Draft List of NDIS supports feedback

Hi, I am a 58yo NDIS participant with a lifelong psychosocial disability, and osteoporosis. I live on my own and have no informal supports. My elderly parents (Mum 83, Dad 85) live 90 mins away and are not considered informal supports due to their age, frailty, and the fact Dad has Alzheimer’s. I don’t talk on the phone, drive or leave the house without support.

I find it hard to follow your list but will give feedback the best I can. I would like to say that I completely disagree with having an in and out list and the limited time that has been given to us to process and give feedback on it. Things that may be reasonable and necessary for some people may not be reasonable and necessary for others.

**Question 3. Do you have any further feedback or concerns with the draft NDIS support lists.**

Absolutely I do! As far as I am aware no other part of Australian society is controlled in this way. Making this list is similar to what the government tried to do with the Cashless Debit Card which was a failure. Politicians and bureaucrats have made a very ableist list of what THEY think people is best for people with disability. I keep hearing about the pub test, but my first question is “is the pub accessible to people with disability?” and then “why are politicians making decisions around what rowdy drunk people want?”. Honestly, if the pub test is so great how about we go and ask them what they think of politicians and bureaucrats! Politicians are dividing Australians with their media accusations that people who get supports deserve contempt.

I’m finding the list very vague and hard to follow, its very restrictive. It’s still open to interpretation so it really does nothing but exclude things based on politicians and bureaucrats’ ableism. It also allows multiple things in the “in list” and then disallows the exact same things in the “out list”.

On the one hand the government and NDIS say that they want us to use innovative technology and use our funds innovatively, but then as soon as we do everyone gets petty and jealous and says “no you can’t have that!”

I’m also specifically concerned about the list targeting psychosocial participants. I don’t use mental health supports as I have finished all my treatment and don’t find them useful. But this list doesn’t make it clear if as a psychosocial participant I will still be able to get social supports, or other supports that I need. Currently I get a “normal” support worker to take me shopping, make phone calls, take me to visit my parents, take me out for exercise and hopefully, eventually day trips. Will I still be allowed to go out each day? Or does the government want me to be a prisoner in my own home even though I’ve never committed a crime? Mental health services are not suited to someone like me who has a life long psychosocial disability and has finished my treatment but still needs support to live.

**Question 1. Do you think the draft list of NDIS supports covers the kinds of disability supports you think should be included? If not what do you suggest?**

It’s not clear if **level 2 support coordination** is allowed by this list. As someone with a psychosocial disability who has no informal supports it is important that I have a support coordinator so that I am not left with the burden of organising supports. Without a support coordinator I am on my own and wouldn’t cope. I understand the government has suggested “Navigators” but as government employees they would have too much power over me, and wouldn’t have the time to get involved the way my support coordinator can. My support coordinator understands that I need regular face to face meetings with him to discuss issues that I am having with supports, its rare that I go 2 weeks without some sort of problem with a support! Providers try to walk all over me. My support coordinator and I are in constant communication, thankfully he doesn’t charge for every single email!

Another thing that doesn’t appear on any list that I can see is the use of **apps for staff management**. Currently I am with a provider that has an app with a calendar and all my information etc. But the provider is walking all over me so I want to see if I can use an app and manage my own workers. But when I ask anyone they say it’s a grey area. The cost for the apps I have looked at is a $50 - $55 per month subscription, the current cost of using a provider is over $1000 a month in management fees! Common sense says this should be allowed. If I didn’t have a disability and the NDIS I wouldn’t be having to manage staff!

I don’t see **headphones or other assistive technology** for those who need them.

**Question 2. Are there goods or services on the draft exclusion list that you think shouldn’t be there? If yes, please list in order of importance**

Well, firstly ALL SUPPORTS ARE IMPORTANT. What might be important to one person might be less important to others. This shouldn’t be a popularity test!

**Smart watches**. They are on the do not have list. However, I have a smart watch so that I can get help in an emergency. As someone who doesn’t use the phone with my disability, and wouldn’t be able to text in a crisis my smart watch is necessary as I can’t contact 000. The particular watch I have doesn’t have an internet browser, so I can’t play games or anything on it. It has a button on the side that I have to press for 4 seconds and the monitoring service (with my particular details) will answer. They know I don’t talk on the phone and to only ask Yes/No questions, they are also a small local company with local knowledge so I’m not restricted to being in the house when I use it.

**Other smart devices**. I don’t see them listed anywhere so I will mention them. I have an UMPs system, which is a bunch of smart plugs that plug into appliances that I use regularly (tv, computer, fridge, bedside lamp) and monitor my movements. This is another safety system that I have in place so that if am incapacitated or if there is no movement in my house when there should be, the company that monitors it checks in and does a welfare check. As someone who lives on my own and has osteoporosis falls are a concern. This device means that if I am not physically (or emotionally) able to press the button on my watch I will still get help and not be left lying on the floor for days.

Both of the smart devices I’ve mentioned are necessary and were allowed at AAT. Even the NDIS lawyer didn’t fight me about them as they are both for my safety and little else.

**Community transport services**. There are specialised disability community transport services, including one I use occasionally. These are for people with disability and take our needs into consideration. Eg, I can’t travel in a bus, so they book me into a car. The driver makes sure I get to my destination so that I can be there on time for my appointment, and they make sure I get picked up afterwards. If we’re running late for an appointment they will call the office that I am going to and let them know. It’s a lot cheaper than using a support worker and having them sit around waiting for me when the support worker isn’t needed for the appointment. Its safer and more reliable than using a taxi. Community transport services should be under the Assistance with Travel/Transport Arrangements category. Its very odd that it isn’t.

**Sex workers**. Okay, this isn’t something that I would currently use personally but I will fight for the right for disabled people to have access to discrete, trained, sex workers. You cannot ask a support worker to position a vibrator, or position someone for sex. Disabled people are still humans. They have rights and for any politician or bureaucrat to deny an adult the right to an adult choice is wrong. Sex work is legal in most states so they aren’t doing anything against the law.

**Holidays.** I agree that participants should pay their own expenses for holidays, but when it comes to support worker accommodation , flights and other costs that should be allowable. The NDIS was meant for people with disability to have an ordinary life. Other Australian citizens can take holidays, so if a disabled person needs a support worker who is familiar to them to assist them on a holiday that’s a disability need.

Its as though the politicians don’t want us to have any pleasure in life. We can exist but that’s it.

I’ll finish by saying that its completely wrong for a non-disabled politician or bureaucrat who has a well paid job to decide what is and isn’t a disability cost. As an NDIS participant I always try and find the lowest cost option for my needs, but its often not allowable under the NDIA rules. Considering this is only a “transitional list” I dread to think what punishments the politicians would put on a real one.