Carers WA Policy Submission

Department of Social Services - Consultation on NDIS Supports Rule

July 2025

'Families shouldn't have to fight this hard just to get basic, disability-related needs met.'
– response from a carer

About Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends with disability, mental health challenges, long term health conditions (including a chronic condition or terminal illness), have an alcohol or drug dependency, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are currently 3.04 million unpaid carers in Australia.
- There are more than 320,000 families and friends in a caring role in Western Australia.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, "The economic value of unpaid care in Australia in 2020" is estimated at $77.9 billion per annum.

Acknowledgement of Country

Carers WA acknowledges the Wadjuk Noongar Nation's lands, water, customs, and culture of which the Carers WA Head Office is located. Carers WA recognises our services reach beyond the Perth (Boorlo) region, and so we also acknowledge the cultural diversity of First Nation Peoples across our state and throughout Australia.

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4. Within the NDIS, the role and rights of a carer:
    - Become mandatory education for all agencies and service providers within the system.
    - Be recognized and supported in their own needs within and beyond the caring role, to achieve greater economic wellbeing and sustainability, and to participate in family, social and community life.
    - Be treated with dignity and respect in practice.
5. Inclusion of the following for each list of the NDIS Supports Rule:
    - Specific examples for different types of disabilities, with a disclaimer that individual circumstances may vary.
    - Reasoning behind inclusions and exclusions.
6. Inclusion of clear definitions in the glossary for terms such as: carer (as per the *Carer Recognition Act 2010* (Cth); care worker (specifying this is a paid care worker); reasonable; extraordinary needs; adapted; modified; complex needs; parental responsibility; reasonable care and support provided by families and carers; etc.
7. Consistency and clarity be ensured between the NDIS Support Rules and other NDIS resources such as the NDIS Pricing Arrangements and Price Limits 2025-26.
8. Additional education and training for NDIS staff and related providers on the application of the NDIS Supports Rule lists in practice.
9. Clear guidelines be developed (inclusive of reasoning behind inclusions/exclusions) for NDIS staff and related providers on the application of the NDIS Supports Rule lists to achieve greater consistency in advice and information given to NDIS participants and carers.
10. In collaboration with participants and carers, resources be developed on the proper application of what is covered by a reasonable expectation of parental responsibility. In addition, this resource also cover what is reasonable to expect families, carers, informal networks and the community to provide.
11. A clear definition be developed for 'parental responsibility' for inclusion in the glossary of the NDIS Supports Rules lists.

12. Guidelines be developed for NDIS staff, providers and the broader community for what is applicable under parental responsibility, and what is above this and a funded support when required.
13. The NDIS Support Rules clearly define what is and isn't covered as a support for carers and families to ensure consistency in funding and advice from the NDIA and related providers.
14. Resources such as the NDIS Supports Rules and lists be made available in easily accessible different languages.
15. Easily visible and accessible cultural supports form part of the standard NDIS assessment process, including language support if required.

2.0 Introduction

Carers WA (CWA) appreciates the opportunity to provide feedback to the Department of Social Services in response to its consultation on the NDIS Supports Rules.

In previous submissions to the NDIS, CWA raised the need for increased awareness and recognition of carers, for increased support for carers, including in areas such as respite supports (including respite for children), mental health support, and other supports which will support the longevity of the caring role for the benefit of the person being cared for

In the approximately nine months since the introduction of the NDIS Support Rule, this has not happened, and in application the NDIS Support Rule has resulted in reduced clarity for participants, carers, providers and NDIS staff. While some carers have found the lists to be clear, the majority of carers consulted have reported them to be ‘vague’, ‘confusing’ and ‘relying too heavily on individual interpretation’. For carers who found the lists to be clear, they found the application of the lists in practice to be problematic, and called for NDIS staff to be retrained in this application. This submission delves further into these issues, and makes carer-informed recommendations for improvement.

For the purposes of this submission, the term ‘carer’ is defined as per the meaning under the *Carer Recognition Act 2010* (Cth), this being that a carer is an individual who provides personal care, support and assistance to another individual who has disability, a medical condition (including a terminal or chronic illness), a mental illness, or who is frail and aged. An individual is not a carer if the care, support or assistance provided is under a contract or services or for provision of services, is in the course of voluntary work for a charitable, welfare or community organisation, or is provided as part of an education or training course.[1]

This submission has been informed by a targeted online carer survey (summary available in Appendix One of this submission), as well as ongoing feedback from carers and stakeholders.

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[1] (Commonwealth of Australia, 2010)

3.0 General Feedback

3.1 Context

> *'It's been traumatic. I have had to go through ART after my son's plan was slashed heavily only to have everything refunded and small increase to meet current support needs. So many hours being put into going up against a NDIS lawyer which are all unpaid. This has all the makings for a class action.' – response from a carer.*

WA carers describe their experience with the NDIS as 'traumatic'; 'frustrating, vague'; 'inconsistent, exhausting and emotionally draining'; a 'nightmare'; a 'rollercoaster'; 'uneducated in disability'. The list of negative experiences and impact goes on.

More than half of WA carers consulted more broadly say they feel unsupported or very unsupported by federal disability services.[2] This stems from gaps in supports for people with disability and carers outside and within the NDIS, as well as a lack of tangible recognition of carers in both these sectors.

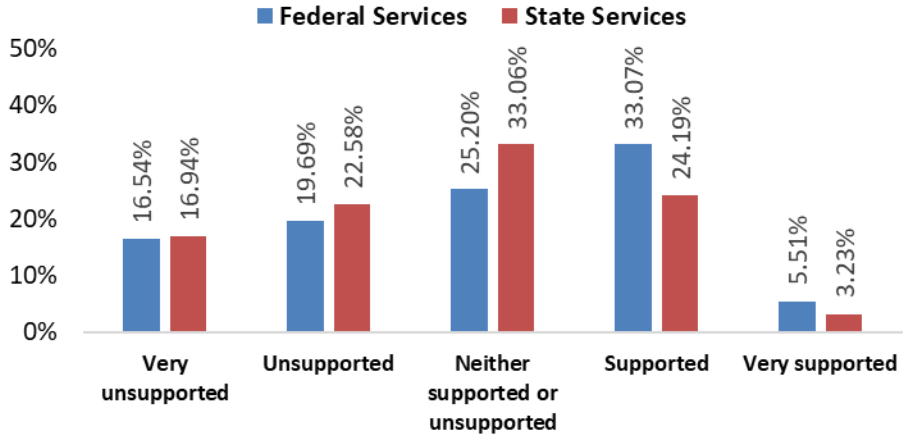

Figure 1 Survey of WA Carers on Disability Services (Carers WA, 2024)

In Australia, 57.6% of carers provided care for someone accessing disability services, and one in five carers provide care for someone not accessing any formal support services.[3] Across all services, carers were commonly not asked about their needs as a carer, including in mental health services (66.7% of carers), disability services (65.8%) and aged care services (55.1%).[4]

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[2] (Carers WA, 2024)

[3] (Carers NSW, 2025)

[4] (Carers NSW, 2025)

WA has more than 320,000 carers[5], who provide $6.6 billion dollars of unpaid care per year and on average provide 104 hours of care per week[6]. The demand for informal care is spiking and is projected to increase 23% by 2030, however the number of carers available is only projected to increase by 16% over this timeframe[7], leaving a shortfall of 22,400 carers at a cost of over $600 million for replacement care.

Carers play a crucial role in supporting the people they care for, working tirelessly to advocate for their loved ones, provide personal care and emotional support, attend and organize appointments, and any other task which may be required of them by their loved ones. However, where carers are not recognized, supported and connected, this significantly impacts their ability to survive and thrive in their caring role, and substantially impacts the longevity of this role.

WA carers feel significantly unrecognized by government bodies, community, service providers and formal services, which does little to help them feel valued[8]. This lack of acknowledgement impacts on carers' level of wellbeing and on their ability to perform their caring role, have longevity in this role, and thrive outside of their caring role. Increasing levels of formal carer recognition can lift carer wellbeing and positively impact other related areas of their lives, including levels of recognition of their caring role from family, friends and those they care for – which in turn further boosts carer wellbeing[9].

However, in addition to a lack of recognition by government services and low wellbeing experienced by carers, NDIS participants and carers must also deal with the stress of the everchanging nuances and uncertainty of the NDIS system in reform.

Carers have reported to Carers WA instances of having the NDIS plans and much needed supports for their loved ones being significantly cut, resulting in regression and deterioration. They have spoken of being shamed by NDIA planners when they asked for needed services to support the person they cared for, being told things were their parental responsibility. They have raised substantial concerns over the stress they felt and the difficulties in trying to navigate a system that would give different advice with each person they spoke to, in the process of trying to support the human rights and independence of those they care for.

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[5] (Government of Western Australia, 2018)
[6] (Deloitte Access Economics, 2020)
[7] (Deloitte Access Economics, 2020)
[8] (SAGE Design and Advisory, 2025)
[9] (SAGE Design and Advisory, 2025)

Carers WA recommends:

1. Carers and families become a priority area within the NDIS.
2. NDIS and related providers and agencies develop a better understanding of Carer Gateway services, as well as what they can and can't cover.
3. The relationship between carers and NDIS participants be recognized and respected.
4. Within the NDIS, the role and rights of a carer:
    - Become mandatory education for all agencies and service providers within the system.
    - Be recognized and supported in their own needs within and beyond the caring role, to achieve greater economic wellbeing and sustainability, and to participate in family, social and community life.
    - Be treated with dignity and respect in practice.

3.2 The NDIS Supports Rule

Carers WA conducted a targeted survey to carers on the consultation on the NDIS Supports Rule. The survey received twelve responses, which were all from current carers.

These carers had a range of caring roles, with 83.33% caring for a child, 8.33% for a sibling, and 8.33% for a parent. Survey respondents also identified that they also provided care to other people, including multiple children, an aunty, and an uncle. Carers who responded to the survey were aged between 36-45 years (58.33%) and 46-55 years old (41.67%), and 16.67% identified as being from a culturally and linguistically diverse background.

This targeted feedback collated from this survey was consistent with and added to ongoing feedback from carers and stakeholders to Carers WA regarding the NDIS, including the NDIS Supports Rules.

3.2.1 Clarity and Definition

Only 1 in 4 respondents to Carers WA's targeted carer survey said that they themselves understood the NDIS Supports Rule well or very well, with the remainder of respondents saying they only somewhat understood them, or did not understand them at all. This was attributed to unclear terminology and language, too many grey areas, and a lack of definitions and specific examples. Carers raised that this was particularly unclear for self-managed NDIS participants and their carers (if applicable), who were navigating the inclusions and exclusions by themselves.

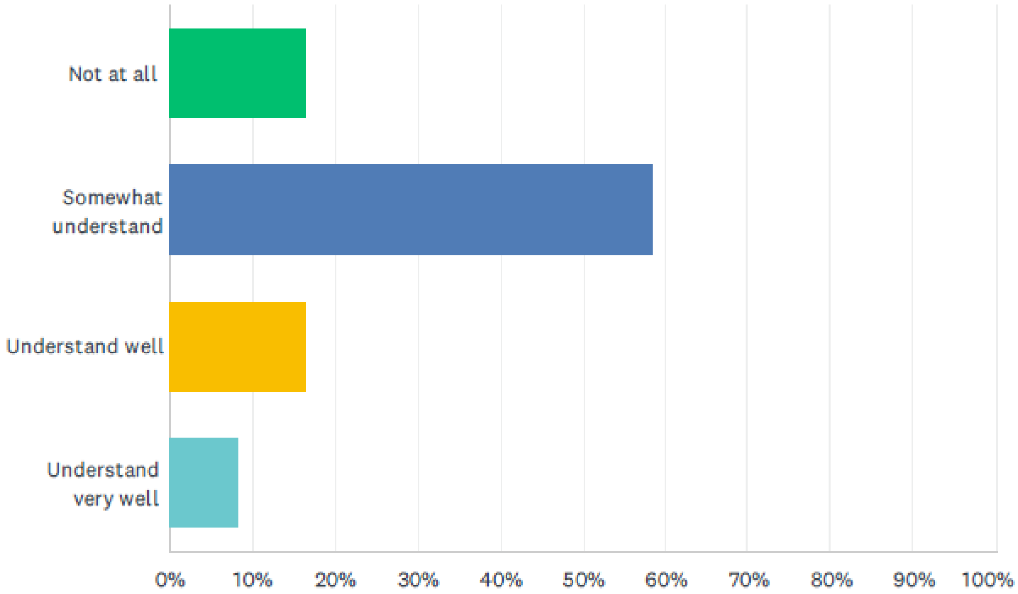

Figure 2 How well do carers understand the NDIS Support Rules?

Carers also raised concerns about inconsistencies between the NDIS Supports Rule lists, with some items or very similar items included on both the list of inclusions and exclusions. Examples given included Group and Centre-based activities inclusions, but a lack of clarity on if this included school holiday disability-specific group programs; as compared to OSHC being on the 'out' list.

Inconsistencies between the lists and the NDIS Pricing Arrangements and Price Limits 2025-26 were also raised which caused confusion. i.e. music being included in the 'lifestyle related' NDIS funding exclusions, but having music therapy included in the pricing. Art therapy not being specified as included or excluded, but having art therapy included in the pricing.

Respondents also raised that where supports fit into NDIS support categories was also often unclear. i.e. whether supports like sensory items, physiotherapy for postural needs, or feeding support fall under core or capacity building. It was reported that the same items are often approved in one NDIS plan and denied in another, which was attributed to language being vague and open to interpretation.

Carers WA recommends:

5. Inclusion of the following for each list of the NDIS Supports Rule:
    - Specific examples for different types of disabilities, with a disclaimer that individual circumstances may vary.
    - Reasoning behind inclusions and exclusions.
6. Inclusion of clear definitions in the glossary for terms such as: carer (as per the *Carer Recognition Act 2010* (Cth); care worker (specifying this is a paid care worker); reasonable; extraordinary needs; adapted; modified; complex needs; parental responsibility; reasonable care and support provided by families and carers; etc.
7. Consistency and clarity be ensured between the NDIS Support Rules and other NDIS resources such as the NDIS Pricing Arrangements and Price Limits 2025-26.

3.2.1 Application in Practice

> *'They [the NDIS Supports Rule] rely too heavily on individual interpretation. What's considered "reasonable and necessary" changes depending on the planner or LAC. This creates confusion, delays, and puts immense pressure on families to constantly advocate and re-explain.' – response from a carer*

Carers report that when the NDIS Supports Rule are applied in practice, the interpretation of the lists is inconsistent and unclear, with advice on what can and cannot be funded varying significantly from person to person. This was reported to be present even when speaking directly with NDIA staff members. It was recommended that NDIS staff and providers who incorrectly deny supports be retrained, and that resources be developed to ensure consistent in-practice application of the lists.

Carers raised experiences in which they would call the NDIA back and receive different advice regarding funding to that from the person they had spoken to previously. They also spoke of instances in which Local Area Coordinators (LACs) were guessing or having no knowledge, resulting in wrong information and advice being given. In addition, carers had experienced information provided verbally by the NDIA not being consistent with the NDIS Pricing Arrangements and Price Limits Guide.

In addition, ongoing issues reported by carers with workforce retention in the NDIS over the last twelve months have exacerbated these other issues and resulted in a lack of skilled workers and assessors. This is an issue in both metropolitan and regional areas, and the impact of newer workers coming through all the time is an increase in inconsistent practice, undertrained staff, and incorrect messaging being told to NDIS participants and carers.

These experiences and inconsistencies were reported to Carers WA as making the NDIS Supports Rules particularly hard to understand and use, and aggravated ongoing challenges with system navigation, as well as participants receiving adequate support as recommended by their specialists.

Carers WA recommends:

8. Additional education and training for NDIS staff and related providers on the application of the NDIS Supports Rule lists in practice.
9. Clear guidelines be developed (inclusive of reasoning behind inclusions/exclusions) for NDIS staff and related providers on the application of the NDIS Supports Rule lists to achieve greater consistency in advice and information given to NDIS participants and carers.

3.2.1 Parental Responsibility

> *'Being a parent of a disabled child is mentally, physically exhausting and challenging. To be told you're not entitled to a support worker for a couple of hours a week because it's a parenting responsibility is insulting.' – response from a carer*

One area in which clarity was lacking in the NDIS Support Rules and more broadly across the NDIS is the concept of parental responsibility and what duties this would standardly cover, as well as where this becomes above and beyond these standard duties a parent would cover.

Carers often report this term being used to deny funding or to try and shame them into what they should and should not be doing. In Case Study 1 of this submission, Julianne* describes how a NDIS Planner denies her funding to cover respite support for her son Alex* because she shouldn't want to leave her son with strangers, despite her already having a support worker known to Alex who was able to provide these services. The planner also made many references to parental responsibility to deny other funding for other services, which contributed to Alex's funding being cut in half. Julianne described how this had resulted in Alex having diminished capacity, and significantly higher support needs. In turn, this impacted Julianne as a carer, including her wellbeing, ability to work or study, and engage with the community – when she filled in where formal supports had done so in the past.

The demands of a parental role and a parent who is also in a caring are very different, and this needs to be better understood within the system. Section 34(e) of the *National Disability Insurance Scheme Act 2013* (Cth) delves into this somewhat, stating that within 'reasonable and necessary' considerations, 'the funding or provision of the support takes account of what is reasonable to expect families, carers, informal networks and the community to provide'[10]. However, yet again, this consideration is subjective based on what a person would consider to be reasonable.

Carers raise that the definition of 'reasonable care and support provided by families and carers' as stated in the NDIS Supports Rules would be significantly different to the NDIS than to a carer who was a parent of three kids with disability.

Carers WA recommends:

10. In collaboration with participants and carers, resources be developed on the proper application of what is covered by a reasonable expectation of parental responsibility. In addition, this resource also cover what is reasonable to expect families, carers, informal networks and the community to provide.
11. A clear definition be developed for 'parental responsibility' for inclusion in the glossary of the NDIS Supports Rules lists.
12. Guidelines be developed for NDIS staff, providers and the broader community for what is applicable under parental responsibility, and what is above this and a funded support when required.

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[10] (Government of Australia, 2025)

3.2.1 Clear supports for carers and families

The new *National Disability Insurance Scheme Act 2013* (Cth) outlines that there should be certainty that people with disability will receive the care and support they need over their lifetime (Section 4(3)). The Act also states that carers, their role and relationship with people with disability are to be recognised and respected.

In addition, the Act also outlines that the:

- In giving effects to the objects of the Act, regard is to be had to the broad context of disability reform provided for in the *Carer Recognition Act 2010* (Section 3 (3)(c)(ii)).
- Agency may provide assistance in the form of funding for persons or entities:
  - for the purposes of enabling those persons or entities to provide assistance in building capacity within the community in connection with the provision of goods and services to people with disability and their families and carers (Section 14 (1)(aa)).
  - for the purposes of enabling those persons or entities to assist people with disability, and their families and carers, to participate in social and economic life (Section 14 (1)(ac)).
- the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:
  - strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer; (Section 25 (1)(c)(iv)).
- The preparation, variation, reassessment and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:
  - strengthen and build capacity of families and carers to support participants who are children (Section 31 (d)).
  - if the participant and the participant's carers agree—strengthen and build the capacity of families and carers to support the participant in adult life (Section 31 (da)).
- the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide (Section 34 (e)).

However, despite these inclusions (and others) within this Act and the direction to give regard to the *Carer Recognition Act 2010* (Cth) (which includes the Statement for Australia's Carers), carers continue to have negative experiences with the NDIA and NDIS which impact on their wellbeing and funding for those they care for.

In Case Study 1, Julianne describes her experience with a NDIS Planner, which included being told off for wasting funds when she undertook carer training in her son's condition to be better able to support him. This is despite the Act allowing funding that builds the capacity of the families and carers.

Carers raise that carer supports within the NDIS need greater visibility and access, including within the NDIS Supports Rules. These include things such as respite, respite for children, parent training, capacity building training for carers, general supports for carers as part of the maintenance of the caring role, etc.

Carers WA recommends:

13. The NDIS Support Rules clearly define what is and isn't covered as a support for carers and families to ensure consistency in funding and advice from the NDIA and related providers.

3.2.1 Culturally and Linguistically Diverse

In the 2024 National Carer Survey, 17.1% (1,707) of respondents were from a culturally and linguistically diverse (CALD) background. Of these, 72.9% provided care for someone living with disability (physical or intellectual disability, ASD, acquired brain injury, or sensory impairment)[11].

CALD carers are more likely to be caring for someone not accessing formal services, and many report challenges accessing or having no available culturally appropriate services. Three in five CALD carers report experiencing financial stress; many (65.6%) report being socially isolated and more than half (53.5%) of CALD carers experience high or very high psychological distress[12].

As at 31 March 2025, there were 63,007 CALD NDIS participants in Australia, 4,827 of whom were located in WA. This translates to 10.1% of NDIS participants nationally who identify as CALD (9.3% in WA)[13]. The underrepresentation of people with disability in the NDIS who identify as CALD, First Nations, who live in regional and remote areas, was an issue raised during the Independent Review into the NDIS[14].

Carers have further raised concerns over the availability of resources such as the NDIS Supports Rules and lists in easily accessible different languages, and have called for greater visibility and access to cultural supports within the NDIS. Carers have also raised a need for older CALD NDIS participants and carers to have more support in language (if required) in order to make informed decisions, as well as be able to choose a person of support to help with daily decision making if desired. This was suggested to form part of the NDIS assessment process.

Carers WA recommends:

14. Resources such as the NDIS Supports Rules and lists be made available in easily accessible different languages.
15. Easily visible and accessible cultural supports form part of the standard NDIS assessment process, including language support if required.

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[11] (Carers NSW, 2025)

[12] (Carers NSW, 2025)

[13] (NDIS, 2025)

[14] (Australian Government NDIS Review, 2023)

3.2.1 Carer experiences with the NDIS

Carers who responded to the survey were asked to describe their experience with the NDIS. These were some of their responses:

Carer Experience 1

'It's been traumatic. I have had to go through ART after my son's plan was slashed heavily only to have everything refunded and small increase to meet current support needs. So many hours being put into going up against a NDIS lawyer which are all unpaid. This has all the makings for a class action' – response from a carer

Carer Experience 2

'Frustrating, vague, trying to fit us all into convenient boxes/ templates rather than understanding individual needs. Says give choice and control but are systematically removing these. Even staff who work there have no understanding of what's going on. Different answers depending on who you talk to. Unnecessarily combative.' – response from a carer

Carer Experience 3

'Inconsistent, exhausting, and emotionally draining, yet essential. I'm a full-time carer and mother to a neurodivergent child, and I spend more time justifying his needs than actually supporting them. The system creates more stress than support at times. Families shouldn't have to fight this hard just to get basic, disability-related needs met.' – response from a carer

Carer Experience 4

'Slow. Uneducated in disability. Lack of understanding and knowledge, and inconsistent. Lots of work for the caregiver or participant. Incomplete documentation and update of plans. Duplicate letters and unwanted phone calls.'- response from a carer

Carer Experience 5

'Lately it has not been as supportive as you would expect for people with severe needs.' – response from a carer

Carer Experience 6

'It has been good but it takes forever to get help.' – response from a carer

Carer Experience 7

‘My LAC isn't supportive, knew nothing about my child's high needs, told me I'd never get funding for things. Never contacted me again after funding to explain anything.’ – response from a carer

Carer Experience 8

‘Still required a carer to help with research into services available and correspondence. NDIS providers can take times with their appointments and that waiting periods depend heavily on loved ones if there is one available to help.’ – response from a carer

Carer Experience 9

‘Nightmare. First plan had everything with me and asked for technology to enlarge stuff for my child. Got told he waited 9yrs, so what is another 12m going to do. Appealed. Got new plan. Then added assessments for the new equipment and got a new plan. 3 plans within 4 months. Next plan got halved and it took me 2 1/2 years through the tribunal to fight for the right things. Got most of the things we asked for and had to let some things go. Then we did more testing and assessment and applied for change of circumstances and got told we were not supposed to file within 12 months of that. They funded the equipment and told me we will need to have a review in 4 months. Got all paperwork together and then it rolls over.’ – response from a carer

Carer Experience 10

‘Roller coaster.’ – response from a carer

Carer Experience 11

‘It’s bloody terrible. Nothing’s covered anymore. How are people supposed to survive in this crisis.’ – response from a carer

Case Study 1 – Julianne and Alex

Julianne is a carer for her 7 year old son Alex*, who has level 3 autism and a PDA profile. Julianne is a single mother, with no other supports and another young daughter as well, whose mental health and wellbeing has also been significantly impacted by Alex's disability. Her daughter's psychologist has specified that she can no longer be involved in helping care for Alex.*

At Alex's recent plan review for the NDIS, he received significantly reduced funding due to a range of reasons, despite having a substantial amount of evidence to support funding requests. Julianne said that the planner they met with seemed to think that autism was a curable and not a long term condition, and made many comments about things being her parental responsibility.

Julianne outlined that:

- *Respite support was rejected because the planner said she shouldn't want to leave her child with strangers. This was raised as not being the case, as respite services were offered by their support worker. Alex would have been cared for during this time by a familiar support worker.*
- *A step down plan for support work was given, with only 26 weeks of support work hours. Julianne raised that this was not even enough to cover her university study hours. The planner said that best practice was for Alex to be in school. Alex is currently home schooled as the adjustments needed to be made for him to attend a mainstream school would not have been 'reasonable' as outlined in the School Education Act 1999 (WA).*
- *Alex needed supports, without which the long term impact would be significant, not only due to lack of benefit from not having early intervention. She worried that Alex would end up in the justice system due to his behavioral difficulties, and said that many children with his disability were in the foster system due to their level of care needs.*
- *Julianne said she felt like the NDIS planner wasn't giving any choice or control at all, and that Alex's human rights as per the UNCRPD were not being supported. The planner had also said that they could no longer use their current support providers, as Alex's need for supports had increased (despite no evidence of this), and said that Julianne had chosen the wrong providers. Julianne tried to explain that her son needed time to adjust to new support providers. The planner also said that Julianne had wasted and misused funding by going to a carer training course specific to her son's disability, and told her off for this (despite there being a line item for this training).*
- *Alex's funding ended up being cut in half, with many requested supports being refused. Julianne said since this, Alex's capacity had diminished significantly, and his support ratio need had increased to 2:1.*

Julianne currently cannot work due to Alex's care needs. She estimated that a job she is currently qualified for would have paid $45 per hour ($90,000 per year). This would give the government $22,000 in tax per year. Julianne currently receives $30,000 per year in carer concession payments from Centrelink. She estimated that this was currently a $50,000 per year financial detriment to the government due to not providing her son the support needed for her to reenter the workforce. Julianne also raised that once she finished her studies, her estimated income would be $200,000, presenting a much larger financial loss to government due to her not being able to work due to caring responsibilities.

**Case studies are deidentified for confidentiality.*

4.0 Conclusion

Should the Department require any further information regarding the comments included within this submission, or assistance from the perspective of WA carers, Carers WA would be delighted to assist. Please contact the Carers WA Policy Team at policy@carerswa.asn.au.

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