

1 February 2022

Disability Employment Reform Branch
Department of Social Services
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Carers NSW welcomes the opportunity to provide a submission to the Department of Social Services in response to the New Disability Employment Support (DES) Model consultation paper. This brief submission will focus on the need for carer recognition and inclusion in the National Disability Employment Support Model, 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, especially as carers report rates of disability higher than those of the general population.

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 melissad@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



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CEO
Carers NSW

Introduction

Carers NSW thanks the Department of Social Services for the opportunity to provide feedback for the Disability Employment Strategy Model (the Model) reform consultation. 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

Many carers also report living with disability themselves. More than one in three (37.4%) primary carers report living with disability, higher than the incidence of disability reported in the broader Australian population.² People with caring responsibilities and disability experience additional barriers to accessing meaningful work and education, community participation and health outcomes, as they navigate and balance their own needs and self-determination with those of the person they care for.

Not all people with disability choose or are able to participate in employment, however, for those who do, informal carers are often key in supporting these activities. 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 in line with the *Carer Recognition Act 2010* (Cth) carers, as key supporters of people with disability and overrepresented within people with disability, should be further recognised and included within the new Model. The Model should ensure that carers are provided with adequate information and support both as service users and support persons. Ensuring adequate resourcing for carers' needs is likely to improve employment outcomes for many people with disability.

Improving outcomes for people with disability and carers

Employment of people with disability can result in positive outcomes for both people with disability and their carers. As highlighted in *Australia's Disability Strategy 2021-2031*³ increasing employment

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

² Ibid.

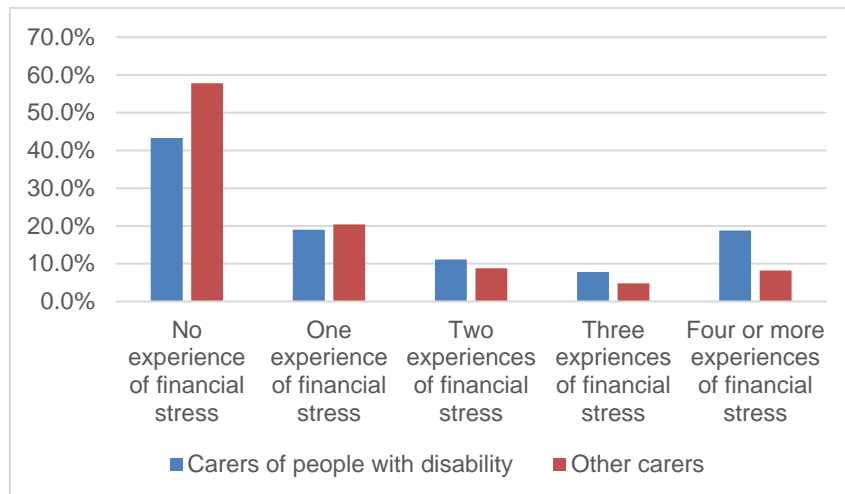
³ Department of Social Services (DSS) (2021a) *Australia's Disability Strategy 2021-2031*.

for people with disability improves their personal wellbeing and financial security, both of which also impact on carer outcomes.

When people with disability are unable to access adequate income through employment or income replacement payments (e.g. Disability Support Pension (DSP), 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 also 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 care for with their living costs, including medication, transport, housing and health services.

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



Furthermore, the engagement of people with disability in employment provides opportunities for social, health and wellbeing benefits to individuals, families and carers. Carers NSW has heard from many carers that the engagement of people with disability in employment or vocational activities provides them with an opportunity to take breaks from their caring role and participate in their own education and employment activities. Where employment of people with disability has been interrupted during the COVID-19 pandemic, carers reported that this reduced the time available to them to attend to their own health and wellbeing, and some carers reported having to reduce their own employment to provide additional care.

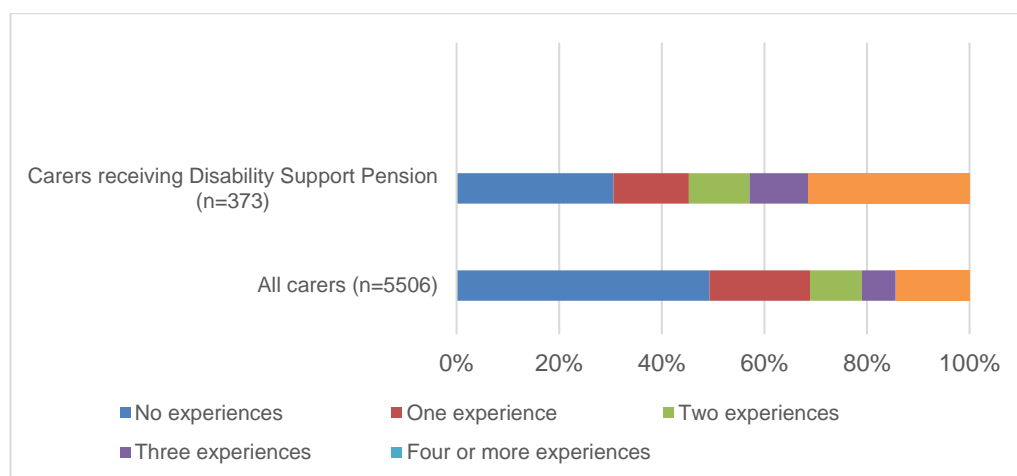
Carers living with disability themselves are also likely to experience higher levels of financial hardship than other carers, especially where their disability directly impacts on their ability to work. The Carers NSW 2020 National Carer Survey⁵ found that carers receiving the DSP as their main source of income experienced greater financial hardship than carers on average (Figure 2). More than two thirds of respondents receiving DSP reported at least one experience of financial stress in the

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

⁵ Ibid.

previous 12 months, and almost one in three were experienced financial distress (4 or more experiences of financial stress in the past 12 months), much higher than for carers on average.

Figure 2. Income source and experiences of financial stress



With significantly more people with disability experiencing unemployment during the pandemic, and many carers also reporting increased costs of living associated with COVID-19, it is even more pressing for people with disability and carers to be able to engage in a flexible and effective DES Model that supports optimal financial, social and health outcomes.

Improving support for carers with disability

Implementing a strengths-based approach for carer participation

Carers experience multiple, complex barriers to employment, and approximately 1 in 5 people with disability also reporting caring responsibilities.⁶ In spite of this, carers with disability who are unemployed or underemployed do not always meet the eligibility criteria for Carer Payment or DSP, and may therefore only be able to access JobSeeker Payment, which creates requirements for them to participate in vocational activities, including DES programs.

Additionally, in some instances, carers with disability who are receiving Carer Payment or DSP can choose to proactively engage with DES programs on a voluntary basis. Carers NSW believes that a strengths-based individualised approach, that also addresses employment barriers associated with caring, is vital within the new Model to enabling meaningful and sustainable employment for carers with disability.

Identification of carers in assessments and reporting

Identification of service users with caring responsibilities at intake and assessment is key to ensuring appropriate carer-aware support within the new Model. Carers NSW has concerns that current reporting on the participation of different cohorts accessing DES programs does not include carers as a cohort,⁷ suggesting that information regarding carer status may not be collected or reported on, despite the likely overrepresentation of carers within these programs. Carers NSW believes that in order to identify and meet the needs of carers, as well as measure the success of the new Model in

⁶ ABS (2019).

⁷ DSS (2021b). *Inclusive, accessible, diverse: Shaping your new disability employment support program, consultation paper.*

supporting carers, carers must be adequately identified in any assessment of employment support needs.

Addressing barriers to employment for carers with disability

Carers experience a number of barriers to employment that are unique to the caring role. Carers may take breaks in employment or allow their qualifications to lapse to provide care. They may also experience difficulty accessing replacement care or be unable to find an employer who provides adequate flexibility to enable them to balance employment with their caring responsibilities.

Carers participating in the paid workforce who responded to the Carers NSW 2020 National Carer Survey⁸ reported that the main issues they had experienced when looking for work included: that the demands on their time would have been too high to keep up their caring role (51%), trouble finding work because they felt that it wouldn't be possible to take enough paid leave to keep up the caring role (48%), that the type of work would have kept them from sufficiently checking on the person they care for (44%), and that there wasn't enough support for carers by the prospective employer (e.g. lack of flexible work) (43%).

Additionally, the Survey found that more than one in three (34%) people caring for someone who is ageing or frail disagreed that aged care services enabled them to continue or return to work. Almost half (46%) of people caring for someone who was accessing NDIS services disagreed that services had enabled them to engage in employment, and over half (59%) of people caring for someone who accesses mental health services felt that mental health services did not enable them to go back to work.⁹

Carers NSW believes that the new Model should identify and assist carers to address barriers to employment related to their caring role. This includes assisting carers to source and secure replacement care, negotiating flexible working conditions with employers, providing financial assistance to support carers to upskill or retrain and providing carer specific post-employment support in the initial stages of their employment.

Furthermore, some carers report difficulty balancing their caring role with mutual obligations, especially where they are unable to access replacement care, or where the person they are required to assist the person they care for to attend health or medical appointments that cannot be rescheduled. In these instances, where carers may be forced to choose between their caring role and having their income support payments suspended, carers can experience significant distress or financial hardship. Carers NSW believes that under the new Model, caring responsibilities must be considered when developing mutual obligations, and that where caring responsibilities exist, mutual obligations must be flexible to minimise any potential additional strain on carers.

Recognising and including carers as supporters of people with disability

Carer recognition and inclusion in education and employment supports

Given the extensive responsibilities many carers have in supporting the person they care for to identify, secure, maintain and maximise employment opportunities, it is important that carers be included in the planning and delivery of employment supports for 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 excluded from discussions and decisions to optimise their care recipient's independence. This is despite the role carers play as partners in care, supporting the person throughout their lifespan to practically access opportunities such as education and employment. While

⁸ Carers NSW (2020).

⁹ Ibid.

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.

Carers NSW believes that, in line with the *Carer Recognition Act 2010* (Cth), the new Model should ensure the recognition and inclusion of carers in the planning and delivery of services and supports as partners in care. This includes the consideration of carers in determining mutual obligations, especially where this may place additional strain on carers to provide support with transport. 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.

Carers NSW also advocates for recommendation 27 in the DES mid-term review, involving the elimination of required face-to-face service provision, and providing flexibility to include phone and video meeting options where this is preferred.¹⁰ Broadening service access pathways for those with mobility issues and their carers, and reducing community movement for people with increased risk of COVID-19 complications, will support active participation in DES and engagement of carers for supported-decision making.

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

Carers NSW believes it is important to ensure a focus in the Model on the development and promotion of information, tools and resources that build the capacity and confidence of carers as advocates and supporters of people with disability. This includes the practicalities of navigating employment pathways and 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.

While some carers may have low expectations of the employment capabilities of the person they care for, often informed by historic societal attitudes, many carers are the ones challenging the low expectations of educators, teachers, career advisors, employers and medical professionals. As key supporters and advocates, many carers support and enable people with disability, especially young people with disability, to exceed societal expectations and overcome barriers to employment.

Supports for carers should also be focused on 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.

Connecting education and employment support

Education is a foundation for employment, and 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 Model must also focus on ensuring adequate supports for people with disability within education settings, and early activation of employment support in schools.

Carers NSW continues to hear from carers of children with disability that ongoing tensions between the 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. This should be prioritised because of the

¹⁰ Department of Social Services (DSS) and Boston Consulting Group (BCG) (2020) *Mid-term Review of the Disability Employment Services (DES) Program: Consultation paper*.

anticipated 50% increase in students with disability accessing NSW public schools, and planning for inclusion remains inadequate even for current school populations.¹¹

Where young people with disability are already experiencing barriers to educational engagement, there is elevated risk of missing the development of key career skills, knowledge and support to ensure a successful transition between education and employment. Additionally, in instances 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 therefore believes that the Model must include a focus on ensuring optimal education outcomes for children and young people with disability, especially in their final years of school, 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 and employment needs are met in an accessible and supportive way.

An important approach to achieve this includes activating earlier integration of DES into education settings, to ensure parents and carers are given the practical tools and resources for supported decision making for young people's employment ambitions. DES program eligibility commences from age 14¹², and DES currently provides support to a small number of students with disability to transition to work¹³.

Expanding transitional programs to eligible high school students with disability, early in their high school education, will enable students and their parents and carers to understand the educational requirements and supports needed to be successful in higher education and career pathways. This strengths-based approach will assist parents and carers to provide appropriate supported decision-making regarding school subjects, work experience opportunities and other factors that elevate the young person's ability to achieve their employment goals and ambitions.

Carers NSW advocates for increased collaboration between DES providers, schools, students and parents and carers to create a cohesive and efficient support mechanism to target and initiate support for the young person. This will likely increase the employability and retention of DES program participants in employment opportunities, and improve financial, social and health outcomes.

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

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

¹¹ 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>

¹² Disability Employment Services (DES) *Eligibility*, available online at: <https://www.jobaccess.gov.au/people-with-disability/eligibility>

¹³ Department of Education, Skills and Employment, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*.

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 Model 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 someone in 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. This will support employers and employees to sustain safe and supported workplace outcomes, and ensure that people with disability are able to remain in the employment context that they have committed to achieving.

Conclusion

Carers NSW supports the upcoming reforms to the Model 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 new Model will be the inclusion of carers, as the key supporters of people with disability, throughout all areas of the Model. Additionally, the recognition of carers as a cohort of DES participants and an increase in program flexibility will ensure greater access and success within the program for carers with disability. Expanding consideration and focus in the Model to include carers as partners in success and people with additional employment barriers is likely to ensure optimal inclusion and participation of both groups.