

# Ageing with a Lifelong Disability Student Project Final Report

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**December 2009**

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## **Acknowledgements**

The authors would like to thank the participants who gave their time and shared their experiences with us. We would also like to thank the student researchers who contributed to this report – you did a fabulous job understanding this complex issue and conducting sound research projects in a short period of time. Finally, we would like to thank the Faculty of Arts and Social Sciences for supporting this research through the Early Career Researcher Scheme, without which this research would not have been possible.

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# 1 Introduction

The Australian population is ageing and so too are people with lifelong disability. While it is acknowledged that people with disability have different needs than the general population, little research has been done on the extent to which these needs are addressed within the current service system.

In this project student researchers from the University of New South Wales (UNSW), overseen by academics from the School of Social Sciences and International Studies (SSIS) and the Social Policy Research Centre (SPRC) have partnered with the Futures Alliance and three other disability peak organisations in NSW. The Futures Alliance is a cooperative of community representatives from disability and aged care providers which includes representation from consumers, academics and peak bodies. The purpose of Alliance is to remove boundaries and to maximise community resources to deliver improved options for people with a disability who are ageing. The Futures Alliance has been formed and has grown via a network of professional relationships with a shared vision of influencing policy pertaining to people with a disability who are ageing and ultimately improving outcomes for this group of people.

This collaborative project aims to capture some of the key issues and concerns of a number of agencies providing direct care or advocacy services to and on behalf of people ageing with a disability. It forms part of a larger study of people with a lifelong disability who are ageing being conducted at UNSW, which explores the intersections between ageing and disability in theory, policy and practice.

The research has three broad objectives, to:

- Understand some of the organisation and/or advocacy issues associated with ageing and disability;
- Explore the experience of service users; and
- Identify the challenges facing service providers/advocacy organisations in understanding and meeting the support needs of their service users as they age.

For the purpose of this project, students in their final year of a Bachelor of Social Science degree conducted research with partner organisations from the Futures Alliance and the NSW disability advocacy sector, including The Spastic Centre NSW, Interchange Respite Care NSW, Sunnyfield, McCall Gardens Community, Physical Disability Council of NSW, NSW Mental Health Coordinating Council, Ability Options, Uniting Care Disability and the Futures Alliance itself. In each participating organisation, a small-scale 'snapshot' study was conducted over a 12 week period from July-October 2009, tailored to focus on specific agency concerns, but relevant to the overall project

This work has aimed to develop insight into the key issues facing advocacy bodies, service providers and people with disabilities in understanding and addressing the needs of people with a lifelong disability who are ageing within the current service system. Through partnering with these agencies, the project has consulted with a wide range of stakeholders within the disability and ageing sectors to cover an extensive set of issues. The research has covered areas including policy and advocacy concerns, the training needs of staff, planning opportunities, residential, community, respite and day program models of support, issues of financial security, cooperation across the ageing and disability sectors and where possible canvassed the views of organizational management and direct

service personnel and the experiences of ageing service users with a disability. The project aims to begin to identify and address a number of substantial gaps within the field and lay the foundational framework for a more sustained project on disability and ageing in the Australian context.

This paper is divided into six parts: The first two sections introduce the student project and set out the overall context of the issue including theoretical positions relevant to both ageing and disability, national and state policy, frameworks, and service provision models and issues relevant to the intersection of disability and ageing. Section Three outlines the methodological approach to the study including the sample and the approach to data collection and analysis. Section Four provides a summary of nine different agency 'snapshot' studies, outlining the aims, specific contextual background, methodology and findings of each. Section Four discusses a number of overall emergent themes, and Section Five concludes with a series of recommendations.

## 2 Background to the Issue

The Australian population is ageing and so too are people with lifelong disability. The emergence of this relatively new demographic has implications for a wide range of stakeholders including governments, service providers, advocacy bodies and people with disabilities and their families. The number of people with intellectual and psychiatric disability increased markedly between 1993-1998 and the number of people who have severe or profound disability who are over 65 has increased from 337,600 in 1993 to 1,238,600 in 2003 (Australian Institute of Health and Welfare (AIHW), 2008). This group has needs and interests which are distinct from those who acquire a disability as a result of the ageing process. In the past, people who had an intellectual disability were not expected to live until older age, and those who did were hidden from society, either in institutions or in family care (Buys et al, 2008, p. 67; Walker & Walker, 1998, p. 26). People with early onset disability, such as intellectual disability often experience the ageing process at an earlier age than the general population (Australian Institute of Health and Welfare, 2000). In addition, people with disability do not make up a homogenous group and consequently people with different types of impairments will have different needs as they age (Standing Committee on Community Affairs, 2007; Burkhardt, 2000).

Contemporary understandings of ageing and disability are delineated by two separate and differing theoretical orientations. As a result conceptualisation of the intersections between disability and ageing is largely underdeveloped. Theoretical approaches to disability have evolved over the past three decades from a predominant concern with personal adjustment and medical treatment or rehabilitation toward an understanding of disability as a social relationship with associated overarching complex discourses of exclusion and inclusion. In the same way that race and gender have been shown to be socially constructed phenomena, critical disability studies scholars have argued for the movement of disability from the pre-social realm of the body to more complex social, political, material and cultural relationships (Meekosha & Dowse, 2007). Disability policy has moved towards enhancing and protecting the rights of people with disabilities, with a broad orientation towards inclusion within mainstream education, employment and recreational activities (Lindsay, 1996) and in the community more generally. However, ageing and older people have largely been left out of contemporary considerations of disability, being under-represented in written accounts emerging from the field of disability studies (Priestley, 2000).

In the field of ageing, critical gerontologists have long challenged the medicalization of old age and have argued that the concept of age is socially constructed (Minichiello et al., 1992). An important component of aged care services in the principle of 'ageing in place' which aims to increase opportunities for people to remain in their home regardless of their increasing care needs (Senate Inquiry report, 2007, p.116). Ageing in place as a policy has been designed to enable residents to remain in the same environment as their care needs increased. Although broad support exists for an ageing in place policy for people ageing with a lifelong disability, there a number of barriers related to jurisdictional overlap, inefficiency of services and siloed funding. In addition, social theories of ageing have largely excluded people with life long disability, in particular taking little account of the cumulative disabling impacts of social, economic, personal and cultural exclusion in the ageing process (Putnam, 2002).

The ageing of people with disability has substantial implications for the service system in Australia. People who are aged 65 and older are served by the aged care system which is headed by the Department of Health and Ageing (DOHA). The Home and Community

Care (HACC) program provides services to older people but also to younger people with a disability and their carers (Standing Committee on Community Affairs, 2007). Service provision for younger people with disability is overseen and delivered by disability portfolios within state and territory governments, and by the Federal Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). The shared arrangement for providing services is laid out in the National Disability Agreement (NDA) (formerly the Commonwealth, State and Territory Disability Agreement).

There are substantial difficulties relating to the suitability, as well as the availability of aged care services once people with a disability turn the age of 65. Although the NDA does not have an upper age limit for its services, it defines people with disabilities as “those with disabilities which manifest before the age of 65 and in practice services are generally directed to people under 65 years of age” (Standing Committee on Community Affairs, 2007, p. 107). The aged care system is geared towards the needs of the frail aged; health care, residential and community supports for this group attract the bulk of resources. Congregate care in large facilities such as nursing homes and hostels is still a major service response for the frail aged. In comparison to the disability sector, there are far less visible strands of policy and fewer resources to foster healthy life styles and develop recreational, educational and productive daytime activities. This means that people ageing with a lifelong disability who enter into the aged care system are likely to be at risk of having neither their disability nor their ageing needs effectively met.

As people become eligible for aged care services at the age of 65, those with a lifelong disability may be disadvantaged as access to valuable disability supports and services may be forfeited within the aged care sector. Particularly in residential aged-care settings there is a fear of “double dipping”. In terms of gaining access to aged care services, people with a lifelong disability are again at a disadvantage due to rigid access requirements which do not recognize that people with disabilities age at an earlier stage. These differences between disability services provided under the NDA and aged care services provided under a federal portfolio impact on the focus of programs, the types of services offered, the main target groups and the expertise of personnel providing the services. While aged care services focus on health needs, broad personal care and self-maintenance, disability support services emphasize non-health needs and can address a broader range of needs, including for example community access and participation. For people with disabilities transitioning to older age the process is characterised by inefficiencies and inconsistent service provision. There are sometimes stringent eligibility requirements, ineffective assessment of needs and inefficient provision of services due to State/Commonwealth jurisdictional disjunctures. With no clear understanding surrounding the intersection of ageing and disability, many people are failing to meet the criteria for either of the two categories, or receiving second rate services from both service sectors because they are the primary responsibility of neither (Bigby, 2002 Bland, Hutchinson, Oakes and Yates, 2003 p. 327 cited in Leverett et al).

The needs of people ageing with a disability within this framework are largely under-researched. Importantly, it must be recognized that disability is far from a unitary category of human experience. Impairments may occur due to medical conditions or manifest as difficulties with sensory, physical, cognitive and psycho-social functioning, with many people with disabilities experiencing multiple involvements across these categories which impact on their lives in different ways. People with disabilities come from a diverse range of backgrounds, lifestyles and beliefs including those from Aboriginal and Torres Strait Islander backgrounds and from culturally and linguistically diverse communities. Their living conditions vary from independence in the community, with or without support from

partners or families, to service-supported accommodation models, to full-time residential care. People with a disability who are ageing are therefore not a homogeneous group and there is no single factor such as age, the age disability is acquired or the type of disability which will reliably indicate their needs as they age. This highlights the importance of tailoring services to the needs of each person and the necessity for services and programs to work across jurisdictional boundaries to meet these individual needs and circumstances (AIHW, 2000, p.38).

Across this diversity of disability experience, research with older people with disabilities suggests that “key importance has been placed on empowerment, active involvement, sense of security, maintaining skills and learning” (Boulton-Lewis et al, 2008, p.70), while dissatisfaction often stems from unfulfilled leisure preferences, lifestyle patterns and living arrangements (Reilly & Conliffe, 2002, p. 2). This theme is prevalent in much research into the experiences of people who are ageing with a lifelong disability, in that “the manner in which older people spend their time has a major impact on other aspects of their life including their well-being and quality of life” (Balandin et al, 2004, p. 240). Importantly the need for maintenance of activity is critical to high levels of life satisfaction as a service user enters old age (Putnam, 2002, p. 800).

The need for more effective policy integration has been recognised by government and non-government bodies over the past half-decade with for example, the Senate Community Affairs References Committee in 2005, recommending that the Commonwealth 'address the need for improved service linkages between aged care and disability services' (Senate Community Affairs References Committee, Quality and Equity in Aged Care, 2005, Recommendation 44, p.167) and National Disability Services (formerly ACROD) the national industry association representing not-for-profit disability services organisations, recommending in 2007 the adoption of a person-centered approach to service planning in both aged care and disability services (NDS, 2007, p.4). This approach proposed customized packages of support to fit the needs and wishes of the individual, rather than trying to make individuals fit into pre-set categories, exemplifying good practice in human services.

As a response to these concerns the Aged Care Innovative Pool Pilot was introduced in selected services in 2004. The Pilot, administered by the Department of Health and Ageing, provided a pool of flexible care outside the annual Aged Care Approvals Round with the aim of trialing new approaches to care for older people with dementia (Hales et al, 2006, p.1). The Pilot clearly showed that the provision of flexible, in-home supports for people with disability living in group homes is an effective way of preventing early entry into nursing homes yet, despite positive outcomes, funding for this project was not renewed on the grounds that further research was needed (Standing Committee on Community Affairs, 2007).

Policy development and service provision to ageing people with a lifelong disability involves a matrix of stakeholders. In Australia a sustained project addressing the range of stakeholder concerns has been slow to develop, although substantial work has addressed the experiences of people with intellectual disability (Bigby, 2004b, 2008). Currently research in the Australian context falls well short of providing a comprehensive picture of systemic concerns and the extent to which these map on to the specificity of differing impairment types and disability trajectories. In addition very little research exists in the area which explores how people with disability themselves define their needs.

### 3 Approach to the Study

In order to investigate the breadth of issues relevant for people with lifelong disabilities who are ageing, including issues for service provision and advocacy concerns, nine sub-projects were conducted by students completing their final third year course in the Bachelor of Social Science program at UNSW, overseen by Dr Leanne Dowse and Dr Shannon McDermott of UNSW. Agencies participating in the research were identified both from within the membership of the Futures Alliance and drawn more broadly from the NSW disability sector to ensure representation across a range of service types, including a variety of direct service provision models and advocacy foci as well as a range of disability experiences including intellectual, physical and psychiatric disability. Two agencies were both disability and aged care providers and were able to provide perspectives on the intersection of aged care, and disability service provision.

Five Futures Alliance member organisations supported projects as did the Futures Alliance itself. Three additional disability related agencies also hosted a project. The following agencies participated:

- The Spastic Centre NSW, which provides services for children and adults with cerebral palsy and other disabilities in NSW
- Uniting Care Disability, which provides a range of service to people with disabilities including assistance with daily living skills, respite care, community linking for people with psychiatric and other disabilities who live in boarding houses, supported employment and supported accommodation.
- Ability Options Limited, which provides services ranging from accommodation and case management to employment to over 1,000 people with a disability in Western Sydney
- McCall Gardens Community, which provides residential, community and support services to people with an intellectual disability in the Baulkham Hills Shire and Hawkesbury District of Sydney.
- Sunnyfield, which provides services to people with intellectual disability including accommodation, supported employment, day options, respite care, and recreation.
- The Futures Alliance, a cooperative of community representatives from disability and aged care providers including consumers, academics and peak bodies
- Mental Health Coordinating Council (MHCC) - MHCC is the peak body for non-government organisations (NGOs) in NSW providing leadership and representing the views and interests of over 200 NGOs. Member organisations specialise in the provision of services for people with a disability as a consequence of mental illness and their carers.
- Physical Disability Council of NSW - the peak body in NSW representing people with life-long physical disability.
- Interchange Respite Care - the peak body for organisations providing respite care and social support services to families who have a member with a disability, or is frail aged.

Each partner organisation was assigned two students to undertake a small-scale 'snapshot' study tailored to the organisation but broadly relevant to the overall project. Agency representatives assisted the students to formulate research questions around ageing with lifelong disability which were specifically relevant to issues currently experienced in delivering or receiving services or related to advocacy efforts or policy processes. Each study was designed individually with its own aims and research questions, literature review, methodology and findings. Individual agency studies are reported in detail in Section 4 below. From these nine studies, a number of common themes were identified which address issues, opportunities and needs within the current service system. These are summarized and discussed in Section 5 below.

Overall, a total of 104 participants took part in this study. Respondents included 47 organizational management or direct service workers in the disability or ageing sector and 57 people with disabilities who were agency service users or members of peak organisations, 40 of whom participated in an online survey. Apart from the work with the Physical Disability Council, which used quantitative data analysis through the use of surveys, the methodology used qualitative data collection methods. Across the studies there were 31 one on one interviews, four interviews with two people, six focus groups and one online survey with 40 respondents.

All interviews and focus groups were recorded with the permission of the participants and transcribed. The resulting material formed the basis for the qualitative data analysis which was undertaken using a thematic coding approach. The initial focus of analysis was driven by individual study research questions, with further thematic analysis, using a method outlined by Sarantakos (2005, p. 345) involving a process of identifying patterns and categories, and comparing and regrouping these categories to elicit the themes and relationships among these themes. The quantitative study was analysed by testing for frequencies and relationships between variables from the survey data using SPSS version 17.

Formal approval from the UNSW Human Research Ethics Advisory Panel was finalized before commencing fieldwork for the project. A consent form was provided to each individual taking part in an interview or focus group, which outlined the background and aims of the research. These forms were signed by respondents indicating their informed consent to take part in the research and included a section setting out how participants could withdraw from the study at any time.

### **Limitations of the study**

The study presented here is intended to be broad and exploratory in nature. It is designed to illicit a snap shot of concerns across a range of organisations, both service provider and peak or advocacy roles and people with a range of impairments. The sample of collaborating agencies is purposeful in that it taps a limited number of Sydney-based non-profit organisations who have expressed concern with issues of ageing and disability. It is not considered representative of the breadth of disability sector organisations at local, state or national level. Likewise, interview, focus group and survey respondents are not considered to be representative of all stakeholders in the issue and therefore it cannot be claimed that the data gathered is either exemplary or extraordinary in terms of the experiences of individual people with disabilities who are ageing. Similarly the data does not represent the only issues for service providers and peak bodies concerned with long

life disability and ageing. Instead it explores some key concerns that have been identified by a limited range of respondents.

As a student project, part of a structured third year university course, the study is necessarily time and content limited. Although the course ran for 12 weeks, a substantial proportion of this time was spent in familiarising students with core concepts and frameworks in the research process and contacting and framing up organisation specific research questions and approaches, leaving limited time for data collection and analysis. The data collected, findings presented and inferences drawn are substantially the work of student researchers, who, for the most part were undertaking research in the real world for the first time. As such the individual studies and the resulting overall analysis are necessarily limited in scope, depth and complexity.



## 4 Individual Agency Studies

### 4.1 The Spastic Centre NSW

This study is specifically focused on the cohort of people with Cerebral Palsy (CP) who are ageing in the community. The central aim is to explore the factors putting people with CP at risk of having to moving into permanent or institutional care as they age and to identify strategies and/or service to assist their ageing in place.

#### Research questions

- Are people with CP currently planning for the ageing process? If so, how are they doing this?
- What are people who have CP's attitudes and opinions toward ageing in the community?
- What are the factors that put people with CP at risk of permanent, institutional care?
- What strategies can be implemented to allow people who have CP to age in place?

#### Background

The population of people with a lifelong disability such as cerebral palsy is now more commonly reaching old age. With the process of ageing comes the need for additional support. Studies have highlighted the importance of providing services to people with CP as they age (Crawford 1996). Research has shown that for the vast majority of people with CP, the ageing process is having an effect on their lifestyle, which has led to increase level of self-care assistance, and with many people needing higher level and more intensive support (Balandin and Morgan 1997; Cooper 1996, p.26).

An underlying theme in many studies is the desire to stay in ones own home for as long as possible (Crawford 1999; Cooper 1996, p. 2). For many people with CP, the continuation of community support services is critical to achieving this goal. Although it is likely that most people with a lifelong disability prefer to live in the community, research has confirmed that housing and support options for older people with a physical disability are extremely limited, inaccessible and inappropriate (Cooper 1996:1-2; Bigby and Balandin 2005). Similarly there are structural and contextual issues such as the availability of staff support and attitudes of other residents (Hawkins1999).

There is growing concern regarding planning for the future and the ability to secure appropriate support if and when, people with CP are to retire from employment. Balandin and Morgan's (1997) and Foy and Campbell's (2002)'s research highlights that there is a considerable lack of planning for retirement by such people. Factors such as unemployment (which translates to lower income), can affect ability to gain formal support with day to day activities. Furthermore, exclusionary experiences such as a lack of adequate education and a lifelong experience in supported employment may work to limit the ability of people with disabilities who are ageing to plan for retirement.

#### Method

A purposive sampling technique was used to identify individuals with CP who are ageing and are currently living in the community. With the assistance of staff from the Spastic Centre, this sampling method identified nine participants who fit the criteria for inclusion in

study, that is, people living in the community who are aged 55 years or older. The sample includes five males and four females, with the average age of 57.5 years.

Six interviews were undertaken, four with individuals and two with couples. The interview schedule was based on a semi-structured set of questions, developed from the overall research questions and aims of the project.. An interpreter assisted in interviews with participants whose speech was unclear, with each interview lasting between 20-40 minutes.

## Findings

Four main subject areas emerged throughout the data collection and analysis processes that signalled themes which were consistently addressed by the participants. These were ageing-in-place, current service use, planning for ageing and views towards the future.

### *Ageing in Place*

All the participants expressed enthusiasm about living in the community and ageing in place, as it provided privacy, independence and a better quality of life. Quality of life is recognized as an important benefit to living in the community and being able to age with more lifestyle options, given the availability of necessary service which will allow them to do so. As one participant points out:

*The independence that I get living in the community that I can make choices without anybody saying you can't do that you have to eat at 5:30, that's what time the nursing home eats dinner, and if you don't eat at that time you go hungry... It's about the choice and independence and the freedom it gives you living in the community.*

Some respondents preferred to live in the community, simply because it was a better alternative to a nursing home.

*I've seen what hostel care is and getting old in that environment; I don't want that at all. That was mainly people with Alzheimer's and dementia. So I don't want to go there... bottom line is, I don't want to go into aged care.*

However, another expressed concern about the over emphasis on the ageing-in-place concept, worrying it could lead to specialised service neglect for people with CP.

*I fancy something like equity housing or hostels. One of the weaknesses of the system in the community at the moment is that if something happens out of hours, there is no backup.*

### *Current service use*

Participants felt that there is a lack of options available when faced with the risk of institutional care. There is a large gap between completely independent living and institutional care. This is a problem for people who need more assistance than provided for by the Home Care program but less assistance than is provided in a permanent institution such as a nursing home. There is a negative perception of nursing homes, due to the belief that there is little specialised care. Participants felt that they need and deserve specialized care if forced to move out of the community and into permanent care.

*"My biggest worry is nursing home, I don't like them, I would rather see a hostel. Something that is catered for us a little bit more".*

The gap most consistently identified by people with CP who are ageing in the community is support services that are responsive and flexible and able to be called upon in the case of acute need but not emergency. While federally funded Home Care services provide day to day support for care needs there is no service which can be called upon in times crisis other than the ambulance service. Many participants felt that calling an ambulance when they fell for example was unnecessary but they had no other choice or option available to them.

*I don't think I should call an ambulance each time I fall, I don't think it's their job to come in and help me up off the floor. I honestly don't know if it wasn't for friends and neighbours who I'd ring. I would have to call an ambulance. So there could be a service where people like me on their own most of the day, could call when they get stuck.*

Several respondents also identified the need for a 'call in' type service providing a worker to check in on them to provide some security and lessen the feeling of vulnerability.

### *Social Networks*

There was a significant degree of anxiety amongst participants regarding the long term viability of their lives in the community as family members and friends are also ageing. There is concern regarding the prospect of losing informal support and being put at risk of permanent institutional care. The study found that living in the community allowed for such informal social networks to form, however losing them meant losing the ability to remain in the community independently.

*Probably the biggest issue is my support network. They're getting older. My support network is older than me... Family and friends... put it this way, my most reliable friend who I call in is 83 years old. He won't be around forever.*

Many participants also expressed a fear of isolation in the community once they transitioned from working life to retirement, which, in terms of lifestyle, they saw as very similar to living in an institutional setting. For the couples interviewed, the prospect of one partner needing to move into residential care was seen as a significant risk factor for the other's isolation, or being forced to do the same.

*We don't want to feel isolated. At the moment our social networks are based around our workplaces.*

*My biggest fear is becoming separated by one of us needing to go into a nursing home.*

### *Planning for ageing*

For the majority of participants it appears that there is a significant lack of planning for the future, mostly due to a lack of options and/or information with regards to getting older.

*No we're not planning for old age. We don't know what's available.*

Additionally, none of the participants were informed throughout their lives of physical changes that lead to people with CP ageing sooner than those without CP.

*Interviewer: "Did anyone tell you in the past about the premature ageing for people with CP?"*

*Respondent: "No one told us".*

Housing and alternative accommodation options are another issue highlighted by participants. In regard to future planning and the risk of being placed in permanent care, respondents indicated the lack of options available if current service provisions were to, for whatever reason, cease to exist, decrease in availability or change in nature. This perceived lack of housing options increased their feelings of vulnerability.

Although regarded negatively, participants felt they had no other choice but to move into a nursing home in the future. The only planning evident was in relation to care services, where participants knew they needed extra help as they aged, however many were happy with the amount of care they received at present and did not plan to extend the hours of care unless they felt it would be necessary due to an immediate health crisis. These findings suggest that participants, although aware of potential increasing care needs as they age, do not actively plan for future retirement or their ageing needs in general. There is a sense that, because options for the future are not available or clear, they will inevitably experience a crisis of some kind which will trigger the worst case scenario and they will have to move into aged care services.

### *The Future*

There were suggestions of a need for a change in attitude amongst the wider community in relation to the role and value of older people with CP. Further, one participant called for more recognition by governments of the key concepts around disability and ageing. There were also practical suggestions that could be implemented in order to improve the quality of life for people who are ageing with CP through addressing the frustrations faced by many of the participants in dealing with policy and service gaps:

*It would be good if it (Vitacall) were extended for non medical purposes, not just for medical emergencies.*

### **Conclusion**

The freedom and independence experienced by people with CP living in the community was a key factor which participants viewed as beneficial to their current lifestyle. However, due to the nature of the disability causing health issues with the ageing process, it is clear that participants in this study believe that without adequate service provision, the likelihood of being able to age in place is limited. Many participants accept the fact that they will need increased support as they age however have not yet planned for this process. Moreover, a significant barrier to this planning for increased need for support is not currently recognised by government policy and service provision.

## 4.2 Sunnyfield

Community access programs, known as day programs, were accessed by 11,012 people in 773 services across the NSW in 2006-2007 (Australian Institute of Health and Welfare, 2008b). These programs have the highest percentage of people over the age of 60 (14%) out of all NDA funded services (National Disability Administrators, 2006). While it is acknowledged that people with disability require assistance when transitioning between programs, little is known about how people in day programs experience the transition into older age. This study seeks to explore how involvement in day programs impacts on ageing service users. More specifically, the research aims to evaluate the capacity of day programs to enhance participation in the community, and whether day programs can prepare people for future transitions.

### Research questions

- Are employees trained to recognise the signs of ageing within day program participants?
- Do the day programs enhance participants' ability to integrate into society?
- How effective are day programs in creating a smooth transition from family based care to service based care?

### Background

Day programs aim to promote social independence for people with disability who are not in school or who are not eligible for transition to work programs. Research has shown that programs do play a role in forming and cementing social relationships, as well as developing skills that can be transferred from one institution to another. Bigby & Knox emphasise that individual planning is particularly important to assisting individuals to reach their full potential (2009).

The two studies that have examined the role of day programs for people who are ageing with lifelong disability have found that they are an integral part of gaining autonomy and independence (Bigby: 1997; Buys: 2004). Day programs provided participants with specialised skills, the chance to build new relationships, as well as social skills which promote individuals living an active and fulfilling life (Buys, 2004; Bigby, 2007). Furthermore, day programs assist people to maintain social connections, particularly as people in their support systems are also ageing. The research suggests, however, that not all day programs will be capable of maximising autonomy and independence for people with disability; Bigby (2005) argues that aged care facilities that are not specifically designed for those with disabilities, are unable to provide programs that meet the needs of this group.

Previous work has attempted to understand and map the dynamics of disability and ageing in the context of the provision of supported accommodation (Chris et al., 2006) and supported employment (McDermott et al., 2009). There has however been a limited focus on issues that arise in the provision of day programs, including opportunities to participate in the community and to undertake meaningful leisure and recreation activities for people with disability who are ageing, with an increasing focus on providing a continuum of support and in the context of person centred planning (DADHC, 2009).

## Method

The St. Peters day program at Sunnyfield was selected as a case study to explore the experiences of service users and service providers in day programs. Qualitative methods were used, and a total of six participants were involved in the study. The results draw on an interview with two employees who had extensive experience within the disability sector and a focus group with three service users and one employee. The participants were selected by the manager of the St Peters program in consultation with the researchers. The interview and focus group were recorded and transcribed, and a thematic analysis of the transcripts was conducted.

## Findings

The findings suggest that promoting or sustaining independence for older service users is a key feature of day programs, which participants aim to achieve through individualised planning. As people age, however, participants discussed the challenges around managing transitions for both service users and families.

### *Individualised planning*

To promote independence amongst service users, participants emphasised the importance of assisting individuals to develop daily living skills necessary for living successfully in the community. Thus, one of the key activities of day program staff is to assist people to become aware of which activities are important to learn, and which may be detrimental to their well being. Maximising independence, however, also needed to be balanced against the fact that some service users required a sustained level of care. To determine the appropriate mix of activities, and to ensure that these activities align with the aspirations of each service user, the organisation holds planning meetings once a year to assist individuals to participate in activities that interest them.

The stated goals and progress in skills development are reassessed on a regular basis. To meet this objective, each staff member will be trained to conduct and organise such meetings:

*I have requested that our staff get the training to hold such meetings, and hopefully that will be happening soon, so we can conduct meetings every three months. We will be the first day program in Sunnyfield to do that.*

Employees at the St Peters program are not trained specifically to address the needs of their ageing service users, so to address the needs of this group, staff work alongside doctors, nutritionists and other health care workers. For example, any issues concerning ageing, decrease in mobility, and ability to participate are relevant when individuals want to participate in various activities. Employees who participated in this research stated that there is a gap in their knowledge about how best to address the needs of their older service users.

### *Managing transitions*

Managing the transitions of older service users from family based care to service based care was one of the challenges facing staff. Participants spoke of the importance of managing this transition through assisting service users to reassess their goals, and also communicating with families. Strong communication is a particularly important element of fostering smooth transitions into day programs and, to accomplish this, staff encourage service users and their carers to participate in program meetings. This allows staff to gain

an understanding of what might be required of the service in the future as people with disability and their support networks age.

Participants reported that strong communication could only be built after staff develop relationships of trust with the family and service users. This is fostered through regular contact with families, such as monthly brochures that encourage families to provide feedback to the service. Employees reported that trust is necessary as some families fear that if they complain or offer suggestions for improvement, that the person with disability will be excluded from the service.

## **Conclusion**

The findings suggest that day programs aim to promote independence of service users through individual planning and assisting people with disability to develop independent living skills. However, as service users age, it can become increasingly difficult to encourage independence due to increasing health issues of service users. It is therefore important that staff closely manage the transitions into day programs and presumably, out of day programs, through communicating closely with the service user's support network. Further training for Sunnyfield staff to address the needs of ageing service users, as well as further liaison with medical professionals, could be useful to meet the needs of older people with disability in day programs.

### 4.3 Ability Options

Ability Options provides accommodation, case management, employment assistance, as well as education and training, to people with disability. Over 1000 people with disability currently access services provided by this organisation. This study analyses the challenges facing Ability Options regarding the provision of appropriate services to people with lifelong disability who are ageing, as well as investigating tools and strategies Ability Options has in place to address the needs of this group.

#### Research questions

- What are the challenges facing Ability Options regarding the expansion of service delivery options for people with a disability who are ageing?
- What are the experiences and needs of ageing individuals with a disability using Ability Options' services?
- What tools and strategies does Ability Options have in place to deal with issues surrounding people with a lifelong disability who are ageing?

#### Background

There is a critical need for appropriate services in both aged care and disability service for people ageing with a disability (Bigby & Balandin, 2005). However, there are many organisational barriers to achieving this including the provider's lack of resources, inflexible service provision as well as attitudinal barriers (Buys: 2004). A reoccurring theme in the literature is the lack of staff training and resources. A study by Botsford indicates that 'the most frequent obstacle was the shortage of both direct care and nursing staff, and inadequate staff training' (2004: p. 7). Bigby & Balandin have shown that despite many service providers being willing to include people ageing with a disability, a very small number have access to these services. This suggests that there is "potential build on, support...and foster" the use of these services by older people with a lifelong disability' (2005: p. 17).

These organisational barriers have significant impacts on service providers, however, little is known about the experiences of service providers within this context. Central themes which have emerged in the literature include the importance of providing leisure activities, independence and choice and power of living arrangements as needs to people ageing with a disability (Buys, 2004; Bigby: 2009; Zarb: 1993). In investigating experiences of ageing service users, Zarb's study has identified that individuals encounter emotional changes throughout the ageing process such as increased anxiety, frustration, loneliness and depression. Some participants perceived the ageing process to be the onset of a 'second disability' with many feeling that their needs had been overlooked (Zarb:1993).

There is currently a large gap in the literature with regards to evaluation of assessment tools for people ageing with a disability. People who are ageing often fall through the net of existing service provision, partly due to lack of appropriate assessment, and the way that services are organised (Arber & Evandrou, 1993). At present, needs are often overlooked due to the lack of knowledge and understanding about ageing with a disability (ibid 44).

#### Method

Qualitative methods were used to answer the research questions. A total of 11 people participated in the study, including: a focus group with six Ability Options personnel as well as five face-to-face interviews with older service users with an intellectual disability. Two

service users lived independently, two lived with other people and one lived in 24-hour supported accommodation.

A secondary focus of the study was a document analysis of the Broad Screen Checklist of Observed Changes (BSCOC), developed by Minda Incorporated, which monitors ageing related changes and determines the need for additional services and support for service users.

The focus group and interviews were recorded and transcribed and analysed by extracting key themes. The BSCOC was analysed by examining the topics covered and in addition, comparing the checklist with data gathered from interview to determine the extent to which the themes that arose in the interviews are addressed and measured in the BSCOC.

## **Findings**

### *Challenges to providing services to older people with disability*

A number of challenges associated with the ageing of people with lifelong disability who are served by Ability Options have emerged around accommodation, staffing, and funding.

The first major challenge facing Ability Options is clients' living arrangements. While a number of services to assist people ageing with a disability to live independently are available, these services do not extend to overnight support, nor can they be provided in group homes. This is problematic because, as in the general population, people who have a lifelong disability are increasingly likely to fall and to require domestic assistance as they age. Furthermore, a number of older Ability Options clients live independently and are resistant to moving into group homes in the future. These clients prefer to move closer to Ability Options but to continue to live alone. The service aims to support clients to do this by,

*Knowing your clients and being there for them, keeping the routine the same and, if needed, increase the support hours.*

The second major challenge facing Ability Options in relation to clients ageing with a lifelong disability is that many older clients and, in particular, those who live independently, require increased support hours and Ability Options often does not have sufficient resources to accommodate this. Mobility was cited as a major issue for this client group, and there were particular concerns about the lack of support available for these clients if they fall and are unable to call for help or reach a phone. These increased support needs are becoming more difficult for the organisation to address. As one stakeholder commented,

*Three years ago it [the roster] was fine but now I'm getting clients coming up saying I need more support.*

This indicates that the ageing of people with lifelong disability is becoming increasingly problematic for Ability Options.

Funding also plays a major role in allowing Ability Options to provide the best quality services to their clients. The service requires an increase in resources to develop homes specifically for ageing clients, to provide staff training and to increase the amount of support hours to support older clients with disability.

A final challenge facing Ability Options, and disability service providers more broadly, is the separation between the disability and aged sectors. The accommodation coordinator noted that it is difficult to

*Access services that are more identifiable and accessible for people who are ageing, not with a disability. It's different funding buckets so you have this constant clash.*

Another participant noted that there has been some initiative taken to address this gap by an aged care pilot which involved teams accessing clients that disability agencies identified as having ageing issues, but that this funding was not renewed once the pilot finished.

#### *The needs of people ageing with a disability*

The service users who participated in the interviews included two who lived independently, two who lived with other people and one who lived in a 24 hour support home. The experiences of these service users indicated all were enjoying life and were content with their current living arrangements and that clients did not want to move in with other older people with disability. The reasons for this included,

*I can't live with other people because I get claustrophobia.*

*I don't get on with other people.*

The two participants who live independently, however, both expressed a desire to move closer to Ability Options so that they could be in closer proximity to the support services that the organisation provides. None of the clients had major fears about getting older. However, some staff suggested that clients struggle to fully understand the concept and possible consequences of ageing.

All of the service users participate in a range of activities such as movies, discos, fishing trips, shopping trips and outings into the city, line dancing classes, painting classes and football games. Furthermore, the majority of the clients' friends were also associated with Ability Options, highlighting how Ability Options facilitates social networks for their clients. The clients who live independently are both frequent visitors to the Ability Options office demonstrating the close ties they have to the agency.

Ability Options service users also indicated that they have interests outside the service which they see as important in their lives and complementary to the services they receive from Ability Options. One client, Cheryl\*, who lives in a 24 hour support home, does painting classes on Tuesdays which is separate from Ability Options. "She's actually entered her paintings in Blacktown and Parramatta show." Another client, Rob\*, is an avid Bulldogs supporters and often goes to their games. He lives with a housemate near Ability Options and participates in many activities. He is enjoying life and doesn't want anything to change. Bob\*, a client who lives in a group home, expressed a desire to work again but he acknowledged that there was little possibility. He did say that he would like more independence but does enjoy different activities with Ability Options such as fishing trips and bowling. This meshing of services and supports from both inside and outside the organisation appears to be a key factor in the satisfaction clients reported about their lives.

## *Tools and strategies for meeting the needs of people ageing with a disability*

A List of Observed Changes (BSCOC) is an assessment tool developed by Minda and employed within Ability Options to monitor changes along a range of dimensions in clients who are ageing. The BSCOC was analysed by examining the topics covered by the checklist. Below is the list of topics and the type of questions asked within each topic:

- Health issues - indicators of change in eating, sleeping, digestion, breathing, circulation, bladder and bowel habits, skin texture, rate and length on infections;
- Physical competencies - indicators of change or decline in gross motor (standing up, walking) and fine motor (use of fingers, likeliness to drop items) skills;
- Sensory integration - indicators of change or decline in vision, hearing and transmitting sensory input into actions such as talking or walking;
- Perceptual/Cognitive - indicators of change or decline in perception, recognition, recall and decision making;
- Social/Emotional - indicators of change or decline in social interaction and emotional responses;
- Activities of daily living - indicators of change or decline in basic functioning skills in everyday life such as showering, going to the toilet, dressing, eating, household tasks, awareness of community dangers (roads, pedestrian crossings) etc.

These topics were found to be relevant to how a person ages and the number of issues that could arise as identified in both the focus group and interviews. The checklist is completed by a carer who has known the client for more than 12 months. This raises the issue of the absence of direct input from the client themselves. Including a structured opportunity to canvas the views and opinions of clients about their own lived experience of ageing may potentially add a value dimension to the information gained from the BSCOC. However overall it was found that the checklist closely reflects issues identified in qualitative interviews in this study and is therefore likely to be a beneficial tool in evaluating the changing needs of a person with a disability who is ageing and determining the need for specialist involvement.

## **Conclusion**

This study has examined some of the issues facing Ability Options in the provision of services to people with a disability who are ageing. The study found a number of major challenges for Ability Options: living arrangements, staffing and funding. The study also explored the experiences of service users with Ability Options and found that the service users were all enjoying their lives, were actively participating in activities with other clients and had good social networks which consisted of other clients, staff and family. The BSCOC was one tool used by Ability Options which appears to identify the issues around people with a disability in a way that is useful for the organisation.

## **4.4 McCall Gardens Community**

This study explores and evaluates staff development issues in working with people ageing with a lifelong disability. This study consulted with professional staff within McCall Gardens to explore the technical, physical and emotional challenges associated with providing care. The study aims to identify relevant work related skills, and assess staff capabilities and training models to better meet the needs of people ageing with a disability.

### **Research Questions**

- What has been learnt through the introduction of McCall Gardens innovative program for disability and ageing?
- What are the skills and competencies required in order to meet the needs of people with a disability who are ageing?
- Do the current available training packages adequately address the relevant issues and skills needed for people ageing with a disability?

### **Background**

The specific aspects of staff training and development when working with people ageing with a disability are yet to be sufficiently explored. Although earlier research has identified many issues faced by service organisations as a whole, the everyday staff experiences are largely unknown.

While there is a clear call for greater staff development, little is known about the specific key competencies and skills required for the care of people ageing with a disability. The few studies which have touched on this area identify the main skill sets as including advocacy, the promotion of a healthy lifestyle, extensive observation and documentation, and specific knowledge surrounding dementia and preventions of falls (Williamson & Harvey: 2007, p. 17; Bigby: 2000, p. 19).

Some researchers have attempted to develop training initiatives including Melville (2006), Williamson and Harvey (2007) and Innovative Pool Pilot initiative (2006). Melville trials a 'training pack' and assesses the competencies of nursing in the United Kingdom. The National Disability Services NSW suggests a staff training approach, which promotes ageing in place. This includes training staff in elements of 'successful ageing', and emphasises increasing skill maintenance and knowledge of specific disabilities. The Innovative Pool Pilot initiative has aimed to develop a staff strategy in order to keep people in their current disability funded living situations. This involves tailoring service provision to individual needs and providing higher levels of personal assistance. All three of these methods have reported relative success; however, together they demonstrate the complexities of implementing and trialling a staff training program. These include economic efficiency and funding barriers, as well as the inability to manage significant medical problems. However, studies are generally concerned with assessing and testing staff skill and knowledge rather than gaining insight into experiences and problems associated with providing services to people ageing with an intellectual disability, which is a considerable gap is key focus for this study.

### **Method**

The study sample included support staff working within McCall Gardens who provide professional support to people with an intellectual disability. Agency liaison personnel

identified appropriate staff members to take part in the research. One focus group and four semi-structured interviews were conducted. The total sample was 10 support staff: eight staff members participated in the focus group and four management staff engaged in in-depth interviews. Two staff members participated in both the interviews and the focus group.

## **Findings**

The results are presented in three broad categories: key skills for staff working with people ageing with a disability; available training pathways; and staff capability.

### *Key skills*

Five categories emerged from the data regarding key skills for staff. They include medical; physical; administration & observation; psychosocial and communication skills.

*Medical* - Several staff noted that there were considerable health challenges that emerged as clients aged, as a result of both of physical and psychological changes. Staff identified a range of medical conditions that are more likely to emerge in this stage and need to be managed including: ulcers, skin management, cerebral vascular strokes, loss of sensory, sight, and hearing arthritis, dementia, diet and dysphasia. There was a strong emphasis on the importance of medical proficiency to prevent people from being transferred prematurely to the aged care sector.

*We have had to put learning and competencies and skills around health care, palliative care...so that we don't prematurely hand people over to aged care.*

New issues have arisen with promoting a duty of care surrounding medical conditions. While staff expressed a critical importance in facilitating choice of people ageing with a disability, it can become harmful if choices are given against medical needs.

*You can give people a choice to some extent, but you have a duty of care to provide the right choices for clothes, food, etc. If a person has dysphagia you wouldn't give them a piece of steak and you have a duty of care to say this might be better.*

*Physical* – Closely connected with medical needs. There was a concern that declining health created difficulties in mobility and the emergence of lifting as part of basic care activities. In addition, as clients age staff experience a greater intensity in the nature of time and effort put into each individual where on a day to day basis.

*It takes longer to do everything with [clients ageing with a disability] because physically they may decline...and then getting them to an appointment or a social outing takes longer.*

This suggests the central necessity for staff to develop knowledge and skills in the proficient use of aids and equipment used by people who are ageing.

*Observation and administration* - Staff indicated that a key skill was the ability to deliver a clear, frequent and accurate record of observation in monitoring changes in client health, functionality and behaviour of clients. An aged care worker shared her experience:

*[Clients who are ageing] need a lot more attention, you need to do a lot more with them. You have to get them assessed regularly, they have care plans done once a year, and they are reviewed every six months. There are always changes.*

To address this, another staff member asserted the need for knowledge of relevant charts and observation techniques “*like blood pressure charts, weight charts, dietary charts, fluid balance charts and the list goes on*”.

*Communication* - Staff believed that it was important to form relationships and communicate with people ageing with a disability. An important skill here is having the right insight, understanding and tone of voice, as well as the ability to connect with people on a personal level. As suggested by the community services manager:

*It's your tone, your [ability to be] genuine, and the time that you take to let them [speak] their thoughts... I think if you get to know someone on a personal level you can understand what their needs are.*

However, staff often found that there were increased challenges preventing effective communication, for example loss of hearing or visual acuity. A team leader commented that:

*As [people with a disability] are ageing they don't have as good communication skills, they can't tell you the subtle things that are changing with their bodies.*

*Psychosocial* - An important point stressed by many of the staff interviewed was the importance of considering problems of social isolation that people ageing with a disability often face. Staff reported that it is important to support people by connecting them with the community and family.

*We all travel all around the earth to pick up a 90 year old family member, to bring them to visit their 60 year old child here, which not a lot of other services do.*

The provision of grief and loss support to clients is also a key function that staff undertake. As people with a disability are ageing, they may lose a parent or sibling. Staff regularly provide support to clients who have lost family members, an area very little considered in the research and practice literature.

*We are having to work through the death of siblings and grief and reactions. We are having to work with parents deaths and assisting clients the process and [staff] are doing a superb job with addressing their feelings.*

This appears to be a key emerging area of practice for support workers and in the case of this service, approaches have been developed at the local level and in response to need rather than as an area recognised in broader policy and practice in the field.

*I saw sixteen years ago a man (with a disability) was told your father passed away, that's what he was told and (the staff member) walked away...but now we are saying "what would you like to do?"*

There is also a need to support for staff, as several identified ‘*issues around bonding, attachment, grieving and loss*’ for themselves as well as the clients.

As the population at McCall Gardens ages many new issues have emerged surrounding palliative care and end of life issues. Again the staff indicated that, in the absence of broader policy and practice guidelines in the field, they have developed their own approach to supporting each other and their clients.

*The guys might go to hospital and then they might never come back or they might move to a nursing home. There are certain supports that the staff need to deal with that. We have our own procedures in dealing with those sorts of things. We might do to support staff with dealing with loss, sitting down with them, talking with and see how they're coping, trying to identify any sort of physical or emotional upset that they're having.*

### *Availability of training*

*Formal training* – Although the staff have a mixture of training experiences, there is a general consensus that neither the disability nor aged care training adequately address the specific skill set needed to provide staff support for people ageing with a disability. The opinions of staff were that ageing training alone was inappropriate for their clients, as it did not promote enough independence or empowerment for clients. Staff essentially wanted a merging of both ageing and disability training and skills.

*Of course there is a certificate IV in aged care, but what would be really useful for our staff is if we have some sort of combined combination of that. I think we would need to look at the competencies of both ageing and disability and ageing courses and bring it together.*

*Experience and on the job training* - Several respondents reported that they continued to learn a variety of skills on the job. The innovative pilot has allowed staff to acquire knowledge and apply workplace practices. McCall Gardens has provided internal training for staff both through service training through senior management team or through the health coordinator.

*External support* – to fill the knowledge gap surrounding ageing, McCall Gardens had assistance from specialist staff such as registered nurses, speech therapists, physical therapists and occupational therapists to provide services to train and supervise support workers. The availability of expert support when problems are particularly complex has been of vital importance and the staff have found this external training support very helpful.

*We will bring in other people to facilitate the training, so when we are doing dysphasia we will bring in a speech pathologists who does work with us.*

### *Staff capability*

Staff generally presented confidence in their knowledge and skill set. They felt they had effectively identified their knowledge gaps and through an innovative and committed approach to enhancing their skills learned new skills very quickly and were able to implement ageing in place strategies effectively. Staff said they had learned about a range of issues from a medical perspective such as pain relief, but also psycho-social issues such as managing grief and loss, palliative care and end of life issues.

*We've proved that we can keep people right to the very end. The only time we are struggling is when people are so physically incapacitated. But we are overcoming this now but the risk isn't to the [client], It's to staff. So ageing in place is what we're promoting...and its what we want to be doing.*

There have been many skills learned from their involvement in the Innovative Pilot Program, which is a specifically designed service for senior people with disabilities. The pilot was established and funded to test ageing in place for people with disability in

supported accommodation. The management staff believed that this was a highly successful program for staff development, and attributed its success to a number of key strategies including: development of knowledge and skills in managing medical conditions; external assistance from specialised health fields, implementing individual and personal plans and open and positive attitudes on the part of staff. Barriers have included the discontinuation of funding for any new clients; difficulties “when people become physically incapacitated” and specifically problems around dementia training. During this time some of the clients support needs have become too great and as a last resort they have been transferred into aged care services.

## **Conclusion**

This project has explored staff experiences associated with providing support services to people ageing with a disability. It has identified a number of key skill areas that contribute towards the development of practical capacities required to meet the needs of people ageing with a disability. The skill set requires both technical proficiency surrounding health care, as well as an emotional approach that promotes social inclusion and facilitation of choice. However, it is evident that formal training options are less than satisfactory in meeting these needs. Rather, McCall Gardens has developed its own innovative and situated approach which includes internal support and training for staff, as well as seeking targeted assistance and training from external health specialists.

## 4.5 Uniting Care

Uniting Care is one of the only organisations in Australia providing services both for people who are ageing and people with lifelong disabilities. As a result, this study provides a unique perspective on the intersection between aged care and disability support. The focus of the work with Uniting Care centred on issues related to meeting the support needs of service users who are ageing with lifelong disabilities in residential aged care.

### Research questions

- In the experience of service providers; what are the common reasons for people who are ageing with lifelong disabilities to enter residential aged care?
- Are service users' [who are ageing with lifelong disabilities] needs being met in the eyes of service providers?
- What issues do service providers identify in meeting the needs of people ageing with a lifelong disability?

### Background

The care environment and living arrangements can have a profound impact on people ageing with a disability. As such, there is a large "concern about the suitability of residential aged care for this group of people due to compatibility with other residents and the narrowness of nursing home focus on nursing care which may come at the expense of quality of life issues" (Fyffe, Bigby & McCubbery, 2006, p.8). This view reflects the perception that aged care systems have a narrow focus primarily on personal and nursing care (Bigby, 2008:81). Past studies have shown that the needs of people with lifelong disability who are ageing are met more effectively in the disability sector than in the aged sector Bigby (2008, p. 79).

There is an absence of formalised partnerships between disability and aged care systems to provide supplementary support (Bigby, 2008, p. 79). Little research or evidence exists which explores the potential for resourcing the aged care sector to foster its use by older people with a life-long disability (Bigby & Balandin, 2005, p. 17). This research gap that exists is likely due to the fractured nature of aged care and disability service systems, such that responses to people with lifelong disability who are ageing have developed in an ad hoc way. Furthermore due to the rarity of such partnerships and programmes, there is little significant data to ascertain the successes of such programmes.

There are a number of factors that influence the transition of people ageing with a disability into aged care facilities. Firstly, there is a lack of forward planning by ageing carers on behalf of their family member. In addition, when ageing families make plans, they often focus on finding a place to live, and rarely take quality of life factors taken into consideration (Reilly & Conliffe, 2002:105). The result is often that a transition into alternate accommodation occurs due to a familial care crisis, markedly hampering a service user's opportunity to age in place (Bigby, 2008, p. 77), something that most scholars now regard as being the optimum care path.

### Method

A qualitative research method was employed in this study; three focus groups of between 4-6 participants were conducted with a total of 14 participants. Focus groups were comprised of employees of three different Uniting Care Ageing Aged Care Homes in different parts of Sydney. The participants varied in their roles within the facilities, with

nursing staff, registered nurses, registered anaesthetists, shift managers, education co-ordinators, activities co-ordinators, nursing directors and facility managers represented. Focus groups were between 30-60 minutes in length and were recorded and later transcribed for analysis purposes.

## **Findings**

### *Living arrangements*

The predominant view expressed by participants was that aged care services should be responsible for providing care for people ageing with lifelong disabilities, with assistance from the specific disability support services needed by individual service users. The reasons advanced for this centred on the belief that most significant needs did in fact arise from the ageing process itself for service users in a residential aged care setting, with disability needs becoming secondary. Therefore it was argued that the primary concerns of people ageing with lifelong disabilities are issues brought on by ageing, and thus the aged care sector was the appropriate place for them.

However, concerns were expressed that aged care environments offer limited living choices for many service users. People with disabilities who experience high levels of support needs often experience ageing at an earlier stage than others and are at risk of being transferred into facilities with residents who are much older than they are. This can lead to detrimental impacts associated with lack of stimulation and social interaction. A further cause for concern in this circumstance was identified by participants as relating to the fact that the needs of people ageing with lifelong disabilities differ greatly from the majority of aged care residents. This is likely to have consequences such as increasing demands on staff, but can also lead to the service user's needs not being met to the fullest potential. Further, the segregation of people with lifelong disabilities in aged care facilities is likely to reduce opportunities for community access and inclusion.

There were several reasons that respondents identified that are likely to be responsible for people with lifelong disabilities entering into residential aged care. This primarily centred on a deterioration in health associated with ageing where for instance loss of mobility or reduced cognition intensified support needs and often led to the development of multiple disabilities. The emergence of such a health crisis can have implications for family members and carers, disability service providers and the individual themselves, with the result that the individual's care, support and service arrangements are no longer appropriate for their needs.

Inadequate planning for ageing by people ageing with a disability or their carers was also identified as a factor which increases the likelihood that an individual with lifelong disability will need to move into residential aged care. It was highlighted that service users and their previous carers most often showed poor practice in forward planning, resulting in a negative outcome for not just service users but also for service providers. Inability of service users to manage their own finances was also cited as relevant here, with intervention often required to ensure service users' resources are effectively managed for their benefit. The emotional and social fallout caused by a sudden change in environment was noted as a key issue that service providers had to resolve, often with difficulty, before any other steps to successful ageing could be undertaken. The need to enter into facilities for emergency care/accommodation means service users are ill-prepared for a change in environment. This was illustrated by one participant's story of a client she works with:

*She's crashed into the situation where the daughter is the main carer, who also has children who are at high school, and also the daughter has a lot of demands on her. So she has been looking to us to try and fill the void, we've had to, particularly our chaplain has had to bear the brunt of this lady's particular inability, no, difficulty in assimilating into an environment where she melts in rather than being the different one, so it's a huge, huge issue*

### *Planning and adaptation*

It was a commonly held view that more flexibility needs to be achieved in order to provide appropriate environments for people who are ageing with a disability as support needs for this group can change quickly, and usually become more complex with increasing age. Changing support needs require a responsive process of individualised care planning as universal care planning will likely not capture changing needs. In addition activities and supports should be able to be modified in accordance with residents' wishes. While respondents indicated that staff '*generally go out of their way to be flexible and ensure appropriate support for residents*', modifying and individualising practices of support is costly both in time and financially. So while aged care practices can be modified to an extent to support people ageing with lifelong disabilities, service providers identified the fact that there are limits to this practice.

Informants cited as useful current processes for seeking feedback from service users and their families, whereby the concerns of residents and their families are acknowledged and responded to. Spot audits are also conducted to ensure consistency in quality of care. In addition, there is use of external resources as required by residents ageing with lifelong disabilities from government, non-profit and privately run organisations.

Modifications to the physical environment (hand rails, curtains, etc.) were also identified as a central requirement for accommodating the needs of clients with disabilities. Most of these modifications to the environment were evident in the low care facility investigated:

*Because they can't hear us and we have to knock before we enter their room, they have their own special [flashing] doorbell so they know when someone wants to enter.*

### *Issues associated with disability*

Service providers are adept at meeting common ageing support needs such as those relating to physical mobility, which may too apply to physically disabled persons. However, addressing the needs of people with intellectual or developmental disabilities was identified as more complex and difficult to provide support for in a typical aged care environment. Conversely, in an environment where dementia and poor cognition is commonplace, people with intellectual disabilities can be more easily accommodated and in practice often prove to be easier to communicate with in comparison. Communication was a major concern raised by service providers. With a range of disabilities manifesting as difficulties with communication, aged care staff identify the complexity in communicating with clients with disability as a significant barrier to understanding the needs of their clients and therefore ultimately meeting those needs. Respondents also recognised that difficulties in communication can sometimes intimidate staff causing them to avoid specific service users. These difficulties can also serve to limit the emotional support available to these service users.

## *Isolation*

The existence of significant age differences between residents with a lifelong disability and aged residents is identified as a problem that often leads to social exclusion for people with a disability who reside in aged care facilities. This coupled with what may at times be vastly differing levels of cognition and independence may further operate to isolate clients with disabilities from the broader community within the aged care facility, in turn placing increased demands on already pressed staff for whom health and personal care needs tend to take precedent over social participation and inclusion.

*I think for them, they're still quite isolated because the other older residents have not had any experience or dealings with people who have to sign so I think they get excluded, not intentionally though.*

Service providers identified the particularly central role of pastoral care staff within Uniting Care in addressing at least some of the psycho-social needs of residents with disabilities. On site chaplains and religious services were identified as a major benefit to service users in all the residential aged care facilities as confidants and advisors, especially for residents who encountered problems with support and transition into these facilities.

## *Staff development*

The aged care providers interviewed in this study indicated well targeted and responsive staff training is crucial to enabling service delivery to be adapted to address the disability specific needs of service users. This can include in-house training programs or consultation with external services or families. External professional assistance might include for instance psychiatrists, dieticians, massage therapists and spiritual representatives.

The experience of service providers in meeting needs precipitated by ageing indicates that additional training, based on needs identified by staff themselves and delivered at a grassroots level, enabled them to enhance the care they were able to provide for their service users. This organisational focus and commitment to enhancing staff skills is identified as central to creating a culture in which staff are encouraged to remain flexible to adapt their skill set to the changing support needs of their clients.

## *Assessment*

All staff viewed the role of comprehensive and timely assessment as key to the successful placement for people with disabilities in aged care facilities. Rather than the segregation of clients with disabilities into separate facilities, informants noted that comprehensive assessment prior to placement is a key mechanism in determining resident compatibility and appropriate placement. Also discussed was the incomplete nature of the ACAT assessment system, with suggestions that it should be modified to provide greater insight into the needs and conditions of persons with a disability. Issues with the current ACAT were expressed in all three focus groups;

*So when they are admitted here, based on a comparison to the ACAT assessment, there is a big difference*

*When they enter we have to gather some of this information, and I will not have anyone come here now unless I've sited them along with their ACAT*

## **Conclusion**

Study participants generally agreed that a far greater level of cooperation is necessary between the disability and ageing sectors in order to promote successful service provision, congruent with the sentiments of the literature already existing in the field. This should allow aged care providers to draw on the specific expertise of disability support services when needed. This study has revealed that the staff of Uniting Care residential aged care facilities are passionate about and for the most part feel able to provide adequate support for service users who are ageing with a lifelong disability, given access to resources and targeted skills training.



## 4.6 Mental Health Coordinating Council

Research into ageing for people with lifelong mental health problems has been a relatively unexplored domain. This study aims to identify the emerging issues for the sector by interviewing a number of MHCC member organisations providing psycho-social rehab and supported accommodation services to ageing consumers. The investigation aims to identify the barriers impacting on access to services, relapse prevention and ongoing maintenance of health and well-being of people ageing with a lifelong mental illness.

### Research questions

- What are the primary issues for people with lifelong mental health problems as they age?
- What issues do organisations face in supporting and providing services for people with lifelong mental health disability who are ageing?
- What can be done to improve the current capacity of mental health service providers in assisting older people with a lifelong mental health disability?
- What can be done to improve access to services for people with mental health disabilities who are ageing?

### Methods

Five 30-minute semi-structured interviews were conducted with four MHCC member organisations:

- New South Wales Consumer Advocacy Group (NSW CAG) - a statewide organisation providing a mechanism for consumers to participate in policy and service development, implementation and evaluation.
- Aftercare: an organisation that supports independent living for people with mental illness and/ or co-morbid intellectual disability with complex need in the community.
- New Horizons; an organisation providing a diversity of supported accommodation; employment and aged care for people with a disability. Two interviews were conducted with workers from physical health coordination and mental health services to people living in boarding houses.
- Psychiatric Rehabilitation Australia (PRA) - a social enterprise providing non clinical rehabilitation community based support services to people with psychosocial disadvantage or psychiatric disability. One interview was conducted with a worker from PRA Embark Cottage, which provides activity programs for adults living with a mental illness.

Interview schedules were developed to gain insight into the primary issues for consumers as they age, to identify the difficulties organizations face in supporting consumers, and make recommendations regarding quality improvements and enhanced access. The qualitative data was analysed and thematically coded to identify key issues and strategies for improvement.

## **Background**

There is a lack of data on aged consumers accessing mental health services and little research evidence on people with lifelong mental health disability. However, as the population ages, a significant number of consumers will need support in the aged care and mental health sectors. Australian Institute of Health and Welfare data indicates that one in four mental health-related illnesses are experienced by people aged 65 years and over; a higher rate than any other aged group, although it does not extrapolate the degree to which these figures represent lifelong disability (AIHW, 2008a, p. 11).

People who live with a mental illness encounter many problems on a daily basis which are magnified as they age. As consumers age, other mental health problems associated with the ageing process are more likely to emerge, including dementia, depression and bipolar disorder (Lee, 2007, p. 16).

A central issue identified in the literature is the capacity of people with a lifelong mental illness to access services. There is a need to provide flexible services that can be tailored to meet the changing needs of consumers as they age, taking into account factors such as episodic unwellness and respite and carer support. Draper et al., (2003) identify access to a diversity of co-ordinated services such as supported accommodation, primary care and other public health services; psychosocial support; respite and employment as critical to maintaining health.

As people with lifelong mental illnesses age, experience cognitive decline and the emergence of age related mental illnesses, their capacity to access services deteriorates. In turn this adds to the complexities associated with stigma and discrimination people with lifelong mental health problems experience when trying to access services (Bartel, Levane and Shea, 1999).

This study builds upon scant literature and minimal data collected by the health and age care sectors, identifying service delivery gaps, and highlighting emerging concerns for an ageing population with growing numbers of people ageing with a lifelong mental health problems and complex need.

## **Findings**

The themes that emerged as the primary issues for people with lifelong mental health issues as they age, include the experience of stigma and discrimination, isolation and difficulties in building and sustaining strong socially inclusive community networks and access to meaningful employment, recreation and respite. The service providers to this group described a disjuncture between the mental health and the aged care systems, difficulties in meeting the needs of clients as a consequence of inadequate funding and the need to build workforce capacity and training.

### *Stigma*

An issue identified across all those interviewed was the experience of stigma and discrimination associated with mental illness, whereby the person experiencing the illness is characterised as different or dangerous, perpetuated by reports in the media. Frequently such perceptions can lead to social exclusion and reduced access to those who may potentially be part of their support network such as family and friends, intensifying their isolation and preventing them from having supportive inter-personal relationships and gaining access to appropriate services.

*I think the stigma thing in the families is a really important thing because we've got clients or residents who would love to spend more time in the family home, especially in big group families where everyone lives together and they are told no, you can come once a month because of the stigma*

Social connectedness is particularly important for people as they age. For everyone in the community the existence of informal support networks of family and friends is a key source of support. People experiencing lifelong mental illness, whether episodic or not, tend to be social excluded and characteristically more vulnerable to lack of support at they age.

### *Funding*

Three out of the five interviewees identified sustainable funding and capacity building as issues. Despite this those individuals interviewed are positive about the growth in funding to the mental health sector from State and Commonwealth sources.

*The State and the Commonwealth government are putting more money into mental health than they ever have before. The Commonwealth particularly over the few years, is putting in enormous amount of extra money in and that's good*

Nevertheless, interviewees acknowledged that whilst the investment to mental health is large, it fails to meet need. In particular areas such as housing for people with a lifelong mental health problems the HASI program has begun to address the issues, but such services need to be expanded to meet complex need and bring sub-acute / age care into the mix.

*There isn't enough money to back it up to provide housing in the community for those people suffering from long term mental illness*

### *Employment*

Several key issues were identified as affecting a consumers' opportunities for employment as a result of the nature of their illness. Many mental illnesses are episodic, requiring that consumers find flexible employment that enables them to access a disability pension when unwell, whilst maintaining ongoing job security. Furthermore, consumers often have little previous work experience, a significant barrier to gaining employment.

As a rule, people become less employable as people age. Combined with mental health implications, this poses a significant challenge for consumers in gaining and retaining employment. This in turn affects access to friendship and social networks, as the workplace is a primary site for many people to develop networks.

An inability to participate in the workforce may lead to difficulties in planning effectively for old age. Without previous employment, and little access superannuation funds or accumulated savings many people with lifelong mental illness live in poverty and isolation unless supported by family and friends.

*I guess people who have had a lifelong mental illness who haven't been able to engage in employment, aren't going to retire. That is a totally different ball game. In some ways some people may go 'oh yay!' they don't have to work but most of these people would rather work*

### *Mental health and the aged care system*

Due to the absence of appropriate services, people with a lifelong mental health disability who are ageing, are not having their needs met by either mental health or the aged care sectors (Hall, Waldo and Harvey 2006, p.7). This is likely to be a marginalised group set to grow over the next decade as middle aged consumers move towards old age.

The study findings suggest that there are a significant number of people ageing with a mental health problems moving from mental health services into aged care where their needs are not appropriately catered for. The capacity and skill set of the aged care workforce is generally unable to meet a holistic mental health focused service delivery model. In fact, it appears that aged care providers are reluctant to take on people who have mental health needs. One interviewee named a boarding house that catered for mental health aged clients. However, they reported that this boarding house was closing down due to the expansion of the main ageing department.

*The primary issue really is that a lot of aged care facilities do not want to or are reluctant to accept a person with mental illness. Aged care is institutional living and they need far deeper support to work efficiently and effectively.*

### *Isolation*

Isolation is a key issue identified by all interviewees. Firstly, a consumer's personal perception of their mental illness can become a barrier and to accessing appropriate services, undermining their confidence and capacity to advocate for themselves in a complex service landscape.

*People's perception of mental illness is going to be a barrier to accessing services, if they see it as a deficit in themselves, they are less likely to acknowledge it and get the services*

When this personal perception combines with inherent discrimination and stigma identified in mainstream services, it appears that there is likely to be a significant level of unmet need for support for people with a lifelong mental health issue as they age.

### *Limited community inclusion*

A major problem experienced by people with a lifelong mental health problems is a lack of socially inclusive programs to help them retain the independence to live in the community into old age. Whilst there has been a move to deinstitutionalisation and an emphasis on involvement in the community, often people with mental health problems are not being provided with adequate primary care, clinical support nor additional activities to maintain social networks.

*There isn't often the support in the community for them to be able to stay in the community and stay in their homes and maintain their connections and other things so often they end up in hospital. So that access to community services is really crucial and its crucial over the whole life course in terms of staying connected with people with family, with friends and with employment and with education..all those really important things*

## **Conclusion**

This study has identified a range of problems that service providers face in providing support to people with lifelong mental health problems who are ageing. The study highlights the complexity of inter-related barriers that impact on the housing and care options consumers have as they age, which arise from both mental health and aged related difficulties. The combined and dynamic effects of personal and systemic issues mean this group of people are particularly vulnerable to falling through the cracks in the current service system.

## **4.7 Interchange Respite Care Inc NSW**

This study aimed to identify how people ageing with a disability can be best supported through respite care programs. In order to achieve this, it explores the strategies utilised by agencies to promote the health and well-being of a person ageing with a lifelong disability, as well as their carers. In addition, the research has investigated the strategies that aid in the transition of clients from disability to aged care respite care programs.

### **Research questions**

- What factors contribute to the decreasing health and well-being of full-time carers of people with a life-long disability who are also ageing?
- What role does respite care play for people with a lifelong disability who are ageing and their carers?
- How can respite care adequately provide services that assist in ensuring and maintaining the health and well-being of carers who are caring for someone with a lifelong disability who is ageing?
- How can further funding assist in ensuring that respite care service providers are able to meet the needs of the ageing clientele at the same time as attending to the support needs of the clients' life-long disability?

### **Methods**

The data was collected through four semi-structured interviews with different agencies across the NSW disability and ageing sector.

The interviewees consisted of:

- The Training and Development Officer, Interchange Respite Care (NSW) Inc
- The General Manager, FRANS Inc (a service provider for people with intellectual disabilities, which includes respite programs)
- The Disability Services Manager, Broken Hill Respite Services
- The Dementia Day Centre Manager, Bankstown City Aged Care

These interviewees were chosen due to relevant past experience and seniority of their positions within agencies. The results were coded according to the proposed research questions. A further level of coding was undertaken to capture common themes prevalent in these responses.

### **Background**

As people with a lifelong disability are living into old age, there is increased need for services which not only support this cohort of people, but also their carers and families. As the push towards deinstitutionalization has shaped aged care and disability policies, a number of studies have argued that respite care can assist people to remain in the community (AIHW, 2001; DH2001, Bigby, 2004). Bigby (2004) has argued that day programs such as respite care programs have become increasingly significant for people ageing with a disability as they can support the ageing process, as well as promote greater flexibility, and provide wider choice than full time programs. There is a double benefit to supporting carers, as respite plays a crucial role in "providing a break". Existing literature

highlights the situation where many older parents continue to care for their adult son or daughter with a disability (Llewellyn, Gething, Kendig and Cant, 2003, p.11). As well as older carers going through the ageing process themselves, there is significant concern “that carers have poorer health, lower life satisfaction and greater stress than non-carers (Dow, Haralambous, Guimmarra & Vrantzidis, 2004, cited in Doyle, 2008, p. 16). The transition between disability and ageing has proven challenging for respite care services, where there is considerable differences between models of aged care and disability. As a result it is becoming increasingly important to explore the role of respite care services at the intersections of disability support and ageing.

These interviewees were chosen due to relevant past experience and seniority of their positions within agencies. The results were coded according to the proposed research questions. A further level of coding was undertaken to capture common themes prevalent in these responses.

## **Findings**

### *The flexibility of respite*

For the carer, respite care plays a significant role for people with a life-long disability who are ageing and their carers. Respite care allows for carers to ‘take a break’ from their caring duties, and thereby supporting the health and well-being of full-time carers.

For people ageing with a disability, the respondents indicated that agencies place a great emphasis on being able to flexibly respond to the changing needs of people with a life-long disability who are also ageing. Most respondents indicated that their programs were fairly flexible, and felt that this responsiveness was central to enabling them to adjust services to effectively cater for their clients’ needs.

One respondent specifically identified the incorporation of a:

*...care plan which can change at any time, so if a person’s health deteriorates then we can adjust our program to meet their needs.*

### *Factors contributing to the decreasing well-being of carers*

A range of factors were identified by the interview respondents which appear to have a potentially negative impact on the well being of carers, a key issue in the well-being of both carers and those for whom they care and in their ability to maintain their living arrangements and therefore ‘age in place’.

*Being unaware of support mechanisms available* - It was found that many clients of respite services were not aware of the different support mechanisms available and are therefore likely to not be taking advantages of the resources available.

*Being able to get respite options, probably knowing what is out there, knowing what support mechanisms are available and what they can get... and getting access to services as well.*

*Interrelated support needs* - The findings show that the health and well-being of full-time carers is often compromised by the need to attend to the needs of the person with a life long disability who is ageing, which are also increasing. One disability services manager stated that:

*...it accelerates the deterioration of the carer, and quite frequently we need to put in place support for both the carer and the care recipient.*

It appears then that the interrelated nature of the needs of older carers and their ageing offspring makes this an increasingly complex yet commonly occurring issue. Within the client base of the services interviewed for this study, all full-time carers of an ageing person with a disability were family members including spouse, parent and child relationships. Increasing care needs for the family member with a disability may put the well-being of all family members at risk:

*It is essential because if the carer doesn't look after their own health then the care recipient will be in respite or placed in respite care... it is usually the spouse that has some other health complaint and it's the stress that is related to it.*

*Social isolation* - The social impacts of caring were mentioned by all respondents 'Social isolation' is a common feeling by carers. One respondent observed that:

*People don't treat you the same, they don't know how to relate to you and so they tend to not include you as much.*

*Inappropriate service provision* - participants believed that the respite care service system itself is not yet completely geared to meet the needs of people ageing with a disability while in practice the needs of this group are growing. This often means *ad hoc* and inadequate responses rather than comprehensive and systematic support is most prevalent.

*The system isn't geared to do the right thing, it's geared to do the minimal thing.*

*Transition from disability to aged care respite services*

Respondents in the study indicated largely that they believed the transition process to be difficult for those people who are moving from disability support to aged care. The main issues identified were the change of living arrangements and the maintenance of skill level and disempowerment associated with this:

*You are at a different stage in your life and I think your needs are a little bit different as far as your ability.*

It is evident that needs change as a person ages and thus it is important to explore the transitional process in order to gain an understanding of ways in which this process can be easier for those people who are ageing with a life-long disability and their carers. Respite care, can play a key role in this transition as it may be one constant in a changing service landscape.

In addition respondents identified the crucial 'cultural' differences between aged care and disability support. One respondent highlighted the issue thus:

*We've institutionalised them, then brought them back out of the institution, shown them that they can be free and do what they want, try to empower them as much as possible, but now we're saying 'oh sorry at 65 the shutter has gone back up again'.*

This signifies the difficulties for people with a life-long disability who are ageing encounter when experiencing the transition process of disability support to aged care.

### *Strategies to ensure and maintain the health and well-being of carers*

#### *Carer information and support*

The role of education and information for carers was highlighted by one respondent, who outlined a valuable initiative aimed at providing support in the form of information through the establishment of a Carer Respite Centre which:

*...has a Carers Support Group that meets monthly... it is a bit educational, they provide information regarding the benefits they can receive through Centrelink, and they normally have a guest speaker who will talk on things like healthy eating.*

Another respondent specified the development of a similar strategy - an education and information sharing session which aims to assist in the maintenance and improvement in the health and well being of carers who are caring for someone with a life-long disability who is ageing.

*So I usually organize for an hour a guest speaker to come in and provide them with information, make them aware of what is available out there and what assistance they can get.*

#### *Flexibility of programs and services*

Respondents identified the need for a more responsive, structured and flexible service. This theme was made apparent by one service who stated:

*We need a system that respects that these people have a totally different reality... so we need a system that is responsive to that'.*

A further respondent indicated that the system:

*...needs to be a bit more structured, it needs to have more activities, it needs to stimulate that person so they can maintain their skills.*

The most prevalent theme that appeared from the interviewees' responses was regarding services, whereby all four agencies suggested the need for more or improved services.

*Definitely day options, day programs are going to need to be looked at.*

#### *Staff training*

Participants identified the need for increased funding and the development of appropriate and targeted staff training which invests in staff specialization, leading to improved retention rates in the respite workforce as there is:

*A transitional work force based on lack of training and not sufficient work through the one organization.*

Staff training is imperative, not only for services and staff, but also in its positive flow-on effect for the person with a disability who is ageing and their full-time carer. Participants believed that improved staff training could lead to more efficient and effective service

delivery and therefore improved capacity to meet the support needs of clients' life-long disability.

### **Conclusion**

Respite care has the potential to play a significant role for people with a life-long disability who are ageing and their carers. Respite care allows for carers to 'take a break' from their caring duties, enabling the health and well-being of full-time carers to be improved.

To resolve this, service providers upheld principles of flexibility and adaptability when allocating their resources to their clients. Service providers also accepted the challenges that were faced by full-time carers and extended their services to incorporate strategies that would provide assistance to them to minimise distress and improve the flow of information about available service options. Although the respite care system was viewed as beneficial for both parties, respondents felt that further improvement in respite care service was necessary, particularly the need for a more responsive and flexible service framework.

#### **4.8 The Physical Disability Council of NSW**

The Physical Disability Council study aimed to evaluate financial security options for people with lifelong physical disability who are ageing. Specifically this study assessed superannuation and the Disability Support Pension (DSP) and Aged Pension (AP) with regards to access and availability, and their effectiveness in relieving financial hardship for people who are ageing with a lifelong physical disability. It explores the experiences of accessing superannuation and canvasses experiences of making ends meet on the DSP and AP schemes.

##### **Research questions**

- What relationships exist for those with a lifelong disability, between the inequalities experienced during working age, which compound into old age, with regard to superannuation contributions?
- What amendments or alterations can be made to the disability support and/or age pension in order to create a more comprehensive and accommodating system of government financial support for those with a disability moving into old age?

##### **Method**

This research project used an online questionnaire to explore the views of members of the Physical Disability Council of New South Wales. Of a total of 180 surveys sent to members, 40 were completed. The online survey was chosen as a method appropriate to this study as it was reasoned that respondents may be more likely to share information about their financial circumstances when anonymity was assured. The survey included a series of questions explicitly geared toward extracting respondent feedback in relation to experiences and perceptions regarding various financial issues and barriers arising as a result of their disability. A combination of qualitative and quantitative questions was used to gain a more comprehensive insight into the perceptions of respondents.

The survey first sought demographic details and then posed a series of questions regarding superannuation, such as the proportion of income derived from this source, the extent to which this income has been or will be used in retirement as well any opportunities that have aided access to superannuation or barriers faced. The survey aimed to gain an understanding of both the disability support and age pensions, with questions focusing on the adequacy of either pension, perceptions of those who have made the transition from the disability support to the aged pension, any changes they may have experienced as a result of that transition and any general financial concerns respondents had for both the long and short term future.

Testing for various frequencies and relationships between variables within the data was conducted through SPSS version 17 in order to gain a greater appreciation of the trends and issues evident. For the qualitative questions, relevant quotations were directly extracted from participants' responses which offered personal perspectives on relevant and specific economic issues.

##### **Background**

There is a general consensus in the literature that a great deal of work needs to occur in order to create a comprehensive scheme which preserves the economic wellbeing of

those with a lifelong disability in ageing. Dew et. al. (2006) extensively discusses the adequacy of the current DSP and AP for people with lifelong disability who are aging. It was found that the current rate for both types of pensions is almost half that of the minimum wage. If individuals transition to the AP they become ineligible to qualify for services such as disability employment services, the disabled Australian apprentice wage support program, special disabilities trust, supported wage system and workplace modifications.

In relation to retirement incomes, Walker (2005) reports a deficiency of superannuation amongst those with a lifelong disability, accounting for it as a by-product of 'exclusion from income sources prior to reaching retirement age, making disabled individuals more susceptible to experiencing superannuation hardships' (Walker,2000, p.13). Inequalities experienced during working age are continued into and compounded in older age (Walker, 2005, p. 15). A lack of sufficient superannuation accumulation significantly limits the opportunities for people with disability to 'remain in control of their lives post-retirement and may place them at risk of social exclusion and associated poor health outcomes' (Rumrill, 2007, p. 8). Hunter further examines the barriers to accessing superannuation for those with a lifelong disability and identifies their inability to work extensive hours coupled with their fragile work history as reducing their capacity to be eligible for promotion and are hence denied the associated benefits such as security of tenure, bonuses and allowances and employer superannuation contribution (Hunter, 1992, p. 157).

Several studies discuss the financial state of people ageing with a disability, with all agreeing that people hold significant and well founded concerns regarding their financial security into older age (Buys et al 2008). Past studies in this area have tended to focus on the perspectives and financial implications of agencies, service providers and other stakeholders. This research aim to provide a snapshot of the financial concerns to people with a lifelong physical disability who are ageing.

## **Findings**

### *Superannuation*

The findings suggest that the current superannuation system is considerably inadequate in addressing the inequality faced by those with a life long disability during their working years and post retirement. Almost two-thirds of respondents (60%) indicated that superannuation will be of no or limited significance for them as they age. Five per cent of respondents had no superannuation at all and only 10.7% of respondents claimed that they had received sufficient income to qualify for the superannuation threshold.

*Not having any large super means if I have any large expenses it will be a real struggle'*

For those who were able to accumulate superannuation, its presence becomes a double-edged sword in relation to eligibility for a pension.

*Superannuation will not meet my enormous needs but unable to get pension due to superannuation*

Similar responses were common across all applicable participants who found themselves financially troubled, as current means testing for pension eligibility was unfavourable to those who had any amount of superannuation.

Superannuation finances are directly linked to the ability to undertake paid employment; 65% of respondents stated that they had the ability to undertake paid employment at some point, but of this group only 4.7% received voluntary contributions towards their superannuation from their employers.

A large proportion of respondents identified the presence of a disability as the main cause of their restricted access to superannuation. It was also found that a disturbed work history, often associated with lifelong disability was the leading concern of participants in being able to accumulate any significant superannuation. Participants reported problems in receiving pensions when having any form of superannuation and reductions to their benefits and allowances as a result gave them no real incentive to work. Means testing for pension eligibility also infringes upon an individuals incentive to accumulate superannuation and those who do have any form of post retirement funding were treated unfavourably in the allocation of benefits and pension payments.

67% of respondents felt that the barriers they have faced were in fact a result of their disability in so much as their physical condition often caused unstable work histories and limited ability to engage in full time employment. 57% of respondents claimed that as a result of their limited ability to engage in paid work they face insurmountable barriers to achieving the full potential of superannuation. Respondents also highlighted issues which are directly related to forms of disability discrimination such as lack of voluntary employer contributions and superannuation companies trying to hinder individuals access to other benefits.

*Up until the 90's my employer was not eligible to pay super so I missed out on 20 odd years of super hence it wasn't worth much so I had to create my own. It's still not worth much.*

*I had to take the superannuation company to a complaint through my union as I was not eligible for death benefits due to my disability.*

### **Pensions**

In relation to the adequacy of pensions it was found that both pensions proved insufficient in meeting the day to day needs of respondents let alone the additional costs of disability. 82% of respondents reported that the current AP and DSP did not adequately meet their needs. This is particularly alarming since almost half (44%) of respondents reported that these pensions were their main source of income.

*There are many financial barriers to remaining at home and living a useful life. Most of these barriers are financial and the Disability Support Pension is woefully inadequate. It does not stretch to normal everyday needs, let alone the extra financial burden imposed by disability.*

Respondents noted that changes in proof of eligibility requirements and in the transition from DSP to AP was vastly inconvenient as they had experienced denial of the DSP and were required to re-justify their disability. Some saw this as almost ludicrous, considering the chronic and often worsening state of their conditions. One respondent commented:

*it is an absolute joke to me how after 25 years of living with a disability, I have to re-justify to the government that my disability still exists in order to be eligible for their deficient pensions*

67% of respondents eligible for the AP claimed that the amount of this benefit in comparison to the DSP less sufficient. There was wide discontent from respondents transferring from the DSP to the AP when they became eligible. 71% of respondents claimed that upon transition from the DSP to the AP their access to other benefits were affected as a result.

*The reduction ratio applied to the DSP is far too high and provides little incentive to work, combined with taxation and work related expenses, I effectively work for no financial gain.*

*I have recently accessed government subsidised home modifications (steel wheelchair ramps), but I am still left with \$280.00 to pay from my pension.*

Of the respondents who claimed that the AP was sufficient, a high percentage lived with a partner or in a care facility. The majority of people who reported the AP to be inadequate lived alone.

## **Conclusion**

With regard to the current Australian superannuation framework a range of issues were found to hinder both the earning and saving capabilities of individuals with a lifelong disability throughout their working life, which further impacted upon them in retirement. Individuals with a disability do face a far wider variety of barriers in accessing superannuation in comparison to those who do not have a disability. Also clearly identified through the study is the fact that current means testing for those wishing to access government provisions in the form of either the DSP or AP impinges on individual incentives to accumulate superannuation, where it was found that those who had accumulated some form of retirement funding were subsequently penalised and do not receive the full extent of government benefits, unless their personal savings are depleted.

As well the study established that present pension provisions are inadequate and ineffective in providing recipients with an overall sense of short term or long term financial security. Pension rates were found to be inadequate in meeting general day to day needs, without even taking into account the added expenses associated with disability. Moreover the study was able to identify that in this sample, for many individuals with a lifelong physical disability who are ageing to survive financially, a reliance was placed on added financial support from family members, and without this such people may face the very real possibility of poverty.

## 4.9 The Futures Alliance

The study undertaken with the Futures Alliance aimed to identify the key barriers to promoting cooperation between the ageing and disability sectors. The research focused on the perspectives in the ageing sector by exploring the experiences and views of service providers and advocacy organisations within this sector. It aims to help position the Futures Alliance at the forefront of advocacy, information and lobbying in order to break down boundaries that hinder effective policy outcomes for people with a lifelong disability who are ageing in both the disability and ageing sectors.

### Research questions

- What organisations in the Ageing sector currently have a policy interest or stake in people with a lifelong disability who are ageing?
- What are the potential avenues and/or barriers for the Futures Alliance to develop relationships with related bodies in the Ageing Sector?
- What is the view of relevant members of the FA who work at the intersection of ageing and disability policy with regard to these issues?

### Background

Promoting cohesion and cooperation between the disability and ageing sector is a critical issue when meeting the needs of people ageing with a disability. Currently, the sectors have two very different policy and service models for their clients (Bigby, 2002, p. 232). As a result, there is considerable difficulty with the transition between these two sectors.

A central question in existing literature is whether the aged sector or the disability sector should be primarily responsible for service provision (Bigby, 2002 p. 232). This is complicated by the fact that both 'systems have a high levels of demand and unmet need' (Bigby, 2002 p. 233). Furthermore, this situation has raised the issue of *double jeopardy* – where people with a lifelong disability who ageing 'are at risk of receiving second rate services from both...service sectors because they are seen to be the primary responsibility of neither.' (Bland, Hutchinson, Oakes and Yates 2003 p. 327, Cited in Leverett et al).

On a policy level, there are considerable funding difficulties between the ageing and disability sectors as a result of Australian federalism. The literature refers to this as 'funding in silos', which captures the insulated nature of funding and responsibility – which through lack of cooperation, coordination and planning between the Commonwealth Government and State Government leads to duplication of services and an inefficient allocation of resources (Sheets & Liebig, 2005; Australian Institute of Health and Welfare, 2000)

Studies have generally focused on resourcing and developing the disability sector as it is believed to better implement strategies tailored to individual needs, with flexibility and ability to facilitate choice (Buys et al, 2008, p. 67; Melville, 2006, p.12). However, while there is considerable focus on exploring the experiences of disability service providers, the experiences and needs of the aged care sector in this context is largely unknown.

There are a number of central issues that need to be addressed at the interface of ageing and disability policy. Firstly, that 'neither sector has appropriate services; secondly, there are problems with quality and access to existing services; thirdly, programmatic and funding mechanisms that create obstacles to accessing services.' (Bigby, 2002, p. 237).

## Method

The approach for this study consisted of four semi-structured in-depth interviews with service providers within the ageing sector, selected via a purposive sample. A profile of the interviews includes: a CEO of a State based peak organisation in the ageing sector with a large membership base; two participants from two of the largest service providers in the disability and aged care services in New South Wales and a CEO from a non-for-profit aged care service provider who had worked at both Commonwealth and State Government at the interface of disability and ageing.

The interviews focused on current understandings on disability-ageing policy by the ageing sector, the perceived barriers, policy issues associated with the growing population of people who are ageing with a lifelong disability, as well as the current state of the legislative framework. In addition, questions explored what the agencies would recommend directly to the Futures Alliance in terms of developing political relationships with areas of the ageing sector.

## Findings

Five interrelated themes emerged which included clarity, funding, responsibility, expertise and advocacy and participation.

### *Lack of clarity*

There is a lack of clarity and limited understanding of this policy area. This has created confusion and ambivalence with regards to developing, locating, and accessing expertise; appropriate funding structures, and therefore governmental responsibility. The findings show that there are problems with the definition of 'ageing' for someone with a life-long disability. Participants believed that the current chronological ageing measure is not necessarily an appropriate measure. This has resulted in a lack of appropriate ageing assessment tools for people with a life long disability and many individuals are not receiving appropriate service provision.

*We are aware that (people a disability who are ageing) needs are different to a usual ageing person, and that is often because they age earlier – where most (ageing sector) organisations are dealing with people where the average age is eighty to eighty-five, where as people with a disability who are ageing could experience the same needs from fifty onwards.*

Secondly, there is widespread concern regarding the breadth of problem and the limited leadership and engagement evident at the policy level. As a member of one peak organisation observed:

*I think the barriers (in policy development) are conceptual almost- there is certainly no government agency taking on the task of trying to find workable, attractive, affordable options and trying to describe what they are and what they do. To my knowledge there is no-one particularly doing that.*

### *Expertise*

The second important theme to emerge was developing, locating and accessing expertise in order to meet the needs of individuals with a life long disability who are ageing. Frequently, interviewees considered that it was unclear how to access appropriate

expertise and services to meet the support needs of people ageing with a lifelong disability.

The findings show that the respondents believe that the ageing sector is lacking in expertise and has a very different culture and focus to that of aged care. Individuals with a life long disability who access the ageing sector as their primary source of care do not have all of their needs met. This stems from the belief that the ageing sector as a whole is generally oriented toward 'end of life' and institutional care, whereas the disability sector has developed a focus on rights and inclusion. As one interviewee said

*The ageing sector thinks about and delivers institutional care – there has always been a lot of innovation by the disability sector – it is just that it always runs into a 'brick wall' of no more funding.*

### *Responsibility*

There is a significant policy question as to who takes responsibility for people who are ageing with a lifelong disability. It was a common opinion among participants that individuals with a life long-disability would remain the responsibility of the disability sector, with the age sector making its funding available to 'top up' any unmet needs. For the most part the research suggested that the transfer of an ageing person with a lifelong disability from the disability sector to the ageing sector was not an appropriate solution.

*I think it is primarily an issue for the disability sector because if they don't own the issue, we will end up with a 'patchwork' of solutions from the Commonwealth*

### *Funding*

Participants generally shared the view that this division of responsibilities between the state and federal government has resulted in inefficient 'cost shifting'. They believed that there is an issue of 'funding in silos' and as a result there is a lack of cooperation, coordination and planning between the levels of government. The funding body for individuals essentially shifts from the disability sector to the aged care sector once the individual has reached sixty to sixty-five years, regardless of their disability status.

*I think sometimes there is an agenda from state government and there always to somehow argue that the commonwealth are skipping out on their responsibilities, and somehow at age sixty or sixty-five this should all transfer to Commonwealth. Whether that is a valid argument or not – sometimes it is a very cynical angle from state government.*

The role of the aged care sector as largely supportive emerged from the findings of the *National Aged Care Innovation Pool Disability Aged Care Interface Pilot*. The funding mechanism trialled in this pilot was deemed 'very successful and cost-effective' (Hales et al., 2006). The Pilot was based on the principle that people living with a permanent impairment should continue to receive the same provision of disability funding as they had always received, in addition to a marginal subsidiary from the Commonwealth Government as top up funding in order to meet additional support needs as a result of ageing. Participants believed the pilot was a cost-effective and adequate strategy to achieve flexible individual centred care. Participants were perplexed as to why funding for the pilot had ceased and why it was not transformed into a permanent solution.

## *Advocacy and Participation*

The issue of whether organisations in the aged sector should participate in the Futures Alliance met with mixed responses. It was felt that the FA already has an incredible pool of expertise with the current representatives, and that greater participation may dilute the momentum of the Alliance's campaign. However, this does not mean that the FA should act exclusively, but moreover employ innovative ways to educate and share information about solutions to the problems facing organisations in providing services for someone living with a lifelong impairment.

Avenues for getting this policy issue on the agenda largely relates to clarifying the nature of the problems and being able to provide evidence as to the extent to which this may impact on the community in the future. As one participant and FA member expressed, when asked what the Futures Alliance could do to get the issue on the agenda:

*You need to have your facts very strong. I think Letters to Ministers – but you have to have your facts straight. For example, look into the pilot programs and go back to government and say look how successful this was, look how cost effective, it keeps them out of residential care, how about we lobby to do something like this as a permanent program?*

## **Conclusion**

The study conducted with the Futures Alliance sought to unearth opinions, experiences and views within the Ageing sector about the issues and challenges facing the Futures Alliance in breaking down boundaries to facilitate cooperation at the interface of disability and ageing. The biggest challenge facing the Alliance in addressing the issue is a lack of clarity about the nature of the problem, the lack of expertise at the interface, and the urgent need to influence government to develop and promote cost effective measures to address the issue.

## **5 Discussion**

### **5.1 Implications for older people with disability**

As for all people, the process of ageing raises new and often difficult issues for people with a lifelong disability. Many of the concerns identified through this research speak to the universal experience of ageing, such as: Where will I live? What will I do with my days? and, Who will I rely on when I need help or get sick? For people with a lifelong disability who may have experienced a range of disadvantage across the lifecourse due to the presence of disability, including limited access to education and employment, lack of financial resources, unstable housing or accommodation, limited social networks and marginalisation in the community, issues of ageing may be intensified as these people may be less likely to have a lifelong or wide support network to tap into. For some people with particular impairments such as those with cognitive or psychiatric issues, the very concept of getting older may not be understood or considered. Nonetheless, across the issues which have emerged in this research there are many that appear to be common across the range of people with lifelong disabilities who are ageing.

#### **Age related changes**

Ageing resulted in a number of changes for people with disability who are ageing, including: changes in health and social support; financial implications; and implications for accommodation and living arrangements.

##### *Health and social support*

Many stakeholders, as well as some people with disability, associated ageing with deterioration of health including the loss of mobility, changing sleep patterns, loss of concentration and co-ordination, and increasing incidents of incontinence. In addition to these health related changes the possibility of the emergence of a serious health problem or crisis have a number of implications for people with disability, who were concerned that this would put them at particular risk of entering institutional care. Furthermore, these changes were associated with a decrease in independence, as they affect people's ability to look after themselves with minimal external assistance.

Health related changes resulted in increasing reliance on informal support networks and, if an older person with disability is supported by an informal network, it is likely that their carers are also ageing. Respite is an important service for both carers and service users, however, it may not provide enough support for older carers who have issues associated with their own health and well-being and experiences of ageing. The development of respite care programs that incorporate the needs of the entire family unit, therefore, is vital for this cohort

There are lifecourse issues for people with disability which compound as people age. For example, people who are ageing with a lifelong mental illness are likely to be at a particular risk of isolation due to the lack of informal networks that have been developed throughout life as well as the stigma around accessing services (National People with Disabilities and Carer Council: 2009). Social connection may also be affected by location and be particularly problematic for older people with lifelong disability who live in regional and rural areas of Australia.

## *Finances*

Ageing also has implications for people's financial situations. The survey of people with physical disability showed that there was a general dissatisfaction regarding the transition from the Disability Support Pension to the Aged Pension because of the change in access to benefits such as the mobility allowance. Furthermore, due to taxation, the inadequacy of pensions and other additional expenses provided no incentive to work let alone generate any considerable superannuation.

Many people reported that they had experienced broken work histories due to their disability which limited their capacity to engage in paid work or an unstable work history. People with mental health problems have difficulty accessing and maintaining employment due to the changeable nature of their illness, and as people age, it becomes increasingly difficult to gain access to employment. As a result, many people did not have the opportunity to contribute to superannuation or other savings schemes targeted at supporting people in old age. To make up for the savings shortfall, many reported seeking assistance from family or friends to finance their day to day activities. People who lived alone expressed particular concern about the adequacy of their saving arrangements.

## *Place*

The ageing process affects people differently depending on their living arrangements. Those in supported accommodation, which is funded by the state government, do not have access to in-home support through HACC or other such programs, which are funded by the Commonwealth, because access to one source of support makes people ineligible for the other (Standing Committee on Community Affairs, 2007).

If a person with disability requires additional in-home supports due to age-related changes but is not yet 65, they are not eligible for more intensive packages because 65 is the lower age limit for the 'frail aged' eligibility for this support. Thus, the age limit can act as an exclusionary criterion that denies services to people with lifelong disability who may experience age-related changes sooner than the general population. People living with aged parent carers or independently risk being unable to maintain their accommodation if they are unable to access aged care supports in the home because they are too young and, given the limited amount of housing stock available, there are few alternatives for older people with disability aside from nursing homes.

People with disability interviewed for this research resisted the idea of moving into more supportive housing environments as they age, indicating that, as in the general population, most older people with disability prefer to age in place. This is supported by the literature, which has found that having a say in living arrangements is important for people with disability to maintain control over their lives (Arber & Evandrou, 1993, Zarb 1993).

Service providers also pointed out that many people with disability have been involved with the same organisations for upward of 30 years, and therefore the organisation is like family to them. For those, usually people with intellectual disability, who have lived in the same location or within one service for the majority of their adult lives, specific concerns arise including the potential trauma of hospitalisation and higher level care provision in unfamiliar environments, support for understanding the ageing process and the psycho-emotional aspects of grief, loss and end of life.

## **Planning for the future**

People with disability interviewed for this research appeared in general to have done little or no planning to prepare for the future. Most had not thought at all about the implications of ageing with a lifelong disability. This was particularly the case for people with cerebral palsy who, when asked whether they held any fears or worries about getting older, almost all replied with a blunt 'No'. Those who had thought about the future made plans that mostly consisted of staying in their current premises, despite recognising that their current living arrangements may not be adequate for the long term. A few participants spoke about beginning to think about the future after a major crisis occurred, causing their support needs to change so if, for example, they had a bad accident and needed to be hospitalized. This finding has been supported in the literature more broadly (Balandin 1997; Reilly & Conliffe 2002).

People delayed planning for a number of reasons. First, there was a perceived lack of accommodation and support options for people ageing with a lifelong disability. Second, people mentioned that there is minimal assistance available to help people with disability or their families and guardians to begin thinking about both ageing and retirement. Finally, participants often did not actively engage in planning for the future because they had never considered it to be necessary. This suggests that the ageing trend poses new challenges and ways of thinking for people with disability who had never expected that they would live as long as they have. For people with intellectual disability limited understanding and education about the ageing process is key.

## **5.2 Implications for services**

Providing support to older people with lifelong disability presents a number of challenges for disability services, the most pressing of which include the need to provide increasing support to clients and to the disability workforce.

### **Increased support needs**

Many older people with disability experience a deterioration in their health, communication skills and other daily living skills. As a result, services struggle to provide increased levels of support, and to also upskill the workforce to address new, age related changes. Workers at disability organisations were also required to become more aware of the service options for older people with disability, and to assist people with disability and their carers to prepare for older age. Many of these activities require additional staff time which is unfunded under the current models (see the next section for further analysis of the policy implications).

Aside from the resource-intensive nature of providing appropriate support to older people with disability, another difficulty emerged around assessing the changing needs of this cohort as they age. Few formal assessment tools exist to track these changes and, without more sensitive methods of assessment, the increasing needs of older people with disability have the potential to be overlooked or misrepresented.

### **Staff development**

Addressing changing support needs requires that staff develop new skills, particularly in relation to meeting the physical, communication, and psychosocial needs of clients. The current training available for workers in the ageing and disability sectors are separate from one another, and there is minimal training available that is specific to people who are ageing with disability. Because of this, the skills required to provide services for this cohort can only be developed informally. To address this gap, some organisations have started to

develop internal training modules; one organisation, for example, employed external consultants to assist staff to address certain medical conditions and to implement personal plans.

There is need throughout the disability sector for more formal training specific to the needs of older people with disability to be developed. This training needs to unite relevant areas of disability and ageing, while also taking into account the needs of people with a disability, such as those in relation to issues of grief and loss as well as end of life issues. This training could be provided as a core component in both disability and ageing training courses and incorporated across a wide range of occupations and levels, but adapted to fit the specific nature of differing support frameworks. This issue has received minimal funding, but it is imperative not only for the person with a disability who is ageing, but also for their full-time carer. Increased funding in this area is likely to have two-fold benefits in that service delivery may become more efficient and effective in meeting the needs of ageing clientele who are experiencing disability for the first time, while also addressing the support needs of the clients with life-long disability.

### **Creative ways of addressing the needs**

Most of the organisations in this research had implemented interesting and innovative ways to provide appropriate services for older people with disability. The most common strategy to address these needs was that organisations tried to use their funding in flexible ways to accommodate the changing needs of their clients. Most organisations also modified the environment so that it was more conducive to people with limited mobility by, for example, putting in hand rails and grab bars. Care plans specific to the needs of the older person were also commonly developed; they provided the person with disability with the opportunity to voice their individual preferences around where they wanted to live as they age, as well as what activities they would like to undertake. This demonstrates that there is a need for more formal recognition of issues of ageing to be introduced in the individual planning process from as early as the 40's or 50's, depending on the client.

Aside from the more formal plans, some organisations made it a point to discuss ageing, and some of the issues associated with this period of life, with their clients more informally. For example, one service actively discussed grief and end of life issues with clients and with staff, as well as bringing additional external experts, such as chaplains, psychiatrists, dieticians, massage therapists and spiritual representatives in to ensure that they were providing adequately for their older service users.

### **5.3 Implications for policy**

The provision of care for older people is primarily the responsibility of the Commonwealth government, which sets policy directions and funds the relevant support systems, such as the retirement income system; Medicare; the Pharmaceutical Benefits Scheme (PBS); community and residential aged care facilities for frail older people; and the Aged Care Assessment Teams (Department of Health and Ageing, 2008). Assistance in the home for people with low levels of care needs is provided by the Home and Community Care (HACC) program, which is administered by state/territory governments but is jointly funded with the Commonwealth (Home and Community Care Program, 2008).

According to the National Disability Agreement, the Commonwealth does play a role in the disability sector, particularly in relation to employment and payments (such as the Disability Support Pension). However, most of the service provision is carried out by states and territories, which are responsible for the provision of most disability services such as

day programs and group homes (Standing Committee on Community Affairs, 2007). The Standing Committee on Community Affairs (2007) noted that this division of responsibility between the Commonwealth government and states/territories led to a substantial amount of inflexibility in the provision of disability services. Because ageing and disability policy are formulated in separate departments, older people with disability can fall into substantial gaps in the service system. This section examines the challenges that ageing with disability presents for policymakers.

### **Philosophical differences**

The ageing of the population is expected to have substantial implications for the Commonwealth government's capacity to fund human services (Productivity Commission, 2005). To combat what is seen as an impending cost burden, governments are focusing on ways to reduce the projected costs and, as a result, the government is increasingly promoting: community care and ageing in place (Barnes, 1997; Russell and Schofield, 1999); individual contributions to retirement income (superannuation) and private health insurance; and the promotion of healthy ageing, which encourages people to make lifestyle choices that optimise physical, social, and mental well-being across the lifespan (Commonwealth Department of Health and Ageing, 2001).

While community care is increasingly emphasised for older people, the provision of care in institutional settings remains an acceptable form of care for older people who meet certain criteria. This is in stark contrast to the disability sector, in which deinstitutionalisation has been one of the primary changes in recent decades. Deinstitutionalisation is believed to be a major step towards the social inclusion of people with disability by providing them with the right to live in ordinary houses within the community (Bostock et al., 2004). When people with disability age, however, there is the risk that they will be transferred into institutional care earlier than the general population.

Aged care policy increasingly encourages individuals to provide for their own care in old age and, while current disability policy supports equal opportunities for people with disability (Metts, 2000; Young and Quibell, 2000), it is questionable whether people with disability do in fact have the equal opportunity to contribute to superannuation. Furthermore, it is unclear whether the people with disability can fit within the idea of healthy ageing that is promoted within the ageing field. Additionally, the overarching culture of the two sectors is at the very least at odds. The aged care system is geared towards the needs of the frail aged; health care, residential and community supports for this group attract the bulk of resources. Congregate care in large facilities such as nursing homes and hostels is still a major service response for the frail aged. In comparison the disability sector has expressly moved away from this approach and prioritises support, participation and inclusion in the community, informed by a rights based model of service.

As a result of the incongruous philosophies and cultures in the two sectors, participants believed that older people with lifelong disabilities should not simply be transferred from one system to another once they reach a particular chronological age and instead there is a need to re-conceptualise those at the intersection of these systems in ways that recognise all their needs without premising one above the other.

### **Service gaps**

The research also supported earlier evidence that older people with lifelong disabilities are not well supported by current government policies. For example, many older people with disability are excluded from aged care programs by age criteria that do not take into

account the fact that people with disability undergo the ageing process at earlier ages than the general population. These people are at risk of being caught between the aged care and the disability sectors, deemed 'too young' for aged care programs and 'low priority' for disability services because of their age (Fyffe, 2007: 73). Although HACC services are based on need and not age, people with disability who are under the age of 65 cannot access Aged Care Assessment Teams or Community Aged Care Packages (Standing Committee on Community Affairs, 2007).

Furthermore, some concerns were raised about the extent to which aged care facilities and settings can appropriately support the needs of people with lifelong disability who are ageing. There is often a significant age difference existed between residents with a lifelong disability and aged residents, as well as differing levels of cognition and independence, which can create significant demands on staff and can exacerbate the exclusion of people with disability within residential aged care settings.

### **Responsibility and advocacy**

There is a general lack of cooperation between the ageing and disability sectors around this issue. This was partly attributed to a lack of understanding in the ageing sector about the issue, but the primary problem is that the sectors are funded and organised differently. This not only results in service gaps for people with disability, but also precludes expertise from being shared across the sectors.

Participants believed it to be possible to develop partnership arrangements between the sectors and that this is vital to adequately addressing the issues experienced by people with lifelong disability who are ageing. Partnerships can also avoid service duplication and can build upon the existing expertise in both sectors. Some participants believed that people ageing with a disability should be the primary responsibility of the ageing sector because the ageing process itself is most immediate for service users should be in a residential aged care setting, with disability needs becoming secondary. Others, however, supported the idea that disability services are the most appropriate place in which to address ageing needs for this group, as they come on top of a lifetime of needs associated with disability.

The breadth of the problem associated with policy issues and practices appears yet to be systematically explored. While multiple issues have been described by peak organisations anecdotally, there appears to be little understanding about when and by whom policy intervention should be initiated.

### **5.4 Conclusion**

The connections between the ageing and disability are complex. Lack of clarity exists at virtually every level of the issue, from conceptualisation, policy and service response to individual experience. The studies presented here have demonstrated the breadth of this complexity and have highlighted the fact that innovative local practices are currently the primary service response. Across the range of stakeholders it is clear that the needs are myriad and resources are scarce. Clearly coordinated political action across the disability service sector and the disability movement is a key first step. This model is demonstrated for instance, by the campaign mounted by Carers who have successfully mobilised to attract significant public and policy attention, with the result that federal and state/territory disability agencies are developing responses to support ageing parent carers, including respite programs and supported accommodation options (Carers Australia, 2005). Key to this success is a coordinated political and advocacy effort underpinned by a strong

evidence base. These are significant challenges indeed for stakeholders in what is an emerging yet critical area of human experience, that of protecting the rights and promoting the well being of people who are ageing with a lifelong disability.

## 6 Recommendations

### Advocacy

It is clear from this research that policies and programs could be altered so that the disability sector is better prepared to address this issue. Some of the suggestions for change that emerged from the research are:

- There is a lack of available training for people working in the disability sector to prepare people with disability for ageing.
- There is also concern that the particular health needs of people with disabilities will not be met under existing aged care arrangements, so training about working with older people with lifelong disability would also benefit aged care providers.
- Disability service providers could provide seminars on a regular basis to encourage people with disability to plan for the future. Such seminars could encourage people to prepare financially, legally (e.g. advance directives, power of attorney) as well as to prepare options for accommodation.
- The lack of sensitivity of existing assessment tools (such as that used by Aged Care Assessment Teams) for capturing age related changes experienced by people with lifelong disability.
- Resourcing programs that provide crisis assistance for older people with lifelong disability who have minor accidents to ensure that minor crises do not turn into major ones.
- Some of the implications of ageing with lifelong disability may be prevented by supporting people throughout the lifespan. For example, isolation increases as people age, and can be better addressed by assisting people to develop broader support networks throughout their lives.

To satisfactorily address the issues arising as a result of ageing with lifelong disability requires coordination between disability and aged care sectors, as well as between State and Federal departments. The challenge facing organisations in the disability sector, including the Futures Alliance and National Disability Services, is how to convince the government and the aged care sector of the importance of addressing this issue systemically, rather than in the current piecemeal approach. To do this requires solid research and evidence about the implications of leaving this issue unaddressed.

The other challenge around convincing the government to collaborate with the disability sector to address this issue is that it is not yet clear whether what message the advocacy bodies are promoting: should they argue that the aged care sector needs to become better at accommodating the unique needs of older people with disabilities or that it is more appropriate for people to be supported within the disability sector? There were mixed results about this in the research and it is important for advocacy bodies to do better at targeting their efforts.

There are a number of examples of how these different messages would lead to different policy solutions. For example, should the sector advocate that criteria for aged care packages become more flexible to meet the needs of older people with lifelong disability or should more funding be given to disability organisations to provide for these needs?

Another consideration is what stance to take about nursing home and institutional care - it is widely recognised that premature entry into nursing homes for people with disability should be avoided for as long as possible, but once a person's health needs are too great, should advocacy bodies argue that people with disability should be better supported in nursing homes or that disability specific facilities should be built? Consultation is needed in the sector to determine how to proceed on these issues before a broad advocacy effort is constructed.

### **Further research**

It is clear that further research is needed on this issue. Research is particularly essential to influence the government that to allocate the resources that are needed to address this issue. The following are a number of research questions and topics that are worth exploring further:

- What is the prevalence of older people with lifelong disability in the general population and in disability services? How will this change in the future?
- What are the financial implications of the ageing of people with disability for disability services, aged care services, and carers? How will this change in the future?
- Develop a clearer conceptualisation of ageing with lifelong disability in relation to common theoretical framework.
- Review existing assessment tools and develop new ones that are sensitive enough to capture ageing changes for people with disability.
- Develop formal trainings that address ageing and disability issues in practice.
- Explore further the place and space of ageing with lifelong disability: How does place impact on transitions into ageing?
- Examine the nature of crisis for older people with lifelong disability.
- Examine grief end of life issues for people with disability who are older.
- Investigate formal and informal care arrangements and how these change as both the carer and people who are cared for age.

Critical exploration of the experiences of people with disabilities who are aged based on a lifecourse perspective, including the issues of isolation, identity, experience of people who were institutionalised.

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