Inquiry into Disability Care and Support
Productivity Commission
GPO Box 1428, Canberra City ACT 2601

Dear Commissioners,

Please find attached the UnitingCare Australia response to the call for submissions to the Productivity Commission regarding the Inquiry into Disability Care and Support.

UnitingCare applauds the Australian Government's commitment to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers. We support the Government's view that the current system is not meeting the needs of people living with a disability and their families and carers, and we believe that a paradigm shift is required to create the best solutions to improve support services for people with 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 –in accommodation and housing support, material aid and financial counselling services, employment programs, family support programs and respite care. This provides UnitingCare with a very broad understanding of the needs of, and challenges 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 living with a disability, and provides examples of promising practices from UnitingCare service providers, and the broader service community in Australia and overseas.

Thank you for the opportunity to contribute to this Inquiry. We welcome any further consultation and feedback that may be sought and look forward to reviewing the industry wide responses.

Yours sincerely

Susan Helyar

National Director
UnitingCare Australia

16 August 2010

UNITINGCARE NETWORK SUBMISSION

to the

PRODUCTIVITY COMMISSION
PUBLIC INQUIRY

into

DISABILITY CARE AND SUPPORT

Contact:
Susan Helyar
National Director
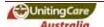UnitingCare Australia

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CONTENTS

1.   INTRODUCTION

UnitingCare Australia is pleased to have the opportunity to lodge a submission to the Productivity Commission Inquiry into Disability Care and Support.

UnitingCare applauds the Australian Government's commitment to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers. We support the Government's view that the current system is not meeting the needs of people living with a disability and their families and carers, and we believe that a paradigm shift is required to create the best solutions to improve support services for people with disability.

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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 further at your request.

2. 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 people with disabilities, older Australians, children, young people and families, Indigenous Australians, people who are homeless or living in at risk environments, people from culturally diverse backgrounds and people 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.

UnitingCare Australia has developed a comprehensive set of principles for Care in the Community. While this was primarily developed in the context of support for older people, we believe that these principles apply equally to people with disabilities. These principles can be found at Attachment D.

3. 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.

4.   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 disability-specific 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.

UnitingCare Australia also supports people with disabilities through a range of community services provided through our network of 1,300 sites across Australia.
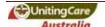
5. DISABILITY SERVICES: GAPS AND STRENGTHS

UnitingCare Australia is very pleased that the Government is considering a National Disability Support Scheme (NDSS), and the UnitingCare Australia network sees this as a critical way forward. An NDSS would ensure more adequate and sustainable funding of disability support services, and provide people living with a disability with assured access to long-term support as needed.

UnitingCare supports the establishment of an insurance scheme within the NDSS, believing that while this would have limitations that require careful safe guarding, the availability of a dedicated funding stream outweighs the disadvantages. However an insurance scheme is only a funding mechanism, and on its own will not be enough of a change to the current disability support system to allow people with a disability the opportunity to choose the life they wish to live. UnitingCare Australia supports a National Disability Support Scheme that would achieve this end.

To achieve fundamental reform, and meet the aspirations of people with disabilities, their carers and families, Australia needs to reconceptualise what disability services look like; to eliminate the tiers, duplication and gaps in services and supports and to transform disability into a mainstream issue, not just the concern of the disability sector. This requires, where possible, that services and facilities provided for all Australians are available, accessible and relevant to people with a disability. This needs to occur in all spheres of activity - education, health, housing, transport, access to facilities, provision of goods and services - and in both the public and privates sectors.

However, any service system response needs to be situated within the broader framework of enabling people with disabilities to have full citizenship within our community, being fully included in community life and having access to a lifestyle that all other citizens of this country expect. The design of a new system should begin with this end in mind. A key to this is the right for all people to be able to access mainstream community resources and facilities, and be guaranteed the right to the additional supports that are needed to compensate for their disability.

Through the current process to develop a National Disability Support Scheme we have the opportunity to create a sustainable service system to support this broader goal of equal citizenship, by enabling people to have control and choice over where they live and how their supports are provided. The scheme should focus not just on supporting individuals but on structural and systemic change to ensure that all people in the community are able to access what they need regardless of their level of impairment.

6. Key areas of concern, and suggestions for change

Through our ongoing work, UnitingCare Australia has identified a number of areas where we feel change is desperately needed.

6.1 Universal access to services and supports

The new strategy needs to guarantee that all people living with a disability that limits their life chances have access to services and resources that enable them to live the life they choose, a life of dignity and opportunity. The objective of the current Inquiry is to define the optimal suite of services that is needed for the long-term wellbeing of people living with a disability. It is necessary to ensure that all people living with a disability have access to the same level of wellbeing regardless of geographic location or advocacy support, being able to access the range of services they need. Some people will require more support to plan and exercise choice than others.

6.2 Inclusion of people with disabilities in community life

The National Disability Support Scheme needs to be delivered in a way that supports people with disabilities to be fully included in community life. The approach needs to be person-centred, but also to do so in a way that utilises people's strengths and interests to enable them to have a meaningful life in the community and the opportunity to contribute and form lasting relationships with a range of people. This is about more than just "being in the community" but enabling people with disabilities to have their social, emotional and spiritual needs met as well as their physical support needs.

The report **Shut Out. The Experience of People with Disabilities and their Families in Australia**[1] stated:

> *'Disability is characterised by desire for positive change and striving for emancipation and flourishing. It is seen every day amongst people living with disability. It is active hope. **We desire a place within the community.** This place is not just somewhere to lay down our heads, but a place which brings comfort and support with daily living, friendship, meaningful work, exciting recreation, spiritual renewal, relationships in which we can be ourselves freely with others. And out of this great things may flourish'.*

A key means of inclusion is the opportunity to work. In 2003 the labour force participation rate for people with a disability aged 15 to 64 years was about 53% and the unemployment rate was 8.6%. This is compared to over 80% and 5% respectively for people without disability. People with disability have lower participation rates in education, and the number of people with disability in receipt of Disability Support Pension has increased by over 36% in the past 10 years.[2] While the National Mental Health and Disability Employment Strategy is a good start, we need to continue to strengthen both specialist and mainstream support for people with disabilities to obtain employment. UnitingCare Australia has made some specific recommendations in relation to employment services in a number of submissions to the Federal Government.[3]

The inclusion of people with disabilities in the community requires a re-orientation of the way in which supports are provided. Disability support workers will be required to shift their role, attitude and skills in order to support community inclusion, being more of a facilitator and connector than a helper. This requires services to review practices from recruitment to defining job roles, training and the supervision and support of workers. The person with a disability needs to be listened to, helped to identify their strengths and interests, and given

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[1] National Disability Strategy Consultations. (2009) **Shut Out: The Experience of People with Disabilities and their Families in Australia.**
[2] FaHCSIA (2009) National Mental Health and Disability Employment Strategy
[3] These can be found on the UnitingCare Australia website www.unitingcare.org.au/policies-a-publications.html

opportunities to experience a range of community activities and settings that they may not have previously had the opportunity to be involved with.

It is also important to recognise that people in the community may still display prejudice against people with disabilities or lack understanding of how to relate to people with impairments. Community facilities may also be inaccessible and present barriers to people with a range of impairments. The facilitation of community inclusion will therefore require a range of strategies to work with the community on access issues, changing attitudes and community building. However the increasing presence of people with disabilities in the community and the development of relationships in the community is the best way to promote inclusion over the long term. For example, research shows that children with disabilities included in mainstream education make more friends, do better academically, and are more likely to gain employment when they leave school. [4]

Inclusion in Faith Communities[5]

An example relevant to the Uniting Church has been the work done in relation to the recognition of the spiritual needs of people with disabilities and the importance of their inclusion in faith communities.

Victorian legislation in relation to people with disabilities is underpinned by the Equal Opportunity Act 1995, the Disability Act 2006 and the Charter of Human Rights and Responsibilities 2006, each affirming the full participation of people with disabilities in **all dimensions** of community life.

The Victorian State Disability Plan, developed for the period 2002-2012 affirmed a number of Guiding Principles: the values of Equality, Dignity and Self-Determination (Choice), Diversity, Non-Discrimination. The Principle of Equality recognises that
"people with a disability are citizens who have the right to be respected and the right to have equal opportunities to participate in the social, economic, cultural, political and spiritual life of society. As citizens, people with a disability also have equal responsibilities towards Victorian society and should be supported to exercise these".

For some people, the spiritual dimension of injury and disability has been described as a 'grand project and everyday task' of coming to terms with finite losses and limitations as well as the infinite possibilities for a meaningful life, and for a relationship with the world and a higher power.[6]

For some people, living with disability may be an opportunity for spiritual growth and meaning-making - a catalyst for profound individual transformation and re-connection with the sacred as a central organising value in life.[7]

Conversely, for some people the onset or ongoing experience of disability may be a catalyst for profound spiritual distress or discontent, and provoke various forms of spiritual struggle.[8] This may include questioning of spiritual beliefs or one's relationship with God or deity, a deep crisis of faith, disillusionment with a previously supportive faith community, or disinterest in previous religious activities.[9]

Either way, the relationship of spirituality and disability is an important one, and some people with disabilities seek involvement within a faith community to explore themes described above, and also

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[4] Jackson, B. (2009) *Why should schools include children with a Disability?*
[5] Source: Rev Andy Calder, Uniting Church, Victoria
[6] Fitzgerald, J. (1997) *Reclaiming the whole self: self, spirit and society.*
[7] Pargament, K. I. (1998) *Stress and the sacred: the spiritual dimensions of coping.*
[8] Fitchett, G., & Murphy, G. (2004) *Religious struggle: Prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients.*
[9] Cressey, R. W., & Winbolt-Lewis, M. (2000) *The forgotten heart of care: a model of spiritual care in the National Health Service.*

seek friendships and social connection. For many people with disabilities participation in the faith context of their choice is a significant dimension of life, and when this does not occur, the risk to diminished quality of life is increased.

The human services sector needs support in its encouragement and facilitation of people with disabilities moving into community-based faith contexts (to attend formal/informal worship, access a range of friendship and social activities offered by many faith communities). As needs and interests become known and shared, the potential for staff and community volunteers/agencies to collaborate is significant. However, this potential has lain dormant. Resource development and awareness-raising are central to this response.

6.3 Utilising existing effective models of service delivery

There is considerable evidence from service delivery and research about effective service models and approaches, and this should be utilised to develop an evidence-based system. It is important to make sure that the effective models and positive outcomes arising from pilots are implemented, rather than being seen as one off trials that don't lead to fundamental change in services. A good example of this was the Innovative Pool Pilot program that provided additional supports for people ageing with a disability, but was discontinued after a pilot phase and positive evaluation. [10]

These service delivery models must be person-centred, tailoring supports around individual needs. People need to have real choices about the supports they receive, how they receive them and these supports need to be flexible and responsive to changing needs.

The Productivity Commission has asked the question about whether block funding of services will still be required until a new scheme. It is important here to re-emphasise that it will take more than funding changes to provide what people with disabilities need.

UnitingCare Australia essentially supports the idea of each individual with a disability having control of their allocated funding to enable them to have choice and control over the supports that they require to both live as independently as possible in the community and to participate fully in community life. However, we understand that this will have implications for service providers and the workforce and would advocate for careful planning to ensure that there remains a range of support options from which people are able to choose. Services that are unable to provide what people want or need should not be "propped up" by block funding.

Significant emphasis has been placed on need to implement individualised or self-directed funding, to enable people living with a disability to take control of planning for their supports and needs; how supports are delivered; how funds are managed. This fits with a philosophy that places value on inclusion, community living, the empowerment of people with disability and the rejection of a 'one size fits all' approach to service delivery.

Many services are re-shaping their practices to align with the above goals within the current funding regime. Practices such as person-centred planning, for example, are re-shaping services to reflect the needs and aspirations of individuals, without relying on individualised funding. Attachment A provides an elaboration by UnitingCare Queensland of what person-centredness means in a service context.

There are a number of considerations in relation to an individualised funding approach:

- Providing people with the funds will not ensure that the options that they want or need are available in the market. This may be due to the fact that such demand has

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[10] Hales C, Ross L & Ryan C (2006). **National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report**.

not been predicted, or that the workforce is not skilled or attuned to meeting this particular need, or are entrenched in more traditional approaches.

- Funding needs to be adequate to enable individuals to access the services and supports they need

- Lessons need to be learned from sectors such as Child Care where funding has been provided and a private market has developed to meet demand. There are also examples of where professionals have been seen to be exploiting insurance-funded services by charging higher costs than for their standard services.

- Funding is not necessarily the solution to a good life in the community so there also needs to be the capacity for the facilitation of informal supports and community links. Facilitation requires skills and resources up front but can have long term benefits.

- Individuals with a disability and their families require good information in order to make choices about support options, and the opportunity to build their capacity to understand what might be possible and to build the kinds of supports that do not currently exist. Funding needs to be made available to build the capacity of services, generic community resources and people with disabilities and their families in order to generate new options that facilitate a good life in the community.

- Individuals may not have the desire or capacity to develop or manage their own support plans, and need choice about how active they are in the administrative aspects of the support they receive. Options need to be available for people to choose individual funding or to choose to use a financial intermediary, or have services managed by a disability service provider or other organisation.

- Some funding may be required to maintain small specialist services that require continuity of expertise (such as early intervention programs) where demand may vary over time.

VICTORIA - State Disability Plan

Victoria is often cited as an example of system that has a progressive approach to the support of people with disabilities. The Victorian State Disability Plan launched in 2002 states that *"The Victorian Government believes that people with a disability should be able to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria."*[11] The strategies have involved introducing individualised funding approaches, but also efforts to promote community inclusion, improve the rights of people with disabilities and make government services more accessible. To some extent the system is still too new to make a judgment on its long term effectiveness. However, we believe there is much that a new National Disability Support Scheme could learn from the Victorian system. The components of this strategy that are seen to have worked best by the UnitingCare services in Victoria include:

- The **individualised funding** and **self-directed** approach is clearly an advance on previous systems. The trials in **Direct Funding** are also seen as an important addition to the choices available to people with disabilities and their families;

- The **integration** of different funding streams into one Individual Support Package (ISP) simplifies the system;

- The inclusion of **planning support** is in principle an important component of the system (see further comments below). It is considered to have worked better for some groups than for others (for example for school leavers when entering the adult service system);

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[11] Victorian Dept. Human Services (2002) **State Disability Plan 2002-2012**.

- The role of the **Senior Practitioner** is seen as an important enhancement of the system. This was established to protect the rights of people with a disability who are subject to restrictive interventions and compulsory treatment. The Office is responsible for authorising, monitoring and reviewing restrictive interventions and compulsory treatment, and sets standards and guidelines in relation to these practices. It is also responsible for research and making recommendations for practice improvements to the Minister and Secretary in relation to restrictive interventions.[12]
- The **Office of the Disability Services Commissioner** is seen as important to make independent investigations of complaints about disability services, and to educate providers about complaints handling mechanisms. The fact that non-government services and government provided services are both covered by this mechanism is seen as particularly crucial in Victoria, given the high level of government service provision in the state;
- The **Quality Framework for Disability Services** is also seen as a positive aspect of the system, enabling independent review of services against the standards. This includes an individual outcome measurement;
- The commitment of the Victorian Government to **deinstitutionalisation** of people with disabilities should be applauded, with a no growth policy in relation to shared supported accommodation. Accompanying that is work being done on alternative **individualised accommodation options** (Alternative Accommodation Support Options)[13], and the provision of housing through the Disability Housing Trust;
- The inclusion of **community strengthening** strategies in the State Disability Plan. The **Office for Disability** within the Dept. of Planning and Community Development is responsible for co-ordinating action plans by all Government Departments and instrumentalities, as well as strategies with Local Government and community awareness campaigns.

There are also a number of aspects of the Victorian system that could be improved, and provide useful learnings for a future National Disability Support Scheme:

- There is still poor knowledge generally about how the system works and this prevents people gaining access when they need it;
- The system remains largely crisis driven, and the planning components still tend to have a short term rather than long term focus;
- Given that people are often entering this planning process in crisis, the process is seen as painfully slow, time consuming and complex, and unable to address urgent needs;
- The process involves four stages:
    Being accepted on to the Disability Support Register having proven eligibility and need;
    Having a plan prepared with a DHS provided or funded planner;
    Having the plan approved by DHS;
    Having a budget allocation approved (which may or may not fund all of the elements of the approved plan)
- The time delay between these stages can be long, and the ultimate outcome may still not meet the identified needs;
- Individuals with a disability and their families find that the planning process is still largely deficit-driven, and that they dislike having to emphasize what they cannot do but believe they need to do this to obtain support. They find the process painful and undermining of their dignity;
- The process for obtaining a change in plans and funding is also cumbersome, and reviews are not conducted often enough for people with changing needs;

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[12] Victorian Dept. Human Services (2010) Disability Services Division,
[13] Victorian Dept. Human Services (2010) Disability Services Division. Accommodation Innovation Grants.

- The individual or family, or the person who assists with the preparation of the plan has no access to decision makers to present their case or answer questions about what has been submitted. The approval process is seen as lacking in transparency;
- Individuals and families do not feel they get enough information about the range of options available as part of the planning process, particularly those that may be outside of the mainstream disability service system.

(Some of this information has been drawn from preliminary focus groups being conducted by Wesley Mission Victoria as part of a review of their planning process).

The lessons that can be drawn from the Victorian experience include:

- The need to invest up front in good information for people with disabilities and their families about and new scheme, how it works and what their options are;
- The need to start planning with people early, and focus on long term as well as short term issues;
- The need for a simple and streamlined process for people to gain access to the scheme, at least initially for a basic level of support, that may then be increased after a longer term planning process and assessment of needs;
- The need for regular reviews and a simpler system of adjusting supports to changing needs or crisis situations;
- A simple eligibility process that does not require people to dwell on their deficits;
- A transparent approval process with opportunities for review and appeal if people are unhappy with the decision;
- The individual planning and support process needs to occur within a context of a range of other strategies to promote systems change, community awareness and community inclusion.

NSW - Individualised Funding Pilots

Recent pilot schemes in NSW designed to explore the effectiveness of the Self-Managed model of funding have allowed people with disabilities and their families to expend their service funding in ways which suit their needs best. This includes using funds to access services which are mainstream as well as disability specific services, being able to purchase equipment that meets the persons individual aspirations, not just that funded by a scheme, and a more flexible approach to staff recruitment which includes the ability to harness family and community members in the support of a person with a disability. The preliminary evaluation results of these programs have been extremely positive and demonstrate an enhanced quality of life and community inclusion for the person with a disability and their family members and carers.

WESTERN AUSTRALIA - Local Area Co-ordination

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.*' 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.

A review of Local Area Co-ordination (LAC) was commissioned by the WA Government and overseen by a Review Steering Committee, reporting in March 2003.[14] The review found that overall the LAC approach had been a success and that there had been high levels of consumer satisfaction with the program. Strengths identified included flexibility, local accessibility, relevance and "hands on" practical approach. There were also concerns raised about inconsistency in quality, the processes to manage dissent and the rate of turnover of staff, especially in non-metropolitan areas. In addition, there had been a major increase in workloads that had reduced the LACs capacity for direct work with consumers. It was also noted that satisfaction among consumer from Indigenous and culturally and linguistically diverse backgrounds was lower.

There are clearly lessons that can be learned from this review of a long running scheme that are applicable to a potential National Disability Support Scheme.

QUEENSLAND – Family Support Program

Queensland implemented a Family Support Program for people with a disability. While this program has changed significantly over time, one program element attempted to slow or stop the flow of children with a disability into the child protection system as they were identified as being higher cost and lesser outcomes in the child protection system.

Key characteristics of this part of the program (Intensive Family Support) was that each family had access to a facilitator or guide who assisted them deal with the myriad of systems they came in contact with (both disability specific and generic community services) and secondly that family through their facilitator had access to up to $25,000 of untied money to respond flexibly to their needs. The program was externally evaluated by a University and these were the two key elements that families identified as assisting them. The importance of developing a relationship with their facilitator or guide was described as a critical component of the success of the program.

6.4   Addressing service gaps and failures

A new scheme needs to be able to address the service gaps and failures that are leading families into the downward spiral of

- family breakdown;

- ongoing crises for parents in the primary caregiving role;

- the parent who is the primary carer needing to relinquish the child with disability to the care and protection system so child can access services more readily;

- leaving adult children in respite services as parents are unable to get the support they need to keep their family member at home.

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[14] Disability Services Commission, WA (2003) **Review of the Local Area Coordination Program Western Australia.**

Family circumstances are critical and developing resilience and appropriate levels of support to families to undertake their caring role without having to carry the burden of replacing services is critical. Mums, dads and families need to be able to be in their typical family roles and have additional the supports needed to help with the person's disability, rather than feel they must take on all of those roles and take up the slack that comes from the absence of appropriate supports.

Parents with a child with a disability frequently ask the question "who will look after my child when I am no longer able to care". These concerns, which arise from the moment of the child's diagnosis, place a burden onto the parent that can lead them to choose pathways that are neither in the best interest of the child or the parent and other siblings.

For parents of children with extreme medical or behavioural support needs, the lack of access to safe, regular and reliable support can lead to children being placed in multiple, or extended respite care arrangements and ultimately can lead to family breakdown and the relinquishment of the child into the child protection system.

UnitingCare operate programs in NSW such as Intensive Family Support and Extended Family Support which allow intensive intervention to support families of children with a disability who are at risk of breakdown. These programs provide families with the support and resources they need to sustain them in caring for their child, however these interventions are time limited (3months for IFS and 2 years for EFS) whereas the child's disability is lifelong.

Parents caring for adults with a disability have often moved through the crises and settled into a lifestyle which, we know from numerous research studies, equates with low levels of household income and reduced health and wellbeing. The question of "what will happen to my child when I die?" has not gone away however is often not audibly articulated by carers due to a perceived lack of services and pathways. Parents are often forced into wishing that they will outlive their own child.

Families often request 24 hour support services, such as group home placements for their adult child, regardless of their actual support needs due to a lack of adequate and reliable support for the person to otherwise live outside the home (see also 6.8 re appropriate housing)

UnitingCare NSW is currently working with the Downs Syndrome Association and House with No Steps to pilot a new model of accommodation support, providing up to 35 hours of drop-in support to people with disabilities to enhance their ability to live in the circumstances they and their family choose, whether that be shared accommodation, independent living, or remaining in the family home. This program will include a significant component devoted to skills development as well as facilitation of Circles of Support to sustain the person with a disability and their family.

6.5 The challenges and risks faced by people living with a disability as they and their families/carers manage key transition points in their lives.

Transition points are a challenging time for all individuals and families, but particularly the case for people with a disability. Each point leads in to a new support system and sometimes to a withdrawal of the kind of support they have become used to. These transition points include entering school; primary school to high school; leaving school; turning 18; entering the workforce; adverse events in the family (family breakdown, unemployment, illness of another family member); loss of capacity of carer to continue to provide support; and the move from disability support to aged care.

For children with a disability the transition into school and then to high school needs to be well planned and supported. Young children with a disability require essential equipment as

well as support to ensure their success both academically and socially, including appropriate communication technology where required. Training of teachers, aides and other school personnel in the use and support of such technology is critical.

The transition into high school can be particularly difficult. During middle childhood years, children with a disability and their families often lose contact with the disability service system and may find re-engaging with therapy services and other supports required for the effective transition to high school challenging. For children with a disability, the transition from a small, nurturing environment to a large high school can mean the dislocation of familiar routines, trusted carers and social networks. For example, a child with Autism Spectrum Disorder relies on consistency, routine and familiar people in order to make sense of their world. At a time when hormonal changes are taking over their confusion is exacerbated by the transition to high school often leading to increased levels of challenging behaviour.

UnitingCare is currently operating two pilot programs in NSW (one in South West Sydney and one on Central Coast) to assist young people with a disability who are at risk of school exclusion to transition to high school and maintain their participation in the school system.

There are systems in place to support young people with a disability to leave school and transition into a suitable option however once the option has been selected there is little opportunity to change as a persons needs, interests and aspirations change. For example, a the lack of appropriate open employment opportunities and subsequent support and guidance for clients who would like to transfer from supported employment to open employment means that people are nervous about making the transition so remain in supported employment where they are supported and guided.

The transition from Disability support to the Aged Care system is problematic and requires urgent attention (see 6.7).

6.6   Appropriate support for people with complex needs and multiple disadvantage

Poor services and outcomes are experienced by individuals with complex problems crossing more than one service agency/portfolio, for example individuals with intellectual disabilities and mental health issues, and/or substance abuse, and/or involvement in the justice system, and/or with a disability as a result of a traumatic injury e.g. an acquired brain injury. Additional factors such as coming from an indigenous or culturally or linguistically diverse background can compound the difficulty of accessing appropriate services. UnitingCare would support a new scheme that caters to situations where multiple issues and disadvantages are present, and promotes the co-ordination of specialist supports to achieve a positive outcomes for the individual rather than an experience of being "passed around" the service system.

Parents with a disability are another group who have not fared well within the current system. The additional supports required to raise a child when the parent has a disability are often considered "out of scope" of existing services. In addition, the child protection system is quick to discount the capacity of parents, especially with intellectual disabilities, to raise a child, rather than looking at what additional supports they require in order to be good parents. (See Case Studies at Attachment B).

The social model of disability informs us that disability is caused by a complex interaction of an impairment and societies responses to that impairment. However, in our highly rationed system, people with perceived "mild" level of impairment are often excluded early on from services and left to negotiate the mainstream system without the support they may require. We now know that people with a mild intellectual disability and or mental illness are over represented in the criminal justice system, in licensed boarding houses and among the homeless.

In NSW, recent initiatives such as the Community Justice Program and the Boarding House Reform Project have attempted to address the consequences of these policies.

The NDSS needs to take a dynamic approach to assessment of disability and or associated need, which includes assessment of a person's social and emotional capacity as well as their personal resources and networks, so as to ensure that this phenomenon is not reinforced.

6.7 People ageing with a disability

The new scheme needs to provide better access to good services and supports for people with disabilities as they age, and get rid of barriers to accessing both disability and aged care services concurrently. In particular, the lack of support to disability service providers to adjust levels of support according to a persons ageing needs, often results in premature placement into residential aged care. People with a disability are living to old age in larger numbers than ever before and the service system has not kept pace with this trend. Providing access to people with a disability who are ageing to Extended Aged Care in Home packages, in addition to their lifelong disability supports, would enable people with a disability to maintain their living circumstances for much longer, support their carers to adapt to changing needs resulting from Ageing and provide a opportunities for workers in both the Ageing and Disability sectors to enhance their knowledge and skills.

The UnitingCare Australia submission to the Senate Inquiry investigating the Planning Options and Services available to people aging with a disability is included at Attachment C. This provides more detailed information about what is required for this group.

6.8 Access to affordable and appropriate housing

A significant issue impacting on effective service delivery is the lack of accessible and affordable housing for both the wider disability population and individuals with particular needs such as the more complex groups referred to above. While housing is a generic service that should be available to all members of the community, and is generally paid for by the individual, it is acknowledged that some community members require assistance in this area, eg through the provision of public housing or rental assistance. Given the current squeeze in Australia's housing market, people with disabilities are at an added disadvantage in accessing affordable housing if they also require physical access or modifications to cater for their disability. The lack of such housing is a major log jam in the current service delivery system and prevents people with disabilities having greater independence and autonomy.

As for other citizens, the need for accommodation and the need for care should be considered as separate issues. People should not be forced to accept a certain type of accommodation in order to receive the level of support they receive, but rather have the option of receive that support in the accommodation of their choice.

QUEENSLAND Forced Co-tenancy[15]

Over the past few years there has emerged a growing practice of people with disability being pressured by Government (and some non -government services) to live in housing situations that are not appropriate for their needs ; they are forced to live with people they don 't know and who they do not choose .

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[15] UnitingCare Queensland. Centre for Social Justice. **Social Justice**. Issue 5. April 2010.

This is named as *forced co-tenancy*. This practice of forced co-tenancies is contra-indicated by the government's own legislation, the Disability Services Act and its Standards and is clearly antithetical to the Church's 1991 Principles for Disability Services.

Quite apart from where people live and what relationships they might or might not develop, there are significant negative impacts arising from the practice of forced co-tenancy including:

- People's individual needs are not met;
- Tenants lose the right to make important lifestyle decisions;
- Psychological wellbeing becomes compromised thus often causing serious behavioural issues, given that many of the people affected cannot otherwise communicate;
- Quality of support becomes sacrificed for short-term cost-cutting - the longer-term cost to the person and society is significant: loss of wellbeing and psychological integrity in the individual, increased hospital admissions, crisis intervention, and creation of specialist behavioural teams;
- Significant increase occurs in risk of abuse, assault, and neglect when people are grouped in atypical ways (as indicated by criminal investigations and other research).
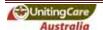
In addition, the planning for long term accommodation options should commence when the person is a young adult, rather than when a carer is become elderly and no longer able to provide the support the person needs.

CASE STUDY – Older Carers

Older carers, particularly those over seventy, feel that it is their duty to continue to care well past the time they are actually physically able to do so. This can lead to unintentional abuse of the person with a disability. For example, a couple presented at this service were caring for their daughter in her forties who has Down Syndrome and is suffering from dementia. Both parents felt it was their duty to care for their daughter until her death. Unfortunately as their health failed they had a near miss of accidental death due to the poor administration of tablets to their daughter, causing her to choke. She also suffered many falls as neither parent were able to support their daughter's weight when assisting her with personal care. In situations such as this, early planning and a clear transition process is essential to avoid inappropriate care and stress on families.

The Commissioners have asked the questions about the economic feasibility of providing individualised accommodation options rather than the traditional group home models. UnitingCare Australia believes that this is not an economic question but rather a moral question about whether people with disabilities have the right to choose where they live and who they live with, in a manner accepted by other members of the community. On the cost question, if the unit cost of a group home setting were redirected towards providing individually tailored supports for people with disabilities to live in a home of their own, this would go a long way towards making such arrangements possible. This is of course taking into account the comments above about available housing. In addition, such arrangements require a combination of paid, unpaid and community supports to enable the person to be part of the community in which they live. There are a growing number of examples both in Australia and overseas of successful individualised accommodation options for people with disabilities, some of whom have high levels of need.[16] Examples of two UnitingCare services are included below.

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[16] See for example the stories from Personalised Lifestyles Assistance (Victoria), Homes West (Brisbane), Onondaga Community Living (Syracuse, USA), Deohaeko Support Network (Toronto, Canada)

South Australia – Home Link Program

UnitingCare Wesley Adelaide has operated a successful and growing state-wide accommodation program that operates very much like foster care for over 10 years. 'Homelink SA' contracts carers to provide care and support in their own homes, which can be owned or rented. The program caters to both adults and children with disabilities and provides respite care, shared arrangements with natural families and fulltime placements on a long term basis. This model utilises existing housing in the community, provides individualised support and maximises inclusive practice by allowing people to live in a manner similarly experienced by the majority of the population.

UnitingCare NSW/ACT is attempting to look broadly at the issue of housing for people with a disability, as well as other vulnerable people, in supported but inclusive settings. They have recently partnered with a community group, HOME Inc. in a feasibility study of an Intentional Community for Department of Ageing Disability and Home Care (NSW). A community of this type would enable vulnerable people, including people with a disability and people who are ageing, to live in an environment with other community members, where people choose to support each other. Ideally, within such a community, people with a disability would have access to the formal supports they require, and these are enhanced by the informal, social supports provided by the community. In turn, the person with a disability can contribute to the community using their own unique talents and abilities.

An NDSS would enable a person with a disability to choose to live in such a community minimising the risk of them requiring 24 hour supports and reducing or delaying admission to residential aged care as they age.

6.9   Employment system issues

The UnitingCare network delivers approximately $105 million of employment support services via a range of Commonwealth funded programs across Australia including those operating under the Disability Employment Network (DEN), Personal Support Program (PSP), the Job Placement, Employment and Training Program (JPET) Community Work Coordinators (CWC) and the Job Network.

In relation to the DEN, UnitingCare expends nearly $10m on services per annum through:
- Uniting Care Wesley Brisbane;
- Ipswich Toowooba Employment Service Queensland
- Prahran Mission;
- Wesley Mission Melbourne;
- Wesley Mission Sydney;
- Uniting Care Wesley Port Pirie;
- Uniting Care Wesley Port Adelaide; and
- Good Samaritan Industries Perth

As with all other spheres of life, where it is possible people with disabilities should be supported through mainstream services to gain open employment. However, it is recognised that some people require specialist training and support to be competitive in open employment, and a small number may never be able to achieve that goal. They require opportunities to have a meaningful occupation; however this may be in the context of a subsidised service. This is an example of where some block funding may be required. There

should also be the opportunity to support microbusinesses that can enable the person to explore their individual interests and utilise their strengths with appropriate support.

7. A NATIONAL DISABILITY SUPPORT SCHEME

UnitingCare Australia supports the establishment of a National Disability Support Scheme. Such a scheme would provide funding for essential support, therapy, aids, equipment, home modifications and access to the community, education and training.

It should be funded by all taxpayers through general revenue or an extension of the Medicare insurance levy. UnitingCare Australia supports the basic elements of a structure that has been articulated by a coalition of disability and community sector organisations, as outlined below.[17] However, some further comments are made on the issue of eligibility.

Eligibility

Principal beneficiaries would be people with profound and severe disabilities who need assistance with daily living tasks (self care, communication and mobility) while people with more moderate disabilities could also be eligible for some assistance based on their lesser needs.

People with permanent disabilities acquired before age 65 would be eligible for life, without reference to cause and treated equally based on needs.

People born with a disability or who acquire a permanent disability through an accident, injury or as a result of a medical condition, including mental illness, would be eligible.

No fault; the provision of support and care for people with disabilities would be separated from legal action for negligence/culpable behaviour.

Benefits for people with disabilities

Care, support, therapy, access (although not income support or housing), based on functional impairment.

Person-centred services and support based on the needs and choices of each person with a disability and their family.

Case management to facilitate independence, maximise potential and plan transitions over the life course, when required.

Early intervention a top priority.

Aids, equipment and home modification needs met on a timely basis.

Training, development and access to work to build self-esteem and reduce long term costs.

New competitive market place for service provision likely to develop, helping to drive efficiency and innovation.

Benefits for families/carers

Families expected to fulfill normal age-appropriate caring roles.

Tailored support for carers, through respite, information, counselling, training and education based on family structure and disability.

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[17] As articulated by the Coalition for a National Disability Insurance Scheme

Families able to choose to work or provide informal care, as for families without disabled members.

Part-time work and labour force engagement facilitated.

Governance and scheme management

Pooling of individual risks.

Mix of Commonwealth and state schemes (including catastrophic injury schemes) with Commonwealth coordination to ensure a consistent national framework.

Coordinated approach to funding, including Commonwealth, states and territories

National standards of assessment, care, support and case management

Governance framework to manage scheme assets, liabilities and data collections to optimise scheme performance and monitor usage.

Active claims management.

Independent review/appeals process.

Some further comments on the issue of eligibility:

People with a moderate disability do not necessarily have a lesser need. Need is determined via a complex assessment of impairment, circumstances and access to other supports (see the diagram at Attachment E as an illustration of this concept).

An "objective" measure of the level of "impairment" does not necessarily capture the level of disability a person experiences in their daily life.

While there clearly need to be boundaries drawn around eligibility for the NDSS, it is also important that people can access supports or increase the level of support when needed, and be able to also decrease supports without a fear of never being able to access them again. The current rationing system encourages people to "hang on" to services. A focus on severe disability also provides perverse incentives to focus on deficits. Initial eligibility assessment and re-assessment processes need to be simple, with the option to engage in more detailed assessments if higher levels of support are being sought.

In relation to the age limit, UnitingCare Australia agrees with the proposal that the scheme support people with disabilities acquired under the aged of 65 years, but continue that support after they turn 65. The proviso on this would be that there is continuity of service for the person, and that they are also entitled to additional support for conditions that may be experienced as a result of the ageing process, without losing their eligibility for their base disability supports.

In relation to the eligibility of people with mental health issues, UnitingCare believes that they should be included if their condition limits their ability to function well in community life without support. The common occurance of dual disabilities means that people would be better served by being part of one scheme, even though supports may be provided through different avenues with particular expertise, hopefully in a well co-ordinated fashion.

8. WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?

8.1   What kinds of services particularly need to be increased or created?

People with disabilities require a range of supports and the ability to access mainstream community services and facilities in order to have a full life in the community. This should be underpinned by individual planning and support, with the ability for the person to be as self-directed as possible and have the availability of facilitation and co-ordination where required. The following are some areas of service delivery that the UnitingCare network has identified as needing additional development.

8.1.1   Information and Access

People with disabilities and their families and advocates will need good information about the Disability Support Scheme, how to access it and what the options are in order to best develop their unique support arrangement. Access to information is currently fragmented and often occurs through a government "intake" team which may be a deterrent to some individuals and families who have had poor experiences with government systems.

The Federal Government is currently undertaking demonstration projects in aged care to establish regional Access Points to community care services.

> "*There are 10 Access Point Demonstration Projects operating in seven states and territories to make access to community services easier for clients and their carers. They offer a resource for people seeking information about community care services and a place where people can participate in a consistent approach to screening and eligibility for services.*"[18]

Where possible, they have been built on existing community care infrastructure in the region. These Access Points, once rolled out to all regions in Australia, would be an ideal point at which to provide information and an entry point into the National Disability Support Scheme and the options available to people to purchase supports in their local area.

8.1.2   Early Intervention

A changed focus from inputs (especially funding) to outcomes would encourage more investment in early intervention. This could mean intervention early in the life of a child with a disability, but also intervention early after the onset of a disability later in life. By focussing on strategies that promote independence, participation and the ability to contribute to the community, costs over the long term will be reduced, and the lives of people with disabilities will be enhanced. This means that the Support Scheme must be able to intervene in a timely manner.

In relation to children, this may mean a willingness to provide support without an official "diagnosis", as such diagnosis is often difficult early on. However, intervention at this time may prevent the need for support later on.

8.1.3   Equipment, technology, home modifications

For many people, access to appropriate equipment in a timely manner is a key to maximising their independence and ability to participate in community life. Such equipment may support their mobility, communication or personal care. Equipment often needs to be tailored to an individual's specific needs.

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[18] Dept. of Health and Ageing. **Access Points Demonstration Projects**

In NSW the PADP scheme which administers the distribution of Products and Appliances for People with a Disability is underfunded and tightly rationed. This leads to people experiencing lengthy waiting times for essential equipment. For children this can mean that the equipment prescribed is no longer appropriate once it is provided. In addition the scheme priorities access to mobility equipment and essential communication technology remains out of reach to most people who require it.

8.2 How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

8.2.1 Investment in support options, innovation and capacity building

A key issue for the National Disability Support Scheme will be how to invest in service development, research and innovation, to ensure that the approached being supported are evidence based and best practice. This area has been poorly supported through current funding approaches, and risks being neglected if funding is only directed at individualised support. With a few exceptions, there is currently a reliance on philanthropic funding to support the trial of new approaches, where government funding is restricted to narrowly defined direct service types. Where there is government support for innovation, this is often short term, and pilots that are proven to be beneficial are not re-funded. There needs to be an investment in research and evaluation that gains the first hand views of people with disabilities and their families, and opportunities to apply the research in new approaches to support.

One method of achieving this may be to add a percentage of funding to each support package that goes to the service provider to enable this developmental work to be funded. So the administrative fee for providing services would include a "developmental levy". Another option would be to have a percentage of the funding allocated to a Research and Development Fund that providers could apply to for funding of specific projects. The National Disability Support Scheme could also establish a National Co-operative Research Centre (CRC) that brings together researchers, service providers and consumer groups to plan a research and development agenda.

> *"The CRC Program provides funding to build critical mass in research ventures between end-users and researchers which tackle clearly-articulated, major challenges for the end-users. CRCs pursue solutions to these challenges that are innovative, of high impact and capable of being effectively deployed by the end-users."* [19]

CRCs have recently been funded for specific disabilities (such as hearing and sight) but not for service system research.

There is also a need to invest in 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.

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[19] Co-operative Research Centres

Examples of such initiatives include:

Personalised Lifestyle Assistance, Victoria[20]
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[21]
CRU aims to:
- Challenge ideas and practices which limit the lives of people with disabilities; and
- Inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

Planned Individual Networks (PIN) WA[22]
PIN aims to support families to plan and create a secure and fulfilling future for their relative with a disability.

Practicalities and Possibilities UK[23]
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.

8.2.2   Respite models

One area that requires critical examination is the provision of respite for people with disabilities. Which it is crucial to support family carers in their roles, it is perceived that governments often increase funding for respite as a "band-aid" solution in crisis, rather than providing funding to create real long-term options for the person with a disability that would have the effect of giving families a break. These include alternative accommodation options, education, work, volunteering opportunities, leisure activities, participation in the community, holidays, camps, staying with friends and relatives and any activity typical for other people of the same age and interests.

Some people with disabilities do not like the notion of "respite" as it causes them to be perceived as a "burden". Instead they would like opportunities and support to have the typical breaks from their families as do all families. An article by Armstrong and Shevellar[24] expands on this issue, describing respite as a "passive" service form, rather than an active attempt to meet the needs of the person with a disability. For individuals to be resilient and able to respond to all the calls on them then there are times they need a break. Respite may be one option to do that but it shouldn't be the only option.

The experience in some jurisdictions is that overnight respite services have become longer term accommodation sites for people with disabilities who have no alternative accommodation, or where families are not getting the supports they need. Thus not only is the person in an inappropriate setting long term, but respite become unavailable to other families.

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[20] Personalised Lifestyles Assistance, Victoria
[21] Community Resource Unit, Queensland
[22] Planned Individual Networks, WA
[23] Practicalities and Possibilities, UK
[24] Armstrong, J. & Shevellar, L. (2006) *Re-thinking Respite.*

8.2.3   Portability of Services

The experience of people with disabilities would be greatly enhanced by a scheme than enables the portability of entitlements across regions and states and territories. Currently a person cannot be guaranteed a similar level of support regardless of where they live.

8.3   How could a new scheme encourage the full participation by people with a disability and their carers in the community and work?

The approach taken by the NDSS will influence the extent to which people with disabilities are able to participate in work and community life. With a person-centred and inclusive focus, supports can be designed to facilitate this goal. Much has been written about models that are strengths-based and focus on wellness, rehabilitation and capitalising on people's capacities.[25] The incentives in the system need to reward increased independence, rather than punishing it as so often now happens with the withdrawal of support.

Family members who have a caring role for a person with a disability also need the opportunity to engage in paid employment if they wish to, in order to support the family income and for their own self-fulfilment and development. This will only be possible if the person with a disability has a fulfilling day time occupation and appropriate supports at home. In addition flexible employment practices are needed to support the family member in their caring role.

8.4   How can a new system ensure that any good aspects of current approaches are preserved?

Funding under the Disability Support Scheme should only be provided for services that are evidence based, either through dedicated research or a proven track record of achievement and effectiveness. This applies to both therapeutic interventions and service delivery models. This will require much greater investment in research and evaluation, and widespread dissemination of these findings.

8.5   What should be done in rural and remote areas where it is harder to get services?

It is often the case that supports in rural and remote areas are already more creative and flexible out of necessity, and make better use of the generic community resources available. However, where specific services are needed, the funding provided generally does not recognise the additional costs of delivering supports to rural and remote areas. The NDSS needs to recognise this and provide a loading for people in these areas to cover the additional costs. The availability of a skilled workforce is also an issue in these areas, and the flexibility for the person with a disability to employ support workers from their existing networks may alleviate this to some extent. However, incentives are needed to ensure specialist services are available when required.

8.6   How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

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[25] Ryburn, B. et al (2008) **The Active Service Model: A conceptual and empirical review of recent Australian and International literature (1996-2007)**.

Better co-ordination could occur if there existed a single record held by the person relevant with information that can be shared between service providers (with relevant privacy protection).

8.7 How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

This question of increasing the power individuals to make decisions is discussed in detail in section 6.3. In terms of appeals, this scheme should take care to avoid the tendency to litigation as has occurred with accident schemes. Instead an administrative appeal mechanism, such as the Social Security Appeals Tribunal would be more appropriate. The Office of the Disability Services Commissioner in Victoria is another relevant model to consider. While avoiding a legalistic model where possible, it is also important that people with disabilities have access to affordable legal support if required.

8.8 How should the amount of financial support and service entitlements of people be decided (and by whom)?

UnitingCare Australia would advocate a simple eligibility assessment process that enables people with a recognised disability to have entitlement to a basic level of support under the Scheme. In order to increase the level of support, more thorough assessments may be required, as well as good support to plan for both the short and long term. The workers who support the planning process should be independent from funding decisions, but able to help the person present a case for the support they need. Many current decision making processes are paper based and do not allow the decision makers to have a good understanding of the person's situation.

It may be possible to provide a transition to this new approach where people can opt to stay with what they have or elect to go into the new scheme – a no disadvantage requirement is probably required.

9. CONCLUSION

UnitingCare Australia is pleased that the Australian Government is examining options to provide a comprehensive national support system for people with disabilities in Australia. We hope that the information provided in this submission will help to inform the shape of such a future scheme. We will be pleased to provide the Productivity Commission with any further information that may be helpful from our network of community services across Australia.

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Victorian Department of Human Services. **Disability Services Division.**
http://www.dhs.vic.gov.au/disability/about_the_division#osp

ATTACHMENT A: Justice in a Human Service: How do we achieve such a thing?

Article from **Social Justice***, Issue 2 March 2009 published by UnitingCare Centre for Social Justice, Queensland.*

Increasingly in modern life, people rely on formal human services to get their needs met. For many people, this evokes feelings of sadness and concern. No matter how much confidence one has in a particular service it is often a matter of regret that a loved one cannot be supported by family, friends, neighbours?

Many human services serve groups of people; by their very nature it is challenging to focus on individuals and even more difficult to craft a set of responses uniquely relevant for each person. Some services do however serve people as individuals and constantly strive to focus on each person.

In striving to be a good human service, to be a socially just human service, several principles or concepts can assist us. That is, social justice in human services requires a focus on, at least, Social Inclusion, Self-Determination, Self-Governance, Right Relationship, and Person-Centredness.

When asked about social justice in the context of human services people often speak about **equity** (of access and service). This idea of equity focuses our attention on how we might ensure fairness and impartiality in providing services. Equity often leads us to think about bureaucracy, that is, the application of rules and regulations applied rigidly to ensure no one gets more than another.

But our concern here is to consider how people might attain equity in life or even more than equity – how people might be assisted to as much as possible get the good things in life. This goes further than the idea of all people getting an equal share and moves into supporting people to get what they need. This is also called positive discrimination or **positive compensation;** or more colloquially, *bending over backwards* to assist people.

Social integration or Social Inclusion can be many things. Here we use it as the participation of devalued people in typical social interactions and relationships with non-devalued citizens, participating in community and society, and contributing to social and cultural life. This means someone who is marginalised, say someone who is long-term unemployed being socially included in meaningful relationships and activities with someone who is well regarded, like a business mentor. Receiving a human service should not restrict one's social inclusion; indeed services providing accommodation support and many others should be focusing on people's personal social integration as a critical aspect of what they provide. The Victorian project 'Count us in!', on social inclusion in residential aged care, is an interesting attempt to address these issues in one human service type.[26]

Self-Determination can be understood as people having the degree of control they desire over those aspects of life that are important to them (this is based on the assumption that the amount of personal control people have in their lives is one, but not the only component, of self-determination). Self-determination refers to the amount of personal control people have over their lives both in how much control they want and/or are most likely to do well with. For example someone with a disability wanting to be able to get a good education, find a job that they enjoy and to control their medical arrangements. The capacity of people to exercise control in life decisions (skills, knowledge, and attitudes and beliefs) and of the environments where they spend time (family, community, residential and employment programs, etc.) needs consideration so they may be supported and encouraged to exercise control in their lives.

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[26] Department of Human Services, "'Count Us In!' - Social Inclusion for People Living in Residential Aged Care," ed. Department of Human Services (Melbourne: Department of Human Services, 2006).

Right Relationship – behaving toward the people we serve in ways that they feel are helpful and respectful, and in ways that such behaviour is considered typical, ordinary, part of our daily practice rather than the exception or something special. There is much we can do to work towards establishing right relationships between services and the people served. This will be explored in a later edition. As a professional working with a person who knows what they want, the professional's role is to look at options, so that the person can choose what option works best for them. For a challenging paper on these matters please read 'Investing In Strategies That Give Life' by Michael Kendrick[27].

Person-Centredness requires putting the person at the centre of decision making regarding what service/s will be delivered and how that will occur. This takes respectful communication with the person in ways that enhance his/her capacity to exercise control. For example, to remain living at home an older person would be assisted by a provider to work out just what forms of support are needed. They may require assistance to participate in this process from a loved one who knows them well. Person-centredness underlies social inclusion, self-determination, and right relationship.

We invite you to read the Centre's discussion paper *Social Justice: Contextual and Relevant* available at www.ucareqld.com.au/SocialJustice.

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[27] Michael Kendrick, "Investing in Strategies That Give Life," in *Like a Sweet Cup of Tea: Sharing Lives, Neighbourhoods and Communities,* ed. Pam Collins (Brisbane: CRU Publications, 2004).

ATTACHMENT B: CHILD PROTECTION AND PARENTS WITH DISABILITY - CASE STUDIES

CASE STUDY 1

19 year old P was referred to a Family Support Program by the mid wife for support to prepare for her second baby. Now in a steady relationship, P had her first child removed when she was 16.

As Family Support is a short term intervention, the Program Manager initiated P reconnecting with Disability Services and she was referred to a longer term Tenancy Support independent living program. A positive case planning meeting was held between the mid wife, Disability service and P's assigned case worker.

P voluntarily achieved all aspects of the case plan including attended parenting courses with her partner facilitated by the Support agency with sessional expertise provided by Child Protection Service, Health, Education and Mental Health. P also attended ante-natal classes at the Health Service, prepared the baby's room with all necessary furnishings and put a pram on layby.

P also lived in hope that she could prove to the Child Protection Service she was "a good mum" and get her first child back. P had consistently kept her fortnightly access visit schedule with her first child at the Child Protection Service and had sought legal help to contest another 12 month order.

The Child Protection Service arranged a meeting with P's case worker to discuss the support being provided to P. The Child Protection Supervisor asked the support case worker to help P understand that she would not be able to keep the baby because in the Supervisors opinion she did not have the higher order thinking skills required of a competent parent. The supervisor stated that it can sometimes be OK when the child is a baby but eventually the child learns it knows more than the parent. The Supervisor provided an example of P's lack of capacity in that she got sun burnt last week while riding her bike so if she couldn't think to protect herself in the sun she wouldn't be able to protect her baby. The worker's statement that she too got sunburnt recently while gardening was countered by the Supervisor claiming it being very different because at least the worker had the capacity to know better. The term "lacks insight" was consistently used by the Supervisor as a reason why P could never raise her children.

All attempts to advocate for P were dismissed. Although P was in a steady relationship where the partner was able to support the parenting of the child The Supervisor claimed this was not relevant, they were not married and he might leave at anytime and P wouldn't be able to cope by herself. References to P participating consistently and competently in the parenting course was countered with the Supervisor claiming that there was a big difference between attending and applying the information in the home.

The child was removed at birth.

CASE STUDY 2

18 year old J was referred by Child Protection Services to Families Program early 2009. The referral history stated that J had an extensive history of involvement as a child with the Child Protection Services through experiencing neglect and physical and sexual abuse.

Assessments by psychologists indicated low functioning in terms of intelligence, difficulty understanding information and poor problem solving skills. J had a 7 month old child in Alternative Care on a 12 month order and was again pregnant. The referral indicated poor housekeeping, budgeting and parenting skills.

Nominated as a high risk infant, the Child Protection Services was making a routine home visit when they found the baby seriously dehydrated and hypothermic. Hospitalised in intensive care, the baby was diagnosed with a "floppy airways" condition. J had noticed the baby was not feeding correctly, making funny noises and sought medical help 5 days prior but his condition was not detected by the doctor during the examination. She took him home and she claims he slept a lot and was not interested in feeding. Over the weekend she became very worried and was preparing him for another trip to the doctor when Child Protection visited.

The referral noted that at the hospital J had limited understanding of the seriousness of the baby's health needs, was putting her own needs ahead of the baby's and was displaying poor parenting skills. The child was placed in alternative care and soon started to thrive.
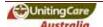
Supervised access visits were arranged 3 times a week and the referral noted that during these J displayed a lack of appreciation of how to manage baby's permanent oxygen tubes and "oppositional behaviours resulting in her not accepting advice and support when offered"..

The Child Protections Service made the referral as they were "concerned J does not have the skills and ability to care for two children particularly babies if left unsupervised when caring for them."

The assigned case worker found a client very open to support with a dogged determination to have a healthy baby and have her first child returned. J even had a twin pram on lay-by in expectation of the return of her first child. J successfully achieved all goals in the case plan including developing a consistent house cleaning routine, attending parenting courses focusing on children's developmental needs and improved budgeting skills.

However, when the second baby arrived it was also taken into care as J was considered too high a risk parent for the child to remain in her care and the 16 year old father was also considered incapable of caring for the new baby.

The concerns of child protection in these cases was valid but unless we are prepared to provide models of support that manage risk and give priority to everyone having an opportunity to try we will end up as in these cases with parents with a disability intent on trying but never given an opportunity to fulfil their full potential.

ATTACHMENT C: SUBMISISON TO THE SENATE INQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY

This document can be obtained from the UnitingCare website:
http://www.unitingcare.org.au/policies-a-publications/submissions.html

ATTACHMENT D: PRINCIPLES FOR CARE IN THE COMMUNITY

INTRODUCTION

"The community care sector provides vital services to a diverse range of Australians. The sector helps maintain the independence of older people, assists those with health and other vulnerabilities, contributes to the independent living capacity of people with disabilities and supports the families and informal carers on which these people depend.

Over the coming decade, the sector will be transformed. Demographic changes, health service arrangements and community preference for care in the community rather than residential aged care will generate sustained growth. How this happens, and how satisfactory the outcomes will be for service users and their carers, service providers and government, is a critical question"

"Moving to Centre Stage: Community Care for the Aged over the next Ten Years" Victorian Community Care Coalition (Prepared by the Nous Group), August 2006.

UnitingCare Australia is a major provider of support for older people, both through services provided in residential settings and also through community care. The above quote acknowledges the increasing importance of the community care sector for the future. In response to this shift the Aged Care National Advisory Committee of Uniting*Care* Australia has had a Community Care Working Group for the last two years, who have developed this set of Community Care Principles.

PURPOSE OF THIS DOCUMENT

This document is intended to inform the work of the Uniting*Care* Network Australia wide as we seek to develop high quality community supports and advocate for systems changes that benefit older people and people with disabilities.

The primary purpose of these principles is to inform the advocacy work of UnitingCare Australia in a bid to reform the community care system. A secondary purpose may be to provide a resource to community care providers within the UnitingCare network for developing their own service principles. However, it is recognized that some agencies already have these well developed, and we thank them for their contribution to the development of these national principles.

DESIRED OUTCOMES OF COMMUNITY SUPPORT

As a UnitingCare network we aim to preserve the dignity and independence of all people who need support, whilst also recognising that we are all interdependent and value our friendships and community networks.

It is our hope that people who need support to maximise their health and wellbeing and ability to participate in the community will:

- have a positive experience of life;
- have the opportunity for full citizenship and community inclusion;
- maintain cultural practices that are integral to their identity;
- continue to learn, grow and develop regardless of frailty or disability;
- be as healthy as possible and able to make a speedy recovery from illness or disabling events;
- be respected as unique and valuable individuals and their strengths and capacities honoured and utilised;
- have valued roles in the community – both "being" and "doing" roles;
- be able to participate in community life;
- be respected for their valuable contribution to the community;
- be in control of their lives and involved in all decisions that affect them.
- be empowered through access to information and participation in planning and evaluation of services that impact on their lives
- have meaning and purpose in life
- be able to meet basic needs for food, shelter and assistance when required

SYSTEMS PRINCIPLES

Uniting*Care* Australia believes that the following principles should underpin the system of community care in Australia.

1. Australia should have an integrated subsidy system which provides funding at a range of levels according to people's care needs, regardless of the source of funds.

2. The system should be easily accessible with easily identifiable points of entry.

3. Subject to privacy principles, assessments and information should be shared to avoid multiple assessments.

4. The first consideration should be the person's preferred living arrangement and seeking to meet their needs in the most cost-effective manner.

5. The community setting should be the natural location for the provision of support, accessing the acute sector as required for episodic care.

6. In general terms, for people within the Disability Services Act target group, the disability service system should be responsible for their ongoing support at an appropriate level, including those currently receiving support in the residential aged care system.

7. The quality of services is consistent, regardless of the funding source, with the use of one overarching quality assessment process.

8. New models of service should be developed in response to changing community & consumer requirements.

9. Facilitation of the continuum of care is seen as a necessary activity in caring for, or supporting, anyone accessing a community service. It should not be identified as another service type.

10. Consumers should be provided with choice through linkages across residential and community streams.

11. There is scope for sharing resources across community and residential arenas to enhance the quality of life and care outcomes for the consumer.

12. Special needs groups require innovative flexible models of care including, people with dementia, Indigenous people, those from diverse cultural and linguistic backgrounds, and those living in rural and remote areas.

13. There is scope for sharing resources across community and residential arenas to enhance the quality of life and care outcomes for the consumer.

14. Workforce is the key to quality care and service, and staff must be well trained and supported.

SERVICE DELIVERY PRINCIPLES

Uniting*Care* Australia believes the following principles should underpin the delivery of community care services.

1. Person-centred

- Support needs to be individualised (person and family centred) and allow for flexible service responses.
- The person should be the focus of service delivery - wherever they sit in the continuum of care settings - rather than the programs and/or service types.
- The level and complexity of the individual needs of people should be a primary consideration in designing care services, rather than fitting individuals to the categories of services that can be offered.

2. Support for families and carers

- A primary aim of care services should be to support family (and other) carers, including the provision of a range of carer support services including respite care and entitlements to material support such as allowances and benefits.
- Services for a care recipient and their carer are integrated given the inextricable link and dependence between the two, including flexible models of respite and integrated health care.
- Services need to balance the sometimes conflicting desires of the carer and the person they care for, seeking to develop services that offer a balance of outcomes for both.

3. Quality of Life

- Recognising human interdependence, older people should be supported to maintain a balance of independence and social connectedness in their life, and to achieve the best quality of life possible.

4. Vulnerability

- The Uniting Church is concerned for the vulnerable and disadvantaged – Uniting*Care* services endeavors to ensure access to community services for these groups.
- Not all people have the capacity to contribute financially to the cost of their care, and no-one should be refused services because of an inability to pay.
- Services are provided first to those who need them most.

5. Information

- People should be assessed for, and informed about, the full range of care and support services available (not just those provided by UnitingCare) and given contact details for

information services, such as the Commonwealth Carelink Centres. This would include assessing beyond the particular service types that the agency offers and providing information about support groups such as Carers Australia, Alzheimer's Australia and the Continence Foundation.

6. Fairness

- Care services should be provided on the basis of assessed need, and priority given to those most in need, based on a standardised and consistent way of understanding and measuring their level of need.
- The special needs of people with a culturally and linguistically different background, and Indigenous people, should be recognised in planning care services in partnership with these communities.
- Indigenous services within the Uniting Church are developed in partnership with the United Aboriginal and Islander Christian Congress.

7. Location of choice

- Individuals should be able to remain within their preferred environment in the location of their choice (eg. their own home, a family member's home, or a retirement unit) and receive support to remain in that setting commensurate with their level of need.
- The option of a more secure and supported environment should be available if their needs cannot be met in their home environment.

8. Wellness & independence

- Services should have a focus on promoting independence, health and wellness with a restorative focus aimed at realising their potential maximum functional gain and rehabilitation.

9. Prevention & early intervention

- Services should consider preventative approaches and community education that strengthen natural and informal supports, ensure appropriate nutrition and physical activity, and support for carers.
- Where possible services should ensure the early detection and pro-active management of conditions such as dementia, depression, incontinence and mobility disorders which are factors that could contribute to early entry to residential aged care.
- There should be timely identification of and intervention to provide appropriate supports that will minimise crisis events.

10. Balance of Care

- The balance between long or short term care/support and/or therapeutic/restorative services should be totally dependent on the needs, aspirations and personal circumstances of the individual and not on funding program parameters.
- Episodic support should be available at times of short term higher levels of need.

11. Control and risk

- Most people wish to be in control of their environment and should be able to influence service delivery, enabling some dignity of risk.

- Consumer choice should be facilitated by encouraging innovation in service provision and recognition of individuals to determine personal risk.
- Consumers should be involved in the design, management and evaluation of services.

12.   Strengths-based

- Services should be designed on the philosophy of strengths based care. This means that services should recognise the strengths and capacities of consumers and not only focus on deficits and disabilities.
- Services should promote a positive image of older people and people with disabilities.

13.   Holistic

- Services should be holistic considering social and spiritual needs as well as physical needs.
- A comprehensive and holistic assessment should be undertaken to identify the most appropriate support and care required which could depend on:
    o   the person's health & ability to perform the activities of daily living;
    o   availability of informal support at home; and
    o   the individuals care needs and goals.

14.   Continuity of Care

- Continuity of care should be preserved as much as possible, both in terms of a gradation of the amount and intensity of services and consistency in terms of the people delivering care and seamless transitions.

15.   Co-ordination

- Where people have complex issues, need higher levels of support and are receiving multiple services, service providers should ensure that services are co-ordinated or case-managed in a way which enables the person to deal with one care manager or co-ordinator and seek to avoid the duplication of coordination functions.

16.   Citizenship

- Services should support citizenship by maintaining the roles and rights of consumers as determined by the individual not the system.
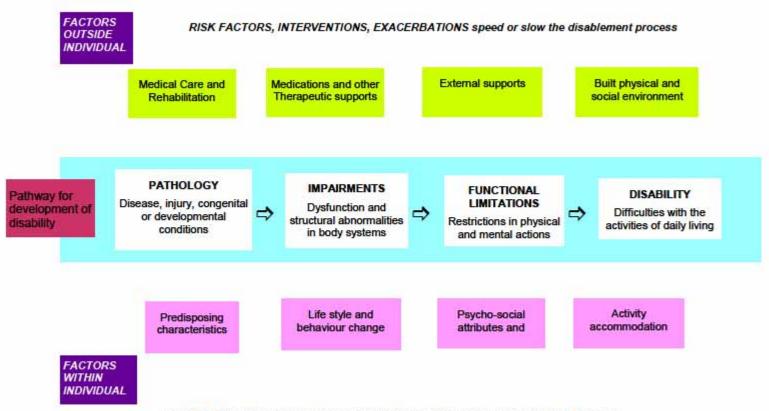
17.   Evidence based

Continuous improvement principles should be incorporated into the planning and delivery of community care services, so that these services are based on sound evidence, and staff are encouraged to participate in research and development activities which seek to optimise the outcomes for clients of community care services.

ATTACHMENT E

THE DISABLEMENT PROCESS AND POTENTIAL INTERVENTIONS

FACTORS OUTSIDE INDIVIDUAL

RISK FACTORS, INTERVENTIONS, EXACERBATIONS speed or slow the disablement process

| Medical Care and Rehabilitation | Medications and other Therapeutic supports | External supports | Built physical and social environment |

Pathway for development of disability

| **PATHOLOGY** Disease, injury, congenital or developmental conditions | ⇨ | **IMPAIRMENTS** Dysfunction and structural abnormalities in body systems | ⇨ | **FUNCTIONAL LIMITATIONS** Restrictions in physical and mental actions | ⇨ | **DISABILITY** Difficulties with the activities of daily living |

| Predisposing characteristics | Life style and behaviour change | Psycho-social attributes and | Activity accommodation |

FACTORS WITHIN INDIVIDUAL

DISABILITY = The gap between personal capability and environmental demand

Verbrugge & Jette (1994)