

Centene Advanced Behavioral Health

White Paper

Advancing Care for Those Living with Autism Spectrum Disorder



The prevalence of autism spectrum disorder (ASD) across our nation has created a growing demand for specialized treatment to better the lives of affected individuals – as well as the lives of their families. ASD is a developmental disability characterized by deficiency in social interaction and the occurrence of restricted, repetitive patterns in activities, interests, or behaviors. In a 12-year span, the number of children diagnosed with ASD tripled from 1 in 155 to 1 in 54¹.

Often, ASD is accompanied by other physical and mental health conditions. Studies show almost 40% of individuals with ASD are diagnosed with an intellectual disability,² nearly 78% have at least one mental health condition, and about 50% have more than one mental health condition.³ Those with ASD also have a significantly higher prevalence of physical comorbidities “affecting various systems of the body including immune conditions, gastrointestinal (GI) disorders, metabolic conditions and seizure disorders,” and premature mortality is commonly attributed to these conditions.⁴

Although ASD has been shown to impact all racial, ethnic, and socioeconomic groups,⁵ treatment disparities still exist. Children from low-income families and minority groups have less access to care, specialized services, and community services, while also receiving reduced service hours.⁶ These discrepancies in care and service further limit children from low-income families and minority groups from realizing their potential.

An ASD diagnosis not only affects the lives of children, it impacts the whole family. Navigating the complex service system to attain a timely, early diagnosis can be difficult, but even after a diagnosis is obtained, the challenges for caregivers do not end.⁷ Because those with ASD often require increased health, educational, and behavioral services, families typically assume the responsibility for crafting a plan for accessing care, scheduling, and getting to those appointments. Not only is this a great time commitment, families of children with ASD may also face the burden of considerable healthcare expenses and reduced earning potential. Compared to mothers of children with no health limitations, mothers of children with ASD earn 56% less, and even when compared to those who have children with another health limitation, mothers of children with ASD earn 35% less.⁸ The economic discrepancy doesn't end with mothers. Families of children with ASD are 9% less likely to have two working parents, and overall family income is 28% less than families of children with no health limitations and 21% less than families of children with another health limitation.⁹

Not only is autism a significant cost to individual families, it is also a sizeable expenditure in our country, with an estimated \$162 billion to \$367 billion spent annually.⁹ If the rate of ASD diagnosis continues to increase at its current rate, costs will only continue to increase. Some analysts have estimated that by 2029 the costs of ASD could reach 15 trillion dollars.¹⁰ Early diagnosis and treatment are not only critical in improving the quality of life of individuals and families, they can decrease the long-term costs of ASD. For our society to achieve positive outcomes for those



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with ASD and tackle the growing costs associated, the gap in industry standards related to treatment and measurement must be addressed. As an industry leader and the largest Medicaid and Marketplace Managed Care organization in the country serving some of the most vulnerable populations, Centene is committed to implementing evidenced-based best practices and standardization of outcomes measures to respond to this need. Through early, timely identification, assuring usage of the most efficacious treatment, and advocating for industry standards, we can advance the care of those with ASD, alleviate some of the familial burden, and decrease obstacles in receiving vital services. The following are recommendations for payers in this pursuit.

Recommendations

IDENTIFICATION

Early identification is vital in ensuring optimized outcomes for those with ASD. There are recognized processes for screening, yet there is still room for payers to support advancing the current state. Through consistent, standard identification processes that are mindful of health disparities, payers can help support better identification.

- » The American Academy of Pediatrics recommends developmental and behavioral screenings during well-child visits at age 9, 18, and 30 months, and specific ASD screenings during well-child doctor visits at 18 and 24 months.¹¹ If a child has a sibling or other family member with ASD or exhibits behaviors associated with ASD, an additional screening may be required.¹¹ Additionally, parents should be educated in how to implement developmental monitoring so they are able to alert their pediatrician to any concerns or observations.
 - » Payers can use member education regarding well-child visits as a way to drive participation and ensure parents/caregivers know what to expect at these visits and what milestones they should be tracking in their child.
- » Those identified as at-risk for ASD should complete a comprehensive diagnostic evaluation that identifies functional level, strengths, and deficits in key areas of development to more accurately identify potential diagnoses and recommendations for treatment, including any other ancillary services. A psychologist or neuropsychologist specializing in developmental or behavioral pediatrics is the ideal source for these comprehensive diagnostic evaluations.
 - » While normally a covered service, payers should continue to ensure this level of evaluation is covered and allowed to be repeated as development occurs or symptoms change.
 - » Payers can also advocate for the standardization of assessments, which help identify autism proof points that will significantly impact the areas of development that should be prioritized and help influence identification of desired outcomes and tracking of progress.

TREATMENT

While there is no cure for ASD, there are a variety of interventions that have been shown to greatly improve individuals' quality of life. With a range of treatment options and the need for individualized care plans, it can be daunting for parents and caregivers to determine where to start. Providers can play a role in helping caregivers find the appropriate therapies that will best fit the individual. Additionally, as a child develops and grows, some therapies that originally helped in addressing symptoms may become ineffective, which is why routine developmental monitoring is important. Providers play a pivotal role in helping caregivers evolve the care plan to fit their child's current stage and assisting in the coordination of tracking progress to inform treatment. Like identification, beginning treatment earlier is more likely to result in positive outcomes.

Because the best treatment is the one that works for a specific individual, it is important that caregivers are made aware of all available treatment types. Successful treatment requires matching interventions to the child's identified behaviors and developmental delays, as well as ensuring caregivers have care plan input. Research shows that when consistent strategies carry over from a school or clinical setting into the home, improvements increase across care settings.

Applied Behavior Analysis (ABA)

While there are various treatment modalities, many are rooted in ABA. In essence, ABA is the application of behavioral principles to everyday situations to increase skills or decrease targeted behaviors. Based in the science of behavior modification, ABA is the careful application of teaching strategies to promote learning. ABA targets socially significant behaviors, increases social skills, decreases behavioral excesses, and is effective in many environments and circumstances. The goal of tailored treatment plans for those with ASD is to help increase socially adaptive skills and decrease challenging behaviors.

- » Payers should work with providers to ensure ABA services are medically necessary in the environment and are not duplicative to other services, such as those that are educationally relevant. Additionally to be most beneficial, there must be a clear identifiable service type, setting, number of hours, and caregiver participation to achieve the treatment plan's goals and objectives. Centene Advanced Behavioral Health's National Autism Center has devoted significant time and resources to developing policies and procedures that ensure our members with ASD receive evidence-based treatment within industry clinical practice guidelines.
- » It is Centene's commitment to ensure appropriate treatment for those we serve. For those with ASD, Centene has garnered much success through case shaping and encouraging providers to utilize evidence-based best practices that produce optimal results for members. Additionally, Centene Advanced Behavioral Health employs a strong team of psychologists who review and escalate cases with consistent criteria to guide program efficacy and streamlined processes. Our clinical utilization management staff is also comprehensively trained to ensure services are tailored to the individual needs of each member.
- » Despite the value of ABA treatment, there is a significant gap in terms of measurement of success and fidelity to the model of care. Through standardization of criteria for initiation of treatment, continuation, and titration of services, and application of ABA therapies, better outcomes can be achieved. To help individuals reach their maximum potential, an improved, more robust industry standard should be implemented for the appropriate dosage, and intensity of treatment that goes beyond the current restrictive model tied to units of time. Industry adoption of evidence-based standards of care is essential. Quality and clinical progress for members should be monitored regularly, and quantitative analyses of outcomes should be conducted.
- » As additional evidence-based behavior therapies become available, payers should consider these treatment models within the Medicaid benefit coverage requirements, increasing access to treatment while encouraging the best treatment model for each individual. For example, models such as the Early Start Denver Model (ESDM) and Developmental Individual-Differences Relationship (DIR) are therapies that have been documented to show developmental progress in early childhood learners and encourage self-regulation, relationship building, and communication. Centene Advanced Behavioral Health is also investigating newer innovative approaches to treating ASD that include telehealth platforms, technology-based interventions, and evidence-based developmental models.



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Holistic Care

By implementing best practices for a holistic treatment approach including other behavioral and physical health services, educational services, and community resources, the member and family have increased access to supports.

- » The autism spectrum is wide, and children, adolescents, and adults require different interventions in order to develop or maintain skills that make their lives easier to manage. Speech, occupational, and physical therapies are often accessed to target specific goals and develop interventions that suit the individual and level of need. For example, occupational therapy invokes a variety of strategies to address play skills, self-care, and even assist in managing sensory issues.
- » Whole health and wellness are just as important for those with ASD as they are for those without. Sleep concerns, especially insomnia, occur significantly more often in those with ASD than the general population.¹² As it does with anyone, sleep deprivation makes learning and retaining information much more difficult, and can contribute to poor mood and unpleasant behavior during the day which, in addition to being unhealthy for the individual, may exacerbate stress on caregivers. Sleep psychologists are often recommended to help develop better sleep routines and identify potential medical concerns, like sleep apnea, before resorting to pharmacotherapy.
- » Centene approaches preventative and specialized care in a holistic manner and connects the various supports through our case management team. Preventative care such as medical, vision and dental exams, as well as proper nutrition, must be part of ongoing care.
 - » To ensure children receive the best care possible, our network development team identifies and contracts with providers who specialize in working with children with autism, creating positive preventative care experiences and encouraging a life-long habit of attending those appointments and improving overall health.
 - » Within some health plans, Centene is able to provide value-add services tailored to each individual child's specific needs. For example, trial or multiple visits may be needed to allow the child to prepare for dental procedures or a blood draw.
 - » Individuals with ASD often have sensory preferences when it comes to the look, texture, and taste of food, often times resulting in poor or very limited diets significantly impacting nutrition and well-being. Caregivers and individuals often seek advice from nutritionists to help improve eating habits to promote a healthy lifestyle, and avoid additional comorbidities.
- » As children with ASD grow into adolescence and adulthood, additional skill training for education, employment, independent living, and daily functioning may be needed to allow them to more fully participate in their communities.
 - » Since 2017, Centene has co-managed the Project SEARCH program with Easterseals Midwest to provide job training for young adults with developmental and intellectual disabilities, preparing them for a future of competitive employment. Together, Centene and Easterseals are establishing initiatives to improve the quality of life of affected individuals, strengthen health plan and provider relationships, and advance industry knowledge through shared best practices.
 - » Through this partnership, Centene is also exploring an ASD program designed to provide enhanced care coordination for children and school-aged youth with challenges related to autism. The program would also provide help and guidance to caregivers and families by connecting them with one-on-one support from individuals with specialized experience and knowledge.



Psychopharmacology

Prescribing of psychotropic medications is seen most commonly in those with ASD as a way to manage certain behaviors or symptoms such as aggression, attention-deficit disorders, anxiety, and depression. Medications are used to treat 25% to 64% of children with ASD, varying by age group.¹³ One study showed 64% of children with ASD used psychotropic medications and 35% had evidence of polypharmacy.¹³ Because it is not uncommon for individuals with ASD to be diagnosed with additional physical and mental health conditions, the coordination of medication prescribing and tracking of improvements from medication use is imperative and should be monitored to inform overall treatment.

» Monitoring programs should be established to promote psychotropic medication prescribing and treatment that aligns with clinical best practice guidelines. Centene Advanced Behavioral Health's Behavioral Health Medication Monitoring (BHMM) program provides a comprehensive case review, identifies alternative therapeutic options, recommends additional care practices, and can refer members to case management for further interventions, if needed, to reduce polypharmacy. Overall, medications used by individuals with ASD should be reviewed and monitored for side effects and as the individual progresses through treatment to ensure alternative treatment options are being considered.

Parents/Caregivers

Parent/caregiver education is critical in understanding treatment options, deciding the best course of treatment, and ensuring physical comorbidities are identified and addressed. Through this, better healthcare can be achieved and quality of life can improve.

- » Coordinating a multi-disciplinary team of physical and behavioral health providers and a social support network can be difficult. Family caregivers serve as a critical extension of the formal healthcare system and their demand is expected to rise by 85% over the next few decades.¹⁴ Payers can serve as a guide for caregivers who may need extra support in navigating care options and accessing community resources for the best outcomes. Harnessing compassion and expertise, Centene's behavioral health team supports caregivers by guiding them through the care planning process and connecting them to additional resources so they feel empowered and knowledgeable about the treatment plan of their loved ones.
- » Caregivers may need training in monitoring progress against treatment plan goals, as well as selecting developmental milestones to keep under observation. Caregiver training may also be needed for learning specific strategies to implement the treatment plan at home to generalize skills to natural environment. In addition to well-child visit resources, payers can help caregivers increase their knowledge through educational materials and support specific to those with ASD.



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Centene's practicing psychologists

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Providers

- » Because the demand for qualified providers to support individuals with ASD has grown exponentially over the past decade, it is not uncommon to wait many months to obtain a comprehensive diagnostic evaluation. For the time period of 2010 to 2018 there was a 1,942% increase, and from 2017 to 2018 a 127% increase, in the demand for Board Certified Behavior Analysts (BCBAs) and BCBA-D (Doctoral level BCBAs).¹⁵ Intensifying the continued need, most ABA providers have waiting lists for services. While Centene works to expand its ABA network, it is also evaluating other evidence-based approaches to increase access to care.
- » Partnering with providers is key to positive outcomes. Centene works hand-in-hand with providers to implement best practices and standardization of outcome measures into treatment plans. By having consistent, comprehensive standards, providers can feel more secure in knowing that their area of expertise fits into a systematic, multi-disciplinary treatment plan that prioritizes skills specific to the appropriate developmental stage and age of children, maximizing their potential.
- » When creating goals, providers should consider the member's baseline level of functioning and prognosis, as well as treatments that may already be in place or were previously ineffective. Additionally, a pragmatic approach should be taken regarding what is developmentally appropriate, which symptoms ABA can treat in a reasonable amount of time and what symptoms ABA cannot treat. In doing so, appropriate referrals should be considered, such as those for medication evaluation because a medication may help improve symptoms including agitation or inattention and increase focus and learning, greatly increasing a member's ability to benefit from ABA.
- » Ongoing assessment should be used to inform goals and evaluate all services, including social skills and communication training to ensure cohesion in treatment. A slow rate of progress, lack of progress, or increase of symptoms should be clearly addressed by each provider for every treatment plan. Barriers to progress should be addressed with a clear action plan.
- » Provider engagement is of the utmost importance to a successful payer strategy. At Centene, providers are called upon to develop unique treatment plans that incorporate best practices with the goal of movement toward progress and outcomes. Education and case shaping recommendations are examples of two pieces of Centene's provider engagement strategy. Centene has a dedicated team of practicing psychologists who perform peer-to-peer reviews with providers. With dedicated rounds focused on care planning and treatment, providers can feel confident and comfortable in receiving consult from their peers. This enables Centene to provide insight and education about the best methods of utilization and prescribing, further enhancing relationships and promoting collaboration.

- » To further promote a culture characterized by the highest quality of care, Centene is currently exploring implementation of innovative value-based contracting, including a pay-for-outcomes model designed to fit provider needs while delivering the right care, at the right time, in the right place to members. Performance is measured by achieving milestones along each member's care journey, resulting in better outcomes and quality of life for members.
- » An industry standard is needed to better assist providers in their planning, measurement of treatment efficacy, and ensuring individuals receive comparable care regardless of payer or provider. Measurement generates behavioral data facilitating evaluation, monitoring, decision making, and reporting progress toward goals.



FEDERAL & STATE POLICY

In absence of defined industry standards and regulations, Centene has conducted literature reviews and assessed the status of ABA implementation and measurement across the United States. Centene strongly supports and encourages the use of evidence-based practices in the treatment of ASD.

- » The federal government and state Medicaid offices have responded to an increasing demand for treatment by implementing insurance reform legislation. The Center for Medicaid and CHIP Services (CMCS) has established that services for those with ASD should be provided as part of state Medicaid plans. Although the policy has limited reference to ABA treatment, many states have begun to include ABA as a benefit for adults and children. To ensure those with ASD have opportunity to achieve their best quality of life, Centene has responded to the need by providing benefit coverage for ABA services and other evidence-based practices as appropriate.
- » States who have implemented more robust autism insurance mandates have achieved growth in care providers, with approximately 39% more Board Certified Behavior Analysts (BCBAs) who provide behavioral therapy, and 17% more child psychiatrists.¹⁶ Continued state support and expansions of these mandates will prove positive in alleviating the intense pressure on the provider workforce and improving care access to members. However, there is need for better coordination among public and private entities to reduce duplication of services and efforts. Payers should advocate for better coordination, which results in enhanced outcomes and an improved experience for the member and the caregiver, and helps reduce health care expenditures on unnecessary services.
 - » Centene Advanced Behavioral Health's National Autism Center coordinates care among multi-disciplinary providers and community resources such as parent support groups and respite services, to help families and caregivers adjust to caring for an individual with ASD and the challenges of navigating treatment.
- » As research has shown, there is inequity in care and the detection of ASD for low-income families and minority groups. A recent study revealed that Black children with ASD experience delays of approximately four years after parents first raised concern in diagnosis and service access.¹⁷ Because the importance of early identification and early treatment initiation is well documented, this must be addressed.
 - » Early in 2020, Centene convened a group of medical, non-profit, and community leaders to form the Centene Health Disparities Task Force. The task force studies the causes of healthcare disparities among the most vulnerable and recommends actions to address such disparities. Through targeted outreach to members, providers, community leaders, non-profit organizations, tribal governments, and government officials, the task force ensures all stakeholders are informed, educated, and empowered to address disparities. As Centene has worked to address inequity in care through these efforts, other payers and government entities must also continue efforts to ensure early, timely, and equitable enrollment in services.



Centene

partners with

**Easterseals
Midwest**

to prepare

young adults

with developmental and
intellectual disabilities

for a future of

**competitive
employment**



- » Payers and providers can advocate for coordination of services such as speech-language pathologists and audiologists as appropriate for evaluation and treatment as part of Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) coverage. Through education initiatives for parents and caregivers, a better understanding of development and barriers to learning can be achieved during participation in the EPSDT, fostering a proactive approach to gaining understanding in next steps for follow-up and support.
- » Medicaid and the Individuals with Disabilities Education Act (IDEA) provide for direct services and funding of most community-based services for those with ASD. There is opportunity to support government programs that assist people with ASD to better function within community domains such as education, employment, transportation, and housing. Centene has long been committed to providing employment opportunities for diverse communities, including people with disabilities.
 - » One of the ways Centene worked to achieve integrated, whole-person health and wellness was by establishing a National Disability Advisory Council (CNDAC) in 2012, made up of top disability rights leaders and heads of national disability-focused advocacy organizations. As an advisory council, the CNDAC provides expertise and a strategic vision for best practices that help shape the company's disability policies, as an employer and as a managed care provider. The CNDAC also brings awareness and partnership to appropriate Centene-supported legislation and policy related to disability rights and advocacy. In 2021, the co-founder of the Autistic Self Advocacy Network (ASAN) and leading advocate in the disability rights and policy community joined the advisory council, helping to strengthen the voice of those with autism.

Summary

Ensuring those with ASD receive the best and most appropriate care is essential, not only for the betterment of individuals' lives, but also the lives of families and for our nation as a whole. As payers, we must address gaps by overcoming disparities in healthcare access, implementing evidenced-based best practices, and standardizing outcome measures. Through partnership with providers, we can strengthen sound clinical decision-making, which is essential to achieving fiscal responsibility and employing the most beneficial treatment. Centene remains unwavering in its commitment to improving the physical and mental health of the vulnerable populations it serves, and is proud to be a leader in advancing the industry's efforts in to care for those diagnosed with ASD, providing guidance and support for caregivers, and mitigating barriers so all can receive the services they need to live their best lives.

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