

Department of Treasury

**Pre-Budget Submission 2009**



A national voice for families of children with a disability

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The Australian Association for Families of Children with a Disability is a national organisation representing children with a disability and their families. We are recognised and funded through the Department of Families, Housing, Communities and Indigenous Affairs (FaHCSIA). We are a non-profit, community-based organisation run by families, for all families who have a child with any type of disability.

## **VISION**

The vision of AAFCD is to provide children with a disability, the opportunity to live meaningful and fulfilling lives within safe, supportive and appropriate environments. As part of this vision AAFCD's acknowledges the critical role that families play in providing the necessary care and support to children with a disability and recognises their need to be supported in this role. AAFCD will achieve this vision by:

1. **Educating** national public policy-makers and the broader community about the needs of children with a disability and their families.
2. **Advocating** on behalf of children with disability to ensure individual choices and the best possible support and services are available to them from government and the community.
3. **Informing** families about the rights and entitlements of the child with a disability to services and support.
4. **Celebrating** the successes and achievements of children with a disability.

## **GUIDING PRINCIPLES**

The principles that guide the work of AAFCD are:

**Children the priority:** that the safety and well-being of children with disability is paramount and consistent with Australia's obligations under the international Convention on the Rights of the Child and the international Convention of the Rights of Persons with Disabilities.

**Respect:** for the views and interests of children with disability and their families.

**Recognition:** for contributions made by families to ensure the safety and well being of children with a disability.

**Inclusion:** to ensure that children with all types of disability, from all cultural and religious backgrounds and from different family structures are supported by the work of AAFCD.

**Responsiveness:** to ensure that full advantage is taken of strategic opportunities that arise from the political and social policy environment that benefit children with a disability.

**Collaboration:** with relevant non-government, government and private sector partners to promote the interests of children with a disability.

**Transparency:** within AAFCD's governance structures, decision-making processes, financial expenditure and reporting activities.

## **EXECUTIVE SUMMARY**

It is acknowledged that over the past twelve months, the Federal Government has responded to the needs of children with a disability and their families. To ensure a continuation of the Rudd Government's commitment to investing in supporting people with a disability to lead full and independent lives, it will be important to maintain a focus on unmet demand for services and support.

Our submission is based on the above premise, covers seven priority areas and is reflective of both our policy position and our representations to Government during 2008.

### **Summary of Recommendations**

#### **Priority 1 Accommodation**

Administered through the National Disability Agreement, increased allocation for independent living and supported accommodation, respite and in-home care options.

#### **Priority 2 Income Support**

Indexation of disability support pension and disability related allowances, in line with CPI and wage benchmarks.

A broadening of the eligibility criteria for the Carer Payment (child) Allowance.

Expansion of concessions available through use of the Health Care Card.

Continued provision of the annual Carer Bonus Payment.

Continued provision of the Carer Adjustment Payment.

Allocation of funds to undertake a feasibility study for the establishment of a government superannuation contribution for people receiving Carer Payment.

#### **Priority 3 Workforce Participation**

Access to individually tailored workforce assistance measures for parents of children with a disability seeking assistance to upgrade their skills or qualifications to re-enter the paid workforce.

Increased funding to support child care, out of school hours care and respite

#### **Priority 4 Aids and Equipment**

Improvement in the provision of aids and equipment to people with a disability, including wheelchairs and vehicle modifications.

Broaden the availability of tax deductions and tax credits for the purchase of disability related aids and equipment.

Allocate funding to examine viability of a national aids and equipment program.

#### **Priority 5 Early Years**

Increased funding for the Inclusion Support Subsidy Program for children with a disability accessing childcare.

Equivalent funding available through the " Helping Children with Autism Package" be provided to all children with any type of disability.

Incentives to attract more paediatric therapists to the early intervention workforce.

### **Priority 6 Education**

Improve teacher training to include core modules covering disability awareness, behaviour management, adaptive technology and specialist education techniques for teaching children with a variety of learning needs.

Address the shortage of fully trained specialist teachers for mainstream and special education settings.

Funding portability across primary and secondary education settings.

Expansion of the out of school hours program for secondary school students with a disability

### **Priority 7 Future Funding Options**

Progress the 2020 Summit recommendation to “Establish a National Disability Insurance Scheme”, to support the families of children with brain injury from birth and other non-insurable injuries.”

Allocate funding to undertake a feasibility study to progress recommendations from the report by The Disability Investment Group into future funding options.

## Priority 1 Accommodation

*"From the day we found out 15 years ago that our son had a disability, we have faced (and got through) many challenges..... but I am worried about the future. It is hard to imagine what life will be like in 10 years when our son will be 25. I am hoping by then that he might have somewhere to live and support to live independently".*

AAFCD believes that all people including those who have a disability should have the option to move out of the home of their first family and live their lives independently of their parents and siblings. For people with a disability this should be an automatic assumption even though added supports are needed to ensure they are able to live full and meaningful lives within a safe, appropriate and nurturing environment.

Overnight residential respite stays for children with a disability often extend into longer-term accommodation due to relinquishment. This tragic and unacceptable situation impacts not only on the family facing the crisis but on other families as available respite placements are reduced.

### **What is needed**

Increased allocation for independent living and supported accommodation, respite and in-home care options.

The Rudd Government's responsible response to the current economic environment includes public investment in infrastructure. AAFCD believes that this expenditure should include disability related projects such as those identified above.

### **Specifically:**

Administered through the National Disability Agreement, increased allocation for independent living and supported accommodation, respite and in-home care options.

An extension beyond the 2008 commitment to provide 24,000 supported accommodation.

Increased residential respite and in home care options available to young people with a disability.

## Priority 2 Income Support

*"My son takes three types of medication, only one of which is listed on the PBS. This means that his medications cost up to \$80 a month."*

AAFCD acknowledges the statement made by Access Economics (2005) that the contribution carers make to society in Australia is estimated to be \$30.5 billion per year in replacement costs. In 2009 there is no doubt that this figure will increase. Care giving can come at a high personal cost to those who provide care, including financial, health and wellbeing and social exclusion.

### **What is needed**

Greater recognition of the support role undertaken by carers.

### **Specifically:**

- Indexation of disability support pension and disability related allowances, in line with CPI and wage benchmarks.

- A broadening of the eligibility criteria for the Carer Payment (child) Allowance.

- Expansion of concessions available through use of the Health Care Card.

- Continued provision of the Carer Adjustment Payment.

As part of the broader Federal review of taxation the financial costs of caring need to be quantified and taken into consideration.

### **Specifically:**

- Tax deductibility of caring expenses.

For many Australians caring is a lifelong responsibility and many have a limited opportunity to accumulate superannuation due to their caring responsibilities. It seems unfair that carers should face financial insecurity in their old age because they chose to take on a caring role.

### **Specifically:**

- Allocate funding to undertake a feasibility study for the establishment of a government superannuation contribution for people receiving Carer Payment.

### **Priority 3 Workforce Participation**

*"Although I have a professional qualification, it is very hard to me to find work that I can fit around my son's needs. I need to work in order to help meet the costs of his therapy and medication."*

For many carers there are reduced opportunities for workforce participation, particularly given the limited availability of support services, such as child care, out of school hours care and respite. There is also an absence of industrial mechanisms that recognise the caring role.

#### **What is needed**

Initiatives that encourage and support carers to return to the workforce are essential.

#### **Specifically:**

A new package of individually tailored workforce assistance measures to be made available to parents of children with a disability seeking assistance to upgrade their skills or qualifications to re-enter the paid workforce.

Increased funding to support child care, out of school hours care and respite.

## Priority 4 Aids and Equipment

*"I had him assessed, but then they said they couldn't actually provide any services. I said "you must be joking!" But they weren't."*

The critical nature of therapeutic interventions in the early stages of diagnosis for children with a disability is well documented. Languishing on waiting lists for the right type of equipment usually means the success of early intervention strategies is severely jeopardised.

Long term effects of caring often expose parents and family members to injury, reducing their capacity to care and impacting on their own health and wellbeing. This is a vexed issue as informal carers sustaining an injury in the home are not covered by occupational health and safety regulations, even though for carers, the home is their workplace.

### **What is needed**

Timely access to aids and equipment to increase the success rate of early intervention strategies and to reduce the risk of carer injury.

### **Specifically:**

Improvement in the provision of aids and equipment to people with a disability, including wheelchairs and vehicle modifications.

Broaden the availability of tax deductions and tax credits for the purchase of disability related aids and equipment.

Allocate funding to examine viability of a national aids and equipment program.

## **Priority 5 Early Years**

*"When I found out that my youngest child had a disability I didn't cope very well at all. When I finally got through the fog to start talking to people about support services, it was a huge disappointment to discover that there were long waiting lists for access to early childhood intervention services. Before it happened to me, I just assumed that if you had a child with a disability there would be services you could access straight away".*

The support children with a disability receive in the early years is a crucial determinant in their overall development. Providing better support early in their lives is a sound long-term economic investment and directly affects their capacity to realise their full potential.

### **What is needed**

A commitment to the provision of a comprehensive system of support for every child with a disability during the early years.

### **Specifically:**

Increased funding for the Inclusion Support Subsidy Program for children with a disability accessing childcare.

Equivalent funding available through the " Helping Children with Autism Package" be provided to all children with any type of disability.

Incentives to attract more paediatric therapists to the early intervention workforce.

## Priority 6 Education

*“When we started out looking at schools, there were some that made it obvious they weren’t enthusiastic about taking our child. So much depends on the attitudes of the school staff. “*

Every child deserves the chance to learn and to realise his/her full potential. When schools are appropriately resourced and committed to working in partnership with families to grow all students’ strengths and abilities, the results that follow benefit everyone.

### **What is needed**

Children with a disability and their families need to be able to choose quality educational options across all types of education settings throughout Australia.

### **Specifically:**

Improve teacher training to include core modules covering disability awareness, behaviour management, adaptive technology and specialist education techniques for teaching children with a variety of learning needs.

Address the shortage of fully trained specialist teachers for mainstream and special education settings.

Funding portability across primary and secondary education settings.

Expansion of the out of school hours program for secondary school students with a disability

## Priority 7 Future Funding Options

*"Our son will need support because we won't live forever. I think every parent with a child with a disability has concerns about the future."*

### What is needed

The disability service system as it is currently configured cannot adequately meet demand. Projected increases in the proportion of the population with a disability, coupled with a decline in the number of unpaid carers available to provide support will lead to very large increases in the costs of disability.

This is similar to the problem identified in the 1980s, when it was recognised that an ageing population dependent on old age pensions would place an extreme burden on taxpayers.

Two insurance schemes are currently being proposed as a means of addressing these issues:

The National Disability Insurance Scheme

The No Fault Catastrophic Injury Insurance Scheme

AAFCD supports all children with a disability and their families living in Australia and therefore sees merit in both schemes.

### Specifically:

Progress the 2020 Summit recommendation to "Establish a National Disability Insurance Scheme", to support the families of children with brain injury from birth and other non-insurable injuries."

Allocate funding to undertake a feasibility study to progress recommendations from the report by The Disability Investment Group into future funding options.

**Elizabeth McGarry**  
Chief Executive Officer