

# NEW PARENT INFORMATION PACKET



**ASAT** Real Science, Real Hope

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

## ***Who is this booklet for?***

This parent packet was created to help guide parents of children recently diagnosed with **Autism Spectrum Disorder** and for parents who have questions concerning their child's development both in the United States and abroad. The initial diagnosis process can be overwhelming, and this packet is primarily for children between ages birth through seven years.

## ***What does this booklet include?***

**Step 1:** Is My Child on the Autism Spectrum?

**Step 2:** Who Could Diagnose My Child?

**Step 3:** What is the Best Treatment for Autism?

**Step 4:** How Do I Find and Pay for Treatment?

**Step 5:** What Does the Future Hold for My Child and Our Family?

## Step 1: Is My Child on the Autism Spectrum?

Use the following parent-administered screening tool, the **Modified C**hecklist for **A**utism in **T**oddlers (the M-CHAT) in the privacy of your own home. Screening simply indicates whether there may be an issue that needs further examination. Resist jumping to conclusions at this stage. The results from the M-CHAT let you know whether to proceed to Step 2 below. The M-CHAT can be accessed through the ASAT website — [Click Here](#).

For more information

## Step 2: Who Could Diagnose My Child?

Autism can be diagnosed by several different types of professionals<sup>1</sup>. In many countries, psychologists, psychiatrists and pediatricians are licensed to diagnose children with autism. It is important for you to find the appropriate professional who is knowledgeable about autism. The best resource to recommend a diagnostician may be parents of children with autism in your area.

For more information

## Step 3: What is the Best Treatment for Autism?

Here at ASAT, we critically evaluate any and all new purported treatments for autism. Today, the only scientifically supported treatment for Autism Spectrum Disorder (ASD) is Early Intensive Behavioral Treatment (EIBT), and Intensive Behavioral Treatment (IBT), based on the principles of Applied Behavioral Analysis (ABA).

In short, your child needs to start an intensive ABA Program as soon as possible.

Although there are over 500 unsubstantiated treatments for autism, beware of personal testimonials claiming to cure or treat your child. Your child's time and your money are too valuable to waste. These treatments have not yet been scientifically validated either by the people who introduced the treatment or by the scientific community. In other words, there is no evidence that they work.

For more information

## Step 4: How Do I Find and Pay for Treatment?

Internationally, funding for autism treatment is different in every country. In very few countries, parents have already fought and won the battle for treatment funding either through the health-care system, the educational system, and/or the social welfare system. It is very important that you find the status of autism treatment funding in your country. The best way to do that is to network with parents who already provide ABA treatment programs for their children and connect with your country's professional ABA associations. If you are in a country where there is no funding for treatment, you may find yourself having to advocate for treatment for your child.

For more information

## Step 5: What Does the Future Hold for My Child and Our Family?

No matter where you and your child are right now, when you start *effective* treatment, your child's capabilities will be much improved, and you will feel much more in control and empowered.

When working with a qualified behavioral consultant, you will set up, implement, and maintain an individualized treatment program for your child. This will provide you with essential tools. In fact, you will eventually become the expert on your child's behavior and know how your child learns best. At that point, you will become very knowledgeable about how to treat your child's autism and be in a better position to make important decisions about your child's education and future independence.

For more information

<sup>1</sup>In the United States, your child's public school may decide on an educational classification of Autism. This is not the same as a formal diagnosis from a professional in the community. The school's classification is for planning purposes, allowing selection of special education services that are commonly helpful to learners with ASD and ASD-like needs. Even if your child has an educational classification of Autism, be sure to pursue a formal diagnostic evaluation from a professional in the community. The formal evaluation will establish or rule out whether a diagnosis of ASD is appropriate.



# Is My Child on the Autism Spectrum?

The fact that you are looking into whether your child is developing on a typical timeline indicates that you or others around you may be seeing signs of developmental differences.

Either way, there are concerns about your child's development, e.g., language, play skills, social interaction, eating habits, repetitive behaviors, toileting skills.

Although children do develop at different rates, if you are receiving this kind of feedback or have any concerns of your own, it is *paramount* to your child's well-being to check whether there is anything to these queries.

To get answers to these questions, take the Modified **C**hecklist for **A**utism in **T**oddlers (the M-CHAT) in the privacy of your own home. This free screening tool takes 3 min (20 questions to answer) and provides instant scoring through the computer. If you want the screening without signing up through the website, we encourage you to download the print version and score it with the straightforward instructions included. Be honest:

if you are not 100% sure of an answer, it is critical to ask your spouse, a trusted family member who knows your child well, your child's caregiver, or preschool teacher. You need accurate answers to ensure that the screening tool is effective.

*Time is of the essence:* An inaccurate screening result will only delay critical treatment that your child needs and deserves.



## PLEASE NOTE:

This is simply a screening tool that will tell you whether it is a good idea to visit a professional to have your child assessed, and when appropriate, diagnosed. Remember, screening is not a substitute for a diagnostic assessment by a professional.

## Selected additional resources:

[What Is Autism?](#)

[This Your Child Has Autism? Screen Your Child](#)

[Is Autism on the Rise?](#)

[What We Know about the Causes of Autism](#)

[Discussing Concerns with Family Members](#)

[What is the Relationship Between Autism Spectrum Disorders and Intellectual Disability?](#)

[DSM-5 Autism Spectrum Disorder](#)



# Who Could Diagnose My Child?

## Why does time matter?

### Why is a timely diagnosis so important?

The sooner you get your child diagnosed, the sooner you can set up a treatment program for your child.

A young child's brain develops quickly; there is strong evidence that early intensive treatment re-routes the neurologic pathways.

For your child to reach their fullest potential, the earlier you receive the diagnosis, the sooner you can start science-based treatment.

Who can make a diagnosis in your country? Depending upon jurisdiction, the place to get a diagnosis may vary. Although pediatricians and psychologists world-wide have the credentials to make a diagnosis, in many countries there are special diagnostic clinics where a healthcare system may cover the costs. If you are not required to use a special clinic, then make an appointment with any professional in your area with a good reputation for autism expertise.

Remember, time is of the essence. Do not accept the advice of, "Give it some time," or "Wait and see what happens before you act." Parents and professionals alike would encourage you to find a professional as soon as you have concerns.



## What if you encounter a long wait list, which is a common issue in some countries?

### You have a few options:

- 1) Offer to take a cancellation appointment, and explain the urgency of your situation in a respectful way to the receptionist (i.e. gatekeeper). Emphasize the fact that you are very concerned about your child;
- 2) Pay for a diagnostic evaluation at a private psychological clinic, pediatrician's office or multidisciplinary diagnostic clinic;
- 3) Hire a qualified professional to start a science-based treatment program in your home while on the wait list for a diagnostic evaluation. To find a qualified treatment professional, see Step 3 below.

### Selected additional resources:

[Autism Diagnosis](#)

[CDC's "Learn the Signs. Act Early."](#)

[Why is early detection so important?](#)

[Resources for Parents](#)

[A Review of Autism: Start Here, What Families Need to Know \(3rd edition\)](#)



# What is the Best Treatment for Autism?

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## What is scientifically supported treatment?

When we speak of treatment, we are not talking about a pill or type of digestible medicine.

Treatment for autism is an intervention performed by a therapy team that implements programs specifically designed to address your child's needs, e.g., language, behavior, socialization, self-help, safety, attention. Data is taken every step of the way so that your child's progress is objectively measured, and the program is modified as needed to increase effectiveness.

## What is *Applied Behavior Analysis*?

The term applied behavior analysis (ABA) is used extensively in autism treatment. ABA refers to the field of behaviorism as applied to human beings. When used with children with autism, it refers to a tool chest of behavioral techniques and strategies to teach your child all the skills needed to reach their full potential.



## What is *Intensive Behavioral Treatment*?

Intensive Behavioral Treatment (IBT) also referred to as Early Intensive Behavioral Treatment (EIBT) or Early Intensive Behavioral Intervention (EIBI) is a technique pioneered in the 1970s.

In 1987, a [landmark study](#) was published on Intensive, one-on-one treatment based on a treatment protocol designed by UCLA psychologist Dr. Ivar Lovaas. Since that original study was published, there have been over a dozen replications from research sites all over the world. Research from these replication sites is peer reviewed and published in scientific journals. These studies provide overwhelming evidence as to the efficacy of IBT, EIBT, and intensive ABA for the treatment of autism.

Today, these intensive behavioral treatment programs, based on an enormous amount of scientific research conducted with children with autism, are considered best practices for autism treatment. In 1997, the U.S. Surgeon General did an exhaustive study of every single purported treatment for autism and agreed that Intensive Behavioral Treatment (IBT), based on the principles of Applied Behavior Analysis (ABA), is the singular most effective treatment for a child with autism.

## What does treatment look like?

You and your family will be part of your child's therapy team. If your child is very young, it is common for therapy to take place in your home. (In a few jurisdictions, there may be certified treatment centers for young children.) Although you will hire a consultant with expertise in IBT as applied to autism, you will be in charge of a team of therapists who will come to your home and work one-on-one with your child. In countries fortunate to have health insurance coverage (i.e. the U.S.), often parents select an ABA agency that becomes the treatment provider. Parents enter into participation agreements that give consent for treatment. In this scenario, the therapists and the consultant work for the provider. Your family will be given the tools to help your child as well so that when the therapists are gone for the day, you will be able to involve your child in your home, family, and community activities. In addition, program consistency, collaboration and ongoing communication between therapists, home, family and school personnel will increase skill acquisition and decrease maladaptive behaviors exhibited by your child. A home-based treatment program offering 40 hours a week including time spent at school is recommended in order for your child to reach their full potential.



# What is the Best Treatment for Autism?

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## How can you provide treatment for your child?

Whether you choose to have your child participate in a home-based or school-based program, treatment programs should be designed by a behavioral consultant with expertise in autism. The programs are individualized and administered by a trained therapy team. Some countries require that the behavior analyst be board certified. To find a behavior analyst or to verify their credentials, visit the [Behavior Analyst Certification Board](#).

**To find a science-based treatment program in your area, take the following steps:**

- 1) Ask your local autism parent support group for the top EIBT, IBT, or Intensive ABA providers;
- 2) Ask your pediatrician or diagnosing psychologist if they can recommend a few qualified treatment providers;
- 3) Go to the [Behavior Analyst Certification Board](#) and search by country, state and/or zip code. You are likely to find someone with expertise in your country. If you are in the U.S., Canada or many European countries, you will likely find several qualified people in your city or town.

## What about other treatments?

There are over 500 purported treatments, most of which have no data supporting their effectiveness.

Other therapies have insufficient data and, therefore, cannot be recommended. We encourage you to explore the ASAT website where we describe the state of the science with respect to these treatments (please see selected resources at the end of this section).

Since setting up a program is time consuming, we recommend starting with evidence-based treatment interventions before researching alternate treatments. We encourage you to explore the [ASAT Treatment Summaries](#) that are updated as new evidence is published.

## Common questions or worries that parents of a newly diagnosed child often have about treatment:

*“I’m worried that treatment won’t help my child.”*

Rest assured that the treatment program you set up for your child under the supervision of a professional behaviorist will be customized to your child’s needs, and data will be taken each step of the way to ensure that the evidence-based intervention is contributing to your child’s progression. A high quality treatment program is modified based on data collected.

*“I’m worried that I won’t understand the treatment.”*

There is a learning curve for everyone involved in your child’s treatment program. Fortunately, there are several excellent publications and videos on evidence-based treatment for autism (please see our list of educational resources). In addition, talk to the qualified professional who is setting up and monitoring your child’s program. Every activity specifically designed for your child has a purpose, and a properly trained professional should be able to explain the purpose to you and your family. In some communities, you can also reach out to local parent groups who have their children in home-based treatment programs. Alternatively, there are many internet based parent groups. These parents are often able to help you understand what the treatment should look like in a home-based program.



# What is the Best Treatment for Autism?

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***“I’m worried that I can’t afford to give my child the treatment he/she needs.”***

This is a legitimate concern. We address the financial issues and solutions below in Step 4 of this New Parent Packet.

***“Will my child become normal?”***

The science demonstrates that the future development of a young child with autism cannot be accurately predicted due to a variety of factors such as the different rates at which children gain skills and the quality and intensity of the treatment plan. Although parents and professionals recognize that children with autism progress at their own rate, several studies have characterized children’s response to treatment into three general groups. Research clearly demonstrates that a subset of children will become indistinguishable from their peers. (Due to the state of the science, there is still debate as to whether the brain has been rewired versus whether individuals gain skills that enable them to become indistinguishable.) That said, those indistinguishable children will be viewed as typically developing and may be able to live on their own and hold a job.

There is a second subset of children who maintain the diagnosis of autism. With quality intervention, they gain tremendous independence and self-reliance and have a high quality of life. These children are taught to communicate and become completely independent when it comes to self-help and daily living skills. In addition, with support, they become active members of their community.

There is a third subset of children who will continue to acquire a variety of skills throughout adulthood. The treatment provides them the skills they need to maintain a high quality of life in a supportive living environment with daily household responsibilities, and participation in leisure activities in the community. With the goal of reaching additional independence, skill acquisition is reinforced and new skills are taught. Communication skills are an ongoing focus of treatment so these individuals can better communicate their needs and emotions (whether verbally or with an augmented communication system).

Although predictions as to the outcome of *your* child can not be made, choosing a science-based treatment will ensure your child will reach his or her full potential.

***“I’ve contacted a few providers who tell me that they will not work with my young child because she is over five years of age!”***

There are some providers who focus only on very young children (18 months to 5 years of age). These providers typically refer children 5 years and older to providers who are more qualified to work with older children. Fortunately, there are many highly qualified providers who accept children of all ages as clients. Please refer to the section in Step 3 that discusses how to access treatment for your child.



# What is the Best Treatment for Autism?

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## Selected additional resources

### *Frequently asked questions about ABA*

- [Meta-Analysis of Early Intensive Behavioral Intervention for Children with Autism](#)
- [ABA and Research, What ABA Can Do for Your Child](#)
- [Early Intensive Behavioural Intervention or Treatment](#)
- [Considerations When Hiring a Behavioral Service Provider](#)
- [Explaining My Decision to Use Science-Based Treatment for Autism](#)
- [Encouraging Parent Participation Home-Based Intervention](#)
- [Systematic Review of Early Intensive Behavioral Interventions for Children with Autism—Rutgers University](#)
- [The Real-World Effectiveness of Early Teaching Interventions for Children with Autism Spectrum Disorder](#)
- [Identifying Applied Behavior Analysis Interventions](#)
- [A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders](#)
- [Change in Autism Core Symptoms with Intervention](#)
- [Efficacy of Applied Behavioral Intervention in Preschool Children with Autism](#)
- [A Comparative Look at School Based and Centre Based ABA Programs](#)
- [Early Behavioral Intervention is Associated with Normalized Brain Activity in Young Children with Autism](#)
- [Intervening in Infancy: Implications for Autism Spectrum Disorders](#)

### *Frequently asked questions about treatment*

- [Is There Science Behind That?](#)
- [The Pitfalls of Testimonials](#)
- [Learn More About Specific Treatments. What Works and What Doesn't](#)
- [Autism Spectrum Disorder: How Do We Measure Effectiveness?](#)
- [Ethics and Evidence-based Practice](#)
- [Evaluating Research](#)
- [ASAT Supports Proven Treatments and Informed Choice](#)
- [What is Evidence-Based Practice and Why Should We Care?](#)
- [Pseudoscientific Therapies - Some Warning Signs](#)
- [Science, Pseudoscience and Antiscience](#)

**NOTE:** For detailed information about how to help your child during a pandemic, please visit [ASATonline.org](https://www.asatonline.org)



# How Do I Find and Pay for Treatment?

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## How do I find the money to pay for treatment? Is funding available?

Funding for treatment can be extremely challenging depending upon where you live. It is critical that you research immediately to find the status of funding available. (Possible sources include private or public health insurance, local school districts or councils, state or provincial disability, social services, or family welfare agencies.) If you start a treatment program immediately, be prepared to use your personal resources until you can access other monies. Consider talking to your family about helping you to pay for treatment or become part of your child's treatment team. Although it is wise to find a behavioral consultant to design your child's treatment plan, all the therapy hours can be conducted by family members or volunteers who have been trained by the consultant. The research indicates that a total of 40 hours a week for a treatment schedule is strongly recommended. The specific number of hours required will be determined by your consultant based on the child's needs.



Whether home-based and/or center-based, a treatment program targets the core characteristics of ASD through interventions that focus on communication, social and play skills, self-help, and learning readiness skills.

The instructions are tailored for early learners using evidence-based interventions. Ultimately, the child will be transitioned into the appropriate least restrictive environment (LRE) based on the child's skills.

(Note: treatment is expensive due to the number of therapy hours, not simply the level of expertise of the consultant. Family members may be trained to be part of the treatment team.)

To begin your online search for information about funding, it is helpful to contact the providers in your country using the following search terms: *name of your country* and *applied behavior analysis*. In addition, network with parents in your area to educate yourself about the availability of funding. There are many parent organizations that include the following words in their name: treatment; ABA; early intervention; intensive behavioral treatment or intervention. Parent groups generally are knowledgeable about whether funding is available and how to access those resources.

Be aware, though, that some parent groups advocate for non-science based treatments and may not be educated in science-based treatments. If there are no parent organizations in your area doing science-based treatment, autism societies in your country may provide you with names of parents who have their children in science-based treatment programs. In some countries, ABA is not yet recognized as medically necessary. **To do your due diligence, [visit our list of treatment reviews](#).**

## How much does treatment cost?

Treatment costs vary from country to country depending on cost of living and level of expertise; however, due to the intensity of the treatment, it can be very expensive. To illustrate, in the United States and Canada, funding can be between 40 - 80 thousand dollars a year.



# How Do I Find and Pay for Treatment?

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## What if there is no funding in my country?

If you are in a country that has not yet understood the importance of providing treatment to children with autism, you are not alone. Tens of thousands of parents have been in your shoes. In fact, the reason that autism treatment is widely available in the United States is due to thousands of courageous parents who fought for funding for their children. They used one of the two strategies below:

### a) Lobbying

There are two kinds of lobbying: personal and group. To personally lobby for your child's right to funding, it is important to have your child's paperwork and treatment team assembled. This includes the child's diagnosis and the consultant's recommendations for treatment. Depending on the system in your area you may find yourself in meetings with social services, school or medical service personnel. You may find yourself having to appeal to the highest levels of the bureaucracy. You may even find yourself sitting across the desk from government leaders. It is critical to document every interaction whether by email, phone, or in person.

Group lobbying is another strategy to convince the government to provide monies for treatment. In this scenario, parents organize as a group and publicly advocate for funding. Whether this strategy will work is dependent on the political system in your country. For models of group lobbying, some *Families for Early Autism Treatment* groups have useful information on their websites.

### b) Lawsuits

Some parents had little luck with their lobbying efforts and, therefore, turned to the courts. These parents sued their governments at a variety of levels forcing health care systems, and/or school districts to fund their children's treatment programs. These parents availed themselves of the services of attorneys with expertise in disability law and were able to create legal precedents that are now used across their jurisdictions. If you are looking to sue your jurisdiction, it is critical to find a lawyer 1) with expertise in litigation and 2) who is prepared to become an expert in disability law. See below for links to helpful legal precedents worldwide and in the United States.

## Selected additional resources:

[Global Court Cases on Autism Treatment](#)

[A List of Important Statutes and Cases in Autism Litigation \(on the Mayerson & Associates website\)](#)

[Council of Parent Attorneys and Advocates, Inc. \(COPAA\)](#)

[Council for Exceptional Children \(Policy and Advocacy\)](#)

[Individuals with Disabilities Education Act \(IDEA\)](#)

[Wrightslaw \(Advocacy for Children with Disabilities in the U.S.\)](#)

[Advocating for Your Child](#)

[Encouraging Parent Participation in Home-Based Interventions](#)

[Video Examples of Effective Instructional Models](#)



# What Does the Future Hold for My Child and Our Family?

## How will autism impact our family life?

The diagnosis and subsequent treatment of a child with autism can cause considerable stress on the family. The stress often comes from the high cost of treatment and the inordinate number of hours spent on one child. That's why it is critical that families carve out time where autism is not the center of their life. Many couples organize a weekly date night where discussing autism is not allowed. In addition, families attempt to give the siblings opportunities that have nothing to do with autism. It is important to remember that your family does not exist solely to treat a child with autism. That's why respite from the intensive treatment program is a must if you want to keep your family strong and intact.

## What if we have different views on what to do with our child?

There are a variety of housing options for children with autism depending on the country. Unfortunately, these housing arrangements are very rarely designed for treatment. If you are lucky enough to be in a country with a network of ABA Teaching Homes, there is generally such a long waiting list that the child will become an adult before becoming eligible. The argument about where to place a child is often irrelevant because the spaces are not available. It is critical that families are on the same page in terms of accessing science-based treatment since it is a group project. If your spouse is not convinced, there are many resources on our website that will discuss the science behind the treatment. Please see Step 3 above.



## How will this impact our work life?

When you have a child in a treatment program, your career priorities may change. Whether one spouse can transition from full-time employment to part-time employment to manage the treatment program, change careers, or power through this stage in life, there is considerable financial and career pressure. Interestingly, the careers of some parents have been positively affected by autism i.e. lawyers who specialize in autism lawsuits or start businesses catering to parents of children with autism. In any case, families should be strategic in terms of career decisions. Understand though, that the first few years of a science-based program are often the most intense and time-consuming for the parent.

## Do you have any additional advice?

Keep calm. Your number one priority is to get treatment for your child. Don't inherit tomorrow's problems, since they may not occur. Talk to your partner, your family and your friends. They may be part of the solution and involved in your child's ABA treatment team. In fact, they can be very helpful if you provide them with training. Once you see your child acquiring skills, the pressure on you regarding your child's future will decrease. Worry and heartache turn to joy when you see your child learning skills and becoming a functional part of the family.

## Selected additional resources

- [Lifespan Resources from the Web](#)
- [What are some adaptive skills for a young adult to gain independence?](#)
- [Defining and Assessing Quality of Life as an Outcome for Adults with Autism](#)
- [Develop Goals for the Future](#)
- [Discussing Concerns with Family Members](#)
- [Does ABA Work for Older Children?](#)
- [Explaining Applied Behavior Analysis to Parents and Colleagues](#)
- [How to Manage the Impact of Child with a Disability on Siblings](#)
- [Preparation for Employment Success](#)
- [Promoting Success in the Community](#)
- [Research Synopses-Lifespan](#)
- [Teaching children with autism to attend religious services](#)