

Navigating Autism Services: Process, Treatment, and Resources in Arizona

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Autism



Prevalence of Autism

- In 2016, approximately 1 in 68 children in the United States has been identified with an Autism Spectrum Disorder (ASD).
- In the 1980s autism prevalence was reported as 1 in 10,000.
 Autism knows no racial, ethnic, social
 boundaries, family income, lifestyle,
 or educational levels and can affect any
 family, and any child.
- Autism is almost 5 times more prevalent in boys than in girls.





Economic Cost

- Lifetime cost for a person with ASD is estimated to be \$3.2 million.
- Total cost per year for children from birth to 17 years old with ASD were estimated to be between \$11.5 billion- \$60.9 billon in 2011.
- Children and adolescents with ASD compared to children and adolescents without ASD have increased medical expenditures on average between \$4,000-\$6,000 per year.
- Intensive Behavioral Intervention for children cost \$40,000-\$60,000 per child per year.



Economic Cost

Table 1. Age-Specific and Lifetime per Capita Incremental Societal Costs of Autism*

•				
Age Group, y	Direct Medical	Direct Nonmedical	Indirect	Total Per Capita Cost
3-7	35 370	10 805	43 066	446 203
8-12	6013	15 708	41 138	314 297
13-17	5014	13 550	38 453	285 082
18-22	2879	10 720	36 090	248 446
23-27	1574	27 539	51 740	404 260
28-32	1454	23 755	35 757	304 828
33-37	1389	20 492	30 852	263 662
38-42	1283	17 676	29 132	240 457
43-47	1440	15 248	26 600	216 439
48-52	1447	13 152	24 531	195 650
53-57	1290	11 292	17 776	151 790
58-62	1218	9489	0	53 535
63-66	1027	7908	0	35 738
Total lifetime costs	305 956	978 761	1 875 667	3 160 384

^{*}Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

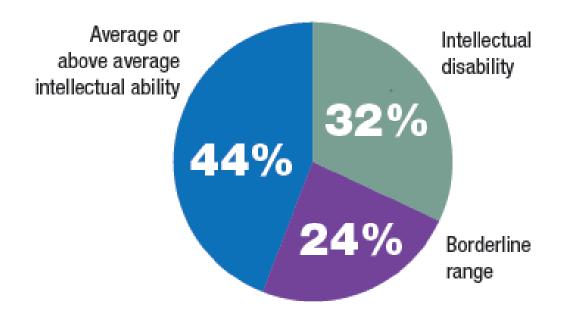
Ganz, M, L., The lifetime distribution of the incremental societal costs of autism. *Archives of pediatrics & adolescent medicine*. 2007; 161, 343-349.



Facts and Statistics

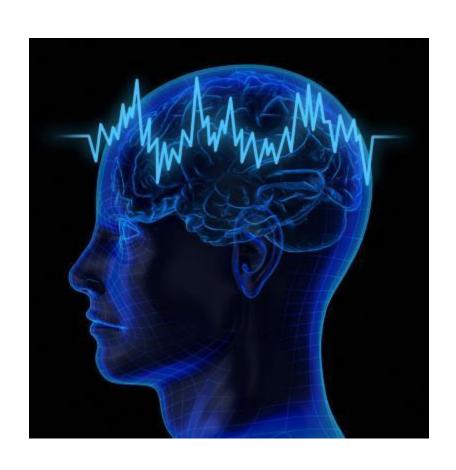
- Autism and comorbidity
 - Autism commonly occurs with other developmental diagnoses is 83%
 - Co-occurrence of one or more psychiatric diagnoses is 10%

Facts and Statistics





Autism Comorbidity



 It is estimated that as many as 1/3 of individuals with Autism also have epilepsy.





Family Impact

80% DIVORCE

for families with an autistic child

MARITAL STRESS

LACK OF REST

LACK OF CHILDCARE

DIAGNOSTIC CHALLENGES

LACK OF SERVICES

FEELINGS OF REJECTION

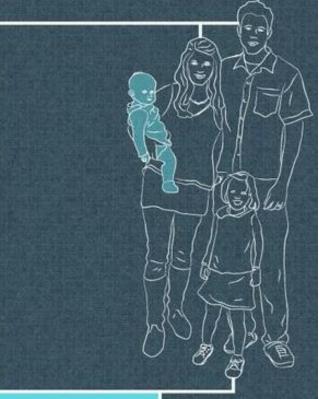
FEELINGS OF GUILT

LOST EXPECTATIONS

COPING WITH GRIEF

DAD WORKS TO MAKE ENDS MEET

MOM BECOMES THE AUTISM EXPERT



SIBLINGS OF ASD CHILDREN

POSITIVE

NEGATIVE

BUILD MATURITY AND RESPONSIBILITY
PROUD OF ASD SIBLING'S ACHIEVEMENTS
STRONG SENSE OF LOYALTY
DEVELOP TOLERANCE AND COMPASSION

FEELINGS OF RESENTMENT
GUILTY OF THEIR OWN GOOD HEALTH
FEAR OF "CATCHING" AUTISM
FEELINGS OF ANXIETY AND REJECTION



Risk Factors

Researchers and scientist believe that there is no single cause.

Strong Evidence

- Advanced parental age
- Prematurely born or with low birth weight are at a greater risk
- Family history of ASD

Emerging Evidence

- Family history of immuneassociated conditions
- Genes/genetic mutations the occur before, during, and immediately after pregnancy
- Factors related to pregnancy:
 - Maternal infection
 - Maternal diabetes or obesity



Why Act Early?

- Extremely limited or long waitlist for services.
- Neural circuits, which create the foundation for learning are most flexible during the first 3 years of life.
- Best practice and cost
 effective as it reduces
 financial cost and improves
 quality of life.
- Reduce cost by up to 2/3 with early identification and treatment.





Demographics in Arizona

 Overall, the Arizona Developmental Disabilities Surveillance Program (ADDSP) identified 530 children with autism spectrum disorder





How many children were identified with ASD?

• 1 in 64 children (or 15.7 per 1,000 8-year-olds) was identified with ASD.

- Boys were 4 times more likely to be identified with ASD than girls.
 - 1 in 40 boys was identified with ASD.
 - 1 in 167 girls was identified with ASD.



When were children first diagnosed?

- On average, children were diagnosed at age 4 years and 11 months, even though children can be diagnosed as early as age 2 years.
- When looking at age of first diagnosis by subtype, on average, children were diagnosed with:
 - Autistic disorder at age 4 years and 10 months.
 - Pervasive developmental disorder-not otherwise specified (PDD-NOS) at age 4 years and 7 months.
 - Asperger disorder at age 6 years and 7 months.



Eligibility for Special Education

- 74% of children either had an eligibility for autism special education services at school or had an ASD diagnosis.
- The remaining 26% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider.



What can we do?

"What you do makes a difference, and you have to decide what kind of difference you want to make"



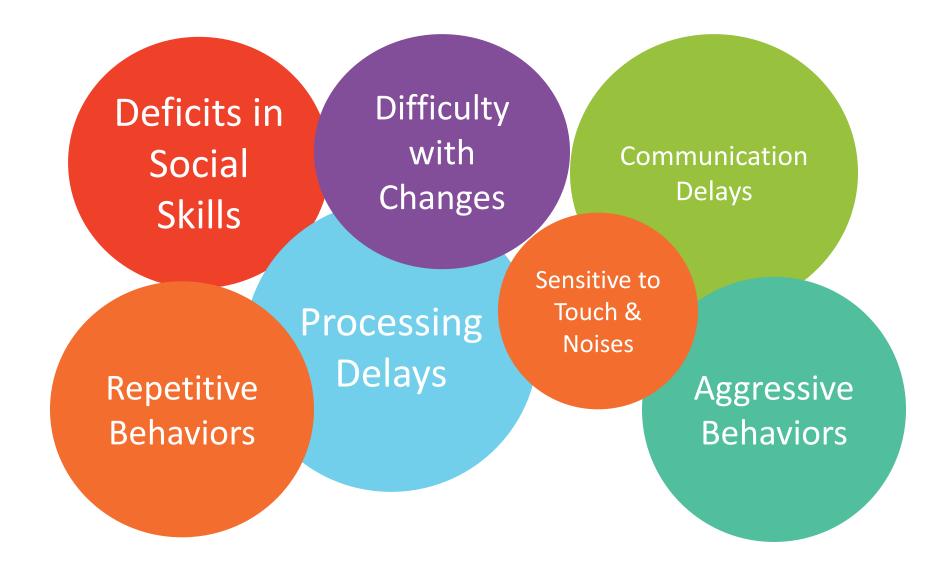
What is Autism?

Autism Spectrum Disorders are characterized by:

- Neurobehavioral disorder that present varying degrees of impairment in:
 - Communication
 - Social interactions
 - Restricted, repetitive, and stereotyped patterns of behavior activities or interests.
- Challenging behaviors that may include aggression or self-injury.
- How ASD is manifested and how severely it affects an individual is unique to each case.



How Does Autism Present?





Early Identification and Screening

- The American Academy of Pediatrics recommends administering a standardized autism specific screening tool on all children at the 18 month well child visit.
- In 2007, the recommendation was expanded to screen at 24 to 30 months of age to identify kiddos that may regress.
- Take home point: Screen as early as possible!



Early Identification and Screening

- There is no medical test for ASD. A medical diagnosis is made after a through evaluation by a qualified team of professionals.
- Evaluations include clinical observations, parent interviews, development history, psychological testing, speech and language assessment.

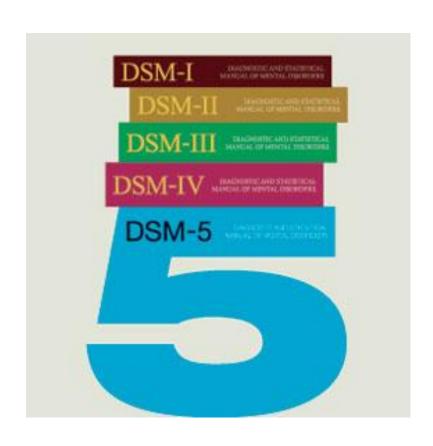


Early Identification and Screening

Screener	Ages	Format	Items	Time to Complete	Available Languages	Information and Free Downloadable Templates	Scoring Templates and Instructions
Checklist for Autism in Toddlers (CHAT)	18–24 mo+	Interview or questionnaire + observations	Section A: 9 yea/no parent questions Section B: 5 clinician observations	5 min	English, Dutch, Greek, Persian, Spanish, Swedish	http://autismresearchcentre. com/arc_tests	www.ny2aap.org/ CHATecoring.pdf
Childhood Autism Spectrum Test (CAST)	4–11 yr	Parent- completed questionnaire	37 items	10 min	English, Dutch, French, Greek, Persian, Slovak, Slovenian, Spanish, Swedish	http://autismresearchcentre. com/arc_tests	www.autismre- searchcentre.com/ tests/cast_test.asp
Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)	16–30 mo	Parent- completed questionnaire	20 items	5–10 min	Arabic, Bangla, Chinese, Dutch, French, German, Greek, Gujarti, Icelandic, Japanese, Kannada, Kurdish, Portuguese, Sinhala, Somalian, Spanish, Tamil, Turkish, Vietnamese, Urdu	https://www.m-chat.org/about. php	https:// www.m-chat. org/_references/ mchatdotorg.pdf
Pervasive Developmental Disorders Screening Test-II, Primary Care Screener (PDDST-II, PCS)	18-48 mo	Parent- completed questionnaire	22 items	10–15 min	English, Spanish	Available for purchase at: http://www. pearsonassessments.com/ haiweb/cultures/en-us/ productdetail.htm?pid=076- 1635-106&Community=CA_ Ed_Al_Early	
Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP) Infant-Toddler Checklist	9–24 mo	Broadband screener used to detect communication delays including in children with ASD	24 items	5–10 min	English, Chinese, German, Slovenian, Spanish	http://firstwords.fsu.edu/pdf/ checklist.pdf	http://firstwords. fsu.edu/pdf/ Checklist_Scoring_ Cutoffs.pdf
Screening Tool for Autism in 2-Year Olds (STAT)	24–36 mo	Screener is administered by trained examiners	12 activities that look at play, imitation, communication	20 min	not applicable	http://kc.vanderbilt.edu/triad/ training/page.aspx?id=821	



Diagnostic Process





Diagnostic process

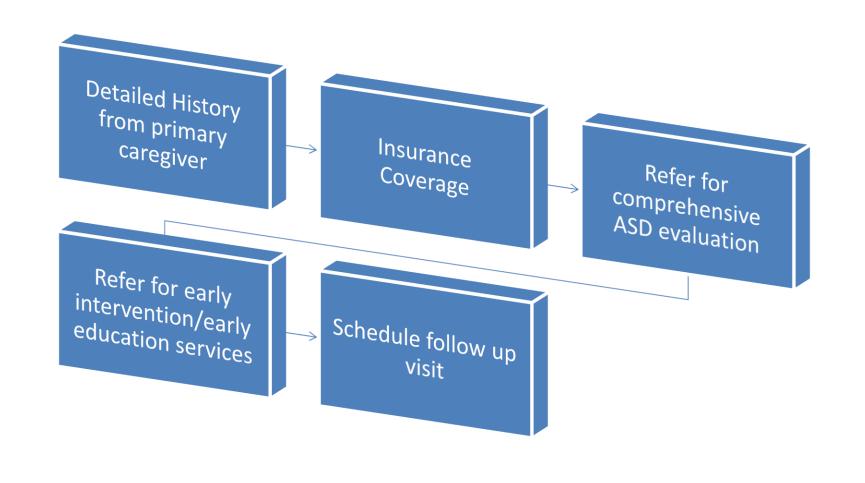
 Research has shown that a diagnosis of Autism as early as 24 months is reliable and valid.



ASD Subtype	Median* Age of Diagnosis
Autistic disorder	3 years, 10 months
Pervasive developmental disorder- not otherwise specified (PDD-NOS)	4 years, 1 month
Asperger disorder	6 years, 2 months



Diagnostic Process





Diagnostic Process/Medicaid

- Refer the child to the Arizona Early Intervention Program (AzIEP)
- AzIEP will contact the child's parent/guardians to arrange comprehensive diagnostic evaluation.
- https://des.az.gov/services/disabilities/develo pmental-infant



Diagnostic Process

- Who can conduct a comprehensive evaluation?
 - A qualified licensed practitioner:
 - A physician with a specialty in psychiatry or neurology
 - A physician with a subspecialty in developmental pediatrics, developmental behavioral pediatrics or a related discipline.
 - A physician with a specialty in pediatrics or other appropriate specialty with training, experience or expertise in ASD and/or behavioral health
 - A psychologist
 - An advanced practice registered nurse with training, experience, or expertise in ASD
 - A clinical social worker, working within their scope of practice, and is qualified and experienced in diagnosing ASD



Diagnostic Process/Medicaid

- What does a comprehensive evaluation consist of?
 - Autism Diagnostic Observation Schedule-Second Edition (ADOS-2)
 - Autism Diagnostic Interview-Revised (ADI-R)
 - Other Tools to determine medical necessity
 - Cognitive/developmental tests
 - Adaptive Behavior tests
 - Symptom questionnaires



Arizona's Autism Insurance Bill

4th State to Mandate Insurance Coverage for Autism Treatment

• Effective July 1, 2009

Autism services required to be covered:

- Diagnosis
- Behavioral therapy services

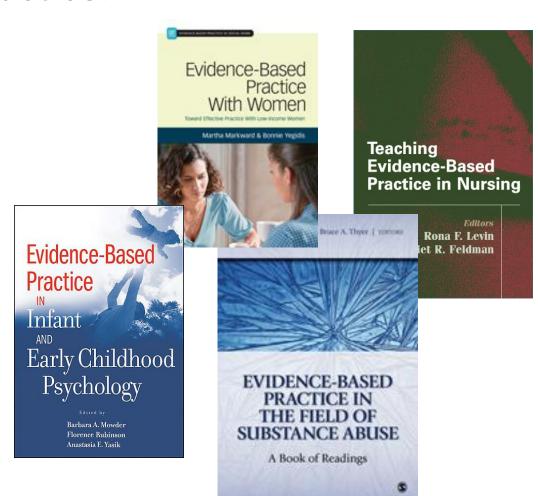


Coverage

- Coverage for behavioral therapy (e.g., ABA) is limited to individuals with autism less than 16 years of age and is subject to annual dollar caps:
- Under the age of 9 = \$50,000/year
- Between the ages of 9 and 16 = \$25,000/year.

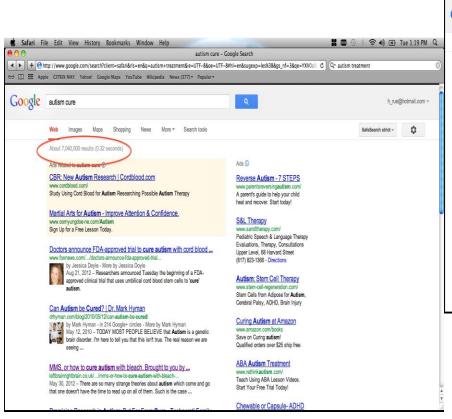


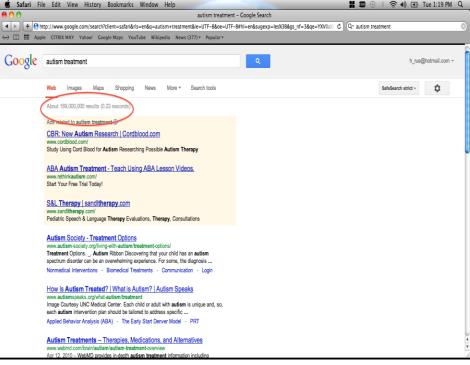
- Evidence Based Practice:
 - Used in....
 - Medicine
 - Nursing
 - Social Work
 - Education
 - Psychology





Google "autism treatment" and over 150,000,000 results.







CLAY BATH
BLEACH ENEMAS
CAMEL MILK
RAPID PROMPTING
CHELATION THERAPY
FECAL TRANSPLANT
REBIRTHING





National Standards Project



NSP₁

- 775 articles
- Research conducted in the field from 1957-2007
- Ages 0-22
- Peer Reviewed

NSP₂

- 389 articles
- Research conducted in the field from 2007-2012
- Across the lifespan
- Peer Reviewed



Established

Several^a published, peer-reviewed articles

- SMRS scores of 3, 4, or 5
- Beneficial intervention effects for a specific target

These may be supplemented by studies with lower scores on the Scientific Merit Rating Scale.

Emerging

Few^b published, peer-reviewed articles

- SMRS scores of 2
- Beneficial intervention effects reported for one dependent variable for a specific target

These may be supplemented by studies with lower scores on the Scientific Merit Rating Scale.

Unestablished

May or may not be based on research

- Beneficial intervention effects reported based on very poorly controlled studies (scores of 0 or 1 on the Scientific Merit Rating Scale)
- Claims based on testimonials, unverified clinical observations, opinions, or speculation
- Ineffective, unknown, or adverse intervention effects reported based on poorly controlled studies



Unestablished Literature Support

- Animal Assisted Therapy
- Auditory Integration Training
- Concept Mapping
- DIR/Floor time
- Facilitated Communication
- Glute-free/Casein Free Diet
- Movement based intervention
- Sensory Intervention Package
- Shock Therapy
- Social Thinking Intervention



Emerging Literature Support

- Augmentative and Alternative Communication Devices
- Developmental Relationship Based Treatment
- Exercise Alone
- Exposure Package
- Functional Communication Training
- Imitation Based Intervention
- Initiation Training
- Language Training
- Massage Therapy
- Multi Component Package

- Music Therapy
- Picture Exchange Communication
 System
- Reductive Package
- Sign Instruction
- Social Communication Intervention
- Structured Teaching
- Technology-Based Intervention
- Theory of Mind Training

Established Interventions

- Behavioral Intervention
- Comprehensive Behavioral Package for Young Children
- Modeling
- Naturalistic Teaching
- Peer Training
- Pivotal Response Training
- Self-Management
- Story Based Intervention
- Schedules
- Cognitive Behavioral Intervention Package
- Scripting
- Parent training



where is Applied Behavior Analysis | ABA?



Behavior Analysis

Experimental Analysis of Behavior Applied Behavior Analysis



Modeling

Token Systems
Schedules

Discrete Trial Teaching

Reinforcement Naturalistic
Teaching

Prompting



ABA is often seen as the gold standard of autism treatment

APPLIED BEHAVIOR ANALYSIS (ABA)



Applied Behavior Analysis

- It is the science of behavior
 - ABA is a scientific approach to behavior change
- Focuses on how ENVIRONMENT impacts behavior
- Focuses on the improvement of socially significant behaviors
- Decades of research to support methodologies and strategies we use in the field of ABA



Applied Behavior Analysis

What it IS....

- Science of behavior (application)
- •Involves MANY techniques
- •Used with <u>MANY</u> different populations
- Large corporations
 - OBM

What it is NOT.....

- Just table top work
- Only discrete trial training
- Only flashcard drills and edibles/food
- Something that only occurs in a therapy room



How ABA Helps

- ABA has been used to help individuals acquire many different skills, such as language skills, self-help skills, and play skills.
- ABA can help to decrease maladaptive behaviors such as aggression, self-stimulatory behaviors, and self-injury.
- ABA can teach toilet training, improve sleep routines, and help address difficult eaters



About Autism Spectrum Therapies

Founded in 2001, AST is one of the leading providers of Applied Behavior Analysis in the country. Led by a talented team of clinicians, AST utilizes evidence based practices with a family focused approach to ensure the best possible results.





Our Locations

AST Provides Services in the following locations:

Arizona

Greater Phoenix Area

Northern California

Greater Bay Area

Sacramento

Southern California

Greater Los Angeles Area

Inland Empire

Greater San Diego Area

Orange County

Illinois

Greater Chicago Area

Louisiana

Greater New Orleans Area

Greater Baton Rouge Area

New Mexico

Albuquerque

Washington State

Greater Seattle Area

Michigan

Dearborn and Surrounding



Our Clinical Practice

Individualization

Our service is not one size fits all. We tailor each program to meet the needs of the individual. Programs are customized to include play based/naturalistic strategies and verbal behavior methodologies

Family centric

We recognize how critical the family is to any program. We prioritize parent training and participation, and always consider the family's needs in our design.

Ethical

We hold ourselves to the highest of standards - because we believe that is what every client deserves.



AST Insurance Advocacy

- AST is in network with most insurance companies
- We have an outstanding team dedicated to navigating the insurance process and informing clients each step of the way
 - Our goal is to help families cut through the red tape and receive top quality services as soon as possible



AST Technology

- Industry leader in utilizing technology for several aspects of our services:
 - Data Collection
 - Programming
 - Reporting
 - Training
 - Family feedback



AST Training

- Comprehensive initial training (40+ hours)
 - Conducted using multiple modalities
 - Meets RBT requirements
- Multiple levels of ongoing support
 - Continued ongoing training
 - Frequent evaluation on skill competencies and professional development goals
- Opportunities for growth and development



Helpful Resources and References



Resources

- Resources for families:
 - www.autismspeaks.org
 - http://www.raisingarizonakids.com
 - http://phxautism.org
 - http://autismtherapies.com/blog/



Resources

- Scientific Research/References related to Autism
 - https://www.cdc.gov/ncbddd/autism/research.html#howmany
 - http://www.asatonline.org/



Thank you for your time!

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