

Emily Mulligan
Manager, Autism Response Team

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The Autism Response Team

- The Autism Response Team (ART) is specially trained to respond to **calls and emails** from people with autism, their families, and community members.
- Provide a link to critical **information, tools and, resources** for all members of the autism community, who might otherwise not have access.
- ART provides a **person centered response** to all requests for information and offers encouragement and support. Information is tailored specifically to individual needs.
- **Navigating** the tangled web of autism resources is difficult. ART provides a reliable place for individuals and families to start.



HAVE A QUESTION? CONTACT ART TODAY!

Toll Free: 1-888-AUTISM 2

Toll Free en Español: 1-888-772-9050

Email : familyservices@autismspeaks.org

Autism Response Team - Who We Are



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Meeting The Needs Of Families

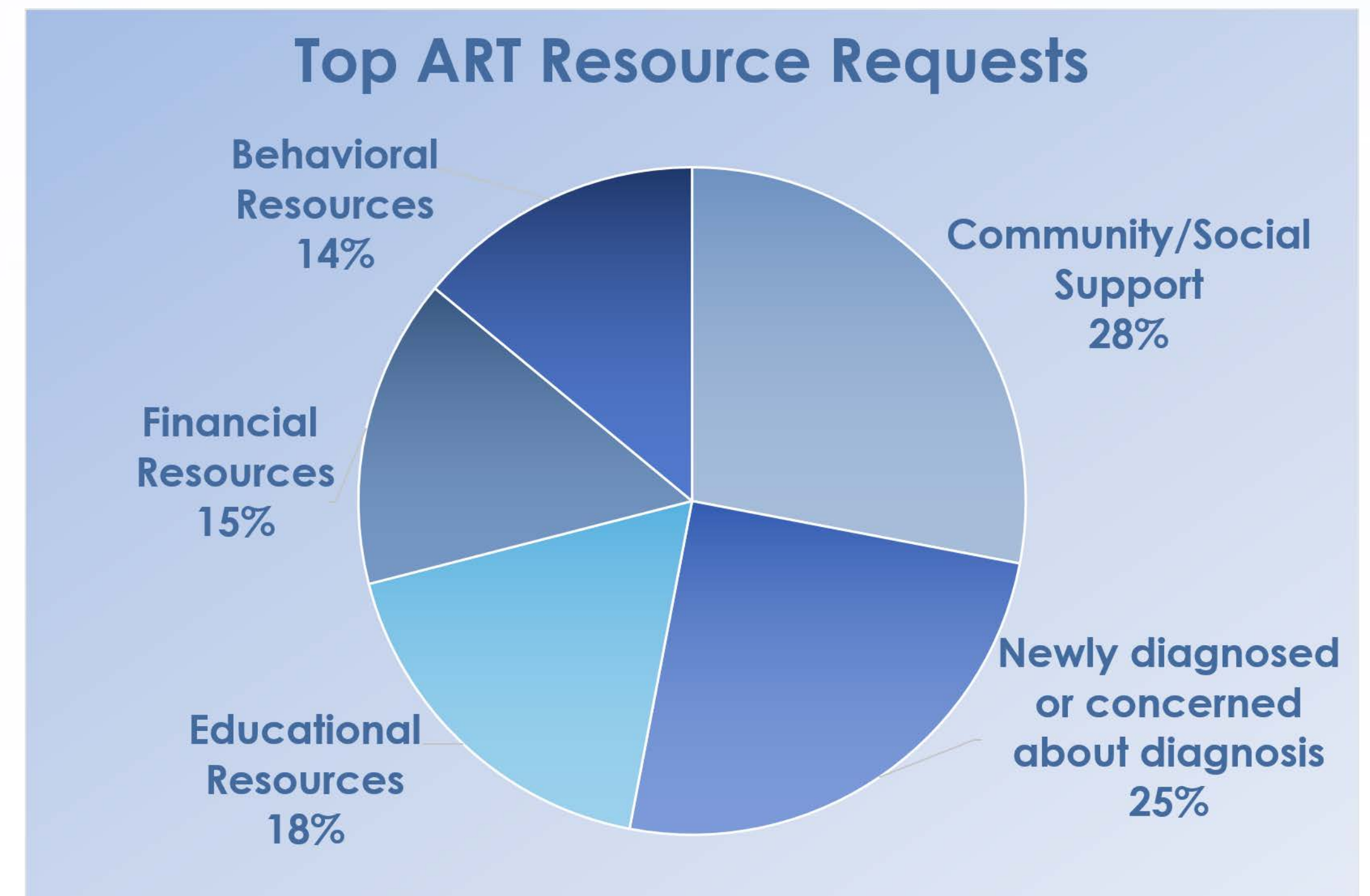
In 2018, ART responded to over **80,000 calls and emails** from individuals with autism and their families and caregivers, as well as teachers, professionals, and community members.

75% overall were looking for a connection to local resources and supports in their community.



Top requests include:

1. Community and social support: 28%
2. Concerned about a diagnosis or newly diagnosed: 25%
3. Educational resources: 18%
4. Financial resources: 15%
5. Behavioral resources: 14%



Meeting The Needs Of Families

Age groups:

- Early Intervention (0-3)
- School age (4-12)
- Transition (13-21)
- Adult (22+)

Who contacts us?

- Parents of people with autism
- Individuals with autism
- Grandparents, friends, and relatives
- Teachers and service providers

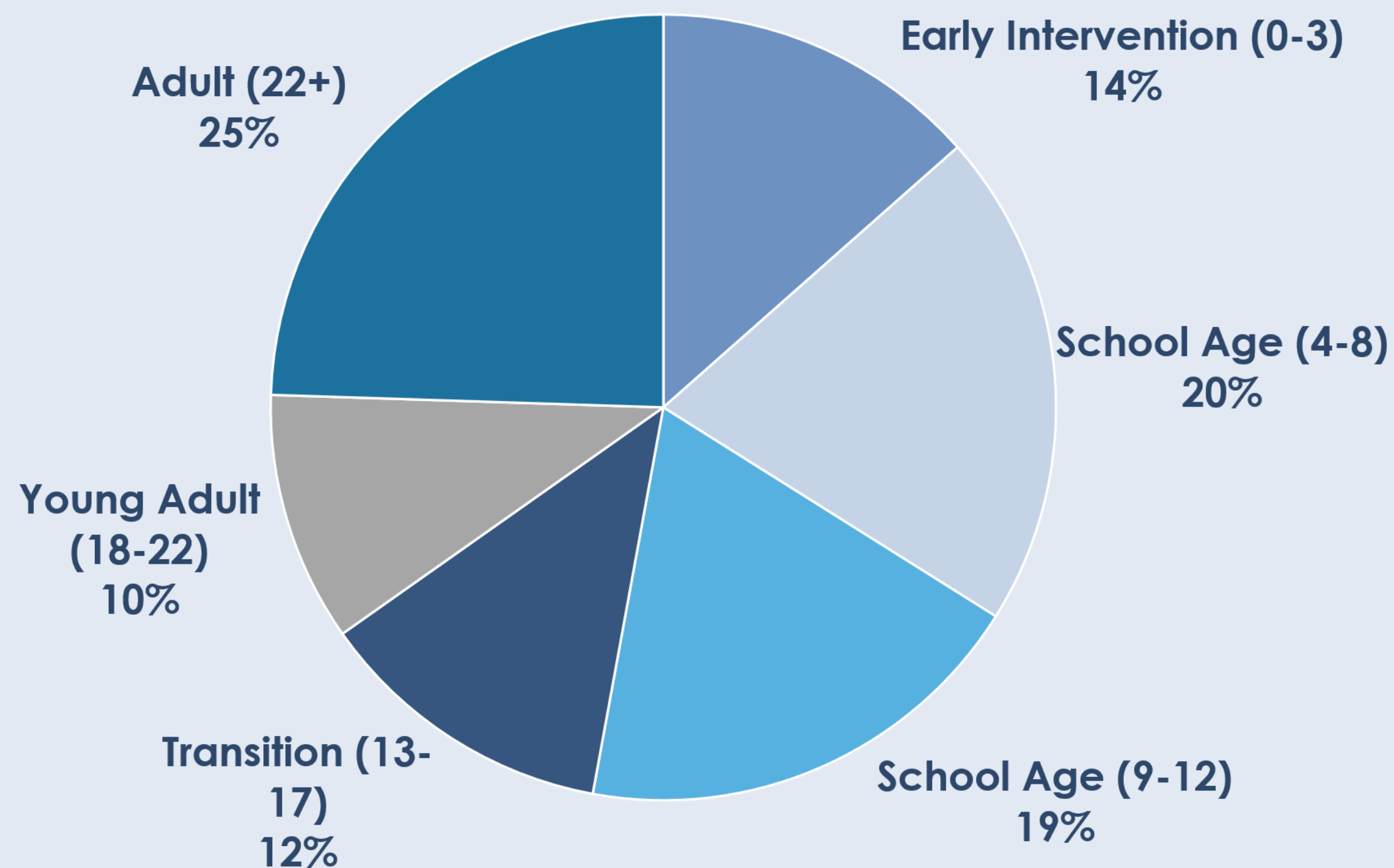
From where?

Top states include:

- California
- Florida
- New York
- Georgia
- Texas



ART Contacts By Age Category



Autism Speaks Resources: Early Access to Care

Autism spectrum disorders are characterized by two main features:

1. **Social communication challenges**
2. **Restricted, repetitive behaviors and interests**



- Autism can be reliably diagnosed by **18-24 months**
- Early diagnosis and treatment can make a lifetime of difference
- If you have concerns, don't wait – trust your instincts, talk to your pediatrician



Autism Speaks Resources: Early Access to Care

Red Flags for ASD

In the first two years

- Limited or no **eye contact** (6 months)
- Little or no **babbling, waving, pointing, response to name** (12 months)
- Very few or **no words** (16 months)
- Very few or no **meaningful, two-word phrases** (not including imitating or repeating) (24 months)

At any age

- **Loss of previously acquired speech**, babbling or social skills
- Difficulty understanding other people's **feelings**
- **Delayed language** development
- Persistent **repetition of words** or phrases (echolalia)
- Resistance to minor **changes in routine** or surroundings
- Restricted interests
- Repetitive behaviors (flapping, rocking, spinning, etc.)
- Unusual and intense reactions to **sounds, smells, tastes, textures, lights, and/or colors**



Autism Speaks Resources: Early Access to Care

What parents can do if they are concerned about signs of autism:

1. Talk to your pediatrician – developmental screening at 18 and 24 months
2. Take the online **M-CHAT screening tool**
3. Seek out an evaluation from a specialist
 - Developmental-behavioral pediatrician
 - Child psychologist
 - Psychiatrist
 - Neurologist
 - Speech-language pathologist
4. Contact your state's Early Intervention Program



Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The AAP has endorsed its use at 18 and 24 months of age to screen for autism spectrum disorders. The questions can be scored in less than 2 minutes using instructions found on <http://www.mchatscreen.com>. A trained professional can discuss the responses and guide you to find the right resource. These 23 questions should be accompanied by a follow-up interview which will clarify some of the responses.

Please fill out the following about how your child **usually** is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	Yes	No
6. Does your child ever use his index finger to point, to ask for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8. Can your child play properly with toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10. Does your child look you in the eye for more than a second or two?	Yes	No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No
12. Does your child smile in response to your face or your smile?	Yes	No
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes	No
14. Does your child respond to his/her name when you call?	Yes	No
15. If you point at a toy across the room, does your child look at it?	Yes	No
16. Does your child walk?	Yes	No
17. Does your child look at things you are looking at?	Yes	No
18. Does your child make unusual finger movements near his/her face?	Yes	No
19. Does your child try to attract your attention to his/her own activity?	Yes	No
20. Have you ever wondered if your child is deaf?	Yes	No
21. Does your child understand what people say?	Yes	No
22. Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

How to score the M-Chat. Please score 1 point if you answered "no" to questions 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 19, 21 or 23, or if you answered "yes" to 11, 18, 20 and 22. If the total score was 3 or higher, your child needs a Follow-Up interview with your provider or a health care professional. Even if you answered "no" to just two or more of questions 2, 7, 9, 13, 14, 15, you should also ask your health care provider to administer the Follow-up interview. These are considered critical items of the MCHAT. Even if your scores are below 3 for the total score, and below 2 for the critical questions, and you still have concerns, bring this completed form and your questions to your provider for a more in depth evaluation or referral.

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www.AutismSpeaks.org

Autism Speaks Resources: Early Access to Care

What to do after the diagnosis:

- 100 Day Tool Kit
 - Connect with Local Services
 - Early intervention
 - Public school services
 - Individualized Education Plan (IEP)
 - Private therapies
 - Parent Training and Information Centers
 - Connection to support, information



Autism Speaks Resources: How Do We Help?

1. Information and Tool Kits: across the spectrum and throughout the lifespan
2. Connection to local providers and services
3. Connection to state agencies and benefits
4. Support





Autism Speaks Tool Kits

Young Children

- First Concern to Action
- 100 Day Kit
- Family Support Tool Kits

School Age Children

- 100 Day Kit - School Age
- Individualized Education Plan
- School Community Tool Kit
- Challenging Behavior Tool Kit

AUTISM SPEAKS 100 DAY KIT

Getting Your Child Services

How Do I Get the Help My Child Needs?

The road ahead will be bumpy. There will be times when your progress stalls or takes an unexpected turn. When it does, try to remind yourself that these are speed bumps, not roadblocks. Take them one at a time. It is important that you start now. There are a variety of services available to treat and educate your child. The article below, from *Does My Child Have Autism?* by Wendy L. Stone, PhD, with Theresa Foy DiGeromino, MEd, explains why:



Early Intervention will improve the outcome for your child.

There is no debate or doubt: early intervention is your child's best hope for the future. Early attention to improving the core behavioral symptoms of autism will give your child – and the rest of the family – several important benefits that you will not gain if you take a wait-and-see approach until your child enters school at age four or five. A good early intervention program has at least four benefits:

1. It will provide your child with instruction that will build on his or her strengths to teach new skills, improve behaviors and remediate areas of weakness.
2. It will provide you with information that will help you better understand your child's behavior and needs.
3. It will offer resources, support and training that will enable you to work and play with your child more effectively.
4. It will improve the outcome for your child.

For these reasons, an intervention program for your child should be implemented as soon as possible after he or she receives a diagnosis. You probably know by now, it can be challenging to teach young children with autism a unique profile of strengths and needs. Intervention services and teaching are sensitive to these needs. That's why that worked for teaching your other child to sit at the dinner table, to play with a toy or to say words simply don't work for your child with autism. In the same way, programs that are generic – rather than specialized – are less likely to be effective for your child. That's why as you begin your early intervention, you must keep in mind that interventions are equal.

AUTISM SPEAKS 100 DAY KIT

What is Autism?

Autism spectrum disorder (ASD) and **autism** are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the fifth edition of the **American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders** (commonly referred to as the DSM-5), all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, **childhood disintegrative disorder**, **pervasive developmental disorder-not otherwise specified (PDD-NOS)** and **Asperger Syndrome**. The DSM is the main diagnostic reference used by mental health professionals and insurance providers in the United States.

You may also hear the terms Classic Autism or Kanner's Autism (named after the first psychiatrist to describe autism) used to describe the most severe form of the disorder. Under the current DSM-5, the diagnosis of autism requires that at least six developmental and behavioral characteristics are observed, that problems are present before the age of three and that there is no evidence of certain other conditions that are similar.

There are two domains where people with ASD must show persistent deficits:

- 1) **persistent social communication and social interaction**
- 2) **restricted and repetitive patterns of behavior**

More specifically, people with ASD must demonstrate (either in the past or in the present) deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction and deficits in developing, maintaining and understanding relationships. In addition, they must show at least two types of repetitive patterns of behavior, including stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests, hyper or



hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history. In addition to the diagnosis, each person evaluated will also be described in terms of any known genetic cause (e.g. Fragile X syndrome, Rett syndrome), level of language and intellectual disability and presence of medical conditions such as seizures, anxiety, depression and/or gastrointestinal (GI) problems.

The DSM-5 has an additional category called **Social Communication Disorder (SCD)**. This allows for a diagnosis of disabilities in social communication, without the presence of repetitive behavior. SCD is a new diagnosis and much more research and information is needed. There are currently few guidelines for the treatment of SCD. Until such guidelines become available, treatments that target social communication, including many autism-specific interventions, should be provided to individuals with SCD.

To read the whole DSM-5 criteria, please visit autismspeaks.org/dsm-5.



Autism Speaks Tool Kits

Transition Age

- Transition Tool Kit
- Community Based Skills Assessment
- Puberty/Adolescence Tool Kit
- Postsecondary Education Guide

Adult

- Employment Tool Kit
- Housing and Residential Supports Tool Kit
- Is It Autism and If So, What's Next?

How Do I Get Evaluated as an Adult If I Suspect I Have Autism?

by David Beversdorf, Ph.D., neurologist at the University of Missouri's Thompson Center for Autism and Neurodevelopmental Disabilities

With awareness of autism so high today, it's no longer as common for an autism diagnosis to be overlooked in childhood. However, this wasn't always the case. As a result, it's not infrequent that I see teens and adults seeking a diagnosis.

Evaluating autism in a previously undiagnosed adult can be challenging. And yes, it's true that the standardized diagnostic checklists we commonly use are designed for children. There are no established diagnostic tests for ASD in adults. However, I'm glad to report that they are currently in development.



Conducting an Adult Evaluation

Because of these limitations, the evaluation of an adult has to lean heavily on direct observation. This will be in the context of a discussion between the clinician and the patient about current challenges in the areas of social interaction and communication, sensory issues and restricted interests or repetitive behaviors.

diagnosis. Clearly, this is not possible when there isn't an older relative available for a reliable report. Sometimes, a person's early development did not have any features suggestive of autism. Instead, they began struggling with social withdrawal and related issues in their teens or adulthood. This suggests a cognitive or mental health issue other than ASD.

Finding Someone Qualified to Evaluate Adults with ASD

Currently, there are relatively few clinicians who specialize in evaluating and treating adults with autism. Nor do we have established criteria to objectively judge such qualifications.

In my opinion, your best bet may be a developmental pediatrician, child psychiatrist or pediatric neurologist who is both experienced in evaluating autism in children and open to seeing older patients. If she or he does not feel qualified to evaluate an adult, he or she may have a respected colleague who would be.

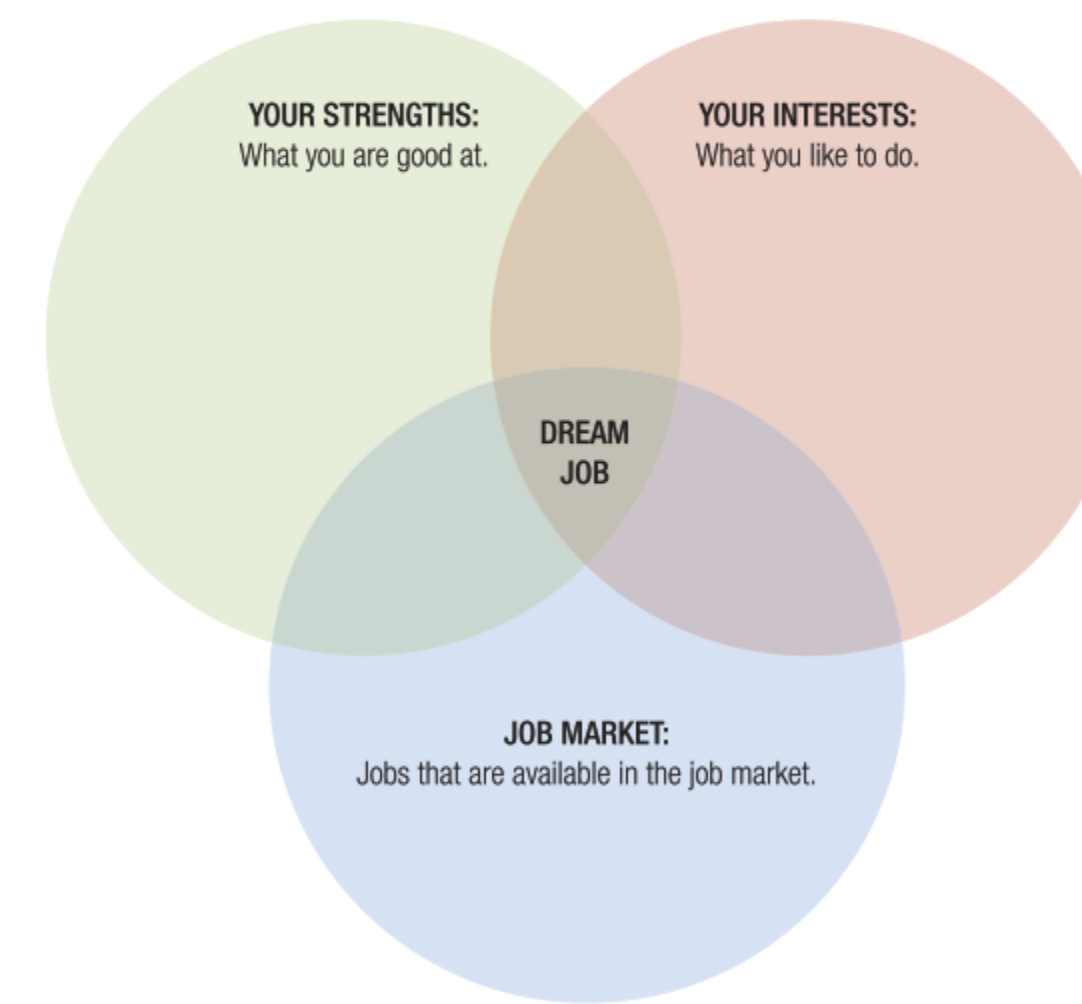
Otherwise I would recommend contacting an established and respected autism center in your area. Examples include the centers in the **Autism Speaks Autism Treatment Network**. To locate an AS-ATN near you, visit autismspeaks.org/ATN. This will provide you with the assurance that the clinician has agreed to adhere to the center's high standards for care for patients with autism, regardless of age.

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What Job is Right for You?

It is important to understand your strengths and interests when you are looking for a job. We all hope to find a job that we are very good at and that we can truly enjoy doing for a long time – our dream job! But being realistic is important, too. Sometimes we need to realize that what we are good at is not always something we can do as paid employment, or there may not be a job available that matches our top interests. That's ok! A good approach is to list your personal strengths and interests, and then search the job market to see what positions are available that match up most closely with those ideals.



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Autism Speaks Tool Kits

ATN-AIR-P Tool Kits

- Medication Decision Aid
- Guide to Exploring Feeding Behavior in Autism
- Parent's Guide to Toilet Training in Autism
- Blood Draw Tool Kit

A Parent's Guide To Blood Draws for Children with Autism Taking the Work Out of Blood Work: Helping Your Child With ASD



A Parent's Guide



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital.



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A Parent's Guide to Exploring Feeding Behavior in Autism presented by Autism Speaks ATN/AIR-P

Feeding issues are common in children with autism spectrum disorders (ASD). Feeding can be very stressful for the child and for the family. Helping your child overcome feeding issues can be a long, slow journey, but it is well worth the reward of better health and food flexibility.

Feeding can present a significant challenge for children with ASD. Language delays (for example) can limit a child's ability to report pain and discomfort that might be interfering with feeding.

This tool kit is designed to help families affected by ASD *understand eating behaviors, give guidance on how to address feeding issues, and review some common questions that families have about eating problems.*

What are feeding problems and why do children with ASD have them?

Believe it or not, feeding is a complicated human behavior. Feeding behavior is dependent on a person's developmental status. Medical, maturation and body mechanics issues relate to oral-motor abilities. How food tastes, smells and feels (sensory issues) and our experiences related to food also impact feeding. When all of these areas work well, feeding goes well. If there are problems in one of these areas, feeding behavior can be affected.

Feeding involves every sensory system (touch, sight, taste, smell and sound). Many children with ASD have difficulties with sensory processing and this can make eating certain foods a challenge for them. Children with autism can also develop behavioral problems at mealtimes. For example, children may learn that they can leave the table and play after refusing a food they do not like.

Researchers found that 69% of children with ASD were unwilling to try new foods and another 46% had rituals surrounding their eating habits.¹

Feeding problems in any child can be stressful for both the child and parents. Children need appropriate nutrients and calories to maintain good health and appropriate growth patterns.

It may be possible to address a feeding problem in a child who has ASD by following these recommendations. When your child's feeding problems have significant consequences, you should seek professional help.



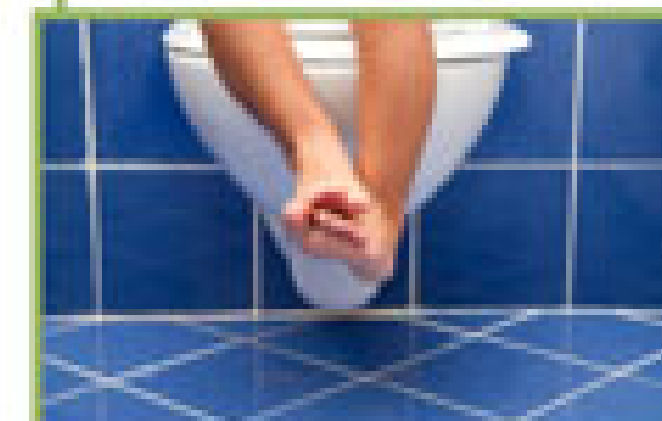
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¹ Williams, PG., Dalrymple, N. & Neal, J. (2000). Eating Habits of Children with Autism. Pediatric Nursing, 26 (3), 259-264.



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Toilet Training



A Parent's Guide



These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital.

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Connection to Local Services

Autism Speaks Resource Guide

- State-by-state listing of providers and programs
- Dozens of service categories
- Searchable by zip code
- Updated version developed and launched this year



Connection to State Resources and Benefits

Local and State Supports

- Parent Training and Information Centers
- Protection and Advocacy System

Benefits

- Medicaid Waivers
- Social Security Income (SSI)
- Developmental Disability Services
- Insurance

Accessing Funding Through State and Federal Programs

Caring for children with autism can be overwhelming. There are so many needs and life is often chaotic, especially when severe behaviors are involved. I have met many parents who were desperate for help and support, yet were too overwhelmed with day-to-day life to be able to figure out their child's rights and their right for support.



This section was prepared by Shirley Blaier-Stein, the author of *Autism Mom: New Ways of Thinking*, an attorney and an autism advocate. Shirley's son has autism. He attends a behavior-focused school in CT and is doing well. Shirley lives and writes autism and is passionate about helping autism parents reach their potential in order to become empowered, exercise their children's rights, achieve the best program and treatment for their children, and help their children thrive.

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The second avenue for services is health-related therapies covered by health insurance. Services such as speech therapy and occupational therapy are typically covered. In recent years, some states have adopted laws that mandate covering behavioral therapy for children with autism. Such therapy is need-based and must be assessed by a medical professional. Once your child gets approved, he/she will receive hours of therapy that typically help tremendously.

The third avenue and the one I will focus on here is government entitlements like Medicaid.

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Special Needs Trusts

Special needs planning involves comprehensive financial planning for the special needs person including income, tax, insurance and retirement planning, as well as estate planning. One of the cornerstones of special needs planning is the creation of a "third party" supplemental or Special Needs Trust.

The primary objectives of a special needs trust include:

Protect the assets left to a special needs beneficiary from predators and creditors.

Provide additional income to facilitate a better quality of life.

Prevent the loss of government benefits, including Supplemental Social Security (SSI) and Medicaid.

Plan for the ultimate future avoiding a burden on siblings once the primary caregivers are no longer able to take care of the person with autism.

State and federal benefits may help cover the basics – food, shelter, and routine medical care – but not specialized treatments. "Extras" like educational programs, therapy equipment or home-modifications are not usually covered.



This section was prepared by Anne St. Clair, a Senior Private Banker for The Private Bank at Wells Fargo with 17 years of experience in the financial sector. Anne services a national clientele of high net worth families, entrepreneurs and closely held businesses.

As a Board member of Community Hope, The Overlook Medical Center Auxiliary and Chairwoman of The Autism Speaks Fall Classic at Baltusrol, Anne is actively involved in her community.

Expenses to plan for:

Medical, dental, or surgical expenses not covered by government benefits

Enrichment programs for educational or recreational experiences

Psychological or behavioral counseling and support

Personal caregivers

Transportation for medical and recreational purposes

Entertainment such as magazines, movies, classes and gym memberships

Physical therapy not covered by insurance or benefits



Connection to Support

For some individuals and families, the day-to-day challenges of living with autism can be overwhelming and isolating. Today, it is estimated that **1 in 59 children** is diagnosed with autism in the United States.

ART can help by listening, answering questions, and connecting individuals and parents with others who know what it's like to “walk in your shoes.”

Navigating the tangled web of autism resources is difficult. ART provides a reliable place for individuals and families to start.

Feedback from families:

“Thank you for listening to my family’s story and providing great resources. Now I know somewhere there is hope for my sons future, thank you for giving me the hope back.”

– Parent of a 24 year old with ASD, ART connected to Housing and Residential Tool Kit & local providers in state Resource Guide.

“Thank you so much for this lifesaving information! I feel so lost and frustrated sometimes because we have been dealing with this on our own for so long without guidance. Your kind assistance has made a big difference.”

– Parent of a adolescent with autism, ART connected to Transition Tool Kit & local employment resources.

“Thank you very much for these resources! I am overjoyed to have somewhere to start in getting my child set, which gives me hope!”

– Parent of a newly diagnosed 2 yr. old, ART connected to 100 Day Kit & local intervention providers.



Thank you!

Contact the Autism Response Team:

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En Espanol 888-772-9050

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