Submission into the inquiry into the “Thriving Kids Initiative”

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Confidentiality: I request all identifying details of my children remain confidential.

Dear Committee Members,

I am the mother of three children who have been supported under the NDIS for the past four years. All three were born extremely premature at 26 weeks. The NDIS has been life-changing for us, it gave my children a chance to develop through therapies we could never dreamt to have afforded on our own. But once they turn six, we are told they will no longer qualify for NDIS support. This is because their needs fall under Global Developmental Delay, which is not considered a “primary disability.” The reality is that their challenges will not disappear at this standardised age of six. They are not disabled “enough” for the NDIS, but they are far from being able to cope without ongoing support. Families like mine are left in a gap that should not exist.

My children continue to struggle with gross motor and fine motor skills, feeding difficulties, ADHD, epilepsy, sensory sensitivities, and significant speech and language delays. They are still underweight MINUS 4% below the weight scale for their age and all require oral nutrition supplements to grow. Behavioural and emotional issues add another layer to their complexity, impulsivity, meltdowns, aggression, and constant dysregulation. I am called to pick them up from preschool early, and I cannot safely take all three children out in the community alone without support workers. Even managing their many medications at home and simple routines at home require help. We have been one of the lucky families, the NDIS has seen my children for the blessing they are but also, the hardships we are going through to order to get them to “catch up” in time.

The progress they have made is because of years of intensive therapy speech, occupational therapy, physiotherapy, psychology, feeding specialists, and dietetics. We have slowly been able to wean some supports but WHEN that support stops, their progress will stop too. Ten therapy sessions a year will not touch the sides of what these children need. Families like mine cannot possibly afford the full cost of ongoing therapy privately, we are already paying privately for their medications, surgeries and now out of pocket for psychology. The NDIS has already invested hundreds of thousands of dollars in my children, and we are so grateful for that. But if this reform goes ahead without children like mine in mind, all that investment will be wasted. More importantly, my children’s futures will be put at risk.

I want to pledge my clear support; I welcome the Thriving Kids initiative. It is desperately needed. But if it does not explicitly include children who fall through the cracks of NDIS eligibility, children with complex overlapping needs, but no single primary disability (like mine). Then my children, and many others like them, will be left to fend for themselves. That is not fair, it is also not sustainable, and it will undo years of progress. I am terrified of what will happen if there is no system to catch them after NDIS. But I will not stop fighting for them. I will advocate until my voice breaks, because they deserve the same chance as every other child to thrive. Please do not leave families like mine in the dark. Please make sure Thriving Kids is designed for children who are still behind, still developing, and still in need of therapy and support to have a fair shot at life.

They will get there, please just give them more time.

Thank you for considering my submission and hearing our voice.

Kindest regards,
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