



# **AUTISM ADVOCACY NETWORK**

**Autism in the United States: Law, Access, and Environmental Equity**

**AAN 2025 Policy Edition**

*A Policy Framework for Fulfilling IDEA's Promise in Illinois and Beyond*

## Preface

This report was written from both sides of the table, as an advocate and as a parent, as someone who has sat through meetings where law and humanity did not always meet. The *Autism in the United States: Law, Access, and Environmental Equity (2025 Policy Edition)* is not a theoretical exercise; it is a blueprint for restoring the public promise of justice that underlies the Individuals with Disabilities Education Act (IDEA).

IDEA was enacted to ensure that every child, regardless of disability, has the right to a Free Appropriate Public Education in the least restrictive environment. That phrase, *appropriate public education*, is more than a legal term; it is the moral heartbeat of the American experiment. It embodies the conviction that freedom and fairness are inseparable, that democracy is not sustained by power but by opportunity.

Yet, in practice, too many families face systems that confuse compliance with compassion. Services are rationed. Evaluations are delayed. Rights that should be self-executing depend on the endurance of parents and the discretion of administrators. What was designed as a safeguard has too often become a struggle.

This report seeks to close that gap between the law as written, and the law as lived. It brings together federal and state data, judicial precedent, and community experience to show not only where systems fall short, but how they can be redeemed through lawful, evidence-based reform. Its goal is simple: to make IDEA's promise visible again, through policy that is principled, enforceable, and humane.

AAN's mission is to serve as the bridge between law and conscience. We believe that advocacy is not adversarial by nature; it is restorative. When schools, families, and agencies act with shared understanding, the law fulfills its purpose: to protect the dignity of every child and to prepare them for independent, meaningful participation in society.

Justice, in this sense, is both a right and a responsibility. As Isaiah wrote, "*Learn to do good; seek justice, correct oppression.*" The Autism Advocacy Network exists to ensure that these words do not remain ancient poetry but become daily practice, in classrooms, in policy rooms, and in the hearts of those entrusted with the care of children.

## Acknowledgments

The *Autism in the United States: Law, Access, and Environmental Equity (AAN 2025 Policy Edition)* was made possible through the collective insight, labor, and lived experience of many who believe that justice for autistic individuals is not a special interest but a public obligation.

The Autism Advocacy Network extends gratitude to the families, educators, clinicians, and advocates who shared their stories, data, and expertise in the preparation of this report. Their testimony, often drawn from personal struggle, provided the clearest evidence that reform is both necessary and achievable.

We also acknowledge the foundational contributions of our partners in the autism and disability rights community, including special education attorneys, early intervention specialists, researchers, and state agency personnel whose dedication to lawful practice and equitable policy continues to shape the path forward.

Special thanks are due to the members of AAN’s working groups who developed and verified the organization’s core frameworks:

- **Procedural and Substantive Safeguards (Verified Edition)**
- **Environmental Access Suite** including the *Checklist, Audit, and Accommodations Guide*
- **Trauma-Informed De-Escalation Model (2025)**
- **Virtue Leadership and Public Interest Governance Framework**

These documents form the backbone of AAN’s advocacy infrastructure, ensuring that each recommendation in this report rests on verified legal authority and ethical governance principles.

Finally, to the parents and self-advocates whose persistence continues to bend systems toward accountability: your courage is the measure of our progress. The Autism Advocacy Network exists because you refuse to be silent and because every child who has been misunderstood, excluded, or underestimated deserves a community that not only recognizes their rights but rejoices in their presence.

## Executive Summary (Policy Abstract)

This policy abstract provides a comprehensive synthesis of national and Illinois-specific autism data integrated with legal analysis under the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act. Drawing on 2023–2025 datasets, this report highlights the intersection between law, access, and equity, offering a model for compliance rooted in public conscience and community stewardship.

Nationally, autism affects approximately 1 in 31 children (CDC, 2025). Illinois reports slightly lower prevalence at 1 in 42 but faces significant diagnostic and service delays, families often wait 9 to 24 months for evaluations due to provider shortages. Although IDEA guarantees every eligible child a Free Appropriate Public Education (FAPE), systemic issues persist. Illinois and 44 other states were rated 'Needs Assistance' in 2023 for IDEA implementation by the U.S. Department of Education.

This analysis identifies three core structural deficits: (1) inconsistent implementation of individualized education programs (IEPs); (2) inadequate behavioral and environmental supports; and (3) fragmented coordination between education, healthcare, and transition services. Compounding these are workforce shortages, over 70% of Illinois districts report unfilled special-education positions and poor post-school outcomes: only 34% of autistic young adults secure employment within eight years of graduation.

Legal precedent reinforces that minimal progress is unlawful. The U.S. Supreme Court's decision in *Endrew F. v. Douglas County School District* (2017) mandates that IEPs must be 'reasonably calculated to enable a child to make progress, appropriate in light of the child's

circumstances. Failure to provide positive behavioral interventions, sensory access, or transition planning therefore constitutes both procedural and substantive denial of FAPE.

#### Key Policy Recommendations:

- Mandate Environmental Access Audits as part of annual IEP reviews statewide.
- Establish an Illinois Autism Navigation Office to coordinate education and healthcare systems.
- Expand neuroaffirming educator preparation to resolve chronic staffing shortages.
- Embed environmental and behavioral metrics into IDEA monitoring.
- Build transition-to-employment pipelines linking schools, community colleges, and local employers.

Autism prevalence has risen fivefold since 2000, but the law’s promise has not yet caught up with lived experience. Implementing these reforms, grounded in IDEA, Section 504, and ADA obligations, will transform compliance from a bureaucratic task into a moral commitment: ensuring that every child learns, participates, and thrives within a system worthy of public trust.

Autism in the United States: A Comprehensive Analysis of Prevalence, Educational Rights, and Systemic Barriers

### The Shifting Landscape of Autism Prevalence and Identification

*As awareness has risen, so too has exposure of the nation’s diagnostic and educational inequities, revealing that progress in identification has outpaced capacity for support.*

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by differences in social communication, social interaction, and behavior. Over the past two decades, the public health and educational landscape surrounding autism in the United States has been fundamentally reshaped by a dramatic and sustained increase in its identified prevalence. This

surge, while reflecting significant progress in public awareness and diagnostic practices, has simultaneously exposed profound and growing crises in the capacity of our nation's diagnostic, educational, and support systems. This section provides a detailed analysis of these epidemiological trends, examining national and Illinois-specific data, the realignment of demographic patterns, and the critical systemic bottlenecks that delay access to essential early identification and intervention services.

### National Trends: A Two-Decade Analysis of Rising Prevalence

*Autism's reported prevalence has soared fivefold in two decades—not because autism itself has changed, but because our ability to see it finally has.*

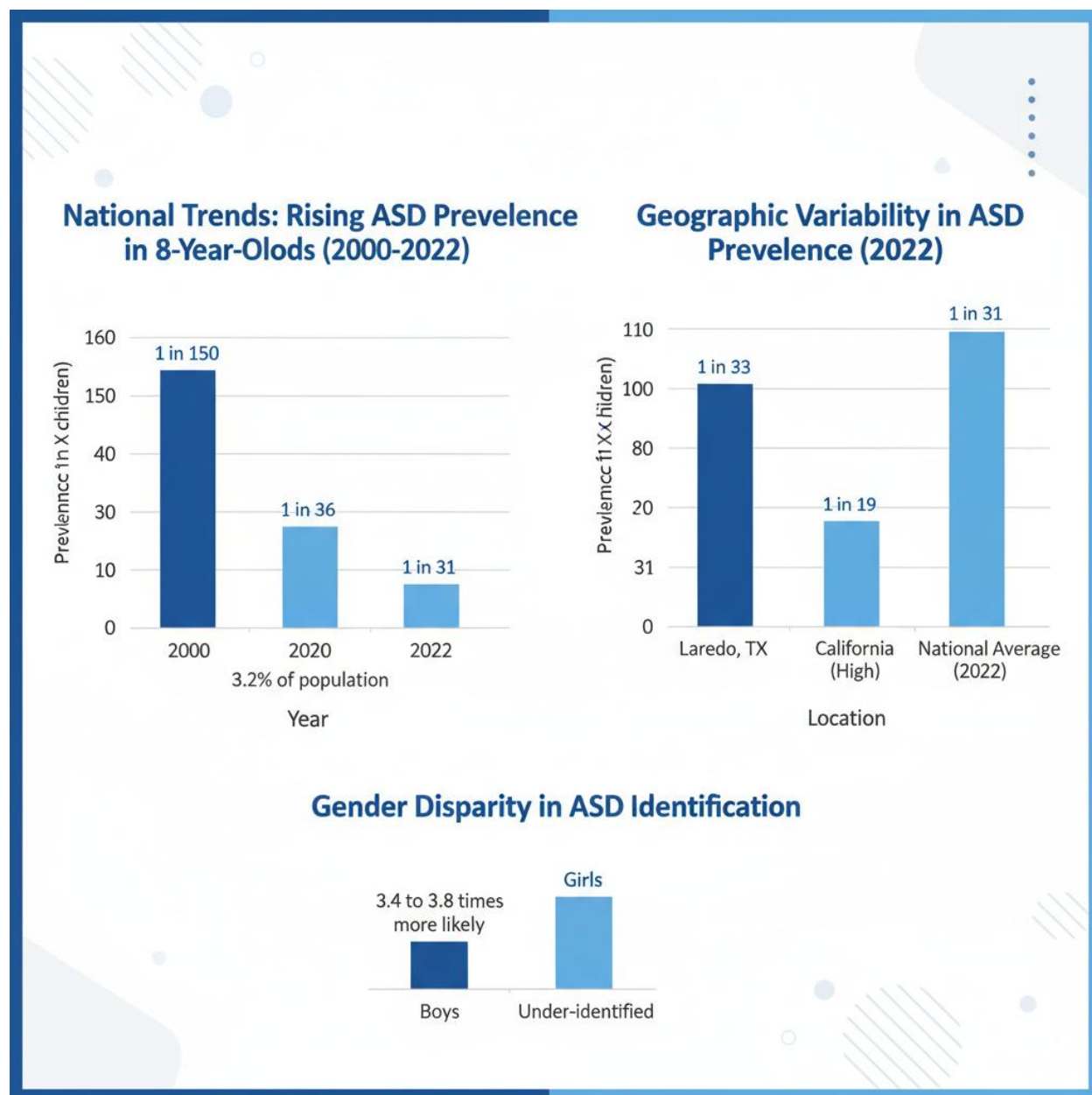
The Centers for Disease Control and Prevention (CDC), through its Autism and Developmental Disabilities Monitoring (ADDM) Network, provides the most robust surveillance data on autism prevalence in the United States. The ADDM Network's findings reveal a striking and consistent upward trend. In the year 2000, the estimated prevalence of ASD among 8-year-old children was 1 in 150. By 2018, this figure had risen to 1 in 44; by 2020, it was 1 in 36. The most recent data, tracking 8-year-olds in 2022, indicates a prevalence of approximately 1 in 31 children, or 3.2% of the population in this age group. This represents a more than five-fold increase in identified prevalence in just over two decades, cementing autism as a major public health and educational priority.

It is crucial to understand the methodology and context behind these figures. The ADDM Network conducts active surveillance of health and special education records at multiple sites across the country; it is not a representative national sample. This methodology accounts for the significant geographic variability in reported prevalence, which in 2022 ranged from a low of 1

in 103 in Laredo, Texas, to a high of 1 in 19 in California. The CDC and other public health bodies primarily attribute the dramatic rise in these numbers not to an actual increase in the occurrence of autism, but rather to a confluence of other factors. These include greater public and professional awareness, the broadening of diagnostic criteria over time (particularly with the publication of the DSM-5 in 2013), and the development and implementation of more effective screening tools and processes.

A persistent feature of the prevalence data is the significant disparity in identification between genders. Across all surveillance years, ASD is identified far more commonly in boys than in girls, with recent data showing boys are 3.4 to 3.8 times more likely to be identified. This long-standing gap points to complex underlying factors, including potential biological differences, but also raises significant concerns about the under-identification of autism in girls. Girls may present with different or more subtle characteristics, leading to missed or delayed diagnoses, a point underscored by data showing that girls are, on average, diagnosed significantly later than boys.





## Demographic Realignment: Examining Shifts in Race, Ethnicity, and Socioeconomic Status

*As diagnostic equity improves, long-hidden need emerges—revealing that awareness without access simply shifts disparity from visibility to support.*

One of the most significant developments in autism epidemiology over the past decade has been the dramatic shift in identification patterns across racial and ethnic groups. For many years, ADDM data showed a higher prevalence of ASD among White children, suggesting that children from minority backgrounds were being systematically under-identified. Recent data indicates that this gap has not only closed but has reversed.

The 2020 ADDM report was the first to show that prevalence among Black, Hispanic, and Asian/Pacific Islander (A/PI) children was higher than among White children. The 2022 data confirms and extends this trend. The estimated prevalence among 8-year-old White children was 2.7% to 2.8%, compared to 3.7% for Black children, 3.3% for Hispanic children, and 3.8% for both A/PI and American Indian/Alaska Native (AI/AN) children. This demographic realignment is largely interpreted as a positive development, signaling meaningful progress in reducing historical disparities in diagnosis. It reflects improved screening, increased awareness, and destigmatization of autism within historically underserved communities. However, this success in identification carries a profound implication: it has uncovered a massive, previously invisible level of need in communities that have long faced barriers to services, placing even greater strain on an already overburdened support system.

The relationship between autism prevalence and socioeconomic status (SES) has also become more nuanced. While some ADDM sites report no clear association between ASD prevalence and median household income, a growing number of sites have found that ASD prevalence is

higher in census tracts with lower SES. This finding challenges older, clinic-based studies that suggested autism was more common in higher-income families and reinforces the understanding that access to screening and care, not income or parenting styles, is the critical factor in diagnosis.

### **The Illinois Context: State-Specific Data and the Challenge of Diagnostic Deserts**

*Illinois's lower autism prevalence does not signal fewer autistic children—it maps the geography of inequity, where diagnosis depends more on ZIP code than on need.*

Illinois reflects the national trend of rising autism identification but also exemplifies the severe challenges in diagnostic access that can suppress reported prevalence rates. According to 2022 data, the estimated prevalence of ASD in Illinois was 1 in 42 children, a rate that, while rising, remains notably lower than the national average of 1 in 31. This disparity is unlikely to reflect a true lower incidence of autism in the state. Instead, it serves as a powerful indicator of systemic barriers that prevent children from being identified in a timely manner.

The state's special education data further illustrates the growing population. In the 2022–23 school year, 21,893 Illinois students between the ages of 3 and 21 received special education services under the primary eligibility category of autism, an increase from 20,506 the previous year. Nationally, autism now accounts for nearly 14% of all students served under the Individuals with Disabilities Education Act (IDEA) and was responsible for over 42% of the total increase in IDEA enrollment in 2023, making it one of the fastest-growing disability categories in the nation's schools.

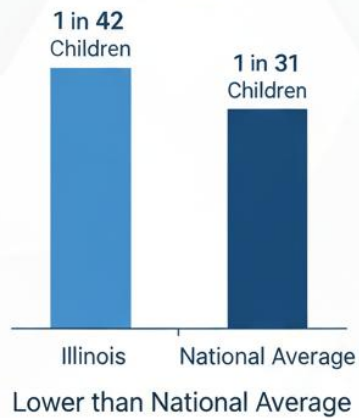
The gap between Illinois's community prevalence estimates and the national average is best understood as a map of systemic inequity in healthcare access. The state suffers from what can

be termed "diagnostic deserts," vast geographic areas with a severe shortage of qualified developmental specialists. This shortage is particularly acute in rural, downstate regions, where there may be only one specialist for every 47,000 children, compared to approximately one per 12,000 children in Cook County. This disparity creates a two-tiered system of access, where families in urban and suburban areas may face long waits, but families in rural areas or those dependent on Medicaid may face a near-total lack of access, with waitlists for both diagnostic evaluations and subsequent therapies stretching for years.

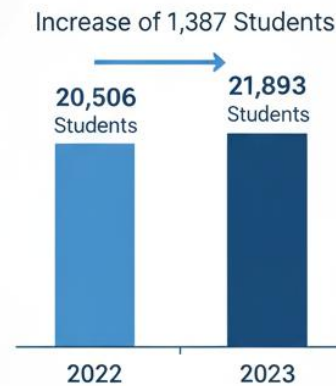
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## The Illinois Context: ASD Prevalence & Diagnostic Challenges (2022-2023)

### Community ASD Prevalence (2022)



### Illinois Special Education: Students with Autism (2022-2023 School Year)



### Autism's Share of Special Fastest-Growing Disability Category (2023 National)



### Diagnostic Deserts: Specialist Shortage

- Rural Illinois: 1 specialist / 47,000 children
- Cook County (Urban): 1 specialist / 12,000 children

Illinois data shows rising identification but lags national rates, indicating systemic barriers to diagnosis, particularly in rural "diagnostic deserts."



## The Diagnostic Bottleneck: Analyzing Wait Times and Barriers to Early Identification

*When diagnosis becomes a waiting game, early intervention becomes a lost opportunity, turning what should be prevention into repair.*

The single greatest barrier to improving outcomes for autistic children is the delay between when concerns are first raised and when a formal diagnosis is made and services begin. Research has established that autism can be reliably diagnosed by age 2, and the American Academy of Pediatrics recommends universal screening at 18 and 24 months. Early intervention during the first few years of life, when the brain is most malleable, can have a transformative impact on a child's developmental trajectory.

Despite this, a significant gap persists. Nationally, the median age of earliest ASD diagnosis remains just under 4 years, at approximately 47 months. This lag is even more pronounced for certain populations; the median age of diagnosis for girls is closer to 5.6 years, and children with subtler presentations or without co-occurring intellectual disability are also typically diagnosed later.

In Illinois, this diagnostic bottleneck has reached crisis levels. Families across the state report average wait times of 9 months to over 2 years simply to secure an appointment for a diagnostic evaluation. For a two-year-old child showing clear signs of autism, a two-year wait means they will not receive a diagnosis, and the access to intensive, insurance-funded therapies that a diagnosis unlocks until they are four, missing the most critical window for early intervention. This systemic failure leaves families in a state of limbo, often forced to navigate a fragmented system of support after their child ages out of the state's Early Intervention program at age 3.

There are, however, signs of progress and concerted efforts to address this crisis. Nationally, the CDC reports that children are being identified at younger ages than in previous cohorts; children

born in 2018 were 1.7 times more likely to be identified by age 4 than those born in 2014, indicating that efforts to improve early screening are having an effect. In Illinois, innovative programs are seeking to bypass the traditional waitlist model. Northwestern University's "Reduce the Wait" project, for example, is training Early Intervention providers to conduct telehealth-based autism evaluations for toddlers, dramatically reducing the time to diagnosis from over a year to just one month for participating families. At the state policy level, the Illinois Autism Task Force has developed a strategic plan aimed at ensuring families can "readily access an array of effective services," leading to legislative proposals such as House Bill 2428 (2023), which seeks to increase reimbursement rates for diagnostic providers to help expand capacity and encourage more professionals to enter the field. These initiatives represent a crucial acknowledgment that identifying a need without providing a timely pathway to meet it is a policy failure that leaves the state's most vulnerable children behind.

Autism Statistic	United States (Nationwide)	Illinois (State)
<b>Prevalence of ASD in Children (8-year-olds)</b>	~1 in 31 children (3.2%) as of 2022. Historical trend: 1 in 150 (2000) → 1 in 44 (2018) → 1 in 36 (2020).	~1 in 42 children (2.4%) as of 2022. Historically lower than the U.S. average, likely reflecting diagnostic access barriers.
<b>Gender Ratio</b>	Boys are identified ~3.4 to 3.8 times more often than girls.	Mirrors national trends.
<b>Racial/Ethnic Prevalence</b>	Higher rates in Black (3.7%),	Data not specified, but state

Autism Statistic	United States (Nationwide)	Illinois (State)
<b>(2022)</b>	Hispanic (3.3%), Asian/Pacific Islander (3.8%), and AI/AN (3.8%) children compared to White children (2.7%).	trends generally follow national shifts.
<b>School-Age Children with Autism (IDEA)</b>	Nearly 14% of students with disabilities (ages 5–21) are classified under autism. Autism accounted for ~42% of the increase in IDEA enrollment in 2023.	21,893 students (ages 3–21) received special education services under the autism category in the 2022–23 school year, up from 20,506 the prior year.
<b>Median Age of Diagnosis</b>	~47 months (just under 4 years). Diagnosis is often later for girls (average ~5.6 years) and children with subtler presentations.	Often significantly delayed due to service bottlenecks. The state median is likely higher than the national median.
<b>Diagnostic Wait Times</b>	Varies widely by region.	Average wait times of 9 months to over 2 years for a diagnostic evaluation. Shortages of specialists are acute, especially in rural downstate regions.



**Table 1: Key Autism Prevalence and Identification Statistics (U.S. vs. Illinois)****The Legal Foundation of Educational Rights for Autistic Students**

*The right to an education for autistic students is not benevolence—it is a civil right secured by law and enforceable through conscience.*

For the millions of autistic children in the United States, the public education system is the primary provider of therapeutic and support services. Their right to receive an education that is tailored to their unique needs is not a matter of charity or choice but is firmly guaranteed by a robust framework of federal and state laws. This legal architecture, built over decades of civil rights advocacy, establishes both substantive rights to an appropriate education and powerful procedural safeguards to ensure those rights are protected. Understanding this legal foundation is essential for families, educators, and policymakers seeking to navigate the special education system and hold it accountable for delivering on its promises.

**The Pillars of Protection: IDEA, Section 504, and the ADA**

*Together, IDEA, Section 504, and the ADA form a triad of justice, ensuring that access, inclusion, and equity are not favors granted, but rights guaranteed.*

Three landmark federal laws form the pillars of educational rights for students with disabilities.

The **Individuals with Disabilities Education Act (IDEA)**, codified at (20 U.S.C. ch. 33, subch. I § 1400 et seq.), is the cornerstone of special education in the United States. First passed in 1975 as the Education for All Handicapped Children Act, IDEA is a grant statute that provides federal funding to states in exchange for their commitment to educating all eligible children with disabilities. Autism is one of the 13 specific disability categories enumerated under the law. For a student with autism to be eligible for services under IDEA, a school-based team must

determine that the child meets the criteria for the disability and, as a result, requires special education and related services to benefit from their education.

The central mandate of IDEA is the provision of a **Free Appropriate Public Education (FAPE)**. FAPE is not a one-size-fits-all concept; it is delivered through an **Individualized Education Program (IEP)**, a legally binding document developed by a team that includes school personnel, parents, and, when appropriate, the student. The IEP details the student's current academic and functional performance, sets measurable annual goals, and specifies the special education services, related services (such as speech, occupational, or physical therapy), accommodations, and modifications the school will provide. IDEA also contains the critical mandate that students be educated in the **Least Restrictive Environment (LRE)**, meaning that, to the maximum extent appropriate, children with disabilities should be educated alongside their nondisabled peers in general education settings, with the use of supplementary aids and services.

Complementing IDEA is **Section 504 of the Rehabilitation Act of 1973** (29 U.S. Code § 794), a broad civil rights law that prohibits discrimination on the basis of disability in any program or activity receiving federal financial assistance. This includes virtually all public schools. Section 504's definition of disability is broader than IDEA's, covering any individual with a physical or mental impairment that substantially limits one or more major life activities. Some autistic students who may not require the specialized instruction of an IEP might still qualify for protections under Section 504. These students are often provided with a **"504 Plan,"** which outlines necessary accommodations and modifications to ensure they have equal access to the educational environment. For example, a student might receive accommodations like preferential seating, sensory breaks, or the use of assistive technology. It is important to note that all students with an IEP are also protected by the anti-discrimination provisions of Section 504.

The **Americans with Disabilities Act (ADA) of 1990** (42 U.S. Code § 12101 *et seq.*) further reinforces and expands these civil rights protections. Title II of the ADA applies to state and local government entities, including public schools, and Title III applies to public accommodations, including private schools. The ADA's requirements largely overlap with Section 504 in the school context but provide a broad mandate for accessibility and non-discrimination in all aspects of school life, from the physical environment to extracurricular activities and communication access.

### **Defining "Appropriate" Education: The Endrew F. Standard and Its Implications for IEPs**

*Endrew F. transformed compliance into accountability, demanding not paperwork, but progress measured in a child's real growth and dignity.*

For decades, a central question in special education law was the meaning of an "appropriate" education under IDEA. Some courts had interpreted the requirement as being met if a school provided an IEP that conferred merely "some" or "more than trivial" educational benefit. This low bar was decisively rejected by the U.S. Supreme Court in its unanimous 2017 landmark decision, *Endrew F. v. Douglas County School District RE-1*.

In *Endrew F.*, the Court established a significantly more rigorous standard. It held that to meet its substantive obligation under IDEA, a school must offer an IEP that is **"reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances."** The Court explicitly stated that "for a child fully integrated in the regular classroom, an IEP typically should... be reasonably calculated to enable the child to achieve passing marks and advance from grade to grade." For children not fully integrated, the standard is equally demanding, requiring an IEP that is "appropriately ambitious in light of his circumstances."

This ruling fundamentally shifted the focus of FAPE from procedural compliance to substantive progress. It is no longer sufficient for a school to simply go through the motions of creating an IEP. The IEP itself must be designed to produce meaningful, measurable growth for the student. The *Endrew F.* standard provides a powerful legal tool for parents and advocates. It empowers them to challenge IEPs that are stagnant, that contain generic or unmeasurable goals, or that fail to result in tangible progress for the child. For autistic students, this means an IEP must be tailored to their unique needs and designed to foster real academic and functional advancement, whether that involves mastering complex social skills, learning to use an augmentative and alternative communication (AAC) device effectively, or developing the executive functioning skills necessary for post-secondary success. The decision underscores the importance of high-quality baseline data in the IEP's "Present Levels of Performance" and the necessity of ambitious, data-driven goals against which progress can be clearly measured.

### **Procedural Safeguards as a Tool for Accountability**

*Procedural safeguards are the law's equalizer, tools that turn parents from bystanders into partners, ensuring that rights on paper become realities in practice.*

Recognizing the inherent power imbalance between families and school districts, IDEA includes a comprehensive set of procedural safeguards designed to protect the rights of children and their parents. These procedures are not mere technicalities; they are the primary mechanism through which the law's substantive guarantees are enforced. They establish parents as equal partners in the IEP process and provide avenues for recourse when disputes arise.

Key procedural safeguards include:

- **Parent Participation:** Parents have the legal right to be full, participating members of the IEP team and to be involved in all decisions regarding their child's identification, evaluation, and educational placement.
- **Prior Written Notice (PWN):** Before a school proposes or refuses to initiate or change the identification, evaluation, or educational placement of a child, it must provide the parents with PWN. This notice must include a description of the action being proposed or refused, an explanation of why, a description of the data used to make the decision, and information about their procedural rights.
- **Independent Educational Evaluation (IEE):** If parents disagree with an evaluation conducted by the school district, they have the right to request an IEE from a qualified, outside professional at public expense. This "second opinion" ensures that the IEP team has access to a comprehensive and unbiased assessment of the child's needs.
- **Dispute Resolution:** When disagreements cannot be resolved informally, IDEA provides several formal dispute resolution options. Parents can file a **state complaint** with the state education agency, engage in voluntary **mediation** with the school district, or file for a **due process hearing**. A due process hearing is a formal, quasi-judicial proceeding presided over by an impartial hearing officer who has the authority to issue a legally binding decision.
- **"Stay-Put" Provision:** During the pendency of any due process hearing, the child generally has the right to "stay put" in their current educational placement, unless the parents and the school agree otherwise. This critical protection prevents the school from unilaterally moving a child to a different setting while a dispute is being litigated.

This system of rights and remedies is designed to function as both a shield and a sword. It shields students from unilateral school actions and ensures a baseline of procedural fairness. However, because these rights are not self-enforcing, the burden often falls on parents to act as the primary enforcers of the law. This reality creates a significant equity challenge, as families with greater resources, time, and knowledge of the system are often better equipped to advocate effectively and utilize these procedural tools to secure an appropriate education for their child.

### **State-Level Implementation: How Illinois Law Shapes Federal Mandates**

*Illinois transforms federal promise into local practice, where the reach of IDEA depends on how faithfully the state turns mandate into measurable support.*

While IDEA, Section 504, and the ADA are federal laws, their implementation is carried out at the state and local levels. States have the authority to enact their own laws and regulations that align with and, in some cases, expand upon federal requirements.

In Illinois, the provisions of IDEA are primarily implemented through **Article 14 of the Illinois School Code** (105 ILCS 5/14-1.01) and the state's special education regulations found in **Title 23 of the Illinois Administrative Code, Part 226**. These state-level rules provide specific guidance on matters such as IEP components, timelines for evaluations, and procedures for due process hearings. For example, Illinois regulations may specify class size and age range limits for certain types of special education classrooms.

Illinois has also enacted several other laws that have a significant impact on children with autism and their families. One of the most important is the state's **autism insurance mandate**. Under Illinois law, most state-regulated private health insurance plans are required to provide coverage for the diagnosis and treatment of autism, including therapies like Applied Behavior Analysis

(ABA), for individuals up to age 21. A 2022 amendment further clarified that this coverage cannot be denied based on where the service is provided, such as in a school or home setting.

This mandate is crucial as it provides a vital funding stream for intensive therapies that often fall outside the scope or capacity of what a school district can provide. Additionally, laws like the **Autism Spectrum Disorders Reporting Act** (410 ILCS 201/1) requires healthcare providers to report new diagnoses to the state, improving data collection for public health and planning purposes.

Law / Policy	Scope	Key Provisions for Autistic Students	Enforcement / Remedies
<b>IDEA (Individuals with Disabilities Education Act)</b>	Entitles eligible children (ages 3–21) with one of 13 disabilities (including autism) to special education and related services in public schools.	Guarantees FAPE via an IEP. The <i>Endrew F.</i> (2017) standard requires IEPs to be "reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." Mandates placement in the LRE. Requires transition planning by	State Complaints, Mediation, Due Process Hearings. Enforced by State Education Agencies (SEAs) and the U.S. Dept. of Education's Office of Special Education Programs (OSEP).

Law / Policy	Scope	Key Provisions for Autistic Students	Enforcement / Remedies
		age 16. Provides extensive procedural safeguards for parents.	
<b>Section 504 of the Rehabilitation Act (1973)</b>	Civil rights law prohibiting disability-based discrimination in any program receiving federal funds (includes public schools). Protects any student with an impairment that substantially limits a major life activity.	Guarantees equal access and reasonable accommodations. Schools must meet the needs of students with disabilities as adequately as the needs of non-disabled peers. Often implemented through a "504 Plan" for students who do not require an IEP.	Internal school district grievance procedures; Complaints to the U.S. Dept. of Education's Office for Civil Rights (OCR); Private lawsuits.
<b>ADA (Americans with Disabilities Act, 1990)</b>	Broad civil rights law extending non-discrimination protections to state/local government	Reinforces Section 504 obligations. Requires effective communication for individuals who use	Complaints to the U.S. Department of Justice or OCR; Private lawsuits.



Law / Policy	Scope	Key Provisions for Autistic Students	Enforcement / Remedies
	services (Title II) and public accommodations, including private schools (Title III).	AAC devices. Mandates reasonable modifications to policies and practices to avoid discrimination. Covers physical accessibility of school facilities.	
<b>Illinois State Laws &amp; Policies</b>	State statutes and regulations that implement federal mandates and add state-specific requirements.	The Illinois School Code (105 \text{ ILCS } 5/14) aligns with IDEA. State regulations (23 Ill. Admin. Code 226) provide specific rules (e.g., class sizes). Mandates private insurance coverage for autism therapies for individuals under 21.	State-level due process hearings; Complaints to the Illinois State Board of Education (ISBE); Enforcement of insurance mandates by the Illinois Department of Insurance.

**Table 2: Key Legal Frameworks Governing Autism and Education**

## Systemic Failures in K-12 Education: The Gap Between Law and Practice

*The failure is not in the law but in its living, where promises of access collapse under systems too slow, too rigid, or too afraid to change.*

While the legal framework protecting the educational rights of autistic students is robust in theory, its practical implementation is fraught with systemic challenges and widespread non-compliance. A significant gap persists between the rights guaranteed on paper and the reality experienced by many students and families in schools across the nation. This implementation crisis is evidenced by federal oversight data, state-level dispute resolution trends, and persistent problems in critical areas such as behavioral support, discipline, and postsecondary transition planning. For many autistic students, the promise of a Free Appropriate Public Education remains elusive, not because the laws are weak, but because the systems responsible for executing them are failing.

### The Implementation Crisis: National Compliance Data and Illinois' "Needs Assistance"

#### Status

*When nearly every state "needs assistance," the problem is not a few bad districts, it is a national failure to practice the law we already know by heart.*

The U.S. Department of Education's Office of Special Education Programs (OSEP) is charged with overseeing states' implementation of IDEA. Each year, under Section 616 of the Act, OSEP issues an annual determination on each state's performance based on its State Performance Plan (SPP) and Annual Performance Report (APR). These determinations serve as a high-level barometer of systemic health. The data reveals a troubling national pattern of underperformance.

In 2023, only six states received the highest rating of "Meets Requirements." The vast majority, 45 states and territories, including Illinois, were rated as "Needs Assistance". A "Needs Assistance" rating for two or more consecutive years indicates a persistent, systemic failure to comply with the core requirements of the law, often related to issues like timely evaluations, provision of services as written in the IEP, and improving student outcomes. This is not an isolated finding but a consistent pattern over many years, pointing to a chronic and nationwide implementation crisis.

At the state level, the Illinois State Board of Education (ISBE) is responsible for the general supervision of all local school districts to ensure they comply with IDEA. ISBE employs a system of cyclical monitoring and risk-based targeting, where districts with poor performance indicators or a high number of parent complaints receive more intensive oversight. Common compliance findings often involve procedural errors, such as missing IEP components (e.g., inadequate transition plans), failure to meet mandated timelines for evaluations and meetings, and, critically, the failure to implement all services and supports specified in a student's IEP. The state's persistent "Needs Assistance" status at the federal level suggests that despite these monitoring efforts, deep-rooted compliance problems remain widespread across Illinois districts.

The consequences of these implementation failures are borne by students. When services are missed, when accommodations are not provided, or when data-driven goals are replaced with boilerplate objectives, student progress stagnates. This implementation gap is a primary cause of conflict between families and schools. Data from Illinois's special education due process system shows that autism is the single largest disability category represented in formal disputes, accounting for 21% of all due process hearing requests in the 2022–23 school year (57 out of 274 cases). The most frequently litigated issues in these cases were placement determinations and the

sufficiency of instructional and related services, directly reflecting parental allegations that schools are failing to provide an appropriate education and implement the IEP as written.

## **Behavior, Discipline, and Discrimination: An Analysis of Restraint, Seclusion, and Manifestation Determination**

*When schools punish communication as misconduct, they mistake distress for defiance, and turn lawful protection into unlawful harm.*

One of the most contentious and high-stakes areas of special education involves the discipline of students with disabilities. National data indicates that students with disabilities, and particularly autistic students, are disproportionately subjected to exclusionary discipline such as suspension and expulsion, as well as aversive practices like physical restraint and seclusion. These practices not only lead to lost instructional time but can also be deeply traumatizing and may constitute illegal discrimination.

IDEA provides specific and powerful protections to prevent schools from punishing students for behavior that is a manifestation of their disability. The core of these protections includes:

- **The 10-Day Rule:** School personnel can suspend a student with a disability for up to 10 consecutive school days for a violation of the student code of conduct, to the same extent they would discipline a nondisabled student. However, once removals exceed 10 cumulative days in a school year, it may constitute a "change of placement," which triggers additional procedural safeguards.
- **Manifestation Determination Review (MDR):** Within 10 school days of any decision to change a student's placement due to a violation of the code of conduct, the school district,

the parents, and relevant members of the IEP team must convene for an MDR. The team must review all relevant information and answer two key questions:

- Was the conduct in question caused by, or did it have a direct and substantial relationship to, the child's disability?
- Was the conduct the direct result of the school's failure to implement the IEP?

If the team answers "yes" to either question, the behavior is deemed a **manifestation of the student's disability**. In this case, the student generally cannot be suspended long-term or expelled and must be returned to their original placement. The school is then required to either conduct a Functional Behavioral Assessment (FBA) to understand the root cause of the behavior or, if one already exists, review and modify the student's Behavior Intervention Plan (BIP) to address the behavior proactively.

Disciplinary action can proceed as it would for a nondisabled student only if the team determines the behavior was *not* a manifestation of the disability. Even then, the school must continue to provide services that allow the student to progress in the general curriculum and advance toward their IEP goals, albeit in an interim alternative educational setting. An exception exists for "special circumstances" involving weapons, illegal drugs, or serious bodily injury, which allow the school to unilaterally move a student to an interim setting for up to 45 school days, though an MDR must still be conducted.

The frequent use of punitive discipline for behaviors that are clearly linked to a student's autism, such as sensory overload, communication frustration, or difficulty with social understanding, represents a fundamental failure to provide FAPE. When a school resorts to suspension or restraint without first seeking to understand the function of a student's behavior and providing

positive supports, it is not only violating the spirit of IDEA but often its letter as well. This cycle of misunderstanding, punishment, and exclusion is a primary driver of the "school-to-prison pipeline," pushing vulnerable students out of the classroom and toward negative long-term outcomes.

## **Beyond Compliance: The Critical Role of Functional Behavior Assessments and Positive Behavior Supports**

*True behavioral support begins with curiosity, not control, seeing every outburst not as defiance to be managed, but as communication to be understood.*

The legal framework around discipline underscores a core principle of IDEA: behavior is a form of communication. Challenging behaviors are often not willful misconduct but rather a student's attempt to communicate an unmet need, escape an overwhelming situation, or regulate a chaotic sensory system. IDEA requires IEP teams to move beyond punishment and instead use a proactive, data-driven approach to understand and support behavior. The primary tools for this are the Functional Behavioral Assessment (FBA) and the Behavior Intervention Plan (BIP).

An **FBA** is a systematic process used to gather information about a specific behavior to determine its underlying purpose, or "function". The process typically involves defining the behavior in observable terms, collecting data on when and where it occurs (antecedents) and what happens afterward (consequences), and forming a hypothesis about why the student is engaging in the behavior. Common functions include seeking attention, escaping a non-preferred task, gaining access to a tangible item, or automatic reinforcement (sensory stimulation).

The information gathered in the FBA is then used to develop a **BIP**. An effective BIP is not a list of punishments. It is a proactive plan of action that focuses on teaching the student a more

appropriate replacement behavior that serves the same function, modifying the environment to prevent the behavior from occurring, and changing how adults respond to reinforce positive behavior and extinguish the challenging behavior. IDEA explicitly requires the IEP team to "consider the use of positive behavioral interventions and supports" for any student whose behavior impedes their own learning or the learning of others.

A frequent and critical compliance failure in schools is the development of poor-quality or "check-the-box" FBAs and BIPs. An FBA that consists of a brief teacher interview without direct observation or data collection is unlikely to identify the true function of a behavior. This leads to the creation of an ineffective BIP that fails to address the student's needs and may even escalate the behavior. When a student's behavior continues or worsens despite a BIP being in place, it is often a sign that the FBA was flawed and the plan is not addressing the correct function. The failure to conduct a proper FBA and implement a data-driven, positive BIP is a denial of FAPE and a primary reason why autistic students are so often subjected to inappropriate and illegal disciplinary measures.

### **The Transition Planning Mandate: Preparing for Life After High School**

*Transition planning is the bridge between law and life, when it's built with intent, students cross into independence; when neglected, they fall into the service cliff below.*

The ultimate goal of IDEA is to prepare students with disabilities for "further education, employment, and independent living". To this end, the law contains a specific and critical mandate for postsecondary transition planning.

Beginning no later than the first IEP to be in effect when the student turns 16 (and often earlier under state laws), the IEP must include:

- **Appropriate measurable postsecondary goals** based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills.
- The **transition services** (including courses of study) needed to assist the child in reaching those goals.

Transition planning is meant to be a "results-oriented process" that facilitates the student's movement from school to post-school activities. It requires a coordinated set of activities that are individualized and based on the student's unique strengths, preferences, and interests. This process should involve not only the student and the school team but also, with parental consent, representatives from outside agencies that are likely to be responsible for providing or paying for services after the student leaves school, such as vocational rehabilitation counselors or staff from the state's developmental disabilities agency.

Unfortunately, transition planning is another area of widespread implementation failure. Too often, school districts treat it as a procedural checkbox rather than a substantive, multi-year planning process. Common failures include:

1. Using generic, boilerplate goals that are not individualized to the student.
2. Failing to conduct age-appropriate transition assessments to gather data on the student's skills and interests.
3. Focusing solely on academics without addressing crucial functional skills needed for employment and independent living.



4. Failing to invite and coordinate with relevant adult service agencies, leaving families to navigate the complex adult system on their own after graduation.

This failure to provide meaningful transition planning is a direct cause of the "service cliff" that so many autistic adults experience. When schools fail to make a "warm handoff" by connecting students and families with the adult service system before graduation, they are failing in their final and most important duty under IDEA. The predictable result is that young adults are left without the supports they need to succeed in employment, postsecondary education, and community life, leading to the poor outcomes detailed in the following section.

### **Life After the Cap and Gown: The Adult "Service Cliff"**

*When entitlement ends, uncertainty begins, the service cliff reveals how adulthood can feel less like a milestone and more like a withdrawal of promise.*

For autistic individuals and their families, the transition out of the public school system represents one of the most perilous moments in their lives. The day a student receives their high school diploma or ages out of special education at 21 or 22, they fall off what is widely known as the "service cliff". They move from a system of legal entitlement under IDEA, where the school district is mandated to provide a Free Appropriate Public Education, to a fragmented and chronically underfunded adult service system based on eligibility and availability. This abrupt cessation of structured support leads to a crisis in outcomes, with a large and growing population of autistic adults facing profound barriers to employment, housing, healthcare, and community inclusion.

## Employment and Economic Inclusion: Deconstructing High Rates of Unemployment and Underemployment

*The crisis is not a lack of ability but a lack of access, autistic talent is abundant yet filtered out by systems built to reward sameness over skill.*

The starkest indicator of the service cliff is the employment crisis facing autistic adults. While the U.S. Bureau of Labor Statistics reported a 2024 unemployment rate of 7.5% for all people with disabilities, roughly double the rate for the non-disabled population, data specific to the autistic community reveals a far more severe problem. Studies and private estimates consistently show that the unemployment rate for autistic adults is staggeringly high, ranging from 39% to as high as 85%. This represents the worst employment gap of any disability group.

These dire statistics are not a reflection of the inability of autistic individuals to work. Rather, they are the result of systemic barriers that filter them out of the workforce. Key barriers include:

1. **Discriminatory Hiring Practices:** The conventional job interview, which heavily prioritizes neurotypical social skills, eye contact, and conversational fluidity, serves as a significant and often insurmountable barrier for many autistic candidates, regardless of their qualifications for the actual job.
2. **Lack of Employer Understanding:** Pervasive stereotypes and a lack of awareness about autism among human resources professionals and hiring managers lead to misconceptions and prejudice. Vague job descriptions, ambiguous interview questions, and an overemphasis on "social fit" rather than technical skills disadvantage autistic applicants.
3. **Workplace Environment and Accommodations:** Sensory sensitivities can make typical office environments (with fluorescent lighting, ambient noise, and open floor plans)

overwhelming and debilitating. While reasonable accommodation is required by the ADA, access to them is inconsistent, and many autistic employees feel unable to disclose their needs for fear of stigma or retaliation.

Even when autistic adults do find work, they are frequently underemployed. Autistic graduates are twice as likely to be unemployed 15 months after graduation as their non-disabled peers and are the most likely of any disability group to be overqualified for the jobs they hold. They also face the largest pay gap and are more likely to be in precarious employment situations, such as part-time or zero-hour contract work. While states like Illinois offer programs through the Department of Rehabilitation Services (DRS) and community employment providers, these efforts are insufficient to address the scale of the crisis. The failure to secure meaningful employment not only limits financial independence but also contributes to social isolation and diminished quality of life.

### **The Housing Crisis: Scarcity of Supportive, Sensory-Friendly, and Affordable Options**

*Home should be refuge, not risk, yet for many autistic adults, housing is where independence ends, and inequity begins.*

Parallel to the employment crisis is a severe shortage of appropriate and affordable housing for autistic adults. For many parents of autistic children, the most pressing fear is what will happen to their adult child when they are no longer able to provide care. The current housing landscape offers few reassuring answers.

The challenges are multi-faceted. The primary barrier is financial; with extremely high rates of unemployment and underemployment, most autistic adults cannot afford market-rate housing.

Over 75% report that affordability is their top concern in securing a place to live. This is

compounded by a dire shortage of publicly funded residential support. Of the 7.4 million citizens with intellectual and developmental disabilities (I/DD) in the U.S., only 17% receive any form of publicly funded residential services.

Beyond affordability, there is a mismatch between available housing options and the specific needs of the autistic population. Many autistic individuals have significant sensory sensitivities, and their home must serve as a sanctuary from a world that can be sensorily overwhelming. This may require specific features like quiet locations, control over lighting and sound, and private spaces for decompression—features that are rarely found in typical apartment buildings or group home settings. The need for support also varies widely, from individuals who can live completely independently to those who require 24-hour supervision and assistance with daily living skills.

The available options are limited and often inadequate:

1. **Living with Family:** The default for the majority of autistic adults, this option becomes untenable as parents age and are no longer able to provide care.
2. **Supervised Group Homes (CILAs in Illinois):** These homes, typically serving several residents in a community setting, are the most common model for publicly funded residential services. However, there is a severe shortage of placements, and the group setting can be challenging for individuals with significant sensory or social difficulties.
3. **Supported Apartments/Independent Living:** For individuals requiring less intensive support, this model provides more independence with periodic check-ins from support staff. However, it is still subject to funding shortages and may not be suitable for those with higher support needs.

The lack of a diverse array of housing models that can be tailored to individual sensory, support, and social needs leaves many autistic adults with no choice but to remain in family homes that may not be sustainable long-term, or to be placed in settings that do not meet their needs, leading to stress, crisis, and institutionalization.

### **Navigating the System: Adult Services and the Illinois PUNS Waitlist**

*The PUNS list is not a backlog, it is a waiting room built by policy choice, where thousands of lives idle while funding catches up to promise.*

The crises in employment and housing are direct consequences of the "service cliff," the structural shift from the entitlement-based special education system to the eligibility-based adult disability system. In Illinois, the gateway to most publicly funded adult services is a database known as the **Prioritization of Urgency of Need for Services (PUNS)**.

PUNS is, in effect, the state's official waiting list for adults with developmental disabilities who need Medicaid waiver-funded services, such as in-home supports, day programs, or placement in a Community Integrated Living Arrangement (CILA) or group home. To access these services, an individual must be enrolled in the PUNS database by their local Independent Service Coordination (ISC) agency.

This system is fundamentally one of rationing, not entitlement. Unlike IDEA, which mandates services for every eligible child, the adult system provides services only to the number of individuals for whom the state legislature has appropriated funding. The PUNS list is the mechanism for managing a demand for services that far exceeds the available supply. Selections from the list are generally based on the cumulative length of time an individual has been in the

"Seeking Services" category since turning 18, unless they are in a state of crisis (e.g., homelessness or abuse).

The result is an unacceptably long wait. Currently, an adult newly entering the PUNS list in the "Seeking Services" category can expect to wait **four to five years** before being selected for funding. This multi-year gap leaves young adults and their families in a state of profound uncertainty and stress precisely when they need support the most—immediately following their exit from the school system. The existence of this massive, state-acknowledged list of individuals with unmet needs represents a policy decision to ration care through chronic underfunding, directly contributing to the poor adult outcomes seen in employment, housing, and overall quality of life.

### **Health and Well-being: Co-occurring Conditions and Healthcare Access Barriers**

*Autistic health is too often treated as an afterthought, when care systems mistake complexity for inevitability, preventable suffering becomes routine.*

Compounding the challenges of navigating adult life are the extremely high rates of co-occurring medical and mental health conditions within the autistic population. These conditions are the norm, not the exception, and they significantly impact health, functioning, and quality of life. The healthcare system, however, is often ill-equipped to diagnose and treat these complex presentations.

Key co-occurring conditions include:

1. **Attention-Deficit/Hyperactivity Disorder (ADHD):** An estimated 50-70% of autistic individuals also meet the criteria for ADHD. A recent large-scale study found that co-occurring ADHD in autistic adults is associated with worse health outcomes, including

higher rates of substance use and injury, though treatment with ADHD medication was shown to mitigate some of these risks.

2. **Anxiety Disorders:** Approximately 40-50% of autistic people experience clinical anxiety disorder, with some studies showing rates as high as 84%. Anxiety can manifest differently in autistic individuals and can exacerbate core characteristics like insistence on sameness, social withdrawal, and repetitive behaviors.
3. **Epilepsy:** Seizure disorders are vastly more common in the autistic population, affecting an estimated 25-40% of individuals, compared to just 2-3% of the general population. The risk is highest for those with co-occurring intellectual disability and tends to increase with age.
4. **Other Conditions:** A wide range of other medical issues are also highly prevalent, including gastrointestinal problems (chronic constipation, reflux), feeding and eating issues (including Avoidant/Restrictive Food Intake Disorder), and significant sleep disruption.

This high degree of medical complexity presents significant challenges. The overlap in symptoms between autism and conditions like ADHD and anxiety can lead to **diagnostic overshadowing**, where a treatable mental health condition is dismissed by clinicians as "just part of the autism". Many healthcare providers lack adequate training and understanding of autism, leading to communication barriers, sensory challenges in clinical settings, and a failure to provide accessible, effective care. Addressing these co-occurring conditions is a critical and often overlooked lever for improving the overall well-being and functional outcomes of autistic adults.

Condition	Estimated Prevalence in Autistic Population	Prevalence in General Population	Key Characteristics & Implications
<b>ADHD</b>	50–70%	~4% (UK adults)	Symptoms of inattention and/or hyperactivity-impulsivity can overlap with or be exacerbated by autism. Co-occurrence is linked to greater functional impairment and poorer health outcomes if untreated.
<b>Anxiety Disorders</b>	40–50% (up to 84% in some studies)	~18%	Can manifest as social anxiety, specific phobias, or generalized anxiety. May be driven by sensory sensitivities, difficulty with uncertainty, and social challenges. Often exacerbates repetitive



Condition	Estimated Prevalence in Autistic Population	Prevalence in General Population	Key Characteristics & Implications
			behaviors and insistence on sameness.
<b>Epilepsy / Seizure Disorders</b>	25–40%	2–3%	Risk increases with age and presence of intellectual disability. A sudden regression in skills or behavior may be a sign of subclinical seizure activity. Can include all seizure types.
<b>Gastrointestinal (GI) Issues</b>	Highly prevalent; specific rates vary. At least 25% report chronic pain, constipation, or diarrhea.	Varies by condition.	Common issues include chronic constipation, diarrhea, abdominal pain, and reflux. May be linked to stress, anxiety, and food sensitivities. Communication challenges can make it

Condition	Estimated Prevalence in Autistic Population	Prevalence in General Population	Key Characteristics & Implications
			difficult to report GI pain.

**Table 3: Common Co-Occurring Conditions in Autism Spectrum Disorder**

Domain	Key Statistic / Indicator	Systemic Barrier
<b>Employment</b>	Unemployment rates estimated at 39% to 85%. Autistic people face the largest employment and pay gaps of any disability group.	Discriminatory hiring practices focused on neurotypical social skills; lack of employer understanding and workplace accommodations; inadequate vocational training and transition services.
<b>Housing</b>	Over 75% of autistic adults report affordability as their top housing concern. Only 17% of people with I/DD receive publicly funded residential supports.	Severe shortage of affordable and supportive housing options; lack of housing models that accommodate sensory needs; insufficient funding for residential services.
<b>Community Support (Illinois)</b>	The wait time for adults entering the PUNS "Seeking	The adult service system is based on eligibility and funding

Domain	Key Statistic / Indicator	Systemic Barrier
	Services" category is 4–5 years.	availability (rationing), not legal entitlement. Chronic underfunding leads to a massive waiting list for essential services like in-home support and group home placements.
<b>Healthcare</b>	Autistic individuals have higher rates of unmet healthcare needs and are more likely to die prematurely compared to the general population.	Lack of provider training on autism; diagnostic overshadowing of co-occurring conditions; communication barriers; sensory challenges in clinical environments.

**Table 4: Adult Outcomes and Service Gaps for Autistic Individuals**

### Evolving Paradigms and Pathways Forward

*Autistic health is too often treated as an afterthought, when care systems mistake complexity for inevitability, preventable suffering becomes routine.*

In the face of these profound systemic challenges, new paradigms are emerging that seek to reshape public policy and societal attitudes toward autism. Driven by the powerful voices of autistic self-advocates, the neurodiversity movement is challenging the traditional medical model of disability and advocating for a future based on acceptance, inclusion, and civil rights.

Simultaneously, a growing understanding of the impact of trauma is promoting more

compassionate and effective approaches to support in schools and service systems. These evolving frameworks, coupled with concrete policy innovations at the state level, offer potential pathways toward a more equitable and supportive society for autistic individuals.

### **The Neurodiversity Movement: From Deficit Model to Disability Rights**

*Neurodiversity reframes autism not as a flaw to fix but as a facet of humanity to respect—demanding that society adapt to minds long asked to adapt to it.*

The neurodiversity movement is a social justice movement that has fundamentally altered the conversation about autism. Coined in the 1990s and propelled by autistic self-advocacy organizations like the Autistic Self Advocacy Network (ASAN), the movement posits that autism and other neurological variations (such as ADHD and dyslexia) are not disorders to be cured but are natural and valuable forms of human diversity.

This perspective is rooted in the **social model of disability**, which distinguishes between "impairment" (an individual's physical or neurological difference) and "disability" (the societal barriers that exclude and disadvantage people with impairments). From this viewpoint, the primary problem is not the autistic brain itself, but a society that is built for and by neurotypical people, failing to accommodate different ways of communicating, sensing, and interacting with the world.

The central tenet of the movement is captured in the disability rights slogan, **"Nothing About Us, Without Us"**. Self-advocates argue that autistic people must be at the center of all conversations and policy decisions that affect their lives. This stands in contrast to historical models where parents or medical professionals were the primary voices in autism advocacy, some of whom focused on a biomedical model aimed at treatment or cure. Major advocacy

organizations like The Arc, which has long supported people with a wide range of intellectual and developmental disabilities, also play a crucial role in advocating for community inclusion and support services.

The impact of this paradigm shift is increasingly visible in policy and practice:

1. **Language:** A preference for "identity-first" language ("autistic person") over "person-first" language ("person with autism") has been widely adopted by the community to signal that autism is an integral part of identity, not a separable disease.
2. **Intervention Goals:** The movement challenges interventions aimed at "normalization" or teaching autistic people to mask their natural traits. Instead, it advocates for supports that build on strengths, teach functional life skills, and promote autonomy and self-determination.
3. **Education:** In special education, the neurodiversity framework encourages a shift from deficit remediation to a strengths-based approach. It calls for creating inclusive classroom environments that provide universal supports, such as visual schedules, sensory-friendly spaces, and flexible communication options, benefiting all learners. This approach is beginning to gain traction in higher education, with initiatives like the Illinois Neurodiversity Initiative at the University of Illinois and support programs at Illinois State University.

### **Trauma-Informed Systems: A Necessary Framework for Supporting Autistic Individuals**

*Trauma-informed systems replace punishment with presence, seeing crisis not as defiance to control, but as pain asking for safety, dignity, and understanding.*

A parallel and complementary shift is occurring with the growing adoption of trauma-informed care as a foundational framework for education and human services. A trauma-informed approach recognizes the high prevalence of trauma and adverse childhood experiences (ACEs) in the population and understands the profound impact that trauma can have on an individual's brain development, behavior, and health.

Autistic individuals are particularly vulnerable to experiencing trauma. They face higher rates of bullying, abuse, and social rejection. Furthermore, the daily experience of navigating a sensorily overwhelming and socially confusing world can itself be a source of chronic stress and trauma. A trauma-informed system operates on a fundamental shift in perspective, moving from asking "What is wrong with you?" to "What has happened to you?". It prioritizes creating environments that are physically and psychologically safe, trustworthy, and empowering.

In the context of schools, this framework offers a powerful alternative to punitive disciplinary practices. A trauma-informed school understands that a student's challenging behavior is often a trauma response, a manifestation of a nervous system in a state of fight, flight, or freeze, rather than willful defiance. Instead of reacting with punishment, which can re-traumatize the student, trauma-informed practices focus on:

1. **Connection and Co-regulation:** Building strong, trusting relationships between students and staff and actively teaching students strategies to regulate their emotions and sensory systems.
2. **Predictability and Safety:** Establishing clear routines, predictable environments, and consistent, non-shaming responses to behavior.

3. **Teaching Resilience:** Explicitly teaching coping skills, problem-solving, and self-advocacy.

This approach aligns perfectly with the principles of Positive Behavioral Interventions and Supports (PBIS) and the need for high-quality FBAs and BIPs as discussed previously. By understanding the "why" behind behavior through a trauma lens, schools can create supportive ecosystems that prevent crises, reduce the need for restraint and seclusion, and foster learning for all students. Illinois has recognized the importance of this framework, with ISBE and other state agencies promoting resources and training for schools to become more trauma-informed.

### Policy Innovations and Pathways Forward

*Policy change begins where conscience meets data, when leadership listens, equity stops being a goal and becomes the standard by which systems are judged.*

The scale of the systemic challenges facing the autism community can seem daunting, but concrete policy actions at the state level demonstrate that progress is possible when data, advocacy, and political will align. Illinois has recently seen several promising developments that can serve as models for future action.

1. **Protecting Civil Rights and Privacy:** In May 2025, Governor JB Pritzker issued **Executive Order 2025-02**, which restricts state agencies and their contractors from engaging in the mass collection or sharing of personally identifiable autism-related data without legal or medical necessity and informed consent. This order was a direct response to concerns from the self-advocacy community about privacy and the potential for discrimination, representing a significant victory for the "Nothing About Us, Without Us" principle.

2. **Strengthening Service Access:** Illinois's long-standing **autism insurance mandate** continues to be a critical lifeline for families, providing access to therapies outside the school system. A 2022 amendment strengthened this law by clarifying that coverage must be provided regardless of the service location, preventing insurers from denying claims for home- or school-based ABA therapy.
3. **Addressing Systemic Bottlenecks:** Legislative proposals like **House Bill 2428** directly target the root cause of long diagnostic waitlists by seeking to increase Medicaid reimbursement rates for applied behavior analysis services. While it has not yet passed, such legislation acknowledges that building provider capacity is essential to meeting the state's growing needs.

These actions, while incremental, provide a blueprint for a broader reform agenda. Based on the comprehensive analysis in this report, the following pathways forward are recommended for policymakers:

1. **Close the Implementation Gap in Education:** State funding for school districts should be more closely tied to demonstrated compliance with the core tenets of IDEA. This includes investing in robust training and oversight to improve the quality of FBAs, BIPs, and, most critically, postsecondary transition plans. Transition planning must become a substantive, multi-year process that ensures a "warm handoff" to adult service agencies before student's graduate.
2. **Break the Diagnostic Bottleneck:** The state must make a significant, targeted investment in building its diagnostic capacity. This should include expanding funding for innovative telehealth evaluation models, increasing training opportunities for developmental



specialists at state universities, and raising Medicaid reimbursement rates to levels that attract and retain qualified professionals, particularly in rural and underserved "diagnostic deserts."

3. **Fund the Adult System to Meet the Known Need:** The PUNS waitlist is not an administrative backlog; it is a policy choice to ration care. The state should develop and fund a multi-year, phased-in plan to eliminate the waiting list and ensure that the adult service system is funded at a level commensurate with the predictable and growing number of individuals exiting the school system who will require support.
4. **Center the Voices of Autistic People:** All future policy development, program design, and system reform efforts must be undertaken in full partnership with autistic self-advocates and their representative organizations. Their lived experience and expertise are invaluable and essential for creating a system that is truly responsive to the needs of the community it is meant to serve.

By pursuing these pathways, Illinois and the nation can begin to move from a system characterized by implementation gaps and service cliffs to one that fulfills the promise of inclusion, opportunity, and support for all autistic individuals across the lifespan.

## Reflection and Discussion: Law, Conscience, and the Human Promise

*IDEA transforms the nation’s founding promise of justice into lived reality—where law, philosophy, and faith converge to affirm that every child’s worth is both a moral truth and a legal duty.*

The Individuals with Disabilities Education Act (IDEA) stands as one of the most morally ambitious laws in the American canon. Beneath its administrative structure lies a profound assertion of human worth, that every child, regardless of difference, holds an unassailable right to an education designed for their unique mind. This principle reaches beyond legality into the realm of philosophy and faith. It is a statement not merely of what government must do, but of what humanity owes itself.

### Law as Moral Architecture

For over two millennia, philosophers have argued that justice is not sameness but fairness in relation to need. Aristotle defined justice as “the virtue that gives each what is due” (*Nicomachean Ethics*, Book V, ca. 350 BCE). In that sense, IDEA is justice made practical: it compels institutions to recognize the individual rather than the average. The Individualized Education Program (IEP) is not a document of bureaucracy but a charter of personhood, a written affirmation that the state sees the student before it sees the system.

John Locke’s doctrine of natural rights and Jean-Jacques Rousseau’s concept of the social contract provided the intellectual foundation for this moral structure. Locke wrote that legitimate government exists only “for the preservation of property, which includes life, liberty, and estate” (*Two Treatises of Government*, 1690), while Rousseau insisted that “the general will” must protect each citizen’s freedom (*The Social Contract*, 1762). IDEA transforms those ideals into

daily practice by making education not a privilege of circumstance, but a public covenant. It is one of the few American laws that truly fulfills the democratic ideal of equality through *individualization*.

### **The American Promise in Practice**

The framers of the U.S. Constitution sought to “form a more perfect Union... establish justice... [and] promote the general welfare” (U.S. Const. Preamble). These are not static aspirations; they are moral verbs. IDEA is a living extension of that founding purpose. When a school district develops an IEP, it does more than comply with regulation, it enacts the constitutional promise of equity in real time.

Thomas Jefferson argued that “an enlightened citizenry is indispensable for the proper functioning of a republic” (Letter to William C. Jarvis, 1820). If education is the safeguard of liberty, inclusive education is its most faithful guardian. The provision of a Free Appropriate Public Education (FAPE) ensures that democracy does not stop at the classroom door. It guarantees that liberty remains accessible not only to those who conform, but also to those whose minds move differently through the world.

### **The Moral Imperative: Justice as Compassion**

IDEA’s architecture of rights mirrors an older command: “*Learn to do good; seek justice, correct oppression; bring justice to the fatherless, plead the widow’s cause*” (Isaiah 1:17, ESV). This verse does not describe abstract ethics but active empathy, justice lived through advocacy. In this sense, IDEA and Isaiah share a common aim: both insist that society be measured by its

treatment of the vulnerable. To seek justice is to restore balance, to correct systems that privilege power over need, and to recognize that dignity is not negotiable.

Faith traditions across the world echo this truth. In the Christian tradition, the concept of *Imago Dei* — that every person is made in the image of God (Genesis 1:27), grounds human rights in divine likeness. In Buddhism, *karuṇā* denotes compassionate action, the practice of responding to suffering with wisdom rather than judgment (*Dhammapada*, ca. 3rd century BCE). Both point to the same moral horizon: every life bears intrinsic value and demands response. In protecting autistic children and adults through law, the nation does not perform charity; it performs justice.

### **The Autism Advocacy Network: Bridging Law and Love**

The Autism Advocacy Network (AAN) exists to embody this synthesis, to be the bridge between legality and humanity. Law without compassion becomes bureaucracy; compassion without structure becomes chaos. AAN's mission is to bind the two into disciplined harmony: *lawful compassion*.

Through its environmental access frameworks, trauma-informed training models, and ethical governance principles, AAN turns statutory rights into lived realities. It insists that IDEA's guarantees of FAPE, Least Restrictive Environment (LRE), and positive behavioral supports cannot remain theoretical. They must be enacted in classrooms, churches, workplaces, and communities. AAN stands as both reformer and reconciler, guiding institutions to fulfill the law through conscience and guiding families to use conscience to uphold the law.

## Vision for the Next Generation

Our vision extends beyond compliance toward transformation. A just society is not one that merely tolerates difference but one that *designs for it*. The goal is not uniformity, but belonging, a nation where a child's neurology is met not with suspicion but with support, where access is not granted as an accommodation but recognized as a birthright.

Martin Luther King Jr. reminded us that “injustice anywhere is a threat to justice everywhere” (*Letter from Birmingham Jail*, 1963). Frederick Douglass wrote that “it is easier to build strong children than to repair broken men” (Speech, 1855). IDEA, at its best, does both, it repairs what was broken and builds anew. It is the law as conscience, the state as caretaker, and education as the truest form of liberation.

The United States was founded on the proposition that all people are created equal. IDEA fulfills that creed not through rhetoric, but through the radical act of individual attention. It is the nation's most persistent attempt to legislate empathy, to transform equality from a word into a way of life.

## Closing Reflection

Justice, then, is not a destination but a discipline. It is learned, practiced, and refined, in classrooms, in policy meetings, and in the quiet persistence of parents who refuse to accept exclusion as normal. In that discipline, the Autism Advocacy Network finds its calling. It exists to remind us that law is not an end in itself but a means of seeing the person before us clearly.

When systems act with both reason and compassion, law becomes love in public form. And in that transformation, in each IEP written with care, each child regulated instead of restrained,

each parent heard instead of dismissed, the nation fulfills its oldest promise: that liberty and justice are not abstract ideals, but shared responsibilities.

## Call to Action: Turning Law into Living Justice

The evidence is clear. The rights are written. The challenge now is not to redefine the law, but to fulfill it. The Individuals with Disabilities Education Act, Section 504, and the Americans with Disabilities Act together represent one of the most comprehensive civil rights frameworks in the world — yet their promise remains unrealized for too many autistic individuals. The moral and legal task before us is to make these guarantees real, measurable, and enduring in every classroom, agency, and community.

### For Legislators and Policymakers

Justice requires funding equal to the promise of the law.

- **Tie state funding to compliance outcomes.** Require districts to demonstrate IDEA implementation — particularly in evaluations, FBAs, and transition planning — as a condition for receiving special education funds.
- **End the rationing of adult services.** Eliminate the PUNS waitlist through a phased, multi-year funding plan that aligns adult system capacity with predictable demand.
- **Expand diagnostic capacity.** Invest in telehealth models, university partnerships, and reimbursement reform to eradicate “diagnostic deserts.”

- **Protect privacy and civil rights.** Uphold the spirit of Executive Order 2025-02 and ensure that data collection serves families, not surveillance.

### For School Districts and Educators

Compliance is not compassion — but compassion must become compliance.

- **Elevate IEP practice.** Move beyond procedural minimalism to measurable progress, guided by *Andrew F.* and grounded in real-time data.
- **Institutionalize trauma-informed education.** Replace punitive discipline with positive supports that respect neurological diversity and student dignity.
- **Train for understanding.** Ensure all staff receive practical instruction in environmental access, sensory regulation, and co-regulation strategies.

### For Families and Self-Advocates

Your advocacy is the engine of accountability.

- **Use your rights.** Invoke procedural safeguards, request Independent Educational Evaluations, and hold districts to measurable standards.
- **Document everything.** The power of IDEA rests on transparency; every communication, every service log, every missed accommodation matters.
- **Join together.** Collective advocacy transforms isolated frustration into systemic change.

## For Faith and Community Leaders

Inclusion is not a program — it is a reflection of conscience.

- **Model accessible design.** Churches, nonprofits, and community spaces must lead in creating sensory-friendly, inclusive environments.
- **Support families publicly.** Normalize advocacy as an act of faith, not confrontation.
- **Teach justice as service.** Isaiah 1:17 reminds us: *“Learn to do good; seek justice, correct oppression.”* To make this real is to embody the Gospel in civic form.

## For the Autism Advocacy Network (AAN)

We will continue to serve as a bridge between law and life.

AAN’s charge is to ensure that the systems meant to educate and support do not merely exist — they *function*. We will expand our Legal and Policy Library, train advocates in lawful practice, and build community partnerships that unite moral courage with statutory authority.

## The Work Ahead

The measure of a nation is not its wealth or innovation, but its treatment of those who depend upon its justice. The United States has already declared that every child has the right to learn. The question now is whether we will act as if we believe it.

When law is practiced with love, bureaucracy becomes humanity, and justice becomes not a dream deferred, but a daily discipline. That is the work before us — and it begins now.



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## Appendix: Advocacy Checklists and Tools

### PWN 20-Second Audit

1. State the action proposed or refused.
2. Explain the reason for the decision.
3. List each record, report, or evaluation relied on.
4. Describe options considered and why rejected.
5. Attach procedural safeguards and how to obtain them.
6. Provide in the parent's native language.

### Transition Planning Rubric

At or before age 16:

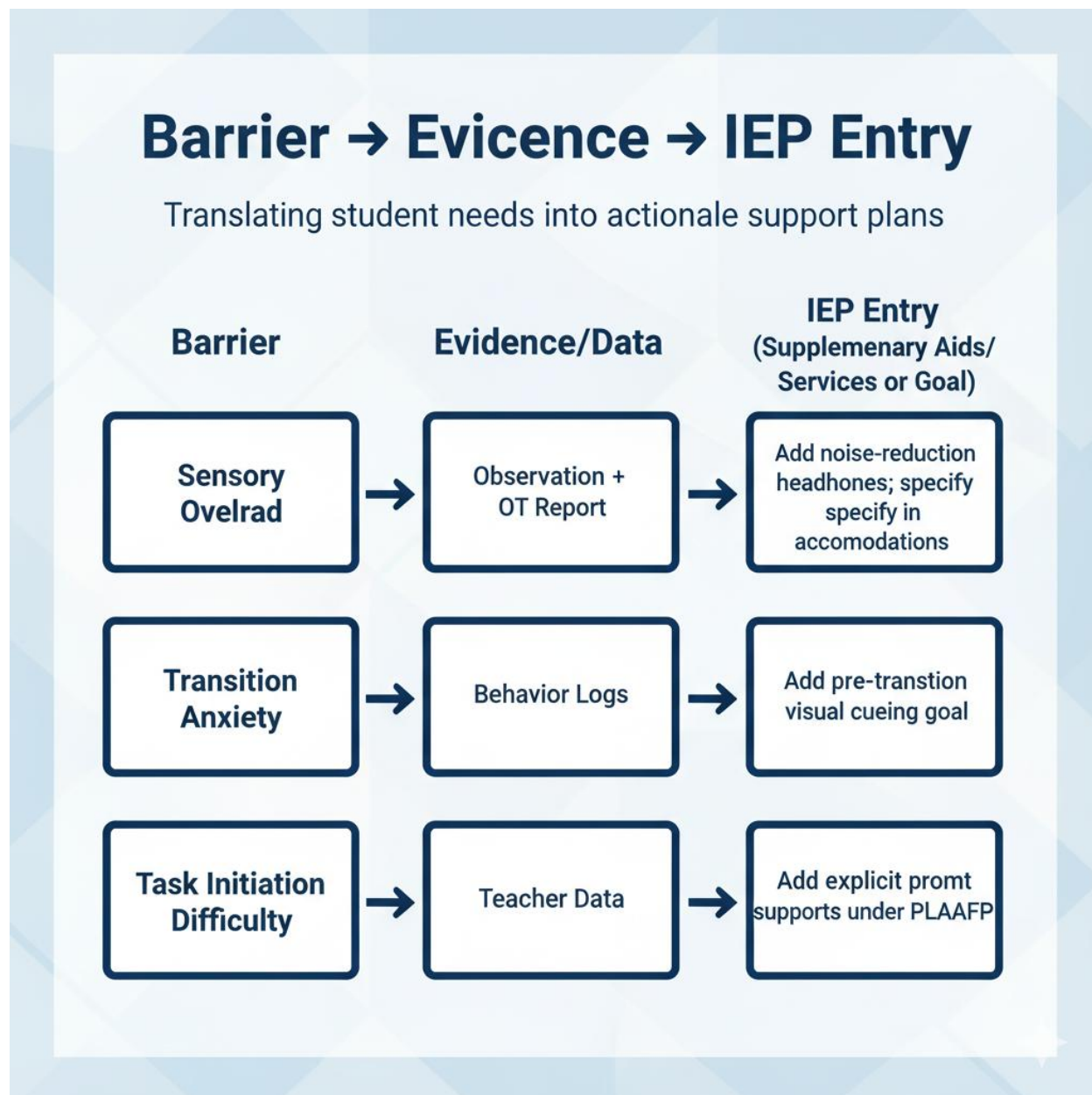
- Include measurable post-secondary goals for education/training, employment, and independent living (as appropriate).
- Identify transition services and course of study.
- Base goals on age-appropriate assessments.
- Update annually.

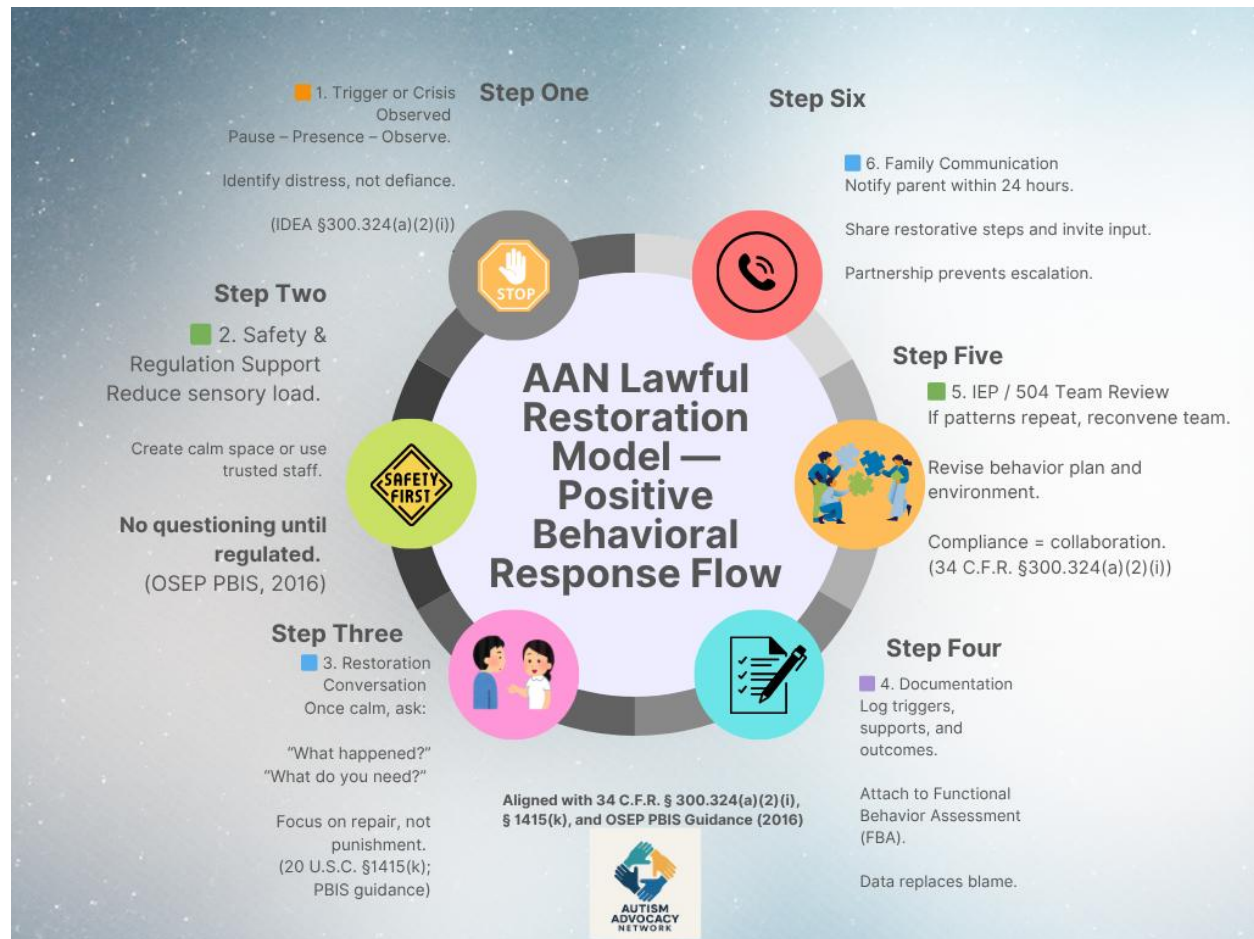
### Environment-as-Access Mini-Checklist

- Lighting and noise control assessed and documented.
- Predictable routines and transition supports.
- Availability of calm and sensory regulation spaces.
- Visual schedules and communication supports.
- Physical and emotional safety monitoring.
- Reviewed quarterly and revised as needed.



## Barrier → Evidence → IEP Entry Table





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### **Autism in the United States: Prevalence, Education Challenges, and Systemic Barriers**

#### **Autism Advocacy Network (AAN) 2025 Policy Research**

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