NATIONAL
FOUNDATION
FOR AUSTRALIAN
WOMEN

Submission to Productivity Commission Inquiry into Disability Care and Support

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OVERVIEW OF SUBMISSION

The Productivity Commission has been asked by the Government to conduct parallel inquiries into means of providing and financing care for people with disabilities and for ageing Australians.

Because there are some points of similarity in background discussions for both inquiries, the National Foundation for Australian Women (NFAW) will incorporate some common elements in each submission.

The key common points are discussions on:

- housing needs;
- the differences between eligibility and entitlement and the implications for new funding models;
- consumer controlled funding per se;
- the need for policy analysis on the basis of gender.

Against this common background, this submission develops some separate arguments concerning consumer controlled funding in the field of disability services (or ageing services).

The disturbing lacuna in the Commission's Issues Paper on Disability Care and Support is the lack of any consideration of the differential effects of disability on women and girls as shown in gender disaggregated data.

While the United Nations Convention on Disability requires equality of treatment of men and women, and although official data collection instruments normally seek descriptions of gender age and income, very few official data sets publish the gender of the respondent – we feel there is little excuse for this neglect. Data collected and published by the Australian Institute of Health and Welfare (AIHW) is an excellent example of where gender disaggregated data is made available. The AIHW Web site[1] is very useful for overall data, and we draw on this source later in this submission.

In developing disability support policies for women and girls the following facts need to be taken into account:

- Women are the primary carers of people with a disability;
- Women with disabilities often function as primary carers for ageing parents;
- Carers are shown to have poorer health than the general population;
- Women reach retirement age with lower savings than men, and are more commonly dependent on the Age Pension than men;
- Low income earners (male and female) are particularly vulnerable in their housing tenure;
- Women with a disability are less likely to access Government funded services for people with a disability than are men;
- Evaluations of Australian attendant care style programs show that their beneficiaries are more likely to be male, employed or studying and with strong informal social supports and live with family members.

We recommend that the Commission address the issue of gender equity in its considerations. We further recommend that the Commission seek from a body such as the AIHW gendered data analysis as part of the Inquiry, including of the most recent relevant Australian Bureau of Statistics collections.

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[1] http://www.aihw.gov.au/

1. FUNDING CONSIDERATIONS

1.1. Emerging pressures for individual control of funding for services

In both aged care and disability care, there has been pressure generated from sectors of the community to consider more options to current policies, with strong advocacy for financing measures which place greater control over decisions and actual allocation of (Government financed) resources in the hands of the individuals who have need of such services.

This pressure for choice is also associated with arguments that if users of services are given choice, (‘direct control’) then the market will respond and offer appropriate service options.

Historically, in the Australian social welfare system considered at a macro level, the Commonwealth’s support for individuals has been through both provision of income support payments to vulnerable individuals through the social security system, and the provision of funds to service providers, allied with some degree of provision to individuals of tax benefits and voucher-style payments, to enable purchase of services from providers.

Thus, for individuals with a disability (acquired or congenital) the Commonwealth has since shortly after Federation paid a specific pension to enable the individual to subsist. Since the 1950s the Commonwealth has also provided an expanding range of payments to service providers, as well more recently income payments to individuals who are formally occupied as primary carers of people with a disability. Initially, many grants went to disability specific programs, to groups established by concerned parents of children with particular disabilities arising from diseases such as poliomyelitis or rubella. The disability sector tended to be fractured, around specific client groups, rather than have a united focus.

A similar pattern exists of providing direct income supports to aged persons through the Age Pension allied with systems of providing grants to organisations to provide services, such as nursing homes or home nursing and home help.

Because income support payments operate on a universal basis for those determined as eligible, under clearly defined income and assets tests, the costs to the revenue are extremely high, and increases in rates of such benefits and pensions are managed very carefully in the Budget context. Costs to Government are contained by constraints on the individual rate as well as by variations to eligibility rules.

1.2. Confusion between eligibility and entitlement

There is no parallel guaranteed universal entitlement to a service. Eligibility for all Government subsidised services is based on pre-determined criteria, differing by service. This applies to all funding mechanisms being used. Programs of services for people with a disability and for aged persons do have eligibility conditions, but there is no guarantee or assurance of entitlement or access.

Full entitlement programs for Veterans have been the only guaranteed entitlements for a range of health and home care programs.

Governments can control access either by increasing or decreasing funding overall, or by tightening eligibility, sometimes by a combination of both. Meeting the eligibility criteria for a service type does not ensure access.

By way of example, the concept of provision of residential beds by region based on the regional over-seventies population does not convey an entitlement to residential care for everyone aged 70 plus.

The difference between the concepts of eligibility and entitlement seem to have been confused by some participants in the debates to date.

Some consumer advocates seem to want the concept of eligibility to be co-extant with the concept of entitlement. There is confusion among some in their understanding that to fall within the disability based target population for the Home and Community Care (HACC) Program does not of itself guarantee eligibility for services or to a specific level or quantum of services.

By way of another example: in the case of services for aged persons, after the introduction by the Commonwealth in the mid Nineteen Sixties of benefits to which all elderly residents in nursing homes were eligible, an exponential growth occurred in the numbers of nursing homes. Not only did the private for-profit sector grow and expand, so did the not-for-profits. States systematically began to transfer to the not-for-profit and the private sector many of those beds for long-term patients which they had previously provided. Not-for-profits found it possible to access Nursing Home benefits for their former 'sick bays' for residents in Independent Living Units, and so access Commonwealth grants for both capital and recurrent costs.

Demonstrably, user-entitlement funding led to a market driven expansion of services by both not-for-profits and for-profits and a rapid growth in Commonwealth outlays.

The existence of an alternative grants-funded system of supporting home help and home nursing services, with annual budgetary limits, was not sufficient to place any restraints on the growth of the nursing home industry. Several large commercial providers became extraordinarily profitable, and developed a degree of market domination. Not all aged persons achieved optimal services for their needs.

In the early years of the Whitlam Government various reviews of policies took place, and again during the Hawke Government. Limits were placed on the numbers of beds per region which would be granted access to the voucher-style nursing home benefits funding; a system of assessment of the individual's need for full nursing care was put in place; the provision of grant-funded home care systems was expanded; and attention was given to development of individual care packages.

This change of direction underpinned the slowing of the rate of growth of nursing homes over the next decades, and allowed more attention to meeting actual needs of individuals so as to enable them to continue to live in the community. This was of particular benefit to those individuals in stable housing settings—many were homeowners. It has also enabled better fiscal control over Government outlays, by comparison with the previous market driven approach.

However, while numbers of beds were controlled, costs per bed have continued to escalate, increasing pressure for reform. The introduction of expensive individual care packages has also led to this form of care eating up a disproportionate share of funding available for care in the community.

Infelicities still remain, and the industry complains of centralised controls, as it once complained of a mix of both State and Commonwealth controls.

1.3. Diverging responsibilities for aged care and disability services

Recently through the Council of Australian Governments (COAG) agreement has been reached for the Commonwealth to take over full responsibility for care services for aged people (apart from Victoria and Western Australia). Pressure for giving care-voucher entitlements to individuals which has emerged in recent years has been given added stimulus with perceived opportunities for cashing out funding for some services (vide the Catholic Health Care submission to the Inquiry into Aged Care). Cashing out is only feasible where the individual’s eligibility and entitlement both exist.

Notwithstanding agreements in the nineteen nineties that the Commonwealth would retain responsibilities for pensions and employment services, whilst transferring all other responsibility for persons with a disability to the States and

Territories, and the move during the eighties onward towards deinstitutionalisation, overall policy underpinning funding and provision of support services for people with disabilities has not gone through any such root and branch restructuring along the lines of that in aged care.

Governmental expenditure on services for people with a disability is growing, but there is a high level of publicly expressed dissatisfaction around access to specialist health services, access to respite care, and access to aids and appliances, for example.

In comparison, there is far less dissatisfaction with aged care services, in part because of the national quality assurance scheme that includes clear avenues for consumer complaints.

Changes made by the Commonwealth in regard to nursing home access means that individuals under the age of 60 are rarely admitted to Commonwealth funded nursing homes, and are reliant in cases of profound or catastrophic disability requiring an equivalent level of care on arrangements made and financed by States/Territories.

There is currently a significant mismatch between demand and supply for services to support people with a disability and their carers, as well as continuing confusions between Commonwealth and State roles.

This submission argues that there is significant under-investment by Governments (both State and Commonwealth) in services for people with a disability and their carers. There are disparities between entitlements in different jurisdictions, between entitlements for individuals depending on the specific disability, as well as on the means by which the disability occurred or was acquired.

1.4. A clearer focus on gender

Data on disability services provided through the Commonwealth State Territory Disability Service Agreements held by the Australian Institute of Health and Welfare suggest that more males than females receive disability services, across most age groups, whereas women far outnumber men as recipients of aged care services.[2]

Given that as a whole disability does not appear to impact more on males than on females, this raises issues worthy of exploration by the Commission in the course of this inquiry.

It would be regrettable if a policy outcome were to be developed which through failure to undertake a gender analysis had an inequitable outcome as between men and women.

The majority of carers of people with disabilities and the frail aged are women.

The issues facing this predominantly female group, often very young people caring for a parent with a disability, have been well documented in research studies and in the House of Representatives Standing Committee on Family Community Housing and Youth.[3]

The recommendations of that Committee include improvements to the income security system for financial support for carers, and greater access in the hands of carers to funds to enable carers to purchase appropriate supports.

The NFAW supports these recommendations.

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[2] AIHW, Functioning and Disability Unit Home page, http://www.aihw.gov.au/disability/index.cfm

[3] Parliament of Australia, House Standing Committee on Family, Community, Housing and Youth, 2009. Who Cares...?: Report on the inquiry into Better Support for Carers. http://www.aph.gov.au/house/committee/fchy/carers/report.htm

2. ISSUES ARISING IN REFORM OF FUNDING AND DELIVERY OF DISABILITY SERVICES

2.1. Moves to extend individualised funding for disability

There is, as mentioned above, pressure for moving away from providing grants to support services for people with a disability, to providing in effect, care-vouchers as entitlements to individuals.

Among the issues to be debated, NFAW identifies the following:

Would voucher-style payments resolve the underlying problems identified in the introduction above?

How will Governments seek to constrain unacceptable levels of outlays through a consumer controlled voucher-entitlement system? For example, will Government hold down the value levels over time, so that the value of vouchers does not keep pace with increases in service costs to consumers?

Will an under-developed service system grow or shrink with voucher style funding? In particular, how will the organisational infrastructure that is essential to supporting care delivery, including sustaining a skilled workforce, be maintained?

What are the risks of perverse outcomes, such as capture of consumer funding by sub-standard providers (e.g. boarding houses)?

Will voucher style funding encourage the development of new approaches to caring for people with disabilities/aged care? Will voucher style funding encourage the provision of a minimum level of care?

Certainly, the introduction of the Medicare Levy has not led, nor indeed was ever intended to lead, to full coverage of all hospital and health care costs for individuals, even though Medicare is seen as a universal entitlement program and essentially works as such.

In fact, the rate of growth of costs, not least of hospitals, has been such that the share of costs met by consumers in out of pocket expenses (or co-payments) have grown very considerably since the introduction of the levy. Not all health costs are comprehended by the levy—for example, some kinds of surgical procedures.

Medicare is seen to be, and is, a universal entitlement program solely for access to (a) bulk billing General Practitioners, and (b) treatment in a public hospital. It is complemented by funding of allied health services and pharmaceuticals through either Commonwealth or State programs. But even when all taken together, and including the private health insurance rebate, public funding does not cover all health costs. Elective surgery in private hospitals is the most costly exception, together with dental care.

Would direct-control models for disability related services with resources placed in the hands of the individual be set at a level to cover all costs, or would there be a continued need for co-payments?

Would it be appropriate to designate the types of services which could be purchased? Would use of a direct control model also permit the individual to continue to access other subsidised services, or should there be some kind of embargo placed on this?

In general terms, if some relationship between use of funded services and access to direct control funding is to be developed, then it **is essential** to further explore the issues of entitlement and eligibility.

2.2. United Kingdom experience with direct payment

It may be useful at this point to consider some of the experiences of the past decade in the United Kingdom in relation to their policy regarding direct payments.

The UK policy originated in the intent to give users of social services (provided by Local Government Authorities in the UK) greater control over their lives. The first candidates were people with learning difficulties—and the policy provided the carers, usually parents of younger people with learning disabilities, with a budget which could be allocated to meeting costs of services directly. It should be noted as stated above that these budgets are for personal care and social services: they do not cover in-home health services, which remain the responsibility of the National Health Service.

Informal advice[4] suggests that the policy was more effective in situations where there were competent adult carers in the family, and somewhat less effective where the person with a disability was not so supported.

More recently the policy has been extended to older people ('adult care') and local government authorities now have a centrally mandated target to reach of the numbers of their clients who are in receipt of direct care payments. Two formats exist- either the individual has control of the budget and makes all decisions, or the Social Service Department case manager assists decision making and holds the budget.

It is understood that one major challenge now for the policy is developing means of ensuring good quality in the individuals being recruited as personal care attendants by recipients of direct care grants.

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[4] Personal communication to author July 2010.

Exploration is taking place as to whether in-service training might be appropriate, whether background checks are necessary, and so forth.[5]

Some might find it surprising that with some very vulnerable clients, attention to quality and standards is taking place only some fourteen years after the introduction of the policy.

While the UK central government agency sets the policy guidelines, implementation rests with individual local authorities, permitting quite significant variations on a geographic basis.

Some of the findings from an evaluation report by the Personal Social Services Research Unit (PSSRU) relevant to the Productivity Commission's Inquiry include the following:

"Direct payments were found to be provided most commonly to people with a physical disability or sensory impairment, compared to other groups, and least commonly to people with a mental health problem, but there was considerable variation across local authorities, underlining how some local authorities have risen to the challenge of implementing user-centred care through direct payments while others lag behind.

"There were wide variations in the proportion of local community care budgets spent on direct payments, both between areas and across user groups. These were largely reflected in the strength in developments for different users groups, for instance, 15.5% of the budgets of English authorities for people with a physical disability was spent on direct payments, compared to 1.1% for people with a learning disability, 0.8% for older people and 0.4% for people with a mental health problem.

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[5] Personal communication to author July 2010

“Expenditure growth between 2003/04 and 2004/05 was notable for all user groups and for most parts of England, but nonetheless modest given the policy emphasis on encouraging the use of direct payments by people with social care needs.

“There were notable differences in the relative expenditure on direct payments across user groups; on average, expenditure on direct payments to people with a learning disability was *lower* than expenditure for mainstream services for this group, whereas the opposite is the case for people with a physical disability; there was no discernible overall pattern for elderly people and people with a mental health problem.[6] These may relate to the effects of standardised direct payment rates across user groups.

“Direct payments provided to older people, people with a learning disability and people with a physical disability tended to be of high intensity (or average size). For instance, three quarters of recipients with a physical disability in England received funding equivalent to over 10 hours of support per week (and nearly one-third received 31 hours per week).

“Approximately three-quarters of local authorities in England and Scotland had made one-off direct payments in the preceding year, but there were wide regional variations in the numbers of such payments; these were most often made to assist the purchase of respite care or equipment, or to meet the set-up costs of longer-term direct payments.

“More authorities had made one-off payments to people with a physical disability than to any other group, but such payments were most commonly made to user groups for which direct payments provision was otherwise very low, such as carers and people with a mental health problem.

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[6] Italics in the original text.

"Local authorities were found to pay similar rates to all user groups, with the exception of people with a learning disability who received higher core hourly rates; there was nonetheless considerable variation in rates across the UK, with lower rates paid by local authorities in Northern Ireland and Wales, compared to England and Scotland; there were also variations across England.

"Average weekly rates for people with a learning disability, people with a physical disability and disabled children were all considerably *lower* than the average unit costs of residential care for these groups, whereas the average weekly live-in rates for older people and people with mental health problems were significantly *higher* than average unit costs for equivalent residential care."[7]

The variations between authorities identified in the PSSRU report could be replicated in Australia were responsibility for managing direct payments be delegated to individual State/Territory agencies, regional authorities, or community agencies.

2.3. Scope of reforms in disability services and funding

Is the debate about the full scope of disability services, or should it focus very clearly on the very high need group?

The Terms of Reference seem to allow the wider scope, while much of the initial discussions seemed to focus on individuals with a truly catastrophic degree of disability.

Moreover, the arguments by some protagonists leave some confusion as to whether their view of catastrophically disabling conditions encompasses individuals

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[7] PSSRU, 2007. Direct Payments: A National Survey of Direct Payments Policy and Practice, p. 1. http://www.pssru.ac.uk/pdf/dprla.pdf, visited 11 July 2010. Our underlining in the last paragraph; the italics are the authors' emphasis.

with psychiatric disabilities, intellectual disabilities, and multiply caused levels of catastrophic disability.

In the view of NFAW a scheme designed to cater for people with disabilities with catastrophic consequences for their capacity to live independently ought to include all people assessed as meeting this criterion, whatever the origin or diagnostic description of the disability.

Basic services for the broad generality of people with a disabling condition are essentially provided by the Home And Community Care program and a range of Commonwealth State Disability Agreement services, and there is no doubt these have considerable scope for improvement. We see some merit in 'ring-fencing' the proportion of HACC funded programs going to disability, to avoid the apparent 'rationing' of such services to many aged recipients.

The high need group who need multiple services cost much more individually.

NFAW is inclined to leave the large numbers using only basic services to one side in discussions of a scheme such as a levy-funded system, and focus on the much smaller very high need/very high cost group, as sorting the needs of this group would relieve many of the pressures on the rest of the 'basic' system.

Making changes for the basic services will require a much bigger overhaul and not necessarily solve the complex group problems. We believe this bigger overhaul is desirable and should be carried out expeditiously.

If in the case of catastrophic disability some form of universal levy is introduced, the Government could:

Establish a basic set of support services at a given cost per annum to which an entitlement is provided for individuals based on specified eligibility criteria;

Guarantee funding to ensure access to the basic service set;

Enable competent eligible individuals to cash out a fixed proportion of the value of the basic set;

Remove eligibility for further access to basic funded services so as to avoid double dipping;

Permit provision of private insurance for those with higher incomes to assist in management of co-payments and top-up services if required.

Government(s) would establish and maintain control over the rate of growth of outlays through budgetary measures, and cost and quality controls over the basic service set.

Medicare and related programs demonstrate how both supply side and demand side controls have been applied to manage outlays, and to allow those who want more to satisfy their demands by accessing privately provided services--noting that virtually all practitioners deliver both privately and publicly funded services.

In the case of disability and aged care however, the great majority of those needing services have limited incomes and hence limited means to purchase services directly or to pay premiums for insurance that could fund services. Private health insurance funds have shown no interest in serving what to them are poor risk groups and for Government to subsidise them to do so does not seem a viable policy option.

Registration requirements prevent undue consumer exploitation--but these protections could be at risk with consumer directed payment systems which allowed the purchase of services from any provider at any quality.

2.4. Market solutions and salutary lessons from child care

It is useful at this point to bring to the discussion the experience of the Commonwealth in outlays on child care over the past few decades. It is common knowledge that concurrent with the move from a system of providing Government subsidies to not-for-profit providers, to a system of demand-driven voucher-style funding of all users of services, there was an explosion not only in provision (and thus costs to Government) but that considerable market-overcrowding developed, with the ultimate collapse of one large provider. Moreover, the service types on offer lack the flexibility to meet specific working conditions of some parents, and geographic spread is very uneven.

3. RESPECTIVE ROLES OF COMMONWEALTH AND STATES AND TERRITORIES

In the case of services for the aged, recent agreements have been reached between the Commonwealth and other jurisdictions (except for Victoria and Western Australia) for the Commonwealth to take over responsibility for all provisions for the aged. This includes acute medical and hospital care, long-term nursing home care, and domiciliary services such as nursing in the home and home help and related services. Inter-governmental financial arrangements and offsets are being negotiated to ensure that funds previously provided by States to such services are being taken into consideration in the new arrangements.

In the case of services for people with a disability, the patterns are less clear.

3.1. Need to address inter-jurisdictional differences in disability funding and injury compensation schemes

There are agreements between the Commonwealth and States providing that broadly the Commonwealth provides for the costs of employment services for individuals with a disability, while States and Territories are responsible for housing and support for a range of other services including respite care, aids and appliances, as well as education and transport and there are some specific purpose payments. (But the Commonwealth does still retain a system of provision of funds for incontinence services, for example, outside this general arrangement and an historical anomaly in that it also retains print services for those who are blind.) The Commonwealth also offers some funds to States/Territories for the costs of individual service packages for individuals with disabilities requiring significant supports.

The majority of media reported problems related to access to services for people with a disability lie within the jurisdictions of the States and Territories, not within the direct control of the Commonwealth.

Suggestions of new funding sources such as a Medicare-type levy raise issues of eligibility, of levels of funding, and any necessary offsets—for example, would the individual in receipt of a direct control allowance also have continued access to other support services, and if so, which services? Some protagonists have offered the thought that direct offsets such as cashing out the value of a nursing home place might pay for direct care allowances.

If cashing out is to be considered, we consider that aged care does not provide an appropriate basis for setting costs for younger people with a disability.

Rather, separate systems are required for funding care of younger people in the community and in supported accommodation, as costs cannot be readily transferred from one of these settings to the other.

While we are in no doubt that there does exist a need for a very significant injection of new and additional resources to support services for people with disabilities, we do see considerable problems in finding equitable solutions unless there are changes agreed between governments comparable with those recently agreed in regard to aged persons.

Moreover, there are significant separate provisions under State and Territory law relating to systems of compensation for the costs of motor car accidents and for work place accidents with differing provisions between jurisdictions, met by differing financing arrangements in each jurisdiction.

It is inequitable that an individual who has acquired a brain injury from a motor car accident in Queensland may have a different entitlement to support from someone who has acquired a similar injury from a similar cause in New South Wales.

We assume that it is **not** proposed that a new Commonwealth scheme for paying for services for people with disabilities would also seek to subsume State and Territory motor car accident and occupation health and safety accident compensation regimes. This matter of equity is an issue previously addressed during the Whitlam Government by the Woodhouse Royal Commission into a National Accident and Compensation Scheme.

It is also inequitable that a person who has acquired a brain injury from, say, a domestic fall might have no comparable entitlement anywhere. The Woodhouse Royal Commission did not address this. However, the subsequent scheme introduced in New Zealand by Mr Justice Woodhouse did ensure equity as to compensation regardless of the origin of the disability.

In the event, the Woodhouse recommendations did not become law in Australia.

We note that through COAG governments are currently pursuing model legislation on occupational health and safety[8], although this may not mean complete harmonisation.

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[8] Commonwealth of Australia, Safe Work Australia, 2009. WRMC 83 Communiqué. http://www.safeworkaustralia.gov.au/swa/Model+Legislation/Public+Comment/WRMC83Communique.htm

4. OPTIONS FOR NEW FUNDING MODELS FOR DISABILITY CARE

4.1. Rationale for different approaches to funding disability and aged care services

We can see only a limited role for the general applicability of direct payment or consumer controlled budgets in the field of aged care, and will address this in more detail in the discussion of aged care.

We note that the Carer Allowance here already constitutes a fair share of consumer controlled Commonwealth Budget outlays—almost as much as Budget provisions for the Home and Community Care Program as a whole.

It is useful to note that ageing is normative, and will happen to most of us, but disability is exceptional.

This difference is a good ground for different kinds of funding.

Numbers in disability programs are much smaller than numbers in programs for ageing, and represent much more diverse needs, again justifying different kinds of funding.

The number of individuals with catastrophic levels of disability (from whatever cause) needs to be identified, and within that, the number who have some eligibility for compensation.

For the group without any compensatory funding, the need for new approaches is self-evident. Many of these will likely have mobility issues and/or a level of cognitive impairment (whether a congenital condition or an acquired brain injury). For some of these individuals, direct control models will have benefit.

For the larger group of people whose extreme disability arises from disease or illness (whether psychiatric or physical) of one kind or another there is likely also to be no form of compensation accessible, and there is again a self-evident need for some innovative approaches.

4.2. Australian experience with individualised funding

Evaluations of individualised funding approaches in Australia have reported widely varying outcomes for different groups of clients with disabilities. Rather than being a limitation in generalising from the findings, the small scale of these evaluations highlights the diversity of client groups and their varying capacity to manage self directed funding.

While Australian experience with direct control models is limited, a number of evaluations report mixed findings. The approach may have validity for some, yet may not be the most appropriate in all cases. Coordinated care is frequently a good approach for people with multiple problems.

We noted above that in a number of Australian jurisdictions a range of direct payment or attendant care schemes is currently in limited existence, sometimes as pilot projects subject to evaluation.

In addition, many jurisdictions have policies providing for payment by the relevant Government agency of funds for a specific managed care package (Individual Service Package or ISP).

Some of these schemes provide for placing funds in the hands of a broker to manage on behalf of the individual, although the individual is given considerable discretion in terms of the services ‘purchased’.

Other schemes essentially coordinate a range of agencies to ensure the individual receives an integrated service package.

In some instances where the individuals have limited competence, their Government pension and any other assets may be managed on their behalf by a statutory office such as Public Trustee.

Offices of Public Trustees and various statutory Guardianship arrangements commonly play a role in the management of the financial affairs of individuals who have limited competence to manage their affairs —notably those with intellectual disabilities, acquired brain injury, and psychiatric disorders.

Relatively few Australian schemes appear to have placed lump sums, whether paid in one lump, or on a periodic basis, into the hands of the individual, apart from compensation payouts.

There does not appear to be any centrally consolidated data set on these schemes which provides analysis by gender and by disability/cluster of disabilities as to who obtains such packages or access to schemes, and of outcome studies.

We reviewed evaluations of projects in NSW and Victoria. Given the diversity of these findings, we summarise two of the studies.

Evaluation of a NSW Government program providing managed Integrated Service Packages (ISP) for individuals living in boarding houses[9]

"As of March 2008, the ISP had provided services to 38 clients; the equivalent annualised net recurrent unit cost per client is $194,000 during the ISP. The average cost per client prior to entry to the ISP was $376,000, as reported by the nominating agencies."

One significant detriment with the current program of granting of an ISP to an individual is the lack of security in funding continuity. This naturally has a high

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[9] University of NSW, Social Policy Research Centre, August 2009. Evaluation of the Integrated Services Program for Clients with Challenging Behaviour: Mid-Term Report. http://www.sprc.unsw.edu.au/media/File/Report14_09_ISP_Evaluation.pdf

impact on both the individual and the primary carers. Although security of some form of assistance is slightly greater when delivered through a Service Provider, similar psychological anxieties are present, especially as the term of an allocation draws to a close.

The Interim evaluation found:

"In summary, the evidence shows an ongoing cost per client of approximately $200,000 per year. The average cost per client prior to entry to the ISP was $376,000, as reported by the nominating agencies. For most clients the preliminary evidence shows returns in terms of:

- Reduced levels and severity of challenging behaviour, supported by evidence of a decrease in contact with criminal justice services, particularly Corrective Services;
- Increased housing stability whilst they are in the ISP and some successful exits into stable housing;
- Reduced use of emergency services and reduced length of stay in inpatient hospital services;
- Decreased imprisonment in Corrective Services;
- Personal wellbeing approaching population norms in satisfaction with future security and feeling part of the community and better than the HASI baseline[10] on this latter measure;
- Similar distribution on self-assessed health to population norm;
- Increased independence in domestic and community skills;
- Increased participation in education and labour market; and

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[10] HASI, the Housing and Accommodation Support Initiative, is a partnership program funded by the New South Wales Government to ensure stable housing linked to specialist support for people with mental illness. http://www.health.nsw.gov.au/pubs/2007/hasi_intiative.html

- Increased social contact with family and friends.

It is not yet clear if these improvements will be sustained.”

2008 report from the University of New South Wales Social Policy Research Centre reviewing an Attendant Care pilot scheme funded by the NSW Government [11]

The evaluation examined scheme participants and a comparison group. It found that the program did improve living conditions for the participants--see for example one case study:

“Michael has developed a detailed system under direct funding with clear policy and procedures for his care, fixed term contracts and review processes, grievance policies and innovative supports for the attendant carers. He has tailored in-home training with the help of respected private occupational therapist. He has structured the contract, pay and conditions (within the parameters of the award) to suit his particular needs and also the needs of his attendant carers at a given time, for example implementing emergency shift loadings and return shift loadings. Attendant carers are more willing to cover undesirable shifts because of the better pay and conditions. For example, he needs to get up at 5 am to attend early classes at the local college (which he was previously unable to do because his attendant carers were not willing to come at that time). His attendant carers are now more responsive to his requests because he is officially managing the arrangements. With flexible and quality care, he has less pain and stress and has returned to his creative work.”

The annual overall costs of the scheme were informative: around $67,800 per person, with associated administrative costs around $2168 per person.

However, we note also this comment:

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[11] University of NSW, Social Policy Research Centre, August 2008. Attendant Care Program Direct Funding Pilot Evaluation. http://www.sprc.unsw.edu.au/media/File/Report11_08_Attendant_Care_PilotEval.pdf

“Only two direct funding participants are women, compared to 69 per cent of the comparison group. This difference probably has implications for other differences between the groups, such as lower socio-economic circumstances in the comparison group.

“The impairments of people in both groups were similar. Differences are that the comparison group included one person with a brain injury and three women had multiple sclerosis. These conditions are more likely to have an impact on their cognitive functioning and emotional wellbeing.

“All direct funding participants have family, friends or housemates who are active members in their lives. Most (eight out of ten) live with family members. In contrast, **23 per cent of the comparison group did not have that level of informal support, and all of these people are women**.[12] In the direct funding group, the family members described themselves as an extension of the attendant carers and a backup. For example, some of them provide the overnight support, cooking, cleaning, shopping, some personal care and additional needs when they are unwell. Some people also call upon neighbours if necessary. This was similar to the comparison group members who had high support needs and family support.

“The biggest contrast between the intervention and comparison group is economic participation. All direct funding participants are employed, retired or studying and were in this position when they entered the program. They are either professionals or business owners. In contrast, only 62 per cent of the comparison group participate in these activities. The groups also differ in their involvement in the community and social networks. In the comparison group, at least five people are significantly socially isolated.

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[12] Our emphasis.

These differences between the groups are taken into account in the interpretation of the findings below. For example, they probably have an impact on participation and wellbeing measures and **on the funding and management model best suited to their support needs.”**[13]

4.3. Children with disability and their parents

The large group of children with a disability, or people with a development delay may be better served by improved access to well designed service systems, rather than direct control models. Many carers have an urgent need for better access to respite.

Subject to establishing how the matter of differing current allocation of responsibilities between the Commonwealth and States and Territories might be settled, services for people with disabilities do require a most significant injection of additional funds to come anywhere to meeting identified need for respite care, support for carers, and for aids and appliances.

It would appear that provision of accessible and affordable housing and transport are not proposed to become the responsibility of the Commonwealth, nor to be financed by any new scheme. Similarly, no changes are proposed in regard to special education services for children with a disability.

4.4. Ageing people with disabilities

There are significant numbers of people with a disability who are now ageing, and who will need disability-specific services throughout their lifetime. They may also come to need aged care services. Transitions from disability to aged care programs need to be managed in the best interests of individuals and what is possible in their local community.

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[13] Our emphasis.

There is a need for careful consideration of the issues at the interface of disability and aged care systems to ensure the most appropriate care is provided to people with disabilities as they age.

Some transfer to the Commonwealth aged care policy and program system of special service needs for certain categories of severe disability in persons over 60 would be appropriate.

We recognise that disability arising from the ageing process is described by the Commission as a separate consideration, but we can foresee some interesting arguments as to whether a condition deterioration say for a person with paraplegia is a consequence of something entirely separate from and other than ageing.

Disability associated with an increased likelihood of dementia is a case in point as all expertise for managing dementia care lies in the aged care system including management of early-onset dementia.

So policy and arrangements must take account of the nature of care needs rather than arbitrary cut-offs on the grounds of age.

The roles of and supports for carers, whether they be carers for a person with a disability, or an aged person, also need cross--policy arrangements consideration.

Of particular concern is what happens to people with disabilities who have been looked after by parents, consequently accessing few if any services, when the parents age and can no longer cope. Many of these individuals will need residential care in aged care hostels--which could be more suited for them if they are in their fifties, than in accommodation for much younger people.

Conversely a person with a long-term disability such as paraplegia may well develop other conditions and symptoms of ageing much earlier. In both cases a designated chronological age for eligibility to services becomes irrelevant.

4.5. Administrative costs

The pressure for direct control of cash resources is strongest from people in the disability sector. However, there is Australian evidence that some persons with intellectual and psychiatric disabilities, persons without high level cognitive function and without a strong surrounding supportive environment, may face difficulties managing such modes and are less likely to benefit from them.

There is argument that people with high support needs (or their carers), see that support dollars are drastically diluted between the funding source, i.e. government, and the point of service delivery by a poorly remunerated support worker, via a series of brokers and care organisations all of which impose administrative charges. Much appears to depend on whether costs for case management, which some disability groups claim can absorb around 30-40% of a care package, are seen as an administrative cost or a direct care cost.

The drive for direct payment of funds comes in part from a desire to by-pass this claimed wastage in the service system, but it is not clear how far the desired outcome would be achieved. Direct payment schemes that are already in operation in some jurisdictions could be informative on this issue.

In our view there is no doubt whatsoever that any move to direct control of cash resources will be accompanied by the growth of market driven providers (including not-for-profits) and potentially increasing issues arising from limits to consumer sovereignty—whether the individual has perfect knowledge of the market, and as well ability to make informed decisions.

It is far from uncommon for individuals who receive lump sum payouts from industrial or motor car accidents, or their associates and others including legal advisers, to spend those monies on other than necessities, and to then become dependent on publicly provided support services, such as might exist.

Individuals who lack competence, intellectual or psychological, will most likely need to engage fund-holders or brokers to manage direct payments on their behalf, and to purchase appropriate service packages. This has the potential to absorb money otherwise intended for service purchase.

4.6. A levy-based funding pool for catastrophic injury

We see considerable benefit flowing from the introduction of a new funding stream, such as the so-called Medicare-levy style of funding, paid into a central pool, and available to defray costs for agreed services for eligible individuals with a catastrophic level of disability. Numbers may well be small in some less populous jurisdictions.

An appropriate model could be some kind of statutory body at the national level, akin to the State bodies responsible for compensation for motor vehicle accidents.

A catastrophic injury insurance scheme would be sensible, but such a scheme does not automatically mean cash payments, and certainly does not imply payment of lump sums.

Many engaged in this debate argue very cogently for funding services in agreed care plans that includes continuing slow stream rehabilitation, and provision of appropriate equipment.

Such a scheme will also cover only a small number of very severely injured individuals.

4.7. A Community Living Allowance

We see value in consideration of additional options for policy changes which could provide more flexibility to match funding to individual needs.

For example, a means-tested Community Disability Living Allowance could be considered as an alternative to the current Carer Allowances.

Such an allowance would be paid to adult competent individuals needing support instead of to carers. Many young people want to be independent of carers and many elderly do not have a carer, but face some additional costs. It would then be possible to increase this allowance, rather than provide consumer directed vouchers for services.

We see this as necessarily continuing to be matched by pay-as-you-go Budget-sourced funding of certain service types, and most likely still requiring individuals to meet many out-of-pocket costs.

We have reservations about a general move to direct funding models, although we see these as being of definite benefit for certain groups of individuals, and applicable to certain specified purposes.

5. HOUSING ISSUES

It is useful to distinguish between people with a disability who also have housing needs that arise for at least three different reasons:

Individuals with low incomes that preclude them from home ownership or private rental;

Individuals with a physical disability that requires accessible housing in which the individual can then live with a high degree of independence, and

Those individuals with very high support needs that limit their capacity to function independently and who are also likely to need accommodation that includes design features that facilitate self care and care by others.

Many in the two latter groups will also have low incomes.

These differing needs require differing responses.

5.1. Reversing the shrinking supply of public and social housing

Without secure tenure of accessible and affordable housing, there will be no chance of success for new policies and new strategic approaches to meeting the needs of Australia’s aging population, and people with a disability.

Before World War II most poor people were forced to do the best they could as renters. The aged and people with a disability unable to survive as renters, especially those with profoundly disabling conditions might become a burden on their families, or perhaps find a place in State institutions.

The Post War Reconstruction Program saw major investments in public housing by Commonwealth and State Governments, in the face of acute housing shortages due to scarcity of housing investments during the Great Depression and the post-war shortage of building materials. The Menzies Coalition Government introduced policies to stimulate affordable home ownership for people of modest incomes. Similarly, the Menzies Government introduced the first Aged Persons Homes Act providing capital grants specifically to encourage the churches and charities to invest in rental housing for the aged. Subsequent introduction of legislation to support disability charities saw the introduction of capital grants for both hostels and sheltered workshops for people with a disability.

Over time, these capital programs for housing were modified or abandoned, and in the case of the aged, the emphasis moved to providing self-funded housing through the not-for-profit sector closely linked to the growth of nursing homes.

Allocations through the Commonwealth State Housing Agreements were gradually phased down, limiting new building and the Commonwealth encouraged the States to give priority in public housing to people with a disability and others with specific disadvantage. Public investment in social housing tapered off.

However, house prices have boomed over the past two decades, and the size of family houses has grown beyond the imaginings of the beneficiaries of the Menzies post-War home ownership policies.

Australia is now experiencing an acute shortage of affordable housing. Within this, there is also a shortage of accessible affordable housing--that is, housing built to a standard which makes it suitable for individuals who for reasons of age-related frailty or of disability require specific design features.

5.2. Priorities for disability accommodation

Affordable housing

The needs of the first group could largely be met by expansion of affordable rental housing as proposed in the recent Discussion Paper, issued by the Minister for Housing, on Regulation and Growth of the Not-for-Profit Housing Sector[14] which states:

“Australia urgently needs to expand the stock of affordable rental housing. The housing supply gap is having a direct impact on housing affordability for both renters and home purchasers. Most of this impact is on low and moderate income earners who were not home purchasers before the housing boom commenced in the late 1990s.

“The affordability of the private rental housing market has declined in the last 12 years, particularly for those households on low or fixed incomes.[15] Between September 2006 and September 2009, real rents increased by 12 per cent.[16] Key

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[14] Commonwealth of Australia, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), 2009, Discussion Paper on Regulation and Growth of the Not-For-Profit Housing Sector. http://www.fahcsia.gov.au/sa/housing/pubs/homelessness/not-for-profithousingsector/Pages/default.aspx

[15] Ibid. citing Australian Government, National Housing Supply Council, 2009, State of Supply Report, p91.

[16] Ibid. citing Australian Bureau of Statistics (ABS), 2009, Consumer Price Index, Australia, Table 7. CPI: Group, Sub-group and expenditure Class, Weighted Average of Eight Capital cities, ABS cat. no. 6401.0.

workers and households on moderate incomes are having difficulty saving with rising rents and increasing house prices.

"This is not a new problem – the shortage of affordable housing and the pressure on renters has been building for over a decade. In 2009, the National Housing Supply Council reported that the supply of affordable rental dwellings for lower income households fell in both absolute and relative terms in the ten years to 2006, despite a 20 per cent growth in the total number of private rental properties (Figure 1). In 2006, the estimated shortfall in the supply of affordable rental housing was around 251,000 dwellings."

Under recent Federal Government housing initiatives[17], new developments are occurring in the affordable and accessible housing sector.

"Through the National Partnership Agreement on Social Housing, it is intended that the states and territories will increase the supply of social housing, providing approximately 1600 to 2100 additional dwellings by 2009-10, and provide opportunities to grow the not-for-profit housing sector."[18]

These will include housing for people with a disability and aged people.

Accessible housing and modifications

The needs of those requiring more accessible housing could best be pursued through two means. First, a national standard in building codes could ensure that the generality of newly built housing is more accessible and appropriate for an

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[17] The National Affordable Housing Agreement (NAHA) aims to ensure that all Australians have access to affordable, safe and sustainable housing that contributes to social and economic participation. It is an agreement by the Council of Australian Governments, commenced on 1 January 2009, which initiated a whole-of-government approach in tackling the problem of housing affordability. It will provide $6.2 billion worth of housing assistance to low and middle income Australians in the first five years.

[18] Commonwealth of Australia, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), 2009. National Partnership Agreement on Social Housing. http://www.facs.gov.au/sa/housing/progserv/affordability/affordablehousing/Pages/NPASocialHousing.aspx

aging population, and for people with a disability (although not necessarily suitable for individuals with very high needs). Second, provision for home modifications in existing housing through the HACC program needs to be expanded.

Group accommodation

There is a marked diversity of views in the disability sector about preferred options for group housing. Thus, while some express a strong antipathy to any approach to the provision of housing clusters for people with a disability, other proposals clearly envisage cluster housing within the wider community. These diverging preferences can only be met by provision of a range of options, and by enabling transitions across the life course in line with housing transitions made by others in the community.

The Australian Housing and Urban Research Institute (AHURI) has noted in a recent report:[19]

"From a disability perspective and from an ageing perspective, health and wellbeing are now a significant influence on the housing transitions of many Australian households. Importantly, whereas the home was a place for the provision of care for children in the second half of the 20th century, in the 21st century it will take on a considerable role in the provision of care for adults.

"There does not appear to be a consensus on appropriate policy interventions, but this work has led to the call for new, more fine-grained, approaches to the provision of housing assistance and the potential re-ordering of priorities in the light of what we know about 21st century housing transitions. Home ownership remains a priority of all tiers of government and both Labor and Coalition parties.

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[19] Australian Housing and Urban Research Institute, July 2008. The Housing Careers of People with a Disability and Carers of People with a Disability. http://www.ahuri.edu.au/publications/download/40427_rp

“Shifts in the relationship between individuals and governments have had an appreciable impact on housing transitions and the need for government assistance. This change is seen most clearly in the areas of housing for older Australians and persons with a disability where established, largely institutionally-based, policy interventions have been abandoned in favour of greater integration with the broader community. This shift has generated new demands for housing assistance and support with independent living, and it is likely that this will be an area of considerable program development over the next two decades.”[20]

Moreover, the great bulk of the older existing public housing built under the former Commonwealth State Housing Agreements is now unsuited to the frail aged or some people with a disability who need accessible housing.

That said it can be fine for the low income disabled who do not need special designs. It is not accessible for wheelchairs, may lack elevators and suitable kitchens and bathrooms. Retro fitting is not feasible in many instances—re-building may be the most appropriate course.

In some cases it can also be unsafe. It has to be recognised that some individuals with a disability may be anti-social in their behaviours at the same time as being extremely vulnerable to other residents who may also have behavioural disorders.

5.3. Engaging social housing agencies in the provision of disability accommodation

It is unrealistic to expect that the private rental sector will be able to respond promptly and effectively to meeting the needs of lower income people with special housing needs without changes to building codes, and even then we do not expect the sector to meet the needs of profoundly disabled individuals.

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[20] ibid, Executive Summary, p viii.

The Ministerial Discussion Paper cited above contains an extensive listing of current players in the not-for-profit housing sector, and outlines options for increasing the engagement of this group. It notes that:

“Australian Housing Ministers agreed in May 2009 that jurisdictions and the Commonwealth develop, over time, a large scale not-for-profit sector comprising up to 35 per cent of social housing by 2014.[21] A not-for-profit sector that leverages private finance against its assets as well as attracting Government subsidies may play an important role in achieving growth in stock to address forecast need. Governments should only responsibly assist not-for-profits to expand their asset base if those providers are well governed, financially sound and able to operate at scale.

“The not-for-profit sector could play a part in building a social housing market that includes strong operators who can deliver growth in affordable rental housing supply. This could occur through the emergence of new models of financing and management through the consolidation and expansion of housing portfolios.

“Currently there are 930 community (housing) organisations in Australia.”[22]

Informal discussions suggest that reliance on the community housing sector to develop new accommodation (rather than manage publicly financed accommodation) may not provide a solution. In particular, community housing providers/developers providing housing for people with disabilities need close contractual agreements with support service providers, to enable them to manage risk. New players with significant resources to invest, such as superannuation funds, could play a role.

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[21] FaHCSIA, op. cit., citing A Progress report to the Council of Australian Governments from Commonwealth, State and Territory Housing Ministers—Implementing the National Housing Reforms, November 2009, published by the Victorian Government Department of Human Services on behalf of the Housing Ministers Conference and available at the COAG Web site, p.26

[22] FaHCSIA, op. cit., citing AIHW, Community Housing 2008-09, Executive Summary, AIHW, 2010.

The need for more affordable accessible housing is urgent.

It is clear that future policies for the provision of affordable and accessible housing for people with a disability and for people who are ageing should be developed as a high priority within the framework of the Commonwealth-States Affordable Housing Agreement and the Council of Australian Governments.

However, it is unfortunately not possible to obtain any gender disaggregated data on the extent to which women are obtaining tenancies in their own right.

There is a limited number of these not-for-profit housing groups making single women, including those with a disability or other special needs, their target population. There is apparently no central data on numbers of women thus accommodated.

Women's housing tenure is likely to be marginal, especially where the women are reliant on Government pensions, and are in the private rental market.

The AHURI study cited above "considers the outcomes of both qualitative and quantitative data collection, with the research focused on three regions of Victoria – Darebin, Gippsland and Melton/Brimbank, as well as four disability groups – the cognitively disabled, the mobility impaired, persons with a psychiatric disability and persons with a sensory disability. This data collection took place in addition to the analysis of data on disability collected as part of the Housing 21 Survey – a national CATI[23] survey of the Australian population.

"(Our) research found that when compared with the general population, households where one or more persons were affected by a disability were:

"Likely to report significantly lower incomes and were more likely to experience housing stress;

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[23] Not explained by the AHURI authors—presumably Computer Assisted Telephone Interviewing.

“Less likely to be home purchasers and more likely to be tenants, especially public tenants;

“Have lower stocks of assets (wealth);

“Have made housing decisions based on the needs associated with a family members disability or long term health condition; and,

“Less likely to live in a family household.[24]

The AHURI report demonstrates the considerable differences in housing needs and experiences arising from particular types of disability: It analyses the housing careers of people with a mobility disability acquired through injury, a mobility disability present since birth, a developmental disability, a psychiatric disability, and with disability due to sensory impairment.

The AHURI report shows that each of these groups has quite distinct experiences in housing careers. Some with acquired disability have better housing and other financial outcomes because the origin of their disabilities lies in a compensable incident. Those with conditions subject to variations of severity (e.g., psychiatric illness) find more difficulty in maintaining housing than those with a fairly stable condition.

6. DISABILITY CARE AND SUPPORT

6.1. Issues for women and girls

As younger women with a disability are a minority and in some cases, more compliant, they are likely to be overlooked in disability services.

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[24] AHURI, op. cit., Executive Summary, p vi.

There are concerns over the assignment of disability associated with mental illness to on-going support rather than addressing treatment–especially when overloaded acute services may move less difficult clients on to other services.

The provision of care is a highly gendered activity, which reproduces inequality between men and women. More women than men provide both paid and unpaid care:[25] An overwhelming 93% of residential workers and 91% of community based workers in the residential and community aged care workforce in 2007 were women.

6.2. Disability in the Australian population

In their report Disability Services 2007-2008, on services funded through the National Disability Agreement, the AIHW makes the following significant points:

Intellectual disability continues as the predominant primary disability, accounting for around one-third of service users in 2007–08 (Section 2.2). The data reveal an ageing service user population of growing cultural diversity (Chapters 2 and 4).

Respite services also registered the highest growth in service users relative to target population. In 2007–08, some 31,500 people used CSTDA-funded respite services compared with 20,500 in 2003–04, corresponding to an increase from 96 respite users per 1,000 target population in 2003–04 to 137 per 1,000 in 2007–08. Over the same period, government expenditure per respite service user fell by 16% in real terms (Section 1.3).

Available data on hours of respite received show a downward trend from an average of 12.1 per respite user per week in 2003–04 to 10.5 hours per week in 2007–08

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[25] Adams, Valerie (forthcoming). Scoping the Australian Care Economy: A Gender Equity Perspective. Canberra, Security4Women.

AIHW goes on to point out that, in 2007–08, service users were more likely to be male than female (Table 2.4). Notable differences between the sexes in relation to primary disability include: males were more likely to report autism (8.2% compared to 2.6%) and females were more likely to report neurological disability (7.0% compared to 4.0%). Similar patterns were seen in 2006–07.[26]

There were questions on disability and carer status in the 2006 Census—the definition of disability meant that the Census data is less comprehensive than the ABS Survey of Disability, Ageing and Carers data, but the differences can be reconciled when these methodological factors are taken into account.

There is a need to make more analyses of the Census data. Perhaps the Commission could follow this up.

6.3. Women as carers

Report after report has identified the problems faced by the women who are carers, their concerns as carers of aging parents or as ageing carers of adult children with disabilities. Commonly asked questions are: Will I be able to access re-training to re-enter the workforce? Why can't I get some Government investment into a superannuation fund as a supplement to my Carer Pension?

For women carers of children with disabilities there are other concerns--their sheer exhaustion and need for access to respite, their concerns as they age as to who will accept responsibility for their child as he or she ages.

In Australia girls are (only) slightly more likely to be a young carer than boys, although significantly more are primary carers.[27] Young carers are a group of young Australians under 26 years of age who provide unpaid care in families where

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[26] AIHW, 2009. Disability support services 2007-08: national data on services provided under the Commonwealth State/Territory Disability Agreement. http://www.aihw.gov.au/publications/index.cfm/title/10751

[27] ibid, p 192.

someone has an illness, a disability, a mental health issue or who has an alcohol or other drug problem. Around 170,600 Australians under the age of 18 years and 380,000 under the age of 26 provide care to a family member. The time that young carers spend caring can be as much as 30 hours a week,[28] which impacts on their education or workforce participation.

Then there is the matter of the individual women who have a disability. Again, we are disadvantaged by the lack of current, accessible gendered data.

We cannot cross analyse the data above by the classifications used by AHURI, nor can we analyse further in terms of those with multiple disabilities.

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[28] ABS, 2003. Disability, Ageing And Carers: Summary Of Findings. ABS cat. no. 4430.0.

7. RECOMMENDATIONS

The Commission has been asked to examine options for new modes of financing and providing care for the most disadvantaged people with a disability, and raised questions about scope and inclusions/exemptions.

This submission provides statistical data, evaluations, survey research and widely reported experience against which we recommend the following:

1. Gender disaggregated data must have a prominent place in the Commission's Report to inform future policy developments if any policy or program is to be assessed as to whether men and women are treated equally. Overall, there is to date a disturbing lack of analysis which might establish whether the United Nations requirement for equitable outcomes for women as well as men is met.

2. The Commission should seek from a body such as the AIHW gendered data analysis as part of the Inquiry, including of the most recent relevant Australian Bureau of Statistics collections.

3. The needs of women as carers are different from the needs of women with disabilities and young carers, as well as young women with a disability, require specific attention. We note that studies of direct control models strongly suggest that the persons benefiting the most from attendant care and/or direct payment approaches tend to be male, educated, workforce attached and with strong informal social supports. The Commission's final recommendations should recognise this and aim to enlarge the gendered socio-economic scope of benefits.

4. Particular approaches that have been found to be appropriate for particular groups call for a thorough understanding of differences in individual needs and their situations.

5. We caution against over-generalisation and too rapid application of these limited research study findings in widespread development of direct control for

individuals for whom it may not be the best option or provide few if any benefits, or benefits to the community by way of reduced impacts of behavioural problems or costs.

6. The role of the Commonwealth is currently limited to the direct payments of benefits and allowances, and support for employment services, plus the provision of grants to States and Territories to support accommodation options and care and management options. Should the Commonwealth decide to develop limited forms of direct payment options to allow individuals greater control over their daily lives, this will not remove the need for more appropriate housing, and may not preclude the individual needing to continue to access services such as nursing and physiotherapy, rehabilitation, and medical and pharmaceutical benefits and outlets to overcome social isolation. Moreover, such a system almost certainly will not be applicable to certain diagnostic groups, or individuals with challenging behaviours and complex needs.

7. There is a need to understand the limits to self-management of many individuals with a single disability or a compounding of multiple disabilities.

8. It is critical to identify different need patterns and different outcomes not only by disability, but also by gender.

9. It is essential that there is close coordination of policy developments in independent accommodation and supported accommodation types, as well as to giving consideration to support service needs, since the latter will be influenced by the former.

10. Direct payments for the most disadvantaged will not remove the need for associated support services of various types, and greater investment is required to

meet the needs of an ageing disability population, of vastly diverse ethnic and cultural backgrounds.[29]

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[29] At the time of writing both Labor and Liberal Parties had made election commitments in relation to improving disability services. This submission has not attempted to assess these proposals.