



Toward a Value-Based Care Model for Children with Autism Spectrum Disorder

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Abstract

Autism spectrum disorder (ASD) is defined as a pervasive developmental disorder and neurodevelopmental condition characterized by impairments in social communication and interaction, repetitive and stereotyped behavior, and a high prevalence of co-occurring medical and psychiatric conditions. The increased prevalence of ASD has necessitated a close examination of autism services and reimbursement structures. Within this article, we review the cost of ASD treatment, its impact on payers and families, and a treatment framework and reimbursement structure that may optimize the quality of life for children with ASD and their families.

Keywords: Autism Spectrum Disorder; Patient-Centered; Diagnostic and Statistical Manual; Clinical Presentation

Introduction

Toward a Value-Based Care Model for Children with Autism Spectrum Disorder

Within this commentary, we assert that care for children with autism spectrum disorder (ASD) should be managed through ASD specific medical homes which are compensated for the outcomes they produce rather than the volume of service hours they amass. Our ultimate objective for this article is to conjoin the conversation centered on payment structures for autism services to what is of paramount importance to children with ASD and their families-that is, relevant and valuable outcomes.

This paper is divided into six sections within the first section; we provide an overview of ASD. Next, we review the overall cost of autism-related services and discuss the impact of state laws related to insurance coverage for the treatment of autism. The third section addresses the current state of

autism treatment and discusses the need for an established model of care (i.e., Patient-Centered Medical Home) to address systemic barriers to quality services for children with ASD. In section four, we explore ideas at the vanguard of planning the future of ASD support. In the fifth section, we examine the current fee-for-service (FFS) reimbursement system for ASD services and recommend a value-based care (VBC) model. We submit that a VBC payment structure provides incentives for meaningful outcomes and compensates professionals for the quality of treatment rather than the quantity of services rendered to children with ASD. Finally, we present a synopsis in the concluding section of the paper.

Autism Spectrum Disorder

ASD is defined as a pervasive developmental disorder and neurodevelopmental condition characterized by impairments in social communication and interaction and repetitive and stereotyped behavior [1]. ASD affects a greater number of families each year. Estimates from the Centers for

Disease Control's Autism and Developmental Disabilities Monitoring Network, using 2018 data, suggest that 1 in 44 children in the United States are diagnosed with ASD. Currently, the worldwide prevalence is around 1% [2].

Variation of the clinical presentation of ASD is a hallmark of the condition, and the severity of ASD can differ significantly from one individual to another. Moreover, for many individuals, the complexity of ASD is exacerbated by co-occurring medical and psychiatric disorders. At least 83% of children and adolescents with ASD present with at least one co-occurring medical condition, and 70% present with a secondary psychiatric disorder [3].

Comorbid medical conditions among children with ASD include immune system abnormalities, gastrointestinal disorders, mitochondrial dysfunction, sleep disorders, and epilepsy. In a recent study by Al-Beltagi [4], a review of comorbidity prevalence data showed that children with ASD, when compared to children without disabilities, are 1.6 times more likely to have eczema or skin allergies, 1.8 times more likely to have asthma and food allergies, 2.1 times more likely to have frequent ear infections, 2.2 times more likely to have severe headaches, 3.5 times more likely to have diarrhea or colitis, and 7 times more likely to report gastrointestinal problems [4].

Co-occurring medical conditions have been positively correlated with the age of a child, the child's Diagnostic and Statistical Manual of Mental Disorders [1] rating of severity of ASD, and the use of pharmacological agents [5]. Furthermore, many children with ASD have co-occurring medical conditions that go undetected—that is, they present with occult, or hidden, medical pathologies. Occult medical conditions are prevalent among children who are nonverbal or possess limited language capabilities [6]. Untreated medical comorbidities, regardless of whether they are observable or occult, hinder a child's developmental progress and render them severely compromised as a learner. Children with ASD are also often affected by co-occurring psychiatric conditions.

Psychiatric comorbidities include social anxiety disorder, oppositional defiant disorder, and attention deficit hyperactivity disorder. Additionally, 14% of children with ASD engage in suicide ideation or attempt suicide [7], a rate that is 28 times greater than that for typically developing children (i.e., 0.5% of the pediatric population). Many of these psychiatric conditions are treated with pharmacological agents. Although the use of pharmacology for the treatment of psychiatric comorbidities has not been firmly established, some studies have estimated that 30% to 50% of children with ASD have been treated with at least one pharmacological agent [8].

A diagnosis of ASD, with or without a co-occurring condition, certainly affects the quality of life (QoL) of children and their families. According to Egilson, et al. [9], when individuals with ASD are compared to their typically developing peers, they have significantly lower self-rating scores across all QoL dimensions. The greatest differences have been found in the areas of social support and physical well-being. However, differences in ratings have also been found across all QoL dimensions. In addition, Bluth, et al. and Sawyer, et al [10,11] have established that the needs of children with ASD place significant emotional, financial, and physical stresses on families.

Given the complexity of ASD and multisystem comorbidities, the overarching implication is that ASD requires a comprehensive, unified, interdisciplinary, coordinated, and compassionate treatment approach.

Cost of Autism-Related Services

Whereas the intangible influences of ASD are highly individualized and incalculable, the societal costs of ASD have been quantified. Rogge and Janssen [12] provided a useful framework for assessing the costs of ASD and identified six types of costs:

- Expenses directly related to medical services;
- Costs associated with therapy, including ABA, speech and language pathology, occupational therapy, and special educational support;
- Special education services;
- Lost productivity among adults with ASD;
- The costs of family support and loss of productivity among family members and caregivers; and
- Costs of accommodation and respite care, and out-of-pocket expenses.

According to Cakir, et al. [13], between 1990 and 2019, there was an increase of two million new cases of ASD, with societal costs amounting to \$7 trillion. To put this in perspective, the disbursement is comparable to two years of federal revenue for the United States. Cakir, et al. [13] suggested that if the trajectory of new ASD cases remains unchanged over the next decade, there will be an estimated increase of another one million cases, resulting in an additional \$4 trillion in societal expenses. On an individual level, Cakir, et al. [13] estimated \$3.6 million in lifetime societal cost for each individual diagnosed with ASD. Cakir, et al. [13] indicated that this estimate aligns with appraisals from other studies.

As a result of the acceleration in the number of children diagnosed with ASD, individual states have required insurance plans to cover the cost of ASD treatment [14]. As of December 2021, all 50 states, the District of Columbia, and the U.S. Virgin Islands have enacted mandates that require

commercial insurers to cover treatment for children with ASD; however, state mandates vary greatly in the level of support provided. In addition, the federal government has apprised state Medicaid agencies that all medically necessary services for autism must be included as part of the Medicaid Early and Periodic Screening, Diagnostic, and Treatment benefit. Since 2014, most state Medicaid agencies have amended their state plans or adopted state regulations that specify ABA as a covered benefit when medically necessary [15]. According to Barry, et al. [16], mandates have been associated with a 3.4 percentage point increase in monthly spending on ASD-related services.

Despite increased insurance coverage, families are still greatly affected. Survey results reported by Sharpe [17] indicate that financial problems for a family are positively correlated with the need for medical interventions, accrued non-reimbursable medical and therapy expenses, and low income. These survey results also indicate that many family members forfeit future financial security and even experience bankruptcy to provide for their child with ASD. For families, the responsibility for caring for a child with ASD is distressing, and many parents are debilitated as a result of their familial obligations.

The Current State of Autism Treatment

The dominant treatment for ASD is ABA. Children with ASD who are severely affected may require up to 40 hours of treatment per week. In a recent meta-analysis focused on an evaluation of the evidence justifying the application of an ABA approach, Yu, et al. [18] reported that outcomes of socialization, communication, and expressive language are promising targets for ABA interventions. However, significant effects for the outcomes related to general symptoms, receptive language, adaptive behavior, daily living skills, IQ, nonverbal IQ, restricted and repetitive behavior, motor skills, and cognition were not observed.

There is also evidence that children with ASD receive subpar treatment for co-occurring medical and psychiatric conditions. Medical appointments typically involve check-in lines, waiting room noises, and other types of overstimulation, all of which are challenging for children with ASD. In addition, many children with ASD are nonverbal and cannot express their symptoms in a way that physicians can understand. Finally, many families' concerns about their children's medical or psychiatric concerns are ignored and disregarded and attributed to their ASD. According to Todorow, et al. [19], children with ASD are less likely to receive care through a pediatric medical home model compared with other children with special health care needs. This is because general pediatricians do not feel equipped to care for children with ASD due to lack of training, time,

and resources [20]. In addition, limited supply of specialists coupled with increasing patient demand results in long wait lists for specialist care [21]. Families manage a large number of specialty provider appointments and often receive conflicting clinical information and treatment plans for their child's comorbidities [22]. Given the complexity of ASD, the societal and personal cost of treatment, and the current state of services, what should treatment look like, and how should it be paid for?

A Recommended Approach for the Treatment of Autism Spectrum Disorder

The treatment of ASD should be based on an effective model of care (MoC) that can be assessed using a set of reliable standards. In the absence of a unified MoC, services may be significantly fragmented and inconsistent. Moreover, without a defined MoC, conversations about important topics are siloed (e.g., family-centered care or compassionate care), care pathways (e.g., clinical practice protocols) are not documented, and clinical efficiencies (e.g., the use of clinical decision support systems) are not dynamically explored. A comprehensive MoC should be consistent with a patient-centered medical home (PCMH) framework. The model should

- Provide *comprehensive care*, including ASD screening and diagnostic services, comprehensive medical, psychiatric, and nutrition evaluations, a home evaluation; primary care, ABA, speech therapy, occupational therapy, and treatment of co-occurring medical and psychiatric conditions;
- Be patient and family-centric, including collaboration with school systems, and prepare a family for life transitions (e.g., transition to adult services);
- Be *accessible*, characterized by localized flexibility and consider equity of access to care;
- Be *coordinated*, including interdisciplinary collaboration and maintaining of a referral network (e.g., specialist, psychiatry);
- Providing a structure for the safeguarding of clients, assent to treatment and high-quality care.

Furthermore, the MoC should be evaluated using a robust and standardized set of outcome measures and evaluation processes. The Behavioral Health Center of Excellence (BHCOE) offers an accreditation for ASD service providers and the BHCOE ABA Outcomes Framework for evaluating the outcomes of autism treatment [23]. In addition, the International Consortium for Health Outcomes Measurement (ICHOM) recently produced a standardized Autism Spectrum Disorder Standard Set (ASDSS) based on input from leading autism researchers, psychologists, board-certified behavior analysts, and service user representatives from Europe, North and South America, and Asia [24]. Specifically, the ASDSS

suggests measuring nine outcomes including (a) restricted and repetitive behaviors, (b) social communication, (c) daily functioning, (d) leisure, (e) QoL, (f) family functioning, (g) emotional regulation, (h) anxiety, and (i) sleep issues. The ASDSS framework provides a clear guide for evaluating treatment outcomes for families, clinicians, and payers.

The Role of the Percipient Payer

Insurance companies (and other risk-bearing entities) are in a prime position to effect change in the entire industry of autism services by holding service providers accountable for producing meaningful outcomes. However, currently, the predominant payment structure for autism services is the FFS reimbursement model, which creates an incentive for clinicians to prescribe more services, including more low-value services. Specifically, the FFS payment model incentivizes clinicians to

- Request a high volume of service hours (e.g., 40 hours per week of ABA treatment) regardless of severity and functional status,
- Maintain authorized hours at a steady state while omitting credible titration and discharge plans from clinical plans of care,
- Advocate for differential payment levels,
- Optimize the diversification of current procedural terminology codes used for billing,
- Deemphasize the coordination of care (as this is often a non-billable activity), and disregard inefficiencies.

An FFS model combined with the absence of a minimum clinical data set to evaluate outcomes and the omission of an MoC is a formula for high expense, poor outcomes, and a disorderly approach to treatment. At a minimum, payers can require an MoC that is consistent with the guiding principles of creating an MoC described above. More importantly, payers are now in a position where they can reference the ICHOM's or BHCOE's standards to evaluate the quality of services they are receiving. In our opinion, the pathway to quality care involves a value-based care (VBC) model, combined with the use of the ASDSS for the evaluation of outcomes [25,26].

Value-Based Care Model

The VBC model is a care delivery model that is reimbursed through payment mechanisms that directly link payment to performance on cost, quality, and patient experience measures. While VBC arrangements have become relatively common in primary and single- specialty care, they are yet to be applied to the ASD population. The reasons for the lack of adoption to date are complex and require an understanding of the pillars that form the foundation of a strong VBC arrangement: attributed population, applicable clinical scope, time horizon, performance measurement, and reimbursement structure [27].

Attributed (or assigned) population refers to the set (or subset) of patients or members to which the VBC arrangement applies. Patient populations are typically either attributed to a provider on a condition-specific and longitudinal basis or on an acute basis, usually anchored to a particular service or procedure. Applicable clinical scope refers to the scope of clinical services that apply to the attributed population and become the basis for measuring performance for cost, quality, and experience measures. Most VBC arrangements implement an explicit collection of the current procedural terminology codes that are relevant to the attributed population. The time horizon refers to a specific bounded time span for which performance will be measured. VBC arrangements that are more longitudinal in nature will have a longer time horizon, whereas procedurally focused arrangements may have on a shorter time horizon [28,29].

Performance measures can be organized into three categories:

- Cost performance, which measures how effectively the participating entity reduces the cost of care associated with the defined clinical scope of services;
- Quality performance, which measures how effective the participating entity was in producing high-quality clinical results; and
- Experience performance, which measures the level of satisfaction that the patients or their caregivers experienced while under the care of the participating entity.

Key metrics across these three domains are often tied to a historical cost benchmark, industry standard quality metrics, and patient- and caregiver-reported experience scores, respectively. Furthermore, reimbursement structure and type of risk relate to all VBC arrangements having a clear definition of how services will be reimbursed and how performance will be incentivized. These arrangements can range from an activity-based incentive program built on a traditional FFS infrastructure (i.e., traditional reimbursement, low risk) to a globally capitated arrangement under which the provider owns 100% of the underwriting risk associated with a defined attributed population and clinical scope (i.e., nontraditional reimbursement, high risk).

Application to Autism Services

Despite a broader trend toward adoption of VBC models in recent years, care delivery models for ASD have remained anchored to an FFS reimbursement model. Consideration of the pillars of strong VBC arrangements is illuminating to understand why this is the case. ASD is a dynamic, lifetime condition that has a broad range of severity based on individual diagnosis and the age of the child or adult.

Furthermore, equally dynamic co-occurring conditions are likely to be present for that individual during their lifespan. The individualized aspect of ASD has contributed to a lack of standardized quality measures by which to judge performance under a VBC arrangement. Lastly, because ASD is a lifetime condition, it has been difficult to apply an appropriate time horizon to a VBC arrangement centered on autism services in a way that continually aligns incentives for the payer, the provider, and, most importantly, the child and their family. Nevertheless, the potential for a highly aligned VBC arrangement in ASD that benefits all stakeholders is immense. A few guiding principles hold true for parties interested in continuing to explore potential partnerships in this space.

Identify Cohorts: ASD Subpopulations

ASD is a lifetime condition, and a wide range of severity and complexities exists within an ASD diagnosis. However, there is also a large enough population to begin risk pooling within subpopulations and scaling the arrangement as all parties become more comfortable in caring for the attributed population. For example, payers may structure a bundled payment around children between 2 and 5 years old and with a low to moderate severity level, with or without co-occurring medical conditions and manage that population for 3 years, with annual performance reconciliations. To do this effectively, it is critical to invest in the people, process, and technology required to identify an attributed population. For example, payers and providers will need to partner to ensure that the severity of ASD is accurately captured in the administrative data used to identify the cohort.

Consider a Total Cost of Care Framework

In order to incentivize a comprehensive and coordinated treatment approach, value based arrangements should ideally be structured to take into account all the healthcare costs associated for a cohort of children with ASD. Such costs would include, but not be limited to, various forms of therapy, outpatient primary care and specialist services, as well as acute and step down medical and psychiatric settings. By including all costs associated with ASD care delivery as part of a VBC arrangement, the principal risk holder has an opportunity to coordinate care in a way that benefits the entirety of the child and family's experience.

For example, Beverly found that use of the emergency department is higher in children with ASD when compared to similar cohorts of children without ASD. Unnecessary emergency department utilization can be prevented if co-occurring conditions are detected early and managed well. Opportunities for improved care delivery also reside in better prescription drug management and more thorough and timely coordination with specialty care providers. In all

these instances, the provider is likely to identify potential problems before they arise and communicate appropriately with the relevant parties to prevent an escalated clinical event before it happens (i.e., anticipatory guidance can be provided) [29].

To amplify a provider's effectiveness via early intervention and effective management of behavioral and medical conditions, and to best succeed in VBC arrangements, we believe it is critical for payers and providers to partner on building data-driven analytical tools. One such application is a predictive analytics tool that focus on identifying children that qualify as "rising risk" of emergency department or hospital use, based on their medical comorbidities and demonstrated behavior while receiving therapy. Such a tool would likely need to integrate clinical and claims data as well as school based data and social determinants of health. These tools, combined with rigorous decision models and clinical pathways for handling the "rising risk" would prevent unnecessary expenses within the ASD population and achieve quality outcomes. Providers would be incentivized to build such infrastructure only under a total cost of care construct, where they are incentivized to coordinate across care settings in a longitudinal manner.

Leverage the Emerging Quality Measurement Infrastructure

The quality standard for outcomes-based ASD care delivery continues to evolve. ICHOM's recently published framework is a promising start for building a VBC arrangement. Payers and providers can begin with a subset of these measures as it fits their specific VBC arrangement and build upon that starting point as the partnership matures. Quality component of the VBC arrangement can be structured based on either absolute or relative performance. Under an absolute performance construct, providers and payers would establish up front the specific levels of performance required to succeed under the VBC arrangement. Under a relative performance construct, a provider would be evaluated against the network average for a particular payer. In this construct, it will be necessary for the payer to be able to gather the relevant outcomes data from all the providers in its network, which will require a higher level of effort and investment. Therefore, it may make sense to start with the absolute approach and move towards a relative approach over time.

Start Small and Iterate

Although we advocate for ending reimbursement services for children with ASD under the auspices of an FFS model, we do understand the value of incrementalism. Consequently, if an FFS model must continue to be part of an overall payment structure, then FFS contracts should include a component of quality- or outcome-based performance reimbursement

at a level sufficient to motivate a substantial change in the behavior of providers [29].

Conclusion

The service delivery system is poised for a paradigm shift—specifically, a shift from a fragmented approach to treatment centered around maximizing billing hours, to an approach guided by a patient-centered medical home model that focuses on the client and their family, optimizes access to treatment, prioritizes interdisciplinary collaboration and coordination of care, monitors efficiency, ensures the safeguarding of clients, uses established outcome measures (e.g., ICHOM) to evaluate the effectiveness of treatment, delivers culturally competent care, and ensures an integrated approach to treatment. Discerning payers are in an optimal position to inspire a paradigm shift from an FFS payment structure to a VBC model. A paradigm shift will result in superior outcomes, reduce treatment costs, and improve preventive care.

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