

A4 - rough comments on Taylor Fry Cost Benefit analysis

Summary and conclusions

The following relates to Taylor Fry Pty Ltd, *NDIS Review - Costs, benefits and frameworks: Final Report (20/9/2023)* for the NDIS. I obtained a copy of the report via the NDIS FoI process.

This report was not shown to (or discussed with) the DRCO Forum or the AAG.

The report provides data showing funding for primary disability associated with up to five severity ratings for participants. These data show substantially lower levels of funding for autistic participants compared to participants with other primary disabilities. Though the analysis of the data does not articulate this issue.

This suggests that severity ratings for autistic NDIS participants do not relate to or promote fairer planning processes ... as the NDIS wants us to believe it would.

A4 finds the discussion of life-time costs incomprehensible ... and shows its own version.

Overall, the report shows extremely poor data collection and reporting from the NDIS on benefits and cost-effectiveness of the NDIS.

Detail

Figure 2.2 - autism & CP have the poorest initial LoF scores. This figure tells us that after 5 years, participants with a primary disability of autism and/or CP have moved the most from their initial LoF ... apparently, requiring greater amounts of upward adjustment.

Better or “More robust, objective data” would benefit the scheme. A4’s experience is that the NDIA resists calls for better data, and even failed/refused to deliver on its promise/commitment to collect better data.

Table 2.2 Severity bands - only spinal chord injury has 5th band. What is that about?

What is the origin and basis for these bands? Has there been any co-design? Are the disability-function bands from the AFSR? Where can we see the data? A properly documented DSM-5 diagnostic report provides multiple levels of functioning - how do these bands related?

Autism has the lowest rate of Band A (least severity) - probably because "Delay" has least rating - and this is probably wrong. Or it may be because parents/family (Informal Supports) meet much of the functional need. This area needs much more careful analysis.

Autism severity has a unique severity distribution - though ID has a more even spread ...

Table 2.3

Autism has low average payments and plans relative to other disability types for the same LoF.

This may be due to very low SIL uptake for Autistic NDIS participants. The NDIS does not seem to appreciate the contribution that Informal Supports provide for Autistic NDIS participants.

In the "C" & "D" severity ratings, autism payments and plan values are mostly < ½ other disability types. And worse utilisation. Lowest SIL rates (need to allow for high rates of <18yo). It seems most burden is on Informal Supports ... who NDIS denigrate.

Following is a restructured table from Table 2.3 shows average budget for disability type and severity rating. It is intended to allow easier comparison of budgets between disability types for their various severity ratings.

| Disability/severity | A | B | C | D | E |
|-----------------------|----------|-----------|-----------|-----------|---|
| Acquired Brain Injury | \$66,600 | \$119,800 | \$221,000 | \$366,100 | |
| Autism | \$22,400 | \$28,300 | \$81,000 | \$101,900 | |
| Cerebral Palsy | \$43,500 | \$238,200 | | | |
| Delay | \$19,900 | \$47,500 | | | |
| Hearing | \$11,900 | \$31,500 | | | |
| Intellectual | \$41,600 | \$76,800 | \$136,300 | \$227,400 | |
| Multiple sclerosis | \$41,500 | \$97,200 | \$232,200 | | |
| Other | \$99,100 | | | | |

| | | | | | |
|-------------------------|----------|-----------|-----------|-----------|-----------|
| Other Neurological | \$57,400 | \$116,500 | \$222,500 | | |
| Other Physical | \$39,600 | \$84,000 | \$143,600 | | |
| Psychosocial disability | \$52,100 | \$67,500 | \$111,400 | | |
| Spinal Cord Injury | \$77,400 | \$110,900 | \$164,100 | \$224,900 | \$365,200 |
| Stroke | \$57,200 | \$159,700 | \$324,100 | | |
| Visual / other sensory | \$28,900 | \$63,300 | | | |

The lower budgets for autism likely reflect that autistic NDIS participants are typically younger with lower funding ... perhaps because Informal Supports (no cost) provide much more support. It is not clear that this approach/outcome is equitable.

There are serious questions about fairness arising from these data.

The payments data shows a similar pattern, with perhaps greater differences for autism. Greater difference means less plan utilisation which may mean autism costs less to the NDIS ... but autistic people get fewer of their needs met.

While it is difficult to compare disability types, I find it hard to understand why autistic people get less support when the DS-IV and DSM-5 seem to suggest that ASD needs more support than Intellectual Disability. Also, there is no indication in these data that people with ASD and primary disability and with ID as a further diagnosis get the support they need for their ID. The data does not even tell us how many people there are in this category (A4 expects it is more people than in some other primary disability types).

Section 4.3.10 Early childhood and positive behaviour supports

This section shows an especially poor understanding of both the historical/legacy supports and recommendations for children with disability, especially children with autism.

It fails to appreciate the PBS context (PBS is related to behaviour science - or ABA). Some adults with disability also need significant levels of behaviour support - but this does not seem to be mentioned. Nor is the lack of credible legacy behaviour support mentioned.

It does not recognise that children diagnosed autistic who the NDIS deems ineligible cannot access early intervention that the legacy HCWA system provided for autistic children previously. This situation breaks one of the promises made when the NDIS was introduced - that no one with a disability would be worse off.

The following shows plan payments from the same source.

| Row Labels | A | B | C | D | E |
|------------|---|---|---|---|---|
|------------|---|---|---|---|---|

| | | | | | |
|-------------------------|----------|-----------|-----------|-----------|-----------|
| Acquired Brain Injury | \$50,400 | \$ 94,200 | \$188,300 | \$327,300 | |
| Autism | \$14,000 | \$18,500 | \$63,000 | \$86,300 | |
| Cerebral Palsy | \$32,000 | \$211,900 | | | |
| Delay | \$11,100 | \$35,400 | | | |
| Hearing | \$5,600 | \$20,800 | | | |
| Intellectual | \$29,700 | \$60,700 | \$114,700 | \$203,100 | |
| Multiple sclerosis | \$27,800 | \$71,000 | \$202,200 | | |
| Other | \$82,000 | | | | |
| Other Neurological | \$41,500 | \$89,900 | \$184,700 | | |
| Other Physical | \$26,600 | \$63,900 | \$118,400 | | |
| Psychosocial disability | \$38,100 | \$52,300 | \$90,100 | | |
| Spinal Cord Injury | \$57,000 | \$87,100 | \$134,800 | \$196,200 | \$351,200 |
| Stroke | \$41,400 | \$127,700 | \$292,700 | | |
| Visual / other sensory | \$20,400 | \$52,700 | | | |

Autism also shows lower utilisation (payment/budget) than most other disability types. So autistic participants seem to have difficulty accessing services even when they have funding.

4.3.11 the legal system (there is no justice system for people with disability in Australia)

This is also an inadequate coverage of the issue.

4.3.12

This section fails to recognise that without school transport, many students with disability cannot access education services. This is a breach of human rights ... and shows that much of the disability sector, those who endorsed "disability access standards" failed to recognise a major access issue for children with disability.

School transport does not relate to children aged 0-5 years.

4.4

Children with DD cannot be considered “unanticipated costs”. If they are, then the scheme designers had very little idea when they defined DD in s9 of the Act.

Here is some data and calculations from the latest (Sep 2023) NDIS data:

| RprtDt | DsbltyGrpNm | AgeBnd | AvgAnlsdCmt dSuppBdgt | ActvPrtpnt | budget |
|-----------|----------------------------------|--------|--------------------------|------------|-----------------|
| 30-Sep-23 | Developmental delay | 0 to 6 | \$ 22,000 | 63,129 | \$1,388,838,000 |
| 30-Sep-23 | Global developmental delay | 0 to 6 | \$ 26,000 | 11,690 | \$303,940,000 |
| 30-Sep-23 | Developmental delay | ALL | \$ 21,000 | 74,364 | \$1,561,644,000 |
| 30-Sep-23 | Global developmental delay | ALL | \$ 25,000 | 15,956 | \$398,900,000 |
| | <i>Cost 7+ years</i> | | | | \$267,766,000 |

This shows that the \$980 million estimate is low - it’s more like \$1.96 billion.

In Mar-23, the cost of “Delay” was around \$1.58 billion.

Over 6 months Mar-Sep 2023, growth in the number of children with “Delay” aged 0-6 years was 28.5% (which is huge), and 7+ years was 23.9% (also huge). Their average NDIS plan decreased by \$1,000 - which is not consistent with cost-of-living increases.

It is hard to be confident in the report when its data does not seem to add up.

4.5 Lifetime cost estimates

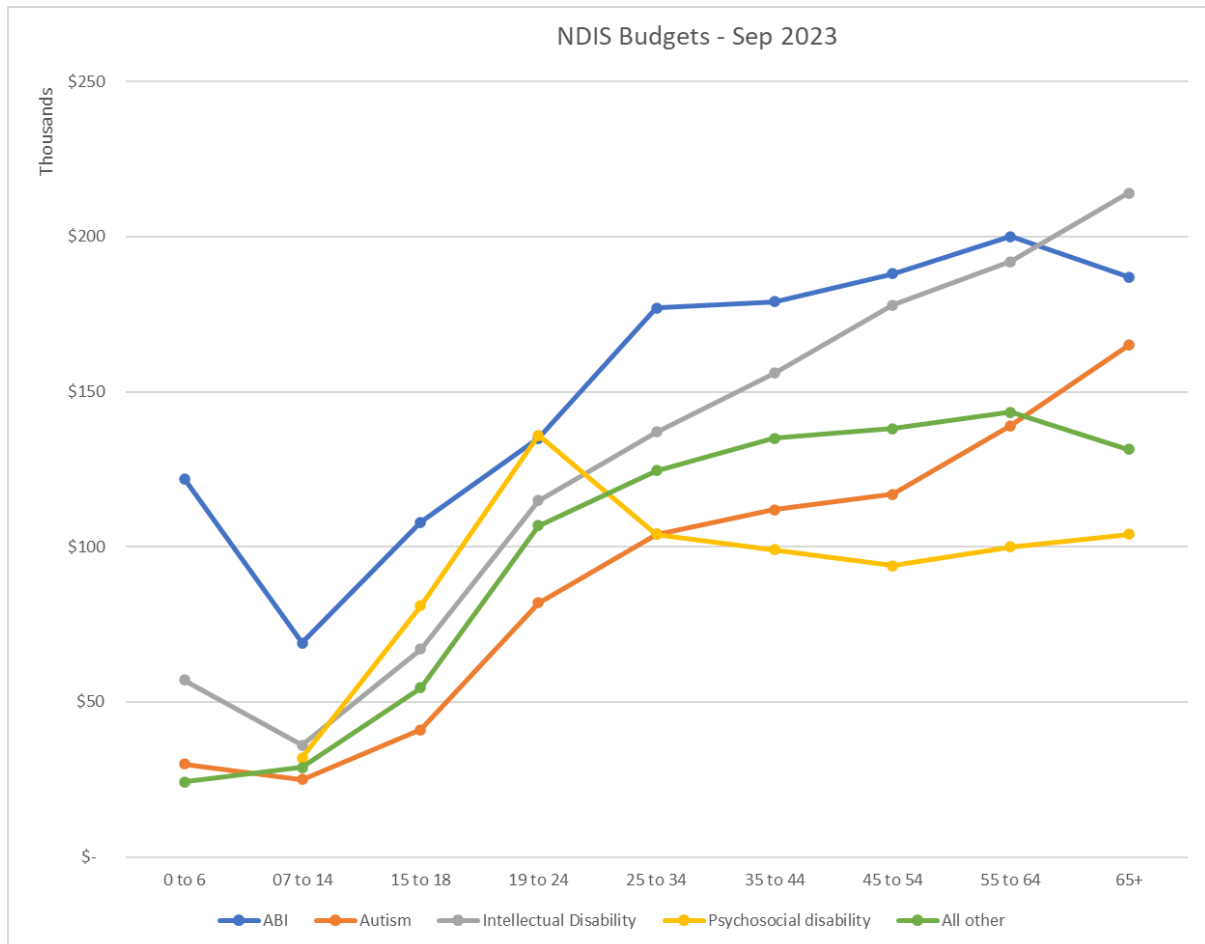
I have no idea what this section is about. I don’t understand what it is meant to show or how the figures are arrived at.

It says “ The NDIA has shared with us the most recent lifetime cost estimates (from their June 2022 AFSR).”

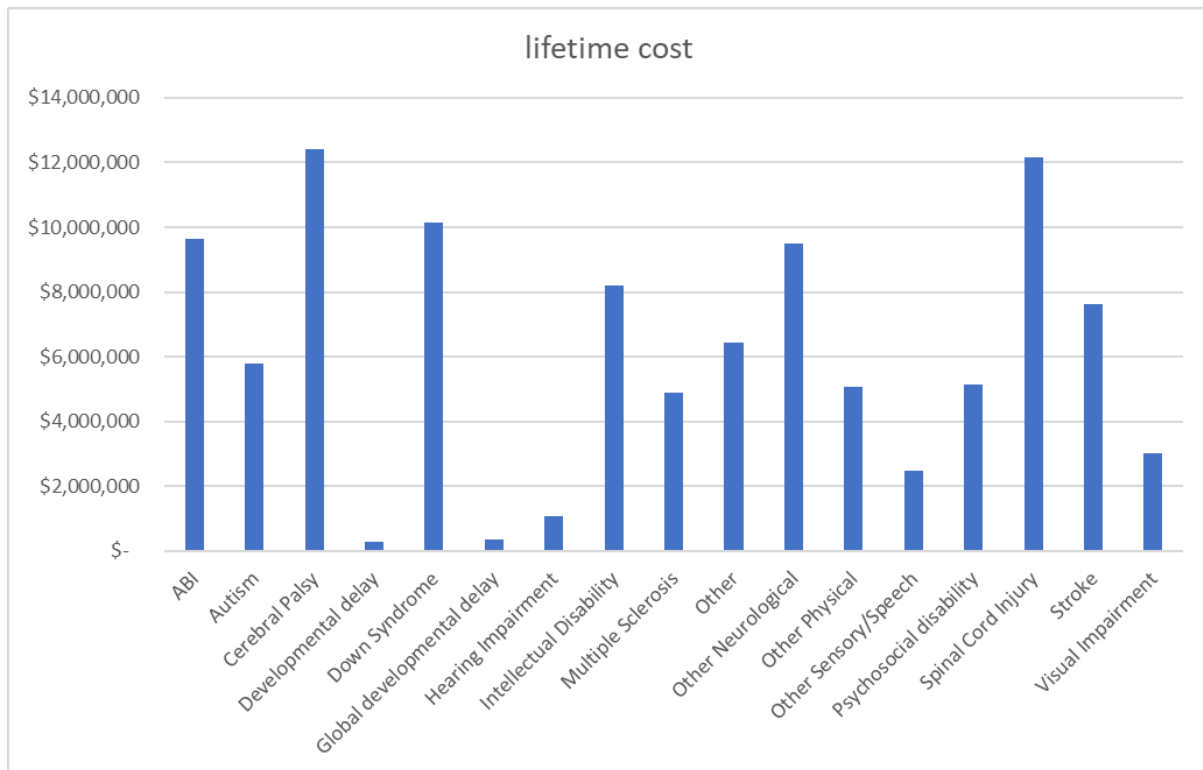
When I look at the lifetime expenses information in the June 2022 AFSR, it makes no sense to me. My estimates of lifetime expenses are substantially different to those here. And the comparisons in the ASFR with GDP seem peculiar.

There are no “lifetime cost estimates” in the June 2023 AFSR.

I did some lifetime cost estimates based on NDIS data (from NDIS’s website, not from this report or the AFSR). This shows the average plan budget by participant age.



Counting these amounts over a lifetime, I get the following lifetime costs based on individual costs associated with primary disability - all amounts are in 2023 dollars.



This is a different result from what the AFSR and the Taylor Fry report describe. We should get the Scheme Actuary to validate these results.

4.6 Variability in NDIS costs across participants

The report says “The NDIS currently takes a subjective approach to determine a participant’s reasonable and necessary level of support, based on the interpretation of how the provider or support coordinator describes a participant’s circumstances.” If in fact the NDIS ignores the participant and relevant clinicians, it is unsurprising that “This can lead to participants in similar situations receiving different support packages.”

Figure 4.4 shows substantial variability ... and inconsistency.

Looking at Figs 4.4.and 4.5, it seems likely that the level of functioning as measured has relatively little to do with support needs or “reasonable and necessary”.

As the report says “The variability also points to potential equity concerns”.

For autism, lower severity (A) gets more funding and is spread across a wider funding range than the next two levels (B & C). This information does not support the NDIS’s claims that they need functional assessments to achieve fairer outcomes. That claim needs much more evidence to justify it.

5.4.1 Mortality

The right side of Figure 5.3 is reassuring for the autism community. Annual mortality is very low compared to other disability types. That is not what we hear in other contexts.

5.8.2 School attainment

It's hard to interpret this section of the report. It probably shows that the NDIS is not having much effect on school Year 12 attainment. Most of the data must be for autistic students.

I'd have hoped for a better outcome.

6 Comparison of costs and benefits

I don't understand this section.

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7 A future measurement framework

7.2.1 The NDIS outcomes framework

“Specialist services” are needed to prepare severely autistic students for school, not just for “everyday life”. They then need to learn in school so that they can participate better as adults.

The indicators are “ableist” rather than neuro-affirming. Given the increasing autism in the community, a more neuro-affirming approach is essential.

The ADS failed to measure or recognise the missing measures for autistic Australians ... which is why we need the NAS.

7.2.2 The Australian Disability Strategy Outcomes Framework

A4 has said before that this work should be aligned to the broad improvements in well-being reporting intended by this government for all Australians.

7.2.3 Other relevant Australian and international frameworks

Australia needs the equivalent of *Closing the Gap* for autistic people. A4 hopes that the NAS will have this result without needing a Royal Commission.

7.5.1 Planning & Goals

The NDIS needs different approaches for children than from adults. For children, the NDIS needs to recognise that Capacity Building is often the primary focus more than Community Access and Daily Living supports.

It is concerning that Figure 7.3 suggests “choice and control” is the biggest goal target. Choice & control are meant to be a fundamental part of the Scheme. Choice and control of one's NDIS Plan should be separate from choice & control in the rest of one's life.

For autism, the ADS is irrelevant because it tracks disability generally and ignores especially poor outcomes, relative to disability generally, for the autism sector. The metaphor that the only lifeboat in the ocean rises with the tide to the benefit of all failed because the lifeboat that most autistic people are in lacks buoyancy - it just stays sitting on the bottom while the tide rises around it.

The section on “Data requirements for outcomes” (p140) is pretty brief.

- For a period, the ABS SDAC was conducted every 3 years - but was recently allowed to lapse - the last one was 2018, and the ABS website now says we can expect a new report in 2024.
- The NDDA pilots have been chronically under-whelming in relation to autism. Most of the pilots give no figures for autism, the most numerous primary disability in the NDIS. The education data from the SA government found only 1 in 5 autistic NDIS participants in the SA education system. This is an extremely poor result in a state that now even has a Minister??? Focused on autism in education.

It is certainly true that “data challenges are greater for people with disability outside the NDIS”.

There is no reason whatsoever to believe “a more frequent SDAC would go some way to address” anything, since there is little or no notice taken of ABS SDAC reports in relation to autistic AUstralians. The ADS, DRC and NDIS Review demonstrate this. Hopefully the NAS will do better.

In relation to “Intersectionality”, there is an increasing need to recognise autistic Australians as a distinct intersectional and vulnerable group ... like other increasingly recognisable groups like AUSLAN, wheelchair users, etc.

In relation to provider-collected outcomes, hopefully this might be based more on clinical/professional aspects rather than for-profit agendas.

Most of the outcomes for children and adolescents with disability are observed as they move between providers ... so this model really makes little sense. The NDIS keeps arguing that it needs Independent Assessors ... then there is this discussion. They really are not clear about what they want or why.

7.5.3 Benefits

The NDIS legislation requires that supports are cost effective. But the NDIS (and its Act) do little to ensure this is the case. There is little or no real measurement of benefit ... while cost is easy to monitor (but poorly executed).

I am unaware of any effort to monitor the benefit of the NDIS’s early intervention provisions.

The NDIS keeps saying it wants to be based not on diagnosis but on functional assessment, but there is no analysis of benefit associated with functional assessments.

A4 questions whether there is a benefit analysis associated with policies like [the NDIS’s intensive ABA policy](#).

7.5.4 Investment

A4 doubts the existence of an investment analysis in relation to autistic NDIS participants ... or any measure of adherence to its seven investment principles.

7.6 Next steps

Basically, this calls for “an enhanced measurement framework”. Given the ongoing poor outcome that the autism sector experiences, then this has potential for driving improvement if it is done properly.

Some of the improvements I believe NDIS measurement and reporting needs include:

- More on goal quality for individuals
- Reporting of the relationship between goals, their budgets and outcomes
- More detailed analysis of both disability and levels of functioning
- The impact of multiple conditions on participants’ needs.
- The value of investment as well as the cost of disability supports.

E.10 Education outcomes for children

This seems the best possible spin from the NDIS’s perspective.

This probably needs to be considered in the context of the DRC finding on education for children with disability, especially in relation to autistic students.