterparts.

The research goal of the current project is to examine the issues and impact of ageing upon the provision of intellectual disability services within regional and remote areas of NSW. The aim is to investigate and determine the emerging issues in individuals with an intellectual disability who are ageing. There were four specific objectives that underpinned this research aim:

- to examine the current models of service available for people with intellectual disabilities as they age,
- to identify the major issues that direct care staff believe impact most upon their capacity to provide appropriate support to the target group,
- to identify areas within the existing disability training and professional support framework which do not currently provide direct care staff with the necessary skills and knowledge to assist people with disabilities as they age, and
- to recommend specific solutions that can be implemented across rural and remote NSW to address the issue of appropriately supporting people with an intellectual disability who are ageing.

1.3 Theoretical Framework for the Current Study

There are a variety of different theoretical perspectives for considering the concept of health in general and, more specifically, the issue of disability. Historically, there has been a strong focus upon medical models and individual rehabilitation in mainstream society; however, the past three decades have seen the proposal of an increasing number of social models of disability (Putnam, 2002). Disability can be defined within a variety of potentially disparate contexts including public health, economics, politics, history and feminism. The newer social models facilitate a greater examination of environmental, community and cultural aspects to disability than the previous medically orientated frameworks.

The past hundred years have seen a major shift in thinking with respect to the perception of disability. It has been previously argued that the presence of an intellectual disability denies the individual ‘personhood’ as a result of a perceived inability for self-awareness. This premise was the basis of many now condemned practices such as widespread compulsory sterilisation and even euthanasia (Hogg, 2007). Through much of the past century, the dominant conceptualisation of disability saw it related to a model of deficit. This approach has been challenged by the alternate view that it is instead a reflection of human diversity (Gilson & DePoy, 2002).

This movement away from a purely medical model is reflected in changes to the research focus of the disability sector. From 1970 to 1972, 42 percent of the papers featured in the *Journal of Intellectual and Developmental Disability* had a medical focus. By the 1990s, this figure had dropped to just 7 percent of articles being framed within the medical model (Foreman, 1997). The World Health Organization (WHO) had initially defined health in 1948 as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 2003, p. 1). This definition effectively categorised the presence of a disability as inferring the point when health ceased. WHO re-conceptualised its definition of health in 2001 to incorporate both medical and social aspects (VanLeit, 2008). These changes in perception were associated with the possible application of a number of different theoretical models and frameworks, ranging from diagnostic medical perspectives through to a social constructionist perspective (Stiker, 1999).

The diagnostic medical approach to disability was based upon the premise of an underpinning medical problem within the individual. It had an internal focus, with the belief that the person with a disability was in some way defective when compared to wider societal norms. This deficit or problem could then be addressed through medical diagnosis and subsequent intervention (Gilson & DePoy, 2002). This framework is predominantly derived from the work of Parsons (1964), who argued that an illness provided the individual with an opportunity to ignore or discard the normal socially enforced beliefs of the society. However, with this reduced expectation was an associated insistence upon compliance with curative medical interventions (Parsons, 1964). People with an intellectual disability would appear to present a significant problem to this paradigm, as the likelihood of medicine providing a cure for their lifelong problems was minimal. It was argued that the diagnostic medical framework was applicable to individuals suffering from a temporary or acute episode of illness, but not necessarily appropriate to people who were elderly or who had a permanent disability (Cheek et al, 1996).

In contrast to the diagnostic medical approach, the social constructionist approach to disability accepted and acknowledged that the individual may have differences in his/her functioning, but that these issues were not necessarily in need of permanent medical remediation (Shakespeare & Watson, 1997). Instead, the effect of the disability was magnified by societal devaluation as well as external factors including a lack of appropriate communication tools, physical aids or modified environments. The social constructionist approach identified the disability as an issue associated with both internal and external forces rather than purely in terms of an individual functional deficit. Social models of disability facilitated a capacity to examine the roles that wider environmental factors such as personal networks, the workplace, community integration, religion and cultural beliefs, could play in the life experience of a person with a disability (Fougeyrollas & Beauregard, 2001).

One of the key components of social models of disability relates to the distinction between an impairment and a disability (Walker, 1993). An impairment was seen as an integral component or permanent attribute of the individual, a definition similar to that inherent to the diagnostic-medical model. A disability, however, was viewed within the context of the immediate situation rather than being continuous and unchanging (Hughes & Paterson, 1997). A person was considered to experience the disability rather than being the disability (Putnam, 2002). For example, an individual is not autistic, rather s/he is a person who lives with and experiences autism in a variety of settings and environments. Rather than being conceptualised purely as a deficit, autism can be seen instead as a difference in perception (Brownlow, 2010).

Two of the key social role perspectives of disability have been normalization, as championed by Nirje (1969), and Wolfensberger's 1983 theory of Social Role Valorization[2]. Both frameworks were based around the premise of people with disabilities having the right and opportunity to experience a quality of life similar to that of any other member of their community and to be valued for their participation. However, while Social Role Valorization was originally based upon the principles of normalization, a number of distinctions between the two models have developed over time.

Normalization was originally developed in the Scandinavian countries of Sweden and Denmark during the 1940s and 1950s. In 1943, the Swedish Government appointed a committee to evaluate and consider support options for people who were considered 'partially able-bodied'. The committee developed a series of recommendations and policies regarding service provision, and coined the term 'normalization principle' to describe their philosophy in supporting people to achieve a higher quality of life (Ericsson, 1985). Denmark underwent a similar review of the rights of people with intellectual disabilities and on 5 June 1959 its Government passed *Danish Act No. 192*. This Act was designed to provide people with disabilities with the opportunity for equality in living standards, with its introductory paragraph specifically stating that people with disabilities should be able to experience a life that was "as near to a normal life as possible" (Ericsson, 1985, p. 3).

The primary goal of normalization was for all people with disabilities to both expect and receive the same rights, entitlements and opportunities as any other individual in their local community. The concept of normalization was defined as

> making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (Nirje, 1969, p. 19)

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[2] While English (Australian) spelling has been used throughout this thesis, specific terms or phrases such as 'normalization' and 'social role valorization' have been maintained in their original English (US) format.

What was particularly innovative about this definition and the way the Scandinavian countries considered the provision of programs was recognition of the need for a long-term approach to support people with disabilities, rather than simply trying to apply a short term treatment regime to 'fix' the problem.

Nirje, the ombudsman of the Swedish Association for Retarded Children, promoted the ideas of normalization at many conferences across Europe. He also contributed two papers on the philosophy of normalization to the 1969 *United States President's Committee on Mental Retardation*. The collection of papers from this Committee was edited by Kugel and Wolfensberger (Nirje, 1992). The impact of Nirje's thinking was demonstrated in Wolfensberger's description of normalization as the

> use of culturally normative means (familiar, valued techniques, tools, methods), in order to enable a person's life conditions (income, housing, health services, etc.) which are at least as good as that of average citizens, and to as much as possible enhance or support their behaviour (skills, competencies, etc.) appearances (clothes, grooming, etc.) experiences (adjustment, feelings, etc.) and status and reputation (labels, attitudes of others, etc.). (Wolfensberger, 1980, p. 80)

After initially advocating this concept within the USA, Wolfensberger developed his own theory based around the principles of normalization, which he termed Social Role Valorization. Wolfensberger (1983, p. 234) presented Social Role Valorization as a scientific theory that was "universal, parsimonious and congruent with social and behavioral sciences". Wolfensberger saw the primary objective of Social Role Valorization being to help establish and support people with disabilities to obtain and maintain socially valued roles within their local community. He believed that, if a person was perceived to have a valued social role, then that person was more likely to be able to access pleasurable or rewarding objects or life experiences that were available within their society, or at least be presented with opportunities for obtaining these socially desirable things (Wolfensberger, 1983). Social Role Valorization proposed that people with disabilities were devalued members of the society and that this negative perception by the wider society was associated with victimisation and loss of control (Wolfensberger, 2000). In order to overcome their devalued status, Social Role Valorization attempted to increase the perceived value of people with disabilities through both image enhancement and skill development (Wolfensberger, 1983).

Perrin and Nirje (1985) were particularly critical of Social Role Valorization in relation to the freedom of choice for the person with a disability. One of their main problems with Social Role Valorization was that it imposed societal beliefs upon people and, in order to attain valued social roles, the individual choice of the person could be over-ridden. What was particularly concerning was the possibility that force may be used, if necessary, when the choice of the individual conflicted with the perceived normalised behaviour. Perrin and Nirje's argument is exemplified by the scenario described by Bigby et al (2009), in which staff were more concerned about ensuring that the physical presentation of a client met community expectation instead of facilitating the individual's right to make personal decisions about his/her daily life. It was argued that Social Role Valorization was too preoccupied with appearance and perceptions rather than the normalization goal of assisting the individual with the disability to make meaningful choices about how s/he lived as part of society (Perrin & Nirje, 1985).

In a critique of Social Role Valorization, an example was cited in which a black woman in North America complained about Wolfensberger's concepts in a workshop by saying "You aren't talking about normalization; you are talking about making people into upper middle class whites" (Perrin & Nirje, 1985, p. 72). As with Sigmund Freud, whose theories of psychoanalysis were open to criticism due to their basis and bias towards a certain class of society (Sandler et al, 1997), Nirje proposed that Wolfensberger had focussed his theories predominantly around limited sections of society rather than attempting to encompass more diverse aspects of the wider community.

Regardless of the criticisms of their respective theories, both Nirje and Wolfensberger have made considerable contributions to the field of disability. The normalization principles and their focus upon human rights of people with an intellectual disability underpin current Australian government legislations that mandate support for individuals to live, integrate and participate in their local community. Wolfensberger's adaptation of normalization proposed the concept of valued status for people with disabilities and provided a framework for service providers to implement normalization principles. The ongoing effect of the work of Nirje and Wolfensberger in relation to both normalization and Social Role Valorization is evident within the current 1993 *NSW Disability Services Act* (DSA) and its accompanying ten *NSW Disability Services Standards*.

This influence can be seen in Standard 5, titled *Participation and Integration*, which states that "Each person with a disability is supported and encouraged to participate and be involved in the life of the community" (Department of Ageing, Disability and Home Care, 2008c, p. 1). Also Standard 6, entitled *Valued Status*, requires all service providers to ensure that

> each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community. (Department of Ageing, Disability and Home Care, 2008c, p. 1)

The theoretical frameworks developed by Nirje and Wolfensberger provided the philosophical underpinnings of these two standards in particular and their work continues to influence and direct the policies and practices of disabilities services across NSW.

The current study is conceptualised generally within a Normalization/Social Role Valorization model of the larger social constructionist theoretical framework. The goal of the study is to examine the impact of ageing and intellectual disability and how the wider provision of services by support staff can address underpinning social disadvantage or discrimination. It is perceived that staff perspectives of how ageing issues affect daily life are most appropriately considered with respect to the individual, as well as the wider societal impacts upon the person with the disability. In particular, the research is designed to review and consider both the internal and external factors of ageing that impact upon people with intellectual disabilities. It also examines how these issues affect quality of life and whether changes to policy and practice in service delivery can achieve a better outcome for the individual. The study also examines how training for staff can be modified to better support people with intellectual disabilities as they age. A Normalization/Social Role Valorization model provides the most appropriate theoretical framework for such an inquiry.

1.4 Significance of the Research

People with an intellectual disability in Australia are likely to live longer than ever before and, as a group, begin to experience issues associated with ageing that previous cohorts have not encountered (Bigby, 2004). This emerging phenomenon presents a considerable problem for both carers and service providers as they have not historically had to deal with the concurrent issues of ageing and intellectual disability. The significance of the present study lies in establishing the issues as perceived by the staff who provide daily support for this group of people. There has been no widespread in-depth research conducted in either metropolitan or rural New South Wales (NSW) that specifically asked direct care support staff for their perceptions and thoughts on how ageing affects the daily life of a person with an intellectual disability. The investigation ranged from the identification of specific issues and problems to recommendations for appropriate training programs and changes to service delivery options.

A widespread absence of input from community services staff with respect to the content of their training and professional development programs has been identified by McAllan et al (2005). Other overseas studies have shown that training programs developed without input from disability workers will not achieve the desired goals (Oliver & Head, 1990; Whitworth, Harris & Jones, 1999). There is potential for any specific education and organisational model recommendations derived from the current study to improve the quality of service provided to people with intellectual disabilities as they age. In particular, the present research is relevant and applicable to rural settings, where access to both other community services sector providers and specialist training organisations have additional complexities to those experienced in an urban context.

1.5 Methodology

A three round Delphi model was utilised to establish a consensus between direct care staff across rural and regional New South Wales (NSW) regarding their perceptions and beliefs of the major issues facing people with intellectual disabilities as they age. A Delphi model was appropriate for this type of inquiry as it is a method of data collection which can determine group consensus on a given issue (Rudolph et al, 2009). It is also a useful fit because a wide range of variables can be investigated with an optimal use of time and resources (Sandrey & Bulger, 2008). A comprehensive justification for the methodology is presented in *Chapter Three - Methodology*.

1.6 The Research Setting

New South Wales (NSW) is the most populous state in Australia. It is located on the south-east side of the Australian continent, bounded by the Pacific Ocean to the east, South Australia to the west, Queensland to the north, and Victoria to the south. In terms of geographic area, it is the fourth largest of the Australian states and has an approximate area of 809 400 square kilometres (GeoScience Australia, 2008a). The capital city of NSW is Sydney, which is also the largest city in Australia.

The following map, shown in Figure 1, is a pictorial representation of the landmass of NSW, with some key towns marked.

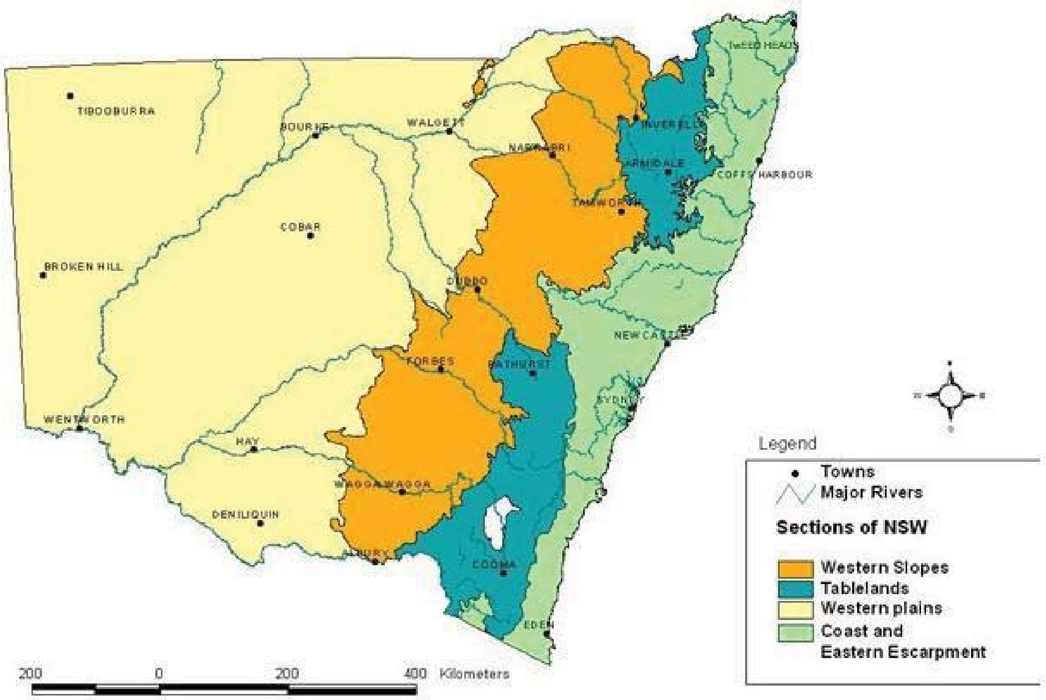

Figure 1 – Map of NSW

(Source: Department of Environment, Climate Change and Water, 2009).

NSW can be informally divided into four main geographic regions. The coastal and eastern escarpment areas of the state range from Tweed Heads on the Queensland border to Eden near the Victorian boarder. The NSW coastline is approximately 2140 kms in length, with a number of inlets, bays and natural harbours (GeoScience Australia, 2008b). The coastal region is considered to include hinterland areas between the coastline and the Great Dividing Range of mountains. Sydney, along with the state's other main metropolitan areas of Newcastle, Wollongong and Gosford, is located in the coastal area. The coastal region can be further delineated into the North Coast, which is generally considered to be areas to the north of Newcastle; the Central Coast, which covers from Newcastle to Sydney; and the South Coast, which extends from south of Sydney to the Victorian border (Australian National Resources Atlas, 2008).

The second main geographic area, the Tablelands, is defined by the Great Dividing Range of mountains and consists of a series of plateaus running from north to south. These Tablelands, divided into the Northern, Central and Southern Tablelands, separate the river systems of NSW, with coastal rivers running to the east to the Pacific Ocean and the inland rivers flowing west to South Australia. The largest mountain in Australia, Mount Kosciusko, is 2 228 metres high and located within the Snowy Mountains region of the Southern Tablelands (Australian National Resources Atlas, 2008).

The Western Slopes form the third main geographic region of NSW. These areas are located to the west of the Tablelands and are predominantly farming and grazing lands with fertile plains surrounding the inland river systems (Australian National Resources Atlas, 2008). Both the Tablelands and the Western Slopes have reasonably high annual rainfall which has resulted in an economic model based primarily upon agriculture, although there is also mining activity for precious metals including gold (Department of Environment, Climate Change and Water, 2008a).

The final geographic area of the state is the Western Plains, which comprises almost two thirds of the total NSW land area (Australian National Resources Atlas, 2008). A combination of poor rainfall, limited harvestable water from rivers and naturally high day-time temperatures means that there is minimal agriculture in the Western Plains. However, there are some successful farming and grazing enterprises with the economy also supplemented by mining operations (Department of Environment, Climate Change and Water, 2008b).

A longstanding lack of rainfall in the first decade of the 21st Century has seen the majority of NSW officially classified as being under drought conditions at various periods. In May 2008, the commencement point for the data capture stage of the study, 48.4 percent of NSW was officially in drought, with a further 23.6 percent of NSW deemed to only have marginal rainfall. During the 12 months of research, the parts of the state affected by drought increased further and had reached a total of 69.2 percent by October 2008. By December 2009, 80.8 percent of the NSW landmass was considered to be in drought, with another 14.8 percent of the state considered marginal. Only 4.4 percent of NSW was classed as having satisfactory rainfall at that time (Department of Primary Industries, 2009). While the detrimental effects of drought upon the economy and environment of Australian rural communities are well established (Horridge, Madden & Wittwer, 2005), there are also considerable social impacts in small communities across regional NSW that include increased health care needs, reduced access to services and familial breakdown (Alston & Kent, 2004).

There are a variety of different systems within Australia that attempt to classify geographic areas based upon their relative population densities and other demographic features. The Australian Government's Rural, Remote and Metropolitan Areas (RRMA) system specifies what regions of Australia are deemed as rural, remote or metropolitan on the basis of various criteria including population, rurality and remoteness (Department of Health and Ageing, 2007a). Under the RRMA system, all geographic areas of NSW outside of the major metropolitan cities of Sydney, Newcastle, Wollongong and Gosford are considered to be either rural or remote.

An alternative classification system, the Australian Standard Geographical Classification – Remoteness Areas (ASGC-RA), was established by the Australian Bureau of Statistics (ABS) in 2001 and it classified all areas of Australia into five categories. These categories include major cities, inner regional, outer regional, remote and very remote (Australian Institute of Health and Welfare, 2008b). Under the ASGC-RA system, all areas other than the four major cities are considered to be either inner or outer regional, remote or very remote (Australian Bureau of Statistics, 2007).

As of 30 March 2010, the population of NSW was estimated to be 7.13 million (m) (Australian Bureau of Statistics, 2010). The current study is focussed upon the rural, regional and remote areas of NSW, which excludes the four major cities. These remaining non-metropolitan areas have an approximate population of 1.6m (Australian Bureau of Statistics, 2009). Some of the largest population areas within rural, regional and remote NSW include Tweed Heads with a population of 86 833, Port Macquarie with 73 870, Coffs Harbour with 70 371, Maitland with 67 621, Wagga Wagga with 61 656, Tamworth with 57 182, and Albury with 49 779 (Australian Bureau of Statistics, 2009).

1.7 Key Assumption

The current research had one key assumption; that the issue of ageing amongst the cohort of people with an intellectual disability was viewed equally critically across all regions of rural and regional New South Wales (NSW). This assumption underpins the research methodology and sampling processes that were utilised within the study.

1.8 Key Terms

The following list is not designed to provide a comprehensive definition of all terms used in the text but is presented as an introduction to key concepts used throughout the thesis. The terms are included below in alphabetical order rather than in relation to importance or occurrence within the text. Further explanations and more detailed definitions of specific terms are presented in Chapter Two.

- Aged Care Assessment Team (ACAT) – refers to a team of health professionals who conduct an assessment of an individual's care needs and then make recommendations for access to government services. These services include home based options, transition care designed to assist a person after a hospital stay, and residential aged care placements (Department of Health and Ageing, 2009b).
- Ageing – for the purpose of the current study, refers generally to any new or emerging issues that an individual starts to experience which are normally associated with the later years of life. Ageing, however, is a difficult concept to quantify, with no universally agreed definition. A more detailed examination of the definitions of ageing is presented in section *2.2.2 What is Ageing?*
- Allied Health Professional – refers to any healthcare professional outside of the specific fields of medicine, dentistry or nursing. Allied health professionals include psychologists, occupational therapists,

physiotherapists and speech pathologists (Allied Health Professionals Australia, 2009).

- Australian Standard Geographical Classification Remoteness Areas (ASGC-RA) – refers to the Australian Bureau of Statistics' (ABS) classification system. These systems divide the geographic areas of NSW on the basis of various criteria including population, rurality and remoteness. In NSW, all towns and areas outside of the major metropolitan cities of Sydney, Newcastle, Wollongong and Gosford are classified as regional or remote (Australian Bureau of Statistics, 2007).
- Carer – refers to a person who, either through an existing family relationship or other close connection, provides regular personal care and support to either a frail older person or someone with a disability (Department of Health and Ageing, 2006b). A carer is not a paid employee of a disability organisation; however, they may receive a Carer's Pension from the Australian Government.
- Day Program – refers to structured alternative day activities provided for individuals with a disability who are assessed by government as not yet being ready to enter employment (Department of Ageing, Disability and Home Care, 2007a). There are currently no government funded day programs specifically for people with intellectual disabilities who have retired from a workplace.
- Direct Care Staff – refers to individuals who are paid to provide support and assistance to a person with an intellectual disability. The term is used interchangeable with 'disability support worker' throughout the text. Similar terms such as 'employee', 'worker', or 'disability professional' are also used. Direct care staff is considered equivalent to terms used in other countries such as 'caregiver', 'attendant', 'aide', or 'personal assistant'.
- Dual Diagnosis – in the context of the current study, refers to a situation in which a person with an existing intellectual disability is diagnosed with a mental illness (White et al, 2005).
- Intellectual Disability – is a recognised term used throughout disability services across Australia and generally refers to any person with an

identified impairment in his/her cognitive functioning. It is considered to be largely interchangeable with similar terms from other countries including 'mental retardation', 'learning disability', 'intellectual or mental handicap' or 'developmental disability' (Leonard & Wen, 2002). A more specific definition of intellectual disability is examined in section *2.2.1 Definitions of Intellectual Disability.*[3]

- Not-for-Profit – refers to organisations operated with any surpluses or additional funds being invested into the provision of programs, rather than returned to shareholders or investors.
- Person Centred Planning - refers to a planning process that focuses on the individual with the disability and how services can be implemented to empower and support him/her to lead an independent and fulfilling life. According to the Department of Ageing, Disability and Home Care (2008d, p. 4) person centred planning "is used to describe and relate to a broader set of crucial elements, which bring about significant change in the lives of people with disability". A more detailed examination of person centred planning is presented in section *2.5.2 Person Centred Planning*.
- Personal Care – refers to any assistance that an individual receives to perform routine daily tasks. These daily tasks are ones that the person would, in normal circumstances, be able to perform independently, but as a consequence of his/her disability or ageing needs, are unable to complete unaided. Some examples of personal care include assistance with showering, getting dressed, hygiene, mobility and cooking.
- Quality of Life – refers to a multi-dimensional assessment or measurement of a specific individual's well-being. There is currently no universally agreed upon definition for this term with respect to people with intellectual disability in Australia. A more detailed analysis of the term is examined

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[3] There are occasions where no clear distinction is made in government policy, research articles and population databases between a person with a disability and a person with an intellectual disability (e.g. United Nations General Assembly, 2006). Every attempt has been made to identify when a situation refers specifically to the sub-set of people with an intellectual disability as opposed to more generic categorisations that incorporates all disability types.

within section *2.5.1 Quality of Life* and section *2.5.2 Quality of Life for People with an Intellectual Disability.*

- Respite – refers to services provided by both government and non-government organisations which are designed to assist carers of people with disabilities through the provision of external staff to facilitate the primary carer to take a temporary break in his/her provision of support (Department of Health and Ageing, 2008c).
- Residential Aged Care Facility – refers to a specialist accommodation model for predominantly older people who are unable to continue living at home. Entry into a residential aged care facility can only occur through referral to, and assessment by, an Aged Care Assessment Team (Department of Health and Ageing, 2009b).
- Rural, Remote and Metropolitan Areas (RRMA) – refers to the Australian Government's classification methodology for determining the areas of medical practice within Australia. In NSW, all towns and areas outside of the major metropolitan cities of Sydney, Newcastle, Wollongong and Gosford are classified as either rural, regional or remote (Department of Health and Ageing, 2007a).
- Successful Ageing – refers to an individual's ability to maintain his/her physical health, intellectual functioning and social life as s/he ages. It has a similar meaning to terms 'active ageing' and 'healthy ageing'. A more detailed definition of successful ageing is provided in section *2.4 Successful Ageing*.
- Supported Accommodation – refers generically to most forms of accommodation assistance provided to a person with an intellectual disability (Department of Ageing, Disability and Home Care, 2006). Supported accommodation is synonymous with other terms, such as 'group home' or 'residential support service'. However, in the context of this thesis, it does not include people residing within specialist residential aged care facilities.

1.9 Organisation of Thesis

This thesis is comprised of six chapters. Chapter One, the current chapter, presents a brief introduction to the study and the theoretical framework for the research. It provides the overall direction, defines the aims of the study, introduces the research methodology and describes the research setting. Key terms are defined and the one underpinning assumption is presented.

The second chapter presents a critical review of the literature relevant to the issues of people with intellectual disabilities who are ageing. Key terms, including 'intellectual disability' and 'ageing', are examined and discussed. The history and development of both intellectual disability and ageing services by government and non-government providers are reviewed. The relevant government legislation, including disability and aged care standards, is discussed. Key concepts, including 'successful ageing' and 'quality of life', are critiqued with respect to their relevance to intellectual disability. The provision of services to people with an intellectual disability is discussed with a focus upon the training and education of direct care staff within the disability sector in Australia. Chapter Two reviews the intersection of previously disparate issues: ageing and intellectual disability. As a consequence of the complexity of these issues and in order to appropriately establish the historical events that have resulted in the current situation, this chapter is necessarily comprehensive.

Chapter Three commences with a justification of the research methodology and the exploratory research design employed in the current study. The rural, regional and remote settings across which the study was conducted are indicated and a general description of the support services for people with an intellectual disability is presented. The survey instruments employed in the data collection are described including the six generic questions that form the basis of the Delphi study. The procedure for the collection of data and ethical issues relating to the research are discussed. The chapter concludes with an overview of the data analysis and a detailed discussion of methodological limitations.

The data analysis and results of the study are presented in Chapter Four. The relevant and available generic demographic data for workers in the disability sector is reviewed. The demographic data for the participants in the current study is detailed. The results for each of the questions used in Round One are presented. An examination of the results from Round Two is given, with any additional issues for inclusion or areas of disagreement from Round One identified. The data gained from the six questions in Round Three follows. The chapter concludes with a summary of the Final Round results as well as the information gained from the participating organisations' senior managers.

Chapter Five provides a detailed interpretation and discussion of the data and results presented in the previous chapter. Important issues relating to intellectual disability and ageing, as identified within Chapter Two, as well as any emerging themes, are individually examined within the context of each question. The findings of the current study are compared to the results of previous relevant research and considered with respect to the existing knowledge and experience.

The final section, Chapter Six, concludes the thesis. A series of training, policy and practice recommendations for government, training entities, disability organisations and direct care staff are proposed on the basis of the results. Suggestions for further research to extend upon the findings of the current study are then described. Chapter Six re-examines the significance of the research in light of the initial goals and the overall key findings. It concludes with a summary of the entire project.

Chapter Two - Background to the Current Research

Introduction

The purpose of the current research was to establish the main issues facing the disability sector workforce as large numbers of people with an intellectual disability begin to experience ageing-related problems. The goal of the study was to explore how the current policy frameworks, training systems and organisational structures prepared direct care staff to support their clients with these emerging issues and to recommend options in order to address any identified gaps within the existing operational practices.

Chapter Two builds on the introductory information presented in Chapter One. It provides a more comprehensive examination of relevant terms including 'intellectual disability' and 'ageing', reviews literature relevant to the field of ageing with an intellectual disability, examines the various federal and state government funded disability and ageing programs, and assesses the current state of training of direct care staff within disability support organisations. The chapter concludes with a summary of the present situation and the relevance of the current study.

2.1 Identification of Relevant Literature

A number of searches were undertaken on a variety of electronic resources and manuals of the relevant literature in order to establish the published research regarding the issue of ageing with an intellectual disability. The primary sources of relevant journal articles were through both electronic databases and published literature reviews. An electronic search in peer reviewed journals of disability, ageing, nursing and social sciences was the first method employed to identify pertinent literature. The following electronic search engines were used to aid this search: Google, Google Scholar, AltaVista, Yahoo, Metacrawler, Informit Online and ISI Web of Knowledge. The electronic databases searched were: Australian Public Affairs Full Text, Emerald Fulltext, Gale databases, JSTOR, Science Direct

(Elsevier), SpringerLink (Metapress), Wiley Interscience Journals, Proquest Central (PQ), AusStats, Australian Bureau of Statistics, Academic ASAP, PsycINFO, MEDITEXT, CINAHL (Cumulative Index of Nursing and Allied Health Literature), Family and Society PLUS, Pubmed, MEDLINE (MEDical Literature Analysis and Retrieval System onLINE), RURAL: Rural and Remote Health, and Web of Science.

To assist in the process of successfully identifying and locating the appropriate research literature a number of key terms and words were employed to help define the search. Some of the search terms used were *accommodation, active, aged, ageing, aging, care, development, direct, disability, education, elderly, frail, group, handicap, health, home, intellectual, learning, life, marte, mental, meo, needs, nursing, old, palliative, quality, region, remote, residential, retardation, rural, support* and *training.* These terms were used both singularly and in varying combinations during the searches of the electronic resources. Following this first electronic review of the literature a number of key authors were identified. These individuals were perceived to have made a considerable contribution towards the total research quantum in the relevant area. Their names were then used specifically as the basis for a second electronic review of the databases. A review was also conducted by manually searching through relevant publications in the key journals of disability, ageing and gerontology in order to minimise the possibility that a piece of relevant literature may be overlooked as a consequence of an inadvertent searching error.

A process of snowballing, in which further relevant research was established by checking the citations and references of the papers and articles identified through the electronic database and manual journal searches, was also undertaken. This system provided a double-checking mechanism, with the number of new articles found through this methodology decreasing until it was considered that a saturation point had been achieved. The review of the literature was completed in March 2010, with no new research after this point being included in Chapter Two.

2.2 Introduction to Intellectual Disability and Ageing

This section presents a review of the various definitions of intellectual disability and the concept of ageing. This introduction is followed by a discussion of the support structures and issues surrounding an individual with an intellectual disability who is experiencing age-related problems and how these changes impact upon the training requirements of the staff who support them. Firstly, the terms intellectual disability and ageing are discussed with a description of the general factors associated with these issues. This overview is followed by a summary of the development of intellectual disability and ageing services in Australia and a review of the relevant literature regarding the changing needs of people with an intellectual disability as they age. The current philosophies, policies and funding frameworks established by the New South Wales and Australian Governments are described. Finally, the training frameworks for staff members who work with people with an intellectual disability are examined. While the current study was designed within a social constructionist framework (see section *1.3 Theoretical Framework for the Current Study*), research from all theoretical models was considered during the compilation of this chapter.

2.2.1 Definitions of Intellectual Disability

The term 'intellectual disability' is currently used in Australia to describe an individual who has significantly below normal intellectual capacity. Other terms for intellectual disability outside Australia include mental retardation, mental handicap, mental impairment, learning disability and developmental disability. Previously commonplace terms such as 'idiot', 'sub-normal', 'handicapped', 'moron', 'imbecile' and 'feeble minded' are now largely obsolete around the world due to their perceived negative connotations. In Australia, intellectual disability has replaced mental retardation because of negativity associated with the term 'retarded'. Mental retardation is still widely used in the United States of America (USA), although there are recent signs that the term is being replaced by intellectual disability. In 2009, the *American Journal on Mental Retardation* officially changed its name to the *American Journal on Intellectual and Developmental Disabilities*. The editor noted that

> in part, the change has been motivated by a desire to avoid the negative connotations that have come to be associated with the term *mental retardation.* I fully endorse this change in terminology because it reflects our field's commitment not only to our science but to the people whose lives we hope to improve through our efforts. Quite simply, the change in terminology is a tangible sign of our respect for, and solidarity with, people who have disabilities and their families. (Abbeduto, 2009, p. 1)

However, mental retardation is still specified in the current fourth edition of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual (DSM-IV) as the appropriate diagnosis for an individual with an intellectual impairment (American Psychiatric Association, 2000).

There have been numerous different definitions of what constitutes an intellectual disability. An early definition within the English legal system was put forward by the judge Sir Anthony Fitzherbert in the 16th Century. In 1534, he made a classification that defined a person with below average intellectual functioning as

> And he who shall be said to be a Sot and Idiot from his Birth, is such a Person who cannot account or number Twenty-pence, nor can he tell who was his Father, or Mother, nor how old he is. (Fitzherbert, 1718, p. 519)

An important distinction also began to be made between a person with a permanent intellectual disability and a person who was suffering from a mental illness. The English philosopher John Locke (1689, on-line) noted that

> in short herein seems to be the difference between Idiots and Madmen, that Madmen put wrong ideas together, and so make wrong propositions, but argue and reason right from them; but idiots make very few or no propositions and reason scarce at all.

This recognition that there was an inherent difference between a person with an intellectual disability and a person with a mental health problem was an important factor in the development of the current definitions.

There is no universally accepted definition of precisely what factors constitute an intellectual disability (McConnell & Llewellyn, 2002). There are currently four primary clinical classification systems used in research and service delivery areas to define intellectual disability (Harris, 2006). The World Health Organization's (WHO) *International Classification of Diseases (ICD) Version 10 - Classification of Mental and Behavioural Disorders* defines intellectual disability as

> a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, ie cognitive, language, motor, and social abilities. (World Health Organization, 1992, p. 226)

WHO also promotes the *International Classification of Functioning, Disability and Health (ICF)* which is designed to complement the ICD-10 (Harris, 2006). Definitions and a framework for the diagnosis of specific diseases and disorders are provided by ICD-10, whereas the ICF has a focus upon determining individual functioning through the use of checklists (e.g. World Health Organisation, 2010). The checklists examine aspects of daily life, including participation and activities, as well as physical and cognitive capacity (Harris, 2006). The purpose of the ICF is to assist the ICD-10 in facilitating clinicians to provide a balanced perspective of the functional skills of a person who may have a disability (World Health Organisation, 2004).

The American Psychiatric Association (APA) includes a definition of intellectual disability within its *Diagnostic and Statistical Manual (DSM) of Mental Disorders Version IV Text Revision (TR)*. This definition states that

> the essential feature of Mental Retardation is significantly subaverage general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety (Criterion B). The onset must occur before age 18 years. (Criterion C). (American Psychiatric Association, 2000, p. 42)

The fourth classification system is the *Mental Retardation: Definition, Classification, and Systems of Supports 10th Edition* as developed by the American Association on Mental Retardation (AAMR). The AAMR definition of intellectual disability, or mental retardation, is

> a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18. (American Association on Mental Retardation, 2002, p. 8)

It is worth noting that the age of eighteen mentioned in the AAMR and DSM-IV definitions is often utilised as a cut-off mark for distinguishing between an intellectual disability and an acquired brain injury. An acquired brain injury is deemed to be any impairment of intellectual functioning that occurs over the age of eighteen as the result of damage to the brain caused by either a traumatic or non-traumatic injury to the head (Brain Injury Association of NSW, 2009). Any permanent injury to the brain prior to the age of eighteen is conversely considered to be a developmental disability, which manifests as an intellectual disability (Australian Institute of Health and Welfare, 1997).

WHO reported that the ICD-10 was the most commonly used classification system world-wide, with 62.3 percent of countries utilising it as the basis for determining intellectual disability. DSM-IV was used by 39.7 percent of countries, and the AAMR definition by 15.1 percent. The least popular methodology was the ICD, with 14.4 percent of nations adopting its widespread usage (World Health Organisation, 2007). In Australia, all four definitions have been used in government and research settings. While these classification systems are, in many ways, conceptually quite consistent, the variance in usage between the models has resulted in data inconsistency with respect to accurately establishing the prevalence of intellectual disability (Australian Institute of Health and Welfare, 1997).

Intellectual disability has one difference to the majority of other disease or disorder classifications within ICD-10-AM and DSM-IV-TR. This distinction is that it cannot be defined or classified as having a single cause or uniform set of distinguishing features. The classification of intellectual disability cannot be characterised by a similar starting point or aetiology, with there being in excess of 300 different causes of intellectual disability identified. Intellectual disability can result from genetic disorders such as Down Syndrome or Angelman Syndrome, brain damage as the result of birth trauma, and childhood illness such as meningitis or encephalitis. However, it is noted in DSM-IV-TR that there is no clear or obvious cause for over 40 percent of cases of intellectual disability (American Psychiatric Association, 2000).

A clinical diagnosis of intellectual disability is primarily based upon the measured Intelligence Quotient (IQ) for the individual. IQ tests were initially developed in the 1800s by researchers including Binet, Galton and Gastrow as an attempt to measure a person's abilities in several areas, including language, numeracy and problem-solving (Brody, 2000). Many additional personal factors, including psychological conditions such as depression or anxiety, can affect a person's IQ score and, as such, the psychologist or psychiatrist must consider these issues prior to definitively concluding that a person has an intellectual disability on the basis of the test scores (American Psychiatric Association, 2000).

Intellectual disability is commonly sub-categorised in relation to its measured severity, although not all classification systems define any set distinctions. The three commonly used classifications in Australia are mild, moderate and severe intellectual disability; however, a fourth category of profound intellectual disability is also used in some settings (Australian Institute of Health and Welfare, 1997). A mild intellectual disability is generally diagnosed in Australia if an individual has an IQ score of between sixty and seventy points, a moderate intellectual disability with a score of fifty to fifty-nine points, and a severe intellectual disability for any score under fifty (Australian Institute of Health and Welfare, 1997). DSM-IV-TR and ICD-10 vary from this IQ categorisation, with both defining borderline mental retardation for IQ scores between seventy and seventy-nine, mild mental retardation for scores of fifty to sixty-nine, moderate mental retardation for scores of thirty-five to forty-nine, severe mental retardation for scores of twenty to thirty-four, and profound mental retardation for any scores below twenty (American Psychiatric Association, 2000; World Health Organization, 1992).

2.2.2 What is Ageing?

There are numerous different, and sometimes conflicting, definitions pertaining to the ageing process that people undergo. There is no universally accepted classification of precisely what factors comprise ageing. It has been variously described as "changes that take place in the organism through the lifespan – good, bad and neutral" (Hooyman & Kiyak, 2005, p. 5); the changes that occur over time that increase the likelihood that an individual will die (Medawar, 1952); and "the progressive loss of function accompanied by decreasing fertility and increasing mortality with advancing age" (Kirkwood & Austad, 2000, p. 233). The common themes of most definitions relate to changes that occur progressively or over time that result in some loss of function for the individual.

To complicate the fact that there are varying and competing definitions of what constitutes ageing, determining precisely when ageing commences or when a specific individual is considered to be old is not simple. Across all of Australian society, ageing is not an event that can be accurately predicted or timetabled. It is a process that takes place over an extended period of time and varies between every person (Bigby, 2004). As such, providing a clear definition of ageing for an entire population sub-group, such as people with intellectual disabilities, is problematic. While ageing should not be viewed as a singularity, many attempts to categorise or define it are usually framed in terms of a specific chronological age. However, this approach has not resulted in a standard definition of ageing as there are no chronologically definitive and consistent physical, psychological or social phenomena associated with ageing that support the establishment of set ageing criteria in the same way that infancy or puberty can be so defined (Roebuck, 1979).

Research into ageing issues have often utilised the retirement age as an easy marker to determine the movement from adulthood to old age (Thane, 1989). Studies have used the ages of sixty or sixty-five because

> 'Ageing' and 'older age' refer to people older than 65 years, reflecting general community understanding of chronology, life-stage transitions regarding retirement and the government boundary common between adult and older age services and supports. (Fyffe, Bigby & McCubbery, 2006, p. 4)

This understanding of ageing appears to be mirrored across many sections of the community. Society's conceptualisation of ageing has been explained as follows:

> The ageing process is of course a biological reality which has its own dynamic, largely beyond human control. However, it is also subject to the constructions by which each society makes sense of old age. In the developed world, chronological time plays a paramount role. The age of 60 or 65, roughly equivalent to retirement ages in most developed countries, is said to be the beginning of old age. (Gorman, 1999, p. 7)

Much of the early ageing research within Western society used the designated retirement figure as the indicator of when ageing commenced. The Nuffield Foundation in England funded research shortly after the cessation of the Second World War to collate and examine information and knowledge on the individual, as well as the social and medical issues associated with ageing and old age (Rowntree, 1947). The target group of this research was

> men over 65 years and women over 60 years, as these ages have been established by the Widow's, Orphan's, and Old Age Contributory Pensions Acts of 1925 and 1940 as the earliest ages at which State Pensions are paid, and in consequence most published statistics relating to old age take the pensionable ages of 65 and 60 as being synonymous with the beginning of old age. (Rowntree, 1947, p. 1)

The use of the pension age to establish a point for the commencement of ageing was "entirely typical of the investigators working in this field after World War II" (Roebuck, 1979, p. 416). In recognition that this definition was imperfect, Rowntree (1947) proposed that there were two categories of people above the age of sixty. One was defined as people who were elderly but still capable of living independently and the second was for those people experiencing a significant loss in abilities due to reduced intellectual and/or physical capacity. However, the report did not explain how to easily make this differentiation across an entire population and the nominated ages of sixty and sixty-five were still used as the baseline for determining ageing within the study.

Researchers worldwide still continue to use the retirement or pension ages as a convenient marker in describing the onset of ageing for entire populations of people (Fyffe, Bigby & McCubbery, 2006). However, the English Government's original rationale for nominating a set figure for aged pension eligibility was based upon questionable logic and purely economic reasons, rather than any specific medical or societal need. Before the introduction of the 1908 *Old Age Pensions Act*, which was mirrored in Australia with the 1908 *Commonwealth Aged Pension Act*, a person's eligibility for aged care assistance varied considerably. The 1601 *Elizabethan Poor Law* and the subsequent 1834 *Poor Law Amendment Act* in the United Kingdom mandated the support of the aged by their local parish but did not define an age at which a person was eligible (Bloy, 2002). Each distinct parish retained the ability to arbitrate every case on its individual merits, with people being supported in age ranges anywhere from their late forties and upwards (Roebuck, 1979).

It was not until the 1880s that a definition of ageing became relevant in England, with parliamentary discussions surrounding the introduction of a nation-wide state administered aged pension system. Various suggestions between fifty and seventy were proposed as the age for initial eligibility for the pension; however, it was ultimately economic rather than medical, social or scientific reasoning that determined the final figure. Three preliminary budgets were established by the Treasury Department, with the cost estimates based around the payment of five shillings a week for people over the age of sixty-five, seventy and seventy-five. The annual cost of introducing a pension at age seventy was found to be more than 40 percent less than at age sixty-five (Roebuck, 1979). Lloyd George, who was responsible for the Government Bill, confirmed that the deciding factor in setting the age at seventy was finance. On 15 June 1908, George commented in the British Parliament that

> I think they ought to begin at 70 – old age pensions as such – this is my answer to the proposal to reduce the limit from 70 to 65. It is because of the fact that it costs more, that is my answer at the moment. (cited in Roebuck, 1979, p. 422)

In 1925, the British Government introduced the *Widow's, Orphan's, and Old Age and Contributory Pensions Act*. This new Act entailed a contributory insurance scheme but reduced the retirement age from seventy to sixty-five years for those making contributions under the 1911 *National Insurance Act*. Once again, the logic underpinning the determination of eligibility for the old age pension was economic. The primary objective of the government in introducing this change in legislation was to encourage older workers to retire, freeing up jobs for the younger unemployed. Future British Prime Minister, Neville Chamberlain, commented on the Bill, saying "the scheme is going to bring about a reduction of unemployment" (cited in Roebuck, 1979, p. 423).

The figure of sixty-five is still often used in research today to designate the commencement of ageing, in spite of the fact there appears limited medical or social reasons for this decision. The United Nations has recognised this problem and nominated the use of chronological age as merely a crude mechanism for the identification of population groups and their respective needs (United Nations Population Fund, 1998). The use of chronological age categorisations is not definitive as it fails to take into account individual differences associated with a variety of factors including environment, culture, personal health and lifestyle choices, amongst many others. Furthermore, the use of the pension or retirement age to indicate the commencement of ageing is based upon premises over a century old and derived from governments' financial needs, rather than evidenced reasoning or demonstrated individual needs.

Various different classifications of ageing have continued to be proposed, with the United Nations generally using the age of sixty to define 'elderly' people (World Health Organization, 2009). There have been some attempts to split the grouping of aged into smaller sub-sets. As one example, one ageing model defines a person aged sixty-five to seventy-five as 'young old', someone seventy-six to eighty-five as 'old old', and people over the age of eighty-five as the 'oldest old' (Riley & Riley, 1986). Another methodology defines people between sixty-five and eighty who are predominantly independent and socially active as 'third age' and people who are over eighty years old and requiring more support as 'fourth age' (Fyffe, Bigby & McCubbery, 2006). However, demarcation on the basis of chronological age alone still implies that there are set timeframes in which all people will start to experience similar changes and alterations. Individual differences are not successfully taken into account, which can result in substantially different levels of functional skill and independence between two people both similarly categorised.

Currently in Australia there are a variety of different government definitions and criteria that are used in relation to ageing. Generally, a person is eligible for the Aged Pension once they reach the age of sixty-five. This figure has not changed for men since the *Commonwealth Aged Pension Act* was first introduced on 10 June 1908; however, until recent years women were eligible for the aged pension at sixty. This figure has recently been standardised for both sexes at sixty-five with the increase in age for women's eligibility being gradually phased in until 2017 (Centrelink, 2009a). The 2009 Australian Government's Budget raised the possibility for a significant change to the *Age Pension*, proposing that, from 2017, the eligibility age increase from sixty-five to sixty-seven years. The need for this change was premised on the argument that, with the improvements in medical care and technology, the population is living longer and spending more years in retirement. The government cites figures that claim only 50 percent of the male workforce in 1909 reached the age sixty-five and they would have spent only eleven years in retirement, whereas the figure now indicates 85 percent of males will have a retirement of in excess of nineteen years (Commonwealth of Australia, 2009a). As with the historical modifications to the aged pension, this current proposed change is again based upon the financial impost for the government; in this instance those costs associated with a society that is living longer.

The *Commonwealth Aged Care Act* of 1997 does not provide a definition of ageing or nominate when a person is considered to be ageing. There is reference on government information web-sites and in departmental literature to 'aged' and 'frail older people'; however, these terms are not specifically defined (Department of Health and Ageing, 2006a, 2009a). The planning ratio that government uses to determine how many residential aged care places are allocated per geographic region is calculated upon the number of people aged over seventy in that area (Department of Health and Ageing, 2006a). Access to government funded residential aged care services in Australia occurs through a formal assessment by Aged Care Assessment Teams (ACAT), which are funded by the Commonwealth Government. There are ACATs located across Australia which consist of

> teams of health professionals, such as doctors, nurses or social workers, who provide information, advice and assistance to older people who are having difficulty living at home. (Department of Health and Ageing, 2009a, p. 12)

The ACAT makes an individual assessment of each person referred to them, and can approve or deny the individual's eligibility for residential aged care services, respite care or other community care packages (Department of Health and Ageing, 2009a). The guidelines for the ACAT assessment process decrees that residential aged care and community care packages are specifically designed for "frail older Australians" (Department of Health and Ageing, 2006a, p. 8). No lower age limit is placed upon access to an ACAT for assessment. However, the guidelines make specific reference to younger people with disabilities and the fact that responsibility for servicing this group is held by the various state and territory governments and not the Australian Government. There remains no clear definition within the guidelines of precisely what constitutes a younger person with a disability or when a person with a disability can also be considered to be ageing.

A number of different chronological ages have been proposed as defining the starting point of ageing for people with intellectual disabilities. While there is ongoing debate about whether there is actually a need to distinguish between individuals with intellectual disabilities and the mainstream population (Bigby, 2004), ages such as forty-five, fifty-five and sixty have been proposed as the beginning of ageing for this group of people (Gatter, 1996; Janicki & Ansello, 2000; Leveratt, Bowers & Webber, 2005). Discussions with disability service organisations across NSW indicate that a cut-off age of sixty-five seems to be applied by some ACATs as providers indicate it is extremely difficult to get a person with a disability under that age assessed (Dowse, McDermott & Watson, 2009; Nicola Chirlian, pers. comm., 15 December 2008; Tina Purdon, pers. comm., 15 December 2008). This issue can be particularly problematic for some sub-groups of people with intellectual disability, particularly those with genetic disorders including Down Syndrome. Such conditions are linked to early onset of ageing-related problems, including the development of Alzheimer's disease in the early to mid fifties (Torr et al, 2010) and the cut-off age of sixty-five is therefore not appropriate.

The Council of Australian Governments (COAG), which is composed of both the Commonwealth and all the state/territory governments in Australia, announced the implementation of the jointly coordinated Young People in Residential Aged Care (YPIRAC) Program in February 2006 (Council of Australian Governments, 2006). This program has the goal of assisting people with a disability to either move out of, or avoid entry into, a Residential Aged Care facility. While the program is generally aimed at individuals aged under sixty-five, which seems to conform to the informally applied ACAT entry criteria, the NSW Government has specified that their focus is upon people aged under fifty (Department of Ageing, Disability and Home Care, 2008b). This prioritisation of people under fifty now appears to leave a distinct gap in the sector's service models for people aged between fifty and sixty-four within NSW. The problem of reduced access for this group of people to Aged Care Assessment Services has been recognised and identified at an Australian Government level (Senate Community Affairs Reference Committee, 2007) but no solution has yet been proposed.

2.2.3 History of Intellectual Disability Services in New South Wales

The last three decades has seen a substantial change in the approach of service provision and support to people with intellectual disabilities in New South Wales (NSW). The introduction of the 1986 *Commonwealth Disability Services Act* and the 1993 *NSW Disability Services Act* have brought about major reforms in the recognition of the human rights for people with intellectual disabilities. Historically, people with intellectual disabilities around the world have been marginalised, demeaned, discriminated against and devalued by society (Stone, 1998; Wolfensberger, 1972). When NSW was first colonised in 1788, Governor Phillip was bestowed with the power to deal with, basically as he saw fit, people classified as "lunaticks and ideots" (Shea, 1999, p. 22). The definition of what constituted a 'lunatick' or 'ideot' was unclear, with the existing medical definitions and classifications of the time often contradictory and confusing. While some distinction was being made between people with intellectual disabilities and those with mental health issues (see section *2.2.1 Definitions of Intellectual Disability*), the models of assistance were not differentiated.

Governor Phillip and his immediate successors primarily placed individuals considered to be lunatics into the care of a relation or another person who was thereafter deemed to be responsible for them (Cummins, 1967). However, a rise in the number of people who would now be diagnosed as having either an intellectual disability or a mental health issue led to the opening of a specific asylum facility in 1811 at Castle Hill (Shea, 1999). This response was largely due to public concern about the number of people with disabilities either wandering the streets or simply being thrown in Parramatta Goal (Westcott, 2004). The original Castle Hill Asylum and other subsequent institutions, such as the Tarban Creek Lunatic Asylum which opened in 1838 and later became Gladesville Hospital, were the default service environment for the majority of people with an intellectual or mental disability. Individuals who were deemed to be 'feebleminded' were often placed involuntarily and with minimal assessment into large scale institutions and mental asylums (Shea, 1999; Williams, 1996).

This process began to change when the NSW Government passed into law the *Lunacy Act* of 1843. The goal of this act was for "the safe custody of, and prevention of offences by persons dangerously insane, and for the care and maintenance of persons of unsound mind" (State Records Authority of New South Wales, 2007, p. 1). This new legislation defined the necessity for having independent medical opinions to confirm an individual was in need of care, as there was considerable concern about potential abuse of the process of institutionalisation in the past. However, the initial drafting of the 1843 *Lunacy Act* contained a number of inconsistencies with respect to how people with disabilities should be diagnosed and cared for and numerous amendments and alterations were made to the Act over the following years (Shea, 1999).

The 1843 *Lunacy Act* was eventually replaced by the 1878 *Lunacy Act*. The definitions within the 1878 Act were modified, replacing the distinction between 'persons dangerously insane' and 'person of unsound mind' with the simpler 'insane person' and 'idiot' (Shea, 1999). These new definitions largely mirror the current separation between a person who has a mental health issue and someone with an intellectual disability. An old military barracks in Newcastle was converted to an asylum in 1872, with part of its purpose being to "separate mental defectives from the rest of the institutionalised lunatic population" (Westcott, 2004, p. 10). A separation in how people were supported, depending upon their disability, started to occur. The predominant form of support for people with intellectual disabilities remained institutionalisation under both the 1843 and 1878 *Lunacy Act*; however, it became more difficult to admit an individual to such care without appropriate medical review under the 1878 Act (Shea, 1999).

It was not until the mid 1900s that a significant shift away from the highly segregated large congregate models of asylum care began to take place. This movement was largely driven by parents who, faced with the option of either coping on their own or placing their child into an institution potentially housing thousands of other people with high support needs, started banding together to form local community based organisations. These parents joined forces to generate money, raise the public awareness of intellectual disability and to place pressure on State and Commonwealth politicians to support people with disabilities. In 1954, the Mentally Incurable Children's Association was formed in this manner, based upon "fundraising barbecues, jumble sales, street appeals, lamington drives and concerts" (Westcott, 2004, p. 14). This same model of community based organisation was replicated across Australia. Examples of these needs driven services are still evident today across NSW, with rurally based disability support organisations such as Challenge Disability Services, Mai-Wel, MultiTask and The

Ascent Group all tracing their origins back to this parent driven movement of the 1950s and 60s (e.g. Edmundson et al, 2005; Mai-Wel, 2009).

The rise of these new organisations saw a movement in the 1970s away from larger institutions towards smaller hostel models that generally housed between twenty and one hundred people. Other services, such as specialist schools, employment opportunities, early intervention programs and day activity centres, followed the initial development of accommodation options (Edmundson et al, 2005). A new style of support, with a focus on education, training and individual development, started to compete with the prevailing medical model (Young, 2003). A service system began to be established in which parents would be advised to "deliver their children into the lifelong care of local charities" (Westcott, 2004, p. 15) following diagnosis of an intellectual disability by a doctor. For parents in rural areas, the options were limited to either providing the care for their child themselves, or sending the young child away to either a non-government organisation or a government operated institution.

The release of the 1983 *Inquiry into Health Services for the Psychiatrically Ill and the Developmentally Disabled* report (Richmond, 1983), commonly known as the *Richmond Report*, provided an impetus to improve services to people with disabilities, to modify the way services were provided to people with disabilities, and to enhance the wider community's understanding of issues facing people with disabilities (NSW Audit Office, 1997). The *Richmond Report* was a catalyst in achieving the next major change in service delivery for people with disabilities through the introduction of the *Commonwealth Disability Services Act* in 1986 and the *NSW Disability Services Act* in 1993.

These Acts facilitated the development of clear policy directions that moved people away from institutionalised care and towards community integrated housing models. Demonstration projects were funded to successfully prove that such options were indeed viable within both metropolitan and rural Australia (Ward, 2006). The smaller hostel models that had been established during the 1960s and

70s, many of which still housed up to one hundred individuals, were broken down further into group home settings of just a handful of people, or even single individuals, living separately in their own dwelling (Edmundson et al, 2005). Such community based housing options have been found to result in increased quality of life, adaptive behaviours and decision making opportunities when compared to the traditional institutional care model (Young, 2006). It is noted by Mansell and Beadle-Brown (2010) that deinstitutionalisation was possibly the biggest reform in government policy for disability service provision since World War II and that this change is now well developed in Australia and other developed countries.

While the goals of deinstitutionalisation were appropriate, there are still considerable issues and problems associated with how this process has been enacted. There has been ongoing criticism of governments, at state, commonwealth and international levels (Mansell & Beadle-Brown, 2010) for their persistent failures to adequately fund the infrastructure and support services associated with closing large-scale institutions. An example of this criticism is seen with a recent report which commented that

> the closure of institutions was not balanced with the development of sufficient housing options that had adequate support for people to build community connections and focus on their psycho-social recovery. (Mental Health Council of Australia, 2009, p. 23)

In 1998, the NSW Minister for Disability Services announced that all large institutions would be closed by 2010 (Department of Ageing, Disability and Home Care, 2006). This policy direction by the NSW Government represented a considerable shift away from the institutionalised models that had dominated service provision since the early 1800s. It is worth noting, however, that in 2010 there were a number of large government run institutions still operating across the state. The NSW Government stated that “In 2005, there is a recognition that group homes work for some, but not for all, that large residences may offer greater freedom to some” (Department of Ageing, Disability and Home Care, 2006, p. 6) and it would appear that there had been a definite move away from their 1998 goal of closing all such institutions.

In January 2006, the Department of Ageing, Disability and Home Care (DADHC) released a position paper titled *Accommodation and Support*. Contained within this paper are a variety of goals for disability service provision into the next decade, including a desire to see a movement away from group homes and towards supporting carers to maintain people with disabilities in their own home. This direction is seen with the statement that

> the new disability system will deliver greater levels of assistance and more flexible options for people with disabilities to live at home with the support of family and friends. (Department of Ageing, Disability and Home Care, 2006, p. 11)

The ongoing existence of large institutions appears uncertain, with the comment that "Large residential centres will close over time. Some will be redeveloped to provide support for people with complex needs and behaviours" (Department of Ageing, Disability and Home Care, 2006, p. 13). The government has moved away from its previous 1998 commitment to closing all institutions by 2010 but it is unclear whether there is any comprehensive plan for the future of large congregate residential care for people with intellectual disabilities.

2.2.4 Disability Legislation in Australia

Australia has historically close ties to the United Kingdom and much of its policy frameworks within government can be traced back to British origins (Lindsay, 2004). The provision of support to people with disabilities had traditionally been viewed in both countries as an issue purely of health. Section 51 of the 1901 Australian Constitution specified that responsibility for both the funding and delivery of all health related programs were the sole domain of the various state governments. However, this clear delineation started to break down in 1908 when the Australian Government introduced invalid pensions for those people deemed incapable of supporting themselves. Individuals with an intellectual disability naturally made up a considerable proportion of people considered unable to support themselves and, as such, the Australian Government had by default assumed partial responsibility for funding this group (Lindsay, 2004).

The two World Wars saw further changes in direction for Commonwealth Government funding for disability services. The Repatriation Commission was instituted in 1919 to assist soldiers with disabilities to gain meaningful employment upon their return to Australia. In 1948, a few years after the end of the Second World War, the Repatriation Commission was replaced when the Government established the Commonwealth Rehabilitation Service (CRS). The purpose of CRS was to provide training and vocational support services, not just for returned servicemen, but also other people with disabilities from the wider community (Lindsay, 2004). A precedent was being established with the Australian Government assuming responsibility for disability pensions and the funding of employment orientated programs for people with disabilities, while the various states continued to provide the health based services.

The Australian Government undertook a comprehensive review of disability service provision across Australia during the early 1980s. This process, called the *Review of Handicapped Programs*, consulted widely with all stakeholders including people with disabilities and their families. The Australian Government released the findings of this review in the mid 1980s (Handicapped Programs Review, 1985). The findings of the Review, called *New Directions*, formed the basis of the *Disability Services Act* passed by the Australian Government in 1986. This Act detailed how services for people with a disability would be provided, established guidelines for the delivery of disability services, and also determined actions that could be taken against organisations who failed to meet these requirements (Lindsay, 2004).

The 1986 Commonwealth Act was a pivotal piece of legislation in facilitating the inclusion of people with disabilities more widely into their local community. The Australian Government is currently responsible for the provision of vocational disability support through mechanisms such as the Disability Support Pension, Wage Subsidies, Supported Wage System and the Workplace Modification Scheme. It is also the funding body overseeing the provision of Supported and Open Employment Services as well as Vocational Rehabilitation Services.

The 1993 *NSW Disability Services Act*, which is modelled upon the 1986 *Commonwealth Disability Services Act*, is the over-arching legislation covering the delivery of the non-employment disability programs that are the responsibility of the NSW Government. These state coordinated services cover options including residential support, respite and day programs. The objectives of the 1993 *NSW Disability Services Act* are to:

> (a) to ensure the provision of services necessary to enable persons with disabilities to achieve their maximum potential as members of the community, and
>
> (b) to ensure the provision of services that:
> (i) further the integration of persons with disabilities in the community and complement services available generally to such persons in the community, and
> (ii) enable persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, and
> (iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem, and
>
> (c) to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services, and
>
> (d) to encourage innovation in the provision of services for persons with disabilities, and
>
> (e) to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities, and
>
> (f) to ensure that designated services for persons with disabilities are developed and reviewed on a periodic basis through the use of forward plans. (New South Wales Government, 1993, p. 1)

The 1993 *NSW Disability Services Act* mandates for the funding and provision of all disability services, both government and non-government, across the state. The NSW Government department responsible for the funding and delivery of disability services, the Department of Ageing, Disability and Home Care (DADHC), developed ten *Disability Services Standards* designed to assist organisations to meet the objectives, principles and applications of principles contained within the Act. These Standards are:

1. **Service Access** - Each consumer seeking a service has access to a service on the basis of relative need and available resources.

2. **Individual Needs** - Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.

3. **Decision Making and Choice** - Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.

4. **Privacy, Dignity and Confidentiality** - Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.

5. **Participation and Integration** - Each person with a disability is supported and encouraged to participate and be involved in the life of the community.

6. **Valued Status** - Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.

7. **Complaints and Disputes** - Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service.

8. **Service Management** - Each service adopts sound management practices which maximise outcomes for consumers.

9. **Family Relationships** - Each person with a disability receives a service which recognises the importance of preserving family relationships, informal social networks and is sensitive to their cultural and linguistic environments.

10. **Rights and Freedom from Abuse** - The agency ensures the legal and human rights of people with a disability are upheld in relation to the prevention of sexual, physical and emotional abuse within the service. (Department of Ageing, Disability and Home Care, 2008c, p. 1)

There are a corresponding set of disability standards based upon the 1986 *Commonwealth Disability Services Act*. These *Commonwealth Disability Standards* differ slightly from the *NSW Disability Standards* in that they are composed of twelve items, rather than ten. The first eight standards are identical; however, the final four Standards of the *Commonwealth Disability Service Standards* are:

9. **Employment conditions**,
10. **Service recipient training and support**,
11. **Staff recruitment employment and training**, and
12. **Protection of human rights and freedom from abuse** (Department of Families, Housing, Community Services and Indigenous Affairs, 2009d, on-line).

The reason for the difference between the State and Commonwealth Standards relates to the different service focus between the two levels of government. The Australian Government has carriage of all disability employment programs, whilst the state governments, including NSW, provide day program and accommodation related programs. As such, the Commonwealth Standards reflect this distinction through the specific emphasis upon employment and training outcomes which are not relevant to state funded programs.

In 2001, the United Nations recognised the need for formal legal agreement amongst all countries with respect to eliminating discrimination against people with disabilities. Over the following five years it developed specific legislation called the *Convention on the Rights of Persons with Disabilities* to address issues of equality. This legislation did not mandate any specific new rights for people with disabilities. Instead, it was designed to clearly prohibit any actions that discriminate against the general rights of people with disabilities (United Nations General Assembly, 2006). The Australian Government was one of the original signatories to the Convention. It was first officially signed on 30 March 2007; however, it did not enter into force in Australia until 16 August 2008 following its ratification in New York on 17 July 2008 (Department of Families, Housing, Community Services and Indigenous Affairs, 2009e). While Australia already had an established and comprehensive system of disability legislation through the State and Commonwealth Disability Acts and their associated standards, the *Convention on the Rights of Persons with Disabilities* represented the first universal and legally binding protocol to protect the rights of people with disabilities (United Nations General Assembly, 2006).

Within the disability sector, the key principles of service provision and the over-arching disability legislation apply throughout the childhood, adolescence and adult years of all individuals with a disability. However, once a person with a disability starts to experience age-related changes, some of these essential practices may be overlooked with the individualised programs either reduced or removed completely. In some programs, DADHC has a stated target group for service provision for people aged eighteen to sixty-five (Department of Ageing, Disability and Home Care, 2007a). In accordance with this position, some service providers report that their clients are deemed ineligible for certain services once they reach their sixty-fifth birthday.

The rationale for this decision appears to be based upon the argument that the primary problem is now considered to be one of ageing rather than disability and that the individual should therefore be funded and serviced by a different government department. This policy does not appear to be uniformly applied across all regions of NSW, with some DADHC officers applying different interpretations of this target age for services (Nicola Chirlian, pers. comm., 31 August 2009; Tina Purdon, pers. comm., 3 November 2008). The approach is consistent with the history of policy development by government, which reveals that it is often dictated by short-term political or cost expediency rather than being developed in the best interests of people with disabilities (Shaddock, 2003).

2.2.5 History of Aged Care and Aged Care Standards in Australia

As with people with disabilities, the early years of colonial Australia saw the provision of care for the aged predominantly being undertaken by their relatives and friends (Sax, 1993). The aged care support system for individuals without a family network to assist them has been historically based upon government run hospitals and institutions to supplement a variety of charitable and other private facilities (Gibson, 1998). Over-crowding of the generic hospital system by people with ageing issues quickly became a problem in the colony of New South Wales (NSW) and specialist facilities were required to reduce the pressure on the mainstream system. An example of this care system was the Rookwood Asylum for the Aged and Infirm which was established in Sydney in the early 1890s. Rookwood provided hospital style care for those individuals who were in need of nursing support but were unable to gain such assistance elsewhere (Fine & Stevens, 1998). Rookwood Asylum later became Lidcombe Hospital (University of Sydney, 2009).

In 1901, Federation saw the introduction of national legislation regarding aged care. The division of care for the ageing was split with the Australian Government responsible for paying pensions and subsidies to aged care facilities while the states were responsible for managing the health care of ageing people through the hospital system (Stein, 1999). Initially, nursing homes were governed by state legislation as they were deemed to be private hospitals. Private institutions supplemented the services provided by government but these were predominantly run by 'for profit' providers and were only available to those individuals with sufficient money to pay for their care (Fine & Stevens, 1998).

The provision of aged care services remained fairly stable until the end of the Second World War. While aged care was still viewed as being a 'family issue', the Australian Government began to provide more money and incentives for the care of the elderly (Kendig & McCallum, 1990). The development of the 1954 *Aged Persons Care Act* extended the range of providers by making available subsidies specifically to not-for-profit entities for the provision of hostel accommodation and self-contained units for aged care (CommLaw, 1954). Initially, nursing care support was only provided as an additional service to a minority of residents. However, a further change in how the Australian Government funded nursing beds in the 1960s saw an increase in such placements from around 4 percent in 1965 to 55 percent by 1980 (Gibson, 1998).

During the final decades of the 20th Century there was a deliberate movement away from the provision of congregate residential aged care and towards community based care that supported people to remain in their own homes. The preference of many ageing people is to remain in their family home and avoid entry into a nursing home facility for as long as possible (Davison et al, 1993; Dowse, McDermott & Watson, 2009); however, it was the financial expense associated with the prevailing reliance upon institutions, when combined with an ageing population, that had the most significant impact on the Commonwealth Government's policy positions. It became a major driving factor in the Australian Government's change towards community based care in the 1970s and 80s, as noted:

> Since 1985, Australia too has been vigorously pursuing a policy of deinstitutionalisation in aged care. Not only was the Australian system at that time faced with a rapid increase in potential demand, it was also a system which was heavily reliant upon expensive forms of residential care. (Gibson, 1998, p. 13)

The problems associated with the primacy of residential aged care was highlighted in the 1975 *Committee of Inquiry into Aged Persons Housing* with specific concerns raised about the reliance upon institutions and the lack of effective and appropriate community care programs (Social Welfare Commission, 1975). The 1980s saw additional government inquiries into the provision of aged care programs. Two of the most important reviews were seen with the 1982 *House of Representatives Standing Committee of Expenditure*, also known as the *McLeay Report*, and the 1985 *Senate Select Committee on Private Hospitals and Nursing Homes*, also known as the *Giles Report*. Both committees recommended changes to how aged care services were funded and provided across Australia (Kendig & McCallum, 1990).

The *McLeay Report* recommended a review of home and community based services. These recommendations were incorporated into the Australian Government's 1983 *Social Justice Strategy* that was designed to bring equality and access to essential services for all Australians (Australian Government, 1988). The introduction into legislation of the *Home and Community Care Act* occurred in 1985. This Act brought together a variety of disparate federal and state community care programs under the one banner of Home and Community Care (HACC) programs (Howe, 1997). The 1985 *Home and Community Care Act* replaced legislation such as the 1956 *Home Nursing Subsidy Act*, the *Delivered Meals Subsidy Act* 1970, *State Grants (Home Care) Act* 1969 and the *State Grants (Paramedical Services) Act* 1969.

The release of these committees' findings and independent reports in the 1980s resulted in the development of the *Aged Care Reform Strategy* by the Australian Government in 1987. One of the most important recommendations of the *Giles Report* was for the establishment of national standards for all nursing homes as there were only limited external checking mechanisms to ensure individuals received an appropriate quality of care (Braithewaite et al, 1992). The 1987 reform strategy resulted in a number of modifications to aged care practices including the development of national quality standards. Other changes included the introduction of Geriatric Assessment Teams, now known as Aged Care Assessment Teams, a charter of Residents' Rights and Responsibilities and a new funding model for the delivery of service. One of the primary goals of the new legislation, a reduction in the reliance upon institutionally based services, was achieved with only very high support needs individuals being deemed eligible for admittance to residential aged care facilities (Sax, 1993). As part of this reform process, the Australian Government adopted recommendations from the *Aged Care Reform Strategy Mid-Term Report*, known as the *Gregory Report*, and assumed complete responsibility from the various state governments for overseeing the provision of all residential aged care services (Gregory, 1991).

In spite of the changes designed to improve the system, the provision of aged care services continued to be the subject of both government and independent review. One of the primary complaints was that the *Aged Care Reform Strategy* was overly complicated and difficult to understand (Australian Law Reform Commission, 1995). These criticisms led to the development of the current over-arching legislation for aged care services: the *Aged Care Act* 1997 and the associated *Aged*

Care Principles (Department of Health and Ageing, 2005). Currently in NSW, all aged care services are required to conform to the *Aged Care Act* of 1997 (Department of Health and Ageing, 2007b). Providers who offer Home and Community Care (HACC) based programs also need to conform to the 1985 *Home and Community Care Act*.

However, unlike disability services in NSW, there are a number of different sets of standards applied to aged care. All residential aged care facilities are assessed against and must conform to the *Aged Care Standards* (Aged Care Standards and Accreditation, 2009). However, home and community based care services are often program dependent with respect to the over-arching standards and may therefore be covered by the HACC *National Service Standards*, the *National Respite for Carers Program (NRCP) Standards*, the *Extended Aged Care at Home (EACH) Standards*, or the *Community Aged Care Package (CACP) Standards*. In addition, it is noted by the Australian Government that some providers may have to report against other standards including *Quality Improvement Council Standards* (QIC), the *Australian Council on Health Care Standards* (EQuIP), International Standards Organisation (ISO) as well as the *Disability Service Standards* (Department of Health and Ageing, 2008a).

The lack of one common set of standards for aged care has resulted in a situation in which many community based organisations will have to conform to, and be independently assessed against, numerous sets of standards. The Australian Government has recognised the problems associated with having different sets of standards and is attempting to address the issue through a review project titled *A New Strategy for Community Care - The Way Forward*. The goal of this project is to review the existing standards, then to develop a set of communal standards and a reporting framework that meets the objectives of the various ageing programs (Department of Health and Ageing, 2009d). While some work has been completed on the mapping of the various standards, the project has not been finalised and no timeframe for the implementation of any new system has been proposed.

2.2.6 Australian Funding of Disability and Aged Care Services

All levels of Australian government have stated policies that mandate for the rights of individuals with an intellectual disability. These frameworks are designed to ensure that this group of people have the same ability to access opportunities and participate in their local community as any other member of the mainstream population. As the cohort of people with intellectual disability experience an increase in life expectancy, there has been a corresponding rise in the need for aged care support for this group. However, a major complicating factor for the provision of appropriate support services pertains to the fact that ageing and disability programs are funded by both state and commonwealth government departments. The current policy frameworks have inherent administrative and bureaucratic blockages that impede the delivery of appropriate ageing services to people with intellectual disabilities (Bigby, 2008a).

The Commonwealth State Territory Disability Agreement (CSTDA) is a formal agreement between the Commonwealth Minister and the relevant state and territory ministers responsible for the provision of disability services. The CSTDA specifies the responsibilities for delivering services to people with disabilities across the states, territories and Australia generically. The current agreement establishes that the states and territories have responsibility for disability accommodation and respite programs as well as community support and community access services.

The Commonwealth retains the responsibility for all employment programs for people with disabilities (Department of Families, Housing, Community Services and Indigenous Affairs, 2009a) and also for the payment of the Disability Support Pension to eligible individuals (Department of Families, Housing, Community Services and Indigenous Affairs, 2009f). Both sectors of government contribute towards the costs of providing Home and Community Care (HACC) services to people with disabilities who reside in their own home. The Australian Government is primarily responsible for the coordination, funding and regulation of residential aged care facilities (Department of Health and Ageing, 2009b).

The Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) administers the Australian Disability Enterprises (ADE) which were recently known as Supported Business Services and historically as Sheltered Workshops. ADEs are specific business units for people with a disability who need substantial ongoing assistance to perform a job within a supported work environment (Department of Families, Housing, Community Services and Indigenous Affairs, 2009b). The Commonwealth Department of Education, Employment and Workplace Relations (DEEWR) coordinates the Disability Employment Services (DES), which assists people with disabilities and social disadvantage to find and maintain jobs within the mainstream community. Specialist DES providers assist people with disabilities through ongoing training and support both prior to commencement and during employment (Department of Education, Employment and Workplace Relations, 2009a). Both Commonwealth Departments have a purely administrative function and they are not directly responsible for the provision of hands-on services. Instead, they oversee the allocation of funding to third party non-government organisations to deliver the employment programs on their behalf.

In NSW, the Department of Ageing, Disability and Home Care (DADHC) is the nominated state government department that oversees the designated disability services in accommodation, respite and community program areas (Department of Ageing, Disability and Home Care, 2009a). DADHC differs from its Commonwealth counterparts in that it is both a direct service provider and a funding body. In addition to funding over nine hundred organisations to provide programs to people with disabilities, DADHC also employs in excess of 12 000 staff in its own disability support sections (Department of Ageing, Disability and Home Care, 2008a).

As well as the state services provided and overseen by DADHC, the NSW Department of Health coordinates a number of disability support programs. These services incorporate the provision of assistive equipment and aids for people with a disability through the Program of Appliances for Disabled People (PAPD), as well as therapy services including early intervention programs for children with disabilities, occupational therapy, physiotherapy, psychology and counselling services (Department of Health, 2009). In addition to the early intervention programs coordinated by the Department of Health, support is also provided for school aged children with a disability through the NSW Department of Education and Training (DET). These programs include the provision of Special Education teachers, specialist intervention from Learning Support Teams and assistance with transportation (Department of Education and Training, 2009).

The local government sector is also a key player in the provision of disability services. Local councils will often have a Disability Services Team, or a combined Aged and Disability Team, whose role is to identify disability issues in the local area and to promote an accessible and integrated community. Employees of each Council's disability team will often manage an information and referral service and support local ageing and disability organisations by coordinating joint interagency meetings. They will also operate specific programs such as leisure activities for people with disabilities, older people and carers, and the International Day of People with Disabilities celebrations (e.g. Greater Taree City Council, 2009; Orange City Council, 2009).

A person with a disability in NSW faces a multitude of different government agencies at local, state and commonwealth level all providing variants of disability support services. Aged care services are similarly convoluted with respect to the over-arching government department. The Home and Community Care (HACC) Agreement is similar to the CSTDA, with the Commonwealth Department of Health and Ageing (DoHA) working with the various state departments with respect to the provision of aged care services. The target group for the HACC programs are frail older people, younger people with a disability and unpaid carers who are living in the community (Department of Health and Ageing, 2009a).

DoHA retains responsibility for overseeing all Residential Aged Care Facilities as well as the home based Extended Aged Care at Home (EACH), Extended Aged Care at Home Dementia (EACHD) and Community Aged Care Packages (CACP) programs. The provision of funding for these programs is currently split between the Commonwealth and the individual, who has to provide a monetary contribution towards the cost of their personal care. The percentage of this contribution can vary quite significantly from person to person and from program to program. On average, the Commonwealth Government funds 95 percent of a $40 650 EACH package, with the remaining 5 percent coming from the individual. However, an average person in a Residential Low Care placement contributes 53 percent of the annual $34 990 cost (Department of Health and Ageing, 2008b).

Commonwealth funded HACC services include specific support programs such as Meals-on-Wheels and Community Transport as well as personal care, linen services, home help, home nursing and respite. It can also assist individuals with home modifications, maintenance and support to access their community. These services are all outsourced to non-government organisations for implementation across Australia (Department of Health and Ageing, 2009a).

In NSW, DADHC is funded through the bi-lateral Commonwealth and State Home and Community Care (HACC) Agreement to directly provide the Home Care Service. This program assists people with domestic and personal care issues as well as the provision of respite (Department of Ageing, Disability and Home Care, 2009c). Currently, the Commonwealth Government funds 60 percent of the cost of the Home and Community Care programs while each of the individual states covers the remaining 40 percent (Department of Health and Ageing, 2008b). Local councils also provide a variety of aged care services such as dementia care support groups and special event functions (e.g. Armidale Dumaresq Council, 2009).

The issue of service provision for people ageing with an intellectual disability has not been adequately addressed within the current service system (Bigby, 2008a). Determining which level of government is relevant, and then which actual government department within that tier is responsible for service provision to a person with a disability, is complicated. However, the situation becomes even more complex when attempting to ascertain what ageing services the person may also be eligible to receive. A common complaint from both service users and providers stems from the considerable confusion that arises from the many different government funding departments for ageing and disability, as described below:

> no firm policies exist that actually provide mechanisms to support ageing in place, define reasonable expectations, or stipulate which system or systems – aged care, community care, disability, or health – has responsibility for funding this strategy. (Bigby, 2008a, p. 81)

While the HACC program specifically mentions support for younger people with disabilities, it also excludes anyone with a disability who is already receiving accommodation support. This distinction is based upon the premise that the individual will be 'double-dipping' and receiving commonwealth funding for support that should be provided by the state funded disability provider (Australian Council for the Rehabilitation of the Disabled, 2002). However, it actually often means that people with disabilities who are ageing are effectively excluded from receiving home care support as their individual needs change (Bigby, 2008a). This problem is not isolated to Australia, and is similarly reported in other countries including Great Britain (Bland et al, 2003; Walker & Walker, 1998b).

As an example of this situation, a person with a mild disability who has been allocated a very small funding package that provides one to two hours per week of independent living support is not able to access HACC services as they start to experience additional support needs associated with their ageing (Kerrie Nixon, pers. comm., 11 December, 2009). There is no easy process for disability accommodation support money to be increased through the state funding body, DADHC, and the avenue of accessing generic aged care support is also denied to people with disabilities who receive accommodation support.

This problem was identified by the Australian Institute of Health and Welfare in a 2006 report which commented on the concerns of disability service organisations by noting

> while they are able to provide services to address a wide range of client needs, the level of those services may be insufficient to fully meet needs that are becoming more complex as clients age. (Australian Institute of Health and Welfare, 2006, p. 181)

People with disabilities and older people are effectively considered as two completely separate groups with respect to support structures funding. Services are established and funded separately by differing levels of government. The current CSTDA identifies the need for greater interaction between the ageing and disability sectors in the various levels of government; however, this goal has not been achieved (National Disability Services, 2007c). The distinctions and boundaries between multiple sets of administrative structures result in difficulties in ascertaining who is responsible for individuals who have issues relating to their ageing and an existing intellectual disability. While DADHC provides and oversees both disability and ageing programs, within their own guidelines for accessing services for people with disabilities there is an exclusion clause covering situations in which

> there are other sources of support available (for example, older people might be assisted to investigate services available through the aged care system before funded assistance is considered). (Department of Ageing, Disability and Home Care, 2003, p. 2)

Discussions with service providers have indicated that this exclusion has been interpreted by some DADHC officers as a means of declaring anyone over the age of sixty-five ineligible for disability programs as they no longer meet the guidelines and a referral to a commonwealth program is the only possible option (Nicola Chirlian, pers. comm., 31 August 2009). The trend of attempting to transfer the responsibility for ageing people with disabilities from a state to Commonwealth Government is not new. Bigby (1998) noted an unwritten, but still implicit, system at a state level of reducing disability services and attempting to move people instead into aged care models.

It was identified in the 1990s that all levels of government had recognised the problems presented by ageing with a disability but as yet no specific solutions or programs had been developed (Kunkel & Applebaum, 1992; Parmenter, 1993). In 2001, it was again recommended that clear policies needed to be developed and implemented by Australian governments to address the issues of ageing and intellectual disability (Andrews, 2001). However, there was no change in policy frameworks at either a state or commonwealth level. Bigby (2008a, p. 80) commented on this issue, saying that "no systematic development of specific arrangements for people ageing with ID has eventuated". In 2010 there is still no unified government policy direction for ageing and intellectual disability. This problem is not limited to Australia, with a similar lack of government direction on ageing with an intellectual disability reported in countries including the USA, UK, Ireland and Canada (Bigby, 2010).

Over the past two decades, the disability sector in NSW has been attempting to achieve a transition from the prevailing model of isolationism and segregation to a newer system of inclusive, individualised and person centred programs (Department of Ageing, Disability and Home Care, 2006). Medium and large scale institutions with hundreds of residents living on-mass at the one site have been closing with the individuals re-located into houses within their local communities (Bigby, 1999; Edmundson et al, 2005; Young & Ashman, 2004). Much of the policy development within the disability sector relates primarily to younger people with disabilities, with the issues associated with the ageing of people only recently being recognised as a high priority (Bigby, 2004). A distinction between the service models of aged care and disability is seen in the individually focussed person centred system now inherent to the disability service provision in NSW (Department of Ageing, Disability and Home Care, 2008b). The focus of disability organisations is upon meeting the individual goals and needs of each person with an intellectual disability. In contrast, many aged care accommodation models are still based around the premise of massed congregated care, such as residential aged care facilities.

As discussed in section *1.3 Theoretical Framework for the Current Study*, the disability sector has moved from the predominant medical model towards a more socially inclusive approach. In contrast, much of the policy within the residential aged care sector relates to dementia and frail aged, with an emphasis upon the provision of health care. The primary focus of residential aged accommodation services is to provide appropriate nursing and clinical care within a safe and comfortable environment (Aged Care Standards and Accreditation, 2009). Residential aged care services are only available for those individuals who are deemed by an Aged Care Assessment Team (ACAT) as being unable to continue to maintain an independent life in their own home environment (Department of Health and Ageing, 2009b). This framework means that most people assessed as eligible for residential aged care have experienced a loss in personal skills. The person centred approach inherent to the disability sector, however, focuses upon the development of new skills, abilities and experiences. It has been noted that

> aged care services are based largely upon a perception of decline, leading inexorably to death. Demands are therefore few and expectations lowered. By contrast, disability services are based upon a developmental approach. (Leveratt, Bowers & Webber, 2005, p. 17)

A number of key elements of the *Disability Service Act* and cornerstones of disability service provision, such as individual planning and a person centred approach, are not necessarily emphasised strongly within the mainstream aged care accommodation system. One of the most common themes within the Commonwealth Government's review of younger people with disabilities within the residential aged care system was the lack of appropriate individual and person centred planning (Department of Families, Community Services and Indigenous Affairs, 2008).

The Ascent Group (formerly known as Challenge Armidale) coordinated the first national conference in Australia on ageing and disability on 12 and 13 May 1994. Titled the 'National Forum of Ageing and Disability', this conference was attended by parents, government officials, academics, service providers and other interested stakeholders from across Australasia. Janet Murphy from the Commonwealth Government Department of Human Services and Health made a presentation to this forum. In her paper, Murphy commented that there were a number of principles which should guide government and community with respect to the issues of ageing with a disability. These included:

- People should be able to access services appropriate to their need,
- Programs should be flexible enough to allow for special circumstances of individuals,
- People should be able to access packages of support, whether funded by both or one level of government, in line with their needs,
- Identified gaps in service delivery should be addressed as a matter of priority,
- People (young or old) should not be denied access to an appropriate service on the basis of age alone,
- Data collection and analysis should underpin major policy or program changes, and
- Cost shifting between levels of government should be minimised. (Murphy, 1994, p. 7)

Murphy concluded that these problems were not easily or quickly resolved when there were multiple levels of government involved. The fact that over fifteen years have passed since Murphy commented on these issues and yet they are still unresolved and as current as they were in 1994 indicates that the existing system of three tiered government bureaucracy is not working for ageing people with disabilities.

2.3 The Ageing of People with Intellectual Disabilities

Many different factors, such as the health and lifestyle of the individual as well as her/his own particular genetic makeup, play a role in determining the ageing process that a person will experience. In the 21st Century, people with an intellectual disability will generally experience similar age-related issues as the mainstream community (Haveman et al, 2009). However, ageing within the intellectual disability population is a relatively new development in terms of a research focus (World Health Organization, 2000). One of the earliest research papers on the issue of ageing and disability was written in USA in the early 1960s, with the report detailing the need for improved planning and additional funding for individuals (Dybwad, 1962). Further research over the following decade was spasmodic, with papers by Baller, Charles and Miller (1967) and O'Connor, Justice and Warren (1970) commenting on the changing requirements of ageing people with a disability who were in residential care placements. Andrews (1972) was one of the first people in Australia to specifically examine the problems associated with the ageing of people with intellectual disabilities.

From the 1970s to the 1990s, studies into the ageing and intellectual disability issue became more prevalent with much of this research undertaken in the United States and Europe. Studies were conducted around the world into a variety of different aspects of ageing and intellectual disability including its occurrence (Epple, Jacobson & Janicki, 1985), predicted life-span (Eyman & Widaman, 1987), language training opportunities for older people (Kleitsch, Whitman & Santos, 1983), deinstitutionalisation (Benz, Halpern & Close, 1986), medical problems (Callison et al, 1971), bereavement and grief (Bonnell-Pascaul et al, 1999), qualify of life (Brown, 1993), and social care issues (Cantor & Little, 1985). Australian researchers studied issues including demographic details (Bigby, 1994), life circumstances (Ashman, Hulme & Suttie, 1990), decision making by ageing carers (Grant, 1989), and health issues (Beange, McElduff & Baker, 1995; Lennox & Kerr, 1997).

The area of ageing with an intellectual disability was not subject to significant research in Australia prior to the 1990s (Bigby, 2004); however, it has expanded in recent years and the literature base has rapidly grown. The processes associated with deinstitutionalisation and community integration, combined with social role valorization, normalization and other similar philosophies, have contributed to a greater acceptance of people with disabilities. Recognition of the problems associated with ageing has occurred in both the government and public media, with the issue of ageing people with an intellectual disability gaining prominence in response to this group's increased life expectancy (Ashman, Hulme & Suttie, 1990).

While ageing cannot be easily or definitively aligned with set chronological figures (see section *2.2.2 What is Ageing?*), many Australian Government departments use the pension age of sixty-five as a starting point for estimating the ageing of the total population (Australian Government, 2007). From 1991 to 2001, the total number of people in Australia over the age of sixty-five increased by 22 percent. It was predicted that the proportion of people over the age of sixty-five will continue to increase until at least 2021, when this cohort will form approximately 18 percent of the national population (Department of Family and Community Services, 2002). In 2006, the average life expectancy of an Australian female was estimated to be eighty-three and a half years, with this figure decreasing to approximately seventy-nine for males (Australian Institute of Health and Welfare, 2008c).

The population of people with an intellectual disability has also followed a similar trend to the mainstream with the past years seeing an increasing proportion of people over the age of sixty-five (Bigby, 2004). An American study has estimated that there is now only a 2 percent difference in life expectancy between the mainstream population and people with a mild intellectual disability (Janicki et al, 1999). A study of people in Western Australia showed that the life expectancy of a person with Down Syndrome was approaching that of the general community (Glasson et al, 2002). It was, however, noted by Torr et al (2010) that the life expectancy for people with Down Syndrome would plateau in the sixties as a result of the likelihood of early onset Alzheimer's related death in this group. Australian research by Bittles et al (2002) made a series of predictions of life expectancy, differentiated on the basis of the extent of the intellectual disability. This study predicted that people with a mild intellectual disability would have a life expectancy of seventy-four years. This figure dropped to sixty-seven years for a person with a moderate intellectual disability while individuals with severe and profound intellectual disabilities were envisaged to have a life expectancy of fifty-nine years.

As a consequence of the variance in data collection and classifications of intellectual disability (see section *2.2.1 Definitions of Intellectual Disability*), an accurate determination of the number of people with an intellectual disability in NSW is not currently available. Figures from government agencies estimated that around 0.5 percent of the population has an intellectual disability (Australian Institute of Health and Welfare, 2000). The Australian Bureau of Statistics (ABS) 1993 Survey of Disability, Ageing and Carers concluded that there were 328 000 people, or 1.86 percent of the total population, with an intellectual disability (Australian Bureau of Statistics, 1993). It is worth noting that there were limitations to this survey with some sub-groups, such as prisoners, not included in the figures and, as such, the actual figure was likely to be higher. The ABS 1998 and 2003 Surveys of Disability, Ageing and Carers used different criteria and methodologies; however, it was believed that the overall percentage of people with an intellectual disability had remained approximately the same as the 1993 Survey results (Australian Bureau of Statistics, 1998, 2003).

However, in 2008 the Australian Institute of Health and Welfare (AIHW) reported that 588 700 people in Australia had an intellectual disability, a figure that represented approximately 3 percent of the total Australian population. In excess of 150 000 people with intellectual disabilities were aged over sixty-five according to this study (Australian Institute of Health and Welfare, 2008a). It was also reported that there were 351 000 people with an intellectual disability with "severe or profound core activity limitation" (Australian Institute of Health and Welfare, 2008a, p. 3), which represents 1.8 percent of the total Australian population. This figure of 1.8 percent equates approximately to the ABS 1993 survey for the total proportion of people with an intellectual disability and may be reflective of variations in diagnosis and classification over the years.

2.3.1 Different Factors of Ageing with an Intellectual Disability

The ageing of people with an intellectual disability is a complex process and can be influenced by a large variety of factors. Within the different sub-groups of people with an intellectual disability, the influence of these factors will have a varied impact and intensity. It is important to recognise the distinction between how ageing issues affect a specific individual in contrast to the ageing of the entire population or sub-groups of it (Gibson, 1998). The issues associated with the ageing of a population of people are primarily viewed with respect to the key demographic factors that become evident within that group. Changes in these demographics can have the potential to cause significant and substantial impacts upon the society. The Australian Institute of Health and Welfare (1999a, p. 3) noted that “population ageing is a result of the interaction of three basic demographic components: fertility, mortality and migration”. The ageing of the people with an intellectual disability sub-group of the Australian community is largely attributable to the decreasing mortality rate, particularly during the early years of life (Australian Institute of Health and Welfare, 2000).

The statistical increase in life-span has resulted in a large number of people with an intellectual disability starting to experience ageing-related problems and to require specialised aged care services; a situation that the government and wider community is largely ill-equipped to deal with at the present time (Bigby, 2008a). A natural consequence of the increased life expectancy is a larger total number of people with an intellectual disability. This change will naturally result in even greater pressures being placed upon the existing residential services and the staff employed by them. Services for people with disabilities in Australia are currently underfunded in many areas, with substantial unmet needs (Australian Institute of Health and Welfare, 2002; 2008a). Within these identified unmet needs, one of the most critical factors is the provision of residential support services (Australian Institute of Health and Welfare, 2008a; Stancliffe, Lakin & Prouty, 2005).

In contrast to the ageing of the entire population of people with an intellectual disability, the ageing of a specific person is best considered with respect to the impact the individual actually experiences as a direct result of the ageing process. These factors may include changes or reductions in the person’s living skills in areas such as sensory, motor, behaviour and cognitive functioning. Individuals will each experience ageing in a manner unique to them, and the speed with which s/he ages will be dependent upon a variety of issues such as biology, psychology, social interactions, support structures and culture (McPherson, 1990). One of the most important aspects of ageing that needs to be recognised by service providers, staff and families is the fact that it is not a one-off event; it is a process that takes place over the entirety of a person's life. Each individual will age at a different rate and will experience age-related changes at different times of his/her life. This viewpoint is summarised succinctly with the statement that "'being old' is not a fixed static state identical for all people, but rather an evolving process affecting each person differently" (Bigby, 2004, p. 41).

Chronological ageing should only be seen as an average benchmark against which assessments can be measured to establish a comparative level of functioning. The natural differences that exist between individuals will mean that there is a substantial variance in the age at which certain factors may become significant. Nonetheless, ageing is still often defined simplistically upon the basis of an individual reaching a specified chronological age. Within the mainstream community, ages such as sixty-five, seventy-five and eighty-five are commonly cited as the basis for delineation (Bigby, 2004). Many government departments will not even consider the ageing needs of an individual unless they have met one of these artificially determined anniversaries (Nicola Chirlian, pers. comm., 6 February 2009). The fundamental flaw with using chronological age as the prime determinant for support is that it implies individuals will acquire a range of problems upon reaching a certain benchmark. While it may appear self-apparent that a multitude of age-related issues do not suddenly appear upon a person's birthday, the lack of flexibility within aged care guidelines, assessments and systems is not necessarily conducive to the concept of an ageing process. Instead it is often predicated on reaching a pre-determined chronological milestone.

Ageing is a multi-factorial issue and cannot be viewed purely in terms of chronology in isolation. Ageing incorporates changes in three primary areas: social, psychological and physical/biological. In the past, there was a focus predominantly on the medical and biological aspects associated with ageing. However, in recent years there has been an increasing recognition of the importance of the psychological and social impacts as people grow older (Hayslip

& Panek, 1989). Ageing is “a holistic, subtle, individual, progressive, and lengthy process of change and adaptation” (Lubinski & Higginbotham, 1997, p. 5). The biological factors of ageing are primarily associated with the changes in a person’s ability to perform everyday tasks that can be attributed to the deterioration of specific physical functions and also in terms of the overall health of the individual (Haveman et al, 2009). Psychological ageing refers to the responses that each individual has to the “biological, cognitive, sensory, motor, emotional, and behavioural changes and to external environmental factors affecting these changes” (Australian Institute of Health and Welfare, 1999a, p. 4). These changes can manifest themselves in terms of the person’s mental capacities, such as memory or the learning of skills, as well as the individual’s personality and emotional state (Baltes & Baltes, 1990).

Social ageing is the way in which a person’s level of involvement with their local community changes, often through a reduction in her/his capacity to interact with the social environment (Minichiello & Coulson, 2005). The social impact of ageing can be seen through an alteration in the relationships with family members and friends, as well as changes in role within the wider community of work and recreational organisations (McPherson, 1990). Social ageing also incorporates aspects of the individual’s history, which takes into account the various opportunities and discriminations the individual may have encountered and how these experiences have shaped his/her life (Haveman et al, 2009). The physical, psychological and social perspectives to ageing each emphasise different associated changes.

While all of these factors are often considered to develop almost independently of each other, Minichiello, Browning and Aroni (1992) proposed a biopsychosocial model that considered the interplay between the three perspectives. They argued that there was a complex inter-relationship between the physical, psychological and social perspectives of ageing. It was considered this relationship could be understood better by examining all health related concerns in conjunction with the psychological and social impacts caused by the decline in physical wellbeing.

In addition to the effect that these changes will have upon the individual who is ageing, there are a number of other issues associated with the expectations, prejudices and biases of the individual's family, the staff that support him/her and the wider community. There are considerable societal pressures and beliefs regarding all people who are ageing, which can manifest in discrimination and devaluation (Minichiello & Coulson, 2005). For a person with an intellectual disability, the process of ageing can compound of the existing stereotypes and disadvantages they have experienced throughout their life (Bigby, 2004).

One of the other significant problems associated with the belief that age is a specific time linked event is that family members and support staff may start to interpret all health, well-being and behavioural issues purely in light of a perception that the individual is ageing. It is easy for families and service providers to assume all changes in a person are age-related, rather than ensuring that the same medical checks are performed as with a younger person with a disability who presented with similar symptomatology.

2.4 Successful Ageing

The recognition of the problems associated with using a set chronological figure as a determinant for the commencing of ageing was one of the driving forces behind the development of theoretical models that more realistically defined the ageing process. A number of alternative definitions have been hypothesised that attempt to more accurately describe the ageing of a person through incorporating the associated physical, social, cultural and psychological components of the ageing process. The World Health Organization (WHO) (e.g. World Health Organization, 2000) and researchers such as Janicki (e.g. Janicki & Dalton, 1999) have attempted to redefine ageing in a more positive light and, through this change, more effectively evaluate its non-chronological aspects.

The concept that ageing should not simply be viewed in negative terms and that ageing is not necessarily linked to a complete decline in functioning has been written about for centuries. The Roman senator Cicero argued strongly in his essay, titled *Cato Maior de Senectute,* that old age provided an opportunity for continued productivity and contribution to society (Cicero, 44 BC). Similarly, William Shakespeare, in *The Merchant of Venice*, promoted the concept that people may be happier in their later years, exemplified by Gratiano's quote that "with mirth and laughter let old wrinkles come" (Shakespeare, 1598, Act Two, Scene One, online). Henry Wadsworth Longfellow was another who considered growing old was not necessarily an undesirable thing and that, with age, could come other opportunities. His poem, *Morituri Salutamus,* noted that

> Age is opportunity no less,
> Than youth itself, though in another dress,
> And as the evening twilight fades away,
> The sky is filled with stars, invisible by day. (Longfellow, 1825, online)

In more recent years, the concept of 'successful ageing' has been proposed (Battersby, 1998) and, in part, attempts to address the belief that ageing is inherently associated with an inevitable and significant decline in individual functioning.

The concepts of successful ageing are largely interchangeable with similar terms such as 'healthy ageing' or 'active ageing' (Barr, 2001). The term 'successful ageing' was first proposed in the 1960s by researchers such as Havighurst (1961) and Williams and Wirths (1965). The development of this concept was in direct competition to 'disengagement theory', which promoted the premise that older people deliberately chose to remove themselves from their usual daily routines in order to prepare themselves for inevitable death (Cumming & Henry, 1961). However, it was not until the 1980s and 90s that successful ageing started to gain widespread acceptance within the gerontology sector (Butt & Beiser, 1987; Rowe & Khan, 1987).

Successful ageing does not have one set definition (Depp & Jeste, 2006) but is considered to refer to an individual's ability to maintain his/her physical health, intellectual functioning and social life as s/he ages (Battersby, 1998). An important component of successful ageing involves ensuring that individuals still retain the right to make decisions and be involved in all practical aspects of their daily life (Rowe & Khan, 1997). Affirmative words such as 'successful' or 'healthy' are used to reinforce the perception that ageing is not necessarily negative and that an individual can still have a high quality of life as s/he grows older. The ageing of a person can be considered healthy or successful when

> an individual retaining his or her capacities to function as independently as possible into old age and promoting the belief that those who age successfully are able to remain out of institutions, maintain their autonomy and competence in all activities of daily living and continue to engage in productive endeavours of their own choosing. (Janicki, 1994, p. 146)

One approach to successful ageing sees it conceptualised across the entire life cycle. The Lifecourse perspective to ageing reviews both current and prior living environments, culture and actions of the individual (Kuh, 2007). The ability to live independently as the person ages is considered to be the culmination of her/his life experiences and circumstances. The Lifecourse approach considers and incorporates the impact that society and culture has upon the ageing process (Priestly, 2003) which, considering the many barriers and discrimination that people with disabilities report experiencing (e.g. Abbott & McConkey, 2006), are issues of particular relevance. It involves factors that can be positively or negatively influenced by the individual such as healthy and appropriate lifestyle choices, as well as uncontrollable factors including socio-economic disadvantage and environmental hazards (National Disability Authority, 2006). The Lifecourse perspective on successful ageing takes into account the often very different timeframes associated with the ageing of people with an intellectual disability, as well as the potentially longstanding experiences of discrimination and disadvantage (Bigby, 2005b).

Baltes and Baltes (1990) proposed a model focussing upon how people age successfully rather than merely noting the meeting of certain set criteria. They considered successful ageing to be reflected by the capacity of a person to compensate for any losses associated with ageing in one life domain with gains in another aspect of living. The research over the past two decades has continued to focus upon the processes of successful ageing and in developing models that detail how the issues of ageing can be managed in order to continue to enjoy and participate in normal activities. Successful ageing is not viewed as a perfect scenario in which no changes occur; rather it is conceptualised as supporting people to maintain their quality of life by appropriately coping with, and adapting to, any negative issues as they arise (Ouwehand, de Ridder & Bensing, 2007).

2.4.1 Successful Ageing for a Person with an Intellectual Disability

The concept of successful ageing is as applicable to the cohort of people with intellectual disabilities as it is to the mainstream population. While it may seem apparent that people with intellectual disabilities face a number of additional barriers in order to age successfully when compared to the mainstream community, it should not be automatically assumed that every individual will experience significantly worse problems (Fyffe, 2003). The World Health Organization (2000, p. 7) commented specifically upon this issue in saying

> it is important to underline the fact that many ageing persons with intellectual disabilities may be just as healthy as other older persons without life-long disabilities.

However, the reality is that there are a number of factors that do impact upon the capacity of people with intellectual disabilities to age successfully. The funding of this group as they age is particularly problematic, with considerable confusion between the various tiers of government regarding who is responsible for the provision of services to this group (see section *2.2.6 Australian Funding of Disability and Aged Care Services*). There are arguments regarding what constitutes the person’s main support needs and what are the predominant problems the individual is experiencing. This approach leads to a focus upon areas of weakness rather than the continuing strengths of the individual. It can result in a distorted view that ageing people with intellectual disabilities are more dependent and require a greater level of care than actually needed. The concentration upon the care needs of the individual rather than upon the maintenance of existing skills and abilities can result in a situation in which people with intellectual disabilities are viewed as being non-productive and reliant upon external assistance as they age (Llewellyn et al, 2004).

It is considered that the generic concepts inherent to the various successful ageing models are fundamentally consistent with the existing philosophies of the disability sector in NSW. The underpinning belief that people do not suddenly develop new problems when a chronological milestone is reached, combined with the rationale of supporting people to maintain their independence with appropriate assistance, are important factors in assisting individuals with intellectual disabilities as they age. Nonetheless, there are a number of specific issues that must be taken into account when considering how to support the successful ageing of people with intellectual disabilities.

2.4.1.1 Health Issues

An important aspect of the current population of people with intellectual disabilities who are ageing relates to their general level of health. As noted by Bigby (2004), this group is the first generation of people with intellectual disabilities to reach old age in considerable numbers. Part of the reason for this change relates to the improved health services provided to people with disabilities during their childhood. Changes in treatment and attitudes in the past century have seen individuals with more severe disabilities supported to live past childhood and into adulthood. However, there is evidence of a generation gap in which the people with intellectual disabilities reaching older age have predominantly been those with more minor health issues. This factor is noted in research in the United Kingdom where they have recognised that

> older people with learning difficulties are likely to have lower levels of learning difficulty than younger cohorts. This difference has mainly come about because babies with severe learning difficulties who were born over 50 years ago would have had much less chance of surviving into adulthood than their contemporary counterparts. (Walker & Walker, 1998a, p. 126)

The World Health Organisation (WHO) also notes this issue, referring to the concept of 'differential mortality' which is the "tendency for healthier people to live longer. Thus older cohorts may actually be healthier in many domains than younger groups of persons with intellectual disabilities" (World Health Organization, 2000, p. 7). The factor of differential mortality may actually be disguising the extent of the problems associated with the successful ageing of people with intellectual disabilities, with the full impact only becoming apparent in the future generations which contain a higher proportion of people with more severe lifelong disabilities and health related problems. However, even when accounting for the issue of differential mortality, research shows that ageing people with intellectual disabilities have a high incidence of many health related problems (Evenhuis et al, 2001).

One of the major impediments to the successful ageing process is a decline in the physical and mental health of the individual. As people with an intellectual disability age many will experience similar health management issues as the general population (Davidson et al, 2004). People with an intellectual disability share with the mainstream community many of the same issues associated with the ageing process; however, they have a series of distinct problems that pose specific impediments to their quality of life. Scheepers et al (2005) reported on the significant health disparities experienced by people with intellectual disabilities in the provision of medical and social services around the world. However, it was noted that there are cultural differences in the prevalence of certain health issues around the world (Haveman et al, 2010).

It has been identified in Australia that people with disabilities were significantly disadvantaged in their health status in comparison to the general community as a result of socioeconomic factors as well as simple "discrimination and ignorance" (Durvasula & Beange, 2001, p. 27). It was noted in the *A Healthier Future For All Australians Interim Report* that

> people with a long-term disability are among the most disadvantaged, and invisible, groups in our community, with very poor health status and a health system that often fails to meet their special needs. This includes people with an intellectual disability ... as well as people with other long-term physical and mental conditions. (National Health and Hospitals Reform Commission, 2009, p. 54)

The report further commented that

> there are stark health and access inequalities for people with an intellectual disability. There are currently over 300,000 Australians with intellectual disabilities, many of whom have health outcomes at least as bad as our Aboriginal and Torres Strait Islander peoples. (National Health and Hospitals Reform Commission, 2009, p. 55)

Individuals with an intellectual disability are likely to experience additional complications that make appropriate clinical management very important (Beange, Lennox & Parmenter, 1999). For people with high support needs and limited communication skills a correct diagnosis can be difficult as the individual may not be able to accurately convey to doctors what s/he is experiencing (Hogg, 2001). It was noted by Haveman (2004) that many carers and staff act as the proxy 'voice' at the doctor for people with communication problems and, as such, the actual prevalence of health conditions may be far higher than currently recorded as a consequence of under-diagnosis. As the person ages, neither the doctor nor the individual's family or carers may recognise the early signs of age-related health problems. This situation is the result of the fact that they may not have had appropriate training to identify when a change is due to a deterioration in health, rather than stemming from behavioural issues associated with the intellectual disability (Alborz et al, 2003; Lennox, Diggens & Ugoni, 1997).

Both Australian and overseas studies have shown that, even before they start ageing, people with intellectual disabilities are more likely to have serious health problems during their lifespan than the mainstream population. An Australian study by Beange, McElduff and Baker (1995) showed that the sub-group of people with intellectual disabilities had, on average, five serious medical conditions. It was believed that, of these five serious conditions, at least half had either not been previously diagnosed or were not undergoing treatment. It was further reported that:

- People with intellectual disabilities both saw doctors and were admitted to hospital at twice the rate of the general community,

- Statistically, more than 50 percent of people with intellectual disabilities took prescription drugs on a daily basis, with over 30 percent taking more than one drug per day,
- Over 30 percent of people with intellectual disabilities also had epilepsy,
- This group was affected by blindness at twenty times and deafness at twelve times the rate of the mainstream community,
- Nearly 10 percent of people with intellectual disabilities had a dual diagnosis with a psychiatric disability, and
- Dental diseases were also extremely commonplace, with 86 percent of people with an intellectual disability having problems with their teeth or gums (Beange, McElduff & Baker, 1995).

Further studies in the 15 years since the work of Beange, McElduff and Baker have continued to reveal a wide range of problems relating to the health of people with intellectual disabilities. Australian people with intellectual disabilities were found to be more likely than the mainstream population to be obese (Moore et al, 2004) and to have higher death rates from cardiovascular disease (Day et al, 2005). Problems with oral health care is particularly prevalent with significant concerns being raised in relation to the linkages of periodontal disease to potentially terminal conditions including stroke and cardiovascular problems (Waldman & Perlman, 2009). The incidence of auditory and visual problems was reported by Janicki and Dalton (1998) at levels higher than their equivalent mainstream peers for American people with intellectual disabilities. Overseas studies by Evenhuis (1997) and Janicki et al (2002) identified the increased risk of mobility problems in ageing people with intellectual disabilities from a variety of underlying causes, including musculoskeletal decline and bone fractures.

Durvasula, Beange and Baker (2002) examined the mortality of people with intellectual disabilities in Sydney and they concluded that, if regular health checks were conducted, some deaths within this sub-group were potentially avoidable. It was also estimated that 57 percent of Australians with an intellectual disability aged under sixty-five had a dual diagnosis of a psychiatric disability and that 24 percent of individuals experienced communication and speech problems (Australian Institute of Health and Welfare, 2008a). High levels of health care problems are strongly linked with a number of genetic conditions associated with an intellectual disability. For example, syndromes such as Angelman, Cornelia de Lange and Cri du Chat are all associated with specific health problems such as diseases of the nervous and digestive systems (Berg et al, 2007).

The *A Healthier Future For All Australians Interim Report* cited examples of health related inequalities for people with intellectual disabilities including:

> - There is a huge burden of undiagnosed illness. Only 29 per cent of health conditions are diagnosed and treated appropriately in this population. Some 42 per cent of health conditions go undiagnosed. And, even when health conditions are diagnosed, half of those patients still have their conditions inadequately managed.
>
> - Psychiatric disorders are among the conditions that are frequently not well diagnosed or managed in people with an intellectual disability.
>
> - Dental disease is up to seven times more common than in the general population. (National Health and Hospitals Reform Commission, 2009, p. 55)

These studies indicate that people with intellectual disabilities have an increased risk of experiencing health problems in comparison to other members of their local community.

In order to successfully address these health issues and inequities, a partnership between the individual, his/her carer and any medical or allied health staff is very desirable (Therapeutic Guidelines Limited, 2005). The general practitioner in rural communities is usually the main 'expert' that provides medical support and advice to people with intellectual disabilities and they have to deal with every medical issue that arises across all sectors of the community (NSW Rural Doctors Network, 2008). It is recommended that people with an intellectual disability have regular scheduled visits with a consistent general practitioner so that a comprehensive health record can be established (Therapeutic Guidelines Limited, 2005). It is noted that the process of an annual clinical review by a medical practitioner can assist in the early identification of both new and existing genetic, health or ageing related issues (Felce et al, 2008) and it allows families and carers to more successfully manage these problems.

In conjunction with the treating general practitioner, many supported accommodation services are starting to use a registered nurse to assess and monitor the genetic conditions, overall health and development of any aged-related problems (Kevin Mead, pers. comm., 7 August 2007). The conditions of particular concern in the older cohort of people with intellectual disabilities include:

> cardiorespiratory disorders, cerebrovascular disorders, hypertension, hyperlipidaemia, diabetes, vision and hearing impairments, osteoporosis, arthritis, impaired mobility, falls and fractures, gastrointestinal conditions such as gastro-oesophageal reflux disease and chronic constipation, incontinence, urinary tract infections, cancer, hypothyroidism, Parkinson's disease, depression, dementia. (Therapeutic Guidelines Limited, 2005, p. 81)

The Australian Association of Developmental Disability Medicine and the National and NSW Councils for Intellectual Disability made a submission to the 2008 *National Health and Hospitals Reform Commission*. This submission identified a number of factors that were considered to contribute to the discrepancy in health outcomes between the mainstream population and the sub-group of people with intellectual disabilities. These factors included:

- 'Diagnostic overlay' – health professionals may assume that the symptoms are part of the intellectual disability, not a separate health condition that requires treatment.

- Communication challenges – there will often be a need to spend much more time with people with an intellectual disability and many health professionals may not have sufficient training in how best to communicate with such patients.

- Workforce challenges – few health professionals will have specialised training or exposure to people with intellectual disabilities, recognising that there is a wide array of disabilities, often accompanied by other health problems.

- There is a lack of targeting of people with intellectual disabilities in health promotion and prevention strategies.

> - Other challenges include the high cost of providing comprehensive and holistic care for some people with an intellectual disability, the lack of support for families and carers, and the lack of societal value attached to people with intellectual disabilities. (National Health and Hospitals Reform Commission, 2009, p. 55)

An Australian study by Iacono et al (2003) reported that medical practitioners were concerned about the appropriate assessment and health care management for people with disabilities. The Ascent Group, a disability support organisation based in rural NSW, successfully applied for funding through the *Reframing the Future Community of Practice* in 2002. The purpose of this project was to establish a regional assessment group with the goal of developing a health care checklist for general practitioners to use with people with intellectual disabilities. The grant enabled the New England region to bring together staff members from the Department of Health, the Department of Ageing, Disability and Home Care (DADHC), allied health practitioners, general practitioners through the New England Division of General Practice, clients and direct care staff (Kevin Mead, pers. comm, 11 December, 2007). This project culminated in the development of the New England Division of General Practice's Intellectual Developmental Disability Health Check List. The purpose of this checklist was to

> provide a structured clinical framework for GPs to comprehensively assess the physical, psychological and social function of patients with an intellectual disability and to identify any medical intervention and preventative health care required. (New England Division of General Practice, 2009b, p. 1)

The checklist received very positive feedback from both internal and external reviewers, including the NSW Community Services Commissioner Robert Fitzgerald, who recommended its implementation across the state (Armidale Express, 2002). The checklist is now widely used by both service providers and medical practitioners across the northern region of NSW (New England Division of General Practice, 2009a, 2009c); however, Fitzgerald's recommendation does not appear to have been followed through in other regions of the state.

The New England Division of General Practice's Intellectual Developmental Disability Health CheckList was specifically developed in accordance with the Medicare Benefits system. In recent years, the Australian Government has made available a number of additional specialised items on the Medicare Benefits Schedule to assist general practitioners to appropriately manage the health care needs of people with chronic medical conditions, such as an intellectual disability. The goal of these Medicare items is to assist the treating general practitioner to plan complex cases and, through this planning process, facilitate the individual with the intellectual disability to access additional allied health services including audiologists, diabetic consultants, chiropodists, podiatrists, chiropractors, exercise physiologists, psychologists and mental health workers, osteopaths, physiotherapists, dieticians, occupational therapists and speech pathologists (Department of Health and Ageing, 2009c).

These Chronic Disease Management (CDM) Medicare items are designed to combine the planning of the general practitioner with the services of the allied health professionals. It is recommended that every person with an intellectual disability should visit their treating doctor at least annually (Therapeutic Guidelines Limited, 2005) for a *GP Management Plan* (often identified as *Medicare Item 721*). During this visit the general practitioner assesses the medical status of the individual with an intellectual disability and develops a management plan that identifies appropriate treatments options, ongoing services and what referrals to other allied health professionals are required. This plan can also be reviewed after a period of six months through *Medicare Item 725 - Review of a GP Management Plan* (Department of Health and Ageing, 2009c).

A second Medicare CDM item of relevance to people with intellectual disabilities is the *Coordination of Team Care Arrangements* (*Medicare Item 723*). This CDM item provides the general practitioner with a rebate specifically to coordinate and oversee medical care for a person with very complex needs that requires consistent and ongoing care from at least three different allied health care providers. This item was designed to be of particular use for people with an intellectual disability who may be either residing in the community or with their parents and who do not have regular assistance from a disability support agency (Department of Health and Ageing, 2009c). The CDM Item *General Practitioner Contribution to a Resident's Care Plan* is of growing importance to ageing people with an intellectual disability. This *Medicare Item 731* allows a general practitioner to contribute to a multidisciplinary care plan that is developed by another health or care provider for a resident of an aged care facility. This process involves the general practitioner collaborating and assisting the residential aged care provider and other associated health professionals in the development of a health care plan for a person with complex needs (Department of Health and Ageing, 2009c).

As the individual gets older, the issues associated with age-related disability, when added to the problems with the pre-existing intellectual disability, potentially result in a very difficult medical case (World Health Organization, 2000). The above mentioned specialist Medicare CDM items facilitate the capacity of doctors to address these complex scenarios. Until recent years, standard health screening options such as Papanicolaou (pap) smears or mammographies were not regularly performed on people with intellectual disabilities (Wilkinson, Culpepper & Cerrato, 2007). Such testing is still not necessarily commonplace in this group (Haveman et al, 2009) and this problem is still significant in later years as preventative health screening of this type is recommended to occur on a scheduled basis until the age of at least seventy-five (Therapeutic Guidelines Limited, 2005). A change in the individual's ability to provide self-care, regardless of the person's overall proficiency in this area, may be an early indicator of age-related decline in competence. As such, it is recommended that an assessment of functional skills should take place on a regular basis, with any changes communicated to the doctor immediately (World Health Organization, 2000). It is vital for the treating general practitioner to seek supporting clinical information from a variety of relevant sources, such as family members, friends, staff and advocates and for the doctor's reports to then be clearly explained to carers (Kerr et al, 2003).

However, it is worth recognising that carers will not always provide an accurate or objective assessment. Staff will often work with the same group of individuals for long periods of time. A person within a group home often lives in this type of supported environment for many decades (e.g. Edmundson et al, 2005). Naturally, staff that support individuals for many years will become very familiar with, and can establish a very strong sense of attachment to, the clients living within the group home. The development of this relationship can present a series of problems as a resident starts to develop age-related health problems. Staff will often mistakenly believe that the emergence of psychological issues such as anxiety, depression and challenging behaviours are simply an ongoing factor associated with the individual's disability, rather than as an age-related problem or as a reaction to bereavement (Hollins & Esterhuyzen, 1997).

There appears to be a commonly held belief that all people with intellectual disabilities will age more quickly than the mainstream community. The origin of this viewpoint can probably be traced to the issues facing people with Down Syndrome, who may experience a number of early onset age-related problems (Evenhuis et al, 2001). Unfortunately, the needs of this sub-group of individuals with Down Syndrome have often simply been extrapolated to incorporate all people with intellectual disabilities. In order to take into account the issues facing people with Down Syndrome, some early researchers suggested that the age of forty should be adopted as the definition of 'ageing' for people with intellectual disabilities (Grant, 2001). While this proposal may have some merit in relation to the people with Down Syndrome, it is simply not appropriate to apply it universally. Many people with mild intellectual disabilities will not begin to experience ageing issues as prematurely as those with Down Syndrome (Haveman et al, 2009) and using the age of forty to define ageing for all the cohort is inaccurate. This phenomenon appears to reflect the problems associated with generically determining the ageing of a group of people, rather than considering the affect ageing has upon a certain individual (see section *2.2.2 What is Ageing?*).

Nonetheless, while the belief that all people with intellectual disabilities will definitely age much faster and at a significantly earlier age than the general community is a fallacy, it is true that some syndromes do experience specific aged-related health problems. For example, a person with Down Syndrome has a statistically higher chance of experiencing early onset dementia than the mainstream population (Dalton et al, 1999). Rates of dementia and Alzheimer's disease are also higher in people with an intellectual disability than the general community (Strydom et al, 2007). The early and accurate detection of dementia is particularly important for people with intellectual disabilities as it can have a major impact upon how services are delivered. Diagnosing dementia or Alzheimer's disease in people with an intellectual disability can be very problematic (Burt et al, 2005), with some standard diagnostic tools, such as the Mini-Mental State Examination, not validated for use in this sub-group (Therapeutic Guidelines Limited, 2005).

Functional decline can be inaccurately attributed to the process of ageing rather than the impact of other factors, including psychiatric and psychological disorders, sensory impairments, medical conditions and even medications (World Health Organization, 2000). If dementia is suspected, it is important that the family or support staff work in conjunction with the general practitioner or neurologist to develop both a baseline functioning level and a case history that can be used to determine deterioration in skills over time (Therapeutic Guidelines Limited, 2005). It is often difficult for a doctor to clearly differentiate between what is a challenging behaviour that may be stemming from an existing intellectual disability and what is a new action that may be a response to an emerging ageing issue, such as dementia or depression (Burt et al, 2005).

An Australian study by Iacono and Sutherland (2006) noted a potential concern relating to doctors who continued to use guidelines derived for the mainstream population without taking into account any disability related conditions. The introduction of specific Medicare CDM items is an encouraging development in the goal of assisting doctors to more appropriately assess and monitor any aged-related declines that may be evident in a person with an intellectual disability (Durvasula & Beange, 2001). These processes are an important component of the wider medical system designed to support people with disabilities to age successfully and live independently for as long as possible.

The need for specific medical assessment protocols is demonstrated by the fact that people with an intellectual disability are more likely to have the dual diagnosis of an additional mental health issue than the mainstream community (Cooper et al, 2007a). Determining the psychiatric health of people with an intellectual disability can present difficulties for families, staff members and general practitioners. Staff often do not have the necessary knowledge or information to accurately identify or recognise mental health issues (Costello, Bouras & Davis, 2007), or how to refer individuals on for further assessment (Piachaud, 1999). Likewise, psychiatrists in Australia believe they are generally "untrained and inexperienced" (Jess et al, 2007, p. 191) in supporting people with both an intellectual disability and a mental health issue.

There are a number of specific psychiatric conditions that need to be considered for people with an intellectual disability as they age. In particular, these conditions include "delirium, dementia, depression and chronic psychiatric disorders" (Therapeutic Guidelines Limited, 2005, p. 87). The symptoms of many psychiatric conditions include impaired attention, a decrease in memory or language, or changes in cognition, motor skills and emotional state (Therapeutic Guidelines Limited, 2005). Many of these symptoms can mirror behavioural problems and it can be difficult for family members or support staff to determine whether there is a new psychiatric condition associated with ageing or if it is simply the continuation of an existing behaviour. It is therefore important that any change in functional skills or behaviour in an older person with an intellectual disability is evaluated carefully (World Health Organization, 2000). The symptoms of some psychiatric conditions can hide the development of other serious diseases and treatment can be unnecessarily delayed until a proper diagnosis takes place (Therapeutic Guidelines Limited, 2005).

2.4.1.2 Ageing in Place

In 1997 the Australian Government reconceptualised its approach to the provision of aged care services. This change included the adoption of the 'ageing in place' support system to complement the existing residential and community based models (Australian Institute of Health and Welfare, 1999b). Ageing in place introduced a philosophy of providing personal assistance to individuals to facilitate them to remain in their own home and own community, and therefore avoid premature movement into a nursing home-style setting (Forbat, 2006). While some people in the general community make a 'sea change' or 'tree change' and move away from their traditional residence upon retirement (Burnley & Murphy, 2004), many older people choose to remain in their familiar home and local community as long as possible (Phillipson, 2007).

While ageing in place is in principle a mainstream concept, it would appear to have equal application to people with intellectual disabilities. However, a precise definition of what ageing in place means for an individual in supported accommodation has not been established. There are no clear government guidelines that outline the goals of ageing in place for people with intellectual disabilities. Within Australia, different service models have quite varied interpretations of exactly what ageing in place entails in reality.
Ageing in place can variously be considered as:

- continuing to reside within the same group home or supported accommodation option, but with additional assistance;
- remaining within the same group home, until such stage as the disability organisation is unable to provide the necessary level of expert care;
- staying within the same house, regardless of the additional expense, until the death of the individual; or
- moving to another group home setting, but with the same disability service provider and normally within the same approximate locality (Fyffe, Bigby & McCubbery, 2006).

Without a clear direction with respect to ageing in place for people with intellectual disabilities, undesirable consequences such as premature admissions to residential aged care facilities and a return to congregate care models remain possible.

As a means of trying to assist people to age successfully (as discussed in section *2.4 Successful Ageing*), community based aged care services have been implemented across New South Wales (NSW) over the past decade. One of the primary goals of this model is to assist people to remain in their familiar environment and to delay their entry into a residential aged care facility. The stated objects of the Commonwealth *Aged Care Act* of 1997 in Section 2.1 include the following clauses:

> (d) to ensure that aged care services are targeted towards the people with the greatest needs for those services;
> (e) to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location;
> (j) to promote ageing in place through the linking of care and support services to the places where older people prefer to live. (Commonwealth of Australia, 1997, pp. 3-4)

Home and Community Care (HACC) services are designed to provide low levels of support in the home, whilst the Community Aged Care Packages (CACP) and Extended Aged Care Packages (EACH) provide greater amounts of individual assistance to facilitate older people to remain living in their local community (Department of Ageing, Disability and Home Care, 2009c; Department of Health and Ageing, 2009a).

However, it is extremely difficult for a person who currently receives funded disability support to then gain additional assistance as they age. The Australian Senate has identified the problem of funding people ageing with an intellectual disability, recommending

> that funding arrangements and eligibility requirements should be made to allow supplemental aged care services to be made available to people with disabilities who are ageing, allowing them to age in place. Administrative funding arrangements should not impede access to aged care services for people with a disability who are ageing. (Senate Community Affairs Reference Committee, 2007, p. xii)

In spite of this key recommendation, the same barriers to obtaining appropriate support were still present in 2010. The 1997 *Aged Care Act* specifies a number of groups as 'people with special needs'. These categories include people in rural and remote locations, people from a non-English speaking background and people from Aboriginal or Torres Strait Islander communities, but do not recognise the special needs of people with disabilities (Commonwealth of Australia, 1997). A person with an intellectual disability who receives minimal independent living support from a disability support agency is not considered eligible to access relevant HACC services if they require additional support associated specifically with their ageing (National Disability Services, 2007c). Studies in Australia have shown that even when an individual with an intellectual disability is diagnosed with serious health issues such as dementia, there is no increased funding for the accommodation providers to deal with these changed support needs (Fyffe, Bigby & McCubbery, 2006; Janicki et al, 2005).

There is no easy process for disability accommodation support money to be increased through the NSW funding body, the Department of Ageing, Disability and Home Care (DADHC). As the avenue of accessing generic aged care support is also denied, people with disabilities who receive accommodation support are therefore often left in a 'limbo' situation. It was noted that "effectively these people are denied the right to 'age in place', a right that the broader community expects" (National Disability Services, 2007c, p. 4). Unfortunately, this situation has often only been resolved by the disability support organisation relinquishing its specific support programs and the individual with the disability moving into a specialist aged care facility (Kevin Mead, pers. comm., 28 July 2009). Surveys across Australia underline this problem, indicating that people with intellectual disabilities become residents within aged care facilities at a much younger age than the general population (Webber et al, 2006). It was also recognised that, as individuals entered a residential aged care facility, their involvement with, and support from, specialist disability providers largely ceased (Bigby, 1997).

These access issues are not limited to disability service providers. It has been identified that there is substantial unmet need for services for people with intellectual disabilities with ageing carers in rural areas of Australia (Eley et al, 2009). A large proportion of people with intellectual disabilities will be supported by, and continue to live with, their parents for the majority of their life (Beange & Taplin, 1996). However, there is an increasing proportion of this cohort who survive their parents and may have no living family members (Bigby, 2008b). It has been identified that the service provider often becomes the de facto advocate for the rights for many older people with intellectual disabilities who have no remaining close relatives who can independently fulfil that role (Bigby & Johnson, 1995).

A number of the key concerns of older parents of people with intellectual disability were identified by Weeks et al (2009) and these included issues such as a lack of funding, worries about the lack of service provider understanding of their needs, and the appropriateness of the proposed support model for their child. One of the most significant problems facing people with intellectual disabilities as they age is how they cope with the loss of their parents or primary caregivers. This issue is of concern to both these individuals and their parents who have provided care for them for many years. This worry was noted by Bigby (2000, p. ix): "'What will happen when I die' has become a major question and source of anxiety for parents of people with an intellectual disability".

The transition from the familiar family environment to a residential setting of some form is often seen as the only option available following the death of a primary carer or when the personal support needs of the individual begin to exceed the capacity of the ageing carers (Chenoweth, Newman & Burke, 2001; McCallion & Janicki, 1997). An Australian study of people with intellectual disabilities in residential aged care facilities identified this phenomenon, commenting that

> the largest proportion of residents were living with family prior to their move into residential aged care, and were generally admitted when their carer became ill or died, when their own health deteriorated or when family members could no longer provide the level of care or support they required. (Webber et al, 2006, p. x)

Griffin (1997) described a situation in which an Australian woman with a mild intellectual disability and Down Syndrome moved into a residential aged care facility at age twenty-seven. This individual did not have any signs of dementia, Alzheimer's disease, or indeed any other ageing related issues. The reason she had moved was because her mother, who was her carer, had to be admitted to a nursing home and the young woman had simply moved in at the same time. She was still living in the aged care facility fourteen years later, well after her mother had passed away.

Moving a person with an intellectual disability into a residential aged care facility is not a decision to be made quickly, regardless of his/her age (Bigby, 2000). Some reported problems with people with intellectual disabilities in residential aged care facilities include social isolation, boredom, an inability to participate in group activities and a shortage of resources to address their specific needs and requirements (Bigby et al, 2008). These issues are not surprising, when the potentially large disparity in age is considered. In one study, 30 percent of people with an intellectual disability in nursing homes were aged between thirty and sixty (Griffin, 1997), whereas the average age of mainstream residents was eighty-three years (Aged Care Association Australia, 2004). Surprisingly, half of this younger group were also considered to only have minor to moderate support needs (Griffin, 1997) and not the higher care needs normally associated with early entry into nursing care facilities (McConkey, 2005). It has been reported by Bigby et al (2008) that people with intellectual disabilities generally entered residential aged facilities at a younger age and then remained within this form of care for longer periods of time than the mainstream population.

Supporting the individual to remain in his/her home rather than move prematurely into a residential aged care facility is the central theme to the philosophy of ageing in place. Bigby (1997) detailed a number of cases where an individual remained in the community following the death of her/his parents and subsequently experienced newfound freedom and independence to pursue a variety of activities with appropriate support. However, ageing in place for people with intellectual disabilities is not readily supported by the government funding structures with the models of care not fitting the needs of this sub-group. Very few of the people surveyed by Bigby (1997) were supported to age in place and instead ended up in some form of residential facility. While the Australian Government has made available specific respite funding to assist older carers to look after their adult children with disabilities (Department of Families, Housing, Community Services and Indigenous Affairs, 2009g), it does not address the problem of what occurs following the death or permanent incapacitation of the carer.

While both aged care and disability service providers appear willing to address the problem, the additional resources required and lack of targeted government financial support prevent relevant ageing programs from occurring as a matter of course (Bigby & Balandin, 2005). It has been proposed that some of these problems could be mitigated if intellectual disability was categorised as a specific category for funding within the existing aged care system (Webber et al, 2006) but this solution has not been enacted. It was also noted that, while concerns about the care needs of adults with an intellectual disability and dementia have been identified, there remains a lack of relevant studies into the impact this issue has on carers and support staff. Gaps in current research include areas such as behavioural interventions, staff training and models of care (Courtenay, Jokinen & Strydom, 2010).

2.4.1.3 Retirement for People with Intellectual Disabilities

Retirement from employment is an important milestone for any worker. A precise definition of retirement is difficult as it varies with context. However, in general terms, retirement is taken to refer to the ending of an individual's paid working time and the commencement of the next stage of the person's life with more free time (Bowlby, 2007). While mainstream community members are able to plan and take advantage of their increased freedom for options such as overseas trips, social activities and more time with their family, the issues for people with an intellectual disability are more complex. Often, people with intellectual disabilities identify strongly with their employment and are loath to leave it voluntarily (Ashman, Suttie & Bramley, 1995). As a consequence, some organisations ultimately enforce retirement against the wishes of the individual (Brown, 1993). The relevance of the concept of retirement for people with intellectual disabilities is questioned (Bigby & Balandin, 2005), as is the issue of whether a person should 'retire' from a lifelong participation in alternative employment options such as a specialist disability day program (Bigby et al, 2004).

Without the day-time routine of going to work, an individual with an intellectual disability can often find his/herself isolated from friends and social opportunities (Bigby, 1997). For many people with an intellectual disability, they do not have a strong social network outside the disability service system (Bigby, 1992, 2008b). For someone with autism, the change in routine following retirement can be extremely problematic, particularly if s/he has been attending an employment option continuously for more than thirty years (Kerrie Sauer, pers. comm., 11 April 2007). Research has also suggested that the individual's financial situation, the level of support required and even his/her personal sense of purpose in life can be affected by retirement (Budge, 1998). If the individual does not have an alternative program in which to participate following retirement, further pressures are placed onto carers who have to provide additional support during the hours the individual would have been otherwise occupied at work.

While everyone should have the same right to retire from employment, people with intellectual disabilities need a structured program of relevant and meaningful activities to prevent social isolation (Bigby & Balandin, 2005), while also taking the following into consideration:

> Rather than focusing on retirement, the focus must shift to how existing or alternative new services can provide optimal living environments, skill maintenance and development, stimulating leisure, recreational and social opportunities appropriate to each individual's rate of ageing. (Bigby, 1997, p. 106)

At this point in time, no such widespread specialist programs are in place for people with intellectual disabilities (National Disability Services, 2007b). A number of individual day programs were identified by Bigby (2005a) as managing to overcome some of the funding imposed barriers associated with ageing and intellectual disability. However, these services were largely conducted as independent joint initiatives between accommodation and day program providers, rather than as a formal part of a larger government structured approach to the problem. If successful ageing is to occur (as discussed in section *2.4 Successful Ageing*), the issue of appropriate day-time programs and options for this cohort of people needs to be resolved through the implementation of funding models that support the needs of the individual. National Disability Services (NDS), which is the peak body for disability support organisations in Australia, made a series of recommendations in 2007 to facilitate and support the retirement of people with intellectual disabilities from the workforce. These recommendations included the development of a specific transition to retirement program and new assessment processes (National Disability Services, 2007b); however, none of these recommendations have as yet been enacted by either the Commonwealth or State Government.

2.4.1.4 People with an Intellectual Disability and Grief

As the life expectancy of people with intellectual disabilities rises, a natural consequence is the greater likelihood of these individuals experiencing the death of a significant other, such as a parent (Blackman, 2003a). If individuals with an intellectual disability are to age successfully, assistance needs to be provided to ensure that this group of people have the support to cope with this situation. Historically, there has been a perception that many people with intellectual disabilities may not have had the necessary understanding of social relationships to feel grief or the capacity to comprehend loss associated with the death of a family member or friend (Speece & Brent, 1984). Much of this argument seems to have been based upon the perception that people with intellectual disabilities were unable to establish the close social and personal relationships with other people that underpin later feelings of grief following a death (McDanial, 1989).

Oswin (1991) considered this viewpoint to be overly simplistic and that it did not take into account personal differences and varying levels of individual capacity. While a person's disability may affect her/his intellectual development, it does not necessarily follow that emotional understanding is similarly impaired. As noted by Dodd, Dowling and Hollins (2005, p. 541) in their review of grief research literature, "people with IDs are not a homogenous group: there are wide differences in experience, environment, personality and ability". Myers (1980) proposed that people with intellectual disabilities had far more similarities in their grief reactions to the mainstream population than identifiable differences. However, the level of intellectual disability will have an effect upon the ability of the individual to understand concepts such as death and dying (McLoughlin, 1986) and the grief process may be delayed in some (Kitching, 1987). It was felt that they may fail to understand the full impact of the loss immediately but the reaction to the loss would then come in the future when they realise the person is not coming back. Individuals with lower levels of intellectual impairment are considered to be more capable than previously thought of understanding the varying components of the concept of death and, therefore more able to prepare for an impending bereavement (McEvoy, Reid & Guerin, 2002).

The death of a close family member, such as a parent, has been linked to a variety of symptoms of grief in people with intellectual disabilities. These reactions include anger and anxiety as well as ongoing problems associated with loneliness and sadness (Harper & Wadsworth, 1993). It was found that people with an intellectual disability experienced significantly greater levels of irritability and inappropriate behaviours following the death of a person near to them (Hollins & Esterhuyzen, 1997). A questionnaire completed by carers reported that people with an intellectual disability who had lost a parent within the previous two years displayed various complicated grief reactions, including difficulty in carrying out normal activities, personal upset when thinking about the deceased, feeling guilty if they enjoy themselves, insecurity, and losing trust in other people (Dodd et al, 2008a).

The people in the best position to assist individuals with intellectual disabilities in their grieving are often the direct care support staff within residential settings (McHale & Carey, 2002). However, this situation can result in a very difficult working environment for the disability support workers. The direct care staff are often placed in the crucial role of trying to explain the concepts of death and dying to a person with an intellectual disability as well as then providing immediate support and comfort (Read & Elliott, 2007). However, these employees often have no specific training, skills or experience in assessing or identifying psychological distress (Blackman, 2003a). A lack of knowledge and skills in the provision of psychological support for individuals with intellectual disabilities in relation to the issue of death and dying was found in support staff by Ng and Li (2003). The actual process of providing support to a grieving person can be both emotionally and psychologically difficult for direct care workers (Murray, McKenzie & Quigley, 2000). It was also reported that staff lacked confidence in knowing the proper responses and protocols following a bereavement (McEvoy et al, 2010).

In the same way that children are often sheltered from the reality of death, many people with intellectual disabilities are not informed when close family members are dying and are sometimes denied the opportunity to grieve normally (Blackman, 2003a). Actually participating in the mourning process, attending the funeral and wake, and being part of a larger emotional support network may all contribute to the individual grieving appropriately (Meeusen-van de Kerkhof et al, 2006; Worden, 1983). By failing to include people with intellectual disabilities in these mainstream processes, the grieving process may be hindered and result in an increase in challenging behaviours and other similar problems (Bicknell, 1983; Blackman, 2003b; Dodd, Dowling & Hollins, 2005). However, it was also noted by Dodd et al (2008a) that a strong involvement in post-bereavement rituals was actually linked to the development of complicated grief symptoms and separation distress. Both family and staff members need to consider the needs and capabilities of each individual carefully in order to minimise the impact of bereavement while still facilitating the person to grieve appropriately.

2.5 Disability Service Provision in Rural New South Wales

The direct provision of services for people with intellectual disabilities are not simply the domain of state and commonwealth government departments. The non-government sector provides a significant proportion of the disability support programs available in Australia. As of 2008, there were in excess of 5 100 people with disabilities who received funding from the New South Wales (NSW) Government for either institutional or group home accommodation care (NSW Ombudsman, 2008). These five thousand placements were either provided directly by the Department of Ageing, Disability and Home Care (DADHC), or through Non-Government Organisations (NGOs) who received funding from the Government under the 1993 *NSW Disability Services Act* to provide this support.

Almost all day programs in NSW are operated by NGOs, as are all Commonwealth resourced employment programs funded either by the Department of Education, Employment and Workplace Relations (DEEWR) or the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). NGOs, such as Aftercare in Sydney, have been providing support to disadvantaged members of their local communities since the early 1900s (Aftercare, 2009). Other charitable and Not-For-Profit (NFP) organisations, such as The Spastic Centre, were similarly established to supplement the services provided by government departments (The Spastic Centre, 2009). Currently in NSW, DADHC funds in excess of nine hundred different NGOs across both metropolitan and rural areas (Department of Ageing, Disability and Home Care, 2008a).

In general, people living in rural and remote areas of NSW are disadvantaged in many regards with respect to their metropolitan counterparts. Rural residents have lower socio-economic status, higher levels of unemployment and poorer access to health care services (Australian Institute of Health and Welfare, 2003; Francis, 2005). There have been obvious differences reported between individuals with an intellectual disability ageing in metropolitan versus rural localities (Ashman, Hulme & Suttie, 1990). In rural areas of NSW during the first half of the 20th Century services for people with intellectual disabilities were very limited. Even in larger regional cities, such as Armidale, support was limited to that provided by either the local doctors or the hospital's social worker (Edmundson et al, 2005). There were either no, or very limited, specialist government services and the options for both parents and people with intellectual disabilities were extremely restricted. It was during the 1950s and 60s that a considerable number of rurally based NGO disability organisations began to be established in response to this lack of access to services provided by government.

A common pattern in the development of these rural organisations was that the driving force in their establishment was through community action by local parents and concerned citizens (e.g. Challenge Disability Services, 2009; Coffs Harbour Challenge, 2009; Edmundson et al, 2005; Mai-Wel, 2009; MultiTask, 2008). During the 1950s, the State Government indicated that it would provide dollar for dollar funding for the development of specialist disability services such as schools and hostel accommodation. This offer led to community based fundraising activities such as lamington drives, street stalls, fetes and even door knocking being conducted to raise the necessary capital to establish the programs that people with disabilities needed (Edmundson et al, 2005). This era was identified as the time when parents began to choose not to send their children away to institutional care but instead to establish local services that would support them within their home community (Gatter, 1996).

Over the past fifty years, further disability organisations have been established across rural NSW. Some towns are still serviced primarily by one or two long-standing providers who offer a range of programs, whereas other towns have a number of smaller services that each offer complementary specialist programs. These services vary from twenty-four hour high support accommodation models through to early intervention, day programs, respite, therapy and behavioural support services (Department of Ageing, Disability and Home Care, 2008f). While DADHC does provide some group home accommodation in rural areas, they are often secondary and smaller in capacity than the equivalent services provided by the NGOs in the same communities (Edmundson et al, 2005). In 2008/09, rural and regional NSW NGOs received a total of $821 million in support programs for ageing and disability services (Department of Ageing, Disability and Home Care, 2008e).

Nonetheless, there remains substantial unmet need with respect to residential support services for people with intellectual disabilities in general (Australian Institute of Health and Welfare, 2006, 2008a; Stancliffe, Lakin & Prouty, 2005) and specifically in rural areas (Eley et al, 2009). The issues surrounding unmet need are further complicated by government mandates that now require disability organisations to ensure their existing services meet both legislative obligations, such as Occupational Health and Safety, and philosophical goals, such as quality of life and person centred planning outcomes. These additional government requirements have had to be implemented largely without the provision of any additional funding. The new concepts of service provision have largely stemmed from the principles of normalization and social constructionism (see section *1.3 Theoretical Framework for the Current Study*) and, while these changes are both welcome and necessary, the lack of financial assistance for their implementation has further increased the pressure upon service delivery (Kevin Mead, pers. comm., 28 July, 2009).

2.5.1 Quality of Life

One of the key concepts that has been strongly promoted in disability service provision is Quality of Life (QoL) (e.g. Department of Ageing, Disability and Home Care, 2007b). However, it would appear that many direct care and support workers are not precisely sure what the term means and, in particular, how it applies to individuals with an intellectual disability who are ageing (Bigby, 2004). Part of the reason for this confusion relates to the fact that 'quality of life' is premised upon a generic concept that is not specific to intellectual disability and the term has been interpreted in disparate ways as a consequence of the difficulty in clearly defining its meaning (Felce & Perry, 1995).

Attempts to define QoL in the mainstream population can be traced back to work conducted by Thorndike, who developed an assessment system with over three hundred items and thirty-seven traits designed to measure the 'goodness of life' that 'good people' would experience while living in different cities in the United States (Thorndike, 1939). Since this initial work, researchers have continued to refine and revise the methodologies and systems for determining QoL (Flanagan, 1978; Schalock et al, 2002; Sirgy, 2002). There have been in excess of two hundred different QoL models developed to assess and measure aspects of an individual's life (Brown, 1998; Cummins, 1997), with one analysis reporting forty-four separate definitions of QoL and 1243 difference measures (Hughes et al, 1995). There are numerous different approaches to assessing and measuring QoL and the various models each incorporate specific dimensions such as psychological, social, cognitive, emotional, judgemental, affective, ecological, aesthetic, psychophysical and phenomenological factors. However, almost all of these different dimensions can be considered as either a subjective or objective indicator (McVilly & Rawlinson, 1998).

Objective indicators are considered to be social measures that relate to primarily external issues or environmental conditions. A number of generic categories of objective indicators have been developed and include:

- Income, work status and overall wealth,
- Environmental issues, with a particular focus upon the domestic home,
- Physical and mental health,
- Education and qualifications,
- Social dysfunctions such as alcoholism, illicit drug use and criminal activities, and
- Social isolation and community participation (Schneider, 1975).

The use of objective measures in determining QoL has a number of advantages. Firstly, they are largely quantifiable, making it relatively easy to establish a score on a measure without relying upon individual perceptions or personal biases. Objective indicators can incorporate a wide variety of people and can be generalised across sub-groups or entire populations, facilitating the ability to make comparisons between sectors or across time. However, these same strengths can also be potential weaknesses. Objective indicators are largely descriptive of the QoL of populations with less of an emphasis upon the individual experience.

It has been argued that there is actually no relationship between objective indicators and a specific individual's QoL (Schneider, 1975) and, as such, objective indicators are insufficient in themselves to provide accurate measurement. Agreement upon how to measure objective indicators can also be difficult to achieve (Diener & Suh, 1997). An example of this problem can be seen with an example of rating the access of a person with an intellectual disability to specialist healthcare facilities. Is the access measurement based upon geographic distance from the service, the length of time it takes from the initial referral until the person is actually seen by the specialist, the length of the waiting list to access the service or a combination of all these factors?

In contrast to objective indicators, subjective measures attempt to assess the actual individual's QoL. This approach is achieved through interaction with the person rather than through a reliance on population statistics. Subjective indicators are seen to be predominantly psychological with a focus upon understanding how the individual rates life satisfaction in accordance with her/his own personal criteria (Costanza et al, 2008). There are two primary approaches to subjective measuring of QoL. The first model involves a generic measure being established as a baseline of psychological well-being with more specific indicators being examined in relation to this global measure. This approach focuses upon how daily life experiences affect the individual's perceptions of happiness.

An example of this model is seen with Bradburn's (1969) *10-Item Affect Balance Scale*. This questionnaire is composed of two separate lists: five questions that examine positive affect issues and five questions that examine negative affect issues. Each of the ten questions requires the individual to respond with either a 'Yes' or 'No' with respect to events that had occurred in their life recently. An example of a positive affect question in this type of model could state 'During the past few weeks, did you ever feel proud because someone complimented you on something you had done?' The positive and negative affect scales are not related to each other; however, it was proposed the individual's well-being and life satisfaction could be estimated through examining the results of the positive and negative affects scales (Bradburn, 1969).

The second model of subjective measurement involves the identification of specific life areas with the individual's QoL assessed and determined by comparison to each of these domains. This approach is traditionally undertaken through direct interview with the individual, with questions being asked that relate to varying aspects of their daily life. The person is asked to rate the relative importance of a variety of different life domains, normally using a five point Likert scale. These life domains can include areas such as financial security, personal relationships, employment, social life and health amongst many others. It is argued that the person's QoL can be estimated through examining the discrepancy between how they currently perceive their life in contrast to what they would actually like to experience in their life. The difference between the perceived and the desired life acts as a measurement of the individual's level of satisfaction and overall well-being (Flanagan, 1978).

One of the main advantages of using either model of subjective measurement of QoL is that they are good at identifying areas of difference whilst remaining consistent in situations of no change. They also allow the researcher to examine more specifically the issues important to the individual (Diener & Suh, 1997). However, subjective measures can also be limited by their reliance upon personal characteristics at the detriment of accurately identifying external or environmental issues. Subjective measures can also be criticised on the basis of perceived methodological limitations associated with the researcher's choice of which variables to use within the questionnaire (Diener & Suh, 1997).

2.5.2 Quality of Life for People with an Intellectual Disability

The use of quality of life (QoL) measures has gained considerable currency in the disability sector as a framework for evaluating the appropriateness of services. There is, however, only a limited amount of research data regarding QoL's suitability and appropriateness to the field of intellectual disability (Brown, Schalock & Brown, 2009). One of the central issues that QoL researchers need to consider is whether there is inherently anything different between an individual with or without an intellectual disability. Does the person's disability mean that the mainstream measures of QoL are not necessarily valid and, therefore, is there a need for a new set of specialised assessment items? Generic QoL measures may not accurately capture the life experiences of a person with an intellectual disability but, conversely, one of the problems with using QoL measures purposefully designed for people with intellectual disabilities is that they can be unduly focussed upon negatives and fail to accurately allow the person to express his/her actual level of happiness (Cummins, 1997).

The assessment and measurement of QoL has become an increasingly important and crucial area of service provision for disability support organisations. It was argued that QoL was the "pre-eminent issue of the 1990s" for intellectual disability services (McVilly & Rawlinson, 1998, p. 200). Interest in assessing and measuring the QoL of people with intellectual disabilities can be traced back to the work of Nirje and the normalization principle (Nirje, 1969), as described in section *1.3 Theoretical Framework for the Current Study*. Normalization originated in a desire to better understand and therefore improve the life conditions of people with intellectual disabilities (Nirje, 1992). Current New South Wales (NSW) Government disability legislation has been partially derived from the work of Nirje and makes specific reference to QoL for people with intellectual disabilities in the Principles and Applications of Principles associated with the *NSW Disability Services Standards*

(Department of Ageing, Disability and Home Care, 2008c). Disability support organisations are assessed in accordance with these Standards and must prove to government how the service works with people with disabilities to “support their attaining a reasonable quality of life” (Department of Ageing, Disability and Home Care, 2008c, p. 2).

There is little agreement on a precise definition of QoL for people with intellectual disabilities or what factors are most appropriate to assess and measure it. The research literature would appear to support the concept of QoL measurement having to occur through a variety of different subjective and objective indicators; however, these dimensions will vary across time and individuals (Chun Yu, Jupp & Taylor, 1996; Felce & Perry, 1997). There is general acceptance that it is essential for the QoL indicators to be both valid and reliable if they are used as a barometer for assessing whether the quality of service provision received by an individual is increasing or deteriorating (Conroy & Feinstein, 1990). Eight key components, or life domains, have been described by Schalock and Verdugo-Alonso (2002) that need to be considered when assessing an individual with an intellectual disability’s QoL. These eight life domains are:

- physical well-being,
- emotional well-being,
- interpersonal relations,
- material well-being,
- personal development,
- self-determination,
- social inclusion, and
- rights.

It is argued that these eight life domains cover the key factors that determine an individual with an intellectual disability’s QoL. However, it is also acknowledged that there are inherent problems with applying QoL measures to people with intellectual disabilities (McVilly & Rawlinson, 1998).

One difficulty with establishing an individual's QoL, particularly for a person with an intellectual disability, is the potential communication barrier. If a person has a severe intellectual disability or has very limited receptive or expressive communication skills it can be hard to clearly establish the individual's understanding of the issue, let alone his/her personal views. This problem can be partially addressed through family, friends and carers responding on behalf of the person with the intellectual disability; however, it is impossible to confirm whether these proxy answers accurately reflect the individual's feelings (Cummins, 1997).

Another major difficulty associated with personal interviews and QoL assessments for people with an intellectual disability is the known phenomenon of 'acquiescence bias', in which participants are increasingly likely to agree with a question without necessarily either understanding or comprehending the meaning of the question (Rapley & Antaki, 1996). The problem of acquiescence bias is an important issue for researchers to consider as it is naturally desirable to have the direct input, whenever possible and practical, of the individual with the intellectual disability with regard to the services they receive. Respondent acquiescence can be overcome, at least partially, through ensuring that the questionnaires utilised in the QoL are grammatically simple (Finlay & Lyons, 2002), do not follow a simple 'yes/no' dichotomy, and provide the respondent with ample opportunity to elaborate and express their feelings on the issue (Burnett, 1989).

The life expectancy of people with intellectual disabilities has undergone a remarkable increase in recent decades (Fisher & Kettl, 2005). However, the mere extension of life does not necessarily equate to a high quality of life (Brown, 1993). One of the problems being experienced by the disability and aged care sectors is that there is limited data and information regarding the expectations and desires of people with an intellectual disability as they age. This lack of knowledge means that there is a very limited understanding of how to accurately measure and assess the QoL for individuals within this sub-group of the community. QoL has become one of the major measures of service provision by disability organisations in the past two decades (Kober & Eggleton, 2009). Regardless of which QoL tool is used, the assessment process must be considered in light of the desired outcomes and what specific information is sought. While objective indicators are vital in providing an over-arching methodology for determining service achievements, it is important to ensure that adequate inclusion of appropriate subjective indicators also occurs, as this mechanism facilitates the direct involvement of people with disabilities in the assessment process.

It has been proposed that there needed to be a greater recognition of process evaluation in comparison to outcome evaluation with respect to QoL assessments of disability support organisations. In process evaluations, the focus is upon examining the policies, practices and work procedures of the service and how these translate into day to day programs. Process evaluations are very good at determining the overall performance of a disability agency and generically how well the organisation supports people with intellectual disabilities. Outcome evaluations, however, are premised upon what the individual manages to achieve with the support of the service. Outcome evaluations are client focussed and, as such, are able to provide more accurate measures of a specific individual's quality of life than process evaluations (McVilly & Rawlinson, 1998). The majority of government conducted audits upon disability services, such as the *Disability Employment Standards Quality Assurance* (DESQA) and the *Integrated Monitoring Framework* (IMF), have a strong focus upon process evaluation. The auditors examine the systems and paperwork in great detail; however, the level of direct interaction with clients and their families is often limited to a brief meeting of around thirty minutes in duration (Kerrie Sauer, pers. comm., 30 September 2009).

The issue of process versus outcome evaluations is particularly important with respect to supporting ageing people with an intellectual disability. At a time in which the individual's personal care needs are increasing but the funding is remaining constant, the individual's quality of life can become secondary to the need to complete the requisite paperwork and documentation to satisfy external auditors. Both auditors and service providers need to be cognisant of the fact that

> the documentation associated with meeting standards and regulations, the primary focus of process evaluation, often becomes a barrier to the happiness of persons who live in those facilities that are overly concerned with certification. (Borthwick-Duffy, 1990, p. 180)

Assessing and determining QoL for people with intellectual disabilities is an ongoing process for most disability organisations. However, the lack of a clear definition and the difficulties associated with the application of QoL measurements to people with intellectual disabilities remain problematic within the sector. These problems can be seen by the fact that there is currently no standardised measurement tool for QoL developed for ageing people with an intellectual disability.

2.5.3 Person Centred Planning

While one of the primary aims of any disability support service is to enhance, or at least maintain, an individual's Quality of Life (QoL), the methods of achieving these goals are not clear or applied consistently across the sector and have changed considerably over time (Beadle-Brown, 2006). Individualised planning has been the process used in the past few decades to achieve specific outcomes for people with intellectual disabilities. Individual planning is a process of developing goals and objectives that the person with the disability wants to achieve (Shaddock, 2002). However, the New South Wales (NSW) Department of Ageing, Disability and Home Care (DADHC) is currently mandating within their tender documents and funding guidelines that all services must take a Person Centred Planning (PCP) approach (e.g. Department of Ageing, Disability and Home Care, 2009e, 2009g) towards ensuring individual outcomes such as QoL. Person centred planning can be viewed as an extension of the previous model of individual planning (Shaddock, 2002).

Any model of service for a person with an intellectual disability should have a primary focus on the needs of the individual as the central component of its delivery (Kendrick, 2009a). The PCP approach is one means of achieving this goal as it emphasises the needs and requirements of each individual over that of other stakeholders, such as the family or the service itself. PCP's focus is on what the individual wants and on his/her aspirations and abilities (O'Brien & O'Brien, 1998). The antithesis of PCP is found in pre-determined models of service such as generic or group based activity programs that are commonplace within some aged care facilities. PCP is designed for all people regardless of their level of disability or support needs (Sanderson et al, 1997). PCP has five central themes that distinguish it from other standard forms of planning, as outlined below:

> 1. The person is at the centre. Planning focuses on establishing what the person wants to do and achieve, her/his abilities and the supports needed;
> 2. If the person chooses, his/her wider social network is involved as a full partner and the contributions and knowledge of families, carers and members of the local community are valued;
> 3. There is a partnership between the person, his/her family, carer or advocate and the service provider. All parties involved have a shared commitment to action;
> 4. The whole of life is considered. Within available resources, services align with the goals and needs of the person and look beyond traditional constraints; and
> 5. There is continued listening, learning and action. New goals are set as a person's experience, needs and expectations grow. (Department of Ageing, Disability and Home Care, 2009g, p. 10)

There are a number of similarities between PCP and previous systems such as Individual Planning (IP). It is argued that the reason PCP is different to any prior models is due to the fact that it focuses on what the individual wishes, irrespective of what services are available. Other planning systems, such as IP, have tended to only offer options that are already available for the individual to access. In contrast, PCP is designed to examine any aspiration of the individual, regardless of whether it appears feasible for the person, his/her family, or the disability support organisation (Kilbane & McLean, 2008).

DADHC believes that the concept of PCP is linked to significant positive outcomes for people with intellectual disabilities (Department of Ageing, Disability and Home Care, 2008d) and are requiring its implementation into the services it funds (Department of Ageing, Disability and Home Care, 2009e). However, it is important to recognise that PCP is not simply a process of assessment by DADHC. Assessment is often utilised by services and government departments as a mechanism to determine eligibility or, in fact, to deny service. As noted by Kendrick (2000, p. 2) "there is a profound temptation to try and translate all desirable human capacities into bureaucratic methodologies". Such assessment, when used in isolation, can be a means of declining appropriate services to individuals who have more complicated or challenging disabilities. This problem can be seen through the statement that "person centred planning in the hands of people that lack sufficient regard for the person could actually be used harmfully" (Kendrick, 2000, p. 3).

In spite of the positive aspects within the process of PCP, it should not be seen as the solution to all problems. An organisation cannot implement widespread changes for the individuals it supports unless it first ensures that the staff it employs are committed to the process (Kendrick, 2009b). The entire organisation must be genuinely dedicated to achieving the best possible outcomes and not merely be paying lip-service to the concept.

> People and what they are authentically like are more predictable of what an organization can achieve than are the formal mission statements, policies and slogans that supposedly guide the individuals in the organization. (Kendrick, 2000, p. 2)

The adoption of PCP within a service is not sufficient; it must be accompanied by a change in thinking by all parties to ensure that the individual continues to remain at the forefront and not disappear as soon as the planning process is completed (Kendrick, 2009b).

Another significant impediment to PCP is the fact that it is often easier for support agencies to provide a standardised model for all service users. The goal of most services is to provide the best possible results for its client group with the least possible problems. The easiest way to achieve this outcome is usually through the use of an existing model rather than developing an inclusive model that is individualised for each person (Clement & Bigby, 2009). However, if PCP is to be successful the introduction of non-standardised systems and options must occur and continue to be applied. It is very possible to use PCP with good intent but for the service not to make the necessary reforms to provide "the kind of ongoing support and dissidence necessary to bring into existence something unique and worthy" (Kendrick, 2004, p. 4).

In spite of the recognised problems with PCP, the inherent concepts provide services with a methodology with which to offer programs which are individualised and based around personal need. PCP and its integration into the many disability services in Australia represents a fundamentally different method of working with people to the traditional approach within the residential aged care system. However, PCP is still a relatively new approach to individual planning and there is limited research and evidence regarding its long term efficacy (Bigby, 2004). PCP will also not achieve any significant outcomes unless resources commensurate with the goals are available. An individual can have many desires very clearly documented within his/her plan but if government funding is inadequate there is only a limited likelihood that they will be achieved, regardless of the intent of stakeholders. This issue is the major drawback with PCP in NSW and can only be overcome by cooperation between government departments, non-government organisations, families, other stakeholders and the individual.

The focus that the disability sector currently places upon the individual through approaches such as PCP, and the process of ensuring that the systems are centred on the needs of the person and not the service, are two ideals that must be maintained as people with intellectual disabilities transition into aged care programs (Bigby & Knox, 2009). One of the major issues that disability service providers report with the integration of a person with an intellectual disability into generic aged care models relates to the fact that this step results in a move backwards for the individual in terms of quality of life and personal skill maintenance (Australian Human Rights Commission, 1989; Julie Derley, pers. comm., 9 June 2009). Likewise, the relocation of an individual with a disability from his/her family home either into a residential aged care facility or another more appropriate community model is a complex and difficult process, the success of which can be contingent upon the effectiveness of the planning. Bigby (2004, p. 59) concluded that PCP needed to be supported by "education and training of staff to counter stereotypical attitudes and to develop the skills necessary to engage older people in the everyday activities of life". Without this associated training for direct care workers there remains the possibility that the desired goals for the individual will not eventuate, regardless of the organisation's overall intent.

The widespread movement towards inclusive policies and the implementation of deinstitutionalisation has resulted in a dramatic change in how disability services support people with intellectual disabilities (Bigby, 2006). Associated with this change is a large reform in the way disability staff are expected to support their client group (Felce, 2005). As noted by Hatton et al (2002, p. 1)

> staff provide the interface through which national, regional and organisational philosophies and policies are translated in practical action directly affecting the quality of life of people with learning disabilities.

Research has shown that the actions and attitudes of staff is significantly related to the quality of life of the people with disabilities that they support (Felce, 1996; Hatton et al, 1999). However, there are substantial challenges facing the disability sector and its workforce, in particular issues such as workplace stress and staff retention (National Disability Services, 2009a). Supporting people with intellectual disabilities, high personal care needs and challenging behaviours has been linked with high staff turnover (Felce, Lowe & Bestwick, 1993; Hatton et al 2002). Studies have shown that between 25 percent (Robertson et al, 2005b) and 32.5 percent (Hatton et al, 1999) of direct care staff experience significant levels of work related stress. In order to address both the predicted shortages of staff and the ongoing problems associated with staff retention, disability organisations have to look at structural reform in how they train and support their staff.

2.6 The Disability Sector Workforce

Concerns are being expressed, both in Australia and overseas, regarding ongoing difficulties in attracting and retaining appropriate workers (McConkey et al, 2007). As with many countries round the world, it is anticipated that Australia is going to experience a shortage of skilled employees across all sectors. It is predicted that these shortages will occur across a large number of different professional occupations including health care workers. It was noted that "shortages have emerged as a result of industry or sector growth, high attrition rates of workers and insufficient investment in training" (NSW Board of Vocational Education and Training, 2005, p. 9).

Disability organisations are considered to be part of the wider Health and Community Services sector. This component of the Australian workforce employs over one million people and is the third largest industry in the country (Victorian Council of Social Services, 2007). To compound the problem of skills shortages, employment growth within the Health and Community Services sector was projected to increase by over 3 percent from 2005 to 2010, with a numerical growth of nearly 18 000 new positions within hospitals and nursing homes alone (NSW Board of Vocational Education and Training, 2005, p. 9). Pay rates for workers in the disability sector are generally regarded as poor and many employees report considerable frustrations with their daily work (Angley & Newman, 2002). However, direct care workers also indicate that they gain significant satisfaction and joy from their daily interactions with people with intellectual disabilities and that this factor is one of the main reasons they remain within the disability workforce (Victorian Association of Health and Extended Care, 2002).

The NSW Department of Education and Training (DET) identified within their 2005-2008 strategic plan for vocational education and training the fact that the ageing demographic will result in an increase in employment opportunities within human services such as "hospital and nursing home care, community support services and personal services which cater for the needs of older people" (NSW Board of Vocational Education and Training, 2005, p. 5). In the follow-up strategic plan for 2008-2010, NSW DET again noted the Health and Community Services sectors as both "high growth" and "regional growth industries" (NSW Board of Vocational Education and Training, 2008, p. 10).

Hatton et al (2002) note that some disability organisations have lower levels of staff stress and overall employee turnover and that these desirable outcomes are associated with factors such as direct care staff's training and skill development, as well as the overall organisational structure and culture. Participation in relevant education programs has been associated with an increase in employee retention rates (Rosen, Yerushalmi & Walker, 1986). A lack of training has been identified as a fact that can result in higher levels of staff turnover (Knapp, Cambridge & Thomason, 1989). Appropriate training and associated modifications to service delivery and organisational structures is considered necessary to assist staff to provide efficient and suitable support to people with intellectual disabilities (Lowe et al, 2007). A research study conducted by Durnin and Freeman (2005) found that levels of knowledge and understanding were significantly higher in a group of staff who had completed a twelve week training course about challenging behaviours than in a control group. Wilkinson, Kerr and Cunningham (2005) argued that support and training for direct care staff is a crucial aspect of successful ageing in place for people with intellectual disabilities. However, they also noted that inappropriate or irrelevant training can actually lead to worse outcomes than no training at all.

Research over the past twenty years has indicated that the interaction of staff and residents within supported accommodation settings and other specialist programs are vital factors in the overall quality of life for the individual with a disability (Janicki & Dalton, 1999). The staff members' experience, attitudes and philosophies have all been linked to the success of the programs in which they work (Baker, Seltzer & Seltzer, 1977; Braddock & Mitchell, 1992; Broadhurst & Mansell, 2007; Racino et al, 1992; Rosen, Yerushalmi & Walker, 1986; Wong & Wong, 2008). Support staff who display individual attributes such as honesty, trust and a nurturing attitude are highly valued by people with intellectual disabilities, whilst characteristics such as immaturity and impatience were perceived negatively and as barriers to forming a good working relationship (Clarkson et al, 2009).

Staff members within disability services are required to serve a number of different and often disparate roles. For example, the job description for a direct care worker within a disability residence may include tasks such as teaching social and independent living skills, assisting individuals to access and integrate into the local community, personal care, administering medications, cleaning and cooking (National Disability Services, 2009c). It is concerning that despite these varied, and at times critical, responsibilities, there is no compulsory accredited training for direct care workers within the disability sector in Australia. It has been reported that many staff within accommodation services have extremely limited education or training in providing support to people with disabilities (Larson, Hewitt & Anderson, 1999; Lime Management Group, 2006). This situation is in spite of the significant association between staffing outcomes and the level of staff training and education (Ford & Honnor, 2000).

At the current time, people with an intellectual disability who are ageing present a unique challenge for support staff. Within the disability field, the focus of programs is predominantly upon the teaching of new personal skills and increasing independence. This situation is in contrast to the aged care sector that has a support model based upon greater levels of personal assistance and specialised nursing interventions. A person with an intellectual disability who is experiencing age-related issues often has needs that fall outside the expertise of the disability sector staff, while the staff within aged care services often have limited or no experience in dealing with people with intellectual disabilities (Hussein & Manthorpe, 2005).

As the disability sector and aged care services attempt to adapt to the changing demands placed upon them by this relatively new phenomenon, the training and organisational support structures available for their staff must be similarly modified to reflect these changes in work practices. Mansell et al (2008) identified that the quality of support provided to people with intellectual disabilities is affected by a number of key factors, which include staffing issues such as qualifications, experience and training, as well as organisational management, culture and structures. Corrigan and McCracken (1998) argued that a combination of both educational training and organisational support for staff were important in the development of relevant and appropriate programs for service users.

Within Australia, there are no prerequisite qualifications or training for people who wish to work as support workers within the disability sector. Studies have shown that accredited training levels vary greatly amongst service providers, with some suggesting that only 5 to 10 percent of staff employed by non-government agencies have accredited relevant qualifications (Department of Human Services, 2005). Areas of weakness in the knowledge base of existing staff members will start to appear as issues associated with ageing become more prevalent and the training and support options must be flexible enough to ensure that these gaps in skills can be addressed. At the same time, the training for new employees must be comprehensive enough to ensure that all staff receive the basic knowledge and information to facilitate their integration into the workplace.

2.6.1 Training for Disability Support Staff

The relationship between service quality and a comprehensive planned system of training for the staff that support people with intellectual disabilities has been researched, albeit somewhat intermittently, for many years (e.g. Hatton et al, 2002; Hogg & Mittler, 1987; Koegel, Russo & Rincover, 1977; Landesman-Dwyer & Knowles, 1987; Lovaas et al, 1973; Mansell et al, 2008; McVilly, 1997; Mittler, 1981). Unfortunately, the disability sector has not traditionally been successful in providing training that is relevant, efficient and effective for its staff (Braddock & Mitchell, 1992).

There is a relative scarcity of research since 2000, specifically in Australia, or generally elsewhere in the world, that examines the outcomes of training for the actual participants. The value of the training for the individual staff member is often noted as a secondary consideration. The majority of studies instead focus upon, and detail improvements for, clients following the implementation of training programs within a service. The lack of appropriate research into evaluation of training for staff was noted by Beech and Leather (2006, p. 39), who concluded that “few trainers have attempted to perform and publish objective evaluations”.

Parmenter (1991) highlighted the disparity between the day to day work requirements of employees and the actual training that is provided to them. This trend is in spite of the fact that studies show a correlation between appropriate training and desirable outcomes such as minimising challenging behaviours (Campbell & Hogg, 2008; Grey, Hastings & McLean, 2006), improving employee’s psychological well-being and reducing personal ‘burnout’ (Chung & Harding, 2009), enhanced communication between staff and clients (McMillan, Bunning & Pring, 2000), and higher levels of individual engagement in daily activities (Mansell et al, 2008). In addition, Dempsey and Arthur (2002) argue that the provision of training can actually positively influence direct care workers’ intent to remain within the disability field.

Within the disability sector there are many different research examples of both successful (e.g. Fahey-McCarthy et al, 2009; Smith, Wun & Cumella, 1996; Tierney, Quinlan & Hastings, 2006) and failed (e.g. Cullen, 1992; Foxx, 1996) training programs for staff members over the past two decades. Staff are often enrolled in education programs but without the opportunity to use the newly acquired knowledge their skills are not developed and any benefit may diminish without appropriate follow-up training (van Oorsouw et al, 2010). The goal of training for staff ultimately must be to achieve an overall benefit to the people with disabilities that are being supported. It was concluded by Whitehurst (2008, p. 10) that

> where staff receive good quality training, it is clear that pathways of care can be identified at an early stage, resulting in good quality, timely, and appropriate intervention, whether psychological, behavioural, or pharmacological.

Hussein and Manthorpe (2005) argued that staff skills, knowledge and values are key components of any high quality support program for people with intellectual disabilities. Positive and appropriate attitudes of direct care staff are vital if generic policies such as inclusivity are to be appropriately implemented (Henry et al, 2004), with training required to ensure all sectors of the disability workforce gain an equal understanding of important issues (Jones et al, 2008). It was noted by Mansell et al (2008) that there were a variety of factors, including staff attitude, management support and supervision, that, while not directly associated with content or delivery, influenced the actual workplace outcomes of training.

Landesman-Dwyer and Knowles (1987) conducted one of the first examinations of the process of staff training within a residential setting. They proposed that the on-the-job performance of employees is multi-faceted, including aspects such as the social environment, personal characteristics, supervision by management and any specific training that is undertaken. The effectiveness of any training program can only be measured accurately if these other factors are also taken into consideration. As noted by Totsika et al (2010), the same education programs can achieve different results in varying training sub-groups.

The social environment in which the staff work, the inter-relationship between the various workers and the support provided by supervisors are all factors that need to be analysed both prior to and after the training and before a conclusion about the effectiveness of the training program can be reached. The social environment of the workplace incorporates the relationship between the individual with the disability, the staff who provide the direct support services, supervisors and the management structure, associated health professionals, case managers, family and advocates (Mascha, 2007). In some circumstances, an excellent and well presented training program may not achieve any significant improvements in service provision, whereas the modification of certain elements in the social environment may result in better outcomes (Landesman-Dwyer & Knowles, 1987). It is proposed that, if training is to be effective, the content of the program must be closely aligned to the staff perception of what they require (Sanders, 2009).

Landesman-Dwyer and Knowles (1987) conceptualised a two stage model that predicts the determinants of the effectiveness of training programs in the short and long term. The immediate consequences of staff training are reliant upon the trainee's perceived relevance of the course to their current work role, how applicable the content of the training is with regard to the actual job requirements, how effectively the trainer presents the information and knowledge to the participants, and the opportunities for the staff member to actually utilise the new skills.

In contrast, the long term effectiveness of training was considered to be reliant upon three primary environmental factors. These three issues were the extent to which the inherent components of the job complement the goals of the training, the proportion of staff within a workplace that have participated in the training, and the perceived importance of the training within the context of the work environment. Research by Totsika et al (2010) indicated that a combination of training methods may be necessary for long term changes in staff behaviours and attitudes. In other fields, such as medical procedures training, it has been found that peer-based learning options can be as effective as those conducted by experienced trainers (Weyrich et al, 2009).

Research has identified three key components within any training program for disability support staff: the implementation phase, the maintenance phase and the evaluation phase (Wood, Berry & Cowell, 1985). The methodology and effectiveness of implementing the training program will have a direct influence on the way the training is maintained. Training can be successfully provided to staff but maintaining a positive change in the staff associated with the knowledge or skill acquisition may be difficult (Campbell & Hogg, 2008). Formal evaluation at the end of the maintenance phase of the training is necessary to allow appropriate judgements on the program’s long term effectiveness. As noted by Smidt et al (2007), short term improvements may not be sustained over an extended period of time.

Wood, Berry and Cowell (1985) defined two approaches to implementing training for a large group of staff who support people with intellectual disabilities. The first option is that all new workers would undergo the training program, and with the turnover of employees over time, the new concepts will infiltrate throughout the entire organisation. Moores and Grant (1976) conducted a study examining the attitudes of staff members within residential settings. They noted that effective training resulted in positive attitudes amongst new staff who work with people with intellectual disabilities. Hatton et al (2002) identified the importance of providing younger and more inexperienced staff in particular with ongoing skills development and training as a means of supporting this group of people to remain within the disability sector workforce.

However, one of the problems with only providing training to new staff is that the positives identified by Moores and Grant (1976) can be diminished by the older and more established staff who are not undergoing the training, through their direct and indirect influence on the new employees' perspectives. A second approach to training is to provide the training to all existing staff concurrently. By taking an all encompassing tactic to training, all staff will be on a level standing and it will be possible to create an environment conducive to implementing the new skills and knowledge. However, this approach will often see the training groups being composed of individuals with very different levels of knowledge and skills. This scenario presents significant problems for the trainer who has to provide content that is suitable for both highly experienced workers and complete newcomers to the disability sector.

Hogg and Mittler (1987) noted a series of systemic problems associated with the provision of training within intellectual disability services. These flaws include the institutional tradition of training which emphasises the paramedical and custodial components of care, the neglect of management and organisational factors in facilitating change management of appropriate practice, a lack of knowledge within generic providers and integration into mainstream community services, and the isolation that exists between staff members. It has also been reported that the prevailing beliefs of direct care staff may be one of the major impediments to the successful provision of training (Grey, McClean & Barnes-Holmes, 2002; Jones & Hastings, 2003). A report by Choy et al (2008) into effective models of training in child care services noted the importance of other potentially conflicting factors including regulatory requirements and the industrial relations environment of the workplace.

McVilly (1997) conducted a study with staff that support individuals with disabilities in community based residential facilities. McVilly's study surveyed eighty-six support staff specifically on the issues of training and professional support. The direct care respondents considered a number of key skills areas such as assessment, dealing with challenging behaviours and communication as being of importance. However, the participants also reported dissatisfaction with the training being provided in these key areas. Some of the comments from the staff indicated that the failings of the training were a key factor in the high turnover of employees. McVilly reported that very few direct care staff considered their employment as part of a longer term career. The main reasons cited for looking for other employment were primarily the lack of pay, career prospects and further educational opportunities. It was noted that

> the quality of staff training may be an important means of minimising staff turnover by laying the foundation to career paths based on accredited courses linked to wage incentives. (McVilly, 1997, p. 21)

McVilly concluded that the quality of the training being provided to direct care staff members was a vital component in reducing the level of turnover. Other studies have reported similar results with issues such as training, supervision and peer support considered important factors in maintaining morale and minimising stress (Mascha, 2007).

Since the study by McVilly (1997), the majority of intellectual disability training research in Australia has focussed upon improvements in client outcomes (e.g. Stancliffe et al, 2005) rather than staff outcomes. Training has also been predominantly targeted towards staff working with younger and middle aged people with intellectual disabilities, with the different issues associated with ageing not featuring strongly (McCallion & McCarron, 2004).

A study in Ireland by Fahey-McCarthy et al (2009) reported that disability staff were generally untrained in areas of aged services including dementia support and palliative care. Dowse, McDermott and Watson (2009) concluded that there was minimal training that met the needs of Australian workers assisting ageing people with disabilities. The lack of appropriate and current research into the efficacy and relevance of training in aged care issues for disability workers in Australia requires addressing, otherwise the successful implementation of any new programs may be jeopardised.

2.6.2 Education and Training Programs in Australia

The provision of training and education programs within Australia falls into two distinct classes: accredited training and non-accredited training. The accredited training category is split further into Nationally Recognised Training and Other Accredited Training. Nationally Recognised Training refers to units and courses that have been reviewed and assessed independently as meeting set government guidelines to ensure their quality and consistency across Australia. These courses are all contained within the Australian Qualifications Framework (AQF) as shown in Figure 2 below.

The AQF specifies exact titles and guidelines for each qualification and ranges from Certificates of Education provided by Schools through Vocational Education courses such as Certificates I, II, III, IV, Diploma and Advanced Diploma, to Tertiary Education qualifications including Bachelor, Masters and Doctoral Degrees (Australian Qualifications Framework Advisory Board, 2007).

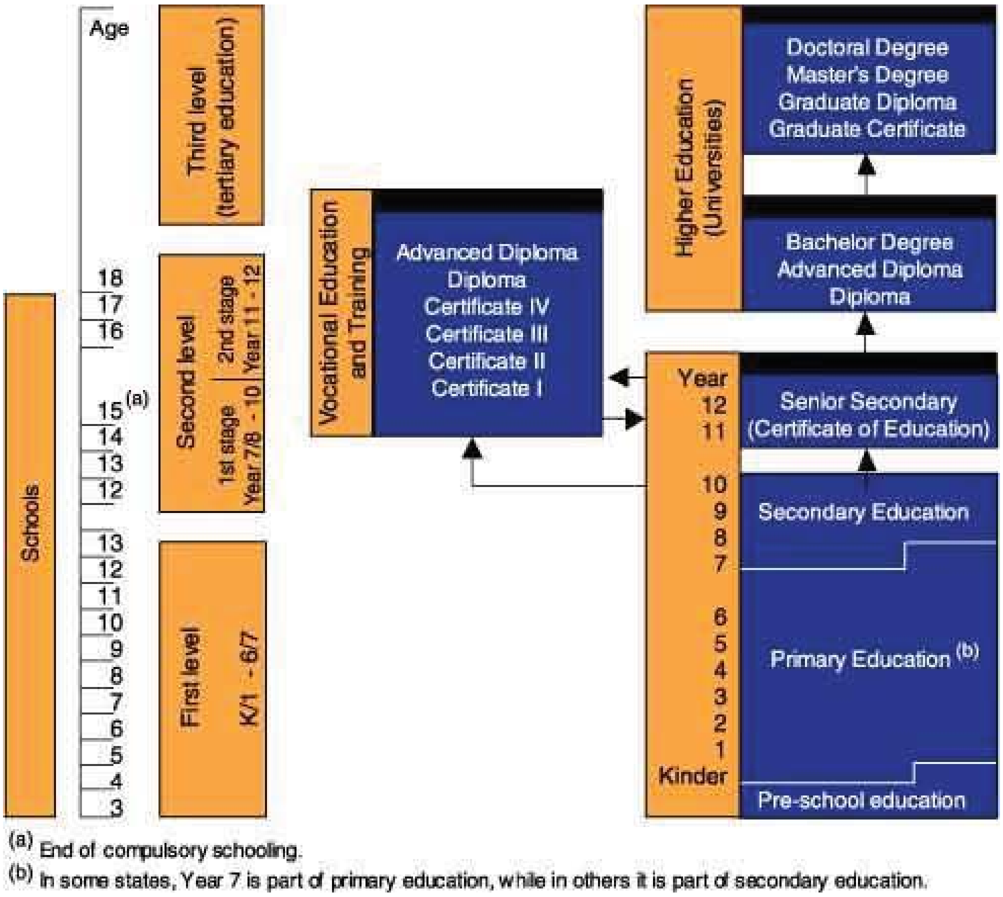

Figure 2 – Australian Qualifications Framework

(Source: Department of Education, Science and Training, 2002).

Other Accredited Training refers to units that provide the individual with a qualification but are not specifically covered by the AQF. Other accredited training courses could include first aid or protective behaviour programs (National Disability Services, 2007d). Non-accredited training refers to any course that has not gone through the external assessment process that is part of the Australian Qualifications Framework. The types of courses that are non-accredited are often highly specific to a certain situation or environment such as an induction program for new workers in a supported residence for people with intellectual disabilities. Other examples of non-accredited training include courses aimed at teaching a very specialised skill within a workplace, in-house or product-based training, or when the trainer is not formally accredited (National Training Information Service, 2008).

The training sector within New South Wales (NSW) has changed dramatically over the past two decades. Vocational Education and Training (VET) has traditionally been considered as providing specialist education in predominantly trade areas such as carpentry and plumbing. However, the VET sector has expanded in the past ten years and currently covers a wide variety of other employment areas including aged care and disability work. As of 31 March 2010, there were 327 different VET courses accredited for use in NSW (National Training Information Service, 2010).

Training and assessment is now based around the concept of demonstrated workplace competency rather than upon classroom based written testing (Department of Education, Science and Training, 2006). An individual is assessed on her/his capacity to perform the requisite duties expected of the position, and the evaluation process will often involve the person having to complete a successful demonstration of workplace based tasks. This change to skill based demonstrations is particular relevant to the disability sector. Disability workers have traditionally had low levels of formal qualifications (Department of Human Services, 2005). It is hoped that the move towards identifying the individual's ability to successfully perform the tasks of the job, rather than merely his/her aptitude in completing written assignments, will facilitate a wider range of staff to achieve a formal qualification.

2.6.3 Aged Care and Disability Work Training Programs in NSW

Within the Australian Qualifications Framework (AQF), both aged care and disability work are classified as part of the larger Community Services and Health Sector. All accredited VET qualifications for ageing and disability employees are specified in the *Community Services and Health Training Package*. This package details the grading and levels of the qualifications as well as providing generic descriptions of job titles and work areas. The current specific aged and disability VET courses accredited within the Community Services Sector are:

- Certificate III in Aged Care,
- Certificate III in Disability,
- Certificate III in Home and Community Care,
- Certificate IV in Aged Care,
- Certificate IV in Disability,
- Certificate IV in Home and Community Care,
- Diploma of Disability, and
- Advanced Diploma of Disability (Community Services and Health Industry Skills Council, 2008a).

There are also several generic courses such as Certificate III and IV in Community Services Work, and Certificate IV in Leisure and Health. These are qualifications in which participants complete a variety of units pertaining to the wider community services sector such as drug and alcohol, children and youth services, disability work, aged care, mental health, community housing and employment support (Community Services and Health Industry Skills Council, 2008a).

There are also a limited number of bachelor level university qualifications specifically designed for direct care disability workers. These options include:

- Bachelor of Applied Science (Disability Studies) at Deakin University,
- Bachelor of Applied Science (Disability) at Royal Melbourne Institute of Technology University (RMIT),
- Bachelor of Disability and Community Rehabilitation at Flinders University,
- Bachelor of Health, Ageing and Community Services at the University of New England,
- Bachelor of Human Services (Disability Studies) at Griffith University,
- Bachelor of Inclusive Education and Disability Studies at Australian Catholic University.

A number of universities also offer postgraduate studies at the Graduate Certificate, Masters and Professional Doctorate levels. Many of these options are aimed at managers and Chief Executive Officers rather than direct care workers. These courses include:

- Graduate Certificate in Educational Studies (Disability Studies) and Master of Disability Studies at the University of Newcastle,
- Graduate Certificate of Health Science (Developmental Disability) and Master of Health Science (Developmental Disability) at the University of Sydney,
- Graduate Diploma in Disability Studies, Masters of Applied Science (Disability Studies) and Doctor of Philosophy (Disability Studies) at RMIT,
- Graduate Diploma in Health Management, Master of Health Management and Doctor of Health Service Management at the University of New England,
- Master of Disability Studies at Flinders University,
- Master of Human Services (Disability Studies) at Griffith University,
- Professional Certificate in Disability Studies and Graduate Certificate in Disability Studies at Edith Cowan University.

Historically, there has also been a specialist training category for Registered Nurses who worked directly with people with intellectual and developmental disabilities. In 1968, the Nursing Registration Board of NSW formally recognised the position of Mental Retardation Nurse to supplement existing nursing categories such as medical/surgical, midwifery and infants. The training for Mental Retardation Nurses was developed over time and by 1980 it involved a total of one thousand hours of training. Other Registered Nurses who wished to change speciality to mental retardation were required to complete 560 hours of training in the area (Nurses Registration Board, 1998).

In 1985, training for nurses changed from being primarily based in teaching hospitals to being a designated university course. This movement saw the amalgamation of the nursing category Mental Retardation, by then known as Developmental Disability, into one general register with other previously separate categories such as Medical/Surgical and Psychiatric. However, this change also resulted in some training in the areas of developmental disability and mental health nursing becoming pre-requisite units for all nurses to complete as part of their education (Nurses Registration Board, 1998). However, studies since the merging of the categories have shown that the disability content in many current universities' nursing curricula in Australia is limited (Johnston & Dixon, 2003) and that attitudes towards people with disabilities amongst the nursing profession are often poor (Seccombe, 2007; Thompson, Emrich & Moore, 2003).

There does remain an association that represents the interests of generalist registered nurses who choose to work in the field of intellectual disability. PANDDA (Professional Association of Nurses in Developmental Disability Areas) holds an annual conference as well as releasing information and position statements on issues around intellectual disability. However, specialist training for registered nurses in this area is limited, and the overall profile of disability work is seen to have decreased considerably since the decision was made to abolish the category of Developmental Disability Nurse (Michael Barry, pers. comm., 8 February, 2010).

As of March 2010, employees in both the aged and disability work sectors were not required to have a minimum qualification. However, the accreditation system for residential aged care facilities mandates that organisations must have appropriately trained staff and, in practice, this requirement is considered to be a minimum of a Certificate III in Aged Care. If a residential aged care facility cannot demonstrate that their staff either have, or are in the process of obtaining, a Certificate III in Aged Care, the facility's accreditation could be removed. There is no equivalent mandatory qualification for disability workers although there is a push by groups such as Disability Professionals NSW (DPNSW) and Disability Professionals Australasia (DPA) to have a Certificate III in Disability as a minimum requirement for workers within the disability sector (e.g. Disability Professionals NSW, 2007b). There appears to be consensus across the disability industry that the need to legislate for minimum qualifications is both appropriate and desirable

(Kevin Mead, pers. comm., 24 February, 2010; National Disability Administrators, 2006); however, after many years of discussion it has not been enacted.

2.7 Summary

The development of disability and ageing support models in Australia since colonisation is complicated and has involved major shifts in both philosophical and operational directions. In order to propose genuine options for service improvement, it is important to understand the history of how disability organisations originated, what support structures are available and which guiding principles for service delivery are currently mandated by government and expected by the community. An examination of the past two centuries of service delivery would indicate that, if realistic solutions to the ageing issues of people with intellectual disabilities are to be reached, leadership and initiative must be shown by both state and Australian government departments, in conjunction with the non-government sector.

At the present time, the existing departmental policy and procedural guidelines often actively work against innovative or practical solutions. The current incompatibility between the disability sector and the aged care service system at a state and commonwealth level means that both jurisdictions need to be actively supportive of innovative options or the current situation will simply continue to worsen. However, during the 20th Century, the implementation of innovative programs by Non-Government Organisations (NGOs), supplemented by appropriate and relevant training for direct care staff members, has been shown to be effective in providing appropriate support options for people with intellectual disabilities.

The current systems are not adequately meeting the needs of people with an intellectual disability, particularly as they age. One major problem is the absence of research that focuses upon identifying the specific needs of disability support workers who support people who are ageing. The direct care staff members are in an ideal position to pinpoint the main issues that pertain to ageing and intellectual disability and to identify the programs and training support required to redress perceived problems. The following chapter outlines the research design used to meet the current study’s goals, as previously described in section *1.2 Research Aims and Objectives*. It details and justifies the choice of methodology, discusses the instruments used and specifies the selection process for the participant group.

Chapter Three – Methodology

Introduction

The purpose of this study was to identify the key issues facing rural disability services' direct care staff with respect to the ageing needs of their clients. Chapter Three begins by outlining the reasons for utilising a Delphi Method approach and reviewing the process, including both its key features and limitations. This section is followed by a justification of this research design with respect to the current project, and the manner in which the study was conducted. The chapter discusses the population sample and how it was recruited, details instrumentation used and describes management of the data. The means used to determine when the participants reached consensus on the importance of each separate item is explained. Chapter Three concludes with a description of the limitations inherent to the research.

3.1 Methodology

The research objective of the current study was to identify the key issues that rural disability workers perceive people with intellectual disabilities face as they age and how these issues impacts on each worker's ability to perform her/his job (see section *1.2 Research Aims and Objectives*). The main underpinning philosophy of the research was to gain the perspective of the front-line disability workers from across rural New South Wales (NSW). This approach was to try and prevent a reliance on the potentially 'second-hand' viewpoint from managers who may be removed from the day to day issues in the provision of personal support.

A variety of both quantitative and qualitative research methodologies such as cross-sectional surveys, focus groups, in-depth structured interviews and case studies were considered as means for meeting the research goals. The large geographic area of NSW made it unviable to successfully conduct face-to-face in-depth interviews with a suitable number and variety of participants. It was also considered that a pre-determined questionnaire or survey model would not provide sufficient flexibility to allow participants to fully contribute and articulate their individual viewpoints.

A research methodology that incorporated both qualitative and quantitative components was deemed to be the most appropriate mechanism for this type of research. This design would facilitate the project participants to have direct input in identifying the key issues facing them, but then also allow for an analysis of the relative importance of each one. The researcher considered the factors involved and decided that the Delphi Method provided the most viable technique to meet the stated research goals of the study.

3.1.1 Overview of the Delphi Method

The Delphi Method is a structured process for collecting information from a variety of different individuals who have a particular expertise, interest or knowledge in a specific area (Adler & Ziglio, 1996; Franklin & Hart, 2007). It was developed by the Rand Corporation during the early 1950s as a means of predicting the effects that war and technology may have upon the world (Beaumont, 2003). In the decades since its development, the Delphi Method has become a widely used instrument for forecasting and decision making in a variety of disciplines (Skulmoski, Hartman & Krahn, 2007). It has been used to evaluate and consolidate a majorative opinion on a specific issue, topic or concept (Linstone & Turoff, 1975). Inherent to this methodology is the process of gathering participants' views and sharing these opinions within a larger group without actually debating the issues in a combative environment (McGraw, Browne & Rees, 1976). The Delphi Method was described as the

> systematic solicitation and collation of judgments on a particular topic through a set of carefully designed sequential questionnaires interspersed with summarized information and feedback of opinions derived from earlier responses. (Delbecq, Van de Ven & Gustafson, 1975, p. 10)

Specifically, the Delphi Method is structured in such a way as to facilitate the researcher's access to the collective knowledge of a disparate group of experts while minimising the negative impact that may result from personal interactions between the participants (Hasson, Keeney & McKenna, 2000).

The four main elements of the Delphi model, as originally identified by Linstone and Turoff (1975), are:

1. individual contributions of information and knowledge,
2. assessment of the group's views into an aggregated response,
3. an opportunity for the participants to re-evaluate their original views, and then to revise and re-submit their thoughts, and
4. the participants in the Delphi having some level of anonymity with respect to expressing their individual viewpoints.

These four key features are considered essential if a research project is to be considered to conform to the Delphi model (Hsu & Sandford, 2007). In the initial phase of a Delphi Method project, information and knowledge about the identified issue is sought from each participant in the study. Typically, this phase of research is quite unstructured which allows the experts sufficient freedom to identify the issues they consider important (Rowe & Wright, 1999). All of the views of the participants are then collated, and the level of agreement and disagreement evaluated (Linstone & Turoff, 1975). The participants are then given an opportunity to reconsider their responses in relation to any identified areas of significant disagreement. The last stage is an analysis of all the information gained from the participants and a final assessment of any group consensus on the issues.

The selection of the individuals to participate in a Delphi project is considered to be one of the most critical factors of the study (Wiersma & Jurs, 2005). It is believed that a Panel member must have a level of 'expertise' in the research area for them to be an appropriate participant (Heath, Neimeyer & Pedersen, 1988). A number of researchers including Sackman (1974), Duffield (1989) and McKenna (1994) all expressed concerns about the application and varying interpretation of what constituted an expert on a topic. Goodman argued that the term 'expert' was potentially dangerous, and instead proposed that

> it would seem more appropriate to recruit individuals who have knowledge of a particular topic and who are consequently willing to engage in discussion upon it without the potentially misleading title of "expert." (Goodman, 1987, p. 732)

The following four attributes were listed as pre-requisite for participants to be selected for a Delphi Panel:

1. every participant has in-depth knowledge of the issue,
2. each individual is willing to allocate the necessary time needed to properly participate in the process,
3. each person feels a personal involvement in the problem, and
4. all participants believe that the information obtained from the study will ultimately be of value, either to themselves individually or to the sector in general. (Delbecq, Van de Ven & Gustafson, 1975)

The number of participants required for a Delphi Panel will vary in accordance with the issue being considered, with no definitive formula for determining the ideal size (Delbecq, Van de Ven & Gustafson, 1975). Linstone and Turoff (1975) proposed that three issues to consider when determining the size of the Panel are:

- the participants are all experts in their own right,
- the number of participants is sufficient to ensure a suitable quantity of diverse viewpoints and opinions, and
- the participants should each bring to the Panel different knowledge and experiences.

Linstone and Turoff (1975) recommended that a Delphi Panel should be composed of anywhere between ten and fifty participants. However, other researchers have narrowed the range to smaller groups. Adler and Ziglio (1996) proposed that a Delphi Panel could be successfully established with between ten to fifteen participants. A Panel consisting of between fifteen and twenty was recommended by Ludwig (1997). Skulmoski, Hartman and Krahn (2007) commented that smaller panels of around fifteen participants were appropriate for homogeneous groups, whereas hetrogenous samples may require hundreds of panel members. It is noted that high levels of participant attrition can occur as a consequence of the long duration and complexity of Delphi studies (Wiersma & Jurs, 2005).

3.1.2 Strengths and Limitations of the Delphi Method

The Delphi Method is considered a relevant research methodology when the issue cannot necessarily be resolved simply through pre-determined survey questions (Rowe & Wright, 1999). The Delphi allows participants to make individual subjective judgements on issues; however, it culminates in a collective decision by the entire Panel (Adler & Ziglio, 1996). It is particularly appropriate when data is collected over a wide geographic area which prohibits the use of individual or small group interviews. The structured system underpinning a Delphi supports individuals from diverse backgrounds, experiences and knowledge to all contribute to the research (Skulmoski, Hartman & Krahn, 2007). As a consequence of the confidentiality of responses, participants are free to disagree on issues in an anonymous and safe environment. It limits the "bandwagon effect" (Linstone & Turoff, 1975, p. 4), whereby one loud or overbearing personality may dominate a group discussion, and the results may not accurately capture the opinions of the wider participants. One of the major benefits of the Delphi structure is that it provides participants with the opportunity to consider and review the issues in their own time before they formally respond.

The Delphi Method has often been seen purely as a quantitative technique (Rowe & Wright, 1999); however, it is a flexible research methodology that allows for the use of qualitative analysis as well (Wiersma & Jurs, 2005). The Delphi technique provides a structured model within which the researcher can use qualitative, quantitative or mixed research methods. This flexibility faciliates the researcher to examine a variety of different questions and contexts by providing the participants with suitable time and opportunity to both suggest and respond to pertinent issues (Skulmoski, Hartman & Krahn, 2007).

The Delphi Method has been criticised by some authors because of various perceived inadequacies and limitations. The main criticisms about the Delphi technique stem from the following issues:

- there is a focus on current events which results in the possibility that past and future events are undervalued,
- the participants tend to judge future events in isolation and, as such, their views may be overly simplistic,
- many participants are experts within a limited field and this specialisation may result in them having similarly limited viewpoints,
- it is easy for the implementation of the Delphi to be compromised by the researcher losing the necessary focus,
- the questionnaire has a large impact upon the results, and any inconsistencies in the format can therefore make it unsuitable for certain participants, and
- the researcher is in a position to influence or manipulate the responses of the participants (Martino, 1983; Hsu & Sandford, 2007).

Sackman published an extensive critique of the Delphi Method in 1974, claiming the method was unscientific and lacking in rigour. He further argued that many researchers had a poor understanding of research methodologies and limited background in social science (Sackman, 1974). According to Hill and Fowles (1975), the surveys used in Delphi-style studies were often poorly worded and overly ambitious. It was also proposed that the perceived ease of implementation of the Delphi Method resulted in its use by people who lacked the necessary skills to implement it appropriately (Linstone & Turoff, 1975). It was also noted by Rowe and Wright (1999) that while the Delphi Method was designed to utilise the expertise of individuals in a specific sector, many studies relied on the input of university students who had to make judgments on issues where they had no particular expertise.

It has been proposed that the Delphi Method is appropriate for addressing a single factor question; however, it is less useful for forecasting complex issues with multiple dimensions (Gatewood & Gatewood, 1983; Gordon & Haywood, 1968). This argument is based upon the premise that the Delphi Method, with expert opinion being refined to achieve consensus, may not appropriately consider the inter-relationship between items (Adler & Ziglio, 1996). However, it is important to recognise that the Delphi Method is not designed to be directly compared to statistical analysis. It has been developed for situations in which pure statistical methods are either not practical or realistic and when the subjective viewpoints of individuals are necessary and desirable (Rowe & Wright, 1999).

3.1.3 Justification of Delphi Method for Current Study

All of the criticisms and methodological issues associated with the use of the Delphi Method, as described in the previous section, were considered and taken into account during the development and implementation of the current study. Linstone and Turoff (1975) established a set of criteria that could be used to determine whether the Delphi technique is appropriate for use in a particular research project. These criteria were:

- when the issue to be examined is not easily assessed by specific analytical processes but may be more suited to a subjective consideration,
- when the subject group is composed of individuals from a variety of different locations, backgrounds and experiences,
- when the number of participants is large enough to mean that holding meetings with all members is impractical,
- when there is potential for serious disagreement between different members of the subject group, and this disagreement would result in communication within the group being compromised, and
- when the potential for any sub-set of the subject group to monopolise or dominate the data collection is large enough to risk the validity of the results.

Each of these issues was individually examined and reviewed by the researcher prior to the commencement of the project. The aims of establishing a consensus position from a group of disability support workers located across the large demographic and geographic area of NSW on the subjective issues of ageing with an intellectual disability would appear to specifically fit the criteria set by Linstone and Turoff (1975). It was considered that the goals of the current study met all of the nominated criteria, and that the Delphi Method would therefore be an appropriate methodology for addressing the research question.

Adler and Ziglio (1996) argued that, after deciding upon using the Delphi Method, there were three key questions that the research must be consider and answer. They proposed that the researcher must evaluate:

- With due consideration to the issue at hand, what is the most appropriate form of communication within the groups of participants?
- Who are the actual experts in relation to this issue and how accessible are they?
- Are there any alternative research techniques available and, if so, why would the researcher expect the application of the Delphi to provide better results than the other options?

Adler and Ziglio (1996) concluded that, if the researcher does not appropriately answer these three key questions prior to commencing the study, the Delphi Method may be inappropriate and the actual research potentially invalid. These three key issues were evaluated by the researcher prior to the project commencing. They also continued to be considered during the development of the current study as a means of ensuring that the Delphi Method was appropriate and relevant. As discussed earlier in section *3.1 Methodology*, it was not believed that there was an alternative research technique which would provide the same information as efficiently or effectively as the Delphi Method. The form of communication for the participants was designed prior to the commencement of the study and is described in greater detail in section *3.5 Data Collection and Management*. The process for determining the composition of the expert panel was considered prior to the research beginning, and is detailed in section *3.3.3 Recruitment of Sample*.

Delbecq, Van de Ven and Gustafson (1975) proposed three elements that were essential if a Delphi Method study was to be successful. The three criteria were that there was sufficient time to complete the study, the study's participants were literate and there was a high level of interest in actually participating. It was concluded that the Delphi technique should not be used if there were less than forty-five days available to complete the study, when the proposed participants had limited literacy, or when the experts were not sufficiently interested in the purpose of the research. After evaluation it was concluded that the present research project was not limited by any of the above considerations. The timeframe for the current study was not restricted and could extend over more than a year if so required. The participants in the study would be sought through self-nomination which would mitigate the concerns regarding both sufficient interest and literacy. The process for determining the panel is described in detail in section *3.3.3 Recruitment of Sample*.

It is believed that the previously mentioned strengths and inherent properties of the Delphi Method demonstrate its particular applicability to the current research project. In order to gain the widest possible geographic representation while still maintaining each individual participant's ability for direct involvement, the Delphi Method was deemed the most suitable research technique for the study. An analysis and review of the proposed research goals and methodology did not find any inherent limitations that would preclude the use of the Delphi Method. As noted in section *1.6 Key Assumption*, the current research had one key assumption. The researcher has assumed that the issue of ageing and intellectual disability was considered to be equally critical across all regions and all non-government disability support organisations in rural New South Wales. This assumption underpins the research methodology and sampling processes that were utilised within the study.

3.2 Ethical Issues

Formal ethics approval for this project was granted by the University of New England's Human Research Ethics Committee (see *Appendix 9*) prior to the commencement of both the pilot study, as described in section *3.4.2 Pilot Study*, and the main project. A second ethics application was approved for the final stage of the research (see *Appendix 9*). As the primary researcher is employed in a management position with The Ascent Group, one of the identified disability organisations operating in New South Wales (NSW), an intermediary research assistant was used in both the pilot and main study to avoid any potential concerns of collusion or coercion. A formal Confidentiality Agreement was signed between the researcher and the intermediary to prevent the inappropriate use of any information (see *Appendix 5*). The use of an intermediary meant that the researcher did not have direct contact with any participants employed by The Ascent Group and was never aware of the identities of these individuals. All contact with these participants was done through the intermediary who provided participants with the surveys and paperwork in hard copy. A separate set of questionnaires and information was provided to participants from The Ascent Group to reflect this slight difference in methodology (see *Appendix 3* and *Appendix 4*).

3.3 Setting, Sample and Recruitment

3.3.1 Population Demographics of NSW

As of 30 March 2010, the population of NSW was estimated to be 7.13 million (m) (Australian Bureau of Statistics, 2010). The rural and remote areas of NSW had a population of 1.6m (Australian Bureau of Statistics, 2009). These figures indicated that approximately 22.5 percent of the population reside in rural and regional areas outside the four main cities of Sydney, Newcastle, Wollongong and Gosford. A more comprehensive description of the study setting was provided in section *1.6 The Research Setting*.

3.3.2 NSW Government Structure for Disability Support Services

As stated in earlier chapters, the Department of Ageing, Disability and Home Care (DADHC) is the New South Wales (NSW) State Government body responsible for the funding and delivery of services to people with disabilities. DADHC administers the *NSW Disability Services Act* (1993), the *Home Care Service Act* (1988) and the 1973 *Youth and Community Services Act*. DADHC funds over 900 non-government and local government organisations across metropolitan and rural areas to provide services and support to the target groups of older people, people with disabilities and their carers (Department of Ageing, Disability and Home Care, 2008a). DADHC delivers services in sixteen Local Planning Areas (LPAs), as seen in the list below. These LPAs are:

1. Cumberland/Prospect;
2. Nepean;
3. Northern Sydney;
4. Inner West;
5. South East Sydney;
6. South West Sydney;
7. Central Coast;
8. Hunter;
9. Far North Coast;
10. Mid North Coast;
11. New England/North West;
12. Illawarra;
13. Southern Highlands;
14. Central West;
15. Orana/Far West; and
16. Riverina/Murray (Department of Ageing, Disability and Home Care, 2008a).

The first six LPAs cover predominantly metropolitan regions associated with Sydney. The remaining ten LPAs cover predominantly regional and rural districts; however, the city of Wollongong is located in the Illawarra area, Newcastle is in the Hunter area and Gosford is in the Central Coast area. The following map, Figure 3, provides a pictorial representation of the DADHC regions.

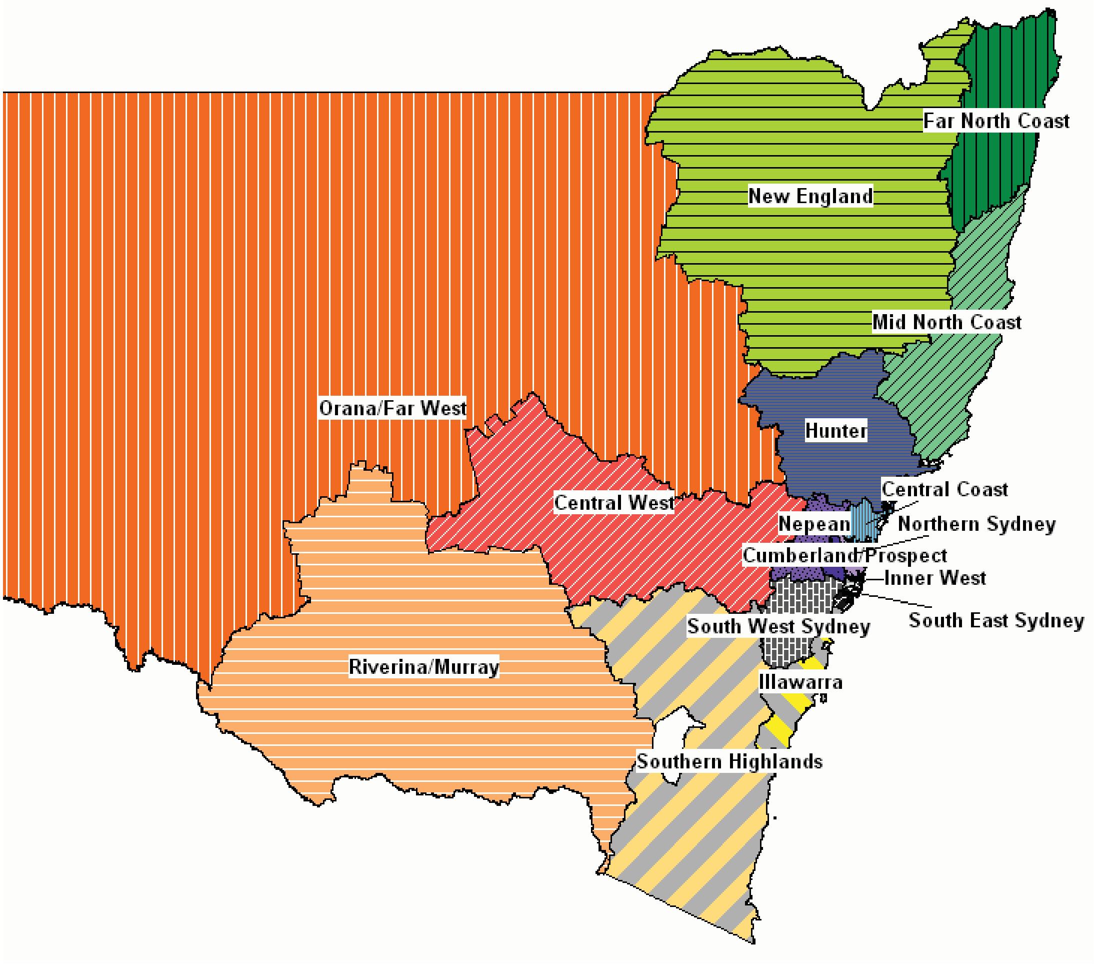

Figure 3 – Map of DADHC Regions

(Source: Local Government and Shires Association, 2008)

3.3.3 Recruitment of Sample

The purpose of the current study was to gain the individual perspective of disability workers within rural areas of New South Wales (NSW) regarding the issues of ageing and intellectual disability. In order to achieve a suitably representative sample an approach was made to the chair of Disability Professionals NSW (DPNSW), a Not-For-Profit (NFP) membership association that represents disability workers in the state. The chair of DPNSW was asked to identify key disability support organisations from each Department of Ageing, Disability and Home Care (DADHC) rural Local Planning Area (LPA). As part of this process, the chair of DPNSW was asked to select organisations that would provide a diverse representation of disability organisations with respect to their overall size and range of programs delivered. The following fifteen key organisations and the DADHC regions they cover, were nominated by the chair of DPNSW:

- Aces (Central and Mid North Coast),
- Challenge Disability Services (New England/North West and Hunter),
- Coffs Harbour Support Services (Mid North Coast),
- GlenRay Industries (Central West),
- Gunnedah Support Services (New England/North West),
- Hunter Integrated Care (Hunter and Central Coast),
- Kurrajong Waratah (Riverina/Murray),
- Lambing Flats Enterprises (Riverina/Murray),
- Mai-Wel (Hunter),
- Multi-Task (Mid North and Far North Coast),
- On-Focus (Mid North Coast and Far North Coast),
- Orange Community Resource Centre (Central West),
- The Ascent Group (New England/North West),
- Tulgeen Group (Southern Highlands), and
- WestHaven (Orana/Far West).

While it was not feasible to ensure that all rural areas of NSW were equally represented, it was considered that the final list of service organisations provided an adequate and appropriate coverage of most areas. There were a number of locations and disability providers which, while geographically located within NSW, were not recommended by DPSNW for the study. Initial discussions with DPNSW indicated that services situated in towns on the borders of NSW, such as Broken Hill and Albury, often accessed health services and training opportunities from neighbouring states. As such, the inclusion of these services would not necessarily accurately reflect the situation within NSW and were therefore not included.

Similarly, a number of providers that were situated in close proximity to the four major cities of Sydney, Newcastle, Wollongong and Gosford were considered by

DPNSW as not being necessarily representative of rural and regional NSW. The rationale for the inclusion of non-metropolitan coastal areas was that, while they are often not popularly viewed as being 'rural', they fit the regional definition within both the Rural, Remote and Metropolitan Areas (RRMA) and Australian Standard Geographical Classification Remoteness Areas (ASGC-RA) classification systems (Australian Institute of Health and Welfare, 2008b; Department of Health and Ageing, 2007a). Details of the RRMA and ASGC-RA are provided in section *1.6 The Research Setting*. It was considered that these coastal regions experience many of the same issues associated with distance and isolation as other rural areas.

The Chief Executive Officer (CEO) of each of the fifteen nominated services was approached by the researcher and asked for assistance to identify volunteers to participate in the study. The target participants were direct care staff as it was felt that this group best met the criteria of being knowledgeable individuals on the desired research topic. Line managers who were still involved in the day to day service delivery were also deemed appropriate potential panel members. The CEOs distributed the survey to all staff who met these criteria. They were requested to seek a minimum of one and a maximum of five participants from their organisation who worked with people with an intellectual disability who were considered to be experiencing ageing related issues. The maximum number of participants was set prior to commencing the research in order to prevent any single organisation having a disproportionate influence on the overall sample. The CEOs distributed the researcher's contact details, with potential participants advised to use this to directly indicate their interest in the project.

3.4 Survey Instruments

The initial questionnaire form (see *Appendix 2)* was developed by the researcher on the basis of the literature review and then revised following feedback received through a pilot study (see section *3.4.2 Pilot Study*). As detailed in section *1.3 Theoretical Framework for the Current Study*, the entire project and questionnaires were developed in line with a social constructionist framework. The belief that both individual issues and the wider society impact upon the life experiences of a person with an intellectual disability was a key component of developing the initial questionnaire. The concept of successful ageing for people with intellectual disabilities (see section *2.4 Successful Ageing*) and how issues associated with ageing affect their quality of life (see section *2.5.2 Quality of Life for People with an Intellectual Disability*) were also paramount in the development of the initial questions designed to start the process of identifying changes in rural service delivery that may achieve a better outcome for the individual. In line with the Delphi model, the information and responses from each round of questionnaires determined the format of the following round. This process is described in greater detail below.

Personal information was sought from the individual participants regarding their age, gender, a contact address, training, work history and their current job role (see *Appendix 2)*. No individuals, other than the researcher and the doctoral supervisory committee (if requested) had or have access to any of the participants' email addresses or personal information. All the participants' results were to be e-mailed or posted back to the researcher's university addresses and imported into a Microsoft Excel (Office Professional Plus 2007 version) spreadsheet for tabulation.

3.4.1 The Rounds of a Delphi Method Study

A Delphi project normally involves at least three rounds of responses from the participants (Ludwig, 1997). Within a classic Delphi study, the rounds of study continue until either a pre-determined consensus level is achieved or when no new information is being obtained. The first stage is a questionnaire that is composed of open-ended questions based around generic issues within the desired field. The second round questionnaire is based upon the responses gained from the participants' first round answers. The researcher provides the participants with a collation of all unique responses as provided in the first round, with the participants then required to review these items for relevance and to note any omissions. The researcher presents all of the issues identified in the first two questionnaires in a third questionnaire, with the participants required to use a Likert-type rating system to indicate the relative importance of each item (Hsu &

Sandford, 2007). Any items on which the Panel fails to reach consensus are then returned to the participants for re-evaluation until a group position is reached.

The current study utilised this construct of the Delphi Method to examine the views of direct care workers regarding the ageing of people with intellectual disabilities. The first round questionnaire was developed through a review of the literature and was composed of six generic questions (see *Appendix 2* and also section *3.4.2 Pilot Study*). These six questions were open-ended and designed to provide the participants with an opportunity to contribute as much information as they believed was relevant and pertinent. The rounds were designed to continue until consensus was reached. However, another stage to the classic Delphi model was added in the current study. The last component of the research involved the participants each being provided with the final lists of prioritised issues for each of the six questions. They were asked to indicate their agreement with the final ranking of the items through the use of a five point Likert scale.

In order to assist the researcher to establish whether there were any key themes emerging from the individual answers a thematic analysis was conducted upon the responses for each of the six questions. As previously detailed in section *1.3 Theoretical Framework for the Current Study*, the theoretical framework for this study is based upon social constructionism. The work of Charmaz (1990, 2006) was utilised to establish three guiding principles for the thematic analysis from a social constructionist perspective. These principles were

- Why do the participants in the study think/feel the way they do about the issue?

- Under what conditions do the participants think/feel the way they do?

- What consequences do the participants perceive as potentially occurring?

The thematic analysis was conducted separately on each of the six questions and was composed of six stages. These six stages were

1. All of the responses were read through to establish a general sense of meaning.

2. The responses were re-read to clarify and confirm the overall meaning of each item.

3. Where applicable, a meaning unit was identified for each separate item. In the context of the current study, a meaning unit was considered to be any string of text that encapsulated a single coherent concept.

4. Each meaning unit was then considered and reviewed with respect to the other meaning units to ensure that a complete change of subject had occurred.

5. The items within each question were then re-assessed to identify any recurring meaning units. The recurring meaning units were then grouped together in a matrix format.

6. A theme word or statement was then generated for each meaning unit to state the underpinning and inherent shared meaning for the grouped items. (Boyatzis, 1998)

Every item in each question was not categorised into a meaning unit as some issues were not considered to fit into a larger theme. At this stage of the project, the participants had not been given an opportunity to either review or rate the importance of each item. The purpose of the thematic analysis was not to generate quantitative data with respect to presence, frequency or intensity. It was instead designed simply to assist the researcher to identify any concepts that recurred throughout the lists of items for additional inspection and analysis.

Any specified themes are detailed in the following review of the responses for each question. The participants were not made aware of this process of theme identification at any time during the research. Prior to the second round of the study, all of the responses were sorted in alphabetical order to remove any perceived bias towards particular issues or themes.

3.4.2 Pilot Study

A pilot study was conducted by the researcher to assess the suitability of the Delphi Model and to provide feedback on the content and format of the initial survey form. The pilot study involved the participation of five volunteers who worked for a rural disability service provider, The Ascent Group. These five individuals all worked with people ageing with an intellectual disability. They were then not permitted to participate in the main study. The pilot study involved the use of an intermediary research assistant to ensure no perceptions of coercion or collusion, with the researcher unaware of the identity of the participants. An expression of interest to participate was provided to all employees within the Day Services section of The Ascent Group and they were asked to directly contact the research assistant to indicate their consent.

The initial stage of the Delphi was composed of a questionnaire with six generic open-ended questions derived from the literature review. These questions were

1. *What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*

2. *What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?*

3. *From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?*

4. *What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?*

5. *What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?*

6. *What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?*

The research assistant allocated an identifying code number (from one to five) to each of the participants and kept this code in a locked filing cabinet. The researcher provided the research assistant with five numbered packages, which contained the information sheet, consent form and survey. The research assistant then passed on the appropriately numbered package to each of the participants. The consent form was completed by the participants and was then maintained by the research assistant in a locked filing cabinet. The completed surveys were returned to the research assistant in the numbered packages. The research assistant then provided the researcher with the completed surveys.

The research assistant continued to act as the intermediary for the following stages of the pilot Delphi study. The numbering system allowed the researcher to identify if any participant had not returned any surveys, whilst still maintaining their anonymity. This situation occurred in stage two when the research assistant was advised that participant number three had not returned the survey in time. The research assistant then checked the code sheet to identify this participant and approached that person directly to request return of the survey.

Following each stage of the pilot study, the participants were asked to identify any areas of concern, or suggestions for improvement. As a consequence of this feedback, the number of rating options on the Likert Scale was increased from the original five points to seven. This alteration was made as participant feedback indicated the five point scale did not always provide sufficient levels of differentiation for the items. A new seven point scale was provided to participants in the pilot. They trialled this option and responded unanimously that it was preferred to the five point scale. The participants did indicate that a five point scale would be desirable for questions that had less than ten responses but the longer lists of issues meant that the seven point scale would be more appropriate.

The six questions used in stage one were considered by all the participants in the pilot study as being appropriate, relevant and sufficiently open-ended. Therefore, it was believed that the questions did not require any modification prior to inclusion in the main study.

3.5 Data Collection and Management

3.5.1 Contact between Researcher and Participants

The researcher's university email and postal addresses were distributed by the fifteen CEOs as the means for interested direct care workers to indicate their willingness to participate. The participants were asked to make contact with the researcher directly through either of these two options. Communication between the researcher and the participants took place through electronic correspondence or Australia Post mail services. The only exception to this process occurred with the staff employed by The Ascent Group who received their information and responded to the surveys through an intermediary to minimise any perceptions of collusion or coercion (see section *3.2 Ethical Issues*). Participants who did not have a personal email address had the information mailed directly to their nominated address via Australia Post. Stamped self-addressed envelopes were provided for the return of paperwork. The data collection process used in the main study is outlined in Figure 4. A more detailed description of the procedures follows.

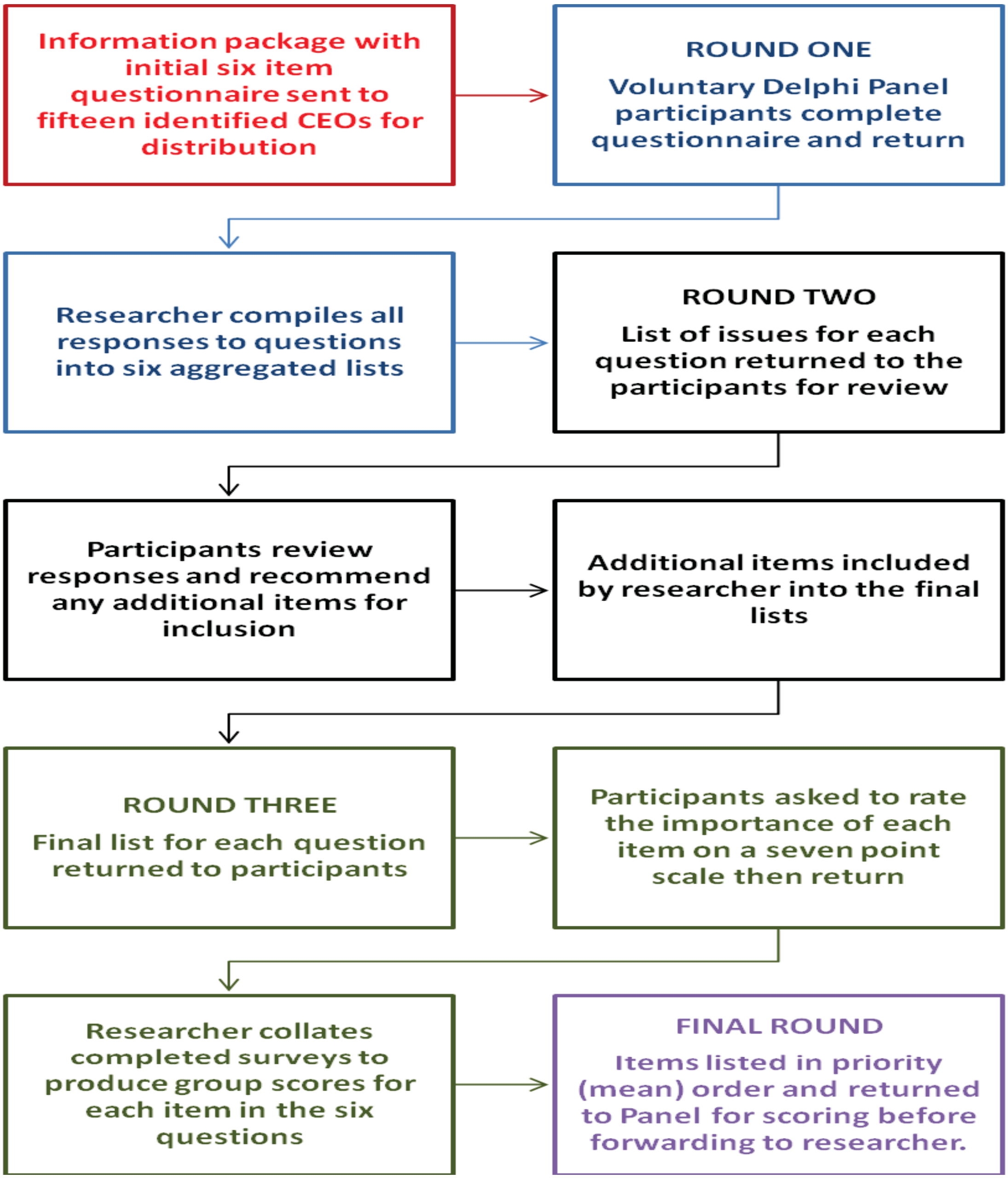

Figure 4 – Delphi Study Process

3.5.2 Data Collection Procedures

An introductory email and a copy of the information packages and survey were sent to the Chief Executive Officers of the fifteen disability support agencies. Each Chief Executive Officer was asked to facilitate the distribution of the study to potential participants within their organisation. Of the fifteen disability organisations approached, thirteen Chief Executive Officers responded directly to the researcher and agreed to distribute the information packages to staff. The two agencies that did not respond to the initial email, the Tulgeen Group and Orange Community Resource Centre, were telephoned directly by the researcher. While they agreed to distribute the survey, there was ultimately no participation from staff employed by these two organisations. Coffs Harbour Support Services did respond positively to the initial email, but no staff decided to participate in the study.

The study was introduced to participants through the use of electronic mail (email) and also paper copies through Australia Post. The Chief Executive Officers of the participating disability agencies distributed the information packages to their staff. Every participant in the Delphi Panel was supplied with a consent form, information that outlined the study and the proposed methodologies to be used (see *Appendix 1*), as well as an indication of the approximate timeframes involved in participation. The participants were also provided with an introductory letter and the first round questionnaire (see *Appendix 2*). The concept of using an on-line Delphi system, in which all participants completed the survey by accessing a web-site, was considered but ultimately rejected, as not all disability workers could be guaranteed to have easy access to a computer with internet access. Initial contact confirmed this situation with a number of participants asking for all information to be provided on paper via normal mail services.

3.5.2.1 First Round of the Delphi

The first stage of the research project involved an initial questionnaire (see *Appendix 2*) being sent to each participant. They were instructed to return their responses either via email or Australia Post to a designated university address. Stamped self-addressed envelopes were provided to those participants who requested a paper copy. A number of participants chose to remain anonymous and not to provide their direct contact details with their responses being returned by the Chief Executive Officer of their company. The instructions for returning the questionnaires were not followed by all participants with many questionnaires being returned to the researcher's workplace and, in two circumstances, his residential address. Many participants were familiar with the researcher from previous contact in non-research settings and therefore inadvertently used these other mechanisms for returning the surveys. It was not believed that this deviation from the provided instructions affected the reliability of the data.

3.5.2.2 Second Round of the Delphi

The responses from the first round questionnaire were compiled into an aggregated list for each of the six questions by the researcher. Identical or largely similar responses were only included once. These lists were presented to the participants as the second questionnaire (see *Appendix 6*) with an instruction to review the responses for any items of disagreement or omissions. The participants were advised that the items were not placed in order of importance, and that the researcher had listed them alphabetically to prevent any perception of bias. The lists were sent out to the participants through their preferred mode of delivery. The majority were distributed electronically via the researcher's university email address. Surveys were also provided in hard copy to either their employing organisation or a specific home address. Participants were asked to respond either by email or Australia Post. Stamped self-addressed envelopes were provided on request for paper-based surveys. Three participants had a total of eight additional recommended items for inclusion with no objections or disagreements to any of the first round issues identified.

3.5.2.3 Third Round of the Delphi

The additional responses to the second questionnaire were reviewed and compiled into a final list of key issue statements for each of the six questions. These lists of the key statements formed the basis of the third questionnaire. The third questionnaire was distributed (see *Appendix 7*) with instructions requesting that each participant rate the individual importance of each statement on a seven point Likert scale. The return mechanism for the third round remained the same as for the previous questionnaires. All returned surveys were coded with the importance and level of group consensus for each item being calculated. A description of the rationale underpinning these decisions is provided in section *3.6 Determinants of Consensus and Importance*. Any items that did not meet the pre-determined level of consensus would then be re-submitted to the group for further consideration. Each participant would be asked to again rate it on the seven point scale. This process of review for individual items would continue until either consensus was reached or it was apparent that there was no likelihood of the group achieving a position of agreement.

3.5.2.4 Final Stage of the Research

The final stage of the Delphi involved the participants being sent a prioritised list of responses based upon the collated scores from the third round of the survey. The participants were asked to indicate their level of agreement, using a five point Likert scale, with the final prioritised listing of issues for each of the six questions (see *Appendix 8*). This step was introduced to provide a checking mechanism for the degree of consensus in the group. The prioritised list of responses gained through the Delphi study was also sent to the Chief Executive Officers of all fifteen organisations that had been originally approached to participate in the study. As with the Delphi panellists, the Chief Executive Officers were asked to indicate their level of agreement with the final prioritised list for each of the six questions using the same five point Likert scale. This final stage of the study was not a formal part of the Delphi rounds but was included to examine whether senior managers were in agreement with the views of their direct care workers.

3.5.3 Duration of the Data Collection

The pilot study commenced on 21 November 2007 and concluded on the 5 March 2008. The Delphi component of the main project commenced on 13 May 2008 with an email being sent to the Chief Executive Officers of the disability support organisations. Initial contact with participants commenced on 14 May, and the first round of the survey started being disseminated the same day. Surveys continued to be provided to all interested participants for a period of one month. One of the significant difficulties faced by the researcher throughout the survey was the delay in receiving participants' responses. As a consequence of the distance between both the researcher and the study participants all communication occurred through electrical or written forms. This situation meant that a considerable amount of time was spent following up with participants who had not responded within the nominated timeframes. The last stage of the project was finalised on 17 July 2009, representing a total duration of data collection of fourteen months.

3.6 Determinants of Consensus and Importance

A comprehensive analysis of the data is presented in the Results section in Chapter Four. However, there was one important aspect of the analysis that had to be determined prior to the commencement of the actual study. This issue related to the concepts of consensus and importance and how these two factors would be determined.

The main statistical processes used in Delphi studies are based on measures of central tendency such as mean, median and mode, or levels of dispersion such as standard deviation (Hsu & Sandford, 2007). One source of criticism for the Delphi Method is that there is no standard measure or cut-off point that definitively determines when consensus is reached by the panel for an item (Crisp et al, 1997). There are a number of different methodologies that have been proposed to determine whether the group has reached consensus on individual issues and also whether the item is considered important.

A measure of consensus, called the coefficient of variation, was first proposed for use in Delphi studies by English and Keran (1976). The coefficient of variation is calculated by dividing the standard deviation for each issue by its mean. An item is considered to have reached consensus if the coefficient of variation value is between 0 and 0.5 (English & Keran, 1976). Other researchers, such as Hill and Fowles (1975), argued that the group had reached consensus on an issue if the standard deviation for that item was less than or equal to 1.0. Schiebe, Skutsch and Schofer (1975) considered consensus had been reached when a pre-determined proportion of votes fell into a prescribed range of scores. However, no set figure either for the proportion of votes or prescribed range of scores was clearly established.

It was proposed that consensus could be considered to be achieved when 80 percent of the scores fall within three consecutive ratings on a seven point Likert scale (Hsu & Sandford, 2007). A different cut-off mark was nominated by Alexandrov et al (1996), who defined consensus as when 67 percent of votes fell in one of two categories, such as a yes-no delineation. Another option suggested that consensus required a figure of 70 percent of scores to fall within one rating (Hsu & Sandford, 2007). Alternatively, it was proposed that a basis of at least 51 percent responding to any given response category could be used to determine consensus (McKenna, 1989).

Determining whether an item is accepted by the group as being ‘important’ is usually based upon its mean, median or mode scores (Hasson, Keeney & McKenna, 2000). The use of the mean score is considered appropriate by some researchers (Murray & Jarman, 1987), while other studies promote the median as being a more reliable measure (Hill & Fowles, 1975). It has also been argued that using the mode is appropriate as there is a possibility that an item may see the participant group presenting two separate and distinctly different views with the scores clustered around these two points. In this situation, either or both the mean and median scores may not truly provide a correct representation of the group’s thoughts (Hsu & Sandford, 2007).

It was decided by the researcher that the mean, median, mode, standard deviation and the coefficient of variation for each item would be calculated following the third round of the current study. It was determined that a number of different measures would be examined for each item in order to ensure the greatest possible reliability and validity of the results. Consensus would be considered to be attained if the coefficient of variation fell between 0 and 0.5, and if the standard deviation for the item was equal to 1.0 or less. If both of the scores were exceeded, consensus would not be deemed to have been reached. For any issue that failed to meet one of the two criteria, the range of scores for that item would be further analysed to establish if 80 percent of the participants’ scores fell within three consecutive scores. If the coefficient of variation exceeded 0.5, or the standard deviation exceeded 1.0, and less than 80 percent of the ratings were within three consecutive scores, it would be considered that consensus was not established for that item. Any items on which the Panel did not reach consensus would be returned to the participants for further consideration.

It was further determined that an item would be considered ‘important’ by the Panel if the mean score was greater than 4.5, indicating that scores were closer to important than the neutral position. However, each item’s median and mode scores would also need to equal or be greater than a score of 5 for importance to be attributed. If any item’s mean score was equal to or less than 4.5, or if the median or mode scores were below 5, the data for that item would be examined to see if 80 percent of ratings were 5 or greater. If the mean was below 4.5, or the median or mode scores for any item were below 5, and less than 80 percent of participants rated the item as ‘important’ or greater, the issue would be considered to be unimportant to the Panel. This rating of unimportant would be tested by returning any identified items back to the participants for review.

When consensus was not reached on an item in a Delphi study, some researchers chose to provide each participant with the overall group’s mean score or inter-quartile range for that question (Wiersma & Jurs, 2005). It was decided not to follow this protocol in the current study. The reason for not providing this information was to ensure that there was no pressure, inadvertent or otherwise, upon the participants to conform to the group view. Instead, any items that did not reach consensus would be returned to all members of the panel, and they would be asked simply to reconsider their initial response, then re-rate and return it.

3.7 Limitations

There were three methodological limitations identified within the current study. These limitations must be considered when examining the results and the applicability of the findings to the wider community. The first of the limitations relates to the suitable coverage of disability workers from across the state of New South Wales (NSW). Three of the initial organisations approached by the researcher, The Tulgeen Group, Orange Community Resource Centre and Coffs Harbour Support Services did not provide any participants to the study. The Orange Community Resource Centre is located within the Central West Local Planning Area (LPA). This LPA is also serviced by GlenRay Industries, which did provide participants for the study. Coffs Harbour Support Services is located within the North Coast region that is also serviced by On-Focus. There were participants from On-Focus within the study and, as such, it was considered both the Central West and North Coast planning areas were represented.

However, no alternative organisation to The Tulgeen Group was nominated by the Chair of DPNSW within the Southern Highlands LPA, and this area was ultimately not represented in the Delphi survey. Time restraints did not allow for another organisation to be sought out in that specific LPA. In total, nine of the ten rural and regional LPAs were represented on the Delphi Panel. The Chief Executive Officer of The Tulgeen Group did complete the final component of the study aimed at senior managers so some representation from the Southern Highlands region did occur in the last stage of the research.

The second methodological limitation pertains to the use of staff from non-government organisations. A decision was made to focus purely on non-government disability services with no participation from direct care staff who work for the NSW Department of Ageing, Disability and Home Care (DADHC). This choice was deliberate as there are significant differences in how government and non-government disability workers were both employed and funded. DADHC disability staff were employed under a different award and have different induction processes and ongoing training. It was felt inappropriate to include both government and non-government staff in the Delphi study as it was considered that the issues they faced would not necessarily be identical. However, this decision does mean that the results of the Delphi study cannot necessarily be generalised to the staff employed through the government body DADHC.

The third limitation of the current study was the use of a convenience sample. In order to reduce the possibility of bias, it was recommended that probability sampling, a process in which every person has an equal likelihood of being surveyed, should be used. Probability sampling is considered the most suitable methodology as it minimises the potential for sampling error or bias (Beanland et al, 1999). With the current study, the purpose was to gain the input and views of a range of participants across rural NSW and, as such, a probability sample was simply not logistically possible. A convenience sample was the only technique that could achieve the desired goal. However, the use of a convenience sample did mean that the motives and perceptions of those people who chose to respond to the survey may have differed from the individuals who did not wish to participate. This potential difference leaves open the possibility that the sample was, therefore, biased (Beanland et al, 1999).

This issue is highlighted by the demographic information of the Panel members, as described in greater detail in section *4.1 Demographic Characteristics of Study Participants.* The participants as a group had a considerably higher level of prior training and education than the limited demographic data of the disability sector would suggest. There were a number of reasons for this disparity (see section *5.1.1 Demographic Issues in Current Study*); however, it remains a possibility that the participants in this Delphi Panel may not accurately reflect the wider disability workforce sector.

It is also worth recognising that a key component of a Delphi study is the use of appropriate ‘experts’ who are interested in participating in the research (Adler & Ziglio, 1996; Delbecq, Van de Ven & Gustafson, 1975). This issue in itself limits the potential participant base. The Panel in a Delphi study must be composed of those individuals who are sufficiently motivated and interested in the issue of ageing and disability to participate in the study. There may be ‘experts’ within the field who were not willing to become involved in the study due to the considerable time commitments for participants involved in this type of research. This factor is inherent to all Delphi studies and determines the selection process for potential panellists. It is not believed that the selection process for participants in the current study was biased in its choice of experts as the opportunity to participate was offered through the Chief Executive Officer to all staff members of the nominated rural disability organisations who worked with people ageing with an intellectual disability. The decision whether each person could commit sufficient time and had sufficient interest in the topic was left to each individual to determine.

3.8 Conclusion

Chapter Three described the Delphi Method, its strengths and weaknesses and its suitability for the current research project. The selection of the Delphi Panel was discussed, as was the methodology and questionnaires used in the study. The chapter described the population group, how the sample was obtained for the survey and the treatment of the data. The use of a pilot study and its impact upon the final instrumentation was discussed. The procedures used within the main study were detailed, along with the methodological limitations. The next section, Chapter Four, provides an overview of the demographics of the Delphi participants and a summary of the findings from each round of the study.

Chapter Four - Results

Introduction

The chapter provides a summary of the results from each stage of the Delphi study as well as an additional stage in which the leaders of the disability organisations responded to the prioritised lists of items gained from the research. The findings are presented, clearly establishing new key knowledge based upon the prioritised issues identified by the participants.

The researcher trialled a number of different options and styles for presenting the data. In order to increase the readability of this section, a large proportion of the tabulated data was initially included as an appendix. However, it was considered that this approach substantially interrupted the flow of information, with the reader constantly referring back to the relevant appendix for specific details. It was decided to present all the relevant data in the form of tables throughout this section. It is acknowledged that the repeated use of tables may not be ideal for the reader; however, it was seen to be a more accessible format.

4.1 Demographic Characteristics of Study Participants

There were a total of thirty-one participants in the first stage of the study. While the figure of thirty-one in the Delphi Panel is slightly higher than the recommended number of participants by Ludwig (1997) and Adler and Ziglio (1996), it still fell within the range of ten to fifty as recommended by Linstone and Turoff (1975). It was considered that thirty-one was not an excessively large Panel and would not present any major logistical problems or impediments to the survey being completed in a timely and efficient manner.

A large proportion of the participants (n=23/31) identified themselves as being primarily direct care workers, with the remaining eight classifying themselves as line managers who still performed direct care work. The Delphi Panel had an average age of 47 years (standard deviation = 9.9), with a range from 22 to 69 years (see Figure 5).

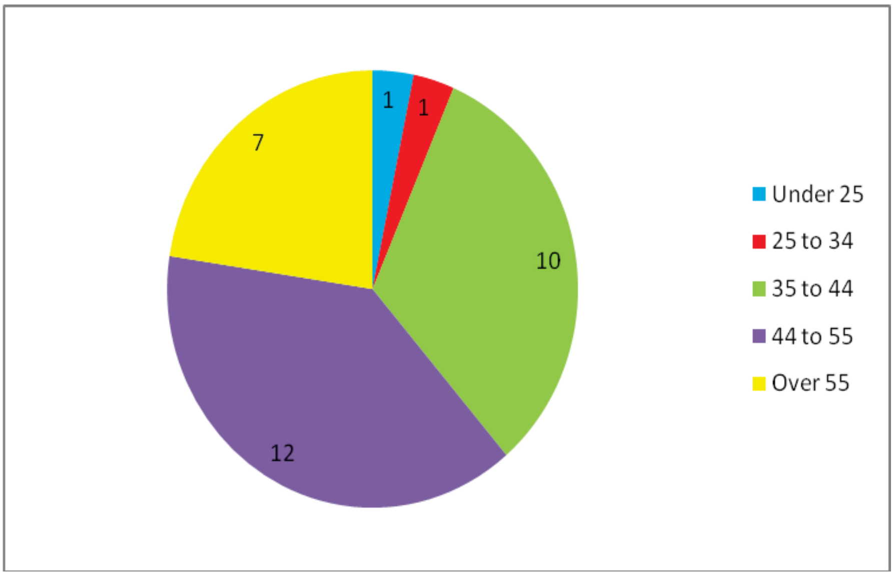

Figure 5 – Age of Panel Members

The average length of time spent working with people with disabilities was 10.0 years (standard deviation = 6.8), with the range of employment experience in the field varying from six months to over thirty years.

Two thirds (67.8 percent) of the Delphi Panel have worked with people with disabilities for a minimum of six years. Figure 6 provides a description of the years of experience of the Panel members in working with people with disabilities.

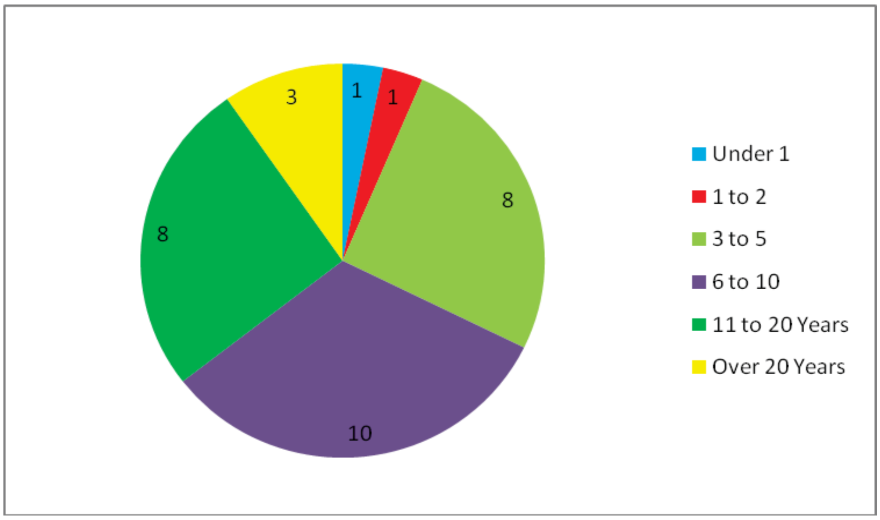

Figure 6 – Years of Experience Working with People with Disabilities

The participants identified their highest level of training and education at stages including secondary school, Certificate III, Certificate IV, diploma, advanced diploma, university degree and postgraduate qualification. Figure 7 displays the highest education level achieved by the participants. Of the Delphi participants, 96.8 percent had completed a post-school qualification in a disability related area.

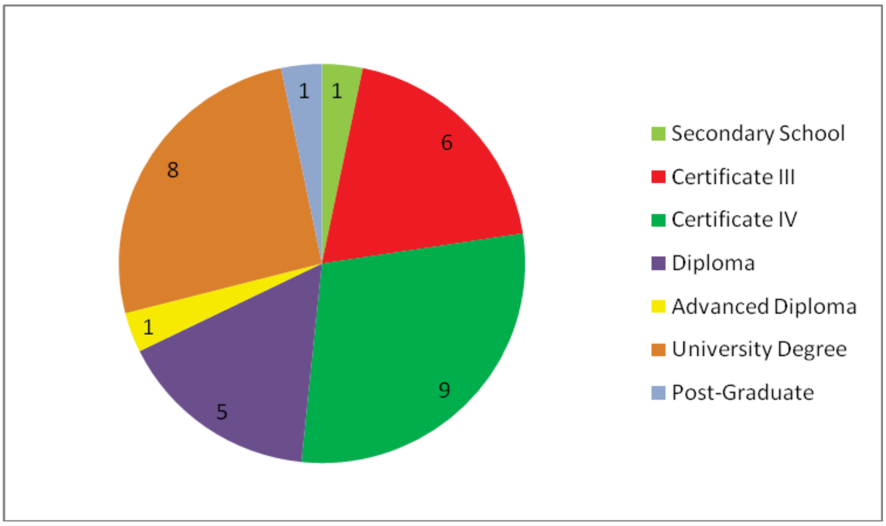

Figure 7 – Highest Education Level Achieved

4.2 First Round of the Delphi

A total of thirty-one participants agreed to participate in the study and they all completed the first stage of the Delphi. The participants were asked to list as many answers as they felt appropriate for each of the six initial generic questions (see section *3.4.2 Pilot Study*). The six questions were open-ended, allowing the participants to provide as many different responses as they felt appropriate. All of the participants' survey results were collated with any identical or predominantly similar responses removed. The actual wording used by the participants in their answers was maintained. In situations in which predominantly similar responses were combined, the researcher used the wording that was considered to best represent the jointly nominated issue.

4.2.1 Issues Identified for Question One

There were a total of twenty-five different issues identified for the first question *"What do you think are the main issues or problems that a person with an intellectual disability will face as they age?"* All twenty-five of the participants' identified issues are presented in alphabetical order in Table 1. The thematic analysis of these responses revealed a number of specific concepts within the identified issues. These themes included issues relating to:

- Access to services: The panel identified a large number of issues relating to a lack of access to appropriate services. The participants' responses commented specifically on problems such as *"Access to specialist services such as gerontology and ACAT teams"*, *"Having appropriate housing to allow them to age in place safely"*, *"Being able to retire and access appropriate recreation and leisure activities (day programs etc)"*, *"Accessing appropriate equipment and aids"*, *"Accessing appropriate transport"*, *"Doctors (and allied health staff) not prioritising medical attention for this group"* and *"Having appropriate support services to allow them to age in place safely"*.

- Training needs: The participants noted a number of issues relating either to a lack of knowledge or the need for appropriate training by both direct care staff and the wider community in issues relating to ageing with an intellectual disability. This theme included responses such as *"Having appropriately trained and qualified support staff"*, *"Confusion by staff and medical practitioners about what is ageing versus disability issues"*, *"Lack of understanding of disabilities within mainstream aged care services"* and *"General lack of understanding about the ageing process by staff"*.

- Individual health: The health of people with intellectual disabilities was identified by participants as one of the main problem areas associated with ageing. These individual health items included *"Decreased communication skills"*, *"Specific medical conditions such as early on-set dementia, osteoporosis etc"*, *"Hygiene (including managing incontinence)"*, *"Decreased physical skills"* and *"Physical deterioration (hearing and sight) and emotional changes (depression)".*

- Funding: There were a number of different issues identified that had an underlying focus upon the perceived inadequacy of the funding provided by government to support people with intellectual disabilities as they age. Examples of these issues includes *"Increasing support needs but no increased support (due to no funding increases)"* and *"Pension not meeting increased financial needs".*

Table 1 – Issues Identified for Question One

Issue Identified
• Access to specialist services such as gerontology and ACAT teams
• Accessing appropriate equipment and aids
• Accessing appropriate transport
• Being able to retire and access appropriate recreation and leisure activities (day programs etc)
• Concerns about "what's next" in their life
• Confusion by staff and medical practitioners about what is ageing versus disability issues
• Correct diagnosis of issues by medical practitioners including mental health
• Decrease in family support as immediate family is often also ageing (and dying themselves)
• Decreased communication skills
• Decreased physical ability
• Doctors (and allied health staff) not prioritising medical attention for this group
• General lack of understanding about the ageing process by staff
• Getting used to new staff
• Having appropriate housing to allow them to age in place safely
• Having appropriate support services to allow them to age in place safely
• Having appropriately trained and qualified support staff
• Having to leave a house they have lived in for many years (and decades)
• Hygiene (including managing incontinence)
• Increasing support needs but no increased support (due to no funding increases)
• Lack of appropriate facilities
• Lack of understanding of disabilities within mainstream aged care services
• Pension not meeting increased financial needs
• Physical deterioration (hearing and sight) and emotional changes (depression)
• Placement into mainstream aged care facilities that have no understanding of disability
• Specific medical conditions such as early on-set dementia, osteoporosis etc

4.2.2 Issues Identified for Question Two

There were a total of thirty-two different issues identified for the second question *"What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?"*All thirty-two of the participants' identified issues are presented in alphabetical order in Table 2. The thematic analysis of these responses revealed a number of key concepts within the identified issues. These themes included issues relating to:

- <u>Mental functioning</u>: A number of the identified signs of ageing in people with intellectual disability related to declines or changes in the mental functioning of the individual. These signs included both generic issues such as *"Deterioration in mental abilities"* and *"Mental health issues such as depression and dementia"*, as well as more specific problems including *"Loss of memory"* and *"Increase in inappropriate and/or aggressive behaviours"*.

- <u>Physical issues</u>: The participants in the study identified a series of physical issues associated with ageing in the cohort of people they support. Issues such as *"Decreased mobility"*, *"Incontinence (bladder and bowel)"*, *"Weight gain"*, *"Physical health issues (including sight and hearing deterioration)"*, *"Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)"* and *"Trips and falls"* were all nominated as problems.

- <u>Emotional or personality issues</u>: There were a number of items identified in the study that pertained to emotional issues or changes in the individual's personality. The participants noted problems in areas such as *"Grief (loss of their own families and friends)"*, *"Loss of confidence"*, *"Disrespect towards staff"* and *"Losing their 'identity' and independence after moving into supported accommodation"*.

- <u>Generic health and support needs</u>: The panel described a number of generic health and support concerns relating to ageing and intellectual disability. Some of these issues included *"Greater support needs"* and *"Increased simple and complex health needs"*.

Table 2 – Issues Identified for Question Two

Issues Identified
• Bullying towards other residents and staff
• Changes in eating habits (inability to eat certain foods)
• Communication problems
• Decreased mobility
• Deterioration in mental abilities
• Disrespect towards staff
• Greater support needs
• Grief (loss of their own families and friends)
• Hormonal issues
• Incontinence (bladder and bowel)
• Increase in inappropriate and/or aggressive behaviours
• Increase in seizure activity
• Increased simple and complex health needs
• Isolation
• Losing their 'identity' and independence after moving into supported accommodation
• Loss of confidence
• Loss of memory
• Loss of motivation
• Mental health issues such as depression and dementia
• Personal hygiene
• Physical health issues (including sight and hearing deterioration)
• Reduced desire to access services
• Reduced desire to participate in activities
• Reduced productivity
• Reduction in ability to access community independently
• Reduction or loss of senses such as vision and hearing
• Set in routine (resistant to change)
• Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)
• Stereotyping of others
• Trips and falls
• Weight gain
• Withdrawal

4.2.3 Issues Identified for Question Three

There were a total of twenty-seven different issues identified for the third question *"From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?"* All twenty-seven issues the participants identified are presented in alphabetical order in Table 3. The thematic analysis of these responses revealed a number of key concepts within the identified issues. These themes included issues relating to:

- Funding: As in Question One, the appropriateness of funding levels was raised as a recurring theme with respect to service provision. The concerns of participants with respect to funding is seen in items including *"Lack of additional funding to meet increasing needs", "Lack of government funding for staff training", "Lack of government funding for appropriate staffing levels"* and *"Being creative in using the funding to meet client needs".*

- Access to Services: Items relating to the lack of appropriate services, or the inability to access generic services, were raised by the participants several times. This theme was also identified for Question One; however, in this context the participants identified items of concern such as *"Accessing appropriate professional support", "Gaining access to appropriate recreational and leisure activities in retirement such as day services programs", "Advocating for clients to get appropriate medical care"* and *"Long distance travel required to see suitable medical specialists".*

- Health Care: There were a number of items noted by the participants that pertained specifically to the provision of health care support to people ageing with an intellectual disability. These issues included *"Maintaining independence, health and well-being", "Manual handling issues as clients lose mobility"* and *"Assisting in increasing personal care needs (such as hygiene)".*

- Time Constraints: The participants raised a number of issues relating to time limitations in performing their job. These items covered generic issues such as *"Time constraints"*; however, specific problems also included *"Dealing with personal frustration in not having sufficient time to meet individual needs", "Excessive paperwork"* and *"Reduced productivity by the person".*

- Family Issues: While the item *"Unrealistic family expectations"* was the only one that specifically mentioned the involvement of the family, the three-way interaction between client, family and staff could be considered as an underlying theme to almost all items in Question Three. It is believed that Question Four, which focussed upon issues involving family and friends, provided additional items and further clarification for this theme.

Table 3 – Issues Identified for Question Three

Issues Identified
• Accessing appropriate professional support
• Advocating for clients to get appropriate aged care services
• Advocating for clients to get appropriate medical care
• Assisting in increasing personal care needs (such as hygiene)
• Being creative in using the funding to meet client needs
• Blending the impact of ageing with issues already faced by people with disabilities
• Breaking bad habits that may become unsafe
• Communication problems
• Dealing with client frustration at not being able to do things
• Dealing with personal frustration in not having sufficient time to meet individual needs
• Excessive paperwork
• Gaining access to appropriate recreational and leisure activities in retirement such as day services programs
• How to assess independence
• Lack of additional funding to meet increasing needs
• Lack of appropriate venues for community access
• Lack of government funding for appropriate staffing levels
• Lack of government funding for staff training
• Long distance travel required to see suitable medical specialists
• Maintaining independence, health and well-being
• Manual handling issues as clients lose mobility
• Providing constant reassurance
• Reduced acceptance of activities
• Reduced concentration by the person
• Reduced productivity by the person
• Reduced stimulation levels
• Time constraints
• Unrealistic family expectations

4.2.4 Issues Identified for Question Four

There were a total of twenty-four different issues identified for the fourth question *"What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?"* All twenty-four issues the participants identified are presented in alphabetical order in Table 4. As mentioned in section *4.2.3 Issues Identified for Question Three*, the theme of Family Issues and the relationship between individual, family and service provider is a wide reaching one. It is believed that the thematic analysis for Question Four helped to clarify some of these issues further. The thematic analysis of the responses for Question Four revealed a number of key concepts. These themes included issues relating to:

- Access to Services: The ability of the family to access appropriate services was seen as an issue of concern. Items that related to access included *"Access to respite"*, *"Lack of information for families to source services"* and *"Access to appropriate facilities to assist people with higher care needs"*. These items were similar to issues raised in Questions One and Three; however, the focus was specifically on the experience of the family members in accessing relevant service options.

- Understanding and Coping with Ageing: There were a number of items raised that were associated with a lack of understanding of the ageing process by family and friends. Some of these items included *"Understanding and separating behavioural issues from physical/mental health issues"*, *"Household members reducing the person's level of independence by attempting to 'help' by doing everything for them"* and *"Fellow residents not understanding what is going on (why the person has changed or moved)"*.

- Ageing Parents: The theme of parent/s ageing concurrently with the person with the intellectual disability was identified by the participants. These included both generic issues such as *"Ageing parents"*, as well as more specific items like *"Family concern about future planning as the person with the disability may outlive the parents"*.

- Increasing Care Needs: There were a number of different issues associated with the effect increasing health care needs has upon family and friends. The participants identified both direct and indirect items that pertained to increasing care needs, and these issues included *"Concerns about person's ongoing and increasing care needs"*, *"Need for major home renovations (e.g. stairs, ramps, rails etc)"*, *"Communication problems"* and *"Coping with increased support needs"*.

Table 4 – Issues Identified for Question Four

Issues Identified
• Access to respite
• Access to appropriate facilities to assist people with higher care needs
• Ageing parents
• Clients with lower needs miss out due to an increased focus on person who is ageing
• Communication problems
• Concerns about person's ongoing and increasing care needs
• Coping with increased support needs
• Family concern about future planning as the person with the disability may outlive the parents
• Financial security and ongoing financial management
• Friends experiencing depression themselves due to worry about their own mortality
• Frustration
• Household members reducing the person's level of independence by attempting to 'help' by doing everything for them
• Impact upon closeness of relationship (affected by dementia)
• Increased pressure on families to provide ongoing advocacy
• Increased reliance upon staff to facilitate family contact (primarily through phone)
• Lack of acceptance of the ageing process
• Lack of information for families to source services
• Lack of patience (everyone wants everything done right now!)
• Legal issues (e.g. making a will or power of attorney)
• Need for major home renovations (e.g. stairs, ramps, rails etc)
• Fellow residents not understanding what is going on (why the person has changed or moved)
• Pressure on friends to cope with changing personality and skills
• The need for greater advocacy by the families to gain additional funding as support needs increase
• Understanding and separating behavioural issues from physical/mental health issues

4.2.5 Issues Identified for Question Five

There were a total of twenty-one different issues identified for the fifth question *"What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?"* All twenty-one issues the participants identified are presented in alphabetical order in Table 5. The thematic analysis of these responses revealed a number of key concepts within the identified issues. These themes included issues relating to:

- Staff Training and Development: The participants identified a series of staff training and development issues specifically relevant to the provision of services. These items included *"Training and education for both disability staff and generic aged care professionals", "Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work)", "Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing"* and *"Recruiting qualified and trained staff"*. It is perceived that Question Six, which directly addressed the issue of training needs, provided additional clarification around this theme.

- Funding: As with Questions One and Three, the theme of funding was again raised by the participants as an issue of concern. Specifically, the participants identified items of concern such as *"Financial viability", "Care needs are constantly increasing, whilst funding is not", "Appropriate funding models for smaller services without large numbers of ageing clients", "Funding for new equipment / home modifications"* and *"Cost in accessing services (travel costs and staffing costs)".*

- Access to Services: The ability, or otherwise, to access appropriate services was identified in Questions One, Three and Four, and the participants again highlighted a number of issues relating to access for rural disability service providers. In particular, items such as *"Lack of mainstream services", "Age cut-off for ACAT prevents people with disabilities accessing services", "Distance to nearest appropriate services", "Availability of complementary services to our own", "Lack of public transport", "Lack of specialist services such as respite and day programs"* and *"No dedicated aged care facility for people with intellectual disabilities"* underline the participants' perception of this problem.

Table 5 – Issues Identified for Question Five

Issues Identified
• Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing • Age cut-off for ACAT prevents people with disabilities accessing services • Appropriate funding models for smaller services without large numbers of ageing clients • Availability of complementary services to our own • Care needs are constantly increasing, whilst funding is not • Competition with the community's focus upon the increasing needs of the generic ageing population • Cost in accessing services (travel costs and staffing costs) • Distance to nearest appropriate services • Financial viability • Funding for new equipment / home modifications • Inflexibility in funding models and structures • Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work) • Lack of mainstream services • Lack of public transport • Lack of specialist services such as respite and day programs • Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability • Mainstream aged care services not understanding how to support someone with a disability • Maintaining qualified and trained staff • No dedicated aged care facility for people with intellectual disabilities • Recruiting qualified and trained staff • Training and education for both disability staff and generic aged care professionals

4.2.6 Issues Identified for Question Six

There were a total of twenty-six different issues identified for the sixth question *"What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?"* All twenty-six issues the participants identified are presented in alphabetical order in Table 6. The thematic analysis of these responses revealed a number of key concepts within the identified issues with themes including:

- Generic Training Issues: Question Six asked the participants specifically about training priorities and, as such, it was not surprising that a theme of generic training needs was identified. Some of the generic training identified by the participants included items such as *"Generic aged care* *courses for disability service providers", "Ability to educate the general public about client abilities", "Comprehensive and accurate record keeping to assess changes over time", "Understanding of the ageing process and stages that people move through", "Attitude training (patience, empathy, consistency, ethics)"* and *"Understanding of different support needs at different stages of ageing".*

- Medical Issues: The participants identified a number of training issues relating to the individual health of the people they supported. Examples of the training priorities in this area included *"Medical management", "Dementia", "Diabetes", "Understanding medication", "Training in observation skills so that changes in client health can be detected early"* and *"Understanding of health issues".*

- Personal Care Issues: There were a series of training priorities proposed by the participants that pertained to personal care assistance. It was considered that these items were different in context to the theme of Medical issues as they did not generally relate to a specific condition but were instead generalised to issues associated with ageing. Examples of these items included *"Dietetics (meal preparation, tube feeding etc)", "OH & S and Manual Handling Training (how to provide appropriate physical support)", "Specialist equipment usage"* and *"Personal care needs".*

- Counselling Support: The need for additional training in the area of counselling was identified by the participants as an important issue. The two main items that referred to this were *"Understanding of emotional issues"* and *"Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend".*

- Quality of Life: The issue of training in how to support people ageing with a disability to maintain their quality of life was identified by the participants. This need was noted in items which included *"Person centred planning"* and *"Quality of life management".*

Table 6 – Issues Identified for Question Six

Issues Identified
• Ability to educate the general public about client abilities
• Advocacy to act as the voice for people who are ageing and seek appropriate facilities
• Alternative communication methods
• Attitude training (patience, empathy, consistency, ethics)
• Behaviour management
• Comprehensive and accurate record keeping to assess changes over time
• Dementia
• Diabetes
• Dietetics (meal preparation, tube feeding etc)
• Generic aged care courses for disability service providers
• How to transition people between services effectively
• Medical management
• OH & S and Manual Handling Training (how to provide appropriate physical support)
• Person centred planning
• Personal care needs
• Quality of life management
• Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend
• Specialist equipment usage
• Time management
• Training in observation skills so that changes in client health can be detected early
• Understanding medication
• Understanding of changes associated with ageing
• Understanding of different support needs at different stages of ageing
• Understanding of emotional issues
• Understanding of health issues
• Understanding of the ageing process and stages that people move through

4.2.7 Summary of Round One of the Delphi

The first round of the Delphi saw a total of 155 items identified by the participants for the six questions. A number of these items were mentioned in more than one question. A simple thematic analysis of the responses was conducted to see whether there were recurring and identifiable trends within the items. There were a total of twenty-five themes identified for the six questions. A number of these themes had a similar title and/or conceptual base; however, the context of the theme was not necessarily consistent across the study as the six questions each addressed different aspects of ageing with an intellectual disability. The participants had not yet had the opportunity to indicate their level of agreement with each individual item and rate the importance of the item. No further dissection of the data or themes was conducted until the remaining stages of the

Delphi study had been completed with the levels of participant consensus and importance being determined for each item.

4.3 Second Round of the Delphi

In the second round of the Delphi study, each of the thirty-one participants was provided with the collated listing of issues for each of the six questions. The items were presented in alphabetical order as detailed in the previous sections. Every participant was asked to review the lists of issues for each of the six questions and consider whether there were any items that they disagreed with, and also to suggest any additional issues that had been previously overlooked. Three of the participants responded with additional suggestions whilst the remaining twenty-eight participants did not identify any further items. None of the participants indicated disagreement with any of the issues identified in the first round. The nominated additional items were for Questions Three, Four and Five.

4.3.1 Additional Items for Question Three

There were two additional issues nominated for Question Three *"From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?"* These items were:

- *"Ignorance and lack of respect by general public towards client issues"*, and
- *"Lack of disability accessible parking spots".*

4.3.2 Additional Items for Question Four

There was one additional issue nominated for Question Four *"What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?"* This item was:

- *"Residing within a complex with other people with disabilities compounds personal problems for those who are ageing".*

4.3.3 Additional Items for Question Five

There were five additional issues nominated for Question Five *"What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?"* These items were:

- *"Lack of flexibility in daily lives due to set routines and restrictive timeframes"*,
- *"Lack of staff skill in utilising and accessing those available mainstream services"*,
- *"Limited opportunities for staff networking (e.g. cross pollination of ideas and knowledge)"*,
- *"Mainstream aged care services not understanding how to support someone with a disability"*, and
- *"Overcrowding in the limited space available and lack of personal space"*.

4.3.4 Summary of Round Two of the Delphi

The participants were all provided with an opportunity to review the first round collated lists of responses and indicate any omissions or items with which they disagreed. The participants did not identify any items with which they disagreed, and only another eight items across the six questions were suggested for inclusion. The additional items raised the total number of responses to the six questions from 155 to 163.

The lack of disagreement with the proposed item listings was considered by the researcher to be an early sign of general consensus with the identified issues, with this thought to be confirmed or rejected in the third round of the Delphi. The eight new items for the six questions were considered in light of the existing identified themes discussed in section *4.2 First Round of the Delphi.* It was not considered that any new themes had emerged on the basis of the additional items.

4.4 Third Round of the Delphi

The third round of the Delphi study involved the thirty-one participants being sent the collated list of issues for each of the six questions. The lists included the additional items suggested from the Second Round and were again presented in alphabetical order to prevent any perception of bias by the researcher. The participants were instructed to read through each list. They were then asked to rate how important they considered each item using a seven point Likert-type scale in which:

1 = Irrelevant,
2 = Very Unimportant,
3 = Unimportant,
4 = Neither Important nor Unimportant,
5 = Important,
6 = Very Important, and
7 = Critical.

There were twenty-six completed third round surveys returned by participants, representing a return rate of 83.9 percent. The participants' individual scores for every item for each of the six questions were recorded. The mean, median, mode, standard deviation and coefficient of variation were calculated. It had been previously determined (see section *3.6 Determinants of Consensus and Importance*) that the group would be considered to have reached consensus on an individual item if the coefficient of variation for that issue fell between 0 and 0.5 and if the standard deviation was equal to 1.0 or less.

If both scores were exceeded, the issue would be deemed to have not reached consensus. For any issue that failed to meet one of the two criteria, the range of scores for that item would be further analysed to establish if 80 percent of the participants' scores fell within a range of three consecutive scores. If the coefficient of variation exceeded 0.5, or the standard deviation exceeded 1.0, and if less than 80 percent of the ratings fell within three consecutive scores, it would be considered that consensus was not established for that item. Any items that were not deemed to have reached consensus would be re-submitted to the participants for review.

As stated earlier in section *3.6 Determinants of Consensus and Importance*, an item would be considered 'important' if the mean score was greater than 4.5, indicating that scores were closer to important than the neutral position. However, each item's median and mode scores would also need to equal or be greater than a score of 5 for importance to be attributed. If any item's mean score was equal to or less than 4.5, or if the median or mode scores were below 5, the data for that item would be examined to see if 80 percent of ratings were 5 or greater. If the mean was below 4.5, or the median or mode scores for any item were below 5, and less than 80 percent of participants rated the item as 'important' or greater, the issue would be considered to be unimportant to the Panel. Any items that were not deemed to be important by the Panel would be re-submitted to the participants for a further round of consideration. The rationale and justification for the decisions regarding the determination of consensus and importance were described in greater detail in section *3.6 Determinants of Consensus and Importance*.

4.4.1 Analysis of Data for Question One Responses

Table 7 presents the mean, median, mode, standard deviation and coefficient of variation scores for the twenty-five issues from Question One. The issues are ordered according to mean from highest to lowest. The analysis of the data for Question One indicated that consensus had been gained on each item. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items were required to be re-submitted to the group for further consideration.

The data also showed that all twenty-five items were considered to be important by the Delphi Panel. Every issue had a mean in excess of 4.5 and median and mode scores equal to or greater than 5. It was decided at this point in the research to review the themes as identified in section *4.2.1 Issues Identified for Question One* as the panel had now prioritised the items in terms of importance. The purpose of this review was to determine whether any themes may have changed or if any new themes had emerged following the prioritisation process. While all twenty-five items had received an overall rating of 'important', it was decided to examine the ten highest rated items as scored by the panel, and determine whether these issues were broadly reflective of the themes identified in section *4.2.1 Issues Identified for Question One*. The ten most important issues for Question One in the Delphi study, in terms of mean score, were:

1. *"Increasing support needs but no increased support (due to no funding increases)",*
2. *"Correct diagnosis of issues by medical practitioners including mental health",*
3. *"Having appropriately trained and qualified support staff",*
4. *"Placement into mainstream aged care facilities that have no understanding of disability",*
5. *"Access to specialist services such as gerontology and ACAT teams",*
6. *"Confusion by staff and medical practitioners about what is ageing versus disability issues",*
7. *"Pension not meeting increased financial needs",*
8. *"Doctors (and allied health staff) not prioritising medical attention for this group",*
9. *"Having appropriate support services to allow them to age in place safely"*, and
10. *"Having appropriate housing to allow them to age in place safely".*

There were four general themes identified from the first round responses for Question One. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. The top ten rated items could all be considered to fit into these four themes. The four themes, and how the top ten identified items fitted into these categories were determined as follows:

- The first theme, Access to Services, was considered to reflect three of the top ten identified issues. These items were *"Access to specialist services such as gerontology and ACAT teams", "Having appropriate support services to allow them to age in place safely"* and *"Having appropriate housing to allow them to age in place safely".*

- The Training Needs theme included the four items *"Correct diagnosis of issues by medical practitioners including mental health", "Having appropriately trained and qualified support staff", "Placement into mainstream aged care facilities that have no understanding of disability"* and *"Confusion by staff and medical practitioners about what is ageing versus disability issues".*

- Individual Health, the third of the themes identified for Question One, covered the item *"Doctors (and allied health staff) not prioritising medical attention for this group".*

- The final identified theme, Funding, was believed to be representative of two items *"Increasing support needs but no increased support (due to no funding increases)"* and *"Pension not meeting increased financial needs".*

It was considered that the top ten items were all adequately covered by the identified four themes and that no obvious themes had been overlooked after the issues had been prioritised according to mean. A more detailed discussion of specific issues and the themes is presented in Chapter Five.

Table 7 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question One

What do you think are the main issues or problems that a person with an intellectual disability will face as they age?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Increasing support needs but no increased support (due to no funding increases)	6.81	7.00	7.00	0.49	0.07
2	Correct diagnosis of issues by medical practitioners including mental health	6.65	7.00	7.00	0.63	0.09
3	Having appropriately trained and qualified support staff	6.62	7.00	7.00	0.64	0.10
4	Placement into mainstream aged care facilities that have no understanding of disability	6.54	7.00	7.00	0.71	0.11
5	Access to specialist services such as gerontology and ACAT teams	6.50	7.00	7.00	0.65	0.10
6	Confusion by staff and medical practitioners about what is ageing versus disability issues	6.46	7.00	7.00	0.90	0.14
7	Pension not meeting increased financial needs	6.46	7.00	7.00	0.71	0.11
8	Doctors (and allied health staff) not prioritising medical attention for this group	6.35	7.00	7.00	0.85	0.13
9	Having appropriate support services to allow them to age in place safely	6.31	6.00	7.00	0.74	0.12
10	Having appropriate housing to allow them to age in place safely	6.27	6.50	7.00	0.83	0.13
11	Lack of understanding of disabilities within mainstream aged care services	6.27	7.00	7.00	0.92	0.15
12	Being able to retire and access appropriate recreation and leisure activities (day programs etc)	6.15	6.00	7.00	0.83	0.14
13	Physical deterioration (hearing and sight) and emotional changes (depression)	6.12	6.00	6.00	0.71	0.12
14	Accessing appropriate equipment and aids	6.08	6.00	7.00	0.89	0.15
15	Decreased communication skills	6.08	6.00	6.00	0.84	0.14
16	Decreased physical ability	6.08	6.00	6.00	0.74	0.12
17	Lack of appropriate facilities	6.08	6.00	6.00	0.74	0.12
18	Specific medical conditions such as early on-set dementia, osteoporosis etc	6.08	6.00	6.00	0.80	0.13
19	General lack of understanding about the ageing process by staff	6.04	6.00	6.00	0.60	0.10
20	Decrease in family support as immediate family is often also ageing (and dying themselves)	5.85	6.00	6.00	0.73	0.13
21	Hygiene (including managing incontinence)	5.85	6.00	6.00	0.83	0.14
22	Accessing appropriate transport	5.81	6.00	6.00	0.90	0.15
23	Having to leave a house they have lived in for many years/decades	5.77	6.00	6.00	0.91	0.16
24	Concerns about "what's next" in their life	5.62	5.50	5.00	0.98	0.18
25	Getting used to new staff	5.58	6.00	6.00	0.58	0.10

4.4.2 Analysis of Data for Question Two Responses

Table 8 presents the mean, median, mode, standard deviation and coefficient of variation scores for the thirty-two issues from Question Two. The issues are ordered according to mean from highest to lowest. The analysis of the data showed that one item, *"Trips and Falls"*, reported a marginal score on one of the two initial tests for consensus. Whilst the coefficient of variation (V) score was in the desired range between 0 and 0.5, the standard deviation (SD) score of 1.0 was right on the cusp of the cut-off mark of scores greater than 1.0. An analysis of the individual ratings revealed that 88.46 percent of participants scored the item with 5 or more. The item therefore met the criteria of 80 percent of scores within three consecutive scores, and it was considered consensus had been achieved. The data indicated that consensus had been gained on the other thirty-one items. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items for Question Two were required to be re-submitted to the group for further consideration.

All thirty-two items were considered to be important by the Delphi Panel. Every issue had a mean score greater than 4.5, and median and mode score equal to or greater than 5. While all thirty-two items received an overall rating of 'important', an examination was conducted on the top ten highest rated items as scored by the panel to see whether they were broadly reflective of the themes identified in section *4.2.2 Issues Identified for Question Two*. The 10 most important issues for Question Two in the Delphi study, in terms of mean score, were:

1. *"Greater support needs"*,

2. *"Increased simple and complex health needs"*,

3. *"Isolation"*,

4. *"Mental health issues such as depression and dementia"*,

5. *"Deterioration in mental abilities"*,

6. *"Loss of memory"*,

7. *"Communication problems"*,

8. *"Trips and falls"*,

9. *"Incontinence (bladder and bowel)"*, and

10. *"Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)"*.

There were four general themes identified from the first round responses for Question Two. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. The top ten rated items could all be considered to fit into these four themes. The four themes, and how the top ten identified items fitted into these categories, were determined as follows:

- Mental Functioning, the first theme, was believed to include the items *"Mental health issues such as depression and dementia"*, *"Deterioration in mental abilities"* and *"Loss of memory"*.

- The second theme, Physical Issues, included *"Communication problems"*, *"Trips and falls"* and *"Incontinence (bladder and bowel)"*.

- The Emotional or Personality issues theme was considered to reflect the issue of *"Isolation"*.

- The last identified theme, Generic Health and Support Needs, covered the three issues of *"Greater support needs"*, *"Increased simple and complex health needs"* and *"Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)"*.

It was considered that the top ten items were all adequately covered by the identified four themes and that no obvious themes had been overlooked after the issues had been prioritised according to mean. A more detailed discussion of the specific issues and over-arching themes is presented in Chapter Five.

Table 8 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Two

What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Greater support needs	6.35	6.50	7.00	0.80	0.13
2	Increased simple and complex health needs	6.27	6.00	7.00	0.78	0.12
3	Isolation	6.15	6.00	6.00	0.78	0.13
4	Mental health issues such as depression and dementia	6.15	6.00	6.00	0.73	0.12
5	Deterioration in mental abilities	6.12	6.00	6.00	0.71	0.12
6	Loss of memory	6.08	6.00	6.00	0.69	0.11
7	Communication problems	6.04	6.00	6.00	0.53	0.09
8	Trips and falls	6.04	6.00	6.00	1.00	0.17
9	Incontinence (bladder and bowel)	6.00	6.00	6.00	0.75	0.12
10	Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)	5.96	6.00	5.00	0.82	0.14
11	Set in routine (resistant to change or even more resistant than previously)	5.92	6.00	6.00	0.80	0.13
12	Changes in eating habits (inability to eat certain foods)	5.88	6.00	7.00	0.99	0.17
13	Decreased mobility	5.88	6.00	6.00	0.77	0.13
14	Grief (loss of their own families and friends)	5.88	6.00	5.00	0.86	0.15
15	Loss of motivation	5.81	6.00	6.00	0.75	0.13
16	Losing their 'identity' and independence after moving into supported accommodation	5.73	6.00	6.00	0.92	0.16
17	Reduction in ability to access community independently	5.73	6.00	6.00	0.87	0.15
18	Withdrawal	5.69	6.00	6.00	0.93	0.16
19	Reduction or loss of senses such as vision and hearing	5.65	6.00	6.00	0.89	0.16
20	Weight gain or weight loss	5.58	6.00	6.00	0.64	0.12
21	Physical health issues (including sight and hearing deterioration)	5.54	6.00	6.00	0.99	0.18
22	Loss of confidence	5.46	5.00	5.00	0.71	0.13
23	Increase in inappropriate and/or aggressive behaviours	5.46	5.00	5.00	0.99	0.18
24	Reduced productivity	5.42	6.00	6.00	0.99	0.18
25	Personal hygiene	5.42	5.00	5.00	0.81	0.15
26	Reduced desire to participate in activities	5.35	6.00	6.00	0.94	0.18
27	Reduced desire to access services	5.23	5.00	6.00	0.99	0.19
28	Increase in seizure activity	5.23	5.00	5.00	0.91	0.17
29	Hormonal issues	5.19	5.50	6.00	0.98	0.19
30	Stereotyping of others	5.19	5.00	5.00	0.94	0.18
31	Bullying towards other residents and staff	5.00	5.00	5.00	0.94	0.19
32	Disrespect towards staff	4.92	5.00	6.00	0.98	0.20

4.4.3 Analysis of Data for Question Three Responses

Table 9 presents the mean, median, mode, standard deviation and coefficient of variation scores for the twenty-nine issues from Question Three. The analysis of the data showed that three items, *"Lack of government funding for training"*, *"Long distance travel required to see suitable medical specialists"* and *"Ignorance and lack of respect by general public towards client issues"* exceeded the cut-off mark on one of the two initial tests for consensus. Whilst the coefficient of variation (V) scores were all in the desired range between 0 and 0.5, the standard deviation (SD) scores for all three items were all equal to or in excess of 1.0. An analysis of the individual ratings revealed that

- for the Item *"Lack of government funding for training"*, 92.3 percent of participants scored the item with five or more; and
- both Item *"Long distance travel required to see suitable medical specialists"* and Item *"Ignorance and lack of respect by general public towards client issues"* had 88.5 percent of scores within range of five to seven.

The three items all met the criteria of 80 percent of scores within the designated range of three scores and it was considered consensus had been achieved on each item. The data indicated that consensus had been gained on the other twenty-six items. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items for Question Three were required to be re-submitted to the group for further consideration.

All twenty-nine items were considered to be important by the Delphi Panel. Every issue had a mean score greater than 4.5 and median and mode score equal to or greater than 5. The issues are ordered according to mean from highest to lowest. While all twenty-nine items received an overall rating of 'important', the ten highest rated items as scored by the panel were again considered separately to examine if they were representative of the themes identified in section *4.2.3 Issues Identified for Question Three*. The 10 most important issues for Question Three in the Delphi study, in terms of mean score, were:

1. *"Lack of government funding for appropriate staffing levels"*,
2. *"Lack of additional funding to meet increasing needs"*,
3. *"Advocating for clients to get appropriate medical care"*,
4. *"Gaining access to appropriate recreational and leisure activities in retirement such as day services programs"*,
5. *"Being creative in using the funding to meet client needs"*,
6. *"Accessing appropriate professional support"*,
7. *"Lack of government funding for staff training"*,
8. *"Maintaining independence, health and well-being"*,
9. *"Blending the impact of ageing with issues already faced by people with disabilities"*, and
10. *"Manual handling issues as clients lose mobility"*.

There were five general themes identified from the first round responses for Question Three. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. Eight of the top ten rated items were considered to fit into three of these five themes. The three themes, and how the eight identified items fitted into these categories, were determined as follows:

- The first theme, Funding, was considered to include the four items *"Lack of government funding for appropriate staffing levels"*, *"Lack of additional funding to meet increasing needs"*, *"Being creative in using the funding to meet client needs"* and *"Lack of government funding for staff training"*.

- The theme Access to Services was believed to incorporate the issues associated with *"Gaining access to appropriate recreational and leisure activities* *in retirement such as day services programs"* and *"Accessing appropriate professional support"*.

- The third theme of Health Care reflected the issues of *"Advocating for clients to get appropriate medical care"* and *"Maintaining independence, health and well-being"*.

The issues rated ninth and tenth most important, *"Blending the impact of ageing with issues already faced by people with disabilities"* and *"Manual handling issues as clients lose mobility"*, were not considered to fall clearly into any of the five designated theme categories. The themes of Time Constraints and Family Issues were not considered to specifically include any of the top ten issues. A review of all twenty-nine items, and the previously identified five themes was performed. It was considered that the remaining nineteen items did include issues that were appropriately categorised into the themes of Time Constraints and Family Issues. As such, it was believed that these two themes were still appropriate. While two of the top ten issues did not fit an identified theme, it was perceived that they were singular items that were not reflective of any larger themes throughout the entire twenty-nine item listing.

The review concluded that the existing five themes were still appropriate, even though there were two items in the top ten that did not fit into these categorisations. An analysis of all the themes identified across the six questions did reveal that the item *"Manual handling issues as clients lose mobility"* was similar to items within the theme Generic Training Issues in section *4.4.6 Analysis of Data for Question Six Responses*. Likewise, the issue of *"Blending the impact of ageing with issues already faced by people with disabilities"* was largely reflective of the theme of Understanding and Coping with Ageing in section *4.4.4 Analysis of Data for Question Four Responses.* A more detailed discussion of the specific issues and over-arching themes is presented in Chapter Five.

Table 9 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Three

From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Lack of government funding for appropriate staffing levels	6.54	7.00	7.00	0.58	0.09
2	Lack of additional funding to meet increasing needs	6.50	7.00	7.00	0.65	0.10
3	Advocating for clients to get appropriate medical care	6.38	7.00	7.00	0.80	0.13
4	Gaining access to appropriate recreational and leisure activities in retirement such as day services programs	6.38	7.00	7.00	0.80	0.13
5	Being creative in using the funding to meet client needs	6.35	6.00	6.00	0.63	0.10
6	Accessing appropriate professional support	6.27	6.50	7.00	0.83	0.13
7	Lack of government funding for staff training	6.23	7.00	7.00	1.18	0.19
8	Maintaining independence, health and well-being	6.23	6.00	6.00	0.65	0.10
9	Blending the impact of ageing with issues already faced by people with disabilities	6.15	6.00	6.00	0.83	0.14
10	Manual handling issues as clients lose mobility	5.96	6.00	6.00	0.66	0.11
11	Advocating for clients to get appropriate aged care services	5.92	6.00	6.00	0.93	0.16
12	Communication problems	5.88	6.00	6.00	0.82	0.14
13	Dealing with personal frustration in not having sufficient time to meet individual needs	5.88	6.00	6.00	0.99	0.17
14	Assisting in increasing personal care needs (such as hygiene)	5.85	6.00	6.00	0.97	0.17
15	Time constraints	5.85	6.00	6.00	0.92	0.16
16	How to assess independence	5.81	6.00	6.00	0.63	0.11
17	Long distance travel required to see suitable medical specialists	5.73	6.00	6.00	1.25	0.22
18	Unrealistic family expectations	5.73	6.00	6.00	0.92	0.16
19	Dealing with client frustration at not being able to do things	5.69	6.00	6.00	0.97	0.17
20	Excessive paperwork	5.69	5.00	5.00	0.97	0.17
21	Breaking bad habits that may become unsafe	5.62	6.00	6.00	0.90	0.16
22	Lack of appropriate venues for community access	5.46	5.00	5.00	0.95	0.17
23	Providing constant reassurance	5.38	5.00	5.00	0.94	0.17
24	Reduced concentration by the person	5.27	5.00	5.00	0.83	0.16
25	Reduced stimulation levels	5.19	5.00	5.00	0.90	0.17
26	Ignorance and lack of respect by general public towards client issues	5.15	5.00	5.00	1.16	0.22
27	Reduced acceptance of activities	5.00	5.00	5.00	0.89	0.18
28	Reduced productivity by the person	5.00	5.00	5.00	0.89	0.18
29	Lack of disability accessible parking spots	5.00	5.00	5.00	0.98	0.20

4.4.4 Analysis of Data for Question Four Responses

Table 10 presents the mean, median, mode, standard deviation and coefficient of variation scores for the twenty five issues from Question Four. The analysis of the data showed that one item, *"Clients with lower needs miss out due to an increased focus on person who is ageing"*, reported a marginal score on one of the two initial tests for consensus. Whilst the coefficient of variation (V) score was in the desired range between 0 and 0.5, the standard deviation (SD) score of 1.0 was exactly on the cut-off limit of scores greater than 1.0. An analysis of the individual ratings revealed that 96.2% of participants scored the item with 5 or more. The item therefore met the criteria of 80% of scores within three consecutive scores, and it was considered consensus had been achieved.

The data indicated that consensus had been gained on the other twenty four items. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items for Question Four were required to be re-submitted to the group for further consideration. All twenty five items were considered to be important by the Delphi Panel. Every issue had a mean score greater than 4.5 and median and mode score equal to or greater than 5. The issues are ordered according to mean from highest to lowest.

While all twenty five items received an overall rating of 'important', a process of reviewing the relevance of the themes, as identified in section *4.2.4 Issues Identified for Question Four*, was conducted. The ten most important issues for Question Four in the Delphi study, in terms of mean score, were:

1. *"Access to appropriate facilities to assist people with higher care needs",*
2. *"Access to respite",*
3. *"Ageing parents",*
4. *"Family concern about future planning as the person with the disability may outlive the parents",*
5. *"Understanding and separating behavioural issues from physical/mental health issues",*
6. *"Coping with increased support needs",*
7. *"Financial security and ongoing financial management",*
8. *"Concerns about person's ongoing and increasing care needs",*
9. *"Clients with lower needs miss out due to an increased focus on person who is ageing",* and
10. *"Communication problems".*

There were four general themes identified from the first round responses for Question Four. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. All of the top ten rated items were considered to fit into these four themes. The four themes, and how the top ten identified items fitted into these categories, was determined as follows:

- The theme, Access to Services, was perceived to incorporate the issues *"Access to appropriate facilities to assist people with higher care needs"* and *"Access to respite"*.

- The second theme, Understanding and Coping with Ageing, included the item *"Understanding and separating behavioural issues from physical/mental health issues"*.

- The theme of Ageing Parents was considered to include the issues associated with *"Ageing parents", "Financial security and ongoing financial management"* and *"Family concern about future planning as the person with the disability may outlive the parents"*.

- Increasing Care Needs, the last of the 4 themes, covered the items of *"Coping with increased support needs", "Concerns about person's ongoing and increasing care needs", "Clients with lower needs miss out due to an increased focus on person who is ageing"* and *"Communication problems"*.

It was considered that the top ten items were all adequately covered by the identified four themes and that no obvious themes had been overlooked after the issues had been prioritised according to mean. A more detailed discussion of the specific issues and over-arching themes is presented in Chapter Five.

Table 10 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Four

What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Access to appropriate facilities to assist people with higher care needs	6.54	7.00	7.00	0.51	0.08
2	Access to respite	6.46	7.00	7.00	0.65	0.10
3	Ageing parents	6.46	7.00	7.00	0.65	0.10
4	Family concern about future planning as the person with the disability may outlive the parents	6.46	7.00	7.00	0.76	0.12
5	Understanding and separating behavioural issues from physical/mental health issues	6.38	6.00	6.00	0.70	0.11
6	Coping with increased support needs	6.31	6.00	6.00	0.74	0.12
7	Financial security and ongoing financial management	6.31	6.00	6.00	0.68	0.11
8	Concerns about person's ongoing and increasing care needs	6.19	6.00	6.00	0.69	0.11
9	Clients with lower needs miss out due to an increased focus on person who is ageing	5.96	6.00	7.00	1.00	0.17
10	Communication problems	5.96	6.00	6.00	0.77	0.13
11	Friends experiencing depression themselves due to worry about their own mortality	5.88	6.00	6.00	0.99	0.17
12	The need for greater advocacy by the families to gain additional funding as support needs increase	5.85	6.00	6.00	0.83	0.14
13	Impact upon closeness of relationship (affected by dementia)	5.73	6.00	6.00	0.83	0.14
14	Legal issues (e.g. making a will or power of attorney)	5.73	6.00	6.00	0.96	0.17
15	Fellow residents not understanding what is going on (why the person has changed or moved)	5.69	6.00	6.00	0.93	0.16
16	Need for major home renovations (e.g. changing stairs to ramps, rails in bathrooms, etc)	5.65	6.00	5.00	0.98	0.17
17	Residing within a complex with other people with disabilities compounds personal problems for those who are ageing	5.65	6.00	6.00	0.85	0.15
18	Lack of patience (everyone wants everything done right now!)	5.62	5.50	5.00	0.70	0.12
19	Household members reducing the person's level of independence by attempting to 'help' by doing everything for them	5.62	5.50	5.00	0.90	0.16
20	Increased pressure on families to provide ongoing advocacy	5.54	6.00	6.00	0.90	0.16
21	Lack of information for families to source services	5.54	6.00	6.00	0.81	0.15
22	Pressure on friends to cope with changing personality and skills	5.54	6.00	6.00	0.76	0.14
23	Frustration	5.46	6.00	6.00	0.95	0.17
24	Increased reliance upon staff to facilitate family contact (primarily through phone)	5.42	5.00	5.00	0.76	0.14
25	Lack of acceptance of the ageing process	5.31	5.00	5.00	0.68	0.13

4.4.5 Analysis of Data for Question Five Responses

Table 11 presents the mean, median, mode, standard deviation and coefficient of variation scores for the twenty-five issues from Question Five. The issues are ordered according to mean from highest to lowest. The analysis of the data indicated that consensus had been gained on each item. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items were required to be re-submitted to the group for further consideration.

The data also showed that all twenty-five items were considered to be important by the Delphi Panel. Every issue had a mean in excess of 4.5 and median and mode scores equal to or greater than 5. While all twenty-five items received an overall rating of 'important', the ten highest rated items as scored by the panel were examined specifically to establish whether they were broadly representative of the themes identified in section *4.2.5 Issues Identified for Question Five*. The ten most important issues for Question Five in the Delphi study, in terms of mean score, were:

1. *"Care needs are constantly increasing, whilst funding is not",*
2. *"Training and education for both disability staff and generic aged care professionals",*
3. *"Recruiting qualified and trained staff",*
4. *"Inflexibility in funding models and structures",*
5. *"Maintaining qualified and trained staff",*
6. *"Age cut-off for ACAT prevents people with disabilities accessing services",*
7. *"Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing",*

8. *"Appropriate funding models for smaller services without large numbers of ageing clients",*

9. *"Lack of mainstream services available to people with disabilities"*, and

10. *"Lack of specialist services such as respite and day programs".*

There were three general themes identified from the first round responses for Question Five. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. All of the top ten rated items were considered to fit into these three themes. The three themes, and how the top ten identified items fitted into these categories, were determined as follows:

- Staff training and development, the first theme, was seen to broadly incorporate the four issues *"Training and education for both disability staff and generic aged care professionals", "Recruiting qualified and trained staff", "Maintaining qualified and trained staff"* and *"Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing".*

- The second theme, Funding, was considered to include the issues *"Care needs are constantly increasing, whilst funding is not", "Inflexibility in funding models and structures"* and *"Appropriate funding models for smaller services without large numbers of ageing clients".*

- The theme of Access to services was perceived to encapsulate the issues *"Age cut-off for ACAT prevents people with disabilities accessing services", "Lack of mainstream services available to people with disabilities"* and *"Lack of specialist services such as respite and day programs".*

It was considered that top ten items were all adequately covered by the identified three themes, and that no obvious themes had been overlooked after the issues had been prioritised according to mean. A more detailed discussion of the specific issues and over-arching themes is presented in Chapter Five.

Table 11 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Five

What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Care needs are constantly increasing, whilst funding is not	6.88	7.00	7.00	0.33	0.05
2	Training and education for both disability staff and generic aged care professionals	6.58	7.00	7.00	0.58	0.09
3	Recruiting qualified and trained staff	6.54	7.00	7.00	0.71	0.11
4	Inflexibility in funding models and Structures	6.50	7.00	7.00	0.71	0.11
5	Maintaining qualified and trained staff	6.50	7.00	7.00	0.81	0.12
6	Age cut-off for ACAT prevents people with disabilities accessing services	6.42	6.50	7.00	0.64	0.10
7	Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing	6.38	7.00	7.00	0.80	0.13
8	Appropriate funding models for smaller services without large numbers of ageing clients	6.35	7.00	7.00	0.80	0.13
9	Lack of mainstream services available to people with disabilities	6.35	6.00	6.00	0.49	0.08
10	Lack of specialist services such as respite and day programs	6.35	6.00	7.00	0.69	0.11
11	Cost in accessing services (travel costs and staffing costs)	6.31	6.00	7.00	0.74	0.12
12	Financial viability	6.27	6.00	7.00	0.78	0.12
13	Mainstream aged care services not understanding how to support someone with a disability	6.27	6.00	6.00	0.67	0.11
14	No dedicated aged care facility for people with intellectual disabilities	6.27	6.50	7.00	0.92	0.15
15	Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work)	6.23	6.00	7.00	0.91	0.15
16	Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability	6.23	6.50	7.00	0.95	0.15
17	Availability of complementary services to our own	6.15	6.00	7.00	0.83	0.14
18	Funding for new equipment / home modifications	5.96	6.00	6.00	0.77	0.13
19	Competition with the community's focus upon the increasing needs of the generic ageing population	5.92	6.00	6.00	0.84	0.14
20	Lack of public transport	5.92	6.00	6.00	0.93	0.16
21	Lack of staff skill in utilising and accessing those available mainstream services	5.92	6.00	6.00	0.89	0.15
22	Distance to nearest appropriate services	5.85	6.00	6.00	0.78	0.13
23	Limited opportunities for staff networking (e.g. cross pollination of ideas and knowledge)	5.54	6.00	6.00	0.95	0.17
24	Overcrowding in the limited space available and lack of personal space	5.54	5.00	5.00	0.95	0.17
25	Lack of flexibility in daily lives due to set routines and restrictive timeframes	5.15	5.00	5.00	0.97	0.19

4.4.6 Analysis of Data for Question Six Responses

Table 12 presents the mean, median, mode, standard deviation and coefficient of variation scores for the twenty-six issues from Question Six. The issues are ordered according to mean from highest to lowest. The analysis of the data indicated that consensus had been gained on each item. The coefficient of variation (V) fell between 0 and 0.5 for every item, and the standard deviation (SD) for each item was less than 1.0. As the Panel had reached the preset levels for consensus, no items were required to be re-submitted to the group for further consideration.

The data also showed that all twenty-six items were considered to be important by the Delphi Panel. Every issue had a mean in excess of 4.5, and median and mode scores equal to or greater than 5. While all twenty-six items received an overall rating of 'important', the same process of reviewing the ten highest rated items as scored by the panel as to whether they were broadly reflective of the themes identified in section *4.2.6 Issues Identified for Question Six* was performed. The ten most important issues for Question Six in the Delphi study, in terms of mean score, were:

1. *"Person centred planning",*
2. *"Medical management",*
3. *"Understanding medication and its effects",*
4. *"Understanding of changes associated with ageing",*
5. *"Quality of life management",*
6. *"Training in observation skills so that changes in client health can be detected early",*
7. *"Behaviour management",*
8. *"Attitude training (patience, empathy, consistency, ethics)",*
9. *"OH & S and Manual Handling Training (how to provide appropriate physical support)",* and
10. *"Personal care needs".*

There were five general themes identified from the first round responses for Question Six. A review of the top ten issues was conducted, specifically examining whether these issues were generally reflective of the themes previously identified. All of the top ten rated items were considered to fit into four of these five themes. The four themes, and how the top ten identified items fitted into these categories, was determined as follows:

- Generic Training Issues, the first theme, was believed to include the issues of *"Training in observation skills so that changes in client health can be detected early", "Behaviour management", "Attitude training (patience, empathy, consistency, ethics)",* and *"OH & S and Manual Handling Training (how to provide appropriate physical support)".*
- The second theme, Medical Issues, incorporated the issues of *"Medical management"* and *"Understanding medication and its effects".*
- The Personal Care Issues theme was considered to include the issue *"Personal care needs".*
- The last theme, Quality of Life, was seen to incorporate the two issues *"Person centred planning"* and *"Quality of life management".*

The theme of Counselling Support was not considered to specifically include any of the top ten issues. A review of all twenty-six items, and the previously identified five themes was performed. It was considered that the remaining sixteen items included issues that were appropriately categorised into the theme of Counselling Support. As such, it was believed that this theme was still appropriate. It was considered that the top ten items were all adequately covered by four of the identified five themes, and that no obvious themes had been overlooked after the issues had been prioritised according to mean. A more detailed discussion of the specific issues and over-arching themes is presented in Chapter Five.

Table 12 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) for Question Six

What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?						
No.	**Issue**	**Mean**	**Median**	**Mode**	**SD**	**V**
1	Person centred planning	6.62	7.00	7.00	0.57	0.09
2	Medical management	6.58	7.00	7.00	0.64	0.10
3	Understanding medication and its effects	6.58	7.00	7.00	0.64	0.10
4	Understanding of changes associated with ageing	6.54	7.00	7.00	0.71	0.11
5	Quality of life management	6.50	6.50	6.00	0.51	0.08
6	Training in observation skills so that changes in client health can be detected early	6.50	7.00	7.00	0.71	0.11
7	Behaviour management	6.42	7.00	7.00	0.70	0.11
8	Attitude training (patience, empathy, consistency, ethics)	6.35	6.00	7.00	0.69	0.11
9	OH & S and Manual Handling Training (how to provide appropriate physical support)	6.35	7.00	7.00	1.09	0.17
10	Personal care needs	6.35	6.00	7.00	0.69	0.11
11	Understanding of health issues	6.35	6.00	6.00	0.56	0.09
12	Understanding of the ageing process and stages that people move through	6.31	6.00	6.00	0.62	0.10
13	Understanding of different support needs at different stages of ageing	6.27	6.00	6.00	0.72	0.12
14	Dementia	6.23	6.00	6.00	0.86	0.14
15	Comprehensive and accurate record keeping to assess changes over time	6.15	6.00	6.00	0.67	0.11
16	Generic aged care courses for disability service providers	6.15	6.00	6.00	0.73	0.12
17	Understanding of emotional issues	6.12	6.00	7.00	0.82	0.13
18	Dietetics (meal preparation, tube feeding etc)	6.04	6.00	6.00	0.92	0.15
19	How to transition people between services effectively	6.04	6.00	6.00	0.72	0.12
20	Time management	6.00	6.00	6.00	0.69	0.12
21	Alternative communication methods	5.92	6	6	0.89	0.15
22	Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend	5.92	6	6	0.69	0.12
23	Advocacy to act as the voice for people who are ageing and seek appropriate facilities	5.88	6	6	0.95	0.16
24	Diabetes	5.62	6	6	0.75	0.13
25	Specialist equipment usage	5.54	6	6	0.65	0.12
26	Ability to educate the general public about client abilities	5.42	6	6	0.95	0.17

4.4.7 Summary of Round Three of the Delphi

It was concluded that all 163 individual items within the six questions had achieved participant consensus and were rated as important. A total of five items from Questions Two, Three and Four had one test score that indicated a need for further review; however, these five items all passed the secondary test of having 80 percent of scores falling into the designated range of three consecutive scores on the seven point scale. There was, therefore, no reason to submit any items back to the Panel for re-evaluation in order to try and gain even higher levels of consensus.

The researcher did not expect this result to occur without the need for the Panel to reconsider some items before determining a final consensus position. However, in light of the fact that the participants had each contributed to the development of this list of issues, and had then reviewed all the items for relevance, it is perhaps not surprising that there was such a high level of agreement. The participants had not identified any items of disagreement during the second round of the Delphi. This outcome had been noted by the researcher as a positive early sign of the group's consensus (see section *4.3.4 Summary of Round Two of the Delphi*), and this belief was confirmed in the Third Round results.

A review of the themes identified following the First Round of the study was performed by considering the top ten items according to mean score with respect to the individual themes. This process was conducted to establish whether any additional themes had emerged, or if any themes appeared redundant, following the prioritisation of the items. It was concluded that the themes identified after the First Round were still relevant and appropriate, and that no additional themes had emerged following the ranking of the items.

4.5 Final Round of the Delphi

A final round of surveys was added to this Delphi study. This step involved the mean-ordered lists for each of the six questions being sent to the participants, with an instruction to rate their level of agreement with the prioritised lists (see *Appendix*

8). This stage is not normally utilised with Delphi studies, with the survey finishing once consensus and importance has been established for each item. However, it was considered appropriate to include another stage in the study as the Third Round of the Delphi had not identified any items of disagreement. It was felt that this additional step was an appropriate checking mechanism to confirm that the participants were in agreement with the final mean ordered lists. Each participant was asked to indicate their level of agreement with each of the six mean ordered lists of issues using a five point Likert scale in which:

1 = Strongly Disagree,
2 = Disagree,
3 = Neither Agree nor Disagree,
4 = Agree, and
5 = Strongly Agree.

The Likert Scale was changed from the seven point scale used in the previous stages of the Delphi to a five point scale. This change was enacted to reflect the simplification of this round and following feedback from the pilot study (see section *3.4.2 Pilot Study*). As there were only six responses required in this survey, one for each of the six questions, the need for more options allowing for greater levels of distinction between items that was evident earlier in the Delphi was not required. The final stage of the survey had twenty of the original thirty-one participants return the completed form, representing a return rate of 64.5 percent of the initial participant group, and 76.9 percent of the twenty-six Third Round Respondents. This attrition rate was not unexpected, considering the length of the survey, and total number of respondents to the final stage still fell within the ranges of desired panel size as discussed in section *3.1.1 Overview of the Delphi Method.*

4.5.1 Analysis of Data for the Final Round

Table 13 presents the mean, median, mode, standard deviation and coefficient of variation scores of the lists for Questions One to Six. The analysis of the data showed that the Delphi Panel were in agreement with the mean ordered lists for all six questions. Each question had a mean equal to or in excess of 4.75 and median and mode scores of 5. The data also indicated that consensus had been gained on each item. The coefficient of variation (V) was between 0 and 0.5 each time, and in fact was below 0.10 for all six questions. Likewise, the standard deviation (SD) for each item was not just less than 1.0 but less than 0.50 for each question. Every participant's response indicated either their agreement or strong agreement with the lists for the six questions. In light of the strong levels of consensus in the previous round of the research, this result is not surprising. However, it did confirm the findings of the three rounds of the Delphi study.

Table 13 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) of the lists for Questions One to Six

No.	Question	Mean	Median	Mode	SD	V
1	What do you think are the main issues or problems that a person with an intellectual disability will face as they age?	4.95	5	5	0.22	0.05
2	What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impact, emotional issue, mental health issue)	4.75	5	5	0.44	0.09
3	From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?	4.85	5	5	0.37	0.08
4	What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?	4.8	5	5	0.41	0.09
5	What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?	4.85	5	5	0.37	0.08
6	What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?	4.75	5	5	0.44	0.09

4.6 Senior Managers' Views

There was one final stage to the research which was completed prior to finalising the data capture component. This step, which was not a component of the Delphi process, involved sending the survey utilised in the final round of the Delphi (see *Appendix 8*) to the Chief Executive Officers of the participating disability organisations for rating. In some situations, the Chief Executive Officer nominated a Senior Service Manager to act as their delegate in completing this survey, as the Chief Executive Officer indicated that this person would provide a more meaningful contribution.

This stage of the study was conducted to see what level of agreement the Chief Executive Officers/Senior Service Managers had with the prioritised listing developed by the direct care staff that composed the Delphi Panel. Each participant was asked to indicate his/her level of agreement with the final prioritised lists of issues using the same five point Likert scale as utilised in the final round of the Delphi in which:

1 = Strongly Disagree,
2 = Disagree,
3 = Neither Agree nor Disagree,
4 = Agree, and
5 = Strongly Agree.

Slightly over 50 percent (8/15) responses were received from the Chief Executive Officers/Senior Service Managers of the originally approached organisations in this additional stage of the research. While there were no direct care participants from The Tulgeen Group in the Delphi study (see section *3.5.2 Data Collection Procedures* and section *3.7 Limitations*), the Chief Executive Officer of that organisation did complete this stage of the project. Attempts were made to increase the number of responses for this component of the study through direct contact with particular individuals. A number of these potential participants indicated that they were extremely busy with other work commitments at that time but that they would attempt to respond. However, these approaches were ultimately not successful in garnering the return of any additional surveys by the designated finish date. While other priorities were provided as an explanation, it is impossible to exclude the possibility that any Chief Executive Officers/Senior Managers who did not agree with the survey results elected not to respond. Similarly, the overall small number of respondents to this stage does mean that this component of the research must be treated with caution; however, the results are still worth reporting.

Table 14 presents the mean, median, mode, standard deviation and coefficient of variation scores for this additional stage of research. The analysis of the data showed that the Chief Executive Officers/Senior Service Managers were in agreement with the prioritised lists for all six questions. Each question had a mean in excess of 4.25, with median and mode scores of 4 or greater. The data also indicated that consensus had been gained on each item. The coefficient of variation (V) for each item was between 0 and 0.5, and the standard deviations (SD) less than 1.0

As with the Final Round results (see section *4.5.1 Analysis of Data for the Final Round)*, every participant's response in this stage indicated their 'agreement' or 'strong agreement' with the prioritised lists for the six questions. Overall, the level of agreement was high but slightly lower than the figure indicated by the actual Delphi participants. That difference was not unexpected, as this stage of the research represented the first time the Chief Executive Officers /Senior Service Managers had seen the items in the lists, as they had not been part of the initial development and review.

While the small sample size is not ideal, the results add further support to the findings of the Delphi study. It is worth noting that there appears to be general agreement between both direct care staff and their senior managers with respect to the identification of the main issues. A further research project could be to reverse the focus of the study, with a new Delphi Panel being composed entirely of Chief Executive Officers and Senior Managers. It would be worth investigating whether the same general themes would again be identified in such a follow-up study, and whether the direct care staff were then similarly in agreement with their senior managers' identified issues.

Table 14 – Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V) of the lists for Questions One to Six as Scored by the CEOs

No.	Question	Mean	Median	Mode	SD	V
1	What do you think are the main issues or problems that a person with an intellectual disability will face as they age?	4.63	5	5	0.52	0.11
2	What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?	4.38	4	4	0.52	0.12
3	From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?	4.63	5	5	0.52	0.11
4	What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?	4.63	5	5	0.52	0.11
5	What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?	4.38	4	4	0.52	0.12
6	What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?	4.75	5	5	0.46	0.10

4.7 Conclusion

Chapter Four contains a summary of the results of the findings from each stage of the Delphi study. It also includes a review of the additional component of the research, in which the leaders of the disability organisations responded to the participants' prioritised lists of issues for each of the six questions in the Delphi study. The demographics of the Delphi participants were presented. The results from the Delphi were outlined, with the priorities of the Panel for each of the six questions clearly established. A series of key meaning units were established through a simple thematic analysis of the items. The prioritised listing of items by the participants provided new key knowledge with respect to ageing and intellectual disability issues. The following chapter discusses both the emerging themes and individual items identified and rated as important by the participants in the study.

Chapter Five - Discussion of Results

Introduction

Chapter Five presents a discussion and examination of the data and findings. It commences with the demographics of the Delphi Panel participants being compared to the available information regarding the wider disability sector workforce. This chapter presents an in-depth discussion of the findings from the six questions that underpinned the Delphi study. The prioritised listing of items gained from the participants facilitated the identification of the specific issues and associated key themes impacting upon rurally based service provision. The focus of the discussion pertains to the identified themes including funding, access to appropriate services, training issues and health care needs. The impact of the ageing needs of people with an intellectual disability is discussed with specific reference to rural workforce issues.

5.1 Disability Sector Workforce Demographics

It was not possible to establish current demographic profiles for employees within the intellectual disability sector in rural New South Wales (NSW). Neither State nor Australian Government data provide an accurate breakdown of the intellectual disability workforce in NSW, or specifically, individuals employed within rural and remote areas of the state. In 2008, the combined State and Commonwealth Governments' Community and Disability Services Ministers' Advisory Council (CDSMAC) commissioned the *Community Services Workforce Profiling Project*, a comprehensive national workforce survey. It was expected that the results of this survey would not be provided to CDSMAC until December 2009 (National Disability Services, 2008b), and a public release of the information may occur sometime in 2010. Until the results from this nation-wide survey are released, smaller-scale studies from across Australia provide the best available demographic profile for the sector.

Dempsey and Arthur (2002) conducted a survey of 357 disability workers in selected non-government disability organisations in NSW and reported:

- 28.5 percent of the participants were male,
- 38 percent of the participants had a qualification relevant to their work,
- 47.5 percent of the participants had worked in the sector for between two and five years, with only 7.2 percent having been disability workers for more than ten years, and
- 91.2 percent of the participants were aged over twenty-six, with 36 percent aged over forty-five.

However, the results of Dempsey and Arthur's research were limited by a number of factors which reduced their general applicability to the current project. Their findings included employees of both state and commonwealth funded services with no differentiation of the data. It was uncertain whether the 357 participants were representative of the wider disability sector workforce across NSW. It was noted that the survey had a moderate return rate of approximately 50 percent. The results are also nearly a decade old, and changes may have occurred in the profile of the data since then.

The Victorian Government's Department of Human Services (2005) reported that approximately 78 percent of its state non-government disability sector workforce was female, with the remaining 22 percent male. It also recorded the following age demographics:

- 8.9 percent were aged less than 25 years,
- 23.2 percent were aged 25-34,
- 27.6 percent were aged 35-44,
- 28.7 percent were aged 45-54, and
- 11.6 percent were aged over 55.

With respect to years of working in the disability sector:

- 31 percent of staff had more than ten years experience,
- 19 percent of staff had between six and ten years experience, and
- Only 18 percent of staff had less than two years experience.

The training qualifications of the cohort included:

- 48.2 percent with completed TAFE qualifications,
- 3 percent had completed an undergraduate qualification, and
- 5.7 percent had completed a postgraduate qualification.

A commissioned report by the Lime Management Group (2006) provided general support for the above figures from Victoria. It indicated that 40 percent of the people employed within the disability sector were over the age of forty-five, and 75 percent were female. 20 percent of the workforce did not have any relevant qualifications, with between 30 and 50 percent of staff having obtained a post-school qualification.

National Disability Services (NDS) completed a national workforce project in 2009. While this project did not specifically collect extensive demographic data, one component of the research was a survey of direct support workers. This survey had 1168 respondents from across Australia, with 73 percent being female and 59 percent of the participants aged over forty (Shaddock & Rose, 2009). These limited participant statistics provided some confirmation to the demographic information gained from the previous research projects.

5.1.1 Demographic Issues in Current Study

In most regards, the demographics of the participants in the current research study (see section *4.1 Demographic Characteristics of Study Participants*) were similar to those seen in previous research. For example, the current study's group was composed of twenty-six females and five males. The higher percentage of female participants was consistent with the findings of the Dempsey and Arthur (2002), Department of Human Services (2005), Lime Management Group (2006) and Shaddock and Rose (2009) studies. However, there was one key area of difference between the current project's participants and the demographic data from the previous studies. This distinction was seen in the levels of training that had been undertaken. The education and training background of the Delphi Panel was higher than would have been expected from the demographic statistics from Dempsey and Arthur (2002), the Department of Human Services (2005) and the Lime Management Group (2006). Of the participants in the current study, approximately 97 percent reported having relevant training and education. This figure was in contrast to the expected rate of between 30 and 50 percent in the previous research.

It was perceived that there are two possible reasons for this higher than expected training and education figure. Firstly, there had been a significant push within the disability sector over the past three or four years to ensure that all staff were appropriately trained. This training had been focussed upon the attainment of a Certificate III or IV in Disability. An example of this focus was seen in The Ascent Group, where all staff were enrolled into a Certificate III in Disability as part of their employment (Kevin Mead, pers. comm., 28 July 2009). Contact was made with the other organisations within the study, and they indicated an adoption of a similar policy within the past few years (Peter Dunstan, pers. comm., 15 July 2008; Fiona Miller, pers. comm., 10 March 2008).

This approach to structured training has only become widespread recently with the re-introduction of service auditing by the Department of Ageing, Disability and Home Care (DADHC) in 2005. DADHC's system of auditing, called the Integrated Monitoring Framework (IMF), examined the training and education provided to staff amongst many other service provision factors. While it was not mandatory to possess qualifications to work in the disability field, such qualifications were looked upon favourably during auditing, and many organisations had therefore implemented structured training programs since 2005.

This new structured approach to accredited training had largely occurred since the Dempsey and Arthur, Department of Human Services and Lime Management Group studies were completed in 2002, 2005 and 2006 respectively. It is likely that the current percentage of NSW staff with an accredited qualification is higher than that reported in the previous studies as a consequence of the subsequent focus upon training over the past five years. As such, it appears possible that the current study's higher than expected education levels is an accurate reflection of the sector, and that the previous data is simply outdated. However, this conclusion is impossible to ratify until an updated demographic study of the NSW disability workforce is conducted.

A second reason for the higher than expected number of participants with a post-school qualification could be that individuals who have successfully completed training are more likely to agree to participate in research studies such as the current one. This rationale was examined carefully prior to the final stages of the research commencing, with a specific focus upon whether it would have any impact upon the results the Panel would generate. After consideration, it was concluded that it was unlikely that the level of education would make a significant difference to the results of the study. It is believed that, even if the level of training did result in participants making different assessments on the impact that ageing has upon someone with an intellectual disability, this difference would largely be a positive one. It was perceived that these individuals would be better skilled and knowledgeable and theoretically in a position to make more accurate observations and judgements. However, this issue cannot be completely discounted, and the results of the study would need to be considered with this factor in mind.

5.2 Discussion of Question One Issues

Participants from the Delphi Panel individually proposed a total of twenty-five different issues for the question "*What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*" The participants achieved a group consensus position, both in terms of fact that all twenty-five issues were considered to be important and also with respect to their priority relative to each other. There were a number of over-arching themes identified within the twenty-five issues. They are discussed in greater detail in the following sections with specific reference to key items which include funding, training needs, access to services and individual health issues.

5.2.1 Funding

One of the key themes identified within Question One was Funding (see section *4.2.1 Issues Identified for Question One*). The wording of the highest priority issue in this question was *"Increasing support needs but no increased support (due to no funding increases)"*. This result indicates that the participants consider the need for adequate funding of services to address ageing issues to be very important. The failure of both the state and commonwealth governments to appropriately address the financing of services for ageing people with intellectual disabilities is reflected by the participants' identification of increasing support needs without similarly increasing funding as its top priority. Nonetheless, it is easy to argue that the sufficiency or otherwise of funding is a factor that is constantly raised across the entire community services sector and is not exclusive to the issue of ageing and disability. In a 2009 Australian Council of Social Services (ACOSS) study, only 8 percent of respondent organisations felt that the level of government funding was sufficient for community services (Australian Council of Social Services, 2009).

Likewise, it has been identified that rural and remote Australia has been experiencing a significant decline in prosperity over the past few decades, reducing the capacity of residents within these areas to pay for support services (Barr, 2004; Budge, 2006). However, why the issue of funding is particularly relevant to disability organisations, and why it deserves closer examination, relates to the establishment of many older supported accommodation services in rural New South Wales (NSW).

The deinstitutionalisation of specialist congregate care disability facilities, where people with intellectual disabilities were re-housed into smaller discrete residences situated within the wider community (see section *2.2.3 History of Intellectual Disability Services in New South Wales*), commenced around two decades after such practices began in the United States of America and Europe (Young & Ashman, 2004). Stimulus for changes in accommodation models started to occur following the release of the *Inquiry into Health Services for the Psychiatrically Ill and the Developmentally Disabled* Report, commonly known as the *Richmond Report*, in 1983.

The principal author, David Richmond, made a number of key recommendations including the funding of a system of small community based accommodation services, backed up by specialist hospital and accommodation services (NSW Audit Office, 1997). In 1998, the NSW Government made a policy decision to work towards closing all government run and funded institutions through the provision of alternative community based support options; however, it must be noted that this goal had still not been achieved over a decade later (Epstein-Frisch, 2007).

In NSW, the first rural demonstration project took place in 1986 when a group of twenty adult residents within a hostel in Armidale were supported to relocate into individual flats and houses by Challenge Armidale (Edmundson et al, 2005). This project was financed initially by the State Government as a demonstration model using a ‘block funding’ grant and was similar to the process undertaken by the metropolitan based Hornsby Challenge (Van Dam & Cameron-McGill, 1995). This model involved the disability organisation receiving one set figure to cover service provision for a group of clients, rather than a specified sum of money per individual. The project was reviewed over the first three years and it was deemed to be a desirable model to replicate (Edmundson et al, 2005). Similar models of deinstitutionalisation then started being introduced over the following years across rural NSW.

Following the success of the project in Armidale, the block funding grant was converted to an annual figure paid to Challenge Armidale. However, over twenty years later the organisation was still being block funded for this same group of people (Kevin Mead, pers. comm., 7 August 2007). Whilst the block grant amount is subject to annual indexing, there is no clear and easy process for reviewing and increasing this total in the situation of new or emerging needs. This same block grant funding model applies to some other rurally based service providers who provide accommodation services (Nicola Chirlian, pers. comm., 31 August 2009). In some circumstances the block funding figure had been converted to individualised funding; however, the calculation of the individual figure was performed simply by splitting the total block grant arbitrarily between each of the residents. There was no process of review and re-evaluation of changing individual need at that point in time.

In recent years, the State Government has pursued a model of providing individual rather than block funding for accommodation services. This change facilitates organisations to structure the provision of service around the specific and changing needs of the individual (Department of Ageing, Disability and Home Care, 2006). However, this model has not necessarily been applied retrospectively, and many disability organisations established prior to the year 2000 still operate with accommodation service based upon a block grant formula calculated decades earlier.

The only way to increase the level of funding for an accommodation service was to apply directly to the Government for viability funding, and to argue that providing living assistance to that group of people was no longer financially feasible. However, in order to prove that the service was unviable, the disability organisation had to provide audited financial statements that showed a serious deficit for each of the past three financial years. The major problem with this system was that very few service providers in rural areas could afford to operate in a substantial deficit situation for twelve months, let alone multiple years. Rural providers, in particular smaller independent charities and non-government organisations, do not generally have significant financial reserves to draw upon in years of loss. Therefore, the decision was often made to reduce the level of service in order to continue operations at a lower cost, which was achieved through cuts in support hours. The decrease in support hours was usually accomplished by focusing primarily on meeting the increasing personal care needs of the individual, while reducing their community integration and participation programs (Kevin Mead, pers. comm., 28 October, 2009).

Unfortunately, the consequence of a decision to operate at a 'break-even' financial position, but with reduced hours, was then used by Government to argue that the service was still viable and therefore not eligible for more funding (Kevin Mead, pers. comm., 28 October, 2009). This scenario is a classic example of a governmental 'Catch-22' policy (Heller, 1995). The disability providers are trapped in a situation when, in order to get additional funding to adequately support people with a disability as they age, the organisations need to prove their lack of viability by demonstrating three consecutive years of serious losses. However, the rural provider is realistically never able to prove this scenario, as they would have ceased operations completely if they had sustained substantial losses over that period of time. The ultimate outcome is that people with a disability do not get any additional funding support as they age, and that many of their quality of life programs are either reduced or completely cease in order to meet the increasing medical and personal care needs.

Block funded services generally originated with the movement of adults with an intellectual disability into the community. It is now twenty four-years since the commencement of the Armidale project, and the passing of nearly a quarter of a century has naturally seen some of the adults within this group start to experience age-related issues. However, as these block funded programs do not have an easy process to gain additional financial support as the needs of people increase, it is not surprising that the direct support workers identify a lack of funding as the major impediment people with a disability face as they age. Bigby (2008a, p. 76) noted that

> the absence of mechanisms to adjust disability funding as needs change, and the existence of policy that denies residents in group homes access to community-based aged care, forces disability services to "go it alone" to support ageing in place.

A recent report by the NSW Ombudsman (2009, p. 64) also commented on this problem and it concluded that

> services generally have to try to meet the changing needs of their ageing clients from within their existing resources, with no increase in funding to take account of increased support needs.

With the ongoing absence of additional funding or a clear process for review, it does not appear that these current problems can be resolved.

The participants rated the fact that the Disability Pension is not meeting the increasing needs of the individual as the seventh most important issue for Question One. This survey was completed prior to the release of the 2009 Federal Budget in which this issue was formally recognised at a national level. The Commonwealth Government implemented an increase for both the Aged and Disability Pensions from 20 September 2009 (Centrelink, 2009b). Whether this proposed increase is sufficient remains to be seen; however, it is an important step towards addressing the problem. A development in the 2009 Federal Budget was the proposal that the retirement age be increased by two years from sixty-five to sixty-seven in 2017 (Commonwealth of Australia, 2009a). This suggestion has received both support and condemnation from various sectors of the community (Australian Broadcasting Corporation, 2009a), and with the implementation date still some a number of years away it is not clear what impact this proposed change will have.

5.2.2 Training Needs

The theme of Training Needs was identified in section *4.2.1 Issues Identified for Question One.* Four of the six highest rated statements for Question One related to issues that could be addressed by training and education programs, either for disability workers or the wider community based health services. These four issues were *"Correct Diagnosis of issues by medical practitioners including mental health"*, *"Having appropriately trained and qualified support staff"*, *Placement into mainstream aged care facilities that have no understanding of disability"* and *"Confusion by staff and medical practitioners about what is ageing versus disability issues"*. Three of these four training priorities made reference to factors external to the role of direct care work in terms of the fact that they nominated either people or situations outside a disability organisation's realm of direct daily influence. In particular, doctors and medical practitioners being able to correctly distinguish between what are pre-existing factors resulting from the disability, as opposed to newer problems that have emerged as part of the ageing process, was clearly of concern to the participants.

In rural areas, the local general practitioner usually has to deal with every medical issue that arises across all sectors of the community (NSW Rural Doctors Network, 2008). It is therefore very difficult for a doctor to remain up to date with all aspects of specialist areas, such as the ageing of people with intellectual disability. The case in which a person with an intellectual disability also has a mental health issue, commonly known as a dual diagnosis, complicates the situation even further for rural general practitioners. It is estimated that between 30 to 40 percent of people with an intellectual disability will also have a mental health issue (NSW Council for Intellectual Disability, 2005). There is also a long-standing shortage of psychiatrists with expertise or even interest in the field of intellectual disability (Molony, 1993).

Cook and Lennox (2000) noted that general practice registrars in Australia had only received approximately six hours of training in the area of intellectual disability. A preliminary examination by the researcher of the curriculum programs at the six medical training schools in New South Wales (Sydney University, University of New South Wales, University of Newcastle, University of New England, University of Wollongong and University of Western Sydney) indicates minimal emphasis upon the issues facing people with an intellectual disability, let alone the combined factors of ageing or mental health within this sub-section of the community. These current results mirror those of a more comprehensive study conducted by Lennox and Diggens (1999), indicating that little has changed with respect to educating medical practitioners about intellectual disability in the past decade.

There were another four issues identified as being important by the Delphi Panel which could be successfully addressed through appropriate training. The third highest rated issue was *"Having appropriately trained and qualified staff"* which was followed by the fourth highest scoring issue *"Placement into mainstream aged care facilities that have no understanding of disability"*. These issues were largely mirrored by later items *"Lack of understanding of disabilities within mainstream aged care services"* and *"General lack of understanding about the ageing process by staff"*. All four of these issues refer largely to generic training concepts. Question Six of the Delphi, which specifically examined training issues for disability workers, provided greater clarification with respect to training and these issues are discussed further in section *5.1.6 Results from Question Six*.

5.2.3 Access to Services

Access to Services was recognised as one of the four themes in Question One (see section *4.2.1 Issues Identified for Question One*). Seven of the issues identified as important by the participants referred to difficulties in people with disabilities accessing and receiving appropriate community based services. The fifth highest rated issue for Question One was *"Access to specialist services such as gerontology and ACAT teams"*, followed by *"Doctors (and allied health staff) not prioritising medical attention for this group"*, *"Having appropriate support services to allow them to age in place safely"*, *"Being able to retire and access appropriate recreation and leisure activities (day programs etc)"*, *"Accessing appropriate equipment and aids"*, *"Lack of appropriate facilities"* and *"Accessing appropriate transport"*.

In June 2009, the Australian Council on Social Services (ACOSS) released a state-wide community sector survey. In this study, 170 agencies across New South Wales (NSW) reported upon their support programs and activities for the Financial Years of 2006/07 and 2007/08. The report asked participating organisations to indicate what their highest priorities were for client need in accessing services outside of their own programs. The third highest priority area for accessing support was ageing and disability. It is worth noting that this survey did not distinguish between various disability types and considered them all generically under the label of 'disability'. While the issue of ageing and disability was rated as less important than long term housing and health care, it was still perceived as more critical than issues such as crisis and supported accommodation, transport, domestic violence and sexual assault services (Australian Council of Social Service, 2009). These findings indicate that accessing ageing and disability services is difficult across all areas of the state. However, the major factor around the world that limits access to appropriate services has been found to be a rural location. It was specifically noted that geographic location has a great impact upon the availability of intellectual disability services in Australia (World Health Organisation, 2007).

Availability of appropriate services in rural and remote areas of NSW is of course not limited to people with intellectual disabilities. Rural residents generally have significantly less access to both general practitioners and allied health professionals, whilst experiencing higher levels of mortality and morbidity that their metropolitan counterparts (NSW Rural Doctors Network, 2008). In 2009, the Commonwealth Government of Australia acknowledged this problem with the appointment of Warren Snowden as the inaugural Minster for Indigenous Health, Rural and Regional Health and Regional Services Delivery. In an interview with ABC Radio, Snowden accepted that rural and remote areas continue to face a number of significant difficulties, and that a shortage of both doctors and allied health professionals was evident (Australian Broadcasting Corporation, 2009b).

While it is recognised that most rural areas face problems in accessing services, the cohort of people with intellectual disabilities do face a number of specific problems in gaining appropriate specialist assistance. The Australian Institute of Health and Welfare's report *General practice in Australia, health priorities and policies 1998 to 2008* did not even identify intellectual disability as an area of concern to general practitioners, although other issues such as mental health were recognised (Australian Institute of Health and Welfare, 2009). People with intellectual disabilities around the developed world face numerous disparities in a variety of medical issues such as preventative care, health promotion and equitable access to health care (Krahn, Hammond & Turner, 2006). It has been identified in Europe that specialist health services have to make a particular effort to engage and interact with ageing people with intellectual disabilities as they are at risk of being overlooked. The planning of services to this group need to be pro-active and designed to deliberately facilitate access (Dodd et al, 2008b). Whilst the overall health of people with intellectual disabilities is generally lower than mainstream society (see section *2.4.1.1 Health Issues*), this difference was found not to correspond necessarily with access rates to generic community health programs in Britain (Webb & Stanton, 2008).

Particularly concerning is the fact that the NSW Ombudsman reported some people with disabilities had died as the consequence of health services failing to provide appropriate levels of treatment. The rationale reportedly given by the health care staff for this failure was that people with disabilities had an inferior quality of life (NSW Ombudsman, 2006). Medical staff also failed to consult appropriately with the individual or family and made independent judgements about the need for treatments, including the non-performance of Cardiopulmonary Resuscitation with minimal or no documentation (NSW Ombudsman, 2007).

Another issue that is of relevance to people with intellectual disabilities, as described in section *2.2.6 Australian Funding of Disability and Aged Care Services*, pertains to the confusion surrounding differing departments within the different levels of government that oversee service delivery (Baker, 2007). In NSW, the Department of Ageing, Disability and Home Care (DADHC) is considered to have carriage of most disability programs. This Department both funds and operates direct care support programs and also employs staff to provide allied health care services such as physiotherapy, psychology, occupational therapy and speech pathology. However, a separate State Government department, NSW Health, also provides disability and allied health services. There are sub-groups of the cohort of people with disabilities who are serviced by NSW Health if they have a minor intellectual disability, but DADHC if they have a moderate intellectual disability (Doherty, 2007).

On the national level, the Department of Education, Employment and Workplace Relations (DEEWR) oversees the Disability Employment Network program, whilst another Commonwealth department, Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), coordinates the Australian Disability Enterprises system. The situation becomes even more convoluted when the issue of ageing becomes a factor. Some aged care services, predominantly those provided in-home, are overseen by DADHC. Residential aged care, as well as community programs such as Extended Aged Care at Home (EACH) and Community Aged Care Packages (CACP), are the responsibility of the Commonwealth Department of Health and Ageing (DoHA). The Aged Care Assessment Teams (ACATs), who determine eligibility for accessing EACH and CACP programs, are overseen by DoHA. The third tier of government in Australia, local councils, also provide generic aged care services such as day programs for aged and dementia care.

With responsibility for the provision and coordination of disability and aged care services split between various departments and different levels of government, it is not unexpected that difficulty in understanding the systems are reported by parents, clients and other stakeholders (Doherty, 2007). The *NSW Ombudsman 2008-2009 Annual Report* concluded that "there is currently no clear policy guidance for services about 'ageing in place' for people with disabilities in care" (NSW Ombudsman, 2009, p. 64). The complication of multiple service levels is particularly relevant to the ageing of people with intellectual disabilities. The concept of 'double-dipping', where a person is deemed to already be serviced and therefore not eligible for additional support, is often used as the rationale to refuse access. As an example, individuals with an intellectual disability residing within a group home are often deemed ineligible to receive specialist in-home aged care support services to maintain this placement (Dowse, McDermott & Watson, 2009; Nicola Chirlian, pers. comm., 31 August 2009). They are considered to be already receiving living support and therefore should not be given any additional assistance, in spite of the fact that the person is experiencing ageing-related issues that were not evident when they first entered the accommodation placement.

The NSW Ombudsman (2009, p. 64) commented specifically on this impediment to services access, noting that

> ageing clients who live in supported accommodation are unable to access community-based aged care supports available to ageing people in the general community – such as Community Aged Care Packages. This is because of the existing separation between the disability and aged care sectors.

Health services, both nationally in Australia and regionally in NSW, are widely viewed as being under-resourced and under-staffed (Van Der Weyden, 2009). This lack of resourcing can result in long waiting lists and the prioritising of access (Queensland Council of Social Service, 2008). Individuals who are considered to be the responsibility of another government department can experience difficulties in gaining access to appropriate services. This problem is evident in situations of ageing, as well as dual diagnosis. A person with an intellectual disability and a mental health issue can experience significant problems in receiving support, with an argument between differing government departments about which is the primary disability and who has ultimate responsibility. If the person is ageing, it merely complicates the situation further. In this environment, and particularly in rural areas where there are fewer doctors and allied health staff, it is hardly surprising that the participants identified access to services as a serious issue.

5.2.4 Individual Health

Five of the twenty-five issues identified as important by the participants related either to medical or physical health issues being experienced by the individual with an intellectual disability (see section *4.2.1 Issues Identified for Question One)*. However, none of these issues were prioritised within the top ten, with *"Physical deterioration (hearing and sight) and emotional changes (depression)"* the highest rated item at number thirteen. Other medical or individual health issues raised by the participants included a decrease in communication and physical abilities, the onset of specific ageing conditions such as dementia and osteoporosis, and personal hygiene. It was considered that Question Two in the Delphi study provided greater clarification with respect to participants' perceptions of individual health issues, and therefore these items are discussed in more detail in section *5.1.2 Results from Question Two*.

5.3 Discussion of Question Two Issues

Participants from the Delphi Panel individually proposed a total of thirty- two different issues for the question *"What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional* *issues, mental health issues)?"* The participants achieved a group consensus position, both in terms of fact that all thirty-two issues were considered to be important and also with respect to their priority relative to each other. There were a number of over-arching themes identified within the thirty-two issues, and they are discussed in greater detail in the following sections with specific reference to key items.

5.3.1 Generic Health and Support Needs

The top two rated issues by the participants were both generic, in terms of referring to *"Greater Support Needs"* and *"Increased simple and complex health needs"*. While both of these issues are undoubtedly important, there is little actual detail in the items regarding specific problems. It is believed that some of the later items within Question Two will provide additional clarification regarding the actual signs of ageing the disability workers were seeing emerge in people with intellectual disabilities.

5.3.2 Mental Functioning

One of the key themes within Question Two related to mental functioning (see section *4.2.2 Issues Identified for Question Two).* A review of the literature on mental health issues experienced by people with intellectual disabilities as they age was presented in section *2.4.1.1 Health Issues in Ageing with an Intellectual Disability*. In the current study, three of the top six issues raised by the participants were related to mental health or diminishing mental capacity issues. *"Mental health issues such as depression and dementia", "Deterioration in mental abilities"* and *"Loss of memory"* were all rated as important by the participants. Some studies have reported that 20 percent of people with intellectual disabilities over the age of sixty-five have a major psychiatric illness, such as depression (Bland et al, 2003). The three mental health issues identified by the participants could all be considered as being generic to the wider aged care sector and certainly not unique to the disability sector. However, mental health issues become particularly significant for this group when considered in light of their existing intellectual disability.

As a sector of society, people with intellectual disabilities already have an existing deficit in their daily functioning when compared to the mainstream ageing community. As they start to experience ageing-related problems such as dementia or memory loss the capacity of this group to cope with normal activities can decrease faster as a consequence of their lifelong disability. The ageing issues can magnify any existing problems, and the individual may also experience a major decrease in any life domains that they were previously competent in. This situation, in which the existing intellectual disability is overlaid with new ageing-related mental issues, presents families, support staff and medical practitioners with a very complex scenario to try and understand.

Three of the issues considered to be important by the participants were *"Withdrawal", "Reduced desire to participate in activities"* and *"Reduced desire to access services"*. While it is not completely clear, it would appear possible that these issues are related to mental health problems such as depression. Studies have shown that people with intellectual disabilities are at risk of developing depression or depressive symptoms, with the incidence of depression possibly even higher than the general population (Cooper et al, 2007b; Lowry, 1998; Meins, 1993; Thorpe, Davidson & Janicki, 2001). Two behaviours designated as symptoms of depression include a "lack of interest and enjoyment" and "reduced energy leading to increased fatigability and diminished activities" (World Health Organization, 1992, p. 119). It is considered that people with forms of intellectual disability display similar depressive symptomatology to the mainstream community (Tsiouris, 2001). Disability staff are not trained in how to deal with mental health issues such as depression and the lack of rural counselling services adds further to the difficulty in addressing these problems.

One of the significant problems that many rural service providers face is finding appropriate activities for people with disabilities. Unlike some larger metropolitan areas, access to a variety of different educational and recreational pastimes in small country towns can be extremely difficult. This problem can become even more significant when the ageing person with a disability starts to lose their ability or desire to take part in programs they have previously enjoyed and been capable of undertaking.

5.3.3 Physical Issues

The third theme identified for Question Two pertained to Physical Issues (see section *4.2.2 Issues Identified for Question Two).* Three of the top ten issues the participants identified as being important related to a reduction in the individual's physical health or physical abilities. These items were *"Trips and falls"*, *"Incontinence (Bladder and bowel)"* and *"Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia"*. Another nine issues with a significant physical component were also considered to be important signs of ageing within people with intellectual disabilities. These items were *"Communication problems", "Changes in eating habits (inability to eat certain foods), "Decreased mobility", "Reduction in ability to access community independently", "Reduction or loss of senses such as vision or hearing", "Weight gain or weight loss", "Physical health issues (including sight and hearing deterioration), "Increase in seizure activity"* and *"Hormonal issues"*.

The physical changes associated with the ageing of a person with an intellectual disability have been well recognised and documented (Janicki & Dalton 1999; Walsh, 2005). All of the twelve physical health items identified by the participants would appear to be quite similar to problems that would be expected to be reported within the mainstream ageing cohort and consistent with the issues discussed in section *2.4.1.1 Health Issues in Ageing with an Intellectual Disability*. There were no ageing issues identified that would appear to be specific to the sub-group of people with intellectual disabilities. The answers of the participants indicate an underlying perception that the physical ageing of people with intellectual disabilities is not markedly different to that experienced by a person without a disability.

The fact that the participants did not identify any significant physical issues specific to the group supports the notion that the physical aspects of aged care training could be introduced generically across the intellectual disability sector.

While there are some aspects of ageing with an intellectual disability that require specifically designed training programs, coordinated access by disability workers to generic aged care training for physical care issues would appear to be sufficient to address the needs of this important issue. However, it is worth noting that, while the physical health issues for people with an intellectual disability may be similar to those experienced by the mainstream, the management of these problems may be complex. There are a number of complicating factors such as the age at which the issues begin emerging, a multiplicity of problems occurring simultaneously, an inability of the individual to correctly articulate their concerns, irregular health checks, and a lack of appropriately trained clinicians. While the physical health issues may be addressed generically, these additional concerns still require consideration at a management level to ensure that the individual receives an appropriate level of care.

5.3.4 Emotional or Personality Issues

The last theme for Question Two related to Emotional or Personality Issues (see section *4.2.2 Issues Identified for Question Two*). The participants identified a number of important issues that pertain largely to emotional factors or personality changes associated specifically with the ageing process. Items included *"Grief (loss of their own families and friends)"*, *"Losing their 'identity' and independence after moving into supported accommodation"*, *'Isolation"*, *"Loss of confidence"*, *"Bullying towards other residents and staff"* and *"Disrespect towards staff"*. Emotional issues and problems associated with coping with loss during ageing have been identified in people with intellectual disabilities (Ludlow, 1999; Moss, 1999) and were previously discussed in greater detail in section *2.4.1.4 People with an Intellectual Disability and Grief*. Studies have shown that that people with intellectual disabilities do experience grief when a friend or family member passes away (Dodd, Dowling & Hollins, 2005; McHale & Carey, 2002), and that this grief reaction is not significantly different to that expected in the general community (Stoddart, Burke & Temple, 2002). However, Read (1998) found that disability support staff experienced difficulty not only in coping with the actual death of the person, but also in how to then provide emotional support to the surviving residents who lived in the same home.

Access to counselling services in rural areas can be limited or non-existent. Often the disability support staff end up as ‘accidental counsellors’ for the remaining residents. Disability workers are generally not trained in how to counsel and emotionally support people in such a situation, and therefore errors and mistakes in judgement can be made, which may result in further distress. The need for counselling is not limited to the residents, as both the deceased individual’s family and co-workers may also require ongoing support following the loss of a relative or a person they have developed a close attachment with after many years of providing personal support.

Facilitating appropriate counselling for a person with an intellectual disability can be difficult, particularly for individuals with limited receptive or expressive communication skills. Open discussion about what happens towards the end of a person’s life can also be stymied by family members, who still believe that their ageing child is in need of constant protection or is incapable of understanding what is occurring. A 'conspiracy of silence' has been reported; a situation in which the family, workers and allied health professionals all avoid discussing the progression of the terminal illness in front of the person with the disability. Tuffrey-Wijne (1997) commented on this phenomenon where carers have a belief that the person is unable to understand what is happening, and therefore the topic is simply avoided to prevent distress. However, the failure to communicate and discuss what is happening prior to the person passing away may then lead not only to confusion in the person with the disability, but also result in a compounding of the grief following the individual’s death (Blackman, 2003b).

Grief and loss is also often experienced following a change in housing. The participants identified this issue with the items *“Losing their ‘identity’ and independence after moving into supported accommodation”* and *“loss of confidence”*. As the individual support needs of the ageing person increase, s/he is often not able to remain in her/his own home, as not all rural disability services are able to provide the necessary level of nursing care to enable this (see section *2.4.1.2 Ageing in Place*). This change results in ageing people with an intellectual disability having to move into the next most suitable alternative accommodation, which in rural areas is often a residential aged care facility, a Multi-Purpose Health Centre or even the local hospital.

The underpinning philosophy of aged support services is fundamentally different to disability services, with an emphasis upon care provision rather than independent living training and skills development (see section *2.2.6 Australian Funding of Disability and Aged Care Services)*. As such, when people move from a disability service into an aged care service the skills and abilities that they still maintain can be quickly lost when staff simply complete tasks for the individual rather than assisting them to do it for themself. It is, therefore, possible to see how the person's sense of identity and independent living skills can diminish following a move into an aged care environment.

5.4 Discussion of Question Three Issues

Participants from the Delphi Panel individually proposed a total of twenty- nine different issues for the question *"From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?"* The participants achieved a group consensus position, both in terms of fact that all twenty-nine issues were considered to be important and also with respect to their priority relative to each other. A large number of the items and themes identified in Question Three overlapped with the previous two questions. The top two items and four of the top ten issues identified by the participants both related to funding issues, which have been discussed in greater detail earlier in section *5.2.1 Funding*. Four of the top eleven items pertained to issues of access to appropriate services and facilities, which was examined in section *5.2.3 Access to Services*. Other issues previously identified and discussed included the theme of Health Care, which was addressed in section *5.3 Discussion of Question Two Issues*. Question Three did prompt the participants to identify a number of specific issues pertaining to Time Constraints, and an item that related specifically to Family Concerns.

5.4.1 Time Constraints

One of the themes identified in Question Three related to Time Constraints (see section *4.2.3 Issues Identified for Question Three).* The participants identified three items relevant to this theme, ranging from the generic *"Time Constraints"*, through to specific examples such as *"Excessive Paperwork"* and *"Dealing with personal frustration in not having sufficient time to meet individual needs"*. These items primarily related to the staff perception of there being an insufficiency of time to get the necessary or desired work tasks completed. Complaints about ever increasing expectations and workloads with respect to paperwork are certainly not specific to disability organisations, let alone the sub-section of support services for ageing people with intellectual disabilities. However, the past decade has seen a major change for all disability services with respect to the amount of information that is required to be kept regarding each individual.

The introduction of compulsory quality assurance through the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs' (FaHCSIA) Disability Employment Standards (DES) and the New South Wales (NSW) Department of Ageing, Disability and Home Care's (DADHC) Integrated Monitoring Framework (IMF), has seen greater government demands on service providers with regard to accountability (Farrow, 2008). The past decade has seen disability organisations having to ensure that comprehensive paperwork and client records are kept for daily progress notes, individual plans, skill training programs, behaviour interventions, risk assessments for all activities, occupational health and safety protocols, positive behaviour management practices, sleep and seizure charts, nutrition and swallowing programs, and medical monitoring amongst other requirements. While many services have kept some or all of this type of information for many years, the mandatory nature of quality assurance requires every provider to dedicate more time to meeting these paperwork requirements.

Another area that has seen a considerable increase in both legal demands and time constraints for disability providers is Occupational Health and Safety (OH & S). The 1993 *Disability Services Act* and the associated Disability Services Standards specifically legislate for the rights of people with disabilities to be integrated and to participate in their local community. However, this legislation is often in direct conflict with the *Occupational Health and Safety Act* 2000 which mandates for all people to be employed within minimal risk work environments (WorkcoverNSW, 2000). A significant part of working with people with intellectual disabilities is the recognition of the person as an individual. Challenging behaviours and aggressive outbursts can be commonplace, particularly within the group of people with moderate to severe intellectual disabilities.

While these issues can be partially addressed with positive behavioural support planning, it is impossible to completely eliminate such problems. The *Occupational Health and Safety Act* 2000 refers to the need for employers to take all reasonably practical steps to prevent injury to a worker (WorkCoverNSW, 2000). There has been an argument put forward that as disability organisations are aware of the challenging behaviours exhibited by clients, they should be able to reasonably predict such incidents and therefore protect workers from any incidents of abuse (Farrow, 2008). This situation now results in services having to complete comprehensive and often excessive risk management paperwork on routine activities to mitigate against a possible future claim.

Disability organisations are required to deal with these numerous new complexities with respect to legislation and administration requirements by government, but the increase in paperwork requirements has not been accompanied by a similar increase in funding from government. Staff are therefore required to try and complete the additional paperwork in the same amount of time as previously allocated to a shift. However, staff are already experiencing pressure to meet the increasing needs of ageing clients without receiving funding (see section *2.4.1.2 Ageing in Place).* This double impact of increasing paperwork requirements and increasing needs of individuals, whilst receiving no extra funding to complete either of these expected tasks, presents logistical difficulties for both direct care staff and management. The result is to reduce the expected goals to be achieved for the individual, which appears to directly contradict the DADHC requirement for person centred planning (see section *2.5.3 Person Centred Planning).* The other alternative is that the staff have to complete these additional written tasks in their own time. Either solution is undesirable, and demonstrate why time constraints have been identified as presenting specific problems for workers assisting ageing people with intellectual disabilities.

5.4.2 Family Issues

One of the issues in Question Three that the participants identified as important was *"Unrealistic family expectations" (*see section *4.2.3 Issues Identified for Question Three).* Additional discussion regarding the issues associated with family and friends is presented in section *5.5 Discussion of Question Four Issues*. However, it is worth recognising that one of the most significant dynamics for any individual revolves around his/her personal relationships. People with intellectual disabilities have seen major shifts in both policy and practice over the past fifty years such as the introduction of the *Disability Services Act* in 1986 and associated Disability Services Standards (Farrow, 2008). These procedural changes include very significant alterations in the focus on the family support structure.

Only thirty years ago some parents in rural areas of NSW were still advised by medical and government experts to send their young children, often under five years of age, to specialist education and residential accommodation located in larger regional centres (Margaret Kennedy, pers. comm., 1999). Visits back to the family for these children then occurred on a scheduled basis and often only after long periods of intervening time. It is not surprising, therefore, that the attachments and familial bonds between individuals and their wider family unit can be tenuous. Studies have indicated that formal support programs, such as early intervention introduced in recent years, not only assist the individual with a disability, but also provide beneficial outcomes for the wider family (Bailey, 2007).

However, these programs were not normally available to most rural families of people with intellectual disabilities who are now ageing.

Conversely, there are also a large group of people with intellectual disabilities who never left the family home (Bigby & Pierce, 2008). In some circumstances, they remain living with their ageing parents until such stage as the situation becomes impossible to sustain, whereupon they move into a form of supported accommodation (Llewellyn et al, 1999). This group of people often has had very limited involvement with the wider community and have never spent time within either respite or residential support services prior to a family crisis occurring. Daily life was often structured around the needs of the person with the disability, with considerable restrictions placed upon the activities in which the wider family unit could participate (Werner, Edwards & Baum, 2009).

Many families have indicated that they still feel very profound guilt about choices they have made, such as the decision to send a child away from home and into an institutional care setting (Werner, Edwards & Baum, 2009). Service providers can often experience a situation in which they have to support not only the ageing individual, but also many other unresolved grief and loss issues within the family unit. However, it is worth noting that some studies have shown a reduction in levels of personal guilt in family members following a person with an intellectual disability moving into a supported residential placement (Baker & Blacher, 2002).

The activities which the individual wishes to participate in can be stymied by the family who believe that their ageing child or sibling is in need of constant protection or is incapable of understanding what is occurring. This attitude is reflective of a common belief within the wider community that people with intellectual disabilities have lower functioning levels than actuality (e.g. McConnell & Llewellyn, 2002). The expectations and beliefs of the family can be unrealistic and based around emotional rather than factual viewpoints. Employees often have to navigate a difficult path between the rights of the individual and the conflicting wishes of their relatives. A lack of training in this area presents disability workers with significant problems in knowing the correct way to respond to, and interact with, the family.

5.5 Discussion of Question Four Issues

Participants from the Delphi Panel individually proposed a total of twenty- five different issues for the question *"What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?"* The participants achieved a group consensus position, both in terms of fact that all twenty-five issues were considered to be important and also with respect to their priority relative to each other. There were a number of over-arching themes identified within the twenty-five issues, and they are discussed in greater detail in the following sections with specific reference to key items. The issues associated with the theme of Access to Services was previously discussed in section *5.2.3 Access to Services*.

5.5.1 Ageing Parents

The theme of Family Issues was previously raised in section *5.4.2 Family Issues.* The theme of Ageing Parents (see section *4.2.4 Issues Identified for Question Four)* provides more specific information about the issues of how families cope with the ageing not only of the person with the intellectual disability, but also the primary carer. These problems were reviewed in section *2.4.1.2 Ageing in Place*.

Two of the top four issues identified for Question Four by the participants were *"Ageing parents"* and *"Family concern about future planning as the person with the disability may outlive the parents"*. Many ageing people continue to look after their adult children who have a disability (Bigby & Pierce, 2008; Heller & Factor, 1991). However, people with disabilities are now consistently outliving their parents (Planned Individual Networks, 2007) and, as such, there is a need for the wider family unit to consider and plan carefully for what will happen following either the death or incapacity of one, or both, parents. Research has shown that comprehensive planning by the family is rare, and there is an element of resistance to the process (Bigby, 2002a; Grant, 1989). In some situations, less than 50 percent of families had made appropriate future plans to meet the accommodation needs of their child (Freedman, Krauss & Seltzer, 1997).

It was noted by Dowse, McDermott and Watson (2009) that many people with disabilities appeared not to do any planning for the future. According to Grant (1990), many ageing parents also struggle to make final decisions about what will happen when they die, particularly in situations where options are limited. The point at which ageing parents either die or become incapable of continuing to look after their adult child can also occur when the person with the disability is in middle-age or starting to age him/herself (Bigby, 2002a). The brothers and sisters of adults with autism may also experience problems with maintaining care for their sibling following the death of the primary caregiver (Orsmond & Seltzer, 2007).

The need for future planning is vital, as both the family and service providers have to prepare the individual for a major change in daily living at the same time as the person may be starting to experience a decrease in his/her functioning levels. It is considered that proper and comprehensive planning by the ageing parents prior to a crisis occurring is vital if people with disabilities are to successfully transition into a new living environment (Smith & Tobin, 1989). However, the capacity and ability of both government and service providers to respond in an appropriate and timely manner is uncertain, even if the families do plan ahead (McCallion & Kolomer, 2003). The perspectives and views of ageing carers of people with an intellectual disability were examined by Hussain and Edwards (2009). This research noted that there was limited future planning occurring and restricted access to appropriate retirement activities and specialist services in rural areas. It was also concluded that one of the main concerns of the ageing carers was the lack of available supported accommodation options in rural areas.

A crisis situation, in which the parents of a person with a disability are suddenly no longer able to look after their child, presents accommodation services and their staff with a very difficult scenario. The person is often suffering from grief associated with the loss of a parent, as well as being disorientated after being moved from their familiar family home (Janicki et al, 1985). The wider extended family is also busy with the various necessary legal requirements following the death of a person, and the needs of their sibling with a disability can be overlooked at this point. This situation leaves the disability workers, who may have limited or no prior experience with the individual, as the main supports for the person with a disability. Without appropriate forward planning, the transition of ageing people with a disability into a supported accommodation can be problematic and potentially traumatic for the individual, his/her family and support workers.

5.5.2 Understanding and Coping with Ageing

The second identified theme for Question Four was Understanding and Coping with Ageing (see section *4.2.4 Issues Identified for Question Four)*. The participants identified a number of issues surrounding the family and friends' understanding of what the ageing person with an intellectual disability was experiencing, and how to assist the individual to cope with these changes. These items included *"Understanding and separating behavioural issues from physical/mental health issues"*, *"Fellow residents not understanding what is going on (why the person has changed or moved)"*, *"Lack of information for families to source services"*, *"Pressure on friends to cope with changing personality and skills"* and *"Lack of acceptance of the ageing process"*.

The ageing of people with intellectual disabilities is a relatively new issue to arise within the community services sector and, as such, the policy frameworks and support structures in Australia are still relatively immature (Bigby, 2002b). Disability support staff do not always have extensive experience or knowledge of ageing issues. Information packages and training opportunities relevant to ageing with an intellectual disability, both for staff and family members, are generally not yet well developed nor widely available in rural areas. Individuals with a disability and their family often view the disability support staff as 'experts', and seek advice and information from them. If the disability staff are not able to provide the people they support with accurate and relevant information, either through its unavailability or their own lack of knowledge, the individual with a disability and his/her family will struggle to understand and cope with aspects of the ageing process.

While there are specific issues that impact directly upon people with intellectual disabilities who are ageing, a greater level of interaction between the ageing and disability providers may help to address aspects of this problem. Mainstream ageing information packages and resources could be readily transferred to the disability sector as a means of ensuring a greater understanding of the generic processes of ageing and how to cope with changes as they occur. By appropriately re-utilising existing materials developed for mainstream ageing issues, staff would be able to provide individuals and their families with information on the topic. In rural areas, collaboration and cooperation between existing ageing and disability providers with respect to joint training opportunities is another mechanism through which the sharing of key knowledge can be maximised (Mohr et al, 2002).

5.5.3 Increasing Care Needs

The final theme for Question Four (see section *4.2.4 Issues Identified for Question Four)* was Increasing Care Needs. There were a number of issues considered important by the participants that related to the increasing care needs of the individual, and how this impacts upon their family, friends and other residents. These items were *"Coping with increased support needs", "Concerns about person's ongoing and increasing care needs", "Clients with lower care needs miss out due to an increased focus on person who is ageing", "Friends experiencing depression themselves due to worry about their own mortality", "Impact upon closeness of relationship (affected by dementia)", "Residing within a complex with other people with disabilities compounds personal problems for those who are ageing"*, and *"Increased reliance upon staff to facilitate family contact (primarily through phone)"*.

As detailed in section *2.4.1.1 Health Issues*, people with intellectual disabilities experience a higher number of health care needs than the mainstream population (Kapell et al, 1998), but these health needs are often not appropriately addressed and treated (Lennox & Kerr, 1997). Ageing is then often associated with a further increase in the incidence of care needs. People with intellectual disabilities around the world already encounter significant inequality in accessing health care services (Durvasula & Beange, 2001; Fisher, 2004; NHS Health Scotland, 2004) even before the secondary factors of ageing start to emerge. It is, therefore, not a surprise that the participants identified health and individual care needs as an important issue. While there were some generic issues identified such as generally increasing care needs, some of the specific items provide greater clarification of the difficulties faced by the individual and the consequences of this upon his/her family and friends.

A number of issues recognised by the participants related to direct and indirect impacts that the ageing of a person with an intellectual disability has upon fellow residents and friends. The lack of additional government funding for organisations to support ageing people with intellectual disabilities has a natural consequence of reducing the level of service available for other residents. If the overall level of funding does not change but the minimum required level of staffing for one person increases, it is inevitable that there must be a reduction in services elsewhere. This issue is particularly relevant for disability services operating under a block grant model of funding to support a group of people, as opposed to a situation where an individual allocation of money is designated to each specific person.

This situation can translate to a fellow resident's quality of life programs being reduced in order to meet the care needs of the person who is ageing. Resources and staff time are reallocated internally within the service, with some clients receiving less support hours than expected in order for the disability organisation to appropriately meet the increasing needs of another resident. At the same time, the individual who is ageing will also experience a reduction in his/her own quality of life programs, with the primary focus of service shifting to meet his/her personal care needs.

A person with dementia will experience an increase in care needs associated with a decline in memory and intellectual functioning (Brodaty, Draper & Low, 2003;

World Health Organization, 1992), and these impairments can have a direct impact upon friends. Decreasing capacities can result in a separation from family and a loss of long-standing friendships. The person's family, friends and the other residents within the house can be impacted by symptoms of grief, both in terms of the loss of friendship with a long term companion who may have dementia, and also through knowledge of the individual's impending death. In some situations, individuals with an intellectual disability may have been cohabitating with the same people for many decades (e.g. Dowse, McDermott & Watson, 2009; Edmundson et al, 2005), and any changes to one resident will naturally have an impact upon the other housemates.

Friends can experience depressive-type symptoms as a result of their grief and loss and also with respect to the contemplation of their own mortality. A Client Services Manager from a rural provider described a situation in which three women with intellectual disabilities lived together for in excess of thirty years. This placement eventually ceased when one of the residents developed dementia and suffered a fall that resulted in hospitalisation. This lady was moved from the hospital into a residential aged care facility in another town an hour away as this was the nearest available bed. She passed away soon afterwards. The remaining women experienced considerable grief and confusion both during the initial stages of the individual's dementia and her eventual residential aged care placement. They were uncertain why their friend's personality had changed and then why she could not continue to live in their home (Nicola Chirlian, pers. comm., 15 December 2008).

The health and personal care needs of ageing people with an intellectual disability usually focus upon the individual; however, his/her increasing support requirements can also negatively affect co-residents, family and friendship groups. Training for staff in this area is required in order to successfully support both the individual and the wider group of family and friends.

5.6 Discussion of Question Five Issues

Participants from the Delphi Panel individually proposed a total of twenty-five different issues for the question *"What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?"* The participants achieved a group consensus position, both in terms of fact that all twenty-five issues were considered to be important and also with respect to their priority relative to each other. There were a number of over-arching themes identified within the twenty-five issues, and they are discussed in greater detail in the following sections with specific reference to key items.

5.6.1 Training and Staff Development

The first identified theme for Question Five related to training and professional development (see section *4.2.5 Issues Identified for Question Five)*. The current framework for the training of disability workers was detailed in section *2.6 The Disability Sector Workforce*. Three of the top five items, and nine of the twenty-five issues identified by the participants for rural service providers, related to knowledge, education and staff development. The top three issues were *"Training and education for both disability staff and generic aged care professionals", "Recruiting qualified and trained staff"* and *"Maintaining qualified and trained staff"*. The remaining six items included *"Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing", "Mainstream aged care services not understanding how to support someone with a disability", "Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Care)", "Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability", "Lack of staff skill in utilising and accessing those available mainstream services"* and *"Limited opportunities for staff networking (e.g. cross pollination of ideas and knowledge)"*.

The issue of training was raised briefly in section *5.2.2 Training Needs* and will be discussed in greater detail in section *5.7 Discussion of Question Six Issues*, which specifically refers to the training and education goals for rural disability workers and organisations. However, there are a couple of specific staff development issues in Question Five that deserve closer examination. In particular, accessing and then retaining qualified staff appears to pose significant difficulties for the rural community services sector.

The interaction and support provided by staff has been identified as one of the key factors in either positive or negative program outcomes for people with intellectual disabilities (Mansell, 2005). In a 2009 Australian Council of Social Service (ACOSS) study, 63 percent of organisations surveyed indicated that they encountered difficulty in recruiting appropriately qualified employees. The rate of staff turn-over can also be very high, with research showing up to 38.8 percent annually (Australian Council of Social Service, 2009). A national study by the Australian Services Union (2007), the largest union in the social and community services sector, found that over 50 percent of respondents did not plan to still be employed within the field in five years time.

The issue of both attracting and retaining appropriate staff is a problem that is inherent to every workforce in every sector of Australian business. Staffing has been identified as one of the four most significant factors in determining the quality of service provision by disability organisations (Mansell et al, 2008). Disability services, particularly those in rural areas, often do not have a considerable pool of potential employees from which they can choose. This problem is then exacerbated by the high turn-over levels of staff. Organisations are naturally reluctant to spend their limited training money and resources on staff who are possibly going to leave their employer within the next twelve months. Likewise, training needs to be provided in a way that maximises the number of staff who are able to participate in and benefit from it. However, the emergence of ageing and intellectual disability presents a new problem for disability service providers with respect to recruitment.

The issue of ageing and intellectual disability was not recognised as being an essential or core unit of accredited training within the Certificate III and IV in

Disability within the Community Services Training Package CHC02 (Community Services and Health Industry Skills Council, 2008b). It is this course that the majority of individuals who have participated in accredited training would have completed. A new training package was formally endorsed as the Community Services Training Package CHC08 on 10 December 2008 (Community Services and Health Industry Skills Council, 2008a), and accredited by the Vocational Education and Training Accreditation Board on 23 February 2009. All training organisations must have switched to the new training package by February 2010 (Community Services and Health Industry Training Accreditation Board, 2009).

However, while the emerging issue of ageing and intellectual disability was highlighted during the review phase prior to the ratification of the Community Services Training Package CHC08, the problem was not fully addressed within this new training package. The relevant ageing and disability training unit of competency, *"CHCDIS313A: Support people with disabilities who are ageing"*, remains as an elective unit that individuals can chose whether they wish to study or not (Community Services and Health Industry Skills Council, 2008a). Therefore, even if staff have completed an entry level course such as the Certificate III in Disability, there is no guarantee that they will have any knowledge about ageing issues. This situation means that disability organisations can employ an appropriately qualified individual but one who has no experience or information about the issues of ageing within people with intellectual disabilities.

The issue of staffing development, and indeed the professionalisation of the disability sector as a whole, has been identified as a priority area by government, peak bodies and non-government bodies (National Council of Social Service, 2008; National Disability Services, 2008a). In order to respond to these problems, a number of innovative projects have been formulated (Disability Professionals NSW, 2007a; National Disability Services, 2009a). In particular, the emergence of a professional organisation for disability workers in NSW is an exciting development. Disability Professionals NSW was established in 2006 with a goal of promoting professional development within the disability sector through the provision of opportunities for recognition, learning and connection (Disability Professionals NSW, 2007b). A sister organisation, Disability Professionals Victoria, has been in existence for a number of years, and a parent company called Disability Professionals Australasia was incorporated in 2010. It is hoped that the professionalisation of the disability sector will be achieved through organisations such as Disability Professionals Australasia, with disability services having a more reliable, consistent and better trained workforce to address issues such as ageing and disability.

5.6.2 Funding

As has been discussed previously in section *5.2.1 Funding*, the theme of appropriate funding of service models and staffing is an important issue for disability organisations. The participants identified a number of generic issues within Question Five that could pertain to any disability service in either metropolitan or rural regions of New South Wales (NSW). These items included *"Care needs are constantly increasing, whilst funding is not"*, *"Financial viability"* and *"Funding for new equipment/home modifications"*. However, there were also some specific issues that do impact particularly upon rural disability support providers, and the participants recognised the following items as being important: *"Inflexibility in funding models and structures"*, *"Appropriate funding models for smaller services without large numbers of ageing clients"* and *"Cost in accessing services (travel costs and staffing costs)"*.

Within rural areas of NSW, the number of disability and ageing services is often very limited. The lack of other providers often results in disability organisations having to provide a majority of services without the opportunity to seek expert assistance or guidance from other support agencies. This problem manifests itself through the economies of scale that can be achieved within larger or metropolitan based services. A small rural organisation may have a limited total number of clients. They cannot always effectively or efficiently co-service a number of ageing clients together, as they may only have one person who is experiencing ageing issues at that point in time.

Similarly, if they are the only disability provider in the area, the organisation is not able to collaboratively work with other agencies who may find themselves in a similar situation. While there may often be an aged care facility of some form in the local community, the major problems associated with ageing and disability funding being split between different departments and different levels of both state and Australian government makes collaborations between disability and ageing providers on shared clients extremely difficult to coordinate.

It is worth noting that some providers believed the level of collaboration between separate disability organisations has decreased substantially in the past ten years. Previously, rural disability services would work together to achieve the best possible outcomes for the clients, even if that meant transferring the funding to a different organisation (Michael Barry, pers. comm., 8 February, 2010). However, with the introduction of competitive tendering by government (e.g. Department of Ageing, Disability and Home Care, 2009h), all disability organisations have been placed in a position where they are forced to compete for limited funding with their neighbour organisations. The introduction of competitive tendering was seen by some providers as a major deterrent to collaboration and the main impediment to the establishment of any joint programs (Michael Barry, pers. comm., 8 February, 2010).

The funding models provided by government do not seem to take into account these discrepancies, with rural services expected to carry the additional costs associated with servicing one person in isolation. There is no flexibility within the government funding structures to account for this issue. Rural and remote providers remain at a significant disadvantage in comparison to their city based counterparts who are able to either work collaboratively with similar organisations in their vicinity or have sufficient client numbers to be able to provide an efficient independent ageing service model.

Rurally based disability organisations also face considerable costs and expenses associated with their location. A large proportion of training and education sessions are held in Sydney, Newcastle or a handful of larger regional centres. An example of this problem can be seen with the locations for the Department of Ageing, Disability and Home Care's (DADHC) "Unit Costing Tool Training" held in March 2009. There were four sessions scheduled outside the main cities of Sydney, Newcastle, Wollongong and Gosford, with these sessions held at Port Macquarie, Wagga Wagga, Grafton and Orange (Department of Ageing, Disability and Home Care, 2009d). Services not located in these regional centres sometimes needed to travel very substantial distances if they wanted to receive the training. Government does usually attempt to repeat sessions and spread the training locations around the state, however, it is simply not logistically or economically possible to provide enough opportunities so that no rural service provider has to travel.

Whilst there appears to be understanding by service providers that training and information sessions cannot be held in every small town across the state, there does not appear to be an equal willingness by the State Government to recognise that many rurally based providers have increased expenses in travel costs and time merely to attend. Many organisations have policies that reflect the WorkCoverNSW (1997) recommendations for managing work related fatigue and, as such, overnight accommodation is also required to attend one day training sessions that involve more than two hours driving to reach the location. Government will occasionally provide some travel cost reimbursement to rural providers, however, this protocol appears to be more the exception than the rule.

The travel cost issue is also problematic in relation to client health and the accessing of specialist medical services. In rural areas, travel to either a larger regional centre or metropolitan area is normally required if a patient needs specialist assessment, intervention or treatment. There are only a minority of medical specialists who situate themselves outside of a few larger regional centres. This situation results in the disability organisation incurring considerable costs associated with the travel, as well as the staff expenses to support the person to access the medical specialist. Examples of this problem can be seen with people in

Armidale having to travel to Coffs Harbour, or people in Cobar travelling to Dubbo for certain specialist treatments. These trips take approximately three hours by car, so a one hour appointment requires a minimum seven hour shift to be rostered. If the medical appointment is scheduled early in the morning, the travel usually has to occur the previous night, and therefore more costs are incurred with overnight accommodation.

Some services have attempted to overcome this problem by bringing the specialist to their own town, rather than travelling away to see the specialist. As an example of this approach, the Chief Executive Officer of a rural disability service provider reported that they use the services of a Newcastle based psychiatrist who specialises in dual diagnosis and intellectual disability issues. This psychiatrist is flown to northern New South Wales on a six monthly basis, sees a full day's listing of clients from various disability organisations across the region, and then flies back to Newcastle. The organisations in that region do not receive any support from DADHC for this program, but the organisation found that it was less disruptive to the individual and significantly more cost effective to bring a psychiatrist to the region rather than take each individual to Newcastle (Kevin Mead, pers. comm., 28 July 2009). Nonetheless, it is still considerably more expensive than for equivalent metropolitan service providers who can access specialist services in their immediate vicinity. It is also only possible to implement this system if a sufficiently large client base is co-located. It is simply not viable, either economically or time-wise, to fly in specialists to see just a couple of patients.

5.6.3 Access to Services

The generic problems associated with access to services for ageing people with intellectual disabilities has been discussed in section *5.2.3 Access to Services*. However, the participants did identify a number of additional access issues that presented specific difficulties for rural disability organisations. These issues included *"Aged cut-off for ACAT prevents people with disabilities accessing services"*, *"Lack of mainstream services available to people with disabilities"*, *"Lack of specialist services such as respite and day programs"*, *"No dedicated aged care facility for people with* *intellectual disabilities", "Availability of complementary services to our own", "Competition with the community's focus upon the increasing needs of the generic aging population", "Lack of public transport", "Distance to nearest appropriate services"* and *"Overcrowding in the limited space available and lack of personal space".*

The rural regions, and particularly smaller country towns, do not have the same range of community and health services as metropolitan areas. This lack of access to support services manifests itself in many ways, with disability support organisations often left to try and fill the void. As a consequence of the small population base, there is usually only a small number of ageing people with an intellectual disability within rural areas. It is not economically viable to have specialist agencies in every town with only a limited number of clients; however, the distance between many towns and their nearest region centre can be hundreds of kilometres.

While services may be nominally available across New South Wales, if access to them requires three hours of travel in each direction, realistically they cannot be considered convenient or able to be used effectively or regularly. To compound the problem, public transport is not readily accessible in many country areas, either within the actual towns or between them. Rail and bus services are restricted, and travel by air prohibitively expensive in the event that it is available. The solution to the problem of isolation is often to either use generic services, in which a person with an intellectual disability is inappropriately placed into a mainstream aged care facility that may have no understanding or knowledge of disability issues, or alternatively for the disability service to continue supporting the person to the best of their ability. However, there are not always places available within mainstream aged care facilities, and attempting to maintain the person's placement at home can have impacts upon both fellow residents and staff as no additional funding from government is readily available to support the increasing needs.

The lack of support programs becomes even more frustrating when access to the few available services in country areas may be stymied by the bureaucratic strictures of government. Whilst the Aged Care Assessment Team (ACAT) guidelines do not specify a minimum age for eligibility (Department of Health and Ageing, 2006a), service providers report that it is difficult to get someone under the age of sixty-five prioritised for an initial assessment (Dowse, McDermott & Watson, 2009). The approach does not appear to be standardised across the state, however, with some regions appearing to apply a different interpretation of the guidelines (Nicola Chirlian, pers. comm., 31 August 2009).

An anomaly has been established recently with the development of specific programs by DADHC for younger people with disabilities who are either currently in, or at risk of entry into, residential aged care facilities. These programs are currently focussed upon people aged under fifty (Department of Ageing, Disability and Home Care, 2008b). The separation of those people over sixty-five years who can more easily access Federally funded ACAT support, and those people under fifty years who are eligible for NSW Government funded programs, leaves a large group of people with disabilities between the ages of fifty and sixty-four who seem to be unable to readily access any ageing services.

5.7 Discussion of Question Six Issues

Participants from the Delphi Panel individually proposed a total of twenty-six different issues for the question *"What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?"*. The participants achieved a group consensus position, both in terms of fact that all twenty six issues were considered to be important and also with respect to their priority relative to each other. The training of disability support staff was previously discussed in section *2.6.1 Training for Disability Support Staff*. While a number of the items and themes raised by the participants have been discussed in the previous sections of this Chapter, Question Six did identify several unique issues which are discussed in greater detail in the following sections.

5.7.1 Quality of Life

The first theme related to Quality of Life (see section *4.2.6 Issues Identified for Question Six)*. The participants identified a number of specific training issues that pertained to improving the quality of daily life for the ageing individual with an intellectual disability. These included *"Person centred planning"*, and *"Quality of life management"*. The concept of Quality of Life (QoL) and its relationship to people with intellectual disabilities has been detailed in section *2.5.2 Quality of Life for People with an Intellectual Disability*. Providing individuals with a good quality of life is an integral component of all disability service provision. Ensuring quality of life for people with disabilities is written into the Principles and Applications associated with the 1993 *NSW Disability Services Act* (Department of Ageing, Disability and Home Care, 2008c). However, maintaining people's quality of life as they start to age and lose some of their skills presents a number of problems for both disability services and their staff. One particular issue relates to the distinction between the provision of services focussed upon meeting emerging health care requirements and those that continue to address the individual's social needs.

The introduction of QoL principles within the past decade has resulted in intellectual disability services moving away from the historic provision of health based programs towards the philosophy of social integration and inclusion. The provision of health care support is part of the larger goal of obtaining a high quality of life, rather than being considered the main priority itself (De Waele et al, 2005). As a person ages, it is not unexpected for her/him to experience an increase in personal care needs and a decrease in some abilities. In such situations, there needs to be a focus on meeting these emerging health and safety issues. However, there also must be a balance to ensure that the meeting of these new care needs does not come at the expense of QoL programs. Ageing of people with intellectual disabilities can see a reversion to a health-care dominated medical model of support, rather than maintaining the existing system of quality of life.

One of the most important aspects of maintaining the quality of life for ageing people with disabilities is providing appropriate and relevant choices (Treece et al, 1999). The current predominant philosophy within intellectual disability services is one of individual empowerment, with a focus upon enhancing and expanding the person's involvement in making real decisions about his/her own life (Reinders, 2008). Meaningful choices is an inherent aspect of Person Centred Planning (PCP), which was detailed in section *2.5.3 Person Centred Planning*. PCP is a process designed to support the family and disability support organisations to ensure that the individual receives a service that is focussed on him/her, rather than just medical and health requirements. As noted by De Waele et al (2005, p. 238), "quality of care on its own, however, is absolutely not a guarantee for quality of life". Unless the individual is supported appropriately to maximise her/his potential, overall quality of life cannot be considered to be optimal.

PCP, which provides a framework for ensuring that all activities and goals are based around the individual needs of the person (O'Brien & O'Brien, 1998), is one avenue that can assist both disability providers and staff in reaching the right balance between quality of life activities and health needs programs. Achieving the correct balance of essential new health care services and maintaining existing personal programs will assist in maximising the quality of life of someone who is ageing with an intellectual disability. The study's participants' recognition that additional education was required in quality of life and PCP issues is important, as this training would assist staff in the appropriate delivery of support to the target group.

5.7.2 Medical Issues

A well identified trend associated with ageing is an increase in medical and health related issues (see section *2.4.1.1 Health Issues)*. This theme has been identified a number of occasions during the study, and again specifically in Question Six (see section *4.2.6 Issues Identified for Question Six).* A number of the main medical issues associated with ageing and intellectual disability were detailed in section *2.4.1.1 Health Issues in Ageing with an Intellectual Disability*. The participants identified the need for greater training and knowledge of health problems including generic *"Medical management"*, *"Understanding medication and its effects"* and *"Understanding* *of health issues"*, as well as more specifically focussed learning and information programs concerning *"Dementia"* and *"Diabetes"*.

The majority of the medical issues identified by the participants as requiring further knowledge relate to generic training needs. None of the items appear to pertain specifically to issues associated with intellectual disability. While it is clear from the participants that a greater understanding of medical issues is required amongst disability support staff, it is not apparent that specialised disability training is necessary for all the identified items. Access to community based training courses which are held across rural NSW is one avenue through which disability workers can gain a greater understanding of health issues such as dementia and diabetes (e.g. Alzheimer's Australia, 2009; Diabetes NSW, 2009). However, the issue of understanding the effect of certain medications cannot be as simply addressed.

Training staff to better understand the role that medication plays in treating various ageing-related symptoms must be provided by an appropriately experienced and qualified practitioner. In rural areas, accessing such expertise is not always easy. There would appear to be a couple of solutions to this problem. In smaller towns, the local pharmacist or chemist, either in private practice or at the hospital, may be able to provide generic information sessions to staff on the use and impact of some common medications. Likewise, a local general practitioner or representative from the regional Division of General Practice may be similarly able to train disability workers in small groups.

One aspect of medication that requires more consideration is the role that direct care staff play in its administration. A key unit within the Certificate III and IV in Disability is the Administration of Medication; however, the participants' recognition of the need for training in the actual effects of the medication, rather than simply its administration, is an important one. A link between the provision of medication and staffing levels has been established in some studies (Carlisle, 1997). It has also been found that the attitudes of staff to the people they support, as well as the residence's day to day work practices, are more closely aligned to the level of medication given to ageing people than any actual symptoms of dementia (Wills et al, 1997). Historically, medication has been administered inappropriately in some settings purely as a mechanism for control of difficult individuals (Chenoweth, 1995) and it is deemed an illegal practice (Department of Ageing, Disability and Home Care, 2009i). Appropriate training is very important amongst disability staff to ensure that the use of inappropriate chemical restraint, accidentally or otherwise, does not occur within the ageing cohort.

5.7.3 Personal Care Issues

The theme of personal care was identified as a key issue for participants in section *4.2.6 Issues Identified for Question Six.* As a person with an intellectual disability ages, it is likely that she/he will experience a decline in physical abilities (Beange, McElduff & Baker, 1995). These issues have been discussed previously in section *2.4.1.1 Health Issues.* The decline in physical capacity results in a need for greater Occupational Health and Safety (OH & S) knowledge and specialist training in the use of new equipment. The participants recognised the importance of these issues with the items *"OH & S and Manual Handling Training (how to provide appropriate physical support)"*, *"Personal care needs"*, *"Dietetics (meal preparation, tube feeding etc)"* and *"Specialist equipment usage"*. OH & S for workers within the disability sector is an issue that is currently receiving attention at State Government level.

A project aimed specifically at increasing organisational awareness of safety issues and ensuring workplace health for workers has recently commenced across New South Wales (National Disability Services, 2009b). This program has grown out of a prior collaboration between representatives of WorkCoverNSW, the Department of Ageing, Disability and Home Care (DADHC) and National Disability Services (NDS) in 2005. This working party was established to examine the various legislative requirements that disability services operated under and, in particular, the discrepancies that existed between OH & S laws and the 1993 *Disability Services Act*. This first project found particular need for resources in areas such as manual handling (National Disability Services, 2007a). The fact that this project is only just being rolled out may explain why the participants still identified OH & S, and in particular manual handling, as priority areas for staff training.

Another issue that impacts upon staff is the need to learn how to implement new protocols and operate new equipment as they support ageing people with intellectual disabilities. As the individual's physical capacity decreases over time, new technologies and support systems are required to maintain quality of life and overall health. Studies have shown that the implementation of specialist equipment and assistive technologies can significantly improve the day to day functioning of a person, facilitating independence and the ability to continue to access his/her local community (Hammel, Lai & Hellers, 2002). As an individual's mobility decreases, equipment to assist with manual handling, such as hoists and slings, are often necessary to prevent worker injury (Jung, 2004).

There are also manual handling risks and associated preventative equipment utilised in assisting people to transfer from beds to wheelchairs, or supporting them with personal care issues, such as showering, toileting and dressing. The process of implementing new technologies to address these issues can result in major changes to how services operate, and extensive training is required to support the staff in these new processes. Particularly in rural areas, there may need to be a large number of operational changes for a very limited number of clients.

It is not only new equipment that requires additional training, but also new systems. People with an intellectual disability may have been completely independent with their eating and diet; however, as they age they may start to experience dysphagia or specific dietary problems (Barr et al, 1999; Evenhuis et al, 2001). Staff are often required to seek out information on and then implement new dietary plans and also may be required to assist with tube feeding or other similar specialist equipment. The need to provide staff with both adequate resources and knowledge is essential if these new systems and methodologies are to effectively support the person to remain independent and to age successfully.

5.7.4 Counselling Support

The problems associated with mental health were nominated previously as a key issue during the research (see section *4.2.2 Issues Identified for Question Two),* and were again specifically identified as a theme in section *4.2.6 Issues Identified for Question Six.* Studies have shown that counselling support can be beneficial for both parents and their children with an intellectual disability (Davis & Rushton, 1991). As people start to age, there is an increase in the incidence of major mental and psychotic disorders (Thorpe, Davidson & Janicki, 2001). With considerable demand upon the limited number of qualified mental health workers within rural areas (Parliament of New South Wales, 2003), the direct support staff in disability organisations often find themselves acting in the position of an 'accidental counsellor'. They are often required to provide emotional support not just to the person who is ageing but also to the other residents and even the wider family. The participants identified two primary training needs associated with counselling support in *"Understanding of emotional issues"* and *"Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend".*

Studies have shown that across Australia there is a lack of information, knowledge and confidence in providing mental health support (Jorm et al, 2005). There is very limited training received by disability staff in areas such as mental health or the provision of basic counselling support to a client. It is not a compulsory unit within either the Certificate III or IV in Disability Work (National Training Information Service, 2009b; TAFE NSW, 2009). It is not a desirable outcome to have untrained and inexperienced employees attempt to provide specialist counselling support to people experiencing mental health issues such as depression. However, there is also a need for direct care disability staff to gain a greater understanding of both mental health and emotional issues, particularly if they are supporting people who are ageing.

One possible solution that has been proposed incorporates aspects of 'accidental counsellor' training into optional units such as *CHCCS9A: Provide support services to clients*. Some counselling courses have been mapped already to this unit (Centre for

Community Welfare Training, 2009). A training unit, in which a basic understanding of counselling was incorporated, would provide staff with guidelines and a framework to establish clear boundaries for their interactions with clients and other stakeholders who may be exhibiting signs of mental health distress. A recognition and understanding of the mental health issues is vital if staff are to correctly identify and discriminate between new mental health problems, factors directly associated with the ageing process, or issues around the existing intellectual disability. A relatively recent training course that has become widely available across New South Wales is Mental Health First Aid. This twelve hour short duration program has been developed to specifically train front-line workers to successfully identify and provide early intervention in the community based support of people with mental illnesses (Mental Health First Aid, 2007).

The Mental Health First Aid course was found to be beneficial for staff, providing them with an increased understanding of mental health problems, as well as improved levels of confidence in the provision of appropriate assistance to people with a mental health issue (Kitchener & Jorm, 2002, 2004; Sartore et al, 2008). Some disability services have implemented this training for a proportion of their staff (Julie Derley, pers. comm., 1 September 2008; Tina Purdon, pers. comm., 3 November 2008); however, priority has generally been given to those staff working with people with an already identified dual diagnosis. Widespread participation in this training may be one simple method through which all staff can gain a greater confidence and knowledge base to assist them to support their client group more effectively.

5.7.5 Generic Training Issues

There were a number of issues identified that fitted largely into the theme of Generic Training Issues (see section *4.2.6 Issues Identified for Question Six*). It was considered that a number of these training needs could be successfully addressed through the existing aged and disability training framework. These issues included *"Behaviour management"*, *"Understanding of the ageing process and stages that people move through"*, *"Alternative communication methods"*, *"Understanding of different* *support needs at different stages of ageing"*, and *"Generic aged care courses for disability service providers"*.

It is perhaps strange that a large number of generic ageing or disability training issues were considered by the participants to be important. The majority of these training issues should have been addressed within the framework of the Certificate III or IV in Disability, or Certificate III or IV in Aged Care. As 96.8 percent of the participants had completed relevant post-school qualifications such as a Certificate III or greater (see section *4.1 Demographic Characteristics of Study Participants*), it is reasonable to expect that the participants would have a good understanding of what information and knowledge is imparted in these training sessions. It is not clear with many of these items whether the participants were reporting the gaps in the existing accredited training framework, or actually highlighting the aspects of the courses that were particularly valuable for new workers to the field. This confusion is an area that would benefit from additional research and consideration, particularly in light of the recent release of the updated CHC08 Community Services Training Package.

A trend in recent years within the Vocational Education and Training Sector has been the use of 'skill sets' to supplement existing training (Department of Education, Employment and Workplace Relations, 2009b). The *National Quality Council Training Package Development Handbook* defines skill sets as either singular training units, or logical clusters of training units, which are specified as a mechanism to address an identified industry need without composing an entire qualification by themselves (Department of Education, Employment and Workplace Relations, 2007). Within the disability sector, the applicable skill set within the new CHC08 Community Services Training Package to address the ageing issues would be *Disability work skill set – people with a disability who are older*. This skill set is composed of five units:

- CHCAC412A: Provide services to older people with complex needs,
- CHCAC416A: Facilitate support responsive to the specific nature of dementia,

- CHCAC417A: Implement interventions with older people at risk of falls,
- CHCCS426A: Provide support and care relating to loss and grief, and
- CHCDIS313A: Support people with disabilities who are ageing.
  (Community Services and Health Industry Skills Council, 2008a)

This skill set would appear to successfully address a number of the generic training needs identified by the participants. However, it appears that there is still concern about not receiving a 'full' qualification. There is a perception that, as skill sets do not provide the employee with a new Certificate III or IV, it is somehow of a lesser value and, as such, staff are less enthusiastic to participate in this type of accredited training (Martin Kingstone, pers. comm., 15 July 2008). This problem has been recognised by the wider sector, with the Community Services and Health Industry Training Council commencing a state-wide project in 2009 to communicate and promote the use of skills sets. The goal of this project is to develop information packages that will explain the roles and legitimacy of skill sets within the training sector (Community Services and Health Industry Skills Council, 2009).

The participants also identified a number of training needs that, while they impacted upon ageing and disability factors, were not specific to these issues. As previously discussed in this section, it is not clear whether the participants were reporting that the training they had received was lacking in these areas, or if they were vital skills that all new disability workers should have. The identified items included *"Training in observation skills so that changes in client health can be detected early"*, *"Attitude training (patience, empathy, consistency, ethics)"*, *"How to transition people between services effectively"*, *"Comprehensive and accurate record keeping to assess changes over time"* and *"Time management"*. The last item, time management, is a common training request in many areas of employment; however, its particular significance for disability workers in light of the increasing paperwork requirements was discussed in section *5.4.1 Time Constraints*.

Staff skill and knowledge in areas such as observation and record keeping are vital if services are to accurately track and evaluate the progression of ageing-related issues. The ability of disability organisations to successfully plan for the future needs of their clients is often dependent upon the direct care staff ability to successfully observe changes and to distinguish between existing disability related issues and emerging ageing problems. An example of this problem was demonstrated in 2006 in the evaluation of the *Aged Care Innovative Pool Disability Aged Care Interface Pilot* (Australian Institute of Health and Welfare, 2006). The South Australian based disability service provider, MINDA, developed a specific tool called the Broad-Screen Checklist of Observed Changes (BSCOC) to measure the clinical changes in a person with a disability as they age. The BSCOC assesses the individual's medical, physical, psychological and social skills, providing a benchmark against which future changes can be considered. The BSCOC has been recognised by NSW Health as an accepted tool for Aged Care Assessment Teams (ACAT) to use as part of their evaluation of client needs (NSW Health, 2007).

Four of the pilot ageing and intellectual disability programs evaluated in 2006 used the BSCOC, however, the report noted concerns that the information gained by using this tool was dependent upon the observation skills of carers, and that there was also low inter-rater reliability demonstrated by inconsistent scoring between staff and services (Australian Institute of Health and Welfare, 2006). If tools such as the BSCOC are to be used as part of the ACAT process, there needs to be appropriate training for all staff in observation skills and record keeping in order to help ensure that the information collected is both current and accurate.

The challenge of transitioning people between services primarily occurs when the ageing issues of the individual means that the disability organisation can no longer effectively or safely continue to support her/him. In rural and remote areas of New South Wales, there are rarely specialist or alternative services that support ageing people with intellectual disabilities. If the disability organisation is no longer able to provide the appropriate level of support, the normal option is to try and access generic aged care services. However, even if the individual is classified as eligible by the ACAT, and if there is a suitable residential aged care facility in the town, there is still a recognised shortage of aged care placements (Parliament of

Australia, 2007). Therefore, there is no guarantee of an available bed in the individual's local community, even if the person is deemed eligible by the ACAT. This situation means that ageing people with intellectual disabilities may be relocated to the nearest available bed, which in rural areas may be in another town a considerable distance away from their friends and family.

Managing this process can be extremely difficult for staff of both the disability service and also the residential aged care facility. Staff at a rural disability service described a situation in which an ageing lady with Down Syndrome and increasingly serious health issues was moved to a residential aged care facility approximately one hundred kms away from the town where she had lived for over sixty years. She was isolated from her friends and family and could not understand why she was not able to return to her home. The staff reported considerable distress was experienced not just by the individual and her friends, but also by all the staff involved (Julie Derley, pers. comm., 9 June 2009).

There are a limited number of training programs designed specifically to address the issues of transition of clients between disability and ageing services. Rather than trying to develop such a course, it would appear more effective for the ageing and disability providers in rural towns to proactively work together in order to plan for future transitions. This type of collaboration would assist both organisations to prepare for the process of transitioning a person from one service to another. It would also allow staff to be involved in planning how the individual with the disability and friends can keep in contact in order to minimise the distress experienced following separation.

The concept of attitude, values and ethics training within disability work is important, but it can be hard for both services and staff to accurately quantify. Shaddock, Hill and van Limbeek (1998) noted a linkage between personal value systems and the rate of 'burn out' in disability workers; however, there is not a significant amount of research or information about the relationship between ethical decision making and factors that affect the personal values of staff in the community services or social work sectors (Doyle, Miller & Mizra, 2009). The lack of clearly defined ethical guidelines for the disability workforce has been recognised within the sector in recent years and, in response to this problem, the Australian Society for the Study of Intellectual Disability (ASSID) developed a Code of Ethics for direct support workers.

This Code of Ethics was subject to national consultation and workshop reviews prior to its launch, and it received support from organisations such as Disability Professionals Victoria (Disability Professionals Victoria, 2007). The Code of Ethics is composed of twelve principles designed to underpin professional conduct. It was specifically written in a manner that would make it easily usable within accredited training courses such as the Certificate III and IV in Disability Work (Australasian Society for the Study of Intellectual Disability, 2007). The chairman of Disability Professionals New South Wales indicated that this Code of Ethics has not yet been widely distributed or incorporated into accredited training options in NSW (Kevin Mead, pers. comm., 13 August 2008). It is therefore not surprising that the participants identified ethics as an issue of concern. The Code is voluntary, but its adoption into both accredited training and workplace inductions is perceived as one simple mechanism through which some of the concerns of the participants regarding attitudes and ethics can be successfully addressed.

5.8 Conclusion

The purpose of the current study was to identify the key issues facing the disability services direct care staff with respect to the ageing needs of their clients. This was achieved through a Delphi study of employees from across rural and regional New South Wales. Chapter Five began with a comparison of the demographics of the current study's participants to the disability workforce statistics attained from other sources. On the basis of the limited information available, it was considered that the study's participants were appropriately representative of the wider sector.

This section was followed with a discussion of the results and new knowledges obtained through the research for each of the six questions. A particular focus was upon the rural and remote issues that face people with intellectual disabilities, their family and friends, and also the disability organisations and staff that support them. The key issues and themes that were discussed included such disparate concepts as access to, and the suitability of, the current funding models; the training needs of both internal staff and the wider support networks for people with disabilities; access to appropriate and relevant ageing services; physical, mental and psychological health issues; parental and family concerns; and work restraints. The following chapter presents a series of recommendations based upon these new knowledge areas and provides an overall summary to the current project.

Chapter Six - Recommendations and Summary

Introduction

Chapter Six reviews the information and new knowledge identified in the previous chapters. It begins with a discussion of priority areas in relation to the ageing care needs for people with intellectual disabilities. These key issues, developed from the findings of the Delphi Panel as detailed in Chapters Four and Five, underpin the proposal of a series of recommendations for both training and practice changes for the rural disability sector. Suggestions for further research that would enhance and expand the findings of the current study are presented. The chapter concludes with an overall summary of the project.

6.1 Discussion of Training Priorities

6.1.1 Accredited Disability and Aged Care Training

Unlike other Community Services areas, such as Child Care or Aged Care, there is no sector-wide expectation of a minimum qualification for a person to be employed by a disability organisation. There is currently a considerable push from associations and peak bodies, such as Disability Professionals New South Wales (DPNSW) and National Disability Services (NDS), to require all direct care workers to obtain and maintain currency with *CHC30408 - Certificate III in Disability*. There is an opportunity to then progress to completion of *CHC40308 - Certificate IV in Disability*. These two courses from the new *CHC08 Community Services Training Package* replace the older qualifications *CHC30302 - Certificate III in Disability Work* and *CHC40302 - Certificate IV in Disability Work* from the previous *CHC02 Community Services Training Package*. However, there remains no necessity for workers to have such a qualification to work within a disability service. Appropriate qualification of all staff is highly regarded within the Department of Ageing, Disability and Home Care's (DADHC) Integrated Monitoring Framework, but it has never been compulsory.

It is possible to achieve widespread acceptance of mandatory accredited training in the Community Services sector with Child Care being a prime example. To underline this point, the demographic information showed that over 95 percent of the direct care participants in the current study had obtained a relevant post-school qualification in the area of disability work. As an essential component of professionalising the disability sector, it would appear vital for all service providers to collaborate to formally establish the Certificate III in Disability as the minimum education entry point for disability workers. It is accepted that not all potential employees will have this qualification when applying for a position, particularly within rural areas. The industry expectation should be for all employees to be enrolled in such training within three months of commencing work.

The concept of adopting a minimum training requirement, however, requires the disability services to recognise its value to them, both in terms of improved daily support to the people they assist and to the overall professionalisation of the sector. It is considered highly appropriate and necessary for the primary disability services funding body, DADHC, to work closely with DPNSW and NDS in order to establish a clear process and defined time-line for the introduction of mandatory qualifications for working within the sector. Accessing such training in rural and remote areas can be difficult, and there would also be a considerable cost impact upon the disability service. The use of school based traineeships and the Australian Apprenticeship system is one mechanism through which both access to, and the costs associated with, providing training to workers can be mitigated. The qualifications of Certificate III and IV in Disability are both included in the approved apprenticeship list (Department of Education and Training, 2010). This avenue enables disability organisations to gain free assistance through Australian Apprentice Centres to support them in applying for and receiving incentive assistance funding in training their staff (Commonwealth of Australia, 2007).

It must be acknowledged, however, that even if all workers within the disability sector have a current Certificate III in Disability, there is still no guarantee that they will possess any knowledge or expertise in areas surrounding ageing. The structure of the Certificate III and IV Disability courses within both the old CHC02 and the new CHC08 Community Services Training Package means that an individual could easily complete a qualification without undertaking any units that address the issues of ageing and disability. These units remain as elective modules, and they are only included at the discretion of the disability service provider and the Registered Training Organisation.

The use of skill sets, and in this particular situation, the disability work skill set *People with a disability who are older*, would appear the most appropriate solution to the issue of staff having completed accredited training but not ageing-specific accredited training. While ageing is an important issue for the overall disability sector, it is not applicable to every person with an intellectual disability. As such, not all staff will necessarily require ageing specific training, depending upon the range of individuals they support. However, it is important that disability services have at least some staff with experience and knowledge of ageing, as this issue will impact upon most organisations over the next decade. It would be appropriate for government to examine funding the provision of the disability work skill set *People with a disability who are older* as a proactive approach towards addressing the emerging problem. This training could be allocated on a pro-rata basis for all disability services in New South Wales to ensure that each organisation has a number of staff with the appropriate ageing skill set. It would be important to ensure that the training is provided across a suitable variety of rural locations, along with travel and replacement staff cost reimbursements to be made available to recompense services that have to travel to participate.

The present project identified a number of training needs that could be classified as being generic to the wider disability sector because they did not specifically relate to the ageing problems associated with a person with an intellectual disability. These issues included time management, observation skills, personal attitudes and ethics, record management, behaviour management and alternative communication methods. It is not clear from the responses whether these training areas were considered particularly important to the participant, or if they were issues that had not been appropriately addressed through existing education models. An inspection of the Certificate III and Certificate IV in Disability qualifications in the new *CHC08 Community Services Training Package* indicates that the concerns of the study's participants should largely be addressed through the existing accredited training options. Generic training concepts, such as the maintenance of records and informed observations, are specified as performance criteria and required skills in the units *CHCDIS323A Contribute to skill development and maintenance* and *CHCDIS301A Work effectively with people with a disability* respectively.

The *CHC30408 Certificate III in Disability* qualification includes the mandatory unit *CHCICS305A Provide behaviour support in the context of individualised plans* which provides specific training for participants in behaviour management issues (Community Services and Health Industry Skills Council, 2008a, p. 745). The first key element of the core unit, *CHCDIS301A Work effectively with people with a disability,* is "Demonstrate an understanding of the delivery of quality services for people with disabilities" (Community Services and Health Industry Skills Council, 2008a, p. 523). Performance criteria 1.4 for this element is *"Take into account personal values and attitudes regarding disability when planning and undertaking work with people with disabilities"* (Community Services and Health Industry Skills Council, 2008a, p. 523). All staff who have completed a Certificate III in Disability should therefore have had some training in values and attitudes as well as behaviour management.

The second key element of the core unit, *CHCDIS301A Work effectively with people with a disability,* is "Communicate effectively with people with a disability" (Community Services and Health Industry Skills Council, 2008a, p. 523). This element specifically focuses on the identification of specific alternative and augmentative communication systems and devices. In addition, while the unit *CHCDIS411A Communicate using augmentative and alternative communication strategies* is not a compulsory one within the Certificate III in Disability, the packaging rules specifically recommend its inclusion in the overall qualification

(Community Services and Health Industry Skills Council, 2008a, p. 68). Participants in the Certificate III in Disability training must have undertaken at least one, and probably two units specifically looking at communication issues for people with disabilities.

There are two possibilities why the current study has identified priority training areas that should have been addressed by accredited training. Although over 95 percent of the participants had undertaken accredited training, it is possible that the results are a recognition that that their peers have not completed a Certificate III or IV in Disability. The most recent demographic studies of the disability workforce indicated that only about 30 to 50 percent of staff had completed relevant training (Lime Management Group, 2006), so the participants may be identifying training from which their fellow employees would benefit. The second possibility is that the training provided by Registered Training Organisations (RTO) in these priority areas is not sufficient or has failed to meet the needs of the participants. In either case, it is strongly recommended that disability organisations and RTOs carefully consider both the content of the units and the choice of electives within any accredited training that is provided to support workers. The identification of a number of priority areas such as time management, observation skills, personal attitudes and ethics, record management, behaviour management and alternative communication methods provides an excellent guideline about the areas of accredited training that require particular focus and emphasis.

6.1.2 Collaborative Training Opportunities

This project identified a number of training priorities that could be successfully addressed through collaborations between disability organisations and other services. One of the most obvious examples of working together could occur between the disability and ageing services that may be located within the same rural community. There is considerable potential for residential aged care facilities, Home and Community Care (HACC) services and disability organisations to jointly coordinate and share training costs on issues of mutual benefit.

These types of collaboration have not traditionally occurred between ageing and disability services, as the issue of ageing in the population of people with intellectual disability is a relatively recent phenomenon. There would appear to be little impediment to collaborations between ageing and disability services occurring quickly and easily. Nonetheless, it is possible that a coordinated state-wide approach to the issue between the relevant industry associations National Disability Services (NDS) and Aged Care Association Australia may assist to successfully bring together the various rural organisations. It would be possible for the two associations to develop a joint training agenda to address common educational needs as a means of initiating greater interaction between the two sectors.

The common training could be coordinated with state-wide organisations, such as the Epilepsy Association of NSW or Alzheimer's Australia, providing specialist and relevant training for both the ageing and disability organisations. These organisations will provide education programs in rural areas if sufficient need is demonstrated; however, finding the minimum number of participants in rural areas is not always easy for a single provider. By combining the personnel of ageing and disability services the training may become financially feasible. Additionally, once the connection has been made between the organisations within a similar location, it is then possible for them to independently build the relationship further if it is seen to be of mutual benefit. It may also be appropriate to explore the use of relevant technology, such as video-conferencing and on-line learning programs, to supplement face-to-face training.

The present project also identified the need for collaboration between the disability organisations and local specialists. In particular, there appears to be great potential for disability organisations to work closely with medical practitioners and allied health professionals to achieve better outcomes for people with intellectual disabilities. Cooperation between disability organisations and their local Division of General Practice would be one simple method to assist in overcoming the concerns expressed by participants regarding doctors either not understanding, or not being interested in, the issue of ageing and intellectual disability. An example of this type of collaboration has occurred between the New England Division of General Practice and the regional disability organisations. This Division of General Practice offers a program in intellectual disability to its members (New England Division of General Practice, 2009a) which was developed in conjunction with local service providers. While it is not possible to ensure that all medical practitioners are interested in the issue of intellectual disability, the provision of such training opportunities facilitates opportunities for those doctors who are willing to continue to learn.

Similar collaborations between disability providers and other health services such as the Hospital, Aged and Community Care Teams (ACAT), nursing staff, counsellors, therapists and social workers could also be valuable in breaking down the barriers between ageing and disability sectors. An artificial separation between ageing and disability services has been established by the various levels of government bureaucracy allocating funding through disparate departments. It would appear that this divide can be overcome, at least partially, by collaborations at a local level, and mutual training opportunities would appear an excellent way to assist this process.

There is also considerable potential for addressing some specialist training and knowledge areas by accessing local expertise from community resources, such as chemists or pharmacists. One area of concern raised by the participants surrounded medication use and its administration. A medical practitioner would be a suitable expert to provide education programs on these issues; however, if this option was not available for any reason, nurse practitioners or pharmacists at the local hospital or chemist would be other very suitable collaborative training partners.

6.1.3 Local Training Opportunities

One of the findings of the current study was that the physical ageing issues experienced by a person with an intellectual disability appear to mirror those of the mainstream community. As such, there would seem to be little need for specialist intellectual disability specific training in the area of physical health. Instead, the generic training that residential aged care facilities currently provide would be suitable. This could be an opportunity for training to be conducted in conjunction with local aged care providers. One method through which this training could occur would be the induction process. Under Occupational Health and Safety (OH & S) legislation, all companies across all sectors of business in New South Wales must provide their new staff with appropriate induction into the workplace to ensure their safety. These inductions sessions, usually held over a period of a few days, must include all essential aspects of the individual's expected work. Experienced disability workers may benefit from attending relevant sections of induction with a local aged care provider. This training could incorporate an introduction to generic aged care issues such as managing physical health and personal care needs.

Collaboration between aged care and disability providers through shared attendance at sections of induction could be of considerable mutual benefit. A reciprocal arrangement in which existing aged care staff attended disability inductions could provide valuable information and knowledge about intellectual disability issues for aged care employees. The ability of staff from both sectors to interact, exchange ideas and learn from each other can only be of benefit for ageing people with intellectual disabilities, irrespective of which service supports them or where they reside.

6.1.4 Specific Mental Health Training Opportunities

The participants identified a number of items that related to the emergence of mental health and cognitive functioning. These issues included depression, as well as memory loss and personality changes associated with dementia. Other issues included emotional problems such as grief following either the death of a close friend or family member, or concerns following the recognition of their own mortality. There is a level of difficulty for any staff member, no matter how experienced, in differentiating between what is a challenging behaviour that stems from the existing intellectual disability, and what is a new action that may be a response to an emerging ageing issue such as dementia or depression.

As a consequence of a lack of suitable mental health workers in rural areas, disability staff often fall into a role of the 'accidental counsellor', a very difficult situation in which an unqualified and inexperienced direct care worker can potentially cause more harm than good in the longer term. Traditionally, direct care staff have not received significant training in the fields of mental health, in spite of the high incidence of dual diagnosis within the cohort of people with intellectual disabilities. This lack of training presents a number of problems for staff in both appropriately identifying and contrasting the emerging mental health issues to the existing factors associated with the intellectual disability as well as then successfully supporting the individual with these issues. The close linkages between ageing factors and mental health issues such as depression, mean that a focus upon mental health training for disability staff is of vital importance.

This training can be achieved successfully in one of two ways. Firstly, it would be highly advantageous for all staff, both direct care and management, to participate in the Mental Health First Aid training that is currently offered across New South Wales. The course content includes detailed information about the symptoms, causes and treatments for relevant mental health issues such as depression, anxiety disorders and psychosis. Additionally, it provides practical guidance in how to deal with mental health crises and what actions to take to assist an individual. While it is not tailored to specifically cover ageing, the course does provide an introduction for direct care staff to many of the issues identified in the current study as presenting in ageing people with intellectual disabilities.

The second option for approaching the issue of mental health training occurs through the selection and modification of accredited units within the Certificate III and IV in Disability. As discussed in section *5.7.4 Counselling Support*, there have already been modified units developed that incorporate aspects of 'accidental counsellor' training. An example of this situation is demonstrated with the unit

CHCCS9A: Provide support services to clients. Some organisations have chosen to incorporate specific counselling support content into this unit (Centre for Community Welfare Training, 2009). Options such as this type of unit, in which an introductory understanding of counselling is established, would provide direct care staff with some guidelines and boundaries for supporting people who may be experiencing mental health issues. This training will also assist staff members to more easily differentiate between what are existing challenging behaviours associated with the intellectual disability and what are new mental health related problems.

It is important to recognise that this type of training should not be seen as a replacement for appropriate and qualified mental health professionals. However, in rural areas where there is a critical shortage of allied health workers such as psychologists and counsellors, the frontline disability workers could serve as a very useful adjunct to the established mental health framework. While the focus of this study is upon the issues associated with ageing and intellectual disability, basic mental health training as described above would be of benefit to the entire disability sector. The high incidence of dual diagnosis within people with intellectual disabilities, combined with the growing ageing dynamic of this cohort, means that some form of mental health knowledge would be advantageous to all employees in the sector.

There is also the secondary issue of providing counselling support to staff members following the death of a client. Disability support organisations need to ensure that they proactively implement an employee assistance program that provides for counselling support services for the staff. While it is naturally up to each organisation to determine how and what is offered under such a program, it is considered that an ongoing relationship with a local counsellor needs to be established prior to any crisis occurring. As an example of this approach, some disability organisations have scheduled annual sessions with a counsellor for all staff employed within group homes that have identified ageing clients. The purpose of these meetings is to prepare their staff for the inevitable loss of a client that will occur at some point in the future (Narelle Marshall, pers. comm., 7 June 2007). This system also means that there is an existing relationship between the staff members and the counsellor when the death does take place, which can assist in the counselling process.

6.1.5 Emerging Needs Training Opportunities

The current study identified a number of problem areas in regard to direct care staff ability to safely operate specialist equipment that are prescribed and implemented to meet the emerging needs of their clients. Examples of these problems include Occupational Health and Safety (OH & S) concerns with the implementation of new hoists and other manual handling assistive devices as people with intellectual disabilities lose some or all of their mobility. An introduction to, and ongoing scheduled updates on, the use of specialist equipment and health procedures, such as percutaneous endoscopic gastrostomies, or 'peg' feeding, to address medical problems would be appropriate for all staff.

As people with disabilities age, there is often an increase in their physical health needs and a reduction in their physical abilities. In order to support the individuals in a safe and effective manner, disability organisations have introduced specialist assistive equipment such as hoists, sliding sheets, pressure beds, showering chairs and lifting belts when a person is no longer capable of independent movement. While staff are generally provided with manual handling education sessions as part of their initial induction, regular updating of this training is required in order to ensure that all disability workers continue to be competent in using workplace technology.

There is also a need for ongoing specialist training in support procedures such as peg feeding. While there is a continuing discussion within the medical community upon the appropriate usage of peg feeding in people with dementia (Angus & Burakoff, 2003; Hoffer, 2006; Murphy & Lipman, 2003), it is a practice that is still occurring in disability services in New South Wales (NSW). This issue was identified as a specific area of concern in the item *Dietetics (meal preparation, tube* *feeding etc)*. As such, staff need to have training and knowledge to support people who require this type of intervention. In particular, the focus of the training needs to be in the actual workplace, with the specific equipment and procedures used on a daily basis.

Disability organisations must also ensure that all procedural and equipment usage sessions are provided by appropriately experienced trainers. There is a tendency within some organisations for training sessions to be conducted by the most convenient person, rather than the best qualified individual. This situation may result in a trainer who is not very familiar or highly experienced in using the specific equipment. It is recommended that specialist training in the correct and proper usage of manual handling equipment is provided by either the supplier or, if they are not qualified to do so, a physiotherapist or occupational therapist. Likewise, it is desirable for specialist medical procedures training to be provided by appropriately experienced registered nurses. It is acknowledged that access to such individuals is not always easy in rural areas; however, at least an annual refresher course for all staff should be achievable with careful advanced planning.

6.1.6 Quality of Life Training

The Panel identified the need for staff to have training in Quality of Life (QoL) programming and Person Centred Planning (PCP) as a means of correctly achieving a balance between the emerging aged care needs and the right to participate in and enjoy existing activities. Studies have shown that PCP helps people with disabilities to achieve higher quality of life across a variety of life domains (Robertson et al, 2005a).

The New South Wales (NSW) Department of Ageing, Disability and Home Care (DADHC) have recognised the need for PCP as an integral component of service delivery for people with intellectual disability. In January 2009, DADHC released an information package called *Exploring and Implementing Person Centred Approaches* (Department of Ageing, Disability and Home Care, 2009e). This booklet was distributed to all Community Participation providers across NSW in July 2009. The purpose of this release was "in recognition of the central importance of person centred planning" (Department of Ageing, Disability and Home Care, 2009e, p. 3). However, this booklet was not a comprehensive guide for the implementation of PCP within disability organisations. In fact, the package specifically states: "The guide is not a manual. It does not give step by step instructions" (Department of Ageing, Disability and Home Care, 2009e, p. 5).

The information package was not accompanied by comprehensive training and education programs to supplement and support the information contained within it. There was some training for Community Participation providers in 2009; however, these sessions were not extended to include other programs such as accommodation. The focus of the booklet was also predominantly upon younger people with intellectual disabilities and their transition from school to post-school life (Department of Ageing, Disability and Home Care, 2009e). While DADHC's recognition of the importance of PCP mirrors the findings of the current study, there remain a number of gaps surrounding the training and implementation of this service philosophy, both widely across the disability sector and specifically within the ageing cohort of people.

One of the main QoL training programs for disability support workers in NSW that has undergone external testing for its effectiveness and efficiency is the Active Support model that originated in the United Kingdom. The Active Support model focuses upon the interaction style between the individual with the intellectual disability and the support workers. The goal is to ensure that the support provided to each individual is designed and enacted around a philosophy of active participation and involvement in daily life. Trials of the Active Support training have shown that it is associated with significant increases in individual participation in both domestic and community based activities (Rhodes & Hamilton, 2006; Stancliffe et al, 2005). It was concluded that

> Active Support represents a highly cost-effective intervention because it yields better outcomes by using existing group-home staff more effectively (not by increasing staffing). If the capacity to deliver high quality Active Support training can be developed within individual agencies and the disability service system, then such training can be provided at a reasonable cost as part of ongoing staff training efforts. (Stancliffe et al, 2005, p. ix)

One of the advantages of the Active Support training model for rurally based disability organisations is that it is established around the premise of internal trainers conducting the sessions rather than external experts. The designated internal staff have to participate in two days of classroom based training; however, they then work with their fellow disability workers in the development of the Active Support system (Stancliffe et al, 2005). This approach means that rural disability organisations can effectively implement the Active Support model without the expense of either bringing an entire team of trainers to the organisation's hometown, or alternatively sending large numbers of staff away to attend training in the nearest capital city.

Another staff training program that is aimed at improving the quality of life of people with disabilities is the Marte Meo method. Developed by Dutch autism expert Maria Aarts in the 1970s, the name 'Marte Meo' is derived from Latin and means "On One's Own Strengths" (Aarts, 2008, p. 39). This model is based upon supporting disability workers through video analysis of their interactions with clients. As with the Active Support model, Marte Meo is designed to be overseen on an ongoing basis by in-house staff rather than through external trainers. Marte Meo has been the subject of studies around the world within different environments and for disparate target groups, including infant care, mental health, intellectual disability, youth detention facilities and dementia (Aarts, 2008).

The training model has been associated with a variety of positive outcomes, such as improved communication and personal interactions, and overall levels of engagement (e.g. Health Services Executive, 2008). It was first introduced into Australia in 2006 by John Lord (Aarts, 2008), a senior psychologist with the NSW Department of Ageing, Disability and Home Care (DADHC). The use of Marte Meo with people with intellectual disabilities has been the subject of an ongoing trial by DADHC within rural NSW since 2008 (Department of Ageing, Disability and Home Care, 2009j), with reported benefits including substantial reductions in behavioural incidents and increased participation in community events (John Lord, pers. comm., 12 April, 2010).

While there are other direct care training systems, the positive outcomes associated with the Active Support and Marte Meo models, combined with their suitability for rurally based disability services, would appear to successfully address the concerns raised in regard to achieving the necessary balance in the provision of individual support to ageing people with an intellectual disability. The cost effectiveness of these styles of training is of particular relevance to remote service provision. It is recommended that disability organisations, industry bodies and DADHC collaborate to ensure that all rural services have access to QoL and PCP training, with the Active Support and Marte Meo models being two possible cost effective solutions.

6.1.7 Family Support Training Opportunities

A 2004 study in Australia forecast that by 2031 more than 50 percent of all carers will be aged over sixty-five (National Centre for Social and Economic Modelling, 2004). While intellectual disability services are not directly responsible for this ageing carer group, the problems associated with transitioning individuals from their home to a supported residential setting following a family crisis means that any support provided to carers will only benefit the organisation and their staff in the longer term. In particular, proactively assisting ageing parents and the wider family to plan for the future of their adult child with an intellectual disability can reduce the stress and trauma associated with the eventual transition.

Groups such as Carers Australia have developed specific resources and provided forums across both metropolitan and rural areas to inform and educate carers on how to plan for the transition of a person with a disability into a supported residential facility. The resources developed by Carers Australia (2006) included a future planning checklist and an information pack about available services. The Australian Government has similarly released a resource package designed to inform carers about future planning issues (Department of Families, Housing, Community Services and Indigenous Affairs, 2007b). Also, the New South Wales (NSW) Office of the Public Guardian provides state-wide information sessions on legal issues relevant to people who are ageing or who have an intellectual disability (NSW Office of the Public Guardian, 2009). The NSW Department of Ageing, Disability and Home Care (DADHC) implemented a program called 'Support Co-ordination' in 2007, with one element being the development of future planning (Department of Ageing, Disability and Home Care, 2007c). However, the results of the current study indicate a perception that many parents and carers in rural areas are either still not aware of, unable to access, or are dissatisfied with, the future planning resources that are available.

It would be advantageous for disability organisations in rural areas to coordinate a visit from bodies such as Carers Australia or the Public Guardian in order to increase ageing carers' ability to plan successfully for the future and also enhance understanding of the legal issues associated with this planning. An approach to both state and commonwealth governments by relevant industry associations, such as National Disability Services (NDS), to obtain funding for these information and training sessions would be desirable as it would facilitate families to start future planning.

A relatively recent development for carers of people with a disability relates to the establishment of a Special Disability Trust by the Australian Commonwealth Government. Special disability trusts were first introduced in 2006 to assist families to put aside money with a goal of supporting either the current or future accommodation and care needs of a direct family member with a severe disability. The rationale for the establishment of these trusts was to prevent the family being adversely affected by the rules on means testing (Department of Families, Housing, Community Services and Indigenous Affairs, 2009c). However, while the Government has provided a model trust deed for people to use in establishment a Special Disability Trust, the Government then highly recommends that families gain advice and support from an appropriately qualified and experienced solicitor to prepare the necessary paperwork and documentation (Department of Families, Housing, Community Services and Indigenous Affairs, 2007a).

One strategy for disability organisations could be to coordinate an information session for carers on wills, trusts and other legal issues and to invite local solicitors to address the group. In rural and remote areas, training may need to be organised through partnership arrangements with other community services, such as ageing or mental health providers, in order to gain sufficient participants for the session to run effectively. This approach will assist both the families and the disability service to prepare and plan for the future needs of people with intellectual disabilities in the local community.

6.1.8 Medical Practitioner Training

The minimal amount of disability specific training for medical practitioners is a serious problem. It would appear difficult to include a significant amount of additional content around ageing and intellectual disability into the current schedule of medical training at an undergraduate level. The most suitable way of addressing this issue would seem to be through a coordinated approach between disability service organisations and their local Divisions of General Practice. For example, the New England Division of General Practice provides a program for doctors within the area specifically relating to issues of intellectual disability (New England Division of General Practice, 2009a). This program could easily be replicated with the support and cooperation of regional disability service providers and their relevant Division of General Practice. Disability organisations could also encourage the doctors who work with their clients to join the Australian Association of Developmental Disability Medicine, which is a network of medical practitioners who have a goal of improving the health outcomes for people with disabilities (Centre for Developmental Disability Health, 2009).

Studies, such as the one by Johnston and Dixon (2003), indicate that a substantial proportion of registered nurses have a negative attitude and minimal interest in issues of intellectual disability. A comprehensive re-evaluation and review of the content of the various universities' nursing curricula with respect to issues of intellectual disability may be of benefit in establishing priority teaching areas with respect to this area of nursing. There is a well established Professional Association of Nurses in Development Disability Areas (PANDDA) which was formed in the 1990s to aid and guide registered nurses who work within the field of intellectual and developmental disability (Professional Association of Nurses in Developmental Disability Areas, 2009). Disability organisations may be able to work in conjunction with PANDDA to highlight the important role that registered nurses play in the health care of people with intellectual disabilities.

6.2 Recommendations from the Study

A series of key recommendations for government, disability organisations and training entities have emerged from the findings of this Delphi study of disability direct care workers from across rural and remote New South Wales (NSW). It is worth noting that, while the inappropriateness of funding was clearly identified within the survey as a key priority for attention on a number of levels, this issue is already well recognised within the disability and wider community services sector. A recommendation for additional funding for ageing issues is an obvious one and certainly something that is very necessary. However, the other primary recommendations from this study instead focus on a series of actions that can be undertaken with minimal cost implications for any specific group and are not contingent on substantial future government funding decisions. The focus of these recommendations is upon interventions and models of support that can easily be implemented and replicated within rural and remote areas of NSW.

6.2.1 Key Recommendation 1 – Mandatory Minimum Qualifications

For the primary disability services funding body in New South Wales (NSW), the Department of Ageing, Disability and Home Care (DADHC), to work with National Disability Services (NDS) and Disability Professionals New South Wales in order to establish a clear process and defined time-line for the introduction of mandatory minimum qualifications for all people working within the disability sector. It is further recommended that this mandatory training requirement for staff members be incorporated in the Integrated Monitoring Framework audit of services conducted by DADHC.

6.2.2 Key Recommendation 2 – Appropriate Accredited Training Options

For disability organisations and Registered Training Organisations (RTO) to carefully consider both the content of the units and the choice of electives within the accredited training that is provided to support workers. In particular, a focus on the identified priority areas such as time management, observation skills, personal attitudes and ethics, record management, behaviour management and alternative communication methods would be highly appropriate.

6.2.3 Key Recommendation 3 – Funded Disability Work Skill Set

That the state and commonwealth governments fund the provision of the disability work skill set *People with a disability who are older* as a proactive approach towards addressing the emerging problem of proving appropriate support for ageing clients. A focus on the identified ageing specific areas within this training would be very appropriate. The Disability Skill Set training should be allocated on a pro-rata basis for all disability services to ensure that every organisation has a minimum number of staff with appropriate training. Travel and replacement staff cost reimbursements should also be provided to recompense services that have to travel to participate.

6.2.4 Key Recommendation 4 – Joint Training Agenda

That the two major peak bodies, NDS and the Aged Care Association Australia, develop a joint training agenda to address common educational needs as a means of initiating greater interaction between the two sectors.

6.2.5 Key Recommendation 5 – Better Networking

That disability organisations be proactive in establishing better networking models with local specialists such as medical practitioners, allied health professionals and pharmacists as a mechanism to raise awareness and understanding of the issues associated with people with an intellectual disability who are ageing. Such an approach could be coordinated through local Divisions of General Practice or other similar professional support associations.

6.2.6 Key Recommendation 6 – Greater Collaboration

That aged care and disability service providers who are located in close proximity collaborate with respect to shared attendance at relevant sessions of their respective induction processes.

6.2.7 Key Recommendation 7 – Mental Health First Aid

That all staff, both direct care and management, participate in the Mental Health First Aid training currently offered across NSW.

6.2.8 Key Recommendation 8 – Accidental Counsellor Training

That disability service providers and Registered Training Organisations work together on the development, selection and modification of accredited units within the Certificate III and IV in Disability to successfully incorporate ‘accidental counsellor’ training.

6.2.9 Key Recommendation 9 – Mandatory Annual Training

That all staff complete a mandatory annual update to their training to ensure competency in using workplace technology, including manual handling equipment and specialist medical equipment. This training should be conducted by an appropriately qualified individual who may need to be external to the organisation. Completion of this training by all staff should be an assessable item within the DADHC’s Integrated Monitoring Framework assessment process.

6.2.10 Key Recommendation 10 – Future Planning Workshops

That the relevant industry bodies and disability organisations make representations to state and commonwealth governments to obtain funding for groups such as Carers Australia to conduct workshops across NSW for families to assist them in their future planning.

6.2.11 Key Recommendation 11 – Quality of Life Training

That disability organisations, industry bodies and state and commonwealth governments collaborate to ensure that all rural services have access to Quality of Life (QoL) training such as the Active Support or Marte Meo models.

6.3 Implications for Future Research

The current study has provided new knowledge regarding the priority areas for training and support for disability workers who are assisting individuals who are ageing. However, there is a considerable amount of information regarding the training needs of ageing and disability support workers that remains to be appropriately investigated, and these areas require further follow-up research to properly clarify the problems. A number of suggestions for additional research areas are detailed below.

6.3.1 Large Scale Study of the Rural Disability Workforce

6.3.1.1 Demographics

One of the major problems identified in the current study relates to the lack of any comprehensive demographic data regarding disability workers within rural New South Wales (NSW). Issues such as age, gender, years of experience, areas of interest and expertise, and future intentions would all be valuable future studies of the training requirements of staff across the entire disability sector. The *Community Services Workforce Profiling Project*, as commissioned by the Community and Disability Services Ministers' Advisory Council, may address some of these issues, but it is unclear whether this study will provide detailed information about the disability sector in general and rural areas in particular.

In August 2009, the Australian Bureau of Statistics (ABS) commenced a survey of financial and activity measures within the Community Services Sector with results expected in mid 2010. This study, however, as with the previous ABS study conducted in 1999/2000, was focused on the entire community services industry and it is unlikely that it will contain detailed information about the disability services workforce (Department of Ageing, Disability and Home Care, 2009f).

A comprehensive set of demographic data of rural NSW disability services and their workforces would be a particularly valuable project, with the findings helping to underpin future research on employment issues. This project would also assist disability organisations in their future workforce planning, facilitating their capacity to effectively and appropriately recruit, train and retain qualified staff.

6.3.1.2 Training and Qualifications

As with the lack of generic demographic data for disability workers, there is minimal information available regarding the current training status for the disability sector in New South Wales (NSW). Over 95 percent of the participants in the current study had post-school qualifications, which is much higher than what would be expected from the limited demographic data available from 2005 and 2006. However, a significant push towards sector wide accredited training has taken place in the past five years, and this change has meant that the studies published were based upon data that may not accurately reflected the current situation. A large scale study of the training and education that both rural and metropolitan disability workers have undertaken would be valuable in planning future training needs.

The current study identified a number of key training areas but it was not possible to precisely determine why they were considered a priority for future education programs. The study did not identify whether the participants were recognising the need for training that had been of particular benefit to them, or conversely, if they were prioritising training that they had not actually received. A comprehensive analysis of what training disability workers have undertaken would help to clarify these issues. Such a study would need to not just look at what qualifications a person had obtained, but how current they were, and whether the individual had also completed refresher courses to remain up to date with current leading practice principles. It is possible that a disability care worker may have completed a relevant university degree a few decades ago and therefore appear to be highly qualified but not actually have any knowledge of current operating procedures.

6.3.1.3 Comparative Study of Rural and Metropolitan Service Provision

The focus of the current study was specifically upon the factors that affect service provision within rural and remote areas of New South Wales (NSW). It would be appropriate to conduct research within metropolitan areas of the state to examine whether similar issues were evident and what additional or new factors emerged. There are some issues specific to rural areas such as the extreme distance and time factors in accessing appropriate support services. However, it would be appropriate to examine how the views and perceptions of metropolitan based disability organisations and their disability staff would compare to those gained from the current rural cohort study.

One of the main issues that presented throughout the current research was the ability of people to access appropriate services. In rural locations, access is restricted due to the fact that many services and specialists simply do not exist in the local area. This problem is a consequence of the smaller population bases inherent to many rural and remote parts of NSW. However, it is worth acknowledging that the mere presence of services does not necessarily imply access. Informal feedback from disability providers in some of the larger regional centres indicates that even if a specialist service is available, actually gaining access to this service is often extremely difficult (Narelle Marshall, pers. comm., 11 March, 2008).

As discussed in section *5.2.3 Access to Services,* many government provided services were under-resourced and over-subscribed. This situation resulted in long waiting lists and the prioritisation of entry. Therefore, even if the specialist options are physically present within a city, there is no guarantee that any disability organisation, whether urban or rural, are actually able to use its expertise in an appropriate and timely manner.

It is possible that many of the issues facing metropolitan service providers would mirror those found in the current study. Similarities in the results of a future project focussing on metropolitan services would help to confirm and reinforce the findings of the current Delphi study and differences would assist in the identification of issues specific to particular geographic areas of NSW. This research would facilitate governments' ability to more appropriately tailor service delivery and training to the individual needs of locations across the state, rather than simply providing generic options for every service in every region.

6.3.2 Training of Doctors and Allied Health Professionals

The data from this study indicates that many medical practitioners and allied health care professionals in rural areas did not display a basic understanding of the issues associated with ageing and intellectual disability. It was not clear from the current research whether this perceived lack of knowledge was due to:

- insufficient education during undergraduate studies,
- lack of appropriate post university training programs,
- limited exposure to people with intellectual disabilities,
- reaction to either a personal or community reinforced prejudice against people with intellectual disabilities, or
- other unidentified reasons.

The training of doctors and allied health professions during both undergraduate and postgraduate courses in intellectual disability issues is an area that would benefit from considerable follow-up research and examination. Such a project should identify the origins from where the identified problem may stem and also propose possible solutions. A comprehensive review of the undergraduate and postgraduate training programs for medical practitioners, nurses and allied health staff within Australia would be a starting point for this research. This project would ideally build upon the research of Lennox, Diggens and Ugoni (1997) and Lennox and Diggens (1999), reviewing what changes have occurred in the period since the publication of their work.

A study by Denham and Shaddock (2004) found that rural allied health professionals who worked in the disability field felt they lacked professional development opportunities and were somewhat unsupported by both management and peers. The findings of the current study, when considered in light of the Denham and Shaddock research, may indicate an underlying lack of understanding of the respective direct care and allied health roles. A review of what postgraduate training and support opportunities are available for allied health workers in rural areas would therefore appear appropriate as a means of trying to bridge this possible divide.

An examination of the individual perceptions held by doctors, nurses and other allied health staff towards people with intellectual disabilities may also be valuable. This research could assist in determining whether personal or community attitudes are actually hindering the provision of medical, nursing and health support services to individuals with an intellectual disability.

6.3.3 Family and Community Needs

The focus of the current study was upon the perceptions of rural and remote direct care workers with respect to the people they support who are ageing with an intellectual disability. Although it was not their central focus, the direct care staff identified a number of specific concerns relating to ageing parents and the wider family networks (see section *5.4.2 Family Issues* and section *5.5.1 Ageing Parents*). There has been very limited work conducted in rural areas of Australia that considers the perspectives and needs of the family members and wider community in regard to this issue. Research by Hussain and Edwards (2009) examined the thoughts and views of ageing carers of people with an intellectual disability. This narrative inquiry project interviewed adults who either had an intellectual disability or were the ageing carer of a person with a lifelong disability. A number of the issues raised by Hussain and Edwards confirmed the outcomes of the current study, with problems such as access to services and health care clearly identified. It was noted that there was only limited future planning occurring, with social events and networks being very important for both the individuals with a disability and their ageing carers.

While Hussain and Edwards (2009) noted the importance of social networks, a re-examination of what the term ‘social networks’ actually means for both people with intellectual disabilities and their carers may be appropriate. For people with intellectual disabilities, finding appropriate friendship groups can be extremely difficult, and paid carers can sometimes be seen as default friends rather than as support staff (Bigby et al, 2008). These issues may be just as personally relevant to the ageing carers of people with disabilities, with the demands of providing ongoing care resulting in similar issues of social isolation. There is a need to distinguish accurately between the various elements of an individual’s social network, rather than simply considering the network as a single entity. This process would entail separating the over-arching structure of the network from the daily functioning of the network’s different components. The structure of the social network can be conceptualised in terms of the linkages between the various people and groups in the network, while the roles and tasks they perform are considered with respect to the actual support they provide (Phillipson et al, 2001).

Additional research that builds upon the 2009 work of Hussain and Edwards to examine the issues directly facing both the ageing carers and wider family networks of people with an intellectual disability would help to clarify and direct the implementation of future programs. In particular, a research emphasis on deconstructing the social networks of rural people and proposing how opportunities for overcoming issues such as isolation and marginalisation may be developed would be a beneficial way to evolve specific support programs for people with intellectual disabilities as well as their ageing carers and family members.

6.3.4 Research on Emerging Needs

Associated with longer life expectancy is a corresponding increase in mortality from conditions such as heart disease, cancer (Jancar, 1990) and respiratory problems (Durvasula, Beange & Baker, 2002; Hogg, Juhlberg & Lambe, 2007). Some research is showing that approximately 10 percent of people with an intellectual disability will become sick with a form of cancer that eventually will be the cause of their death (Cooke, 1997). People with intellectual disability have an increased likelihood of developing cancers such as testicular, pancreatic, ovarian, uterine and skin, as well as retinoblastoma and brain tumours (Patja, Molsa & Iivanainen, 2001). Sub-groups of people with intellectual disability, such as those individuals with Down Syndrome, are at increased risk of diseases such as leukaemia (Goldacre et al 2004; Sullivan, et al, 2007). The prevalence of cardiac disease is greater in people with intellectual disability (Draheim, 2006), and in one study was found to be 14 percent, approximately 5 percent higher than the equivalent general population (van den Akker, Maaskant & van der Meijden, 2006).

These changing health demographics have lead to an emerging and increasing need for palliative care support for people with intellectual disabilities; however, there are a number of issues that prevent this group of people accessing these services (Tuffrey-Wijne et al, 2008). No research has been reported that examines palliative care for ageing people with intellectual disabilities within rural and remote areas of Australia. At the present time, there is considerable confusion surrounding the responsibility for the provision of such care. The need for appropriate and responsive palliative care for people with intellectual disabilities will continue to increase in response to the growth in life expectancy. While the participants in the current study did not specifically nominate palliative care as a high priority, they did identify a number of issues associated with end of life care and support that relate to such needs. Further research is required in this area to begin to understand how to appropriately support people with intellectual disabilities in their final stages of life.

6.4 Conclusion of the Present Study

As a consequence of improved access to health care services and better recognition of the rights of individuals with intellectual disabilities, the past century has seen a dramatic improvement in the life expectancy of this group of people. It is now becoming the norm for a person with an intellectual disability to out-live their parents and to experience similar age-related issues as the rest of the population. These changes demonstrate the need to review organisational practices and how direct care employees are trained to support the successful ageing of people with intellectual disabilities. It is apparent that the over-arching government policy frameworks do not readily support individuals, their family and disability support organisations to provide appropriate and necessary assistance.

Workers in the disability sector are generally poorly remunerated and report considerable frustrations in completing their daily work. However, these same staff report that the satisfaction and joy they gain from making a positive contribution to the lives of people with intellectual disabilities is a major factor in their decision to initially join and remain within the disability workforce. As of 31 March 2010, no study of rural and regional disability support workers in New South Wales (NSW) has taken place to clearly establish what they require to support people with intellectual disabilities to age successfully. The major aim of the current study was to investigate the emerging issues surrounding individuals with an intellectual disability who are ageing within rural areas of NSW and determine the organisational practices and necessary training that will provide direct care staff members with the requisite support and knowledge to assist this group of people to age appropriately. To meet this aim, four specific objectives were formulated to:

- examine the current models of service available for people with intellectual disabilities as they age,
- identify the major issues that direct care staff believe impact most upon their capacity to provide appropriate support to the target group,
- identify areas within the existing disability training and professional support framework which do not currently provide direct care staff with the necessary skills and knowledge to assist people with disabilities as they age, and

- recommend specific solutions that can be implemented across rural and remote NSW to address the issue of appropriately supporting people with an intellectual disability who are ageing.

The current study has met the overall research aim and each of the four specific objectives. The current aged care models of service for people with intellectual disabilities were reviewed, and the existing training models for support staff were examined. The project clearly identified a range of issues considered important with respect to the ageing of people with intellectual disabilities and what factors impacted upon the ability of direct care workers to provide the desired level of support. The study has established a set of priority areas as perceived by a representative sample of state-wide direct care workers employed within rural and remote areas. These problems and issues were seen by the workers as the main barriers preventing people with intellectual disabilities in rural areas from having the same opportunities and rights as the rest of the mainstream ageing population. A series of specific recommendations were formulated to address the problem areas identified in the project. The knowledge gained through the current study provides government departments, non-government agencies and registered training organisations with new options to support direct care staff to continue in their valuable work with people with intellectual disabilities who are ageing.

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Appendix Contents Page

Appendix 1 - Letter of Invitation, Information Sheet and Consent Form

UNE
The University of
NEW ENGLAND

School of Health
Armidale, NSW 2351,
Australia

Letter of Invitation

Dear _____,

As a disability professional who assists people with intellectual disabilities, I would like to invite you to participate in a research project looking at the issues associated with ageing. This study seeks to explore the specific age- related issues that individuals with an intellectual disability encounter as they age, and what impact this ageing has upon the training needs of the staff who support them. Further information on the project is provided in the accompanying Information Sheet.

It is hoped that this study will give all participants an opportunity to express their personal views and opinions. The results of the study will be presented to both state and national government bodies such as the Department of Ageing, Disability and Home Care, the Department of Family, Community Services and Indigenous Affairs, the Department of Education and Training, and the Department of Education, Science and Training. It will also be submitted to the Community Services and Health Industry Training Advisory Board. A summary of the findings will be provided to all participants.

Your participation and time is greatly appreciated. The survey should only take around a maximum of thirty minutes to complete. If you would like any further information, please do not hesitate to contact me. The contact details are contained below.

If you are willing to participate, I would ask that you complete the attached consent form and return it to me at the following address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.

Yours,

Stuart Wark

School of Health
Armidale, NSW 2351,
Australia

Information Sheet for Participants

This study seeks to explore the specific age-related issues that individuals with an intellectual disability encounter as they age, and what impact this ageing has upon the training needs of the staff who support them.
As a volunteer, you will be invited to participate in this research project by;

1. Completing a Delphi survey questionnaire to collect data to about the major issues associated with the ageing of people with intellectual disabilities. A modified questionnaire is then re-issued to all participants until a general level of consensus on an issue is achieved. You have the right to withdraw from participation at any point during the research project.
2. The questionnaires will be emailed to you. You can either choose to return the questionnaire via email, or you can print it out and return it through the normal postal service or fax.
3. This is a research project, and you do not have to participate if you do not wish to. If you do not wish to be involved, you will not be affected in any way, either personally or professionally.

All information will be stored confidentially. All records will be locked up for five years. Then the records will be destroyed as per rules of the University for ethical conduct of research. No personal details will be shared with any other parties. You have the right to request that information you provide is not used in the research.

The aim of this project is to provide government and training authorities with information regarding the issues of ageing and intellectual disability. It is not perceived that there is any foreseen risk to any participant.

This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE07/167, Valid to 12/11/2008)

If you have any questions about this survey, please do not hesitate to either contact me via email at swark3@une.edu.au, or at the following postal address:
Stuart Wark
School of Health
University of New England
Armidale NSW 2351.
Phone : 040 867 3898

If you wish to speak with another person about this survey, please contact Dr Rafat Hussain at the School of Health, University of New England on (02) 6773 3678 or via email at **rhussain@une.edu.au.**

Should you have any complaints about this research, please contact the Research Ethics Officer at the following address:

Research Services
University of New England
Armidale, NSW 2351.
Telephone: (02) 6773 3449 / Fax (02) 6773 3543
Email: Ethics@metz.une.edu.au

School of Health
Armidale, NSW 2351,
Australia

Consent Form

Title: The changing training needs of staff who support people with intellectual disabilities who are ageing

NOTE: This consent form will remain with the researcher for their records

I agree to take part in the University of New England research project specified above. I have read the information sheet which I keep for my records. I understand that agreeing to take part means that:

- I am willing to be interviewed by the researcher
- I am willing to make myself available for a further interview if required
- I am willing to complete questionnaires asking me about the issues of ageing and intellectual disability.
- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the questionnaires for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the questionnaires will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed unless I consent to it being used in future research.

I (the participant) have read the information contained in the Information Sheet for Participants and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

……………………………………………… ………………………
Participant Name (please print) Date

………………………………………………
Participant Signature

Appendix 2 - Introductory Letter and First Round Questionnaire

The University of
NEW ENGLAND

School of Health
Armidale, NSW 2351,
Australia

Dear ____.

Thank you for agreeing to participate in this study, and taking the necessary time to complete the questionnaires. There are around 50 participants from across NSW taking part in the study.

The Delphi method, which is the basis for this research project, entails a series of questionnaires being used to establish a consensus viewpoint from experts (the Delphi Panel) within a specific sector. The responses from all participants for a questionnaire are compiled, and then returned to the Delphi Panel to check for agreement. You will be asked to rank the importance of the identified issues with a simple five-point scale.

Each questionnaire should not take more than twenty minutes to complete, and they may actually be completed in far less time.

In this case, you have been identified as an expert because you have particular knowledge or interest in relation to the ageing of people with intellectual disabilities, and the affect these changes have upon the staff that assist them. The results from this study will be used to provide recommendations to training organisations with a goal of enhancing the relevant ageing specific training provided to staff in the disability sector. The results will also be provided to government with a recommendation of allocating specific funding to address the identified training priorities.

If you have any questions or queries, please do not hesitate to contact me via return email (swark3@une.edu.au), or through regular mail at the following address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.

Many thanks,

Stuart Wark.

School of Health
Armidale, NSW 2351,
Australia

Dear ____,

Thank you again for agreeing to participate in this research project regarding the issues associated with ageing and disability.

The purpose of this first questionnaire is to gain your opinion on the main issues that face people with an intellectual disability as they age, and the impact these changes have upon the staff that assist them.

I would ask that you read through the entire questionnaire before you start responding. I am interested in your thoughts and ideas, however, I don't expect you to spend time doing research or looking up answers. I am interested in your opinion and viewpoint based upon your experiences. There are no right or wrong answers, but I would ask that you do not discuss your responses with any other participants in the study that you may either work with or know are participating in the study.

In particular, I am interested in your comments on each question, and what factors you consider particularly relevant to the rural setting that you work in. Your answers from this first questionnaire will utilised in the development of subsequent questionnaires.

If you have any questions or queries, please do not hesitate to contact me via return email (swark3@une.edu.au), or through mail at the following address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.

Please return the completed questionnaire via email, or please print out your answers and return it by mail to the above address.

Many thanks,

Stuart Wark

The University of NEW ENGLAND

School of Health
Armidale, NSW 2351,
Australia

Questionnaire No. 1

Background Information
Please complete the following information;

1. Age: ________________________________
2. Gender: ________________________________
3. Town where you work: ________________________________
4. Years working with people with disabilities: __________________
5. Training (please circle and also indicate course titles as relevant):

   Secondary School

   Year 12

   Certificate I ________________________________

   Certificate II ________________________________

   Certificate III ________________________________

   Certificate IV ________________________________

   Diploma ________________________________

   Advanced Diploma ________________________________

   Bachelor Degree ________________________________

   Post-Graduate Studies ________________________________

6. Are you a (please circle) :

   Direct Care Worker
   Manager
   Trainer
   Other (please nominate) ________________________________

Instructions to Participants

Please read all the questions before beginning your responses. Also, please take as much space as you need, and feel free to write as many issues as you feel relevant. If you need more room, please feel free to add additional pages as required. Your responses may fit into more than one category, so feel free to include them wherever you considered appropriate.

1. *What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*

2. *What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues,, social impacts, emotional issues, mental health issues)?*

3. *From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?*

4. *What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?*

5. *What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?*

6. *What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?*

Appendix 3 - Letter of Invitation, Information Sheet and Consent Form for The Ascent Group Staff only

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UNE
The University of
NEW ENGLAND

School of Health
Armidale, NSW 2351,
Australia

Letter of Invitation for Ascent Group Employees

As a disability professional who assists people with intellectual disabilities, I would like to invite you to participate in a research project looking at the issues associated with ageing. This study seeks to explore the specific age-related issues that individuals with an intellectual disability encounter as they age, and what impact this ageing has upon the training needs of the staff who support them. Further information on the project is provided in the accompanying Information Sheet.

It is hoped that this study will give all participants an opportunity to express their personal views and opinions. The results of the study will be presented to both state and national government bodies such as the Department of Ageing, Disability and Home Care, the Department of Family, Community Services and Indigenous Affairs, the Department of Education and Training, and the Department of Education, Science and Training. It will also be submitted to the Community Services and Health Industry Training Advisory Board. A summary of the findings will be provided to all participants.

Your participation and time is greatly appreciated. The survey should only take around a maximum of thirty minutes to complete. To ensure the confidentiality and privacy for Ascent staff members, I will be utilising the services of an intermediary research assistant, Mr Martin Kingstone. Martin will coordinate the distribution and collection of the questionnaires for Ascent employees. Martin has completed a confidentiality undertaking to not disclose any information relating to this study.

Martin will allocate an individual identifying number to each of the maximum of five participants from the Ascent Group. This participant number will be used by myself for the purposes of data collection, however, at no time either during or after the project will I know the names of Ascent Group participants or what their individual responses may have been.

If you are willing to participate, I would ask that you complete the attached consent form and return it to Martin at the following address;

Martin Kingstone
Day Services
PO Box 18
Armidale NSW 2350

If you have any specific questions that you wish to ask in relation to this, please do not hesitate to contact me at the following address;

Stuart Wark
School of Health
University of New England, NSW, 2351
Phone : 040 867 3898
Email : swark3@une.edu.au

Yours,

Stuart Wark

School of Health
Armidale, NSW 2351,
Australia

Information Sheet for Participants from the Ascent Group

This study seeks to explore the specific age-related issues that individuals with an intellectual disability encounter as they age, and what impact this ageing has upon the training needs of the staff who support them.

As a volunteer, you will be invited to participate in this research project by;

1. Completing a Delphi survey questionnaire to collect data to about the major issues associated with the ageing of people with intellectual disabilities. A modified questionnaire is then re-issued to all participants until a general level of consensus on an issue is achieved. You have the right to withdraw from participation at any point during the research project.
2. The questionnaires will be given to you in a hard copy by Mr Martin Kingstone. You will be asked to complete this form and return it to Martin in a sealed envelope, either in person or through the normal postal service. Martin will pass this sealed envelope onto me without opening it or reading the contents.
3. This is a research project, and you do not have to participate if you do not wish to. If you do not wish to be involved, you will not be affected in any way, either personally or professionally. You may withdraw from participation in the project at any time without consequences.

All information will be stored confidentially. All records will be locked up for five years. Then the records will be destroyed as per rules of the University for ethical conduct of research. No personal details will be shared with any other parties. You have the right to request that information you provide is not used in the research.

The aim of this project is to provide government and training authorities with information regarding the issues of ageing and intellectual disability. It is not perceived that there is any foreseen risk to any participant.

This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE07/167, Valid to 12/11/2008)

If you have any questions about this survey, please do not hesitate to either contact me via email at swark3@une.edu.au, or at the following postal address:

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.
Phone : 040 867 3898

If you wish to speak with another person about this survey, please contact Dr Rafat Hussain at the School of Health, University of New England on (02) 6773 3678 or via email at rhussain@une.edu.au.

Should you have any complaints about this research, please contact the Research Ethics Officer at the following address:

Research Services
University of New England
Armidale, NSW 2351.
Telephone: (02) 6773 3449 / Fax (02) 6773 3543
Email: Ethics@metz.une.edu.au

School of Health
Armidale, NSW 2351,
Australia

Consent Form for Ascent Group Participants

Title: The changing training needs of staff who support people with intellectual disabilities who are ageing

NOTE: This consent form will remain with Martin Kingstone in a locked filing cabinet.

I agree to take part in the University of New England research project specified above. I have read the information sheet which I keep for my records. I understand that agreeing to take part means that:

- I am willing to make myself available for a further interview if required
- I am willing to complete questionnaires asking me about the issues of ageing and intellectual disability.
- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the questionnaires for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the questionnaires will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed unless I consent to it being used in future research.

I (the participant) have read the information contained in the Information Sheet for Participants and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time. I agree that research data gathered for the study may be published, provided my name is not used.

…………………………………………… ………………………
Participant Name (please print) Date

……………………………………………
Participant Signature

Appendix 4 - Introductory Letter and First Round Questionnaire for The Ascent Group staff only

School of Health

Armidale, NSW 2351,

Australia

Introductory Letter for each Ascent Group participant

Dear colleague,

Thank you for agreeing to participate in this study, and taking the necessary time to complete the questionnaires. There are around 50 participants from across NSW taking part in the study.

The Delphi method, which is the basis for this research project, entails a series of questionnaires being used to establish a consensus viewpoint from experts (the Delphi Panel) within a specific sector. The responses from all participants for a questionnaire are compiled, and then returned to the Delphi Panel to check for agreement. You will be asked to rank the importance of the identified issues with a simple five-point scale.

Each questionnaire should not take more than twenty minutes to complete, and they may actually be completed in far less time.

In this case, you have been identified as an expert because you have particular knowledge or interest in relation to the ageing of people with intellectual disabilities, and the affect these changes have upon the staff that assist them. The results from this study will be used to provide recommendations to training organisations with a goal of enhancing the relevant ageing specific training provided to staff in the disability sector. The results will also be provided to government with a recommendation of allocating specific funding to address the identified training priorities.

If you have any questions or queries, please do not hesitate to contact me via return email (swark3@une.edu.au), or through regular mail at the following address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.

The University of New England

School of Health
Armidale, NSW 2351,
Australia

Initial Questionnaire sent to Ascent Group Delphi Panel Members

Dear colleague,

Thank you again for agreeing to participate in this research project regarding the issues associated with ageing and disability.

The purpose of this first questionnaire is to gain your opinion on the main issues that face people with an intellectual disability as they age, and the impact these changes have upon the staff that assist them.

I would ask that you read through the entire questionnaire before you start responding. I am interested in your thoughts and ideas, however, I don’t expect you to spend time doing research or looking up answers. I am interested in your opinion and viewpoint based upon your experiences. There are no right or wrong answers, but I would ask that you do not discuss your responses with any other participants in the study that you may either work with or know are participating in the study.

In particular, I am interested in your comments on each question, and what factors you consider particularly relevant to the rural setting that you work in. Your answers from this first questionnaire will utilised in the development of subsequent questionnaires.

If you have any questions or queries, please do not hesitate to contact me via return email (swark3@une.edu.au), or through mail at the following address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351.

As mentioned in previous correspondence, Mr Martin Kingstone will be a research assistant in this project and will act as an intermediary to ensure the confidentiality and privacy of all Ascent employees. I would ask therefore that you complete the questionnaire and seal it in the provided envelope, before returning it to Martin Kingstone either in person, or via regular mail at the following address;

Martin Kingstone
Day Services
PO Box 18
Armidale NSW 2350

Many thanks,

Stuart Wark

School of Health
Armidale, NSW 2351,
Australia

Questionnaire No. 1 for Ascent Group Participants

Background Information

Please complete the following information;

1. Age: ________________________________
2. Gender: ________________________________
3. Town where you work: ________________________________
4. Years working with people with disabilities: __________________
5. Training (please circle and also indicate course titles as relevant):

   Secondary School

   Year 12

   Certificate I ________________________________

   Certificate II ________________________________

   Certificate III ________________________________

   Certificate IV ________________________________

   Diploma ________________________________

   Advanced Diploma ________________________________

   Bachelor Degree ________________________________

   Post-Graduate Studies ________________________________

6. Are you a (please circle) :

   Direct Care Worker
   Manager
   Trainer
   Other (please nominate) ________________________________

Instructions to Participants

Please read all the questions before beginning your responses. Also, please take as much space as you need, and feel free to write as many issues as you feel relevant. If you need more room, please feel free to add additional pages as required. Your responses may fit into more than one category, so feel free to include them wherever you considered appropriate.

1. *What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*

2. *What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues,, social impacts, emotional issues, mental health issues)?*

3. *From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?*

4. *What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?*

5. *What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?*

6. *What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?*

Appendix 5 - Confidentiality Agreement between Principal Researcher and the Research Assistant

CONFIDENTIALITY AGREEMENT

THIS AGREEMENT is made on the 8th day November 2007

BETWEEN

Stuart Wark, UNE School of Health

AND

Martin Kingstone, research assistant

IT IS AGREED AS FOLLOWS

Mr Martin Kingstone has agreed to act as a conduit for employees (the disclosing party) from The Ascent Group to participate in the proposed research project being conducted by Dr Rafat Hussain, Dr Lyn Irwin and Mr Stuart Wark. The reason for Mr Kingstone acting in this capacity is to ensure the anonymity of employees. Mr Kingstone will distribute surveys and receive completed surveys in sealed envelopes. Mr Kingstone will not open or view the contents of the sealed envelopes, and will not disclose to any other party his coding methodology as specified in the Ethics application.

Mr Kingstone agrees to;

(a) keep all Confidential Information confidential unless strictly required otherwise by law;

(b) not use Confidential Information in any way which would be harmful to the best interests of the Disclosing Party;

(d) immediately notify the Disclosing Party of any disclosure required by law;

(e) not use any Confidential Information in any way other than for the Purpose or as otherwise contemplated by this Agreement without the prior written permission of the Disclosing Party;

(f) not copy, in whole or in part, any Confidential Information without the prior written permission of the Disclosing Party; and

RETURN OF INFORMATION

At any time upon the written request of the Disclosing Party, Mr Kingstone must return to the Disclosing Party any documents originating from the Disclosing Party which embody Confidential Information and must not keep any copies in any form.

Confidentiality Agreement

This Agreement may only be amended in writing.

EXECUTED as an Agreement this ……………………. day of …………………..……………….2007

SIGNED by Mr Martin Kingstone)
in the presence of:)
)

………………………………….	………………………………….
Signature of Witness	Signature of Mr Kingstone
	Research Assistant
………………………………….	………………………………….
Name of Witness (block letters)	Name of authorised person (block letters)

SIGNED for and on behalf of **THE SECOND PARTY**)
in the presence of:)

………………………………….	………………………………….
Signature of Witness	Signature of authorised person
	Researcher
………………………………….	………………………………….
Name of Witness (block letters)	Name of authorised person (block letters)

Appendix 6 - Second Round of Delphi Questionnaire

Thank you very much for your responses to the first round of questions. I greatly appreciate the assistance that you are giving me through completing this study.

The second stage of this study involves you re-examining your initial responses, and also considering the views of the other participants in the study.

Please read the following answers for each of the six questions. They are the responses of each individual respondent collated into one form. A lot of them are very similar, however, I have tried to ensure that all variations are included. However, when more than one person has written the same issue I have not repeated it. They are not listed in any sort of priority; I have put them into alphabetically order.

Could you please carefully re-read the main question, and then consider the nominated responses from all participants. If the responses prompt you to consider a new issue that hasn't been mentioned, or if you disagree with any of the other participant's responses, please write them down with your reason (if you disagree). If you require more space, please feel free to attach additional pages.

If you are happy with the provided responses, and don't feel you wish to add anything further, you do not have to respond to this stage of the survey.

If you do have some additional responses, could you please return them to me either via email (swark3@une.edu.au) or through the below mailing address;

Stuart Wark
School of Health
University of New England
Armidale NSW 2351

I would like to have all responses back within two weeks so that we can start the final round as soon as possible.

Many thanks again for your ongoing assistance with this project.

Cheers,

Stuart

1. *What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*

- Access to specialist services such as gerontology and ACAT teams
- Accessing appropriate equipment and aids
- Accessing appropriate transport
- Being able to retire and access appropriate recreation and leisure activities (day programs etc)
- Concerns about "what's next" in their life
- Confusion by staff and medical practitioners about what is ageing versus disability issues
- Correct diagnosis of issues by medical practitioners including mental health
- Decrease in family support as immediate family is often also ageing (and dying themselves)
- Decreased communication skills
- Decreased physical ability
- Doctors (and allied health staff) not prioritizing medical attention for this group
- General lack of understanding about the ageing process by staff
- Getting used to new staff
- Having appropriate housing to allow them to age in place safely
- Having appropriate support services to allow them to age in place safely
- Having appropriately trained and qualified support staff
- Having to leave a house they have lived in for many years (and decades)
- Hygiene (including managing incontinence)
- Increasing support needs but no increased support (due to no funding increases)
- Lack of appropriate facilities
- Lack of understanding of disabilities within mainstream aged care services
- Pension not meeting increased financial needs
- Physical deterioration (hearing and sight) and emotional changes (depression)
- Placement into mainstream aged care facilities that have no understanding of disability
- Specific medical conditions such as early on-set dementia, osteoporosis etc

2. *What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?*

- Bullying towards other residents and staff
- Changes in eating habits (inability to eat certain foods)
- Communication problems
- Decreased mobility
- Deterioration in mental abilities
- Disrespect towards staff
- Greater support needs
- Grief (loss of their own families and friends)
- Hormonal issues
- Incontinence (bladder and bowel)
- Increase in inappropriate and/or aggressive behaviours
- Increase in seizure activity
- Increased simple and complex health needs
- Isolation
- Losing their 'identity' and independence after moving into supported accommodation
- Loss of confidence
- Loss of memory
- Loss of motivation
- Mental health issues such as depression and dementia
- Personal hygiene
- Physical health issues (including sight and hearing deterioration)
- Reduced desire to access services
- Reduced desire to participate in activities
- Reduced Productivity
- Reduction in ability to access community independently
- Reduction or loss of senses such as vision and hearing
- Set in routine (resistant to change)
- Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)
- Stereotyping of others
- Trips and falls
- Weight gain
- Withdrawal

3. *From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?*

- Accessing appropriate professional support
- Advocating for clients to get appropriate aged care services
- Advocating for clients to get appropriate medical care
- Assisting in increasing personal care needs (such as hygiene)
- Being creative in using the funding to meet client needs
- Blending the impact of ageing with issues already faced by people with disabilities
- Breaking bad habits that may become unsafe
- Communication problems
- Dealing with client frustration at not being able to do things
- Dealing with personal frustration in not having sufficient time to meet individual needs
- Excessive paperwork
- Gaining access to appropriate recreational and leisure activities in retirement such as day services programs
- How to assess independence
- Lack of additional funding to meet increasing needs
- Lack of appropriate venues for community access
- Lack of government funding for appropriate staffing levels
- Lack of government funding for staff training
- Long distance travel required to see suitable medical specialists
- Maintaining independence, health and well-being
- Manual handling issues as clients lose mobility
- Providing constant reassurance
- Reduced acceptance of activities
- Reduced concentration by the person
- Reduced productivity by the person
- Reduced stimulation levels
- Time constraints
- Unrealistic family expectations

4. *What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?*

- Access to respite
- Access to appropriate facilities to assist people with higher care needs
- Ageing parents
- Clients with lower needs miss out due to an increased focus on person who is ageing
- Communication problems
- Concerns about person’s ongoing and increasing care needs
- Coping with increased support needs
- Family concern about future planning as the person with the disability may outlive the parents
- Financial security and ongoing financial management
- Friends experiencing depression themselves due to worry about their own mortality
- Frustration
- Household members reducing the person’s level of independence by attempting to ‘help’ by doing everything for them
- Impact upon closeness of relationship (affected by dementia)
- Increased pressure on families to provide ongoing advocacy
- Increased reliance upon staff to facilitate family contact (primarily through phone)
- Lack of acceptance of the ageing process
- Lack of information for families to source services
- Lack of patience (everyone wants everything done right now!)
- Legal issues (e.g. making a will or power of attorney)
- Need for major home renovations (e.g. stairs, ramps, rails etc)
- Fellow residents not understanding what is going on (why the person has changed or moved)
- Pressure on friends to cope with changing personality and skills
- The need for greater advocacy by the families to gain additional funding as support needs increase
- Understanding and separating behavioural issues from physical/mental health issues

5. *What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?*

- Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing
- Age cut-off for ACAT prevents people with disabilities accessing services
- Appropriate funding models for smaller services without large numbers of ageing clients
- Availability of complementary services to our own
- Care needs are constantly increasing, whilst funding is not
- Competition with the community's focus upon the increasing needs of the generic ageing population
- Cost in accessing services (travel costs and staffing costs)
- Distance to nearest appropriate services
- Financial viability
- Funding for new equipment / home modifications
- Inflexibility in funding models and structures
- Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work)
- Lack of mainstream services
- Lack of public transport
- Lack of specialist services such as respite and day programs
- Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability
- Mainstream aged care services not understanding how to support someone with a disability
- Maintaining qualified and trained staff
- No dedicated aged care facility for people with intellectual disabilities
- Recruiting qualified and trained staff
- Training and education for both disability staff and generic aged care professionals

6. *What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?*

- Ability to educate the general public about client abilities
- Advocacy to act as the voice for people who are ageing and seek appropriate facilities
- Alternative communication methods
- Attitude training (patience, empathy, consistency, ethics)
- Behaviour management
- Comprehensive and accurate record keeping to assess changes over time
- Dementia
- Diabetes
- Dietetics (meal preparation, tube feeding etc)
- Generic aged care courses for disability service providers
- How to transition people between services effectively
- Medical management
- OH & S and Manual Handling Training (how to provide appropriate physical support)
- Person centred planning
- Personal care needs
- Quality of life management
- Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend
- Specialist equipment usage
- Time management
- Training in observation skills so that changes in client health can be detected early
- Understanding medication
- Understanding of changes associated with ageing
- Understanding of different support needs at different stages of ageing
- Understanding of emotional issues
- Understanding of health issues
- Understanding of the ageing process and stages that people move through

Appendix 7 - Third Round of Delphi Questionnaire

Third Round

Thank you very much for your responses to the first two rounds of questions. I greatly appreciate the assistance that you are giving me through completing this study.
The final stage of this study involves you rating the importance of each issue that the study participants have identified for each question.

The issues are the responses from each individual participant from both the first and second rounds. For the sake of simplicity, when more than one person has put down the same issue I have not repeated it.

Please read each of the key issue statements carefully, and consider it with respect to the over-arching question at the top of the page. For each of the statements, please use the following scale and place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Scale
1 – Irrelevant
2 – Very unimportant
3 – Unimportant
4 – Neither important or unimportant
5 – Important
6 – Very important
7 – Critical

Once completed, could you please return this form either via email or post as per the previous rounds.

Many thanks again for your ongoing assistance with this project. If you have any questions or are not sure about anything, please don't hesitate to either email me at swark3@une.edu.au or via post at

Stuart Wark
School of Health
University of New England
UNE, Armidale 2351

Cheers,

Stuart

1. ***What do you think are the main issues or problems that a person with an intellectual disability will face as they age?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issues	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Access to specialist services such as gerontology and ACAT teams							
Accessing appropriate equipment and aids							
Accessing appropriate transport							
Being able to retire and access appropriate recreation and leisure activities (day programs etc)							
Concerns about "what's next" in their life							
Confusion by staff and medical practitioners about what is ageing versus disability issues							
Correct diagnosis of issues by medical practitioners including mental health							
Decrease in family support as immediate family is often also ageing (and dying themselves)							
Decreased communication skills							
Decreased physical ability							
Doctors (and allied health staff) not prioritizing medical attention for this group							

General lack of understanding about the ageing process by staff							
Getting used to new staff							
Having appropriate housing to allow them to age in place safely							
Having appropriate support services to allow them to age in place safely							
Having appropriately trained and qualified support staff							
Having to leave a house they have lived in for many years/decades							
Hygiene (including managing incontinence)							
Increasing support needs but no increased support (due to no funding increases)							
Lack of appropriate facilities							
Lack of understanding of disabilities within mainstream aged care services							
Pension not meeting increased financial needs							
Physical deterioration (hearing and sight) and emotional changes (depression)							
Placement into mainstream aged care facilities that have no understanding of disability							
Specific medical conditions such as early on-set dementia, osteoporosis etc							

2. ***What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issue Statements	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Bullying towards other residents and staff							
Changes in eating habits (inability to eat certain foods)							
Communication problems							
Decreased mobility							
Deterioration in mental abilities							
Disrespect towards staff							
Greater support needs							
Grief (loss of their own families and friends)							
Hormonal issues							
Incontinence (bladder and bowel)							
Increase in inappropriate and/or aggressive behaviours							
Increase in seizure activity							
Increased simple and complex health needs							
Isolation							
Losing their 'identity' and independence after moving into supported accommodation							
Loss of confidence							
Loss of memory							
Loss of motivation							

Mental health issues such as depression and dementia							
Personal hygiene							
Physical health issues (including sight and hearing deterioration)							
Reduced desire to access services							
Reduced desire to participate in activities							
Reduced Productivity							
Reduction in ability to access community independently							
Reduction or loss of senses such as vision and hearing							
Set in routine (resistant to change or even more resistant than previously)							
Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)							
Stereotyping of others							
Trips and falls							
Weight gain or weight loss							
Withdrawal							

3. ***From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issue Statements	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Accessing appropriate professional support							
Advocating for clients to get appropriate aged care services							
Advocating for clients to get appropriate medical care							
Assisting in increasing personal care needs (such as hygiene)							
Being creative in using the funding to meet client needs							
Blending the impact of ageing with issues already faced by people with disabilities							
Breaking bad habits that may become unsafe							
Communication problems							
Dealing with client frustration at not being able to do things							
Dealing with personal frustration in not having sufficient time to meet individual needs							
Excessive paperwork							
Gaining access to appropriate recreational and leisure activities in retirement such as day services programs							
How to assess independence							

Ignorance and lack of respect by general public towards client issues							
Lack of additional funding to meet increasing needs							
Lack of appropriate venues for community access							
Lack of government funding for appropriate staffing levels							
Lack of government funding for staff training							
Lack of disability accessible parking spots							
Long distance travel required to see suitable medical specialists							
Maintaining independence, health and well-being							
Manual handling issues as clients lose mobility							
Providing constant reassurance							
Reduced acceptance of activities							
Reduced concentration by the person							
Reduced productivity by the person							
Reduced stimulation levels							
Time constraints							
Unrealistic family expectations							

4. ***What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issue Statements	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Access to respite							
Access to appropriate facilities to assist people with higher care needs							
Ageing parents							
Clients with lower needs miss out due to an increased focus on person who is ageing							
Communication problems							
Concerns about person's ongoing and increasing care needs							
Coping with increased support needs							
Family concern about future planning as the person with the disability may outlive the parents							
Financial security and ongoing financial management							
Friends experiencing depression themselves due to worry about their own mortality							
Frustration							
Household members reducing the person's level of independence by attempting to 'help' by doing everything for them							

Impact upon closeness of relationship (affected by dementia)							
Increased pressure on families to provide ongoing advocacy							
Increased reliance upon staff to facilitate family contact (primarily through phone)							
Lack of acceptance of the ageing process							
Lack of information for families to source services							
Lack of patience (everyone wants everything done right now!)							
Legal issues (e.g. making a will or power of attorney)							
Need for major home renovations (e.g. changing stairs to ramps, rails in bathrooms, etc							
Fellow residents not understanding what is going on (why the person has changed or moved)							
Pressure on friends to cope with changing personality and skills							
Residing within a complex with other people with disabilities compounds personal problems for those who are ageing							
The need for greater advocacy by the families to gain additional funding as support needs increase							
Understanding and separating behavioural issues from physical/mental health issues							

5. ***What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issue Statements	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing							
Age cut-off for ACAT prevents people with disabilities accessing services							
Appropriate funding models for smaller services without large numbers of ageing clients							
Availability of complementary services to our own							
Care needs are constantly increasing, whilst funding is not							
Competition with the community's focus upon the increasing needs of the generic ageing population							
Cost in accessing services (travel costs and staffing costs)							
Distance to nearest appropriate services							
Financial viability							
Funding for new equipment / home modifications							
Inflexibility in funding models and structures							

Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work)							
Lack of flexibility in daily lives due to set routines and restrictive timeframes							
Lack of mainstream services available to people with disabilities							
Lack of public transport							
Lack of specialist services such as respite and day programs							
Lack of staff skill in utilising and accessing those available mainstream services							
Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability							
Limited opportunities for staff networking (e.g. cross pollination of ideas and knowledge)							
Mainstream aged care services not understanding how to support someone with a disability							
Maintaining qualified and trained staff							
No dedicated aged care facility for people with intellectual disabilities							
Overcrowding in the limited space available and lack of personal space							
Recruiting qualified and trained staff							
Training and education for both disability staff and generic aged care professionals							

6. ***What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?***

Please consider each of the below key issues in relation to the above question. For each of the below key issues, please place a tick or mark into the box that reflects how important you feel that issue is to yourself and your experiences as a disability professional.

Issue Statements	**Scale**						
	Irrelevant	**Very unimportant**	**Unimportant**	**Neither important or unimportant**	**Important**	**Very Important**	**Critical**
Ability to educate the general public about client abilities							
Advocacy to act as the voice for people who are ageing and seek appropriate facilities							
Alternative communication methods							
Attitude training (patience, empathy, consistency, ethics)							
Behaviour management							
Comprehensive and accurate record keeping to assess changes over time							
Dementia							
Diabetes							
Dietetics (meal preparation, tube feeding etc)							
Generic aged care courses for disability service providers							
How to transition people between services effectively							
Medical management							
OH & S and Manual Handling Training (how to provide appropriate physical support)							

Person centred planning							
Personal care needs							
Quality of life management							
Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend							
Specialist equipment usage							
Time management							
Training in observation skills so that changes in client health can be detected early							
Understanding medication and its effects							
Understanding of changes associated with ageing							
Understanding of different support needs at different stages of ageing							
Understanding of emotional issues							
Understanding of health issues							
Understanding of the ageing process and stages that people move through							

Appendix 8 - Final Round of Delphi Questionnaire

Instructions to Participants

On the next few pages are six generic questions relating to the ageing of people with disabilities. What follows each question is a prioritised list of the issues as identified by direct care workers from across rural New South Wales.

Please read carefully through the list of identified issues. At the bottom of the page, there will be a statement such as this;

> **I believe that the above list accurately reflects the main issues or problems that a person with an intellectual disability will face as they age.**

Underneath this statement will be the following five point scale.

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Please indicate your level of agreement with the statement by either bolding or highlight your desired response if you are returning via email, or circle/tick your answer if you are printing this questionnaire and returning it via postal mail.

If you have any questions, please do not hesitate to get in touch with me through any of the contact details provided in the introduction.

Question Number One - *What do you think are the main issues or problems that a person with an intellectual disability will face as they age?*

1. Increasing support needs but no increased support (due to no funding increases)
2. Correct diagnosis of issues by medical practitioners including mental health
3. Having appropriately trained and qualified support staff
4. Placement into mainstream aged care facilities that have no understanding of disability
5. Access to specialist services such as gerontology and ACAT teams
6. Confusion by staff and medical practitioners about what is ageing versus disability issues
7. Pension not meeting increased financial needs
8. Doctors (and allied health staff) not prioritizing medical attention for this group
9. Having appropriate support services to allow them to age in place safely
10. Having appropriate housing to allow them to age in place safely
11. Lack of understanding of disabilities within mainstream aged care services
12. Being able to retire and access appropriate recreation and leisure activities (day programs etc)
13. Physical deterioration (hearing and sight) and emotional changes (depression)
14. Accessing appropriate equipment and aids
15. Decreased communication skills
16. Decreased physical ability
17. Lack of appropriate facilities
18. Specific medical conditions such as early on-set dementia, osteoporosis etc
19. General lack of understanding about the ageing process by staff
20. Decrease in family support as immediate family is often also ageing (and dying themselves)
21. Hygiene (including managing incontinence)
22. Accessing appropriate transport
23. Having to leave a house they have lived in for many years/decades
24. Concerns about "what's next" in their life
25. Getting used to new staff

I believe that the above list accurately reflects the main issues or problems that a person with an intellectual disability will face as they age.

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Question Number Two - *What are the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues)?*

1. Greater support needs
2. Increased simple and complex health needs
3. Isolation
4. Mental health issues such as depression and dementia
5. Deterioration in mental abilities
6. Loss of memory
7. Communication problems
8. Trips and falls
9. Incontinence (bladder and bowel)
10. Specific medical conditions (e.g. urinary tract infections, cancer, diabetes and dementia)
11. Set in routine (resistant to change or even more resistant than previously)
12. Changes in eating habits (inability to eat certain foods)
13. Decreased mobility
14. Grief (loss of their own families and friends)
15. Loss of motivation
16. Losing their 'identity' and independence after moving into supported accommodation
17. Reduction in ability to access community independently
18. Withdrawal
19. Reduction or loss of senses such as vision and hearing
20. Weight gain or weight loss
21. Physical health issues (including sight and hearing deterioration)
22. Loss of confidence
23. Increase in inappropriate and/or aggressive behaviours
24. Reduced Productivity
25. Personal hygiene
26. Reduced desire to participate in activities
27. Reduced desire to access services
28. Increase in seizure activity
29. Hormonal issues
30. Stereotyping of others
31. Bullying towards other residents and staff
32. Disrespect towards staff

I believe that the above list accurately reflects the main signs of ageing that you have seen in people with intellectual disabilities (i.e. physical health issues, social impacts, emotional issues, mental health issues).

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Question No. Three - *From an individual staff perspective, what are the main issues you experience in providing support to someone with an intellectual disability who is ageing?*

1. Lack of government funding for appropriate staffing levels
2. Lack of additional funding to meet increasing needs
3. Advocating for clients to get appropriate medical care
4. Gaining access to appropriate recreational and leisure activities in retirement such as day services programs
5. Being creative in using the funding to meet client needs
6. Accessing appropriate professional support
7. Lack of government funding for staff training
8. Maintaining independence, health and well-being
9. Blending the impact of ageing with issues already faced by people with disabilities
10. Manual handling issues as clients lose mobility
11. Advocating for clients to get appropriate aged care services
12. Communication problems
13. Dealing with personal frustration in not having sufficient time to meet individual needs
14. Assisting in increasing personal care needs (such as hygiene)
15. Time constraints
16. How to assess independence
17. Long distance travel required to see suitable medical specialists
18. Unrealistic family expectations
19. Dealing with client frustration at not being able to do things
20. Excessive paperwork
21. Breaking bad habits that may become unsafe
22. Lack of appropriate venues for community access
23. Providing constant reassurance
24. Reduced concentration by the person
25. Reduced stimulation levels
26. Ignorance and lack of respect by general public towards client issues
27. Reduced acceptance of activities
28. Reduced productivity by the person
29. Lack of disability accessible parking spots

I believe that the above list accurately reflects the main issues direct care staff experience in providing support to someone with an intellectual disability who is ageing.

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Question No. Four - *What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?*

1. Access to appropriate facilities to assist people with higher care needs
2. Access to respite
3. Ageing parents
4. Family concern about future planning as the person with the disability may outlive the parents
5. Understanding and separating behavioural issues from physical/mental health issues
6. Coping with increased support needs
7. Financial security and ongoing financial management
8. Concerns about person's ongoing and increasing care needs
9. Clients with lower needs miss out due to an increased focus on person who is ageing
10. Communication problems
11. Friends experiencing depression themselves due to worry about their own mortality
12. The need for greater advocacy by the families to gain additional funding as support needs increase
13. Impact upon closeness of relationship (affected by dementia)
14. Legal issues (e.g. making a will or power of attorney)
15. Fellow residents not understanding what is going on (why the person has changed or moved)
16. Need for major home renovations (e.g. changing stairs to ramps, rails in bathrooms, etc)
17. Residing within a complex with other people with disabilities compounds personal problems for those who are ageing
18. Lack of patience (everyone wants everything done right now!)
19. Household members reducing the person's level of independence by attempting to 'help' by doing everything for them
20. Increased pressure on families to provide ongoing advocacy
21. Lack of information for families to source services
22. Pressure on friends to cope with changing personality and skills
23. Frustration
24. Increased reliance upon staff to facilitate family contact (primarily through phone)
25. Lack of acceptance of the ageing process

I believe that the above list accurately reflects the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing.

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Question No. Five - *What do you think are the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing?*

1. Care needs are constantly increasing, whilst funding is not
2. Training and education for both disability staff and generic aged care professionals
3. Recruiting qualified and trained staff
4. Inflexibility in funding models and structures
5. Maintaining qualified and trained staff
6. Age cut-off for ACAT prevents people with disabilities accessing services
7. Access to appropriate and relevant training for staff re ageing and support for a person with a disability who is ageing
8. Appropriate funding models for smaller services without large numbers of ageing clients
9. Lack of mainstream services available to people with disabilities
10. Lack of specialist services such as respite and day programs
11. Cost in accessing services (travel costs and staffing costs)
12. Financial viability
13. Mainstream aged care services not understanding how to support someone with a disability
14. No dedicated aged care facility for people with intellectual disabilities
15. Lack of entry requirements into the industry (such as a minimum of Cert III in Aged or Disability Work)
16. Lack of understanding (and willingness to act) by medical profession (doctors and hospital staff) regarding the ageing process for people with a disability
17. Availability of complementary services to our own
18. Funding for new equipment / home modifications
19. Competition with the community's focus upon the increasing needs of the generic ageing population
20. Lack of public transport
21. Lack of staff skill in utilising and accessing those available mainstream services
22. Distance to nearest appropriate services
23. Limited opportunities for staff networking (e.g. cross pollination of ideas and knowledge)
24. Overcrowding in the limited space available and lack of personal space
25. Lack of flexibility in daily lives due to set routines and restrictive timeframes

I believe that the above list accurately reflects the main issues or problems facing a rural organisation that provides support to someone with an intellectual disability who is ageing.

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

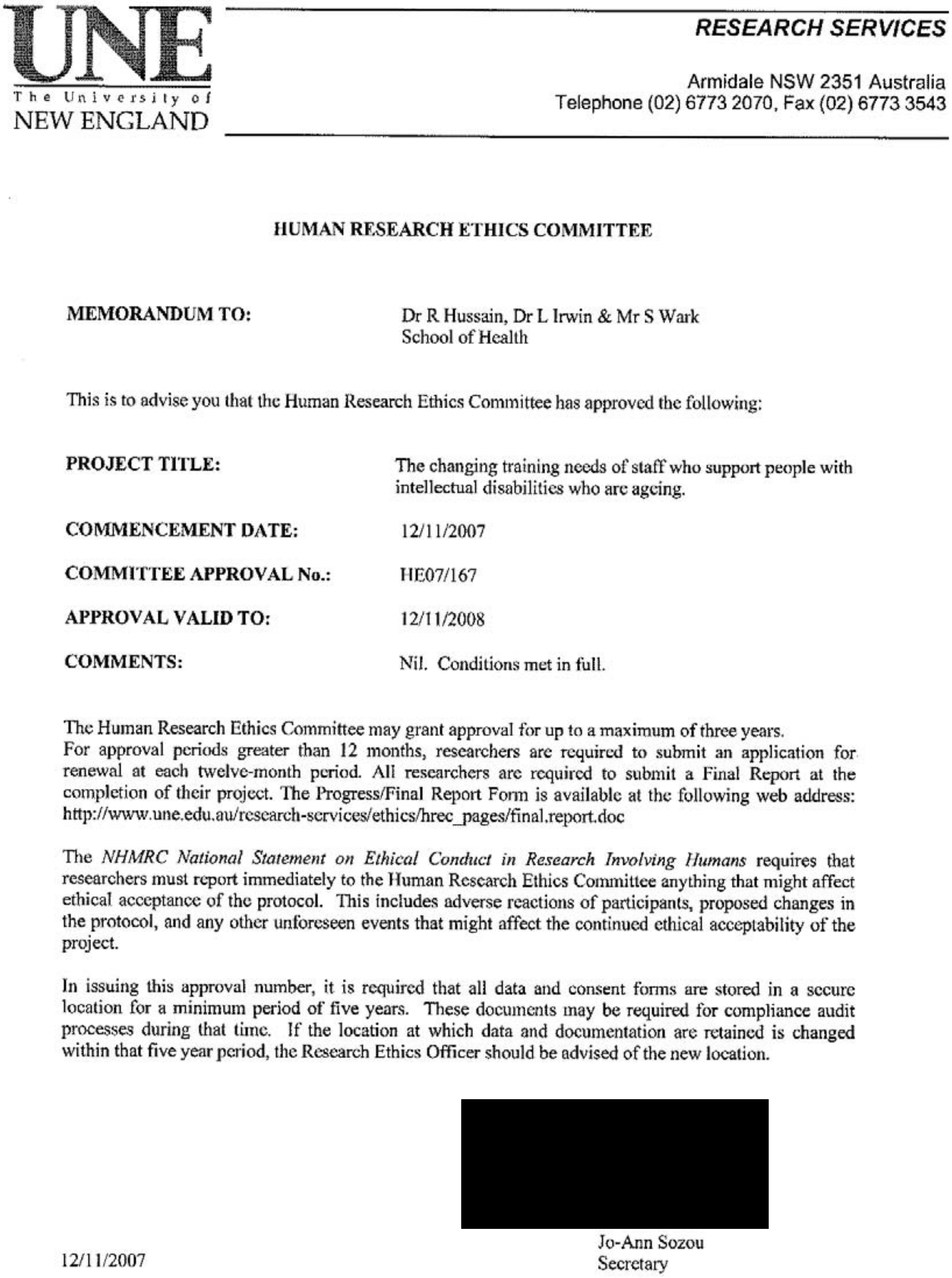
Question No. Six - *What do you think are the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?*

1. Person centred planning
2. Medical management
3. Understanding medication and its effects
4. Understanding of changes associated with ageing
5. Quality of life management
6. Training in observation skills so that changes in client health can be detected early
7. Behaviour management
8. Attitude training (patience, empathy, consistency, ethics)
9. OH & S and Manual Handling Training (how to provide appropriate physical support)
10. Personal care needs
11. Understanding of health issues
12. Understanding of the ageing process and stages that people move through
13. Understanding of different support needs at different stages of ageing
14. Dementia
15. Comprehensive and accurate record keeping to assess changes over time
16. Generic aged care courses for disability service providers
17. Understanding of emotional issues
18. Dietetics (meal preparation, tube feeding etc)
19. How to transition people between services effectively
20. Time management
21. Alternative communication methods
22. Skills (such as counselling) in supporting other service users/housemates in dealing with the ageing issues of their friend
23. Advocacy to act as the voice for people who are ageing and seek appropriate facilities
24. Diabetes
25. Specialist equipment usage
26. Ability to educate the general public about client abilities

I believe that the above list accurately reflects the highest priorities in training for staff who assist individuals with an intellectual disability who are ageing?

1 – Completely Disagree
2 – Disagree
3 – Neither Agree or Disagree
4 – Agree
5 – Strongly Agree

Appendix 9 – Ethics Approval



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Telephone (02) 6773 2070, Fax (02) 6773 3543

HUMAN RESEARCH ETHICS COMMITTEE

MEMORANDUM TO:	Dr R Hussain, Dr L Irwin & Mr S Wark School of Health

This is to advise you that the Human Research Ethics Committee has approved the following:

PROJECT TITLE:	The changing training needs of staff who support people with intellectual disabilities who are ageing.
COMMENCEMENT DATE:	12/11/2007
COMMITTEE APPROVAL No.:	HE07/167
APPROVAL VALID TO:	12/11/2008
COMMENTS:	Nil. Conditions met in full.

The Human Research Ethics Committee may grant approval for up to a maximum of three years. For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Progress/Final Report Form is available at the following web address: http://www.une.edu.au/research-services/ethics/hrec_pages/final.report.doc

The *NHMRC National Statement on Ethical Conduct in Research Involving Humans* requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

In issuing this approval number, it is required that all data and consent forms are stored in a secure location for a minimum period of five years. These documents may be required for compliance audit processes during that time. If the location at which data and documentation are retained is changed within that five year period, the Research Ethics Officer should be advised of the new location.

[redacted]

12/11/2007

Jo-Ann Sozou
Secretary

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HUMAN RESEARCH ETHICS COMMITTEE

MEMORANDUM TO:	Dr R Hussain, Dr H Edwards & Mr S Wark School of Health

This is to advise you that the Human Research Ethics Committee has approved the following:

PROJECT TITLE:	The changing training needs of staff who support people with intellectual disabilities who are ageing.
COMMENCEMENT DATE:	15/04/2009
COMMITTEE APPROVAL No.:	HE09/057
APPROVAL VALID TO:	15/04/2010
COMMENTS:	Nil. Conditions met in full.

The Human Research Ethics Committee may grant approval for up to a maximum of three years.
For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Progress/Final Report Form is available at the following web address: http://www.une.edu.au/research-services/ethics/human-ethics/hrecforms.php

The *NHMRC National Statement on Ethical Conduct in Research Involving Humans* requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

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[redacted]

Jo-Ann Sozou
Secretary

31/03/2009