Angelman syndrome and the NDIS

A guide for participants, families and carers working out what the NDIS funds for Angelman syndrome, and how to ask for it.

FOR PARTICIPANTS & FAMILIES PUBLISHED SEPTEMBER 2026 VERSION 2.0

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About this guide

This guide is for people living with Angelman syndrome, and for the families and carers around them. It is written by Independent Life Disability Supports (InLife), a registered NDIS provider working with families across Victoria.

We wrote it because the NDIS is complicated, and the people who need it most usually have the least time to work it out. We have kept it plain. Where the NDIS uses jargon, we explain it. Where Angelman syndrome has its own vocabulary, we explain that too.

WHO THIS IS FOR

Three groups of readers

People recently diagnosed with Angelman syndrome, or told they may qualify for the NDIS. Families and carers supporting someone living with it. Health professionals helping a person prepare an application.

WHAT YOU WILL FIND

Six sections, and the last is yours

What Angelman syndrome is, and how it affects daily life. How the NDIS works and how to apply. The supports it commonly funds. How InLife works as a provider. Who to call. Pages to fill in and bring to your planning meeting.

A NOTE ON LANGUAGE

This guide is written in English. InLife supports families in Farsi, Urdu, Hindi, Punjabi and English, and this guide is published in eleven languages. Ask, and we will work in the language that suits your household. Interpreters are free at every NDIS meeting, and you never have to ask a family member to interpret their own health conversation.

CONTENTS

What is in here

THE WORKBOOK IS YOURS

The last four pages are a workbook: your details, a map of your week, and space for your goals. Fill them in and bring this guide to your planning meeting. A planner who can see your week does not have to imagine it.

SECTION ONE

About Angelman Syndrome

What Angelman syndrome is, how it affects daily life, and where the NDIS fits in.

What is AS?

Angelman Syndrome (AS) is a rare genetic condition caused by a change to the UBE3A gene on chromosome 15. It is present from birth, although diagnosis often follows the first one to two years when developmental milestones do not arrive as expected. AS affects communication, movement and balance, often sleep, and for many people brings seizures during childhood. Most people with AS do not use spoken language but understand far more than they can express — receptive language is consistently stronger than expressive language.

Angelman Syndrome is lifelong. It is not progressive in the way some conditions are — the underlying genetic difference does not get worse — but the supports a person needs change across childhood, adolescence and adulthood. Many people with AS are described by their families as warm, sociable and quick to laugh. The NDIS funds the supports that make a full life across decades possible: communication systems, allied health, support workers, equipment, and the home environment that holds it all together.

Common signs and symptoms

- Significant communication differences — most people do not use spoken language, though receptive understanding is strong.
- Balance and coordination differences (ataxia) — many people walk, often with a wide- based gait, some use mobility aids.
- Seizures, often beginning in early childhood — present for around 80 per cent of people with AS.
- Sleep differences — shorter sleep duration and more frequent night waking are common.
- A characteristically sociable demeanour, with frequent smiling and laughter.
- Intellectual disability that varies in degree from person to person.
- Fine motor differences — hand use for object manipulation is often affected.

The medical context

- AS is confirmed by genetic testing — most commonly DNA methylation analysis of chromosome 15q11–13.
- The four genetic mechanisms are: deletion (most common), uniparental disomy, imprinting defect, and UBE3A mutation.
- Seizure management often involves anti-epileptic medication — valproate, clobazam, levetiracetam and others, guided by a paediatric or adult neurologist.
- Sleep disturbance is often managed with melatonin, sleep hygiene plans, and behavioural strategies.
- Scoliosis can develop in adolescence and adulthood and benefits from physiotherapy and orthopaedic monitoring.
- Multidisciplinary clinic care is the gold standard — neurology, genetics, paediatrics, allied health.

ASISNOT

Angelman Syndrome is not a behavioural condition and it is not a form of autism, although some traits overlap. The smiling and laughter that often accompany AS are part of how the person experiences the world — they are not 'happy all the time' and feel the full range of human emotion. Most importantly, a person with AS understands far more than they can say — assumptions about cognition based on speech are wrong and harmful.

WHERE TO LEARN MORE

FAST Australia (Foundation for Angelman Syndrome Therapeutics) maintains a current Australian clinician directory and family resource library. The Angelman Syndrome Foundation (US) and the international Angelman Syndrome Alliance publish family guides.

ABOUT ANGELMAN SYNDROME

How Angelman Syndrome can affect daily life

Everyone's experience of AS is different. The list below covers areas the NDIS commonly funds support around — it is not a prediction. The conversation with your treating team and the NDIA Planner is what shapes your supports.

COMMUNICATION

How you connect

Most people with AS use AAC, gesture, vocalisation and partner support — not spoken language. Receptive understanding is strong. The right AAC system, used by everyone around the person, changes everything.

SEIZURES

How seizures fit

Around 80 per cent of people with AS have seizures, most commonly in childhood. Workers trained in seizure response and a clear plan turn an unpredictable event into a managed one.

DAILY LIVING

How you live each day

Personal care, mealtimes, getting out into the community. Support workers who know the person and the AAC make routine into rhythm.

MOVEMENT

How you move

Balance, gait and coordination are usually affected. Many people walk; some use mobility aids. Physio across the lifespan keeps movement safe and pain-free.

SLEEP

How you rest

Sleep is shorter and more broken for most people with AS. Sleep hygiene, environmental design, melatonin and routine all play a part — the family's rest matters too.

ADULT LIFE

How life unfolds

Adulthood with AS is still a full life — day programs, supported work where suitable, friendships, community participation, family relationships. The plan grows up with the person.

An ordinary life

A diagnosis of AS is not a closed door. The NDIS exists to fund what each person needs to live an ordinary life — to work or study, to spend time with family, to participate in

> **"A person with Angelman Syndrome is fully present, fully a person, and fully connected to the people around them. The supports we build are how the world meets them where they are."**
>
> INDEPENDENT LIFE · HOW WE BEGIN EVERY PLAN

What an ordinary life can look like

- their community, to enjoy the things they enjoy.
- What "ordinary life" looks like
- Living at home with family or in supported accommodation
- Using an AAC device to ask, refuse, request and connect
- Day programs, community participation, supported employment
- Hydrotherapy, music, art, swimming, riding for the disabled
- Spending time at the gurdwara, mosque, church or community centre
- Family birthdays, weddings, festivals — fully included
- Travel — domestic holidays and family trips overseas with the right planning
- Long-term, trusted friendships with workers and peers
- A predictable rhythm of week, with the same faces showing up
- Sensory-rich experiences — water, music, movement, the bush

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SECTION TWO

The NDIS basics

What the scheme is, whether you can access it, and how to prepare for a planning meeting.

What is the NDIS?

The National Disability Insurance Scheme funds the supports a person needs because of disability. It is not income support and it is not health care.

THE WORD	WHAT IT ACTUALLY MEANS
National	It runs across the whole country, wherever you live.
Disability	It funds support for intellectual, physical, sensory, cognitive, neurological and psychosocial disability, where the functional impact is substantial and likely to be lifelong.
Insurance	It takes a lifetime view, investing earlier so that less support is needed later where that is possible.
Scheme	It funds what you need to build skills, stay independent and live an ordinary life.

Who runs it

The **NDIA** (National Disability Insurance Agency) makes funding decisions. The **NDIS Quality and Safeguards Commission** regulates providers, handles complaints and protects participant rights.

The NDIS in one sentence

It funds "reasonable and necessary" supports so you can live an ordinary life. What that means in practice is the conversation you will have at your planning meeting.

Can I access the NDIS?

The four basic rules

- You are under 65 when you apply.
- You are an Australian citizen, permanent resident, or hold a Protected Special Category Visa.
- You have a permanent disability that substantially affects how you do everyday activities.
- You need support in at least one of: communication, mobility, social interaction, learning, self-care, self-management.

How to apply

- Phone the NDIA on 1800 800 110 to request an Access Request Form.
- Your GP or treating team completes the evidence sections. They are usually the ones who can describe your functional impact.
- The NDIA aims to decide within 21 days of a complete form.

FOR ANGELMAN SYNDROME SPECIFICALLY

Angelman Syndrome is on the NDIS List A (conditions that automatically meet the disability requirements). Access is straightforward where genetic confirmation is documented. The strongest applications include the genetic test report, a paediatric neurologist or geneticist letter, and a recent Functional Capacity Assessment from an OT. Where AS was diagnosed in childhood and the participant is now an adult, an updated FCA carries the most weight. How to apply

IF YOUR APPLICATION IS DECLINED

You can ask the NDIA for an **internal review** (a section 100 review) within three months of the decision. If you are still dissatisfied, you can apply to the **Administrative Review Tribunal** on 1800 228 333 or at art.gov.au. The ART took over this work from the AAT in October 2024, so older letters and websites may still use the old name. Many decisions are changed at the internal review stage once stronger evidence is supplied, so it is worth gathering evidence before you escalate.

Before the planning meeting

The planning meeting is where your first plan gets built with the NDIA. It runs about ninety minutes. Going in prepared changes what comes out.

ONE

Write your goals

Big and small. Where do you want to be in twelve months? In five years? Goals are written in everyday language, not medical terms.

TWO

Map your day

Use the workbook at the back of this guide. Note where help would change things, and be specific about the hard parts of the day.

THREE

Gather evidence

Functional Capacity Assessment, GP letters, hospital discharge summaries, allied health reports, current medication list.

FOUR

Bring someone

Family, an advocate or a support coordinator. You can ask for a free interpreter, and you should if English is not your first language.

EXAMPLE GOALS

Goals are written in everyday language, not medical terms. The NDIA accepts goals like "I want to be able to make my own breakfast" or "I want to volunteer at the local library."

At the planning meeting

The meeting is run by an NDIA planner or a Local Area Coordinator. Both can build your plan with you.

What they will ask

- Your personal details and how you would like to be contacted.
- Which community or mainstream supports you already use: GP, hospital, family, church, mosque, gurdwara, temple.
- Your safety at home and in the community.
- Your goals, for the next twelve months and beyond.
- The kind of support that would help you reach them.

What you can do

- Take your time. Pause, think, ask for the question again.
- Use pictures, photos or other communication aids.
- Have family or a support person speak on your behalf.
- Ask for an interpreter, at no cost to you.
- Decline to answer anything that feels invasive.

> **BRING THIS GUIDE**
>
> The workbook pages at the back are designed for this meeting. Filled in, they give the planner a coherent picture of who you are and what you need, without you having to hold it all in your head on the day.

“Reasonable and necessary” supports

Your plan is built from supports the NDIA considers reasonable and necessary. Reasonable means fair, taking into account what is already available to you. Necessary means you need it to live an ordinary life or work toward your goals.

A support must meet all six tests

- Related to your disability, not general living costs.
- Value for money, judged against the alternatives.
- Likely to be effective and beneficial, with evidence behind it.
- Takes into account informal supports: family, carers, community.
- Most appropriately funded by the NDIS, not by health, education or housing.
- Not a day-to-day living cost everyone has, such as rent, food or ordinary internet.

WHAT THIS LOOKS LIKE FOR ANGELMAN SYNDROME

For Angelman Syndrome, supports that pass the test almost always include allied health (Speech for AAC, OT for daily living and equipment, Physio for mobility and posture, Psychology for behaviour support and family support), AAC devices and the training to use them, support workers trained in seizure response and AAC, equipment that addresses balance, transfers and sleep safety, and home modifications where the home environment creates a safety risk. Capacity-building therapies are funded explicitly to build communication and independence across the lifespan.

Three ways to manage your funds

At the planning meeting you choose how your funding is paid out. You can change this at any time during the plan, and you can use a different method for different parts of your budget.

OPTION ONE

NDIA managed

The NDIA pays your providers directly. No paperwork for you, and no invoices to check. You can only use registered providers.

OPTION TWO

Plan managed

A plan manager processes invoices and tracks your budget. You can use both registered and unregistered providers. Plan management is funded by the NDIS on top of your other budgets, at no cost to you.

OPTION THREE

Self managed

You pay providers yourself and claim back from the NDIA. The most flexibility, including on price, and the most administration.

> **THIS IS YOUR CHOICE, NOT YOUR PROVIDER'S**
>
> Each option suits different households, and no provider should push you toward one. Ask your planner or Local Area Coordinator to talk you through the trade-offs, and change it later if it is not working. InLife works under all three.

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SECTION THREE

Your supports

The therapies, equipment and support workers the NDIS commonly funds for Angelman syndrome.

Allied health for Angelman Syndrome

Allied health is the clinical layer of your supports — therapies and assessments delivered by registered professionals. For AS, the disciplines most commonly funded are: Allied health is funded under Capacity Building — Improved Daily Living.

SPEECH PATHOLOGY

Speech — unlocking communication

AAC assessment and trial, eye-gaze and switch access, partner training, building communication into every routine. Speech is often the lead clinician — communication unlocks everything else.

PHYSIOTHERAPY

Physio — movement and joints

Gait training, balance work, scoliosis monitoring and management, contracture prevention, hydrotherapy. Critical across the lifespan as the body changes.

MUSIC THERAPY

Music Therapy — engagement and regulation

Music is a strong channel for many people with AS — engagement, mood regulation, communication building. Often used in groups and one-to-one.

OCCUPATIONAL THERAPY

OT — daily life and equipment

Daily living routines, fine motor strategies, equipment prescription, sensory regulation, sleep environment, home modifications. The OT designs the day around the person.

PSYCHOLOGY / BEHAVIOUR SUPPORT

Behaviour Support — understanding behaviour

Functional behaviour assessment, positive behaviour support plans, family coaching. Behaviour is communication — the plan reads it that way.

DIETETICS

Dietitian — nutrition and weight

Reduced mobility, medication interactions, and a tendency toward weight gain in adulthood make dietetic input important across the lifespan.

A NOTE ON FUNDING CATEGORIES

Allied health is funded under Capacity Building, Improved Daily Living, and is given to you in hours. You can use any registered allied health provider you choose. Hourly rates are capped by the NDIS price limits, so a provider cannot charge you above the cap. InLife coordinates allied health; we do not deliver it, and we are not registered for therapeutic supports.

Equipment commonly funded

The NDIS funds disability-related equipment under Capital, as assistive technology. These are the items most often funded for Angelman syndrome.

EQUIPMENT	WHAT IT IS FOR
AAC device (eye-gaze or switch)	The communication system — voice output, vocabulary, partner-supported. Often the single most life-changing item in a plan.
Seizure-alert mattress or wearable	Overnight monitoring for tonic-clonic seizures, peace of mind for family and supported accommodation.
Padded helmet (where appropriate)	Where falls from atonic seizures or balance differences risk head injury.
Manual wheelchair (some)	Distance mobility where walking is fatiguing or community access is difficult.
Adjustable bed / safe sleep system	Safe sleep environment given seizures and sleep difficulties — sometimes including bed rails and enclosure systems.
Postural seating	Supportive seating where scoliosis or low tone make standard chairs unsafe.
Home modifications	Bathroom safety, secure outdoor space, sensory-calm bedroom, kitchen safety.
GPS tracking device	Where wandering is a risk — wearable trackers tied to family or carer phones.

How a request works

- An occupational therapist or other clinician assesses the need and writes a report.
- The report, with quotes where required, goes to the NDIA.
- Low-cost items can come straight out of an existing budget. Higher-cost items need the assessment and approval first.

Home modifications

Minor home modifications cost up to $20,000 and do not change the structure of the home. **Complex** modifications go beyond that, or affect the structure, and the NDIS funds a building construction practitioner to work alongside your home modification assessor. Neither is the same thing as Specialist Disability Accommodation, which is a separate funding stream for purpose-built housing.

Support workers, the everyday backbone

Support workers help with the daily tasks that disability makes harder: personal care, getting to appointments, cooking, medication prompting, community access, staying connected.

Most participants have a named team of three to five workers across the week. The right team feels like a small group of familiar people who know how you like things done, not a roster of strangers.

What good looks like

- The same workers week after week, not whoever is free that day.
- Workers who speak your home language at the door.
- Respect for your faith, dietary practice and household norms.
- Trained on your specific clinical needs before the first shift.

And what you should expect

- Backup workers you have met and approved in advance.
- Shift notes shared within 24 hours, in plain language.
- One escalation point when something is wrong.
- The right to change your team without having to explain why.

> **THE INLIFE MEET-AND-APPROVE PROMISE**
>
> No worker meets a participant for the first time on a shift. You meet them, you decide, then we roster. That holds across every plan we deliver.

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SECTION FOUR

Why InLife

How we roster, how we match workers to households, and what we commit to.

How InLife is different

Plenty of providers fill shifts from a rotating casual pool drawn across several agencies. For someone living with Angelman syndrome, that is the wrong shape. We roster deliberately instead: a named team around each household, and no worker on a shift the household has not already met and approved.

CONSISTENCY

The same workers

A named team who know your routine, your preferences and your clinical needs. No strangers on a Tuesday because somebody called in sick.

LANGUAGE

Your language at the door

Our team works in Farsi, Urdu, Hindi, Punjabi and English. Workers are matched to the language your household actually speaks, including the language you fall back on when you are tired or unwell.

ONE POINT OF CONTACT

No call trees

One phone number and one email, both reaching the managing directors. No agency switchboard, and no "someone will get back to you".

RECORDS

Written so you can read them

Every shift note and every report written in plain language, and a monthly summary of what has been used, copied to your support coordinator.

REGISTERED, AND VERIFIABLE

InLife is a registered NDIS provider, regulated by the NDIS Quality and Safeguards Commission, covering Core supports, Module 1 high-intensity daily personal activities and Module 2A behaviour support plan implementation. Every registration group is public on the Commission's provider register. We do not deliver therapeutic supports or Specialist Disability Accommodation, and we will tell you so rather than stretch to fit.

How we match workers to households

Matching is the part most providers skip. We treat it as the most important conversation we have with a new household.

ONE

Language

The languages spoken at home, including the one a person reaches for in moments of stress or confusion.

TWO

Gender

Cultural and personal preferences about who delivers personal care, taken as a requirement rather than a preference.

THREE

Cultural fit

Faith observance, dietary practice, household norms and family hierarchy.

FOUR

Clinical competency

The specific skills the person's support requires: medication, transfers, mealtime management, seizure response.

FIVE

Geography

Close enough that workers arrive on time and stay reliable over a long placement.

SIX

You decide

We shortlist, you meet them, you approve. Only then do we roster. If it is not working, say so and we change it.

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SECTION FIVE

Resources & next steps

Where to turn, how plan reviews work, your rights, and the words the NDIS uses.

Where to turn

About the NDIS

ORGANISATION	HOW TO REACH THEM	WHAT THEY DO
NDIA	1800 800 110 · ndis.gov.au	Access decisions, plan reviews, general NDIS enquiries.
NDIS Commission	1800 035 544 · ndiscommission.gov.au	Complaints about providers and workers, conduct, restrictive practices.
Administrative Review Tribunal	1800 228 333 · art.gov.au	External review of NDIA decisions after an internal review. Took over from the AAT in October 2024.
Disability Advocacy Network	1300 365 085 · da.org.au	Independent advocacy when you feel unheard.
TIS National	131 450	Free interpreting, in more than 150 languages.

For Angelman Syndrome specifically

ORGANISATION	HOW TO REACH THEM	WHAT THEY DO
FAST Australia (Foundation for Angelman.	1300 078 108 · cureangelman.org.au	Australian health promotion charity focused on Angelman therapeutics.
Angelman Syndrome Association Australia.	angelmansyndrome.org	Australia's peak advocacy body for Angelman syndrome. Family-led peer support, regional groups, conferences,
Rare Voices Australia	rarevoices.org.au · RARE Helpline 0499 549.	National peak body for rare diseases — advocacy, NDIS navigation, family support.
Genetic Support Network of Victoria	03 8341 6315 · gsnv.org.au	Family information and peer connection for genetic conditions across Victoria.
Communication Rights Australia	communicationrights.org.au	Advocacy and information for people who use AAC. Critical for AS families.

Reviewing your plan

About two months before your plan ends you will be contacted to begin a reassessment. This is your chance to reshape supports around the year you have actually had.

Questions worth bringing

- What worked? What did not?
- Which goals did you reach, and which need more time?
- Where did you underspend or overspend, and why?
- Are your funding categories the right shape?
- Has your clinical picture changed?

Reasons to ask early

- A hospital admission or a significant clinical change.
- You need more support hours than the plan funds.
- Equipment you did not know you needed at the start of the year.
- A change in informal supports, such as losing a primary carer or moving house.

> **BRING EVIDENCE, NOT ARGUMENT**
>
> Shift notes that show the gap, allied health reports, hospital letters. Your support coordinator can help you build the case. InLife will provide every shift note and report you need, and we do not charge you for asking.

Your rights, and raising a concern

As an NDIS participant you have the right to

- Decide what supports you receive, and from whom.
- Be treated with dignity and respect.
- Receive supports that are safe and culturally appropriate.
- Get information in your preferred language.
- Make a complaint without losing supports.
- Choose someone to act for you: a nominee, an advocate or a guardian.
- An interpreter, at no cost.

If something is wrong

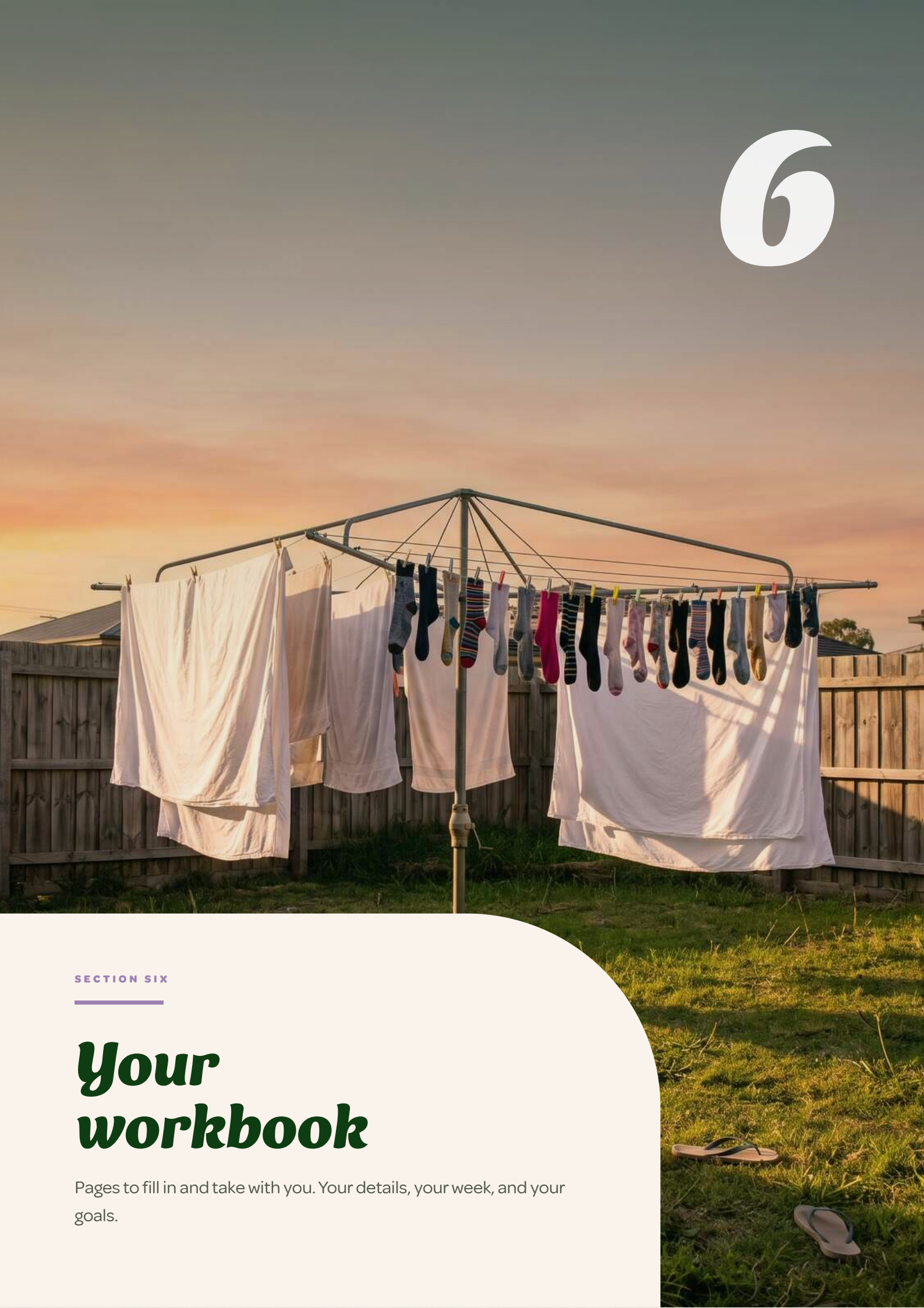
About a decision	NDIA · 1800 800 110
About a provider or worker	NDIS Commission · 1800 035 544
About InLife specifically	admin@independentlife.au, which reaches both managing directors
To appeal an NDIA decision	Internal review first, then the Administrative Review Tribunal · 1800 228 333
Independent advocate	Disability Advocacy Network · 1300 365 085
Interpreter	TIS National · 131 450

COMPLAINING IS PROTECTED

Raising a complaint is a legally protected action. No provider may reduce your support, treat you differently, or end your service because you complained. That is enforced by the NDIS Commission, and it applies to us as much as to anyone else.

The words the NDIS uses

ARF	Access Request Form. What you submit to apply.
ART	Administrative Review Tribunal. Reviews NDIA decisions after an internal review. It took over from the AAT in October 2024, so older paperwork may use the old name.
Core	The flexible budget covering daily personal care, community access and consumables.
Capacity Building	Funding to build skills: allied health, support coordination, employment supports.
Capital	Funding for equipment and home modifications. It cannot be moved to other categories.
FCA	Functional Capacity Assessment. A clinician's report on what you can and cannot do day to day.
LAC	Local Area Coordinator. An NDIA partner who can build your plan with you.
NDIA	National Disability Insurance Agency. Makes the funding decisions.
NDIS Commission	NDIS Quality and Safeguards Commission. Regulates providers and handles complaints.
Plan manager	A third party who processes invoices and tracks your budget for you.
SC	Support Coordinator. A funded role that helps you put your plan into practice.
SDA	Specialist Disability Accommodation. A separate funding stream for purpose-built housing. It is not a home-modification threshold.



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SECTION SIX

Your workbook

Pages to fill in and take with you. Your details, your week, and your goals.

About me

Take this page to your planning meeting. The planner will want to know who you are before deciding what supports you need.

MY NAME

NDIS NUMBER

DATE OF BIRTH

PHONE

MY ADDRESS

PERSON HELPING ME

THEIR RELATIONSHIP TO ME

MY LANGUAGES

CULTURAL BACKGROUND

MY GP

MY SPECIALIST OR TREATING TEAM

EMERGENCY CONTACT

My week

Sketch a typical week as it is now, and mark the points where help would change things. The gaps are the argument.

Monday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Tuesday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Wednesday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Thursday

MORNING

YOUR WORKBOOK

AFTERNOON

My week, continued

EVENING

Friday

OVERNIGHT

MORNING

AFTERNOON

EVENING

OVERNIGHT

Saturday

MORNING

AFTERNOON

EVENING

OVERNIGHT

Sunday

MORNING

AFTERNOON

EVENING

OVERNIGHT

My goals

Three things you want, and what would have to be true for you to do them. Written in your words, not clinical ones.

My top three goals for the next twelve months

1 _____

2 _____

3 _____

Three things I need to be able to do them

1 _____

2 _____

3 _____

QUESTIONS TO ASK ON THE DAY

What did you fund, and why that amount? Which budget does each support come from? What happens if my needs change mid-plan? Who do I contact if something is not working? When does this plan end?


GOOD W