Executive Summary.

Our family faces extraordinary challenges caring for a child with a Pathological Demand Avoidance (PDA) profile of autism - the neuroaffirming term for which is Persistent Drive for Autonomy profile.

Masking extensively outside the home but experienceing intense post-masking dysregulation at home, including physical and verbal aggression. This results in profound functional impairment, frequent inability or refusal to leave the house or attend school, and a constant need for adult supervision. (school disengagement isn't helped by a schooling system that doesn't habe trained staff on PDA)

The withdrawal of sensory aide funding from the NDIS has forced us to personally fund sensory and regulatory tools. Despite this, our children's needs are often invisible in mainstream settings but devastating in private. As their primary carer and chosen "safe person," I am at high risk of carer burnout, depression, and anxiety.

We are asking Thriving Kids to:

-Recognise masking

-Post-masking dysregulation

-School refusal

all as indicators of high need.

Additionally provide specialist staff trained in PDA and trauma-informed, low-demand practice.

Reinstate or dedicate funding for sensory aids.

Support parental mental health and provide emergency respite and crisis planning , to ensure families remain families.

Publicly educate to reduce stigma around technology use and invisible disabilities and the importance of acceptance of differences.

Advocate for broader policies that financially support and value primary caregivers.

Without intensive, trauma-informed support, families like ours risk collapse.

We believe Thriving Kids can be a catalyst for system-wide change by explicitly addressing these needs and the wider cultural factors that affect children's mental health.

Introduction

I am the parent of a child with a PDA profile of autism. While they may appear outwardly regulated at school or in public, at home they experience severe emotional and behavioural dysregulation, including aggression and panic-driven avoidance of everyday demands. This "masking–collapse" pattern places them and our family at a high and complex level of need that is not reflected in outward appearances.

Evidence and Context

Research consistently shows that autistic children who mask experience elevated stress and trauma responses. PDA profiles are linked to extreme anxiety, avoidance, and difficulty with self-regulation. Polyvagal theory explains how prolonged masking depletes nervous system resources and triggers fight, flight, or shutdown behaviours once the child feels safe at home.

Despite decades of early childhood and school-based programs, children like mine remain largely invisible to systems built on short observations and demand-based models. This mismatch leaves families unsupported even as behaviours escalate privately.

Impact on Daily Life

Leaving the House: Our childs extreme anxiety and dysregulation mean they cannot reliably leave home, attend school, or participate in community activities. At times they refuse to leave altogether; at other times their aggression makes outings unsafe.

Social Isolation: This unpredictability has forced us into isolation, missing key social, educational, and developmental opportunities.

Parent Workforce Impact: Managing the needs has made maintaining regular employment nearly impossible. I have had to resign from my job to prioritise his care, despite once being a full-time professional.

Safety & Supervision: Require constant adult presence even for routine transitions or outings.

A typical day... On mornings when I attempt to take my child to school, they may become physically aggressive, then collapse in tears. Even when successful, he holds himself together all day only to “unravel” the moment he gets into the car, overwhelmed by sensory and social demands.

Financial Strain and on going Burden

The reduction of NDIS support for sensory aides has had a devastating financial impact.

I recognise our privilege in being able to purchase these items at all — many families cannot. Yet even for us, the costs are unsustainable. It is deeply unjust that these vital supports are treated as optional extras rather than necessities.

Parent Mental Health & Carer Burnout

As the primary carer and “safe person,” I carry an intense and unrelenting load:

Burnout Risk: Constant co-regulation with little downtime.

Career & Financial Strain: Reduced income and career progression due to unreliable work attendance.

Administrative Overload: Many hours each week on therapy applications, funding requests, and school meetings.

Emotional Stress: Exposure to aggression, unpredictability, and public judgement contributes to chronic anxiety and depression.

Loss of Social Support: Fear of public meltdowns and exhaustion have eroded friendship groups, family support and made us the family that hides away.

Disconnected from community and far from Thriving.

Please help us & many like us.

Research shows approximately 2% of ASD profile people have PDA profile meaning numbers are massive, not just a few but thousands.