



Inclusion Australia

National Carer Strategy

Department of Social Services Consultation

Submission from Inclusion Australia

September 2024

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Background

Inclusion Australia is the national peak organisation representing the rights and interests of Australians with an intellectual disability and their families. Founded 70 years ago in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability.

Our strength is in our national representation and our connection to our community. We have a member organisation in every state and territory across Australia:

- ACT Down Syndrome and Intellectual Disability (ACT DSID)
- Council for Intellectual Disability (NSW)
- Developmental Disability WA (DDWA)
- Inclusion Northern Territory (Inclusion NT)
- Parent to Parent (P2P, Queensland)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Advocacy (Tasmania)
- Victorian Advocacy League for Individuals with Disability (VALID).

We are pleased to have the opportunity to take part in this consultation. As the national representative organisation for people with an intellectual disability and their families, Inclusion Australia hears from many people across the country. Many families we work with do not refer to themselves as, or identify as, carers, instead focusing on their roles as mums, dads, siblings, and other family members. For this reason, we will generally refer to family members or 'people providing informal/unpaid care' rather than carers in our submission.

By responding to this consultation, we would like to draw attention to the important role that family members play in the lives of people with an intellectual disability and acknowledge that appropriate support for families can benefit the individual with disability as well.

In this submission, we draw upon consultations we were involved in that were conducted by Disability Advocacy Network Australia (DANA) and commissioned by the Department of Social Services to provide feedback for the proposed National Carer Strategy. These consultations were conducted in July 2024 and with members of [Inclusion Australia's peer Services for One Community of Practice](#) and roundtables with carer stakeholders associated with Inclusion Australia.

The Service for One Community of Practice is a national group of parents with lived experience of supporting a family member with an intellectual disability and complex support needs, via a self-managed or plan managed NDIS plan and/or a formal individualised model for supporting one person. This group has been meeting regularly for more than three years and informs IA's systemic advocacy from a family perspective. IA also recognises and represents the interests of their family members with an intellectual disability.

These groups shared their personal experiences caring for family members with an intellectual disability and very high support needs, including complex communication support needs, serious mental illnesses and self-harm. We appreciate their frankness in sharing personal circumstances and support needs and hope that their views and suggestions can inform Australia's National Carer Strategy.

We also draw the Department's attention to a submission we provided to the Australian Parliamentary Select Committee on Work and Care in 2022.¹

¹ <https://www.inclusionaustralia.org.au/wp-content/uploads/2023/06/Select-Committee-on-Work-and-Care-Inclusion-Australia-submission-final.pdf>

Summary of recommendations

Recommendation 1

Embed evidence-based principles in the Strategy, including:

- Supports for people providing unpaid care are positive investments that can promote their well-being and the sustainability and longevity of informal care.
- Supports for people providing unpaid care should be person-centred and family focused.
- Supports should be multi-dimensional, taking into account carer well-being including physical health, mental health, social inclusion, and finances.
- Supports should meet people where there are at, acknowledging that those in care roles may not recognise themselves as carers and seek out carer supports and may instead require proactive outreach that recognises their relational role (e.g., parent, spouse).
- Supports should help people appreciate the positive aspects of their care roles, and encourage a sense of meaning, purpose and optimism.

Recommendation 2

Establish a carer reference group to monitor the implementation of the National Carer Strategy, with diverse representation, including family members of people with an intellectual disability.

Recommendation 3

Develop a comprehensive suite of co-designed resources developed for and with carers of people with disabilities, on how to navigate NDIS planning, supports and services, that are independent and evidence-based. This could be considered as part of the current foundational supports work stemming from the NDIS Review. This should include:

- Exploring resources currently available, assess quality and identify gaps
- Working with family members of people with disability and others providing unpaid care to co-design clear and accessible resources.
- Ensuring resources are easily available and are promoted through trusted community organisations, not just the Carer Gateway and Disability Gateway.

Recommendation 4

Expand Disability Liaison Officer roles within mainstream supports such as health systems, to assist carers with coordinating care or responding to emergencies for people with complex support needs.

Recommendation 5

Provide assistance for carers to utilise digital technology to access supports for themselves and the person for whom they care.

Recommendation 6

Ensure that the National Carer Strategy recognises that the role of carer continues when the person who is receiving care lives somewhere else. Consider how this may be accommodated in social security payments.

Recommendation 7

Align with the Foundational Supports Strategy currently under development to ensure nation-wide access to family capacity building, on important issues like succession planning / future-proofing, Circles of Support, Microboards, and other strategies that facilitate supported decision making, collective approaches, and long-term care planning.

Recommendation 8

Expand funding for relationship and personal counselling for carers, to strengthen family relationships and promote personal wellness.

Recommendation 9

Expand opportunities for peer support through the National Carer Strategy, to ensure nation-wide reach and consistency in provision, so that family members and people providing unpaid care can build informal support relationships with each other.

Recommendation 10

Provide opportunities for carers to be trained in peer support facilitation, to build capacity for more carer-led support groups.

Recommendation 11

Ensure that there are robust protections for people providing unpaid care to utilise workplace accommodations and an accessible dispute mechanism if requests for flexible work are declined by employers.

Recommendation 12

Provide evidence-based guidance to universities so they can offer supports to students who are providing unpaid care, such as carer leave and special considerations for course assessments when needed due to carer responsibilities.

Recommendation 13

Enable people who can demonstrate significant carer responsibilities when the person they care for lives somewhere else to qualify for Carer Allowance.

Principles of the strategy

People providing informal care deliver supports that are essential to the functioning of society, which would otherwise require great cost to government. Our current service systems, including the National Disability Insurance Scheme (NDIS), are built on the assumption and foundation of ‘informal supports’ in the lives of people with disability.

Carers Australia’s report, *The Value of Informal Care in 2020*, found that it would have cost \$77.9 billion in that year alone to replace the care provided by informal carers if substituted by formal supports funded through My Aged Care or the NDIS.² Investing in infrastructural supports to enable the sustainability and longevity of informal care makes good fiscal sense, above and beyond the moral and ethical imperatives to support carers.

Caregiving is an essential quality of being human. At different points over their lives, almost everyone will provide and receive care. For some people, including many families of people with an intellectual disability, this carer role can be decades long. People with an intellectual disability are also carers of their family members, including caring for aging parents.

“It’s a massive responsibility to make sure you’re doing the right thing by someone and respecting what you think their choices might be, and making sure you involve others in that decision making, which takes work.”

Family member, July 2024

Policy attention to people undertaking care work is often reactive to problems and piecemeal in response, leaving gaps in supports that can undermine the well-being of the carer and person they are supporting, and risk the sustainability of the care arrangement. The goal of carer support should be to promote flourishing, which is linked to positive emotions, engagement in one’s life activities, relationships with others and finding purpose and meaning, through holistic and accessible supports.³

“We love our family members and children, whether they’re young or adult, it’s so difficult to ensure and maintain your own energy to make sure that they are supported.”

Family member, July 2024

Supports for carers can reduce stressors and promote their well-being, which has flow-on positive effects to those for whom they provide care.⁴ When compared to their peers,

² Carers Australia & Deloitte Access Economics (2020). *The value of informal care in 2020*. <https://www.carersaustralia.com.au/wp-content/uploads/2020/07/FINAL-Value-of-Informal-Care-22-May-2020-No-CIC.pdf>

³ Beach, B., Bélanger-Hardy, L., Harding, S., Rodrigues Perracini, M., Garcia, L., Tripathi, I., & Dow, B. (2022). Caring for the caregiver: Why policy must shift from addressing needs to enabling caregivers to flourish. *Frontiers in Public Health*, 10, 997981.

⁴ Zhang, Y. & Bennett, M.R. (2024). Insights into informal caregivers’ well-being: A longitudinal analysis of care intensity, care location, and care relationship." *The Journals of Gerontology: Series B* 79, no. 2 (2024): gbad166.

research evidence supports an association between informal caregiving and increased stress leading to poorer psychological health and poorer well-being, depression and anxiety;⁵ poorer physical health including higher rates of chronic disease and impaired health behaviours;⁶ and poorer workforce participation leading to increased risk of unemployment and poverty.⁷

Whether people providing informal care can access appropriate supports depends on the availability, affordability, ease of access, intensity, quality and effectiveness of services. Additionally, how families and people providing unpaid care perceive their role and whether they self-identify as carers also has implications for accessing supports, as carers often minimise their own self-care needs to focus on meeting the support needs of the person for whom they care.⁸ Self-identification as a carer is often necessary to be able to find and access carer supports, including connecting with others who have similar responsibilities through peer supports.⁹

“For me, again, it's unpaid carer. I think we need to say it with pride, and it needs to be valued, and that needs to change.”

Family member, July 2024

Many families associated with Inclusion Australia did not use the term ‘carer’ to describe themselves, indicating that it caused confusion for other who might think they were in a paid care roles such as support worker. They were also sensitive that being called a carer could be perceived to disempower from their family member and would not be the family member’s preferred term. Instead, many who would fit the definition of informal carer see themselves in terms of their relationship with the person for whom they care and consider their carer responsibilities as part of their role as parent, sibling, adult child, partner or spouse.

“No, I don’t really use the term carer. I’m either mum or daughter. When I’m home I’m mum. If it’s concerning dad and all his appointments, I’m his daughter. I don’t really use the term carer, but I suppose that’s what it is. But I don’t use the term. I just, I’m there.”

Family member, July 2024

⁵ Oyeboode, J. (2003). Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, 9(1), 45-53.

⁶ Farquhar, M. (2016). Supporting informal carers. *Palliative Care in Respiratory Disease (ERS Monograph)*. Sheffield, European Respiratory Society, 51-69.

⁷ Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of informal caregiving on caregiver employment, health, and family. *Journal of Population Ageing*, 8, 113-145.

⁸ Broady, T., & Aggar, C. (2017). Carer interventions: an overview of service effectiveness. *Journal of the Australasian Rehabilitation Nurses Association*, 20(2), 5-11.

⁹ Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2011). Reconsidering the term ‘carer’: a critique of the universal adoption of the term ‘carer’. *Ageing & Society*, 31(3), 422-437.

Research on the positive aspects of caregiving highlights the benefits and sense of meaning that people can gain from their role providing care. It is clear from conversations with family members we speak with that their experiences supporting their family members with an intellectual disability are shaped by mutual care and love, and that the relationships are not one-sided, with benefits received by families too. The challenges faced by people providing unpaid care tend to be related to system failures and the impact of administrative requirements to access support, rather than being inherent in the care relationship.

Thinking positively about their role as a carer, such as expressing a sense of meaning and purpose, has also been shown to be positive for carer well-being.¹⁰ Among the carers who participated in the 2022 National Carer Survey, most (54%) found being a carer satisfying and a positive experience (52%), with about two-thirds reporting that being a carer has strengthened their relationship with the person for whom they care (63%) and taught them new skills (68%). Carer supports, such as carer coaching and peer support, can help people appreciate the positive aspects of caring for others.

In our view, a National Carer Strategy is an important opportunity to highlight the mutual benefit of care relationships and to identify – and set the scene to address – the administrative and system challenges that can impede these relationships.

Recommendation 1

Embed evidence-based principles in the Strategy, including:

- Supports for people providing unpaid care are positive investments that can promote their well-being and the sustainability and longevity of informal care.
- Supports for people providing unpaid care should be person-centred and family focused.
- Supports should be multi-dimensional, taking into account carer well-being including physical health, mental health, social inclusion, and finances.
- Supports should meet people where there are at, acknowledging that those in care roles may not recognise themselves as carers (and should not need to, in order to access support) and may instead require proactive outreach that recognises their relational role (e.g., parent, spouse).
- Supports should help people appreciate the positive aspects of their care roles, and encourage a sense of meaning, purpose and optimism.

To ensure the best chances of its success, it will be important that the Carer Strategy is robustly implemented, with financial investment behind it and attention to potential unintended consequences and gaps in service delivery access. We recommend establishing a carer reference group with nationwide representation, including family members and other supporters of people with different types of disabilities including people with an

¹⁰ Carbonneau, H., Caron, C. and Desrosiers, J. (2010) Development of a conceptual framework of positive aspects of caregiving in dementia, *Dementia*, 9(3): 327–53.

intellectual disability, as well as representation by First Nations and Culturally and Linguistically Diverse people providing informal care.

Recommendation 2

Establish a carer reference group to monitor the implementation of the National Carer Strategy, with diverse representation, including family members of people with an intellectual disability.

Support for carers

The family members we have spoken to around the Carer Strategy report facing a high level of stress caused by the gaps in services for their family members with an intellectual disability. They are stalwart advocates for their family members and face significant challenges as they support their loved one to be part of decision making and accessing fundamental services and supports. They frequently referred to having to ‘fight’ constantly to have their loved one’s support needs met. Carers also referred to the mental load they carry and the responsibilities around decision making that can be tiring and difficult to reconcile with their other responsibilities, including work. This points to a need for greater community inclusion and understanding of supported decision making, so that the support of an individual’s decisions or helping them communicate are not centralised in one or two people.

“We care passionately about the people that we’re caring for. We want them to have the best quality of life, and we love them dearly, but it’s just hard to fight day in day out, just to get basic needs. We’re not even talking about anything out of the ordinary, human rights, basic living human rights.”

Family member, July 2024

People with an intellectual disability and their families tell Inclusion Australia every day about the huge administrative load they face in trying to get the support they need.

People with an intellectual disability and their families are navigating multiple state, territory and federal government systems and agencies, which often have multiple and conflicting eligibility criteria and program rules. These include:

- Disability Employment Services (DES)
- Centrelink and the Disability Support Pension (DSP)
- National Disability Insurance Scheme (NDIS)
- Education systems
- Housing
- Health and Medicare.

Lack of appropriate supports for people with an intellectual disability – or challenges in accessing them – can place significant pressure on their family members. Family members may neglect their own self-care and health, which can put them in danger. In the 2022 National Carer Survey, the great majority of participants spent more time providing care than they wanted to (67.1%) and less time than they wanted to on desired activities

including recreational activities (85%), exercise (80%), spending time with family and friends (78%), and sleep (75%).¹¹

Appropriate support options for people with an intellectual disability, including short-term accommodation, either at night or during the day and in or out of their home, was identified as the most difficult service type to access by carers participating in the National Carer Survey.¹²

“The last couple of months, since my son’s been well, I’ve reached out and got that breast screen that’s 15 years overdue, because literally, I just haven’t done anything [for myself].”

Family member, July 2024

The NDIS is a hugely complex system and brings a large administrative load that requires significant time and effort to manage.

For many people with an intellectual disability, NDIS administrative work is done by family members (as NDIS processes are inaccessible and supported decision making is not routinely built into them). Many family members tell us managing their loved one’s NDIS plans is effectively another full-time job. Research has confirmed this, finding that “individuals need considerable skills and networks to successfully negotiate the scheme’s complex administrative processes”.¹³ The administrative load only increases when other service systems (like the Disability Support Pension and carer entitlements) are involved.¹⁴

Navigating these complexities has specific challenges for people providing unpaid care who themselves have an intellectual disability, with little accessible information and support for how to do this.

Recommendation 3

Develop a comprehensive suite of co-designed resources developed for and with carers of people with disabilities, on how to navigate NDIS planning, supports and services, that are independent and evidence-based. This could be considered as part of the current foundational supports work stemming from the NDIS Review. This should include:

- Exploring resources currently available, assess quality and identify gaps

¹¹ Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

¹² Ibid

¹³ Gemma Carey, Eleanor Malbon, and James Blackwell, “Administering Inequality? The National Disability Insurance Scheme and Administrative Burdens on Individuals,” *Australian Journal of Public Administration* 80, no. 4 (August 10, 2021): 854–72, <https://doi.org/10.1111/1467-8500.12508>

¹⁴ We explored the significant administrative load and challenges in system navigation through interviews with families for our 2022 report, *Equal Pay, Equal Rights*: <https://www.inclusionaustralia.org.au/submission/equal-pay-equal-rights/>.

- Working with family members of people with disability and others providing unpaid care to co-design clear and accessible resources.
- Ensuring resources are easily available and are promoted through trusted community organisations, not just the Carer Gateway and Disability Gateway.

Family members are often important advocates for people with an intellectual disability and can support their family member with making decisions about their lives and the supports they need. However, it is not easy for family members to find suitable resources that are designed by peers and evidence-based, to guide them. They can also face opposition and hostility in their advocacy efforts on behalf of their family member.

There are also very few resources currently available to support families to learn about supported decision making and how to put it into practice. When talking with families for a recent project we undertook, they clearly identified gaps in practical information about what supported decision making is and how to build it into daily life through different decisions and ages.¹⁵

“They [government systems] had this idea that if someone’s doing a good job and looking after their family member, speaking up for their needs, looking at what they’re entitled to and what their rights are, somehow that made them a pain to deal with.”

Consultation participant, July 2024

Family members we spoke to about the Carer Strategy talked about the importance of centralised roles like Disability Liaison Officers. They saw this role as being able to assist with coordinating care for their family members with complex support needs within mainstream services such as health, particularly in moments of crisis such as emergency room admission. One family member described this as “access to a direct line” who could support them when they are making life changing decisions, particularly in emergency contexts.

Family members suggested this role could be delivered as an on-call hotline and embedded in state services such as health services. While some states and territories (and some health centres within them) have these kinds of care coordination roles, the families we spoke to said they are too limited and inconsistent to meet the level of need in the community.

Recommendation 4

Expand Disability Liaison Officer roles within mainstream supports such as health systems, to assist carers with coordinating care or responding to emergencies for people with complex needs.

¹⁵ This informed the development of our family resources (written guide and webinar) about financial decision making. This was identified as a key gap: <https://www.inclusionaustralia.org.au/make-decisions-real/learn/money-information-for-families/>.

An example of this would be a mental health admission for a person with an intellectual disability, where mainstream mental health services are often not knowledgeable about how to provide support for people dually affected by mental ill-health and intellectual disability. People with family members who have an intellectual disability and a mental illness indicated that accessing support during challenging moments could help avert crisis.

One family member we spoke with pointed out that some families feel pressured to relinquish care of their child because our service systems do not provide adequate or integrated support to manage complex health and disability support needs. Targeted support and care coordination in these cases could make a huge difference to a family's ability to continue to provide care and ensure their family member's support needs are met.

“My son's been suffering for eight weeks, and you have to fight, and you fight, and you fight. I really want to be a carer. And I know many people who've given up the fight, have to give up their children. And if you're looking practically as a country, it's more sustainable if we help our carers and kids to stay in the care of their families. It's much better for society. It's cheaper for the government, but we can't fight for everything.

In the end, it's totally exhausting. You shouldn't have to be a PhD to look after your child. You shouldn't have to be eloquent to be able to get the help that you need. And you shouldn't have to be the squeaky wheel to forever be pushing and pushing and pushing and pushing to get help.”

Family member, July 2024

Some family members we have spoken to, particularly those who are older and did not grow up using digital technology, would value the opportunity to receive 1:1 assistance with technology, including the NDIS portal and Carer Gateway. As more and more government services are delivered online, this can exacerbate the digital divide, which disproportionately affects particular groups of Australians including those with disabilities and those over 75 years of age.¹⁶ Indeed, the National Carer Survey confirmed that one in three carers (34%) lacked good access to high-speed, reliable internet.¹⁷ Carers who participated in consultations also emphasised the importance of 'in real life' supports through events in local communities. They pointed out that not everyone uses phones and computers.

¹⁶ Australian Digital Inclusion Index (2024). 2023 Australian Digital Inclusion Index. <https://www.digitalinclusionindex.org.au/digital-inclusion-the-australian-context-in-2023/>

¹⁷ Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

Positive work has been done by the Good Things Foundation in partnership with Down Syndrome Australia around the digital divide for people with an intellectual disability and their families.¹⁸

Recommendation 5

Provide assistance for carers to utilise digital technology to access supports for themselves and the person for whom they care.

Family members we spoke with made it clear that they continue to provide essential care for their family member with an intellectual disability even when they live out of home, independently or in supported accommodation (group homes). They wanted the Carer Strategy to recognise and acknowledge the importance of their ongoing carer role. Families in this situation wanted it to be understood that they continued to be in their carer role and very involved in different ways when their family member lived in supported accommodation.

“I think that a strategy should definitely address the issue, that if the person is living at home with you, it is a different level of care maybe, or the nature of the caring role is different, but if they’re not living at home with you, it does not necessarily assume that you’re not involved daily with their care.”

Family member, July 2024

At the moment, the legal definitions of care and the activities that are recognised as care work do not adequately cover families in these situations, and people providing this kind of support (especially administrative support or system navigation) may not be covered under carer entitlements and social security payments, even when their care responsibilities affect their capacity to engage in paid employment. We have discussed this issue with the Department of Social Services at various times and would be interested to see it explored further through the Strategy.

Recommendation 6

Ensure that the National Carer Strategy recognises that the role of carer may continue when the person who is receiving care lives somewhere else. Consider how this may be accommodated in social security payments.

Parents caring for their adult children express significant worry about who will carry on their role of advocate and supporter after they become too unwell to perform the role or pass away. Most carers who participated in the National Carer Survey 2022 worried about the future of the person for whom they care (70%).¹⁹ Many families we speak to are working

¹⁸ <https://www.downsyndrome.org.au/blog/2022/02/07/bridging-the-digital-divide-for-people-with-intellectual-disability/>

¹⁹ Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

very hard to set up sustainable support systems around their family member with an intellectual disability, whether through services-for-one, family systems, or paid supports to ensure support will be able to be provided through the individual's life. However, there is little guidance or formal support available to assist with this planning, and most that is available is delivered by community sector organisations like small advocacy organisations, rather than widespread delivery.

For example, our member organisation, the South Australian Council on Intellectual Disability (SACID), provides free workshops on 'future proofing' to help family members and caregivers of people with an intellectual disability prepare for the future, including establishing Circles or Support and Microboards.²⁰ Models such as Circle of Supports²¹ and Microboards²² can share the caring responsibility amongst a group of people, which can promote long-term sustainability. These models can also facilitate supported decision making approaches which can build independence and capacity over time.

"Even when you're in the up part and things are going relatively okay, [your] heart is in your hands, and you're touching wood and hoping that things stay like that. My husband and I, we're both 70, and it changes to the next steps, and I've had some health issues, and you do worry so much about it. While we have family and other kids, who really can take that on to the degree that we have?"

Family member, July 2024

Recommendation 7

Align with the Foundational Supports Strategy currently under development to ensure nation-wide access to family capacity building, on important issues like succession planning / future-proofing, Circles of Support, Microboards, and other strategies that facilitate supported decision making, collective approaches, and long-term care planning.

Several family members identified the importance of counselling, both relationship counselling and personal counselling, as important for the wellbeing of people providing unpaid care. One family member, who also holds a professional role related to carers/families, noted that families often experience extreme stress and this can lead to marital breakdown. This person used to refer carers to Relationships Australia to get

²⁰ South Australian Council on Intellectual Disability (SACID) (n.d). *SACID Community Workshop—Future Proofing*. <https://sacid.org.au/events/sacid-community-workshop-future-proofing/>

²¹ National Resource Centre for Circles of Support and Microboards define a Circle of Support as "A group of people who regularly meet..and assist with the thinking, planning and implementation of personal goals," noting that Circles can be established for people of any age and can provide a wide range of assistance on topics including finding a job, community connections, living independently and pursuing a dream. <https://cosam.org.au/national-resource-centre/circles-of-support/>

²² Microboards Australia defines Microboards as: "A group of people in unpaid relationships with a person with disability who meet regularly to support that person to make plans, make decisions, be socially included, be safe and well and to have the life they want." <https://microboards.org.au/microboards-community/what-is-a-microboard/>

relationship counselling but reported that service is no longer available. Research on the impacts on family relationships of providing unpaid care work in a fragmented social service system found a heightened risk of arguments and potential for relationship breakdown within the early years of caring.²³

Family members in our community who participated in consultations generally had positive views of the Australian Government's Carer Gateway online platform but noted that demand outstripped the supply of services. One family member noted that there was a six-week waitlist for counselling via the Carer Gateway, which could leave a family without supports while they are experiencing trauma.

Recommendation 8

Expand funding for relationship and personal counselling for carers, to strengthen family relationships and promote personal wellness.

Providing more information to the community about the supports that are available to people who provide unpaid care – while being careful not to stigmatise people with disability or others who receive support from family members – would also be valuable. People can't access supports if they don't know about them.

Advertising campaigns such as billboards for Carers Gateway are one strategy for making the availability of existing supports widely known.

“One of the greatest things we find from families that assist them is knowledge and understanding what's available, what their rights are, trying to get through litigious speaking. We have a lot of strategies, tools and resources helping them to understand their role and not take on more than needs to be taken on and understanding policies. It's advocacy, but it's empowering them and making them feel that they're not asking for too much. Knowledge is important for people to have a sense of “I know what I'm doing now, and I'm to continue this” and that makes a big difference to the health stresses.”

Consultation participant, July 2024

Any advertising campaigns or promotional activities must be careful not to focus on the concept of 'burden of care'. The use of this language and concept stigmatises people with disability and can have a harmful impact on their sense of belonging and acceptance in the community. We provided feedback to the government on a campaign promoting carer supports several years ago on this point. It also incorrectly locates the challenges faced by people with disability and people providing unpaid care as inherently belonging to the person with disability, rather than being caused by fragmented and inadequate service

²³ Edwards, B. (n.d.) Caring for families caring for a person with a disability. https://melbourneinstitute.unimelb.edu.au/assets/documents/hilda-bibliography/other-publications/pre2010/Edwards_AIFS_newsletter_no11.pdf

systems and inaccessible environments and processes (we would instead say, the burden of administration or ineffective systems).

As such, the language of 'burden of care' is inconsistent with the social model of disability which holds that the cause of disability is the interaction of impairments with an inaccessible environment and not the impairment itself. We ask that the Strategy and any advertising campaigns are human-rights based, considering the rights of the people providing and receiving care.

Peer support

People providing informal care can often become socially isolated.²⁴ Peer support groups can be an effective way of addressing this and creating spaces with a trusting environment where people can mutually provide emotional support and share information.²⁵ Widespread usage of web-based meeting technology has opened up new opportunities for family members to connect remotely, across states and territories and around their work and support schedules.²⁶

During consultations, family members we spoke to indicated that they have learned more about supporting their family member with an intellectual disability from other family members, rather than professionals. They also expressed the importance of forming connections and friendships with others who shared their experiences.

“I find that this group has been my main support. Being able to talk with other parents all through [my daughter’s] life, I found that they’ve always given me the greatest support. I might have gone to see doctors or talk to counsellors or things but for me, it’s always been other parents who have given me the greatest support.”

Family member, July 2024

“Often the medical system and other places where you need to go for help, have absolutely no idea how best to help. You need people who understand, like this group and support workers who are with you every day. They are helpful.”

Family member, July 2024)

Recommendation 9

Expand opportunities for peer support through the National Carer Strategy, to ensure nation-wide reach and consistency in provision, so that family members and people providing unpaid care can build informal support relationships with each other.

The opportunity to mutually give and receive support is a feature of peer support groups that participants highly appreciate. Mutual aid groups are characterised by reciprocating the role of ‘helper and helpee’ through sharing personal lived experience, knowledge and

²⁴ International Alliance of Carer Organisations (2021). *Global state of caring*. <https://internationalcarers.org/wp-content/uploads/2021/07/IACO-Global-State-of-Caring- July-13.pdf>

²⁵ Worrall, H., Schweizer, R., Marks, E., Yuan, L., Lloyd, C., & Ramjan, R. (2018). The effectiveness of support groups: a literature review. *Mental Health and Social Inclusion*, 22(2), 85-93.

²⁶ Wasilewski, M. B., Webster, F., Stinson, J. N., & Cameron, J. I. (2016). Adult children caregivers' experiences with online and in-person peer support. *Computers in Human Behavior*, 65, 14-22.

insights.²⁷ Carers themselves, rather than paid professionals, are often preferred as peer group facilitators.

“Find your people. Find people that understand, find your peers. Get help from people who’ve walked ahead of you, and then your role is to reach back and help those walking after you.”

Consultation participant, July 2024

Recommendation 10

Provide opportunities for carers to be trained in peer support facilitation, to build capacity for more carer-led support groups.

²⁷ Borkman, T., Munn-Giddings, C., & Boyce, M. (2020). Self-help/mutual aid groups and peer support: A literature review. *Voluntaristics Review*, 5(2-3), 1-219.

Case study: Services for One

Inclusion Australia facilitates monthly meetings for a group of families who have set up a Service for One. A Service for One involves directly employing staff (not employing staff through a service provider) and conducting their own business processes.

A Service for One is often set up by families to provide support for people with complex support needs and multiple disabilities. Many people with complex support needs in our community have experienced severe neglect and abuse in mainstream disability services, and families developed services-for-one after trying a range of other options. This has enabled the family member with disability to receive the level of tailored and individualised supports they need, provided in a way that centres their needs and preferences.

These families are navigating complex systems that are not designed to suit their needs, yet they are achieving much more positive outcomes in terms of quality of life and reduction in use of restrictive practices compared to service providers in group-based settings.²⁸

While this group was set up to provide policy and practice expertise rather than for the goal of peer support, family members who participate in the Services for One group reported considerable benefits from being in the peer environment and getting to know each other over years, including:

- Debriefing and sharing their stories
- Learning from others how to set up models of care
- Observing how other parents advocate in the context of disability services
- Receiving support for their unique needs and those of their family member with an intellectual disability.

²⁸ Disability Royal Commission, "Statement of Dariane McLean," Public Hearing 6, September 9, 2020, <https://disability.royalcommission.gov.au/system/files/2020-09/STAT.0158.0001.0001.pdf>

Case study: The benefits of peer support for Mary and Marcus*

Mary* shared her experiences of participating in a peer support group and the benefits for her son Marcus,* who has an intellectual disability and lives in specialist disability accommodation.

“I just wish to say that without the support of the peer group, I would not have had the support or learnt the tools & strategies of other families who had experience with their loved one living in a system which was described to me by our behavioural therapist as my son ‘waking up to death’ each day in care.

Marcus’ quality of life was deplorable, and the complexity of rosters arranged by external agencies resulted in flaws for him which were life threatening, as his support needs were not able to be met.

I highly recommend carer support and particularly peer support groups because is it such a lonely journey without knowing other families who are having similar experiences with their loved ones. Together we can join in caring for our loved ones with our service-for-one models of care, which in our case has changed my son’s life. We have the respect and admiration of professionals supporting us who see the life and independence Marcus is now living with the support of the NDIA.”

**Names have been changed.*

Employment, education and financial support

The role of ‘carer’ can dominate and shape other roles in a person’s life, including their role as an employee or worker. Where there are role conflicts between being care responsibilities and performing in one’s job, this can cause significant stress. Carers participating in the National Carer survey were twice as likely to be underemployed and doing fewer hours of work than desired (45%) than the general Australian workforce (23%). Of these carers, most (69%) attributed this to their caring responsibilities.²⁹

Work can be an important part of people’s lives and identities. Helping people to combine work and caring can have many positive outcomes for carers, including accessing social connections outside their caring role and feeling a sense of purpose.³⁰

“My personal support has been working. Work is my panacea. It’s a shift into a different place, that’s my cup filling methodology, and peer support.”

Consultation participant, July 2024

Workplace accommodations, including flexible and remote work, can enable carers to change the pattern of their work to accommodate their caring responsibilities, rather than leaving the workforce.³¹ Having a supportive manager and work environment is important for carers, but only half of carers who participated in the 2022 National Carer Survey felt they could discuss their caring responsibilities with their manager anytime they needed to (48%). While most survey participants had some flexibility in their work, a significant portion (23%) reported having no flexibility.³²

Family members in our community who were consulted about the Carer Strategy highlighted the importance of flexible work, noting many people preferred to work during school hours. They also identified the unpredictability of care responsibilities as a challenge for organising their regular work hours, and the need for employers to be understanding if they needed to make last-minute adjustments to their working hours or work from home.

As family members noted, providing unpaid care in our current service environment is difficult and it can be difficult to maintain a job and perform well while simultaneously juggling caring responsibilities. Although the NDIS was intended to provide flexible supports to people with disability and facilitate increased employment capacity for people providing

²⁹ Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

³⁰ Ibid

³¹ Aspen Institute (2020). *The true cost of caregiving*. <https://www.aspeninstitute.org/wp-content/uploads/2020/05/The-True-Cost-of-Caregiving.pdf>

³² Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

unpaid care, data show there has been little change so far.³³ In the 2022 National Carer Survey, only 1 in 4 (26%) of respondents reported that disability services to support the person for whom they provided care enabled them to stay in or return to work.

“Employers need to comprehend that you’re not putting it on if you have caring responsibilities. They must have flexibility in the same way they talk about family responsibilities. If your kid’s sick, you’re not chucking a sickie yourself. It’s a role that has to be fulfilled by society to allow that flexibility.”

Family member, July 2024

Recommendation 11

Ensure that there are robust protections for people providing unpaid care to utilise workplace accommodations and an accessible dispute mechanism if requests for flexible work are declined by employers.

The ability to participate in education while providing care for a family member can also be challenging. For carers participating in the National Carer Survey 2022, a majority (53%) reported that their carer role impeded their ability to progress their studies/education³⁴.

During our consultations, a participant shared their story about studying for a university degree while holding caring responsibilities for an adult child in supported accommodation. Due to the stress of dealing with challenges and emergencies, this carer sought support through their university’s Disability Liaison Unit. They were able to utilise special considerations so that they could complete assessments tasks and ultimately their degree. By contrast, another parent-carer shared that they had to leave university because there was no acknowledgement of their additional carer responsibilities and the impact they had.

There are well-evidenced models of providing support to people providing unpaid care who are undertaking education and training. The Carers Trust in the United Kingdom provides resources that describe good practices that universities can use to support students who are carers across their educational journey.³⁵ Several Australian universities, such as Australian National University, University of South Australia and University of Tasmania, offer support to students who are carers, often through their Access & Inclusion programs.

“Disability allowed me to access those special considerations, and I think that should be available at all universities for people who are undergoing tertiary studies, who have a caring role. I’m not sure if that is available. It may be available in some

³³ <https://theconversation.com/the-ndis-hasnt-made-much-difference-to-carers-opportunities-for-paid-work-98157>

³⁴ Ibid

³⁵ Carers Trust (2015). Supporting higher education students with caring responsibilities. <https://carers.org/resources/all-resources/13-supporting-higher-education-students-with-caring-responsibilities>

universities but is not universal or promoted. It would be great to be part of a national strategy, wouldn't it, to ensure that offering is available to everybody."

Consultation participant, July 2024

Recommendation 12

Provide evidence-based guidance to universities so they can offer supports to students who are providing unpaid care, such as carer leave and special considerations for course assessments when needed due to carer responsibilities.

Family members in our community who were consulted about the National Carer Strategy also emphasised the financial stressors facing many families with carer responsibilities. This was also evident in the National Carer Survey, with carers (54%) nearly twice as likely to have experienced significant financial stress, such as being unable to pay bills on time or going without meals, than the general population (32%).³⁶

Of the families involved with Inclusion Australia who participated in consultations, many reported they had cut down from two income earners to one, to allow a parent to provide full-time care. Some participants suggested access to financial literacy or counselling would be helpful to support families in developing budgets and financially plan for their futures.

"I think there is a lot of financial stress for carers, and I don't know how that can be improved. Sometimes financial literacy services would help, financial counselling to understand how to better do your budget to support someone in your household. You have to be in a financial default before financial literacy training is available. You've got to have maxed out your credit card or can't pay your rent before you can be referred for financial counselling so that you don't max out your credit card and get in arrears in your rent."

Consultation participant, July 2024

Access to Centrelink benefits was also discussed in the two consultation groups. As noted earlier, family members generally continue to actively provide care to their family members when they are not residing together, but they are no longer eligible for the Services Australia Carer Allowance. This puts family members in a difficult bind, where their significant care responsibilities mean that they cannot work, yet they cannot access income support through Carer Allowance. The residence rules should be reviewed, and consideration given to allowing people to retain their eligibility for carer allowance when they continue to provide daily care for family members who live separately.

"I no longer get Carer Allowance, but I'm still spending the equivalent amount of time that I did supporting him, but not in my home. Now I need to go there and do all the

³⁶ Carers NSW Australia (2023). 2022 National Carer Survey Full Report. https://www.carersnsw.org.au/uploads/main/Files/3.Resources/Policy-Research/Carers-NSW_2022_National_Carer_Survey-Report.pdf

administration standing in his kitchen. I still go and pick up his meds. I still organise his Centrelink. I'm still his primary carer, but because we are not in the one residence, I have no entitlement to Centrelink supports."

Consultation participant, July 2024

Recommendation 13

Enable people who can demonstrate significant carer responsibilities when the person they care for lives somewhere else to qualify for Carer Allowance.

Conclusion: Priorities for the National Carer's Strategy

It is critical that Australia's National Carer Strategy delivers meaningful, tailored supports that can promote the well-being of people providing unpaid care and thereby sustain their ability to provide care long-term. Their own well-being and that of their family members depends upon a system of supports for each person and families together.

These supports need to be designed along a spectrum of caring, including caring for those with high support needs.

"The strategy has to be relevant. The Carers Gateway doesn't even touch the support needs for carers who have family members with complex issues, dual disabilities and in some cases, multiple family members in the same family. I hope they are thinking about how to make the offerings of the Carers Gateway more relevant to everybody on that spectrum of caring."

Family member, July 2024

Simplifying NDIS and other social service processes – and ensuring better integration – and providing care coordination supports within mainstream services, such as Disability Liaison Officer roles in health systems, would reduce the amount of stress people providing unpaid care are under. Families also tell us they want to be listened to and recognised for the essential role they hold in the lives of their family members and respected for the knowledge that they hold about the person and their support needs.

Family members in our community are clear that they don't want "to be thanked with a morning tea." They want real and accessible supports for their loved ones with an intellectual disability so that providing unpaid care is less of an ongoing 'fight', and they want support to be available for themselves that recognises their unique roles and experiences.