



ABA TOOLKIT FOR ANGELMAN SYNDROME

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PURPOSE OF THIS TOOLKIT

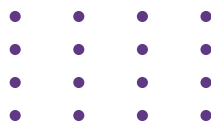
This toolkit is designed to support families of individuals with Angelman syndrome (AS) as they consider, implement, or reassess Applied Behavior Analysis (ABA) as part of a broader, whole-child support plan.

It is guidance-based, not prescriptive. The goal is to provide context, shared language, practical tools, and reflective questions so families can make informed decisions about if, when, and how ABA may be appropriate for their child and family.

ASF recognizes that there is no one-size-fits-all approach for Angelman syndrome. Developmental trajectories, medical complexity, communication needs, and family capacity vary widely. Any behavioral support—ABA included—should prioritize communication, safety, dignity, autonomy, and quality of life, while honoring the individual’s personality, joy, and strengths.

This toolkit also acknowledges that families are often asked to navigate ABA systems originally designed for other populations. ASF’s intent is to help families adapt—not adopt—ABA in ways that are Angelman-informed, ethical, and realistic.

Applied Behavior Analysis (ABA) is a therapy that uses evidence-based strategies to help individuals learn skills and reduce challenging behaviors by understanding how behavior works and how it is influenced by the environment. It is often used to support communication, daily living skills, and independence.



WHAT THE RESEARCH SAYS • • AND DOESN'T SAY • •

• WHAT WE KNOW •

There is limited Angelman-specific research evaluating ABA. One frequently cited study (Summers & Hall, 2008) showed that parents of children with Angelman syndrome could successfully learn and apply ABA teaching strategies when given structured guidance and support.

Importantly, hands-on coaching was more effective than written instruction alone—highlighting the importance of collaboration and real-time adaptation.

• WHAT WE DON'T KNOW •

Because Angelman syndrome is rare, large randomized trials are uncommon. Most knowledge comes from:

- Broader developmental disability research
- Clinical expertise from Angelman-informed providers
- Lived experience and family-reported outcomes

This doesn't weaken the evidence—it makes context and individualization essential.

• WHAT THIS MEANS FOR FAMILIES •

- Goals should be flexible and individualized
- Progress may look different than in autism-centered ABA models
- Success may be measured by engagement, communication, safety, and reduced frustration
- Clinical judgment and family insight should guide decisions

-To read the research publication: <https://pubmed.ncbi.nlm.nih.gov/22646082/>

• EMERGING INSIGHTS ON ACCESS TO ABA SERVICES •

Preliminary findings from a small survey conducted through the LADDER Learning Network, currently under review at the Journal of Autism and Developmental Disorders, provide insight into patterns of access to Applied Behavior Analysis services among families affected by neurogenetic conditions. Although based on a limited sample, the results highlight important trends and systemic considerations.

FINDINGS INCLUDE:

- A substantial proportion of families reported seeking ABA services.
- Most families who pursued services were able to obtain them.
- More than half reported that an Autism Spectrum Disorder diagnosis was required to secure insurance coverage.
- Parents reported varying impressions of autism-related behaviors, reflecting the complexity of diagnostic overlap in neurogenetic conditions.

These findings underscore ongoing barriers to care and highlight the importance of individualized clinical assessment, informed advocacy, and equitable access to services



• WHAT ABA CAN LOOK LIKE FOR ANGELMAN SYNDROME •

When ABA is used with individuals with Angelman syndrome, it is most effective when it is:

- **Functional:** Focused on communication, daily living, safety, and participation
- **Individualized:** Adapted to seizures, fatigue, motor challenges, and sensory needs
- **Positive and supportive:** Never compliance-driven or punitive
- **Integrated:** Embedded into daily routines, not limited to a therapy table

ABA strategies may support:

- **Functional communication (including AAC)**
- **Reducing frustration-related behaviors**
- **Increasing independence in daily routines**
- **Improving attention and engagement**

ABA should never aim to suppress joy, stimming, or personality—hallmark strengths of Angelman syndrome. (Stimming (self-stimulatory behavior) refers to repetitive movements or sounds—like hand-flapping, rocking, or vocalizing—that can help a person regulate emotions, process sensory input, or express themselves).

• ANGELMAN-SPECIFIC CLINICAL CONSIDERATIONS •

Families should ensure ABA providers understand key Angelman-related needs, including:

- **Seizure disorders and post-ictal fatigue**
- **Motor planning, balance, and gait instability**
- **Sensory processing differences**
- **Sleep disruption and its behavioral impact**
- **High social motivation paired with limited expressive language**

Providers unfamiliar with Angelman may unintentionally set unrealistic goals or misinterpret behavior.

• ACCESSING ABA THERAPY •

Many families encounter challenges when seeking Applied Behavior Analysis (ABA) services, with insurance coverage representing one of the most common barriers. In many states, insurance reimbursement for ABA therapy requires a diagnosis of Autism Spectrum Disorder (ASD). As a result, some individuals with Angelman syndrome receive a dual diagnosis of Angelman syndrome and ASD to access medically necessary services. Requirements vary by state, insurer, and policy.

• ABA IS NOT THE ONLY OPTION •

ABA should be viewed as one tool—not the only intervention. Many families use ABA strategies alongside:

- **Speech-language therapy (with AAC emphasis)**
- **Occupational therapy**
- **Physical therapy**
- **Positive Behavior Support (PBS)**
- **Naturalistic, relationship-based approaches**



• ACCESSING ABA THERAPY CONTINUED •

Families seeking ABA services may consider the following steps:

- Consulting with their child’s neurologist, developmental pediatrician, geneticist, or psychologist.
- Contacting their insurance provider to understand eligibility criteria and coverage requirements.
- Seeking guidance from advocacy organizations such as the Angelman Syndrome Foundation.
- Connecting with other families and support networks for shared experiences and recommendations.
- Exploring early intervention programs, school-based services, Medicaid waivers, and state disability programs.

IMPORTANT NOTE

This toolkit provides general information and is not intended to offer medical, legal, or insurance advice. Families should consult qualified professionals regarding diagnoses and coverage decisions.

• UNDERSTANDING DUAL DIAGNOSIS OF AUTISM & ANGELMAN SYNDROME •

Some individuals with Angelman syndrome also receive a diagnosis of Autism Spectrum Disorder (ASD). This can be complex for families, particularly when autism-related characteristics overlap with features of Angelman syndrome.

It is important to understand:

- A dual diagnosis does not change the underlying genetic cause of Angelman syndrome.
- It may help individuals access therapies, educational supports, and insurance coverage.
- Autism-related characteristics—such as communication differences, sensory sensitivities, and repetitive behaviors—can occur in Angelman syndrome and may overlap diagnostically.
- For some families, an ASD diagnosis serves as a practical pathway to accessing services rather than representing a separate condition to manage.
- Diagnostic decisions should be individualized and guided by qualified clinicians familiar with both Angelman syndrome and autism.

This perspective supports informed decision-making while recognizing the clinical and systemic realities faced by families.

• HOW ABA CAN HELP WITH CHALLENGING BEHAVIORS •

Below are examples of how ABA strategies may be used in real-life settings:

UNDERSTANDING BEHAVIOR: A Functional Behavioral Assessment (FBA) looks at triggers, behaviors, and outcomes to identify what is driving a behavior.

REDUCING UNINTENTIONAL REINFORCEMENT: Helps caregivers recognize when responses may be reinforcing behaviors and adjust accordingly.

CREATING CONSISTENT PLANS: Ensures caregivers, teachers, and staff respond in aligned ways.

TRACKING PROGRESS: Uses data to determine if strategies are working and adjust when needed.

BUILDING RELATIONSHIPS: Strong one-on-one connections can reduce attention-seeking behaviors and increase engagement.



• ABA TREATMENT GOALS IN ANGELMAN SYNDROME •

- Supporting safe ways to gain attention and meet social needs
- Reducing distress during separation transitions (e.g., school drop-off)
- Gradual introduction to new caregivers or providers
- Using “first this, then that” systems to support transitions
- Building tolerance for waiting using short, gradual intervals
- Teaching how to request breaks to reduce frustration

• MODIFICATIONS TO ABA PROGRAMS FOR ANGELMAN SYNDROME •

- Use immediate reinforcement instead of delayed reward systems
- Start with very short expectations (e.g., 5–10 seconds waiting)
- Focus on safely meeting strong social needs—not reducing them. For example: hair pulling, hitting, biting in public.
- Avoid ignoring behaviors that may escalate to unsafe actions
- Use meaningful social rewards. For example: Looking at family photos, watching videos of loved ones, video calls.

• ETHICS, AUTONOMY, AND NEURODIVERSITY •

ASF encourages behavioral approaches that are ethical, neurodiversity-affirming, and rooted in respect.

This includes approaches that:

- **Respect autonomy and consent** (as appropriate)
- **Preserve joy, laughter, stimming, and self-expression**
- **Support communication rather than compliance**
- **Prioritize well-being over appearance or performance**

ASF does not support therapy goals that suppress personality, joy, or natural regulation strategies.

For individuals with Angelman syndrome, behaviors are often a form of communication—especially in the absence of verbal speech.

Ethical behavioral support should help individuals:

- **Express needs and preferences**
- **Participate meaningfully in daily life**
- **Feel safe, understood, and supported**

Behavioral intervention should never feel punitive, coercive, or disconnected from quality of life.

• EXAMPLE: FAMILY-CREATED ABA ASSESSMENT & REASSESSMENT •

This toolkit includes real-world examples of how one family documented progress:

Initial Assessment (Nov 2021):

- **Focused on communication, safety, and routines**
- **Identified meaningful goals**
- **Reflected Angelman-specific strengths**

Reassessment (June 2022):

- **Updated goals based on growth**
- **Measured engagement and independence**
- **Adjusted expectations over increasing demands**

KEY TAKEAWAY: Families can—and should—help shape assessments to reflect real life.



• RED FLAGS AND GREEN FLAGS IN ABA PROVIDERS •

Choosing the right provider matters just as much as choosing ABA itself.

GREEN FLAGS

- Adapts goals for nonverbal individuals
- Integrates AAC meaningfully
- Collaborates with speech, OT, PT, and medical teams
- Can meet physical limitations.
- Adjusts expectations based on fatigue or illness
- Defines success with quality of life in mind
- Strives to empower families

RED FLAGS

- Focus on compliance over communication
- Dismisses medical complexity
- Discourages AAC
- Rigid session intensity
- Attempts to eliminate joy, stimming, or laughter

Families should feel empowered to ask questions, pause services, or change providers.

• QUESTIONS TO ASK AN ABA PROVIDER •

A good provider will welcome these questions.

- How do you adapt ABA for nonverbal individuals?
- How do you incorporate AAC?
- How do you define success?
- How do you account for seizures or fatigue?
- How do you collaborate with other therapies?

• BOTTOM LINE •

ABA-based strategies can be helpful for some individuals with Angelman syndrome when they are:

- Adapted to Angelman-specific needs
- Family-centered and collaborative
- Focused on quality of life—not compliance

Families are encouraged to trust their instincts, ask questions, and remember: you are the expert on your child.

