

# Helping the Whole Child: Let's Take 'Triple Aim' at Autism

Integrating the Autism Care System



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## EXECUTIVE SUMMARY

State-level policies have shaped the national landscape for Applied Behavior Analysis (ABA)-based therapeutic interventions for disabilities associated with Autism Spectrum Disorder (ASD). However, state-to-state variation in policies and criteria for access, quality, and expectations for outcomes may be impeding the capacity to effectively reduce the burden of ASD-related disability on individuals, families, and society. These variations limit the ability for consistent achievement of optimal outcomes for individuals with ASD, as well as their families and caregivers; reduce the potential valuable contribution to society; and increase the risk of persistent, preventable disability. Taking a more clinically integrated approach to the systems of care that have evolved to serve the population of individuals with ASD would improve the experience and quality of care, and improve the quality of life, for persons with ASD, while reducing the economic burden of ASD-related disability across the lifespan.

## INTRODUCTION

Since 2001, 46 states, the District of Columbia, and the US Virgin Islands have enacted insurance reform laws requiring some form of coverage for therapy based on the principles of Applied Behavior Analysis (ABA) for children with Autism Spectrum Disorder (ASD) and their families.<sup>1</sup> The foundation of these legislative efforts rests on activism by families and advocates, and several pivotal court cases that reviewed the evidence and determined (as summarized in one judgement) that “it is imperative that autistic children . . . receive ABA immediately to prevent irreversible harm to these children’s health and development.”<sup>2</sup> These legislative mandates have effectively created an independent system of care for persons with ASD where the locus of control and payment is divided between health, mental health, and educational systems. The delivery of behavioral health services through independent systems of care and payment (also known as carve-outs) is known to lead to “fragmented and uncoordinated care.”<sup>3</sup>

ABA is a framework for therapeutic interventions based on the principles of learning theory.<sup>4</sup> ABA-based interventions have demonstrated their capacity to improve contingent, functional, and socially significant behaviors, including communication, social interaction and relationships, academic performance, and adaptive living skills in individuals with ASD.<sup>5,6,7</sup> ABA can also help reduce or eliminate disruptive, aggressive, or significantly repetitive behaviors, as well as family stress and conflict.<sup>8,9</sup> As a therapeutic modality, ABA has also been applied to substance abuse, disease prevention, lifestyle management, seatbelt use, dementia, medical procedures, and feeding disorders.<sup>10</sup> ABA-based interventions are directed by Behavior Analysts who are certified by an independent professional board that sets standards for ABA training and practice.<sup>11</sup>



ASD is a uniquely complex neuropsychological condition with highly-variable expression. As such, and unlike other therapies for other behavioral and developmental disorders, ABA requires high levels of intensity and duration of therapy, driven by the complexity and aspirations of treatment goals for the child.<sup>12</sup> Comprehensive behavioral interventions, defined as 25-40 hours per week of therapy, consider the “whole child” and focus on producing changes in skills that impact global functioning, including communications, adaptive skills, social functioning, learning, and behavior.<sup>13,14</sup> Focused behavioral interventions are less intensive in nature (10-25 hours per week) and are designed to target a limited number of key functional skills or behavioral targets.

While the academic community continues to study and gather evidence on ABA, from a practical perspective, ABA-based therapies are the most pervasive and accessible evidence-based forms of treatment currently available for children with ASD and their families.<sup>15,16</sup> Gains in adaptive behavior achieved with ABA are maintained over long periods of time and are associated with a reduced need for special services or supports in school and an increased likelihood of independent living later in life.<sup>17,18</sup>

## **POLICY VARIATIONS IMPEDE OPTIMAL OUTCOMES**

While ASD treatment policies and mandates could be viewed as success for access advocates, a review reveals striking variations across the spectrum related to eligibility, quality, and expectations for outcomes associated with ABA therapy.<sup>19</sup>

- Variation in annual dollar caps and age limits on coverage become artificial barriers to comprehensive treatment plans and the coordination of care appropriate for optimal outcomes. Some states have set fee schedules which make it unsustainable to deliver quality, coordinated services.<sup>20</sup>
- Differential standards and practices between Medicaid, commercial insurers, and self-insured employers result in disparities in treatment opportunity for children in the same community.<sup>21,22</sup>
- Variation in the definition of “medical necessity” by some commercial insurers limits provision of services or exposes loopholes in coverage mandates.<sup>23</sup>
- Categorical conflicts between health and educational interventions sometimes place ABA outside the protection of mental health parity laws.<sup>24</sup>



- State-level autism treatment initiatives are based on a framework associated with the Individuals with Disabilities Education Act (IDEA),<sup>25</sup> and all states have integrated their autism services programs with their IDEA efforts. This results in two-tier systems of care with disparate, and often conflicting, perspectives on the nature of disability and the goals of and approaches to intervention.<sup>26</sup>

There are disparities across assessment standards, allocation and accessibility of professional resources, and focus and alignment of treatment plan goals.<sup>27</sup>

- Generally, early childhood initiatives are led by state-level departments of health or mental health. These often focus on broad developmental, neuropsychological, and behavioral domains, as well as functionality in the home and community, and incorporate family priorities. These early childhood initiatives utilize intervention strategies that are largely based on ABA.
- However, at school-age, the lead changes to local school districts, which shifts the focus towards academic and non-academic functional goals, often to the exclusion (directly or tacitly) of developmental domains.<sup>25</sup> School based intervention strategies are generally based on a mixed approach to intervention, incorporating special education, speech and occupational therapy, and principles of ABA, despite data showing that ‘mixed’ or eclectic treatment plans based on special education do not work as well, or have as sustained positive effects as ABA-dominant treatment plans.<sup>28,29,30,31</sup>

These disparities and complexities are demonstrated upon review of Michigan guidelines for ASD interventions. According to Michigan guidelines, eligibility for special education school district services is not based on clinical diagnosis of ASD, but rather “education-based eligibility criteria.”<sup>32</sup> Furthermore, the guidelines state that, “because the process and purpose for evaluations are different, a clinical diagnosis of ASD is not required or sufficient for the determination of special education eligibility,” and “a student may meet the eligibility criteria for ASD but not be eligible for special education because access and progress in the general education curriculum or environment is not affected by the ASD.” Therefore, while a child may be clinically diagnosed for ASD, and require a level of tailored educational services, they may not receive those tailored services unless they also meet the education-based eligibility criteria. This creates significant disparities in the nature of treatment planning between early childhood and school age cohorts. The potential adverse effect of this disparity was validated by the recent U.S. Supreme Court ruling in *Endrew F vs Douglas County School District*, where the court found that the level of variation in standards and practices in school-based special needs programs can have negative consequences on children’s developmental achievement at any age.<sup>33</sup>



Such variances increase the risk of preventable persistence of disability and subsequent need for special services and supports, not just in childhood but throughout the lifespan of an individual with ASD. Under the current, non-harmonized, and uncoordinated approach, there is little understanding of the distribution of quality as defined by service intensity and expected outcomes. Such variability impedes progress on societal goals to reduce the burden of ASD-related disability on individuals or society.

With this as the backdrop, it is imperative that we take a more whole person, collaborative, and organized approach to the goals, benefits, and value created by our systems of care. Policies and clinical operations must be developed, designed, and supported by a set of measures to serve as standardized indicators, and benchmarks for performance and continuous quality improvement to help individuals with ASD achieve optimal outcomes and goals.

## **IT'S TIME TO TAKE “TRIPLE AIM” AT AUTISM.**

A clinically-integrated approach—which encompasses mental, social, and physical health—is ideal to establishing standards and best practices to achieve goals to reduce the burden of ASD-related disability on individuals, their families, and communities, while reducing costs and improving the quality of care and quality of life for all individuals with ASD and their families. As an established and validated framework for optimizing performance of systems of care delivery, the Triple Aim is an established and ideal approach to developing standards and best practices to achieve these goals.<sup>34</sup> As applied to ABA mandates, the Triple Aim would seek to:

### **1. Improve the quality of, access to, and satisfaction with, ABA therapy for individuals with ASD.**

A core principle of the collaborative states that no single sector alone can achieve its goals. The diverse stakeholder and professional resource-communities supporting children with ASD and their families must invest in and support delivery systems and social infrastructure, which are consistent in their approach to the provision of ABA based therapy. As a condition, ASD is complex and cross-disciplinary, and benchmarks for ABA programs for persons with ASD should be developed with input from trans-disciplinary stakeholders, including those from healthcare, behavior analysis, education, developmental science, and other disciplines. Furthermore, children with ASD are best served by treatment using a shared decision-making model that balances best practices and expected outcomes with family aspirations, preferences, and values. Process and outcome measures based on the six Institute of Medicine (IOM) quality aims would allow for more uniform and consistent standards for program design, performance, and continuous improvement of our efforts to support every child with ASD equally.<sup>35</sup>



## **2. Improve quality of health across the ASD condition-community**

Early and equitable access to ABA-based therapy is critical to optimizing and improving outcomes for individuals with ASD. Under a population health perspective, the underlying focus of ASD treatment programs would shift from assuring that every eligible child receives some services to a broader view of the quality and outcomes expected from those services and the value they provide to the individual and to the community. For ABA in ASD, this would reduce the current variation in the quality of care, and ultimately the quality of life, of individuals with ASD and their families. It would also involve a critical assessment of whether existing disabilities' models are valid or appropriate for children with autism.<sup>36</sup>

Setting standards for wait times from diagnosis to access of intensive behavioral intervention and considering what factors should be taken into account for developing a treatment plan, could generate more dependence-free life years until age 65,<sup>37</sup> ABA could also be used to improve medication compliance in children with comorbid conditions.<sup>38</sup>

## **3. Lower per-capita costs for ASD across the lifespan.**

Looking beyond disability to consider the whole child provides children with ASD the opportunity to have the best developmental experience possible, and to acquire the skills to live independently and succeed in the world on their own terms. The lifetime per capita incremental societal cost of autism has been estimated between \$2.4 and \$3.2 million; persons with ASD cost between \$200,000-\$300,000 more in educational services and supports between kindergarten and until age 18, and millions more in social, economic, and housing supports between 18 and 65 years of age.<sup>39,40,41</sup> Children with ASD use more health care resources as determined by emergency department and outpatient visits, and incur costs 4-6 times higher than children without ASD.<sup>42,43</sup> Adults with ASD spend twice as much in direct medical costs as the typical American over their lifetimes.<sup>41</sup>

However, the costs of ASD go far beyond the need for health care and special educational services. The true cost is the loss of opportunity for a person with ASD to be a productive, contributing member of the community, and be able to pursue their interests, relationships, goals, and dreams. Unemployment rates for adults with ASD have ranged between 30 percent and 88 percent (depending on level of intellectual disability), far above those for other developmental disabilities.<sup>44</sup> Only about 17 percent of young adults on the spectrum of ages 21 to 25 have ever lived independently; half that of those with an intellectual disability.<sup>45</sup> It is not only the person with ASD who is effected, parents of children with ASD are also more likely to be unemployed or underemployed and remain deeply involved in their children's lives far into adulthood, disrupting their own lives.<sup>46</sup>



Achieving integrated care goals for ASD will require reconsideration of the economic model for public investments in children. The traditional funding siloes of health, education, and social services should not, and no longer can, be treated in isolation; health investments in childhood have benefits that accrue to education and social services throughout the lifespan.

This speaks to the need for a “whole child” economic model which breaks down the current funding siloes and acknowledges the “total cost of childhood.” The “whole child” economic model would integrate the societal costs (health, education, and social services) of ASD from birth to age 18 into the value equation of the lifelong benefit and value that can be derived from investment in intensive treatment services.

In an evaluation of the downstream effect of investment in ABA-based early intensive behavioral intervention (EIBI) before school entry on the subsequent cost of special education and adult developmental disability services, the savings (in 1998 dollars) associated with early intervention with ABA-based treatment ranged from \$187,000 - \$203,000 in education costs per child for ages 3-22 years. Additionally, savings in per person costs ranged from \$656,000 - \$1,082,000 for social services, housing and vocational support services, special payments, and health care costs associated with persistent disability until 55 years of age.<sup>47</sup>

A subsequent study demonstrated that an average of 3 years of ABA-based EIBI before school entry would save \$208,500 per child across 18 years of education, even accounting for varying rates of ABA effectiveness.<sup>48</sup> Access to ASD services has also been shown to significantly reduce the risk that parents of children with ASD will stop working.<sup>49</sup>

Therefore, it is imperative to improve and enhance rapid post-diagnosis access to ABA-based therapies across the country in addition to ensuring a more consistent approach to coverage standards across localities and payers.

## PROMOTING SUSTAINABILITY AND OUTCOMES

Population-level frameworks for ASD must also consider the sustainability of ABA service operations which require high levels of staffing and care coordination to achieve optimal outcomes, as well as the measures of value associated with ABA related outcomes. This could be achieved by enhancing fee-for-service (FFS) with merit-based incentive payments; a fee adjustment for complex or high-acuity clients; shared savings or payment associated with socially valid measures of quality or other forms of defined value (such as kindergarten readiness, reduced need for special service and supports in school, independent living).



## SUMMARY

Comprehensive interventions based on principles of ABA have the capacity to offer all children with ASD the opportunity to: have the best developmental experience possible; acquire the skills to succeed in the world on their own terms; and pursue their interests, goals and dreams.

In order to improve the current delivery of services and supports available to those with ASD, stakeholders should harmonize their practices and build consistency in policies and program design to evolve the quality of care delivered and enhance the potential for better health and development of children with ASD and their families. This can be achieved by developing a consensus on policies and standards related to timely access to care, treatment planning, intensity and continuity of care, and shared decision making and collaboration between the health and education systems responsible for supporting children with ASD-related disabilities. These will reduce variation, improve the quality of care for persons with ASD, and reduce the economic burden of ASD-related disability across the lifespan.

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