



NDIS: Behind The Curtain

TERMINOLOGY AND EVIDENCE

FEBRUARY 2023

A Glitch in the Matrix?



How to describe Angelman syndrome

Angelman syndrome is a **rare, genetic neurological condition**, often diagnosed in the first 2 years of life but may be mis-diagnosed as **Cerebral Palsy or Autism Level 3 (non-verbal)**, or may go undiagnosed for years as intellectual disability or global developmental delay.

Angelman syndrome has **multi-system impacts severely affecting all functional domains** including motor (fine & gross), communication, learning, self-care, socialising etc, and these impacts **are permanent**.

People with Angelman syndrome will **lifelong significant health needs** including due to severe and sometimes intractable epilepsy, feeding and bowel management, and skeletal and muscular impacts resulting in scoliosis and painful mobility. They are almost **exclusively non-verbal and require targeted assistive technology** that is age-appropriate and consistent, targeted and sometimes intensive allied health supports that are reflective of their goals and aspirations. This includes Positive Behaviour Support due to challenging behaviours.

Carer strain and burnout are evidenced in research due to the severe sleep disorder, a minimum of 1:1 24/7 high care needs, and the requirement for constant vigilance for seizures, falls, and other risks.

High Intensity Support – Personal Care

Epilepsy

PEG Feeding/Enteral Feeding

Complex Bowel Care

Positive Behaviour Support - >1 instance per shift

Mealtime Management/Dysphagia



NDIS Practice Standards: High intensity support skills descriptors

Guidance for NDIS providers and
auditors

November 2022

Version 3

Support Workers

In-home support

1 hour of self-care in AM/ PM

Not for taking a child to therapy, school, dance classes or swimming

Short Term Accommodation/Respite

Difficult to get for <12year old

Maximum 28 days for STA

Active verses Inactive Overnight Support

Social and Community Access

Difficult to get for <10 year olds

Parental Responsibility vs Parental Capacity

Evidence of challenges

For adults, consider what a typical same-age peer does

Capacity Building

Social skills, independence, transport

What are they talking about?

Plan Reassessment

- Scheduled Plan Reassessment – nominally 56 days before plan review by date
- Early Plan Reassessment - >56 up to 100 days before plan review by date
- Change of Situation/Circumstances – Request with evidence, and then proceed to a meeting

Plan Variation – change one area but leave the rest

- Change of Funds Management

Assistive Technology Request – >\$1,500 value – for mid- and high-cost assistive technology, or previously unfunded AT at the low-cost end and there are insufficient funds; generates a New Plan (note: no unspent funds are carried forward)

Plan auto-extension – while you wait for a Plan Variation/Reassessment if the plan review by date has passed

Plan renewal – same funding added to your remaining budget at Plan Review by Date (carry forward underspend); plan end date changed on the portal; no new paper plan generated

Plan Review of Reviewable Decision (RORD) – \$100 – within 3 months of receiving the new plan and you believe there is something wrong/missed

Note: Priority Review – less than 2 weeks funding remaining – vulnerable person

Urgent Plan Re-set – if there is an imminent risk of serious harm or cessation of support

Evidence

Carer Impact Statement – Ask for the support you need including Support Coordination

Functional Capacity Assessment – and Addendum if the assessments are still within the past 2 years and not much has changed

Positive Behaviour Support Letter – needs to include updated data since the PBS Plan

Make sure all Recommendations are aligned

Primary v Secondary diagnoses – clarify what is on the system

List all diagnoses

Participant Information Access Request – Planner's Assumptions and funding decisions

Freedom of Information Request – any communication related to the participant between any NDIA staff

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