

Inquiry into the Capability and Culture of the NDIA

Statement by Tim and Emily

Introduction

is our beautiful 15y.o. profoundly autistic son, who faces a mountain of adversity each day. Full of energy, with a cheeky glint in his eye, he enjoys a wonderful, unique sense of humour. spends his days reciting his echolalic phrases, delighting when a trusted carer joins in. He struggles to be in the same space as children and only accepts certain adults. When anxiety and sensory overload combine, as they do frequently, will communicate his profound distress through biting, grabbing, kicking, hair-pulling and devastating self-harm – often banging his head on corners, windows, or brick walls. His daily existence is a fragile balance between contentment and pleasure and chaos and utter distress.

In diagnostic terms, has a complex neurodevelopmental presentation of multiple co-morbid conditions including ASD Level 3 in association with a severe intellectual disability (ID), a severe communication disorder, severe sensory processing difficulties and Generalised Anxiety Disorder.

Over the last 12+ years we have adapted our lives, re-setting our priorities, limiting our involvement in almost all areas of life to care for our precious son, with such overwhelming and complex support needs.

number one goal on his NDIS plan is to continue living with his family for as long as possible and for us all to feel safe. We undertake as much of the care of that we can manage. This is an all-consuming challenge. It dominates our lives and leaves us exhausted, scarred and bruised, physically and mentally. The focus however remains on , who confronts torment and distress each day with incredible human spirit, breaking our hearts but inspiring us and strengthening our resolve.

The NDIS has had a substantial positive and life-changing impact on life and wellbeing; however, the capability and culture of the NDIA is poorly adapted for someone like . Our statement focuses on profound disability and complex needs, the challenges of getting properly informed decisions and reviews for those well outside of standard ‘boxes’, and our experience of NDIA competency and ‘big bureaucracy’ culture. We share some positive and negative experiences.

Key points in statement

1. NDIA interacts as an impersonal bureaucracy lacking competence with complex needs

After some poorly justified decisions and internal reviews, we have experienced extended delays in the AAT appeal process, caused by the NDIA. The power the Agency exercises seems to give it a cavalier approach to accountability, including its Model Litigant Obligations.

NDIS ideals include working together and gaining a rich understanding of the participant’s needs and adopting a relationship-based approach. We approach the planning process in this spirit, including celebrating the NDIS-enabled successes. However, the NDIA’s culture and process has often not demonstrated this stated ideal.

Our experience of the NDIA is one of a big, impersonal bureaucracy that is not prepared to engage competently with complex needs. The Agency seems concerningly reluctant to engage experts and people close to participants. When we ask them to contact the advising health experts, they tell us that they don’t do that anymore! Instead, they appear more comfortable sending important decisions to faceless decision makers, who are remote from the participant and who often demonstrate extraordinary ignorance and power. This reflects the culture of the NDIA as we perceive it.

Internal decision reviews have been farcical, with reviewers failing to consider key documentation. The AAT appeals process is prolonged and was used by the NDIA to delay decisions concerning [redacted] by more than a year. While the NDIA and its legal representation failed, during this extended period, to contact any of the health experts who contributed supporting material, they did summons their case notes at the last minute, delaying the scheduled hearing by another three months! This demonstrates shortfalls in both culture and competence and is far from the stated ideals of gaining a rich understanding of the participant's needs and adopting a relationship-based approach. We have received apologies for poorly made and justified decisions, but these are accompanied with, "Sorry, we pressed the button and now we can't help, but you can go to the AAT".

This NDIA holds enormous power to impact the lives of disabled people but lacks real accountability. When we complained that the NDIA did not uphold its Model Litigant Obligations, there appeared to be scant accountability for that commitment, apart from opaque self-assessment. This aspect of its culture has surely resulted in a great deal of mistrust of the Agency.

2. Family-centred support models are still undervalued

Enabled largely by the NDIS, we now have a wonderful team around [redacted]. His safety, wellbeing and quality of life have improved significantly as a result. Working together with his parents, the team includes specialised health professionals (Psychiatrist, Psychologist, OT, Behavioural Support Practitioner, etc.) and a carefully chosen team of skilled, competent, and highly dedicated Support Workers who love [redacted] and are committed to the long term to make his life as good as it can be.

This family-centred model, however, does not fit comfortably with the NDIA and NDIS Commission norms. Where Positive Behaviour Support Plans (PBSPs) are used, the family role is assumed to be largely supplanted by registered entities. This is not respectful or affirming of the critical role of families. We and other supportive, loving families of NDIS participants with PBSPs are let down and hindered by the legislation in providing care for some of the most vulnerable in our society. We seek flexible options suited to a family-centred support model to give our son his best life. This contrasts with a support model based on large, registered, high-cost service providers which have proven to offer poor options and outcomes for this cohort. Exploration of 'light touch' registration for small providers and 'proportional' audits, don't seem to have resulted in more family-friendly policies.

3. Focus on those with profound impairments

The NDIS was designed and created for those with the most profound impairments. To live up to that vision, focus is needed. The NDIA presents as a large, unwieldy bureaucracy where those with the most profound impairments are likely to be let down because they don't fit into standard boxes.

Those with **profound autism**¹ are inadequately represented by nearly all disability representative organisations. Those with severe or profound impairments, including Intellectual Disability and serious, debilitating Behaviours of Concern (BOC) are often extremely vulnerable. The voices that represent them are few and small and they remain in the 'too-hard basket'. For someone like [redacted], almost universally, advocacy groups, researchers and private and state services fail them routinely. They typically end up having very low quality of life, invisible to most.

¹ **Profound autism** is defined according to the 2021 Lancet Commission recommendation, which includes being **nonverbal or minimally verbal, with IQ < 50 and needing 24/7 support**. This definition provides critical specificity to the extremely broad spectrum. A 2023 CDC Public Health Report on The Prevalence and Characteristics of Children with Profound Autism, using data from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, found that 26.7% of 8-year-old children with autism suffer from profound autism, with an overall birth-cohort prevalence of 0.46% of 8-year-olds. For the children with IQ data available in the records, the profound autism rate was 29.4%.

With work under way on the National Autism Strategy (NAS), we can only call out on behalf of our son who can't speak for himself, that it looks destined to marginalise or even to screen out the existence of profound autism and people like . Despite the guidance in the Senate Committee's 2022 report on Autism, which called for the NAS, the realities of profound autism do not sit comfortably with the dominant perspective and so are sanitised from such initiatives. Such **"partial representation"**² leaves the most vulnerable behind. We confidently anticipate that people like our son will be marginalised in the NAS, so the NDIS must focus on those with the most profound impairments.

is on the Complex Needs NDIS stream, which is a commendable initiative. However, we still experience opaque decision making, impersonal bureaucracy and a concerning lack of engagement with the relevant specialised health professionals. Our trust in the competence and integrity of NDIA decision makers has been eroded and we seek more transparent and informed decisions. It is not realistic to expect the NDIA to develop expertise in the broad spectrum of disabilities including profound autism, but the Agency needs to engage effectively with those who have that expertise and intimate knowledge of participants and their support needs.

Recommendations to improve culture and capability of NDIA:

- a) NDIA planners and decision makers should engage with health experts treating participants up front. 'Right first time' takes longer initially but builds trust and saves in the long run.
- b) NDIS Legislation, Rules and Guidelines need to be refreshed to enable more flexible and family-centred models to thrive even when complex needs and behaviours are present.
- c) Focus on those with the most profound impairments, even when others marginalise them.

² McCoy et al. (2020) coined the term "partial representation" to describe situations in which an actor or subset of a population claims to represent an entire group of people but appropriately engages with only a subset of that group. Common in autism advocacy, the term "partial" reflects that such advocacy is necessarily both incomplete and biased.

Ref: McCoy, M. S., Liu, E. Y., Lutz, A. S. F., & Sisti, D. (2020). *Ethical advocacy across the autism Spectrum: Beyond partial representation*. *The American Journal of Bioethics*, 20(4), 13–24.