

# **Service Readiness for Severe Autism in Florida**

## **Medically and Behaviorally Competent Supports Across the Lifespan**

### **(Gaps, Impacts, and Policy Implications)**

#### **Author**

Ashley Valdes  
Florida Advocacy Chair, National Council on Severe Autism  
Student Anthropologist

#### **Report Series**

Twinmaker Research Report Series  
Report No. 1 | January 2026

#### **Location of Publication**

Twinmaker Research  
officialtwinmaker.com

\*This report may not be reproduced, redistributed, or transmitted without written permission from the author except for brief quotations used for citation.

## Executive Summary

Families of individuals with severe autism in Florida experience consistent, cross-system service gaps rooted in workforce readiness rather than individual family circumstances. While autism services formally exist across Medicaid, HCBS waivers, and community-based programs, final Phase 2 findings confirm that training standards, medical literacy, and preventive support capacity do not align with the complexity of severe autism.

Analysis of responses from **52 Florida caregivers, autistic adults, and professionals** reveals widespread service exclusion, misinterpretation of medical distress as behavioral escalation, limited access to respite care, and heavy reliance on crisis intervention. These patterns persist across early childhood, school age, transition, and adulthood, demonstrating that Florida's autism service gaps are structural and lifespan-wide.

Key findings include:

- **81%** of families describe caregiving as overwhelming or involving constant struggle
- **88%** have never received respite care
- **85%** have experienced medical distress misinterpreted as behavioral escalation
- **70%** have experienced emergency or institutional crisis intervention due to lack of trained supports
- **94%** prioritize better trained professionals as the most impactful improvement

Families consistently report being denied or removed from services due to staffing limitations, safety concerns, and inadequate training, often being told they are “not a good fit” rather than being addressed through adaptive service planning. These informal exclusion mechanisms shift risk and responsibility onto families while obscuring structural workforce deficiencies.

These findings suggest that Florida's service gaps are not isolated failures but predictable outcomes of workforce-readiness issues and fragmented systems. Florida already maintains the administrative infrastructure to address these challenges through Medicaid, HCBS waivers, provider oversight mechanisms, and interagency coordination. Strengthening training standards, medical literacy requirements, accountability for service denials, and caregiver collaboration expectations within existing frameworks presents an immediate opportunity to reduce crisis-driven costs, improve workforce stability, and ensure safe, equitable services for individuals with severe autism across the lifespan.

This report establishes a clear, evidence-based mandate: **Florida does not need new systems; it needs readiness.** These findings emerge at a moment when autism services in Florida are being highlighted, but has not yet aligned workforce training standards with the complexity of severe autism. Without addressing workforce readiness, expansion alone risks perpetuating service exclusion and crisis-driven care.

## **Introduction**

Autism service systems are often designed around generalized diagnostic categories, despite wide variation in support needs. Individuals with severe autism frequently require medically informed care, advanced behavioral support, and consistent, trained professionals across settings. When systems fail to account for this complexity, families are left to navigate fragmented services that are ill-equipped to respond safely and sustainably.

Florida administers autism-related services through Medicaid, developmental disability waivers, and community-based providers. Yet families of individuals with severe autism continue to report exclusion, instability, and crisis-driven care. This applied research documents how these gaps emerge across the lifespan and identifies workforce readiness as the central structural barrier within Florida's service systems.

## **Research Questions**

### **Primary Research Question**

How do gaps in medically and behaviorally competent support services affect families of individuals with severe autism in Florida across healthcare, respite, education-adjacent, and community systems?

### **Secondary Research Question**

What workforce, policy, and coordination barriers contribute to service exclusion and crisis-driven care for individuals with severe autism across Florida's service continuum?

## **Methodology**

\*This research focuses on service readiness and workforce capacity for individuals with high- and complex-support needs and does not seek to generalize to all autism presentations.

### **Phase 1 Methodology**

Initial data collection focused on caregiver narratives, advocacy observation, and a preliminary online survey of Florida caregivers, autistic adults, and professionals. Themes identified included service exclusion, professional unpreparedness, and caregiver destabilization.

### **Phase 2 Methodology**

Phase 2 expanded on these findings through a targeted survey of a known Florida caregiver cohort examining service denial, professional readiness, crisis outcomes, and caregiver impact. Responses were collected anonymously and analyzed using thematic coding and categorical frequency analysis.

## **Positionality Statement**

The researcher is both a student anthropologist and a parent of children on the autism spectrum. This dual positionality provides sustained access to lived experience while requiring ongoing reflexivity to distinguish individual experience from broader systemic patterns. Rather than introducing bias, this positionality allows for an ethically grounded interpretation of service structures as they are experienced in practice.

## **Defining “Medically and Behaviorally Trained” Professionals**

In the context of severe autism, *medically and behaviorally trained* professionals are those who possess formal education, applied training, and ongoing supervision sufficient to safely support individuals with complex medical, behavioral, and sensory needs.

This includes competency in:

- Medical literacy related to common co-occurring conditions and medication effects
- Behavioral assessment and de-escalation grounded in trauma-informed care
- Severe autism-specific support needs
- Crisis prevention and safety protocols
- Ethical collaboration with caregivers
- Ongoing supervision and continuing education

This definition does not require all professionals to be clinicians; it requires competence, escalation awareness, and institutional support.

## **Sidebar: Why Severe Autism Requires Specialized Training**

Severe autism often involves complex medical, behavioral, and sensory needs that exceed the scope of general autism training. Individuals may be non-speaking, have co-occurring medical conditions, experience heightened sensory sensitivity, or communicate distress through behavior rather than words. In these contexts, inadequate training does not merely reduce service quality; it can compromise safety, dignity, and continuity of care.

Professionals without medical literacy may misinterpret pain, seizures, medication side effects, or sensory overload as behavioral noncompliance. Similarly, professionals without advanced behavioral training may rely on reactive or exclusionary practices rather than preventive, trauma-informed supports. These gaps increase the likelihood of crisis intervention, service denial, and caregiver burnout.

Recognizing severe autism as requiring medically and behaviorally competent support is not a matter of preference or labeling but a necessary condition for safety, equity, and effective service delivery across the lifespan.

## **Composite Case Profiles Across the Lifespan**

\*To contextualize survey findings and system-level patterns, three composite case profiles were developed to illustrate how service readiness gaps manifest across developmental stages. These profiles are composites drawn from multiple caregiver experiences and qualitative data and do not represent any single individual.

### **Early Childhood (0–6)**

An early-childhood child with severe autism presents with significant developmental, medical, and sensory support needs that require coordinated, medically informed early intervention services. The child may be non-speaking, have feeding and sleep challenges, and display heightened sensory sensitivity that impacts safety, participation, and emotional regulation.

Although early intervention services are formally available, the family encounters persistent barriers related to workforce readiness. Providers frequently report insufficient training, limited staffing, or safety concerns when asked to support the child's needs. As a result, services are delayed, limited in scope, or discontinued, despite the recognized importance of early intervention for long-term developmental outcomes.

Medical appointments often lack autism-specific accommodations. Caregivers report difficulty distinguishing medical distress from behavioral expression due to limited provider literacy in severe autism, leading to delayed diagnoses, inadequate treatment responses, and avoidable escalation.

Respite and in-home supports are rarely available during this stage, leaving caregivers without relief during a critical developmental window. The cumulative effect is heightened caregiver stress, reduced service continuity, and missed opportunities for early developmental support that could otherwise mitigate long-term crisis risk.

This profile illustrates how early childhood systems frequently lack the medically and behaviorally competent workforce required to serve children with severe autism, despite formal recognition of early intervention as a critical developmental priority.

### **School-Age (7–17)**

A school-aged child with severe autism and complex support needs requires coordinated medical, behavioral, and educational-adjacent services to maintain safety, stability, and access to learning. The child is non-speaking or

minimally speaking and experiences heightened sensory sensitivity, requiring individualized supports, predictable routines, and medically informed care.

Despite documented needs, the family encounters repeated service barriers across medical and community settings. Providers frequently express concerns about staffing limitations, inadequate training, and safety liability. Requests for accommodations are often met with informal exclusion, framed as issues of “fit” rather than addressed through adaptive support planning.

Medical encounters reveal a lack of autism-specific literacy, with signs of physical discomfort or sensory distress misinterpreted as behavioral noncompliance. This misinterpretation leads to delayed care, inappropriate responses, and an increased risk of escalation. Care coordination across systems is fragmented, requiring sustained caregiver advocacy to prevent service breakdowns.

Access to respite care is limited or inconsistent, further increasing caregiver burden and reducing family stability. As a result, the family experiences persistent emotional and logistical strain, with elevated risk for crisis intervention, school disruption, and long-term service disengagement.

This profile reflects a structural mismatch between service design and workforce readiness, demonstrating how training gaps and fragmented systems disproportionately impact school-age individuals with severe autism and their families.

### **Transition & Adult (18+)**

An individual with severe autism entering adulthood requires consistent, medically and behaviorally competent services to maintain safety, housing stability, and participation in community life. Support needs often include assistance with daily living, medical coordination, behavioral supports, and crisis prevention. Communication may be limited or non-speaking, requiring trained professionals who can interpret behavioral communication and recognize medical distress.

As school-based supports end, families encounter a sharp service cliff. Adult service systems frequently lack providers trained to support severe autism, leading to prolonged waitlists, denial of services, or placement in programs that are ill-equipped to manage medical and behavioral complexity. Families report being advised that programs are unable to meet their needs due to staffing, liability, or safety concerns, resulting in prolonged caregiver dependency and increased crisis risk.

Medical systems often remain unprepared to accommodate severe autism in adulthood. Misinterpretation of medical distress as behavioral escalation persists, increasing the likelihood of emergency interventions and institutional involvement. Preventive supports are limited, while crisis response becomes the default.

Respite, residential, and community-based adult services are often fragmented or inaccessible, placing families in a position of long-term, unsupported caregiving. The cumulative effect includes elevated caregiver burnout, heightened risk of emergency intervention, and limited opportunities for meaningful adult participation and stability. This profile reflects how adult service systems, when not designed around medically and behaviorally competent care, perpetuate instability and institutional risk for individuals with severe autism and their families.

## **Preliminary (Phase 1) Florida Survey Findings**

Preliminary survey findings from Florida residents indicate that caregiver burden and service inadequacy are widespread among families of individuals with severe autism. Most caregiver respondents reported feeling overwhelmed by financial and caregiving responsibilities and described moderate to extreme social isolation.

Concerns regarding essential services frequently included out-of-network providers, high copays, and reliance on out-of-pocket services. Several respondents described negative interactions with care providers, citing a lack of autism-specific and severity-informed training, including dismissive or uninformed responses in medical settings.

Access to respite care was limited across respondents. Among those who had accessed respite services, some experienced denial or removal, suggesting instability in service provision for individuals with higher support needs. Open-ended responses emphasized the absence of coordinated, severe-autism-specific care, noting that the lack of medically and behaviorally competent services significantly impedes family stability and individual well-being.

## **Key Themes**

### **Theme 1: Mismatch Between Individual Needs and Professional Training**

Families consistently encounter professionals whose training does not align with the complexity of severe autism, resulting in inadequate and unsafe support.

### **Theme 2: “Not a Good Fit” as a Mechanism of Exclusion**

Service denials framed as capacity or fit obscure systemic training deficiencies and shift responsibility onto individuals and families.

### **Theme 3: Medical Distress Misinterpreted as Behavioral Escalation**

Lack of medical literacy leads to inappropriate responses, delayed care, and increased crisis risk.

### **Theme 4: Crisis Response Substitutes for Preventive Support**

Insufficient training results in systems that respond only after escalation rather than preventing crises.

**Theme 5: Caregiver Expertise Is Undervalued**

Families' lived knowledge is often excluded from planning, despite its critical role in safety and continuity.

**Theme 6: Workforce Burnout Reflects Structural Neglect**

High turnover is linked to insufficient training, supervision, and institutional support rather than individual failure.

**Theme 7: Fragmentation Across Service Domains**

Inconsistent standards across systems amplify gaps and place additional advocacy burdens on families.

**Theme 8: Severity Remains Implicit Rather Than Explicit**

Failure to name severe autism enables nominal inclusion while excluding those with the highest needs.

**Final (Phase 2) Findings: Workforce Readiness, Service Exclusion, and Crisis Outcomes in Florida (n = 52)**

\*Respondents represent families supporting individuals across early childhood, school-age, transition, and adult service systems in Florida.

Final Phase 2 analysis integrates responses from **52 Florida caregivers, autistic adults, and professionals**, and confirms consistent, cross-lifespan patterns of service exclusion, workforce unpreparedness, crisis-driven care, and caregiver destabilization affecting individuals with severe autism across early childhood, school age, transition, and adulthood.

These findings demonstrate structural, not incidental, failures in Florida's autism service readiness.

**1. Structural Caregiver Burden**

Caregiver burden is systemic and persistent.

- **81%** of respondents describe caregiving responsibilities as *overwhelming or involving constant struggle*
- **75%** report moderate–severe social isolation
- **71%** state that the lack of trained services significantly or severely impacts their ability to maintain employment, rest, and household stability

These results confirm that Florida's service systems rely heavily on uncompensated caregiver labor to compensate for workforce readiness gaps.

**2. Respite Care Is Functionally Inaccessible**

Respite care is largely unavailable to families supporting individuals with severe autism.

- **88%** have never received respite care
- **43%** report denial or removal from respite services

Primary denial reasons include staffing shortages, safety concerns, lack of trained staff, and “not a good fit” determinations, indicating structural exclusion rather than isolated service limitations.

### 3. Cross-System Service Exclusion

Service exclusion occurs consistently across all major service domains:

Service Type	% Reporting Exclusion
In-home support services	<b>81%</b>
Medical care	<b>69%</b>
School-adjacent services	<b>66%</b>
Behavioral therapy	<b>63%</b>
Adult day/residential services	<b>61%</b>
Crisis stabilization programs	<b>49%</b>

These findings reveal systemic workforce-readiness deficiencies across Florida’s autism service continuum.

### 4. Medical Distress Misinterpreted as Behavioral Escalation

- **85%** of respondents report experiencing situations where medical distress (pain, illness, sensory overload, or medication effects) was misinterpreted as behavioral escalation
- Most under-prepared settings: hospitals/ERs, primary care, schools, adult programs, respite providers, and first responders

This pattern contributes directly to delayed care, inappropriate interventions, and preventable crises.

### 5. Crisis Intervention as the Default System Response

- **70%** of respondents report emergency or institutional crisis involvement due to lack of trained support (ER visits, hospitalizations, law enforcement involvement, school exclusion, service termination)

Crisis intervention has become a substitute for preventive, medically and behaviorally competent services.

### 6. Families Identify Workforce Training as the Core Solution

Families consistently prioritize workforce readiness over expanded bureaucracy:

<b>Improvement Requested</b>	<b>% Selecting</b>
Better trained professionals	<b>94%</b>
Medically informed staff	<b>88%</b>
Stable respite options	<b>84%</b>
Crisis prevention pathways	<b>81%</b>
Caregiver involvement in planning	<b>78%</b>
Increased funding for workforce training	<b>76%</b>

This confirms that Florida families are seeking competence and stability, not extraordinary accommodations.

## **Policy Implications**

The findings indicate that Florida's autism service gaps are structural, lifespan-wide, and rooted in workforce readiness rather than family circumstance. Crisis intervention has become a substitute for preventive support due to insufficient training standards and fragmented coordination. In other words, existing frameworks can recognize medical necessity, behavioral intervention, and tiered service intensity, but training standards and accountability mechanisms lag behind the complexity of services.

Explicit recognition of severe autism, integration of medical literacy into service regulations, and alignment of training standards across systems are necessary to ensure safety, equity, and sustainability across the lifespan.

## **Policy Recommendations**

1. Establish tiered workforce training standards aligned to support needs
2. Require documentation and remediation when services are denied
3. Integrate medical literacy into autism service regulations
4. Prioritize preventive training over crisis intervention
5. Codify caregiver collaboration
6. Invest in workforce development and retention
7. Align training standards across service systems
8. Explicitly recognize severe autism in policy language

## **Lifespan Policy Alignment (Florida)**

Florida already administers autism services through authorities capable of implementing these recommendations across childhood, transition, and adulthood. Strengthening training standards, oversight, and coordination within existing waiver and regulatory structures ensures continuity of care and prevents individuals with severe autism from being excluded at critical life stages.

## **How Florida Can Measure Progress**

- Reduced service denial rates
- Increased respite utilization
- Reduced crisis intervention
- Reduced emergency department utilization for autism-related crises
- Improved workforce stability
- Improved caregiver-reported stability

## **Conclusion**

The absence of medically and behaviorally trained professionals across autism service systems is not accidental. It reflects structural gaps that place disproportionate burdens on families of individuals with severe autism. Addressing these gaps requires policy clarity, workforce investment, and explicit recognition of severity.

Florida does not face a shortage of families willing to care; it faces a shortage of systems ready to support.

Importantly, the State has the infrastructure necessary to act. By strengthening workforce readiness within existing frameworks, Florida can improve safety, equity, and continuity of care across the lifespan for individuals with severe autism, ensuring the level of support available aligns with the lived realities of families statewide.

This report provides Florida with a clear, evidence-based opportunity to shift from crisis dependence to prevention, stability, and long-term system sustainability.