

Telephone: 07 3247 5525
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5 December 2008

National Disability Strategy
PO Box 7442
Canberra Business Centre
ACT 2610

To Whom It May Concern

We are pleased to enclose a submission on the National Disability Strategy.

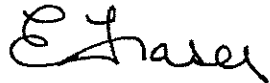
This submission is prepared jointly by the following:

- Ms Elizabeth Fraser, Commissioner for Children and Young People and Child Guardian, Queensland
- Ms Gillian Calvert, Commissioner for Children and Young People, New South Wales
- Ms Pam Simmons, Guardian for Children and Young People, South Australia
- Mr Bernie Geary, Child Safety Commissioner, Victoria
- Mr Paul Mason, Commissioner for Children, Tasmania
- Ms Michelle Scott, Commissioner for Children and Young People, Western Australia
- Dr Howard Bath, Children's Commissioner, Northern Territory
- Dr Helen Watchirs, Acting Children and Young People Commissioner and Human Rights and Discrimination Commissioner, Australian Capital Territory

With your approval we would like to place a copy of the submission on the Commissions' and Guardians' websites. Making work such as this publicly available is one way of demonstrating our accountability to the children and young people in our jurisdictions. Your consideration of this request at the appropriate time would be much appreciated.

If you require any further information, please contact the Director, Strategic Policy and Research at the Queensland Commission for Children and Young People and Child Guardian's, Ms Julie Harcourt on 07 3247 5051 or at julie.harcourt@ccypcg.qld.gov.au.

Yours sincerely

A handwritten signature in black ink, appearing to read 'E Fraser', written in a cursive style.

Elizabeth Fraser
**Commissioner for Children and Young People
and Child Guardian**
(on behalf of the other Commissioners)

The Commission for Children and Young People and Child Guardian

promoting and protecting the rights, interests and wellbeing of all Queenslanders under 18

Advice to: The Department of Families, Housing, Community Services and Indigenous Affairs

Topic: Developing a *National Disability Strategy* for Australia Discussion Paper

Date due: 1 December 2008

Thank you for providing an opportunity to comment on the *National Disability Strategy* (the Strategy) Discussion Paper.

This submission is a coordinated response on behalf of the members of the Australian Children's Commissioners and Guardians* (the Commissioners and Guardians) and is endorsed by:

- Ms Elizabeth Fraser, Commissioner for Children and Young People and Child Guardian, Queensland
- Ms Gillian Calvert, Commissioner for Children and Young People, New South Wales
- Ms Pam Simmons, Guardian for Children and Young People, South Australia
- Mr Bernie Geary, Child Safety Commissioner, Victoria
- Mr Paul Mason, Commissioner for Children, Tasmania
- Ms Michelle Scott, Commissioner for Children and Young People, Western Australia
- Dr Howard Bath, Children's Commissioner, Northern Territory
- Dr Helen Watchirs, Acting Children and Young People Commissioner and Human Rights and Discrimination Commissioner, Australian Capital Territory

The prime focus of the Commissioners and Guardians is on promoting the safety, interests and wellbeing of children and young people, particularly those most vulnerable.

The Commissioners and Guardians support the Australian Government's development of a *National Disability Strategy* (the Strategy) and endorse its intention to incorporate the National Disability Reform Agenda and align the Strategy with the *United Nations Convention on the Rights of Persons with Disabilities*. The Commissioners and Guardians also strongly endorse the Strategy's intention to acknowledge the need to tackle attitudinal barriers preventing those with disabilities from realising their aspirations and achieving full participation.

The following recommendations focus predominantly on children and young people (herein referred to as children and accounting for those up to 18 years of age) with a disability and their families, but it also recognises the issues of siblings of children with disabilities and children as carers of parents and family members with disabilities.

* The Australian Children's Commissioners and Guardians is comprised of all Australian Children's Commissioners and Child Guardians..

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The Commissioners and Guardians recommend that the Strategy include and/or address the following:

1. Be based on a rights entitlement
2. Consult with and listen to the views of children in the Strategy's development and implementation – avoid labels
3. Tackle barriers and promote social inclusion
4. Improve access to support services for children and their families using a flexible whole of family approach
5. Address the care and living needs of high care children
6. Identify and address the care needs of children with a disability in state care
7. Provide support for young people with a disability to live as independently as possible
8. Address the support needs of children as carers of parents, siblings and others with a disability and as siblings of children with a disability
9. Build a sustainable workforce
10. Identify the monitoring processes for respite services
11. Negotiate national definitions of disability
12. Improve data collection by funded services

1. Be based on rights entitlement

The Commissioners and Guardians are of the view that the Strategy should be based on rights entitlement, informed by, but not limited to, the United Nations (UN) Convention on the Rights of the Child, the United Nations Convention of the Rights of People with Disabilities and the *Disability Discrimination Act 1992* (Cwth). This aligns with the Strategy's focus on disability inequality. The needs of people with disabilities should be at the centre of planning and service provision. Article 4 (1) (c) of the UN Convention on the Rights of Persons with Disabilities states that countries must 'take into account the protection and promotion of human rights of persons with disabilities in all policies and programs'. International human rights is underpinned by substantive equality and allows for positive action that goes beyond temporary special measures to accommodate fundamental differences and achieve equal treatment. There is a trend internationally towards a more pro-active model of eliminating discrimination, including South Africa, England, Northern Ireland, Scotland and Wales.

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2. Consult with and listen to the views of children in the Strategy's development and implementation – avoid labels

Article 4(3) of the UN Convention on Rights of Persons with Disabilities, states that in implementing this treaty, countries 'shall closely consult with and actively involve persons with disabilities, including children with disabilities'. Further, Article 12 of the UN Convention on the Rights of the Child, provides that a child has the right to express their views in all matters affecting them. The Strategy will be best formed, and subsequently implemented, through flexible and accessible consultation with children with disabilities, carers and siblings to ensure that their needs are most appropriately met and their opportunities to reach their potential are optimised.

Where the Commissions have talked with children with disabilities, a recurring theme is that they want to be normalised rather than labelled as 'disabled'. Similarly children caring for family members with a disability don't want to be labelled as 'young carers'. As with other children, first and foremost they want to be recognised as a person. As such, they want services and support provided in as 'normal' a context as possible given their physical and/ or intellectual circumstances.

3. Tackle barriers and promote social inclusion

The Strategy should promote whole of government action to tackle the attitudinal barriers and potential stigma associated with disability. A key tenet should be the commitment to collaborative action at a state and national level to address such attitudes rather than approaches that are limited to existing responsibilities of Commonwealth or state departments.

The Strategy needs to address the serious disadvantage and discrimination which children with a disability and their families face in influencing and accessing a wide range of normative environments, experiences, opportunities and activities. Potential for optimising healthy development, independence and long term wellbeing is dependent on having 'a voice' and meaningful participation. It is unreasonable that children with a disability, and their families, have to struggle for access and participation rights to social processes that we all take for granted.

4. Improve access to support services using a flexible whole of family approach

One of the key matters impacting on children with a disability is access to appropriate support services at each stage of development from infancy and early childhood, through to adulthood. Access to appropriate services at the right time can make the difference between a family coping and not coping or a child engaging in universal services or becoming marginalised. It is important that the Strategy recognise the potential impacts and support needs of the whole family, particularly, where a family member has a profound disability.

Families require more flexibility in service delivery to respond to changing circumstances and the unique needs of their child. For example more respite care may be needed at times when families are under increased stress and domestic support needs often change during school holiday periods. Services should be

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sufficiently flexible so that children and their families are able to access support when they need it.

For children with a disability the Strategy needs to focus on improving access to universal services, not only for routine public health monitoring, surveillance and service delivery, but also for early diagnoses; early intervention services; and therapy and education services to enable them to participate as fully as possible and reach their development potential. To recognise and plan for the effective support services needed for the whole family the Strategy needs to:

- **Provide support so that young children with a disability below school age can access universal services** - currently, most access to universal services for children with a disability is for those aged six and upwards. Those children with a disability under school age need support to access universal services such as child care, kindergarten, prep and pre-school.
- **Improve access to early intervention services** – being able to access appropriate services early, such as one-to-one programs and tailored activities for small numbers of children and their families improves children’s participation and development, as well as family functioning
- **Improve access to therapy services for pre-school and school aged children** – currently demand for therapy services for pre-school and school aged children with a disability outweighs supply many times over. Being unable to access therapy reduces children’s capacity to participate in education or other training, including vocational training.
- **Improve services to support the educational needs of children with a disability** – the educational needs of children with a disability can be met through their inclusion in mainstream classes, specialised services co-located with mainstream services, or in separate facilities, as appropriate to the needs of each child. Children need to be supported in each of these settings and in particular, supported to attend the most appropriate setting for their needs. For example, children who, with some support, could attend mainstream classes should not be denied such involvement because the relevant supports are not available.
- **Improve access to early diagnostic services** – it is important that children’s disabilities are diagnosed as early as possible so that appropriate supports and therapies can be put into place. The greater the delay the more detrimental the impact on the child’s social and educational functioning. Currently, many children miss out on appropriate support at school, and also become socially marginalised because their problems are not diagnosed early.
- **Improve the range of, and access to, community and centre-based support for families with a child with disability** – Families with a child with a disability can become very isolated as they struggle with the physical,

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emotional and financial burden of caring for the child. Community and centre-based supports can provide coordinated opportunities for families to connect with other families with a child with a similar disability, or access to other group or community interaction and support for the family. Community support should not be seen as the entire solution, however, as families will still require services such as respite services and specific programs to support their individual needs.

- **Improve the accessibility of public transport**

Another key area where people with a disability face difficulties is the accessibility of public transport. The Australian Bureau of Statistics Survey of Disability, Ageing & Caring suggests that governments should predict and provide for an increased reliance on accessible transport services. This can impact on children with a disability as a lack of accessible public transport can lead to marginalisation and dependency and increase difficulties to do all things that people without a disability take for granted¹.

The Strategy will need to identify that these services are to be standard for children with a disability so that appropriate funding allocations are made to provide these services. This may involve reassessing the cost effectiveness of current programs and comparing them with the longer-term effects of supporting children at a younger age.

5. **Address the care and living needs of high care children**

The Strategy should identify how it will address the high level care needs of children with profound disabilities that require care that is beyond the capacity of a family to provide. Providing care for a child with extreme disabilities is demanding beyond measure. It is not sufficient to hope or expect that families can or should be able to cope with this situation around the clock for years on end with minimal support services and occasional respite care.

The issue of centre based care is one that for several decades has been consistently avoided, both from a philosophical perspective and from a consideration of the cost. Currently, in most jurisdictions, the only option for parents when they can no longer cope with providing the level of care for a child with extreme high care needs is for them to relinquish the child to the child protection system, which means parents lose guardianship and consequently a say in their child's upbringing, as well as being tainted by the 'abusive parent' tag associated with the child protection system.

It is not appropriate that the negatives associated with relinquishing a child into the care of an agency outside the family unit is used as a demand control measure to prevent parents from seeking out of home care for their child. The framework needs to be open in its recognition of the extent of the care needs of some extreme care children and address the options for how they can be cared for.

¹ From "The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport" The Human Rights Commission of New Zealand October 2005

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The Strategy also should recognise and address the support needs for families who do maintain such extreme needs children at home and recognise the potential impacts and need for support across the whole family. In such cases the best outcomes for the child may come through support to the parents including access to regular respite care and recognising the costs of equipment, aides, medications and dietary preparations, home modifications and special vehicles.

6. Identify and address the needs of children with disabilities in state care

The Strategy needs to identify how it will address the care needs of children with a disability who are in the care of the State, so that these children's needs are resourced in a manner sufficient to meet additional needs and costs related to their disability.

7. Provide support for young people with a disability to live as independently as possible

It is recommended that appropriate and effective programs and support are identified to enable young people with disabilities to sustain developmentally appropriate independence or respectful co-dependence in adulthood. This may be achieved in part by encouraging and supporting sporting, social, recreational, occupational and post-secondary educational activities and past-time access; participation and inclusion of children with a disability commensurate with the level of access and participation expected by children generally.

8. Address the support needs of children as carers of parents, siblings and others with a disability and as siblings of children with disabilities

The Strategy needs to recognise the support needs of children caring for parents or family members with a disability and provide adequate support to the whole family to reduce and prevent the need for children to take on inappropriate caring roles. This includes recognising children who are both primary and secondary carers. Children with caring roles face significant challenges maintaining school attendance, completing their schooling, and participating in the social and sporting activities of their peers. The challenges and difficulties of these children need to be considered and addressed in the Strategy. Similarly, children with a sibling with a disability can miss out on opportunities through the demands on their parents' time and emotional and financial resources. Children may also need support to deal with the perceived stigma or attitudinal issues that arise from a parent or sibling with a disability. The Strategy should identify these children as stakeholders and recognise their support needs.

9. Build a sustainable workforce

The Strategy needs to include systems to sustain and build the workforce providing support services to people with a disability. This will need to take into account the likelihood of reduced levels of volunteerism in Australia; the need for improved staffing levels for respite care; the staffing implications relating to the increased expectations around maximising independence for young people with a disability; and the additional staffing requirements resulting from the increased life expectancy for preterm, medically compromised infants.

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Additional staffing is needed to provide a coordinated response to support families earlier in their caring role. Investment in improved training, supervision, wages, conditions for people who are employed to provide support services are required to recognise the value and importance of the role that staff perform in society. Providing such a continuum of care requires a level of service collaboration that currently does not exist.

10. Identify the monitoring processes for respite services

The Strategy needs to identify how respite and other care services for children with a disability will be monitored and regulated to ensure that quality and standards are maintained. This will also necessitate identifying the training needs of staff and the levels of resourcing and support required in such services.

11. Negotiate national definitions of disability

To ensure consistency across jurisdictions, the Strategy should negotiate national definitions of disability, common assessment tools and a national data base in support of:

- the use of internationally accepted benchmarks and definitions
- greater agreement across jurisdictions about diagnosis, need, thresholds for access, and capacity in the system
- more seamless service provision across the states and across state-national jurisdictions, and
- greater interdisciplinary capacity for responding more holistically to the needs of children with a disability.

The *Disability Discrimination Act 1992* is not aligned to the *World Health Organisations 2001* terminology relating to 'disability'. This is leading to jurisdictions defining 'children with disability' to fit with available funding rather than an agreed national/international definition.

This tension between the classifications of disability and the allocation of services providing support is leading to some children with a disability being overlooked for appropriate, needs-led care and support because of the nature of their disability and perceived likelihood of fulfilling their potential.

The Strategy will be best formed, and subsequently implemented, through consistent and regular consultation with children with disabilities, carers and siblings to ensure that their needs are most appropriately met and their opportunities to reach their potential are optimised.

12. Improve data collection by funded services

There is limited information available from funded services about the numbers and nature of the services they provide and the effectiveness of those services. Consequently, it is recommended that the Strategy include a requirement for funded services to collect data on:

- the number of children with a disability who use the service

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- the nature of the disability and whether or not the agency has strategies, policies, programmes etc for facilitating/encouraging access, participation, complaints and feedback, and
- the outcomes for children with a disability receiving the service.

Every effort should be made to ensure that the effect of collecting such information is to enhance service provision, rather than hinder service provision or impose an undue administrative burden on the agency, and to encourage best practice and awareness of disability as a challenge for agencies, children and their families, and increase individual achievement for children with disabilities.

Please do not hesitate to contact Julie Harcourt, Director, Strategic Policy and Research at the Queensland Commission for Children and Young People and Child Guardian (ph: 07 3008 8985; e-mail: julie.harcourt@ccypcg.qld.gov.au) should any aspects of this advice require clarification.