

What's Going On With Autism Services?

By Amanda Ralston, M.Ed., BCBA, LBA, IBA

In 1999 when I first learned about autism in my textbook at Centre College, it told me that autism was diagnosed in 1 in every 1,000 individuals. And that the “gold standard” treatment for autism was something called Applied Behavior Analysis or “ABA” therapy.

There was no funding. There was no insurance coverage. There were very few providers. And certification for Behavior Analysts had just started.

Today autism is as prevalent as 1:36 individuals.

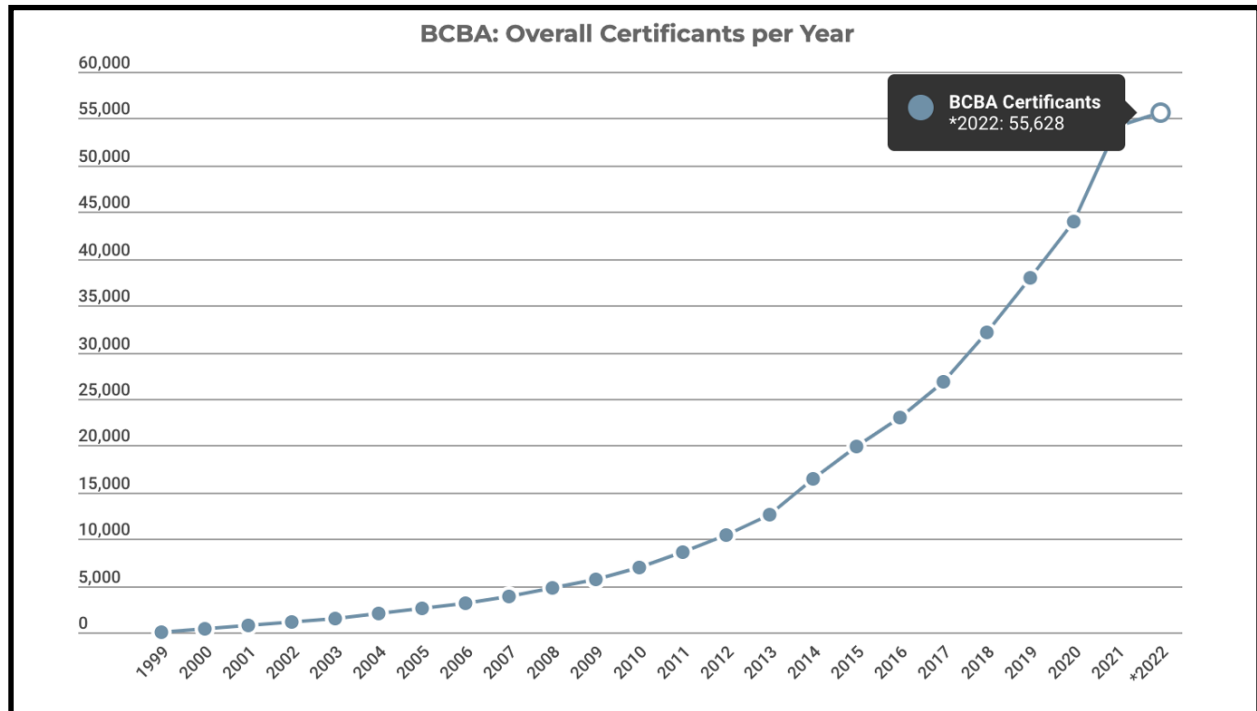
In the resulting two decades, autism service market has outpace quality. The has been a collision between three forces - Provider growth, autism rate increases, and funding in all 50 states via commercial insurance.

Provider Growth

The Behavior Analyst Certification Board (BACB) was established in 1998 to meet the credentialing needs of ABA practitioners, governments, and consumers of ABA services. Much of this demand was born out of a large state-led investigation into the treatment of individuals with intellectual and developmental disabilities in the Florida state-run programs.

“Early on, behavior analysts were interested in certification processes that would protect both consumers and the profession. The primary concerns expressed at the time dealt with poorly trained individuals who would harm both consumers and the profession’s reputation through their incompetence. The primary example from this era was a doctoral-level professional in south Florida whose institutional treatment of adolescents with borderline intellectual disability – in the name of behavior modification – was so abhorrent that it ultimately led to a highly publicized state investigation (Michael, [1972](#)).”

In the BACB's early years, its certification programs grew consistently but slowly. In its first 13 years, the BACB certified 10,000 individuals. In the last several years, this number has grown to more than 60,000 certificants. Additionally, since 2009, 34 states have passed laws to license behavior analysts.



From the Behavior Analyst Certification Board (BACB)

With the increase in autism-awareness, earlier diagnosis, and mandated insurance coverage for treatment all moving up and to the right on their respective graphs - the demand for providers who have demonstrated a minimally-competent credential have exploded.

There has been a 500% increase in providers in the past 10 years. **Over half** of the providers have less than 3 years experience. And there are **STILL** not enough providers.

Private Equity's arrival into the sector in the past decade has thrown gasoline on the fire of growth. Providers who were merely credentialed one year ago are able to then begin supervising the next cohort of interns immediately - turning many of the groups with the capital to scale quickly into provider "puppy mills."

“Private equity firms do not acquire portfolio companies for the long haul. The funds formed by private equity firms generally have a life span of five to seven years, meaning that from the time a private equity firm makes a new investment it is “on the clock” to improve the financial results of that company to make it attractive to a new buyer.”

With an average billing per hour rate of \$60 per hour, the providers are worth upwards of \$1,000,000 of revenue annually. In an effort to “improve the financial result of these investments,” providers are given increasingly larger caseloads of clients and technicians to supervise within their clinics. Quality is lost in these breakneck speeds for growth.

Just last month the Private Equity Stakeholder Project [issued a report](#) concluding that expansion of these companies into behavioral health services for vulnerable and at-risk youth has led to safety issues, quality of care issues, and even “horrific conditions” when short-term profits trump other considerations.

Autism Rates

Autism rates exploded around the turn of the 21st century. There has been wide conjecture and speculation about this trend in the past twenty years, including a 1998 now-debunked theory that the MMR vaccines may have caused autism in large numbers. The data for this assertion was fraudulent, the publication hasty, and the physician who once touted this claim are barred from practicing medicine in the United States.

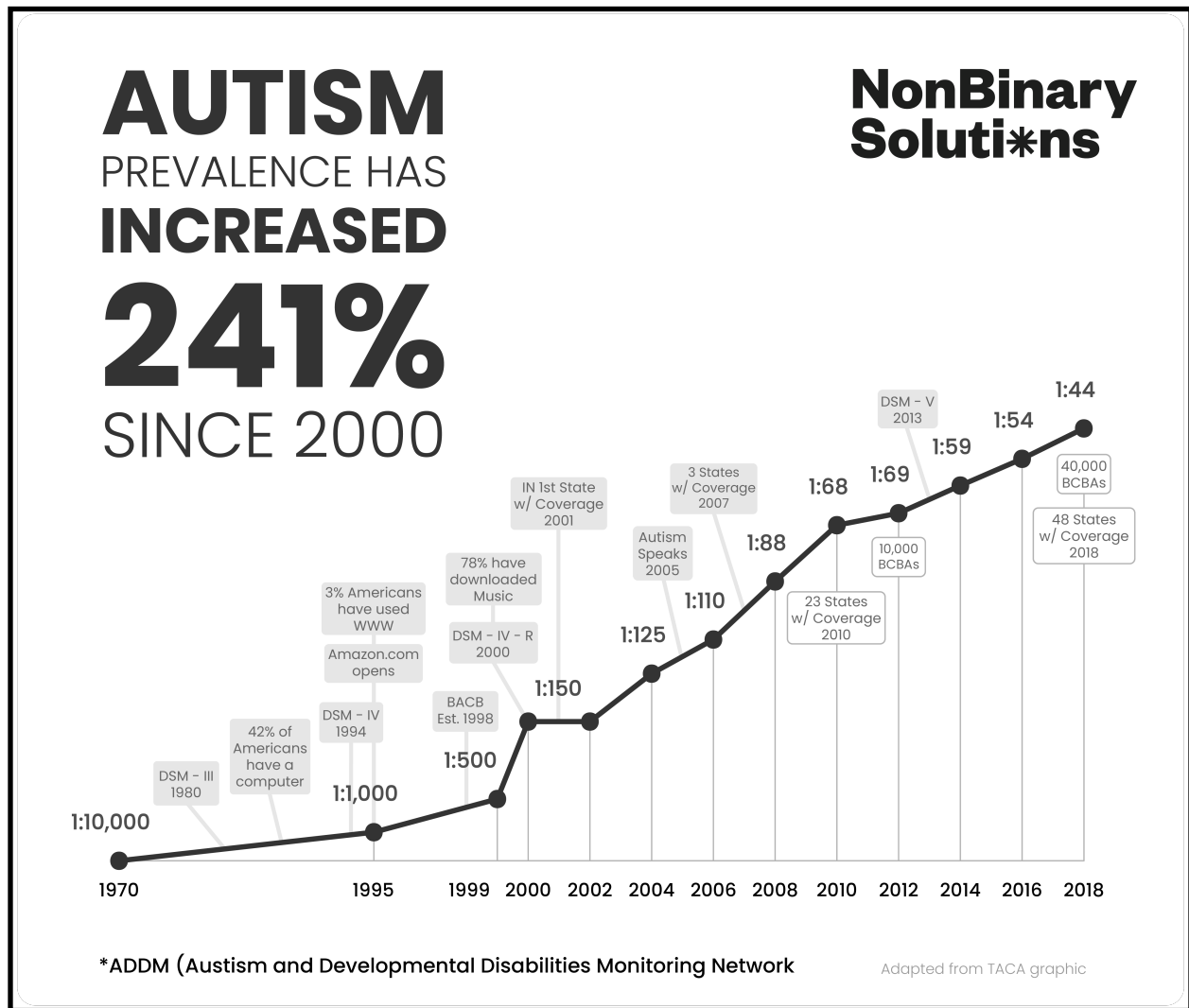
There are a number of factors that are contributing to the increase. Awareness, changing diagnostic criteria, and the information era likely have the majority of impact in the trend. However, there are still other biological or environmental risk-factors that may be at play.

There is no biological test for autism. The diagnosis is conferred via the “Diagnostic and Statistical Manual of Mental Disorders” (DSM) in the United States. The criteria for achieving this diagnosis has changed dramatically since its first mention by Dr. Leo Kanner in 1943. Kanner characterized autism as socially-isolated and withdrawn - the name itself from the Latin for “into one’s self.”

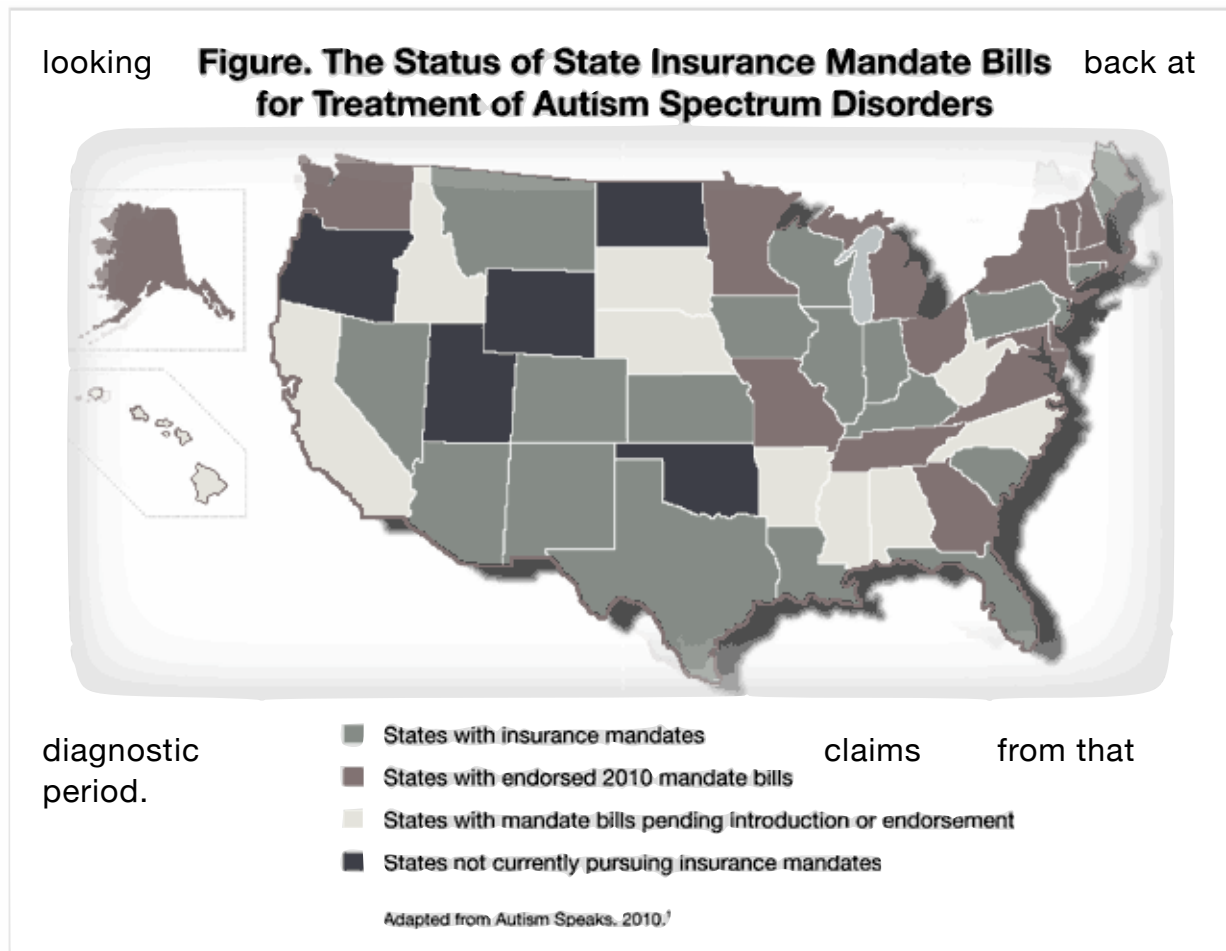
Not until the *DSM-III* in 1980 would Infantile Autism appear as a diagnosis that was separate from childhood schizophrenia. Six diagnostic criteria were required,

including appearance *before* 30 months of age, gross distortions or deficits in language development, and peculiar, sometimes rigid attachments to objects. The *DSM-III-R* (1987) changed the title of the diagnosis to Autistic Disorder and described autism as “pervasive lack of responsiveness to other people.”

Here begins the rapid growth of the autism in the United States as tracked by the CDC. I have intersected those data points with various cultural and technological events in American history to help show the effects on information and awareness.



When I first learned about autism in 1999 at Centre College, my textbook stated that autism affected one in every 10,000 individuals. This data, retrospectively provided by the CDC, didn't reflect the actual prevalence at the time. It required



In 1980, the DSM-3 marked a significant change. For the first time, autism was separated from childhood schizophrenia as a distinct diagnosis. This separation, however, also marked the beginning of the stigma associated with an autism diagnosis. Pediatricians, often the first to suggest an evaluation, would frequently tell families, "He's just a boy. He'll develop later. Let's wait and see." This approach, unfortunately, resulted in lost time for children who might have benefited from early intervention.

Fast forward to 1994, when 42% of Americans owned a computer - a far cry from today's devices. These were bulky machines with black screens and green text, requiring floppy disks to operate. That same year, the DSM-IV was published, introducing five distinct diagnoses: autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, Rett syndrome, and Asperger syndrome. Coincidentally, 1994 also saw the birth of Amazon.com in Jeff Bezos' garage.

By 1995, only 3% of Americans had used the World Wide Web, and autism prevalence was estimated at one in every 1,000 individuals. The dawn of the internet era had begun. In 1998, the BACB was founded, marking the beginning of our industry's formal structure, though the field itself had existed much longer. At this point, autism prevalence had increased to one in every 500 individuals.

The early 2000s saw rapid technological adoption. By 2000, 78% of Americans were downloading music, a stark contrast to just five years earlier when only 3% had used the World Wide Web. During this same period, autism prevalence jumped from 1 in 500 to 1 in 150.

In 2001, Indiana became the first state to mandate insurance coverage for autism treatment. By 2005, when Autism Speaks launched its global awareness campaign, prevalence had reached 1 in 110. Their efforts, regardless of one's opinion of the organization, significantly increased autism awareness.

By 2010, 23 states had mandated insurance coverage, yet there were fewer than 10,000 BCBAs worldwide. This disparity between coverage and available providers created a significant challenge. The internet played a crucial role in connecting parents, sharing information about treatments like ABA therapy, and driving demand for services and insurance coverage.

By 2020, autism prevalence had reached 1 in 44 individuals, with 40,000 BCBAs worldwide. This growth reflects the increasing demand for behavior analysts and the recognition of autism treatment as a viable career path. It's a flywheel effect of information and demand over time, driven by increased awareness, insurance mandates, and the growing need for qualified professionals in the field.

Wildly Varied “Training”

When I first began my training to become eligible for certification in 1999, I traveled to Jacksonville, FL for a 2-week (90 hour) bootcamp of coursework with one of the most prominent leaders in the field, Dr. Vincent Carbone, PhD, BCBA-D. My cohort of ~20 individuals studied day and night, reading dozens of journal articles, discussing them, presenting on them, writing about them, and learning the listed set of Knowledge, Skills, and Abilities (KSAs) deemed needed to pass the BACB’s exam.

The bootcamp was predicated on the notion that there were skilled and interested individuals in the field who could take their current or historical experience and apply these learnings, coupled with a year of mentorship with a senior BCBA, and be grandfathered into the certification program as a Board Certified Assistant Behavior Analyst¹.

As specialized as my training was - I was categorically unprepared to approach my clients’ needs scientifically and systematically. It took many more years of contingency-based learnings to hone my skills. And all the while, new data, research, and literature were fruiting without a succinct delivery vehicle to my personal knowledge base.

The landscape of regulation, policy, and procedures moved like lava. And my latency for adoption was largely determined by access and environmental impact, which is to say that it was delayed at best. I could continue to practice with my burgeoning skill set in the small corner of the world in which I operated, with little to no oversight. It was not optimal, but it was still cutting edge.

Flash forward 20 years and not much is materially different. The KSAs have been revised and upgraded a number of times into the Task List (currently in its 5th edition) to outline the content that candidates will be examined on. However, the education and training leading up to that exam is based on wide categories which can be broadly interpreted and vary in quality and rigor.

The coursework requirements can be found [here](#).

And the supervision guidelines can be found [here](#).

¹ In 1999 the BACB had used “Assistant” and a capital “A” in the designation of BCABA. It was later changed to Board Certified Association Behavior Analyst with a new designation of BCaBA.

Thought leaders in our field, yours truly included, tend to agree that the best solution to this crisis of quality is a post-certification residency program and specialization. Allow for more hands-on, mentorship and experience in a learning space prior to being licensed to practice independently. And choose a more focused area to practice in, rather than being a general practitioner to all clients.

That, however, will take time and infrastructure. In the meantime, Clinical Decision Support Systems could be an elegant technological solution to the outnumbered mentors to mentees ratio that is untenable.