



Changing Stories, Changing Lives.

A New Chapter for
Autism and I/DD Care



INTRODUCTION

U.S. Healthcare Faces Major Challenges

And behavioral health care is no exception.

Access is limited, with major disparities between families with resources and those who face socioeconomic challenges and other determinants of health. Investments in care can be driven more by money-making opportunities than by need. Care is often fragmented and not coordinated; quality and availability vary by geography.

In this report, we'll review the landscape, explore the challenges of delivering high-quality autism and I/DD treatment and lay out the vision for changing the story through coordinated, targeted actions.



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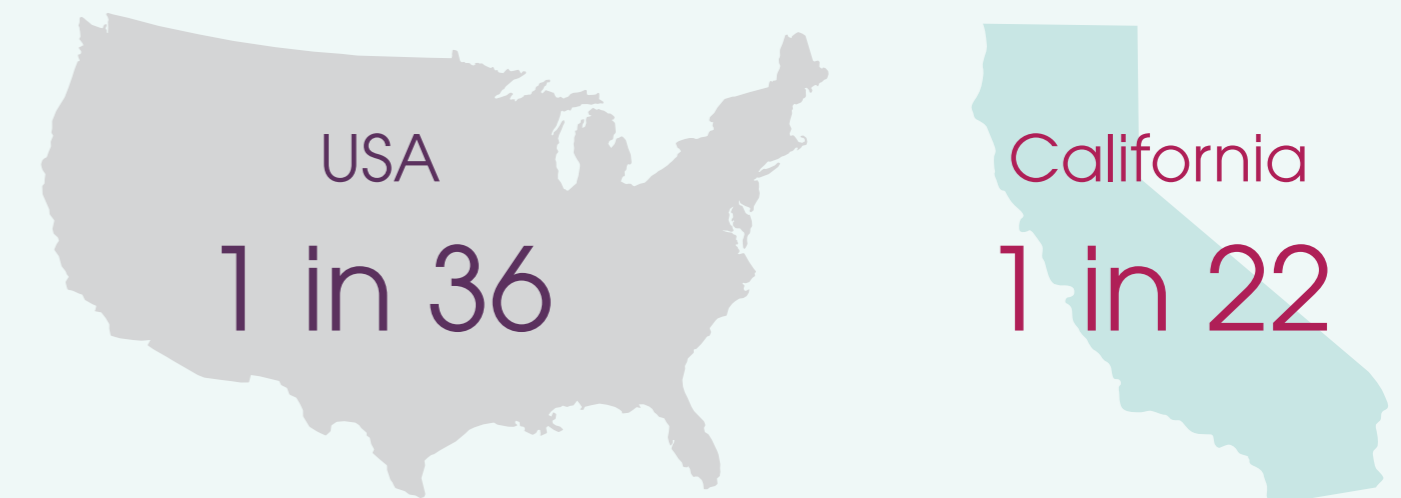
The Landscape Today

The reasons for the increase in autism spectrum disorder (ASD) aren't entirely clear, but it's partially because of growing awareness and shifting diagnostic criteria. Boys are four times more likely to be diagnosed than girls. And girls are often diagnosed later, which may be partially attributable to bias and because autism manifests differently in girls.

Research shows that children from lower-income, minority and rural backgrounds are also more likely to be diagnosed later. Early diagnosis is critical in improving outcomes and is linked to lowering the costs for the family in the long term.

Options for treatment vary widely by location, with urban areas often better served. In some areas, wait times for treatment can stretch for up to two years, and treatment is sometimes not available at all. Other factors contribute, such as lower awareness, lack of healthcare infrastructure and limited provider resources.

Prevalence of Autism



Source: [CDC](#)

1 in 6

Children with one or more I/DDs



Source: [CDC](#)

The Current Story



The ripple effects of an autism diagnosis are hard to overstate. The economic impact is enormous: Between 1990 and 2029, the lifetime societal costs of autism are estimated to total [\\$15 trillion](#). Per individual diagnosis, total therapeutic and societal lifetime costs are estimated to reach [\\$3.6 million](#).

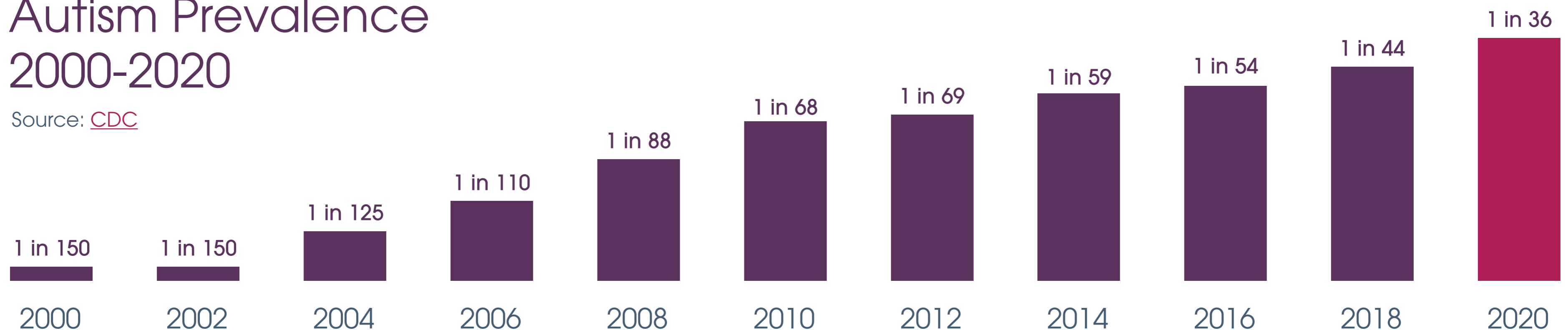
On a family level, an autism diagnosis has a cascade of impacts. Often, parents take time away from work in addition to bearing the financial realities of autism care. Studies [have shown](#) that mothers with a child on the spectrum earn significantly less than

mothers of children with other health challenges and are less likely to be employed. For parents of autistic children where intellectual disability is also present, the impact is even [more significant](#).

Parents of autistic children, particularly those with high support needs, are among the most stressed parent populations. That matters for more reasons than the parents' wellbeing and mental health; higher stress among parents is [related to poorer outcomes for children](#).

Autism Prevalence 2000-2020

Source: [CDC](#)



The Importance of Early Diagnosis

It's known that a specialist can reliably diagnose autism in children by the time they are two years old. Aside from the risk of overdiagnosis or missed diagnosis that can result in the wrong treatment, early diagnosis and intervention are critical for improved outcomes because young brains are highly adaptable, and therapies such as speech and occupational therapy and behavioral interventions produce lasting impacts. [Studies have concluded](#) that early intervention has significant positive effects on daily living and motor skills that are so important for everyday life and communication.

Delayed diagnosis [can lead to other problems](#), like mental health issues or substance abuse later in life. Early diagnosis also gives the whole family time to adjust and learn skills to support the child. But the [average age at diagnosis](#) across the U.S. is five. Unfortunately, disparities by race and socioeconomic circumstances are [further magnified](#) when diagnosis and intervention are delayed. Early intervention is just as critical as early diagnosis. [One study](#) found that Black children were diagnosed at around age five and a half—about six months later than White children—despite parents raising concerns more than three years earlier.

Children with Autism

37.9%

Who Also Have Intellectual Disability

Source: [CDC](#)

23.5%

Borderline Intellectual Disability

Source: [CDC](#)

2 Years

Time to Offset Costs of High-Quality Early Interventions

Source: [Penn Medicine](#)

Let's Eliminate the Wait

Parts of the United States don't have adequate treatment resources, let alone the specialists required to get an initial evaluation.

At the [Catalight Foundation](#), we aim to radically reduce the time between the moment a parent or caregiver starts to suspect their child may have a delay, and the start of treatment. That means getting to a specialist within 10 days, so we can help families choose the best path for their child.

To get there, we are committed to expanding provider networks by finding and training practitioners with our [Catalight Classroom](#) continuing education platform, RUBI training and our [post-doctoral](#) program to credential more diagnostic evaluators.

84%

U.S. counties without adequate evaluation resources

Source: [JMIR](#)

2 Years

Waitlist in some parts of the U.S.

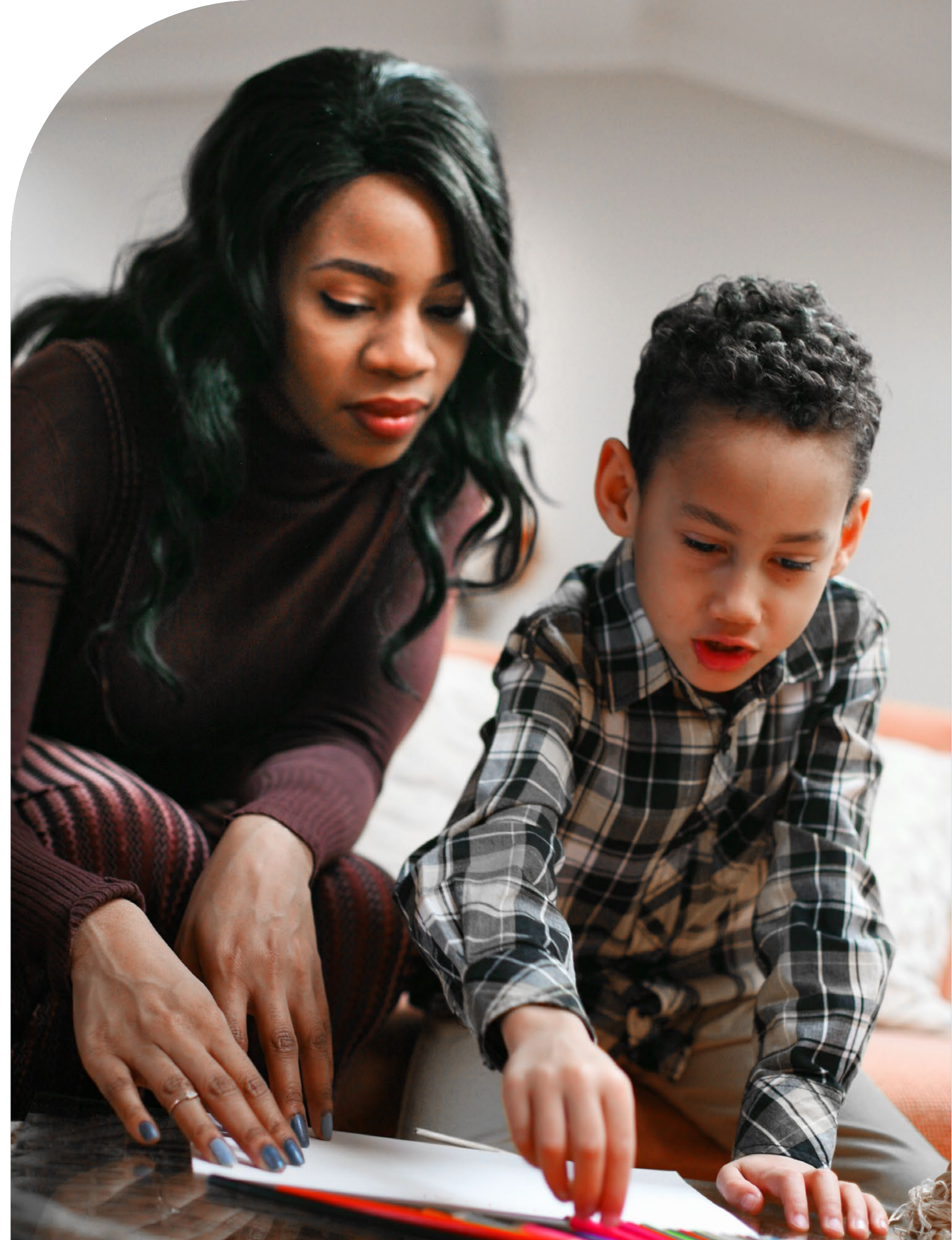
Source: [CMS](#)

One Size Does Not Fit All

As these disabilities are better understood, it has become clear that the individuals affected are a very diverse population. That's led providers to realize that the same interventions at the same dosages aren't suitable for every unique individual. Long held as the gold standard, it has become apparent that applied behavioral analysis (ABA) isn't the best treatment for everyone.

For example, someone with depression, ASD and low support needs may benefit from a treatment plan focused on mental health care rather than ABA. High-hour ABA isn't always necessary; [research has shown](#) that 15 hours of ABA is just as effective as 25 hours of ABA. If outcomes can be achieved with fewer hours, the cost burden for families and payers is reduced, and providers effectively have more capacity, potentially increasing access.

That may also help with the pervasive problem of workforce shortages. A shortage of trained professionals (behavioral therapists, special educators, paraprofessionals and the like) causes long wait times for families. As ABA became the standard for autism care, the number of Board-Certified Behavior Analysts, master's degree-trained providers who directly or indirectly administer treatment programs, [ballooned](#). However, according to [recent research](#), the supply is still insufficient to meet demand.



Adult Services and Care Coordination

Support for adults with autism is not as widely available as it is for children. Adults with autism may face a shortage of services, limited insurance, communication difficulties with providers, and may lack the advocacy of family members as they age. Their circumstances may be further complicated by intellectual disability or any number of co-occurring conditions.

Care is often not well-coordinated across services, providers and agencies. For providers, coordination activities are not typically reimbursed. That leaves families and individuals struggling to manage appointments and care plans on their own, which leads to delays in care and services.

Housing is a major issue for adults with I/DD. About 75% of adults with an I/DD live with family. But what happens when parents pass away and no other family options remain? Residential support for people with I/DDs is insufficient, and support staff are a high turnover field. Escalating rent and home prices have exacerbated the issue. For example, in California, an income of \$98,545 is needed to rent a two-bedroom home at the Department of Housing and Urban Development's fair market rent rate.



5.4M

2.2% of U.S. Adults are Living with Autism

Source: [CDC](#)



48.5K

Children with Autism Who Become Adults, Annually

Source: [Canadian Journal of Psychiatry](#)

Access for Everyone

We envision a world where every individual, regardless of race, gender, geography or socioeconomic status, has equal access to timely, individualized, high-quality care. Each individual is celebrated for their unique contribution and has the opportunity to reach their full potential on their terms and defined by their dreams.

“Health equity is achieved when everyone can attain their full potential for health and wellbeing.”

Source: [WHO](#)



A Pathway to Equity

The following are the pillars of our endeavor to drive change:



ACCESS

Access includes more than just being able to make an appointment with a qualified provider. It means having access to a dedicated team of multidisciplinary professionals who can deliver timely care and help adjust the treatment plan according to changing needs and circumstances. It means a consistent support network of educators and healthcare providers trained to recognize the signs of autism, thereby driving early diagnosis and intervention. It also means that care is affordable for every family.



ADVOCACY

Change cannot be achieved without the advocacy, education and policy work that creates the framework for lasting change. This kind of support and representation has brought autism treatment coverage to all 50 states.



PERSONALIZED CARE

One size does not fit all in a highly heterogeneous population like individuals diagnosed with autism or other I/DDs. The best care is tailored to the specific needs, circumstances and preferences of each person and their family.



CLINICAL INNOVATION

The portfolio of effective treatments for autism and other I/DDs has grown beyond ABA to include a variety of options. Some of these innovations have helped to expand capacity and increase access through treatments that don't require as much intensive intervention or that can be done within the family and community environment. Further research and innovation will help understand the causes and differing expressions of I/DDs, and develop effective treatments.



FAMILY WELLBEING

The best indicator of success for meaningful care is wellbeing, an umbrella measure that gauges overall health, happiness and quality of life for individuals and their families. Treatment choice and services like respite care and other social and community supports help stressed parents better manage their families and their own wellbeing.



Changing Stories, One at a Time

[Learn how to join our journey](#)

