(Inquiry into better support for carers)

Are needs being met?

An assessment of the new Federal Government's disability and carer activities

Research, analysis and commentary prepared by

Margaret Ryan

Victorian Metro Liaison

National Carers Coalition

Tel (03) 9509 7803 Email mryan136@optusnet.com.au

Summary

This is a detailed paper about what is taking place at the Federal Government level to determine the future shape of services to people with dependent disabilities and their families. To each activity under consideration it applies a merit test: *What is the potential of this activity to meet the needs of people with dependent disabilities under 65 and their families?*

Under disability policy, funding initiatives and funding reviews it overviews and critiques 13 activities:

- 1 COAG Reform Agenda
- 2 New Framework for Federal Financial Relations
- 3 Development of Commonwealth State Territory Disability Agreement
- 4 National Disability Strategy
- 5 National Mental Health and Disability Employment Strategy
- 6 Ratification of UN Convention on Rights of Persons with Disabilities and Not Signing Optional Protocol
- 7 Redirection of funding from Disability Assistance Package
- 8 Transfer to disability sector of COAG Health Services program Younger People in Residential Aged Care
- 9 National Partnership Payment for supported accommodation
- 10 Extension of utilities allowance to Disability Support Pensioners
- 11 Special Disability Trusts Senate Inquiry
- 12 Disability Investment Group
- 13 National Disability Insurance Scheme

Under carer policy, funding initiatives and funding reviews it overviews and critiques seven activities:

- 14 Better support for carers House of Representatives Inquiry
- 15 Carer legislation reform
- 16 Lump sum bonus payment to carers
- 17 Extension of utilities allowance to Carer Payment recipients
- 18 Changes to the Carer Payment (Child)
- 19 Australia's Future Tax System review
- 20 Financial security of carers and seniors

The paper identifies that there is no first order initiative for meeting care needs as a population continuum - children, younger people, ageing people – and meeting the needs of people currently providing unpaid care. It is considered that the failure to acknowledge the significance of carers as being the core of service provision, and the failure to recognise that individuals requiring care at a particular stage in the continuum will more than likely always require care, consigns the matter of policy and funding to a second order or lesser issue

The paper concludes that five commitments are required:

- A commitment to the provision of care as a first order issue
- A commitment to meet the needs of people with dependent disabilities and their families
- A commitment to eliminating unmet and under met need and its adverse effects
- A commitment to the rule of law, to legislating a right to services
- A commitment to transparent policy accountability, to indicators and benchmarks, to make economic and social rights a reality

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INTRODUCTION

Since winning the election on 27 November 2007, the new Federal government has been active in putting its stamp on the social, economic and environmental landscape of Australia, laying the foundations for the future.

While there is a lot of activity in areas which affect people with dependent disabilities aged under 65, their families and carers, there is no holistic focus on meeting the needs of these people.

Unmet need is the cancer of disability services. One only has to consider how few people receive a funded service to get some measure of the depth of unmet need:

- Only 5 per cent of people potentially requiring accommodation support get a service 95 per cent miss out
- Around 13 per cent get community support 87 per cent miss out
- Less than 7 per cent get community access 93 per cent miss out

And it is similar for respite and employment. (Source: Table 2.2, AIHW 2007, Disability Support Services 2005-06, national data on services provided under the Commonwealth State/Territory Disability Agreement) Further, this count of people receiving a service does not provide a measure of those who receive an inadequate service, that is, have under-met needs.

Just as destructive is the plight of ageing parents and their sons and daughters. Currently there are around 60,000 people with a severe or profound disability aged 35 years or more still living with their parents. Not necessarily because they want to but because there is no other accommodation available. (*Source: ABS customised data, 2003 Survey of Disability Ageing and Carers*) Accommodation and support therefore, although always having been an issue, will become even more significant over coming years as ageing parents die or become incapable of continuing to function as unpaid care-givers.

Intrinsic to the cancer of unmet need is the fact that neither federal nor state disability legislation enshrines the basic right of access to services; even though this right of access to services is the foundation for realising equal opportunity and a fair go for people with dependent disabilities. Based on relative need, disability legislation actually excludes from appropriate services people who fit the eligibility criteria. There is no federal legislation recognising the needs and social and economic rights of families or carers.

The purpose of this paper is to survey and critique the major reforms being undertaken by the new Federal government which impact particularly on people with dependent disabilities and their families. This is to encourage and assist debate on the issues and direct attention to the outcomes needed to ensure the reforms benefit people with dependent disabilities and their families. It is the families who are the core service providers, but the impact on families, and their needs, are too often treated as peripheral issues when decisions are being made.

The paper tests the merit of each activity by asking the question: What is the potential of this activity to meet the needs of people with dependent disabilities under 65 and their families?

A DISABILITY POLICY

In this new era of co-operative federalism at the Council of Australian Governments (COAG), the needs of people with disabilities and their families are excluded as a first-order issue from the new dynamic rigor of COAG policy making. Disability services is not part of the seven working groups that have been established to drive ongoing change, and to develop and implement the COAG reform agenda, despite being flagged as a sector for specific purpose payment. It is obvious that the needs of people with disabilities and their families are not a matter of national priority.

The policy work around disability services is bunkered down within negotiations to renew the Commonwealth State/Territory Disability Agreement (CSTDA). Advice is primarily being provided by officials and advocates who have consistently ignored the families providing the vast majority of accommodation and support to people with dependent disabilities.

The changes flowing from the reform of Federal Financial Relations will create a new playing field for the disability sector with new rules of engagement. This is, however, unlikely to bring about the fundamental change required to build a sector with service funding and delivery models, and performance indicators, which accommodate the factors driving need and demand, and met and unmet needs.

The development of a National Disability Strategy over four years is without rigor and has all the appearances of being captured by State and Federal bureaucracies and so called experts who stifle and suffocate rather than stimulate and energise informed considerations on policy and funding.

A Mental Health and Disability Employment Strategy is being developed separately from, and well ahead of, the National Disability Strategy. The combining of mental illness and disability adds complexity to any monitoring and accountability of the Federal government. It is not apparent how any strategy will be aligned with Federal employment responsibilities under the CSTDA.

The National Interest Statement (NIS) on ratifying the new United Nations Convention on Rights of Persons with Disabilities is a reality check as to the rights-based provision of disability services and the federal government's funding commitments. The NIS makes it clear that:

- the Convention does not create any new rights,
- enhancements to the processes of eliminating discrimination and improvements in disability services are already being financed,
- ratification is unlikely to impose any significant costs on governments (noting that Queensland does not share this view).

Despite proceeding with ratifying the convention, it is an indictment on the new Federal government that it demonstrates no intention of signing and ratifying the Optional Protocol to the Convention. The Optional Protocol sets up a complaints mechanism to the Committee on the Rights of Persons with Disabilities for individuals and groups from

those countries who have signed and ratified the Protocol. Australian individuals or groups with complaints will be unable to access this international forum to test adherence to the Convention.

The following table sets out details on activities and reform initiatives impacting on disability policy and assesses the potential to alleviate unmet and under-met needs. This encompasses:

- 1. COAG Reform Agenda Potential Dubious
- 2. New Framework for Federal Financial Relations Potential Minimal
- 3. Development of Commonwealth State Territory Disability Agreement Potential Limited
- 4. National Disability Strategy Potential Unlikely
- 5. National Mental Health and Disability Employment Strategy Potential Limited
- Ratification of UN Convention on Rights of Persons with Disabilities and Not Signing Optional Protocol Potential None

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
No	Activity COAG Reform Agenda As of December 2007 Seven Working Groups Four meetings in 2008 Treasurers attend COAG meetings, in recognition of the importance of the new framework for federal financial relations to underpin the COAG reform agenda COAG Reform Fund Board of Guardians	 Working Groups chaired by Federal Ministers with senior State and Federal officials in the sectors of Health and Ageing, which includes consideration of community based care interface between disability and ageing workforce development Productivity, which includes early childhood development and childcare schooling skilling training Regulation and Competition, which includes building codes OH& S national system for trade and professional registration and licensing Housing, which includes Audit of Commonwealth/State - government land Improvement to social and community housing Federal National Housing Supply Research Council Indigenous reform, which includes specific targets in new SPPs Climate Change & Water Infrastructure 	
		Also, National Health and Hospitals Reform Commission (NHHRC) COAG Reform Council (CRC) <u>www.coag.gov.au</u> ; <u>www.budget.gov.au</u> , <u>www.treasurer.gov.au</u>	

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
2	New Framework for Federal Financial Relations Three categories of payments to States and Territories: (a) Specific Purpose Payments (b) National Partnership Payments with three facets: facilitation, incentive, reward – funded from the COAG Reform Fund (c) General revenue assistance Three Future Funds, May 2008 (a) Building Australia Fund to finance roads, rail, ports and broadband, \$20 billion; (b) Education Investment Fund to finance skills, TAFE colleges and universities, \$11 billion; (c) Health and Hospitals Fund to finance improvements to hospitals and the health care system, \$10 billion. Initial allocations from 07-08 and 08-09 surpluses	Reform of Specific Purpose Payments (SPPs) by Council of Australian Governments (COAG) and Treasurers, to take effect 1/1/2009. - Reduction from the current 92 SPPs to five or six new national agreements in the sectors of health, affordable housing, early childhood and schools, vocational education and training, and disability services - Overall funding arrangements will be negotiated as one financial package by Treasurers. - Focus on agreed outputs and outcomes - Ongoing funding (i.e. no fixed term and subject to re-negotiation). - No requirement for matching funds - State determines allocation within sector - Periodic reviews for maintenance of funding adequacy and relevance of objectives - Oversight by COAG Reform Council on referral - New reporting framework for accountability - Accountability of the State governments to their own communities for their service delivery performances Unclear what will happen with annual Productivity Commission Secretariat Report on Government Services. www.coag.gov.au, Communiques; www.budget.gov.au, Federal Budget Papers Nos 2 and 3; www.pc.gov.au	Potential: Dubious Disability services notable as only SPP not a national priority for COAG Outcome/output measures of service delivery difficult to define, measure and enforce in a robust way Potential dependent on establishment of transparent base measures of quantity of service provision to ensure met, unmet and under-met need quantified Dependent on States for quality data Possibility of multiple agreements and payments - National Partnership facilitation, incentive and reward payments as well as Specific Purpose Payments - adds complexity to reporting and analyses and holding governments accountable No first-order funding initiatives such as a Provision of Care Fund. Unless a long-term view is established, where not only today's funds are allocated but also where future funds are committed as a genuine recognition that care is ongoing, then the service will always be variable

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
3	Development of Commonwealth State Territory Disability Agreement (CSTDA) In new Federal Financial Relations framework will become disability sector Specific Purpose Payment plus National Partnership Payments Previous agreement extended until 31 December 2008	Ministers to work on eight key priority areas identified in Labor election policy: • Better measurement of current and future need for disability services; • Making older carers a priority for all disability services under the CSTDA; • Quality improvement systems based on the National Disability Service Standards for all Agreement services; • Improved service planning and strategies to simplify access to services under the CSTDA; • Focusing on early intervention, lifelong planning and increasing the independence and social participation of people with a disability; • Improved workforce capacities, and • Access to services by Indigenous people with disabilities. Ministers May 2008 communiqué announced improvement needed in advocacy, measurement of unmet need, innovative policy development, quality assurance, research, national consistency for provision of aids and equipment The Commonwealth provides funds to the States under the home and community care (HACC) program for the provision of appropriate community care services to help frail aged people, people with a disability and veterans live in their homes for as long as possible. Funding for this program will continue beyond 2008-09, although its treatment under the new framework for federal financial relations is yet to be decided. Implications for funding not transparent: HACC has significantly different funding split (60 per cent Federal, 40 per cent States) to current CSTDA, and different legislative base. Prior to 2008-09 the services for veterans were classified as Australian Government own-purpose expenses. COAG Health Service program for younger people in residential aged care to be subsumed into disability sector. The treatment of local government payments under the new framework for federal financial relations is yet to be decided. There is disability services funding in payments to local government. www.facs.gov.au, Ministers; www.alp.org.au, Policy www.budget.gov.au, Federal Budget Papers Nos 2 and 3	 Dider Met Needs Potential: Limited A fair and rational basis for the provision of public funds to support people with dependent disabilities and meet their needs is possible <u>if</u> national population benchmarks for disability services are implemented. This involves the use of population data to establish benchmarks or planning ratios that allow resource provision over time to be monitored and targets to be set. Measurement of current and future need depends on State and Territory service systems, which are known as failing quality data measures. Giving older carers priority will exacerbate the unmet and under-met needs of the younger cohort ie those people aged under 40 years with carers under 65. Completely new time and trend lines at 1 January 09 with new SPP which includes programs transferred from other sectors. Clear explanation and quantification of new time and trend lines unlikely, as good opportunity for obfuscation of service provision and funding, as happened with first CSTDA, base year 1989/90. Other inclusions in Disability SPP, eg HACC or parts thereof , will muddy the landscape, as will inclusion of Veterans, whose disabilities arise from service to the nation, will be to their detriment as they join the queue like everyone else. If the Veterans service system and budget cannot accommodate their needs, must ensure Federal responsibility to update the Veterans system, not seek out-of-sight, out-of-mind short-term solutions from disability providers.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
4	National Disability Strategy Part of Labor election policy No timeliness announced	The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) using funding over four years from within existing resourcing to develop a National Disability Strategy. To include a national policy statement setting the directions and priorities for the development of legislation, policy and financing of disability services. Federal government's agenda-setting consultation: private invitation only for government funded individuals. www.budget.gov.au/2008-09, Budget Paper No 2 www.facs.gov.au, Ministers, joint media release 13 May 08	 Potential: None Extended time frame indicates most likely a vehicle for governments to defer and delay decision making on providing adequate services. Will cobble together existing Commonwealth, state and territories approaches. Unlikely to be underpinned by rigorous understanding and analyses of flaws and shortcomings of existing policies and practices, and the burden being carried by families, to develop strategy options. Unlikely to incorporate lessons learned from the evaluation of the Commonwealth Disability Strategy especially re performance reporting. The likely mix of objectives related to discrimination and objectives related to service provision will be foundation for a strategy nebulous in nature. Rights based policy requires relevant and accountable performance indicators, which are non-existent in disability services eg population based benchmarks

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
5	National Mental Health and Disability Employment Strategy Terms of reference released 15 February 2008 Discussion paper Submissions close 30 June 08 Strategy to be released end 2008 Part of Social Inclusion Agenda	The Strategy aims to address the barriers faced by people with disability and/or mental illness that make it harder for them to gain and keep work. The National Mental Health and Disability Employment Strategy will outline how policy and programs across portfolios and state, territory and Commonwealth governments can work together to help people with disability and mental illness gain and retain work. There is an overarching Employment Services Review also being conducted, but as the Government has decided to extend Disability Employment Network (DEN) and Vocational Rehabilitation Services (VRS) contracts until 28 February 2010 to enable further consideration of the future of disability employment services, including the outcomes of the National Mental Health and Disability Employment Strategy, employment assistance delivered through DEN and VRS is not considered in the Employment Services Review discussion paper. http://www.workplace.gov.au/workplace/Pub lications/PolicyReviews/EmploymentStrateg y/NationalMentalHealthandDisabilityEmploy mentStrategy http://www.workplace.gov.au/workplace/Pub lications/PolicyReviews/Employment+Servic es+Review/ http://www.humanrights.gov.au/disability_rig hts/employment_inquiry/index.htm	 Potential: Limited The HREOC Workability II: Solutions recommendation for a National Employment Strategy included recognition that there needed to be a streamlined system to provide adequate (i) income support; (ii) transport, equipment and health care subsidies and concessions; (iii) workplace supports and modifications; and (iv) personal care in the home and workplace; National population benchmarks for services which account for disability and/or mental illness employment- specific needs are a necessity for resource provision over time to be monitored and targets to be set. The development work to date does not give equal consideration to both attributes of the person's environment and personal characteristics as contributing to impairment, activity limitation and participation restrictions and the need for support. Over-emphasis on environmental attributes means strategy will be removed from reality.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
<mark>Nо</mark> 6	Activity Ratification of UN Convention on Rights of Persons with Disabilities Australia has signed Convention Australia has <u>not</u> signed the Optional Protocol to the Convention which sets up a complaints procedure on behalf of individuals or groups to the Committee on the Rights of Persons with Disabilities.	 Ratification of Convention by Australia Joint Standing Treaties Committee has recommended ratification (19 June 08) prior to final report on inquiry National Interest Analysis of Convention tabled House of Representatives 4 June 2008. <i> Ratification of the Convention is likely to:</i> raise awareness of disability issues and foster a more inclusive and cohesive society by giving prominence to ensuring human rights are available to all, including people with disability; promote the active participation of people with disability in the community, including workforce participation, which may reduce pressure on welfare services; enhance the independence of people with 	Under-Met Needs Potential: None The Analysis states <i>inter alia</i> that there are negligible financial or regulatory implications for the proposed treaty action given: the Convention does not create any new rights; Australia's compliance with immediately applicable obligations and substantial implementation of progressively realisable obligations; and pre- existing funding for disability services. Further, enhancements to the processes of eliminating discrimination and improvements in disability services are already being financed
		enhance the independence of people with disability, thereby potentially reducing direct support services costs; promote universal design, resulting in more accessible and therefore more functional and sustainable built and information environments; and improve the self-esteem of people with disability, enabling them to enjoy dignity and respect.	Article 4(2) provides that those obligations in the Convention that stem from economic, social and cultural rights are subject to progressive realisation, which means fulfilling or achieving those rights over time, taking into account available resources.
		No signing/ratifying of Optional Protocol www.humanrights.gov.au/disability_rights/c onvention.htm	Not signing Optional Protocol precludes external scrutiny of Australia's adherence to Convention.

B DISABILITY FUNDING INITIATIVES

Since the change of Federal government there has been no change in the spin put on funding announcements. These announcements would have most people believing that there is a rosy future for people with dependent disabilities and their families, when this is not the case.

In May the Ministers announced an output of more than 24,500 places for respite, individual packages, and accommodation support from the funding being provided over the years up to and including 2011-12. This announcement did not include any definition of what services would be provided in a 'place' yet the number is set down alongside the Australian Institute of Health and Welfare (AIHW) estimate of 23,800 people with unmet demand for accommodation and respite services, creating the impression that all these people and more will have their needs met. No mention was made by the Ministers of the unmet demand for community access services, conservatively estimated by the AIHW as being in the range 1,000 to 6,600 people

No mention was made of the 23,800 people being the <u>conservative</u> estimate by the AIHW for <u>2005</u> unmet demand, with the possibility that the estimate could be as high as 31,700 (and as low as 15,900) people. No mention is made either that the population of people with severe and profound disabilities is estimated to increase by nearly 5 per cent between 2006 and 2010 (34,600 people). No mention was made that the funding will be paid over four years, and that the full complement of Federal relief will not be available until 2011-12: \$124.5 million in 2008-09; \$154.4 million in 2009-10; \$252.6 million in 2010-11; and \$369.7 million in 2011-12. The cancerous unmet need is being deeply entrenched.

Government acknowledgements that more needs to be done are cold comfort, when there is no appearance of more being done by way of substantial funding commitments, and little transparency around what is being done or planned to be done. Moving the COAG program for people under 50 in residential aged care into the disability sector is akin to putting more deck chairs on the Titanic.

The Federal government has actually let State and Territory governments off the hook to the tune of foregoing \$151 million in matching funds it could have required for the \$100 million it has committed for supported accommodation (being paid in 2007-08) and \$51 million in existing respite contracts being transferred to the Sates and Territories. The two to three hundred supported accommodation 'places' being provided from the \$100 million for capital works is breathtaking in its inadequacy, given the thousands of ageing co-resident parent carers in Australia.

The payment of allowances, such as that for utilities and telephone assistance, distracts attention from serious consideration of the adequacy of income support, currently tied to one-quarter of male total average weekly earnings. Allowances are also a way of limiting financial commitments, by using a household as the basis, rather than the persons on a pension. Further, as the disability pension is not payable until the age of 16, when it is only a part pension anyway, families who may only be receiving the disability allowance (child) are excluded from payments tied to pensions.

The following table sets out details on activities and reform initiatives regarding funding, and assesses the potential to alleviate unmet and under-met needs. This encompasses:

- 7. Redirection of funding from Disability Assistance Package Potential Very Little
- Transfer to disability sector of COAG Health Services of younger people in residential aged care Potential Limited
- 9. National Partnership Payment for supported accommodation Potential Miniscule
- 10. Extension of utilities allowance to Disability Support Pensioners Potential Minimal

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
7	Redirection of funding from (Howard Government) Disability Assistance Package to CSTDA Howard Government DAP funding was \$962 million	The Government will redirect funding of \$901.2 million over four years from the Disability Assistance Package (DAP) to the Commonwealth State Territory Disability Agreement. The funds to be transferred in each year are: \$124.5 million in 2008-09; \$154.4 million in 2009-10; \$252.6 million in 2010-11; and \$369.7 million in 2011-12. Considered to deliver on commitment to responsible economic management. May 2008 Ministers announced that added to State Territory funding this would provide: 2,300 in-home support places; 2,300 supported accommodation places; 9,900 individual support packages and 10,000 respite places, in a range of forms, across Australia. In total more than 24,500 places. www.budget.gov.au, Budget Papers 2 and 3 http://www.dadhc.nsw.gov.au/NR/rdonlyres/E643036 8-595B-4F8A-8664- 7A28E692C368/3671/Disability_Ministers_Communiq ue_30May08.pdf	 Potential: Very little Total lack of transparency and accountability as to which jurisidiction will provide what amount of service for what amount of dollars. "Place" and "package" output measures of service not defined. Output commitment means a 2 per cent increase in number of people getting an accommodation support service and 5 per cent increase in people getting a respite service. Current potential populations not getting a service still over 80 per cent. No considerations as to service adequacy No matched funding of \$50 million allocated to respite from the DAP.
8	Inclusion in Disability sector Specific Purpose Payment (SPP) funding from the current COAG Health Services program for Younger People with Disability in Residential Aged Care	As from July 2006 a five-year \$244 million agreement, with \$122 million funding from Federal Government and \$122 million from States and Territories, for the purpose of reducing the number of younger people with a disability in residential aged care, with priority given to people aged less than 50 years. www.budget.gov.au, Budget Papers 2 and 3	Potential: Limited This is very tight funding for replacing inadequate service for the people aged under 50 in residential aged care (just over 1000 at 30 June 2006) and possibly reducing admissions of younger people into residential aged care, as well as providing so new people under 50 do not enter residential aged care. In 05-06 around 5500 aged 50 -65 in residential aged care. Lack of transparency and accountability as to outputs/outcomes. Depends on States and Territories reporting.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
9	National Partnership Payment for supported accommodation	\$100 million in capital funds in 2007-08, under the Commonwealth State Territory Disability Agreement, to assist the States to provide supported accommodation services for people with a disability. These new supported accommodation places will be available to people with a disability who may not currently have appropriate accommodation. They will also be available for people with a disability whose parents are ageing and can no longer care for them at home. <u>www.budget.gov.au</u> , Budget Papers 2 and 3 <u>http://www.pm.gov.au/media/Release/2008/ media_release_0235.cfm http://www.dadhc.nsw.gov.au/NR/rdonlyres/ E6430368-595B-4F8A-8664- 7A28E692C368/3671/Disability_Ministers_ <u>Communique_30May08.pdf</u></u>	Potential: Miniscule To provide 309 supported accommodation places. There are around 60,000 parent carers providing accommodation and support to their sons and daughters aged 35 years or more with severe and profound disabilities. In the absence of any publicly advised basis for the provision, it is at best tokenistic.
10	Extension of Utilities Allowance to Disability Support Pensioners Assistance with home internet connections	From March 2008, the Utilities Allowance annual rate increased to \$500 for singles (or couples combined) irrespective of age. It will be paid quarterly with payments in March, June, September and December (\$125 per quarter). People who receive the telephone allowance eligible for home internet connection. The internet service must be in the recipient's or their partner's name to qualify for the increased rate. Telephone Allowance increased by \$44, from \$88 to \$132 a year. Increase around 85 cents a week. <u>www.budget.gov.au</u> , Budget Speech and Budget Paper 2	Potential: Minimal An increase of \$9.60 a week to a single person income of maximum rate Disability Pension of \$546.80 a fortnight/\$14,216 a year adds minimally to weekly income. Note that 1 July 2008 personal income tax cuts mean a worker on \$48,000 — average weekly earnings — will receive a weekly tax cut of \$20. Pension not available until person aged 16,and then only a part pension, but utilities allowance not extended to Carer Allowance (Child),thus excluding a significant cohort.

C DISABILITY FUNDING REVIEWS

There are also some reviews related to the funding of disability services whose findings will be impacted by the Australia's Future Tax System review. Consequently, the merit of these activities will be found in their potential input into the Tax review. Thus the potential of each activity to alleviate unmet and under met needs has been assessed as modest.

The three activities are:

- 11. Special Disability Trusts Potential Modest
- 12. Disability Investment Group Potential Modest
- 13. National Disability Insurance Scheme Potential Modest

No	Activity	Reform Initiatives	Potential to Alleviate Unmet
			and Under-Met Needs
11	Senate Inquiry into Special Disability Trusts Reference made 15 May 2008. Closing date for submissions 13 June 08 To report by 18 September 2008	 The Senate noted the inclusion in 2006 into the Social Security Act 1991 of Part 3.18A – Private financial provision for certain people with disabilities to enable the establishment of special disability trusts, and noted that as at 31 December 2007 only 22 trusts had been established. The Senate made a reference to the Community Affairs Committee of matters relating to Special Disability Trusts (a) why more families of dependents with disabilities are not making use of the current provisions to establish Special Disability Trusts; (b) the effectiveness of Part 3.18A of the <i>Social Security Act 1991</i>; (c) barriers in the relevant legislation to the establishment of Special Disability Trusts; and (d) possible amendments to the relevant legislation. 	Potential: Modest A Special Disability Trust was perceived as a vehicle to meet the expressed need of (families) wishing to provide for the person with disabilities without affecting that person's pension eligibility. Twenty-one submissions have been received by the Inquiry. All make interesting and enlightening reading as to why the market has not embraced this product, particularly regarding its considerable complexities. There has been no published consideration of how many Australian families would be able to fully fund or make a significant contribution to the annual costs of residential and non-residential care outside the parental/family and thus alleviate current and future demand for support.

Νο	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
12	Disability Investment Group Established April 08 No published work plan or timelines for reporting Diversion of Disability Assistance Package funding for an inquiry into delivery options for supported accommodation and barriers to be addressed	The Australian Government has established a seven-member Disability Investment Group to: Identify international best practice in leveraging greater investment in disability support. Identify opportunities to increase private sector involvement and investment in the funding of disability services and related infrastructure, including new innovations to develop alternative funding sources and arrangements for people with disability and their families; identify barriers to this and how they might be overcome. Identify current and potential avenues for philanthropic investment in disability support. Explore government assistance to encourage family and private investment in the provision of housing, education, employment, equipment and other support for people with disability. Consider, with the community and financial institutions, avenues for new products and services to assist families plan for the future of their child with a disability. Develop options for investment in housing for people with disability through private and shared equity. Develop ways to assist people with disability, their families and not-for-profit organisations to engage with the private sector to enable development of accommodation and support options. Identifying research reforms to encourage private sector engagement in research. http://www.facs.gov.au/internet/facsinternet.nsf/disa bilities/policy-dig.htm	Potential: Modest The difficulty for this inquiry is that it is taking place in the context of there being no national policy considerations around care needs as a population continuum, and the structural reform required to alleviate unmet and under- met needs. Recommendations are likely to be made obsolete by the Australia's Future Tax System inquiry (see below). No consideration given as to whether tax-driven financing is equitable and whether disability investment should be charity based or rights- based. The assumption in its terms of reference that families can contribute more does not inspire confidence that there is understanding of the diversity of the impact of disability on families, and that as well as financial pressures there are physical and mental pressures. An oblique way of opening up sector to private (for profit) organisations with dependence on access to parental or family assets.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
13	National Disability Insurance Scheme Australia 2020 Summit Prime Minister commitment that by the end of 2008 the government will have responded to the recommendations put forward by the 10 summit streams. No indications as to which sector of government will be working on response to recommendations	At Australian 2020 Summit held in Canberra 19 & 20 April 2008 disability issues given consideration in the <i>Strengthening communities, supporting</i> <i>families and social inclusion</i> stream In her concluding remarks, co-chair <i>Minister Plibersek asked the group for</i> <i>agreement to include the National</i> <i>Disability Insurance Scheme as an idea</i> <i>for further work and consideration. There</i> <i>were no objections to this proposal.</i> <u>www.australia2020.gov.au</u>	Potential: Modest The idea of there being some kind of national insurance scheme to fund disability is not new and in reality it is another tax. Refer the review of Australia's Future Tax System below.

D CARER POLICY

A fundamental question in any discussion about carers is 'Who is a carer?" The ABS Survey of Disability, Ageing and Carers is the basis for defining who is a carer in Australia. The integrity and professionalism of the ABS means its survey terminology is tightly defined, as is apparent from the nine page glossary for the Disability, Ageing and Carers survey.

The ABS answer to "Who is a carer?" includes consideration of the assistance, that is, help or supervision, being:

- to persons with disabilities or long term conditions or older persons
- informal, meaning unpaid, though it can be paid if the provider is living in the same household
- ongoing for at least six months
- where the care recipient lives in the same household, the assistance is for one or more of 10 defined activities
- where the care recipient lives in a different household, the assistance relates to 'everyday types of activities'

The survey then identifies primary carers in the carer population, being the person who provided the most informal assistance for one or more of the three core activities: communication, mobility and self care. The three core activities have defined tasks.

The most recent survey is from 2003, the next is scheduled for 2009. In terms of quantifying carers, in round figures the 2003 survey identified around 2.6 million carers. (*ABS Disability, Ageing and Carers, Summary of Findings, 2004*) The carer landscape is, however, more complex than the simple round figure, for example:

Carers

- 13% of people living in households were carers (2 557000 people out of 9 628 200)
- When you exclude persons aged less than 15 years, 12.5% were carers (2 455 400 of 15 728 200)
- There were 101,600 carers aged less than 15 years

Primary carers

• 2.4% of the population aged 15 years and over were primary carers (464 600 out of 2 455 400) or 1 in 5 of the carer population is a primary carer, so the qualifier for being a primary carer makes a significant

difference to the numbers who are counted as carers and those who are counted as primary carers

• 78% of primary carers (371,200 people) cared for a person living in the same household

In *Australia's Welfare 2007* the AIHW reported that the issues for carers of people with different types of disability have been highlighted by recent work. For example,

• A review of mental health care in Australia found that the carers of people with psychiatric disability may find their role more demanding due to an ongoing lack of treatment and accommodation services for the person they care for.

 A substantial proportion of parents of younger children with disability report a need for more support (48%). Respite care and financial assistance are the most frequently requested types of support for primary carers of children aged 0–14 years.

The work of the AIHW and other studies makes it obvious that

- the age of the person requiring assistance and the age of onset of disability, and
- the type of disability and the support available for a person with a particular disability

are two key factors driving the work carers undertake, the demands this work creates, and the extent of met and unmet need.

As well, there is also the impact on carers of the adequacy of service from three sectors:

- mental illness,
- disability and people aged under 65, and
- aged care for those 65 or more

There are two policy initiatives on the table for carers. These are:

- 14. Better support for carers inquiry Potential Doubtful
- 15. Carer legislation reform Potential Unknown

No Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
14 Better support for carers inquiry. House of Representative Standing Committee on Family, Community, Housing and Youth Inquiry announced 14 May 08 Submissions due 4 July 2008 To report early 2009	 Purpose of the inquiry is to obtain an improved understanding of the challenges facing carers and their support needs. The committee is to inquire into and report on: the role and contribution of carers in society and how this should be recognised; the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment; the practical measures required to better support carers, including key priorities for action; and strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future. For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'. The terms of reference do not contain legislation considerations, even though in the 13 May 2008 Budget publication <i>Working Families Support Package, Recognising and rewarding carers</i> it was stated that: An inquiry will be established to consider ways to provide more secure long-term support for carers and the introduction of federal carer recognition legislation. Refer to Carer legislation reform, below http://www.aph.gov.au/house/committee/fchy/ca refs www.facs.gov.au, Minister Macklin, media 15 May 08 http://www.budget.gov.au/2008-09/content/overview2/html/overview_24.htm 	 Potential: Doubtful The sending of this reference to a parliamentary committee is an expedient way of papering over the void of the lack of national priority for meeting care needs. It is more than likely that submissions will be re-stating what is already well known, particularly given the 2007 Senate report into the funding and operation of the CSTDA. The recommendation of that report for the commitment of substantial additional funding is without doubt the statement of the obvious. The qualifier is that this funding be for identified unmet need, yet the report did not address the obvious short-comings and manipulations of the States and Territories in identifying the unmet needs for which the additional funding is required.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
15	Carer legislation reform Election commitment to review the need for legislative reform to recognise the role and rights of carers through the Office of Work and Family, Prime Minister's Department No action or timetable yet announced	The Office of Work and Family commenced operation on 13 December 2007 To date there has been no announcement about the Office of Work and Family undertaking the election commitment to review the need for legislative reform to recognise the role and rights of carers. The subject has arisen in the context of the <i>Better support for carers inquiry</i> , see above. Carer legislation regarding services has already been enacted by some State and Territory jurisdictions.	 Potential: Unknown There is undoubted merit in there being national review of legislative basis for recognising the role and rights of carers, and considering carers within the ambit of the rule of law. Federal legislation could be expected to deliver a national commitment to carers which would hold irrespective of where they live. The merit of such legislation will depend on there being a legislated entitlement to services

E CARER FUNDING INITIATIVE

The critical aspect of funding initiatives for carers is that the benefit depends on the carer being in receipt of either:

- Carer Payment (Child) or (Adult), which is income and asset tested and may be taxable currently around \$550 a fortnight
- or
- Carer Allowance (Child) and/or (Adult) which is free of the income and assets test and is non taxable currently around \$100 a fortnight.

Detailed assessment is required to be eligible for the Payment and the Allowance. The Carer Payments (Child) and (Adult) have participation restrictions on work and study. These restrictions deny the ability to undertake care tasks outside of standard working hours.

It is not well known that less than 5 per cent of Australia's 2.6 million carers get a Carer payment, and less than 15 per cent get the Carer Allowance. (Based on *Australia's Welfare 2007* figures as at 31 December 2006 of Carer Payment: 111,419 people and Carer Allowance: 382,490)

A significant shortcoming of tying carer funding to the Payment and Allowance is that particularly carers of children and carers over the age of 65 can 'miss out' because of the difficulties with accessing the payment and allowance. For example, in the recent review of Carer Payment (Child) about 10 per cent of those getting Carer Payment were not getting Carer Allowance (Child). The changes to the Carer Payment (Child) do not come into operation until 1 July 2009.

The nuances of the Payment and Allowance also permit spin, presenting to the population at large a very favourable but nonetheless biased and misleading rendition of government action. For example, in his address to the ALP at the Gold Coast on 21 June 2008 the Prime Minister commented on *An additional \$1.1 billion for Australia's 430,000 carers in this Budget - giving recipients of both the carer's payments and the carer's allowance an additional payment this year of \$2,100.*

In actual fact the vast majority of carers getting funding, that is, those getting only the Carer Allowance, will get an additional payment this year of \$600, as a one-off bonus which has been paid since 2004-05, which is \$1500 less than what is being touted. To mention 430,000 carers in the same breath as an additional payment of \$2,100 is at the very least despicably misleading of the general public and an unacceptable creation of ignorance about 2.6 million carers.

There have been three funding activities aligned with the Carer Payment or Carer Allowance. This alignment highlights need to rigorously consider reliance on allowances to increase income support and the benchmarking of the pension at onequarter of Male Total Average Weekly Earnings (MTAWE) as being proper financial recompense for services provided. The activities are:

- 16. Lump sum bonus payment to carers Potential Modest
- 17. Extension of Utilities Allowance to Carer Payment recipients Potential Minimal
- 18. Carer Payment (child) assessment Potential Modest

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
16	Lump sum bonus payment to carers	The initiative in this payment is that the government is making a one-off payment which was not an election commitment. The Government will provide a lump sum payment to carers in recognition of their contribution in caring for people with disabilities and the frail aged. Carer Payment recipients will receive \$1,000 and recipients of Carer Allowance will receive \$600 for each eligible person in their care. The payments will be exempt from income tax. Those receiving both payments on 13 May 2008 will receive both lump sum payments. www.budget.gov.au, Budget paper 2 www.fahcsia.gov.au, Minister Macklin, media release, 13 May 05	Potential: Modest There was controversy earlier this year as to whether or not the bonus payment would be made. The furore from carers, as if salt had been rubbed into their wounds, highlighted the sensitivities around financial support for unpaid carers. The government has recognised the payment as a modest measure to relieve some of the financial pressure on carers. Did not take opportunity to build the lump sum payment into the social security system, as was done with the Child Disability Assistance payment, which provides an annual \$1000 lump sum each July for people receiving Carer Allowance (Child). There is to be a departmental report on financial security for carers to the Tax System review (see below).
17	Extension of Utilities Allowance to Carer Payment recipients Assistance with home internet connections	From March 2008 the Utilities Allowance annual rate increased to \$500 for singles (or couples combined) irrespective of age. It will be paid quarterly with payments in March, June, September and December (\$125 per quarter). People who receive the telephone allowance eligible for home internet connection. The internet service must be in the recipient's or their partner's name to qualify for the increased rate. Telephone Allowance increased by \$44, from \$88 to \$132 a year. Increase around 85 cents a week. www.budget.gov.au, Budget Speech and Budget Paper 2	Potential: Minimal The Utilities Allowance increase of \$9.60 a week to a single person maximum rate Carer Payment of \$546.80 a fortnight/\$14,216 a year adds minimally to weekly income. Note that 1 July 2008 personal income tax cuts mean a worker on \$48,000 — average weekly earnings — will receive a weekly tax cut of \$20. Extending to Carer Payment recipients means extending to the least possible number of acknowledged carers.

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
18	Changes affecting Carer Payment (Child)	This reform does not commence until 1 July 2009. There is: - a new assessment process to determine eligibility for Carer Payment (Child) based on care required and provided; - Carer Payment (child) recipients automatically eligible for Carer Allowance (child); - Access to Carer Payment (child) for short-term or episodic care, with a required minimum period of care of 12 weeks and a maximum period of care of 26 weeks; and - streamlining the transitions from Carer Payment (child) to Carer Payment (adult) - more generous arrangements for carers of children in replacing 63 day, hospital stay rule with a new review arrangement every 12 weeks. <u>www.budget.gov.au</u> , Budget Papers 2 and 3 <u>www.facs.gov.au</u> , Minister Macklin, media 13 May 08; speech Every Child Matters 15 May 08	
			\$74.00 a fortnight (\$1900 a year).

F CARER FUNDING REVIEWS

In his May Budget speech the Treasurer confirmed the undertaking of "The most comprehensive review of Australia's tax system since World War 2." It is a worry as to whether or not in the myriad of reforms taking place there is sufficient intellectual capacity and diversity of views to arrive at balanced decisions which can withstand changes to the tax system.

The reviews which will impact on carer funding are:

- 19. Review of Australia's Future Tax System Potential Unknown
- 20. Investigation and report re financial security of carers and seniors Potential Limited

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
19	Review of Australia's Future Tax System (AFTS)	Henry Commission of inquiry into tax, into income support and into retirement incomes policy.	Potential: Unknown
	(AFTS) Discussion paper to be released end of July 2008 Final report to Treasurer end 2009	The review panel will be chaired by the Secretary to the Treasury, Dr Ken Henry AC. Members are Mr Greg Smith (Australian Catholic University); Dr Jeff Harmer (Secretary of FaHCSIA), Heather Ridout (Australian Industry Group), and Professor John Piggott (University of New South Wales). The review panel will be supported by a working group from within the Treasury, with representation from the Department of Families, Housing, Community Services and Indigenous Affairs, and drawing on other Australian Government and State agencies as appropriate. Public will be consulted to allow for community and business input. The review will also, where necessary, draw on external expertise and shall have the co-operation of State Governments and their Treasuries as well as relevant COAG working groups. The Future Tax system review will also take into account the relationships of the tax system with the transfer payments and other social support payments, rules and concessions with a view to improving incentives to work, reducing complexity and maintaining cohesion. With the upset of employees in the charitable sector over changes to income definition, the government has also asked the Henry Commission to examine the complexity of existing fringe benefit arrangements and make recommendations to improve equity and simplicity in the longer term. www.budget.gov.au, Budget speech www.treasury.gov.au, Inquiries and Consultations, 13 05 08 Australia's Future Tax System www.treasurer.gov.au, Media and Speeches	It remains to be seen whether tax driven social policy will enrich the lives and improve the well-being of people with disabilities and carers. There is a separate investigation into financial security for carers and seniors which will report to this review (see below)

No	Activity	Reform Initiatives	Potential to Alleviate Unmet and Under-Met Needs
20	Investigation and report re financial security of carers and seniors FaHCSIA report to AFTS review To report to Treasurer and Minister by 28 Feb 09	As part of the Australia's Future Tax System the Minister for Families, Housing, Communities Services and Indigenous Affairs will provide input on issues related to transfer payments, family assistance and retirement incomes. Secretary of Department of Families, Housing, Community Services and Indigenous Affairs is to investigate and report on possible measures for financial security of carers and seniors. Will report on: the appropriate levels of income support and allowances, including the base rate of the pension, with reference to the stated purpose of the payment; the frequency of payments, including the efficacy of lump sum versus on going support; and the structure and payment, concessions or other entitlements that would improve the financial circumstances and security of carers and older Australians. Meant to provide carers and seniors with genuine financial security and certainty. Reference group from carer and senior groups to be convened to meet regularly until February 2009. www.fahcsia.gov.au, Minister Macklin, speech, Certainty and security for seniors and carers 15 May 08; Centenary of the Age Pension, 03 June 06 www.treasury.gov.au, Inquiries and Consultations, 13 05 08 Australia's Future Tax System	 Potential: Limited The potential for this activity depends on whether or not there is deep consideration given to the needs of Australia's 2.6 million carers. Carving out carers and seniors in isolation from other income support and allowances is unlikely to give an integrated assessment and reduce complexity and and maintain cohesiveness. The impact on household income where carers are co-resident with other income support Pension, is at risk of being given minimal consideration. The results of this investigation are for submission to Tax review (see above)

G SOME OTHER ACTIVITIES

There are other activities taking place which impact on disability and carer activities. These have not been given detailed consideration as they are considered to be more a continuation of the previous government's actions than reflecting the new government's reform of the landscape.

Also not given detailed consideration are the universal reforms, especially in health and education and building, which will have a flow on effect for children, young people and adults with disabilities and their families.

There is the proposed legislated universal Access to Early Childhood Education for all Australian four-year olds of 15 hours per week, 40 weeks per year, of play-based learning and development programs. This is to be delivered by university gualified early childhood teachers. Funding of \$520 million has been provided, with most of this (\$300 million) budgeted for 2011-12.

The government has committed to working with the States and Territories to harmonise Occupational Health and Safety legislation within 5 years. Removal of the appalling third-party liability of families whose private dwellings become workplaces with 'in home' paid carers could possibly be put on the agenda for this harmonization.

A Social Inclusion Unit has been established in the Department of the Prime Minister and Cabinet, and a Social Inclusion Board appointed. Interestingly, the Chair of this Board was the Secretary of Victoria's Department of Human Services when the Department developed the highly exclusionary Disability Services Act 2006. For example, as well as legislating the rationing of services, autism is excluded as a disability under this Act.

There is the Helping Children with Autism package which acknowledges the need for support and services for children with autism spectrum disorders (ASDs). Funding and activities are spread over four years and three departments (Families, Housing, Community Services and Indigenous Affairs; Education, Employment and Workplace Relations; Health and Ageing). Early childhood intervention funding for 0-6 year olds means that every parent of a child who has a diagnosis of autism, some degree of autism on the spectrum disorder, can receive up to \$6000 per annum, up to \$12,000 available for parents across two years. The parent will go to an approved service provider, and the approved service provider will rebate up to \$6000 worth of hours of care. There is an additional \$2000 if in a remote and regional Australia location. The early childhood intervention funding is estimated to provide 250 to 300 hours a year, when the benchmark is 1000 hours. Thus unmet need is being perpetuated. In addition to the Helping Children with Autism package, six autism-specific early intervention child care centres will be established.

The development of the MyTime peer support groups for parents of children with disabilities, established under the previous government, is continuing.

The Government is providing \$22.8 million over five years to assist the Australian Paralympic Committee to prepare for major upcoming sporting events, including the Beijing and London Summer Paralympics in 2008 and 2012 respectively and the Vancouver Winter Paralympics in 2010. This funding includes \$8.0 million for the Australian Paralympic Committee, \$1.0 million for televising the Beijing Paralympics and \$13.8 million to assist athletes in their preparations Are Needs Being Met? 28

for major sporting events. Special Olympics Australia, which provides year-round training and competition for children and adults with intellectual disability, is to have its annual funding increased to \$300,000.

In January a draft report was released reviewing disability standards for accessible public transport. The Disability Standards for Accessible Public Transport 2002 took effect on 23 October 2002. The Standards require the Minister for Transport and Regional Services, in consultation with the Attorney-General, to review the efficiency and effectiveness of the Transport Standards within five years of the Transport Standards coming into effect and every five years thereafter. A final report to the Minister is expected by 30 June.

As well as the work being undertaken by the COAG working group for Health and Ageing, in aged care there is a review of the current aged care planning ratios to take account of the ageing population. This highlights the failure to consider care as a continuum, as such a review could be extended to establishing population based benchmarking for people under 65 with disabilities.

CONCLUSION

After having made this detailed exploration of activities which are taking place under the new Federal government, it is apparent that:

There is a lack of consideration of Care as a first order issue.

There is no lack of activity around disability and carers. What is lacking is a commitment that this activity will meet the needs of people with dependent disabilities and their families.

There is no lack of information about the adverse effects of unmet and under-met need. It has been a concern for many years. What is lacking is a commitment by governments to eliminating unmet and under-met need and its adverse effects.

There is no lack of talk about economic and social rights for people with disabilities and their families. What is lacking is a commitment to the rule of law, to legislating a right to services; and a commitment to policy accountability, the indicators and benchmarks, to make these rights a reality.

What is needed is:

- A commitment to the provision of care as a first-order issue
- A commitment to meet the needs of people with dependent disabilities and their families
- A commitment to eliminating unmet and under met need and its adverse effects
- A commitment to the rule of law, to legislating a right to services
- A commitment to transparent policy accountability, to indicators and benchmarks, to make economic and social rights a reality