14th November 2017

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Phone: +61 2 6277 3083
Fax: +61 2 6277 5829
ndis.sen@aph.gov.au

Dear Committee Members,

I am writing to you both as a parent of a child with a disability and as an individual who has a disability. Both I and my daughter have incurable genetic condition that is a hereditable Connective Tissue Disorder. My daughter meets the current clinical classification for diagnosis as Ehlers-Danlos Syndrome, I have the same condition but due to the current clinical classification I do not meet the diagnostic criteria for Ehlers-Danlos Syndrome but do have a diagnosis of a Connective Tissue Disorder.

Access to NDIS for all individuals is hampered by the processes, in this day and age with the use of technology why are people not able to down load an application form or have an application form sent to them by email. This seems to be a deliberate strategy to make the process as difficult and as slow as possible. Especially when staff seem to be able to "loose things in the mail" as happened twice to my application. After the intervention on my behalf by the NSW Department of Family Services it was "found". Are the Senate committee able to investigate why the NDIA is trying to make access more difficult for individuals than is necessary and are not allowing the application form to be available electronically. (It is not as though a blank application form has any confidential or sensitive information!)

For those with Connective Tissue Disorders and Ehlers-Danlos a further issue seems to be that Hereditable Connective tissue disorders and Ehlers-Danlos Syndrome not included in List B in the operating Guidelines. i.e. Access to the NDIS 15. List B – Permanent conditions for which functional capacity are variable and further assessment of functional capacity generally is required.

This is complete stupidity. How does an incurable genetic condition get to be temporary?? The stress caused by this failure to have up-to-date and accurate guidelines to so many already distressed families is heartbreaking. The time of advocates being used to address this stupid failing of the system is so unnecessary.

How are the operational guidelines developed for the NDIS? Who are they developed by? And why are connective tissue disorders and Ehlers-Danlos Syndrome not included on the list B?

From discussions on various facebook sites for those with and those caring for individuals with Ehlers-Danlos it is becoming increasingly evident that NDIS staff are not aware of and/or have received inappropriate advice in relation to connective tissue disorders such as Ehlers-Danlos syndrome. So many individuals are being declined because they are being told that their condition is not permanent. This is complete stupidity. How does an incurable genetic condition get to be temporary??

Can the Senate committee investigate what can be done to update the operational guidelines to include connective tissue disorders and Ehlers-Danlos Syndrome onto the List B immediately.

Yours sincerely