

19 February 2010

The Director  
General Purpose Standing Committee No. 2  
Parliament House  
Macquarie St  
Sydney NSW 2000

## Re: Inquiry into the provision of education to students with disabilities or special needs

Carers NSW thanks the General Purpose Standing Committee No. 2 for the opportunity to provide submission into the Inquiry into the provision of education to students with disabilities or special needs attending primary or secondary schools.

### 1. Introduction

#### 1.1 About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by the community and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

#### 1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW, there are estimated to be approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

Carers exist in all communities, including amongst Aboriginal communities, those of cultural and linguistically diverse backgrounds, amongst Gay, Lesbian, Bisexual, Transgender and Intersex communities, and throughout metropolitan, regional and rural NSW.

### **1.3 Submission format**

This response addresses aspects of the Inquiry in regards to the relationship between teachers, children with disabilities and their carers, and provides an overview of the issues for carers, and young carers in particular, in regards to the education system. The submission also addresses the level and adequacy of funding for provision of education to students with disabilities or special needs.

It is not the intention of Carers NSW to respond to all of the questions posed in the Inquiry.

## **2. Education needs of students with disabilities or special needs**

Education determines not only a child's economic future but it is also important for a child's social and emotional development and establishing a sense of identity and a sense of place in the world.<sup>1</sup> The importance of education is even more pronounced in the case of a child with a disability, as it represents an important factor in creating an alternative future for a person with a disability and their social inclusion.

The social model of disability proposes that systemic barriers, negative attitudes and exclusion by society are the ultimate factors defining who has a disability. It argues that disability is not so much an attribute of the individual as much as it is of the social and physical environment in which a person with a disability lives. It could be argued that the social model of disability is adopted in the national and state educational policies, as they explicitly adopt principles of equality and inclusion for all students, including students with disabilities. However, the evidence suggests that there is a lot to be done to achieve better attainment indicators for students with disabilities.

A recently released report by the National People with Disabilities and Carer Council concludes that the current education indicators are "not a reflection of a lack of ability of students but of the failure of the system to meet their individual needs."<sup>2</sup> Many of the comments received by Carers NSW in response to this Inquiry raise the need for systemic changes in funding and administration of educational programs for children with disabilities and special needs.

The Australian Institute of Health and Welfare reported that approximately 58 per cent of people age under 20 with disability had schooling restriction, with 30 per cent having severe or profound schooling restriction.<sup>3</sup>

According to the ABS Survey of Disability Ageing and Carers in 2003 there were 95,900 persons aged 5-14 years with reported disability in NSW.

## **3. Recognition of role of carers in their child's education**

It is widely recognised that carers make a significant social and economic contribution to society.<sup>4</sup> Carers of children with disabilities have a crucial role in their children's lives not only as parents but also as primary decision makers for the child's health and wellbeing.

The *NSW State Health Plan*, together with the *NSW Carers Action Plan 2007-2012* have placed a strong emphasis on 'carers as partners in care', identifying the integral role that carers and families play in supporting people with health needs, both while using formal services, and at

home in the community. The *NSW Carers Action Plan 2007-2012* places specific emphasis on the acknowledgement that improving the quality of life and health and wellbeing of carers directly benefits the recipients of care.<sup>5</sup>

The recognition of a carer's role needs to be readily acknowledged in the education system and related policies and programs. The following section provides an overview of specific issues that carers have raised with Carers NSW in relation to the education of their children.

Carers of children with disabilities often report that school staff are unaware of the levels of frustration and anxiety experienced by parents in their caring role, and do not respond well to the assertive approach parents may take in their dealings with school. In some cases, school staff may consider the parent to be annoying or demanding, as they do not understand the necessity of the assertiveness shown by parents to secure the support their child needs.

Parents of children with disabilities and/or special needs also report being judged or blamed by teaching staff for the difficulties experienced by the child in the educational system. In the words of one carer:

*"Parents should be treated better and supported more and they should be listened to and not judged by teachers and staff with regard to their child's disability."*

*"Teachers should have meetings with the parents of these children to learn more about how best to provide for their child who they know better than anyone else..."*

It has been recognised that service providers who acknowledge the value of carers and work closely with carers provide better services to the person needing care.<sup>6</sup> This is as relevant to education providers as it is to health care providers. Carers are often the best informed party in regards to the needs and capabilities of the student with a disability and thus have a vital role to play in the planning of education provision to the student.

Carers have also reported a lack of communication with teachers and other staff as a common problem. In some cases, parents are not kept informed of what is being done for their child within the school, and may be anxious that they are not receiving the assistance they need. Not only does this unnecessarily increase the frustration and anxiety experienced by carers, it can also undermine or preclude the partnership that needs to be developed if the student is to receive the best education possible.

RECOMMENDATION 1: Carers NSW recommends that the role of carers as partners in care, as identified in the <i>NSW Carers Action Plan 2007-2012</i> , is recognised and supported in relevant policies and programs of the NSW Department of Education and Training.
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#### 4. Allocation of funding

The following issues were raised by carers in respect to the level and adequacy of funding for students with disabilities and special needs in both public and private schools:

- Funding needs to be available to ensure that students are able to participate in all school activities and programs. For example, often the child with the support grant is provided with an aide for very limited hours and a choice has to be made between having the aide's assistance in the classroom or on the playground but not for both activities.

- The allocation of funding should take into account the needs of the student with a disability as well as the needs of the teacher that may arise from having the student with a disability in the classroom. This may include employment of additional teachers and assistants.
- The allocation of funding for students with a disability should be allocated fairly for learning difficulties, behavioral disabilities and physical and intellectual disabilities. For example, students with a hearing impairment are entitled to special provisions, in particular the re-phrasing of exam questions. Students with a language disorder would benefit from this provision, for much the same reasons as hearing impaired students and yet students with language disorders do not have access to this assistance.
- Carers of children with profound and severe disabilities raised the overall lack of adequate education resources to support the complex needs of their children. Some carers took up a difficult decision to re-locate to another city or even another country so that their child can attend a school with the capacity to integrate the child into the mainstream education system. The Australian Broadcasting Corporation program 'Four Corners' on 15 February 2010 highlighted the lack of appropriate educational facilities for children with severe disabilities.<sup>7</sup>
- Carers strongly supported an assessment based on individual needs of each student with disability. While there were perceived benefits based on functioning capacity, there were concerns that once the child's progress is recorded, the funding was ceased.

*“Funding should be viewed as a positive thing in schools and not a negative thing that you have to fight for and get limited funding which can be taken away and given to another child if your child is doing well at school.”*

#### **4.1 Adequacy of special education places**

Responses from carers indicated that there is a greater need for special education places to respond to the needs of students with a disability. This was of particular concern to carers of children with Autism and other specific learning disabilities, as the unmet need for special education often escalates in a behavioral problem and they often “fall between the gaps”. There is a need for more special education places, and for more and better information for parents regarding services available.

The following case study illustrates the consequence of such practices:

*“My younger daughter was still reading and spelling at age 6 Grade 1-2 level when age 11 in Grade 6. During the years in between she was assessed and the schools (both public and private) all said there were many children several years behind they considered that normal and because her IQ is normal she did not qualify for any special assistance. We did not have sufficient income to pay for private tutoring... It was not until a two year wait (until she was in Grade 6) for assessment from the speech pathologist that her severe dyslexia was picked up and a remediation program put into place for the remainder of Grade 6.”*

*“Unfortunately that community health service did not extend beyond primary school and she had to then go on a waiting list for the adolescent services (again a two year wait). She had no bridging for the high school experience and by Grade 9 she gave up on school and dropped out with her self esteem under the carpet... She still can't read a chart, timetable, follow a recipe or written instructions, tell time, spell or find information from reading but because her IQ is normal she is not eligible for any assistance or disability support services now as a young adult.”*

<p><b>RECOMMENDATION 2:</b> Carers NSW recommends that the funding formula for the allocation of resources for children with disabilities and special needs is revised so it takes into account the child's individual needs assessment as well as whole of family approaches.</p>
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## 4.2 Provision of professional support and services

Students with a disability and their carers need more access to professional support and services, such as school counsellors, speech and occupational therapy, and physiotherapy. Carers reported that waiting lists for these services are simply too long and inadequate to meet the needs of their children and strongly recommended employment of more counsellors in each school, instead of 'sharing' school counsellors between several schools in one area.

*"We have one school counsellor at my son's school who is also a school counsellor at several other schools in the area and is never available to talk and cannot keep up with who the children are and what their diagnosis is, as she is too busy."*

Carers also suggested placement of allied health professionals, particularly speech pathologists and occupational therapists, on the school campus, so that students can access these professionals with a minimum disruption to schooling. Other benefits of such practice are opportunities for teachers and parents to meet frequently with allied professionals as well as the 'normalising' of various therapies, as therapy is held in a school setting rather than a distant clinic. This was perceived beneficial in dispelling stigma about disability among the students.

In 2009 the Australian Government implemented revised eligibility criteria for carers of children with disabilities under the age of 16 years for the Carer Payment (Child). Up to this stage very few carers of children under the age of years were eligible, and the revised criteria placed an emphasis on the eligibility of carers of children with challenging behaviours as well as the previously clinical or disability-specific focus eligibility. It has been estimated that an additional 19,000 families would be eligible for the Carer Payment (Child) because of these revisions. Carers NSW believes that this revised criteria should be systemically reflected in the education system so that resources for students with disabilities or special needs are readily available and responsive to student's individual needs.

<p><b>RECOMMENDATION 3:</b> Carers NSW recommends that, similarly to Recommendation 2, funding for provision of professional support and services for children with disabilities and special needs is revised in accordance to the principles of best practice.</p>
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## 5. Support needs of young carers and siblings of children with a disability

There is strong evidence to suggest that having a sibling with a disability can negatively impact upon other children in the family. Although caring for a person with a disability may bring the carer and family positive outcomes, it also entails substantial social, emotional and economic cost not only for the primary carer but also for the family.<sup>8</sup> The increased time and energy that is spent caring for a family member with a disability, particularly by mothers who often assume the extra care responsibilities, reduces the physical and emotional time available to other members of the family.<sup>9</sup>

Research conducted for Carers Australia regarding sole parent carers of children with a disability found that just over half of all participating households were in a situation where the disability has a negative impact on other children in the household. Thirty two per cent of respondents indicated that other children in the household were greatly affected by the disability of their sibling.<sup>10</sup>

Carers NSW is particularly concerned about identification and support of young carers who have specific support needs similar to their siblings with disabilities. A young carer is defined as a person under 26 years of age who provides unpaid care in families where someone has an illness, a disability, a mental illness or who has alcohol or drug dependencies. The idea that

young people (sometimes under the age of 10) are undertaking caring responsibilities goes against societal norms where children should themselves be looked after, rather than looking after someone. As a result those administering adult services often fail to recognise that a young person is taking an active caring role in the family, often excluding them from discussion about services for the family and, as a result, their particular needs are ignored.

### **5.1 Issues faced by young carers in the education system**

In NSW there are estimated to be approximately 90,200 young carers aged under 25.<sup>11</sup> According to the Australian Institute of Health and Welfare, “young people who become carers may experience a restricted social life, lower educational achievement and increased stress”.<sup>12</sup> Young carers mental health may also be affected through social isolation and the stress of extra responsibilities.

Many young carers have attendance difficulties. They find it difficult to complete homework, and feel that their academic performance has been negatively impacted upon by the pressures of caring.<sup>13</sup> Some young carers have also reported times when they had felt angry and upset about things that were going on at home and had taken this out on others at school or acted out as a result.<sup>14</sup>

The difficulties experienced by these young carers are often compounded by inflexible and unresponsive school systems, and the failure of teachers to recognise that they have young carers in their classes, and that absenteeism, incomplete or late homework, and a lack of concentration may be a result of caring responsibilities, and not misbehaviour.<sup>15</sup>

Young carers have testified to positive experiences of the education system and the potential for schools to be a locus of support. However, the services of school counsellors need to be available to them, as many young carers indicated. They could act as an advocate within the school, and mediate with other teachers and staff who perhaps do not understand the impact of caring on the student.<sup>16</sup>

Schools need to be more proactive in identifying and supporting young carers. Primary and secondary school teacher information kits have been sent out by Carers Australia in an attempt to raise awareness in schools about young carer identification, needs and issues. However, additional follow-up is required by the states in terms of implementing information and recommendations. Carers NSW would like to see participation of young carers in education, training and employment at rates approaching that of their peers who do not have caring responsibilities.

**RECOMMENDATION 4:** Carers NSW recommends that the NSW Government, through the NSW Department of Education and Training, increases awareness and training programs to schools and teachers about young carers and the supports they require to remain in school.

**RECOMMENDATION 5:** Carers NSW recommends that NSW Government, through the NSW Department of Education and Training, increases young carers social participation programs to provide young carers with linkages to support each other in their caring role.

**RECOMMENDATION 6:** Carers NSW recommends that NSW Government, through the NSW Department of Education and Training, provides additional funding to provide case management and service coordination to meet the ongoing and individual needs of young carers and their families.

## 6. Conclusion

Carers NSW thanks the General Purpose Standing Committee No. 2 for the opportunity to comment on this Inquiry and welcomes its commitment to improve educational outcomes for students with disabilities or special needs. Carers NSW also wishes to thank the many carers who generously provided their input to this submission.

For any further information please contact Maja Frölich, Multicultural Policy and Development Officer on 02 9280 4744 or [majaf@carersnsw.asn.au](mailto:majaf@carersnsw.asn.au).

Yours sincerely

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

Elena Katrakis  
CEO  
Carers NSW

## Endnotes

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<sup>1</sup> Australian Government (2009). *Shut Out: the Experience of People with Disabilities and their Families in Australia*, National Disability Strategy Consultation Report, prepared by the National People with Disabilities and Carer Council, Commonwealth of Australia, Canberra

<sup>2</sup> Ibid, p47

<sup>3</sup> Australian Institute of Health and Welfare (2009). Disability in Australia: multiple disabilities and need for assistance, Australian Institute of Health and Welfare, Canberra, Cat. No. Dis 55

<sup>4</sup> Access Economics (2005). *The Economic Value of Informal Care*, Access Economics Report for Carers Australia, Canberra

<sup>5</sup> NSW Health (2007). *Carers Action Plan 2007-2012*, NSW Health, Sydney p 10

<sup>6</sup> Ibid p 10

<sup>7</sup> Australian Broadcasting Commission (2010). "Breaking Point. Will Australia's flawed disability support system be reformed in time to save the families now at breaking point?" by Wendie Carslie Four Corners, Australian Broadcasting Corporation, broadcasted on 15 February 2010, available at: <http://www.abc.net.au/4corners/content/2010/s2817123.htm>

<sup>8</sup> Edwards B, Higgins D J, Gray M, Zmijewski N and Kingston M (2008). *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Australian Institute of Family Studies Research Report no. 16, Commonwealth of Australia

<sup>9</sup> Moore T, McArthur M, Morrow R (2008). 'Attendance, achievement and participation: Young carers' experiences of school in Australia' in *Australian Journal of Education* April 2009; 53, 1; ProQuest Education Journals, in Edwards B, Higgins D J, Gray M, Zmijewski N and Kingston M (2008). *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Australian Institute of Family Studies Research Report no. 16, Commonwealth of Australia

<sup>10</sup> StollzNow Research and Insights Advisory (2005). 'Market Research Report: A crisis in caring or a system that works? (Sole parent caring)' prepared for Carers Australia

<sup>11</sup> Australian Bureau of Statistics (2004). 2003 Survey of Disability, Ageing and Carers (SDAC) Summary of Findings, Australian Bureau of Statistics, Canberra

<sup>12</sup> Mukherjee S, Sloper P & Lewin R (2002). The meaning of parental illness to young people: the case of inflammatory bowel disease. *Child: Care, Health and Development* 28(6):479–85; in Australian Institute of Health and Welfare (2007). *Young Australians Their Health and Wellbeing*, Australian institute of Health and Welfare, Canberra AIHW cat. No. PHE 87

<sup>13</sup> Carers Australia (2008). Background paper: A literature review Young Carers and Education, Carers Australia, Canberra. Viewed on 17/02/2010 at: [http://www.carersaustralia.com.au/uploads/Carers%20Australia/Bring%20it%202008/20081029\\_Education\\_web.pdf](http://www.carersaustralia.com.au/uploads/Carers%20Australia/Bring%20it%202008/20081029_Education_web.pdf)

<sup>14</sup> Moore at all (2008)

<sup>15</sup> Carers Australia (2008)

<sup>16</sup> Moore at al (2008)