Submission No 11

# INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR FAMILIES

Organisation: Carers NSW

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The Director Standing Committee on Social Issues Parliament House Macquarie St Sydney NSW 2000

# Re: Inquiry into transition support for students with additional or complex needs and their families

Carers NSW is pleased to provide this response to the Inquiry into transition support for students with additional or complex needs and their families. This submission will address the Terms of Reference of the Inquiry with a focus on carers, and has been informed by feedback received from carers of children with disabilities.

#### **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.

#### **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.

Across NSW, there are estimated to be approximately 850,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

## **Summary of Recommendations**

**Recommendation 1:** Carers NSW recommends that the Department of Education and Training ensure that all employees, and employees of private schools, are aware of the *Carers (Recognition) Act 2010* and how this applies to supporting parents and carers in the education system.

**Recommendation 2:** Carers NSW recommends that the Department of Education and Training develop specific policies and promotional materials for staff in order to increase awareness of the *Carers (Recognition) Act 2010.* 

**Recommendation 3:** Carers NSW recommends that the NSW Department of Education and Training, ensure that staff provide carers with sufficient information and that they are respected, and listened to.

**Recommendation 4:** Carers NSW recommends that the NSW Department of Education and Training ensures teachers and other school staff provide support to carers and referrals to appropriate support services.

**Recommendation 5:** Carers NSW recommends that the NSW Department of Education and Training change the culture of the education system regarding education for children with additional and/or complex needs through:

- a. appropriate training for staff to identify and assess appropriate levels of support for children with a disability and, or, complex needs
- b. improved mechanisms for communication between schools at transition points of students moving from one school or school level to another
- c. implementing mechanisms to identify successful ways that schools support transition for children with disability or complex needs
- d. implementing a whole of school or holistic approach to the integration of students with disability or complex needs in mainstream schools
- e. provision of appropriate level of funding to ensure successful transition of children with a disability or complex needs at the four different transition levels into education.

**Recommendation 6:** Carers NSW recommends that the NSW Government fund research into the support needs, including transitioning from one education level to another, of children with disability or complex needs and their carers and families.

**Recommendation 7:** Carers NSW recommends that the NSW Department of Education and Training provides increased support for young carers to remain in school and also to transition successfully to further education and employment.

#### 1. Introduction

Carers NSW believes that significant improvements to the quality and consistency of the transition experiences of children with additional and/or complex needs and their carers are essential. The feedback that Carers NSW has received from carers indicates that there is significant variation, and often significant inadequacies, in the support that is provided to children and their families during transitions in education. In addition to variable and inadequate support, the transition in and of itself is often flawed.

This submission will focus on the role and needs of carers in transition stages, and in the education system in general. The principles of the *Carers (Recognition) Act 2010* and the *NSW Carers Charter* will underpin discussion of the need to better recognise, support and work with carers, particularly during transition stages. In particular, this submission will address the needs and role of carers, and how they can best be supported and engaged with by the education system in order to facilitate the best outcomes for students. The comments of carers who provided feedback to Carers NSW for this submission are included throughout the submission.

Although this submission will primarily focus on the needs of parents who are caring for children with additional and/or complex needs, it will also consider the needs of the siblings of these children, who often have a caring role themselves, are affected by the challenges and stresses of this role, and have their own needs for support within the education system.

Carers NSW has contributed to previous inquiries into education for students with additional or complex needs, including the Inquiry into the provision of education to students with disabilities or special needs in 2010. Many of the issues raised in that submission are also relevant to this Inquiry.

#### 2. Recognising and working with carers

Recognition and support of carers is crucial to the success of both education and educational transitions for a student with additional or complex needs Carers play a crucial role in supporting their child, yet educational providers and staff often fail to appreciate their role. The roles played by carers in relation to the education of the person they are caring for include:

- · transport to and from education and other activities and appointments
- emotional support and mentoring
- liaising with the school or institution
- advocating on behalf of the student
- assistance with career planning and goal setting.

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 are able to provide advice and information which could inform and improve the capacity of individuals and schools to support the child, particularly in transition stages. Unfortunately, the value of this information is often underappreciated, and the opinion and knowledge of the carer not sought, or respected.

# 2.1 Carers (Recognition) Act 2010 and NSW Carers Charter

In 2010 the *Carers (Recognition) Act 2010* (the Act) was enacted in NSW. The Act acknowledges the role and contribution of carers to the community and to the people they

care for. The Act contains the *NSW Carers Charter*, establishes obligations for public sector agencies, and establishes the NSW Carer Advisory Council.

The NSW Carers Charter contains ten principles, including that the views and needs of carers must be taken into account regarding services provided to persons who are cared for, that carers should made aware of services to assist them in their caring role and that carers' unique knowledge and experience should be acknowledged and recognised. Under the Act, public sector agencies, including the NSW Department of Education and Training, are obliged to take all reasonable steps to ensure that members of staff and agents of the agency have an awareness and understanding of the NSW Carers Charter.

Despite the passing of the Act, it is clear that many staff and public servants in the education sector fail to appreciate the need to recognise and respect carers. It appears that as yet there is a lack of awareness of the Act and how it applies to interactions with carers in education. This will be demonstrated throughout this submission, particularly through the comments and experiences of carers.

Given the lack of support and recognition for carers despite policies and legislation to the contrary, it is clear that a pro-active approach needs to be taken across the board, including in programs and support relating to transition, to transform attitudes towards carers and the degree to which they are recognised, included and supported.

**Recommendation 1:** Carers NSW recommends that the Department of Education and Training ensure that all employees, and employees of private schools, are aware of the *Carers (Recognition) Act 2010* and how this applies to supporting parents and carers in the education system.

Carers NSW believes that creating and distributing informational materials such as posters or cards outlining the key components of the Act relevant to young people in an education environment would be effective in further raising awareness of the need for carer recognition, including amongst carers and parents. Carers NSW would be happy to work with the Department in developing these resources for staff and carers and family members.

**Recommendation 2:** Carers NSW recommends that the Department of Education and Training develop specific policies and promotional materials for staff in order to increase awareness of the *Carers (Recognition) Act 2010.* 

#### 2.2 Informing carers

In order for carer recognition to be meaningful, teachers and other school staff must communicate with carers and parents of children with additional and/or complex needs. Schools, teachers, support staff and carers and the children they care for must work in partnership in order to achieve a positive outcome. An effective partnership is only possible if carers are kept informed by schools and educational professionals, while at the same time carers are also listened to and respected. Furthermore, the anxiety that accompanies transitions will be exacerbated if the carer is not included in discussions, if their expertise is not recognised or respected or if they are not kept fully informed.

Carers must be fully informed about the options available for their child, the kind of support which will be available, the curriculum and any developments in relation to their child's education. This is vital in order to ensure carers and family members can make the best decision for the education of their child. Failure to keep carers informed or involved in discussions not only jeopardises the education of the child but also increases the stress for carers at what is often a very stressful time.

Carers NSW has heard from many carers who have not been fully informed of the options available, and this lack of information can potentially lead to poor decision making. For instance, one carer believes that she and her husband's ability to make informed and considered decisions was hampered by the lack of timely and accurate information.

Our experience highlighted the vulnerability of students, parents/carers when provision of untimely, little or inaccurate information, choice/ options to allow us to make correct decisions. Policy and reality are poles apart.

Another carer advised that carers need to be provided with realistic information about the likely level of support for their child so that they do not have false expectations, providing the example of students who are allocated funding for four hours a week when their needs are closer to four hours a day.

#### 2.3 Listening to carers

In conjunction with fully informing carers, school staff, teachers and other staff in the education sector must listen to carers and respect their knowledge and expertise. This is one of the key principles of the *NSW Carers Charter* and is essential in ensuring that transitions are successful in the long term and that the student receives the most appropriate support.

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...

Another carer describes how not being listened to, despite being the most knowledgeable person regarding her son's needs and abilities, would 'get her down' and would make her second guess herself, 'just because you don't have the letters after your name'.

The value of effective communication is enormous, for all involved. One carer did share her experience of effective communication and partnering. The carer described how she has been able to work constructively with a team of people involved in supporting her daughter with multiple disabilities through Individual Education Plan (IEP) meetings. The attendees at the meeting include her daughter's teacher, the school principal, the Catholic Education Office, paediatricians and other health professionals, as well as the child's parents. The team at the IEP meetings work together to understand how to best support the child's needs and set goals for each term, such as improving behaviour in the classroom or increasing independence.

The positive experiences of this carer, and the benefits that have been experienced by all concerned demonstrates the significant potential of policies and practices such as IEPs when they are actually implemented effectively, and carers are included as partners in the process, in practice, not just in theory.

**Recommendation 3:** Carers NSW recommends that the NSW Department of Education and Training, ensure that staff provide carers with sufficient information and that they are respected, and listened to.

#### 2.4 Support for carers

Recognising carers also involves recognising the individual needs of carers for support in order to maintain their own health and wellbeing, and to acknowledge the high levels of stress, financial pressure and time commitments that carers of children with a disability often have. For instance, research reveals that overall carers have higher rates of poverty and that

the financial cost of caring is very high. For example, 39 per cent of respondents to Carers NSW 2010 Carer Survey had trouble paying for basic items such as groceries. Social connectedness and relationships are often affected. Parents caring for a child with a disability have an increased risk of separation/divorce. Caring can also have a detrimental impact on the health and wellbeing of carers. For example, the 2007 Australian Unity Wellbeing Index Survey found carers to have the lowest collective wellbeing of any known population group, with the wellbeing of carers who live with the care recipient being the lowest ever recorded for a large group of people.

Transitions between stages of education can create further stress and anxiety for carers, who may need support themselves at this time. In the word of one carer, describing her own feelings and needs when her son was transitioning to a school for specific purposes:

It was very confronting and there wasn't anyone asking me (parent/carer) how I was going through this process which is an extremely daunting, scary, sad and lonely time.

The additional pressures faced by carers can make the transition process and dealing with educational bureaucracies even more challenging for carers.

Therefore, in line with the *NSW Carers Charter*, it is important that teachers and other school staff take every effort to support carers, including by informing carers of support services such as the Carer Line, the local Commonwealth Respite and Carelink Centre (CRCC) and counselling services.

**Recommendation 4:** Carers NSW recommends that the NSW Department of Education and Training ensures teachers and other school staff provide support to carers and referrals to appropriate support services.

# 3. Changing the culture of education for students with additional or complex needs

In order to achieve successful outcomes for students with additional or complex needs, Carers NSW believes that the culture of schools and the education system needs to change. Part of this change is recognition of carers and improving communication between carers and staff. However, it is clear that the likelihood of a successful transition is highly dependent upon the culture of both schools and whether they provide, or have the resources to provide, adequate support for the student from day to day as well as during the initial transition. Therefore, Carers NSW believes that the issue of transition support is closely linked to the bigger picture of the need for increased funding and support for education for students with disabilities and additional or complex needs.

#### 3.1 Changing attitudes

Carers NSW acknowledges that the NSW Government and the Department have taken many steps in the right direction towards an inclusive and strengths based approach to education for all students. However, Carers NSW is concerned that the reality is that in many schools there is a culture which sees students with additional needs as belonging in segregated support units rather than in the mainstream classroom, and that there is a negative attitude towards the potential of these students.

It would appear that our efforts to follow a mainstream pathway for [our son] have been hampered at every stage of his schooling since our arrival in NSW... This was and is directly in contrast to our wishes.

#### 3.2 Funding and resources

Carers NSW is concerned that there is insufficient funding and resources for students with additional or complex needs. This concern was also raised in Carers NSW's submission to the *Inquiry into the provision of education to students with disabilities or special needs* in 2010, and by hundreds of other submissions from teachers and parents.<sup>vi</sup>

Feedback received by Carers NSW indicates that many students are assessed as requiring less support than their parents, and often teachers, believe is necessary. When students are not provided with sufficient support for their education there is a risk in triggering behavioural problems which further impact on the students' ability to succeed in education. Carers NSW is also concerned that part of the more negative culture towards students with additional needs is due to the increased pressure they place on teachers and schools unless they are adequately supported.

For instance, one carer believes that due to the severity of her son's disability, he requires full time supervision (30 hours per week), however he has been assessed as only requiring six hours per week. Despite only receiving funding for six hours of support each week, the school has managed to provide almost full time supervision by 'manipulating' the funding received. The carer believes these additional hours of support were crucial to her son successfully transitioning to his new school and to continuing to achieve successful outcomes.

In another case, a student who was assessed as requiring four days support in another state was assessed as requiring much less support in NSW.

This reduction in support time and the potential consequence of reducing access to curriculum... will directly [impact] his ability of meeting his educational outcomes.

A related issue is the way that carers and parents feel that they have to 'fight' for adequate support for their children from the school and from the Department. The experience of many carers is that their children's needs are not met unless they continue to advocate for support, which can be very stressful and time consuming for carers, and can lead to tension between the parents and the school.

This is a frustrating, time consuming and exhausting process as Mark's parents, time we would prefer to spend with Mark and our other son.

The continual fight for funding for our children's education and therefore their future is a drain on schools and parents – one that takes away from our children's lives because we already have enormous responsibilities to just to take care for our children.

# 3.3 An holistic approach

It is clear from feedback from carers that a whole-school approach is the most effective and sustainable way to support students with disabilities and additional or complex needs. One carer believes that her son's new school's holistic approach to supporting her child is crucial to her his positive experience and achievements. She explained how the school recognised that a 'special needs child also has a special needs family' and that they also need to support the child's family and carers.

Another carer describes her daughter's primary school and her transition from preschool as "brilliant". This carer's daughter has multiple disabilities including physical, sensory, intellectual and behavioural disabilities. However, despite the difficulties in meeting her needs, her daughter is able to participate in mainstream education due to the school's 'whole school approach' to support. The carer praised the changes made by the school, such as building new facilities and play equipment, and introducing social groups to help children who find it difficult to socialise. The school community has also worked to change the attitudes of other children so that they are accepting and supportive of students who are different. The school is also very mindful of the needs of carers and the pressures that carers may be under.

#### 3.4 Working together: communication between schools and between staff

As part of changing the culture in education, schools and teachers need to be encouraged and supported to communicate and work together in order to best support students with additional needs. For example, one carer explained how her son's primary school had worked hard for three years to support him in transitioning to high school. However, she and her family were very disappointed that despite three years of transitions 'it went belly up on day one' at his new school. This shows the importance of having support from both schools and staff in transitions as the hard work of one party is useless if the preparation, communication and support is not reciprocated by the other school.

In another case, a carer was very concerned about the lack of communication between teachers, which increased the risk of triggering her son's severe anxiety and causing behavioural problems.

What has lacked in the transition process is the communication between the people (teachers of both schools) to communicate the individual learning style, disability, quirks and ways of the individuals with a disability. I have on too many occasions said to the high school 'I give you consent to arrange a meeting with the two key workers from his primary school'. It will help the high school teachers and support workers to gain a better understanding of our son, rather than start from scratch. They can talk to people who had already put strategies in place to work with different triggers that stimulate behaviours, understand the mental illness of the child with a disability.

While shifting the culture towards education of students with additional and/or complex needs of the thousands of schools, including both public and private, will be a major challenge, this is crucial to improving the outcomes of students. Policies, programs and other changes designed to change the culture towards students with disabilities would ideally take place concurrently with measures designed to promote recognition and support for carers.

**Recommendation 5:** Carers NSW recommends that the NSW Department of Education and Training change the culture of the education system regarding education for children with additional and/or complex needs through:

- a. appropriate training for staff to identify and assess appropriate levels of support for children with a disability and, or, complex needs
- b. improved mechanisms for communication between schools at transition points of students moving from one school or school level to another
- c. implementing mechanisms to identify successful ways that schools support transition for children with disability or complex needs

- d. implementing a whole of school or holistic approach to the integration of students with disability or complex needs in mainstream schools
- e. provision of appropriate level of funding to ensure successful transition of children with a disability or complex needs at the four different transition levels into education.

## 4. Variation in the quality and level of support provided

Like the Committee, Carers NSW is also concerned about the variations in services provided to students and their families. Carers NSW is very concerned that the quality of support provided and the likelihood of a successful transition is a lottery with great variation between the quality of support provided to students, the support provided to carers, and the way in which carers are treated. The level and quality of support changes from school to school, at times from teacher to teacher, geographically, and depending on the condition or particular support needs of the child. This lottery applies to transition support as well as to general support and education standards for children with a disability.

The uneven and highly varied nature of support increases the anxiety of carers and family members regarding transition stages. Most carers, if not all, have experienced their child receiving inadequate or inappropriate services, support, and treatment, and will be anxious at transition stages that they will be worse off in the next stage – whether it be with a new teacher, in a new educational setting, or post-school. For instance, one carer said she was 'petrified' of having to transition her daughter to high school in the future.

Carers NSW has received feedback from some carers of children with a disability who have at times had positive experiences with transitioning between schools or classes. It is telling that those carers who have had positive experiences consider themselves 'lucky'.

I have been one of the lucky ones I suppose, our family's experience of transitions from preschool to high school has run quite smoothly... It depends on the passion and motivation of the school you are leaving and the place you are going to for things to work out right.

The best practice approaches to ensure seamless and streamlined assistance during transitions involve the same elements which help facilitate a positive learning experience for students. This includes communication between the schools and the carer and family of student with additional or complex needs, listening to carers, accessible information for the carer and the student and support for the carer. A holistic approach and co-operation and support from both schools are also important.

#### 5. Other transitions

Carers NSW acknowledges that this Inquiry is considering four important transitions in education:

- into early childhood education for the first time
- from early childhood education to primary school
- from primary to secondary school
- from secondary school to employment, further education, or other post-school options.

Much of the focus of services, research and other resources is the transition post-secondary school, as well as to a lesser extent the other conventional transitions. However, it is

important that the Committee also gives due consideration to the additional transitions that many children with additional and/or complex needs experience.

Many children with additional and/or complex needs change schools as a result of inadequate support provided by their school. This can have considerably implications beyond their experience within the school as it may mean extra travelling time to and from school, and often that they have to attend a different school to their siblings. In too many cases families are forced to relocate, with all the implications this entails, to secure a better education experience for their child.

Children with additional or complex needs may also transition from one type of education to another, for example from a special school or unit to a mainstream classroom. For students with additional or complex needs, even the ordinary changes from year to year or the introduction of a new teacher can be challenging, and potentially require transition support.

**Recommendation 6:** Carers NSW recommends that the NSW Government fund research into the support needs, including transitioning from one education level to another, of children with disability or complex needs and their carers and families.

# 6. Impact of waiting times for services on transition process

Carers NSW is also concerned at accounts from carers regarding waiting times for services and support. Transition processes will clearly be undermined when services and supports are not in place at the time of transition. No amount of support can compensate for a six month wait to get into the next stage of education, for example. Nor is transition support likely to compensate for inadequate supports or services in the next stage of education. The following case study from the Multicultural Disability Advocacy Association illustrates the significant waiting times experienced.

Cha initially attended a school for the blind. His family were worried that he was not progressing but didn't know how to alleviate their concerns. Eventually the teachers suggested he be tested and only then was the extent of his intellectual disability realised. With DET assistance an appropriate school placement was found but Cha had to wait for 6 months before he could start. Cha also has physical disability and needs transport to and from school. It was another 6 weeks before the bus could start taking him to and from school. Vii

This issue has been raised previously with the NSW Government, and applies not only to support and services within the education system, but to access to other services such as early intervention, speech therapy, physiotherapy and access to equipment such as wheelchairs. If children with disability or additional needs are not provided with the necessary support this will limit their ability to participate in education and potentially lead to increased costs in the future if they are less able to become independent.

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... 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... 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...

#### 7. Young carers

Young carers can play an important role in supporting the transition of the student with additional or complex needs from one school to the next. If the student with a disability is being prepared to attend the school that the young carer is attending, they can support their sibling as they settle into their new school.

I have three girls – they're all massively affected by his disability, and they're all young carers. Now one of my daughters has started at the same school as John and has slipped straight back into looking after him there too.

However, young carers have more difficulty than others of their age making the transition from school into further education or work and may require transition support themselves. 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". Young carers may be unable to complete assignments and homework tasks on time due to the demands of caring, or may have difficulty concentrating in class due to lack of sleep or stress. This can be detrimental to young carers' prospects of being accepted into further education or employment as their results may be poor and not reflect their ability. According to one study, only 4 per cent of primary carers between the ages of 15–25 years were still in education compared to 23 per cent of the general population in that age group. However, even if they are accepted into university, TAFE or other further education, young carers may continue to have difficulty balancing care and study, and even be forced to abandon their studies if this is not possible.

Carers NSW acknowledges that the Department of Education and Training is a member of the Interagency Young Carers Steering Committee and a key partner in the NSW Young Carers Interagency Action Plan. Carers NSW is very supportive of this initiative and believes that this will enhance the support provided to young carers while also assisting in raising awareness of and identifying young carers in schools.

Recommendation 7: Carers NSW recommends that the NSW Department of Education and Training provides increased support for young carers to remain in school and also to transition successfully to further education and employment.

# 8. Conclusion

Carers NSW thanks the Standing Committee on Social Issues for the opportunity to participate in this Inquiry. Carers NSW also acknowledges and thanks the carers who provided input to this submission.

Yours sincerely

Elena Katrakis CEO Carers NSW

#### **End notes**

<sup>&</sup>lt;sup>i</sup> Australian Bureau of Statistics, 2009 Survey of Disability, Ageing and Carers, Canberra, 2010 <sup>ii</sup> T Hill, C Thomson C and B Cass, Social Policy Research Paper No. 43: The costs of caring and the living standards of carers, Social Policy Research Centre, University of New South Wales, Sydney 2011.

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D Risdal and G H S Singer, 'Marital adjustment in parents of children with disabilities: A historical review and meta-analysis' *Research and Practice for Persons with Severe Disabilities*, 29(2), 95-103, United States, 2004.

<sup>&</sup>lt;sup>v</sup> R Cummins et al, *The wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1 Special Report, Canberra, 2007.

vi General Purpose Standing Committee No. 2, *The provision of education to students with a disability or special needs*, Sydney, 2010.

Multicultural Disability Advocacy Association, *All I want is what's best for my child*, Sydney, 2005. S Mukherjee, P Sloper and R Lewin, '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, *Young Australians Their Health and Welfbeing*, Australian institute of Health and Welfare, AIHW cat. No. PHE 87, Canberra, 2007.

<sup>&</sup>lt;sup>ix</sup> T Moore, R Morrow, M McArthur, D Noble-Carr and J Gray, *Reading, Writing & Responsibility*, Institute of Child Protection Studies, Australian Catholic University, Canberra, 2006.

<sup>&</sup>lt;sup>x</sup> Carers Australia, *Young carers research project: Final report*, Department of Family and Community Services, Canberra, 2002.