|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Diagnosis** | **Type** | **Impact** | **Treatment** | **Treatment Cost (If calculable)** | **Responsibility (Currently)** |
| ASD L2 | Developmental | Major sensory |  |  | NDIA |
| Gilbert’s Syndrome | Benign Liver Disease | Exacerbated by stress |  |  | Medical |
| Functional Neurological Disorder |  | Physical | Neuropsychiatry  Neurophysio  Stress management  Diet/Excercise |  | Medical |
| ADHD | Learning | Executive function, working memory, time management and organization | Stimulants  Guafacine |  | Medical |
| Migraines | Physical | Severe pain - brain | Daily preventative medication  Or Treating medication |  | Medical |
| Fibromyalgia | Physical | Chronic pain  Fatigue | Anti-depressants  Low-Dose Naltrexone (Not PBS)  Diet and Excercise | $72 monthly | Medical |
| Internal Carotid Artery Dissection |  |  | Radiological Monitoring  BP Control  Aspirin | $??  $3 monthly | Medical |
| EDS (Ehlers-Danlos Syndrome) | Physical (Connective Tissue Disease) |  |  |  | Medical |
| OCPD (Obsessive Compulsive Personality Disorder) |  |  |  |  | NDIA |
| PTSD |  |  |  |  | NDIA |
| Borderline Personality Disorder |  |  |  |  | NDIA |
| Severe Dust Mite Allergies |  | Chronic Rhinitis  Frequent Respiratory Infections | Prescription Nasal Spray (Non-PBS)  Prescription Eye Drops (Non-PBS)  Zyrtec (double dose, non-prescription) | $47.99 monthly  $49.99 monthly  $32.99 monthly | Medical |
| Visual Snowfield Syndrome |  |  |  |  | No treatment, no responsibility |
| LPR (Laryngopharyngeal Reflux) | Physical | Like GERD, but acid goes past voicebox  Feeling of lump in throat  Hoarseness  Difficulty swallowing + breathing  Choking Episodes | Lifestyle – including diet, timing and size of meals, weight management, intake restrictions, tightness of clothing.  Nexium | $13.70 monthly | Medical |
| Stable OVT (ovarian vein thrombus) |  |  | Eliquis | $6.7 | Medical |
| Insomnia |  |  |  |  |  |
| **TOTAL COST** |  |  |  | **$226.37 monthly** |  |

**Treating Professionals**

|  |  |  |
| --- | --- | --- |
| Type | Public/Private/NDIA |  |
| Pain Management Specialist | Private | Ongoing 6-weekly |
| Gynocologist | Private | Ongoing until healthy enough for surgery |
| Neurologist | Public  Private |  |
| Vascular Surgeon | Public  Private |  |
| Opthamologist | Private |  |
| Endocronologist | Private |  |
| Rheumatologist | Private |  |
| Gastroenterologist | Private (first available appointment March 2025)  Was denied through public |  |
| ENT | Private |  |
| Allergist | Private | No further need |

**Income:**

|  |  |
| --- | --- |
| Income Type | Monthly |
| Carer’s Payment | $2000 |
| Carer’s Allowance (x3) | $900 |
| Family Assistance and Rent Assistance (3 dependents) | $2000 |
| Child Support | $600 |
| **TOTAL** | **$5500** |

**Expenses:**

|  |  |
| --- | --- |
| Expense Type | Monthly |
| Rent | $2720 |
| Hospital Cover | $295 |
| Childcare | $600 |
| Car Expenses | $800 |
| Utilities:  Water  Electricity  Internet  Mobile Phone | $50  $150  $69  $35 |
| Medication | $226.37 |
| **TOTAL** | **$5000** |

# Introduction

Above, you will find a partial history of an actual participant. We’ve established after basics, that there is $500 a month ($6,000) left for groceries and medical/disability-related “daily living expenses”. This disregards the $2,465.75 in gap fees she has already spent on medical appointments this calendar year, and the $750 excess for her admission to private hospital – because of trauma related to the public system every time she has been there. All examples below, should be read in context of this complex case.

We need to carefully define a daily living cost. You’ll note from some examples, that yes, an item may be a daily living cost – BUT, the specifications on the item are disability related.

There are many more recommendations available to reduce costs, that DON’T cause harm/distress to the participants – who already had to fight a seemingly endless battle to gain access to the scheme, and this bill is wanting to cause more fighting and distress to access what they need. I simply did not have the capacity to address this from all angles.

**A summary of the areas include:**

Education and clear definitions across the industry

Provider registration – WITH relevant rates relevant to the PERSON, associated with the registration

Companies who provide the admin umbrellas to providers, are to charge no more than the cost of employment of that provider + a percentage towards admin costs

And to that end, disability is not a profit sector – stop allowing it

Stop calling it “Price guidelines”, providers fool vulnerable participants saying “we are increasing our rates in line with NDIS Price Guidelines” – call it what it is, MAX rates allowable

Stop underfunding supports, necessitating “unnecessary” CoC reviews

Set the plan based on level of support needed THEN ALLOW CHOICE and CONTROL on how the supports are delivered. The participants know what they need

# Example 1:

Participant wants to replace current clothes dryer with a condenser dryer, and replace her washing machine with one that has a bigger capacity.

Currently has LG 7kg Direct Drive Front Loader (which she purchased prior to her older toddler’s birth in 2020) and 7kg Vent Dryer

Wants LG 12kg DD FL and 10kg Condenser Dryer – total $3,200 (after shopping around and getting the best deal with price matching and so forth, something she would not and could not entrust to anyone, because of a “good enough” mentality most people seem to have)

She does not want to have to open the door, because of the noise from the road, the likelihood of her forgetting to close it again or to close it if it rains. She is also worried about it causing other doors to slam due to wind, as well as dust coming in and the potential for living things/people to enter uninvited. Her previous neighbours ran their washer and dryer outside her bedroom window day and night, resulting in no sleep and overstimulation, and heightened sensitivity to the sound of the dryer. This was a significant factor in her deterioration in all areas of functioning, due to the impact the nervous system has on many of her conditions (including FND, ASD, fibromyalgia, PTSD).

Due to the current need to open the door, she has a severely limited timeframe to do laundry, often resulting in more dirty laundry than clean, and clothes needing to be rewashed due to being in the washer 2-3 days. She is already limited by the times her children are home, due to their sensitivity to noise – so on a good day, she has between 9:30 and 14:45 to both wash and dry. So currently, assuming she remembers, she COULD get 2 loads washed and 1 load dried. However, due to her various medical conditions and specialists – and those of her children, she is very rarely able to use all this time, due to appointments and associated administration. This is why she would like to get a bigger size washing machine and ensure the dryer has a big enough capacity to dry all the laundry from the washing machine at once, to reduce the quantity of loads required. This will also reduce the demand on her executive functioning, memory and physical symptoms.

Current barriers - The participant struggles with communication, and even if this were not the case – her OT (and likely most others) will not provide the evidence the NDIA would require, stating it as an everyday item/expense and perhaps even that because it is due to more than just her NDIS listed disabilities. Her support coordinator and plan managers state the same, as well as the LAC and NDIA representative on the enquiries line. Now, let’s assume that the OT would do assessment and recommendation for the item. Due to her OCPD, RSD (associated with AuDHD) and PTSD, the participant will not engage/attempt something that is likely to fail – which due to the NDIA information, LAC, SC and PM, she believes this request will. But, for the sake of argument, let’s say she doesn’t believe it will fail… her PM tells her that (even though she has available funding in Core) this request needs to be submitted to the NDIA for approval, because it is an everyday item and this is essentially lodging a “change of circumstances”, which currently takes nearly a year to complete. Lastly, let’s assume that if she could get the OT to do the assessment, it would be as simple as providing it to the PM and she could purchase it… because of her OCPD, ASD and limitations caused by her other conditions, the participant lives her life by doing cost-benefit analysis, in the spirit of reasonable and necessary, efficiency and what is right. Thus, she is unwilling to use her funding – even if it is government funding, to pay someone upward of $600 to provide evidence for a $3,200 set of assistive technology.

Proposed “carveouts” mean that she would not even be able to request this as a support. Now, as we know, our participant has very limited of her own funds available and has no capacity to jump through the hurdles of a no-interest loan (assuming her SC even has knowledge of this community support to refer her to). But she absolutely needs this, because it will improve her life greatly and she knows it – so she waits till financial year supplements come in and uses them to fund this.

# Example 2:

Our participant requires and requests funding for a Xero subscription, in order to manage her financial affairs, her and her children’s plans and rostering supports and appointments to ensure providers are paid, but also that they are only invoicing and being paid for services rendered/where late cancellation by the participant applies. She has applied for self-managing all plans, due to incompetencies of plan managers – eg. declining specifically stated supports as included on NDIS plan funding breakdown, paying 2 invoices from the same provider for the same child on the same day, making it clear to providers that she is the one asking for accurate invoices – instead of checking that invoices meet NDIS requirements and following-up themselves. She has control issues (OCPD) and needs everything to be done right, she has executive dysfunction on various levels and thus needs to manage her finances with something like Xero (which she used to, but stopped being able to pay for it due to health and disability expenses being more important), Xero would also help with the organizational side and record-keeping in all areas.

She provides the NDIA with an estimated pricing $115 per month, she points out that this is less than the monthly cost to the NDIA for ONE plan to be plan managed – and her household has 3. So it is value for money.

She gets approved for self-management for the 2 children, bet denied self-management for her own plan – claiming “evidence indicates self-management of this plan would present an **unreasonable risk to the participant** - s44(2)(a), s44(2A)”.

She is also denied funding for Xero:

“NDIS (Supports for Participants) Rule 5.1(d): Support relates to **day-to-day living**

costs.

The NDIS is unable to provide a support that relates to a day-to-day living cost such

as rent, groceries or utility bills that **are not directly related or caused by a**

**participant’s disability support needs**. This support is a day to day living cost and

cannot be funded by the NDIS.

Any assistive technology that we fund must relate to your disability. We don’t fund

**general items that everyone needs**, whether or not they have a disability. This

includes things like everyday household items, which are seen as a day-to-day living

**cost that all households have to pay**. Ultimately, we won’t fund a support if it’s not

related to your disability.

NDIS Act Section 34(1)(c) criteria: Value for money.

NDIS supports need to represent **value for money** in that the costs of the support are

**reasonable relative to both the benefits achieved and the cost of alternate support**

**when compared to the benefits to be achieved**. For example, whether purchasing the

support is likely to **reduce the cost of funding other supports in the long term** and

when compared to **alternative options that may provide the same outcome at a**

**similar or lower cost**. I am not satisfied the requested support meets this criteria.

Even when your disability means you may benefit from accounting software, the cost

is unlikely to be an extra cost solely and directly because of your disability needs.

This is considered a **day-to-day living cost** and therefore is not considered value for

money to fund.

Questions to ask yourself about Example 2:

* If the current management style is detrimental to the participant’s physical and mental health, secondary to a listed disability, how can self-management (choice and control) present and “unreasonable risk” to a qualified bookkeeper, nearly bachelor degree educated accountant?
* How many people (individuals who are not running any business activity) do you know who NEED accounting software in their day-to-day lives?
* How many households do you know (individuals who are not running any business activity) that pay for accounting software?

Impact so far on participant, and how approval would have prevented it:

* Ex-support worker has used participant’s card details in more than one purchase. Xero matches all transactions entered, to the bank statement – the participant would have IMMEDIATELY seen that there was an unauthorised charge. She has since cancelled and had all cards reissued, but somehow the support worker made a charge again – perhaps having put the card on google wallet, and not simply having written down the information. This is noticed 3 months after supports have stopped, and now the participant has to run through all her bank statements to look for and hopefully recognise/remember transactions. Again, if she had had access to Xero, her reconciliation would have been up to date, and she would know if there were unauthorised transactions from that period.
* Whilst awaiting the outcome of this s100 review, she paid Xero out of pocket, hoping it would only be a while – and given her miniscule budget after necessities, you can imagine how distressing that would have been, and ultimately she had to stop paying for it.
* The childcare centre messed up and changed the CCS hours for a period of 2 weeks, resulting in $470 being taken from her account for 1 week – instead of $150. She has too many other important things going on and she has asked them to fix it, but they can’t figure it out, and she can’t draw them a picture because she can’t do a historical transaction list and tell them what to fix and how much they owe. She only remembers the issue when she gets to the centre, but then it is always the rush of dropping the kids or picking them up. This has been going on for 7 weeks. Again, on a budget like hers, this is causing significant distress.

# Example 3

Participant assessment scores as per OT :

CANS 4.3 – requiring daily support up to 11 hours per day

WHODAS 2.0 89.58% (where 0% = no disability and 100% = full disability)

Barthel Index (measure of physical disability) 80/100 – moderate dependency in ADL

OT has the following documentation available:

All medical reports

All other treating professionals’ reports – and availability for calls to discuss anything

Current support worker and family input

Actually having been present in the living environment of the participant

All other diagnosis

Everything about the children that the participant is trying to parent

OT Recommendations for core supports:

1. 5 hours a day (35 per week) of support worker assistance for personal care – so already reduced from CANS max recommendation.
2. 5 hours, 3 days a week (15 per week) of support worker assistance to get to appointments, do shopping etc.
3. 2 hours a week cleaning
4. 4 hours a month yard maintenance
5. Recommendation that assistive technology be available in order to facilitate this reduction in support hours recommended. Specific recommendations made, robotic vacuum that empties itself, fills itself with clean mop water and empties the dirty mor water itself + air purifier to reduce sensory overload with smells, dust causing itching and coughing, etc + intensity controlled lights.

Psychologist recommends AT where possible to minimize distress from inadequate support workers and people in the participant’s space too long or too often too.

NDIS delegate funding decision core:

1. 5 hours per **week** weekday only
2. 10 hours a week weekday only
3. Approved
4. 2 hours a month
5. NONE

OT Recommendations for capacity building supports:

1. 2 hours a week psychology
2. 50 hours a year behaviour support
3. 62 hours OT (26 fortnightly sessions, 26 for travel to participant since she was not driving due to neurological symptoms, and 10 for report writing for next review)
4. 52 hours speech (fortnightly appointment + travel to participant)
5. 52 hours physiotherapy (fortnightly appointment + travel to participant)
6. 1 hour per fortnight exercise physiology
7. 1hr a month dietician

NDIS delegate funding decision capacity building:

1. 1 hour per fortnight (26 per year and needs to allow for report writing)
2. NONE – planner told participant and support coordinator that the NDIA considers PBS a duplication of psychology (untrue, but SC was too uneducated to know this and participant was forced by planner to choose + now told she cannot use PBS with her current funding, to allow her to request funding at next review)
3. 39hours per year
4. 12 per year
5. 12 per year
6. NONE
7. 4 per year

So, the participant has **wasted NDIS funds** to obtain a professional’s assessment of their capacity for the NDIA (about $2,000-$3,000), gone through all the distress of having people in her space, repeating her short-comings as a human-being and a parent – only to have an unqualified person with only the report as their information source, contradict the assessment.

Next Steps:

Apply for an s100 review, wasting more tax-payer dollars to correct this outcome, causing further delays to people applying for access or change of circumstances. This is the NDIA’s fault, NOT the participant’s.

OR

Spend more tax-payer dollars for a new report/FCA (another $2,000-$4,000 this time) to provide further evidence, then apply for a change of circumstances – even though circumstances have not changed.

***Participant opted for s100 review***, asking for:

* A minimum **24 hours at item 2 for core funding**, it was denied, stating based on the evidence, the 10 hours is reasonable and necessary, and cited “effective and beneficial” likely referring to the OT and psych recommendations for AT over support workers where possible. But they declined AT, and they are declining evidence based hours of support.

**Robotic vacuum**, declined stating “NDIS (Supports for Participants) Rule 5.1(d): Support relates to day-to-day living costs” and “”NDIS Act Section 34(1)(c) criteria: **Value for money**. “There is **7 hours per week of assistance with daily life support worker** which includes household cleaning. A robotic vacuum is not considered value for money as it considered a day-to-day living cost and support worker funding has been included in the plan.””

* Participant agrees that A **vacuum** is a day-to-day expense, that is why she has a portable one with a detachable dust buster, as well as a Numatic George wet-and-dry vacuum. BUT the robotic one that is self-cleaning is specifically disability related (task initiation, OCPD and a lack of ASD spoons available to execute, sensory overload with the noise and smell, and other criteria as assessed by the OT)
* 7 hours a week for ADL, which includes cleaning, planning the week, planning meals, eating, dressing, showering, medication taking, other grooming and self-management (booking and keeping track of appointments, paying bills on time, etc)… and this should be enough for someone with OCPD standards – OCPD which is listed as a disability on their plan. Where there are 3 other humans causing chaos in the environment every day, and the task of tidying before the participant can clean, is so mentally and physically exhausting – let alone then still having to use the vacuum.
  + But let’s assume 7 hours a week was sufficient, how is it value for money to pay someone $65 an hour to vacuum at least 3 times a week = $10,140 versus the $1,400-$1,700 evidence based AT item which only needs to be emptied and refilled by either a paid or unpaid support?
* Air purifier declined again as day-to-day living cost not directly related to disability or participant’s disability related support needs (rule 5.1(d)).. also declined under NDIS Act Section 34(1)(c) value for money, and I quote “…While it is acknowledged that you keep your windows and blinds shut due to your sensory sensitives, air purifiers are considered a day-to-day living cost and therefore is not considered value for money.”
  + So, first they say it isn’t disability related (rule 5.1(d)) and then state that they acknowledge that it is required due to ASD and PTSD (both listed as disabilities with NDIA for this participant), but they won’t fund it because it is a day-to-day living expense. I ask again, how many people do you know that NEED a purifier in daily life, and how many people do you know who actually have this item in their home?
* Behaviour support funding declined under value for money, stating “In order to include funding for a behaviour support practitioner we require evidence of the behaviours of concern, such as, incident reports showing frequency and duration and relate to, for example, physical or verbal aggression, property damage, inappropriate sexual behaviour, disinhibited and impulsive behaviour and/or restricted practices.
  + The OT and psychologist has the evidence and the examples required for this recommendation, for what purpose does the participant have to give access to no-names at a government institute, to their personal medical, mental and disability details? So the delegates and planners can use their bias on certain conditions to minimise supports?

Reason 2- “NDIS Act Section 34(1)(d) criteria: Effective and beneficial.

To meet this criteria the support will be, or is likely to be effective and beneficial,

having regard to current good practice and evidence. This means we consider if

there is sufficient evidence to demonstrate the requested support is likely to be

effective and beneficial for someone with similar disability support needs and assist

in progressing towards NDIS goals. I am not satisfied this support meets this criteria.

We can only fund supports where we are the most appropriate funding body. We

can’t fund supports more appropriately funded or provided through other general

systems of service delivery or support, including as part of a universal service

obligation. The health system is responsible for clinical mental health supports. The

evidence provided has not indicated behaviours of concern or indicated why

occupational therapy cannot provide support for the requests.”

* This was also the reason they determined 26 hours a year of psychology was sufficient. OT has determined based on the evidence they were provided, that OT couldn’t provide support for the behaviours they recommended PBS for, that’s why they recommended it.

Conclusion:

The NDIA is either directly or indirectly responsible for the majority of funds/tax-payer money being wasted. They insist on professional assessment, then disregard the assessments for their on opinions and provide massively inadequate supports, then blame the vulnerable participants for spending beyond what they were funded and requesting top-ups or change of circumstances. If they simply funded exactly, or even just close to, what professionals have recommended – there would be fewer CoC required and thus less wait time for those trying to access or get reviews in. **Or**, the NDIA could simply stop requiring professional assessments/reports – that will save you at least $1,298,000,000 per year right there. And if reports aren’t read or used as evidence for supports, then we don’t need them?

Day-to-day expenses need much clearer definitions, and more people are eligible based on disability related, than not.

Points to remember:

Plan funds are not funds given to the participant; they are funds available to pay for disability related expenses. Even if the full capacity building recommendations were funded, that does not mean the participant would use it all (choice and control) they may use supports 1-4 and leave the rest to avoid burnout, or because they may not see it as beneficial to them specifically. Core funds are mainly based on support worker hours, but participants should have autonomy (choice and control) to fund assistive tech that will minimize their person-to-person support needs. This frees up the few paid carers that are available, to help others for whom person-to-person supports do more good than harm.

# Example 4:

NDIA currently provides 70% towards cost of ready-made meals to eligible participants. If a participant meets that criteria, but has allergies which means they have to read all ingredients etc, they should be able to substitute for Hello Fresh or similar (where they can pick meals without allergens or exclude allergens whilst still allowing their kids to explore healthy meals). Paying a support worker to help with meal planning, shopping, prep, etc costs more than $230 a week (4 hours support) and the participant is unable to go to the shops, unable to meal plan or organise or anything – let them have choice and control and gain independence in cooking.