



Shaping the future,
supporting today



ASAA DAY 2

CONFERENCE RESOURCES



WE ARE SO GLAD YOU ARE HERE FINDING YOUR TRIBE



Post-Conference Reflection

The 2025 Angelman Syndrome Collaborative Conference (19 & 20 September) in Sydney brought community, connection, and curiosity together in a powerful way.

Thank you to everyone who travelled, contributed, and shared; your presence made the conference meaningful and practical. We welcomed many for whom this was their first collaborative conference - including children and adults with Angelman syndrome, newly diagnosed families, adult siblings, and families who were able to find support to attend for the first time. We were so glad you were all able to share this event and meet this extraordinary community.

Special thanks to the speakers who gave up their Saturday and many extra hours to prepare, to the committee who planned and delivered the program over 11 months, and to the amazing volunteers and supporters who generously prepared resources and helped to ensure the event ran smoothly.

We are grateful to our sponsors and donors who contributed much-needed financial support to help us host the events and provide resources. Please show them your support too.

Thank you to the ASAA Committee for hosting the Angelman Family Night and to the Laneway Sports Bar, Pyrmont, for their hospitality. A special congratulations to Kevin Kennedy on 33 years of outstanding service to the Angelman Syndrome Community.

A note about how you might feel now

Feeling a post-conference lull, overwhelm, or tiredness after a concentrated few days is common. Be gentle with yourself — you are already doing enough. Daily life resumes quickly, and absorbing new information takes time.

How to use these summaries

These summaries are a handy reference to help you decide whether there is anything you want to review, research, read, or try.

Scan the key takeaways, reflect on what stood out, and consider if there are one or two practical actions you might like to trial, rather than attempting everything at once.

Small, focused steps can often make the biggest difference.

Fiona Lawton, President



THE CONFERENCE HAS FINISHED - WHAT DO I DO NOW?

You've just spent time in a space filled with stories, knowledge, and emotion. Whether you're feeling inspired, overwhelmed, or somewhere in between, here are some ways to process and carry the experience forward:

TAKE TIME TO DECOMPRESS



Rest is essential: Conferences can be emotionally intense. Give yourself permission to slow down.

Journal or reflect: Write down what moved you—moments, quotes, people. It helps make sense of it all. It can become a resource to reflect on later.

Talk it out: Share your experience with someone you trust. Sometimes, just being heard is healing.



STAY CONNECTED

Reach out: If you have any questions please contact either FAST Australia or ASAA.

Join the community: Follow social media pages, newsletters, make sure you are a part of the facebook family pages and know your ASAA state representative.

Share your feedback: Your voice helps shape future events. Let us know what worked and what could improve.



HONOUR YOUR JOURNEY

Celebrate your courage: Showing up, listening, and sharing takes strength. You did that.

Acknowledge your emotions: It's okay to feel grief, hope, anger, or joy. All of it belongs.

Remember, you're not alone: The AS community exists because of people like you. You're part of something powerful.



**Big journeys begin
with small steps!**

DISABILITY ADVOCACY

Speaker: Erin Papps, Advocacy and Policy Manager, presenting on consortium advocacy led by Down Syndrome Australia.

Focus: How Disability Representative Organisations work together through a national consortium to influence policy and build advocacy capacity.

Key takeaways for Angelman families

- **National coordination matters:** a coordinated DRO consortium amplifies family voices and targets national policy levers rather than fragmented local approaches.
- **Targeted advocacy drives outcomes:** focused, evidence-based asks are more likely to change practice and funding decisions than general appeals.
- **Priority policy areas align with daily needs:** NDIS access, health system navigation, supported employment, inclusive education, prenatal information, and migration policy have a dedicated advocacy focus.
- **Multiple channels for influence:** ASAA can help influence change through written submissions, video submissions, participation in DRO meetings, and targeted advocacy campaigns.

How families' contributions are used

- **Evidence gathering:** real stories and concise data feed into submissions to NDIS, health reviews, and parliamentary inquiries.
- **Targeted influence:** consortium advocacy focuses on specific policy levers where change is achievable.
- **Power building:** repeated, coordinated inputs from families increase credibility with decision makers and create sustainable change.

Next Steps - What can you do?

- **ASAA Membership:** Sign up for free membership to ASAA to ensure you receive email newsletters and updates
- **Newsletters:**
 - Sign up for Down Syndrome Australia newsletters
 - Sign up for Inclusion Australia and State Organisation newsletters
- **Advocacy Submissions:** Read the DRO Consortium Advocacy submissions
- **Support advocacy efforts:** Email ASAA at info@angelmansyndrome.org or Erin Papps at advocacy@downsyndrome.org.au with your top one or two priorities and offer a short written or video submission.

Resources

- DRO Consortium Advocacy submissions - <https://www.downsyndrome.org.au/national/advocacy/submissions/>
- Inclusion Australia - Intellectual Disability National Peak Body and State organisations - <https://www.inclusionaustralia.org.au/about-us/our-members/>



NEUROPSYCHIATRY IN AS

Speaker: Associate Professor Rebecca Koncz, Chair of Intellectual Disability Mental Health, UNSW Sydney.

Focus: The neuropsychiatry of neurodevelopmental disorders with applied guidance on diagnosing and managing behaviours of concern. Mental health is common and treatable with appropriate assessment, reasonable adjustments, and evidence-based interventions.

Key clinical takeaways for Angelman families

- **High vigilance for change:** any new or worsening behaviour requires assessment rather than assuming it is “just Angelman Syndrome.”
- **Look for treatable medical causes first:** such as bowel, urinary, vision, hearing, dental problems, and medication changes.
- **Gather baseline documentation** showing “who they are when well,” recent behaviour logs, sleep records, medication lists, and recent medical results.
- Bring supports to assessments, including communication aids, sensory aids, and a written one-page summary for clinicians.
- Request a three-part assessment consisting of a **medical** review, a **mental health** assessment with reasonable adjustments, and a **functional behaviour** assessment.
- Insist on multidisciplinary input, including a Behaviour Support Practitioner, OT for sensory/ADL strategies, speech pathology for communication/AAC, and exercise physiology for general health.
- **Escalate or seek a second opinion** if concerns are dismissed, and document all interactions clearly for advocacy.

Next Steps - What can you do?

- **Documentation:** Keep good records of changing episodes, clinical contact, test results, and treatment trials to support clinical decision-making and NDIS support
- **Care Team:** Insist on informed family partnership in care decisions and demand second opinions when necessary.
- **NDIS Support:**
 - Engage support coordination or a local clinician advocate (i.e. nurse navigator or hospital social worker) to check whether current supports and NDIS funding match clinical needs and to request plan reviews if required
 - Engage with a Behaviour Support practitioner if needed.

Resources

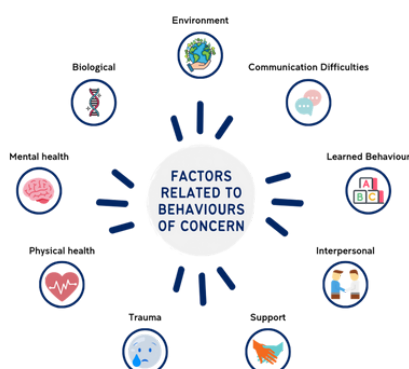
- **National Centre of Excellence in Intellectual Disability Health (NCEIDH)** for clinical guidance and links to services.
- **For appointments,** bring a one-page baseline summary, behaviour and sleep logs, medication list, communication aids, and recent health records.



What about in Angelman Syndrome?



Den Besten et al., Am J Med Genetics, 2021; 185A:168-181; Duijs et al., Mol Genet Genomic Med, 2022;10:e1843



NAVIGATING THE NDIS

Speaker: Fiona Lawton, ASAA President and CEO, Neu Pathways Australia;

Focus: Navigating NDIS reform, data integrity for rare disease cohorts, implications for supports and planning, and practical steps.

Key takeaways for Angelman families

- **NDIS participant data can be incomplete or incorrect;** participants must request reviews and supply evidence aligned with NDIS access requirements.
- **Essential evidence to add/change/confirm a diagnosis:**
 - Diagnosis confirmation - Angelman syndrome with intellectual disability (intellectual impairment)
 - Provide level of intellectual disability if confirmed - Moderate to Profound
 - Other disabilities/impairments – physical, sensory, psychosocial
 - Other medical conditions – e.g. epilepsy
 - Explicitly state permanency - 'there is no treatment available that will remedy the condition/impairments; treatments are focused on managing the symptoms and maintaining function'
 - Functional impact assessment (within last 12 months)
 - This person has a lifelong need for NDIS Supports.
- **Impairment Categories for AS**
 - **Intellectual impairment (Primary):** Significant and permanent limitations in intellectual functioning (reasoning, learning, problem solving) combined with deficits in adaptive behaviour (everyday social and practical skills).
 - **Physical impairment (Often):** Loss or difference in bodily function—such as strength, mobility, or motor coordination—that leads to substantially reduced functional capacity.
 - **Neurological impairment (if epilepsy is present):** A permanent condition affecting the central or peripheral nervous system (e.g. epilepsy or multiple sclerosis) resulting in substantial functional limitations.
 - **Rare: Cognitive impairment** is usually non-genetic and acquired (e.g. acquired brain injury); **Psychosocial impairments** must severely impact daily function to be considered (e.g. catatonia, bipolar affective disorder)



Chat online

Next Steps - What can you do?

How to check records:

- **a. Quick way (10 minutes)** - NDIS Webchat - request the Listed Disabilities - Primary, Secondary, and other conditions on the participant's profile
- **b. Full request (28+ days)** - make a free [Participant Information Access Request](#).
 - Request to review Medical Access records
 - the Listed Disabilities page and
 - Planner Justifications
- **How to change records** - Request a Change of Impairment as per instructions in the Notice of Impairment (2025+ participants only)
- Request a change of diagnosis through a plan reassessment meeting.

Note: A request to change information may trigger a full reassessment.

NDIS MYTH BUSTERS

Speakers: Fiona Lawton, ASAA President and CEO, Neu Pathways Australia; Mirella Manna, My Plan Manager, Victoria White, Social Worker and Specialist Support Coordinator

- **Myth 1** — NDIS can't be used for health expenses. NDIS funds can support **disability-related health items** when they align with a person's impairments and plan goals, and the needs have been accepted by NDIS.
- **Myth 2** — *Tablets and communication software aren't claimable* Assistive technology, tablets and communication apps can be funded, but you must show that the language system can only be used on an iOS device. You must use the **Replacement Support request form** and receive explicit approval to purchase the iPad or apps. You can't just do it.
- **Myth 3** — *Plan managers don't need a copy of your plan.* Sharing your plan with your plan manager helps them manage your budget correctly, process payments, and help guide you.
- **Myth 4** - *The reforms mean massive cuts to supports for everyone* — The reforms aim to tighten eligibility and value-for-money tests for some supports; **however evidence requirements have increased.** If you don't provide the evidence, NDIS will not fund the support.
- **Myth 5** - *You can no longer use your plan flexibly at all* — Plans still allow flexibility where supports align with your assessed impairments and goals; **check the plan for stated v flexible funding.**
- **Myth 6** - *The longer the report, the better* — Clear, targeted evidence of functional impact with data summaries (sleep, behaviour, support needs) and a **one-page executive summary** is more persuasive. All reports should list the diagnoses in the same way. Inconsistency causes chaos!

Helpful reminders:

- Order confirmations: aren't tax invoices; many online receipts need extra documentation; always check alignment with your plan before purchasing.
- Invoice essentials: business name and ABN; date; item description; total price.
- NDIA debt recovery: NDIA can raise debts against participants and plan managers. Debt is commonly raised against plan managers first after NDIA payments; staying organised with documents and communication reduces the risk of unexpected issues.



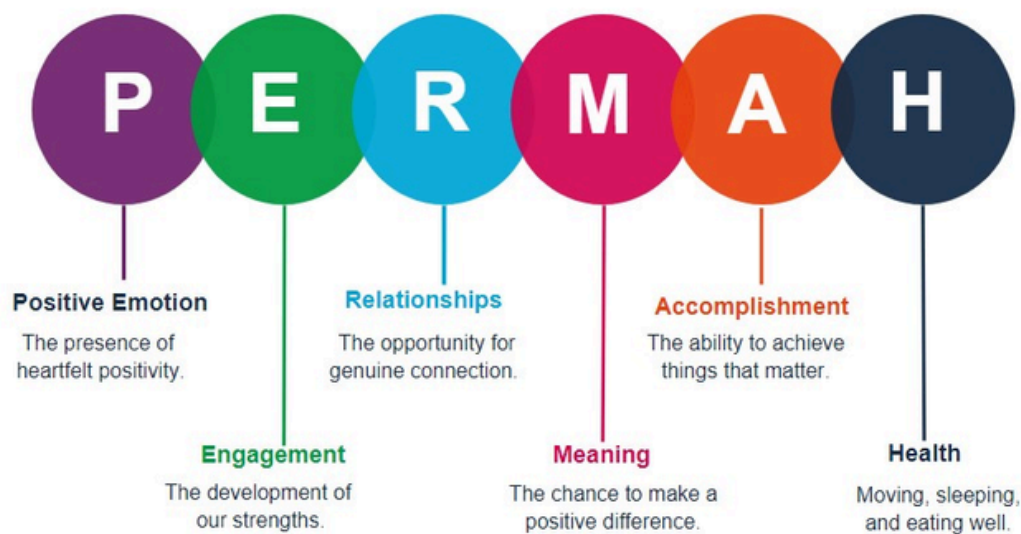
CARING THROUGHOUT THE AGES

Speaker: Sylvana Mahmic, CEO Plumtree Children's Services

Focus: Supporting parent wellbeing through Positive Psychology and peer support.

Key takeaways for Angelman families:

- **Families need more than therapy;** the challenge is creating a good life together. Let's learn from one another through peer support.
- **Hopeful stories** and peer connections reduce isolation and build confidence.
- The **Now & Next program** uses the PERMAH framework (Positive Emotion, Engagement, Relationships, Meaning, Accomplishment, Health).
- **PERMAH** helps parents celebrate wins, sustain health, and find meaning and purpose.
- Together, these tools **shift families from surviving to thriving.**



(Seligman, 2012)

Resources

Plumtree Services

<https://www.plumtree.org.au/>



CARING THROUGHOUT THE AGES

continued

Speaker: Kelly Reid, Program Manager, Belongside Families

Focus: From Diagnosis to Resilience, Grief, Growth and Finding Balance.

Key takeaways for Angelman families:

1. The Journey is Emotional and Non-Linear

- Receiving a diagnosis for your child can feel overwhelming, bringing emotions like grief, fear, and uncertainty.
- It's normal to move back and forth between different stages—shock, searching for answers, and finding new routines.

2. You Are Not Alone

- Many parents feel isolated or anxious, but support is available. Over half of parents report needing more help—reaching out is a strength.

3. Building Knowledge and Confidence

- The search for information can be exhausting, but over time, it empowers you to advocate for your child and family.
- Parents often become experts in their child's needs and play a vital role in educating others.

4. Creating a Nurturing Environment

- As you gain experience, your focus shifts from searching for answers to building a safe, supportive space for your family.
- Your voice matters—when parents are heard, outcomes improve.

5. Rediscovering Balance and Self-Care

- Once supports are in place, it's important to reconnect with your own identity, passions, and relationships.
- Social connections and self-care are proven to improve well-being for both you and your family.

6. Support for Mothers and Families

- Programs like "Healthy Mothers, Healthy Families" offer practical strategies for routines, self-care, and social connection, leading to better well-being and reduced isolation.

7. Community Matters

- Connecting with other families through groups and resources can provide ongoing support, information, and a sense of belonging.



Resources

Belongside Families

<https://belongsidefamilies.org.au/>

<https://belongsidefamilies.org.au/healthy-mothers-healthy-families/>



**Belongside
Families**

CARING THROUGHOUT THE AGES

continued

Speakers: Jasmine Young, QLD Representative ASAA, mother to Weston (6) and Sue Hones, ASAA Vice-President, mother of Alanna (35)

Focus: Navigating our roles as carers through different stages of life, fostering sibling relationships

Key clinical takeaways for Angelman families

- **It takes a village:** find your people and lean in. Reach out when you need a break (even a quick lunch with your friends will do wonders for your mental health)
- **Ask for help:** this can be tiring and relentless work. You can't pour from an empty cup
- **Connect with other AS families** (Facebook, Committee, International Angelman Day events etc). Nothing compares to being with people who just "get it".
- **Involve siblings wherever possible:** Weston's big sister is his biggest motivation, and she has spent many hours at his therapy sessions with us. So she has always understood how hard he has to work.
- **Get siblings involved in educating others:** There are some beautiful books on children living with AS. Our daughter takes these into her new class every year so they can better understand Weston.
- **Keep doing the things you love with your whole family:** camping, holidays; and beach trips. Don't let your life change too much.
- **At the end of the day, your person living with Angelman syndrome has a wonderful life full of love and happiness. Never forget this!**

Resources

Books for siblings

- **Good morning, Gus** - <https://www.amazon.com.au/Good-Morning-Gus-Kelsey-Laskowski/dp/B0CN2P48J2>
- **Sibling Stories - Getting to Know You**
<https://www.amazon.com/Getting-Know-You-Sibling-Stories/dp/B0B1NQYK8R>



GUT HEALTH IN AS

Speaker: Dr Vinita Prasad, Developmental Paediatrician and Head of Angelman Syndrome Clinic, Queensland Children's Hospital

Focus: Why GI problems are common in AS, how the gut-brain axis and gut microbiota are involved, common presentations by genetic subtype, and practical assessment and treatment pathways. The absence of functioning UBE3A in Angelman syndrome impacts the neurons in the gut (Enteric Nervous System), leading to GI dysfunction.

Key clinical takeaways for Angelman families

- **GI problems in AS are common**, often chronic, can worsen sleep/behaviour/seizures, and usually require long-term, multidisciplinary management rather than one single fix.
- **GI problems feature of AS:** constipation (~70%) and reflux (~44%) are the most frequent, with swallowing dysfunction, cyclic vomiting, and eosinophilic oesophagitis also important.
- **Gut-brain interactions matter:** dysmotility and microbiota changes can both influence neurological symptoms.
- **Genetic subtype can influence presentation:** some problems (poor infant feeding, cyclic vomiting, eosinophilic oesophagitis (EoE)) are more common in deletion and UPD subtypes.
- **Multidisciplinary care is essential:** assessment and management usually require gastroenterology, speech pathology, dietetics, OT and ongoing follow-up.
- **Safety risks to watch for:** malnutrition, choking/aspiration, and complications from unmanaged dysmotility.



Next Steps - What can you do?

- **Data:** Start a 2–4 week bowel and feeding diary (stool frequency/consistency, vomiting episodes, choking, feed duration, behaviour/sleep changes).
- **Referrals:** Ask your GP for referral to a paediatric/adult gastroenterologist and to speech pathology for swallow assessment if choking, wet voice, prolonged feeds or recurrent chest infections occur.
- **Investigations:** Request specific investigations if signs indicate (videofluoroscopy, endoscopy + biopsies, transit studies).
- **Bowel care regimen:** Review or establish a safe bowel regimen with documented instructions and intervention guidance for carers.
- Discuss **probiotics/prebiotics** with your clinician before starting them, as they can upset the stomach for some people.
- **NDIS:** Talk to your NDIS planner/support coordinator about allied-health funding, disability-related health supports for dysphagia/mealtime management, and complex bowel care training and support.

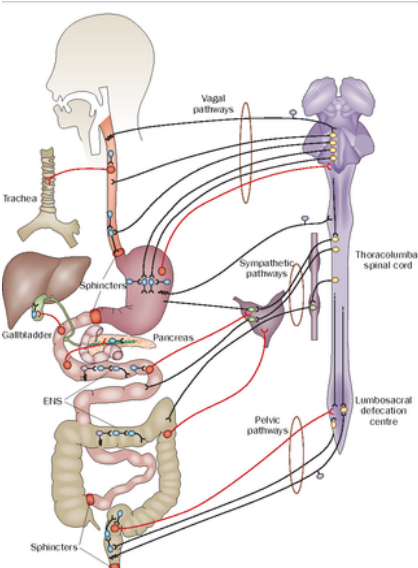


Figure 1 | The innervation of the gastrointestinal tract. The neural connections

GUT HEALTH IN AS continued

General Clinical Management - Where to start?

- Common diagnostic investigations to request when clinically indicated:
 - Videofluoroscopy (swallow study) for suspected silent aspiration.
 - Endoscopy with biopsies for persistent reflux or suspected eosinophilic oesophagitis.
 - Transit/motility studies for chronic constipation or suspected dysmotility.
 - Allergy review if EoE is suspected.

Management and treatment

• Constipation:

- Treat impaction first if needed, then start a medically supervised maintenance regimen (osmotic laxatives like polyethylene glycol are common).
- Gradually increase fluids and fibre where tolerated; monitor for bloating or intolerance.
- Consider enemas, promotility agents, motility testing or surgical options (ACE procedure) for refractory cases.

• Reflux and eosinophilic oesophagitis:

- Diet modification, thickened feeds where appropriate, and PPI therapy for acid suppression.
- Endoscopy + biopsies required for EoE diagnosis; treatment may include dietary changes and specialist medication.

• Swallowing dysfunction:

- Speech pathology-led assessment and feeding plan (posture, texture, pacing).
- If aspiration risk is high, consider alternative feeding strategies and close monitoring.

• Cyclic vomiting:

- Specialist gastroenterology review; some treatments overlap with migraine management but evidence is limited.

• Microbiota and adjuncts:

- Prebiotics and probiotics may be considered if standard treatments don't resolve symptoms; discuss choices with your clinician.

• Safety considerations:

- Avoid unsupervised changes to laxatives or supplements in people with high aspiration risk. Seek urgent care for severe vomiting, blood in vomit/stool, severe pain, or rapid weight loss.

Resources

Happy Poop - Toilet Journal Log (Google Play and App Store) - charts bowel and bladder care, food and fluid intake, and exercise and wellbeing

SNappD® - The Sleep Nap App Diary is a simple-to-use sleep and nap diary app that allows sleep statistics and the impact of poor sleep, to be recorded. Developed for neurodevelopmental conditions such as autism.

Video - [Angelman Syndrome Foundation Video - GI Dysfunction in AS \(2024\)](#)

Research Paper - [Global Angelman Registry Gut Issues \(2022\)](#)



CONTINENCE IN AS

Speaker: Sara Horsey, Registered Nurse, Continence Nurse Advisor and Director, Engage Care Services

Focus: Effective continence care in Angelman syndrome can be life-changing for the individual and their family.

Summary

Continence in Angelman syndrome is often delayed or lifelong, affecting both bladder and bowel; contributors include neurological differences that limit recognition or communication of toileting needs, low muscle tone, slow gut motility, reduced mobility, toileting anxiety and “holding,” medication side effects, and coordination difficulties. These factors increase risks of constipation, urinary tract infections and seizure triggers.

Building a Continence Management Plan

Hydration and fluids

- **Daily plan:** Calculate daily fluid needs and track intake; fluids can be hard to achieve, so consider adding fluids to foods.
- **Nighttime plan:** usually avoid drinks after 6 pm to reduce nighttime incontinence, but allow exceptions for medication-related dry mouth or safety (a supervised water bottle in bed).

Diet and gut management

- **Review diet with an AS-aware dietitian:** standard high-fibre strategies don't always work and can worsen constipation if fluids are inadequate.
- **High fibre needs high fluid:** without enough hydration fibre can harden the stool and be counterproductive.
- **Trial microbiome supports carefully:** pre/probiotics may improve stool volume, consistency and reduce accidents for some; discuss with clinicians.
- **Simple intervention:** try 150 ml pear juice each morning, increasing to twice daily if no effect within a few days.

Bowel and bladder scheduling

- **Set regular toilet times** rather than waiting for cues; identify the individual's ideal “poo time.”
- **Aim for regularity:** daily BM is ideal for most; up to every 2 days acceptable; 5+ days is unacceptable.
- **Toilet frequency balance:** target toileting about every 3 hours during the day to support bladder capacity and avoid reducing it by over-toileting.

Communication and behavioural supports

- **Use consistent visual aids and routines:** picture cards, social stories, timers, songs, or specific music to cue toilet times across all environments.

Managing attention and rewards

- **Keep pad changes low attention:** minimise eye contact and interaction during changes so toileting becomes a more appealing activity for those seeking attention.
- **Celebrate toileting success:** even sitting on the toilet needs positive reinforcement.



Resources



EARLY YEARS



Speakers: Rachael Parry, Tasmanian ASAA Representative, teacher and mother of Robbie (6) who lives with Angelman syndrome and Chrissy Cimino, Victorian ASAA Representative, nurse and mother of Elliott (8) who lives with Angelman syndrome

Focus: Dealing with diagnosis, grief, education and moving forward. Finding the balance between therapy, home life and what works for you and your family.

Key takeaways for Angelman families:

- Make sure to take time for yourself and your family away from the Angelman Syndrome diagnosis.
- Seek appropriate services for your loved ones. There is no right or wrong!
- Surround yourself with people who have knowledge regarding Angelman Syndrome including professionals, other AS families and loved ones.
- Ask questions! DO NOT rely on Google for your information. Remember you know your child best.
- Do not compare yourself and your loved one to other children. Every child is different and unique!

EARLY YEARS

continued

Speaker: Anna Bech, Speech Pathologist, Skyward Speech

Focus: Augmentative and Alternative Communication (AAC) in Angelman Syndrome

Key takeaways for Angelman families:

- There are different types of communication, and our kids are often multi form communicators (eg noises, gestures, signs, switches/ low tech and/or high tech devices like iPads)
- It's never too early to start AAC communication journey. Modelling is important
- Include communication apart of your everyday routine

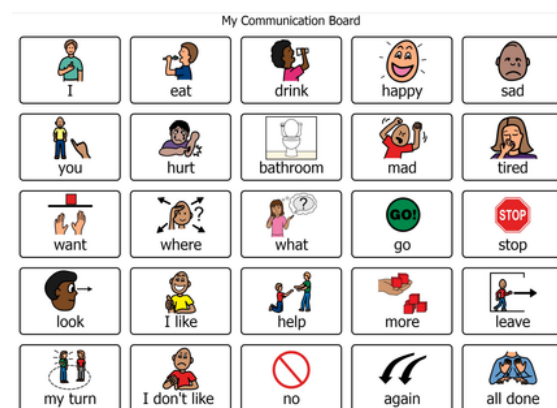


Speaker: Sylvana Mamic (CEO Plumtree Children's Services)

Focus: Positive psychology post diagnosis

Key takeaways for Angelman families:

- The Bridge to a Good Life shows a clear pathway from diagnosis to belonging and citizenship, helping families to focus on starting early with a focus on these positive outcomes.
- The Child Voice Model ensures children's choices guide planning from the start.
- The Seesaw Model balances professional expertise with family strengths "we've got this."
- Inclusive, family-centred practice and peer programs like Now & Next give families the tools to thrive. Free for 2025 and early 2026



Resources

- **ASAA first 100 days journey book** - <https://angelmansyndrome.org/family-support-services/>
- **Plumtree Services:** <https://www.plumtree.org.au/> search program "Now and next", bridge to good life & child voice model
- **Belongsigde Families: Healthy Mothers Healthy Families:** <https://belongsidefamilies.org.au/healthymothershealthyfamilies/>
- **Key Word Sign:** <https://kwsa.org.au/>



SCHOOL YEARS

Speaker: Eliza Hoare, Senior Peer Facilitator, Belongsid Families

Focus: Building a partnership with your child's school

Key takeaways for Angelman families:

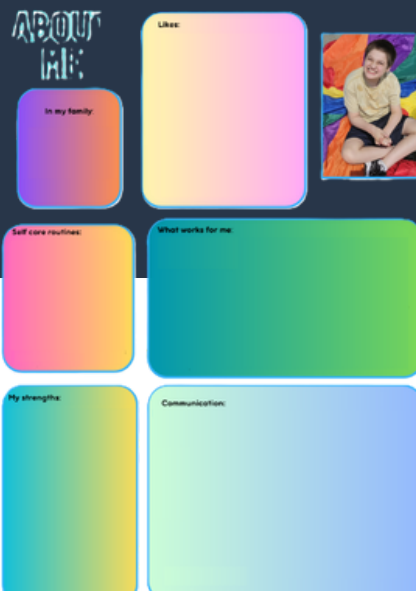
- **Identify key priorities** (goals) and ensure these are shared with your child's school.
- **Collaboration is critical:** Families, educators, and therapists must work as a team with shared goals.
- **Strong partnerships are grounded in:**
 - **Shared priorities** – aligning on goals that matter most for your child's well-being.
 - **Respectful relationships** – valuing each person's role and fostering trust.
 - **Good communication** – consistent, clear, and constructive dialogue.
- **Tough conversations benefit from a structured approach:**
 - **Observation → Impact → Need → Request** – a respectful, needs-based framework to stay focused and empathetic.

Speaker: Diana Backhouse, AS Mum & Award-winning Special Education Teacher

Focus: Communication and the school relationship

Key takeaways for Angelman families:

- A good relationship is built on a foundation of mutual trust and respect. School/teachers value your expertise and knowledge in your child, help them help your child!
- Create bespoke collateral like 'All about me', 'Communication diary' and the 'Parent questionnaire' to ensure that educators/staff have a better understanding of your child.
- Ensure the teacher presumes competence about your child .
- Share reports and updates e.g. therapy/medical reports, what works at home and any changes.
- Be specific in communication e.g. 'he needs 5 mins to process the transition so give him time before expecting him to move'.
- Clarify your expectations i.e. that you want updates on the 'good and bad'.
- Understand contact and escalation points: Classroom teacher > Leadership > Stakeholder meeting.
- Check out the Department of Education page for your state.



SCHOOL YEARS

continued

Speaker: Dr Vinita Prasad, Developmental Pediatrician and Head of Angelman Syndrome Clinic, Queensland Children's Hospital

Focus: Puberty in Angelman Syndrome (AS)

Key takeaways for Angelman families:

- Individuals with AS go through puberty like peers; the onset may be slightly delayed
- Typical challenges experienced in AS include hyperphagia and obesity, scoliosis, and menstrual issues, including increased seizure activity.
- Females: breast development generally occurs ~9.3 years and menses ~2.6 years after. Consult an endocrinologist /gynaecologist to discuss potential sex hormone treatment and to manage growth and pubertal changes.
- Males: testicular enlargement 9 - 13 years, penile growth, and pubic hair ~6 months after.
- Seek medical advice, especially in the event of delayed puberty (females: lack of breast development by 12 - 13 years)(males: lack of testicular enlargement by 13 - 14 years; ensuring testes remain descended is important and may require intervention).
- Regular baseline health checks and tests should be conducted pre and post-puberty
- Close monitoring of height, BMI, and general health is important during puberty and into adulthood.
- Bone health – Depo Provera causes a reduction in bone mineral density, increasing the risk of osteoporosis and bone fractures. This needs to be monitored with a health professional.



Resources

- [Use the QR to receive the 'What Matters Most' checklist & 'Working On The Building Blocks'](#)
- <https://belongsidefamilies.org.au/resources/understanding-the-iep-process/>
- <https://belongsidefamilies.org.au/resources/your-childs-rights-in-school/>
- <https://belongsidefamilies.org.au/resources/whos-who-at-your-childs-school/>
- <https://belongsidefamilies.org.au/resources/all-about-me/>
- [Diana Backhouse - All about me template \(Canva\)](#)
- [Diana Backhouse - Communication dictionary template \(Canva\)](#)



Assessment frameworks:

- Communication: ROCC assessment, pragmatics profile for people who use AAC:
<https://aaclanguagelab.com/resources/pragmatics-profile>
- Bridge assessment (early literacy and language assessment): adapted by AS mum Erin Sheldon for AAC users:
<http://www.aacintervention.com/home/180009852/180009852/Tips/2019/tip%203/Modified%20Bridge%20Sheldon.pdf>
- Other literacy assessments: Sturm's developmental writing scale
- Sensory profile: helps identify sensory processing challenges

16+ THE INDEPENDENT YEARS



Speakers: Prof Kylie Valentine, UNSW, Anne Funke (AS Parent), Victoria White, Social Worker and Specialist Support Coordinator, and Fiona Lawton, ASAA President and CEO, Neu Pathways Australia.

Focus: Housing options for AS Adult Individuals

Prof Kylie Valentine spoke on the important and greater role Governments could play in providing innovative housing models for people with complex support needs.

Anne Funke shared her experience in setting up housing and support for her son Mitchell, taking a greater role in all aspects of the process, from sourcing accommodation, staffing, and administration.

Victoria White answered questions on how to navigate NDIS funding for the supports your loved one will need as they enter adulthood, and to support your housing choices.

Key takeaways for Angelman families:

- **Current housing options** for our AS adult loved ones, including SIL, SDA, social housing, or remaining at home, each present their own challenges. There is no definitive right or wrong choice; rather, it is about selecting the option that best meets the needs and preferences of the AS individuals and their families. Having a greater range of options to choose from would help.
- **Innovative models** such as 'Good Directions' create a tailored solution and an alternative to traditional service providers.
- **Significant and specific evidence** is needed to secure NDIS-funded supports for SDA and SIL; engage with specialist housing, support coordination, and occupational therapists who can prepare quality reports.
- **Other considerations** include decision-making protocols and legal structures (Guardianship), Financial Administration (Trust, Management Orders), and emotional support for long-term carers transitioning out of that role. Get legal advice and be aware that there are state variations in law regarding these matters.



Resources

- [The Housing Hub -NDIS Housing Advice Line](#)
- [The Housing Hub - Roadmap Directory](#)
- [The Summer Foundation Housing and Support Research library](#)
- [Good Directions: https://www.gooddirections.com.au/](https://www.gooddirections.com.au/)
- [The Growing Space: http://thegrowingspace.com.au](http://thegrowingspace.com.au)
- [The Role of Housing Providers in Supporting Clients with Complex Needs](#)
- [Microboards Australia: https://microboards.org.au/](https://microboards.org.au/)



ASAA MERCHANDISE



 **Still keen to grab some ASAA merch? You're in luck!**

We've got hats, tattoos, and sticky notes. And our gorgeous new addition - the ASAA Zebras!

The zebra is a symbol often used to represent the uniqueness of people living with rare conditions such as Angelman syndrome - no two zebras have the same pattern. These much-sought-after treasures are a hit with AS individuals and siblings, and make great gifts too!

Just scan the QR code, include shipping, and we'll handle the rest.

Every dollar supports the Angelman Syndrome Association Australia — funding advocacy, support, and awareness initiatives.

Thanks for being part of our Angelman syndrome community 



SPONSORS AND SUPPORTERS



ANGELMAN SYNDROME
**COLLABORATIVE
CONFERENCE**

Commonwealth Bank



What Ability
FOUNDATION



First Walkers
shoes well fit for growing feet

UNISSON | 100 YEARS
DISABILITY of heart



www.angelmansyndrome.org

Huge thanks to our amazing sponsors

Your support made the 2025 Angelman Syndrome Collaborative Conference in Sydney (19 & 20 September) possible and powerful. Because of you, we brought together families, professionals, and advocates to share knowledge, build community, and champion inclusion. We were able to support people living with Angelman syndrome and their families to enjoy some fun and good times through our conference activities.

- **Commonwealth Bank - ASAA Family Night Sponsor**
- **What Ability Foundation - ASAA Angelman Activities Sponsor**
- **Independent Living Specialists Kids - ASAA Poster Series Sponsor**
- **Exhibitors - First Walkers, Sameview, Unisson Disability, Therapies for Kids**

Thank you to our generous donors who contributed to support ASAA to host the event - ASA NSW, ASASA, Jesse Brann and David and Belinda Perugini. We are grateful to our allies and supporters who contributed to the Conference Swag Bags - NAPA, Bupa Australia, and Link Assistive, and to all the volunteers who helped!



ANGELMAN SYNDROME ASSOCIATION AUSTRALIA

STRATEGIC ACTION PLAN 2024-2027

SYSTEMIC ADVOCACY

- Develop and contribute to submissions to Government on issues that impact AS
- Participate in Disability Representative Organisation (DRO) consortium work
- Provide advocacy support on Adult Health
- Develop systemic advocacy resources for Media and Government
- Attend Parliamentary events and disability and rare disease conferences



FAMILY SUPPORT

- Support families with Newly Diagnosed Family Welcome Packs
- Develop resources and guides for milestones/transitions (e.g First 100 Days, Adulthood)
- Support families in crisis through the Family Support Fund
- Coordinate local practical support for families in need
- Provide sponsorship/small grants for AS community events (i.e. IAD/Carer weekends)

AWARENESS CAMPAIGNS

- Promote Angelman Clinics and Adult Health Services
- Engage with disability services providers to increase knowledge of AS
- Promote research into AS (i.e. behaviour, sleep, carer support) and clinical trials
- Collaborate with Foundation for Angelman Syndrome Therapeutics (FAST) Australia
- Host International Angelman Day events, Angelman Syndrome Conference/Training seminars



FUNDRAISING

- Grants, including peer support, corporate and sector grants
- Donations - GiveNow, PayPal and other platforms
- ASAA and Angelman syndrome merchandise
- Corporate donations, matching, and sponsorship
- Containers for Change - nominate ASAA as a charity for return and earn programs

COMMUNICATION

- Engage with a webmaster to update and maintain the website
- Host Australian content, relevant international resources & links to highly valued social media channels/information
- Host and contribute to informative community webinars
- Directly engage with the community through emails and e-newsletters
- Maintain a strong social media presence



Advocacy. Support. Awareness

