20 April 2010

Ms Patricia Scott
Commissioner, Productivity Commission
Level 2, 15 Moore Street
Canberra ACT 2600

Dear Ms Scott

Submission to inquiry into National Disability Long-term Care and Support Scheme

1. Summary

The national disability insurance scheme proposed by the Disability Investment Group has a high and very uncertain cost. Microsimulations using AIHW-based assumptions for 123 diseases suggest that the numbers of beneficiaries may be about 50% higher than estimated by PwC (appendix D7). A variety of exclusions have been suggested, raising concerns about the treatment of those excluded.

Surveys show that the present disability system, together with voluntary and family assistance, is meeting many of the needs of most persons with disabilities. Improvements to the present system may be more equitable, cost-effective and politically acceptable than the long-term care and support scheme in the inquiry's terms of reference.

Current expenditure on aids and equipment by the states is uneven, ranging from $3.90 a person in NSW to $9.78 in the ACT. Bringing all the states to the ACT level would cost about $100m a year. Better aids and equipment could improve education and employment opportunities for many persons with disabilities.

FaHCSIA projects 09-10 disability support payments as $11,581m. Many of the recipients are amongst the poorest in the community. Removing the asset and income tests might have cost about $260m in 09-10 (C1).

FaHCSIA projects 09-10 carer payments as $4,133m. 47% of primary carers providing less than 20 hours of care a week reported difficulty meeting everyday costs, rising to 68% for those providing 40 or more hours of care (A6). Removing the carer asset and income tests might have cost about $770m in 09-10 (C3).

Replacing primary carers with professional carers might increase annual care costs from $4,133m to about $27,000m. Primary carers providing 20 or more hours of care a week receive an average of about $5.20 an hour, compared with the $30 an hour needed by professional carers (C5). Reducing the financial difficulties currently experienced by many carers could retain their services for longer, and be cost-effective.

FaHCSIA executives should accept responsibility for the slow, rude and inaccurate service received by many carers at Centrelink. Streamlined processes, better data capture and specialist staff were recommended by the Standing Committee on Family, Community, Housing and Youth. Fewer income and asset tests would also help.

2. Personal background

As a consulting actuary, I have had extensive experience in accident compensation. I am completing a PhD at the ANU actuarial school, titled “New techniques for household microsimulation, and their application to Australia.” The microsimulation model I have developed at ANU has been used to simulate the numbers of persons eligible under the proposed national disability insurance scheme (appendix D). This submission represents my own views, and not those of any client or interest group.

3. Proposed national disability insurance scheme

The inquiry is requested to assess an approach which “provides long-term essential care and support for people with a severe or profound disability, on an entitlement basis”. This appears to be the national disability insurance scheme proposed by the Disability Investment Group in their September 2009 report “The way forward - a new disability policy framework for Australia”.

The approach is intended to “cover people with disabilities not acquired as part of the natural process of ageing”. How are such disabilities to be identified? Many diseases, such as dementia and deafness, are progressive, sometimes starting well before age 65. Is the help provided to depend on the age at which the disease reaches a defined severity level? What should be done about persons with several disabilities, not all of them considered to be acquired as part of the natural process of ageing?

Such an approach may be ineffective for young persons with mental illness, who often need prompt help, but may have hard to diagnose or unstable conditions. Persons diagnosed with cancer, and those recovering from heart attacks, may also need prompt short-term help. Why should disabilities be severe or profound before help is provided? Particularly for persons with mental conditions, ways to promptly determine eligibility for short-term help are needed, without any implication that this help will be needed for life.

In his February 2010 review of PwC’s report to the Disability Investment Group, the Australian Government Actuary suggested that benefits under the scheme should commence 12 months after disability onset, and cease at age 65. He concluded that the “other physical” and “mental health” groups would be likely to present particular challenges.

Using the microsimulation program described in appendix D, the number of persons with severe or profound core activity limitations were projected to increase from 1.248m in 2003 to 1.318m at 30/6/10. Of these, 0.862m are estimated to have reached this threshold before age 65. This is 49% higher than the 0.579m estimated by PwC (p5). While there are many uncertainties in the microsimulations, this result suggests that PwC may be underestimating the cost of the scheme.

The scheme recommended by the Disability Investment Group appears to assume the continuance of the present disability support pensions and carer payments.

4. Performance of present disability and carer support systems

The Survey of Disability Ageing and Carers 2003 found that only about 2% of those with profound core activity limitations, and 4% of those with severe limitations, do not have their needs met at all (A1). About 50% of those with profound limitations, and 42% of those with severe limitations, have their needs not fully met. These estimates suggest that most persons with severe or profound limitations are receiving help, but in many cases not as much help as they consider needed.

Young males with severe or profound core activity limitations may have higher levels of unmet needs than young females, but the differences may not be statistically significant (A2). Levels of unmet needs appear to be higher in the Northern Territory and the ACT, but the differences are unlikely to be statistically significant (A3). Persons with mental disorders may have higher than average levels of unmet needs (A4). Reasons for incomplete assistance are varied, with no one reason dominating (A5).

47% of primary carers providing less than 20 hours of care a week reported difficulty meeting everyday costs, rising to 68% for those providing 40 or more hours of care (A6). These reported difficulty levels appear very high.

5. Inadequate state expenditure on aids and appliances

Table A5 shows strong disparities between the states and territories, with the costs of aids and appliances ranging from $3.90 per person in NSW up to $9.78 in the ACT. Bringing all the states up to the ACT level would increase total expenditure from $118m to $209m. This modest extra expenditure might have major benefits for some of the disabled, and help reduce their need for future support. In many fields, better equipment has given productivity gains and a better quality of life.

"Shut out", the 2009 National Disability Strategy Consultation Report, gives the following example of a poorly designed aid (and an unhelpful teacher):

> *"I remember my Year 8 science teacher said she couldn't wear my Microphone because it put holes in her clothes. I couldn't do anything about it … she was the teacher - I was the student. For the record - I failed Year 8 science - and it had nothing to do with my ability because in Year 9 science, I had a teacher who wore the Mic and I topped the class." (2.6)*

Delays for aids can be unacceptably long:

> *"...a family required a hoist to lift their adult son in and out of bed. But they were unable to apply for funding until an occupational therapist conducted an assessment. The waiting time for an assessment was 18 months."*

In many cases, difficulties occur with eligibility for aids, rather than unavailability of aids:

> *"Difficulties with eligibility were particularly experienced by those who required wheelchairs or hearing aids. A number of submissions noted that government subsidies for hearing aids are not available for working people over the age of 21."*

The report of the Disability Investment Group said (p30)

> *"Disability leads to a much higher cost of living for many. During its consultations, the DIG repeatedly heard that ongoing costs of home modifications and purchase of aids and equipment drains the family budget. These items are not luxuries, they are necessities ... support needs to respond to individual needs".*

Relaxing the eligibility conditions for aids, and ensuring that appropriately designed aids are nationally available, could help many disabled persons lead more productive lives, and reduce the heavy burdens on carers.

6. Inadequate disability support pensions, and employment disincentives

Many submissions to "Shut Out"

> *"...noted the inflexibility of the application process and eligibility criteria of the Disability Support Pension, which acts as a disincentive to full employment. These submissions reported that the transition from the Disability Support Pension to paid employment often incurs significant financial costs, including transport and increased fees for support services. Such costs often lead to decreased income, and therefore act as a disincentive to seeking employment. These submissions argued that the rules and policies around the payment of the pension require review." (2.3.6)*

The Disability Investment Group noted (p30)

> "The background paper prepared by FaHCSIA for the Pension Review found that people on a DSP are amongst the poorest in the community and show greater signs of financial stress than single old age pensioners."

FaHCSIA projects 09-10 disability support payments as $11,581m. Based on FaHCSIA data for June 2008, removing the asset and income tests might have cost about $260m in 09-10 (C1). Reducing the single person income taper to the 25% for couples might have cost about $120m.

7. Inadequate carer payments, and employment disincentives

"Who cares ...?", the April 2009 report of the House of Representatives Standing Committee on Family, Community, Housing and Youth, said

> *"The Committee understands that current restrictions force carers to reduce to a state of near poverty before they can receive support, which when received, is insufficient to lift them out of poverty again. Further, the income test thresholds and taper rates for Carer Payment, act as a disincentive to carers seeking to supplement the payments by gaining full or part time employment." (p128)*

The Committee recommended a significant increase in the base rate of carer payments, and reduction of the disincentive for carers to earn supplementary income.

FaHCSIA projects 09-10 carer payments as $4,133m. 47% of primary carers providing less than 20 hours of care a week reported difficulty meeting everyday costs, rising to 68% for those providing 40 or more hours of care (A6). Based on unit records from the 2003 Survey of Disability, Ageing and Carers, removing the carer asset and income tests might have cost about $770m in 09-10 (C3). Reducing the single person income taper to the 25% for couples might have cost about $400m. There are many uncertainties in these estimates.

Replacing primary carers with professional carers might increase annual care costs from $4,133m to about $27,000m. Primary carers providing 20 or more hours of care a week receive an average of about $5.20 an hour, compared with the $30 an hour needed by professional carers (C5). Reducing the financial difficulties currently experienced by many carers could retain their services for longer, and be cost-effective.

8. Poor service received by many carers at Centrelink

“Who cares ...?” quoted one carer

> *“Sending us to Centrelink to claim carer’s allowance was the most terrifying experience of my life with all the drug addicts and alcoholics punching and shoving and screaming” (129)*

A carer for a husband with partial paralysis told the Standing Committee

> *“The staff are rude and often unhelpful, the queues almost impossible and the office we visited has poor disabled access.” (130)*

A carer for a mother with multiple sclerosis said

> *“...we are often made to feel that we should be grateful for everything that we receive, the information is inconsistent and often incorrect and phone calls for assistance are often not returned” (131)*

FaHCSIA executives should accept responsibility for the slow, rude and inaccurate service received by many carers at Centrelink. Streamlined processes, better data capture and specialist staff were recommended by the Standing Committee. Fewer income and asset tests would also help.

9. Further information about this submission

I would be happy to provide further information about this submission, to the inquiry’s support staff, or in evidence before the inquiry. Assumption and calculation details could be supplied for the microsimulation model.

Yours sincerely

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Director, JR Cumpston Pty Ltd
Victoria

Appendix A How well is the present system working?

A1 Extent to which needs for assistance were being met in 2003

Table A1 Persons living in households in 2003

Level of limitation	Needs fully met m	Needs partly met m	Needs not met m	% not fully met
Profoundly limited in core activities	0.219	0.214	0.005	50%
Severely limited in core activities	0.361	0.243	0.015	42%
Moderately limited in core activities	0.299	0.153	0.031	38%
Mildly limited in core activities	0.350	0.136	0.037	33%
Restricted in schooling or employment	0.098	0.051	0.009	38%
Total	1.327	0.798	0.097	40%

Table A1 gives estimates derived from the unit record file released from the Survey of Disability, Ageing and Carers 2003. The estimated number of persons are close to those in table 14 of “Disability, Ageing and Carers: Summary of Findings Australia 2003” (Australian Bureau of Statistics 15/9/04). The data in unit record files are slightly randomised for confidentiality reasons, so that it is not possible to fully replicate published results by making tabulations from the unit record files. These survey results are almost 7 years out of date, and results from the 2008 survey may show a different picture.

Only about 2% of those with profound core activity limitations, and 4% of those with severe limitations, do not have their needs met at all. About 50% of those with profound limitations, and 42% of those with severe limitations, have their needs not fully met. These estimates suggest that most persons with severe or profound limitations are receiving help, but in many cases not as much help as they consider needed.

A2 Age and sex variations in the receipt of help

Figure A1 Percentages of persons with severe or profound core activity limitations with needs not fully met

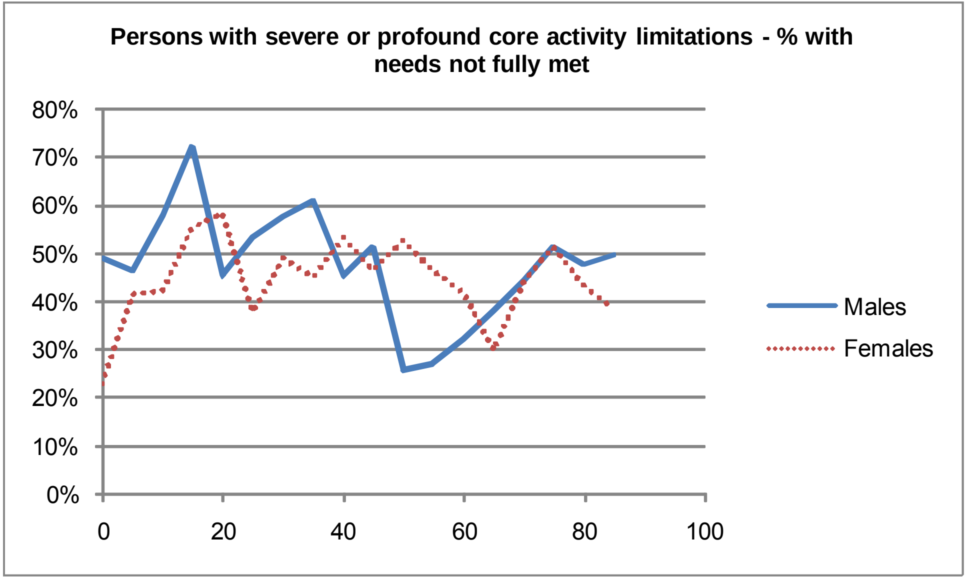
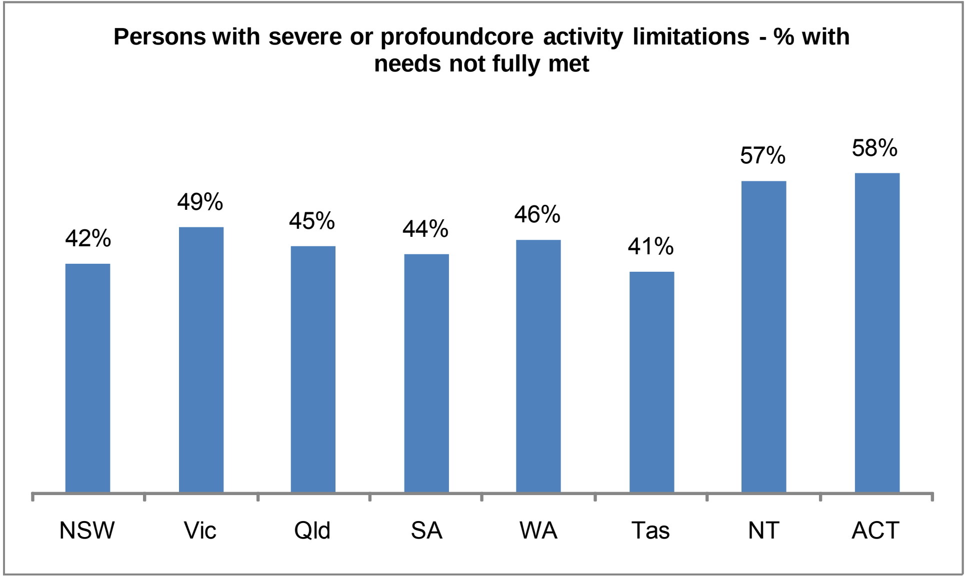


Figure A1 suggests that young males with severe or profound core activity limitations may have higher levels of unmet needs than young females, but the differences may not be statistically significant.

A3 Variations by state in unmet needs

Figure A2 Percentages of persons with severe or profound core activity limitations with needs not fully met



Although figure A2 suggests that levels of unmet needs are higher in the Northern Territory and the ACT, the differences are unlikely to be statistically significant. Larger samples would be needed to reliably detect state differences.

A4 Variations by disease chapter in unmet needs

Table A2 Estimated numbers of persons with severe or profound core activity limitations in 2003

Chapter	Description of main condition	SDAC03 persons m	% with unmet needs
A	Infectious and parasitic diseases	0.006	50%
D	Birth trauma and asphyxia	0.001	
F	Malignant neoplasms	0.023	38%
H	Diabetes mellitus	0.027	43%
I	Endocrine and metabolic disorders	0.005	46%
J	Mental disorders	0.126	54%
K	Nervous system and sense organ disorders	0.327	49%
L	Cardiovascular disease	0.117	43%
M	Chronic respiratory disease	0.068	33%
N	Diseases of the digestive system	0.012	52%
O	Genitourinary diseases	0.009	42%
P	Skin diseases	0.011	28%
Q	Musculoskeletal diseases	0.373	44%
R	Congenital anomalies	0.017	32%
T	Injuries	0.065	44%
Z	Ill-defined conditions	0.053	44%
Total		1.239	45%

Table A2 shows that there were about 1.239m persons with severe of profound core activity limitations living in households. Also shown are the percentages of those living in households with needs for assistance partly or wholly unmet. Persons with mental disorders may have higher than average levels of unmet needs.

A5 Reasons why needs were not fully met

Table A3 Reasons why needs of persons with severe or profound core activity limitations were not fully met

Category	Commu- nication	Mobility	Self- care
Did not know of service	9%	12%	9%
Need not important enough	7%	21%	34%
Wont ask because of pride	11%	21%	15%
Unable to arrange service	8%	4%	1%
No service available	16%	11%	6%
Not eligible for service	7%	5%	2%
Service costs too much	11%	9%	7%
Service does not provide sufficient hours	13%	5%	5%
Other	17%	12%	20%
Total	100%	100%	100%

Table A3 shows, for persons who did receive some assistance with a core activity limitation, the main reasons why their needs were not fully met. The source numbers are small, so that random variations and data randomization may account for some of the variations across types of core activity. Reasons for incomplete assistance are varied, with no one reason dominating.

A6 Primary carers reporting difficulties in meeting everyday costs

Figure A3 Primary carers reporting difficulties in meeting everyday costs

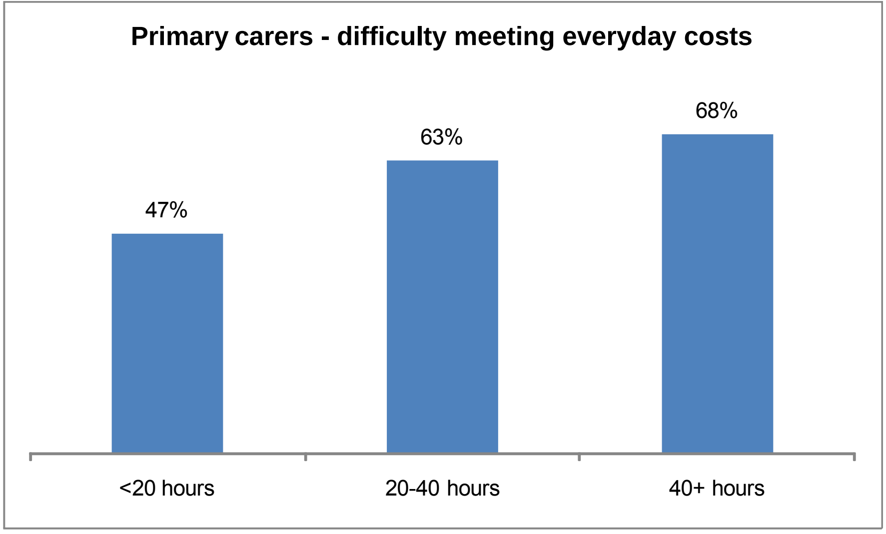


Figure A3 shows the percentages of primary carers in the SDAC 2003 who reported having difficulty in meeting everyday costs, as a result of their caring roles. 47% of primary carers providing less than 20 hours of care a week reported difficulty meeting everyday costs, rising to 68% for those providing 40 or more hours of care.

A7 Relationships between principal carers and care recipients

Table A4 Relationship of principal carer to recipient

Age of Recipient	Partner	Parent	Child	Other	Total
0-		15845			15845
5-		18209			18209
10-		20718	616		21334
15-	1227	11792		823	13842
20-	957	9180		1519	11656
25-	4551	4474		710	9735
30-	2965	1696	1976	1001	7638
35-	7149	3348	1343		11840
40-	9467	1398	2924	2500	16289
45-	13887	596	2501	502	17486
50-	16189	3750	3381	1977	25297
55-	27252		1069	2321	30642
60-	25049		2387	3952	31388
65-	25293		2337	943	28573
70-	25336		9545	2832	37713
75-	29246	1139	7260		37645
80-	19526	732	11776	3606	35640
85-	7522		19404	3013	29939
Total	215616	92877	66519	25699	400711
Percent	53.8%	23.2%	16.6%	6.4%	100.0%

The numbers in table A4 were estimated from the unit records for persons from the SDAC 2003.

A8 Aids and appliances

Table A5 State expenditure on aids and appliances

State	Cost $m	Persons 30/6/08 m	Cost per person $	Cost as % of ACT level	Cost at ACT level $m
NSW	27.200	6.967	3.90	40%	68.2
Vic	31.900	5.298	6.02	62%	51.8
Qld	33.656	4.279	7.86	80%	41.9
SA	8.578	1.602	5.36	55%	15.7
WA	8.750	2.163	4.04	41%	21.2
Tas	3.108	0.498	6.24	64%	4.9
NT	1.512	0.220	6.88	70%	2.2
ACT	3.367	0.344	9.78	100%	3.4
Total	118.071	21.372	5.52	56%	209.1

State costs are from appendix B to PwC's "National Disability Insurance Scheme", October 2009 (available from www.fahcsia.gov.au). These government expenditures are for various years from 06-07 to 08-09. Person numbers are from "Australian Demographic Statistics June 2008", catalog no 3101.0 (available from www.abs.gov.au). The $118m of state expenditure on aids and appliances is less than 1% of FaHCSIA's 09-10 expenditure of $16,244m on disability and carers (B2).

Appendix B Commonwealth expenditure through FaHCSIA

Table B1 Commonwealth expenditure in 08-09 and 09-10 through FaHCSIA

Program number	Description	08-09 $m	09-10 $m	Increase
1.1	Family support	8,275	238	-97%
1.2	Family tax benefit	17,334	17,321	0%
1.3	Parental payments & care incentives	1,495	1,474	-1%
2.1	Affordable housing	26	40	56%
2.2	Housing assistance & homelessness	771	135	-83%
3.1	Financial management	273	323	18%
3.2	Community investment	89	93	4%
3.3	Income support for vulnerable people	77	67	-13%
3.4	Support for people in special circumstances	196	43	-78%
3.5	Supplementary payments and support	1,265	293	-77%
4.1	Income support for seniors	28,592	29,360	3%
4.2	Allowances, concessions & services for seniors	499	169	-66%
5.1	Targeted community care	156	154	-1%
5.2	Disability support pension	11,156	11,581	4%
5.3	Income support for carers	4,554	4,133	-9%
5.4	Services & support for people with disability	751	353	-53%
5.5	Support for carers	20	23	15%
6.1	Gender equity for women	34	42	24%
7.1	Economic development & participation	491	671	37%
7.2	Indigenous housing & infrastructure	318	177	-45%
7.3	Native title and land rights	75	81	8%
7.4	Indigenous capability & development	556	508	-9%
7.5	Closing the gap in the Northern Territory	327	216	-34%
Total		77,329	67,495	-13%

The expenditure estimates in table B1 are from FaHCSIA's "Portfolio Budget Statements 2009-10" (available from www.fahcsia.gov.au). Reasons for large drops in 09-10 expenditure include

- The 97% drop in family support "reflects one-off payments in special appropriations related to the Budget measures for the Economic Security Strategy and Nation Building and Jobs Plan."
- The 83% drop in housing assistance and homelessness "reflects the new framework for Federal Financial Relations. Under these arrangements payments to states and territories will now be made by the Treasury."
- The 78% drop in support for people in exceptional circumstances "reflects one-off funding provided in 2008-09 for the 2008-09 Queensland floods and Victorian bushfires."
- The 77% drop in supplementary payments and support "reflects the new framework for the Federal Financial Relations. Under these arrangements payments for the Compensation for Extension of Fringe Benefits will now be made by the Treasury. The reduction also reflects one-off funding for the farmer's Hardship Bonus."
- The 66% drop in allowances, concessions and services for seniors "reflects one-off payments related to the budget measures for the Economic Security Strategy."
- The 9% drop in income support for carers appears to be due to non-payment of carer supplements in 09-10 (an estimate of $434m was made for 10-11)

- The 53% drop in services and support for people with disability “reflects the new framework for the Federal Financial Relations. Under these arrangements payments to states and territories will now be made by the Treasury.”

The modest growth rate for most of the benefits paid through Centrelink appears to be due to direct appropriations to Centrelink for their expenses, rather than through FaHCSIA’s appropriations prior to 09-10. This is likely to further weaken FaHCSIA’s ability to achieve even minimal standards of service delivery through Centrelink.

Table B2 Commonwealth expenditure in 08-09 and 09-10 through FaHCSIA by program

Program number	Description	08-09 $m	09-10 $m	Increase
1	Families	27,104	19,034	-30%
2	Housing	796	174	-78%
3	Community capability & the vulnerable	1,900	820	-57%
4	Seniors	29,091	29,529	2%
5	Disability & carers	16,637	16,244	-2%
6	Women	34	42	24%
7	Indigenous	1,767	1,652	-7%
Total		77,329	67,495	-13%

Table B2 is a summary of table B1.

Appendix C Costs of removing asset & income tests

C1 Disability support pensions

Table C1 Estimates of disability support pensions with and without asset & income tests

Earnings Jun-08 $pf	Number persons	Earnings Jun-08 $pf	Earnings Jun-10 $pf	DSP Jun-10 $pf	Cost Jun-10 $m pa	Cost no tests $m pa
0-	660514	0	0	644.2	11323	11323
1-	14498	50	55	644.2	249	249
100-	15912	150	165	632.7	268	273
200-	9760	240	264	583.2	151	167
300-	6280	340	374	528.2	88	108
400-	4930	440	484	473.2	62	85
500-	14472	700	770	330.2	127	248
1000-	4490	1200	1320	55.2	7	77
1500-	1511	2100	2310	0	0	26
Total	732367				12275	12555
Increase in cost if no asset or income tests						2.3%
FaHCSIA estimated disability support pensions 09-10					11581	
Total cost estimate as % of FaHCSIA estimate for 09-10					106%	

Numbers in each earnings band are from "Characteristics of disability support pension recipients June 2008", downloaded 14/4/10 from www.fahcsia.gov.au/sa/disability/pubs/policy/DSP_rpt_2008.

Assumed earnings increase factor from 6/08 to 6/10	1.10
(based on 7.5% increase in seasonally adjusted AWE from 5/08 to 11/09)	
Assumed population growth factor from 30/6/03 to 30/6/10	1.02
Single pension per fortnight at 6/10	644.2
Start of income taper for single pensioners	142
Present taper rate for singles	50%
Present taper rate for couples	25%
Start of income taper for single age pensioners	392

All persons on disability support pensions have been assumed to be single. "Characteristics of disability support pension recipients June 2008" shows that 66% were single.

The cost estimates derived from FaHCSIA June 2008 data are about 6% higher than FaHCSIA's 09-10 estimates. Estimates of costs with changes to asset and income tests were derived from this data, then divided by 1.06. These estimates are in table C2.

Table C2 Estimates of extra disability support pensions costs with test changes

Test changes	Benefit costs $m	Cost increase $m	Cost increase as %
None	11581		
Remove all tests	11845	264	2.3%
Single taper as for couples	11705	124	1.1%

C2 Carer payments

Table C3 Estimates of carer payments with and without asset & income tests

Income 2003 $pf	Number persons 2003	Income Jun-10 $pf	Earnings Jun-10 $pf	Carer payment $pf	Cost Jun-10 $m pa	Cost no tests $m pa
0-	20683	174	0	644.2	375	375
258-	53941	427	0	644.2	977	977
374-	49965	556	0	644.2	905	905
450-	60640	710	0	644.2	1099	1099
640-	23797	1004	578	426.0	285	431
900-	22365	1350	1270	80.4	51	405
1150-	9432	1690	1690	0.0	0	171
1404-	8152	2090	2090	0.0	0	148
1764-	6337	2672	2672	0.0	0	115
2302-	5490	3545	3545	0.0	0	99
Total	260802				3692	4383
Increase in cost if no asset or income tests						18.7%
FaHCSIA estimated carer support pensions 09-10					4133	
Total cost estimate as % of FaHCSIA estimate for 09-10					89%	

Numbers of principal carers in each income band in 2003 are from the unit record data of the Survey of Disability and Carers 2003, counting only those providing 20 or more hours of care each week. This threshold was chosen to approximately match the required provision of “constant care” for eligibility for carer payments.

Assumed income increase factor from 6/03 to 6/10 1.35
(based on 31.9% increase in seasonally adjusted AWE from 5/08 to 11/09)
Assumed population growth factor from 30/6/03 to 30/6/10 1.078

Approximate formula used to estimate earnings from June 2010 income

income = base pension - (earnings - start) * taper + earnings
income - base pension - start * taper) = earnings(1 - taper)
earnings = (income - base pension - start*taper) / (1 - taper)

but earnings cannot be greater than income or less than zero.

All persons receiving carer payments have been assumed to be single, although the SDAC 2003 unit record data shows that only 26% of principal carers providing 20 or more hours of care a week are single. More detailed data, and more complex analyses, would be needed for better estimates.

The cost estimates derived from SDAC 2003 data are about 89% of FaHCSIA’s 09-10 estimates. This is surprisingly close, given the limited nature of the source data, the approximate procedure used to derive 09-10 earnings, and the assumption that all persons receiving carer payments are single. Estimates of costs with various changes to asset and income tests were derived from this data, then divided by 0.89. These estimates are in table C4.

Table C4 Estimates of extra carer payments with test changes

Test changes	Benefit costs $m	Cost increase $m	Cost increase as %
None	4133		
Remove all tests	4907	774	19%
Single taper as for couples	4532	399	10%

C3 Costs of replacing primary carers with paid care

Table C5 Costs or replacing primary carers with paid care in 09-10

Hours care pw	Number carers Jun-03	Number carers Jun-10	Assumed hours pw	Number hours pa m	Assumed cost ph $	Cost Jun-10 $m pa
Less than 20	191362	206288	10	108	34.22	3,684
20 to less than 40	93367	100650	30	158	27.38	4,314
40 or more	187759	202404	60	634	30.42	19,277
Total	472488	509342		899	30.34	27,275
Carer payments 09-10						4,133
Cost as % carer payments						660%
Hourly rate for carers providing 20 or more hours					5.22	

Numbers of primary carers are from the SDAC 2003 unit records.
Carer growth factor from 30/6/03 to 30/6/10 assumed to be 7.8%.
Assumed hours per week are midpoints of the two lowest ranges, with those reporting 40 or more hours per week assumed to provide 60 hours.
Assumed costs per hour are derived from table 22 of the PwC October 2009 report to the Disability Investment Group, using the annual costs and hours per day for disabled persons 15 and over.

Appendix D Disease microsimulation model for Australia

D1 Disease incidences, durations and prevalences

Table D1 Disease groups with AIHW incidence estimates

Chapter	Description	Diseases	Incidence m	Duration years	Prevalence m
A	Infectious and parasitic diseases	23	17.566	*0.12*	*2.091*
B	Acute respiratory infections	3	29.460	*0.01*	*0.419*
C	Maternal haemorrhage	3	0.072	*6.92*	*0.498*
D	Birth trauma and asphyxia	3	0.012	*11.09*	*0.131*
E	Nutritional deficiencies	3	0.943	*1.02*	*0.962*
F	Malignant neoplasms	26	0.470	*0.74*	*0.349*
G	Other neoplasms	2	0.021	*0.23*	*0.005*
H	Diabetes mellitus	2	0.097	12.07	1.171
I	Endocrine and metabolic disorders	3	0.001	52.23	0.028
J	Mental disorders	13	0.495	7.72	3.818
K	Nervous system and sense organ disorders	24	1.001	6.87	6.879
L	Cardiovascular disease	9	0.121	6.37	0.770
M	Chronic respiratory disease	2	0.099	17.63	1.744
N	Diseases of the digestive system	9	0.368	0.69	0.255
O	Genitourinary diseases	4	0.106	4.14	0.437
P	Skin diseases	4	0.200	2.59	0.519
Q	Musculoskeletal diseases	6	9.355	0.19	1.771
R	Congenital anomalies	10	0.004	*42.34*	*0.177*
S	Oral conditions	4	7.387	0.40	2.970
T	Unintentional injuries	12	0.290	*1.15*	*0.334*
U	Intentional injuries	3	0.041	*0.34*	*0.014*
Z	Ill-defined conditions	1	0.005	6.31	0.029
Total		169	68.113	0.37	25.369

Table D1 shows summary details of 169 diseases, grouped into chapters. Nearly all the incidence numbers are from annex table 15 to Begg et al (2007), and are estimates of the numbers of new incidents in 2003. Prevalence figures not in italics are from annex table 16, and are estimates of the numbers of persons with that condition at the middle of 2003. Durations not in italics were derived by dividing prevalences by incidences.

Unfortunately, chapters A to G, R, T and U were not included in annex table 16. For these diseases, average duration estimates were obtained from the spreadsheets available on www.aihw.goc.au/bod as part of “The burden of disease and injury in Australia 1996”. Prevalence estimates were then obtained by multiplying incidences by durations.

The average duration of infectious and parasitic diseases is about 6 weeks, with most of the order of a week, and a few more serious infections, such as HIV/AIDS and chronic hepatitis being much longer. Unintentional injuries have an average duration of 1.15 years, as they are based on accidents resulting in hospital admissions or treatment in emergency departments. Data on intentional injuries are similarly based on hospital records.

D2 Diseases and disease stages simulated

Many of the 169 diseases in table D1 can be subdivided by type or development stage. For example, the spreadsheets available as part of "The burden of disease and injury in Australia 1996" include 3 types of breast cancer, each with 4 development stages:

Table D2 Breast cancer types and stages

Type	Stage Number	Stage	Disability weight	Recovery constant	Transition constant
Tumour <2 cm	1	Diagnosis & primary treatment	0.26		4.62
Tumour <2 cm	2	Remission	0.26	0.29	0.10
Tumour <2 cm	3	Disseminated cancer	0.79		0.57
Tumour <2 cm	4	Terminal stage	0.93		
Tumour 2-5 cm	1	Diagnosis & primary treatment	0.69		2.83
Tumour 2-5 cm	2	Remission	0.26	0.28	0.23
Tumour 2-5 cm	3	Disseminated cancer	0.79		0.57
Tumour 2-5 cm	4	Terminal stage	0.93		
Tumour >5 cm	1	Diagnosis & primary treatment	0.81		1.50
Tumour >5 cm	2	Remission	0.26	0.23	0.55
Tumour >5 cm	3	Disseminated cancer	0.79		0.57
Tumour >5 cm	4	Terminal stage	0.93		

Disability weights are those assumed by Begg et al (2007, 17). They are intended to "quantify societal preferences for health states in relation to the societal idea of good health". Other examples are 0.07 for diabetes, 0.125 for a slipped disc with chronic pain, 0.27 for mild dementia, 0.43 for blindness, 0.57 for paraplegia and 0.76 for unremitting unipolar major depression. These disability weights are inherently subjective, and may not be appropriate as admission criteria for disability benefits.

The only pathways assumed from each disease stage are recovery, transition to the next stage of the disease, and death. Probabilities of each of these events occurring for each event for each disease stage are assumed to be constants depending only on sex and age. If f(x) is the probability of being in a particular disease stage at time x, given the person is in that state at time 0, then

$$df(x)/dx = - (\lambda_m + \lambda_r + \lambda_t) f(x) \qquad (D1)$$

where λ_m is the mortality constant, λ_r the recovery constant and λ_t the transition constant. With this notation

$$f(x) = \exp[- (\lambda_m + \lambda_r + \lambda_t) x] \qquad (D2)$$

Mortality, recovery and transition constants were estimated a range of information in the "The burden of disease and injury in Australia 1996" spreadsheets, including average stage durations, relative mortality rates and 5-year survival rates.

In all, 123 of the 169 diseases were chosen for simulation, with the omitted diseases being those with durations under 6 months or very low disability weights. These 123 selected diseases were identified as having a total of 583 stages. For all but one of these stages, disability weights and recovery, transition and mortality parameters were estimated from the spreadsheets. The exception was a one-stage disease called "back problems", where the spreadsheet assumed high incidences, each with an average duration of 0.011 years. Incidence rates for chronic back pain, assuming no recovery or extra mortality, were estimated from the unit record data for the Survey of Disability, Ageing and Carers 2003 (ABS 2003).

D3 Continuous time disease simulation within projection periods

Some of the average durations for disease stages are very short. For example, the average duration assumed for the terminal stages of most cancers is one month. To allow for short durations without excessive calculation times, continuous time simulation is used for disease events within projection periods. From equation D2, the time x since entering a disease state is

$$x = -\ln(f(x)) \; / \; (\lambda_m + \lambda_r + \lambda_t) \qquad \text{(D3)}$$

For example, a person in remission from breast cancer with tumours under 2 cm has a recovery time constant of 0.29, and a transition time constant of 0.10. The mortality constant is zero, as no deaths from cancer are assumed until the terminal stage. The time until either remission or transition occurs is simulated by selecting a random number r between 0 and 1, and calculating the time as - ln(r) / 0.39. If this simulated time is less than the time remaining to the end of the simulation period, an event is assumed to occur. If more than one type of event is possible, then the choice between event types is made by selecting another random number, and choosing in proportion to the time constants of the possible events.

D4 Constructing base diseases in 2001 using AIHW disease models

The initial diseases and disease stages for each of the 175,044 persons in the baseline data at 30/6/01 were simulated by an iterative process

- For persons born in Australia, the occurrence of a congenital or birth-related defect was simulated
- Stepping forward a year at a time from their birth or immigration date, the occurrence of new diseases, and the development of existing diseases, was simulated
- Each year, death from each disease was simulated, taking into account only the extra risks of death from disease
- If death from disease occurred, the process was restarted at the birth or immigration date.

This process assumes that the age-specific incidence, recovery, transition and mortality risks from each disease have remained unchanged up to 2001. The Australian Bureau of Statistics (2004 3) noted that there was “little change in the disability rate between 1998 (20.1%) and 2003 (20.0%)”. Begg et al (2007 33-34) noted the considerable increase in the incidence of type 2 diabetes, and the lack of any data suggesting trends in mental health, hearing loss, vision loss and musculoskeletal disorders. Given the reductions in road accident deaths, assuming current accident rates seems likely to underestimate the numbers of long-term disabilities at 30/6/01 from head injuries.

The above process also assumes that immigrants come to Australia with no diseases. Kennedy, McDonald and Biddle (2007) provide evidence of the “healthy immigrant effect” in the US, Canada, UK and Australia. For Australia, they show that the incidence of chronic conditions is substantially lower for all immigrant regions, self-assessed health generally better, and obesity and smoking rates lower. Chronic hepatitis B prevalence rates are however higher in some immigrants, particularly those from the Asia-Pacific region (Butler, Korda, Watson & Watson 2009 11). More exact allowances for immigration effects could be included in the above process.

The above process assumes that existing diseases are uncorrelated with a person’s employment and household status. In practice, however, persons with severe disabilities are less likely to be employed, and less likely to be in partnerships or living in private dwellings. Adjustments to the above process are needed to approximately allow for the observed patterns of employment and household status of persons with disabilities.

D5 Comparing simulated diseases with 2003 survey data

Table D3 compares the numbers of each disability estimated from the unit records from the 2003 Survey of Disability and Carers (ABS 2005) with those simulated as at 2001, and then projected forward two years allowing for births, deaths, immigration and emigration, and for disease incidence and development. As in the baseline projection to 2001, immigrants are assumed to come to Australia with no diseases.

Table D3 Observed and simulated numbers of persons with each disability

Chapter	Description of main condition	Simulated conditions m	SDAC03 Conditions M
A	Infectious and parasitic diseases	0.026	0.060
B	Acute respiratory infections	0.002	
D	Birth trauma and asphyxia	0.073	0.006
E	Nutritional deficiencies	0.594	
F	Malignant neoplasms	0.242	0.202
G	Other neoplasms	0.020	
H	Diabetes mellitus	0.606	0.635
I	Endocrine and metabolic disorders	0.050	0.115
J	Mental disorders	1.561	1.822
K	Nervous system and sense organ disorders	2.572	2.750
L	Cardiovascular disease	0.360	1.236
M	Chronic respiratory disease	1.270	1.908
N	Diseases of the digestive system	0.087	0.433
O	Genitourinary diseases	0.412	0.190
P	Skin diseases	0.559	0.130
Q	Musculoskeletal diseases	2.256	4.246
R	Congenital anomalies	0.109	0.110
T	Unintentional injuries	1.778	1.399
U	Intentional injuries	0.062	
Z	Chronic fatigue syndrome	0.013	0.029
	Disorders of the thyroid gland		0.218
	High cholesterol		0.596
	Hypertension		1.837
	Pain n.f.d.		0.099
	Other symptoms/signs		0.113
	Restriction in physical activity		0.081
	Other codes with no ICD-10 equivalent		0.209
Total		12.651	18.421

The numbers of each condition were estimated from the all conditions in the unit record file DAC03CON.DTA, using the person weights in that file. They are thus estimates of the numbers of persons in Australia suffering from that condition at 30/6/03. The simulated numbers were obtained by the process described in 15.5, and multiplied by 19.719/ 0.178 (the ratio of the Australian population at 30/6/03 to the simulated numbers of persons at 30/6/03). Where possible, conditions are shown in the disease and injury chapters used by Begg et al (2007). Seven ABS conditions which could not be allocated to a chapter are shown at the end of the table.

There are many reasons to expect differences between the survey and simulated numbers:

- There were 59,493 disability conditions reported in the survey, so that on average each disability was multiplied by 309.6 to get the 18.421m estimated conditions in table 15.3. The estimated number of 0.060m persons with infectious or parasitic diseases is thus based on about 200 persons reporting these conditions. Random variations in this number are likely to give a standard error of about 0.07.

- As the simulated numbers were obtained by Monte Carlo simulation, they will also have random variations. For example, the 0.026m simulated with breast cancer are based on 234 simulated persons, also giving a standard error of about 0.07. Like most of the differences between simulated and observed numbers in the table, the differences are likely to be due to simulation assumptions or disease definitions, rather than random variation.

- Some persons may not have reported certain conditions because of the sensitive nature of the condition – eg alcohol and drug-related conditions, schizophrenia, mental retardation or mental degeneration (ABS 2004b 60)

- Some conditions may be episodic or seasonal – eg asthma, epilepsy

- Lack of awareness of the presence of a condition, such as mild diabetes

- Lack of comprehensive medical information kept by cared-accommodation establishments, who completed survey returns on behalf of their residents

- The simulations rest on incidence, recovery, transition and mortality assumptions separately derived for each of 123 diseases, together with the assumption that these rates have not changed in the past.

Even given these possible reasons for differences, the differences in cardiovascular disease, diseases of the digestive system, skin diseases and musculoskeletal diseases are disturbingly large.

D6 Comparing numbers of persons with severe or profound core activity limitations

Table D4 compares the numbers of persons with severe or profound core activity limitations estimated from the unit records for the 2003 Survey of Disability, Ageing and Carers with those simulated as at 2003. In the simulations, a combined disability weight for each person is calculated with the multiplicative formula used by Begg et al (2007, 26). For example, a person with diabetes (disability weight 0.07) and severe vision loss (0.43) has a combined disability weight of

$$1 - (1 - 0.07) * (1 - 0.43) \qquad \text{ie} \qquad 0.4699.$$

Persons with combined disability weights of 0.37 or more were assumed to have severe or profound core activity limitations. This threshold was chosen so as to approximately replicate the numbers of such persons found by the 2003 Survey of Disability, Ageing and Carers. Table D4 classifies the simulated results according to the disease chapter for the condition with the highest disability weight.

Table D4 Observed and simulated numbers of persons with severe or profound core activity limitations

Chapter	Description of main condition	Simulated persons m	SDAC03 Persons M
A	Infectious and parasitic diseases	0.004	0.006
D	Birth trauma and asphyxia	0.006	0.001
F	Malignant neoplasms	0.103	0.023
G	Other neoplasms	0.001	
H	Diabetes mellitus		0.023
I	Endocrine and metabolic disorders	0.021	0.009
J	Mental disorders	0.279	0.233
K	Nervous system and sense organ disorders	0.403	0.231
L	Cardiovascular disease	0.106	0.101
M	Chronic respiratory disease	0.083	0.071
N	Diseases of the digestive system	0.005	0.012
O	Genitourinary diseases	0.007	0.009
P	Skin diseases		0.011
Q	Musculoskeletal diseases	0.100	0.373
R	Congenital anomalies	0.028	0.017
T	Unintentional injuries	0.080	0.065
U	Intentional injuries	0.011	
Z	Chronic fatigue syndrome	0.010	0.006
	Hypertension		0.016
	Pain n.f.d.		0.006
	Other symptoms/signs		0.008
	Restriction in physical activity		0.009
	Other codes with no ICD-10 equivalent		0.009
Total		1.248	1.239

Reasonable agreement between the simulated and observed numbers exists for most of the disease chapters. The observed number of persons with malignant neoplasms is surprisingly low, and may reflect some under-reporting. No persons were simulated with diabetes as their main condition, but this probably reflects the 0.07 weight for disability, as compared with the 0.37 threshold. The simulated numbers with a nervous condition or sense organ disorder as their main condition seem high, and those with a musculoskeletal disease as their main condition seem low.

D7 Projected persons with severe or profound core activity limitations at 30/6/10

Table D5 Estimated persons with severe or profound core activity limitations at 30/6/10

Chapter	Description of main condition	Estimated persons m	Severe before 65 m	% severe before 65
A	Infectious and parasitic diseases	0.003	0.003	96%
D	Birth trauma and asphyxia	0.005	0.005	100%
F	Malignant neoplasms	0.107	0.045	43%
G	Other neoplasms	0.001	0.000	57%
I	Endocrine and metabolic disorders	0.019	0.015	83%
J	Mental disorders	0.299	0.292	98%
K	Nervous system and sense organ disorders	0.429	0.169	39%
L	Cardiovascular disease	0.116	0.052	45%
M	Chronic respiratory disease	0.088	0.076	86%
N	Diseases of the digestive system	0.004	0.002	51%
O	Genitourinary diseases	0.007	0.003	48%
Q	Musculoskeletal diseases	0.111	0.085	76%
R	Congenital anomalies	0.026	0.026	100%
T	Unintentional injuries	0.081	0.067	82%
U	Intentional injuries	0.011	0.010	85%
Z	Ill-defined conditions	0.011	0.011	100%
Total		1.318	0.862	65%

Table D5 gives estimates obtained using the household microsimulation program. About 1.318m persons are estimated to have a severe or profound core activity limitation, the threshold proposed by Walsh & Johnson (2009). Of these, 0.862m are estimated to have reached this threshold before age 65. This is 49% higher than the 0.579m estimated by Walsh & Johnson (p5) as the 2009 prevalence with age at onset to age 65. There are considerable uncertainties in both the microsimulation and Walsh & Johnson estimates, so that this order of disagreement is not surprising.

D8 References for this appendix

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