Submission

Consultation on draft lists of NDIS supports

August 2024

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While I compiled this submission, it is the product of feedback from hundreds of disabled people, families and other interested parties in the disability sector.

About me, Sam Paior:

- Solo parent of two young adult men with disability who are NDIS participants, one of whom lives with Down syndrome and autism.
- Founder of The Growing Space, an independent 10 year old NDIS registered National Support Coordination and Specialist Support Coordination, information sharing and consultancy service.
- Person with congenital hearing impairment (bilateral hearing aids), ADHD and Stickler syndrome.
- Member, NDIS Independent Advisory Council
- Member, NDIS IAC Intellectual Disability Reference Group
- Member, Workforce Registration Taskforce Academic and Policy Working Group
- Member, Better Planning Reform for Outcomes Co-design group
- Member, Flinders University Up The Hill Advisory Group
- Board Member, Self Manager Hub and Count Me In Foundation

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Notes: in response to Legislation Amendments

I would like to note that after the responses in the body of this submission were collected, there were amendments introduced and accepted by government which addressed some of the overall concerns expressed, though not the specific “out” item lists.

I would also like to point out the following concerns with the consultation, and with some of the related proposed amendments to the NDIS Bill.

Extended Consultation period

1. While the extension of one week is welcomed, it is not long enough, particularly given my concerns around the Easy Read version of the lists provided

Easy Read Out Lists

2. The Easy Read Out lists (released with only a week to respond to this consultation) do not explicitly include most of the more contentious items from the regular list version. These translations are also contradictory.
3. This feels like profound discrimination against people with cognitive or other language barriers, particularly those with intellectual disability for whom the concepts of “day to day supports” are exceptionally difficult, and for whom a switch to incorporate the concrete lists “smart watch”, “appliances”, “sex toys” etc would be more meaningful and give cause for them to respond and contribute to this consultation.
4. I do understand (deeply) the principles and practicalities of Easy Read and Easy English translations, but this version does not provide the necessary information for its readers to provide and informed response, thus discriminating against them and excluding them.

Exceptions to the NDIS Supports List and Carve outs

5. An amendment which allows for exceptions to the lists and carve outs, with some kind of form or mechanism to apply for a claim which would not otherwise be allowed.
6. However, for that claim to be accepted it must be the same cost or cheaper, AND provide the same or better outcome AND replace another NDIS Support (as defined in the Rules).
7. These requirements do not define "better outcome" or the timeframe which might apply. For example, an electronic camera doorbell might not provide a better outcome to allowing a participant greater independence to be at home alone without a support worker for some time. It might be years before the disabled person achieves that independence (along with their parents' comfort to allow it) until the use of that video doorbell has proven that the young person is safe at home alone, and has the skills to answer and not answer the door as appropriate.
8. What and how might a threshold be applied to defining or proving a "same or better outcome" – what if there is an innovative support or new way of trying to meet a disability related support need that does not yet have evidence for this particular participant and/or is unable to be trialled.
9. The Same and Lower cost threshold should not always be expected to be met. Sometimes, a higher cost support will produce far greater outcomes and there must be allowances for this to be balanced.
10. This legislation appears to not offer any appeal mechanism if an exclusion request is denied. Individual items/supports are not labelled in new NDIS plans, and there will be no mechanism to request a review of specific items when plans are not being built line by line. It would be impossible to appeal the whole plan when an innovative item or service has been denied, because the plans will now be a "total bucket" without specific items or services. Ie: will this mechanism allow for the appeal of any specific item or service from the "OUT" lists for which a claim is denied?

Introduction

“NDIS In and Out Lists”:

This submission consolidates feedback data from hundreds of participants, carers, and providers in response to the examples we illustrated with just five selected examples from the Draft Transitional NDIS Rules NDIS Supports “OUT” list. It also includes a significant number of comments illustrating the various ways these “excluded” supports provide better outcomes, greater community access and inclusion, and often, lower costs.

These examples were chosen as simple samples, and should be used to extrapolate that the vast majority of supports, services and expenses listed in the “OUT” list should be reconsidered with a careful lens, noting that EVERY NDIS participant is a unique individual with unique needs, unique ways to meet those needs, and all have a human right to choice.

We could just as easily have chosen Yoga Therapy, or Dishwashers, or the severe restrictions on Specialised Driver Training or Short Term Accommodation in grouped situations (what a retrograde disaster for building independence and inclusion in community!)

Each of the five examples chosen were posted within a 24 hour period over August 7th and 8th on The Growing Space Facebook page (https://www.facebook.com/TheGrowingSpaceAustralia) , which has just under 40,000 followers and reached more than 2 million people over the past year as per the table below which shows the statistics of reach, engagement and interaction.

Post engagement and reach overall statistics

Post Topic	**People Reached**	**Post Engagements**	**Reactions**	**Comments**	**Shares**	**Link Clicks**
Smart watches	11,929	3,077	575	197	53	3,077
Hair therapy, hair & beauty	4,025	1,773	188	154	14	1,417
School uniforms	4,017	1,129	82	60	4	983
Washing machine	3,045	533	69	23	6	435
Sex toys	3,873	1,509	148	132	18	1,509
Summary: Draft Lists	2,601	688	125	76	18	469
Total	**29,490**	**8,709**	**1,187**	**642**	**113**	**7,890**

Here is the last post of the series, which is a good way for this submission to start!

📜The NDIS Rules: IN and OUT Transitional Draft Lists: My Call for Sensible Flexible Spending

💬It’s time for me to tell you what I really think (which is no less or more important than what YOU think). You may have seen the lively discussions on the posts over the last few days on here.

Here’s why I am concerned about the Draft Rules and associated consultation:

⏰ **1. Timeline:** The timeline for this consultation is absolutely unacceptable.

🌍 **2. Accessibility:** The process of this consultation will not reach disadvantaged or remote communities. There is still no Easy English or Auslan versions of the draft lists, let alone translations into other languages or ways to even know about the list if you don’t have internet access and literacy.

📝 **3. Clarity:** The lists are written in a contradictory and inconsistent manner, unintelligible to mere mortals. There are 182 items (I counted!) on the “OUT” list, and some of them are also on the “IN” list. Weird.

But apart from this very flawed process, I think the lists themselves are misguided and potentially dangerous.

🚫 Fundamental Flaws in Concept

🔍 The concept of having these detailed lists goes against the fundamentals of the NDIS. The “I” in NDIS stands for “Insurance”—which is all about preventative measures to prevent or reduce future costs. When people pitch in now and pay a bit, that ideally works to prevent paying more later. These “payments” or “investments” are not just in terms of dollars, but also in independence, dignity, and quality of life.

For example (for context you'll need to read the posts over on Facebook):

💵- Paying for a washing machine now prevents ten years of professional laundry costs.

❤️- Paying for a sex aid to help someone masturbate can prevent huge support work-related costs, property damage, personal harms, and justice system-related costs later.

💇- Paying for a hairdresser to wash hair prevents the need for more support workers and saves someone’s dignity.

⌚- Paying for a smartwatch pays back in reduced worker costs, reduced health costs, and in greater independence.

🏡- Paying rent for a housemate in exchange for overnight support saves thousands of dollars in paid support and has even greater returns in terms of building community.

These are just a few of the literally hundreds of use cases that will not be "right" for the vast majority of NDIS participants but will be "right" for some individuals for whom they are life-changing.

🚷**Sensible Items for the OUT List**

👍I think everyone can agree that there are items that can easily go on any OUT list—pokie machines, tequila, heroin, crystal healing therapy, and guns.

✅**Refining the IN List**

📋The IN list is not terrible, but it could be simplified to state: "Anything needed due to disability that you would not otherwise purchase, and is not funded by another government body, is illegal or will hurt you or others."

📄**Legislative Changes and Our Rights**

🚫Remember, we're not talking about paying for all this stuff—the new legislation means we won't be able to fight for and expect extra funding for individual items anymore. We're simply asking to be able to spend the money we're already allocated in ways that make sense to us and work for us. New software at the NDIS is already starting to collect and analyse data on the types of spending, and participants will (and should) be required to let the NDIS know where the money was spent.

💰**The Cost of Extensive OUT Lists**

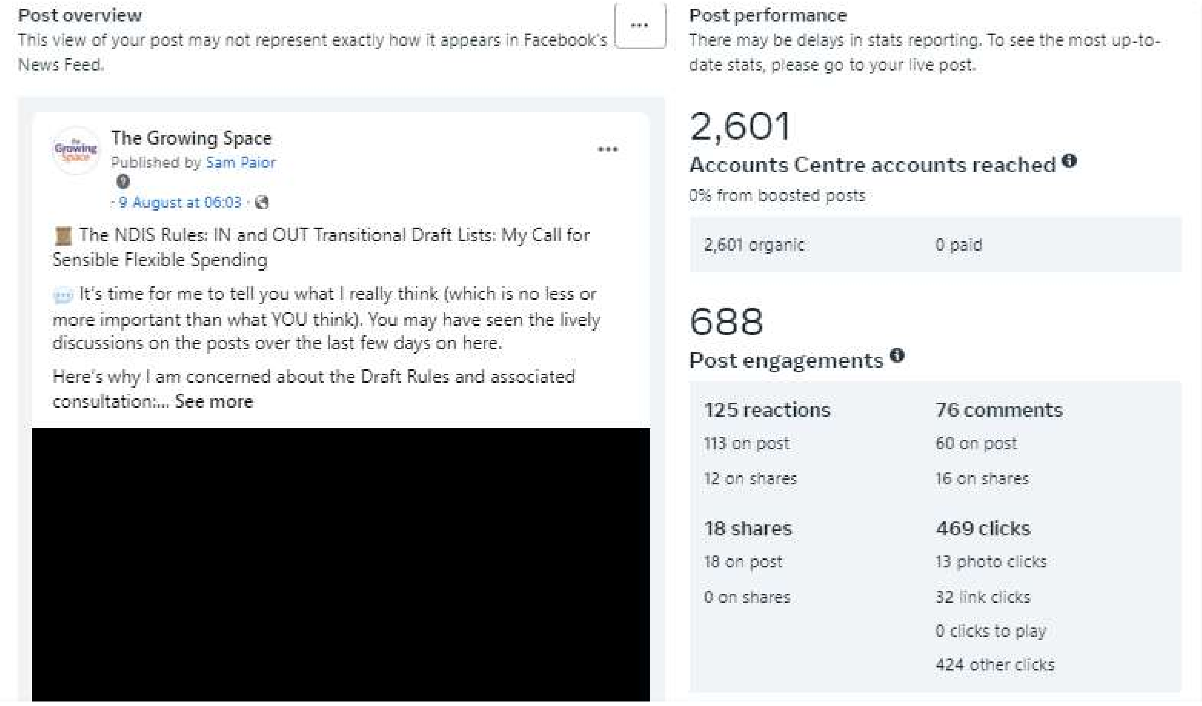
💼An extensive OUT list does not cost the NDIS less—it's likely to cost MORE—driving participants and families to use support workers for everything, as if they are the golden panacea to all our woes.

✊Hands off our NDIS. It's our lives we're talking about.

Join the discussion and make our voices are heard - you have until Wednesday to make your own submission at https://engage.dss.gov.au/consultation-on-draft-lists-of.../

pic desc: Sam, exhausted, in the dark, needing sleep (a black square of nothing)

Post reach and engagement statistics



Post overview

This view of your post may not represent exactly how it appears in Facebook's News Feed.

The Growing Space

Published by Sam Paior

· 9 August at 06:03 ·

📜 The NDIS Rules: IN and OUT Transitional Draft Lists: My Call for Sensible Flexible Spending

💬 It's time for me to tell you what I really think (which is no less or more important than what YOU think). You may have seen the lively discussions on the posts over the last few days on here.

Here's why I am concerned about the Draft Rules and associated consultation:... See more

[redacted]

Post performance

There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

2,601

Accounts Centre accounts reached

0% from boosted posts

2,601 organic	0 paid

688

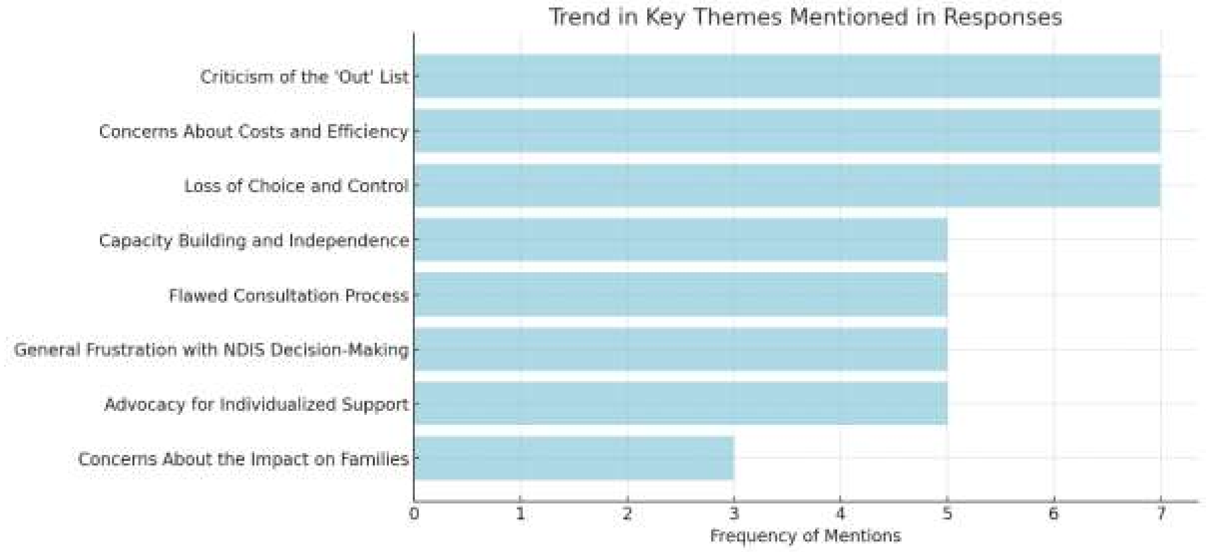
Post engagements

125 reactions	76 comments
113 on post	60 on post
12 on shares	16 on shares
18 shares	469 clicks
18 on post	13 photo clicks
0 on shares	32 link clicks
	0 clicks to play
	424 other clicks

The comments made on this post highlight concerns about the draft NDIS "Out" list, the loss of choice and control, the financial inefficiencies, and the need for a more individualized approach to support. They emphasize the importance of capacity building, independence, and the impact of these changes on families and participants.

1. **Key Themes**
    1. *Criticism of the "Out" List:* Many comments express disappointment with the items on the "Out" list, arguing that they are detrimental to participants, especially those in regional areas. There is concern that the list was created without considering the specific needs of individuals and the potential for better outcomes.
    2. *Concerns About Costs and Efficiency:* Several responses highlight the inefficiency and higher costs associated with some decisions, such as preferring support workers over more cost-effective alternatives. There is also concern about the financial impact of requiring specialized technology that may not be well-defined.

3. *Loss of Choice and Control:* There is a recurring theme of concern over the loss of choice and control for participants, particularly in how they can use their NDIS funding. This theme includes frustration with the perceived rigidity of the system and the potential for reduced independence.
4. *Reduced Capacity Building and Independence:* Comments emphasize the importance of capacity-building tools and technologies that promote independence. The removal of certain items from the list is seen as a step backward in supporting participants to live more independent lives.
5. *Flawed Consultation Process:* Many comments criticize the consultation process as being too short, inaccessible, and not genuinely open to feedback. There is a call for a more extended and inclusive consultation period that considers individual circumstances.
6. *General Frustration with NDIS Decision-Making:* Some comments express general frustration with the NDIS decision-making process, describing it as disconnected from the realities faced by participants and overly focused on cost-saving at the expense of individualized support.
7. *Advocacy for Individualized Support:* There is a strong advocacy for a more individualized approach to support, arguing against a one-size-fits-all model. Comments stress the need for the NDIS to consider the unique circumstances of each participant.
8. *Concerns About the Impact on Families:* Comments also focus on the potential negative impact on families, particularly those with disabled children. The removal of support for family-related services is seen as harmful and short-sighted.



Frequency of mentions for each key theme in the responses. This highlights which concerns were most commonly raised in community responses.

2. Community Responses (verbatim but de-identified)

- Yoga Therapy is sitting in the list amongst crystal healing therapy… No NDIS decision makers… they are absolutely nothing like each other. Yoga Therapy has changed my life and this has been proven with evidence based articles and reports.

- Like so many things, this "Out" list will be more detrimental for regional folk who already can't get support workers to fill shifts. I'm so disappointed with the items on this list, it takes us back to the days of other people knowing what we need better than we do. It flies directly in the face of UNCRPD and the "choice and control" mantra of the NDIS.

- They haven’t really thought a lot of things through $$$ wise. Costs a lot more for a support worker to wash your hair than a hairdresser - costs a lot more to stick your PWD in a respite Centre than to go to a mainstream accommodation supported by their dedicated team of support workers. Not to mention the better outcomes for the participants.
  This list is purely based on the general public freaking out over what

funding is being spent on - spurred on by ignorant media trying to get a headline.

- So many of the ‘out’ list is really at the heart of the sticking pot that is about capacity building. There are so many tech solutions that support independence, trialling different strategies to improve executive function and give credence to many NDIS clients who have difficulties with communication- which NDIS and its over focus on engaging with providers actually just exacerbates. Is there a dominant underlying ‘employment figures’ agenda here as it is surely not always cost effective- nor showing understanding that developing capacity and balancing between requiring external assistance is very nuanced.

- I think they are very cunning with their timelines they don't want any objections. It will reduce our choice and control & our independence. I certainly won't be putting off buying a No item as once it's changed it will be nearly impossible to get these things. Hopefully there will be a transition period.

- The IN list is disability specific services that are delivered to people with disability, though not necessarily meeting their disability support needs. Disability specific services will cost more, stifle innovation, create more segregation/congregation (that’s just how services work) and lead to poorer outcomes.

- It’s absolutely ludicrous for the NDIS to insist on prescribing how we determine to have the support they have determined we are eligible for delivered. If they have funded support for personal care why should they be concerned if people have found a way to have that delivered that has met our needs and costs either the same or in many cases less. My big bug bear is cruises…. we have STA specifically mentioned in our plan, we have utilized Cruises for this because they have been cheaper than price guide rates and more importantly they have provided greater community connection outcomes. Our first plan was in place for 4.5 years and we underspent that plan by hundreds of thousands of dollars...... except for therapy we have never paid price guide rates for anything.

- I agree with everything you've raised. I'd add that requiring assistive technology to be "specialist" is ill-defined (or actually zero defined), is going to cost significantly more (AKA the "Disability Tax"), and it will severely limit choice to the point of participants often not being able to find anything suitable.
  Having an unusual disability - an energy impairment - means that disability stores do not cater to my needs, at all. I often need to buy mainstream items and adapt them. For example, I recently bought a children's activity station for the car. I use it as a lap desk on the couch/bed to make Lego because I cannot sit up at a table. Under the new Lists, I wouldn't be able to buy this with my NDIS funds.

- I'd also like to say that hiring support workers is not an easy fix for some. If they only need a few hours a week will the support worker be reliable. If they only have to come over 2 hrs twice a week for hair washing will they consistently do this, how long to find someone who is reliable, what happens when they are sick does the participant have a stranger while in a vulnerable position or just remain dirty. How to hire, are you an employer?
  Loss of independence can cause poor mental health and further loss of independence.
  I also think this push for exhausted carers to take on someone from a body that isn't yet properly regulated opens it up for the wrong people to be there.
  Predators watch for opportunities and this is a big one.
  I have already seen some awful posts about what sw have done and just disappeared into the ether.
  Sometimes it's safer (and cheaper) to support the carer with a cleaner, yard maintenance, home maintenance, meals etc to free their time to look after their family member.

Particularly when it is children and young people which is when the NDIS is most likely to refuse it.

- Let’s take for example the banning of white goods like air fryers and microwaves that talk. Having these items on the out list is going to increase costs and reduce independence, and it’s gonna cost the scheme more. You have highlighted beautifully your examples this week of the In-N-Out list. The consultation period is too short and the accessible word document well that’s not really accessible either.

- Another big one—they have narrowed down the definition of specialized driving lessons to when in modified vehicles or using adaptive equipment.
  There is a massive cohort of autistic participants, participants with ID, ABI, anxiety, fatigue, etc who have benefited greatly by having extra driving lessons funded, as per the current NDIS guidelines on driving supports.
  If this is not an oversight but intentional, it is very short-sighted, as assisting participants to gain the license potentially cuts down the need to fund transport.

- I've written to them highlighting how inaccessible their consultation process is and requesting a time extension. I'd urge others to do the same.

- And I’m assuming Google Homes and automation is certainly on the out list as that certainly will assist in developing independence and saving support costs. Very short-sighted.

- I agree with all you have said! The consultation for such a big change is too short for true consultation.
  Limiting services to participants that enable participation in the community limits quality of life but also costs more money to the government in other areas (your examples have highlighted this

beautifully).
There is no way I will be able to make a submission by the time frame - it needs to be extended.
But also, what on earth happened to the 'focus' on fraud and scamming the system? It seems we have gone from ensuring that fraud and scams aren't able to occur to limiting how participants can use their funds (and ultimately blaming participants for the blowout).
I agree changes are needed but this proposed change is not the answer and provides NO consideration of a person's circumstances or value for money!
We need our politicians to step up and advocate for greater consultation time (at the very least!) but also a review of how this proposed change aligns with a person-centred model of support for people with a disability!

- The cynic in me, which has only intensified since WA joined NDIS, is not surprised. My business partner and I have a saying, expect the expected. I honestly expect the agency and government to act in a way that they think will save dollars, ensure a consultation process is flawed and skewed in their favour, and I expect them to have no insight into individualized needs or rights. Despite all of this a tiny bit of hope remains, and I wish they would just do better!

- I find it so upsetting that an easy-read version is still not available to access.

- I'm not sure whether people are reading the consultation page as well as the lists. These are proposals for 'transitional rules' because the Bill on new rules hasn't been passed. The consultation page states that these lists reflect the 2013 Act. The overarching principles are 1) directly related to disability and 2) who pays for them. But a few extra toppings have been tossed on too.
  Bit of a boo-boo that it's taken 11 years to let people know what was on the secretly guarded exclusion 'list' - more specifically at the coalface

which is the LAC. If these hastily drafted transitional rules presage the new Bill, what's in that new Bill? If this is a correction to an 11 year-old oversight, then it has to be in line with the times. Technology has moved rapidly and yet it's quite obviously targeted as a no in favour of support work which may not be more efficient nor as economical. The principles remain sound, but the rules are fast becoming redundant.

- Thanks Sam for all your hard work around the proposed list.
  The things on the out list that really bothered me was all the support for families (parenting programs, family therapy, support to families who are at risk of child protection intervention, couples counselling, dating support) families who have disabled children need this kind of support to survive sometimes. Again, it needs to be focused on individual needs of participants.

- Any generic list that defines the support needs of people with disability as a homogeneous group reinforces the barriers to full participation in Australian contemporary life for people with disability.
  In other words, making lists for people with disability without all the different circumstances that people have, does not improve access to the operations of the NDIS, or help people at the NDIA work together in the co-design of plans. We need better access to the NDIA, actual people, to reinforce all the good things about what the NDIS can do. We need to stop wasting money on all the operations that do not compliment this need but double up on processes because of bureaucratic barriers and imagined evidence based measures that create discrimination and bias against choice and control in one's life.

- I find this list very vague and difficult to understand, and I do not have a disability! Is there somewhere that lists the specific items, eg, smart watch, washing machine, yoga therapy etc etc - all the things they are proposing to place on the NO list?

- I’ve just done the survey and it is wrong! They expect you to list all the things you think should be changed on the outs list. I wrote what I thought about this and I’m guessing because I haven’t addressed each dot point I think is inappropriate they’ll say it wasn’t disagreed with.

- I just read what I think are the ins and outs…I think. Extremely concerning if some of these are excluded because a group decided they don’t fit in with their understanding of what works for a participant and what doesn’t. Very concerning what a group deemed as evidence based which assumes everyone has the same needs and wants as each other…one box fits all!

“NDIS In and Out Lists”:

4. SMART WATCHES

This was the *first* post of the series and gained the most traction and engagement, probably due to Facebook algorithms and it being the first post.

🌟 NDIS In and Out Lists - Smart Watches (long read, but important)
📋 The government has made new draft lists and they want your feedback.
📚 These lists show what you can and cannot buy with NDIS money.
⚠️ This is a big potential change.
🔗 You can read more about these lists in the comment below.
📝 I will write about different things on these lists this week.
🧐 I will tell you why I think some things should not be "OUT."
⌚ Here's a story about why Smart watches Should Be "IN"
✍️ Share Your Story - Please tell your smartwatch story in the comments!
⌚ Imagine Matt, who is a young adult with intellectual disability and autism.
Matt falls, not frequently, but more than his non-disabled peers. Most people without disability will get back up, clean themselves up and continue with their day.
But Matt is running to the bus (he’s very particular about getting to the stop early) but he trips and falls hard, injuring both his hands. He sits on the ground, crying and wiping blood all over himself, and is unable to use his 📱 phone to contact anyone due to his distress. He throws and smashes his phone in frustration due to his distressed state. He won’t wear an ID band or MedicAlert as it’s “not cool” but loves his trendy smart watch.
The apple watch falls alert notifies his family, who call him. They use “find my friends” to locate him, go to him and help take him to the doctor to clean and dress his injuries. After a week of extra support, his hands are healed, and he is back to his regular life.
Cost: approx. $410/year for a watch with a 2 year lifespan and $5/month for the cellular connection)

🚫 And here is Matt’s story without a smart watch:
Matt sits distressed on the footpath for twenty minutes until a local resident notices him and tries to help him, but he doesn’t trust them and won’t show them his wounds. The concerned passerby calls an ambulance, putting needless strain on the emergency room/health system, as well as wasting Matt’s day. His family are distressed as he doesn’t come home at the usual time (the hospital are treating him as a John Doe as they are unable to communicate with Matt and his phone is

smashed). There is also a delay in getting support (as does his distrust of the rushed ED doctors who don’t have the skills to communicate with Matt at the hospital, along with Matt’s previous medical trauma), so the hospital seeks an order from SACAT to restrain him and treat his wounds, which takes some time, and further increases Matt’s trauma and distrust in health workers.

💊 Due to these delays, Matt’s wounds then get infected and take longer to heal, placing further strain on the health and disability system, as Matt now requires full assistance to bathe, toilet and eat for three weeks as the wounds got infected due to delays in getting him cleaned up.

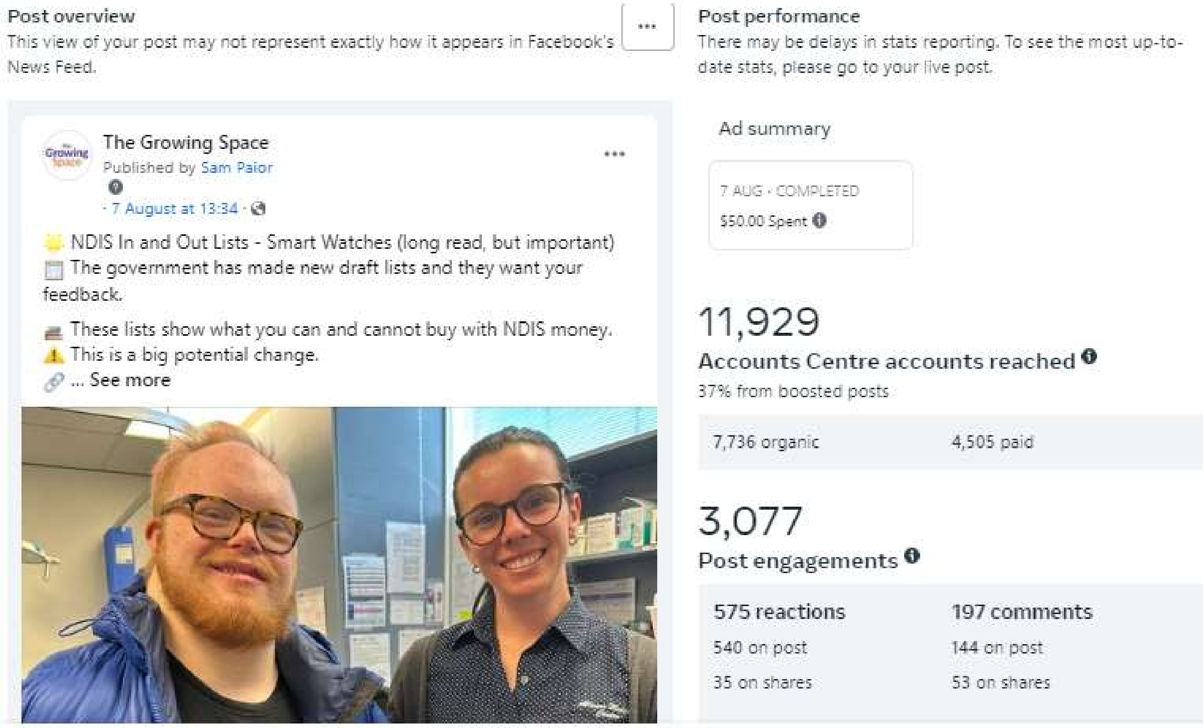
🚑 Several months later, Matt refuses to get in an ambulance or go to hospital due to this trauma, and ends up suffering a much longer hospital stay and permanent reduction in his functional capacity due to the domino effect. The costs on the health and disability system exponentially increase, and Matt’s quality of life decreases profoundly.

OR

💰 Matt employs a support worker to shadow him everywhere – Matt’s independence decreases, his skills decrease, his friendships decrease, his quality of life decreases and its costs the NDIS a bucketload more.

pic desc: A young man with injured, bandaged hands (not Matt) and a health care worker at a local doctor's surgery, both smiling. Yes, most elements (and all that are relevant to the "OUT" list containing lots of errors) of this story are true. And yes, there is a smartwatch under that blue puffy jacket. Photo used with permission of both people.

Post reach and engagement statistics



Post overview

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The Growing Space

Published by Sam Paior

· 7 August at 13:34 ·

☀️ NDIS In and Out Lists - Smart Watches (long read, but important)

📅 The government has made new draft lists and they want your feedback.

These lists show what you can and cannot buy with NDIS money.

⚠️ This is a big potential change.

🔗 ... See more

Post performance

There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

Ad summary

7 AUG · COMPLETED

$50.00 Spent

11,929

Accounts Centre accounts reached

37% from boosted posts

7,736 organic	4,505 paid

3,077

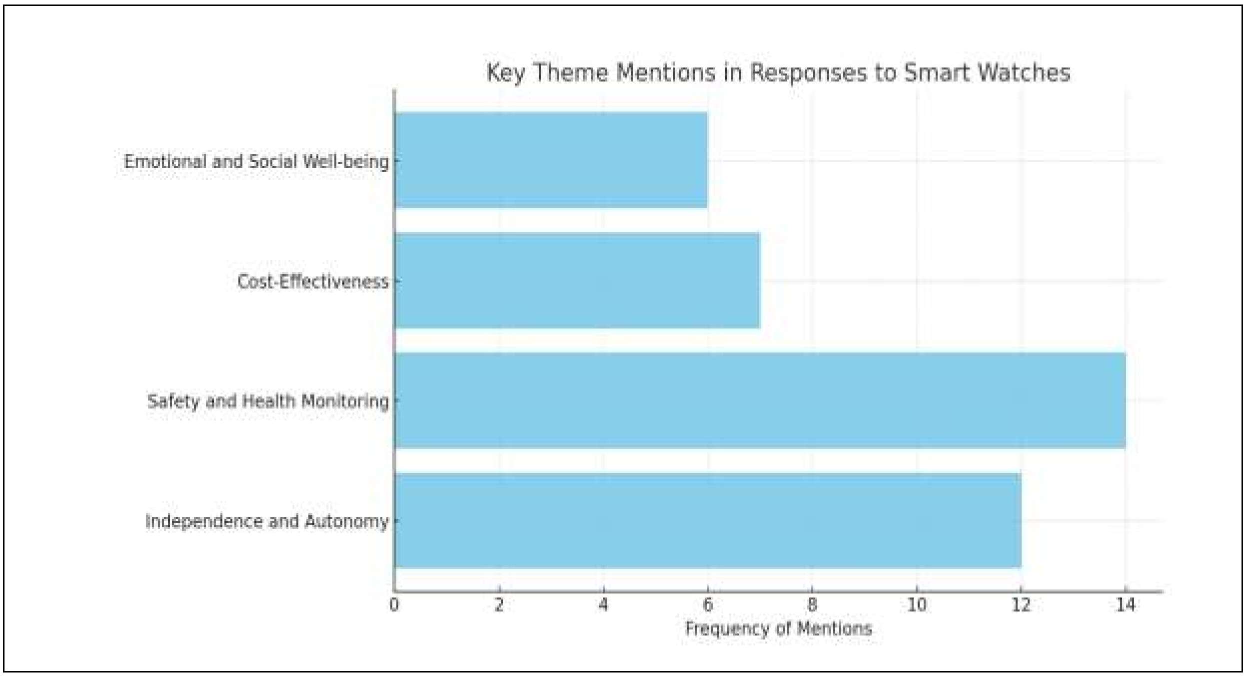
Post engagements

575 reactions	197 comments
540 on post	144 on post
35 on shares	53 on shares

1. Key Themes

- *Independence and Autonomy:* Building Independence: Many comments highlight how smart watches empower individuals with disabilities to manage their health and daily activities with minimal external assistance.
- *Communication and Accessibility:* Smart watches provide essential communication tools, especially for those with speech impairments, hearing impairments, or cognitive disabilities. The ability to send messages, make calls, and receive reminders is crucial for maintaining independence.
- *Safety and Health Monitoring:* Fall Detection: For individuals with conditions like Multiple Sclerosis, physical disabilities, or balance issues, the fall detection feature is life-saving.
- *Heart Rate and Health Monitoring:* Continuous heart rate monitoring helps manage conditions such as heart problems, anxiety, and fatigue, allowing for timely intervention.

2. **Cost-Effectiveness:**
    - *Efficient Use of NDIS Funds:* Compared to the costs of continuous support or multiple specialized devices, smart watches offer a cost-effective solution by integrating various necessary functions into a single device.
    - *Reducing Reliance on Support Workers:* Smart watches enable participants to perform tasks independently, reducing the need for constant supervision and support.
3. **Emotional and Social Well-being:**
    - *Discretion and Normalcy:* Participants appreciate the subtle and non-intrusive nature of smart watches, which blend into everyday life without drawing attention to their disabilities.
    - *Emotional Regulation:* Features like breathing exercises and mindfulness apps help manage anxiety and stress, contributing to better emotional health.



2. Community Responses (verbatim, de-identified)

- The fact that so many devices are being declined because they are "everyday" items and not typical "assistive technology" is so frustrating. Why are we trying to limit the types of tools/devices/technology that can be included to only those with the stigma and label that comes with "assistive tech"? Why are people being punished for creative solutions to problems?

- My daughter with ASD uses it to remind her to take meds, to eat, to regulate her heart and identify anxiety. It is very important.

- We use a smart watch for sleep monitoring as part of our daughter's disability. We also use it to monitor her heart rate for certain episodes that require intervention by support and guardians. She can't monitor any of this herself. We have been buying the least expensive model though purchasing it privately. Sad to see this on the no list. Everybody can buy these privately but some of our people with disabilities require usage above what's normal.

- Smart watches are also for pacing using heart rate data for people with ME/CFS. The watch also helps with energy conservation it can be used to find their phone, it alerts them when an email or message arrives, it saves them having to go to or get their phone when it rings. These things sound minor to an able-bodied person and/or one without a severe energy impairment like ME/CFS. However a smart watch is life-changing for a person who is severely disabled by ME/CFS. The level of disability experienced by people severely affected by ME/CFS is so great that things that appear low energy or appear to use negligible to people not affected are huge energy tasks ie opening up a computer to check for emails that may or may not be there, picking up the phone, finding a misplaced phone. The smart phone also addresses the need hit a fall detector.

- I have an energy limiting condition and I need to buy a smart watch. My orthostatic intolerance makes my heart rate dangerously high and with a smart watch I would be able to monitor it to do heart rate pacing to prevent Post Exertional Malaise. Without it, pacing is difficult and my disability is made worse.

- If I would’ve had my Apple Watch I would not have been able to call an ambulance when I injured myself and couldn’t move. I couldn’t connect in any other way. I would have been alone in excruciating pain for many hours if it weren’t for my Apple Watch. It’s saved my life many times.

- Smart watches are such an important support for so many people. As a provider we have recommended them for:
  -Falls alert (often the only product that will be worn by a participant for this purpose)
  -For easy access to phone calls at all times
  -Use of gestures and voice assistant
  -Reminders and alerts, audio and haptic
  -Medication reminders
  -Health monitoring and feedback
  -Directions and independence navigating to new places
  -Tap and pay
  -Integration with smart home products to control environment
  -Fitness monitoring/goal setting

- Please please tell them Sam 🙏 .
  Before disability, I had a simple (not smart) watch that lasted decades. I only needed to know the time. Since becoming severely disabled, a Fitbit has become the most essential piece of AT that I have. It's literally life-sustaining and helps to maximise my functioning:
  A memory aid: I take life-sustaining medications 3x a day. I must take my meds strictly on time or I risk hospitalisation. Due to my disabilities - Energy Impairment (brain fog) and Autism (hyperfocus) - I can easily forget. The snooze function is especially helpful to keep reminding me if I put it off while transitioning tasks (slow to switch tasks due to Autism).
  As data for exercise physiology: I have ME/CFS with exertion intolerance. If I do too much activity, I risk significant functional set-backs. When I start a new exercise program, I feedback heart rate data from my smart watch to my exercise physiologist. She uses this to

ensure that I'm not over-exerting myself and adjusts my exercise program accordingly.

Self pacing: I run an app on my smart watch that alerts me whenever my HR goes above my anaerobic threshold. This is gold standard management for ME/CFS, again ensuring that I don't overdo it and reducing the risk of becoming further disabled.

Emotional regulation: My Fitbit also alerts me when my HR goes up due to psychological stress. Due to my Autism, I'm not always aware this is happening. I have a medical condition that makes getting stressed potentially deadly for me.

I can't replace it with any other supports. It monitors my HR constantly, and reminds me to take meds at 7am, 1pm and 9:30pm (my SWs aren't around for those times).

- My 6yr old AuDHD granddaughter with complex trauma has a smart watch. She is an absconder and I am easily able to check her location with GPS, I've also set up a safety fence and am notified if she moves outside this area. Also due to her past trauma shes able to call me and i her if she becomes distressed. Without the smart watch we would need SAPOL to search for her when she takes off, she would be alone and lost and wouldn't be able to make contact with me and would spiral without that needed contact. What a dumb decision 🙄 which will create more trauma to already vulnerable people.

- My SC, who didn’t understand my disability, told me I should get a pendant not a smart watch because it was cheaper. So silly me listened and got that. It needs a SIM card & phone plan to work. So I can’t see how a ban on ndis funding cellular is going to work as many things these days rely on technology. The problem was it hurt my neck to wear due to an injury. Then I kept dropping it from my pocket or off the belt clip. I’d then forget to put it on or didn’t have pockets in those clothes so it wasn’t much use if I’m not wearing it. One day when I was on the toilet someone rang me, a wrong number, and I had no choice over answering or not. They just started talking at me. Scared the 💩 out of me. Luckily I was in the right location for that! Finally it broke after another drop which was a relief.

I replaced it with a smart watch. Would have been cheaper to just get the right solution in the first place. The watch detects falls and will call an ambulance and text friends & my family the location. I got a cellular model so it will always connect to 112/000 but I don't pay the connection fee because most of the time I'm home with wifi or Bluetooth to fall back. The extra cost to have the Watch connected was $5 but I'd have to pay for a much more expensive phone plan for it to work. Having that cellular backup for 000 gives me the reassurance that if I forget my phone (often) when I go out or if I wander out the backyard out of range or am at my parents when they aren't home that I have some security. My watch also allows me to phone for help if I'm too ill to move or have fallen and can choose who I think will be available at that time to help me. The pendant doesn't give that flexibility.

It also does a lot more other things that I need due to my disability.

It helps me pace my activity using heart rate monitoring and timers as is recommended by experts. So I need a sensor on me to do the HR monitoring. This is minutes and seconds for activity so needs to be with me always. When I track and pace carefully I feel better and can do more. Pacing helps prevent my disability from getting worse which costs ndis more.

I can set timers and reminders immediately on my watch. By the time I go and get my phone and unlock it to set one I've forgotten what I was setting it for!

I can quickly & with minimal movement control my heater and aircon from bed or the couch using an IR smart remote. I need to get more remote controlled things in my house so having those all workable from my watch will also make it easy for me. Otherwise I'll have to cart a box of remote controls from bed to couch multiple times a day.

I can acknowledge a text message without moving too and can see who is calling so I don't waste energy reaching for my phone if it's a scammer.

I knew I'd use the watch for a fall alert when I got it and pacing but had no idea just how helpful it'd be for someone with severe fatigue and memory issues.
There's so many things on the everyday living cost list that are brilliant for supporting my disability. The authors are so privileged to think all that's on that list are everyday living costs. They also don't understand that we need the best solutions which often are not the clunky disability shop ones.

- These are not every day items for a person with a disability on a pension without income.
  I see how it can be an everyday item for someone with with a good income, not a pensioner. So many "every day items" are inaccessible due to lack of funds. I feel discriminated against when they think all these wonderful items every day items. I certainly can't afford them, with them my life is safer and more manageable. This needs to be made clear to the people at the helm of NDIS.
  Most participants are on a pension, they don't have the funds to purchase what they see as every day, off the shelf items.
  NDIS looks to be created to support middle to high income earners…

- My main reason for wearable smart watch is as a heart rate monitor (hrm) to pace as per best practise for my neurological condition.
  The smart watch offers both hrm and falls option as very impotent functions to me.
  First part-
  HRM is researched and evidenced as both beneficial and effective in managing energy limiting impairments.
  It is value for money as it prevents me being fully bed bound needing nursing level care, SDA 24/7.
  Even more so - it keeps me alive as if I use up too much energy reserves (I'm talking basis metabolic rate ie energy for the autonomic nervous system to function), I did a slow and painful death (think mobile phone battery that fails to recharge).

2nd part -

For some, ME comes with orthstatic intolerance where oxygen to the brain is reduced and even shut off for short periods.

When there is insufficient blood oxygen to the brain the person passes out, ie they feint and fall (unconscious).

I currently have stand by assistance to toilet as sitting upright in such a fashion is high risk. And I toilet several times a day as normal.

The falls alerts means my dignity is maintained as the support/care don't need to "hover" outside the door. They can do tasks but be available to respond straight away if notified by the folks alert on my smart watch.

So, even within the home the smart watch falls alert has great value to me. It's beneficial and effective in my "in home" support care. Its value for money cannot is much more than the actual cost.

Dignity.

Safety.

Remaining in my own home.

No value - it's too great to have a price tag placed in that!

It's Priceless. 🫶

The condition i have is Myalgic Encephalomyelitis- cellular metabolic energy dysfunction so severe it kills peoples unless they take their own life first.

If a smart watch/heart rate monitoring device is not available ie I cannot afford one as on a pension, my life expectancy drops significantly, but first I'll be invisible to doctors, AHP, providers and ndis in general.

The Ann Marie Smith neglect case won't be down to the sw or providers neglect but to ndis failure to fund essential disabillty needs.

Forget reasonable and necessary! Or "Needs Assessment". I'm taking "essential to life" needs, like a respirator or nutritional feeding.

The ndis needs list should not come down to a means tests, either.

Just because one person can fund a smart watch themselves doesn't mean the ndis is not responsible to fund it.

Let's not open that can of worms of "entitlement" and "shaming".

- My ‘smart watch’ is the primary means by which I independently operate the automation within and without my home.
  It is critical for my access but also my friends, family and support workers.
  It keeps me from being at risk and somewhat ‘captive’. Something for me that is a significant risk factor for poorer mental health and emergency needs.

- I'm with TGS, a few things on the out list that there is a strong case to keep in. Definately smart watches is one of those items. I have a husband who is at risk of falls due to his Disabilities and I can't always be there for him so that's concerning for us. Hairdressers and nails is another that should remain I think. Have already put my 2 cents worth in to the government. As always, thanks for the heads-up TGS.

- Not funded, however, my son CP & ID uses his smart watch for independence in many area's. As a buzzing alarm, to wake, for medication reminders, appointments etc and is even easier for him to answer a phonecall with control & one hand. Tracks his steps and exercise, which is great motivation for his required movement/exercise. Must be kept as a funded item going forward!!!!!!

- Quite a few times I’ve fallen because of my physical disability and was unable to get to my phone to call for help. My client with MS does it even more often- in her backyard, in her toilet.. she lives on her own and need to call ambulance when she falls 😞

- Smart watch is one of our very best tools for my teen with complex health and Autism - it builds so much independence for him - medications, falls, reminders, alarms, helps find missing phone, tracks exercise, monitors heart rate (heart condition). Amazing!

- We have been using a smart watch for close to 4 years now with heart rate monitoring. By building independence skills for teen to learn bodily signs of strenuous exercise and the effect on her body so she can rest, use the mindful gesture for breathing to ensure that is regulated and as an indicator heart rate back within a limit to continue activity. Initially needed significant support with this and now a number of years on can use with only minimal reminders or prompts. Still needing someone with her but as she heads towards adulthood we hope this capacity building will result in less reliance on present support workers and instead give her the independence she craves with the safety she needs for life.

- I have a watch. I use a power wheelchair. I like my independence and do not want someone with me all the time. It would cost the ndis a lot to have someone with me all the time.
  If I drop my phone, I can contact someone with my watch. If I fall out of my chair (rare) the fall detect can alert emergency services
  I have medical episodes in which my jaw locks open. I can use the AAC on my watch to tell people where to find my medication that will stop it
  I have to take medication every two hours. Without this medication I can't make my speech understood and I'm significantly more disabled, so I wouldn't be able to work. I can't have my phone on my lap in my work. The watch with its vibrating alarm allows me to work and get 2 hourly reminders to take the medication.

- They are essential who are HOH/Deaf and use Auslan to communicate. Add this to people who need other reminders, the ability to found if they don't respond to their name being called, the ability to have a video call (using Auslan - our son can't read and write well enough to communicate meaningful information with us), medication reminders all strapped onto you where you can't misplace it as well as alerts for running water that has been left on and smoke alarms when you can't hear it are all life saving technology only smart watches can provide! They will be putting people's lives at risk!

- As a person living with MS with awful balance and walking issues if I fall, I can't physically get back up due to leg weakness. And I am a high falls risk. This item is literally life saving for me.

- I need my smart watch for medication reminders, to tell me when I've over done it as I have trouble with interception, when to eat, again trouble with interception, I have days where I don't go near my phone as I need down time from media, so I need my watch

- Yes smart watches should be in if related to disability. I'm hearing impaired. My smart watch buzzes on my wrist alerting me to activity on my phone. I can't hear any of the alerts buzzes etc that the phone has. It's not practical to always hold your phone to feel the vibration. I'm a carer. My family needs to be able to contact me asap in an emergency. Without the watch I would (and used to) miss urgent and vital text messages.

- I was funded for a falls monitor as my disability is physical (I also have ASD 2 but that is not included in my ndis). My disability also makes my heart rate too high and unpredictable. This adds to the falls risk because of light headedness and fainting but also makes activity and events outside my home risky and much more complicated than it is for most people. There are not always triggers for my heart rate and sometimes my heart rate may be too high but I can still manage to do things if I'm careful and monitor it. I also have chronic fatigue related to my disability, pacing is an important strategy to manage fatigue and my conditions mean managing that heart rate and monitoring it help me to pace as best as possible. Being able to check my heart rate and reassure myself that I'm ok when I am in the community helps me to make safe decisions and not feel too anxious. It also helps me to show support workers why I may be having a hard time communicating or need extra help. My watch can alert me to when my heart rate is too high when I may not realise how bad it is and I can take action on that before it gets worse instead of having to wonder what is going on. My

adhd and asd make paying attention to these things and acting on them difficult. My specialists also find it helpful to use data to interpret what is going on with my body. I have not always been physically disabled and did not monitor my heart rate before so have not ever owned a smart watch or similar device as I didn't need one, I would love to not need one now.
I'm self managed so I did the research on the price difference between a good falls monitor and the cheapest effective tech that would monitor all these things related to my disability and found the Apple Watch to meet all the needs and only cost slightly more. It's also nice to have a "normal device" that doesn't further highlight my disabilities. I had an iPhone already so I knew the tech would match up and be as easy as possible. I asked my specialist for a small supporting letter which I retained and I purchased an Apple Watch. I did not purchase cellular as from all the information I could see from ndis that would not be accepted, it would have been better to have cellular but I live on dsp and couldn't afford the difference myself. My lac was very young and inexperienced and when I attempted to talk to her about my funding she responded "oh one of my friends has a child with that condition and he's doing pretty fine" I knew there was no point trying to get understood from there and there is not any way of getting more informed information from ndis itself. So I based my choices on legislation and ndis written information and determined that I met criteria for a smart watch. I am still constantly anxious about "getting in trouble" at review and second guess every decision I make related to ndis. I'm too scared to even try to add my asd2 to my plan as I have no confidence that they won't take things from me instead and I've fought too much and have nothing left.

- This video shows Cameron using a smart watch as a reminder and to let family know his whereabouts. Cameron is a man with limited language. The alternate scenario is Cameron always having a support worker with him.
  https://m.youtube.com/watch?v=GfvCGhSn2yM Check 2:30 to 3:00

- My friend is quadriplegic and uses a smart watch to pay for things. It allows him to navigate many more things without a support worker.

- I have an energy-limiting disability. I use a smart watch to help me stay within my energy envelope and alert to me to when I might be going into my unsafe zone. If I go into it, results can include weakness, shaking, dropping things, lots of concentration, bumping into things or presyncope. If I use the watch to help me stay in my safe zone I can move about safely and do some things for myself. If I do not, I end up bed bound and my meals need to be brought to me. This is the single thing that helps me to have quality of life. Managing my activity means that I can access the community sometimes and sometimes I can go outside and enjoy the fresh air.
  Not having one means that my world gets smaller as I can do less and less.

- I have a smart watch and I would be lost without it literally. I don't always have my phone due to forgetting it, forgetting to charge it or it being too overwhelming and anxiety provoking to look at it. I have poor executive function skills and I have trouble remembering things. I use my smart watch to remind me to take my meds, appointments, tell me how to get places etc. it has my anxiety reminders, my meditation tools and the list goes on. On a dsp it is definately not an everyday expense but without it I would have to relearn all my acquired skills and tools all over again.

- I have multiple sclerosis, from this I have foot drop and unsteady walking, memory issues, fatigue, falls issues and more.
  My Apple Watch provide me not only confidence but security. Being able to have it auto call my emergency contact or an ambulance.
  It also provides recording of my walking steadiness, stride and records my energy spent which I can then provide my Neuro to better

understand how I have been only 6 months. I could keep going on and on but I won't lol
A smart watch to NDIA might seem like a everyday item but for someone with a disability it can be a life changer

- My eldest has a smart watch which allows him more independence. I can see where he is but I don't have to go with him. He sets alarms instead of having me or a support worker remind him. He uses a breathing app when he gets overwhelmed. He doesn't have to pull his phone out of his bag to pay for things/make calls etc - which often results in his phone being lost. If he loses/forgets his phone he has the back up - avoiding meltdown.
  My youngest would have one if I can keep it on his wrist for all these reasons and more.

- When I first started with NDIS 8+yrs ago I was funded a pendant for falls detection which needed a monthly sim plan. Pendant died so then I was then funded a smart watch no cellular function. About a month later I had a fall outside late one night when taking my dog outside, unfortunately it didn't connect with my mobile & I had to yell out to a neighbour to help me, I layed (sic) outside in the cold for over 2hrs. After that fall I got a new Cellular smart watch funded I was told yes they might fund the $5 a month for connection if I could show I'd only use that feature in an emergency & not for everyday calls. I also argued what's the difference between a smart watch & a pendant, my OT supported this & so did my GP. I also use my watch for O2 monitoring, pacing, alarms, reminders to get up & move etc. There are many features on a smart watch that aid our disability.

- Our non verbal adult son uses his smart watch as a back up for if stopped by authorities. It's dangerous to put your hand in your pocket and reach for a phone when the police are asking your name. Being able to point to your watch and quickly activate a message explaining you are non verbal and need your phone to communicate could be a life saver

- I have a dissociative experience of life. I don't know when I'm overdoing things but the smartwatch is monitoring everything and will alert me. This works for my neuro disability too as I can set off an episode that will have me incapacitated for days if I overdo things.
  It tracks data so I know if I've been up overnight but don't remember.
  It helps me with on-wrist reminders and calendar events, reminds me to move, helps me track my water intake - all things I have difficulties with.
  Since I've had my watch I'm able to go walking more as the watch is catching my hr before I overdo it and I can stop for a moment - I have more capacity across the day because of this.
  Has calming/breathing stuff built in which I can use so that I can recentre myself and get help.

- Apart from all the comments, smart watches offer:
  -Tap & pay (less movement/organisation required)
  -Digital assistant as per examples above,
  -Braille smartwatches,
  -Emergency uses,
  -Emotional regulation (through Breathe app & others)
  -Fitness monitoring,
  -Health metrics (heart rate app, O2 app)
  -Calling, plus sending/receiving voicemail/messages
  -silent alerts
  -potential for future integration with health and other services.
  Moreover, complete personalisation to requirements.

  Smart watches Safety Alerts, time management alerts, time telling, emotion regulation, temp control regulation, medication prompts, breathing controls anxiety heightened state, heart rate visual to alert ‼️
  .

prof Tony Atwood valuable in Emotional Toolbox! Just
Some vaild Disability Benefits!

- I used my funding to get an Apple Watch. I had periods of paralysis and seizures that meant I needed falls alert plus a means of contacting emergency or family if I ended up collapsed somewhere unable to reach my phone. It also allows me to track my heart rate which is essential when I'm out to monitor whether my body has had enough and needs to get horizontal while maintaining my dignity by blending in as a normal watch as part of my general style. I have used it to provide essential information on my heart rate and my step count to my physio, GP and OT. It gives me subtle reminders and takes notes for me which I need for my poor cognitive ability. Plus it's waterproof so I no longer had to worry about collapsing in the shower and I can wear it in hydrotherapy too. Prior to my disability I had a normal watch but I had stopped using it in favor of my phone use. A watch is always on you and is essential for my disability.
  Prior to my watch I had times when I collapsed behind a mulch pile or in the house and could not let anyone know. I was frightened to use the shower alone and I couldn't explain to my OT how little I could actually move without causing worsening symptoms and mobility.

- Declining functional capacity means needing more assistance with personal care on a daily basis. A smart watch is therefore a smart investment.
  I am also autistic and have ADHD and a smart watch will assist me to overcome numerous impacts of my disabilities. Real time physiological data will assist me to understand whats (sic) going on in my body because poor interoception means I fail to recognise my body's internal signals. Similarly, it will assist me to recognise the impact which emotional dysregulation and anxiety are having on my body and implement management strategies in real time. Reminders and alerts (which are always with me, unlike a phone) will support me to

overcome executive functioning challenges and manage basic self care.
This is not an everyday expense. I haven't worn a watch in 20 years and never saw the need for a smart watch until it was recommended to me by my allied health professionals specifically to manage my disability and prevent worsening of my functional capacity.
Most people buy smart watches to support an active lifestyle. Exercise intolerance is a feature of ME/CFS. (It is one of very few conditions for which exercise is actually dangerous). We wish we could be active but cannot dream of using a smart watch to track our runs or optimise our training regimes.
And, given fewer than 15% of people with ME/CFS are able to work even part-time, we do not have the kind of income that puts a smart watch in the "everyday" category. It's expensive for us.
But in NDIS terms - noting the cost of a smart watch is equivalent to 2-3 sessions with an allied health professional or about 8 hours with a support worker - a smart watch (providing 24/7 assistance for years) represents incredible value for money.

- I'm a full time wheelchair user. I needed a fall protection device for many years, but hate all the things I need to my disability. Looking different from my peers affects my mental health.
  Apple are a phenomenal company who build access into their devices. I bought my original Apple Watch because I wanted a fitness tracker and they were the only watch on the market to offer specific wheelchair accessibility to these devices.
  My watch was still working perfectly when my OT recommended the latest Apple Watch as a falls protection device. Through my plan I upgraded my watch.
  Prior to purchase I did a cost benefit analysis. The Apple Watch was cheaper than other devices to buy outright. And at $5/month sim cost, was astronomically cheaper to run than commercial calls detection devices.

It had added benefits. When I fall I am able to call my support company or my partner to have someone come and hoist me back to my wheelchair.
Unlike the falls device which will also notify the ambulance. Causing undue pressure on their services.
Further. I have used to the Apple Watch to call someone for assistance when my wheelchair has rolled away from me, especially while toileting (long story involving overzealous smart drives). Without causing undue embarrassment by pressing emergency alert buttons while at work, I was able to call a trusted coworker to come and retrieve my chair for me.
My Smart Drive watch has busted. It's so old I can't buy another one. My Apple Watch is now able to control my Smart Drive. It's not quite as accurate as the watch the initially came from with the Smart Drive. But it allows it to keep working.
It also means I only need one device to cover a number of very important disability specific things.
(I don't always have my phone where I can reach it when I fall/loose my wheelchair, but I always have my watch on my wrist).
I wear my watch because it does the job I need. I wear my watch because I can feel the same as my peers with it.
It is also the most cost effective way for me to do these things. Saving the government money.
Without my smart watch, if I can't reach my phone I would be stuck where I fell. Sitting on the floor without pressure relief. I could potentially get a pressure sore. The last wound like this I had put me to bed for 2 years. Leading to increased care costs, permanent loss of function, and led to me medically retiring. Another injury like this would have catastrophic effects.

- My son has a similar watch that detects falls, it also monitors his heart & can do an ecg. It gives him peace of mind.
  I am loving your posts.

- I recognise it is not perfect. One mother became suspicious of what was being provided for her son. She started checking and discovered the provider was a religious cult and what he was being given came from members of the cult. This is why the government is vetting the providers more carefully than previously and determining what should and should not be available on the program.

- There are soooo many benefits a smart watch offers that can help provide a level of support and independence! It’s a no brainer for the tiny cost involved! For a couple of years of support it costs the same as ONLY TWO therapy hours!

“NDIS In and Out Lists”:

HAIR THERAPY, HAIR AND BEAUTY SERVICES, INCLUDING NAIL SALONS

🌟 NDIS In and Out Lists - "Hair therapy, hair and beauty services including nail salons"
🗒️ The government has made new draft lists and they want your feedback.
[snip as repeated from first post]
⌚ Here's a story about why Hairdressers should Be "IN"
✍️ Share Your Story - Please tell your hair or beauty salon or barber story in the comments, because we don't think it should be on that "OUT" list for everybody!

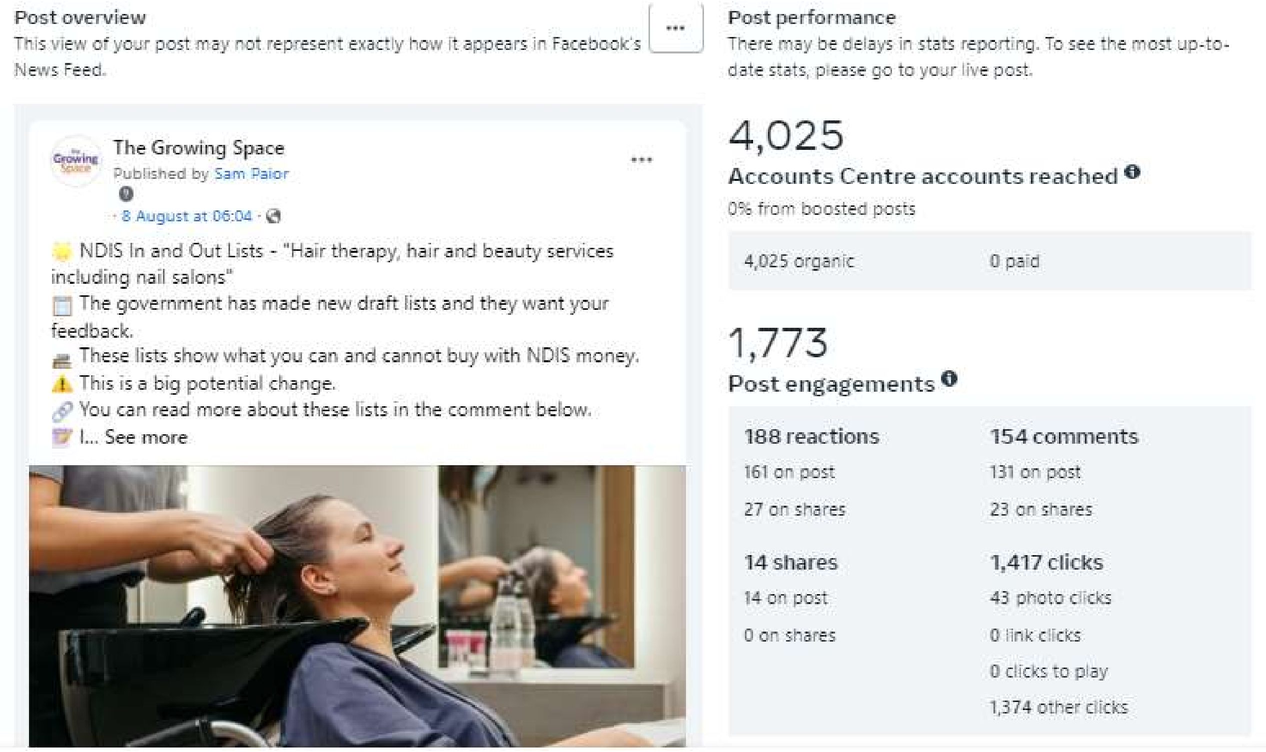
👩🏾 Imagine Aisha, a married woman in her 30's who has a physical disability and cannot raise her hands above her shoulders.
👩‍🦼 Aisha goes in her electric wheelchair to her local hairdressing salon every Tuesday and Friday. In her tilt recline wheelchair she is able to tilt back to the special hair washing basin at the hairdresser, where the apprentice, washes and blow-dries her hair. This costs $20, twice a week (a total of $2,100/year).
Aisha is well known at the hairdresser’s as she such a regular, and after going there for some time, she ends up out for a coffee with the salon staff at the end of their workday. As the staff talk about their poor bookkeeping skills, Aisha, who was working as an office manager before her accident, offers to help out. Aisha ends up working half a day a week, straight after her morning hair appointment on Tuesdays, earning a small income, but also making deep friendships in her local community, keeping busy and rebuilding her career, something she sorely missed when she stopped working in an office.

🚫 And here is Aisha's story without being allowed to use her funds at the local hairdresser.
Aisha does not want her husband to wash her hair in the shower. He’s no good at it, and when she’s menstruating, it’s culturally unacceptable for her to have him in the bathroom, helping. He’s also a shift worker, so the timing hardly ever works.
She hires a support worker to come in twice a week, with a minimum 2 hour shift, which costs $268/week, a total of around $14,000/year. Aisha does not want other support work done at home as her husband is happy to do

the housework and she looks after the cooking. She doesn't need help with shopping, but she likes to use the online shopping delivery service, rather than go with a worker. She rarely uses a support worker in her home.
She is deeply uncomfortable with having a worker see her naked in the shower (she was once assaulted as a teen by a worker), but there is no way around this, so she often cancels the shift (which she still has to pay for) and she also cancels her visit to her study group (and coffee chat afterwards) at her place of worship, as she doesn't feel presentable or clean enough to meet her cultural and religious needs.
The worker is also often sick or unreliable, and sometimes the company sends a male worker, so she culturally can't use him for any personal care, and so he does a bit of other work in their home, and she sends him home early.

pic desc:: a woman in a wheelchair leaning back in her wheelchair to a sink in a salon while someone washes her hair. ai generated and while not perfect is a million times better than the first shot, which I will put in the comments for your amusement...

Post reach and engagement statistics



Post overview
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The Growing Space
Published by Sam Paior
· 8 August at 06:04 ·

☀️ NDIS In and Out Lists - "Hair therapy, hair and beauty services including nail salons"
📅 The government has made new draft lists and they want your feedback.
🛒 These lists show what you can and cannot buy with NDIS money.
⚠️ This is a big potential change.
🔗 You can read more about these lists in the comment below.
📝 I... See more

Post performance
There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

4,025
Accounts Centre accounts reached
0% from boosted posts

4,025 organic
0 paid

1,773
Post engagements

188 reactions
161 on post
27 on shares

154 comments
131 on post
23 on shares

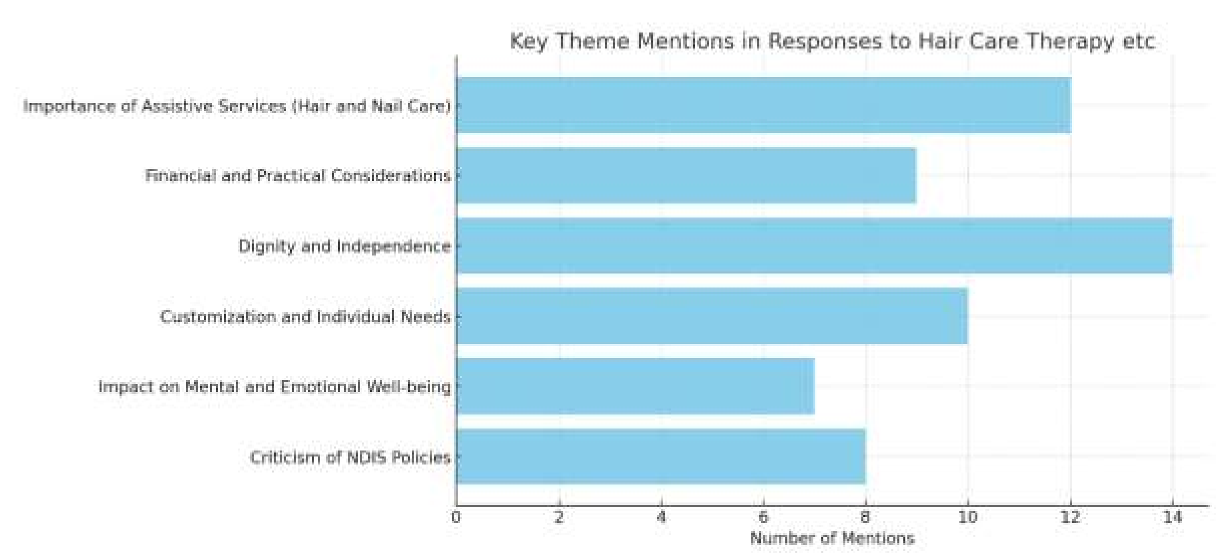
14 shares
14 on post
0 on shares

1,417 clicks
43 photo clicks
0 link clicks
0 clicks to play
1,374 other clicks

1. Key Themes

1. *Importance of Assistive Services (Hair and Nail Care)*: Many respondents emphasize the critical need for assistive services such as hair washing and nail care. These services are seen as essential for maintaining personal hygiene, dignity, and independence, particularly for individuals who cannot perform these tasks themselves due to physical or neurological disabilities.
2. *Financial and Practical Considerations:* There is significant concern over the financial implications of cutting these services from NDIS funding. Respondents argue that using specialized services like hairdressers or nail salons is often more cost-effective and practical than employing support workers or medical professionals for the same tasks.
3. *Dignity and Independence:* A recurring theme is the importance of maintaining dignity and independence for individuals with disabilities. Respondents highlight how these services allow them or their loved ones to engage in the community, manage their own care, and avoid the embarrassment or discomfort associated with more invasive alternatives.
4. *Customization and Individual Needs*: Respondents express frustration with the "one size fits all" approach, advocating for individualized assessments and solutions. They argue that each person's needs are unique, and funding decisions should reflect the specific circumstances of each participant rather than applying blanket rules.
5. *Impact on Mental and Emotional Well-being:* Several responses point out the psychological and emotional benefits of these services, such as boosting self-confidence, reducing anxiety, and preserving personal relationships. The removal of funding for these services is seen as a threat to the overall well-being of individuals with disabilities.
6. *Criticism of NDIS Policies:* There is a strong undercurrent of criticism towards the NDIS and its decision-making processes. Respondents express disappointment and frustration with policies that they

perceive as being disconnected from the real needs of participants, and they call for more inclusive and well-thought-out consultations.



2. Community Responses (verbatim, de-identified)

- I am copy-pasting my response from a similar thread elsewhere, because I don't want to aggravate my fingers on my phone screen again. I cannot type on my fingertips because it triggers severe neuropathic pain. I use artificial nails as orthosis to type.
  Without them, I cannot use a computer for more than about 5 hours per week, and that only with extreme, disabling pain.
  With them, I can type 100 hours per week with mild to moderate pain. This means that I can continue to work, supporting both myself and my husband rather than us both being on welfare, and pay a significant amount of tax. The combined benefit to the federal budget from me keeping the ability to work gives a budget improvement of around $100 for each dollar spent on artificial nails.
  There is no alternative support that I can use that will enable me to work, or to do many of the things I do on my computer on a daily basis. Speech to text does not work well enough, isn't available for Linux, does not work in most of the software I use, and due to my autoimmune condition I can't speak continuously for long because my throat dries out too much and then tears.

There are no medical orthotics that can do the same job. Medical orthotics are usually designed for supporting joints, holding tendons or bones in fixed/neutral positions to allow them to heal, etc. They wrap around the fingers/hands putting pressure on the skin which is exactly what triggers the neuropathic pain to increase. They often also add bulk between the fingers, which for me causes tendinitis in my fingers/hands. They don't protect the tip of the finger from pressure contact, which is what I need them to do. Overall, they are designed to solve a different set of problems and are unusable for my issues.
Artificial nails do not apply pressure to the skin or add bulk between the fingers, and give me a reliable typing surface. They take the impact from the keyboard keys and disperse the forces so that they don't trigger neuropathic pain. They are an ideal solution to a tricky problem that the medical/disability markets have not got any products that can help.
My natural nails are too weak/brittle to use for typing. This is a very common consequence from autoimmune disease. Having to say to your boss "I am sorry, but I can't work for the rest of the week because I broke some nails" is a horrible feeling even if they know and understand why that is such a problem.
Capacitive touch screens do not work either - simply typing this response on my phone has caused my finger to feel crushed/bruised as if I had jammed it in a door a few minutes ago.

- My adult daughter doesn't want me (or anyone else) to be in the shower with her, or see her naked just so her hair can be washed properly!! She is unable to do this in such a way that she is hygienically clean, and not ending up with scalp issues! Totally unable to wash and rinse correctly. Once a week at the hairdressers just for a wash and dry keeps her feeling clean and ready once again to face the world! As for nail salons, this is a better use of funds for her nails to be cut correctly and safely than paying a podiatrist to do this. There's the added benefit of feeling pampered whilst having something done that she is totally unable to do herself. These services are utilised by her totally due to her disability, so funding used correctly as far as we are concerned! Stripping away the ability to utilise these supports totally takes away her feelings of independence and being treated just like everyone else! She can get herself to these appointments, be out and about in the community and socialising at the same time!

- Yes or even for many with ME/CFS - Long Covid being upright is near impossible so having a mobile hairdresser is the only option for a proper wash and cut while reclined at home. Heartbreaking to see this.

- My teenage daughter cannot physically wash her hair and keep it clean. She has had 5 years with an OT to help her learn the skill but it has not stuck due to the physical nature of the task. She refuses assistance in the shower - as any 15 year old would and hates to be different from her peers. She attends a hair dresser once a week for a proper hair wash by a young female who talks to her about boys and makes her feel like the hair washing is more a beauty routine rather then a task she has to do because she is disabled. The once a week task allows her to have clean hair, avoid scalp issues, have her hair properly brushed and knots removed, she attends on her own and pays for it with her card. She has to keep track of appointments and plan. All of this helps her with her disability and something I cannot bear the thought of her losing...... now let's hear from me, her mother. I have CIDP with limited use of my hands and mobility issues. I also cannot wash my own hair or brush it. I do not want my husband to do the task for me, I do not want a support worker coming into the shower with me. The one difference is, I don't like having to take the time to go and get my hair washed.... It is just another appointment I have to endure due to my disability.... But it does get me out, it keeps my hair clean and tidy which means I am not embarrassed to go out in public and the girls are always lovely to me. Again - $25 a week vs a support worker who charges $60 an hour with a two-hour minimum.
  Where is the dignity in all of this for us participants and why do they assume we are unable to make good financial decisions???
  I am lost for words for some of the things on the out list......

- Excellent example of how poorly thought through some of the list is. The list driven by reducing costs now looks to make some inexpensive choices way more expensive to the scheme both financially and in terms of human dignity and social connections in our community.

- It's moving away from individualism & catering for personal needs.
  My daughter doesn't need to use a hairdresser for washing her hair but I'd never deny that to someone who does.
  Goes back to putting disabilities into 'a one size fits all' scenario.

- I had a very similar situation a few years ago. I usually assist our daughter who has an NDIS plan washing her hair in the shower. I went on holidays for two weeks and my daughter and husband stayed at home. Quite typically our teenage daughter did not want her father seeing her in the shower and helping her wash her hair. She went for the time I was away to our local salon where she was already known to get her hair washed for around $15 a visit. Alternative would have been to recruit a support worker for a minimum of 2-3 hours each week which she would have been extremely uncomfortable with and would have cost the NDIS almost 10 times more.

- Another example is people who are housebound or avoiding COVID due to their disabilities, and they cannot attend a hair salon for a haircut. They should be able to use their NDIS funds for any extra cost associated with getting a home visit.

- I genuinely do not know how a PWD gets their fingernails cut if you can't use a nail salon.
  Like there is no alternative.
  My understanding is SW can't do it and most are terrified and terrible.
  Way more dangerous as they have no training. They cost more.
  Podiatrist do feet. Even there unless someone finds another 1000

podiatrists just to get a degree to cut healthy PWD toenails I don't know how they will get done.

- I am unable to wash my hair as I cannot lift my arms but also due to an energy limiting disability where washing my hair would become my only activity for the week as I would take a week of being bedbound to recover.
  The solution of a support worker washing my hair takes so much longer than at a salon which burns through my available energy which can be lost from even sitting up. This is exacerbated by awkward positions to try to be supported while my hair is being washed. Having my hair washed in the shower adds time and energy I don't have. I already can only shower once a week if lucky. I also don't wish to be naked with a support worker or as some have been suggested by NDIS to wear a swimsuit which would prevent normal showering and getting it off would take even more energy.
  I do not wish for my husband to do this kind of personal care. He is not only not good at it but our relationship is strained from him being my carer and we deserve to have the right to have some form of a husband-wife relationship.
  Going to the hairdressers I would be able to get it done more often (so I am no longer embarrassed by my hair) while still costing dramatically less than my support worker doing it would cost. It would also be able to be done in ways that don't waste my precious energy which is so limited because they would have the right equipment.
  A large amount of time I am unable to even leave the house and so I should have the choice to have a hairdresser attend the home for a cut (of course I would pay for the cut) but the travel which is an extra cost should be claimable. I should not be forced to have poor condition long hair where its maintenance as well as how I can sleep with it just because hair is now not covered. Correctly used hair salons are a huge need of many disabled Australians.
  In regards to nail salons I can see where this makes the public go oh no they are using it for styled coloured nails this shouldn't be allowed. But

this isn’t what we need it for. Support workers aren’t allowed to cut nails so we should be able to go and get our feet and hands maintained if we can’t physically do it ourselves and just need a simple nail cut. Instead, the NDIS wants us to go to podiatrists for exfoliation of dead skin and a nail cut, and this costs astronomically more.
I also believe that those of us who physically cannot do maintenance of body hair should be able to use hair removal services at a salon. I have previously always maintained all areas myself. I no longer can, and so my only option is supposed to be getting shaved by a support worker. This is not always safe (blades and cutting) and honestly, for me, it is humiliating. Again, I don’t want a support worker in the shower with me as well. I also do not want a support worker grooming my private parts. This is now affecting my relationship with my husband.
I also suffer from POTS and in my case, I need to wear compression stockings 24/7. These cause ingrown hairs which are then an issue to deal with. Shaving and waxing do not help with this. Permanently removing hair is the only solution. These issues are only happening due to management of my disability and impairments. Laser hair removal should be able to be considered as I could get my hair permanently removed for considerably less than a support worker shaving it for less than 6 months. Yet NDIS’s answer would be support worker shaving for the rest of my life. This is both reasonable and necessary and would save a lot of money.
NDIS does not realize that so many of these changes taking away choice and control will cost more within a disability economy. Participants using choice and control to use cheaper options save the scheme money. It maintains our dignity (it’s about the participants, yes). And it helps our budgets stretch longer. These are things they should want!!!

- We’ve never used funds for a hairdresser as I always thought it was a bit of a grey area. But I wish I had. If my daughter had gone regularly ie weekly to a hairdresser who could have reiterated how often to wash and how much product to use, the entire planet would have benefited!

Seriously, she became obsessed with washing once she took over the task at 17 - up to 5 times a day at one stage - and used excessive shampoo & conditioner because she wasn't capable of judging the right amount. The water bills were horrendous, probably shedding mass microplastics into the water, the shower full of hoarded 7/8ths used bottles, no-one could get in to clean it, there were piles of damp towels - a total health hazard. And yet not one OT or LAC ever suggested solutions like taking her for hair washes. It's taken 6 years to get it down to twice daily. And in terms of disability it came down to a lack of conceptual ability and dexterity skills squeezing bottles. So, perhaps this is more an example of how accessing professionals might have developed better outcomes.

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- I run a small mobile hair care business. I cater to every disability and every age, however, I would say 65% of my clientele are children.
  The majority of my clients all experience severe sensory deficits and need support through every aspect of anything to do with their hair.

Cutting, combing, brushing, washing, and blow-drying.

The anxiety that creates the barriers in achieving any of these tasks alone needs great deals of support and understanding, and most of all my TIME, so that my clients can process and hopefully have a trauma-free experience.

My role as a support worker first and foremost, followed by being a qualified hairdresser, is to support emotional dysregulation when experiencing hair care activities - which can look like clients experiencing high behaviours of concern whilst trying to support them to break these sensory barriers preventing them from having any form of hair care attended to.

It takes time and patience. We may start on just brushing as an example and learning how to do that, and sit with the discomfort for short periods of time, and build on that until it feels comfortable and safe for the client. This isn't achieved in just one session. I build trust and relationships with my clients over time, and their goal becomes our goal and together we break barriers.

Many of my clients also cannot wash their own hair due to many reasons, like sensory overload, or lacking in fine motor skills needed to scrub their scalp. I support clients where possible when my portable basin is compatible with their wet area.

I also work with clients in wheelchairs who cannot wash their own hair, and I use a portable basin in the comfort of their own home which decreases the anxiety about accessing a salon when sensory input is too overwhelming. I work with clients in cloud chairs who cannot move their own heads, and it takes 2 support workers to hold the client's head upright so that I can maintain their hair hygiene.

There is a much bigger picture to this than just "a parental responsibility or personal responsibility " to have your hair cut, washed, or blow-dried.

I don't do chemical work as I'm not working as a hairdresser. I'm working as a support worker who mentors clients in maintaining healthy hair hygiene. It's an absolute MUST to have this kind of service available to clients like mine.

- The LAC told my girlfriend to cut off her teenage daughter's hair. It's a disgusting attitude by the LAC. They also refused to reimburse them for a basin at home (a few hundred dollars). I was shocked they would even suggest this.

- So who helps her have showers or baths if she doesn't want the husband to help and he isn't allowed to when she's menstruating?

- Nail Salons on the out list is a huge bugbear of mine. People who have neurological disorders such as Parkinson's Disease find it near to impossible to be able to take care of their nails due to uncontrolled tremors. Additionally, while Podiatry still remains on the in list, people who have diabetes need to pay particular attention to both feet and hands. Someone who has Parkinson's Disease and Diabetes needs support for both areas.

- I too was advised by LAC that hair washing would not be allowed to be claimed for my daughter (21 - disability related) which I take her to, wash, and dry off once a week, charged at $25. Was suggested to get a standalone hair washing basin and a support worker to come and do it at home.
  How is this value for money and sustainable for the scheme?

- This is absolutely awful, I know many people with psychosocial disabilities who struggle with their self-care, not being able to get their hair washed and dried will impact them in so many ways. It is so much cheaper for them to get their hair done at a hairdresser rather than paying a SW to do it. It's a cost-effective measure and a vital service for some people. To deny them that is appalling! I also know people who do get their nails done because a) they can't do them themselves and b) they have a skin-picking disorder that means they will literally dig holes in themselves without their thick nails stopping them from doing it! How can the NDIS blanket ban these things? Absolutely short-sighted and appalling!

- My hair washing is also a necessary service, I only use it every 7-10 days.
  Completely unable to wash independently.
  I thought my stress levels couldn’t get any higher with NDIS ... but this proves me wrong.
  When my hair is ‘done’ - as in color, cut, etc., I pay for that from personal funds.
  But being unable to wash my hair is directly related to my disability. I have had shocking inconsistency with support workers and there is zero room in my shower and/or bathroom for two people. Mobile hairdresser was trialed (sic) but also wasn’t consistently turning up on time or at all, and I had increased neck/back pain from equipment used to try and fit over my sinks.
  Such a service being ripped away is a tipping point.

- Having nails cut at a Salon is so much cheaper than the other alternative of using a podiatrist.

- I have written an entire essay on this that is much too long to share in the comments—I absolutely plan to submit it as feedback on the proposal once I have had a chance to write more on some of the other things that they want to ban, but I will share the basics of it.
  My hair is naturally super curly, and I really like to keep it long. Unfortunately, looking after curly hair properly is an extremely involved and time-consuming process that I am simply unable to manage myself due to the impacts of my disabilities. I spent over a year trying to manage it myself before I had to accept that it wasn't possible and would either need to have a support worker help out, or cut my hair short/shave my head. Or I could do what I ended up doing, which was going to the hairdressing school at my local TAFE and getting my hair chemically straightened.
  I was able to keep my hair long, and I can now look after my hair completely independently, except for the rare occasions when I am

struggling and need a support worker to help me braid it at the start of a normal shift so I don't have to worry about brushing it for a few days.
The visit to the hairdresser only cost about $100, and I only need to go once every 8-12 months, depending on how fast my hair grows.
Here is the cost of getting a support worker to help out instead: $66.46/hour, with a minimum shift length of 2 hours, so $132.92/week just on getting my hair washed. A total of $6,911.84/year at a minimum. Not to mention the loss of dignity and independence.

- My 19yo doesn't want any random support or care worker in the bathroom or toilet with them.
  We don't have an easy access shower (functional wheelchair) or disability-type or accessible bathroom.
  I don't know if this is why, but hair and beauty are not in the personal care worker industry and if an actual paid carer isn't providing the service, then they are doing someone out of a job. Same reason why the parent can't be a paid carer only an unpaid carer for their own child? Who knows!?
  I assume the most affordable option would be at a home salon—but not always available when you need to book in. May have to book in advance. Worrying sign of ableism. All due to the absurd cost of AUKUS submarines and protecting trade routes. Looking into getting our own hair wash unit fitted in our home somehow like a home hair salon. But do not want it in the garage, prefer in laundry or outside. Therapy or OT does not solve everything.

- I have a family member in her 30s who cannot wash her hair. She was born very premature with a genetic condition which affects the bones in her hands, wrists, and forearms. She is unable to move her wrists into a position to touch her scalp and holding a brush or other device is ineffective and she lacks the strength needed.
  Her bathroom is dangerous for her and is pending NDIS modifying the bathroom to make it accessible. She was also born with hip dysplasia, which has required surgery, and the next one coming up is hip

replacement. So the already risky shower becomes more risky.
She is a young woman and self-conscious about her physical condition related to her genetic condition. She would not be comfortable having a support worker helping her shower and maintains as much independence in her life as possible.
I haven't been able to convince her that having a hairdresser wash her hair once a week is OK by NDIS, she doesn't like to cause trouble. She does her best with the backs of her hands but has to do it more often because it's not being done properly. This greatly impacts her fatigue and she doesn't have energy for other things.

- I work, I need to look presentable. I can't wash my own hair due to not being able to hold my hands above my head and if I close my eyes I will fall over. Heat sensitivity means I need to be in and out of a shower quickly, so even if my husband can wash it, I then spend the day in bed (and not at work) from the heat. He also works different hours to me and we wouldn't line up suitable times very often. I can't see my teenage son being willing to wash his mum's hair even if he was home too.
  What I can do is go to my hairdresser and for $30 a week I can get my hair washed and dried in physical comfort in a way that doesn't cause more harm.
  Buying an NDIS-funded hair wash basin and a chair comfortable enough to sit in and then a support worker for 2 hours would not be cost-effective.

- My son is not confident shaving, it is sensory overload for him, so he goes to a barber every 1.5 weeks to be shaved.

- We can't even get into our bathroom to use the tilt to the basin as the bathroom is too small.
  Currently manually lifting an adult into a bath chair and using a hand-held shower to wash hair, can only wash twice a week due to manually lifting, and resort to bed baths and shampoo shower caps on alternate

days.
Attending a hairdresser would be amazing for our family member, have not bothered to try go or claim due to so many inconsistent advice given by NDIS planners.

- My adult daughter tries to wash her hair but it’s never fully washed or rinsed off, she wastes the shampoo, etc. After a couple of days, she starts to itch, scratch, and then if stressed it becomes a tic and then her scalp has scabs. So I wash it in the shower, everyone says it’s not really appropriate, so occasionally I take her to the hairdresser to have it washed. My daughter can’t dry her hair, I do this most days too. My daughter wouldn’t let anyone in the bathroom with her and struggles with time, so a support person would be near impossible to utilize and the cost would be 100x the cost of a weekly wash at the hairdresser. One therapist/one LAC mentioned it would be easier if my daughter CUT her hair short!

- Having hair washed should be a human right! I never claim, but I should when I can’t due to having stents or catheters. It’s so hard to manage, and I don’t want to be in a shower with a SW.
  Let us have some DIGNITY! please!

- This is going to have a very negative impact.
  Participant with Moebius syndrome, hair wash $20 p/w at the salon, maintains her dignity vs support worker 2 x hours p/w $135.12. Meets R&N and value for money.
  Participant legally blind and MS, $30 every few weeks at nail salon to have fingernails cut, meets R&N and value for money. Only alternative is podiatrist at $98 for 30 mins.
  Where’s the common sense in this? Every person is an individual with individual disability-related needs.
  Shorten and the media love to condemn PWD using these services, making out PWD is getting a cut, colour, and style or fake, painted nails.

- You will also need to find a SW that is happy to take on just a 2-hour shift, which can be hard at times.

- My 15-year-old long-haired lad goes to the local hairdressers once per week to get his hair washed. It's been such a game changer and done so much for his self-confidence, both in feeling better about himself, and having the independence to get it sorted without us.

- Cutting nails and hair removal are my usual unconventional support I pay for from my NDIS plan. I don’t have enough dexterity to do it myself. Am I supposed to ask my husband to do that? Who would want that? I don’t think DSWs would be cheaper or do a good job.

- My son, ASD, 30, refused anyone but me, and I am NO hairdresser. Going bald so it looks horrible. Finally found a hairdresser he knew from school, and now, ONLY she can do his hair.
  Can’t bite the bullet and go totally bald, too different.
  I think hairdressers should be IN.
  If even a co-payment.

“NDIS In and Out Lists”:

SCHOOL UNIFORMS

🌟 **NDIS In and Out Lists - "School uniforms"** 👕
📋 The government has made new draft lists and they want your feedback. [snip]
⌚ Here's a story about why School Uniforms should be "IN" (but as with all NDIS spending, only in certain circumstances and situations)
✍️ Share Your Story - Please tell your School Uniform in the comments, because we don't think it should be on that "OUT" list for everybody – there will and should always be exceptions!

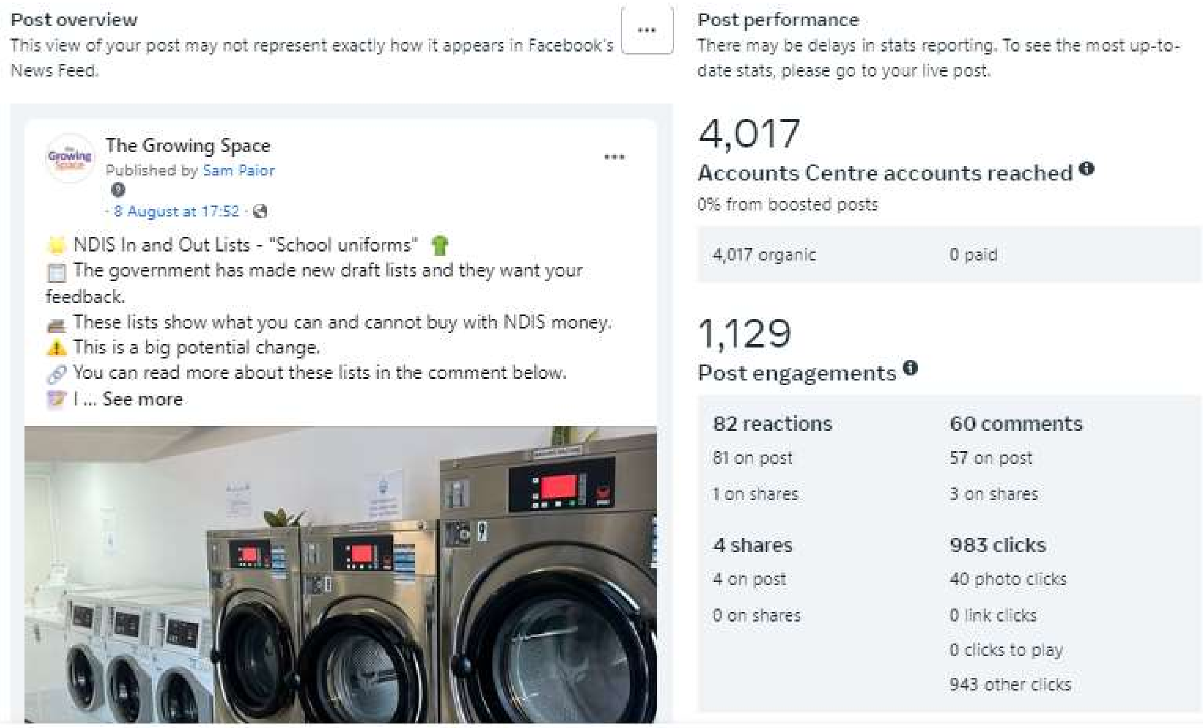
🩳 Imagine Coen. Coen is 14 years old and doubly incontinent due to his disability. Part of his genetic disability means he doesn’t process food the same way and his bowel movements are always, shall we say, “loose”.
He is one of four kids to a single parent and his Mum is on a carer payment. They’re currently living regionally in a caravan park due to the housing crisis while they sit on a very long public housing waiting list.
Coen “gets through” 💩 2-3 sets of school uniform everyday, and his Mum has to provide 3 spare sets of uniform to be at the school each day, several of which are sent home most days for washing. She has to soak some of these clothes overnight first, especially as it’s not acceptable to put soiled clothes in the shared washing machines at the caravan park, and this way she can put a bunch of them through in one load, saving on the park’s expensive washing machine costs. Coen needs around 9 sets of school uniform (and the kid is growing like a weed at this age) to be able to keep clean. For 9 t’shirts, 9 pr shorts, 9 pr pants and 5 windcheaters, This would cost his Mum about $900 from the uniform shop new, but she gets them secondhand for $530. If Coen were not disabled, he would have three sets at a cost of $180. Coen claims the difference of $350 on his NDIS plan and the family can now pay for a phone to replace her old one which just died.

🚫 And here is Coen’s story without being allowed to use his funds for school uniforms. Coen’s Mum can’t afford school uniforms with the logo. She buys a range of similarly coloured t’shirts and shorts from the op shop, and the school turn a blind eye (forgive the ableism in that comment), so now Coen is even more othered from his peers. It’s not the end of the world, but it not fair to heap this extra disadvantage on him, just because of his disability.

OR Coen’s Mum engages a daily professional laundry service which costs $120/week (though in reality, that doesn’t exist in regional Australia).

Pic desc: a photo of a laundromat showing a row of washers and dryers and a bench 🌀

Post reach and engagement statistics



Post overview

This view of your post may not represent exactly how it appears in Facebook's News Feed.

The Growing Space

Published by Sam Paior

· 8 August at 17:52 ·

🌟 NDIS In and Out Lists - "School uniforms" 👕
🗒️ The government has made new draft lists and they want your feedback.
📚 These lists show what you can and cannot buy with NDIS money.
⚠️ This is a big potential change.
🔗 You can read more about these lists in the comment below.
📝 I ... See more

Post performance

There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

4,017
Accounts Centre accounts reached
0% from boosted posts

4,017 organic
0 paid

1,129
Post engagements

82 reactions
81 on post
1 on shares

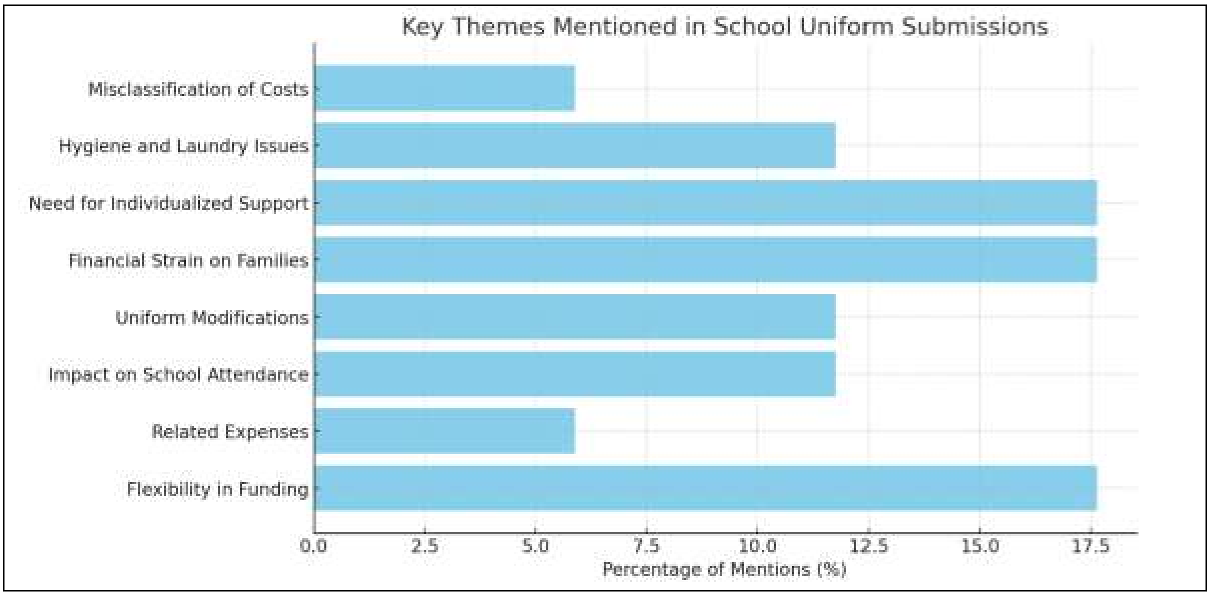
60 comments
57 on post
3 on shares

4 shares
4 on post
0 on shares

983 clicks
40 photo clicks
0 link clicks
0 clicks to play
943 other clicks

1. **Key Themes**
    1. *Misclassification of Costs:* There is concern that school uniforms are wrongly categorized under "Mainstream," leading to a lack of funding for what are actually disability-related expenses.
    2. *Hygiene and Laundry Issues:* Families face significant challenges managing laundry due to frequent accidents or incontinence, which creates a need for additional uniforms. Without proper funding, this can be a heavy burden.
    3. *Need for Individualized Support:* The cost and necessity of school uniforms vary greatly depending on the child’s disability. A one-size-fits-all approach doesn't work; funding should be tailored to each individual's needs.

4. *Financial Strain on Families:* The extra cost of buying additional uniforms because of a disability is a serious financial burden for many families, especially when there is no option to buy second-hand.
5. *Uniform Modifications:* Some children need their uniforms to be specially modified to accommodate their disabilities, such as adding stretch waistbands or custom sizing. These modifications should be funded by the NDIS.
6. *Impact on School Attendance:* Without enough uniforms, children might miss school, leading to academic and social setbacks. This highlights the importance of funding for uniforms to ensure consistent school attendance.
7. *Related Expenses:* The discussion also covers whether the NDIS should fund related necessities, like extra bed linens or laundry services, which are crucial for families managing disabilities.
8. *Flexibility in Funding:* Many submissions call for a more flexible approach, allowing funding decisions to be made on a case-by-case basis rather than sticking to a rigid list of what's covered.



2. Community Responses (verbatim, de-identified)

- What I've noticed in relation to the list, is that school uniforms fall under 'Mainstream'. From what I can deduce 'Mainstream' seems to mean another department or agency, state or federal, not 'mainstream' in the ordinary sense of the word. Is this an exercise in defraying costs that may legitimately be disability related to other non-existent funding sources to make the bottom line look better? It's like a cut and paste job of what might be incurred in a mainstream support, xed out without consideration of unusual and extreme circumstances. Most home budgeting would go the way of 'fixed, variable, intermittent, discretionary.' Extra school uniforms might normally be discretionary but in the examples given they become variable expenses. This seems to be an overarching issue. Also, I would very much like to know how taxidermy is an everyday expense! It's an entirely irrelevant discretionary expense for sure. I think this document is flawed and badly written

- Can we talk about the laundry component of this too it's important point : and one that impacts us daily Even at home it's challenging to put fecal clothes into the same machine (without extensive cleaning)as other washing can become contaminated easily

- My daughter is 13 and has always had toileting (urine) accidents and has a spare set of clothes in her bag. She is also prone to getting her clothes dirty due to dribbling or just not having the motor skills around her mouth and so needs a clean set every day. In primary school, I bought 6 sets of clothes for school - one for each day and one for the bag. She's now in a Catholic high school, that has winter and summer uniform as well as a sport uniform. She also has two pairs of shoes as she often wets them. The cost of keeping up with all of this is excessive. However, It's my choice to send her to a private school, and it's my choice to make sure she is always well presented. I think this is another grey area that should be decided on an individual basis.

- A perfect example of why the ndis needs to look at everything on a case by case. To your typical joe or jo uniforms are a typical cost. Only for a small percentage uniforms are a huge expense that is because of disability! Its a small amount of people but they need this help and its totally within reason. We just had to buy a lot of extra uniforms for a school camp so we could have extra it cost us hunderds (sic) of dollars in the middle (sic) of winter too $70 for a long sleve (sic) top, 90 for a jacket, pants we can get from big w. Because of needs relating to my childs (sic) disability. Even then the school had to wash clothes. We are lucky we are privileged enough to be able to buy them. There is no seccond (sic) hand market the school is only 2 years old. Without buying these clothes our son would hqve (sic) stayed home. These cuts are not fair or resonable (sic). Fair and resonable (sic) is looking at things from a case by case. Instead of a no list why not a list that requiers (sic) more information? The mostly no's but with excpeptions (sic) for those who have a more unique journey.

- The story leading to all the comments is my son’s to a tee, except I pay out of pocket for all of his extra uniforms, I often buy just the extra shorts x12 and let his legs be cold in winter because he grows every season and we can’t afford to just keep buying at this rate. I don’t need a new phone but my mum just ended up replacing our washing machine that died and because of our son’s high needs my husband lost his job in the military. So now we are being evicted from Defence housing.

- As a middle income privileged family who did not need to be careful about costs we only ever bought 5 uniforms (one for each day) ……. of course the additional uniforms are a disability related expense…… only a public servant being paid hundreds of thousands of dollars each year from our taxes would consider this a claim that is a burden to taxpayers

- Seems totally disability related to me - a usual parent responsibility would be maybe 2 uniforms - without the disability this is all that would be required. Why is this a "grey" area and even up for discussion. Sorry but the example really highlights people you are in NEED of support. The other option is child has no clean uniform and what - starts not attending school because they don't have anything to wear and here starts a new issue - getting behind with work, loss of social interaction with peers etc.

- What about if people need modifications to uniforms on top of needing more of them? Extra clothing & uniforms should be covered Not just school students but what about disabilities that cause incontinence or body fluids spills? Shouldn't extra bed linen and industrial washing machines or laundry services be covered? For participants with hearing loss, fire alarms, security cameras, vibrating smart watches need to be covered. What will be covered with things like slope board? Will things like this suddenly be educational expenses and not covered? Will AT such as computer softwear (sic) to overcome dyslexia (eg read and write text help) still be claimable? What will be covered for getting older teens into further study or work? Will the school leaver programs still be there or will they have to go through Centrelink? Will family or child specialist camps still be an option? (Eg Down Syndrome, Autism, Auslan - deaf, hard of hearing) or will these all be classed as holidays?

- This is an excellent point I hadn't thought about. A kid who is happy in track pants and crocks on the weekend might need Special socks that cost more and don't itch or hurt Zip around shoes for sport and every day Pay a person to add stretch waist, not buttons or zip If someone has limb differences or they are bigger or smaller than most students their age, they might need to pay more for someone the change their uniform or make one just for them. I am getting married soon and I can tell you it costs a lot more to get a dress made just for me than if I buy it from a shop! If that was a school uniform I needed because of my disability I think NDIS should pay for it. (Can you talk about how weddings are on the list? I am really confused by that. Does it mean they won't pay for my cake or does it mean nobody can bring a support worker to help them eat dinner?)

- I currently have no useable washing machine and two children who are my sole responsibility to get to two different schools, and about eleventy billion ways this can go wrong. And I can't even wash regular ones let alone spares at the moment, or find the ones the support workers put in the wrong baskets, or work out which kid needs which uniform on which day with which modifications. I sleep in my clothes coz it's easier and now we can't use the bath coz it's full of wee washing No evidence to support increased supports because I can't do more meetings and forms about it because I can't get anywhere to jump through form - hoops. And when I do no one is doing the washing or they are doing it wrong. School doesn't believe this refrigerator mother when I attempt to advocate for uniform exemptions 'because she's fine here' and 'it's important that everyone is consistent' and I'm consistently baffled at the fact that people who are supposed to be teaching source analysis and critical thinking cannot see the significance bias that if they are seeing her at school then it is, by definition, a good day. So I buy multiple uniforms in multiple sizes and styles often only to be worn rarely in an attempt to predict which will be ok, then I have to do more forms and meetings about it. Last year's teacher didn't pass on the information to this year's teacher and no one can find her spare uniform box in the office and when her spare uniform box in the classroom gets wrecked no one notices nor does anything except tell me and I'm expected to magically fix it immediately—without using one participant's funding on another participant while simultaneously doing what would reasonably be expected to be parental responsibility. With no washing machine connected and without buying extra uniforms and while getting three people to the correct place at the correct time with the correct clothes and items and meds and forms. But we couldn't find the right socks and no one washed the wee-uniform needed that day so I didn't get to the appointment to get the report (that I had canceled (sic) another appointment to go to) about it. So insufficient evidence to justify funding.

- Agreed—eg seizure disorders with absolutely no control fully opening bladder +/- bowels every night washing Kylie's plus bed linen plus clothing.

“NDIS In and Out Lists”:

WASHING MACHINES

🌟NDIS In and Out Lists - "Washing Machine" 🌀

🗒The government has made new draft lists and they want your feedback.
[snip]

🌀 Here's a story about why a Washing Machine should be "IN" (but as with all NDIS spending, only in certain circumstances and situations)

✍ Share Your Story - Please tell your Washing Machine (or other appliance) story in the comments, because we don't think it should be on that "OUT" list for everybody – there will and should always be exceptions!

💩 Imagine Coen again. He’s 14 years old and doubly incontinent due to his disability. “Code Brown” happens overnight, every night at their place.

Coen is one of four kids to a single parent and his Mum is on a carer payment.

🏡 They’ve now got a house (YAY!) and a regular washing machine.

Coen “gets through” 2-3 sets of school uniforms everyday, as well as a 🛏full sheet set, as well as other clothes. Coen is a sensory seeker, and enjoys the sensation of feeling and playing with stuff that is seriously unhygienic, and very messy.

With five kids in the family, their washing machine gets quite a workout, but Coen’s laundry alone takes up 2-3 wash loads per day, and it’s laundry that is very soiled.

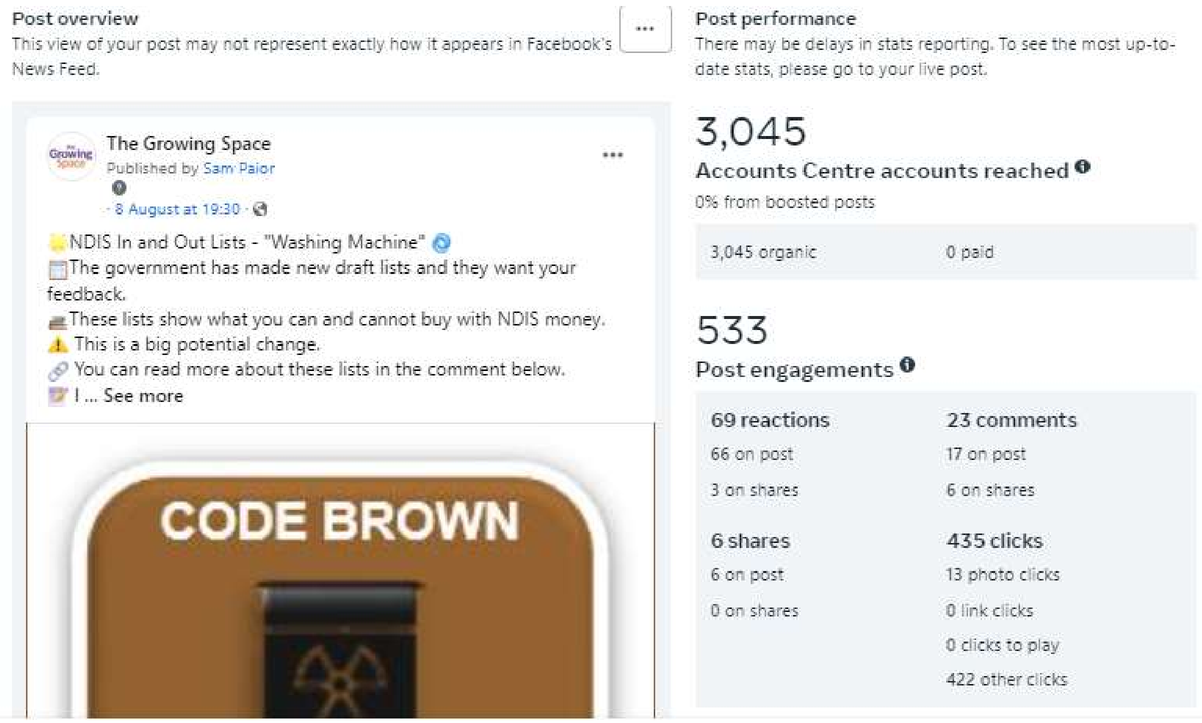
The family buy a second, industrial, washing machine to cope with and sanitise all of their soiled laundry. It costs about $2,500 and is expected to last at least 10 years (so about $250/year). Now the soiled laundry does not contaminate the whole family’s laundry.

🛏 And here is Coen’s story without being allowed to use his funds for a second washing machine

Coen’s Mum engages a professional laundry service which costs $120/week ($6,240/year) to pick up twice a week (though in reality, that doesn’t exist in her area of regional Australia). Coen’s family and neighbours loathe that there are almost always bags of stinky laundry in the driveway, and Coen’s Mum has to buy an extra 10 sheet sets to cover the timing.

Pic desc: a sign used in a hospital that says “CODE BROWN: In facility Hazardous spill”.

Post reach and engagement statistics


Post overview

This view of your post may not represent exactly how it appears in Facebook's News Feed.

The Growing Space
Published by Sam Paior
· 8 August at 19:30 ·

NDIS In and Out Lists - "Washing Machine"

The government has made new draft lists and they want your feedback.

These lists show what you can and cannot buy with NDIS money.

This is a big potential change.

You can read more about these lists in the comment below.

I ... See more

Post performance

There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

3,045
Accounts Centre accounts reached
0% from boosted posts

3,045 organic	0 paid

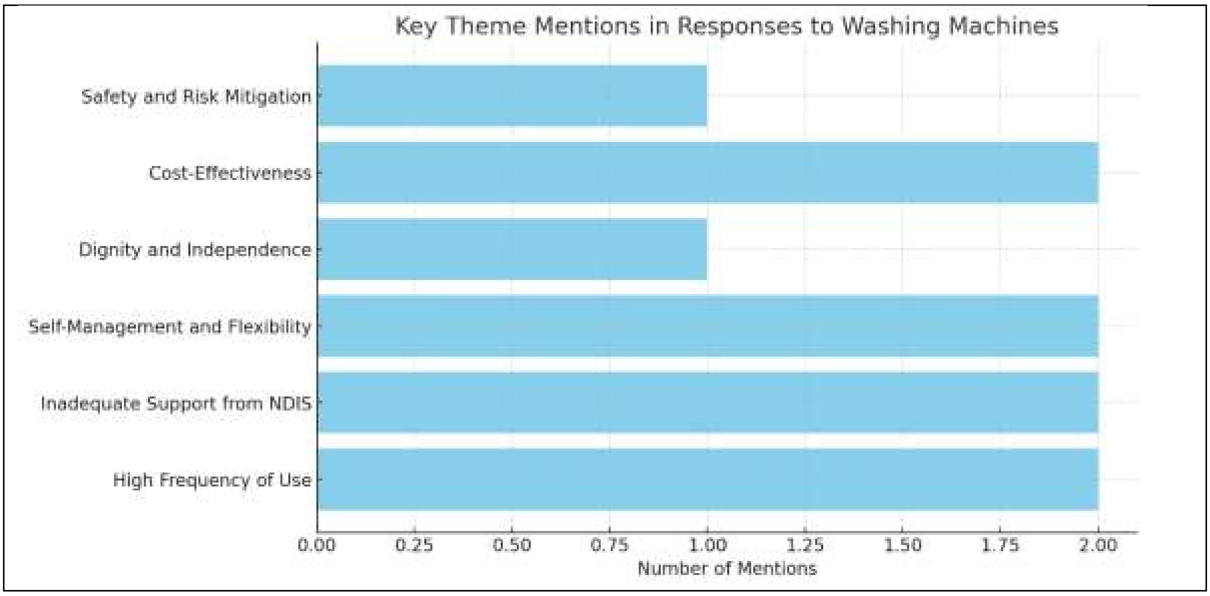
533
Post engagements

69 reactions	**23 comments**
66 on post	17 on post
3 on shares	6 on shares
6 shares	**435 clicks**
6 on post	13 photo clicks
0 on shares	0 link clicks
	0 clicks to play
	422 other clicks

3. Key themes

1. *Safety and Risk Mitigation:* Several submissions highlight the importance of certain household appliances, such as dishwashers and washing machines, in mitigating safety risks, particularly for individuals with disabilities that affect their physical abilities.
2. *Cost-Effectiveness:* There is a recurring emphasis on the financial benefits of using certain services or appliances (e.g., laundry services, dishwashers) instead of more expensive alternatives like hiring a support worker.
3. *Dignity and Independence:* The importance of maintaining dignity and promoting independence through the use of appliances or services is a significant theme. Respondents argue that these tools help individuals manage their daily tasks without reliance on others.
4. *Self-Management and Flexibility:* Respondents value the ability to self-manage their NDIS funds to meet their unique needs. There is concern that strict IN/OUT lists would remove the flexibility needed to make cost-effective and individualized decisions that best support their circumstances.

5. *Inadequate Support from NDIS:* Some submissions express frustration with the NDIS's refusal to fund essential appliances or services, such as washing machines or dryers, even when they are clearly needed due to disability-related circumstances. This theme reflects a broader concern about the disconnect between NDIS policies and the actual needs of participants.
6. *High Frequency of Use:* The submissions also mention the increased wear and tear on household appliances due to the high frequency of use, particularly in households managing significant disability-related needs, such as frequent laundry due to incontinence or other conditions.



4. Community Responses

- These scenarios show why self management is so important and why a sound understanding of how to self manage effectively is important. A lot of questions posed in self management specific facebook pages are no-brainers. A specific in/out list will create disadvantage and fear of claiming anything and the point of self management is creating cost effective, innovative, safe solutions to issues directly attributable to a persons disability.

- That would make perfect sense and also reduce some of the hard labour involved with continuous soaking and heavy wet laundry
- Third scenario- Carer Gateway just funded a brand new washing machine and clothes drier in our home since we deal with code brown on the regular
- I have extra linen washing because I'm mostly bedbound. We've never had a clothes dryer before and can't fit the extra sheets on our washing line. I've been told that the NDIS won't fund a dryer or washer dryer combo for us. Instead I pay someone to do the linen off-site. It's more expensive and I can't contribute to doing it (I could have if we had a washer-dryer).
- Definitely think it should be "in". We have numerous changes of clothing daily, often bedding too, and the machine runs at least three or four times a day. Also, used by many different people, and just does not last as long as a normal machine.
- I wash Sammy Joes clothes sheets and towels everyday four to five washes a day the NDIS has never once replaced my washing machine they have refused several times it’s not right they need to help in these situations

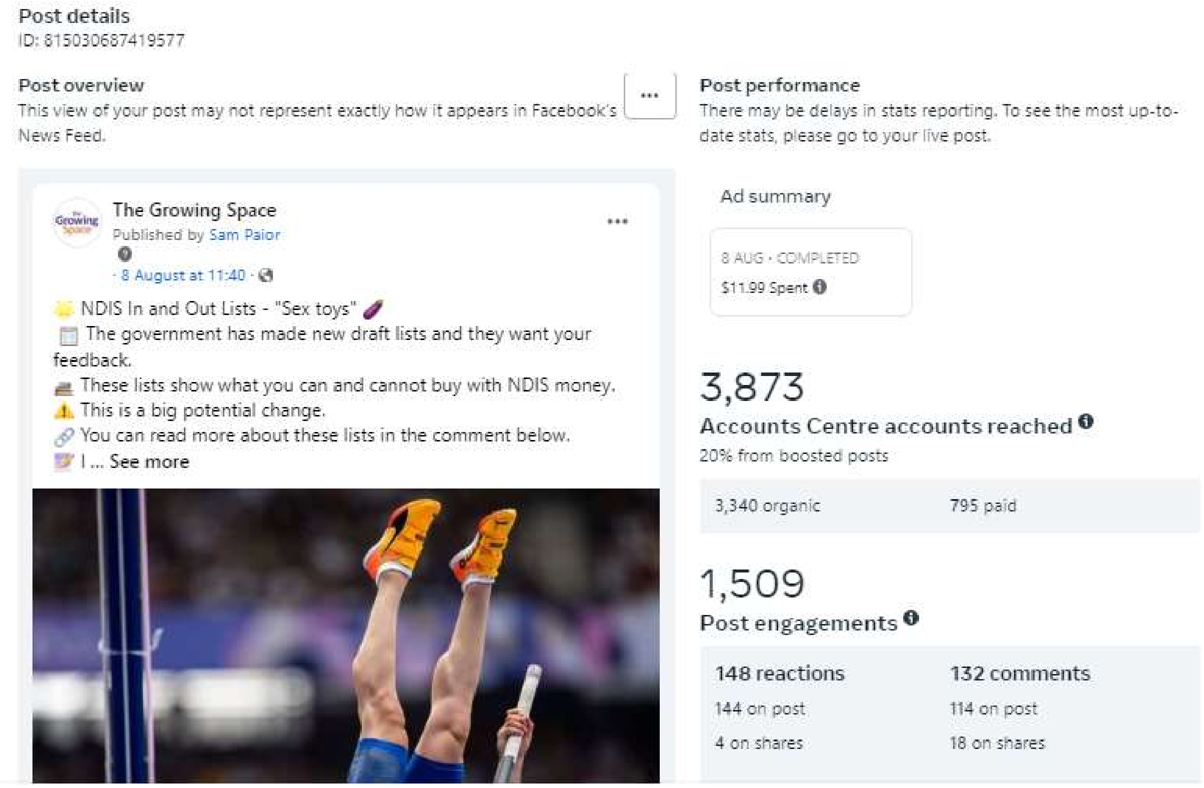
“NDIS In and Out Lists”:

SEX TOYS

🌟 NDIS In and Out Lists - "Sex toys" 🍆
📋 The government has made new draft lists and they want your feedback. [snip
✍️ Share Your Story - Please tell your sexual aid story in the comments if you’re game, because we don't think it should be on that "OUT" list for everybody – there will and should always be exceptions!
🛌 Imagine Bruce, a single 40 year old guy who lives in a group home and has both intellectual and physical disability.
Bruce can’t masturbate without help because his hands and arms just don’t work that well. He gets frustrated and grumpy when he tries, and his behaviours of concern increase, along with his vocalisations, which are very loud and distressing to other residents. He’s not a happy chap. His OT and workers take him to an Adult store to check out some of the 🔋 “Male masturbators” that are available (yes, I cleared my cookies after I googled that!). They choose one and a trusted worker helps Bruce to learn how to use it, demonstrating its use on various vegetables (now I’m just having fun writing this, right?).
Bruce learns how to use the device, enjoys using it regularly. His disruptive loud vocalisations and occasional lashing out behaviours reduce, and he’s a much happier chap. The device cost $200. He pays for the lube out of pocket, because he’d likely want that anyway.
🚫 And here is Bruce’s story without being allowed to use his funds for a “sex toy”.
Bruce is not happy. He is frustrated, grumpy, lashes out at workers and housemates. He hurts himself with his clumsy attempts to masturbate using inappropriate things. The costs of his extra support needs when he is deemed unable to live with any housemates are immense, and he loses the friendships he had, and he has a revolving door or support workers as he’s considered “too difficult”. Life is not good for Bruce, and because “Sex Toys” are on the out list, no-one even thinks about this important part of his well-being. And yes, he could use his own money to buy the aid, but he’s under financial trusteeship and they’re not exactly forthcoming with releasing his funds. 👎
Pic desc: Olympic pole vaulter Anthony Ammirati who may or may not have similar issues. It’s not my job to judge 🤸. credit: Kevin Voigt/GettyImages

This is not the image I wanted to use, but I got scared people would get grumpy with me.

Post reach and engagement statistics



Post details
ID: 815030687419577

Post overview
This view of your post may not represent exactly how it appears in Facebook's News Feed.

The Growing Space
Published by Sam Paior
· 8 August at 11:40 ·

NDIS In and Out Lists - "Sex toys" 🍆
📅 The government has made new draft lists and they want your feedback.
These lists show what you can and cannot buy with NDIS money.
⚠️ This is a big potential change.
🔗 You can read more about these lists in the comment below.
I ... See more

Post performance
There may be delays in stats reporting. To see the most up-to-date stats, please go to your live post.

Ad summary
8 AUG · COMPLETED
$11.99 Spent

3,873
Accounts Centre accounts reached
20% from boosted posts

3,340 organic
795 paid

1,509
Post engagements

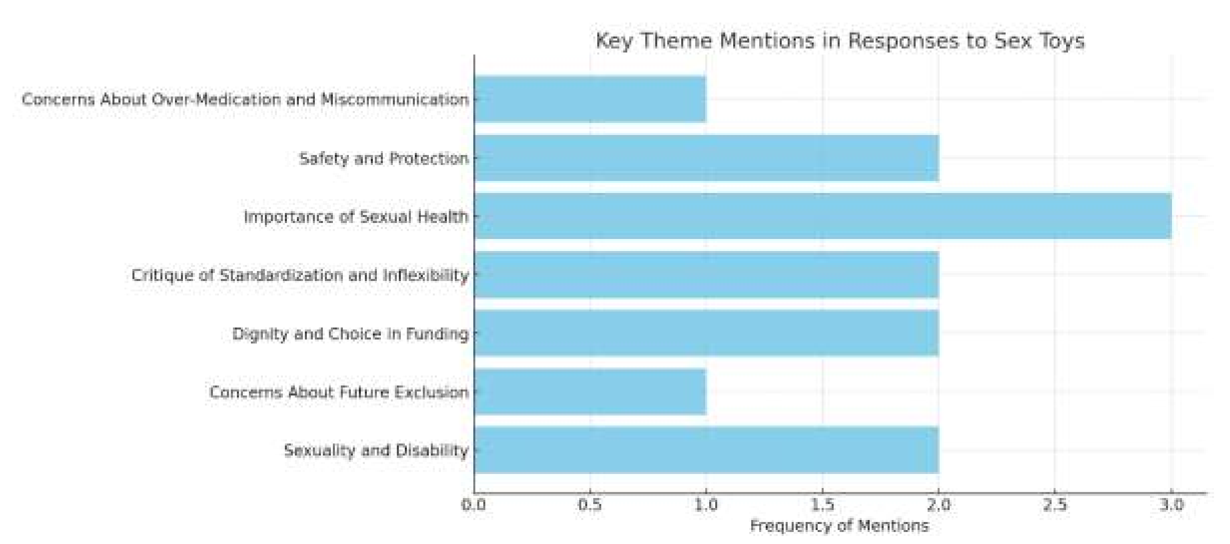
148 reactions
144 on post
4 on shares

132 comments
114 on post
18 on shares

1. Key Themes

1. *Concerns About Over-Medication and Miscommunication:* There is concern that individuals with disabilities might be over-medicated and misunderstood due to poor communication and advocacy. This underscores the need to address the root causes of behaviors rather than relying on medication.
2. *Safety and Protection:* Some submissions highlight worries about participants' safety, particularly in relationships. There is a suggestion that certain tools or measures could help protect participants from unsafe situations.
3. *Importance of Sexual Health:* A recurring theme is the importance of recognizing sexual health as a vital part of individual support plans. Contributors argue against blanket bans, advocating instead for personalized approaches that address the sexual health needs of people with disabilities.

4. *Critique of Standardization and Inflexibility:* Many submissions criticize the use of rigid lists or standardized rules for managing disability support. There is a strong call for a more individualized approach that considers each person's unique needs.
5. *Dignity and Choice in Funding:* There is discussion around the need for people with disabilities to have dignity and choice in managing their funds. Some suggest that current systems may not fully support this need.
6. *Concerns About Future Exclusion:* There is fear that future rules might exclude individuals with less severe disabilities or those with high care needs from receiving necessary support. Contributors worry this could lead to greater inequality and unmet needs.
7. *Sexuality and Disability:* Many submissions recognize sexuality as a fundamental aspect of life. They stress that individuals with disabilities should have access to the necessary aids and tools to fulfill their sexual needs in a safe and dignified manner.



2. **Community Responses (verbatim, deidentified).** On this post there was one person who did not agree and felt participants should use their own personal funds for purchasing sex aids)

- Thanks Sam for these stories and educating us all on what's on the horizon with the lists. If I could add to the Bruce story "without" He'd end up being taken to his GP and the sw would ask for medication to control his behaviors and several would be tried and he'd be sent to a psychiatrist and several more would be added and he'd be sedated to the eyeballs- all because none of his advocates/ sw / service providers understood what he was trying to communicate!!!
- I wonder if these tools also help keep some participants safe from seeking unsafe relationships also?
- Hahaha I know the exact image you want to use
  This is such an important part of support and the entire needs of people. Their sexual health and healthy outlets like masturbation are so often overlooked, especially within group home/SIL accommodation settings. There should be no blanket bans on ANYTHING! Every person is an individual with individual needs and requirements! This goes against the entire idea of what the NDIS was designed for. This just confirms the fears advocates have had for the NDIS since day 1. Why aren't they listening and why are they insisting on taking the NDIS away from everything it was supposed to be for every individual?? This is not wholistic or individual care & support!
- This is exactly why there shouldn't be an in or out list. We need to keep the NDIS individual focused. Not put everyone into a box.
- Great example! It would great to see the people making these lists do without showering, personal care, access to community and personal fun time and see how quickly they change their tune
- I had always previously thought the use of personal funds (from a pension or similar) would be more appropriate in this situation, however I hadn't considered trustee managed funds, and the difficulty involved in that, so thanks in bringing that information to the table.
- Why won't the NEEDS ASSESSMENT cover this need and other things on the exclusions list? A. Because the Needs Assessment won't be a complete or whole of person assessment. A box tick on the PACE

system, the OT accesses the info to confirm that it’s been assessed and Bruce is funded what is effective and beneficial AT which is value for money. Oh yeah! But r&n is not the criteria anymore. The new list of criteria doesn’t care what’s effective or beneficial it’s just a “take it, or leave it” scenario.

- Loving most of the conversations being generated, and hoping some information is challenging some different ideals and consideration when we are talking about people with disabilities, and NDIS participants to self determine, and direct funding with dignity and choice.
- How is it not just another form of AT that could be scripted? So loving this series of case studies team
- This is concerning. Only because if they are going to rule in, rule out, specifics, then only people with severe disability or high care needs will be able to claim anything going forward or be participants going forward. Perhaps this is where it is heading anyway.
- A participant can't use their hands or arms at all, they have no hands or arms, their spasticity physically hurts then if they try, they need Bluetooth control or other technology to meet their needs with privacy and dignity which is well out of an everyday expense price point (especially if on DSP, living in SILS, under guardianship) - they engage in risky behaviours to have their needs met eg use something not fit for purpose (a massage gun with a long handle, cleaning tools) and injure themselves and risk infection, they try to meet their needs in public (bouncing up and down on a bumpy train or bus ride) they act inappropriately with support workers to meet that need, they go out into the public and proposition people to do it for them (inappropriately and open themselves up to all sorts of personal and legal dangers) There are journal articles exploring the risk of people's sexual needs not being met Sexuality is not a choice or privilege that you can just suppress if you have a disability

- This post is about more than masturbation, 'toys' can be necessary aids to make intercourse possible eg too much/little sensory input, inability to attain or maintain erection And would banning "toys" lead to misinformation about necessary positioning aids etc (as is so often the case in the scheme)

The NDIS Draft Transitional Rules

August 2024

📄 Our Make It Easy letter to the Government about some new Rules for NDIS Supports

📝 Introduction

🗣️ This is feedback for the government on the draft lists for NDIS supports.

🚫 The list says there are 182 things you can not buy with your NDIS plan.

❌ We call that the “OUT” list.

👥 The Growing Space asked lots of people on Facebook what they think.

👩‍🦽 These people have disabilities, are carers, or work with people with disability.

🔍 We looked at 5 things from the "Out" list.

✍️ We wrote comments on how these things might help people.

💬 Then lots of people made comments.

📖 They told us their stories.

✅ They told why the things on the OUT list should be on the IN list.

🌟 We know every person with a disability is unique.

✅ Each person should have the right to choose what they need.

⏰ The Timeline and Easy Read

🕒 The time to give feedback is too short.

💻 Many people do not know about these lists.

📄 Some people cannot read the lists because they are hard to understand.

❌ Easy Read and Auslan came very late.

⌚ The Easy Read list does not include important things like smart watches and sex aids.

➡️ The Easy Read says the same things are on the OUT list and the IN list.

🤷‍♂️ It does not make sense.

🔄 The Easy Read list from the Government is not the same as the regular list.

🔧 We think that people who need Easy Read deserve better.

❌ The Idea of the Lists is Bad

⚠️ The "In and Out" lists do not fit with what the NDIS should be.

💡 NDIS is about helping people now so they need less help later.

💵 If we pay for some things we can save money later.

🚫 But these lists do not help save money.

⌚ Smartwatches are on the OUT list

👨‍🦽 Here is Matt’s story. He has a disability.

🤕 He often falls and hurts himself.

⌚ A smartwatch can help his family find him and get help quickly.

🚑 Without a smartwatch, Matt might need an ambulance and hospital care.

💸 This costs more money and is upsetting for Matt.

💬 People said smartwatches help them be independent.

🚶 They said it helps them not need a support worker all the time.

📱 People said smartwatches help with keeping safe, like calling for help when they fall.

💇‍♀️ Hair and Beauty Services are on the OUT list

🚶‍♀️ Aisha cannot wash her hair by herself.

💇‍♀️ She goes to the hairdresser twice a week.

💵 This costs $40 a week.

👩‍⚕️ If she had to hire a support worker instead, it would cost $268 a week.

😊 The hairdresser also helps Aisha feel good about herself.

💭 People said hairdressers help them stay clean and feel good.

💵 They said going to the hairdresser is cheaper than paying a support worker.

💇 People also said they do not want someone washing their hair at home because it feels yucky to be naked with workers.

👕 School Uniforms are on the OUT list

🧒 Coen is 14 years old and has a disability.

🧺 He needs lots of school uniforms because he poos and wees in his clothes and gets dirty often.

💵 His mum cannot afford lots of new uniforms.

🤝 If NDIS pays for the extra uniforms, it will help Coen fit in at school.

😔 Without help, Coen might have to wear other clothes, making him feel different from his friends.

💬 People said extra school uniforms help kids with disabilities fit in.

👕 They said kids need more uniforms because they get dirty more often.

👚 People also said clean uniforms help kids feel the same as their friends.

🧺 Washing Machines are on the OUT list

🏠 Coen’s family needs a special washing machine.

👚 They do lots of washing because of Coen’s disability.

💸 Buying a washing machine is cheaper than paying for a laundry service.

🚫 Without the machine, the family has to have lots of dirty clothes at the house.

🤢 This is not healthy for Coen and his family.

💬 People said washing machines help families keep their homes clean.

💵 They said washing clothes at home is cheaper than using a laundry service.

👚 People also said it’s important to have clean clothes, especially when a family does a lot of washing.

🛏️ Sex Toys are on the OUT list

👨‍🦽 Bruce lives in a group home.

😔 He cannot masturbate without help.

🍆 A sex toy helps him do this by himself.

🛠️ We call that a sex aid – not a "toy".

😡 Without the sex aid, Bruce gets frustrated and upset.

💸 This makes him act out, which makes his life worse and his care more expensive.

💵 The aid costs $200.

😊 It helps Bruce feel happier and costs less than other things.

💬 People said sex aids help some people feel calm and happy.

🧑‍⚕️ They said this stops them from needing more help from support workers.

💸 People also said it saves money because it helps stop problems that cost more to help later.

🚫 Problems with the "Out" List

📃 The "Out" list has lots of things that some people with disabilities need.

🤝 These things help them live independently.

🚶 People will need more help from support workers if they can not get the things.

💸 This costs more money and is bad for their independence.

📝 What lots of disabled people and carers said

✅ The NDIS should let people with disabilities to use their funds in ways that make sense for them.

🖲 People should be allowed to use NDIS funds to buy things they need because of their disability.

🔄 The "In and Out" lists should be flexible.

👥 They should think about the unique needs of each person.

👐 People with disabilities should have the right to choose how they spend their NDIS money.

📚 Hard Words

- 🛠️ **NDIS**: National Disability Insurance Scheme. It provides support for Australians with disabilities.
- 👋 **Auslan**: Australian Sign Language, used by people who are deaf or hard of hearing.
- ⌚ **Smartwatch**: A watch that can do more than just tell the time, like telling others when you fall or helping when you get lost.
- ✋ **Masturbate**: Touch your body in private places for good sexy feelings.
- 👣 **Independence**: Do things on your own without needing help.

Make it Easy (no emojis)

The NDIS Draft Transitional Rules Submission
August 2024

Our Make It Easy letter to the Government about some new Rules for NDIS Supports

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The Easy Read says the same things are on the OUT list and the IN list.
It does not make sense.
The Easy Read list from the Government is not the same as the regular list.
We think that people who need Easy Read deserve better.

The Idea of the Lists is Bad

The "In and Out" lists do not fit with what the NDIS should be.
NDIS is about helping people now so they need less help later.
If we pay for some things we can save money later.
But these lists do not help save money.

Smartwatches are on the OUT list

Here is Matt’s story. He has a disability.
He often falls and hurts himself.
A smartwatch can help his family find him and get help quickly.
Without a smartwatch, Matt might need an ambulance and hospital care.
This costs more money and is upsetting for Matt.
People said smartwatches help them be independent.
They said it helps them not need a support worker all the time.
People said smartwatches help with keeping safe, like calling for help when they fall.

Hair and Beauty Services are on the OUT list

Aisha cannot wash her hair by herself.
She goes to the hairdresser twice a week.
This costs $40 a week.
If she had to hire a support worker instead, it would cost $268 a week.
The hairdresser also helps Aisha feel good about herself.
People said hairdressers help them stay clean and feel good.
They said going to the hairdresser is cheaper than paying a support worker.
People also said they do not want someone washing their hair at home because it feels yucky to be naked with workers.

School Uniforms are on the OUT list

Coen is 14 years old and has a disability.
He needs lots of school uniforms because he poos and wees in his clothes and gets dirty often.
His mum cannot afford lots of new uniforms.
If NDIS pays for the extra uniforms, it will help Coen fit in at school.
Without help, Coen might have to wear other clothes, making him feel different from his friends.
People said extra school uniforms help kids with disabilities fit in.
They said kids need more uniforms because they get dirty more often.
People also said clean uniforms help kids feel the same as their friends.

Washing Machines are on the OUT list

Coen’s family needs a special washing machine.
They do lots of washing because of Coen’s disability.

Buying a washing machine is cheaper than paying for a laundry service.
Without the machine, the family has to have lots of dirty clothes at the house.
This is not healthy for Coen and his family.
People said washing machines help families keep their homes clean.
They said washing clothes at home is cheaper than using a laundry service.
People also said it's important to have clean clothes, especially when a family does a lot of washing.

Sex Toys are on the OUT list

Bruce lives in a group home.
He cannot masturbate without help.
A sex toy helps him do this by himself.
We call that a sex aid – not a "toy".
Without the sex aid, Bruce gets frustrated and upset.
This makes him act out, which makes his life worse and his care more expensive.
The aid costs $200.
It helps Bruce feel happier and costs less than other things.
People said sex aids help some people feel calm and happy.
They said this stops them from needing more help from support workers.
People also said it saves money because it helps stop problems that cost more to help later.

Problems with the "Out" List

The "Out" list has lots of things that some people with disabilities need.
These things help them live independently.
People will need more help from support workers if they can not get the things.
This costs more money and is bad for their independence.

What lots of disabled people and carers said

The NDIS should let people with disabilities to use their funds in ways that make sense for them.
People should be allowed to use NDIS funds to buy things they need because of their disability.
The "In and Out" lists should be flexible.
They should think about the unique needs of each person.

People with disabilities should have the right to choose how they spend their NDIS money.

Hard Words

NDIS: National Disability Insurance Scheme. It provides support for Australians with disabilities.
Auslan: Australian Sign Language, used by people who are deaf or hard of hearing.
Smartwatch: A watch that can do more than just tell the time, like telling others when you fall or helping when you get lost.
Masturbate: Touch your body in private places for good sexy feelings.
Independence: Do things on your own without needing help.