

**Submission on  
National Human Rights Consultation**

**June 2009**



A national voice for families of children with a disability

Suite 2, 98 Morang Road, Hawthorn 3122

Phone (03) 9818 2000 or 0419 595 468

[www.aafcd.org.au](http://www.aafcd.org.au)

Contact: Elizabeth McGarry, Chief Executive Officer  
Stephanie Gotlib, Policy and Membership Co-ordinator

The Australian Association for Families of Children with a Disability (AAFCD) is a national organisation representing children with a disability and their families. We are funded through the Department of Families, Housing, Communities and Indigenous Affairs (FaHCSIA). We are a non-profit, community-based organisation. We work alongside families of children and young people with disability.

## **VISION**

The vision of AAFCD is for children with a disability to be provided with the opportunity to live meaningful and fulfilling lives within safe, supportive and appropriate environments. As part of this vision AAFCD 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.

## **Introduction**

Many in our community assume human rights are well protected within Australia. This sentiment was often expressed during the National Human Rights community consultation which AAFCD attended. The reality for many children with a disability and their families is diverse. This consultation is timely and AAFCD welcomes the opportunity to provide a submission on the National Human Rights Consultation. It is hoped that extensive consideration and action is taken to ensure human rights are better protected and promoted in Australia.

AAFCD is passionately committed to working towards creating a society that recognises and protects the rights of children with a disability. Furthermore, it strongly believes that there needs to be formal recognition of human rights which in turn is reflected in the every day life experiences of children with a disability and their families.

AAFCD applauds the ratification of the Convention of the Rights of Persons with Disabilities. Despite Australia being a Party to this Convention, children with a disability and their families too frequently cite experiences in Australia where their human rights are simply not recognised and at times blatantly violated.

## **Which Human Rights (including corresponding responsibilities) should be protected and promoted?**

The human rights which are defined in International Human Rights treaties to which Australia is presently a Party, should be protected and promoted at all times across the broader community.

AAFCD particularly stresses those rights and obligations which are contained in the Convention of the Rights of People with Disabilities -

- equality before the law without discrimination
- right to life, liberty and security of the person
- equal recognition before the law and legal capacity
- freedom from torture
- freedom from exploitation, violence and abuse
- right to respect physical and mental integrity
- freedom of movement and nationality
- right to live in the community
- freedom of expression and opinion
- respect for privacy
- respect for home and the family
- right to education
- right to health
- right to work
- right to an adequate standard of living
- right to participate in political and public life
- right to participate in cultural life

## **Are these Human Rights currently sufficiently protected and promoted?**

Members of AAFCD are still too frequently confronted with situations where their children are subjected to discrimination, low expectations, limited resources and opportunities and poor quality support in most areas of their lives. It is the view of AAFCD that the rights of children with a disability are not sufficiently protected and promoted in Australia.

Central to the work of AAFCD is gathering evidence of the direct experiences of children with a disability and their families. Families tell us first hand about their daily lives and the challenges they face. Their stories inform our representations to policy makers and key stakeholders. All too often families of children with a disability have to engage in robust advocacy or take legal action to ensure that their child is afforded the same rights and opportunities as other children.

Equally AAFCD has observed that families of children with a disability are often either unaware of their children's rights or are under the mistaken impression that to have a child with a disability means accepting inadequate solutions that compromise their child's quality of life and undermine their human rights. It is just seen as "part of the deal".

Some families tire from their ongoing battle to have their children's rights recognised. Families are often faced with having to continually advocate for their children's rights to access services, resources and opportunities. It is a time consuming and exhausting process. As a consequence, families are often forced to prioritise their issues of concern and acquiesce in some situations thereby forfeiting recognition of their children's rights.

Below are real life examples which highlight the experiences of children with disability and their families:

- **An 8-year-old boy (fully continent) was utilising bus transport provided by government to travel to and from a disability specific school. Average travel time from home to school was 2 hours. If the boy needed to go to the toilet during the trip he was unable to use toilet facilities. The policy covering such situations consisted of the provision of an absorbent towel in the event that the child had a toilet accident because he could not wait any longer.**
- **A child with a neuro-degenerative condition waited more than a year for a wheelchair before being given an unsuitable one he was unable to use.**
- **A family was considering the best school options for their pre-school aged son who has a disability. For a variety of reasons the preferred option was the local primary school. His parents were told he will only be able to attend the local primary school until the end of Grade 3 as classes for the remaining primary school years are not held in rooms on the ground level and therefore are not wheelchair accessible.**

- **A 9-year-old boy attends a mainstream school on a full time basis with inclusion support. His inclusion aide is unwell. The school does not take responsibility for securing a replacement aide, but rather informs the family that their son cannot attend school until his aide returns to school.**
- **A boy was accessing residential respite for the weekend. Staff were informed of his needs and were provided with a well documented history of his epilepsy which required ongoing supervision. He had a seizure in the bath whilst unsupervised and drowned.**
- **A young adolescent male wanted to attend a local rock concert. Concert organizers informed him that there were no wheelchair accessible tickets available. He arranged to attend the concert with his parents who had undertaken to lift him from his wheelchair into 'general' seating. Upon arrival he observed that the area normally designated for wheelchairs had been reallocated as able bodied seating.**
- **A child was excluded from a teacher's classroom and eventually the whole school because he had a "death stare" - he had autism.**
- **A 14-year-old boy was taken to a riverside community attraction for his weekend respite activity. He was left unsupervised and went missing. He was subsequently found some days later after he had drowned in the river.**
- **For 17 years a mother has attempted to secure permanent supported accommodation for her son who has physical and intellectual disability. Her son is now 32 years of age. She comments "I believe I have more chance of winning the lottery than obtaining accommodation for my son".**
- **As an acceptable strategy to safeguard a student from hitting his head, school personnel tied a student to his chair for all class lessons and then tied him to a pillow on the floor during other activities.**

## **How could Australia better protect and promote human rights?**

AAFCD believes it is imperative that Australia develops legislation to define, recognise and protect the human rights of all Australians, including children with a disability. This formal recognition of rights sends a clear message to the Australian community of the importance of rights and that they must be acknowledged, protected and afforded at all times.

Australian children with a disability are too often being denied their rights. As a consequence these children are denied opportunities to realise their full potential, subjected to unacceptable treatment and suffering, and on occasion premature death has resulted. The impact on their lives and their families is significant. Every possible action must be taken to improve this situation. It is believed that the introduction of a National Bill of Rights is a vital first step.

It is also essential that a comprehensive promotion and implementation strategy to accompany a National Bill of Rights needs to be developed. Such a strategy must not only involve educating all sectors of the community but must ensure laws and policies developed as a result of the Bill translate into the every day experiences of all Australians, including children with a disability.



Elizabeth McGarry  
**CHIEF EXECUTIVE OFFICER**