

Elder and disability carers

Introduction

Profile of elder and disability caring in Australia

- 8.1 The Australian Bureau of Statistics defines a person with a disability as someone who has 'a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities'.¹ This definition includes limitations caused by ageing.
- 8.2 In its survey of disability, ageing and carers in 2003, 20 per cent of the population reported having a disability within this umbrella definition.²
- 8.3 There are a wide range of disability classifications. The most limiting type of disability is where it interferes with the core activities of communication, mobility and self-care. The four categories of core-activity limitation are:
- profound core-activity limitation: where the person is unable to do, or always needs help with, a core-activity task;
 - severe core-activity limitation: where the person sometimes needs help with a core-activity task, has difficulty understanding or being

1 Australian Bureau of Statistics, *Disability, ageing and carers: Summary of findings, Australia, 2003 (2004)*, Cat No 4430.0, p 72.

2 Australian Bureau of Statistics, *Disability, ageing and carers: Summary of findings, Australia, 2003 (2004)*, Cat No 4430.0, p 16.

understood by family or friends, or can communicate more easily using sign language or other non-spoken communication;

- moderate core-activity limitation: where the person needs no help but has difficulty with a core-activity task; and
- mild core-activity limitation: where the person needs no help and has no difficulty with a core-activity task, but has other limitations, such as using aids and equipment and not being able to walk 200 metres easily.³

8.4 As an overlapping category, the Bureau also classifies people whether they cannot attend school or work on a normal basis. This category includes people who have difficulty at school, attend a special school, are restricted in the work they can do, or need at least one day off a week on average. The proportion of the population with a disability in Australia is reported below:

Table 8.1 Disability status rates by sex, 2003 (%)

	Profound core activity limitation	Severe core activity limitation	Moderate core activity limitation	Mild core activity limitation	School or work restriction	All with a disability
Men	2.4	3.1	3.3	5.6	9.6	19.8
Women	3.6	3.5	3.7	5.1	8.2	20.1
Persons	3.0	3.3	3.5	5.3	8.9	20.0

Source: Australian Bureau of Statistics, *Disability, ageing and carers: Summary of findings, Australia, 2003 (2004), Cat No 4430.0, p 16.*

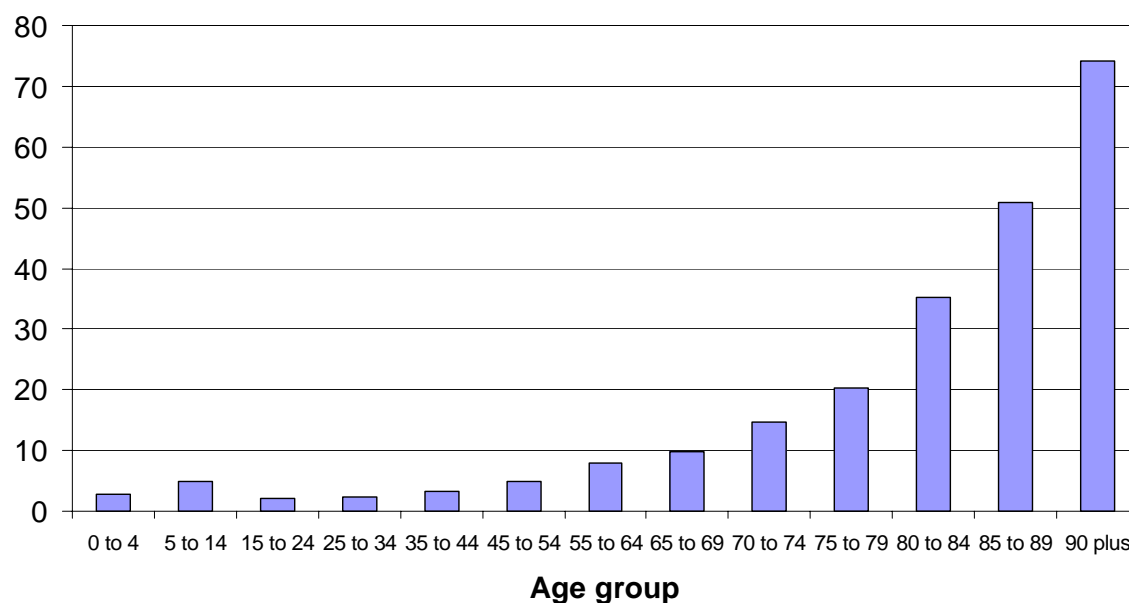
8.5 Almost nine per cent of people aged between five and 64 has a school or employment restriction. Twenty per cent of the population has reported a disability of one sort or another. Over six per cent of the population have either a profound or severe core activity limitation and need high levels of care and assistance.

8.6 The prevalence of the more limiting types of disability is relevant to this inquiry because of the impact these people have on their families and how the adults in these families can participate in the workforce.

8.7 As a person ages, the chances increase that they may develop a more limiting disability, such as a profound or severe core activity limitation. The relationship between disability and age is demonstrated in the next figure.

3 Australian Bureau of Statistics, *Disability, ageing and carers: Summary of findings, Australia, 2003 (2004), Cat No 4430.0, p 72.*

Figure 8.1 Profound or severe core activity limitation rates by age, 2003 (%)



Source: Australian Bureau of Statistics, Disability, ageing and carers: Summary of findings, Australia, 2003 (2004), Cat No 4430.0, p 18.

- 8.8 Once a person reaches the age of 80, the chance that they will need significant levels of care increases greatly. The ageing of the population, combined with the increase of age at which mothers give birth, means that many parents are now faced with the responsibility of looking after their own parents as well. These parents are now called the 'sandwich generation'.
- 8.9 The Australian Institute of Family Studies suggests that the number of employed people who will be caring for elderly or disabled adults is likely to increase.⁴
- 8.10 Table 8.2 outlines which sections of the Australian population are providing care for the disabled and elderly. Women are more likely to be a primary carer than men, but the rates of being a secondary, or non-primary carer, are the same. The older a person is, the more likely they are to provide this sort of care, especially after the age of 35. Men's rates of care continue to rise as they age, possibly because they are less likely to have competing work commitments, which they would normally prioritise over caring responsibilities.

4 Australian Institute of Family Studies, sub 76, p 25.

Table 8.2 Carer status by age and gender, 2003 (%)

	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75 plus	Total
Males									
Primary carer	0.1**	0.3*	0.6*	1.2	2.4	2.5	3.6	5.7	1.4
Other carer	3.5	8.8	8.8	12.1	13.9	17.0	18.5	18.5	10.6
Females									
Primary carer	0.1**	1.3	2.4	4.4	6.2	7.6	5.7	4.5	3.4
Other carer	3.5	7.7	9.7	15.1	16.2	16.5	13.5	8.9	10.6

Source: Australian Bureau of Statistics, Disability, ageing and carers: Summary of findings, Australia, 2003 (2004), Cat No 4430.0, p 49. * indicates estimate has a relative standard error of 25% to 50% and should be used with caution. ** indicates estimate has a standard error greater than 50% and is considered too unreliable for general use.

8.11 The Australian Institute of Family Studies provided an interesting insight into men's caring behaviour:

The rates are different... in terms of the role in caring for children as opposed to caring for elderly parents. You find greater engagement of men in the care of elderly parents, typically their own parents, though it seems within the family there is a split between whose parents they actually are...⁵

8.12 In summary, a large number of people in Australia require care, either through ageing or having a disability. These rates of care will affect a significant number of people in how they manage their work and family lives.

Economic value of informal care

8.13 In 2005, Access Economics estimated the annual value of informal (unpaid) care in Australia. Using the opportunity cost method (that is, the amount that carers could earn if they entered the workforce, rather than caring), Access estimated the value of this care at \$4.9 billion.⁶

8.14 Using the replacement value method (that is, the cost of employing someone to do the work instead), Access estimated the value of this care at \$30.5 billion.⁷

5 Hayes A, transcript, 2 August 2005, p 40.

6 Access Economics, *The economic value of informal care* (2005), Carers Australia, p 13.

7 Access Economics, *The economic value of informal care* (2005), Carers Australia, p 15.

8.15 Informal carers are making a considerable contribution to the Australian economy and shoulder a sizeable burden that might otherwise be placed on the Australian taxpayer. In comparison with these sums, Commonwealth assistance to unpaid carers under the carer payment and carer allowance is approximately \$2.4 billion (see chapter two).

Effect of caring on labour force status

8.16 Clearly, having significant caring obligations will affect whether a person can work or otherwise participate in the workforce. The table below demonstrates this effect:

Table 8.3 Labour force status of carers, 2003 (%)

	Primary carer	Other carer	Total carers	Not a carer	Total
Unemployment rate	3.1*	6.2	5.7	5.3	5.3
Participation rate	39.0	60.2	56.1	67.9	66.1

Source: Australian Bureau of Statistics, *Disability, ageing and carers: Summary of findings, Australia, 2003 (2004), Cat No 4430.0, p 51.* * indicates estimate has a relative standard error of 25% to 50% and should be used with caution.

8.17 Being a primary carer significantly reduces the chances of a person being in the workforce by almost 30 per cent. Being a secondary carer also reduces the chance of being in the workforce, but the effect is much smaller.

8.18 Using data from the Australian Bureau of Statistics' 1998 survey on disability, ageing and carers, the Australian Institute of Health and Welfare calculated the effects of caring on employment and income. The results are reproduced in table 8.4.

8.19 In terms of income, approximately half of carers experienced no effect, but the other half stated they were worse off. In terms of employment, 10 per cent of carers said they had to leave work to meet their caring responsibilities. Although not picked up in the table, a significant number of people would also fail to re-enter the workforce due to caring responsibilities.

Table 8.4 Impact of caring on primary carers regarding employment and income, 1998 (%)

	Age group				Total
	15-24	25-54	55-64	65 +	
Effect on income					
Not affected	71.5	39.3	49.2	57.2	45.9
Has increased	2.4**	2.8*	2.0**	1.9**	2.5
Has decreased	5.4**	27.2	18.8	6.8*	20.7
Has extra expenses	16.7**	25.5	26.0	28.1	25.8
NA	4.0**	5.2	4.0**	6.0*	5.2
	100.0	100.0	100.0	100.0	100.0
Effect on hours of paid work					
No effect	37.0*	36.8	14.5	2.8*	25.6
Reduced hours	-	11.2	5.1*	0.4**	7.5
Increased hours	5.8**	3.4*	2.8**	0.5**	2.8
Not applicable	57.2*	48.6	77.6	96.3	64.2
	100.0	100.0	100.0	100.0	100.0
Left work	-	11.4	17.2	4.4*	10.6
Total number ('000)	13.6	259.0	79.1	96.4	448.1

Source: Australian Institute of Health and Welfare, *Carers in Australia (2004) Aged Care Series no 8*, p 23.
 * indicates estimate has a relative standard error of 25% to 50% and should be used with caution.
 ** indicates estimate has a relative standard error over 50% and is considered too unreliable for general use. - indicates rounded to zero.

8.20 UnitingCare Burnside's submission gave a sense of how a carer of a child with a disability slipped out of the workforce:

Balancing work and family life?... It's very hard... I was actually working full-time and then I had to go part-time... I then took leave without pay, and now I've given up work altogether. Coping on a sole parents' pension.... don't get me wrong... I appreciate the benefit the government gives but with a child with a disability, even with the extra \$90, it's not enough... Sometimes I'm up all night with him... and for me to get up at 6 am and to function, head-wise... it doesn't work... I'm tired... he's tired.⁸

8.21 Another parent recounted the struggle to stay within the labour market:

Adding up school holidays and sick days, I lose an average of seven weeks pay each year, taking up all of my annual leave and sick leave entitlements. Not to mention my credibility in

8 UnitingCare Burnside, sub 89, p 10.

the workplace, my efficiency at getting the job done, and my sanity through all the worrying, prioritizing and organising that takes up my week. All this because the system is not designed for working mothers with special needs children.⁹

8.22 Currently, the Commonwealth spends \$1.3 billion per annum on the carer payment (means tested) and \$1 billion per annum on the carer allowance (not means tested).

8.23 Although these payments help an individual with a disability receive a higher level of care, they do not give the carer any additional options to help them with their burden. The Taskforce on Care Costs stated in evidence:

We do not have anything supportive for elder care and disability care for people who want to stay in the work force. The emphasis on the benefits that we currently have available, particularly in relation to elder care and disability care, is supporting people to stay at home, and that is not what people want to do. They want to be in the work force, but they just cannot do the juggle with the two of them.¹⁰

8.24 In the view of the Australian Institute of Health and Welfare, a carer's attachment to the labour market is at the most risk during the early stages of caring:

... workplace flexibility is crucial in the early stages of caring. Carers in countries with high levels of community support and well-developed formal services are reportedly more able to adapt their working lives to new caring roles, gradually easing back to earlier patterns of work when support arrangements with formal providers are in place. In countries with fewer and less coordinated sources of formal support, carers tend to withdraw from the workforce or reduce their hours of paid employment. There is evidence that once these changes are made, earlier work patterns are not recovered when caring ceases.¹¹

8.25 This evidence suggests that the barriers to workforce participation for the carers covered by this chapter are very great. Further, this situation

9 Stanford J, sub 173, p 2.

10 Bourke J, transcript, 19 April 2005, p 10.

11 Australian Institute of Health and Welfare, *Carers in Australia* (2004), Aged Care Series no 8, pp 25-26.

can be addressed, but it requires intervention during the early stages of caring.

Family friendly work arrangements

8.26 The Australian Institute of Family Studies outlined how women generally adapt their work around their caring responsibilities for children, whereas men do not. In the case of elder care, however, the situation is different:

Mothers with child-care responsibilities are much more likely than fathers with child-care responsibilities to make use of family-friendly work arrangements and also report that they made job changes to assist in balancing their work and family responsibilities. For elder care it changes. Where men are reporting having caring responsibility for a disabled adult, a sick adult or an older person and that care is of an ongoing nature, their rate of using family-friendly work arrangements is similar to that of women with elder care responsibility... In part I think that is because many fathers still do not take the primary role in caring for children.¹²

8.27 One interpretation of this evidence is that it is somehow more manly to care for one's parents, but not one's children.

8.28 Further, the Institute advised that all parents are less likely to be able to negotiate family friendly arrangements for elder and disability care at the workplace:

While rates of unmet need for flexible work practices and provisions are relatively low overall, they are higher for elderly and/or disabled care than for child care. This applies to almost all types of work arrangements except shift, casual or part-time work and unpaid leave. The reasons given suggest that people think employers are more likely to refuse use of flexible work practices and provisions for elder and/or disabled care than for child care.¹³

Psychological and physical impact on carers

8.29 The National Carers Coalition advised the committee that informal caring is an isolating task that increases the carer's risk of depression

12 Gray M, transcript, 2 August 2005, p 40.

13 Australian Institute of Family Studies, sub 76, p 26.

and the physical effects of depression. They are more likely to become disabled themselves, due to the stress of caring and physical demands, such as lifting.¹⁴ The Australian Institute of Health and Welfare reports that there is a link between carer burden and some of the symptoms of dementia.¹⁵

- 8.30 The burden of caring can also end marriages. As Amanda Stapledon, a parent of a child with a disability, stated:

I believe that was the last nail in the coffin, definitely. We couldn't cope with the constant trips to hospital. We were often being rushed to hospital. I have had to revive my son more times than I care to remember. That put a lot of stress on me. It also put a lot of stress on my husband but he simply could not cope with all that was involved. It is all-encompassing, Mrs Bishop. I cannot tell you. It consumes, every day, every waking hour of my day.¹⁶

- 8.31 On the other hand, being able to go to work is of great help to carers. It offers them a break from caring and reduces isolation.¹⁷ Amanda Stapledon advised the committee:

It is the interaction. I have worked here for 10 years, and the people here are like a family. To come to work, to be dressed in a suit, to put on my make-up, to do my hair – it probably sounds insignificant to someone else, but it is important to me – and to interact with so many wonderful people keeps that isolation down. I feel that if I were at home – probably working is a better alternative to not working – I could become depressed. I often try to fight that.¹⁸

- 8.32 While parents benefit from being able to go to work, the children benefit from being placed in care programs. Casey Kidz Klub in Melbourne, which has provided after school care for intellectually disabled children, has delivered promising results:

These children used to be pretty boisterous at the start and they were just really hard to handle, very difficult children. They're

14 National Carers Coalition, sub 199, pp 3, 9.

15 Australian Institute of Health and Welfare, *Carers in Australia* (2004), Aged Care Series no 8, p 25.

16 Stapledon A, transcript, 16 August 2006, p 6.

17 Australian Institute of Health and Welfare, *Carers in Australia* (2004), Aged Care Series no 8, p 23.

18 Stapledon A, transcript, 16 August 2006, p 10.

communicating a lot better with one another, their social skills have improved out of sight. This program has just helped them integrate into normal mainstream a lot better. If we could have these sort of programs happening all the time I think they'd improve and to the point where they may even be able to get jobs and be really useful to society. That's what it's all about.¹⁹

- 8.33 A common theme in this inquiry is the benefits that paid employment gives to families. This theme is also relevant for families with members requiring elderly or disability care.

Policy issues

Cost of care

- 8.34 Although governments in Australia provide respite care and other programs to carers, the main financial support to carers comes from the Carer Payment, which pays up to \$10,847 per annum, and the Carer Allowance, which is \$2,462 per annum.
- 8.35 To put these sums in context, Catholic Welfare Australia advised the committee:

It was interesting that a carer for a child with a disability, for someone with a disability or for an older person gets a \$50 allowance per week at the moment for caring for that person.

When we are looking for foster carers – people outside of a traditional family – to provide care for a child the rate is about \$175 per child per week and it is an allowance that is paid to cover their out-of-pocket expenses. That goes up to about \$250 per child per week if the child has a disability or any special needs. The feedback we get from our foster carers – and it is increasingly difficult to find foster carers – is that this barely covers their costs, and in many cases they are out of pocket.

So, if you are trying to put a figure on what it costs to care for a child, we are finding it very difficult to find people who will do it for between \$170 and \$250 per week per child just to cover their costs. We are also trying to have foster carers, or people

19 Farley M, quoted in Hall C, 'Governments turn their backs on after school program for disabled', Stateline Victoria, transcript, 27 October 2006, viewed on 1 November 2006 at <http://www.abc.net.au/stateline/vic/content/2006/s1775428.htm>.

who are available, to take children at short notice and to encourage them to stay out of the workforce and be available for this we are trying things like retainers, but even with those retainers, which are \$300 at the moment, we cannot find enough people and we are looking at possibly raising that to \$500. So there are some real issues in terms of what it actually costs to have somebody looking after a child, and that is not even taking into account the lost opportunity of employment and that sort of thing. So it is a fairly significant issue, we think.²⁰

- 8.36 At the maximum rates of assistance, someone caring for a person with a disability will receive \$13,000 per annum. A foster parent will receive a similar amount for caring for a child with a disability, and Catholic Welfare Australia has noted that this is the minimum needed to attract people to do the work. Using the replacement value method, it appears that the rates of assistance for disability carers have been set at the absolute minimum.
- 8.37 The most significant financial support to parents, the Carer Payment, is means tested. One result of this is that higher income earners, who make the effort to work, do not receive it. However, due to the absence of accessible and affordable after hours school care and vacation care for children with disabilities, a working carer needs to pay for additional formal care.
- 8.38 The National Carers Coalition gave the committee the example of a sole parent, Mary, who earns \$85,000 per annum. Her tax is \$29,000, leaving her \$56,000. From this after tax income, she pays \$22,500 to a nanny to look after her son outside his program hours of 9 am to 3 pm. This leaves her with \$24,500 per annum for her family's basic living expenses.²¹ If she were to receive a tax deduction for the nanny, this would reduce her tax bill by \$13,500, leaving her with \$38,000 instead.²²
- 8.39 In the view of the committee, unpaid carers are making an enormous contribution to the community at considerable personal cost to themselves. They sacrifice their health, social networks, career and

20 Boerma B, transcript, 19 April 2005, p 31.

21 National Carers Coalition, sub 199, p 8.

22 Using the comprehensive calculator on the website of the Australian Taxation Office, viewed on 20 November 2006 at <http://calculators.ato.gov.au/scripts/axos/axos.asp?CONTEXT=&KBS=ctax2006.xr4&go=ok>.

finances to care for a loved one in return for modest government support.

- 8.40 The Australian Government needs to address the plight of carers. The model detailed earlier in the report in relation to taxation relief for child care generally is a useful template. Some submissions suggested that the Child Care Tax Rebate be extended to this type of care.²³ Many carers themselves use paid care in order to work. The bar against private expenses not being a tax deduction is no longer defensible because so many women participate in the workforce.
- 8.41 The committee, therefore, agrees that making caring expenses a tax deduction to allow carers to work should be thoroughly investigated by the government.²⁴

Recommendation 18

- 8.42 **The Australian Government consider allowing adults, who incur care costs for the care of elderly relatives or relatives with a disability, to have the choice of either receiving all current carers' benefits or claiming these costs as a tax deduction where they can demonstrate that paid care was necessary to allow them to work.**

Program flexibility

- 8.43 A common theme in the submissions from the carers of children with a disability was that there is insufficient after school hours care and vacation care, which will take disabled children, to permit carers to work or look for paid employment.²⁵
- 8.44 For parents with a teenager with a disability, the problems appears to be as follows:
- Commonwealth funding for mainstream vacation care programs is limited to primary school children;

23 Autism Early Intervention Outcomes Units, sub 222, p 2; Women's Lawyers' Association of New South Wales, sub 99, p 8; Taskforce on Care Costs, sub 6, p 4.

24 The reason why the committee does not fully recommend that the proposal be implemented is because it received much less evidence on this issue.

25 National Carers Council, sub 199, p 6; Stanford J, sub 173, pp 1-2; Australian Association for Families of Children with a Disability, sub 174, p 1.

- Commonwealth funding for child care programs for children with a disability extends to the age of 17, but only for 'Commonwealth approved programs';
 - an approved program includes the requirement that children without a disability also use it (the inclusive model);
 - but the Commonwealth does not fund vacation care for teenagers, therefore, there is no demand for mainstream vacation care for secondary school children and, therefore, none exists;
 - so although the inclusive model exists on paper, it does not exist in practice because there are no mainstream programs for teenagers with a disability to use.²⁶
- 8.45 The committee agrees with the Australian Association for Families of Children with a Disability that the current situation is a Catch-22. This Commonwealth funding has been applied in a circuitous, bureaucratic manner that does not assist these families.
- 8.46 It appears that the inclusion requirement may be based more on reducing the Commonwealth's exposure to funding these services, rather than delivering outcomes for people in need. The Commonwealth argues that these services are respite care and a state responsibility. The states argue that they are after school care and a Commonwealth responsibility.²⁷
- 8.47 Such negotiations are unlikely to resolve the matter because these programs have elements of both respite care and after school care. In the view of the committee, viewing this issue as one of after school care and helping these parents work is the most complete approach. Mainstream child care empowers the parents and assists the development of the children. Denying children with a disability access to these benefits through bureaucratic rules amounts to discrimination. Families looking after children with a disability should be able to access these benefits as well.
- 8.48 The committee received a submission on a related matter from Autism Early Intervention Outcomes Units Inc (AEIOU). This group wishes to attach early intervention pods to mainstream child care centres to provide intensive early intervention for 25 hours per week per child. To
-

26 Australian Association for Families of Children with a Disability, 'Vacation Care "Catch 22"', March 2004, Edition 12, pp 1-2.

27 Hall C, 'Governments turn their backs on after school program for disabled', Stateline Victoria, 27 October 2006, viewed on 1 November 2006 at <http://www.abc.net.au/stateline/vic/content/2006/s1775428.htm>.

be of benefit, each child requires two years in the program. AEIOU estimate the savings to governments from these programs at \$1 billion annually (up to \$2 million per child over their lifetime, with 800 new diagnoses per year).²⁸

- 8.49 In order to fund the annual \$37,000 required for a placement, AEIOU would like to access the \$19,000 per child allowable under the Inclusion Support Scheme. The cost to the Commonwealth would be \$30 million annually (\$19,000 per child for two years). Funds under the scheme are available for special needs children at mainstream centres, with a maximum of 10 per cent of a centre's population being able to receive the support.
- 8.50 However, under the guidelines for the Inclusion Support Scheme, the funds can only be disbursed for the period while the child is in the mainstream centre, not the AEIOU pod. The \$19,000 per annum would be reduced on a pro-rata basis.
- 8.51 The most troubling aspect of this situation is that the Commonwealth is prepared to spend \$19,000 per annum per child on attendance at a child care centre with staff that are not required to have any expertise in caring for someone with a disability. While time spent out of the home and being around other children may be of benefit, it is unlikely to deliver the long term outcomes of an intensive early intervention program.
- 8.52 Once again, this issue appears based on a dispute between governments over responsibility. These facilities involve both child care and early intervention. Attendance at these centres allows parents to work and assist with the children's development. If community groups have the initiative to establish specialised child care centres that deliver such large returns to the community, then the committee sees no reason why Commonwealth funding should not be available.

28 Early Intervention Outcomes Units Inc, sub 222, p 2.

Recommendation 19

- 8.53 **The Department of Families, Community Services and Indigenous Affairs make access to its funding programs more flexible, including the \$19,000 per child per annum under the Inclusion Support Scheme, so that community groups and businesses can establish child care centres that have expertise in the needs of children with a disability and allow the development of after school hours care and vacation care for special needs children.**

**Hon Bronwyn Bishop MP
Chairman**

