

# PARENTS GUIDE FOR NEWLY DIAGNOSED CHILDREN



A NEURODIVERSITY AFFIRMING  
INTRODUCTION TO AUTISM

A free  
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## 02

# WHAT IS AUTISM?

Autism is a lifelong, neurodevelopmental disability that results from structural differences in the brain. Autism is a spectrum condition, which means several related but different conditions, that present as a collection of traits influencing an Autistic person's communication, social behaviors, interests, thinking style, sensory experiences, and more. Though there are similarities amongst Autistics, how these differences present are individual. Autism is a genetic and heritable condition though some cases may be due to environmental causes during pregnancy.

Autism is often accompanied by other conditions that also impact experience, behaviors, and quality of life. Some of these are genetic and some are environmental. They may include sleep disorders, ADHD, gastrointestinal disorders, mental health conditions, epilepsy, motor disorders, and others. Understanding your child's needs allows you to accommodate them.

## HOW WORRIED SHOULD I BE?

It might seem scary and overwhelming to learn your child is Autistic, but you and your child are in good company. At least 1 in 36 people are Autistic including history's greatest minds. Some Autistics you may know include Einstein, Greta Thunberg, Isaac Newton, Emily Dickinson, Michaelangelo, Courtney Love, Da Vinci, and many, many more.

Most Autistic children grow to be happy, well-adjusted Autistic adults with rich lives. Your child's future isn't written. No one can tell you today what outcomes to expect for your child. While Autism is a disability, many aspects of Autism improve life such as experiencing the world with wonder, seeing patterns others miss, seeing the bigger picture, a connection with animals, intensely rewarding interests, study and expertise, hyper empathy, or novel observations. Non-speaking Autistics were once assumed to have an intellectual disability. This is now known to be incorrect and non-speakers are learning to communicate and even giving valedictorian speeches via devices.

This guide will help you by providing information and resources to support you and your child.

# 03

## HOW MUCH HELP WILL MY CHILD NEED?

**You may have been told a “level” at diagnosis. This is an assessment of how much support your child is needing now. This may change or remain the same.**

Levels 1-3 describe the amount of support needed with level 1: requires support, level 2: requiring substantial support, and level 3: requires very substantial support. It is possible that the level can change. You may find it more helpful to talk about your child’s particular strengths and needs instead of the level of required support.

How much support your child will need depends on many factors most notably the other conditions your child has. Children who have a motor planning disorder, for example, will have different needs than an Autistic child without significant motor planning issues.

The most important elements of growing up for your child will be your love, acceptance and support, in that order. Your job will be facilitating the removal of barriers that result from your child’s unique needs and society’s misunderstandings of what it means to be Autistic.

## WHAT DO I DO NOW?

1. Take a deep breath. Everything is going to be ok. Here are some to-do items for you:
2. Ask about other conditions that have been identified during the evaluation process. Do these require follow-up or management?
3. Find your people! Look for neurodiversity-affirming organizations, groups, and individuals online. Autistic adults have been where your child is and maybe where you are if they also have children.
4. Get support. Those online communities will become part of your support. You also need family, friends, schools, and others who accept and protect your child as they are and support you in taking breaks and helping your child. Include following Autistic adults and Autistic professionals in online spaces.

## 04

# LEARN ABOUT NEURODIVERSITY

Neurodiversity is the concept that the world benefits from having all types of minds. Autistic brains work differently, and though that can sometimes be challenging in a world that isn't made for them, it's also a source of innovation and adaptation. The concept comes from biodiversity in evolution.

“Neurodiversity affirming” takes a positive view of brain differences as being a range of normal. It's a movement of acceptance of differences including Autism and a movement focused on accommodation of needs. Schools and therapies are often not neurodiversity-affirming, so you can familiarize yourself with the concept, ask questions before selecting therapists or schools, and even help spread acceptance in the process. So, what does being neurodiversity-affirming look like in practice?

- Providing robust opportunities for communication and respecting all forms of communication.
- Promoting and accepting self-advocacy and autonomy, which avoids compliance-based methods, and doesn't push a child past their limits.
- Adapting the environment and expectations to meet the needs and abilities of the individual.
- Rejecting the notion that their differences or disabilities must be changed.
- Using affirming language and does not use functioning labels (high or low functioning) or mental age.
- Presuming competence: assuming a person has the ability to learn and understand even if they can't demonstrate that at the time.
- Prioritizing the knowledge and wisdom of those with learned experience while staying aware of new information about the community and condition.
- Accepting their special interests, social preferences, and stimming behaviors.

The **MOST IMPORTANT THING** to know in supporting your child is that traditional parenting, advice, rewards and punishments, education, etc often do not help neurodivergent kids. It's up to you to radically parent the child you have with love and acceptance.

## 05

# SHOW THEM THE (BIG) PICTURE

**Learn about Autistic learning styles including Gestalt Processing**

Autistic people think differently. Knowing how your child's brain works will make it easier to connect and support them.

Temple Grandin famously stated that many Autistic people are visual thinkers. Many Autistics are like Grandin and think in pictures, but some are verbal and others are pattern-based thinkers, the majority are probably some mix of the three.

Why visuals are important: One of the most common pieces of advice is to use visuals for Autistic children, but often the execution misses some important aspects of Autistic thinking. There are a few purposes for using visuals: communicating new experiences, letting the child know what to expect, and giving both the wide view and the close-up of a task, event, day, etc.

Autistic children and adults are more prone to anxiety, and new experiences can be both exciting and anxiety-provoking. Using visuals to familiarize a child with a new place, event, or experience can minimize anxiety by taking some of the mystery out of the experience.

Similarly, visual schedules let children know what to expect or what to do next. They are most helpful when they incorporate changes to the usual routine. For example, if a classroom is using a schedule only to tell the child what to do, they are missing opportunities to prepare the child for changes that could potentially lead to anxiety, meltdowns (outward expressions of dysregulation), or shutdowns (turning off for a short time when dysregulated).

Autistics may be focused on details, but many need to see the whole picture to understand a concept. This should be offered as a framework upfront. This is part of a Gestalt processing style, which may manifest most clearly in speech processing. Gestalt means seeing the whole as greater than the sum of its parts. Gestalt language includes echolalia and scripting.

## 06

# COMMUNICATION

## FROM BEHAVIOR IS COMMUNICATION TO AAC

Most Autistic children will go on to be speakers. Probably around 80%. Social communication issues are a core feature of Autism meaning all Autistic people have some level of struggle with communication even for Autistics with no speaking impairments.

Autistics tend to be more straightforward communicators who value honesty and tend not to intuitively know the social rules for behavior and communication that neurotypical people do. Autistic people can and do learn some, most, or even all of these rules, but they do not come naturally, can seem confusing, and unnecessary. Indirectness can feel manipulative to some Autistics. Some Autistics have a set of traits sometimes called Pathological Demand Avoidance, in which perceived demands are deemed threatening by the nervous system. Indirect communication can sometimes trigger this response.

There's a saying common in the Autism world as well as others: behavior is communication. And it is, but Autistic people's behaviors aren't neurotypical and they aren't even universal to Autistic people. The best way to interpret behaviors is to provide access to a robust communication system for Autistics who are non-speaking, minimally speaking, unreliably speaking, or have situational (also called selective) mutism where they are unable to speak at certain times. Yes, behavior is communication, but if you don't speak their language, you can't interpret it. Autistics tend to be lateral thinkers, so communication through behavior may sometimes be creative.

When children are pre-verbal or lack typical speech, alternative and augmentative communication (AAC) methods are a must. You probably think of iPads and Dynavox's, but AAC can be anything other than speech that your child can access including pictures, sign language, pointing to spell methods, eye gaze, and more.

Finding the right fit can be a challenge but one that's well worth the effort. And remember, using AAC is not a barrier to gaining speech.

# 07

## SENSORY SUPPORTS

### THE SENSES ARE THE WINDOWS TO THE WORLD

Our eyes, ears, taste buds, nerve cells, and more are all tools our bodies use to collect data, but that data is made meaningful in the brain. Studies show that Autistic brains have more connections in some areas and less in others in comparison to neurotypicals AND in comparison to each other. That means that Autistic brains are hyper-connected and under-connected in patterns that aren't universal with other Autistic or neurodivergent people. Because of these connection differences, the information the body takes in can be relayed differently than others experiencing the same stimuli.

Most Autistics and other neurodivergents with sensory differences have mixed sensory needs. They may seek sensory input in some types of senses like movement (proprioceptive) and avoid stimuli like sound.

Watch your child's signals. What do they like to do? What do they react negatively to? Here are some possible sensory supports. An occupational therapist (OT) is a great way to learn more about your child's sensory needs and how to meet them. An OT can help evaluate your child's sensitivities and hyposensitivities and create a plan to meet those needs. This is called a sensory diet. They can help you plan what equipment might help in your home, and what formal activities you might want to pursue like gymnastics or sports.

Some basics that can help to start with follow, but know that not all of these will work for your child depending upon their needs.

- Ear defenders or ear plugs
- Sunglasses and/or brimmed hats
- Tagless clothing
- Weighted blanket, hoodie, vest, or a backpack with some weight to it. The guidance is usually no more than 10% of the child's body weight
- Swings, trampolines, tricycles, balance bikes, or other movement toys
- Soft, warm lighting at home
- A quiet, calm space to retreat to

## 08

## THERAPIES & SUPPORTIVE SERVICES: OVERVIEW

You may have received some recommendations for therapies when your child was diagnosed. These usually include speech therapy, occupational therapy, Applied Behavioral Analysis, early intervention preschool services or special education services, and parent training.

What therapies your child participates in will be based on their needs, your resources, and what services are the best fit. Here is some guidance on how to select the right therapies and providers for your child.

- When you get a referral for a service, you are interviewing a provider to see if they are a good fit. You can always change providers or stop a service that isn't working. You're in charge. They are providing a service.
- Neurodiversity affirming-The purpose of therapies for Autistic children and adults is to help them learn skills they are struggling to obtain in a way that maintains their autonomy and respects their strengths and disabilities. It's not to "fix" and it's not to encourage a child to mask their neurodivergent traits. It's to support. All therapies should be in line with neurodiversity-affirming, anti-ableist principles.
- You should be welcomed to be present for sessions or watch sessions on a live video feed. This is a safety issue, but it's also to confirm that your child's services are in line with your values.
- It's not fun if it's forced. Children shouldn't be forced to do therapies. If they are crying, eloping, or refusing to go, this is a sign that this therapist, clinic, or approach isn't working. Therapy for children should be fun. Play is the work of childhood.
- You should be aware of the controversy around ABA. Become informed and decide whether this is an approach you want to use for your child. There are alternatives to this type of intensive intervention available as well such as Floortime and SCERTS. If you decide not to use ABA, be sure these providers are not also BCBAs.



## 09

# THERAPIES & SUPPORTIVE SERVICES: BEHAVIORISM

## WHY IS THE MOST COMMON APPROACH TO AUTISM INTERVENTION IS ALSO THE MOST DISLIKED BY AUTISTICS?

Behaviorism is a theory of learning that states that people and animals learn by the conditioning of environmental factors (rewards and punishments) without the influence of thinking or feeling. Rewards and punishments are widely used in teaching and managing the behaviors of children. Sticker charts, token systems, and taking away access to play and toys for “bad behaviors” are all examples of behaviorism.

Though behavior approaches can lead to behavior changes, how these programs are implemented including the founding principles are based on teaching Autistic children to hide their Autistic traits to gain rewards and avoid further discomfort in therapies. Autistic masking or camouflaging is an attempt to protect an Autistic person. It's a stress response, and excessive masking leads to negative outcomes including restraint collapse, meltdowns, shutdowns, and over time, Autistic burnout, depression, and anxiety.

As noted above, ABA isn't the only setting where you may encounter behaviorism. Classrooms, occupational therapies, speech therapies, sports, and other activities may also use these methods. There is a great deal of controversy about ABA and disagreement as to whether or not it can be neurodiversity-affirming. If behaviorism is something you want to avoid, interview your potential providers and ask about their practices, and ask some questions like:


- Do you use rewards and punishments, discrete trials, or exposure in therapies?
- Is your practice child-led?
- What do you do when the child is upset and doesn't want to participate?
- What does neurodiversity-affirming mean in the context of your practice?

For more information on neurodiversity-affirming practices, alternatives to ABA, and to find affirming therapists, go to the Therapist Neurodiversity Collective: <https://therapistndc.org/therapy/non-aba-evidence-based-practice/>


## 10


# THERAPIES & SUPPORTIVE SERVICES: RED FLAGS, GREEN FLAGS


## THE LOWDOWN ON NEUROAFFIRMING THERAPIES


 Parents aren't allowed in therapy rooms and there is no live video feed.


 Kids have to earn breaks.


 The therapist's goals are compliance-based.


 The therapist uses functioning labels, mental age, or baby talk.

 The therapist focuses on table work without first doing regulation.


 The child cries before and during the session.


 The therapist attempts to reduce stimming behaviors that aren't causing harm.


 Demands eye contact. Demands anything,


 The therapist uses the child's interests in therapy.


 Sensory needs are met intentionally.


 The therapist's goals are built collaboratively with the child and family.

 The therapist builds and maintains trust with the child. And parents.

 The therapist works to help the child gain skills without goals of being more neurotypical.

 The child has fun and doesn't resist attending,

 The therapist does not attempt to suppress stims.

 The therapist meets the child where they are instead of making any demands.

**"PLAY IS THE WORK OF THE CHILD"**

*-Maria Montessori*

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# ADOPT A NEURODIVERGENT LIFESTYLE

## EMBRACE DIFFERENT

Adopting a neurodivergent lifestyle means setting up aspects of life to be intentionally different from how neurotypical people approach the same things.

Do you have to change things to accommodate your children or is it better to make them conform to a world not made for them? While it's true the world doesn't bend to our wills, it's also true that each of us has a lot of control over how much joy we get out of life. Teaching your child to expect to live a life they enjoy is advocacy. So is acceptance, and teaching self-acceptance.

Areas that need attention and adjustment:

- Meeting sensory needs
- How your home is set up, decorated, and maintained
- Work for the primary caregiver
- School (IEP? Homeschool? Online school?)
- Relationships and boundaries
- Activities, routines, rituals
- Holidays and traditions
- Obligations

Look at each area of your life and your child's life and determine if there are ways to make things more enjoyable and easier.

For more details on living a neurodivergent lifestyle, see my blog post or look for my upcoming course, Living Outside The Box: <https://www.divergentautismservices.com/post/adopting-a-neurodivergent-lifestyle>

