



Submission to the National Carers Strategy

Supporting Carers of Children with Disability

September 2024

Belongsid Families: Empowering Parents of Children with Disability

Belongsid Families is a family-led, independent, not-for-profit organisation supporting families raising children with developmental delay, disability and autism across New South Wales.

Through free online programs and peer groups, trusted resources, and supportive community, we empower over 5,000 parents and carers each year to build the skills, knowledge, and confidence to help their child and family to thrive.

Belongsid Families' purpose is to provide essential support for families early in their journey enabling them to live their best lives and discover a future full of possibility.

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Introduction

The Australian Government's initiative to develop a new National Carer Strategy provides a crucial opportunity to address the unique and complex challenges faced by carers of children with disability.

Carers of children with disability play an invaluable role in our society, providing round-the-clock care and support that is often under-recognised and undervalued. This submission is based on a survey of 54 parents and carers of children with disability, offering insights into their experiences, challenges, and needs. It highlights the specific issues carers face and presents practical recommendations based on their feedback.

Key findings include the need for increased financial support, improved access to respite care, better mental health support, and greater recognition of the carer role. Our recommendations aim to address these issues through practical, achievable measures that can significantly enhance the lives of carers, with a strong emphasis on personalised and tailored solutions.

It is crucial to recognise that carers of children with disability face distinct challenges compared to other carer groups. Their caring role often extends throughout their child's life, requiring constant adaptation to changing needs and long-term planning. This unique position demands equally unique and tailored support solutions. Furthermore, carers do not exist in isolation from the children they care for - when the systems their child interacts with fail, it directly impacts the carer's wellbeing, often leading to burnout, exhaustion, and financial strain.

This submission provides a detailed overview of the challenges faced by carers and proposes recommendations based on family feedback to ensure the new National Carer Strategy delivers meaningful, systemic change for carers of children with disability.

Key Findings

Balancing Caring Responsibilities with Work or Other Commitments

Carers of children with disability often face difficulties maintaining employment or fulfilling personal commitments due to the intense and unpredictable nature of caregiving. This makes it difficult to commit to regular work hours or engage in activities outside of caregiving.

“If I had more certainty and stability in my daughter’s supports and didn’t have to spend so much time advocating I would be able to work (and pay taxes!) but at the moment I just don’t have the headspace or time or energy.”

“I had to leave my job to care for my child full-time, and now we’re struggling financially. It’s nearly impossible to balance work and the level of care my child needs.”

76% of carers reported difficulty in balancing caregiving duties with work or other commitments.

36% of carers identified balancing caregiving responsibilities with work or other commitments as one of their top three challenges.

Financial Strain

Carers are often forced to reduce work hours or leave employment entirely due to their caregiving responsibilities, leading to financial strain. The existing Carer Payment does not adequately reflect the true costs of providing care.

“I had to quit my job, and the \$153 per fortnight from the carer allowance doesn’t even begin to cover the costs. The financial strain is huge.”

74% of carers highlighted the need for increased financial support.

47% of carers reported financial strain due to limited income or lack of financial support in their top three challenges they face as a carer.

Social Isolation from Friends and Community

The demands of caregiving often lead to social isolation for carers, making it difficult for them to maintain relationships or participate in community activities. A lack of understanding or awareness about their child’s disability can further isolate them, as carers may feel excluded or misunderstood within their community. This social isolation can have a significant negative impact on carers' mental health and overall wellbeing.

“It’s isolating, it puts the family dynamics under strain, there is not enough information out there to help parents understand their role is a caring one, it disrupts other relationships, it can create overwhelm & burnout.”

"I feel completely alone. I can't remember the last time I went out with friends or did something just for myself. People don't understand what it's like."

26.7% of carers identified social isolation as one of their top challenges, with many stating that their caring responsibilities leave them with little time or energy to maintain social connections.

Inadequate and Inconsistent Respite Care

A common concern among carers is that respite care services are either unavailable, difficult to access, or unsuitable for their child's specific needs. Without access to adequate respite, carers are left to provide constant care, leading to burnout and affecting their ability to continue caregiving in the long term.

"We need more respite care that's easy to access and reliable. Right now, we're barely getting any help, and it's overwhelming."

68% of carers reported that lack of access to respite care is a major issue, with many stating that existing services are insufficient or inappropriate for their child's needs.

Challenges in Accessing and Navigating Support Systems

Carers struggle to access necessary support due to fragmented, complex, and confusing information systems. Understanding and applying for available support is often complicated and time-consuming, adding to the mental load of caring. This is exacerbated by the complexity of navigating support systems like NDIS, healthcare, and education for their child. The mental and emotional load of paperwork and advocacy adds to their stress and contributes to burnout.

"Between the NDIS paperwork and advocating for my child at school, I'm constantly battling the system. It's draining, and it's affecting my ability to care for my child."

"The bureaucratic processes are so complicated that they add a whole new layer of stress. Instead of focusing on caring for my child, I'm drowning in paperwork."

"Getting help should be easy, but it's not. The system feels like it's set up to make things harder for carers, not easier."

"Information is not centralised, it's hard to know what you can have access to because it's in a hundred different places."

43% of carers found it difficult to understand or locate information about the support available.

42% reported one of the biggest challenges is the lack of flexibility in support services.

Emotional and Physical Exhaustion (Carer Burnout)

Carers of children with disability frequently experience emotional and physical exhaustion due to the continuous demands of caregiving. Many carers also take on advocacy roles, navigating complex systems such as NDIS, healthcare, and education, further adding to their stress and exhaustion.

“Financial stress as burnout and poor health leaves carers unable to fulfill full time work hours. Little time to look after own health.”

“It’s not just about my child not getting the support they need; it’s that I’m left to pick up the pieces. The system isn’t working, and it’s exhausting constantly having to fight for basic supports.”

“I am a qualified teacher and had aspirations of completing my psychology qualifications to become a psychologist, both roles that are greatly needed. With properly targeted support I could have fulfilled these roles in the community and ensured my children have the early interventions they need to reduce their support needs in the future. Instead, my own health has deteriorated to such a degree that even if I weren’t overwhelmed with carer duties, I would now struggle to work in any capacity.”

93% of carers reported emotional and physical exhaustion in the top three challenges faced as a carer.

Carer Gateway: A Need for Redesign

Carers expressed dissatisfaction with the current Carer Gateway system, which offers the same support package regardless of the carer’s responsibilities. This one-size-fits-all approach does not meet the diverse needs of carers, particularly those providing full-time care or those without informal support networks.

“There are so many steps to seek support or assistance, all require a lot of time and energy. Something we already lack. After dealing with the NDIS, where we have to remain on guard, ready to advocate and defend our loved one/s, when we are defeated we are expected to place our trust in another government service where we disclose our sensitive information to another stranger, sharing significant vulnerabilities and await the outcome for ourselves to access the support available. So many of us are used to putting on a brave face / masking that the thought of another battle to prove our needs is just too much.”

“I’m a single parent and have health issues. I had to fight for a package and was then offered two cleaning sessions and was told that I couldn’t access anything else. It was disheartening when I was hearing from other parents of the high level of ongoing support and items they received and they themselves said they didn’t really need it but they could get it so why not. But I really need it to survive.”

“Carers Gateway was traumatising.”

52% of carers indicated that the Carer Gateway system does not meet their needs, calling for more personalised support options.

Recommendations

To address these challenges, we propose the following:

- 1** Ensure that Carer Gateway support is truly personalised and tailored to the specific circumstances of each family, recognising that caregiving roles vary significantly in intensity and complexity.
- 2** Expand flexible respite care options tailored to the unique needs of families caring for children with disability.
- 3** Ongoing investment in peer support tailored specifically to carers of children with disability, offering both in-person and online opportunities for connection. This support not only reduces social isolation and improves mental health but also provides vital peer-to-peer guidance on navigating complex systems.
- 4** Increase the Carer Payment/Allowance to better reflect the true cost of caregiving.
- 5** Introduce superannuation contributions to carer payments, similar to the planned introduction for Paid Parental Leave, recognising the long-term financial disadvantage faced by carers who reduce or cease workforce participation.
- 6** Create a nationally recognised Carer Card offering meaningful benefits such as utility, health insurance and fuel discounts, grocery delivery, and other essential services.
- 7** Increase access to mental health support for carers, including subsidised counselling services and mental health services beyond what is available for the general population.
- 8** Ongoing investment in free and accessible education programs tailored to carers of children with disability to learn how they can support their own well-being and enhance their caregiving skills.
- 9** Develop a coordinated outreach campaign to carers of children with disability to increase awareness and utilisation of existing government platforms, such as Service NSW's Savings Finder and other support services for parents and carers.

Informed by Families

The survey captured responses from a diverse group of carers of children with disabilities, providing valuable insights into their backgrounds, caregiving experiences, and support needs:

Cultural and Regional Diversity:

- 11% of respondents identified as being from a culturally and linguistically diverse (CALD) background.
- 3% of respondents identified as First Nations.
- 77% of respondents reside in New South Wales, with 30% living in regional areas and 11% in rural communities.

Age and Family Responsibilities:

- 89% of respondents are aged between 35 and 54 years, in their prime working years.
- 43% of respondents reported caring for another person in addition to their child with a disability, reflecting the often multifaceted nature of their caregiving roles.

Child Demographics and Disability Types:

- 81% of respondents were caring for a child under the age of 12 years.
- 62% of respondents were caring for a child diagnosed with Autism.

Care Hours and Access to Support

- 34% of respondents provided 24/7 care for their child with a disability, while 32% reported providing 41+ hours of care per week. An additional 18% provided between 31 and 40 hours of care weekly.
- 50% of respondents stated that they had occasional help with caregiving, while 28% reported having no support at all, including family or friends.

Perception of the 'Carer' Role:

- 19% of respondents indicated that they do not feel comfortable identifying as a "carer."
- 46% only use the term "carer" when they need to access supports, highlighting the complexities around the use of this term within the caregiving community.