Individual Submission to the Parliamentary Joint Standing Committee -

Title: Inclusion of Cystic Fibrosis as a disability type for NDIS funded supports.

Recommendation: That the Parliamentary Joint Standing Committee:

1. : **Note** and discuss the gap between mainstream supports and the eligibility for NDIS funded health related supports for people living with Cystic Fibrosis (CF).

2. : **Agree** to include Cystic Fibrosis to the list of disability types eligible for NDIS funded support.

Background:

3. October 2019 saw the inclusion of NDIS funded health related supports, and this is applauded, however; there remains a gap for people living with life long and life shortening disabilities; who are not able to readily access the NDIS health funded supports. Eg Cystic Fibrosis.

4. NDIS is a National response to those in the community living with a disability and I understand the operationalisation of this biggest social reform has achieved full roll-out across the nation. There is still gaps for inclusion of disability types such as Cystic Fibrosis, who are not readily eligible to access NDIS funded support. NDIS lists A and B for Disability types does not included Cystic Fibrosis.

5. Cystic fibrosis is Australia's most common genetic life-shortening condition that affects the respiratory, digestive and reproductive systems. Over 3,400 people across Australia have Cystic Fibrosis. Cystic Fibrosis is demanding and requires a rigorous regime of daily physiotherapy, multiple medications, frequent medical appointments and hospitalisations. The average life expectancy is 37 years at birth and there is still no cure.

6. Impacts of Cystic Fibrosis is reduced lung function, digestion difficulties and malnutrition, muscle weakness, fatigue, and other conditions such as osteoporosis and CF-related diabetes are just some of the ways that CF impacts on a person's ability to live the life they choose. Mental health issues may surface due to depression and anxiety about CF and how it is impairing their ability to achieve their goals and the life they wish to lead. This is exacerbated as people's condition progresses and they may require supplementary oxygen, a wheelchair, or assistance with daily activities such as cleaning the house, preparing meals, and getting to appointments.

7. There are new treatments and medications being developed, However, they are only effective for people who have specific gene changes (there are approximately 1,800 gene changes that cause CF) and they are unable to reverse scarring and lung damage that has

already occurred. These medications are not a cure, but for some people who have Cystic Fibrosis these medications can slow the rate of progression of Cystic Fibrosis. These better treatments and medications have improved the average life expectancy of people living with Cystic Fibrosis. Today, over half the people who live with this chronic, lifelong condition are aged 18 years and above. As people who live with Cystic Fibrosis age and live for longer the way Cystic Fibrosis impairs a person's ability to live their life changes.

8. The mainstream Health response to Cystic Fibrosis relies on a centralised model of support using large hospitals with dedicated teams to assess and monitor individuals. This allows affordable diagnosis and assessment for people living with Cystic Fibrosis, it does not provide a localised response system of support, nor does it subsidise or fully fund vital health equipment and treatment.

9. Cystic Fibrosis Community Care (CFCC) is the primary agency who has been providing support, advocacy and information to people living with Cystic Fibrosis in Victoria and NSW, their families, and the broader community since 1974. This includes providing education and information to child care centres and schools and their staff about Cystic Fibrosis through free online learning modules, information sessions, or working with individual schools, to ensure that all children with Cystic Fibrosis can have the best learning opportunities and experiences while managing their Cystic Fibrosis. Most other states and territories have equivalent Cystic Fibrosis organisations.

10. CFCC are limited in their financial supports to subsidise equipment to individuals living with Cystic Fibrosis to purchase equipment, with their small budget.

11. On the DSS website Cystic Fibrosis is listed as a Recognised Disability (15. Cystic Fibrosis). https://www.dss.gov.au/our-responsibilities/disability-and-carers/benefits-payments/carer-allowance/guide-to-the-list-of-recognised-disabilities

    Parents of children with Cystic Fibrosis qualify for a Carer's Allowance. But strangely there is an absence of support for adults with Cystic Fibrosis, for whom the disease is inevitably a greater burden due to the progressive nature of the disease.

12. Daily therapies, such as the use of nebulisers, incurs a regular cost to individuals living with Cystic Fibrosis and this is challenged when higher rates of un-employment in this community result from reduced status of an individual's health. When equipment breaks down this can cause a significant impact to the maintenance regime for individuals, and risk hospital admissions to reinstate previous functioning. Items regularly used by people living with Cystic Fibrosis are now identified in the NDIS list of health-related supports.

13. Assess to NDIS for people living with Cystic Fibrosis is less than other disability types, and from the limited numbers of people living with Cystic Fibrosis who have access to the NDIS this has been met via a secondary disability such as mental health, related to the primary cause Cystic Fibrosis.

14. Commonwealth funded programs such as Home and Community Care (HACC) support younger and older people to remain living at home when providing domestic and respite supports. There has been a significant change to implementation of HACC services with the advent of NDIS. This has resulted in varied experiences by many recipients with a diminished service response depending on where they live and who delivers the service. HACC services have a history of a basic allocation of supports and these do not meet the needs of community members living with Cystic Fibrosis.

15. The decision to close Mobility Allowance to new applicants from 1 July 2020 was announced in the 2016-17 Budget in the context of the establishment of the National Disability Insurance Scheme. This is a vital support towards transport needs for people living with Cystic Fibrosis, who are challenged in their access to NDIS funded supports. The Department of Social Services have ceased all reviews for Mobility Allowance in recognition of the unprecedented circumstances surrounding the Coronavirus outbreak which has had a significant impact on people's daily lives.

    However, the matter is now under review and there is no legislation currently before the Parliament to enact this change. The Cystic Fibrosis community are now left with uncertainty with this decision.

16. The NDIS primarily works under the premise of being an evidence based and cost-effective funded service response. When comparing the daily cost of a running a hospital bed approx $1000, to the lesser cost of keeping individuals living with Cystic Fibrosis managing their condition at home, it would meet the economy of scale for affordability under NDIS. The average stay in a hospital for a person living with Cystic Fibrosis at times of acute symptomatic onset and inability to regulate these, is 2 to 12 weeks (some of this on HITH).

Supports for people with cystic fibrosis fall into three main areas:

17. 1.Services that reduce the need to perform tasks that would otherwise significantly drain energy for someone with Cystic Fibrosis-related disability. This allows the person with Cystic Fibrosis to preserve energy for paid work, pursuing their goals, and participating in the community.

    2. Services that reduce the risk of lung infection, which has a high likelihood of reducing function in both the short and long term (ie increasing disability).

    3. Services/assistive technology that is required to maintain function (to participate in paid work and community). This also falls under early intervention to reduce the impact of the disability in the future.

18. The average value of the supports under a NDIS funded plan is estimated to be $20,000-$30,000, and where a one off costs related to equipment is included, this will reduce the subsequent year funded supports. People with Cystic Fibrosis strive to lead normal lives and be independent. Some people with Cystic Fibrosis, particularly younger adults, do not feel that Cystic Fibrosis inhibits them significantly, and will not need to access supports until much later in the progression of the condition.

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: **Agree** to include Cystic fibrosis to the list of disability types eligible for NDIS funded support.

The Impact of living with Cystic Fibrosis is identified in my statement of impact as attachment A

Attachment A: My lived experience with Cystic Fibrosis.