

11 May 2021

Disability Employment Policy
GPO Box 9820
Department of Social Services
Canberra ACT 2601
DEP@dss.gov.au

Carers NSW welcomes the opportunity to provide a submission to the Department of Social Services in response to the National Disability Employment Strategy: Consultation paper. This brief submission will focus on the need for carer recognition and inclusion in the National Disability Employment Strategy as carers are often key supporters of people with disability engaging in employment and employment-related activities. This submission will also highlight the need for adequate formal support for people with disability to ensure optimal employment outcomes.

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, Policy Officer at melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



Elena Katrakis
CEO
Carers NSW

Introduction

Carers NSW thanks the Department of Social Services for the opportunity to provide feedback on the development of the National Disability Employment Strategy (the Strategy). Carers NSW supports reforms that aim to improve employment outcomes people with disability, as employment is critical in promoting independence and financial stability, and also supports social and community engagement and a sense of meaningful contribution.

Carers NSW believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their meaningful participation in community life. While we recognise that not all people with disability receive informal support or would identify as having a carer, or carers, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians with disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.¹ More than one third (37.4%) of primary carers also have a reported disability themselves.²

While Carers NSW recognises that not all people with disability are able to or choose to participate in employment, for many people with disability who choose to engage in employment or vocational activities, informal carers are often key supporters. Carers provide a range of supports to people with disability in regards to employment, including but not limited to:

- Supporting people with disability to identify and pursue educational and career goals and pathways
- Supporting people with disability to navigate disability, education, employment and income support systems
- Providing advocacy and communication support when the rights of the person with disability are infringed within educational or employment settings
- Providing ongoing emotional support for people with disability throughout their employment journey
- Providing practical support to facilitate participation in education and employment activities, such as transport to and from activities, assistance preparing for interviews or job trials
- Providing ongoing financial support during periods of unemployment or underemployment

Carers NSW believes that as key supporters of people with disability, carers should be recognised within the Strategy, and the Strategy should ensure that carers are provided with adequate information and support to effectively support the person they care for. Ensuring adequate resourcing for carers' needs in this context is likely to also improve employment outcomes for many people with disability.

¹ Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au

² Ibid.

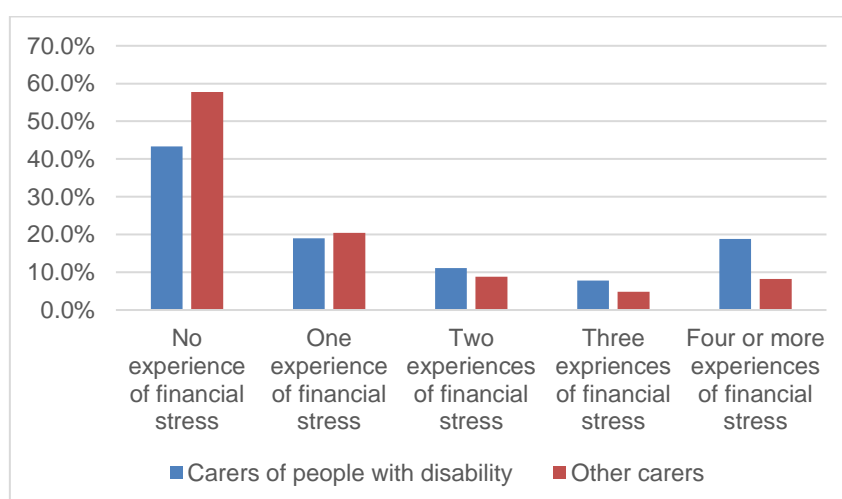
Improving financial and wellbeing outcomes for carers

Employment of people with disability has positive outcomes for both people with disability and their carers. As highlighted in the Consultation Paper,³ increasing employment for people with disability improves the personal wellbeing and financial security for people with disability and their carers.

When people with disability are unable to access adequate income through employment or income replacement payments (e.g. Disability Support Pension, JobSeeker Payment), there is often additional financial strain placed on carers to support those that they are caring for to meet their living and care costs. Carers often experience reduced income and earning capacity due to the impact of their caring role on their own education and employment. The additional financial strain associated with supporting the person that they care for financially often creates additional distress and financial insecurity for many carers.

The Carers NSW 2020 National Carer Survey⁴ found that carers of people with disability reported higher levels of financial distress than other carers. The Survey found that compared to other carers, carers of people with disability were more likely to report at least one instance of financial stress in the past 12 months, and more likely to report financial distress (four or more instances of financial stress in the past 12 months) than other carers. Carers of people with disability were also more likely to support the person they are caring for with their living costs, including medication, transport, housing and health services, likely contributing to their financial distress and long term financial insecurity.

Figure 1. Carer experiences of financial stress in the past 12 months



In addition to items that focus directly on employment, Carers NSW believes that in order to improve financial outcomes for carers, the Strategy should also include a focus on the adequacy of income support payments for people with disability. Carers NSW believes that this is necessary to ensure that where people with disability are unable to engage in or secure employment, payments adequately meet their financial needs and do not create additional financial strain on carers to meet caring and living costs.

Furthermore, the engagement of people with disability in employment provides opportunities for social, health and wellbeing benefits to individuals, families and carers. Carers NSW heard during COVID-19 that for many carers, the engagement of people with disability in employment or vocational activities provides carers with an opportunity to take breaks from their caring role to support their own health and wellbeing, as well as to participate in their own education and employment activities. Where employment of people with disability was interrupted during COVID-19, often

³ Department of Social Services (DSS) (2021) *National Disability Employment Strategy: Consultation paper*.

⁴ Carers NSW (2020) *2020 National Carer Survey: Unpublished data*.

disproportionately so, carers reported that this reduced the time available to them to attend to their own health and wellbeing and some carers reported needing to reduce their own employment to provide additional care and support in these instances.

Carer recognition and inclusion in education and employment supports

Given the extensive roles of many carers in supporting the person that they care for to identify, secure, maintain and maximise employment opportunities, it is important that carers are included in the planning and delivery of employment supports for young people with disability. Many carers report to Carers NSW that when the person they care for reaches 18 years of age, they are often immediately “shut out” of discussions and decisions to optimise their care recipient’s independence. While Carers NSW supports the autonomy and independence of people with disability, in many cases, carers are key supporters of people with disability, facilitating communication and supported decision making.

The exclusion of carers, who often provide practical, emotional and financial support to young people with disability at this time, often a key transition point in a young person’s career journey, can be significantly detrimental to both the person with disability and their carer. Carers NSW believes that, in line with the *Carer Recognition Act (Cth) 2010*, the Strategy should ensure the recognition and inclusion of carers in the planning and delivery of services and supports as partners in care.

The coordination and collaboration of formal and informal supports is likely to result in optimal education and employment outcomes for people with disability, both in the short and long term. Furthermore, Carer NSW believes that carers should also be considered, recognised, included and consulted in the development, implementation and evaluation of the Strategy.

Information, tools and resources to build the capacity of support networks

Carers NSW supports a focus in the Strategy on the development and promotion of information, tools and resources to build the capacity and confidence of parents and carers as advocates and supporters of people with disability on their employment journey. However, we believe that this support should be targeted at understanding education and employment rights of the person that they care for, complaints avenues, service navigation and best practices for supporting someone with disability on their employment journey.

Carers NSW believes that while some carers may have low expectations of employment capabilities, often informed by historic societal attitudes, many parents and carers are the ones challenging the expectations of educators, teachers, career advisors, employers and medical professionals in regards to the education and employment prospects of the person that they care for. As key supporters and advocates, many parents and carers support and enable people with disability to exceed societal expectations and overcome barriers to employment.

Supports for parents and carers should be focused on practical supports and key transition points for young people with disability to provide carers and parents information, tools and resources that enable them to provide best practice support to those that they care for throughout their employment journey. Carers NSW also believes that there should be additional support and information for carers in regards to service navigation of education and employment systems and greater support with advocacy with or on behalf of the person they care for.

Access to adequate education and employment supports

Education is a foundation for employment, not only academically, but also socially and emotionally. Inadequate education support for children and young people with disability is likely to result in lower education outcomes, impacting long term employment prospects. As such, the Strategy must also focus on ensuring adequate supports for people with disability within education settings.

Carers NSW continues to hear from carers of children with disability that ongoing tensions between the National Disability Insurance Scheme (NDIS) and school education system create barriers to education support for children with disability. Furthermore, while it is expected by the NDIS that mainstream supports, such as education, should be inclusive and equipped to support people with disability, despite an anticipated 50% increase in students in NSW with disability accessing public schools, planning for inclusion remains inadequate even for current school populations.⁵

Where inadequate support is available through the NDIS or education system, parents or carers of children with disability must advocate significantly to access the appropriate level of support for their child or provide high levels of support with education themselves. Carers NSW believes that the Strategy must include a focus on ensuring optimal education outcomes for children with disability in order to optimise long term employment and career goals for children with disability and reduce strain on parents and carers to ensure that their children's educational needs are met in an accessible and supportive way.

Protecting carers providing support in the workplace

Carers NSW has recently heard of several instances where informal carers have been seeking to provide support to the person they care for in the workplace, causing tension and conflict with the person's employer. While Carers NSW supports people with disability and their carers choosing support arrangements that best work for their own circumstances, Carers NSW believes that adequate formal supports must be made available to support people with disability in the workplace to ensure that family arrangements are not the only option.

Carers NSW therefore believes that the Strategy should encourage exploration of currently available workplace supports and their adequacy, as well as the legislation and provisions that enable or limit informal carers providing support to their care recipient within their workplace, where required or appropriate. Carers NSW believes that as supporters of people with disability in fulfilling their employment goals, carers should be protected under the appropriate work cover arrangements to ensure that if an injury does occur within the workplace, carers are adequately covered and supported.

Lisa is the carer for her partner Sam who has recently returned to work. Michelle has been attending Sam's workplace with them as their carer. The workplace has recently raised concerns that as an informal carer, Lisa may not be covered by any type of workers compensation insurance. The employer is concerned that if Lisa is injured, they may be liable for damages.*

*Names changed to protect privacy

Conclusion

Carers NSW supports the development of a National Disability Employment Strategy which aims to improve employment outcomes for people with disability as this is likely to result in improved outcomes for parents and carers as well. Carers NSW believes that a key to the success of the Strategy will be the inclusion of carers, as the key supporters of people with disability, throughout all areas of the Strategy. A dual focus throughout the Strategy on the overlapping and unique needs of people with disability and their carers is likely to ensure optimal inclusion and participation of both groups.

⁵ Baker, J. (2020) 'Schools must prepare for 50 per cent rise in students with disabilities: report', *Sydney Morning Herald*, 2 September 2020, available online at: <https://www.smh.com.au/national/nsw/schools-must-prepare-for-50-per-cent-rise-in-students-with-disabilities-report-20200902-p55rrm.html>