To the Inquiry Into The Thriving Kids Initiative

My name is Shane Mathew Scriven. I am an autistic adult living with co-morbid Attention Deficit Hyperactivity Disorder and Obsessive Compulsive Disorder. I am an NDIS participant, and currently a Bachelor of Social Work student at the University of South Australia, on my second work placement in a child therapy context, to graduate at the close of the year.

I am making this submission due to my extreme misgivings at the course taken by the federal government over the rising costs of the NDIS, and the arbitrary, harmful and futile targeting of autistic individuals as a way of “reducing” those costs. I wish to speak on three points relevant to the inquiry.

1: “Mild to Moderate”

The terms that the federal government has used to indicate which autistic children and adults will be removed are vague to the point of uselessness; “mild to moderate” does not fit the measures used by the DSM or the autistic community, and has caused a great deal of fear and worry among families that the supports they need will be ripped away from them.

The DSM categories of 1, 2 and 3 are not static constructs that an autistic person can be assigned and will remain true forever or even unilaterally; most autistic individuals have differing degrees of support needed in differing situations, and depending on the context, most autistic people can fit into any of the categories at a given time. Further, over time the “general” category someone has been placed under can no longer be accurate or appropriate, due to factors such as ageing, burnout, major life transitions and various forms of trauma.

This attempt to “flatten” autistic individuals into easily-sorted categories is inaccurate, not based in any form of scientific or qualitative evidence, and directly harmful. I personally was placed in the “2” category, and qualified for permanent DSP. Due to the NDIS I have been able to “rise” to a 1 in some situations, allowing me to attend university and enter the workforce with ongoing support. If I were to be classed as “moderate”, I would not have been able to do this, and would remain in limbo for my entire life.

I recommend that clarity regarding how and why classifications will be made, and the process by which to have these classifications reviewed or changed be an urgent priority for the Minister, as trust in this initiative among the autistic community is extremely low at the current time.

2: Evidence-Based Support in “Thriving Kids”

There are concerns among the autistic community that this program will be focused upon CBT principles, which when applied to young autistic children has the potential to go very wrong, very quickly. Due to the theoretical base of this therapy, autistic children are more likely to take away the lesson of suppressing autistic behaviours, sensory distress and trauma from abuse. CBT has become the hot therapeutic tool, but when used recklessly, especially with neurodivergent clients by a neurotypical therapist, can do much more harm than good.

It is my recommendation that the inquiry calls upon autistic adults who underwent any considered therapeutic intervention as children themselves as the authorities on whether it is appropriate, as no rigorous studies into the negative effects of CBT on neurodivergent individuals or any in general have been conducted.

3: Costs of the NDIS
The foundational concept that this will reduce the rising costs of the NDIS is fundamentally flawed. The ballooning costs are due to a number of different factors, and this measure will not slow the rise.

First, there is no means of efficiently connecting clients to services for approved supports. As such, clients and their families are forced to rely upon word-of-mouth and advertising to connect to services, and often end up contracting a service quite a large distance away while much closer services exist causing large travel costs. This could be very easily remedied without needing to change policy, as the NDIS has the addresses of both clients and approved providers. It would be quite simple, when a client is approved for supports, to compare them to the list of providers for that support and give to them a list of providers and the distance to them. This is simply an IT solution, not one that requires legislation.

Second, there is no reason for providers to stop raising prices. Usually prices on the free market are restrained from growth by whether consumers can afford them, how much the consumer needs the service and how willing they are to pay the price. These together mean that a provider can only raise the price so high before people stop buying; however under the NDIS these three things are null, as clients require the services, can afford them and are willing to buy. No matter how many cohorts are removed from the NDIS, providers can simply raise the prices further to make up their losses. This cannot be fixed without the government rationalising prices and pegging them to inflation; setting how much a given service is worth, how much a given workers labor is worth and how much administration costs are reasonable.

Third, the layout of the Australian residential landscape. The fact that most of Australia is suburban, speaking demographically, is a major factor as to why the NDIS costs so much to run. With clients so separated by distance, there is no economy of scale in effect in regards to much support work. Every single client is singular, no matter whether they would be willing to live in closer proximity to other clients, and as such each and every one requires a minimum amount of support workers. If the option for closer habitation, or even co-habitation was available, a large number of NDIS clients, especially adult ones, would be happy to live with or next to people who understand their struggles and their lives, and through this the sheer number of support workers and other contractor services required would be significantly reduced.

In Conclusion

While I wholeheartedly support the provision of supports for autistic children who do not fall under the aegis of the NDIS, the changes that the federal government are intent on enacting are not fit for purpose; they will not address the issues they claim to address, are causing significant distress and concern for the community at large, have no useful evidence-base to work with and are not being targeted accurately or effectively. As such I call upon the federal government to listen to stakeholders on why this is not going to work, and make changes in order to address the issues in an effective manner. If the federal government remains on this course into 2027 without adjustment, I cannot see a positive electoral opinion coming from the autistic community, whether autistic adults or the parents of autistic children.