

**Submission  
No 59**

**INQUIRY INTO CHILDREN AND YOUNG PEOPLE WITH  
DISABILITY IN NEW SOUTH WALES EDUCATIONAL  
SETTINGS**

**Organisation:** Carers NSW  
**Date Received:** 6 March 2024

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Portfolio Committee No. 3 - Education  
NSW Legislative Council

### **Children and young people with disability in New South Wales educational settings**

Carers NSW welcomes the opportunity to respond to the NSW Legislative Council Portfolio Committee No.3 Education (the Committee) inquiry on children and young people with disability in NSW educational settings. Following the release of the final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which included a number of recommendations relating to education, Carers NSW welcomes the NSW Government's recent initiatives aimed at improving inclusion and support for children and young people living with disability in NSW. However, Carers NSW believes that there are further opportunities to improve recognition, information and support for the families and carers of these children and young people into the future.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Thank you for accepting our submission. For further information, please contact Melissa Docker, Senior Policy and Development Officer at

Yours sincerely,

Elena Katrakis  
CEO  
Carers NSW

## Introduction

Carers NSW believes in the importance of autonomy and self-determination for people living with disability and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. Carers NSW has fully supported the transition towards more person-centred approaches to service delivery for people living with disability and believes this human rights approach to disability support continues to enable people living with disability and their families and carers to have more choice and control over their life and wellbeing, including their inclusion and participation in society.

Carers NSW welcomes the opportunity to provide a submission to the Committee on the experiences of children and young people living with disability in NSW educational settings. Carers continue to raise with Carers NSW significant challenges associated with navigating the NSW education system with or on behalf of a child or young person living with disability to ensure adequate academic, practical, social, behavioural and emotional support for them within these settings. As supporters, navigators and advocates, many carers report having to invest significant time and energy in understanding and overcoming barriers to education on behalf of the child or young person they care for. Furthermore, Carers NSW has heard anecdotally of an increasing reliance on siblings or other young carers of children and young people living with disability for support within school settings, especially where schools or educators are not adequately resourced or trained to provide effective, inclusive support to children and young people living with disability.

Given the invaluable role of carers in supporting optimal educational and social outcomes of children and young people living with disability, this submission will highlight the need for greater recognition, information and support for carers within education systems. Furthermore, the submission will also highlight the need for the development of guidance for educators and administrative staff on the roles and supports for young carers of children and young people living with disability in the context of school or educational settings.

## Carer recognition in NSW educational settings

To ensure adequate support for carers of children and young people living with disability in the context of educational settings, it is essential that the term carer is accurately defined. All parents, foster carers and kinship carers experience challenges associated with navigating education systems, especially when things are not going well. However, carers, as defined under the *NSW Carers (Recognition) Act 2010*<sup>1</sup> experience additional, nuanced challenges, often associated with ensuring that their child's additional needs are met within school settings. Carers of children and young people living with disability may require specialised information, support or resources to enable them to effectively support the child or young person they care for to navigate or participate in educational activities.

Under the *NSW Carers (Recognition) Act 2010* (the Act), NSW public service agencies have obligations to carers, including ensuring that all members of staff have an awareness and understanding of the *NSW Carers Charter* and consulting with carers or bodies representing carers when developing policies that impact on carers. Additionally, as a human service agency under the Act, the NSW Department of Education must also take all reasonable steps to ensure that staff, and the agency as a whole take action to reflect the principles of the *NSW Carers Charter*.

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<sup>1</sup> *NSW Carers (Recognition) Act 2010*, Section 5 (1): a person is a carer if the person is an individual who provides ongoing personal care, support and assistance to any other individual who needs it because that other individual: is a person with disability within the meaning of the Disability Inclusion Act 2014, or has a medical condition (including a terminal or chronic illness), or has a mental illness, or is frail and aged.

## Carer-inclusive educational approaches

As advocates and supporters of children and young people living with disability, carers are integral in the participation of children and young people living with disability in NSW educational settings. However, without adequate recognition, information and support to enable carers to fulfil these important roles, children and young people living with disability are unlikely to be able to access the essential educational supports they need. Carers NSW believes that a carer-inclusive, transparent approach must be utilised in NSW educational settings to ensure that carers are equipped and empowered to enable the children and young people living with disability they care for to achieve optimal educational outcomes.

Carers NSW has heard from a number of carers that on seeking assistance with accessing or initiating additional support for the child or young person they care for, or raising concerns or complaints with an education provider or the Department of Education about the support needs of their child, many carers find it difficult to identify or establish contact with the appropriate persons. When carers do make contact with the correct person, many carers have reported that they are unsatisfied with the outcome. In some cases, carers report that in response to their requests or concerns, they are often met with hostility within the education system. In some instances, carers report that they receive no response. Alternatively, where a response is received, carers often feel there is no change following the raising of concerns or requests for additional support. Carers have also reported to Carers NSW that on seeking assistance with school refusal, they have been unable to access adequate support to assist the child or young person they care for to overcome barriers to attending school.

Carers NSW believes that to support carers who are navigating the education system with or on behalf of children and young people living with disability, there is a need for further investment in navigation support and advocacy services. This includes information and support with understanding education pathways and options, requesting support or adjustments within school settings and providing evidence as needed, raising complaints or concerns about quality or safety of education settings and addressing potential instances of discrimination against the child or young person they care for. This is likely to have positive impacts for not only children and young people living with disability who will be better supported to access the support they need, but also carers themselves, reducing the psychological distress and administrative load experienced by many carers engaging with education systems.

Carers NSW has also heard from carers that there is a need for trauma-informed approaches when working with carers of children and young people living with disability given that they are often navigating multiple service systems and may have had to share their story repeatedly, or may have had negative experiences in other service systems. Taking a trauma-informed approach to working with carers is likely to result in the best outcomes for both carers and education providers.

## Addressing gaps in support within educational settings

In addition to difficulty navigating education systems, Carers NSW has also heard anecdotally of ongoing challenges accessing adequate care or support for children and young people living with

*Alicia\* cares for her 10-year-old son Mason\*, living with disability, who attends a NSW public school. Alicia has repeatedly raised concerns with Mason's teacher about Mason not receiving adequate support in the classroom and falling behind socially and academically. Alicia attempted to arrange a meeting with the principal to discuss her concerns however this was very difficult, and when Alicia was able to finally meet with the principal, Alicia was frustrated that she had to tell the whole story from the beginning as her concerns hadn't been escalated as requested. Additionally, Alicia was frustrated as she felt that the principal implied that it was Alicia's fault and their home situation that was resulting in Mason's academic challenges and school refusal.*

\*Names changed

disability within education settings due to poor integration between the NDIS and NSW education system, resulting in gaps between service systems. This also extends to pre- and post- school transport, which falls within the remit of the NSW Government. Carers NSW has heard from carers that the current scheme does not provide adequate flexibility to enable all children and young people living with disability to access it. In some instances, inability to secure adequate support for children and young people living with disability within school settings due to ongoing service boundaries of NDIS and the NSW Government has resulted in some carers exiting the workforce to home school their children as this is the only way to ensure an adequate level of support for the child or young person they care for. This can have significant impacts for the economic participation and financial security of these carers, as well as the educational and social outcomes of children and young people living with disability.

Carers NSW is confident that recent agreement between state and federal governments in relation to improving the ecosystem of support for all people living with disability in Australia<sup>2</sup> will see improvements in support at intersections of key service systems such as the NDIS and education systems. However, Carers NSW believes that additional focus on addressing service system boundaries and gaps between education and the NDIS is needed to ensure that all children and young people living with disability, and their families and carers are able to access adequate supports seamlessly.

### **Supporting young carers of children and young people living with disability in educational settings**

Young carers, carers who are aged 25 years or under, are often key supporters of children and young people living with disability in education settings. This may include siblings, family members and peers of children and young people living with disability who provide fluctuating levels or types of assistance to support or facilitate their participation in educational activities or in educational settings.

Of particular note, Carers NSW has heard anecdotally from young carers and parents of young carers that in some instances, they may be called out of class to assist with providing behavioural support to their sibling or family member living with disability. Carers NSW has also heard from young carers that they have been relied on by educators to facilitate communication between the educator or administrator, and the child or young person living with disability.

While Carers NSW recognises the important role that young carers play, as both experts and providers of supports for children and young people living with disability, Carers NSW has concerns that in some instances, this can impact on the participation of the young carer in their own educational activities. Additionally, where no consistent policies or processes are in place to support decision-making around when it may or may not be appropriate to seek support from a young carer in school settings to assist a child or young person living with disability, this can create distress for young carers who may be put

*Paul\* cares for his 8-year-old daughter Iris\* who is living with disability. Paul has been advocating to the NDIA and Iris's school to increase the level of support for Iris within the classroom as her needs cannot currently be met within existing arrangements, however the NDIS and school have been unable to come to an agreement about who is responsible for supports within the school setting. As a result, Paul has left his executive level job to home school Iris as NDIS funded support workers can provide the level of support that Iris needs throughout the day within their home, which cannot be provided within the school setting.*

\*Names changed

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<sup>2</sup> The Hon. Anthony Albanese MP (2023) *Meeting of National Cabinet – the Federation working for Australia* [Media release: 6 December 2023], available online at: <https://www.pm.gov.au/media/meeting-national-cabinet-federation-working-australia>.



*Michelle\* has two children who attend the same primary school, Lachie\* who is living with disability and Sam\*, his brother and young carer. During the school day, Lachie's teacher often calls on Sam to provide emotional and behavioural support to Lachie, during both class time and breaks. During a recent incident, the decision was made not to withdraw Sam from class to provide behavioural support to Lachie, this decision was made without consulting Sam. The incident resulted in Lachie being suspended from school and Sam reported feeling guilty and distressed as he may have been able to support a more positive outcome if he had been there. Michelle noted that while she understands the need to ensure Sam's education is not significantly impacted by his caring role, there does not appear to be consistency in the school's approach which has exacerbated Sam's confusion and distress.*

\*Names changed

in the position of choosing between their own education or the education of the person they care for, or who may be inappropriately asked to or denied from providing support.

Furthermore, Carers NSW recent consultation with stakeholders involved in our Young Carer Inclusion Network<sup>3</sup> found that stakeholders have significant concerns about transitional arrangements within schools associated with changes to funding models or approaches to supporting children living with disability in NSW educational settings. Stakeholders expressed concerns that where transitional arrangements result in reduced formal support for children and young people living with disability in school settings, there is likely to be increased reliance on young carers to fill any emerging gaps. As such, Carers NSW believes that the NSW Government must take proactive steps to ensure that young carers are not disproportionately disadvantaged throughout this transition and into the future.

Carers NSW believes that in order to ensure optimal outcomes for young carers of children and young people living with disability in educational settings, the NSW Government must invest in establishing guidance for educators on supporting young carers,

inclusive of siblings as well as other family members, friends and peers who may be providing ongoing support or assistance in educational settings. This guidance should outline processes and practices for effectively responding to the needs of children and young people living with disability in a way that is both carer inclusive, but also takes into consideration the needs and preferences of young carers in educational settings. This guidance could be embedded within existing, known resources such as the NSW Department of Education's *Being a Carer, Being a Student and Being a Kid: A Resource for schools*,<sup>4</sup> which is currently being reviewed and updated as an action under the *NSW Carers Strategy 2nd Action Plan: 2023-24*.

<sup>3</sup> Carers NSW (2024) *Young Carer Inclusion Network: Information for professionals*, available online at: [https://www.carersnsw.org.au/uploads/main/Files/2.Services-and-Support/Our-programs-and-services/YC/YCIN-Factsheets\\_Professionals.pdf](https://www.carersnsw.org.au/uploads/main/Files/2.Services-and-Support/Our-programs-and-services/YC/YCIN-Factsheets_Professionals.pdf).

<sup>4</sup> NSW Government (2020) *Being a Carer, Being a Student and Being a Kid: Resource for schools*, available online at: [https://education.nsw.gov.au/content/dam/main-education/student-wellbeing/behaviour-and-engagement/Being\\_a\\_Carer\\_Being\\_a\\_Student\\_and\\_Being\\_a\\_Kid.pdf](https://education.nsw.gov.au/content/dam/main-education/student-wellbeing/behaviour-and-engagement/Being_a_Carer_Being_a_Student_and_Being_a_Kid.pdf).

*"My name is Sophie\* and I care for my younger sister who has an intellectual disability. During high school we were at the same school so I supported her through various different things... I would check on her in between classes and make sure that everything was going okay in her day, this could include making sure that she had food, so helping her out to buy food from the canteen or if there was something that happened or a special circumstance where she needed particular support I would often come and support her during that and that sometimes involved being pulled out of class.*

*During times when I had to be pulled out of class, it was often unexpected and the teachers or the teachers' aides would come to my class and ask for me, and I would go to my sister and help her with whatever they needed. Sometimes they would want me to explain something that had happened to her or deliver some news to her or if she needed help with something I would be helping her through it and supporting her through that emotional time.*

*I was always happy to do it because she is my sister and obviously, I do care for her very much and wanted to help her where I can, but at the same time, it meant that they were taking me away from my class and my schooling experience and there wasn't a lot of support for when this would happen. They didn't give me notice, because didn't know that they were going to need me, but just calling on me unexpectedly because I was her sister, and this was well known throughout school, put a bit of pressure on me, that I felt like I had to help her and I really had to step up and resume my caring role when I had switched off and was just at school with my friends...*

*... For some of us, school is the only time we have a break... I support my sister before school and after school, but during school was my time to learn, spend time with my friends, play sport, and when I had to be taken away from that... my caring role came back on, I put my caring hat back on, and I resumed that...*

*... Young carers have their own schooling experience to focus on, and if you are asking them to help out, and placing extra pressure on them, it is important to check in with them and make sure that they feel comfortable with the expectations you are placing on them..."*

- Young carer, 21 (\*name changed)

## **Conclusion**

Carers NSW again thanks the Committee for the opportunity to respond to this matter. Carers NSW believes that ensuring a carer-inclusive approach to supporting children and young people living with disability in NSW educational settings both now and into the future is likely to support the best outcomes for these children and young people, as well as their families and carers.