From: [redacted]
To: NDIS Consultations
Subject: Submission for ndis supports consultation
Date: Monday, 28 July 2025 10:49:54 AM

I know it was due yesterday, and wasn't going to try sending but my peers encouraged me that you may find leniency. I have narcolepsy being a problem again and i literally have a video of me falling asleep right after telling my daughter i was going to be submitting feedback. First time I ever saw myself dropout of consciousness, heh.

So please understand I in no way wish to cause a problem, it's just that people really wanted me to submit this so i didn't want to let them down:

In Defence of putting the no list on a no list

I'm writing this in the middle of a sensory storm. Depending on my neurological state, every sound either assaults me or fully manifests inside me. The crinkling of plastic isn't just annoying, it's pain. It's measured by how far away the sound is, how many walls or bodies are between me and it. It feels like the inside of my ears are being bitten by fire ants. It hurts. It makes me mad. It makes me unreasonable, even when I'm otherwise well-regulated.

And I'm working on that. But I don't have an answer yet.

Right now, spontaneous package-opening or fidgeting with certain bags near me still feels like a direct offence. I know it's not. But my body doesn't care. So, I wear noise-filtering headphones. Constantly. And yet somehow, these are on the "out" list? Portable sound filtering that fits my head and produces pain relief that replaces the need for opioids, that lets me understand what people are saying when I'm in public, that lets me be around my children without being a terror is banned? How?

These headphones are not a luxury. They are core assistive technology. Without them, I can't be an engaged parent. I can't function in crowds. I can't even sit in some meeting rooms, because I can hear the machines in the building and the movements of people on the streets. Whether or not I can participate or not often comes down to whether I have this gear, and whether I can meet my individual goals requires other similar supports that are disability specific to me but are goods in the open market, things like: cable ties that allow me to secure things so I don't knock them off, padding that lets me modify my painting area to be accessible while still being able to keep it clean, or even just combinations of supports that as an ensemble make sense to anyone who would ask, but which may not seem like disability specific supports to a narrow scrutiniser who might pick things out as being "not NDIS supports" just because they seem like everyday expenses.

Although I have noise cancelling headphones, they won't last forever. Based on hygiene alone, I should have two pairs, one to wash, one to wear (but also due to how devastating it is to be without a backup is called for) because I wear them that often. They allow me to be with people. Without them, my version of "engagement" quickly becomes a countdown to meltdown from something others don't even notice.

This is why the prescriptive lists are dangerous. I don't know how to legally run my support system under this new modality that eschews the principles. I suspect there's a way, but I haven't figured it out yet and that uncertainty and risk is a problem in itself.

Maybe there could be a functioning informative list IF built carefully, with real community co-design, nuance, and trust in the diverse needs of participants. But this isn't that.

Can you imagine how good this scheme could be? How safe, useful, multidimensional it would be if the people designing it were actually building community? If we had leadership capable of robust, flexible, grounded design?