



**UNITINGCARE NETWORK SUBMISSION**

**to the**

**SENATE COMMUNITY AFFAIRS  
REFERENCE COMMITTEE'S**

**INQUIRY INTO PLANNING AND SERVICES  
FOR PEOPLE AGEING WITH A DISABILITY**

**Contact:**  
Susan Helyar  
National Director  
UnitingCare Australia

02 6249 6717

The National Body for Community Services in the Uniting Church  
supporting service delivery and advocacy for children, young people, families, people with disabilities and older people

## INTRODUCTION

UnitingCare Australia is pleased to have the opportunity to lodge a submission with respect to the Inquiry into Planning Options and Services for People Ageing with a Disability.

UnitingCare provides services and supports in all states and territories to people living with a disability and their carers and families through a wide range of programs and initiatives. Many of these are specifically targeted at people living with a disability, many others have a broader target and support clients who are living with a disability – such as accommodation and housing support, financial services, employment programs, family support programs and respite care. This provides UnitingCare with a very broad understanding of the needs of, and constraints faced by people living with a disability and their carers and families throughout their lifetimes. This understanding informs this submission which draws on the experience and expertise of staff in the UnitingCare network throughout Australia. It highlights key issues faced by people who are ageing with a disability, and provides examples of promising practices in this area from UnitingCare service providers, and the broader service community in Australia and overseas.

UnitingCare Australia would welcome the opportunity to expand or discuss the issues raised in this submission further, and would be happy to address the Committee at your request. We are able to provide a respondent from within our agency, and facilitate the participation of service users.

## EXECUTIVE SUMMARY

This submission provides a review of the issues that have been identified by the UnitingCare network throughout Australia. It highlights key issues faced by people who are ageing with a disability and their carers and families, and provides examples of promising practices in this area from UnitingCare service providers, and the broader service community in Australia and overseas.

It is clear from the examination of current processes within the various states and territories that there is a diversity of approaches, with some states being far more progressive in their support for people ageing with a disability. It is also clear that generally there is a lack of equity in funding, lack of transferability and a lack of entitlement to services. The complexity of different funding programs supported by states and the Commonwealth makes it difficult for individuals with a disability and their families to know what is available.

A common trend with the move to individualised funding arrangements across states that have pursued this reform, is that guidelines become more restrictive over time, resources do not keep pace with costs, and people are being forced into congregate options as the funding does not adequately support individualised arrangements in accommodation or community support. What results is a growing gap between the rhetoric of individualised support and the reality for people with disabilities and their families.

This submission identifies that there is a range of needs to be considered in relation to supporting people with a disability as they journey through the ageing process. These include: planning for the longer term that is inclusive, managed and realistic; housing options; health and aged care; community participation; income and financial support; transport; staff availability and skills/knowledge; and policy. These areas are discussed, and issues outside the portfolio area of disability are identified, including power of attorney, legal aid, the National Disability Insurance Scheme, the Charter for Human Rights and Responsibilities and generational change regarding care for the ageing.

While the needs in the sector are complex and high, there are many examples of promising practice from within the UnitingCare network and beyond that can be used to inform better policy and practice. This submission details a number of these programs, and makes recommendations for consideration by the Reference Committee.

## RECOMMENDATIONS

1. An acceptance of the fact that disability supports are provided to compensate for the things a person is unable to do for themselves due to their life-long disability. Any additional needs associated with the ageing process should be met by the aged care system without the need to forfeit pre-existing disability supports.
2. Funding needs to be universally available (eg through a National Insurance Scheme), equitably distributed and allocated to individuals according to their needs. Funding should be transportable across regions and states. Self-directed models of support need to be available to people who choose such an approach, with support to arrange services for those who require it.
3. While individuals and families may be the budget holders of services, governments need to support an innovative and robust service sector that provides a range of services for people to purchase that will meet their needs. There needs to be an investment in attracting and developing the workforce in both the disability and aged care sectors to meet the needs of people ageing with a disability, and an investment in leadership development to drive the reforms needed in the service system.
4. A range of planning supports needs to be available to people with disabilities and their families over the life course to be able to anticipate emerging needs and issues and avoid crisis driven responses. This includes capacity building for individuals and families to be informed and inspired about a range of possible approaches to long-term accommodation and support for people with disabilities as they age.
5. New initiatives for people ageing with a disability should be based on people's strengths; provide opportunities for learning, growth and participation in community life; and build a range of activities, interests and networks in preparation for retirement.
6. A variety of forms of accessible and affordable housing needs to be available to expand the range of options for people with disabilities to be supported in typical community settings. These need to be in 'liveable communities' that are also accessible and include a full range of relevant community resources.
7. The development of service infrastructure needs to be accompanied by the resourcing of initiatives that strengthen informal networks and communities to have a role in supporting and including people with disabilities, such as Circles of Support and Community Inclusion Facilitators. For people ageing with a disability, it would be preferable to build such networks before they age or reach a crisis, but it is never too late to engage in such community strengthening activities.
8. Investments are needed in technology to support ageing people with disabilities to continue to be active in the community of their choice. There is considerable capacity now with very common technology (iPhone, iPad) to look at ways in which this mainstream technology can be used to enhance the lives and participation in the community.

## Contents

Introduction .....	2
Executive Summary .....	3
Recommendations .....	4
UnitingCare Australia .....	6
Values statement regarding people living with a disability .....	6
Profile of current relevant UnitingCare services.....	7
A discussion of current State and Territory processes .....	8
Victoria.....	8
Western Australia .....	9
South Australia .....	10
New South Wales .....	10
Queensland .....	11
Australian Capital Territory .....	12
Summary .....	12
Key unmet needs and issues for people with disabilities who are ageing - Limitations and issues with the current service system .....	14
Definition Issues .....	14
Research .....	14
Living arrangements .....	14
Planning.....	15
Work and retirement .....	15
Housing Options .....	15
Health and Aged Care .....	16
Citizenship and Community participation.....	17
Income and Financial Support.....	17
Transport .....	18
Staff availability and skills/knowledge.....	18
Policy Vacuum .....	19
Promising practices from within the UnitingCare network and beyond.....	20
National Community Care Principles .....	20
Innovative pool Pilots.....	20
UnitingCare Community Options (UCCO - Victoria) .....	21
Wesley Mission Adelaide.....	23
Wesley Mission Victoria.....	24
Stepping Stones for Life (ACT).....	26
UnitingCare West (WA) .....	26
Good Samaritan Industries (GSI - WA) .....	27
UnitingCare Queensland .....	27
Beyond the UnitingCare Network .....	28
Issues in other portfolio areas outside disability that need to be addressed to improve planning for this group .....	30
Stories that illustrate the situation of people ageing with a disability .....	31
References.....	33

## UNITINGCARE AUSTRALIA

UnitingCare Australia is an agency of the National Assembly of the Uniting Church in Australia. We represent the Uniting Church's network of UnitingCare community services of which there are over 1,300 service delivery sites nationwide.

The UnitingCare network is one of the largest providers of community services in Australia, providing services and supports to more than 2 million Australians each year, employing 35,000 staff with the support of 24,000 volunteers. We provide services to older Australians, children, young people and families, Indigenous Australians, people with disabilities, the poor and disadvantaged, people from culturally diverse backgrounds and older Australians in urban, rural and remote communities.

UnitingCare Australia works with and on behalf of the UnitingCare network to advocate for policies and programs that will improve people's quality of life. UnitingCare Australia is committed to speaking with and on behalf of those who are the most vulnerable and disadvantaged for the common good.

UnitingCare Australia believes that all people have the right to access a decent standard of living. This includes access to:

- appropriate food, clothing, housing and health care;
- meaningful work, education, rest and recreation;
- the opportunity to meaningfully express and explore spiritual needs; and
- the opportunity to participate in and contribute to communities.

UnitingCare Australia believes that belonging in community is fundamental to people's well being. UnitingCare Australia values an inclusive community that strives to remove all barriers that prevent people from belonging and participating as fully as they wish and are able.

## VALUES STATEMENT REGARDING PEOPLE LIVING WITH A DISABILITY

UnitingCare Australia believes that disability is caused by barriers or elements of social organisation which take no or little account of people who have impairments. An impairment is an illness, injury or congenital condition that causes or is likely to cause a long-term effect on physical appearance and/or limitation of function within the individual that differs from the commonplace.

UnitingCare Australia values:

- inclusive communities in which all people are supported in friendships which are independent and mutual and which strive to enable all to participate as fully as they wish and are able;
- a holistic response to people with impairments which recognises all people as individuals with a just claim to be heard, either directly or through those who are close to them and recognises each person's physical, spiritual and social needs and their strengths and hopes; and
- a society which cares for its most vulnerable.

## PROFILE OF CURRENT RELEVANT UNITINGCARE SERVICES

UnitingCare services across Australia support people with disabilities including those who are ageing, and the carers of those people, through a range of federal and state-funded programs and self-funded programs.

The services provided include:

- Individual planning, facilitation, coordination and case management
- Individualised funding to support people in the community and in supported accommodation
- Home and Community Care Services, including transport, personal care, allied health, day activities, social support and assessment
- Recreation and community inclusion supports
- Facilitating Circles of Support
- Employment services
- Alternatives to employment and support for transition to retirement
- Respite and support for carers, including carer mediation services
- Various forms of accommodation – supported group homes and individualised accommodation arrangements
- Advocacy
- Rural and remote services through Frontier Services and other UnitingCare agencies.

## A DISCUSSION OF CURRENT STATE AND TERRITORY PROCESSES

This section provides an examination of current processes within the various state disability systems to facilitate planning for people with disabilities, and particularly planning for those who are ageing. Issues with the interface between services for people with a disability and those who are ageing are also discussed.

### VICTORIA

The State Disability Plan in Victoria (2002-2012) has seen the introduction of individualised funding for people with disabilities over recent years, with an associated planning process to determine support needs and funding levels.

Within this system:

- The Department of Human Services (DHS), Disability Services, funds facilitators of Individual Support Plans who engage in some element of planning with individuals/families.
- Case managers do engage in planning as part of a Disability Support Register (DSR) application. This however is problematic in terms of an ongoing planning process with a view from DHS that ongoing case management is not generally required, favouring the funding of the less expensive form of 'Support Co-ordination'.

In terms of complementary federal processes, the Commonwealth Respite and Carelink Centre does engage in planning with carers. While this involves some preliminary planning, it is mostly about referral and respite co-ordination.

The most problematic issue with the current processes (or rather, lack of) is that responses remain reactive and crisis driven with little element of pro-activity in planning systematically and strategically for an individual's future.

A lack of government funding has seen the allocation, approval and resourcing of individual plans become a gate keeping and cost saving/capping exercise that bears no relation to the individual needs or aspirations. Plans are not able to achieve any meaningful outcomes and are not realistic. Unnecessary bureaucratic authority is overriding important personal choices and this undermines the spirit of the legislation, policy and services.

The episodic natures of interventions mean that there is little continuity for the participant, and future episodes of care can be more difficult to obtain as opposed to an ongoing care and care management role. 'Planning for change' is not a feature of the current processes.

A participant-driven limitation of the current process is that ageing carers are generally reluctant to plan for crisis or transition. This therefore feeds into a system which does not generally encourage forward planning, leaving families and carers ill prepared for future crisis events or change.

While there has been the recently tendered Support for Older Carers program which attempts to address the issues of planning for those with caring responsibilities, the system as a whole is largely reactive and crisis driven, with a primary focus on immediate needs.

In regards to *advantages*, it has been acknowledged that the current processes require individuals to engage with case managers or facilitators, and this then brings individuals into the service system where they are able to find out what is available.



## WESTERN AUSTRALIA

Western Australia was one of the first states to introduce an individualised response to the needs of people with disabilities using the approach of Local Area Co-ordination (LAC) across the state. The Disability Services Commission (DSC) describes LAC as follows:

Local Area Coordinators (LACs) assist people with disabilities to plan, organise and access supports and services which enhance their participation in and contribution to their local community. LACs provide support that is personalised, flexible and responsive.

LACs work with family members and others involved in supporting people with disabilities so that they are strengthened and supported in their caring role. LACs also work with people with disabilities and their families/carers to make local communities more inclusive and welcoming through education, advocacy and development of partnerships with local community members and organisations, government agencies and businesses.

Local Area Coordination is available to people with intellectual, physical, sensory, neurological and/or cognitive disability *'who are under the age of 65 at the time they apply for LAC support.'*<sup>1</sup>

Western Australia has introduced a Combined Application Process which identifies individual needs for accommodation support funding, intensive family support funding and alternatives to employment funding. For some funding streams, allocations are based on individually identified needs, in other streams people's individual needs are categorised into need levels and allocated a set funding amount accordingly. A small amount of funding is also available to individuals through the Community Living Plan to support community based living arrangements. Individuals in receipt of individualised funding (a form of Personalised Budget) can choose to approach a service provider prequalified to deliver the specified services or choose to share the management of the services under a 'shared management model' or have the DSC approach services on their behalf.

The experience of UnitingCare services is that the funding is generally inadequate for what is needed. This has led people to choose congregate care services for accommodation and alternatives to employment (day options) rather than individualised arrangements so that the shared funding amounts can provide adequate support. Services find that the LACs, who may support families in the application process, often do not have a realistic view of how much services cost to operate. Providers find the guidelines for service provision restrictive and there is inadequate funding for service overheads to support the delivery of services.

The adequacy of planning processes through LAC for people with disabilities who are ageing will depend on the situation of families and their willingness to think about the future. There can be a conflict of interest with service providers doing planning as the options may be easily limited by what the providers know to be currently available. In response to this, some independent planning organisations have been set up in WA (see good practice section below).

The Disability Services Commission *Count Me In Disability Future Directions (2010)* document highlights the need to develop personalised supports and responses for people with disabilities and identifies the importance of developing collaborative response to the needs of people with a disability who are ageing. Five strategies are identified to enable this outcome to be achieved encompassing improved interfaces between aged care and disability service providers, aged care facilities that cater for the needs of people with disabilities, culturally responsive services, promotion of healthy ageing and ageing in place for people with disabilities, access to aged care community based services and supports, workforce education and planning support for families and carers.

---

<sup>1</sup> DSC Website [www.disability.wa.gov.au](http://www.disability.wa.gov.au)

## SOUTH AUSTRALIA

South Australia also has an individualised approach to supporting people with disabilities through Disability SA, a division of the Department for Families and Communities (DFC). The key mechanism is service co-ordination, described as follows<sup>2</sup>:

Service Coordinators are Disability SA workers who help people with a disability to find and use the services they need. This can include:

- linking people with community services;
- helping people to choose and arrange support at home, respite and other services;
- arranging specialist Disability SA services, where needed.

Many people with disabilities only require access to information, short-term assistance or occasional services. In these cases, Disability Service Coordinators will help people to enhance their independence. For people with high or complex support needs, the Service Coordinator will carry out a detailed needs assessment and develop a support plan with the person with disability and their family.

The system has moved from a specialised Options Co-ordination model, to a more generalised support process, with people allocated to a team rather than an individual co-ordinator. Initial intake and assessment is undertaken by telephone, and the co-ordinators carry high caseloads. With the allocation to a team, individuals and their families do not form a personal connection with one co-ordinator. If people enter the system prior to age 65, they will continue to be supported by Disability SA after turning 65.

UnitingCare services see the current system engaged mainly in reactive planning rather than supporting longer-term planning for individuals. Resources are often allocated in response to political pressure, for example a recent focus on funding for wheelchairs in response to a political campaign.

## NEW SOUTH WALES

The disability sector in NSW has benefited from a substantial increase in funding over the last several years under the Stronger Together strategy. The first stage of Stronger Together was largely targeted at services for young children with a disability and their families with some provision for enhancement of respite services and a limited provision for day places under the Life Choices and Active Ageing programs. Stronger Together Two promises to address some of the vast unmet need in relation to provision of supported accommodation however these places are targeted at specific groups such as young people in residential aged care, young people leaving the care of the state and people with a disability leaving the criminal justice system.

In NSW there is no specific planning or policy initiative devoted to people ageing with a disability. The allocation of funding, in particular access to accommodation places in NSW, is crisis driven and the unmet need remains huge despite the provision of recent new funding rounds. The main service response has been targeted at older carers rather than older people with a disability themselves and this has largely involved the provision of respite.

The provision of individualised services is in the very early stages in NSW, consisting of a few targeted pilot programs.

---

<sup>2</sup> Disability SA Website [www.sa.gov.au/subject/Community+Support/Disability](http://www.sa.gov.au/subject/Community+Support/Disability)

## QUEENSLAND

In Queensland disability Services have a mixed funding approach with both individualised short and longer-term funding and block funding. Generally for the individual packaged there is considerably more demand than resources available and packages are subject to rising operating costs which are incompatible with the increase in funding due to indexation, having a net effect of reduced capacity within the package.

A significant impact is the need for people with individual packages being compromised with their choice of living arrangements including place and co-tenants because of limitations in the funding. At a time when other jurisdictions appear to be moving to a greater reliance on individual funding Queensland seems to be going in a different direction with a focus on sustainability of shared support arrangements. In a disturbing number of cases this has been taken to mean that people have to live together to have a viable support arrangement rather than the intention of the conceivers of the approach of people in a geographic area being able to share support.

Many people attempt to supplement their disability packages with funding from other sources. Eligibility for HACC services when in receipt of disability funding has long been a contentious issue. Pathways for transition for people who are ageing from disability service models to other models are limited. However some work is happening to support people who have ageing parents to plan for the future, both through planning and service provision within the Ageing Carers Program.

There is a local co-ordination model in place where case co-ordination and management is available for some clients. Queensland has also recently introduced Positive Futures legislation focusing on restrictive practices for people with cognitive and behavioural disabilities. Considerable resources have been devoted to implementing this strategy.

The Local Area Coordination model from Western Australia has been used as an approach in Queensland where there has been a traditional skewing of services in the coastal strip. LAC has been used in communities to build capacity and to link people with a disability into mainstream services or to assist mainstream community services become more accessible. Recently there have been two LAC projects in urban areas and this is a welcome and encouraging initiative.

Disability Services have transferred to the Department of Communities in Queensland, and the full effect of this is yet to impact. On one hand there is greater opportunity for collaboration, but also greater risk for compromise of the values contained within the program and reallocation of funds. Centralised contracting is an initial outcome. Work in the Department of Communities has focused on a 'No closed door' approach as a strategy to respond to some of the people who this broader Department deals with that are suffering marginalisation in more than one arena in their life. This is a welcome approach and has allowed innovative public servants to try and take a positive outcomes approach rather than a silos or boundaries approach to not doing something. There is still much to be learned from this and how it can be applied to individuals whose choices, behaviours or histories make their support challenging, complex and appear to present risks.

Queensland is also part way through rolling out a Positive Behaviour Support approach after a comprehensive review by Justice Carter. This has exposed a range of restrictive practices that people with a disability were exposed to that led them to lead more restricted, excluded and lesser lives. While this approach has received widespread support it has challenged many of the parts of the broader disability system from the Queensland Civil and Administrative Tribunal (QCAT) which has responsibility for the appointment of Guardians for Restrictive Practices through the Department of Communities which has established a Specialist Response Service to agencies who have had to comply with the new legislation.

Some of the challenges include for QCAT the number and complexity of applications being made for Guardians for Restrictive Practices, the Department of Communities which has faced considerable challenges in recruiting suitably qualified and experienced people to their Specialist Response Teams to assist the sector in developing meaningful and relevant Positive Behaviour Support Plans to agencies who have had to comply with complex legislative requirements without access to resources commensurate to meet their legislative obligations.

One current process involves the introduction of the growing stronger program – which includes an outputs-based funding approach to be rolled out in the future and a centralised assessment model. One wonders whether this approach will necessarily result in a similar outcome to the Training Guarantee where organisations having established clearly what they are funded to do by the Department of Communities will focus on this.

Along with short fall of funds and therefore access to services, another emerging issue for people with disabilities who are ageing is the lack of services for people with acquired disabilities such as Multiple Sclerosis, Parkinson's Disease and other progressive neurological conditions. Referrals are being made to packaged care programs such as EACH for this group of people but the allocation of funds does not often provide the level of support required for the living situation to be viable. In Queensland YoungCare has developed and promoted a congregated living option for this group of people, however it does not meet all needs and there are few places available. This is probably a very good example of the approaches implemented by a funding body with the best of intentions to respond to a clearly identified need. It is an initiative that responds to that need rather than a broader life approach that assists people with a disability to move in and out of disability and main stream services as and when they need them. These comments are not intended as a criticism of the initiative but as a critique of the approach of funders and the need to 'pick winners' rather than invest in a comprehensive system that can address issues like the capacity to age in place.

Sadly one of the most common questions that is asked of practitioners in the disability sector by family members is: 'what will happen to my son or daughter when I die?' Simply we do not have an answer, we cannot give people the certainty to die in peace knowing that their family member will have the right to expect the same as other members of society.

## AUSTRALIAN CAPITAL TERRITORY

The ACT currently operates in a crisis-driven system, and although planning is encouraged through case-management projects such as UnitingCare's Stepping Stones for Life and other non-profit organisations (eg. CarersACT) gaining financial support for living support and accommodation needs is a long, drawn out process. The funding system is largely via individualised packages, however access to packages is limited and few families are getting the level of support required.

## SUMMARY

Clearly one of the issues for people with disabilities who are ageing in Australia is the diversity of approaches across states, the lack of equity in funding, lack of transferability and lack of entitlement to services, leading to long waiting lists. In addition, the complexity of different funding programs supported by States and the Federal Government makes it difficult for individuals with a disability and their families to know what is available. Competing with the frail aged is an issue within the HACC and other programs – often the complexity of need is much higher for people with disabilities compared to frail aged who are greater in numbers within the programs – a disparity that is likely to increase.

A common trend with the move to individualised funding arrangements across states that have pursued this reform, is that guidelines become more restrictive over time, resources do not keep pace with costs, and people are being forced into congregate options as the funding does not adequately support individualised arrangements in accommodation or community support. What results is a growing gap between the rhetoric of individualized support and the reality for people with disabilities and their families.

There appears a prevailing concern to control access to funds in the belief that if there is a focus on the managerial expertise of people in funding agencies then greater efficiency will flow from this money. The contrary view that can be argued is that greater control of funds in the hands of people with a disability and their families leads to greater focus on desired outcomes and better use of available funds.

There is also a need for certainty so people with a disability and their families have the opportunity to plan and live their lives rather than having to worry about the consequences of their next hurdle.

## KEY UNMET NEEDS AND ISSUES FOR PEOPLE WITH DISABILITIES WHO ARE AGEING - LIMITATIONS AND ISSUES WITH THE CURRENT SERVICE SYSTEM

### DEFINITION ISSUES

Every person with a disability who is ageing is a unique individual with particular strengths, characteristics, networks and needs. However, there are also some needs in common across all people, and across people ageing with a disability. All people need a home, the opportunity to learn, a sense of purpose, work or meaningful activity, relationships and the ability to participate in community life, adequate income, good health care, the recognition of their cultural background, spiritual needs, and the need for safety and security.

It is important to recognise the variation across different sub-groups that exist among people ageing with a disability. It is also important for this Inquiry to not only consider the current group of people ageing with a disability, but also future projections, so that planning can take place at both the personal and systems level for the future.

New initiatives for people ageing with a disability should be based on people's strengths, provide opportunities for learning growth and participation in community life, and build a range of activities, interests and networks in preparation for retirement.

### RESEARCH

A significant amount of literature has been written about the measure of disability prevalence across age ranges, ageing trends of people with a disability, the problems and challenges of managing the support of people with disabilities as they age, and the inadequacies of the aged care and disability services interface<sup>3</sup>. Other investigations<sup>4</sup> also show that research in functional change and ageing with a long standing disability was at a stage where the published research has thoroughly documented findings related to ageing.

However, whilst there is a good understanding of the issue of ageing and disability the literature is not robust about practical solutions that would constitute sound, practical, on the ground practice<sup>5</sup> of direct benefit to people with disabilities as they age.

There is a range of needs to be considered in relation to this age group.

### LIVING ARRANGEMENTS

People with disabilities who are ageing are living in a variety of arrangements:

- In the community with family (often ageing carers) or in supported individual arrangements
- Living in shared supported accommodation (ranging from group homes to larger facilities)
- In aged care facilities

<sup>3</sup> Barbara Gatter – The Changing Support Requirements of People with a Disability as they Age – A Guide to Good Practice, UnitingCare West, September 2008

<sup>4</sup> Casey M, Cole, J, & Boldy D. A Brief Review of Ageing with a Longstanding Disability in Western Australia. Centre for Research into Aged Care Services, Curtin University of Technology, Perth WA. 2002

<sup>5</sup> *ibid*



## PLANNING

Many states now have a mechanism for individual planning related to funding, although this tends to be short to medium-term planning rather than long-term. Many people ageing with a disability were not expected to live as long as they have, and little thought was given in the past to issues such as retirement from work. Families may be reluctant to think about the longer term as they are aware of the lack of potential options to meet their family member's needs. But mostly they are consumed with living and coping with the moment. While funding may be only one part of a longer term plan, it is also important not to raise people's expectations through a planning process when there will not be the access to resources to help implement the plan.

A range of planning supports needs to be available to people with disabilities and their families over the life course to be able to anticipate emerging needs and issues and avoid crisis driven responses. This includes capacity building for individuals and families to be informed and inspired about a range of possible approaches to long-term accommodation and support for people with disabilities as they age.

## WORK AND RETIREMENT

We know for those people with disabilities at work their standard of living may be higher than those people with disabilities who are unemployed<sup>6</sup>. In employment services there are many people who are reducing their hours of work<sup>7</sup> as they age and many who are reaching the end of their working life would benefit greatly from improvements in how they access the community and plan for their retirements. This lack of services and active solutions impacts on an individual's health and wellbeing. Work often provides a sense of purpose and social connections that are crucial and the prospect of losing this can be devastating.

People living in supported accommodation settings often have their support arrangements designed around the fact that they are out during the day. Should they choose to work part time as part of a transition to retirement, alternative funding and support arrangements are required.

## HOUSING OPTIONS

Only 6 per cent of people in Australia who have a disability leading to a core activity limitation live in accommodation with care services included<sup>8</sup>. Therefore the majority of people with disabilities live with families or in private accommodation in the community. For those who are ageing and living with parents who are also ageing, concern arises for the future of the person with a disability when the parents die or are no longer able to care for the person. In most systems, alternatives only become available after the crisis occurs, rather than through a process of planning ahead.

Most states have a shortage of shared supported accommodation places, and some states such as Victoria have made a policy decision not to increase the number of places. However, shared accommodation arrangements are not necessarily the solution to the long-term support needs of people, especially those who have lived all of their lives in a family and community setting. Support to pursue individualised accommodation arrangements is increasing but still extremely limited, some examples are included in the "promising practice"

---

<sup>6</sup> Peter Saunders, Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies, Social Policy Research Centre Discussion Paper No. 145, December 2005, outlines the hardships faced by people with disabilities who are unemployed.

<sup>7</sup> Disability Census 2007 Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), 2007

<sup>8</sup> ABS, 2003

section (see below). People with disabilities who are ageing may require home modifications which can make access to private rental accommodation challenging. While technology to support independent living is now becoming more available, the ability of older people with disabilities to learn to use this technology is a factor.

As for the general population who are ageing, the development of inclusive liveable communities is important, where design features accommodate disability access and promote safety and security for people of all abilities.

A variety of forms of accessible and affordable housing needs to be available to expand the range of options for people with disabilities to be supported in typical community settings. These need to be in inclusive 'liveable communities' that are also accessible and include a full range of relevant community resources.

## HEALTH AND AGED CARE

There has been little emphasis on preventative measures and health promotion activities to maintain good health among people ageing with a disability. Thus some opportunities to reduce the health impacts of the ageing process have been lost.

People ageing with a disability may need increased access to hospitals, who can struggle to accommodate the needs of people with disabilities. There are also differences in eligibility and assistance for people with disabilities and people who are ageing in relation to items such as continence aids and equipment.

Many people with lifelong disability will experience early ageing. Despite earlier onset of ageing in many cases aged care services provide limited support to people with a disability. In addition, in some aged care programs, receiving disability services funding is seen as double dipping and access to aged care services is denied. Aged care services have difficulty catering to the particular needs of some disability groups. There is a need for the development of sensitive assessment tools to identify ageing conditions in people with disabilities. Many such conditions can be attributed to the continuing impact of the lifelong disability, rather than a condition relating to the ageing process that could benefit from the expertise of aged care professionals.

Information from the Evaluation of the Disability Aged Care Interface Pilot within the Innovative Pool Pilot programs<sup>9</sup> outlines the factors that tend to place people who are ageing with disability at risk of needing a more intensive placement, usually in an aged care facility.

Risk factors for people in supported accommodation needing to enter residential aged care identified in the pilots included:

- severe mobility limitation that would require, for example, the use of a lifter and the presence of two members of staff for transfers
- a need for extended periods of supervision and assistance during daytime hours when disability support staff are not in attendance
- sleep disturbance and wandering, especially if the accommodation service does not operate with active night staff
- altered psychological and behavioural patterns that impact on other residents and staff
- physical home environments that cannot be suitably adapted for the use of aids and equipment—privately leased homes may present difficulties in respect of the type of modifications that assist to maintain people who are ageing at home
- major health events leading to severe and steady decline in health status.

<sup>9</sup> Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report*. Aged Care Series No. 12. Cat. no. AGE 50. Australian Institute of Health and Welfare: Canberra, 2006



One reason given for these pilot programs not being extended is that people in the pilots were 'double dipping', accessing two sources of funding. However, disability funding is provided to people to enable them to have access to the typical things in life that people without disabilities take for granted. In addition, many will not have partners or children to support them as they age. They should therefore be entitled to the additional supports relate to the ageing process (such as community care packages) in the same way as the general population, without losing their base disability supports.

There has been much discussion of the difficulty and inappropriateness of accommodating people ageing with a disability in aged care facilities. The campaign around Young People in Nursing Homes has increased the reluctance of aged care facilities to accommodate younger people with disabilities. Although people may be ageing with a disability, their average age is still generally much younger than the average age of the general population of people, especially those in high care facilities. While people with some disabilities such as Down Syndrome have a high likelihood of the onset of dementia, the impact of the disease may be different from that in the general ageing population. Staff in aged care facilities can find this difficult to manage while also meeting the needs of the other residents.

### **CITIZENSHIP AND COMMUNITY PARTICIPATION**

The recent report prepared by the National People with Disabilities and Carer Council (2009) entitled *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*<sup>10</sup> highlights the continued experience of social exclusion of people with disabilities in Australia. The process of ageing is likely to exacerbate this, especially where people are retiring from work and have limited opportunities to participate in the community outside of work.

Accessibility of housing and general community facilities can limit the participation of some people with disabilities as they age. Also, implementing improvements in access to Assistive Technology is required to support people with a disability to age well.

The development of service infrastructure needs to be accompanied by the resourcing of initiatives that strengthen informal networks and communities to have a role in supporting and including people with disabilities, such as Circles of Support and Community Inclusion Facilitators. For people ageing with a disability, it would be preferable to build such networks before they age or reach a crisis, but it is never too late to engage in such community strengthening activities.

### **INCOME AND FINANCIAL SUPPORT**

There is concern among people with disabilities regarding the transition from the Disability Support Pensions to the Aged Pension due to changes in access to benefits such as the Mobility Allowance<sup>11</sup>.

There is no entitlement to disability support in Australia, therefore services are 'rationed' through waiting lists and consequently often provided on the basis of a crisis that has occurred. The proposed National Disability Insurance Scheme would provide much needed resources to improve support for people ageing with a disability. There have been various trials around the country in individualised funding, direct payments and consumer-directed or

---

<sup>10</sup> National People with Disabilities and Carer Council *SHUT OUT: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report, 2009*

<sup>11</sup> Dowse et al, *Ageing with a Lifelong Disability*. Student Project Final Report. University of NSW, 2009

family-governed models of support. The local and international research<sup>12</sup> has indicated substantial benefits for people with disabilities and their families as a result of having more control over their support arrangements through such approaches. However such schemes need to retain their flexibility and responsiveness, and not be subject to increasing bureaucratic constraints, as seems to have occurred in some states.

Services also report tension between the wishes of older carers and some of these new models of service that require an active role for families and a lot of energy to maintain. These families require sustainable models of service that are adequately funded to support the person with a disability in a secure and sustainable setting if the parents are no longer around or able to support them.

As a community we need to accept the fact that disability supports are provided to compensate for the things a person is unable to do for themselves due to their life-long disability. Any additional needs associated with the ageing process should be met by the aged care system without the need to forfeit pre-existing disability supports.

Funding needs to be universally available (eg through a National Disability Insurance Scheme), equitably distributed and allocated to individuals according to their needs. Funding should be transportable across regions and states. Self-directed models of support need to be available to people who choose such an approach, with support to arrange services for those who require it.

## TRANSPORT

Access to appropriate transport is an ongoing issue for people with disabilities, which may become an increasing issue as they age and have reduced mobility or are no longer able to use public transport.

## STAFF AVAILABILITY AND SKILLS/KNOWLEDGE

Both the aged care and disability workforce lack knowledge in skills related to ageing and disability. Staff shortages will hamper progress in this area. There is evidence that an investment in training can improve the skills and willingness of staff to cater to the needs of people ageing with a disability, and that the support to: 'age in place' has improved in recent years<sup>13</sup>. However there are examples in some jurisdictions where the capacity to age in place is difficult because the service infrastructure, disability and mainstream services focus on those higher population centres.

While individuals and families may be the budget holders of services, governments need to support an innovative and robust service sector that provides a range of services for people to purchase that will meet their needs. There needs to be an investment in attracting and developing the workforce in both the disability and aged care sectors to meet the needs of people ageing with a disability, and an investment in leadership development to drive the reforms needed in the service system.

---

<sup>12</sup> Bigby et al. *People with disabilities who are ageing, their changing needs and the capacity of the disability and aged care sectors to support them to age positively*. National Disability Administrators, 2006.

<sup>13</sup> *ibid*

## POLICY VACUUM

Bigby et al<sup>14</sup> discuss some of the policy challenges in catering for the needs of this group:

There is an absence of specific policy about provision of support for older people with lifelong disabilities. As a result informal policy exists at service provider level, which means the situation regarding access to support is inconsistent, unpredictable, unfair and possibly untenable. Among service providers in given localities a lot has happened, but not in a reliable or predictable way across the country. At a policy level across sectors few jurisdictions have a concerted commitment to this issue, but rather a preoccupation with who pays and debate about what is the equitable rationing of scarce resources. This contrasts with the service provider level where joint commitment to the issues is much more evident. Different rationales underpin the quite different approaches of these two groups to the interface between the Aged Care and Disability Sectors, with service providers regarding it as an opportunity for partnerships and combined funding, while policy makers tend to see the sectors as mutually exclusive and the interface as creating the risk of double dipping that should be avoided by exclusion from concurrent access to both sectors. Therefore, rigid sector boundaries are more likely to dominate in relation to shared supported accommodation, which is equated with residential aged care by the Aged Care Sector.

UnitingCare Queensland has, over the last year, looked at how it responds to the challenges of people with a disability who appear to be encouraged to live together to make their resources stretch. Within the Department of Communities this began as their Shared Support approach but was seen on the ground by many as the 'Forced Co Tenancies' approach. UCQ is a member of a Community Safeguards Coalition which is trying to dissect this approach and produce a better, more reasoned and person centred approach.

UCQ Executive Leadership Team established a UCQ group to look at how it might respond to this and there have been many individual and collective outcomes from the work of this small group, notably a motion passed at the recent Synod: *Theology and Foundational Principles for Relating to People Experiencing Marginalization*. People with a disability are a key group in this approach.

---

<sup>14</sup> Bigby et al. *People with disabilities who are ageing, their changing needs and the capacity of the disability and aged care sectors to support them to age positively*. National Disability Administrators, 2006

## PROMISING PRACTICES FROM WITHIN THE UNITINGCARE NETWORK AND BEYOND

### NATIONAL COMMUNITY CARE PRINCIPLES

UnitingCare Australia has developed a set of principles to that are seen as crucial to the support of older people in the community (see Attachment A). These principles apply equally to people ageing with a life-long disability.

### INNOVATIVE POOL PILOTS

The Disability Aged Care Interface Pilot was established under the Aged Care Innovative Pool, and funded by the Federal Department of Health and Ageing. A pool of flexible care places was made available to trial new approaches to aged care for specific population groups. This particular pilot was aimed at people with aged care needs who live in supported accommodation facilities funded under the Commonwealth State/Territory Disability Agreement (CSTDA) and who are at risk of entering residential aged care. These pilots commenced in 2003/04 and the evaluation released in 2006, but these projects were not re-funded.

UnitingCare Services were involved in the pilots in NSW and SA.

The Innovative Pool evaluation<sup>15</sup> documents success in supporting people with disabilities in CSTDA funded accommodation services that are ageing, through the additional support of aged care assessment and community care services.

The evaluation revealed that with additional support people in the pilot were able to increase their participation in community and social life (40 per cent), interpersonal relationships (35 per cent), and take a more active role in domestic tasks (30 per cent).

'...Pilot services provide clients with greater opportunity to take part in activities inside and outside the home through care plans that incorporate individually tailored lifestyle and skills development program and increased day-time supervision and accompaniment'. (p 29)

Other objectives of the program were less easy to measure, such as whether the program had delayed entry into aged care services.

Risk factors for people in supported accommodation needing to enter residential aged care identified in the pilots included:

- severe mobility limitation that would require, for example, the use of a lifter and the presence of two members of staff for transfers
- a need for extended periods of supervision and assistance during daytime hours when disability support staff are not in attendance
- sleep disturbance and wandering, especially if the accommodation service does not operate with active night staff
- altered psychological & behavioural patterns that impact on other residents and staff
- physical home environments that cannot be suitably adapted for the use of aids and equipment—privately leased homes may present difficulties in respect of the type of modifications that assist to maintain people who are ageing at home
- major health events leading to severe and steady decline in health status. (p 14-15)

<sup>15</sup> Hales C, Ross L & Ryan C, *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report*. Aged Care Series No. 12. Cat. no. AGE 50. Australian Institute of Health and Welfare: Canberra, 2006

## UNITINGCARE COMMUNITY OPTIONS (UCCO - VICTORIA)

UCCO works with a person-directed, strengths-based framework to service development and delivery. This focuses on peoples' strengths, capacities and interests, to facilitate a good life in the community.

These frameworks and approaches are based on:

- A belief that people with disabilities and carers know what they need to achieve a good life and should be at the centre of the planning process. Services need to work on equal terms with people in assisting them to plan for their future.
- A belief that people with disabilities and carers want to take responsibility for their own situation in order to develop independence and a belief in themselves.
- A belief that people with disabilities and carers can help us provide even better support through their participation and involvement with the organisation.
- A commitment to assisting people with disabilities and carers to develop both formal and informal networks of support.
- A desire to help people with disabilities and carers to not just live in the community, but to be a part of their community.
- A commitment to people with disabilities and carers to regularly review and reassess the support provided where necessary.
- A belief in the importance of positive partnerships and right relationships.

UCCO staff utilise a planning and facilitation approach which seeks to understand the real issues facing individuals and more importantly, enhances their existing strengths, resources, dreams and aspirations. The goal of this approach is to provide short-term assistance through a range of activities:

- Immediate short-term practical assistance;
- Goal-oriented assistance to facilitate greater independence or social connectedness;
- Facilitation of a person-centred planning process to assist with medium- to longer-term planning for individuals and families;
- Linking people with generic community resources, prior to or in concert with the use of funded service provision;
- Where appropriate, linking people with volunteers
- Through the community liaison worker link people with generic community resources;
- Provide information and resources through a range of means including public information sessions;
- Offering time-limited group sessions for people with common circumstances that enable them to network, problem-solve and share with other people they can relate to;
- Through advocacy, community education and community development.

Where possible staff assist people with disabilities and carers to establish goals and networks that provide them with the ability to access both community resources and the formal service system, as well as maintaining and strengthening informal networks. It is important that both formal (where required) and informal supports are well coordinated with the person themselves as author of the support network. Planners support people to choose the service providers most relevant to their individual needs.

The planning and facilitation approach encompasses the exploration of formal and informal supports within a planning framework that is strengths based. Planning and facilitation as used at UCCO has staff engaging with people on a short-term basis, who utilise a number of planning tools including (but not limited to) MAPS and PATH. This approach assists people to explore their own fundamental needs.

These discussions and planning sessions enable people to identify goals that are important to them and are not restricted in thinking to only a funding response. The goals developed through the Planning and Facilitation approach encompass all of the life areas as identified in the Quality Framework for Disability. The discussions that planners hold with people and their carers explore community responses to their goals before utilising paid services.

Through the Planning and Facilitation approach people are often supported effectively using generic community resources, which may be augmented with targeted and disability specific paid service provision. This approach can delay or prevent people from having to become reliant upon a Department of Human Services funding response to meet their needs. In addition the person and their family members are strengthened in their ability to self-govern and make informed decisions.

### **Individual Arrangements**

In 2003 UCCO worked closely with a number of family members who wished to have more direct influence over the management of their family members' individually attached funding. The Individual Lifestyles and the Living Distinctive Lives projects were established and set the foundation for UCCO to expand the support of individually and family-governed arrangements to other people with attached funding.

The role of families in the planning and governance has been critical for the success of these arrangements. UCCO's approach has been to work in a partnership that emphasises right relationships that work with families to develop plans that are creative and targeted to meet the needs of their family member.

### **Circles of Support**

During 2005 UCCO commenced a Preventative Respite Project using Circles of Support that assists families and individuals to build sustainable networks to achieve a better quality of life. At the core of the Circles concept is the fact that many people with disabilities are primarily supported within a family unit and therefore it is important that the family is supported and nurtured.

The work with families in this concept is built upon the notion of safeguarding that is strengths based. It acknowledges the frailties and often isolation of families who are supporting a member with a disability. Circles of Support are a method of safeguarding families from potential break down by engaging the support of other people that are connected to the family as a whole. The Circles coordinator will assist the family to plan and implement the development of the circle of support, and once established will enable and skill the family to maintain the circle eventually without support.

### **Commonwealth Respite and Carelink Centre (CRCC)**

Since 2006 UCCO has been the host agency for the CCRC within the Eastern Metropolitan Region of Victoria. The CCRC has provided us with the opportunity to work with many Carers of people with disabilities, who are not formally connected to UCCO (and often no formal service) through funded programs.

This program has provided many insights into the issues faced by Carers, particularly where they or their family member is not formally connected to any specific disability agency. The CCRC workers will support these Carers to meet their initial respite needs. They will also engage with those families over time to plan for the future needs of their family members.



The CCRC will often refer the person to a range of appropriate agencies for support, as well as assist the families to build upon their natural support networks.

### **People at Centre Stage (PaCS)**

Within the Ageing Stream UCCO is currently engaged in a major research project 'People at Centre Stage' (PACS), which utilises an individual funding approach. This project tests the capacity of older carers to self-govern packaged care and respite funding provided to them. Within the PACS project a suite of tools have been specifically designed for older people, and identifies care planning areas such as estate planning; substituted decision-making processes; and succession planning should they be a carer of another person.

The intention is that the staff would have access to these tools and would be able to utilise them in their discussions and plans with people receiving support through their program. In addition to the PACS project, Direct2Care also use the Australian Community Care Needs Assessment (Revised) (ACCNA-R) tool which identifies need areas such as succession and estate planning as topics for exploration and further discussion with the older person.

### **WESLEY MISSION ADELAIDE**

Wesley Mission Adelaide has a number of programs catering to the needs of people ageing with a disability and their carers. They also support people living in rural and remote areas of South Australia.

### **Home Link**

Homelink SA is committed to providing quality home-based accommodation for young adolescents and adults with an intellectual disability and who are unable to live with, or wish to live independently from their birth family. Homelink also aims to ensure that people have the opportunity to develop greater independence and community living skills through skilled support provided by Homelink carers who share their home, family and friendship. This alternative accommodation service provides either full time or shared care. Homelink families are paid a contract fee based on the level of need of the person with a disability.

### **Carers Mediation and Counselling Service**

This service supports families to undertake future planning for their family member with a severe disability (including mental health). Families can be faced with many issues surrounding the needs of not only the person with the disability, but the needs of parents, siblings, and significant others. The service can provide counselling, family mediation, information and referral and group support programs. The service has been very successful in assisting carers who are ageing to plan for the future needs of people ageing with a disability. The service is funded by the Commonwealth Department of Families, Housing Community Services, & Indigenous Affairs, but the contract finishes in June 2011 and ongoing funding is not assured.

A family who has cared for their 51-year-old son since the age of six with a significant disability that requires assistance to wash, toilet, feed, dress and assist him in the operation of his wheelchair. His father is 81 and his mother is 79. His parents are still living in the family home with their son. The father is significantly visually impaired and hearing impaired he has recently had heart problems. This family was referred to the CMACS counselling from Take 5 (respite program) after the case worker noticed significant signs of carer stress. The mother's stress is so acute that on arrival at a carer function she was unable to take off her coat because in her frantic attempt to attend to everyone's needs she had forgotten to pull her dress over her petticoat.

The family, including the son, attended family counselling with CMACS where the difficult conversation of what is going to happen when the parents are no longer able to care was discussed. To assist in this conversation the parents were referred to Planning in

Partnership. The mother attended this program. This family is supported by the disability and aged care system and attract hours to help them in their home. However both parents health is failing and they are afraid of what will happen to their son when they are gone as there is no other family that can care for their son when they are gone.

CMACS counselling gave this family an opportunity to consider what the future might look like and what needs to be put in place to ensure the continuing care of her son. Although she and her husband are not ready to give up the day to day care of their son the mother is now considering what the future might look like and how and what she needs to do to facilitate that.

A small step in the planning process but one that will enable services and family begin to have conversations around what is realistically available and affordable before things slide into crisis.

### Planning in Partnership

This program aims to help families address the question 'What will happen when it becomes harder to care for my child?' Through a series of six sessions, the program assists older parent carers of a child with a disability (over 25), to plan and prepare ahead for a time when the caring role will change and an alternative care plan will be required. Planning in Partnership is organised by North and West Metro Adelaide Commonwealth Respite and Carelink Centre and South and East Metro Carer Support.

The six week program includes:

- Week 1: Carers perspective what would you like to know/How can this program assist you
- Week 2: Respite and other community options
- Week 3: Legal issues – speaker from office of public advocate
- Week 4: Accommodation placement processes
- Week 5: Caring for Carer- counsellors from UnitingCare Wesley Adelaide carers mediation and counselling team
- Week 6: Any questions and social lunch

This is an excellent program for older carers to put a structure around the future planning process.

### WESLEY MISSION VICTORIA

Wesley Mission Victoria (WMV) has a number of programs working with people with a disability, including supported residential services, provision of day programs, a range of planning and facilitation services and disability employment services. Wesley also has a HACC funded homeshare program for people living with a disability.

#### Homeshare

The Wesley **Homeshare** is a good example of a creative approach to the support of people ageing with a disability. The program provides a professional matching and monitoring service to bring together older householders or householders with a disability with people of integrity for mutual benefit. It is a social and accommodation support service that fills the gap in the currently available support services of security, company and support at night. The Homeshare program works on the principles of reciprocity, social exchange, and mutual benefit. There is no power imbalance – the householder is not a 'recipient' nor the homesharer a 'provider'. Both are users of the service and participants in the Homeshare



program. Both are valued and respected for their contribution to the Homeshare arrangement. Homeshare allows both parties to give and play a significant role.

### **Journey into older age for people with a lifelong disability**

This is an action research project within Wesley's Disability Residential Services funded through matching funds from the Helen Macpherson Smith Fund. Wesley has been piloting a number of different approaches to supporting people as they age, identifying and trialling flexible and responsive innovations in service provision.

The program is working with individuals who currently live in Community Residential Units managed by WMV. The overall objective of the program is to develop flexible service responses to support people to maintain their current home as they age and reduce the acceleration of ageing and transition into aged care. Three innovations were identified through discussion with residents, families and staff. These were piloted over the last year, and are currently being evaluated.

These are briefly described below:

#### **Supported semi-retirement using day program staff**

This pilot aims to enable people to stay at home rather than attend their day program for a couple of days a week. This pilot is working with a group of women who are ageing, and who live in CRUs that WMV manages. Using existing planning processes, the service worked with the individuals and their families to group their individualised funding to enable changes to what the women do during the day, and how they are supported. On two days a week, rather than attending the program provided at a local day centre, the women remain at home and are supported by staff from the program in their own homes. It involves a lower level of formal service provision, and is more responsive to individuals needs, allowing individuals to structure their activities themselves for example choosing to have a nap at any time in their own beds.

#### **Supported semi-retirement using volunteers**

This pilot similarly enables individuals to stay at home for two days a week by matching them with a volunteer who visits and supports them at home. Initially, the volunteer would be supported by residential unit staff until routines and comfort is established between the individual and the volunteer, allowing the staff member to progressively withdraw from the support situation. Volunteers are provided with appropriate training and the match is monitored to ensure the individual's needs are met in a safe and appropriate manner. This model enables individuals to stay at home if they wish to, but additionally builds their access with the community and broadens their social networks. This project requires individual funding to be in place for the individuals, in order that the initial support can be provided by the residential worker. The pilot will be completed once individual funding has been rolled out fully in the relevant DHS region.

#### **Collaborative Healthy Ageing Plans**

Families and staff identified the need for a process that involves individuals, their families and their residential service providers in developing long term healthy ageing plans. The project is working to identify elements of a collaborative, long-term plan, including social needs, community access, health needs and financial arrangements for individuals when family circumstance change, particularly around the illness or death of a parent or other family member who is a key part of the individual's care and support. It is hoped that the pilot project will also trial a process for developing a plan, within the current planning arrangements in place in Victoria.

### STEPPING STONES FOR LIFE (ACT)

Stepping Stones for Life (ACT) was established to create unique, family-driven responses in succession planning for mature age carers and their son or daughter with disability. This approach draws on the knowledge and strength of the family in their long-term caring for their offspring. As a result, we aim to find a unique scenario that is suitable to the person, their family and their circumstances in alternate accommodation, daily support and future guardianship. This process is achieved through a pastoral care/counselling approach that allows the family to develop plans, and 'let go', at their own pace.

Stepping Stones for Life also has a focus on network activities that provide peer support for carers and their sons or daughters in a variety of social occasions and ongoing activities.

The network is firmly grounded in the St Margaret's Church community, and even though not all of our network members are church members, the voluntary support received from the Church in administration and from individual people is vital to the strength and survival of Stepping Stones for Life.

### UNITINGCARE WEST (WA)

UnitingCare West provides a range of services to support people with disabilities including accommodation services, intensive family support, day activities, alternatives to employment (in partnership with Frontier Services) and individual advocacy services. UnitingCare West's disability services are provided from a strengths based, person centred approach.

In 2008, in response to identified service users needs and with support from the W.A Disability Services Commission, UnitingCare West conducted a project to identify good practice for residents with disabilities as they age<sup>16</sup>. The literature review identified a number of important principles, including:

- Attention to individual needs and circumstances
- Flexible service types and provision across programs
- Disability and aged care service linkages.

UnitingCare West has implemented the recommendations across the accommodation services including reviewing service design, looking at the age compatibility of residents, obtaining funding for alternatives to employment, providing staff training, utilizing person-centred planning and supporting ageing in place. The outcomes of this approach have ensured regular evaluation of individuals at risk of early onset ageing, preparation of timely plans to support ageing in place and/or development of alternative supports to meet individual's needs.

In 2009 UnitingCare West with support from the W.A Disability Services Commission, undertook further work to enhance the citizenship of people with disabilities who were resident in supported accommodation in the community. The report highlighted a number of factors relevant to the support of individuals with disabilities who were ageing including the importance of evidence based services and training. The report supported the implementation of Active Support in all UnitingCare West accommodation services and the importance of adequately resourcing independent person centred planning to ensure consideration of needs beyond those provided by the funded accommodation provider.

---

<sup>16</sup> Gatter, B. *The Changing Support Requirements of People with a Disability as they Age. A Guide to Good Practice for UnitingCare West.* 2008

## **GOOD SAMARITAN INDUSTRIES (GSI - WA)**

Good Samaritan Industries in Western Australia has developed an action research project to assist their employees with the transition to retirement.

One challenge for GSI in supporting an employee in the ageing transition - whether it is from employment to retirement to a disability setting with higher levels of support or other transitions - is that it is likely that the employee with a disability will have less family support at this stage of their life, especially from parents. An individually planned approach will ensure a focus on their individual circumstances and needs, even if the client does not have a close family member as their advocate.

The target group is those people in the care of family or individuals where their living situations are at risk of breakdown or because of the current circumstances will not appropriately support the individual once they have left work. Once these people are identified the project will:

- Develop plans that respond to individual needs and circumstances;
- Develop flexible service responses and provision across organisations/programs;
- Where relevant improve disability and aged care services linkages;
- Consult with the people concerned; and
- Implement at least 50 per cent of the individual plans that are developed.

In systemic terms, the aim of the project is to shift the 'imbalance' that exists between work and access to the community for these individuals to a more normalised situation.

## **UNITINGCARE QUEENSLAND**

Key amongst our approaches is to try and establish productive, respectful and meaningful dialogue with people who have a disability and their families about what they want from their service provider, what their life goals are and how services can meaningfully assist them with identifying these and then working on them.

This leads to work like the Community Safeguards Coalition, the recent Synod motion and to engaging in discussions about where someone wants to live and who, if anyone, they want to live with. This approach focuses strongly on the mix of paid and unpaid supports and how people can lead more meaningful lives.

### **Youngcare**

Wesley Mission Brisbane (WMB) in partnership with Youngcare Foundation established the 'Youngcare Apartments' in Brisbane. WMB donated land at the Sinnamon Village campus and Youngcare Foundation, utilising their connections with Brisbane's corporate community raised the funds (both in-kind and cash) to build the apartments. There are 14 apartments (12 single bedrooms and 2 x 2 bedrooms). All residents were residing in aged care facilities or at immediate risk of entering an aged care facility prior to their entry to the Youngcare Apartments. WMB holds the service agreement and responsibility for the long-term care of residents at the Youngcare Apartments.

The vision of the Youngcare Apartments is to enable young people to live as young people.

Some challenges we have been presented with:

- Entry criteria and independent review of potential eligible residents set by Disability Services Queensland did not always match the original rationale and capacity of the Youngcare Apartments (i.e. level of medical intervention now required by a number of Youngcare residents was not thoroughly understood by that independent process;

- Ensuring we are able to resource adequately the additional support required to residents' children, spouses, etc. This was not initially factored into the funding model and should have been. Having the capacity to involve/include children/spouses is obviously very important to residents;
- WMB's commitment to Youngcare residents as they age and the future funding dilemma;
- Significant and ongoing up skilling of staff from external providers (i.e. MS Society and ABIOS);
- Workplace culture issues – boundaries and balance in relation to necessary clinical supports and enabling young people to do the things they strive to do and achieve. This also has a cost in relation to staff training, review and recruitment.

Overall, the Youngcare Apartments has provided a successful alternative to 16 people who would have been residing in aged care facilities.

## BEYOND THE UNITINGCARE NETWORK

Staff in UnitingCare services also identified other models that may be helpful for this group.

The **Microboards** concept developed in Canada<sup>17</sup> extends the Circles of Support model to form a small Board that is responsible for managing the funds for the support of a person with a disability. The benefit for ageing carers is that they essentially create an 'organisation' to care for their family member once they are no longer able to do so. This model has been successful in Canada and has been introduced to a number of other countries, with an Australian chapter having been established in Perth.

**Peer-based support services** are also important, and available in a range of different forms and demographics. The opportunity and space to discuss issues (especially for the carer) with someone who has been through the same situation is crucial.

The **Wallara/Wintringham Model** enables people ageing with a disability to move from supported living arrangements to an aged care level of support when they need to, with little disruption on the same site, with people they know. This also enables the aged parent of a person with a disability to move into aged care accommodation and have their ageing son or daughter live and be supported on the same site.

**Capacity Building for organisations and families.** There are a number of examples of services that focus on building the capacity of leaders both within services and also within people with disabilities and their families to lead positive change in the support for people with disabilities. A focus of these initiatives is to help people to 'imagine better', to focus on people's strengths and the capacity of the community to create opportunities for people with disabilities to be truly included in their communities.

Examples of such initiatives include:

**Personalised Lifestyle Assistance**, Victoria [www.plavic.net.au](http://www.plavic.net.au) PLA is a small community based advisory service that builds capacity and knowledge predominantly in people with a disability and their families to enable them to have opportunities typical of other citizens in the community.

**The Community Resource Unit (CRU)**, Queensland [www.cru.org.au](http://www.cru.org.au) CRU aims to:

- Challenge ideas and practices which limit the lives of people with disabilities; and

---

<sup>17</sup> Vela Microboards [www.microboard.org](http://www.microboard.org) ; Vela Microboards Australia [www.microboard.org.au](http://www.microboard.org.au)

- Inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

**Planned Individual Networks (PIN)** WA <http://pin0.businesscatalyst.com> PIN aims to support families to plan and create a secure and fulfilling future for their relative with a disability.

**Practicalities and Possibilities** UK, [www.cpa.org.uk/PandP](http://www.cpa.org.uk/PandP) This is a development program designed to initiate and support nine small scale projects to apply the principles and practices of self directed support with and for older people who need support to live their daily lives.

**Sheffield Model**<sup>18</sup> Since 1996, Sheffield has been working hard to develop robust systems for supporting older families, as a result of sustained lobbying from family carers concerned about what would happen to their relatives when they died or could no longer care for them. Currently, the situation in Sheffield is as follows:

- The majority of family carers over the age of 65 (around 400 families) are known by the Sheffield Case Register.
- All families where the family carer is aged 70 or over are offered regular contact through the Older Carers Support Service. Information about their needs and the needs of the people they support is recorded at least once a year.
- The oldest and most isolated older families who have no funded support from statutory services are being prioritised and helped to plan ahead by a specialist team, the Older Families Planning Project (OFPP). The aim is to make sure plans are in place for people before a crisis develops. As a result, many people have been supported to make planned moves or to make a choice to stay on in their family home with the right support in the future.
- Older families remain a priority group within accommodation and support strategies and on other agendas.

The voluntary and statutory services have become far better able to meet the needs of older families. The emphasis is on:

- a demonstrable commitment to this group;
- partnership working between health and social care services, the voluntary sector and families;
- identifying older families;
- involving older families in developing the framework for supporting them;
- regular, low-level contact with older families to prevent crisis;
- person-centred planning, with an emphasis on a family-centred approach;
- advocacy and support, provided by the voluntary sector; and
- identifying 'invest to save' outcomes through prevention and planning work.

This has not tackled the issue fully, but it has proved to be a good and effective start. The main challenge for the future is developing more robust links with services for older people, and ensuring that this specialist work is not considered a luxury or at a tangent to the mainstream.

<sup>18</sup> Dept. Health (UK) (2010) **Valuing Older Families Now** [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

## ISSUES IN OTHER PORTFOLIO AREAS OUTSIDE DISABILITY THAT NEED TO BE ADDRESSED TO IMPROVE PLANNING FOR THIS GROUP

### Power of Attorney

Power of Attorney is clearly an issue of importance for carers of a person with a disability. Provision of information to families about such legal issues is critical.

### Legal Aid

The current cut-off to receiving legal aid is having equity of \$100,000 or more. This makes legal aid inaccessible to most participants who have any equity in their own home, yet legal aid is still an important need as disposable income is not readily accessible or available.

### National Disability Insurance Scheme (NDIS)

All of the issues raised above will have limited resolution by mere structural or policy changes. Structural and policy changes need to be supported by adequate ongoing secure funding to enable realistic and appropriate outcomes for individuals, rather than just positive intentions with a frustrating lack of resources.

Any recommendation regarding planning options and services will need to consider how this will be funded, and a mechanism such as a NDIS is a necessary foundational factor to ensure that policy and system responses can be funded appropriately and securely.

The NDIS will also need to ensure that the criteria cover the needs of these people as they continue to age, as well as the ongoing and emerging needs of their carers.

### Charter of Human Rights and Responsibilities

Increasingly, state and federal governments are considering the development (or have already developed) Charters of Human Rights and Responsibilities.

Within these existing and emerging Charters should be social and economic rights which enshrine Ageing and Disability services as basic human rights. This would form a positive, equitable foundation to future development of services and provide a lens through which existing Acts, services, and the functions of public authorities can be measured and improved.

### Generational change

The service system will not be able to continue to rely on the cultural assumption that carers will continue to take full responsibility for people with a disability. Increasingly, younger carers will not be as inclined to take full responsibility (especially in regards to accommodation) for people with a disability, placing increased pressure on the service system. The option of leaving people with disabilities at home with unpaid and paid care can no longer be assumed to be the expectation in many cases.



## STORIES THAT ILLUSTRATE THE SITUATION OF PEOPLE AGEING WITH A DISABILITY

Pam is a vibrant mother who lived with her husband and children. Pam had a stroke which left her with very high care needs, which were being met solely by her husband. When her husband unexpectedly passed away the family felt that they had no other option than to place their mother in a care facility. Pam's high and complex support needs had been completely catered for by her husband and she had been doing very little for herself, and this had dictated her residential options. It was after this occurred that Pam was referred to our Planning and Facilitation team, for assistance to look at other options.

Through extensive planning and strong support she was able to return home to live with her children. With support from a planner Pam was able to organise support for the chores she was unable to do such as gardening and some household duties. After some time she was able to develop a reciprocal relationship with her network of friends through exchanging favours.

A recent plan review showed that not only had she successfully proven that a person with high care needs could reside in their own home successfully, but also that she continues to manage well, and only requires paid services for specific tasks.

Once this plan was developed with the action being facilitated Pam was able to reduce the level of support offered from the planner and 'graduated' from the service.

The story of Pam highlights how planners can work with people to realise their dreams, and assist them to build appropriate supports as part of the implementation phase of the plan. It would have been too easy to have assessed Pam's support needs and to conclude that her physical needs could only be supported within a care facility. The planner worked with Pam, her family and her extended networks to make her dream to return home a reality. This is an example of where a person has been successfully assisted to leave a high care facility and be supported to live in their own home.

Lynn is a 57 year old woman who has an intellectual disability. Her mother, now in her early 80's, has been her main support and this has been augmented occasionally by Lynn's brother. Lynn has strong social skills and is competent in using public transport once taught. She is a student at CAE classes in the city and is currently attending twice a week.

Her mother is no longer driving and although her health is good, is concerned as to how Lynn will manage once she dies. Whilst used to managing all aspects of Lynn's life, her mother is learning to give Lynn the opportunity to express her wishes and explore her life goals. This enables her to explore new experiences in order to build her local community network and to improve independence in domestic activities of daily living. Much work was undertaken by the planner with Lynn's mother to get her 'on board' with this process.

Goals that Lynn set in November 2008 were to:

1. To become a volunteer in a hospitality-type setting
2. To participate in local community art or craft group and meet local people

3. To become more confident with her cooking skills
4. To reconnect with old friends in order to increase her circle of support.

Lynn attended a cooking class at a Neighbourhood House and is currently attending a beading class at the same location. She was given the opportunity to train as a volunteer at Box Hill Hospital Kiosk. This was not successful but she is keen to explore other opportunities in the future.

Lynn was referred to UCCO's Circle of Support Worker and she has met with Lyn and her mother on two occasions and is now working towards inviting contacts to a Circles meeting.

Lynn has just been referred to a program offers the person the opportunity to be taught living skills in their own home once a week for up to 24 months. Specific areas of learning within this program include cooking, money handling, and household shopping.

Through a sustained process of planning, action and review, Lynn has been able to identify and work towards life goals that she never believed possible prior her involvement with the planners. So too, her family has also been able to see her potential for change and growth.

Lynn's mother, with the support of the staff has now registered for ageing specific support, has had an assessment by Aged Care Assessment Team to determine her own support requirements. The staff member has also prompted family discussions to commence estate and decision making processes for the event that Lynn's mother is unable to care for her.



## REFERENCES

Bigby et al, People with disabilities who are ageing, their changing needs and the capacity of the disability and aged care sectors to support them to age positively. National Disability Administrators, 2006

Casey M, Cole, J, & Boldy D. *A Brief Review of Ageing with a Longstanding Disability in Western Australia*. Centre for Research into Aged Care Services, Curtin University of Technology, Perth WA. 2002

Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Disability Census, 2007*

Dept. Health (UK), *Valuing Older Families Now* [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications) , 2010

Disability SA Website, [www.sa.gov.au/subject/Community+Support/Disability](http://www.sa.gov.au/subject/Community+Support/Disability)

Disability Services Commission, Western Australia Website [www.disability.wa.gov.au](http://www.disability.wa.gov.au)

Dowse et al *Ageing with a Lifelong Disability*. Student Project Final Report. University of NSW, 2009

Gatter, B. *The Changing Support Requirements of People with a Disability as they Age – A Guide to Good Practice*, UnitingCare West, September 2008

Hales C, Ross L & Ryan C, National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report. Aged Care Series No. 12. Cat. no. AGE 50. Australian Institute of Health and Welfare: Canberra, 2006

National People with Disabilities and Carer Council *SHUT OUT: The Experience of People with Disabilities and their Families in Australia*, National Disability Strategy Consultation Report, 2009

Ottmann, G., Allen, J., Feldman, P. *Self Directed Community Aged Care for People with Complex Needs: A Literature Review*. UCCO/Deakin University QRN, Melbourne, 2009

Saunders, P. *Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies*, Social Policy Research Centre Discussion Paper No. 145, December 2005,

Vela Microboards [www.microboard.org](http://www.microboard.org),