Recognising interdependence: promoting a good life for all

Carers Victoria's submission to the Productivity Commission Inquiry into Disability Care and Support

23 August 2010

Carers Victoria is the state wide voice for family carers, and provides support to family carers in the community. We provide systemic advocacy and representation, education and training, information and support, professional counselling and policy and research. We manage the delivery of Respite Connections – the Commonwealth Respite and Carelink Centre in the Western Metropolitan Region of Melbourne.

Our members are partners, children and parents who provide support and assistance to people with a disability, mental or chronic illness or who are frail aged.

Carers Victoria is a member of the national network of carer associations.

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Carers Victoria presents the following proposals to the Productivity Commission. Our submission is not inclusive of all the issues raised in the Commissions' Issues Paper or the report of the Disability Investment Group. It reflects our thinking to date. We will review other submissions with a keen interest to assist us in formulating our responses to the Commissions draft report in February 2011.

We wish the Productivity Commission well in its deliberations on essential reforms to the Disability Care and Support system.

1 INTRODUCTION

Within Australia in 2003, 97.5% of people with severe or profound limitations aged between 5 and 64 years live in the community. Only 2.5% live in cared accommodation, a fall of 40% since 1981. Importantly, while 10% of these people who live in the community live alone, 84% of people with severe or profound limitations live with family and a further 3.2% live with unrelated people[i] probably friends.

Over the last decades there has been a marked decrease in the numbers of people with a severe or profound disability living in cared accommodation, from 9.6% in 1981 to 2.5% in 2003. Fewer people who enter disability services access cared accommodation; most remain in the community with family, partners and friends[i].

The above estimates of people with severe and profound limitations were identified through progressive Surveys of Disability Ageing and Carers (ABS). They overlap with but are not the same as those estimated by PricewaterhouseCoopers [ii] as potentially eligible for a National Disability Care and Support scheme. However, they demonstrate the reality of the living arrangements of many people with a disability and their connections with families and friends. They give an indication of the extent of rich relational interaction, mutual support and 'caring about' that is often provided between people with a disability and their families and friends.

Interdependence, caring about, and supporting and understanding one another characterise most relationships within families, partnerships and friendship networks. The same applies to many people with a disability and their partners, families and friends.

There is a common understanding and recognition in the disability sector and the wider community about the roles of families in raising and supporting children and in delegated authority and decision making. However, the roles of partners, families and friends in supporting, assisting and nurturing the well being of adults with a disability and the reciprocity in such relationships is rarely recognised, addressed or discussed, despite their importance.

There is diversity in the nature and extent of such interdependence, for example:

- As it applies to adults with various levels of decision making disabilities who live with their families and who may not readily be self determining or able to make daily life decisions
- Adults with physical or sensory disabilities but no cognitive disability who may choose to live with family, partners or friends where the needs of individuals in the household impact on one another and are frequently interdependent.
- Children and young people whose parent has a significant disability and who are involved in the provision of support and assistance.
- Siblings who have significant care responsibilities in relation to a family member.
- Adults with a disability and their family members and friends who continue to care for and about one another regardless of whether they live together or not.

In addition, it is recognised that not all people with a disability have access to the support of a partner, family or friendship network, including older people with a disability, those where relationship breakdown has occurred, and those who have experienced long term institutionalisation and lost family contact. Some of these people may require higher levels of formal support.

In Australia, community living policy and current services systems feature parallel and poorly resourced and coordinated programs and funding systems for people with a disability and for the partners, families and friends who support and assist them. Separate policy discourses between the disability rights movement and the carer movement are accompanied by separate services systems with different goals. There are shortfalls in the amounts, nature and funding of services for both groups. They compete for available resources with separate discourses, different goals and little reference to each other. What is needed is a shared discourse which recognises interdependence and common needs. System fragmentation and resource wastage are a consequence of the failure of the system to address interrelated needs and to interweave services for families with those of the person they support.

The disability rights movement[iii] has successfully promoted deinstitutionalisation and community living policies; individual choice, autonomy and control as well as participation and inclusion in employment and community life. But it rarely addresses the reality of the lived experience of interdependence, the importance of supportive relationships with partners, families and friends or the needs family members may have for support and assistance themselves.

The carer movement[iii] has ensured consideration of the role and contribution of caring family members and friends by government. It has recognised that caring in a context of inadequate community support services can increasingly shift care costs onto families. This can have negative effects on health and well being of caring family members,[iv] on their workforce or civic participation[v] and on family wellbeing. It can result in poverty and social isolation[vi] for caring families.

However, government policy is underpinned by the desirability of keeping family carers caring. Current policies and funding offer information and education services, income security for those shut out of employment and respite, counselling and emotional support. Symbolically these regard families as either ‘resources’, as ‘co workers’ or as ‘clients[vii]’ when they display signs of stress. Services for family carers focus on the alleviation of stress rather than its prevention. It can be argued that adequate accessible and quality services and supports for the person with a disability which ensure a normal rhythm of life, rich patterns of relationships and participation opportunities for the person with a disability also provide a significant form of family support and can assist family members to also live ordinary lives.

The basis of our submission is to make suggestions concerning the design and development of a National Disability Care and Support Scheme that is family inclusive where necessary. It will seek to focus on the whole system which makes up the lived experience of people with a disability and their partners, family and friends. It will aim to end the separations based on those who have a disability and those who support and assist them. Australia has the potential to develop a system that puts it in the forefront of the world by integrating the perspectives and expertise of the disability and carer movements into a common discourse and shared goals.

2 KEY PRINCIPLES FOR A DISABILITY CARE AND SUPPORT SCHEME

Carers Victoria broadly supports the principles underlying the proposed provision of a National Disability Care and Support Scheme[viii], including universal tax payer contributions via a social insurance scheme; responsive income support systems; ‘entitlement’ to individualised life time disability care and support for eligible people and their families; a focus on functional and other identified needs for support and assistance; evidence based interventions such as early intervention and education to maximise the independence and participation of people with a disability and their families; longitudinal evidence based planning supported by research and independent governance of such a scheme. We support the need for increased private investment in housing where this is feasible by people with a disability and their families. We support the notion of national harmonisation of mainstream and specialist services, portability of entitlements and transparency regarding the funding of specialist supports. We are hopeful that the National Disability Care and Support Scheme (NDC&SS) will incorporate the national harmonisation of current state based traumatic injury insurance schemes into no fault lifetime care and support schemes. This will extend current eligibility for support after a traumatic injury and reduce the need for litigation.

We note that the notion of ‘entitlement’ needs qualification in a system that must operate through risk management and balancing demand and supply. This is a form of rationing. Adequate and sustainable system resourcing is the key issue. We wholeheartedly support the proposal to move away from the unpredictability of the current rationed pay-as-you-go funding schemes, and their replacement with the design of a sustainable funding method that manages future liabilities and risks. It is understood it would consolidate existing specialist disability funding sources, from Commonwealth, State and Territory programs, including the disaggregation of disability funding in the Home and Community Care Program.

The design and actuarial costing of a National Disability Care and Support Scheme must also be based on the following principles.

2.1 Eligibility for both people with a disability and for their families[ix] for care and support

Delivery of a National Disability Care and Support Scheme must acknowledge the interdependency that exists within families while also preserving the individual autonomy of a person with a disability. It must be both person centred and family focused and aim to achieve a good life for people with a disability and for their caring families. This applies to:

- Practice of needs assessment, the identification of individual and interrelated needs and the planning of sustainable ongoing care for the individual and their family. This includes planning together in partnership at key transition points in the lifecycle when the interrelated needs of family members can significantly change with entry to a new set of services. It includes
    - The provision of support and assistance which cannot be fairly delivered solely through ordinary family relationships and roles.
    - The development of tools to assist needs assessment and funds allocation processes. These will weight the relative risks and needs of different family care situations. For example, high intensity family care; families with multiple care responsibilities; families where challenging behaviours are an issue; families with or without informal support; family age and health; families where young carers are at risk.
    - Care planning which explicitly combines the resources of formal and informal care and supports and encourages the sharing of informal care between friends and family members.
- The need for responsiveness of funding allocations within a NDC&SS to likely changes in the circumstances of people with a disability and their families, including:
    - People with a disability with progressive or degenerative conditions whose needs for care and support are likely to increase.
    - People with a disability where restoration of function or increasing independence reduces the level of formal care required.
    - Changes in the health or behaviours of the person with a disability or in the health and wellbeing of their family which may put family situations at risk. This includes addressing the needs of episodic or fluctuating conditions where support needs periodically change.
    - Family crises or changes in circumstances which require emergency or episodic increases in formal care for a period until family equilibrium are restored.

These considerations apply where family members provide ongoing support and assistance. They apply regardless of co residency.

2.2 Differentiation of policies, programs and practices through affirmative funding and resources

The most significant issue which remains unresolved in disability and carer policies and programs is the non differentiated description of the issues facing people with very different disabilities and how this impacts on their partners, families and friends as well as on formal services providers. This is reflected in:

- Policy assumptions that every person with a disability's life experiences can parallel the challenges and opportunities of non disabled people. There is a weak evidence base that 'unqualified' participation and community integration are possible for all people with disabilities. As a consequence, sector priorities may skew towards supporting people with a disability who are most likely to achieve their aspirations for increased independence and participation.
- Policy and program assumptions about autonomy, self determination and choice for all people with a disability without examination of what this means for adults with decision making disabilities who are not self determining and have difficulty making major life decisions. As a consequence:
    - There has been insufficient attention paid to evidence based models for community living for this group of people.
    - There may have been a de-emphasis on the value of the social benefits of group participation with peers which can be non judgemental and an active individual choice.
    - There has been little policy or program attention paid to understanding delegated authority and decision making for adults with significant intellectual disability. Assumptions about adult autonomy and choice can override the life long support and assistance provided by their parents in deciding 'for' or 'with.' They can create an uneven partnership with services providers. The notion of 'individual choice' can be too simplistic.

2.3 Integration of services systems for people with a disability with services which support their partners, and families

There is potential to draw together services for people with a disability and for their partner or family carers to:

- Support the achievement of common goals
- Make more efficient and effective use of limited program resources by reducing duplication and fragmentation and improving program coordination and the continuity of care.
- Better match the lived experience of people with a disability and their partners, families and friends.

2.4 Sharing family caring to ensure a good life for all

With the ageing of the population and increases in the numbers of older people with a disability or chronic illness, there will be a greater need for caring in the future but proportionally fewer people to provide informal care[x]. This is attributed to Australia's low fertility rate, higher rates of family breakdown, fewer people living in nuclear families and the increasing participation of women in the workforce. The decreasing 'caretaker ratio' creates an urgent policy challenge around how people with disabilities (including older people) will be supported in the future, how formal services will be funded, how family caring can be shared within and between families and friends and how unpaid family care can be delivered without too great a cost to individual family carers. It also creates a government policy challenge concerning how to sustain the economy as the population ages and proportionately fewer people will be in the workforce.

Individual parents, partners and siblings are already and will increasingly be engaged in the provision of support and assistance for the person with a disability as well as assisting with the care of their parents, partners and other relatives as the population ages.

The old paradigm of family caring being a major responsibility of women, supported by men in full time employment, no longer sits with social reality and is not economically viable. A new paradigm concerning family care is needed. It would

- See family care as compatible with paid work and support caring families of working age to continue to participate in, rather than be separated from, the workforce.
- Support ready transitions between work and full or part time care.
- Support families to share informal caring within family units and between extended family members regardless of gender. This will reduce the costs of caring for individuals and make caring more attractive for those considering caring.
- Provide quality and accessible services which provide real options, complement informal family care and make caring sustainable.
- Support longer workforce participation for all people of workforce age with the aim of increasing the tax revenue available to support a strong economy.

There are a number of systemic reform issues for family carers in relation to income security payments, taxation and workforce participation. These are discussed further below.

3 WHO SHOULD BE ELIGIBLE FOR A NDC&SS AND HOW SHOULD THEY BE IDENTIFIED?

Carers Victoria considers that the following should be considered in relation to determining eligibility for a National Disability Care and Support Scheme.

The World Health Organisation (WHO) defines disability as follows[xi]:

“Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in their involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives”.

The WHO has produced an International Classification of Functioning, Disability and Health (ICF) that provides more detail about how these concepts can be understood and applied.

The Australian Institute of Health and Welfare (AIHW) has conducted a substantial piece of work, “Disability and its relationship to health conditions and other factors[xii]”, on the subject of defining and understanding disability and its levels of severity. This discusses the limitations, strengths and complexities of different data sets, including the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) and the National Health Survey. It compares these to the ICF.

PricewaterhouseCoopers’ NDIS report[xiii] also comments on the utility of SDAC and the AIHW’s Australian Burden of Disease Study (BoD). It states that “the use of either of these data sources individually is problematic. A planning and data approach needs to be developed by a NDC&SS, over time and within the framework of the ICF.”

Carers Victoria makes the following observations about some of the consequences of using current disability definitions to establish eligibility, particularly SDAC in its current form:

- The design of the SDAC leads to a model which focuses largely on impairment and activity limitations, and takes insufficient account of participation restrictions and environmental factors. This can lead to an expert or medical model of disability rather than a social one, and can lead to bias towards disabilities that are more easily objectively identified and measured.
- Severity of disability is currently based on the need for assistance to perform core activities. These core activities; self-care, mobility and communication, are largely physical restrictions rather than cognitive or psychological. There are concerns that this emphasis may lead to an under assessment of the eligibility of people with psychiatric or intellectual disabilities who may have significant difficulties in participating in education, employment or social activities. This is consistent with data that shows there is a large discrepancy between the numbers of people who have a psychiatric disability as identified through SDAC compared with the prevalence of mental illness as quantified through AIHW Burden of Disease study (BoD) (It also points to the complexity of the relationship between mental illness and psychiatric disability). A further example of the impacts of a bias towards physical activity limitations is given by the Adult Disability Assessment Tool (ADAT) and its use in determining eligibility for Carer Payment and Carer Allowance. Anecdotally, very few carers of people with a psychiatric disability receive either of these benefits. People with a psychiatric disability and/or intellectual disability who are socially excluded may have much need for, and much to gain from, a NDC&SS and should not be excluded.
- PricewaterhouseCoopers and the Disability Investment Group reports both use SDAC’s working definition of disability. It refers to a person having activity restrictions that last for 6 months or more. If applied to the letter, this would provide a barrier to intervening early to assist someone with a newly acquired illness or impairment. It could result in someone becoming more disabled while waiting to become eligible. It is important that the more proactive SDAC interpretation is used. It includes those with impairments that are *likely to last for 6 months or more.*
- A NDC&SS should be flexible enough to respond appropriately to establishing eligibility for conditions that are episodic. To achieve this, eligibility assessment

may have to collect information over a significant period of time rather than at a point in time.

- There are particular issues that relate to the eligibility of children and the need and effectiveness of early intervention. Without a diagnosed impairment, it may be difficult for a developmentally delayed infant or young child to become eligible for the scheme, thus missing the opportunity to access services that could prevent future disability. Specialist eligibility assessment tools and professional skills will be needed to determine activity and functional limitations for this group.

The formation of a specialist working group to develop the eligibility criteria for a NDC&SS may be necessary. The criteria should take a greater account of the limitations to a person's social participation, consistent with the ICF, than SDAC currently does, and model the impacts on particular groups such as people with a psychiatric disability.

It is anticipated that a new scheme's increased emphasis on the impacts of disability on participation will require the development and use of different eligibility assessment tools. More importantly, it will require a high level of skill, sophistication, supervision and training for accredited professionals who assess for eligibility.

In order to move towards a social model of disability, eligibility should take into account a person's access to services, family circumstances and so on. It is unlikely, however, that these factors can be weighted or assessed in a prescribed or formulaic way. Assessors will need to use professional judgement in addition to appropriate tools to determine both eligibility and the extent and characteristics of a person's and their family's needs.

Consistent with Carers Victoria's recommended principles, carers and other family members may also be eligible, based on assessment of their needs and how these intersect with those of the person with a disability. By using a family focussed model rather than a dual disability and carer model, it is expected that there will be some efficiencies and cost offsets. That is, the needs of family members will often be met by meeting the care needs of the person with a disability in a family sensitive way. There will also be families where individual family members will need separate interventions from those of the person with a disability, because of the nature of the impacts of caring. Examples include individual, relationship or grief counselling, education and capacity building and a variety of in home supports.

In the name of fairness, it is tempting to attempt to design a scheme in which there is a formula or mechanism for determining the weighting that should be given to carer needs as compared with those of the person with a disability. For example, should a person with a disability receive less formal support if they are also receiving informal support, and vice versa? Carers Victoria considers that it is not possible to answer such questions at this stage of the design process without contradicting recommended principles. These principles call for assessment to be undertaken on a case basis, to be multifaceted and have a focus on the whole family's needs. We are concerned about the potential difficulties and disputes that would arise from comparing inevitably heterogenous circumstances. With detailed data collection and analysis over time, it may be possible to monitor these issues at an aggregated level.

There are workforce implications that arise from the needs assessment of people with a disability and their families. Assessors will need to come from professional backgrounds such as social work and occupational therapy which give them firm grounding in family based and environmental approaches. Regular supervision and professional development will also be necessary. The success and efficiency of a NDC&SS is dependent on good practice and sound professional judgement. This will not occur without support.

4 WHICH GROUPS ARE IN NEED OF ADDITIONAL SUPPORT AND HELP?

Carers Victoria considers on the basis of practice wisdom and dialogue with several thousand member families that the following groups are particularly disadvantaged in the current services system. Affirmative, evidence based action will be needed to ensure their appropriate support.

- People with a disability or mental illness who require secure, affordable housing and support. This is a priority need and is discussed further below.
- People with a long standing intellectual disability or psychiatric disability who live with or are supported by ageing parent(s). Their numbers will increase markedly in the next decades as baby boomer parents reach 65+. In home support, housing and support and assistance with planning for the future are urgently required. Significant government investment is required for this group prior to the implementation of a National Disability Care and Support Scheme.
- People with a psychiatric disability and their families. PricewaterhouseCoopers[xiv], in a combined analysis of data from the Survey of Disability Ageing and Carers and data from the Burden of Disease study estimate there are 206,000 people with a severe or profound mental illness/ psychiatric disability. Currently the community care services system, including housing and support and psychosocial support is underdeveloped for this group. This is a consequence of deinstitutionalisation without adequate investment in community care support. Acute care and step up and step down care are also difficult to access. Families are disempowered in their caring role and experience considerable stress as a consequence of an inadequate support system. The prevalence of people under 65 in this group is 34% of the current estimates of severe and profound activity restrictions made by PricewaterhouseCoopers[xv].
- People with high levels of combined functional limitation – in mobility, communication and self care and their families. These may be high intensity care situations.
- People with a significant intellectual disability who have challenges in making daily life decisions and their families.
- People with very challenging behaviours and their families. These include some people with ADHD or Autism Spectrum Disorder who display challenging

behaviours which are beyond the management capacity of ordinary family relationships and roles. Attention to improving the support and services available, and their continuity, for adults with Autism Spectrum Disorder and their families in the post school environment is urgently needed. Exploration of international evidence based best practice for adults with Autism Spectrum Disorder should ensure this group do not remain the forgotten people.

- People with catastrophic injuries and their families who are currently ineligible for compensation. These include victims of assault, and people injured as a result of uninsured at home, sporting and recreational accidents. It is anticipated that the needs of all people with a catastrophic injury can be addressed through the development of a NDC&SS.

5 SERVICES WHICH NEED TO BE DELIVERED

The further development and delivery of disability care and support services for people with a disability and their families requires:

- Negotiated whole of government and across portfolio compacts (and leverage) which establish joint objectives, policies and procedures. These will ensure people with a disability and their families can access the mainstream services and resources which are available to other members of the community, consistent with their age and lifecycle stage.
  - A systemic approach to the establishment and monitoring of shared objectives and targets between key mainstream or universal portfolios and a NDC&SS will be essential.
  - A whole of government commitment to support and monitor the progress of implementation of a NDC&SS across portfolios and the achievement of common objectives with mainstream services will be required.
- Specialist disability support services which will aim to support and enhance the participation and social inclusion of people with a disability and their families in universal or mainstream services. Specialist support services are the enablers of the outcomes of the scheme. They should be funded by a Disability Care and Support Scheme and delivered largely through non government organisations.

Our perspectives are based on our experience of both disability and universal services systems in Victoria. It is likely that a variety of national reforms will be required to ensure that there are consistent policy commitments between states concerning the responsibilities of universal or mainstream services in relation to access by people with a disability. Key universal services include pre-school, education, employment, housing, acute and primary health services and transport as well as community recreation and leisure services.

A notional breakdown of specialist and mainstream responsibilities is illustrated in the following table.

Lifecycle stage	**Responsibilities Mainstream Services**	**Responsibilities Specialist NDC&S Scheme**	**Outcomes**
Early identification / diagnosis	Specialist diagnostic practitioners or teams: • Diagnose developmental delay, congenital or acquired disability. • Provide information concerning the condition and its pathway. • Refer individuals and families appropriately for support and assistance	• Establish eligibility and assess needs	• Informed people with a disability and their families • Transparent access to care and support
Early childhood services Birth to school entry	Department(s) of Education/ Early Child Development or equivalents provide • Access to mainstream preschool and child care • Group based early developmental intervention programs including specialist groups (e.g. autism)	• Needs based specialist care planning and care management • Counselling and support. • Administration of specialist funding for care and support • Home based developmental intervention and therapies • Integration support for preschool and day care- from integration aides to consultative support • Aids and Equipment • Transition support for school entry • Data collection and feedback	• Reduced dependence on high cost, intensive services through early intervention, maximising skills acquisition. • Improved family capacity and functioning • Appropriate lifecycle transitions

Lifecycle stage	**Responsibilities Mainstream Services**	**Responsibilities Specialist NDC&S Scheme**	**Outcomes**
School age services	Departments of Education and the private sector provide: • Delivery of mainstream and specialist schools/ classes • Delivery of mainstream outside school hours care programs for children	• Needs based specialist care planning and care management • Administration of specialist funding for care and support • Individual and family counselling • Disability consultancy, therapy and behaviour management support to schools, continence management • Integration support – integration aides for schools (primary/ secondary) • Adolescent outside school hours activity programs • Recreation participation programs, camps and holidays • Emergency care • Intensive individual and family in home support programs • Aids and equipment • Transport assistance • Data collection and feedback • Transition support to secondary and post school options to assist families to plan	• Ongoing care management • Promoting education and development with peers • Promoting family participation in employment • Maximising social skills and community participation • Enhancing skills acquisition and family capacity • Informed choices

Lifecycle stage	Responsibilities Mainstream Services	Responsibilities Specialist NDC&S Scheme	Outcomes
Post school, adult and family support services This section clusters services for people with lifelong and congenital disabilities, and adults with later onset neurological or acquired disabilities or psychiatric disabilities.		• Needs based specialist care planning and management • Administration of specialist funding for care and support • Individual and family counselling	• Ongoing care management
	Health services provide diagnostic and clinical intervention and health maintenance support for acquired disabilities	• Early intervention through specialist restorative and rehabilitation programs to promote functional gains and facilitate independence (early intervention) • Therapy programs • Attendant care support	• Maximising skills (re) acquisition
		• Equipment and appliances/ vehicle modifications • Home help and child care support	• Enhancing participation and social inclusion • Sustaining family functioning
	FaHCSIA funds • Supported employment/ disability enterprises	• Alternatives to employment programs • Psychosocial support programs for people with a psychiatric disability	• Skills development and participation

Lifecycle stage	Responsibilities Mainstream Services	Responsibilities Specialist NDC&S Scheme	Outcomes
Post school, adult and family support services cont'd Family constellations will variously include parents, partners and children.	DEEWR funds • Individually tailored and group disability employment services which include targeting to disability enterprises • Employer awareness and assistance (especially concerning carer and disability friendly workplace practices.)	• Specialist adult programs (eg. Autism) • Adult outside day program hours and vacation care activities • Group and individual recreation participation programs, camps and holidays • Workplace transitional support • Personal care assistance • Transport • Aids and equipment, vehicle modifications • Data collection and feedback	• Move from disability to wage income • Promoting family participation in employment • Participation for individuals; a respite effect for families. • Social and employment participation

Lifecycle stage	Responsibilities Mainstream Services	Responsibilities Specialist NDC&S Scheme	Outcomes
Older people with pre existing disabilities	Department of Health and Ageing, and aged care providers ensure • Access to mainstream residential care and • Access to community care to support ageing in place • Access to sub acute and palliative care services	• Needs based specialist care planning and care management • Administration of specialist funding for care and support • Individual and family counselling • Support with transitions	• Ongoing care management • Appropriate lifecycle transitions
	• Access to aged care advice and intervention via ACAS • Access to behavioural management advice through Psycho geriatric Assessment Teams	• Psychosocial support /day programs • Integration support for individual and group community leisure access from integration aides to consultant support.	• Enhancing community participation/ inclusion
		• Ongoing specialist housing and support • In home support, people with a disability and family. • Attendant care assistance • Equipment/ appliances • Specialist transport	• Ageing in place

Lifecycle stage	Responsibilities Mainstream Services	Responsibilities Specialist NDC&S Scheme	Outcomes
Housing and Support	Housing Authorities ensure • Reduced access barriers to public and community housing • Targeted, differentiated action plans for housing for people with a disability/ mental illness in partnership with NDC&SS • Common definitions and common waiting lists for housing • Improved leverage for people with a disability to access public, private and community housing (Housing Affordability Assistance Scheme, HAAS plus; market based rental assistance) • Increased long term housing investment	• Care planning and care management • Administration of specialist funding for care and support • Tailored mixed band packages of support for individual, couple and group housing • Tailored in home outreach support for people with a psychiatric disability • Cross portfolio targeted and differentiated housing and support strategic plans • Housing modifications • Specialist housing capital • Home based support for families needing increased assistance to sustain home care • Emergency and episodic care	• Options in community living support and participation • Reduced relapse for people with a psychiatric disability • Improved access to community and public housing • Accessible housing options • Prevention of breakdown of family care

Lifecycle stage	**Responsibilities Mainstream Services**	**Responsibilities Specialist NDC&S Scheme**	**Outcomes**
Housing and Support cont'd		• Family support with legal and financial planning, emergency care planning and planning transitions to care outside the family home	• Explicit future planning within families
Young people with care responsibilities	• State and Federally funded universal services e.g. education, health services, and private education providers to improve identification of young people with care responsibilities • Advocacy and referral to specialist services	• Disability, mental health, drug and alcohol, family support services identify young people with care responsibilities through family focused practice • Counselling and support, peer programs • Advocacy and referral for family member needing care and/or young person providing care	• Reduce negative impacts of caring • Improve social, educational and workforce participation
Advocacy support		• Funded by NDC&SS, independently operated and targeted to individuals with a disability and their families	• Issues resolution • Improved access to mainstream and other options.
Community development		Resources to: • build inclusive communities • identify examples and consequences of market failure • develop programs for identified need	• enhances market provision

6 COST OFFSETS IN A NEW SYSTEM

Carers Victoria has read the discussion and data about the predicted cost offsets of a new scheme with great interest. There are additional indirect cost offsets, however, that have received insufficient attention. It is hoped that these additional potential savings will help increase community and government support for implementing a scheme.

The first of these are the opportunity costs borne by carers. That is, the income foregone by family members because their workforce participation has been reduced due to their caring responsibilities. A new disability support scheme could significantly improve the workforce participation of carers in the following ways:

- By increasing the level of care provided to people with a disability so that the care responsibilities of family members are reduced
- By improving the quality of care services so that family carers are confident to go to work either full or part time.
- By improving the co-ordination of formal care services with family needs so that the provision of formal care aligns with the paid employment of carers.

Access Economics and Carers Australia produced a report, “The Economic Value of Informal Care[xvi]” in which these opportunity costs were estimated to be between $4.9 and $11.5 billion a year for carers. This also costs in excess of $1.36 billion to the economy in foregone tax revenue, and a further $390 million per year in efficiency costs. The PricewaterhouseCoopers report also documents that $2.7 billion is spent per year on Carer Payment and Carer Allowances.

Secondly further cost savings could result from the improved health of caring families as a result of access to lifelong care and support services. Numerous studies have shown that family carers, particularly long term primary carers, have much higher incidences of chronic mental and physical illnesses than the Australian average (Cummins[xvii], Gill[xviii], Edwards et al[xix]). Illnesses include depression, anxiety, arthritis, heart disease and diabetes. Because poor health can result from a combination of social exclusion, poverty and stress, it is reasonable to presume that carer health could be improved by reforms to care provision. Existing data and accepted burden of disease methodology could be used to determine the economic cost of poor carer health.

7 IMPROVED CONSUMER AND FAMILY CHOICE AND CONTROL: WHO GETS THE POWER?

In the current services system the choices of people with a disability and their families are limited by shortages in the availability, range and quality of available services - a consequence of inadequate supply and stringently boundaried funding programs.

Carers Victoria considers that there is a case for the introduction of individual budgets and self management of funding allocations for some people with a disability and their families. It must be subject to a detailed review of the implementation and outcomes of individual budgets internationally. Participation must be governed by choice and 'readiness' of the person with a disability and/or their family – when family situations have reached an equilibrium. It should also take account of the spectrum of disability. That is, self management may be appropriate for people with physical or sensory disabilities who have the capacity and wish to do so and whose disability is stable. For people with decision making disabilities the capacity and choice of key family members is important.

A single service delivery model will not accommodate the needs and preferences of diverse family situations. Nevertheless there is empowerment and choice in the delegation of care management to a third party or to traditional services providers.

Our research through a literature review[xx] indicates that the take up of individual budgets internationally has been slow and variable across different cohorts. The highest take up appears to be among people with physical and sensory disabilities, with significantly lower take up among families of people with an intellectual disability as well as the aged care cohort. Many individuals and families find individual budgets and self management burdensome as it can be akin to running a small business. Reporting and accountability requirements need to be simple.

In a variety of countries, for example the UK, attempts to pool budgets across a variety of program types have been found to be difficult to administer. In addition, the evidence concerning the cost effectiveness of individual budgets and self management is thin as existing evaluations have been short term, complex and fraught with methodological problems.

It is unlikely that 'the market' alone can provide improved choice through competition. The market in disability care is constrained with gaps between demand and supply and limited competition. The administration of current packaged care programs for older people demonstrates considerable resource wastage in transaction costs and profit making in an unregulated market. 'Cherry picking,' that is, providing services and resources for those who are easier to support can be a feature of a market driven system and can disadvantage very challenging people with a disability and their families. Paid community development resources will inevitably be required to generate new and responsive programs and to fill gaps in the system. In addition, it can be assumed that governance of an NDC&SS and its data collection will result in the identification of gaps in the services system and investment in the development of essential innovative services.

Carers Victoria considers there must be clear parameters around essential core services, not 'rubbery' boundaries. While consumer and family expectations of what is possible in a National Disability Care and Support Scheme are extremely high, and choice is desirable, there will be a need to control and regulate the boundaries of essential core services[xxi] to ensure people with a disability and their families get access to efficient and sustainable core services. There must be boundaries around reasonable choices.

Internationally, there are variable practices in relation to the direct employment of family members to provide support services. Carers Victoria considers that this should be discouraged in the long term as it risks making informal care a commodity, blurring the boundaries between formal and informal assistance and creating a degraded grey economy[xxii]rather than a valued workforce. Direct employment of family members may need to be an option for a minority of people with a disability and their families such as rural and remote families or CALD and indigenous families. In these circumstances, employment of family members or friends through an agency and their access to supervision and support could be considered as a short term option.

8 MEANS TESTING AND CO PAYMENTS

Carers Victoria supports the proposal that the costs of a NDC&SS will be shared by the whole community through universal contributions. Means testing and co payments by people with a disability and their families with the highest incomes could also be considered. Risks could include disincentives to employment or income and asset reduction.

To our knowledge there has not been a systematic analysis of available data concerning household incomes and assets of people with a disability who are under 65 and their families. Most analyses conflate the household incomes of people with severe or profound disabilities regardless of their age. In these general studies, a significant proportion of household incomes are in the lowest 2 income quintiles. There is a need to ensure a separate analysis of available data sets on household and individual income for those with a disability who are aged under 65.

A number of factors require consideration in determining the appropriateness of income and assets testing including;

- The high costs of disability and care.
- The opportunity costs experienced by people with a disability and their partners or parents.
- The long standing nature of many disabilities, and their lengthy costs to informal care.
- The timing of onset of disability in the lifecycle and its impact on family circumstances.

9 WHO MAKES THE DECISIONS ABOUT ELIGIBILITY?

Independent gatekeepers will be required to assess and establish eligibility for a NDC&SS, perhaps using a similar model to the multidisciplinary Aged Care Assessment Services. Gatekeeping should be undertaken within a legislated basis for eligibility (see above) and with clear program parameters about core services.

This would aim to prevent ‘boundary creep’[xxiii] and to ensure that appropriate people receive the support they need.

9.1 Appeals

There should be an independent appeals mechanism concerning eligibility, assessed needs and funding allocations. Dispute resolution should occur by mediation and ensure that mediators are informed about the boundaries, limits and viability of the scheme. Mediators must make decisions with reference to the scheme as a whole. Uninformed litigation, as in New Zealand, can readily place a NDC&SS at risk[xxiv].

10 ISSUES AT THE INTERFACE WITH OTHER SERVICES SYSTEMS

10.1 Housing

Access to secure and suitable housing is important for all people with a disability and their families. For many this is their most pressing issue. There is a strong body of evidence linking outcomes for people with a disability to the well co-ordinated provision of both housing and support. Please refer to Carers Victoria’s amendment to its presentation to the Productivity Commission[xxv]. Given that the success or otherwise of a new disability support scheme depends on access to housing, Carers Victoria feels that neither the PricewaterhouseCoopers report or the DIG report has paid significant attention to this systemic issue and its challenges.

In 2009, AHURI published a ground breaking report, “The housing careers of people with a disability and carers of people with a disability[xxvi]” The report described the particular challenges that people with different kinds of disabilities face and how these affect their lives. It explained the interdependence of housing issues for family members. Although family carers have prioritised the purchasing of housing for their family members in the past, many are now unable to do so because of the combination of housing inaffordability and low workforce participation. It concludes that this will result in the further dependence of people with a disability and their families on social housing in the future.

Where the PwC, DIG reports and the Productivity Commission do mention housing, it is addressed in a somewhat piecemeal way. For example:

- It might be assumed from the reports that people who are currently housed in, for example, Shared Supported Accommodation through the CSTDA, would be eligible for the same service through a new scheme, and that current CSTDA costs would be offsets. However, this accommodation type only meets the needs of a very small proportion of people with a disability. A continuum of housing types and models is necessary to meet the range of housing needs and preferences of people with a disability and their families. If all housing needs are to be funded directly through a disability support scheme, it is possible that the costs of doing so will be prohibitive. On the other hand, it will be necessary to consider the possible distorting effects and inequities of having some sorts of housing needs met through the scheme and others not.

- New South Wales's HASI model is used as an example of a successful and cost effective way of providing housing and support for people with a psychiatric disability. However, there is no analysis of how many people might need or be eligible for such a scheme, or how this would affect the costings of the scheme as a whole. Because the housing component of HASI is provided by the NSW housing authority, it is not possible to use it as a cost offset because it is an additional cost. There is also no discussion about how the necessary agreements with state housing authorities and social housing providers might be achieved.

- There is some discussion in the reports about supporting people with a disability and their families to purchase their own homes through improved taxation applications and mixed or shared equity schemes. There are certainly families who would like to purchase houses for the security of their family member who has a disability. They are sometimes thwarted by red tape and adverse tax implications. At this stage, there is little comprehensive data to show how many caring families might be in this position. The Allen Consulting Group (ACG)'s report, "Development of a Model(s) for Families and Individuals to Invest in Housing provided by the Disability Housing Trust[xxvii]" analysed ABS data to determine that the majority of families of people with a disability are either asset or income rich. This runs counter to the aforementioned AHURI report's findings which showed that 35% of its sampled households had incomes of less than $25,000 a year and that households with a person with a disability were more likely than average to be in mortgage stress or social housing. ACG's report acknowledges this discrepancy and suggests a methodological reason for it. ACG's report is also inconsistent with what we know about the reduced workforce participation of caring families and the costs of disability. More work is needed to arrive at detailed population figures of housing need and personal resources of this group. It should pay particular attention to different age cohorts. It is likely that such figures will show that only a proportion of families will be able to meet their housing needs by contributing private means[xxviii].

There is a need to collect and analyse population data about the range of housing needs, housing and support preferences and financial resources of people with a disability and their families. It is anticipated that a high proportion of people with even severe and profound disabilities can successfully, and would prefer to, live in affordable and secure housing in the general community (read as "social housing") with sufficient levels of co-ordinated support. There will also be a smaller proportion of people who will need 24 hour care.

A mapping exercise of this type would inform the design and costs of a NDC&SS. It would assist decisions about which accommodation types a new scheme might fund, for whom and how, and how housing needs not included directly in the scheme would be met.

10.2 Income Security and Taxation

There are issues at the interface of a National Disability Care and Support Scheme and the income security and taxation systems. These require reform to encourage family caring across the life course and the sharing of care across a broader section of the population[xxix]. Issues include:

- Minimising the risks and costs involved in making transitions from paid work into caring and vice versa. Currently family care responsibilities may require a primary carer to give up employment, reduce hours, or reduce responsibilities and pay through casual and other work with consequent financial hardship for some.
- Minimising the risks and costs for people with a disability in moving into and out of paid work and away from income security payments by reducing the impact of Effective Marginal Tax Rates on both people with a disability and their families. These can be a disincentive to participation in, or increasing paid employment and to sharing caring to ensure its sustainability.
  - There is no capacity for dividing Carer Payment as an incentive to sharing the care between more than one person; income and assets tests are based on couple rather than individual income.
  - For Carer Payment recipients, the 25 hour maximum work, care or study and travel rule may result in a reluctance to loose income security and health card benefits.
  - The effect of high Effective Marginal Tax Rates on income earned minimise the benefits of increased workforce participation[xxx].
  - For people in receipt of the Disability Support Payment, high Effective Marginal Tax Rates, and the risk of loss of financial benefits and health care access can be disincentives to increasing hours of employment, as can loss of rent assistance and the obligation to pay market rent in Public Housing.

  Work undertaken by Moullin[xxxi] and Howe[xxxii] concerning a single income replacement benefit to replace all other pensions could be explored regarding their potential to encourage sharing of care across the life course and the sharing of care beyond a primary carer.
- Addressing the current inequities for caring families of adolescents and adults with a disability. There is no equivalent to a Child Care rebate or Child Care Allowance for families of adolescents and adults with a disability[xxxiii].
- There is currently no income support which is designed to meet additional direct expenses due to disability. These include the costs of aids and equipment but also extend to the costs of vehicle and housing modification and additional health and transport costs. In the absence of income support, it is invariably family members (if available) who attempt to meet these costs. The Social Policy and Research Centre's (SPRC)[xxxiv] research and modelling into the costs of physical disability found that the average cost of disability was 29% of (equivalised) household income, rising to between 40% and 49% of income for those with a severe or profound restriction.
  FaHCSIA's Pension Review Report[xxxv] discussed this issue in some detail and arrived at the conclusion that, because of the diversity of needs and costs, this sort of support is better provided through targeted direct services rather than universal payments to all people with a disability. The report acknowledged that

the service system needed to improve considerably before this could be reliably achieved. Even where existing programs do provide direct support, there is often a significant co-payment required from the person receiving services, a residual incurred cost.

10.3 Workplace Regulation Reforms

Changes to the income security and taxation systems which aim to encourage the combination of caring and paid work need to be accompanied by changes in workplace regulation which ensure flexible work arrangements, both for people with a disability and their family.

The right to request flexible work arrangements ('Right to Request') is an important measure for those who care for children, adults and older people. It is equally important for people with a disability. It provides a right for employees to request variations in their work arrangements and an obligation for employers to seriously or reasonably consider the request. Employers can only refuse the request based on 'reasonable business grounds.' There is a need for modifications to the Fair Work Act to extend eligibility for the right to request. A universal right for all employees could be considered.

Successful requests for flexible work can:

- Make it easier and more viable for families to combine caring and working roles and for two or more people to share the responsibilities of caring.

- Extend the opportunities for those who provide care to take up or remain in paid work, with its accompanying social and economic benefits for families and contribution to the economy.

- Extend the opportunities for people with a disability to take up or remain in paid work.

Reforms to the National Employment Standards could also consider:

- The development of policy guidelines concerning what constitutes 'reasonable grounds for refusal' of the right to request flexible work.
- The implications of modifying unpaid parental leave to become unpaid disability or care leave. This would ensure eligibility for ongoing leave both for those who care for people with a disability and people with a disability themselves.
    - It would provide flexibility for unpaid leave following the onset of an acquired or neurological disability and for episodic mental illnesses. These frequently result in people with a disability and their families withdrawing from work.
    - It may assist the promotion of sharing the care between family members who take consecutive periods of unpaid leave.

10.4 Aged Care

Particular attention is required to address the emergence of older people with a pre-existing disability into old age, as well as, at times, the needs of their very old parents. This will obviously be a consideration for the Inquiry into Caring for Older

Australians[xxxvi]. Shared policies, protocols and procedures across portfolios are likely to be required to address:

- The current barriers to accessing aged care packages which are experienced by older people with pre existing disabilities who live in the community and use services funded under the National Disability Agreement.
- The need to assist older people with pre existing disabilities to age in place in shared supported accommodation or Supported Residential Services through reducing the barriers to accessing aged care resources (such as Care Packages).
- Mechanisms for blending care packages including:
    - The blending of aged care packages with disability shared supported accommodation funding.
    - The blending of the management and delivery of an aged care package received by ageing parents with a disability funded care package received by their son or daughter. This will ensure the integration of family support services.
- The need to sustain care relationships through enhanced joint access to residential aged care where interdependence is best maintained.
- Enhancing access to Aged Care Assessment for people with life long disabilities who experience premature ageing, accompanied by improved guidance to ACAS staff concerning difficult eligibility decisions.

10.5 Health

Key interfaces with the health care system will require shared policies, protocols and procedures. These include;

- Enhancing primary care for people with a disability through training and payment incentives for General Practitioners.
- The systematic development of prevention and recovery care for people with a psychiatric disability who are acutely ill and require step up or step down support before or after an acute episode. Together with acute care, these will be complemented by community based housing and preventive psychosocial supports which prevent relapse and reduce high cost hospital admissions.[xxxvii]
- Medical and specialist services with the capacity for early identification and referral of people with a disability will be required.
- Access to disability sensitive and family inclusive acute, medical and dental care, rehabilitation and sub acute care. Access to community and hospital based palliative care will also be required.

10.6 Aids and Equipment

There is currently an archaic and inefficient patchwork of 100 programs which provide subsidised aids and equipment, home and vehicle modifications for people with a disability including those who are ageing and disabled. Services are severely rationed despite their pivotal importance on individual and family health and well being, their role in enhancing participation in education and employment and their potential to reduce some of the costs associated with community care.

Currently people with a disability and their families are the major purchasers of aids and equipment, and home and vehicle modifications in Australia. Private purchases as well as significant co payments for essential equipment from government schemes are required. The AIHW estimates that 73% of expenditure on health related aids and equipment is private, out of pocket expenditure[xxxviii]. Costs must often be met by individuals and families on very low incomes.

There is evidence of significant unmet or under met need and rising demand.[xxxix] In addition, there is increasing international evidence concerning the capacity of timely provision of aids and equipment to:

- Reduce some staffing costs of intensive home care.
- Prevent accidents and reduce secondary problems such as contractures and pressure sores.
- Prevent musculoskeletal damage and improve the quality of life for family carers.
- Prevent the waste caused by underfunding and delay. This includes the extended take up of hospital beds because a delay in providing aids and equipment in the home prevents timely discharge. It may be possible to calculate the potential cost offsets a NDC&S scheme could offer in this regard.

Large scale across jurisdictional reform is required to improve the affordability, quality and accessibility of aids and equipment in Australia and to address historical underfunding. This will require consideration of the national harmonisation of publicly funded schemes across the states and territories as well as insurance schemes such as TAC, Workcover and private health insurance. It would be supported by the increased implementation of universal design principles in the built environment. Carers Victoria notes the work done on these issues by MS Australia[xl] and the national summit of peak organisations, June 2010.

11 NEW CONCEPTS FOR RESPITE

The term “respite’ has become ambiguous and has many interpretations as a service, an activity and an outcome. The concept itself, when interpreted in the narrow sense of needing a break, can imply that caring is inherently burdensome. This risks undermining the dignity and value of the person needing care. When occasional respite is promoted as a primary form of carer support, this reinforces the perception that caring a negative experience and that the state should only intervene when the family is struggling to cope. For some carers, accessing respite services carries connotations of guilt and failure.

Family caring may have negative outcomes for family members in the absence of adequate ongoing support for both the person with a disability and for their family. In preference, ongoing and preventative supports are needed.

Use of the term respite to refer to an outcome is useful. A wide variety of services provide a “respite effect” within families. Access to adequate education, day programs, employment, participation in recreation, holiday opportunities, and leisure and community access programs may reduce the need for formal respite programs and provide better options for families and for the person with a disability. However, it must be acknowledged that options for emergency and occasional formal support services to address periods of changed family equilibrium may always be needed.

Carers Victoria recommends that the term respite is avoided in the development of a National Disability Care and Support Scheme, or at least used sparingly to refer to a person's reported outcome. A new conceptual framework should see such support as ongoing and preventive rather than episodic or crisis support. Outcomes would include sustaining family functioning, preventing family breakdown and preserving family health, well being and social inclusion.

12 WORKFORCE ISSUES

The disability care workforce is in general characterised by difficulties with recruitment, retention and remuneration of its workforce, with limited training and support and few career paths. Direct care workers are commonly underpaid and their work has a limited status which undervalues people with a disability and their families. Program improvements in qualifications, remuneration, skills acquisition, supervision and support will be required in an increasingly competitive and shrinking workforce. Higher levels of skill and training will be needed to ensure scheme objectives can be realised.

In addition, the following should be considered.
- Matching person centred work with rostering minimum shift hours for paid staff.
- Addressing in a person and family sensitive way the OH&S issues that can arise in private homes which become the workplace.
- The development of minimum qualifications for staff through the mandatory inclusion of competencies (eg. CHCICS 410A- support relationships with carers and families) these will provide essential underpinning knowledge and skill for direct care staff to deliver person centred and family focused care.

REFERENCES

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[i] AIHW (2008) Disability in Australia: trends in prevalence, education, employme-nt and community living. Bulletin 61 AIHW

[ii] PriceWaterhouseCoopers (2009) Disability Investment Group: National Disability Insurance Scheme, Final Report. Department of Families, Housing, Community Services and Indigenous Affairs, Commonwealth of Australia.

[iii] Fyffe C; Pierce G; Ilsley B and Paul P. The next steps: adults with a disability and family carers. Draft for discussion. www.carersvictoria.com.au

[iv] Refer to evidence drawn from Cummins et al (2007, ‘Special report: the wellbeing of Australians: carer health and wellbeing'; Gill, T et al (2007) The health and well being of adult family carers in South Australia; Edwards et al (2008) The nature and impact of caring for family members with a disability in Australia, AIFS; and ABS data on the Surveys of Disability, Ageing and Carers.

[v] Refer to Gray M et al. (2008) Caring and women’s labour market participation, AIFS; Access Economics (2005) The economic value of informal care; Task Force on Care Costs (2007) The hidden face of care: combining work and caring responsibilities for the aged and disabled; Kruehn et al, (2007) The housing careers of persons with a disability. AHURI; Cummins at al (2007); Edwards et al (2008); Squire and Tilley (2007) It’s about time: women, men, work and family; Moullin, S (2007) Care in a new welfare society: unpaid care, welfare and employment; Howe, B (2007) Weighing up Australian values: balancing transitions and risks to work and family in modern Australia.

[vi] Refer to NATSEM (2009) Women carers in financial stress; Kruehn et al (2007); Edwards et al (2008); ABS surveys on disability, ageing and carers; Squire and Tilley (2007)

[vii] Twigg and Atkin (1994) Carers perceived; policy and practice in informal care.

[viii] Disability Investment Group (2009) The Way Forward

[ix] Family in this context refers to significant others in the life of the person with a disability – partners, parents, nuclear families and caring friends.

[x] Percival and Kelly (2004) Who’s going to care? Informal care and an ageing population.

[xi] WHO (World Health Organisation) 2001. International classification of functioning disability and health

[xii] AIHW (2004) Disability and its relationship to health conditions and other factors.

[xiii] PricewaterhouseCoopers (2009) Disability Investment Group: National Disability Insurance Scheme, Final Report.

[xiv] PricewaterhouseCoopers (2009) Disability Investment Group: National Disability Insurance Scheme, Final Report.

[xv] PricewaterhouseCoopers (2009) as above

[xvi] Access Economics (2005) The economic value of informal care

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[xvii] Cummins et al (2007) Above

[xviii] Gill et al (2007) Above

[xix] Edwards et al (2008) Above

[xx] Carers Victoria and Carers NSW (2009) Individualised Support Models – Towards Consumer Directed Care? Discussion paper of the network of carer associations, unpublished.

[xxi] Maree Dyson, Dyson Consulting Group; personal communication

[xxii] Carers Victoria and Carers New South Wales (2009) Individualised Support Models: towards consumer directed care? Discussion paper of the network of carer associations, unpublished.

[xxiii] Dyson,M (2010) Possibilities and Practicalities of Fully Funded Disability Support. Presentation to the National Disability Summit.

[xxiv] Maree Dyson, Dyson Consulting Group; personal communication

[xxv] Carers Victoria, Access to Public and Community Housing (in Victoria), Amendment to presentation to Productivity Commission 19/7/2010

[xxvi] Beer and Faulkner (2009). The housing careers of people with a disability and carers of people with a disability, AHURI

[xxvii] Allen Consulting Group (2008) Development of a Model(s) for families and Individuals to Invest in Housing provided by the Disability Housing Trust.

[xxviii] Pinnegar et al (2008) Innovative financing for home ownership: the potential for shared equity initiatives in Australia, AHURI

[xxix] Carers Victoria (2008) Sharing the care: The Future of caring in Australia, Submission to the inquiry into better support for carers, House of Representatives Standing Committee on Family, Community, Housing and Youth

[xxx] Harding, A, Vu, QN, Payne, A & Percival, R (2006) 'Trends in effective marginal tax rates 1996-97 to 2006-07, *AMP.NATSEM income and wealth report*, issue 14, September NATSEM

[xxxi] Moullin, S, (2007) Care in a new welfare society: unpaid care, welfare and employment. IPPR London

[xxxii] Howe, B.(2007) Weighing up Australian values: balancing transitions and risks to work and family in modern Australia;

[xxxiii] Task Force on Care Costs (2007) The hidden face of care: combining work and caring responsibilities for the aged and disabled.

[xxxiv] P. Saunders (2006) "The Costs of Disability and the incidence of poverty", Social Policy Research Centre (SPRC)

[xxxv] Australia's Future Tax System Pension Review report (2009), FaHCSIA

[xxxvi] Productivity Commission (2010) Caring for Older Australians. Carers Victoria (2010), Partners in Care, Submission to the productivity Commission Inquiry

[xxxvii] Boston Consulting Group (2006) Improving Mental Health Outcomes in Victoria: The Next Wave of Reform

[xxxviii] AIHW (2009) Australia's Health Expenditure 2007-2008: 75

[xxxix] Summers, M. (2010) National Aids and Equipment reform Agenda: draft background paper.

[xl] Summers, M. (2010) National Aids and Equipment reform Agenda: draft background paper.