338 Tapleys Hill Road,
Seaton SA 5023
PO Box 422,
Fulham Gardens SA 5024
P 08 8291 5600
Freecall 1800 422 737
info@carerssa.com.au
www.carerssa.com.au

Response to the
Draft State Disability Inclusion Plan 2025 – 2029

About Carers SA

Carers SA is the peak advocacy body for Carers in South Australia. Raising the voice and recognition of Carers, their rights, wellbeing and needs are at the heart of Carers SA's efforts. We persistently advocate across governments, health and social services and systems, business and communities to prioritise appropriate and meaningful support and services for Carers. Carers SA aims to ensure that Carers needs, wishes, values and perspectives are elevated and able to inform and influence decision-making by government, service providers, policy makers, legislators, and systems and services to improve the lives and wellbeing of Carers in South Australia.

Carers SA is both a peak body and a service provider for Carers through the Carer Gateway and other state funded programs. This provides us with a unique opportunity to understand the needs of Carers and identify and implement ways to improve the services they use. It enables us to engage with many and diverse Carers across South Australia through our broad networks and through services and supports this positions Carers SA to raise awareness of issues facing Carers and raise the voice of Carers to inform and influence policy and decision-making about issues that impact them.

About Carers & Disability Link

Carers & Disability Link supports carers, people with disability and people over 65 in regional South Australia and Carers and people living with disability find disability support and resources. Carers & Disability Link also help provide valuable aged care services to their local communities. For over 25 years Carers and Disability Link has been a trusted and compassionate community service organisation in South Australia. Carers & Disability Link support carers, people with disability and people over the age of 65 to live enriched lives by offering a listening ear as well as providing a professional, high-quality, accessible, and timely service in regional South Australia.

…………

We thank the Minister for the opportunity to respond to the draft State Disability Inclusion Plan and commend the Minister and the Department for Human Services for developing a person-centred, rights-based approach to the Draft State Disability Inclusion Plan which recognises the need for a stronger commitment from government to ensure access, equity and inclusion of people living with disability in South Australia. The five priority domains reflect a whole of life approach to improving the lives of people living with disability. The inclusion of Justice as a unique domain further embeds the protection and enforcement of the rights of people with disability, in government policy and mandates these rights across all state authorities.

Carers experience of disability

There is an overall lack of recognition in this document as to the importance of Carers in the lives of people with disability, the role Carers play, and the supports/structures Carers need within our communities to assist people with disability to have equal access and inclusion and the large number of Carers who live with disability.

- At least one in every ten Australians, or around 2.65 million people in 2018, provides unpaid or informal care for someone with a disability, medical condition, mental illness or who is frail because of their age.[1]
- More than one third (37.4%) of Carers have a disability themselves (twice the rate of non-carers).[2]
- Australian carers provide 2.2 billion hours of unpaid care each year. If these hours were provided as paid formal care, this care would have a value of $77.9 billion per year. The demand for unpaid care is expected to grow by 23 per cent between 2020 and 2030 as Australia's population changes.[3]
- Most people with disability (96.8%) lived in households. 71.6% received assistance from Carers, most likely from a spouse/partner (36.0%) or daughter (23.5%) or son (23.0%). One third of Carers spend an average of 40 hours or more per week caring 18.5% spending an average of 20-39 hours per week caring.[4]

Carer support for people with disability

Carers are the silent provider of services, supports, health care, emotional and mental health support for people with disability and enable people with disability to live as independently as possible. Informal, unpaid Carers are treated differently from formal, paid carer workers, even though the support they provide can be similarly ongoing and can involve significant hours of care and the same activities and intensity of care (more than one third of Carers provide more than 40 hours of care per week).

When referring to the Carers role the use of terms 'personal care, support and assistance' significantly understates the level of care and skill required by Carers who care for people with disability. Care can include a broad range of support from household management and maintenance to complex health care tasks and at times, complex first aid and emergency procedures that require training by health professionals.

It is important to note that many Carers are not family members and while most provide care out of love or a sense of duty, some Carers are providing care because they have no other choice. This may be due to factors such as, there are no other care options available, there is no other person who can or will provide care, the person being cared for is not eligible for funded support, the cost of care is prohibitive or there are no funded care options available. Carers fill these gaps.

Whist the *National Disability Insurance Scheme Act 2013* was amended in 2022 to include stronger recognition of the role of Carers and the nature of the role and relationship they have with the people with disability they care for, often, Carers continue to take on caring roles because of a lack of available, accessible, and affordable services, or where the person with a disability they care for falls through the cracks of NDIS eligibility, and do so with limited access to supports including respite.[5]

Carers make significant contributions to the economy and society however this comes at a significant personal cost. Caring responsibilities can directly affect carers' physical, mental and financial wellbeing. Carers often sacrifice their careers and retirement plans, education goals, social lives, and health and wellbeing to look after the needs of others, and many do so with little support.[6]

---

[1] Disability, Ageing and Carers, Australia: Summary of Findings, 2022 | Australian Bureau of Statistics

[2] ibid

[3] ibid

[4] ibid

[5] Recognising, valuing and supporting unpaid carers

[6] Recognising, valuing and supporting unpaid carers

General Comments

Language and writing style

This document uses contrasting language that weakens it.

Consistent, strong goal focused statements provide a clear intent i.e., is the intent of the Plan to be *a more inclusive South Australia*, or is the goal to ensure *equal access and inclusion in South Australia*? Equal access is equal access, it isn't 'more accessible and inclusive'. Clear and consistent statements of intent will significantly strengthen the Inclusion Plan.

As examples

- *'Building a more accessible, inclusive and knowledgeable South Australia......' (pg. 3)*
- *'Australia's Disability Strategy 2021 – 2031 outlines a vision for a more inclusive and accessible......' (pg. 4)*
- *'The benefits of achieving a more accessible and inclusive South Australia extend......' (pg. 9)*

And yet it also uses statements like

- *'...achieving an accessible and inclusive South Australia where people with disability can....' (pg. 3)*
- *'...continue to face significant barriers to equal access and inclusion in South Australia....' (pg. 9)*
- and this is on the same page as this statement *'The benefits of achieving a more accessible and inclusive South Australia....'*

Further, the writing style of this document is at times immature or unrefined and there are areas in which the language could be seen as offensive to people with disabilities and Carers. Pg. 3 under the section titled '*Our journey thus far'* states *'While significant progress has been made across access and inclusion, the job is not yet done....'* Believing the job will ever be complete is naïve and asserting as such feels fundamentally misguided. The rate of change in our communities needs, structures, infrastructure, etc., is rapid. Work will be ongoing to ensure equality in access and inclusion.

Similarly, the comment here that *'However, government action alone is not enough'* is weak and adds to the feel of immaturity in the writing of this document. This could be written in much stronger way that explains why we all need to be working at equal access and inclusion.

As another example under the section titled *'Language and terminology'*. (pg. 6) Paragraph 4 states '*There are many misconceptions and misunderstanding in the community about what it truly means to have a disability'*. The use of the word *'truly'* is unnecessary and leans to emotive and rather than trying to influence the reader there is greater strength in objectivity.

Outcomes and Measures

It is disappointing that the majority of Measures in the State Disability Inclusion Plan to assess success are quantitative in nature, with the exception of three measures from *Australia's Disability Strategy*. Whilst quantitative measures allow for the collection of large amounts of data quickly and efficiently to measure performance, it fails to capture the nuances of lived experience and the rich and holistic viewpoints that provide insight into peoples' experience that better enables systemic change. Inclusion cannot be measured by quantitative data alone.

The aim of this Plan is ultimately to address the challenges and barriers faced by people with disability every day - to feel and be active, accepted and welcomed members of their community and have the same rights, access and opportunities as people without disability. It is a lost opportunity not to include person reported experience and outcomes as a means to provide quality and value-based measures of performance that reflects the impact of the Inclusion Plan on the lives of people with disability. Equally, the language of the outcomes should be more person-centred and reflect people with disabilities rights to choice and control.

Well intentioned services that have not been appropriately informed by the needs, wants and expectations of people with disability can easily fail to 'hit the target'. A measure that only looks at quantity as an indicator of inclusion and does not measure quality and impact of such measures is not a sound measure of success.

Recommendations

It is imperative that the State Disability Inclusion Plan recognises the significant role of Carers, both those caring for people with disability and those Carers with disability themselves and caring for others. In doing so the State Disability Inclusion Plan will play a vital role in reducing the burden of Carers and in supporting them, improve the lives of the people with disabilities that they support.

The voice of those with lived experience (p3)

- Responding to recommendations: the statement *'For this reason, we will continue to listen, consult and respond to the needs of people with disability through our disability access and inclusion planning',* highlights the power imbalance between people with disability and the government. This statement should be reworded to express that government value input from people with disability and the government have a responsibility to ensure inclusion and access.

Outcomes and Measures

- All outcomes should be written as person-centred outcomes throughout the Domains. *'People with disability have access to appropriate housing of their choosing'*(p17), *'Children with disability feel valued, welcomed and included in education'*(p18). This ensures Measures require evidence of person reported outcomes and experienced, and
- Include qualitative measures as well as quantitative measures which include person reported outcomes and experience to ensure quality and value-based measures of performance that reflect the impact of the Inclusion Plan on the lives of people with disability.

Facts at a Glance (p7)

- Include language about Carers roles in supporting people with disability and as people with disability.
- Include evidence from the Australian Bureau of Statistics. Disability, Ageing and Carers Australia of the percentage of people with disability supported by unpaid Carers and the percentage of Carers who have disability.

A spotlight on our seven Priority Groups (p8):

- Carers with disability be included as a priority group, in recognition that more than one third of Carers who have a disability themselves (twice the rate of non-carers), are at higher risk of vulnerability as their caring responsibilities further affect their physical, mental, emotional, social and financial wellbeing.
- The comments under each of the seven priority groups should be written in a way that they are consistent with each other so the reader can see the similarities/differences between each of the priority groups more clearly and understand why they have been identified as priority groups.
- The statement *'Aboriginal people with disability may have a very different understanding or concept of disability'* be reworded to remove ambiguity. The unique needs and experiences of Aboriginal people with disability is not in question, but the statement is very loose and lacks clarity.

Domain 1: Access

- This domain should include Carers in the priority areas, Outcomes and Measures across Domain 1 to demonstrate recognition that many people with disability utilise Carers to assist them to access community as evidenced at the beginning if this response.
- **Priority Area 2 (Understanding and Acceptance) Outcome:** should be better framed as *'The South Australian community is aware of and understands the barriers to access and inclusion for people with disability and understands how to work and interact with Carers of people with disability.*
- **Priority Area 8 (Housing) Outcome:** should read *'People with disability have access to appropriate housing of their choosing'.* Many people with disability are forced (as they have no choice) to live with people they aren't compatible with. This is leading to poor health and wellbeing outcomes and has many other significantly concerning outcomes.

Domain 2 Opportunities

- **Introductory paragraph 3:** should be written as a more powerful statement *'People with disability have a right to inclusive educational experiences and genuine employment opportunities'.* The current statement is reductive and outdated language. With the inception of the NDIS in 2013 more people with disability and their Carers are recognising they have a right to choice and control.
- **Priority Area 3 (Targeted transitional supports):** should include a Measure related to transitional supports being connected to other disability supports and providers so that people with disability have supported access/awareness of transitional supports. There currently isn't enough connection or awareness of these transitional services so many people with disability aren't able to access them.
- **Priority area 4 (Access and Employment Opportunities):** should include outcomes and measures for Carers with disabilities to enhance their opportunity for employment, increased earning capacity and access to superannuation through flexible workforce arrangements for their caring role (for example increase carers leave entitlements, hybrid work arrangements and recognition of changing caring circumstances that may require greater flexibility).
- **Priority Area 5 (Supportive environments) Outcome:** should read *'People with disability have access to supportive places to learn and earn'*. This better reflects that people with disability do not need a separate place that is supportive of them, but all places are supportive.
- **Priority area 6 (Data and Reporting):** should include outcomes and measures for national disability data to identify and report findings on Carers with disabilities as a priority area in all State Government Agencies.

Domain 3 Support

- **Priority area 2 (Access and Supports) Outcome**: Often people with disability are unable to advocate for themselves and/or are not aware they need to advocate for themselves, or even that there are issues they should address. This means many people with disabilities who need advocacy support remain hidden. How will these people with disability be identified in order to be provided with disability advocacy support when they're unable to advocate for themselves? The Plan needs to address this?
- **An additional Outcome under this priority area** should include advocacy and supports for Carers of people with disability to access advocacy services to assist in ensuring the people with disabilities they care for have the type and level of support they need that acts to reduce the burden of Carers.
- **Priority area 4 (Family and carer support) Measure 4.1:** should include outcomes and measures broader than access to respite services for the person with a disability they care for and include services such as but not limited to training and education for carers (e.g., manual handling, safe use of medicines, infection control, health care tasks and procedures, mental health first aid, personal safety and safeguarding). Further, targeted services and supports for Carers with disability as a priority group.

Domain 4: Wellbeing

- **Priority Area 2, Outcome:** should read *'Our healthcare system is knowledgeable, understands the intersectionality and diversity of disability and understands how to work and interact and engage with Carers of people with disability.'* This should also include specific Measures of how the healthcare system does this.

Domain 5 Justice

- **Priority area 1:** should include measures and strategies to provide for access to independent advocacy for people with disability and Carers who care for people with disability, which remains unfunded in South Australia.
- **Priority Area 5 (Safeguarding) Outcome states:** *'People with disability can access safeguarding supports and services.'* This outcome falls significantly short of what is needed. This outcome must address the significant risk of people with disability to abuse, violence and neglect. It falls short however of immediate safeguarding action measures to address the earliest identification, intervention and safeguarding - such as the need for emergency responders to identify those people with disability who aren't able to ask for help to access safeguarding services; the role of disability support workers as mandatory notifiers, etc when people with disability are the most at risk.

Carers SA convenes the Carer Services Network of South Australia. Carers & Disability Link, as a member organisation of the Network, is a co-contributor to this response.

CARERS &
DISABILITY LINK

May 2025