

National Disability Insurance Scheme Secretariat  
Department of the Prime Minister and Cabinet  
PO Box 6500  
CANBERRA ACT 2600

20 January 2023

Dear Secretariat,

### Formal submission – NDIS Independent Review

The NSW Carers Advisory Council (the Council) writes to you regarding the review of the National Disability Insurance Scheme (NDIS).

The Council provides advice to the NSW Government on legislation, policy and other matters relating to carers. For more information, about the Council and our members, the majority of whom are carers, please visit our website at [www.facs.nsw.gov.au/inclusion/advisory-councils/carers](http://www.facs.nsw.gov.au/inclusion/advisory-councils/carers).

Following are the Council's responses to the questions you provided to guide our written submission.

Questions	CAC feedback
1. What are your three main problems or concerns with the NDIS?	<ol style="list-style-type: none"><li>1 There is a lack of support for carers to engage with the system. There needs to be effective referral processes that are required to link both applicants and their carers, with mainstream support services and/or the Carers Gateway.</li><li>2 There is a lack of understanding of the relationship between the person with a disability and their carer; and the impact of any support, or lack of support has on a carer. NDIS assessors often fail to focus on the functional limitations arising from disability, resulting in many eligible applicants being erroneously excluded from the Scheme. This is of particular concern for people living with chronic illness such as cystic fibrosis and mental health issues. For example, less than 13 percent of eligible applicants with cystic fibrosis who applied for an NDIS package, were approved in 2016-2019 (see Broady T, Weber N. Carers missing out. A Scoping Study following the introduction of the National Disability Insurance Scheme. Prepared for the NSW Carers Advisory Council, 2021. NSW Department of Communities and Justice).</li></ol>

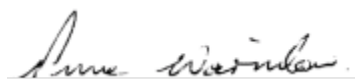
Questions	CAC feedback
	<p><b>3</b> The disappearance of a Carers statement which was originally mentioned to be part of the NDIS process. Carers of applicants are often excluded from the assessment process.</p>
<p>2. How do these three main problems affect you and/or others?</p>	<p>When carers are not included or have limited input into plans, this can result in a poor understanding of the applicant's needs, particularly where the applicant has an intellectual disability, poor mental health, and/or very limited communication capacity. The contribution that carers can realistically make to the individual's care is often grossly overestimated. The carer is left to pick up any slack or missing pieces from any support plan through their informal support.</p> <p>When a NDIS plan does not take into account how much support a carer is currently providing to the person with a disability it can result in an inadequate plan going forward. It cannot be assumed that carers are willing or able to continue in this voluntary capacity to provide this level of care. For example, for people with severe functional limitations arising from cystic fibrosis may not have daily lung clearance by qualified physiotherapists or domestic assistance when they are too ill to care for themselves included in their NDIS plan. This places a high physical, emotional and financial burden on their carers.</p> <p>A carer is more likely to suffer burnout, stress and anxiety whenever their needs are not met and/or their person with a disability receives an inadequate NDIS plan. Both applicants and their carers miss out on essential support services. This can result in poor physical and mental health. It can also result in severe limitations on an applicant or carer's capacity for economic participation.</p>
<p>3. What do you think are possible solutions to those problems?</p>	<p>Make sure the applicant (and their carer/family member if appropriate) knows what the requirements are and how to best collect the evidence. Work with the NDIA to be specific about what evidence is required, what is acceptable and any required format. A descriptive overview and diagram/flow chart, including an easy to read version, of the step by step process would be helpful. It could include who to initially contact and a designated contact person; the role of the nominee/carer; information required; time frames; step by step sequential guide; and what evidence is required to support the planning process. Make sure the informal support any carer/family member provides is included to give a holistic approach to</p>

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	gaining evidence of support needs. It should also include the ability for the carer to nominate what support they may need to assist them in their caring role. Allow for a Carers Statement whenever a carer is involved, to ensure a holistic approach to support.
4. What parts of the NDIS are working well for you?	People with severe physical disabilities are often empowered to live much more independent and richer lives. They have far greater control over the support services they receive.

On behalf of the Council and carers across NSW, I ask that you review our feedback taking into consideration needs and the role of carers. We also give permission for our submission to be published.

If you wish to discuss this further, please contact me on the contact details below.

Yours sincerely,



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