

Arizona Autism Parent Resource Guide

This guide provides information and resources for parents of children with a new diagnosis of Autism. Its purpose is to help families navigate services and support for their children.

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Autism Spectrum Disorder (ASD), is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. Autism is defined by specific behaviors and is often referred to as a "spectrum condition" that affects people differently and to varying degrees.

While there is currently no known single cause of Autism, early diagnosis helps a person receive resources that can support the choices and opportunities needed to live fully. Autism is estimated to occur in as many as 1 in 36 individuals (CDC).¹

Autism Levels

The DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) classifies Autism Spectrum Disorder (ASD) into three levels based on the severity of symptoms and the level of support needed. These levels help clinicians understand the challenges individuals face in areas like social communication, and restricted or repetitive behaviors. Each level reflects the degree of support needed, and individuals with ASD may move between levels depending on changes in their environment or support systems.

Level 1: Requiring Support

Social Communication: Difficulty initiating social interactions and maintaining backand-forth conversations. May seem awkward in social settings and struggle with understanding social cues or body language. Can speak and communicate, but might have difficulty making and keeping friends.

Restricted/Repetitive Behaviors: Difficulty switching between activities. Struggles with organization and planning, which may impact independence.

Support Needs: Requires some support, but individuals can live relatively independently. Challenges may be apparent in less-structured environments, such as work or social gatherings.

¹ Reference: Autism Society of Greater Phoenix, <u>What is Autism? - Autism Society of Greater Phoenix</u> (<u>phxautism.org</u>)

Level 2: Requiring Substantial Support

Social Communication: Significant difficulty with verbal and nonverbal communication. Reduced interest in social interactions, and may only interact with others when necessary. Conversations are often limited to specific topics or interests, and they may struggle with more complex social dynamics.

Restricted/Repetitive Behaviors: Greater difficulty coping with changes and transitioning between activities. Repetitive behaviors and rituals that interfere with daily functioning.Unusual behaviors or intense interests may be noticeable to others.

Support Needs: Requires substantial support to function in daily life.May need assistance with communication, decision-making, and adapting to new situations.

Level 3: Requiring Very Substantial Support

Social Communication: Severe deficits in verbal and nonverbal communication. Limited understanding of social interactions, with minimal interest in others. Nonverbal communication or very limited speech is common, and conversations may be extremely rare or absent.

Restricted/Repetitive Behaviors: Extreme difficulty coping with changes and significant distress when routines are disrupted. Highly restricted interests and rigid, repetitive behaviors that severely impact daily life.

Support Needs: Requires very substantial support in all areas of life. Often needs one-on-one support, and individuals may live in highly structured or supported environments.

Next Steps

Here are the next steps for parents following their child's autism diagnosis.

- 1. Apply for the Division of Developmental Disabilities (DDD). They provide support coordination and authorize the child's treatments and services.
 - a. To qualify for DDD your child must be a resident of Arizona, from ages 3-6 and be at risk of having a developmental disability. After age six, the child must be diagnosed with: autism, cerebral palsy, epilepsy, or a cognitive disability. The child must be diagnosed before the age of 18. The child must also have functional limitations in 3 of 7 major life areas: learning mobility, independent living, selfcare, language, economic self-sufficiency, or self-direction. Based on these requirements, it is possible to have a child with autism who does not qualify for DDD.
 - b. Click here for the link to apply for DDD: <u>https://des.az.gov/sites/default/files/dl/DDD-</u> 2069A.pdf?time=1617121708084
 - c. For children under 3
 - i. Apply for the Arizona Early Intervention Program (AzEIP) it is Arizona's statewide interagency system of services and supports for families of infants and toddlers, birth through two years of age, with disabilities or delays.
 - ii. Apply for AZEIP here: <u>How to Apply for Early Intervention</u> <u>Services for Your Child | Arizona Department of Economic</u> <u>Security (az.gov)</u>
- 2. Apply for Arizona Long Term Care System (ALTCS after DDD approval). They provide Arizona's Medicaid funding, which pays for the child's treatments and services. There are several steps in the ALTCS application process.

Financial Interview

- i. ALTCS members cannot have more than \$2,000 in their name. Your child may have an ABLE account or money in a Special Needs Trust. They may not have money in their name in a typical bank account in excess of \$2,000.
- b. Pre-Admission Screening (PAS) Interview
 - i. A parent interview will typically be completed in the home. The interviewer has to see the child, but the child does not have to stay in the same room or at home for the entire interview. You are allowed to make copies or take pictures of the interviewers' notes. They are considered part of your child's medical history. You may also record the interview, as Arizona is a one-party state.
 - ii. When answering the interview questions, you should answer no if your child doesn't do something independently 100% of the time. The answer is also no, if their disability prevents them from performing the activity like a neurotypical child. If your child has an IEP or other medical records, they will most likely collect those and compare your answers to those documents. ** During the interview ensure that the interviewer is asking all questions, including 0 - 3 portions. You are able to request an in-person interview. **
- c. To qualify for ALTCS, your child has to score 40 or more points on the PAS evaluation. If your child does not pass, you can call and ask for their score and how it was scored. If the answers do not match the answers you gave (to verify, you can refer back to your recording), you can dispute the results. Also, if the points are close to 40, you can dispute the results.
- d. Reviewing the PAS tool will help you prepare for the interview. The PAS tool adjusts as your child ages. Click on the link below for the PAS tool that applies to your child:
 - i. PAS Tool 3-5 (azahcccs.gov)
 - ii. PAS Tool 6-11 (azahcccs.gov)

- iii. PAS Tool 12+ (azahcccs.gov)
- e. If approved, ALTCS will contact the parent to ask which insurance carrier they prefer.
 - i. The options include: Banner-University Medical Care; Mercy Care Plan and United healthcare.
 - ii. Many families choose the insurance that their providers (doctor, dentist and therapists) accept.

Health Plan	Treating Provider List
Arizona Complete Health	Providers who Specialize in Treatment of Autism Spectrum Disorder (ASD) and Applied Behavior Analysis (ABA)
Banner-University Family Care	Banner-University Family Care Autism Spectrum Disorder (ASD) Services
Care1st	Care 1st Autism Spectrum Disorder Treating Provider
СНР	DCS CHP Autism Spectrum Disorder Providers
Health Choice	Health Choice Health Choice Arizona Autism Spectrum Disorder (ASD) Treating Providers
Mercy Care	Mercy Care Autism Spectrum Disorder Providers
Molina HealthCare	Molina Autism Spectrum Disorder Treating Providers
United Healthcare Community Plan	United Autism Spectrum Disorder Treatment Providers
r questions, please email <u>ASD@azahcccs</u>	804
801 East Jeffersor	n, Phoenix, AZ 85034 • PO Box 25520, Phoenix, AZ 85002 • 802-417-4000 • www.azahocos.gov Rev. 02/02/24

3. Contact your local public school district's special education department

- a. Contact the school district's special education department in writing to request a complete psychoeducational evaluation.
- b. Find your local school district here: <u>http://www.ade.az.gov/</u>
- c. The Arizona Empowerment Scholarship (ESA) is available for all students in Arizona.
 - i. With the ESA program, the money that would pay for that student's education in a public school follows that student to whichever school the parents choose for their child, including education at home.
 - ii. ESA dollars cover multiple educational expenses such as private school tuition, curricula, educational supplies, and

tutoring. In addition, students who qualify under a disability category may use ESA funds for therapies, associated goods, and assistive technology.

- iii. More information regarding ESA: <u>Welcome to</u> <u>Empowerment Scholarship Account | Arizona Department</u> <u>of Education (azed.gov)</u>
- 4. If you have attempted to complete steps 1-3 and you are having difficulties and/or could use extra support, apply for assistance through our Family Liaison Program:

https://thegentryfoundation.org/apply/

What do DDD and ALTCS cover?²

Therapies

- Habilitation and/or Applied Behavioral Analysis (ABA)³
- Attendant Care (under age 3)
- Feeding Therapy
- Occupational Therapy
- Physical Therapy
- Speech Therapy

² This list is not exhaustive. For a complete list, please refer to <u>Available DDD Services & Supports |</u> <u>Arizona Department of Economic Security (az.gov)</u>

³ ABA is covered through ALTCS (medicaid) insurance

Services

- Dental
- Day treatment
- Employment Services
- Habilitation
- Home Health Aide
- Home Health Nurse
- Medical, including well visits
- Respite
- Residential Support Services
- Respiratory Therapy
- Transportation (medically necessary, non-emergency)
- Vision services

References and Resources

100 Day Kit https://www.autismspeaks.org/tool-kit/100-day-kit-young-children

ALTCS Member Handbook Arizona Long Term Care System (ALTCS) Member Handbook (English) | Arizona Department of Economic Security (az.gov)

Arizona Department of Education Special Education Resources Special Education Resources for Parents and Families | Arizona Department of Education (azed.gov)

Arizona Empowerment Scholarship (ESA) <u>Welcome to Empowerment</u> Scholarship Account | Arizona Department of Education (azed.gov) Autism Society of Greater Phoenix "Autism 101" class <u>Autism 101 Class</u> -<u>Autism Society of Greater Phoenix (phxautism.org)</u>

AZA United Family Support <u>Support for Families | Arizona Autism United (AZA</u> <u>United)</u>

AZEIP <u>Arizona Early Intervention Program (AzEIP) | Arizona Department of</u> <u>Economic Security</u>

Caregiver Support Groups

- <u>Caregiver Support Groups Autism Society of Greater Phoenix</u> (phxautism.org)
- Events Care 4 the Caregivers

List of Available DDD Services and Supports <u>Available DDD Services &</u> Supports | Arizona Department of Economic Security (az.gov)

Mercycare Member Handbook <u>Materials and Forms | Mercy Care ACC-RBHA</u> (mercycareaz.org)

United Healthcare Member Handbook Arizona Developmental Disabilities Program | UnitedHealthcare Community Plan (uhc.com)Add in 100 Day Kit from Autism Speaks?