

Australian CF Hub
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20 July 2020

Joint Standing Committee on the National Disability Insurance Scheme
Access to NDIS
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Parliament House
Canberra ACT 2600
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Inquiry: General issues around the implementation and performance of the NDIS

Title: Inclusion of Cystic Fibrosis as a disability type for NDIS funding

Recommendation: That the Parliamentary Joint Standing Committee:

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

B: **Agree** to include Cystic fibrosis on List A of conditions likely to meet the requirements for NDIS funded support

C: **Note** and discuss the frequent rejection of NDIS applications by people with Cystic Fibrosis-related disability.

D: **Agree** to create a 'Rare and Chronic Disease Specialist Assessor' role - so those assessing applications for Cystic Fibrosis (and other disabilities with a chronic illness aspect) have sufficient knowledge to provide fair and equitable assessments.

About the Australian CF Hub

The Australian CF Hub is an independent community group made up exclusively of Australian adults with cystic fibrosis (CF). We interact online as face to face interactions are deemed high risk due to potential for cross-infection with dangerous respiratory infections. We provide informal peer support, facilitate knowledge sharing, and are involved in CF advocacy. Our mission is to connect and empower adults living with CF so that all people with CF have the support, knowledge, and confidence to manage their disability well, pursue their goals, and participate fully in all aspects of life. While the Australian CF Hub is not affiliated with any organisation we do work collaboratively with our CF organisations and CF clinics for the benefit of all Australians living with CF.

Our lived experience of CF

Managing our disability is extremely challenging

Cystic fibrosis (CF) is an insidious and invisible condition. It impacts every aspect of our lives, including our mental health, and creates social isolation. Living with CF is extremely challenging, increasingly so as it progresses. The COVID-19 pandemic has further increased the barriers and challenges we regularly face.

The severity and symptoms of CF vary greatly between people. We are impaired in multiple ways, especially from chronic and extreme fatigue as our bodies fight ever present lung infections. We often get insufficient sleep due to breathing difficulties/coughing at night. Those of us who have mild or moderate lung disease appear healthy but this appearance can be misleading as we frequently battle brutal fatigue that greatly interferes with our daily lives. For those of us with severe lung disease, CF often prevents us reaching our goals.

Managing CF is time consuming

Every day of the year we need to spend hours on time-consuming but essential treatments multiple times per day (e.g. airway clearance, inhaling medications via nebulisers, taking numerous medications, exercise therapy, consuming large meals and additional snacks throughout the day to maintain proper nutrition, taking essential nutritional supplements etc). Failure to adhere to our medically prescribed treatment plans inevitably leads to 1) continually diminished functional capacity and greater treatment burden in the short term often with associated hospitalisations and 2) greater irreversible impairment in the longer term.

“Even when I'm not sick, and haven't adjusted all my treatments up to max, I'm left with very little time in the day to do anything else let alone have the energy to do it.” Chris, 40.

“The time factors are really quite significant. My morning nebuliser treatment often takes me two hours because my body is sluggish. Then there is the washing of the nebuliser afterwards in mild detergent etc. And same for my 45 minute walk. It takes me 15 mins to get ready and I'm pretty stuffed when I come home and need to recover for half an hour before doing anything else. And when my sugar levels go up and down (and need correcting with insulin or meals/sugar), then I get really tired and need a nap of 1-2 hours in the afternoon. That's not including the time out required when my blood sugar levels drop below 3.” Walter, 55

The health system does not meet our disability needs

The health system provides us with insufficient support to manage our disability in the community. What it does well is 1) prescribing medications and 2) providing reactive care when we experience episodic 'exacerbations'. For example, we receive intravenous antibiotics during hospitalisations of 2-4 week duration with each exacerbation. What the health system does not do well is 1) provide early intervention supports to allow us to proactively manage our disability the rest of the time as well as allow us to maintain more normal and productive lives 2) assist with the significant out-of-pocket costs borne by us to adhere to our treatment regime 3) help us mitigate the debilitating consequences of CF.

Many adults with CF who are clinically stable and in the early stages of the condition visit CF clinics four times per year. That amounts to about 20 hours a year of contact with the healthcare system to manage an extremely complex condition.

“While the medical part is managed, our lives outside of the treatment of our condition are extremely difficult and there is no support in place. We even lose access to a healthcare card once we finish school and leave home.” Bryson, 45

Supports we need to proactively manage our disability

With access to appropriate NDIS supports and services we could better manage our CF, resulting in better quality of life and reduced disability in the years to come. NDIS supports will give people living with CF more independence to participate in and contribute to society.. This means spending less time in hospital, being able to work more, being able to spend more quality time with our families and friends, and participate more in our communities.

Supports and services that would allow us to proactively manage our CF in the community and/or mitigate the debilitating effects of CF.

- Respiratory physiotherapy (Community based)
- Exercise therapy/Personal trainers (Community based)
- Respiratory supports (e.g. nebuliser and consumables)
- Diabetic management supports
- Nutrition supports
- Support with domestic tasks/cleaning/garden maintenance
- Transport budget
- Continence supports
- Hearing aids

Please clarify whether CF is eligible for early intervention

Based on the responses from the NDIA¹ a pervasive belief has formed in our CF community that we will only qualify for NDIS access when we develop severe lung disease.

We seek clarification. Does CF qualify for early intervention?

¹*“Due to the nature of your medical condition early intervention supports are unlikely to reduce future support needs in relation to disability”* Internal review (s 100) of access decision (s 20), 28/5/2019.

Our experience of NDIS

Our applications are frequently rejected

Outright rejections

To date, few people with CF have applied for access to the NDIS, with the majority having been denied access. For example, a survey conducted by Australian CF Hub of 50 adults with CF from around Australia found just three people currently have an NDIS plan while six people had their NDIS applications rejected (Table 1).

Table 1. NDIS access for people with cystic fibrosis (based on community survey). Note: more people have had their application for NDIS access denied (13) than approved (10)*.

People with Cystic Fibrosis	Currently an NDIS Participant	Application for access Rejected	Have not applied for NDIS access	Total
Children	7*	7	99	113
Adults	3*	6	41	50
Total	10* (6%)*	13 (8%)	140 (86%)	163

*Anecdotally, the small number of people with cystic fibrosis who have been granted access to the NDIS have been approved for the following reasons: a) presence of a coexisting condition, b) they were receiving disability supports prior to roll-out of the NDIS, or c) they were assigned the incorrect disability by the initial assessment officer. We are not aware of anyone who has been granted access to the NDIS due to cystic fibrosis alone.

Reasons the NDIA have provided for denying people with CF access to the NDIS:

1. CF is a health condition not a disability, where supports related to health are the responsibility of the state and territory run public health systems.
2. The early intervention services were available elsewhere.
3. CF is not a lifelong disability.

We believe these reasons are all factually incorrect. Our CF community is confused. We do not understand why our applications are being rejected when we clearly have a CF-related disability.

These rejections have led to a sense of defeat and demoralisation in our CF community, including among our CF organisations and CF hospital clinics. Many people with CF do not believe they can qualify for NDIS. Our CF organisations and CF Hospital clinics no longer encourage us to apply.

“At the moment many people with CF are being told by their CF clinics that NDIA won’t accept CF as we are “health”. This is incorrect as NDIS is actually about impairment and many people with CF experience impairment.” Kate, 50

Applications rejected despite meeting s 21(2) of the NDIS Act

Prior to the roll out of the NDIS several people with CF living in NSW received disability supports (in home physiotherapy) that were administered by Ageing, Disability and Home Care (ADHC). In theory these people should have automatically qualified for NDIS access based on the promise that ‘no one will be worse off under the NDIS’. That has not been their experience.

The Australian CF Hub is aware of several rejection cases. Two had their first application and subsequent appeals rejected. Both took their cases to the AAT and were successful. NDIA agreed they met the access criteria for the NDIS on the basis of receiving disability supports that were administered by ADHC, prior to the introduction of the NDIS (s 21(2) of the NDIS Act). We note that due to a NDIS legislative loophole these cases were unable to set a precedent.

"I lodged an application to become an NDIS participant. My CF team wrote great documentation, coordinated by a Social Worker. This was rejected. The formal reason given was that CF is treatable and does not qualify for "early interventions". Over the phone I was told (a) I manage part-time work so do not require disability support and (2) CF is curable with a transplant. Obviously, all three reasons are ridiculously absurd.

I appealed the above decision with a "Request to review a reviewable decision". Again, my CF team wrote great documentation this time refuting their reasons. This was also rejected.

I appealed the appeal through the Administrative Appeals Tribunal. Legal Aid agreed to represent me due to this being a novel/unique case with the possibility of setting a precedence for others. I did win: the AAT ruled that I should gain access to NDIS. However, due to some loophole my case did not qualify as a precedent." Cath, 33

"I was basically told by the NDIA person reviewing their initial decision that CF is health because we die of it and it's not permanent as we can have transplants!! Crazy." Kate, 50

"It took me a good two years from when I first applied for the NDIS to when I gained entry. This was incredibly stressful and negatively impacted on my mental health. The stress probably also resulted in a slight increase in my impairment levels. I lost around 15% lung function over these two years." Kate, 50

Concerning lack of awareness amongst NDIA assessors

The above comments by NDIA assessors demonstrate a concerning lack of understanding of impact of CF. They view CF as a treatable disease, which implies a cure. There is no cure for cystic fibrosis. The available treatments and therapies only serve to slow the speed of this degenerative disease. People with CF who receive a lung transplant must closely follow an extremely complicated medication regime and also be closely monitored at tertiary hospitals for the rest of their lives. CF still affects the rest of their body and they still have to manage all the other consequences of CF like diabetes and pancreatic insufficiency etc. Five years post transplant, the Australian survival rate is 68% (Paraskeva *et al.*, 2018). Just 30% of 5-year lung transplant survivors are capable of working part time (Paraskeva *et al.*, 2018).

Barriers to accessing the NDIS

Lack of information

There is a distinct lack of information for people living with CF on the range of supports available through an NDIS package of support. Given the experience of access for our community has been very difficult, it is perhaps not surprising we are not aware of what people with living CF could access that has the ability to greatly improve our quality of life and increase our participation in

society. Based on our survey of 50 Australian adults with CF, 79% of people said they have not been given sufficient information about how NDIS can support someone with CF.

Complexity of CF makes application process time-consuming

CF is a complex multi-organ condition that affects our ability to function in multiple ways (communication, mobility, getting along with people, life activities, participation in society, and even self care). Multiple parts of our bodies don't function properly and we see multiple health professionals. To obtain medical evidence from all our treating specialists is daunting.

Health professionals commonly involved in our treatment include:

- CF respiratory specialist
- CF referred endocrinologist
- CF referred Ear Nose and Throat specialist
- CF referred gastroenterologist specialist
- CF referred sleep medicine specialist
- CF physiotherapist
- CF referred psychologist
- CF recommended exercise physiologist/personal trainer/therapeutic assistant
- CF referred audiologist
- CF referred fertility specialist
- CF social worker
- CF dietician
- CF referred occupational therapist

We don't have the correct language

Most of our conversations about CF take place with health care professionals in health care settings. We know how to describe CF in medical terms but not in terms of functional impairment. This probably contributes to assessors incorrectly viewing CF as a 'health condition' instead of a disability.

"Until now, we have taken the burden of CF onto ourselves and our families, who are our carers. We haven't been focused on fighting for other ways to live something closer to a normal life. Until this generation, we didn't live long enough to be able to be effective advocates." Bryson, 45

Some of us are too impacted by our disability

For those of us who are very unwell and battling brutal fatigue daily, we need to be very careful about how we use our limited energy as it takes all our reserves just to do our rigorous, time-consuming and burdensome treatment and helps us stay alive. Often we are so overwhelmed and burdened with our daily reality we just don't have the capacity to go through the application process.

"People in our community are too exhausted or trying too hard to live a normal life." Cath, 33

Psychological barriers

Many of us do not identify as having a disability

Many people with CF do not currently identify as having a disability despite experiencing functional impairment. We try to focus on what we can still do, rather than what we have lost, to protect our mental health.

“A challenge for people with CF realising their levels of impairment is we were all born with CF and over time we become increasingly impaired. People with CF are constantly adjusting to increased impairment often without consciously realising as it is often a very subtle and gradual process. Additionally a common coping strategy is to keep a strong focus on what we can still do, NOT what we can’t do, this can help people with CF to feel like they have a good quality of life.” Kate, 50

Significant stigma and discrimination still exists in society around the use of the term ‘disability’, with ingrained assumptions around what a disability is and looks like. Chronic illness related disabilities are invisible and still not commonly viewed as disabilities by the public. Many of us try so hard to live a regular life and not be limited by CF that it’s hard for us to acknowledge we have a disability.

“People with CF fight so hard to not be considered “disabled” even though we are seriously impacted by it.” Bryson, 45

Many of us don’t think we are entitled to support

The CF community is very used to not getting the reasonable and necessary support required to help us participate in the community to our capacity, which consequently normalises a view that we don’t even expect it or believe we’re entitled/worthy of it.

“The NDIS might help me. I sort of feel like I’m not “bad enough” to push for it but I’m probably just undermining myself.” Janette, 37

Many of us are avoiding yet another disappointment

Many of us have learnt it is easier to have low expectations of our bodies and our health care system. Why set ourselves up for yet another disappointment by applying to the NDIS when we hear from others that our applications for access are likely to be rejected?

Many of us are scared that we may lose other supports

There is fear in the CF community that applying for the NDIS could jeopardise other supports we need. Some people are worried they may not qualify for the disability support pension. Others worry access to the NDIS may jeopardise access to life-giving medications and health services. For example, people with CF need a large number of prescription medications. Without access to a Health Care Card (HCC) we incur substantial out-of-pocket costs. Once we become an NDIS

participant we will not be able to apply for mobility allowance – one of the few ways we can qualify for a HCC.

Signatures

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References

Paraskeva, MA, Levin KC, Westall, GP, Snell, GI. Lung transplantation in Australia, 1986-2018: more than 30 years in the making. MJA 208(10) 2018.