

28/3/2023

## RE: NDIS General Issues Inquiry

To the Joint Standing Committee on the National Disability Insurance Scheme,

I am writing to emphasise that the more the NDIS puts in place stringent 'rules' and 'guidelines' to cut costs, the less 'choice and control' people with disabilities have. These measures unintentionally strip people with disabilities of the flexibility to ensure their basic human needs are met. Even if we live in a country where economics trumps human rights, the irony is that it is almost always more economically sound in the long term to just provide disabled people with what they need to live healthy, equal, and productive lives – due to the savings incurred on the health care system, etc. I am a severely unwell person so I will be limiting this brief submission to personal examples only, in the absence of having the capacity to present broader data.

### **Increased regulations around meal preparation limiting choice and control of PWD**

One example where NDIS has guidelines in place to limit the freedoms of people with a disability is meal preparation. I have heard from various cross-sections of the disability community that one must often 'fight for' meal preparation to be included in a plan, the alternative NDIS preference being to have support workers prepare all of one's meals (or to deny support for food preparation altogether, and lump the burden of care on an informal support).

As I found out last year, **you are unable to order meal preparation, even if case of an emergency** or short term change of circumstances (such as an informal carer or support worker falling ill), if it is not included in your plan. I had just assumed, as a matter of logic, that if my informal carers (parents) were going away for a fortnight, I'd be able to order pre-prepared meals in their absence (because of my disability, I am unable to prepare food). It's lucky that I double checked with my plan manager, because apparently this was not the case, and there was nothing really that could be done about it. There was no 'short term special concession' that could be applied – as because it didn't exist in my plan – I simply wasn't allowed it. This occurred when I was new to the NDIS and had no formal supports in place who were able to cook for me. I hope this example serves to illustrate then when 'choice and control' are taken away from participants – it leaves disabled people vulnerable to ridiculous and illogical circumstances, not to mention circumstances that cause them distress, stress and have health ramifications. The impact of stress on someone with health conditions is typically far worse than on healthy, able bodied people.

### **Applying an ‘ideal world’ scenario to the people’s lives during the planning process**

My two main priorities during the NDIS planning process (for my first plan) were being able to access a healthy, balanced diet and a wheelchair. As a disabled person of 5.5 years, with no support, there have been lengthy periods of time (years) when I have gone with only eating foods from packets, due to lack of support. Ironically, it was not due to a lack of finances and being able to afford food – but rather not having the support to either prepare food, or even consider and choose a meal delivery service and how that would fit into my budget as that was beyond my cognitive capacity.

Moving back into my familiar home only improved the situation in a minor way, as my parents don’t eat a proper breakfast or lunch, and despite me being near-bedridden at that time, did not see it as a priority to prepare meals for me – which in some ways makes sense as healthy meals are not a priority for themselves either. Lack of a healthy diet has been a source of emotional distress for me, and I’ve been largely powerless to change it. I also have metabolic issues and am now overweight because of inadequate diet to manage my health condition. Choice and control over my diet would change this, but unfortunately in my first plan I wasn’t afforded any considerations for meal preparation.

I explained my person circumstances to my Local Area Coordinator, however, because the NDIS likes to apply an ‘ideal world’ scenario to your life, and totally disregard your actual living circumstances – they did not accept that I should get any support at all for meal preparation – whether through a delivery company or support worker.

Let’s also consider that I am a 31 year old and the only reason that I’m living with my parents is due to a prior lack of disability supports and a current lack of disability housing – so if I did live in ‘ideal world’ circumstances – I wouldn’t even be living at home and I’d be preparing my own meals.

We know that the Standard Australian Diet is already quite poor, so the NDIS isn’t even applying actual reality or data to their decision making process – instead inventing some ‘ideal world’ in which people with disabilities have informal supports who magically cook really healthy meals for them – and if they don’t live in that ‘ideal world’ – then too bad, apparently.

Should adults with disabilities be forced to rely on informal support from family members (who also eat poor diets) for their food and have no choice or control over this? It’s not actually my parent’s job to feed me at 31 years old, and even if it was, I’ve already told the NDIS they’re not doing it. To make matters worse, my parents don’t want support workers in the house either, so I can’t even flexibly use other support worker hours for meal preparation within the home.

Of course, there are many other issues with forcing disabled people to use support workers as opposed to meal delivery, hopefully some of which can be imagined by the committee (although one perhaps less obvious to consider is for people with cognitive disabilities its an extraordinary effort of arranging and managing support workers to prepare three meals a

day, discussing with them what will be planned for weekly meals, liaising with them for all parts of shopping, meal planning, budgeting etc).

Thank you kindly for your time,