CYSTIC
FIBROSIS
Australia

Additional information for the

Senate Community Affairs Legislation Committee on the National Disability Insurance Scheme, Bill 2012 No. 2012
Following the Committee's Hearing in Newcastle on 31 January, 2012.

Submission 6 February, 2013

This submission follows the Committee's request for further information on specific issues and an invitation to make additional comments.

Infertility

One of the many physical and psychological implications of cystic fibrosis (CF) is male infertility and difficulty conceiving for women. The impact is felt not only by the person with the disease but also by their partner and extended family. In addition, should conception occur, couples face the dilemma of whether to pursue a pregnancy that has a greatly increased chance of a child being born with CF.

Individuals and couples living with CF require access to specialist counselling and information services. The time, cost and availability of genetic and fertility counselling, IVF and PGD (Pre-implantation Genetic Diagnosis), and other medical, nutritional and emotional support is required.

Transplants

Cystic fibrosis is a degenerative disease. Physical health deteriorates over time and is often associated with a decline in mental health. For some people, a transplant becomes their only hope of extending or improving their quality of life.

The most common transplants for a person with CF are double lung and liver. The process of being listed for a transplant can be long and is emotionally and physically taxing at a time when the person's health is already in serious decline. In addition to being confronted by the terminal phase of their CF, individuals and families often experience a wide range of mental health issues as transplant recipients – pre and post operatively.

Access to funding and support services that specifically relate to transplants are vital inclusions in the NDIS for the recipient, and their carers. While a transplant is expected to improve a person's health and wellbeing it is not a 'cure all'. New and different chronic health issues may emerge and necessitate ongoing access to the NDIS.

Episodic changes

A significant difference between CF and some other chronic diseases is the unpredictability, severity and impact of acute or episodic decline. Indiscriminately, usually due to an infection, a person with CF may change from being able to work full-time to being hospitalised or needing in-home care within just a few hours.

The legislation should presume **perpetual entitlement** to alleviate repeatedly proving the need for support. If a person had CF yesterday they will have it today and tomorrow irrespective of changes in the health, place of residence, age, personal or family circumstances. As examples:

- A two parent family on the Central Coast of NSW has 3 children of primary school age. Two of the children have CF. The parents can manage the twice daily home percussion regime while everyone is well but if anyone gets sick, or is away from home, they need immediate access to Home Care staff. Their usual government funded agency provides the service for $10 per session but rarely has casual vacancies at the time they're needed. They must be able to access other service providers at $50+ per session.
- A 32 year woman lived independently and worked full-time until she acquired an infection. She was hospitalised for weeks. By the time she was discharged she had lost her job, then her apartment, and needed to move home to her parents. She couldn't drive and was too weak to travel by public transport. The cost of her medicines and equipment increased significantly and she needed a PEP mask and nebulizer. The woman, and her parents, also needed to access counselling for the first time in many years. Her application for a Disability Support Pension was declined twice and only approved weeks before her transplant surgery. Three years after surgery her health has improved but she's only able to work casual hours and is still physically and financially dependent on her (ageing) parents.
- A single mother with a 15 month old toddler needed a physio table so she could safely give him his percussion treatment. They tables typically cost over $200 which was completely prohibitive. There are no funded services providing tables so her only option was to seek financial assistance (which was provided by the CF organisation in New South Wales).

Health Care Card

Eligibility and ongoing entitlement to the Health Care Card are essential. To be eligible for a Card a person must be a recipient of the Disability Support Pension or a Carers Allowance. When a child turns 16 they may not be eligible for a pension because of their parents' circumstances, and therefor lose the Card they had previously been entitled to (as a child), although they may have some other entitlements as a student.

The same disadvantage is experienced by adults. They are forced to be cared for by a partner, parents or to limit their own financial independence because of the criticality of maintaining a Card as the only means of meeting the cost of their health care needs. The cost of CF increases as a person with becomes older which means the need for the Health Care Card becomes even more important.