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#### Autistic and Neurodivergent People Are Being Systematically Excluded from the NDIS - And It Must Stop

From its original promise of empowerment, autonomy, and inclusion, the National Disability Insurance Scheme (NDIS) is drifting dangerously away from its rights-based foundations. The recent introduction of funding periods, starting *today* (19 May 2025), where participants receive their supports in quarterly or monthly instalments rather than up-front, is just the latest in a long line of policy shifts that fail to serve, and actively disadvantage, Autistic and Neurodivergent people.

This shift creates new administrative burdens, reduces flexibility, and increases the likelihood of claim rejections. It poses particular challenges for people with executive functioning challenges, fluctuating needs, and limited support networks, exactly the people the NDIS is meant to support.

Let's be clear: this isn't just a bureaucratic change. It's a systemic act of exclusion.

#### Autistic People Are Being Left Behind

Autistic individuals, especially those with non-apparent or dynamic support needs, are already facing:

Expensive, unfunded diagnostic pathways, especially for low-income and culturally diverse communities.

Deficit-based eligibility criteria that pathologise Autistic traits and demand participants prove how "broken", "disordered", and "dysfunctional" they are to qualify.

Therapy models focused on compliance and conformity rather than neuro-affirming, strengths-based support.

Shrinking eligibility via the rollout of "Foundational Supports" that offer generic, underfunded group programs with limited individualised funding or guaranteed access.

Now, funding periods add yet another layer of control, limiting when and how funds are accessed, increasing the risk of delays, gaps in service, and the loss of critical supports due to administrative errors or life fluctuations.

The NDIS was never meant to be a behavioural compliance program or a means to pathologise difference. Yet, the increasing medicalisation of the scheme, coupled with the shift of disability governance into the newly-formed Department of Health, Disability, and Ageing, suggests a retreat from social inclusion back to institutional control.

#### **Our Position at GRANN**

We reject a version of the NDIS that:

- X Demands Autistic people be "disabled enough" to access support.
- X Frames executive functioning challenges and sensory needs as personal failures.
  - X Forces people to plan their distress and support needs on a quarterly timeline.
- X Offers rigid, deficit-based supports instead of dynamic, peer-led, neuro-affirming models.
- X Undermines autonomy through endless paperwork, reassessments, and gatekeeping.

The introduction of funding periods, without proper consultation or co-design with Autistic and Disabled people, is yet another example of how bureaucracy can overshadow humanity. Flexibility and trust have been replaced with surveillance and scarcity logic.

#### What Needs to Change

Restore upfront access for participants with fluctuating needs, equipment costs, and front-loaded supports (e.g. individual supports, therapy, assistive tech). End deficit-based eligibility and honour Autistic and Neurodivergent needs as valid and worthy of support, without trauma performance.

Ensure Autistic leadership in co-designing supports, governance structures, and funding models.

Invest in peer-led, neuro-affirming services, not generic workshops and tokenistic "foundational supports."

Abolish gatekeeping practices that exclude Autistic adults from ongoing access due to "functioning labels" or rigid participation expectations.

#### **GRANN's Position**

The NDIS was built on a promise: to support all Australians with disability to live a full, autonomous, and inclusive life. For Autistic and Neurodivergent

people, that promise remains unfulfilled.

We are not asking for special treatment, we are demanding equal access to a scheme built in our name. We demand that Autistic and Neurodivergent perspectives be heard, funded, and empowered - not monitored, restricted, or erased through policy disguised as "efficiency."

Until that happens, GRANN stands firmly against these changes and with every Autistic and Neurodivergent person currently being pushed to the margins of a system that promised them more.

*In solidarity, The Collaborators @ GRANN* 



## NDIS Alert: New Funding Periods Start 19 May 2025

From 19 May 2025, all *new or reassessed* NDIS plans will have funding released in smaller chunks over time—usually every 3 months (called funding periods) instead of one full upfront amount.

#### **Key Points:**

Funds are released quarterly (some monthly or per item, e.g. for housing or assistive tech).

Unused funds roll into the *next* period but *not* into your next plan.

Claims must match the correct funding period.

Overspending = rejected claims.

You cannot shift funds between periods - but you *can* request a plan variation or reassessment.

Core and Capacity Building supports remain flexible *within each period*.

Applies to *all new plans*, including Early Childhood.

#### **Planning Tips:**

Ask for more funds upfront if needed (e.g. behaviour support, therapy setup). Check your service agreements match your funding periods to avoid out-of-pocket costs.

Contact NDIA early if your needs change - don't wait for a crisis.

These changes don't affect plans approved *before* 19 May.

For more information, speak with your support coordinator, LAC, or call the NDIS directly. You can also check out the links below:

 $\frac{\text{https://www.dss.gov.au/national-disability-insurance-scheme-review-and-reforms/changes-ndislegislation}{\text{legislation}}$ 

https://www.intermediaries.org.au/news/section-33-ndis-plan-funding-periods/

GRANN stands with our community in navigating these changes, and pushing back on systems that create more barriers than support.



#### Spoons, Forks & Knives: Making Sense of Invisible Energy and Stress

Last week, we explored the well-known *Spoon Theory* - a way to understand how people, especially those who are disabled, chronically ill, or Autistic and Neurodivergent, have limited energy ("spoons") to get through daily tasks. This week, we thought it was a fitting time to dive deeper into the metaphorical cutlery drawer and explore two lesser-known, but equally powerful concepts:

\*Fork Theory\* and Knife Theory\*.

These theories were shared by *Jen Rosenberg*, a disabled and Neurodivergent writer, to help explain the often non-apparent build-up of stress and what happens when someone reaches their absolute limit.

#### What Is Fork Theory?

Fork Theory comes from the phrase "Stick a fork in me, I'm done." It describes how, throughout the day, we are each "stuck" with metaphorical forks, stressful

events or small irritations. These forks can range from little things like forgetting where you put your keys, to big stressors like sensory overload, emotional conflict, or a major life event. Everyone's fork threshold is different. Importantly, *forks accumulate*. One fork might not feel like a big deal. But after a long day filled with lots of them, even a tiny one - a dropped spoon, a change in plans, or an itchy tag - might be the final straw that tips someone into shutdown, meltdown, or withdrawal.

#### **Forks Represent:**

Input - the stressful or draining things that happen to us.

Build-up - they accumulate throughout the day.

Individual variation - what counts as a "big" or "small" fork is unique to each person.

#### 6 Ways Forks Show Up:

Sudden noises or overstimulation
Feeling hungry, tired, or unwell
Changes to routine
Conflict or miscommunication
Internalised pressure or masking
Lack of support or unmet access needs

#### What Is Knife Theory?

Knife Theory takes the metaphor one step further. When all the *spoons* (energy) are used up and someone is already maxed out on *forks* (stressors), they may be forced to reach for a *knife* - a last-resort source of energy.

A knife isn't always the right tool. It gets the job done, but at a serious cost. Imagine trying to eat soup with a knife - it's messy, exhausting, and inefficient. It works, but only just. The energy used is not sustainable. In real life, using knives might look like someone pushing through when they're already burnt out, smiling through pain, or masking distress until they crash.

#### **Knife Theory Highlights:**

Knives = borrowing energy from tomorrow

The result = delayed burnout, shutdown, or illness

People using knives often look "fine," but are in survival mode

Recovery from knife-use takes longer and is deeper

# How Can We Support Our Autistic & Neurodivergent Community (and Ourselves)?

Reduce Forks Where You Can: Help manage the daily stressors before they pile

Respect the "No": Just because a meltdown seems sudden doesn't mean it wasn't building all day.

Offer Safe Tools, Not Knives: If someone is out of spoons, give rest, not demands.

Create Recovery Time: Let people restore their spoons in ways that work for them.

Don't Be a Fork Thrower: Avoid adding pressure, criticism, or unrealistic expectations.

#### Carrying the Cutlery Together

These metaphors - spoons, forks, and knives - may sound whimsical, but they speak to something deeply real. For Autistic and Neurodivergent people, every day involves a complex dance of energy, stress, and survival.

By learning and honouring these tools, we create space for compassion, not correction. We start listening for signs of distress beneath the behaviour. And we become better allies in helping each other feel safe, seen, and supported.

So next time someone seems to "snap" over something small, ask:

Are they out of spoons?

How many forks have they already collected?

Are they reaching for a knife?

And most importantly, how can I be someone who carries the cutlery, not adds to the load?

Want to learn more about Fork Theory? Visit Jen Rosenberg's original post: <a href="https://jenrose.com/fork-theory/">https://jenrose.com/fork-theory/</a>

Want to chat more about this or share your story? Message or email us at GRANN, your neuro-affirming community of understanding, advocacy, and hope.



#### What Is Body Doubling?

Body doubling is a gentle, supportive strategy where someone works alongside you, either in person or virtually, while you focus on a task that may feel overwhelming, monotonous, or hard to start. The other person doesn't need to help with the task itself; their calm presence and parallel focus can create just enough structure and connection to help you get going.

It's not about pressure or productivity. It's about co-regulation, mutual presence, and making space for tasks that might otherwise feel unreachable on your own.

#### Why Does Body Doubling Work?

For many Autistic & Neurodivergent people, tasks that seem "simple" can become incredibly difficult without the right scaffolding (or processes and supports). Research suggests that body doubling may support motivation and attention by engaging our dopamine systems, and it's not just about focus. The emotional experience of being seen, not judged, and gently held in a shared space can boost confidence and ease.

#### Six Gentle Benefits of Body Doubling

- **Increased Motivation** A calm presence helps you start and stick with tasks.
- Improved Emotional Regulation You're not alone in the task; nervous systems can co-regulate.
  - **Reduced Isolation** Connection, even silent, matters.
  - New Tools and Insights Watching others' strategies can inspire your own.
- **Built-in Accountability** Having someone nearby can help you stay on track.
  - **© Creative Flow** Parallel play can spark ideas and shift energy.

Whether it's folding laundry, replying to emails, or finishing an assignment, body doubling can be a soft and powerful practice for meeting your brain where it is, with compassion and community.

Would you like to try virtual body doubling through GRANN's peer circles or coworking sessions? Let us know!

### **GRANN's Online Low-Energy Hangout Body-doubling sessions starting in June.**

We're restarting our no-pressure online body-doubling sessions - where cameras can be off, fidgeting is encouraged, and chat about your passions is welcome.

Let's remind each other we're not alone.

More information coming next week!



#### Supports Help, But Alone They Aren't Enough

Spoon theory, the metaphor that helps describe the limited energy (spoons) many disabled, Autistic and Neurodivergent folks have to get through the day, fork theory (the pain of overstimulation), and knife theory (the deeper cuts of trauma and systemic harm) are tools that can be harnessed. These tools give us a language. They help others visualise what they cannot see.

But tools, metaphors, and even coping strategies like *body doubling*, working alongside another person to stay on task, are not enough when the systems themselves are not set up to support us.

From our community voices, we've heard loud and clear: unless adapted specifically for Autistic and Neurodivergent minds, behavioural therapies like DBT and CBT often gaslight rather than support us. They reframe survival strategies, born from trauma, sensory overload, or burnout, as "maladaptive behaviours" or "non-compliance." They centre control and compliance over context and compassion.

This isn't support. This is harm repackaged as help.

Just as a spoon isn't enough to dig out of a collapsed system, therapeutic frameworks that ignore systemic abuse, poverty, ableism, or Autistic and Neurodivergent communication styles only deepen the wound. When our pain is labelled as pathology, our distress becomes a personal failure rather than a valid reaction to injustice, a natural reaction to distress.

And it's not just therapy. *Traditional social skills training* too often tells Autistic and Neurodivergent people that our way of being is wrong. Our honesty, directness, deep empathy, and need for clarity are labelled deficits. Our natural rhythms - routines, sensory needs, emotional processing styles, deep interests - are turned into problems to fix, rather than differences to understand, accommodate, and embrace.

Meanwhile, the advocacy spaces that should support us have become part of the problem. Much of what's labelled "disability advocacy" is now becoming little more than a performance, one that relies on tokenism, unpaid labour, and government-approved scripts. Our presence is welcomed only when it's

polished, palatable, and non-confrontational. Challenge the status quo, and we're told we're too "angry," "ungrateful," or "not representative."

There's a brutal irony in a system that praises "lived experience" but refuses to pay for it. That asks for our wisdom but won't help fund our businesses, relying on our "resilience". That tells us to advocate while silently insisting we stay quiet.

We need more than forks, spoons, or body doubles.

We need justice. We need spaces built *by* us, *for* us.

We need therapy that recognises systemic harm.

Employment pathways that allow for self-paced, self-defined success.

Advocacy that centres real power, not performative inclusion.

Let's talk about what true support looks like. What going beyond the cutlery drawer looks like. Let's demand systems that don't just offer tools, but dismantle the need for them in the first place.

Because what use are coping strategies when the systems designed to support us, like the NDIS, are increasingly structured to exclude us?

Let's be clear: these new changes to the NDIS aren't simple funding tweaks, it's systemic exclusion.

The NDIS was built on the promise of autonomy, inclusion, and equity. But that promise is being broken, especially for those who don't meet traditional models of "disability" or whose needs don't follow a neat, quarterly timeline.

- We reject a system that demands our suffering before it will see our needs.
  - We reject a system that asks us to advocate, then silences our truth.
  - We reject a system that rewards conformity but punishes authenticity.

We need a system that recognises Autistic and Neurodivergent ways of being as valid, that funds support without pathologising difference, and that centres Autistic leadership at every level.

Because until then, no matter how many spoons we count, how many forks we dodge, or how many knives we survive, we are still being set up to fail.

And that is not care.

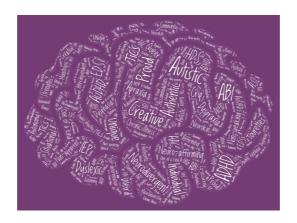
That is not belonging.

That is not justice.

It's time to rebuild something better, by us, for us, with us at the centre.

With collective rage and radical hope,

*In solidarity, The Collaborators @ GRANN* 



#### Books by Autistic and Neurodivergent Authors

#### **Identity, Advocacy & Lived Experience**

"Late Bloomer" - Clem Bastow

A powerful memoir exploring late Autism diagnosis, identity, and embracing a life authentically lived outside the norm.

"We're All Neurodiverse" - Sonny Jane Wise

A bold call to reframe neurodiversity as a universal human experience, blending personal insight with radical advocacy.

"Love & Autism" - Kay Kerr
An affirming exploration of how Autistic people love, connect, and build relationships on their own terms.

"The Whole-Brain Child" - Daniel Siegel, MD & Tina Payne Bryson, PHD A science-based parenting guide offering practical strategies to support children's emotional development and brain integration.

"Co-Regulation Handbook" - Linda K. Murphy MS

A practical resource for understanding and nurturing connection through coregulation, especially for neurodivergent children.

"The New Normal" - David Gray-Hammond
A candid account of addiction, recovery, and Autistic identity, challenging stigma through lived experience.

"Queerly Autistic" - Erin Ekins
A passionate and accessible guide to navigating the intersection of queerness and Autism with pride and self-acceptance.

Children, Youth & Young Adult Books

"When My Brain Is Messy" - Tania Wieclaw
A children's picture book about autism and how to regulate BIG emotions related to sensory processing differences.

#### "Some Brains" - Nelly Thomas

A heart warming and funny picture book celebrating neurodiversity talking us through how people's neurotypes can look different.

"All Cats Are on the Autism Spectrum" - Kathy Hoopmann
A warm and humorous visual introduction to autism through cat photography,
ideal for kids and families learning together.

#### "My Brother Otto" - Meg Raby

A sweet story of a little crow with Autism told through the loving eyes of his sister, offering an age-appropriate lens on Autistic traits and family dynamics.

#### "A Friend for Henry" - Jenn Bailey

Told from the perspective of an Autistic boy navigating social connection at school, this story affirms Neurodivergent needs in friendship.

"The Spectrum Girl's Survival Guide" - Siena Castellon Part journal, part manual, this empowering guide helps girls and AFAB teens navigate life with confidence and pride in their Neurodivergence.



#### Australian Autistic & Neurodivergent Resources: Organisations & Community

ANPA - Australian Neurodivergent Parents Association
Website: <a href="https://sites.google.com/view/theanpa/home">https://sites.google.com/view/theanpa/home</a>
advocates for the rights, inclusion, and safety of Neurodivergent parents and their families across Australia.

## TARA - The Autistic Realm Australia Website: <a href="https://facebook.com/autisticrealm">https://facebook.com/autisticrealm</a> TARA is creating change through lived experience advocacy.

Rockabilby - Neurokin Events Website: <a href="http://www.neurokin.org.au">http://www.neurokin.org.au</a>

Carving their own way in life, living life intentionally, and passing on the freedom of individuality, zest for life, and creativity through their life's journey.

Heidi La Paglia Reid Consulting
Website: <a href="https://www.lapagliareidconsulting.com/">https://www.lapagliareidconsulting.com/</a>
An Autistic lived experience advocate and policy consultant in all areas related to gender equality and disability rights.

Disability Leadership Institute
Website: <a href="http://disabilityleaders.com.au/">http://disabilityleaders.com.au/</a>
By disability leaders for disability leaders.



# © Don't forget to share your thoughts on the GRANN Inc. Name Change

Gladstone Region Autistic & Neurodivergent Network Inc. is evolving! We're exploring a name that better reflects our vision, values, and growing impact as an Autistic & Neurodivergent-led social enterprise.

We're committed to keeping the acronym "GRANN Inc." to honour our roots, but we'd love your views in helping shape what it stands for moving forward. Please take a few minutes to share your thoughts by filling out the form via the link below or via the QR code.

#### https://forms.office.com/r/8f59ac9RE9

Thank you for contributing to the future of GRANN Inc.

Your views help ensure we stay community-led, inclusive, and affirming of Autistic and Neurodivergent identity.



### Rockabilby & Neurokin Events- Supporting RAD Artists

Are you a RAD (Regional Australian Disabled) Artist?

Did you know that RAD artists are the lowest paid people in the Australian creative industries?

Want to be part of a collective action to improve the payment and representation of and services for RAD artists?

Rockabilby & Neurokin Events are looking for Neurodivergent, D/deaf and Disabled artists from across regional and remote Australia to be part of our Tshirt Drive on October 23, National Giving Day to the Arts.

We won't let RAD artists die from exposure!

Featured artists will be paid \$10 per tshirt sold with their design on it.

Express your interest & submit a design (they don't have to relate to disability)

<a href="https://forms.gle/Wcd4enEdL9sMQTsXA">https://forms.gle/Wcd4enEdL9sMQTsXA</a>



#### Neurokin Arts Festival

Showcasing diverse Neurodivergent creativity whilst fostering community, culture and leadership

Full schedule of both weekends available now, one online and one in person in Castlemaine central Victoria, with two ways to pay, from your own pocket or NDIS budget.

Get an invoice for NDIS: <a href="https://forms.gle/27dDqctDeEjyHb2C8">https://forms.gle/27dDqctDeEjyHb2C8</a>

Find out more about the festival & buy tickets: www.neurokin.org.au







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