

Proposed NDIS Legislation and Rule Changes
Submission to Department of Social Services from Gail and Lewis Tyson 7/10/21

To Whom It May Concern

I am writing in response to the proposed NDIS legislation changes which will impact on the NDIS Act and NDIS Rules. The introduction of a 'Tap and Go card' has been proposed to facilitate payment of providers. If this is the only method for NDIS participants to access the payment facility then participants will be restricted from accessing their chosen services if this card only caters for NDIS registered providers.

If the legislative changes restrict access to non-registered NDIS providers, I wish to object strongly to these proposed changes. My comments are based on my experience as both mother and carer to our 34yo son who suffered a severe Traumatic Brain Injury (TBI) following a fall in 2011 and is therefore non-compensable. After hospitalisation and rehabilitation it was 6 months before he returned home with multiple cognitive and physical issues which, as a parent, were totally overwhelming. The hospital informed us that he would spend his life either in a nursing home or at home under the care of a full time carer.

The strength of the current NDIS system is the flexibility for those closest to the participant to investigate a broad range of options and identify the most effective pathways to improvement/recovery. A significant challenge, but I believe the motivation of a parent or family member to find the most effective pathways can rarely be matched by others.

When the enormity of this task was realised I resigned from my paid employment. It took a couple of years of painstaking and expensive trial and error, but after extensive research and consultations with many practitioners our son now has a talented team of professionals working with him, some of whom are not NDIS registered. It's impossible for someone removed from the daily experience to achieve this. The criteria were always to identify those therapies that would improve his functional ability, thereby leading to an increase in capacity and independence.

From the beginning I have attended appointments together with our son, enabling us to evaluate the therapy and whether or not the practitioner also had the ability to relate to and motivate him. His current therapy team not only treat his disabilities, they counsel and motivate him to strive for both improvement and greater independence, which are equally important. If an obstacle seems insurmountable they are often able to provide practical strategies. To his credit, our son does the prescribed homework to ensure ongoing improvement in his capacity and independence.

From very early days my husband took our son to his office a couple of days a week for a few hours to maintain connection to a workplace and the associated discipline. Because of the severity of his injury, even alphabetical filing was a challenge. He has come a long way in the past 10 years and we know further improvement lies ahead.

My semi-retired husband is 71yo and I am 68yo. We are striving to push our son to independence while we still can. We have recently moved into a purpose built property which provides a fully independent living area for him, including a separate entrance. Having directed our financial resources to this major project, our son is now totally reliant on his NDIS funding to maintain his current therapy program.

Proposed NDIS Legislation and Rule Changes
Submission to Department of Social Services from Gail and Lewis Tyson 7/10/21

Being in the driver's seat has been the strength of our son's self-managed program. Choice and control provide the flexibility to create a customised program ensuring a future with greater capacity and independence. Our family is very grateful for the NDIS funding we have received from 2017 to date as it has enabled our son to continue his highly effective therapy program. Our son's therapists are not all NDIS registered, but they are all highly skilled and leaders in their field. If we have to change any of his current providers because they are not NDIS registered, the effect on our son's motivation and progress would be nothing short of devastating.

The most recent Physio report submitted to the NDIS states "For several years Lachlan has engaged with a Traditional Chinese Medicine practitioner which has given him significant benefit in terms of pain relief and improved flexibility. This in turn has a very positive benefit to his quality of life and engagement in activities."

These words from our son:

"I am fast approaching a decade since my unfortunate accident which resulted in a traumatic brain injury, a stroke and a left side hemianopia. My life has changed dramatically since that fateful day and it has sadly become truly apparent just how difficult it is to find effective treatments / practitioners.

One thing I have been very fortunate with is my family. The initial diagnosis was that I may never walk or regain continence again. I am eternally grateful to my mum who was studying Chinese medicine at the time, she brought in a Chinese medicine practitioner who turned things around for me.

Today I am still seeing two different Chinese medicine practitioners who are driving me forward in the pursuit of returning to work and functional life activities. Courtesy of the stroke I suffer from blindness out the left and impaired fine motor control in my left arm/shoulder. One of the practitioners provides a session of remedial massage which goes above and beyond anything I receive at physio sessions. This provides a phenomenal release of tightness and allows me to continue through the week without the constant hassle of dystonia and muscle contractions.

Without these practitioners I would not be anywhere close to where I am right now. They have been and still are critical to my recovery and are able to achieve things which are well above the goals set by other practitioners"

Thank you for taking the time to read our submission.

Yours sincerely,

Gail and Lewis Tyson

E: gailmtyson@gmail.com