

16 August 2010
CSCD/10/746

Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

Dear Sir/Madam

The Victorian Office of the Child Safety Commissioner (OCSC) welcomes the opportunity to provide a submission to the Productivity Commission's Issues Paper on Disability Care and Support. In general terms, the OCSC has a fairly wide legislative mandate to focus on the safety and wellbeing of all children in Victoria. Consistent with the *Child Wellbeing and Safety Act (Vic) 2005*, all references to 'child' in this submission are to those who are aged under 18 years. This inquiry provides an important opportunity to create a system which provides appropriate support to children whose lives are impacted either by their own disability or by the disability of a parent, carer or other family member.

The OCSC also has particular legislative functions in relation to the safety and wellbeing of the very vulnerable children known to child protection and those who live in out-of-home care. Some of these children have a disability themselves or have a parent with a disability. Any new system of funding and service provision for people with disabilities should also explicitly consider how the best interests of children will be protected for those children and families who are known to both disability services and child protection services.

Rather than address the broad range of issues canvassed in the discussion paper, we have focused our comments on the following issues:

- Ensure children have access to services which are appropriate to their age and development and further their best interests
- Strengthen and support families
- Prioritise funding for the education of children with disabilities
- Enhance services to those very vulnerable children with disabilities who are also known to child protection
- Be founded on core human rights principles

We have discussed each of these issues in more detail below.

Ensure children have access to systems and services which are appropriate to their age and development

"In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." (Convention on the Rights of the Child, Article 3)

The terms of reference for this inquiry seek options for the development of "long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account of the desired outcomes for each person over a lifetime". While the word "person" is clearly intended to include 'child', it is important to ensure that children are a specific focus of the inquiry. This is particularly important in:

- *Formulating the criteria and processes for determining who qualifies for benefits under any new scheme.* For some young children it may not be possible at the outset to identify with precision the nature of a child's disability or its ongoing impact and for some the severity of the impact of the disability may also vary over time. Lack of precision in diagnosis or assessment should not equate to lack of services for children. Given the importance of early intervention services, criteria for children to access entitlements should be inclusive and flexible. Any doubt as to whether a child qualifies for an entitlement should be resolved by assuming the child is entitled to receive services, rather than denying entitlement.
- *The types of services provided.* Children with disabilities should be supported to the maximum extent feasible to participate in life's ordinary childhood experiences. Any new service system should foster the development of child friendly and child appropriate services and the development of inclusive early childhood and educational services. Children with disabilities should not be expected to reside in services, such as nursing homes, which are clearly designed to meet the needs of adults. New funding arrangements should foster the development of services and professionals who have specific expertise in providing services to children with a disability.
- *New governance and accountability arrangements.* Any new system should expressly include requirements that at least some of those charged with overseeing or administering the systems have expertise in, or take on the role of advocating for, children with disabilities. Similarly, any new governance bodies should be required to ensure that the perspectives of parents of children with disabilities are included on any boards or in the development of any policies and procedures.

Strengthen and support families

Testimony and submissions provided to date to the Commission have highlighted the profound impact families can have in advocating for and supporting their children. Many parents not only support the day to day needs of their children, but also champion their rights as they battle service systems which at times appear to be ineffective or obstructive. We strongly support the creation of a service system which actively supports families, minimises the administrative burden placed upon them to apply for, locate and coordinate services while still providing a real choice in services. We also support the creation of strong advocates for those children whose families are not able to advocate for their children's best interests.

The Commission should also ensure any new scheme recognises the impact of disability on those children whose parents or siblings have a severe or profound disability. Many of the submissions have powerfully highlighted the challenges confronting parents as they try to care

for their child/ren with a disability and at the same time care for other children within the family. A voice which appears to be missing from the submissions is that of children who have parents with disabilities. We would encourage the Commission to actively seek out these children, so that their experiences and aspirations can inform the inquiry. In determining the level of support to which a parent with a disability may be entitled, the Commission should ensure provision is made to best support the parent to care for his/her children and to enable their children to participate in normal childhood activities.

Prioritise funding for education of children with disabilities

"ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development" (Convention on the Rights of the Child, Article 23)

The OCSC is aware that children with disabilities often confront a range of challenges in accessing appropriate educational services. We hear from parents and advocates that 'the system' is failing children because resource levels are inadequate. Of particular concern is the lack of sufficient resources for integration aides and the challenges of applying (and reapplying) for the limited funding which is available. This review provides a unique opportunity to consider the issue of funding for educational supports; moving beyond questions such as 'whose responsibility is it to provide funding for the integration aide' to the real issue of 'what type of supports will best enable this child to maximise his/her potential'.

Another concern which has been brought to our attention is that of long travel times for children who attend specialist schools. Our office has been contacted by a parent whose son travels for up to four hours a day on the bus to attend a school. Being confined to a bus for such a large part of the day has an adverse impact on his health and wellbeing and his ability to maximise his educational opportunities. This child's parents have taken every opportunity to advocate for their son while still trying to provide the best possible care for him. Any new system must ensure that as a minimum, children, such as this young boy, can attend school without it having an adverse impact on their health and wellbeing, and without the need for their parents to constantly battle for basic services.

Any new scheme will fail to meet the needs of children if it does not create new sources of funds to enable children with disabilities to fully participate in education. We note the focus of the inquiry is on those people with severe or profound disabilities. In the context of education and early intervention services, funding should also be provided for children with more 'moderate' disabilities. We note that some of the submissions received to date have referred to the particular issues faced by children who have autism spectrum disorders who may not have a significant intellectual disability but who do need specialist supports in school. The new system should ensure these children are provided with the resources required to ensure they can participate in education.

Enhance services to those very vulnerable children with disabilities who are also known to child protection - overlap between disability services and child protection

The out-of-home care sector in Victoria comprises children who live in statutory kinship care, foster care or residential care. Approximately 8,000 children in Victoria experienced out-of-home care in 2008-09.¹ Issues relating to support for people with a disability overlap with those of protecting these very vulnerable children. A recent investigation into the Victorian out-of-home care system by the Ombudsman noted:

¹ Ombudsman Victoria (May 2010) *Own Motion Investigation into Child Protection- out of home care*, available at www.ombudsman.vic.gov.au.

"Data generated for the 'Looking After Children Data Outcomes Project Report' suggests an over-representation in the number of children in out of home care with 'a condition likely to have [a] profound impact on his or her cognitive and socio-emotional development'. More than one half of the study sample (aged three to 17 years) were identified as having a developmental delay or learning difficulty.

A 2008 report titled 'Educational Characteristics of Children and Young People in the DHS Out of Home Care Caseload' found 12.4 per cent of the sample of school aged children were receiving funding from programs for students with a disability or attending a specialist school setting."²

In considering who might be most in need of support, the Commission should expressly consider the needs of those children with a disability who are also clients of the child protection system. For some children with a disability, the State has assumed the role of parent. Such children are extremely vulnerable and would be among those most in need of support. Any new service and funding system must ensure that children in the care of the State have no less entitlement to services and funding than those who live with their families. Entering the care system should not result in exiting the funding and service system available to other children.

In addition, for children who are in the care of the State, extra safeguards must be put into place to ensure that they have independent and effective champions to advocate for them. The Ombudsman's report includes examples of the challenges faced by some of the children who in a sense are clients of two service systems, neither of which seems to be able to adequately meet their needs:

"I reviewed a number of cases in which appropriate placement matching did not occur and children involved were not provided with the level of supervision necessary to ensure their safety.

In one instance, a five year old child with autism was sexually assaulted in a residential care unit by a 16 year old boy. The five year old was in the unit under a contingency arrangement because the region lacked funded placement options that were able to meet his specialised care needs."³

Participation Rights of Children

"States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child." (Convention on the Rights of the Child, Article 12)

The Convention on the Rights of the Child emphasises the importance of supporting children to be informed about and participate in the decisions which impact upon their lives. For most very young children and those children with significant intellectual disabilities, parents are best placed to make decisions on behalf of their children. The new system should be one which recognises the expertise of parents in terms of the needs and abilities of their own children and families. However, as children's capacities develop, their own expertise in terms of what they themselves want and need should also be acknowledged and respected. If parents are to be given new responsibilities to manage funds and services, they must be supported to do so. Mechanisms will also need to be created to allow for appropriate ways to determine when children should be able to make decisions for themselves and to resolve any conflicts when the expressed desires of children are contrary to those of their parents. In addition, safeguards must be put into place to ensure that for those children whose parents are unable to act in their child's best interests, an appropriately resourced advocate is able to do so.

² Ibid, p. 82.

³ Ibid.

We believe this inquiry provides an important opportunity to address the quite desperate situation faced by many children and their families arising from a lack of effective services and resources to support people with disabilities. We look forward to learning more about the progress of this inquiry and are happy to provide further information should you wish us to do so.

Yours sincerely

Bernie Geary OAM
Child Safety Commissioner