



Understanding and Supporting Demand-Related Distress and Avoidance

An evidence-informed guide and practical toolkit for families, educators and support teams

Open Circle · Behaviour Support Practice Resource

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What this resource is

This guide brings together current peer-reviewed research, lived experience and practice guidance on what is often called the "PDA profile" (pathological or extreme demand avoidance; persistent drive for autonomy). It then translates that evidence into twelve practical tools that can be printed, adapted and used.

Evidence labels appear throughout so you can see whether a point comes from systematic reviews, individual studies, qualitative evidence, lived experience, practice guidance or theory.

No individual participant information is included. The tools are generic and are designed to be completed for the child or young person you are supporting.

What this resource is not

This is not a diagnostic instrument and cannot determine whether a child or young person "has PDA". It does not replace individual assessment, a functional behaviour assessment, a Behaviour Support Plan, clinical supervision or NDIS Quality and Safeguards Commission requirements.

It does not provide medical, legal or NDIS eligibility advice. It does not recommend restraint, seclusion, punishment or forced compliance.

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About this resource

Who it is for

- Parents, carers and family members of children and young people whose distress and avoidance are triggered by everyday demands and expectations.
- Teachers, education support staff and school leaders.
- Behaviour support practitioners, allied health professionals and support coordinators working within the Australian NDIS context.

How to use it

Start with Part A for a short overview of the evidence. Then choose the tools that fit the question in front of you - you do not need to use them all. Tools 2, 3 and 4 help explore why distress may be happening; Tools 6, 7 and 8 support day-to-day decisions; Tools 9 to 12 help build skills, share approaches across settings, support carers and review whether the plan is helping. Part C sets out safeguards and evidence limits.

The stance this resource takes

Start with curiosity, not blame

When a child goes to extreme lengths to avoid an ordinary request, this resource starts from the working hypothesis that they are experiencing a threat response driven by anxiety, a perceived loss of autonomy, sensory overload, or a combination - "can't, not won't" - rather than defiance to be overcome.

Hold that hypothesis lightly and test it against the individual child's data. Compliance is not an outcome measure in this resource. The outcomes that matter are distress, participation, communication, quality of life and family wellbeing.

At a glance

- Demand-related distress can be profound. Treat avoidance as communication or self-protection until the individual evidence suggests otherwise.
- PDA is not a diagnosis in DSM-5-TR or ICD-11; in Australia it is recognised in national autism guidance as a behavioural profile within autism.
- No single cause has been established, and there are no randomised controlled trials of PDA-specific interventions.
- Use the profile to prompt questions, not to replace individual formulation.
- Measure distress, participation, communication, quality of life and family wellbeing - not compliance.

How the evidence is graded

Throughout, claims carry a grey tag showing the type of evidence behind them. The grades, from most to least able to support a strong conclusion:

Grade	What it means	How to use it
Systematic-review finding	A structured review of peer-reviewed studies using formal appraisal methods.	Strongest evidence here about the overall state of the research.
Single empirical study (parent-report)	One quantitative study, usually relying on parent-report data.	Suggestive; look for replication by independent teams.
Qualitative evidence	Interviews or thematic studies describing experience in depth.	Rich context; does not establish cause or effect.
Feasibility-level evidence	An uncontrolled pilot showing an approach can be delivered and accepted.	Shows feasibility, not whether it works better than alternatives.
Consensus / practice guidance	Guidance from professional bodies, practitioners or charities.	A reasonable practice starting point that has not been formally tested.
Lived-experience account	First-person accounts from autistic and demand-avoidant people and families.	Essential for dignity and design; not representative of everyone.
Theoretical proposal (untested)	A proposed mechanism without direct supporting evidence.	An idea to explore, not evidence for a plan.
Extrapolation from adjacent evidence	Findings from broader autism or behaviour-support research applied here.	May not transfer; treat as a hypothesis for the individual.

Part A - What the evidence says

A1 What people mean by the PDA profile

The terms people use

Several terms describe the same broad presentation: **pathological demand avoidance (PDA)**, **extreme demand avoidance (EDA)**, the **PDA profile**, and **persistent or pervasive drive for autonomy**. Some autistic people prefer identity-first terms such as "PDAer". Some dislike the word "pathological" as stigmatising; others feel it captures how all-consuming the experience is. *[lived-experience account; qualitative evidence - Nawaz & Speer, 2025; Carter, 2024; Company & Rotella, 2026]*

Practice point: use the terms the individual and family prefer, and say so in any plan.

Where the profile stands

- PDA is **not a recognised diagnosis** in the DSM-5-TR or ICD-11. *[consensus; stated in every source held]*
- In Australia, the Autism CRC *National Guideline for the Assessment and Diagnosis of Autism* (2nd ed., 2023, Good Practice Point 45.8) recognises PDA as a behavioural profile within autism - also referred to as persistent drive for autonomy - and asks practitioners to consider whether extreme demand avoidance is driven by an anxiety-based need for control rather than viewing the person as oppositional. The *National Autism Strategy* (2025) names support for people with a PDA profile. *[consensus / practice guidance - Autism CRC, 2023; Commonwealth of Australia, 2025; as also cited by Carlozzi et al., 2025]*
- Autism remains the diagnosis relevant to NDIS access. PDA is a *description* that informs support planning; it is not an eligibility category and no questionnaire can make it one.

What two systematic reviews found

Two systematic reviews have examined how PDA has been identified in research. Their findings are the most important thing to know before using any "PDA strategy":

- **Kildahl et al. (2021)**, 13 studies: identification of PDA in every study traced back, directly or indirectly, to Newson's original description, whose development was never clearly explained; almost all studies relied on parent report; alternative explanations for the behaviours were generally not considered; no study included the perspectives of demand-avoidant people themselves; and none focused on treatment. The reviewers concluded that evidence for PDA as a separate disorder, or as a stable subtype within autism, is currently lacking - while also stating plainly that demand-avoidant behaviours are a profound challenge for some individuals and families. *[systematic-review finding]*
- **Company & Rotella (2026)**, 12 studies, Australian-led: all twelve were rated at high risk of bias in every QUADAS-2 domain; the two identification tools (EDA-Q and DISCO) were applied inconsistently - three studies each chose *different* DISCO items; most samples were recruited from overlapping sources such as PDA forums; and the reviewers raised the problem of circular logic (a tool identifies PDA in a person because the person was already identified as having PDA). They concluded that supporting a distinct diagnosis is "highly improbable at this stage". *[systematic-review finding]*

Holding both truths

Truth one: families describing this presentation are describing something real, impactful and, in Australia, formally recognised as a profile. Dismissing it because the construct is contested harms families. *[qualitative evidence - Nawaz & Speer, 2025; consensus - Autism CRC, 2023]*

Truth two: the evidence that PDA is a distinct syndrome, and the evidence for any PDA-specific intervention, is preliminary. Presenting it as settled science also harms families, because a label can become a substitute for understanding. *[systematic-review findings - Kildahl et al., 2021; Company & Rotella, 2026]*

The way through is to **formulate for the individual child rather than plan from the label** - which is exactly what the tools in Part B are for.

A2 Why demand-related distress may happen

No single cause has been established. The research points to several contributing factors that differ from child to child, which is why individual formulation matters.

Anxiety and threat response

Higher anxiety and higher autistic traits predicted more demand avoidance in every group studied - autistic children identified with PDA, autistic children without PDA, and non-autistic children. *[single empirical study (parent-report), n = 795 - Rai et al., 2026]* Parents describe meltdowns as sudden and overwhelming, often best understood as panic responses rather than deliberate behaviour. *[qualitative evidence - O'Nions et al., 2018; Nawaz & Speer, 2025; consensus - Carlozzi et al., 2025]* Both systematic reviews note that anxiety, stress or trauma may underlie avoidance and are under-investigated. *[systematic-review finding - Kildahl et al., 2021]*

Sensory reactivity - a specific and new finding

In the largest mechanistic study to date, **sensory reactivity was the only factor that uniquely predicted demand avoidance in autistic children identified with PDA** - specifically tactile sensitivity, taste/smell sensitivity, and under-responsive/sensation-seeking patterns - after accounting for anxiety and autistic traits. The authors recommend that support address environmental sensory demands. *[single empirical study (parent-report) - Rai et al., 2026]* Parents independently describe clothing, uniforms and food as flashpoints. *[qualitative evidence - Nawaz & Speer, 2025; O'Nions et al., 2018]*

Practice point: an occupational-therapy sensory assessment is a routine early step in this resource, not an optional extra.

Autonomy, control and predictability

In interviews with 26 parents, almost all children needed things done "on their terms", most insisted others follow their rules, and all showed rapid mood switches and outbursts when pressed to comply. The researchers described the avoidance strategies - distraction, excuses, refusal, charm, passivity - as **strategic rather than "manipulative"**: often blunt attempts to escape pressure that do not require the insight subtle manipulation would. *[qualitative evidence - O'Nions et al., 2018]* One clinical view is that rigidity motivates the child to control events so they unfold as expected, with any deviation experienced as acutely aversive. *[consensus; authors' interpretation - O'Nions et al., 2018; Malik & Baird, 2018]*

Uncertainty and novelty - hold this lightly

Intolerance of uncertainty has been proposed as a key driver and has been associated with PDA in earlier parent-report work. *[single empirical study (parent-report) - Stuart et al., 2020, as summarised in Westby, 2025 and Kildahl et al., 2021]* However, the larger 2026 study found that intolerance of uncertainty predicted demand avoidance **only in non-autistic children, not in either autistic group**. *[single empirical study (parent-report) - Rai et al., 2026]* Novelty and anticipation still worsened avoidance for many children, and for more than half of families precise triggers were hard to identify. *[qualitative evidence - O'Nions et al., 2018]* Treat uncertainty as one possible driver to test for the individual, not as the assumed explanation.

Other contributors to check

- Health, pain, sleep, hunger and medication effects - always screened, because they lower tolerance for everything else. *[consensus / practice guidance]*
- Communication load and task difficulty - demands that outstrip language or executive capacity. *[extrapolation from adjacent (non-PDA) evidence]*
- Relational safety and prior experience - including past compliance-based approaches that may have made demand contexts more aversive. *[systematic-review finding on transactional development - Kildahl et al., 2021; consensus]*
- School pressure, masking and burnout - many parents date the crisis to increasing demands for conformity at school. *[qualitative evidence - O'Nions et al., 2018; Nawaz & Speer, 2025]*

- Age - demand avoidance scores decline with age in both the original questionnaire study and the 2026 study. *[single empirical studies (parent-report) - O'Nions et al., 2014; Rai et al., 2026]*

Alternative explanations that must stay on the table

Clinicians reviewing the interview evidence note that the features described richly overlap with autism itself, oppositional defiant disorder, conduct problems, and anxiety and mood presentations - but may have a different underlying basis. Their clinical impression is of *less* provocative behaviour and *more* rigidity and intolerance of uncertainty in demand-avoidant autistic children than in typical ODD. They also flag that parents recruited through PDA-aware channels may interpret behaviour through that lens, and that parent-child interaction factors are an unexplored research gap. Their conclusion: recognising the underpinning factors, rather than finding the right single word, is what opens an avenue for change. *[consensus / clinical commentary - Malik & Baird, 2018]*

A theory to think with, not to plan from

One hypothesis paper proposes that being told to act makes otherwise automatic actions consciously effortful ("mental process opacity"), which would fit the "can't, not won't" description. The author states that specific evidence for the claim is lacking. *[theoretical proposal (untested) - Frankle, 2025]*

A3 What helps and what tends to escalate

What the intervention evidence can - and cannot - tell us

As of September 2026 there are no randomised controlled trials of any PDA-specific intervention. Neither systematic review identified a treatment study. The intervention evidence consists of one uncontrolled parent-program pilot, parent-report and qualitative studies, practitioner consensus, and extrapolation from adjacent evidence. Any plan should say this plainly. *[systematic-review findings - Kildahl et al., 2021; Company & Rotella, 2026]*

The one intervention study - read it precisely

A 12-week virtual parent program (the Paradigm Shift Program®) was evaluated in a single-arm pre/post pilot with 76 enrolled parents and 60 completing both assessments. It teaches a "5 A's" curriculum (awareness, acceptance, accommodation, affirmation, advocacy) built on nervous-system/threat-response framing, radical acceptance and accommodations such as lowering demands, declarative language, humour, novelty and co-regulation. *[feasibility-level evidence - Carlozzi et al., 2025]*

- **Parents/guardians:** significant improvement in 10 of 13 quality-of-life domains, largest for caregiver strain (effect size 0.64), perceived stress (0.61), anxiety (0.60), anger (0.54) and depression (0.48); no change in self-efficacy, emotional support or physical function. About 90% felt more confident de-escalating and reported a better relationship with their child.
- **Children (proxy-report):** demand-avoidance scores on the EDA-8 improved significantly but modestly (effect size 0.27, small). All Strengths and Difficulties Questionnaire scales were non-significant. Parents themselves reported they did not believe their child's behaviour improved except for outbursts.
- **Limits:** no control group; a paying, voluntary, mostly white and higher-income sample; and a declared conflict of interest - a co-author founded and runs the company that sells the program (blinded to participation; the university ethics board judged no management was needed). The authors call for a randomised trial.

How to cite it honestly: as evidence that a low-demand, accommodation-based parent program is *feasible and acceptable* and *improves carer wellbeing* with moderate effects. Not as evidence that it changes child behaviour, and never as a "proven treatment".

Why reward-and-consequence approaches are not the default

Three separate sources describe reward, praise and consequence systems failing or backfiring for this presentation:

- 11 of 26 parents said their child appeared to dislike praise or recognition, and two described behaviour *worsening* after their child earned a prize. *[qualitative evidence - O'Nions et al., 2018]*
- Parents reported that "rewards and consequences" parenting did not work, that standard autism strategies such as sticker charts made things worse because performance expectations were experienced as demands, and that low-demand, control-sharing and sensory-accommodating approaches helped. *[qualitative evidence - Nawaz & Speer, 2025]*
- Practitioner guidance consistently advises against reward charts and consequence hierarchies for this profile. *[consensus / practice guidance - PDA Society PANDA approach, via Westby, 2025; Truman, 2021 and Kerbey, 2021, via Carter, 2024]*

This is qualitative and consensus-grade evidence, not experimental proof, and the reviewers caution that a distinct non-response to behavioural methods has not been demonstrated. *[systematic-review finding - Kildahl et al., 2021; consensus - Malik & Baird, 2018]* The safe, rights-based inference is: **do not assume compliance-based methods are harmless here**. Any contingency-based element in a plan is a hypothesis to be trialled individually, with the child's distress and safety as the stop criteria.

Approaches families and practitioners report as helpful

- Reducing overall demand load and picking battles; rephrasing requests as statements or invitations; sharing control; using humour, novelty and interests to invite rather than leverage; adjusting the sensory environment; building trusted relationships; and structuring in recovery time. *[qualitative evidence - Nawaz & Speer, 2025; O'Nions et al., 2018; feasibility-level - Carlozzi et al., 2025; consensus - PDA Society PANDA]*
- The PANDA framework (Pick battles; Anxiety management; Negotiation and collaboration; Disguise and manage demands; Adaptation) summarises the consensus approach. *[consensus / practice guidance - PDA Society, via Westby, 2025]*
- One parent described that when the family and clinical team together structured a low-demand day with sufficient downtime and the right language, demand avoidance was rarely seen any more. *[qualitative evidence - Nawaz & Speer, 2025]*

What families report about services

Interviews with 21 UK parents found four themes: understanding of the presentation is lacking across family, education and health; parents - mostly mothers - are blamed, in some cases formally accused of fabricating or inducing illness; support is not tailored, with one-size-fits-all autism strategies applied; and the journey produces distress for everyone, including school-based anxiety, complete school refusal, placement breakdown (over half of children had more than one placement) and family breakdown. Parents said unfair judgement led to self-blame and to fear of asking for help. Where families and professionals worked together to make tailored adaptations, children were helped. *[qualitative evidence - Nawaz & Speer, 2025]*

Practice point: carer strain and wellbeing are primary outcomes in this resource, and the tools include explicit anti-blame guidance for professionals (Tool 10).

A4 Questionnaires: what they can and cannot do

Tool	What the evidence says	How this resource uses it
Extreme Demand Avoidance Questionnaire (EDA-Q), 26 items, ages 5 - 17	Parent-report; developed from Newson's criteria. Good internal consistency and it distinguished parent-identified PDA groups from autism-plus-disruptive-behaviour groups at group level. The authors themselves state that scores should be viewed as an indicator of risk and a pointer toward possibly relevant approaches, not a diagnostic measure; no diagnoses were independently verified; scores fall with age and were higher in girls. <i>[single empirical study (parent-report) - O'Nions et al., 2014]</i> Rated high risk of bias by both systematic reviews.	The 2014 cut-off scores are not used . Individual items can prompt conversation; totals are not interpreted.
EDA-8, 8 items	A shorter research version; explicitly not a diagnostic test. High scores may have non-PDA explanations; low scores do not rule out quieter, internalised presentations such as shutdown. It can be used to gather descriptive information and to compare perspectives between home and school. <i>[consensus / practice guidance - Westby, 2025; O'Nions et al., 2021]</i>	Preferred brief descriptive aid, used dimensionally (looking at the pattern, not a threshold). Available via the PDA Society and NovoPsych.
DISCO (PDA items)	Different studies selected different items, so there is no consistent version. <i>[systematic-review finding - Company & Rotella, 2026; Kildahl et al., 2021]</i>	Not used.
Anxiety measures (e.g., SCAS-P, RCADS)	Validated for use with autistic children; used in the PDA research. <i>[extrapolation from adjacent evidence]</i>	Useful to characterise anxiety as part of formulation, with a psychologist.
Intolerance of Uncertainty Scale - parent report	Associated with PDA in earlier work but did not predict demand avoidance in autistic groups in the largest study. <i>[single empirical studies (parent-report) - Stuart et al., 2020; Rai et al., 2026]</i>	Optional descriptive information; results do not settle the formulation.
OT-administered sensory assessment (e.g., Short Sensory Profile)	Sensory reactivity uniquely predicted demand avoidance in the autism-plus-PDA group. <i>[single empirical study (parent-report) - Rai et al., 2026]</i>	Routinely recommended. See Tool 5 for the prompts that inform referral.
Quality-of-life and carer-strain measures	Carer strain was the outcome that changed most in the only intervention study. <i>[feasibility-level - Carlozzi et al., 2025]</i>	Used as primary outcomes (Tool 12).

Three rules for every questionnaire

1. No questionnaire confirms or excludes PDA, and none is NDIS eligibility evidence.
2. Use them to structure information-gathering and to compare perspectives, never to close the question.
3. Behaviour that scores highly on any of them can have other explanations; the formulation (Tool 2) is where those are worked through.

Part B - The tools

Each tool states its purpose, who it is for, the evidence behind it, and how to use it. Worksheets are designed to be printed or copied into your own documents. Nothing in Part B requires a diagnosis of any kind to be useful.

Tool 1 A shared language guide

For: everyone around the child. Evidence: qualitative evidence (O'Nions et al., 2018; Nawaz & Speer, 2025) and consensus. Purpose: language shapes what adults do next; these swaps keep the focus on drivers rather than character.

Instead of	Try	Why
"Manipulative"	"Strategic" - distraction, excuses, refusal, charm are ways of escaping pressure	Researchers who analysed 26 parent interviews replaced "manipulative" with "strategic" because the behaviours were mostly blunt attempts to avoid demands rather than subtle manipulation. <i>[qualitative evidence - O'Nions et al., 2018]</i>
"Non-compliant", "defiant", "won't"	"Unable to right now", "demand-related distress", "can't, not won't"	Frames the behaviour as a capacity problem under threat, which is the working hypothesis this resource tests. <i>[consensus; Autism CRC, 2023 GPP 45.8]</i>
"Tantrum", "bad behaviour"	"Meltdown" or "shutdown" - a panic response	Parents describe sudden, overwhelming escalation that the child cannot control; treating it as panic changes the response from consequences to safety and calm. <i>[qualitative evidence - O'Nions et al., 2018; consensus - Carlozzi et al., 2025]</i>
"Attention-seeking"	"Connection-seeking" or "signalling distress"	Keeps the adult curious about need rather than motive.
"Controlling" (as a character trait)	"Needs a sense of autonomy and safety"; "seeking predictability"	Need for control is real and prominent, but describing it as a need rather than a flaw points to what to change in the environment. <i>[qualitative evidence - O'Nions et al., 2018]</i>
"Too soft", "permissive", "no boundaries"	"Adapted, low-demand parenting"	Parents report being judged as permissive for using approaches they found effective; this judgement damages families and blocks help. <i>[qualitative evidence - Nawaz & Speer, 2025]</i>
"PDA explains it"	"The profile describes it; the formulation explains it"	A label that becomes an explanation can stop people looking for anxiety, trauma, pain or sensory drivers. <i>[systematic-review finding - Kildahl et al., 2021; consensus - Malik & Baird, 2018]</i>
"Autism is the problem"	"The mismatch between demands, environment and this child's nervous system is the problem"	Neuroaffirming and points to changeable things.

Terminology preference - record it

The child and family's preferred term (e.g., PDA profile, EDA, persistent drive for autonomy, PDAer):

Words the child finds distressing or shaming and that should not be used: _____

Tool 2 Formulation worksheet: why might this be happening?

For: practitioners, with families and schools. Evidence: the drivers listed are drawn from Rai et al. (2026), O'Nions et al. (2018), Malik & Baird (2018), Kildahl et al. (2021) and consensus guidance. Purpose: turn a label into a set of testable, individual hypotheses.

Work through each possible driver. Tick what applies, note what you have actually observed (not assumed), and record who could assess it further. Most children will have several drivers interacting.

Possible driver	Questions to ask	What might indicate it	Who can help assess
Anxiety / threat response [single empirical study - Rai et al., 2026; qualitative - O'Nions et al., 2018]	Does distress look like panic (fast onset, physical signs, loss of language)? Is there worry, avoidance of many situations, sleep disturbance?	Escalation out of proportion to the request; relief when the demand is withdrawn; anxiety in non-demand settings too.	Psychologist; GP/paediatrician
Autonomy threat / loss of control [qualitative - O'Nions et al., 2018]	Is it the <i>being asked</i> rather than the task? Does the child do the same thing willingly when it is their idea?	Refuses preferred activities when suggested by others; needs things "on their terms"; insists others follow their rules.	Behaviour support practitioner; family observation
Sensory reactivity [single empirical study - Rai et al., 2026]	Are there tactile (clothing, hygiene, touch), taste/smell, noise, light or movement sensitivities? Does the child seek intense input?	Avoidance clusters around dressing, teeth, hair, food, crowded or loud places; distress rises with sensory load even without a request.	Occupational therapist (sensory assessment) - routine referral
Uncertainty / novelty [mixed evidence - Stuart et al., 2020; Rai et al., 2026; O'Nions et al., 2018]	Are new places, changes, surprises or waiting particular flashpoints? Does the child need to know exactly what will happen?	Distress before events; questions repeated; better on known routines but also resists routines imposed by others.	Psychologist; test individually - do not assume
Communication load [extrapolation from adjacent evidence]	Does the child understand what is being asked? Are demands verbal, fast, layered? Can the child say no, help, later?	Distress increases with more words; better with visual or written information; limited ways to decline safely.	Speech pathologist
Task difficulty / executive load [extrapolation from adjacent evidence]	Is the task actually hard - starting, sequencing, sustaining? Is there time pressure?	Avoidance specific to multi-step or open-ended tasks; can do it with a scaffold or alongside someone.	OT; psychologist; teacher
Health, pain, sleep, hunger, medication [consensus]	Any pain, constipation, dental, ear, reflux, sleep problems, missed meals, medication changes?	Bad days cluster; worse at particular times; physical signs.	GP / paediatrician; prescriber for medication
Relational safety, trauma, prior compliance-based approaches [systematic-review - Kildahl et al., 2021; consensus]	What has been tried before (rewards, consequences, forced completion, restraint)? Any adverse experiences at school or elsewhere?	Distress specific to certain people or settings; hypervigilance; avoidance of places where past approaches were used.	Psychologist; safeguarding processes where indicated
School pressure, masking, burnout [qualitative - O'Nions et al., 2018; Nawaz & Speer, 2025]	Does the child "hold it together" at school and release at home? Is attendance dropping?	After-school meltdowns; Sunday-night distress; partial or complete school refusal.	School team; psychologist
Family stress and capacity [qualitative - Nawaz & Speer, 2025]	How exhausted is the household? Is there conflict about approach? Do carers feel blamed?	Carers describe walking on eggshells; disagreement between parents; fear of asking for help.	Behaviour support practitioner; carer supports (Tool 10)

Alternative explanations to keep on the table

The features overlap with other presentations. Considering these is a mark of good practice, not scepticism about the family. [consensus - Malik & Baird, 2018; systematic-review finding - Kildahl et al., 2021]

Alternative	What would fit it	What would help distinguish
Oppositional pattern (ODD-type)	Provocative, goal-directed refusal to gain something concrete; irritability across contexts; less anxiety.	Clinicians report <i>less</i> provocation and <i>more</i> rigidity/uncertainty intolerance in demand-avoidant autistic children; look at what relieves the behaviour (control/withdrawal vs gaining an item).

Alternative	What would fit it	What would help distinguish
Anxiety disorder	Worry and avoidance across many situations, not specific to being asked.	Anxiety assessment; does distress remain when demands are removed?
Attachment-related or trauma response	Onset after adverse experience; hypervigilance; specific to relationships or settings.	History; psychology assessment; safeguarding review.
Situational / environmental	Behaviour appears in one setting first (often school) and generalises.	Setting comparison; what is different about the demands there?
Co-occurring ADHD or other neurodevelopmental differences	Impulsivity, inattention, task initiation difficulty.	Paediatric / psychology assessment; note that most children in the research had multiple co-occurring conditions.

Write the working hypotheses in both languages

Plans in the NDIS context need a functional statement; families and schools need a plain formulation. Write both, so the same idea can serve both purposes.

Functional statement (for the FBA)	Formulation statement (for the family and school)
Example: When a direct verbal request is made during a transition, the child screams and runs, which results in the demand being withdrawn - hypothesised function: escape from demand-related aversive arousal; access to control and predictability.	Example: Being told what to do at a moment of change tips the child into a threat response; running away is how the body gets safe. Reducing demands at transitions and giving a real choice should reduce distress.
Your draft:	Your draft:

What data would tell us which hypothesis is right?

Tool 3 Demand audit and daily demand-load map

For: families, schools, practitioners. Evidence: consensus / practice guidance (PDA Society PANDA "pick battles"; Carlozzi et al., 2025 program content) and qualitative evidence that demands include far more than instructions (O'Nions et al., 2018; Nawaz & Speer, 2025). Purpose: see the whole demand load, including the hidden demands, so it can be reduced.

Demands are broader than instructions

Type of demand	Examples	Why it can count as a demand
Direct requests and instructions	"Put your shoes on." "Time for a shower."	The obvious kind.
Questions	"What do you want for lunch?" "How was school?"	A question requires an answer - that is an expectation.
Praise and recognition	"Good job!" Stickers, certificates, being singled out	Praise implies a standard to keep meeting; nearly half of interviewed parents said their child disliked it. <i>[qualitative - O'Nions et al., 2018]</i>
Transitions	Leaving the house; stopping a game; moving between rooms or lessons	Each transition is a demand to stop one thing and start another; even house-to-car can provoke anxiety. <i>[qualitative - O'Nions et al., 2018]</i>
Choices presented under pressure	"Red cup or blue cup - quickly!"	A choice with a deadline is still a demand.
Anticipation and waiting	Knowing an appointment is coming; a countdown	Anticipation of a demand can be as hard as the demand.
Self-generated expectations	Wanting to finish a drawing perfectly; wanting to go to the party	Children may be unable to do things they themselves want to do. <i>[consensus; theoretical - Frankle, 2025]</i>
Preferred activities	The favourite meal; the game they asked for	Once suggested by someone else, even a preferred activity can become impossible.
Routines and visual schedules	A fixed morning sequence; a picture timetable	Structure that helps many autistic children can itself be a demand for this presentation; use flexibly.
Social expectations	Greeting a visitor; taking turns; eye contact	Implicit rules are demands too.
Sensory demands	Wearing the uniform; the noise of the canteen; toothpaste	These stack on top of task demands and, for this group, predict avoidance in their own right. <i>[single empirical study - Rai et al., 2026]</i>
Time pressure	"We have to leave in two minutes."	Pressure to conform provokes frustration; one parent described self-injury under time pressure. <i>[qualitative - O'Nions et al., 2018]</i>

Demand audit worksheet

Record a typical day, or the situations that most often lead to distress. Rate distress 0 (none) to 4 (meltdown/shutdown). Use the last column honestly: dropping or deferring a demand is a strategy, not a failure.

Demand (incl. hidden)	How it was presented	Child's response	Distress 0 - 4	Recovery time	Drop / defer / reshape / keep?

Demand (incl. hidden)	How it was presented	Child's response	Distress 0 - 4	Recovery time	Drop / defer / reshape / keep?

Daily demand-load map

Sort the day's demands into three groups. The aim is a day that the child's current capacity can absorb, with recovery time built in.

Part of the day	Necessary now (safety, health)	Negotiable (reshape, choose timing)	Droppable for now
Morning			
School / day program			
After school			
Evening / bedtime			

Tool 4 Episode record: what happened before, during and after

For: families and school staff, feeding into practitioner assessment. Evidence: functional behaviour assessment method (consensus / NDIS requirement) adapted with the demand audit because the demands eliciting behaviour have rarely been studied systematically (Kildahl et al., 2021). Purpose: capture what actually happened, in observable terms, without blame.

Complete after things have settled - never during. If a full record is too much on a hard day, use the five-item version at the bottom. Parents in the only program study found detailed tracking burdensome; brief and consistent beats detailed and abandoned. *[feasibility-level - Carlozzi et al., 2025]*

Date, time, setting, people present	
What happened just before - the demand or expectation (include hidden demands: a question, praise, a transition, a change, sensory load, time pressure)	
How the demand was presented (words used, tone, who by, how much notice)	
Early warning signs noticed (body, voice, movement, words)	
What the child did - in observable terms, no interpretation	
How it escalated and how long it lasted	
What adults did (what helped, what did not)	
Recovery time and what recovery looked like	
Background factors today (sleep, pain, hunger, medication, earlier events, school day)	
Any risks (to child, others, property) and any safeguarding consideration	
Your best guess at what the behaviour achieved for the child (escape, control, sensory relief, communicating distress)	

Five-item version for hard days

Date/time	The demand (incl. hidden)	What the child did	Distress 0 - 4	What helped / recovery time

Tool 5 Sensory considerations prompt list

For: families and schools preparing for an occupational-therapy referral; practitioners screening for sensory drivers. Evidence: single empirical study (parent-report) - Rai et al. (2026) - finding tactile sensitivity, taste/smell sensitivity and sensation-seeking/under-responsiveness uniquely predicted demand avoidance in autistic children identified with PDA; plus consensus guidance on environmental adjustments. Purpose: these are prompts, not an assessment. They help you notice patterns and give an OT useful information.

Sensory area	Things to notice	Common flashpoints
Touch (tactile)	Reactions to clothing seams, labels, socks, uniform fabric; hair brushing and washing; teeth cleaning; nail cutting; unexpected touch; messy play; being hugged.	Getting dressed, hygiene routines, uniform days, crowded corridors.
Taste and smell	Food textures and temperatures; toothpaste; smells in rooms, canteens, bathrooms; perfumes and cleaning products.	Meals, teeth cleaning, particular rooms or people.
Seeking and under-responsiveness	Craves movement, crashing, spinning, chewing, loud sound; seems not to notice pain, cold or hunger; needs intense input to settle.	Sitting still for long periods, quiet-and-still expectations, waiting.
Sound	Covers ears; distressed by sudden or layered noise; hums or makes noise to block out requests. <i>[qualitative - O'Nions et al., 2018 noted noise used to block requests]</i>	Assemblies, canteens, playgrounds, busy shops.
Sight and light	Bright or flickering lights; visual clutter; screens as calming or over-stimulating.	Classrooms, supermarkets.
Movement and body position	Avoids or seeks swings, stairs, playground equipment; poor tolerance of being moved by others.	Physical prompting, being "moved along".
Stacking	How sensory load <i>adds</i> to task demands - a manageable request becomes impossible in a loud, bright, busy room.	Any demand delivered in a high-sensory setting.

Environmental adjustments to trial now (while awaiting assessment)

- Lower lighting, reduce visual clutter, offer noise-reducing headphones, and create a predictable quiet space the child can go to without asking. *[consensus, cited in Rai et al., 2026]*
- Remove or soften sensory demands that sit on top of a necessary task (uniform alternatives, different toothpaste, seating away from noise).
- Deliver necessary requests in low-sensory moments, not in the middle of overload.

Notes for the OT referral (patterns noticed, worst times, what soothes):

Tool 6 Preventative strategies menu

For: families, schools, practitioners. Evidence: consensus / practice guidance (PDA Society PANDA; practitioner texts via Carter, 2024), qualitative evidence (O'Nions et al., 2018; Nawaz & Speer, 2025), feasibility-level evidence on what parents found usable (Carlozzi et al., 2025), and one empirical study on sensory drivers (Rai et al., 2026). Purpose: prevention is the bulk of any good plan. Choose strategies that match the drivers you identified in Tool 2, and monitor distress, not compliance.

Before you start

None of these strategies has been tested in a controlled trial. Each is a **hypothesis for this child**: try it in a calmer period, watch distress and recovery, and be ready to drop it. Rotate approaches - any single method can stop working once the child recognises it. [consensus; O'Nions et al., 2018]

Strategy	What it looks like	Driver it addresses	Evidence grade	Watch-outs
Reduce overall demand load; pick battles	Use Tool 3 to drop or defer non-essential demands for now. Keep only what is needed for safety and health, and reshape how those are delivered.	Threat response; autonomy; capacity	Consensus (PANDA); qualitative (Nawaz & Speer, 2025)	Reduction is a starting point, not a life sentence - revisit as capacity grows. Explain the rationale to relatives who see it as "giving in".
Declarative and indirect language	State rather than instruct: "The toothbrush is ready" instead of "brush your teeth"; "I wonder if..."; "I'm going to get my shoes"; narrate aloud; leave a note.	Autonomy threat; communication load	Consensus; qualitative; parents rated helpful in the pilot (Carlozzi et al., 2025)	Keep it genuine - a disguised order is still an order and children notice.
Genuine choice and shared control	Offer real options including "not now"; let the child set the order, the timing or the method; do the task "together".	Autonomy; predictability	Qualitative (O'Nions et al., 2018: agency via choice reportedly helpful); consensus	Choices under time pressure become demands. Two fake options are not a choice.
Collaborative problem-solving and negotiation	When calm, work out together what makes a task hard and what would make it possible; agree the plan in the child's words.	Autonomy; task difficulty; uncertainty	Consensus (PANDA "N")	Do this in calm, connected periods only, never as the price of ending a meltdown.
Humour, novelty and interests as invitations	Make the task playful or silly; embed it in the child's interest; change the format; "strew" materials for the child to discover.	Threat response; anticipation	Qualitative (Newson tradition via O'Nions et al., 2018); parents rated humour, novelty and strewing helpful (Carlozzi et al., 2025)	Interests used as leverage ("you can have X when...") become demands. Novelty itself triggers some children - check Tool 2.
Sensory environment adjustments	Lower lights, reduce noise and clutter, headphones, quiet retreat space, uniform and hygiene-product alternatives; deliver requests in low-sensory moments.	Sensory reactivity	Single empirical study (Rai et al., 2026); consensus	Get OT input; sensory needs change with context and age.
Flexible predictability	Give a rough shape to the day ("after lunch we might..."), tell the child what will happen without requiring anything of them, avoid countdowns and rigid schedules.	Uncertainty; anticipation	Consensus; caution from qualitative data that rigid routines are themselves demands	Test whether structure helps or harms this child; the evidence is mixed.
Co-regulation and low-arousal adults	Calm body, fewer words, lower voice, no rush; sit alongside rather than face-on; regulate yourself first.	Threat response	Consensus (low-arousal approach); parents reported greater de-escalation confidence (Carlozzi et al., 2025)	Adults need their own support to stay regulated (Tool 10).

Strategy	What it looks like	Driver it addresses	Evidence grade	Watch-outs
Trusted relationships as the platform	Prioritise connection over task; treat the child as an equal partner; one or two consistent adults at school.	Relational safety; autonomy	Qualitative (child-led settings praised - Nawaz & Speer, 2025); consensus (Truman's "colleague rule" via Carter, 2024)	Relationship takes time; do not load it with demands once it forms.
Recovery time built in	Schedule downtime after school and after any necessary demand; protect it.	Capacity; masking/burnout	Qualitative (Nawaz & Speer, 2025)	Recovery is not "reward"; it is not conditional on anything.
Allowing opt-out and diffusion	Make it clear and safe to say no or stop; when tension rises, change the subject, step back, or let it go.	Autonomy; threat response	Parents rated opt-out and diffusion helpful (Carlozzi et al., 2025) - feasibility-level	Opt-out must be real; if "no" is punished later it stops being safe.
Praise and reward - low-key or none	Notice quietly; comment on the activity rather than the child; avoid public recognition and charts.	Autonomy threat	Qualitative (O'Nions et al., 2018; Nawaz & Speer, 2025)	Some children enjoy specific, private acknowledgement - test individually and watch for worsening.

Strategies chosen for this child and the driver each targets: _____ Distress
 measure we will watch (Tool 12): _____ Review date: _____

Tool 7 Demand triage decision aid

For: families and staff making moment-to-moment decisions. Evidence: consensus / practice guidance (PDA Society PANDA "pick battles"; Carlozzi et al., 2025 "cost - benefit" decision-making), informed by qualitative evidence that pressure to conform provokes escalation (O'Nions et al., 2018). Purpose: a quick, repeatable way to decide whether to keep, reshape, defer or drop a demand.

Step	Ask	Then
1	Is this about immediate safety or essential health (medication, a medical appointment, danger)?	If yes: keep it, but reshape <i>how</i> it is delivered (declarative language, do it together, choice of method or timing, humour, minimal words). Plan it for the child's best time of day.
2	Does it really need to happen today ?	If no: defer or drop it. Write it on the "later" list so it is not forgotten and nobody feels they failed.
3	What is the child's capacity right now ? (Recent distress, sleep, illness, sensory load today, a hard school day, a transition just happened.)	Low capacity: drop or defer anything that is not step 1. Adequate capacity: proceed to step 4.
4	Can the demand be reshaped so it is not experienced as an order? (Statement instead of instruction; genuine choice; alongside rather than at; invitation via interest; a note or visual instead of words; more time.)	Reshape and offer once. Do not repeat, chase or escalate. If it is refused, accept the refusal.
5	Are early warning signs appearing?	Stop. The demand is now a trigger; switch to Tool 8. Dropping it here is the correct decision.
6	Record what you decided and what happened.	Feeds Tool 4 and Tool 12, and helps everyone make the same decisions.

Three reminders

Dropping a demand is a strategy, not a failure, and it is not "letting the child win" - there is no contest.

Consistency means consistent **principles** across adults, not identical methods or "follow-through" at any cost.

If you notice that demands keep getting pushed harder, or that adults are reaching for locks, removal of possessions, or holding - stop and revisit the plan (see Part C).

Tool 8 In-the-moment response card

For: everyone. Print, laminate, keep it where meltdowns happen. Evidence: consensus / practice guidance (low-arousal approach; PDA Society; Carlozzi et al., 2025 program content), grounded in qualitative descriptions of meltdowns as panic-like and escalated by pressure (O'Nions et al., 2018). Purpose: safety, dignity and the shortest possible route back to calm.

Safety first

Follow the child's **approved safety plan** if one exists. Call **000** if there is immediate danger to life. Do not use any physical hold, block or seclusion unless it is part of an authorised plan you are trained in. Physical intervention is a regulated restrictive practice in the NDIS context (see Part C).

Before (early warning signs)	Know this child's signs: _____. When you see them: drop the demand now, reduce words, move sensory input down, offer space or a known safe place, stay calm and available.
During - do	Make the environment safe (move objects, people, siblings). Say almost nothing; if you speak, use a few calm, low words. Reduce noise, light and crowding. Give physical space - sit side-on, lower yourself, do not loom. Keep your own body calm and slow. Stay near enough to be safe. Let it run its course. Protect the child's dignity - move onlookers, not the child.
During - do not	Do not restate the demand, negotiate, reason, threaten, count down or promise consequences. Do not touch or move the child unless safety absolutely requires it and your plan allows it. Do not film the child for others to see. Do not say "calm down".
Threats to self-harm	Almost all interviewed parents had heard threats or seen self-injury under pressure to comply. <i>[qualitative - O'Nions et al., 2018]</i> Take every threat seriously: remove the pressure, keep the child safe, and make sure a professional safety plan exists. Never respond with consequences.
After	No consequences for a panic response. Offer comfort, food, water, quiet - whatever this child accepts. Reconnect on their terms: a favourite activity, sitting nearby, humour if welcome. Repair if needed ("that was really hard; we're okay"). Protect recovery time - no debrief, no demands, for as long as it takes. Later, record it (Tool 4).
Shutdowns	A quiet withdrawal - going silent, still, hiding - is the same response in a different form. Treat it the same way: no demands, reduce input, stay available, let recovery happen.

Tool 9 Skills to grow, at the child's pace

For: families, schools, allied health. Evidence: consensus / practice guidance and extrapolation from adjacent (non-PDA) evidence on communication and regulation; developmental-timing note from feasibility-level evidence (Carlozzi et al., 2025). Purpose: expand what the child can do without turning skill-building into a new set of demands.

The non-negotiables

Skills are invited in **calm, connected periods only** - never during or immediately after distress, and never as a condition of anything.

Nothing here is a "compliance ladder". The measure of success is that the child has more ways to be safe and heard, not that they do more of what adults want.

The child's **assent** matters: if they disengage, that is the answer for today.

Skill	How to invite it	When	Not this
Ways to say "no", "help", "break", "later" that work	Model the words yourself; offer cards, a hand signal, a text message, or AAC; honour every use of it immediately so it stays reliable. Speech pathologist input for the child's communication style.	Everyday, low-stakes moments; when the child is regulated.	Requiring the "correct" words before honouring a refusal.
Noticing body signals	Name your own signals aloud ("my shoulders are tight - I need a minute"); notice the child's without instructing ("looks like the loud room is a lot"); use interests (characters, games) as a bridge.	Calm times; after the fact only if the child wants to.	Feelings worksheets delivered as tasks; asking "what are you feeling?" in the moment.

Skill	How to invite it	When	Not this
Co-regulation moving toward self-regulation	Be the calm; offer regulating activities the child already likes (movement, deep pressure, music, quiet); let the child lead in choosing them; gradually the child reaches for them alone.	Build a menu together during good periods.	Timetabled "regulation breaks" that become demands; sensory strategies imposed rather than offered.
Tolerating small uncertainties and small demands	Only child-led: the child chooses what to try, when, and how far. Tiny, optional, reversible steps inside safe relationships and preferred activities. Stop at the first sign of distress.	Weeks or months into a period of reduced demand and rebuilt trust.	Graded exposure that overrides distress signals; anything the child did not agree to.
Understanding themselves and self-advocacy	For older children who want it: talking about what demands feel like, naming the profile in their preferred words, planning what they need at school.	Readiness for this often arrives in early adolescence; parents of younger children did not find naming the threat response useful. <i>[feasibility-level - Carlozzi et al., 2025]</i>	Pushing a label on a child; expecting a child in crisis to reflect.

Tool 10 Carer wellbeing check-in and anti-blame guide

For: carers, and every professional who meets them. Evidence: qualitative evidence (Nawaz & Speer, 2025) on blame, isolation and family breakdown; feasibility-level evidence (Carlozzi et al., 2025) that carer strain is the outcome most responsive to support; consensus. Purpose: carer wellbeing is a primary outcome, and blame narratives are a documented harm to prevent.

Monthly carer check-in (rate 0 = not at all, 4 = severely)

In the last month...	Month 1	Month 2	Month 3	
I have felt exhausted most days				
My sleep has been badly disrupted				
I have felt isolated from friends or family				
My partner/co-parent and I have clashed about how to respond				
I have felt blamed or judged by a professional, teacher or relative				
I have avoided asking for help for fear of being blamed				
I have felt I know what to do when things escalate				
I have had time for something that is just for me				
Total (first six items; higher = more strain)				

This is a conversation starter, not a validated scale. Rising scores are a reason to increase carer support in the plan, not a judgement.

For professionals meeting a family: an anti-blame checklist

Parents in the interview study reported dismissal, "it's all parenting", and in some cases formal allegations of fabricated or induced illness - even with an autism diagnosis in hand. The consequence was self-blame, poor mental health and fear of seeking help. *[qualitative - Nawaz & Speer, 2025]*

- **Listen first.** Ask what the family has already tried and what happened. Assume they know their child.
- **Do not default to standard autism strategies** (sticker charts, firm boundaries, "consistency and follow-through") - families report these made things worse, and the reinforcement evidence is not on their side (Part A3).
- **Recognise low-demand parenting as an adaptation, not permissiveness.** If you disagree with an approach, say what evidence you are drawing on and its grade.
- **Do not treat a private assessment, a parent's expertise, or a presentation you have not seen before as a red flag.**
- **Name the fear.** Many carers self-censor. Make it explicit that asking for help is not evidence against them.
- **Make carer wellbeing an outcome in the plan** and review it (Tool 12).

For carers: a short script for talking with services

You can say

"Here is what we have observed, in specific terms (Tool 4 records)."

"Here is what we have tried - including reward systems and firm boundaries - and here is what happened."

"We are using a low-demand approach because it reduces our child's distress. We are measuring distress, participation and our own strain, not compliance."

"The approach we are asking for is consistent with the Australian National Guideline's recognition of this profile and with the NDIS Commission's expectation that plans are formulation-based and least restrictive."

"What we need from you is: _____."

When adults disagree about the approach

Parents described relationships breaking down over "too soft" versus "needs rules and boundaries".

[*qualitative* - Nawaz & Speer, 2025] What tends to help: share the formulation (Tool 2) rather than the label; agree on the *principles* (safety, reduce distress, no consequences for panic) and allow different styles; look at the data together (Tool 12); and seek a session with the practitioner for the disagreeing adult, without blame. Siblings need their own explanation, their own protected time, and a safe place to go during meltdowns.

Tool 11 Home - school shared support plan

For: families and school or day-program staff, facilitated by the practitioner where possible. Evidence: qualitative evidence that rule-heavy settings trigger school-based anxiety and placement breakdown while flexible, child-led, trusting settings were praised (Nawaz & Speer, 2025; O'Nions et al., 2018); consensus / practice guidance for educators (Truman, 2021; Kerbey, 2021, via Carter, 2024). Purpose: one page that every adult around the child can follow - consistent in principle, flexible in method.

Preferred name, pronouns, and preferred term for the profile	
Our shared principles (safety first; reduce distress, not enforce compliance; no consequences for panic; relationships before tasks)	
Likely drivers (from Tool 2)	
Strengths, interests, what the child says helps	
Demands reduced or dropped for now (and why)	
How necessary demands are delivered (language, choice, timing, who)	
Sensory adjustments in place	
Early warning signs and what to do (Tool 8)	
Safe place, trusted adult, how the child can leave	
What escalates this child - never do	
Attendance plan (partial days, flexible start, no pressure on re-entry)	
What we measure (Tool 12) and who records it	
Contacts and review date	

Coaching points for staff

- The approach can look like the opposite of standard behaviour management - explain the formulation and the evidence grade, not just the rule.
- Treat the child as an equal partner: invite rather than instruct, offer genuine choice, avoid public praise or correction. *[consensus - Truman, 2021 via Carter, 2024]*
- One or two consistent, trusted adults matter more than the label on the placement. Build the relationship first and load it lightly.
- School-based anxiety takes a long time to recover from; any return plan must be child-paced and free of attendance pressure. *[qualitative - Nawaz & Speer, 2025]*

When settings disagree about the PDA framing itself

Agreement on the label is not needed to agree on the plan. Set it aside and agree on the observed behaviours, the hypothesised drivers, the data to collect, and the principle that rising distress means the plan changes - the formulation-first approach both systematic reviews support. *[systematic-review findings - Kildahl et al., 2021; Company & Rotella, 2026]*

Tool 12 Measurement and review sheet

For: practitioners, families and schools. Evidence: consensus / NDIS practice standards for plan review; outcome selection informed by the only intervention study (Carlozzi et al., 2025), which found carer strain the most responsive outcome and detailed indicator tracking the least usable program element. Purpose: know whether things are getting better for the child and the family - and change course early if they are not.

What we do not measure

Compliance counts ("did what was asked X times") are **not** an outcome here: they reward pressure, and pressure escalates this presentation. Measure distress, participation, communication, quality of life, carer wellbeing and whether the plan is being followed.

Weekly tracker (keep it to one line a day)

Day	Distress episodes (count)	Peak intensity 0 - 4	Longest recovery time	Participation / engagement (0 - 4, child's own goals)	Communication of no / help / break used?	Carer strain today 0 - 4
Mon						
Tue						
Wed						
Thu						
Fri						
Sat						
Sun						

Add where relevant: school attendance (including partial days, recorded without judgement); a quality-of-life rating from the child in their own terms; an implementation check (were the agreed strategies used?).

Review rules

Review point	What to decide
Two weeks	Is the plan being used? Is anything making distress worse? Adjust delivery, not goals.
Four to six weeks	Compare distress frequency, intensity and recovery time with baseline. Compare carer strain. Ask the child what is better or worse.
Then monthly, and at each NDIS plan review	Continue, adapt, pause or stop each strategy on the basis of the data and the child's and family's views.
Trigger	Action
Distress is rising	Revise the plan now. Look for a new driver (health, sensory, a change at school) and for demands that have crept back in.
Adults are drifting toward pressure, holding, locking, removing access to things, or asking about medication "for meltdowns"	Stop and escalate to the practitioner and, where relevant, the provider's restrictive-practice processes (Part C). This drift is predictable for this presentation and is a plan failure, not a child failure.
Carer strain is rising or not falling	Increase carer support; reduce data burden; check for blame from other services.
Distress is falling and capacity is growing	Do not rush to reintroduce demands. Let the child lead any expansion (Tool 9).

Part C - Safeguards, referrals and evidence limits

C1 Safeguards, referrals and what this resource does not recommend

NDIS Quality and Safeguards Commission requirements - in brief

For participants with NDIS behaviour support funding, plans must be based on a functional behaviour assessment; an interim plan is expected within one month where a restrictive practice is in use; any restrictive practice must be a last resort, authorised under the relevant state or territory process, reported to the Commission, and accompanied by a plan to reduce and eliminate it; and emergency responses must be distinguished from planned interventions. Check the Commission's current guidance, as requirements are updated. *[consensus / regulatory guidance - NDIS Quality and Safeguards Commission]*

The predictable drift for this presentation - name it in every plan

When adults are told to be "consistent" and to "follow through" with a child whose distress is driven by demands, the pressure escalates and the distress escalates with it. That is the point at which locking doors or removing belongings to force a task (environmental restraint), requesting medication "for meltdowns" (potential chemical restraint), holding the child (physical restraint) or putting them in a room alone (seclusion) can start to look reasonable. *[qualitative evidence on escalation under pressure - O'Nions et al., 2018; Nawaz & Speer, 2025; consensus]*

Autonomy-preserving, demand-reduction strategies are the **least restrictive alternative** for this presentation and should be documented as such. If a plan is drifting toward restriction, that is the signal to revise the formulation and reduce demand load, not to authorise the restriction.

Referral map

Professional	For	Typical trigger
GP / paediatrician	Pain, sleep, constipation, dental, hearing and health screening; medication review; coordination of referrals.	Any plan - health screening is routine. Never advise starting, stopping or changing medication yourself; document observations for the prescriber.
Occupational therapist	Sensory assessment and sensory-informed environmental plan; task and executive supports.	Routine in this resource, given the sensory-reactivity evidence (Tool 5).
Psychologist	Anxiety and trauma assessment; differential formulation (anxiety disorder, oppositional pattern, attachment-related); support for the child that is assent-based.	Distress beyond demand contexts; adverse history; when the formulation is unclear.
Speech pathologist	Communication assessment; ways to say no, help, break and later; AAC where relevant.	Any child whose refusal has few safe channels.
Psychiatrist	Where mental-health assessment or medication questions arise.	Via GP / paediatrician.
Authorised behaviour support practitioner	Functional behaviour assessment, plan authorship, restrictive-practice processes, plan review.	NDIS-funded behaviour support; any question about restrictive practice.
Safeguarding and child protection processes	Where there is risk of harm.	Follow your organisation's and state's mandatory processes. This resource does not make legal determinations.

What this resource does not recommend

Because compliance is not the goal and pressure escalates this presentation, the following are not used as strategies in this resource:

- Compliance as the outcome, or forcing completion of a demand.

- Planned ignoring of distress, or "escape extinction" (continuing to present a demand through a meltdown).
- Token economies, reward charts and consequence hierarchies as default strategies. *[qualitative evidence - O'Nions et al., 2018; Nawaz & Speer, 2025]*
- "Consistency and firm boundaries" framed as the corrective for demand avoidance.
- Graded exposure that overrides distress signals or is delivered without the child's assent.
- Suppression of harmless autistic traits, or of the child's autonomy-seeking itself.
- Withholding needs, comfort or communication; punishment intended to cause distress; humiliation.
- Unapproved restraint or seclusion of any kind.
- Blaming or pathologising parents.
- Presenting any commercial program as a proven treatment, or presenting PDA as either a confirmed diagnosis or a fabrication.

C2 Evidence limitations statement

Read this before relying on anything above

PDA is not a recognised diagnosis in DSM-5-TR or ICD-11. Two systematic reviews rate the entire identification literature as high risk of bias, with problems of circular logic and reliance on parent report. *[systematic-review findings - Kildahl et al., 2021; Company & Rotella, 2026]*

The presentation is nevertheless real and impactful, and is recognised as a behavioural profile in the Australian national autism guideline. *[qualitative evidence - Nawaz & Speer, 2025; consensus - Autism CRC, 2023]*

There are no randomised controlled trials of any PDA-specific intervention. The single intervention study is an uncontrolled pilot with a commercial conflict of interest; it supports feasibility and carer-wellbeing benefit only. *[feasibility-level - Carlozzi et al., 2025]*

The mechanism evidence (anxiety, autistic traits and - uniquely for autism-plus-PDA - sensory reactivity; not intolerance of uncertainty) comes from one large parent-report study and needs replication. *[single empirical study - Rai et al., 2026]*

The reports that rewards and consequences fail or backfire are qualitative and consensus-grade, not experimental proof. *[qualitative - O'Nions et al., 2018; Nawaz & Speer, 2025]*

The tools in Part B are practice aids built from this evidence. None is a validated instrument. Every strategy is a hypothesis for the individual child, to be monitored against distress and safety, never against compliance.

Nothing here replaces individual assessment, clinical judgement, supervision, collaboration with the child and family, or compliance with the NDIS Quality and Safeguards Commission and state or territory law.

C3 Sources

Sources marked † were reviewed in full text in preparing this resource. Sources marked ‡ are cited as described in the † sources or in publicly available summaries and should be consulted directly before being relied on for any individual decision.

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Conflict-of-interest notes recorded in the sources: Carlozzi et al. (2025) - a co-author founded and leads the company that sells the evaluated program. Company & Rotella (2026) - the senior author declares a non-financial personal connection (their child has been assigned a PDA diagnosis). Nawaz & Speer (2025) - one author has a family connection with autism and E/PDA. These are disclosed here so readers can weigh them; none invalidates the work.

C4 Glossary

Demand	Any expectation, request, question, transition, choice, routine or internal wish that requires the child to do something - not only instructions.
Demand-related distress	The anxiety, panic or overwhelm triggered by demands; the thing this resource aims to reduce.
Declarative language	Statements and observations ("the bath is running") rather than instructions ("get in the bath").
Formulation	A shared, testable explanation of why a child's distress is happening for them, built from individual assessment rather than from a label.
Functional behaviour assessment (FBA)	The structured process, required for NDIS behaviour support plans, of identifying what a behaviour achieves for the person and what maintains it.
Low-arousal approach	A way of responding to escalation that reduces stimulation, words and demands and keeps adults calm.
Meltdown / shutdown	A panic-like response to overwhelm - outward (crying, shouting, hitting, running) or inward (silence, stillness, hiding). Not a tantrum and not a choice.
PANDA	The PDA Society's consensus framework: Pick battles; Anxiety management; Negotiation and collaboration; Disguise and manage demands; Adaptation.
PDA profile / EDA / persistent drive for autonomy	Terms for a presentation of extreme, anxiety-linked avoidance of everyday demands. Not a diagnosis; recognised as a behavioural profile in the Australian national autism guideline.
Restrictive practice	Any practice that restricts a person's rights or freedom of movement - physical, mechanical, chemical or environmental restraint, and seclusion. Regulated under the NDIS Quality and Safeguards Commission.
Strewing	Leaving interesting materials or activities available for the child to discover, with no expectation attached.

About Open Circle Behaviour Support

Open Circle Behaviour Support provides person-centred Positive Behaviour Support across the Greater Bendigo Region, Victoria. Open Circle Behaviour Support is an NDIS-registered provider under the Behaviour Support registration group.

hello@opencircle.au | opencircle.au

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This resource was prepared from a review of peer-reviewed research and practice guidance current to September 2026. It will be reviewed as new evidence is published. Feedback from autistic people, families and practitioners is welcome and will shape the next version.