



**Australian Federation of Disability Organisations -
Submission to the House of Representatives Inquiry
into Better Support for Carers**

CONTENTS

- 1. Introduction**
- 2. About AFDO**
- 3. Summary**
- 4. Social Inclusion**
- 5. Statistics**
- 6. Response to Terms of Reference**
- 7. Focusing on Outcomes**
- 8. Monitoring**
- 9. Better Integration of Disability Services with the Boarder Community**
 - 9.1 Choice and Independence Audits
 - 9.2 Housing
 - 9.3 Packages
 - 9.4 No Fault Insurance Schemes
 - 9.5 National Schemes
 - 9.6 Cross Departmental Responsibility
 - 9.7 Increased Opportunity for Employment of People with Disabilities
 - 9.8 Other
- 10. Choice**
- 11. Transitions Into and Out of Caring**
- 12. Effective Planning for the Future**
- 13. References**

Appendix A - UK Office for Disability Issues Annual Report 2007

**Appendix B - AFDO Submission into the National Mental Health & Disability
Employment Strategy**

Introduction

As the peak national body representing organisations of people with disability, the Australian Federation of Disability Organisations would like to make the following submission to the Inquiry into Better Support for Carers.

Our submission will focus on the Terms of Reference of the Inquiry and how they relate to the role people with disabilities play in the lives of individuals providing unpaid support. Although our submission will focus more specifically on people with disabilities, the issues raised are and can still be relevant to people living with chronic illness or who are frail and aged. The Australian Federation of Disability Organisations acknowledges the significant role unpaid carers (usually family members) play in supporting people with disabilities and by no means wishes to undermine their contribution.

About the Australian Federation of Disability Organisations

The Australian Federation of Disability Organisations (AFDO) is the peak national body representing organisations of people with disability. Our mission is to champion the rights of people with disability in Australia. Our national and state based members are detailed overleaf.

National Members

- Australian Mental Health Consumer Network
- Blind Citizens Australia
- Brain Injury Australia
- Deaf Australia
- Deafness Forum of Australia
- National Association of People Living with HIV/AIDS
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- Physical Disability Council of Australia
- Women with Disabilities Australia

State Members

- Access for All Hervey Bay
- Disability Resources Centre

- People with Disability, Western Australia

The Australian Federation of Disability Organisations also has a number of Associate Members.

Summary

AFDO would like to comment that by conducting an Inquiry into How to Better Support Carers, the Inquiry is addressing only one aspect of the care and support equation. Identifying the needs of unpaid carers does not equate with addressing the whole of life needs of the people they support. People with disabilities are not a by-product of carers; by addressing the needs of people with disabilities the by-product will be a better quality of life, not just for people with disabilities but for those who are in the unpaid caring role.

AFDO would recommend that if the inquiry truly wants to address the needs of unpaid carers then it needs to first and foremost address the needs of people with disability.

Social Inclusion

In February this year, ACOSS held a conference focusing on Social Inclusion. The conference held a disability specific stream where ideas were formulated to present to the Deputy Prime Minister the Hon. Julia Gillard at the end of the Conference. The following is what was presented:

- People with disabilities are very excited about the Social Inclusion agenda. We say to the Government: Nothing About Us, Without us! People with disabilities need to be included at all stages of the development of the Social Inclusion agenda, the development, the monitoring and the evaluation.

It is essential that any Agenda, Consultation or Inquiry, including the Inquiry into How to Better Support Carers reach those people with disability who are isolated either geographically or because of communication barriers, especially those who cannot speak. These are the people who are usually ignored or under-represented in any government policy or legislative development.

Real inclusion of people with disability will take a dedicated effort by Government to make sure that consultations are effective.

- People with disabilities are particularly concerned about the social exclusion of those Indigenous Australians living with a disability.
- Social inclusion for people with disability is about life, not services. It is both wide – for example, cross disability discrimination – and deep – for example, the barriers faced by people with complex needs.

Social inclusion is about making sure that people living disability can have the usual life experiences that everyone has – building a home, making friends, taking part in education and employment and other forms of meaningful life participation. Inclusion is about choice.

- Achieving inclusion means recognising difference and accepting diversity as normal. It should be a matter of course that people involved in program planning and delivery think about everyone's individual needs and circumstances.
- Government, in partnership with the community need to achieve an accessible built environment, positive community attitudes and high quality, responsive support services.

As the above indicates, people with disabilities have made it clear to government that in any developmental direction being undertaken by government that involves and will have an effect on the lives of people with disabilities, then people with disabilities have to be involved in the full process. This is no different to the Inquiry into Better Support for Carers.

Statistics

The following Australian Bureau of Statistics data on disability indicates the need for better support for people with disabilities. It also highlights the role of unpaid carers.

- Over 3 million Australians live with limitations arising from disability or ageing.

- 79 per cent of people with a disability who live in households receive care from relatives and friends, mainly partners, parents or children.
- 1.25 million people have a disability that results in profound or severe limitations. Of this group, 1.07 million people (85.6 per cent) live in private households.
- 64 per cent of primary carers over the age of 15 caring for a person with a profound core activity limitation spend more than 40 hours per week caring.
- Individual carers on average contribute 104 hours per week caring for a person with a mental illness (ABS 2004).

The above statistics indicate the need to ensure that people with disabilities are provided with a wide range of life choices the same as those Australians who live without a disability.

Response to Terms of Reference

Carers are often dedicated and passionate about the people they care for, but they are ultimately acting to replace government and/or community based services. This is a cost saving to government and the community. Family members should not be forced into an unpaid caring role due to a lack of other choices for the person they support or to replace services for the benefit of cost saving purposes. More choice, more services and better resourced services would allow better choice for those being cared for. This would enable individuals and their family's greater access to support workers for personal care tasks, communication assistance/methods, age appropriate activity choice, medical management, education, employment, and the wider community as a whole.

Many people with disabilities are not afforded freedom of choice about who cares for them and when. This can lead to a conflict of interest, role confusion, role definition, relationship breakdown, family breakdown and isolation. Examples include the case of a spouse

interpreting for their Deaf partner at a counselling session; a husband performing personal care tasks for a wife; and a child assisting a parent with parental responsibilities. These situations can create a sense of powerlessness, frustration, possible abuse and neglect, or a sense of misunderstanding by all parties.

Some of these situations may come about with the best of intentions, but the fact remains that if people with disabilities had adequate access to personal care, interpreters, and alternate communication methods and well trained allied health staff, they would be better placed to access community activities, education, and employment, pursue friendships and relationships outside the home. These are the aspects of life that people living without a disability expect to participate in without question. Provide for the person with a disability and the emotionally fraught situations which can occur when an unpaid carer is used out of necessity can be diminished.

Carers are placed under enormous stress, leading to greater stress for people with disabilities. People with disabilities want to belong in society at all levels and can be or are valued members of the community. Often they rely on only one or two primary carers, with no choice for any of the parties involved. When their carers become stressed and burnt out, people with disabilities may feel disenfranchised, disconnected and devalued. People with disabilities can also believe they are a burden on the carer or family and will often compromise their wants and needs to make life easier for the unpaid carer. This creates a situation where the potential value to the community of both the person with a disability and the unpaid carer could be lost and or never discovered.

AFDO would like to see carers acknowledged for their contribution to society, but that acknowledgement should also include an understanding that the work of carers should actually be the work of paid professionals. Additionally, AFDO would also like it to be recognised that people with disabilities themselves can, and do, act as carers for others.

Social and economic participation for carers will only improve when the social and economic participation of people with disabilities

improves. If people with disabilities are given opportunities to engage in recreation, education, employment and other key social activities, their carers will have the time and energy to participate in similar activities. Offering these activities to people with disabilities should not be considered 'respite' for carers; people with disabilities can and should have an active, valued contribution to Australian society in their own right.

For effective and genuine participation for people with disabilities to occur, adequate funding needs to be provided to ensure that people with disabilities have a range of choices available to them. Offering genuine life choices allows people with disabilities as so offered to any other individual allows any person to further develop their skills; provide a greater sense of independence wherever possible, and create incentive for ongoing participation, greater well being, relationship development and personal growth. This can enrich all the relationships a person with a disability might have, including their relationships with any carers in their life. Participation should not necessarily be facilitated by a carer, unless this is a freely made choice of both the person with a disability and their carer.

Although funding and resources are 'key' to increasing the participation of both people with disabilities and carers in employment, the stigma associated with some disabilities may also create barriers to participation. For example, someone with schizophrenia or HIV/AIDS is less likely to be able to get and keep a job if their workplace is ignorant about these disabilities; this can also be the case for carers who disclose their caring role. Increasing participation in employment and in the community relies on better community awareness reducing stigma and negative attitudes towards people with disabilities. The current National Mental Health & Disability Employment Strategy can go a long way to increasing the social and economic opportunities for people with disabilities and their carers.

Again, better measures for people with disabilities equates to better measures for carers. These measures include the following:

Focussing on Outcomes

The primary focus of all National Disability funded initiatives must be the wellbeing of people with disability; all services/initiatives should have a direct, positive impact on the quality of life of people with disability. However we currently have no way of knowing if services are achieving these outcomes.

We need an outcomes focussed measurement framework to assess the effectiveness of disability services in helping to achieve equality for people with disability.

The Office for Disability Issues in the UK measures the Government's progress against its commitment to equality using indicators across 3 areas:

1. educational progress and material wellbeing of young people with disability;
2. employment rates and experiences of adults with disability; and
3. the inclusiveness of the community in civic, social and economic terms

(See Appendix A for more detail)

Monitoring

Australia needs an outcomes focussed measurement framework:

- Commonwealth and State/Territories should demonstrate that disability services funding has led to improvements across a range of quality of life indicators.
- These indicators should be agreed nationally and be developed with input from people with disability.
- One indicator could focus on people who newly acquire a disability this enter the service system. This could measure the extent of meeting unmet need.

Better Integration of Disability Services with the Broader Community

The National Disability Strategy should more explicitly link disability funded services with initiatives in the broader community.

- Departments of Health & Ageing should be included in the National Disability Strategy negotiations
- Each party should commit to the maintenance of effort – no cost shifting
- Dual eligibility for programme support should be maintained, for example a person should be able to receive HACC & disability services concurrently
- State and Commonwealth disability departments should ensure that their Disability Action Plans (DAP) place their services in the context of broader government commitments.
- States and the Commonwealth should support life planning services to identify, and resolve where possible, barriers to the inclusion of people with disability in the general community. Information about the nature of these barriers should be collected to identify commonly recurring problems and to allow State and Commonwealth Departments to work with other parties (including disability advocacy organisations) to redress outstanding barriers.
- Bring Aids & Equipment schemes into the National Disability Strategy and start work to achieve national buying power and nationally consistent guidelines
- Uncap Aids & Equipment schemes
- New funding should be directed to initiatives that increase the independence of people with disability. For example, early intervention initiatives, the provision of aids and equipment, and inclusion initiatives such as the Companion Card.

Choice and Independence Audits

The Disability Services Standards should be revised to ensure that all services focus on achieving maximum independence, inclusion and choice for people with disability. All organisations funded by disability services should be audited against the revised Standards.

For example: A service is audited and it is found that many of the people it supports are engaged in centre-based activities. The organisation is told to move people to more appropriate, community based activities, such as those offered at the local neighbourhood house.

Housing

People with disability should be supported to find accommodation in the same places as the general population, that is, public and private rental, social housing and private ownership.

- The Commonwealth should require that its funding not be used for the construction or upkeep of disability specific or age inappropriate accommodation.
- States should ensure that the needs of people with disability are given adequate consideration in the development of public and social housing.

Packages

All states should move towards providing individualised funding packages to people with disability. The packages should be subject to Choice and Independence Audits (see above).

Life planning services should be provided separately from other service provision. In particular, no agency that provides accommodation to a person with disability should be allowed to provide life planning services.

Improving transitions, for example between school and post-school options should be identified as a priority for further development work.

No Fault Insurance Schemes for Catastrophic Injury

Around forty percent of young people living in residential aged care facilities are there because of a catastrophic injury and many of the people with disability with the highest support costs have experienced a catastrophic injury.

NSW and Victoria have no fault insurance schemes for catastrophic injury funded by levies on car insurance (the TAC in Victoria and Lifetime Care in NSW). It has been demonstrated that these schemes are cost effective and allow for life-time planning by people with disability.

Similar schemes should be introduced in all states and territories.

In addition, research should be conducted to:

- Model the costs/benefits of extending the schemes to cover all catastrophic injuries on a no-fault basis (beyond those involving vehicles)
- Model the costs/benefits of extending the schemes to cover other long term illness resulting in life long disability

National Schemes

The ALP has committed to introduce nationally consistent Disability Parking Permit guidelines. Other schemes would benefit from having nationally consistent guidelines:

- Companion Card
- Taxi Subsidy Schemes
- Public Transport Concession Schemes

Cross Departmental Responsibility

All State, Territory and Commonwealth Departments should have Disability Action Plans that aim to:

- improve the accessibility of generic services
- ensure that the needs of people with disability are explicitly considered in policy development and
- improve the employment of people with disability within the department.

Progress against the Plans should be overseen by a central agency and should form part of the KPIs of senior departmental staff (eg, departmental secretaries).

Increased Opportunity for Employment of People with Disabilities

The more skills people with disabilities have, the more able they are to participate in society. As a result, they become more socially and financially independent, meaning that family-based carers are less necessary.

Employment should be one of the critical goals for all people with disabilities who are able to obtain it. In addition to establishing the National Mental Health and Disability Employment Strategy, AFDO believes that the Federal government should be seeking to link employment policies, practices and services to those centred on education.

Attached is AFDO's submission to the National Mental Health & Disability Employment Strategy. Our submission highlights the fundamental elements that should be addressed in a National Mental Health and Disability Employment Strategy, and provides supporting information about the employment of people with disability in Australia. (*Appendix B*)

Other

The Australian government has recently ratified the UN Convention on the Rights of Persons with Disability. By doing so it will be required to actively educate the public about disability. This should be made a priority to increase the ability of both people with disabilities and their carers to participate in society.

FaHCSIA should prioritise in the Stronger Families, Stronger Communities program projects that will increase the resilience of families with a child with disability by increasing their connectedness to the general community. This will reduce isolation and increase sources of informal support for both the child and their parents and siblings.

Choice

People with disabilities and carers should, wherever possible, be able to make choices in partnership. In some cases this will require ready access to an advocate working on behalf of the person with a

disability, to ensure that all choices, aspects, views are explored and the needs of the person with a disability as well as those of the carer are being met to the best possible advantage.

To facilitate choices, it is important that information and referral services are readily available. Too often people with disabilities and their carers are not offered choices which might promote their independence and thus the achieved outcome is not the best for all stakeholders but a compromised position.

Transitions into and out of caring

People with disabilities and carers should not be 'forced' into – or out of – a caring situation. Those receiving care and those giving should be provided the opportunity to choose when they wish to participate in each role. Ongoing flexible resources should be available for families to have an adequate range of choices in terms of funded support, participation activities, medical assistance and other key life activities. Circumstances where care is unavoidable should be minimised, but when these circumstances exist, personal support through advocacy, counselling or other required services should be on hand to minimise the possible negative effects of a tenuous support arrangement those which continue to exist should be supported by advocates. These services should be provided to all parties involved.

Effectively planning for the future

Planning should always involve the rights and needs of people with disabilities, both at an individual level and the systemic. Situations of unmet need should be minimised into the future. We are already aware that our ageing population will increase the numbers of people with disabilities and the number of carers who have disabilities themselves. The broader issues surrounding these two cohorts should be examined within the National Disability Strategy and should be put in place by government to ensure that all present and future stakeholders can look forward to active productive lives.

References

Australian Bureau of Statistics (2004), Summary of findings: 2003 ABS Survey of Disability, Ageing and Carers, Canberra

UK Office for Disability Issues Annual Report 2007

Annex two: Indicators data

Section 1: Disabled children and young people

1. Use of childcare
2. Unauthorised absences from school
3. Achievements at Key Stage 2
4. Achievements at Key Stage 3
5. The percentage of 16 year olds achieving 5 A*-C grade GCSEs
6. The proportion of 16 year olds studying for Level 3 qualifications
7. The proportion of young people who attain Level 3 qualifications by age 18
8. Proportion of young people with experience of higher education by age 19
9. The proportion of first degree qualifiers attaining a first or upper second class degree
10. The proportion of students who do not continue in higher education after their first year
11. Satisfaction with higher education courses
12. The first destination of graduates 6 months after graduating
13. Percentage of children living in income poverty
14. Material deprivations

Section 2: Work

15. Employment rates
16. Employment rates of disabled people, by main impairment type
17. Economic activity
18. Employment by occupation
19. The percentage of working age people who have never had a paid job
20. The percentage of working age people in work who would like to work more hours

21. Hourly wage rates
22. Percentage of working age population with at least Level 2 qualifications or equivalent
23. Unfair treatment at work

Section 3: Independent living

24. Full size buses with low floor wheelchair access
25. Percentage of disabled people experiencing any difficulties in using transport related to their health problem or disability
26. Volunteering
27. Civic participation
28. Percentage of households with access to the internet
29. Participation in cultural, sporting and leisure activities
30. Awareness of the Disability Discrimination Act in the general population
31. Difficulties in accessing goods and services

Section 3: Independent living cont.

32. Suitability of accommodation for disabled people requiring adaptations to their home
33. Percentage of households living in non-decent accommodation
34. Individuals living in income poverty
35. Fuel poverty
36. Psychosocial wellbeing

(from:

<http://www.officefordisability.gov.uk/publications/report/2007/pdf/annex-two.pdf>)



Submission to the National Mental Health and Disability Employment Strategy

Introduction

As the peak national body representing organisations of people with disability, the Australian Federation of Disability Organisations welcomes the Government's initiative in developing a National Mental Health and Disability Employment Strategy.

The Terms of Reference for the National Mental Health and Disability Employment Strategy acknowledge the complex interplay of factors impacting on the capacity of people with disability to find and retain employment and highlight that efforts to improve employment will fail unless a holistic approach to reform is taken.

This submission is organised in two sections: the first section details the fundamental elements that should be addressed in a National Mental Health and Disability Employment Strategy; and the second provides supporting information about the employment of people with disability in Australia.

The submission complements the Australian Federation of Disability Organisations' submission to the review of the Job Network.

About the Australian Federation of Disability Organisations

The Australian Federation of Disability Organisations is the peak national body representing organisations of people with disability. Our mission is to champion the rights of people with disability in Australia. Our national and state based members include:

National Members

- Australian Mental Health Consumer Network
- Blind Citizens Australia
- Brain Injury Australia
- Deaf Australia
- Deafness Forum of Australia
- National Association of People Living with HIV/AIDS
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- Physical Disability Council of Australia
- Women with Disabilities Australia

State Members

- Access for All Hervey Bay
- Disability Resources Centre
- People with Disability, Western Australia

The Australian Federation of Disability Organisations also has a number of Associate Members.

Section 1: Fundamentals of a NMH&DES

To be effective, a National Mental Health and Disability Employment Strategy must address, at a minimum:

- the need for additional financial support for people with disability who are participating in the labour market;
- increasing the employment of people with disability in the public service, and improving retention rates;
- improving public transport and access to the built environment;
- reform of the income support and employment support systems to promote access to education and work experience opportunities for people with disability; and,
- defining an appropriate role for business services.

Fundamental 1: Financial Support for the Costs of Participating

Many people will require support at different points in their lives and some may require it for longer periods. Whatever

their circumstances, the social support system should seek to optimise their capacity for participation.

- McClure Report (2000: 3)

Introduction of a Cost of Disability Supplement

People with disability face higher costs associated with working and looking for work due to their impairment. This includes:

- the cost of accessible taxis;
- increased need for medication and therapeutic services; and,
- increased wear and tear on equipment.

A series of examples is provided at Attachment A.

These non-discretionary costs leave people with disability at high risk of poverty – the median income of households which include a person with disability is 23% lower than households without a member with disability (Saunders 2005: 7). Higher costs also make it harder for people with disability to make work pay. Productivity Commission analysis of employment and wage data from 2001 concluded that more than 14,000 men with disability did not take up work because the wages they were offered were too low (Productivity Commission 2004: A.27).

Our current system of income support provides inadequate compensation for these costs of disability. Even with significant Commonwealth Government support in the form of the Pensioner Concession Card, Pharmaceutical and Telephone Allowances, Mobility Allowance and Health Care Card, and a range of State and local government concessions, people with disability in employment face substantial out-of-pocket costs associated with their disability.

As the examples in Attachment A demonstrate, many people with disability who are employed are close to 'break-even' point, when their additional costs are held against their earnings. In these cases any decline in real earnings could be enough to tip the balance, forcing the individual out of the work force.

New Zealand provides an example of a system providing comprehensive assistance with the additional costs of disability. In

New Zealand, basic income support assistance is supplemented by financial assistance to overcome barriers to participation. The assistance is provided through three support funds: for people who are studying, working or looking for work, or establishing a business.¹

The Government should expand the financial assistance it provides to people with disability, identifying the most effective and equitable system in consultation with people with disability and others.

Recommendation

That the Department of Families, Housing, Community Services and Indigenous Affairs, in cooperation with people with disability, undertake a project to investigate models for a cost of disability supplement.

Chronic Condition Entitlement Card

I have put myself in debt paying for things that, you know – I mean I can't work if I don't have a massage at least once a fortnight, so I just have to factor that into my wage and it's not the best wage in the world

- quoted in Humpage (2006: 24)

Until a comprehensive and coordinated model for assisting with the non-optional costs of disability is developed there is an urgent need to provide immediate relief to the many people with disability who are incurring substantial costs for medication, therapeutic equipment and services and treatment by medical specialists.

¹ For more information, refer to the Workbridge Support Funds website: <http://www.workbridge.co.nz/support-funds/index.shtml>

Case Example

Mark is no longer able to work full time due to the progression of his Multiple Sclerosis, but is working part time and trying to stay in employment for as long as possible. Mark spends around \$400 per month on health expenses, including: \$30 per month to fill 6 scripts for medications that are subsidised through the Pharmaceutical Benefits Scheme (PBS); \$50 per month on a non-PBS muscle relaxant; and, \$120 per month on 3 types of neurological pain killers. Mark also uses at least another three PBS medications on a less regular basis. Mark would like to use anti-fatigue medication that would increase his energy and activity levels, but cannot afford the \$260 per month it would cost.

As the above example shows, the financial assistance provided to people on low incomes for the costs of health care is crucial and it is understandable that people with disability place an extremely high premium on retaining the Health Care Card.

The 2003/2004 *Job Network Disability Support Pension Pilot Project* identified concerns related to the costs of health care as significant disincentives to people with disability seeking and taking paid work. Participants in the Pilot reported the following related barriers:

- the need to retain the Health Care Card and other benefits and
- the difficulty of finding a job that pays enough to offset the loss of benefits and concessions (DEWR 2004: 10).

This is demonstrated in the following case example.

Case Example

George has HIV and needs to take 10 prescription medications, as well as 4 full priced vitamin supplements. George is currently on the Disability Support Pension and spends \$50 per month on his prescription medication and \$120 per month on supplements. Were George to lose the Health Care Card his prescription medication costs would increase to \$300 per month. While George would become eligible for the PBS Safety Net in around 3 months, but in the meantime would be left having to fund extreme medical costs.

People on income support who move off payment because of earnings are entitled to keep their Health Care Cards for 12 months. However, the income levels at which people cease being eligible for either a part-payment or the Low Income Earners Health Care Card are low. People earning as little as \$22,698 per year can be ineligible to receive financial assistance.

Eligibility for financial support with health care costs needs to be expanded beyond the very low cut off point for the Health Care Card.

Recommendation

That the Government introduce a Chronic Condition Entitlement Card to assist people who are not eligible for the Health Care Card with the high cost of medical services and pharmaceuticals. The Chronic Condition Entitlement Card should be means tested at a higher threshold than the Health Care Card. It should entitle the holder to receive PBS medications at the discounted price.

An Expanded Workplace Modifications Programme

The workplace support needs of some people with disability cannot be met under current Workplace Modifications Programme rules.

Recommendation

That the Workplace Modifications Programme be reformed to allow the provision of an expanded range of supports and assistance, including:

- hearing aids;
- ongoing personal assistance; and,
- ongoing AUSLAN interpreting.

And that consideration be given to:

- liberalising the rules covering reimbursement of the cost of equipment purchased by an employer; and,
- extending the Workplace Modifications Programme to cover ongoing voluntary work.

Fundamental 2: Improving Public Service Employment

For employees with disability, representation declined again this year to 3.3%, down from 3.6% at June 2006. The number of ongoing employees with disability fell from 4,818 at June 2006 to 4,717 at June 2007.

- State of the Service Report, APSC, 2006-07

In June 1998, 5.2% of Australian public servants identified as having a disability. Since then, this has declined steadily to 3.3% in 2007. Clearly, the total rate of employment in the public service is a significant concern. Also concerning is the rate of retention in the public service. In 2005, the Australian Public Service Commission found that employees with disability were 60% more likely than other staff to be retrenched (MAC 2006: 54).

The Federal Government must set the standard in employing people with disability.

Recommendation

That the Federal Government commit to increasing the employment rate of people with disability in the Australian public service to 7% by 2011. The Government should have a particular focus on reducing the retrenchment rate of people with disability.

Fundamental 3: Accessible Built Environment

Full implementation of the Disability Discrimination Act 1992 would go a long way to help. In the workplace all businesses should practice universal access irrespective of the size of the business. As it stands now many disabled persons are unable to work as paid or unpaid staff in small to medium businesses which makes nonsense of the Welfare to Work policy as many disabled prefer to work in a small business.

- woman from metropolitan Victoria, Post Polio Syndrome, Damaged Spine, Type II Diabetes and Cardiomyopathy

Under the *Disability Discrimination Act* (Cth) 1992, it is illegal to discriminate directly or indirectly against a person with disability.

In the fourteen years since the Act passed, Australia has made significant steps towards the creation of accessible communities, primarily through the adoption of Disability Standards under the Act. Disability Standards act like guidelines or instructions for detailing how a good or service should be provided so that it is accessible to the greatest number of people. The *Disability Standards for Accessible Public Transport* came into effect in 2002. The *Disability Standards for Education* came into effect this year. Standards covering the design and construction of buildings are currently being developed.

The Standards have progressive timetables for the introduction of accessibility. For example, the *Disability Standards for Accessible Public Transport* have a 30 year compliance schedule. Transport operators do not have to install handrails for another six years and it is a further sixteen years before all buses have to be accessible.

In the meantime, people with disability must participate as best they can in a world that does not cater to their needs and in which services which may assist them to overcome this disadvantage are rationed, as the table over leaf illustrates.

Six percent of people with disability who need assistance with mobility cannot obtain that assistance. A further 8% of people require assistance with transport, but do not receive it.

Ten percent of people with disability who need assistance with self care (eg toileting, dressing) cannot obtain that assistance.

ABS data show that 446, 700 Australians rely on aids or equipment to move around the community. Yet the Building Code of Australia does not require lifts to be installed in multi-storey buildings.

The accessibility of the community needs to be improved to allow people with disability to participate to the extent of their capacity.

Unmet Need for Assistance with Activities of Daily Living, 2003

Activity for which assistance is required	% unmet need - profound limitation	% unmet need - severe limitation	% unmet need - moderate limitation	% unmet need - mild limitation	% unmet need - all with limitation	Number of people with unmet need
Self care	7	12	-	-	10	52,960
Mobility	4	8	-	-	6	48,630
Communication	3	3	-	-	3	6,198
Cognition or emotion	3	4	11	8	6	45,096
Health care	5	4	7	11	6	57,198
Paperwork	4	3	10	6	5	19,050
Transport	5	5	13	19	8	68,680
Housework	2	4	8	10	5	45,470
Property maintenance	3	3	7	9	6	72,810
Meal preparation	3	1	1	4	2	6,220

Source: 2003 Survey of Ageing, Disability and Carers, ABS, Table 14

In the meantime, Commonwealth, State and local governments must work with stakeholders, including people with disability, to improve support systems for people with disability.

Recommendation

That the Government urgently introduce an Access to Premises Standard under the *Disability Discrimination Act (Cth) 1992* and offer financial incentives to small enterprise to upgrade existing buildings to the Standard.

Recommendation

That the Government urgently move to introduce improvements to the *Disability Standards for Accessible Public Transport* identified in the recent review of the Standards.

Recommendation

That the Government work with local government authorities to introduce universal standards for the accessibility of local streets.

Fundamental 4: Reforming Income Support & Employment Assistance Rules

"[T]hey wanted me to be a filing clerk and they made me go and do a test to see whether I knew the alphabet and I just burst into tears and said 'I'm a qualified secondary teacher' and they were so embarrassed that they got it wrong but there were quite a few slip-ups like that where you were just in the system".

- quoted in Humpage (2005: 22)

In 2006, substantial changes to the income support and employment assistance systems came into effect, following the passage of the Australian Government's *Welfare to Work* package.

The primary change for people with disability has been a tightening of the work capacity test from 30 hours to 15 hours.

That is, to be eligible to receive the Disability Support Pension, a person must be assessed as being unable to work independently in the open labour market for at least 15 hours per week (a reduction from 30 hours).

The Australian Federation of Disability Organisations did not support the introduction of *Welfare to Work* for three reasons:

1. cuts in base payments to people with disability would leave people in poverty and increase disincentives to work;
2. the requirements placed on people did not adequately take into account the impact of disability; and,
3. people with disability would be particularly vulnerable to punishment under the new regime.

Further disincentives and adverse outcomes became apparent as *Welfare to Work* rolled-out, including:

- a) take home pay has reduced;
- b) people who volunteered to look for work were punished;
- c) it became more difficult for people to undertake education and training; and,
- d) the assessment of capacity was inaccurate.

The Government is currently reviewing the Job Capacity Assessment system and the Australian Federation of Disability Organisations is hopeful that this will remove disincentives. However, the other problems still need to be addressed.

Making work pay

"If you had to work and get the pension and were still earning as much as you were on the pension, that's not really the greatest thing for you physically, because physically it's going to be a strain to work.. it's not an incentive to work."

- quoted in Humpage (2005: 26)

People with disability who were reliant on income support were already struggling to make ends meet; *Welfare to Work* made their financial situation more perilous.

Far from making it more attractive to work, the *Welfare to Work* policy made it harder for people with disability to make work pay. Analysis by NATSEM at the time *Welfare to Work* was proposed in 2005 showed that a person working 15 hours per week at the minimum wage would take home \$99 per week less if they received Newstart Allowance instead of the Disability Support Pension. The person would be working for less than \$3 an hour in effect, as a result of the high effective marginal tax rates associated with the Newstart Allowance.

Reducing base payments also failed to recognise the higher costs people with disability face when they work because of their impairment, such as transport, additional medication and increased wear and tear on equipment.

The combination of higher costs of disability and higher effective marginal tax rates meant that taking or keeping a part time job actually left some people with disability worse off.

Recommendation

That the rate of income support paid to people receiving Newstart (Partial Capacity) be increased to the level of the Disability Support Pension.

Making it easier to give work a go

since my illness has progressed ... I cannot work full time in fact some days I cannot get out of bed at all ... I have learnt to work with my illness and not fight it, do as my body says and in doing that there is no way that I could commit to permanent employment. It is not easy living on a Disability Pension, a fixed income but at least I know it will be there every fortnight.

- from a speech by Robert Pask, MS Society Victoria

As stated above, a substantial disincentive to people with disability looking for and accepting work has been the fear of being unable to return to the pension should the job not work out.

To address this, the Government announced that under *Welfare to Work* a person who became ineligible to receive the Disability Support Pension because of earnings could return to the Disability Support Pension for any reason within 2 years.

This was a positive step. Unfortunately, it has been undermined by the approach being taken to people on the Disability Support Pension who volunteer to look for work.

People on the Disability Support Pension who want assistance with finding work from an employment service provider must first have a Job Capacity Assessment. The result of this assessment is then used to review the person's eligibility for the Disability Support Pension - in effect, people are punished for showing initiative and trying to participate.

The impact of this change on the ground was an increase in fear and uncertainty, which in turn led to a sharp reduction in the number of Disability Support Pension recipients volunteering to look for work.

Recommendation

That an assessment undertaken to identify employment supports not be linked to eligibility for income support.

Making it easier to study or train

Welfare to Work was particularly harsh for people with disability wishing to undertake further education or training; the combination of substantially reduced income and the introduction of activity testing made this option impossible for many people.

The difference in payment rate between the Disability Support Pension and Austudy is currently around \$100 per week.

Moreover, students with disability find it more difficult to supplement their income than other Austudy recipients.

Under current income support and employment assistance rules, extended study is not encouraged. Study can satisfy a person's mutual obligation activities in only very limited circumstances. Anyone wanting to study a more extended course is required to do this on top of their other activity requirements.

This leaves a person with disability who is not eligible for the Disability Support Pension and who wants to undertake a generalist or degree course in a no win situation. If they can undertake at least three quarters of a full-time load, they can qualify for a poverty level Austudy payment. Those receiving Newstart or Youth Allowance (Partial Capacity) have to combine study, looking for part time work and undertaking mutual obligation activities – all with an assessed work capacity of less than 30 hours per week.

Recommendation

That the rate of Austudy be raised to the same level as Newstart Allowance.

Recommendation

That the Pensioner Education Supplement be extend to people receiving a Partial Capacity Allowance payment.

Recommendation

That undertaking an education or training course for at least 15 hours per week should fully satisfy activity and mutual obligation requirements.

Recommendation

That outcome payments for employment service providers be adjusted to reflect the benefit to people with disability undertaking education and training.

Fundamental Issue 4: Defining a Role for Business Services

The Australian Federation of Disability Organisations is concerned that the role for Business Services be defined appropriately in the National Mental Health and Disability Employment Strategy. Business Services are segregated workplaces and as such cannot form a part of a Social Inclusion agenda. It is our view that participation in a business service should be viewed as a participation option of last resort.

Recommendation

That all people with disability should be given the opportunity and support to succeed in the open labour market before placement in a Business Service is considered.

Recommendation

That no-one should be referred to a business service by a Job Capacity Assessment.

It is arguable that the types of jobs undertaken in Business Services are not materially different to those undertaken in the open labour market. Similarly, the abilities of people working in business services and open labour market situations are comparable; in both situations, people are supported at funding levels 1 through to 4. Given this, the extremely low rates of income provided to some people working in business services – as little as \$1 an hour – cannot be explained or justified.

We are also concerned that the Supported Wages System and the Business Services Wages Assessment Tool are not being universally applied to all people with disability working in business services. The proliferation of Wage Assessment Tools is leaving people with disability at high risk of exploitation.

Recommendation

That no more enterprise-specific wage assessment tools be approved for use.

Recommendation

That all Business Services be required to move towards using either the Supported Wages System or the Business Services Wages Assessment Tool to assess wages.

Section 2: What We Know About Employment

Past Government policies for the employment of people with disability have been based on the following flawed assumptions:

- that through rehabilitation and support programs, people with disability can return to a state of 'wellness';
- that all people with disability should be on a path to increasing their participation in the labour market; and
- that a person's success in obtaining paid employment is a reflection of their capacity and motivation.

The Australian Federation of Disability Organisations does not accept these premises. They are grounded in a framework that views disability as a medical problem, attributed to the individual, which can only be overcome through medical treatment and rehabilitation.

The Australian Federation of Disability Organisations views disability as a function of societal inaccessibility. People have impairments that limit their functionality. However these only become disabling when resources, goods and services are offered in such a way that people with impairments cannot use or access them.

A social understanding of disability acknowledges the rights of people with disability to not be discriminated against on the basis of their impairment. It accepts that disability is simply another life event, like raising children and caring for others, that needs to be accounted for in the work place and the broader community.

A social view of disability focuses attention away from individuals towards:

- the accessibility of essential infrastructure including transport and the built environment;
- the use of reasonable accommodations for people with disability in the provision of infrastructure, goods and services;

- the provision of financial assistance to compensate for the additional costs of disability;
- the need for flexible work-place arrangements; and,
- discriminatory attitudes held by the community.

What we know about Australians with disability

People with disability are not homogenous. Like the general population, people with disability have a range of experiences, skills, abilities and interests. Some people have been impaired from birth or a young age, while others have acquired their impairment as an adult. People with disability can have a range of impairments, including multiple impairments.

Like everyone else, people with disability want employment that utilises their extensive skills, knowledge and experience. This is also essential for economic reasons – demographic changes make it essential that we maximise our human capital.

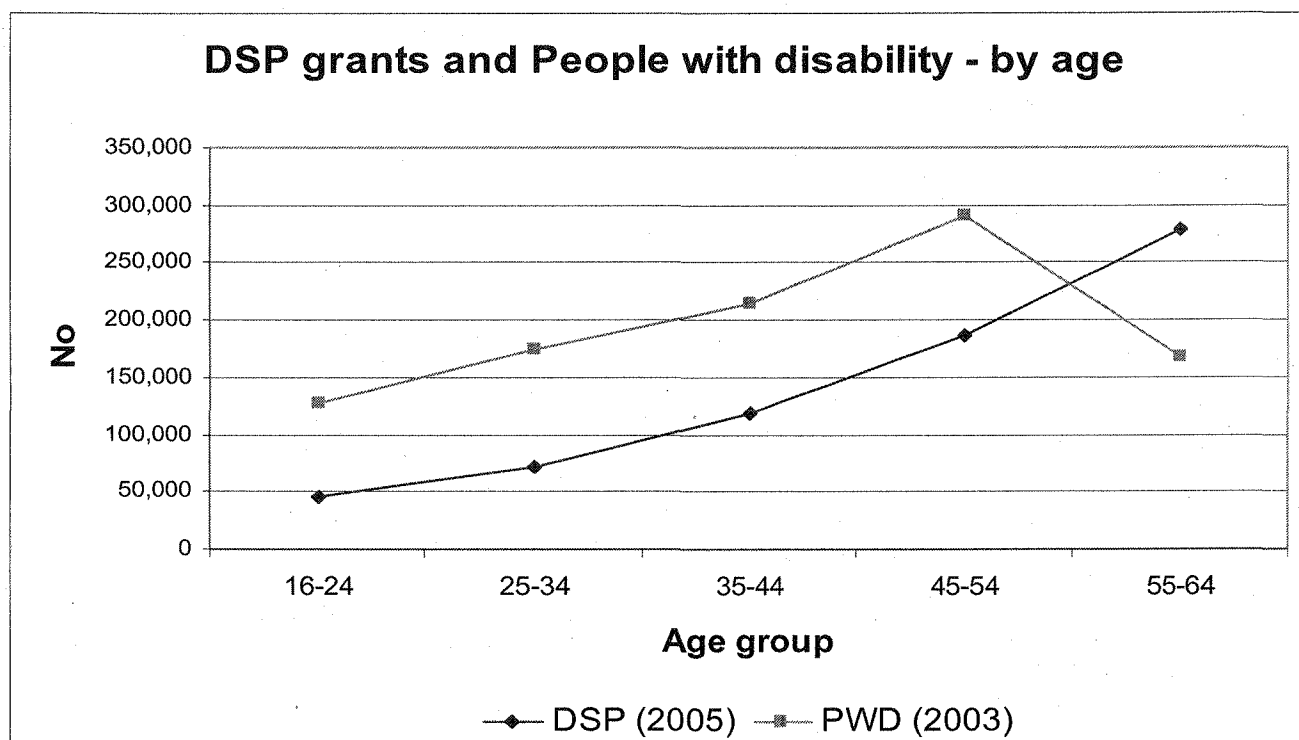
The Government should have regard to this heterogeneity when developing its National Mental Health and Disability Employment Strategy. Just as there is no “one size fits all” policy solution for improving employment among the general community, so we need to utilise a range of strategies to successfully engage people with disability.

Australian Bureau of Statistics data shows that workforce aged people with disability are most likely to acquire their impairment between the ages of 35 – 59 (ABS 2003: 5). This is reflected in grant figures for the Disability Support Pension (FaCS 2003: 6). This means that most people are employed at the time that they acquire their impairment. As a result, people with disability are as a group more experienced than the general population.

...if work experience were the only factor influencing wages, people with disabilities would have higher wages than people without disabilities.

- (Productivity Commission 2004: A.27)

As the following graph demonstrates, people with disability who are aged between 55 and 64 years are over-represented on the Disability Support Pension. This reflects the double disadvantage experienced by mature age workers in the labour market.



Source: *Characteristics of Disability Support Pension Customers 2005, DEWR Disability, Ageing and Carers Survey 2003, ABS, Australian Federation of Disability Organisations analysis*

Analysis shows that the proportion of the Disability Support Pension population that is female had increased from a low of 26.2% in 1989 to 40.6% in 2005 (DEWR 2005: 6).

Little is known about the pathway to unemployment for the majority of people with disability who acquire their impairments as adults.

The experience of people with disability is that for many, the onset of disability is the precursor to unemployment, often through involuntary 'voluntary' redundancy.

"my contract ran out and... that was the end of it"

-quoted in Humpage (2005: 14)

Human Rights and Equal Opportunity Commission data show that forty-four percent (44%) of complaints made under the Disability Discrimination Act relate to discrimination in employment.

International research indicates that people who lose their sight as adults are highly likely to lose their job as a result. 70-90% of blind people who were unemployed had been employed before they lost their sight and the majority left their employment involuntarily (Dryden 2001: 2). This reflects the Australian Public Service Commission data around the retrenchment of people with disability, quoted earlier.

In 2005, a research study by the Centre for Applied Social Research examined the attitudes of people with disability on the Disability Support Pension towards undertaking paid work. Although only a small study, the Australian Federation of Disability Organisations believes that the research findings are reflective of the broader experience of people with disability in Australia.

The research found that all participants held positive attitudes towards paid work and did not need to be encouraged to work. Research participants were reluctant to apply for the Disability Support Pension.

I had [a] psychiatric disability really for a long time but I've fought on tenaciously to stay in the workforce until I absolutely couldn't... I had my shrink telling me to stop working full-time and I was trying to ignore her but I had a lot of time off

- quoted in Humpage (2005: 9)

Participants had undertaken extensive education and training to try to improve their chances of finding work and were involved in unpaid work, sometimes in addition to paid work.

As these data show, serious efforts to improve the participation of people in the labour market, where this is possible, should be directed first at improving the employment retention of people with disability, particularly in the public service.

The role of the Disability Support Pension

In public discussion about employment and people with disability, reliance on the Disability Support Pension is presented negatively; as an escape from the labour market. In reality, for many people with disability, receiving the Disability Support Pension is appropriate recognition of their inability to engage in paid employment at all, or to a degree that would allow them to support themselves financially, as a result of the impact of a medical condition. Other people are left to rely on the Disability Support Pension for income as a result of endemic and chronic discrimination in the labour market.

Barriers to participation for people with disability

In addition to those issues identified in Section 1, there are factors that impact on the capacity of people with disability to work including:

1. direct discrimination and
2. the impact of a person's medical condition.

1. Direct discrimination

The discriminatory attitude of employers is the most significant barrier to people with disability finding and retaining employment. In its 2004 review of the *Disability Discrimination Act*, the Productivity Commission found that:

- People with disability face substantial discrimination in the workforce and,
- Women with disability are especially disadvantaged, facing discrimination on the twin grounds of gender and disability (Productivity Commission 2004: A.28).

Little has been done in Australia to address this discrimination systemically.

2. The impact of medical conditions

Many people with disability have underlying medical conditions that can impact on their work capacity. People can experience fatigue and/or pain, and many people have conditions that are exacerbated by stress. The impact of a person's medical condition can fluctuate, and people can have conditions that are degenerative or episodic, requiring periods of extended leave.

This need for flexibility is poorly accounted for in workplace employment policies.

It's taken me many, many years to learn, but I won't be able to cope [in a stressful job], so I have to avoid that and that gets mixed up with avoiding work. It's not avoiding work, it's trying to get yourself located in something that's not going to be patronising but not going to stress you and that is actually quite hard to do.

- quoted in Humpage (2005: 29)

Quite frankly, I know people that are doing volunteer work at or near 15 hours a week, and in some cases more than 15 hours a week, who would have Buckley's of getting and keeping a job in open employment.... [employers] don't want low productivity workers anyway and, frankly, if your productivity is very low you don't want to live on half the award wage or less.

I have had jobs where I've taken something on and two months later I've had to resign and no one wants to employ someone that's potentially going to do that.

- quoted in Humpage (2005: 15)

The Management Advisory Committee report on the employment of people with disability in the public service suggests a range of improvements to work place flexibility.

Increasing employment of people with disability: what works

As stated above, the Australian Federation of Disability Organisations considers that policies to increase the employment of people with disability in the workforce need to focus on improving the employment retention of existing employees, as well as assisting people to re-enter the workforce, where possible and appropriate.

Assisting people back into the workforce

A comprehensive review of international literature related to employment and people with disability identified that the most important predictor of an employer's preparedness to employ people with disability was a previous positive experience of employing a person with disability (Graffam et al 2004: 8). This makes providing effective employment programs crucial.

Evidence demonstrates that the provision of careful job matching and ongoing support on the job will lead to improved employment outcomes for people with disability, particularly in the long term. Unfortunately, these supports are under resourced in Australia. The Organisation for Economic Cooperation and Development has found that the lack of support provided to people with disability in the open labour market in Australia affected people with moderate and severe impairments and left people aged over 50 at particular disadvantage (OECD 2003: 1).

Australian initiatives include the Disability Support Pension Pilot Project, conducted by the Australian Government, and the Australian Fair Pay Commission has considered the role of wages in the employment of people with disability.

Disability Support Pension Pilot Project

From December 2003 to June 2004, the Commonwealth Department of Employment and Workplace Relations undertook a project called the *Job Network Disability Support Pension Pilot*. The pilot was aimed at increasing the participation of people in

receipt of the Disability Support Pension in the Job Network system (DEWR 2004).

The pilot involved twelve specialist disability Job Network members, across 37 sites. The Job Network members used a range of approaches to engage people in receipt of the Disability Support Pension, including direct marketing and referral from Centrelink and other employment agencies.

More than 1,100 Disability Support Pension recipients expressed initial interest in taking part in the pilot. Of these:

- 342 (30%) did not commence because they were ineligible or unsuitable, or because they decided not to take part;
- 74 people agreed to take part but subsequently withdrew, primarily due to a decline in their health; and,
- A further 88 people left after commencing.

In total 45% (504) of those who initially expressed interest did not enter or stay with the program. The majority of people who had to withdraw due to ill health were people with episodic illness.

By October 2004, 626 people had entered and remained with the program. Of these:

- 344 continued to receive assistance and,
- 43 were waiting to enter the Intensive Assistance program.

At the end of the pilot period, 239 people had been placed in employment or study:

- 17 entered full time study;
- 2 entered part time study;
- 53 commenced full time employment;
- 75 commenced part time employment; and,
- 92 commenced casual employment.

That is, at the end of the pilot period, only 35% of participants had found employment. Of these, almost 42% were employed in insecure casual positions and only around 10% had been employed for more than 13 weeks.

Casual employment has been found not to support a stable transition back into the work force from unemployment. A Productivity Commission research paper *The Role of Non-Traditional Work* found that people with disability are 30% more likely than others to leave a casual job within a year (2006: 104). The Commission concluded that low paid work did not act as a stepping stone to more secure, better paid work for people with disability. This point emphasises that the intention of 'Casual Employment' as a type was not designed for the sole purpose of introducing the 'Unemployed' back into the workforce.

It is telling that only one in five people who initially expressed interest in the pilot project could be supported to an employment outcome. This is despite the Job Network members that took part in the pilot being disability specialists and having access to greater than usual resources to support job seekers.

It should be noted that the participants in the Pilot were not representative of the general Disability Support Pension population in a number of significant ways:

- People who were defined as requiring 'ongoing support' were not eligible to take part in the pilot. When combined with the very low uptake of the Workplace Modifications Program during the Pilot, this suggests that outcomes may have been achieved for people who were easier to place.
- The people who took place in the pilot were younger than the general Disability Support Pension population. This could be expected to have improved the employment outcomes, given the double disadvantage experienced by mature age job seekers with a disability.
- Most job seekers who found employment had been receiving the Disability Support Pension for around 2 years. More than 70% of people receiving the Disability Support Pension have been on the pension for 2 years or more.
- People with psychological/psychiatric or sensory impairments were overrepresented in the pilot. People with intellectual/learning and musculoskeletal impairments were substantially underrepresented.

Key findings of the Interim Evaluation were that:

- people with disabilities were keen to work;
- the voluntary nature of participation in the pilot was key to its success; and,
- there was a demonstration effect, with the number of Disability Support Pension recipients taking part in the Job Network increasing at all sites of the pilot.

Despite being disability specialists, the Job Network members that took part in the pilot reported a lack of confidence in their capacity to assist people with episodic illnesses, particularly mental illnesses.

A final evaluation report was not publicly released.

The role of wages and subsidies

The Australian Fair Pay Commission sets minimum wages in Australia and is charged with setting a minimum wage for people with disability. In its 2006 submission to the AFPC, the Australian Federation of Disability Organisations noted that:

- Although people with disability already earn less than their peers because of discrimination, this has not led to an increase in employment opportunities (Productivity Commission 2004: A.28).
- Surveys of employer attitudes have repeatedly found that employers are disinterested in financial incentives to employ people with disability (refer to Graffam et al. 2004).
- Extensive national and international research has found that the initial costs of employing people with disability are extremely low or non-existent in the majority of cases and that over the long term it costs employers less to employ people with disability than other employees because of factors such as: improved retention, improved organisational productivity and the benefits of adjustments for the workforce as a whole (see Productivity Commission 2004 and Graffam et al. 2004).

The Australian Federation of Disability Organisations also noted that in situations where a person's productivity was substantially lower as a result of disability, employers could take advantage of the Supported Wages System.

Would a 'disability wage' work?

The Australian Fair Pay Commission considered whether setting a lower wage for people with disability would lead to their increased employment. The Australian Federation of Disability Organisations argued that evidence indicated that such a move would harm the employment opportunities of people with disability. The stigma associated with receiving a disability wage would be considerable and would be likely to lead to reduced employment of people with disability.

Being labelled as 'disabled' reduces a person's likelihood of finding work; Martz (2003) found that people with invisible disability are sixteen times more likely to be employed than people with visible disability (quoted in Graffam et al 2004: 7).

A disability wage would also reduce the incentive to work, given the difficulty making work pay, already discussed.

The Australian Fair Pay Commission set the special disability wage at the same level as the general minimum wage.

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