

# Autism Spectrum Disorder

A DEVELOPMENTAL DISORDER AFFECTING COMMUNICATION AND BEHAVIOR

## Why It's Important

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by differences in communication, social interaction, and repetitive or restrictive behaviors or interests.<sup>1</sup> It is identified as a spectrum because the severity of symptoms and support needs presents differently in each person. People with ASD also have an increased risk of co-occurring physical and mental health conditions such as sleep disorders, gastrointestinal disorders, anxiety, suicide, seizures, overweight/obesity, and visits to the emergency department.<sup>2</sup>

Signs of ASD begin in early childhood, and sometimes can be seen as early as one year of age.<sup>1</sup> It is important to be able to identify the early symptoms of ASD to connect individuals with ASD and their families to supports and services and plan for future needs. Early intervention services and supports help babies and toddlers with developmental delays or disabilities and their families.<sup>3</sup> This may include speech therapy and physical therapy. Research suggests that the cost of lifelong supports can be significantly reduced by as much as two-thirds with effective early diagnosis and appropriate intervention with lifetime savings per individual with ASD to ranging from \$656,000 to \$1,082,000.<sup>5,6</sup>

Although there is an increased need for health care services, compared to other children and youth with special health needs (CYSHN), children and youth with ASD are more likely to have difficulties receiving referrals, report financial difficulties related to health care costs, and report that care was not “family-centered”.<sup>7</sup>

## The Long Road to Diagnosis and Services

The Minnesota Autism and Developmental Disabilities Monitoring (MN-ADDM) Network, one of 11 national centers funded by the Center for Disease Control to collect data on autism prevalence, found that Minnesota’s prevalence rate for autism is 1 in 44 - the third highest rate nationally.<sup>4</sup> The average age of autism diagnosis in Minnesota is 4 years, 8 months – far later than the age ASD can be reliably detected (18 months). Of all records reviewed for MN-ADDM, 76 percent of records had evidence of autism as early as age three. Yet, only 39 percent received a comprehensive developmental evaluation by three years of age.<sup>4</sup> This discrepancy indicates that while parents and providers are picking up on the need for a developmental evaluation and supports early, systems barriers extend the time to when individuals with ASD and their families can reach those needed interventions.

The average time reported by most providers when referring children for a diagnostic evaluation for ASD is eight to ten months; after which children are often added to a new wait list to receive intervention. This can mean waiting multiple years to get a diagnosis, evaluation, and enrollment in services.

## Diagnosis Starts with Screening

Although the American Academy of Pediatrics (AAP) recommends universal screening for ASD, follow through in pediatric primary care providers is limited. A recent national study of 481 family practice physicians and pediatricians found that only 17 percent of them routinely screened for ASD according to the AAP guidelines.<sup>8</sup> In Minnesota, social-emotional or mental health screening for Medicaid-eligible

children is recommended, however, since it is not required, providers can still choose whether to provide this screening.

## Knowledge Gaps and System Barriers for Providers and Organizations

Qualitative research has found that although providers report a desire to improve their services for children with Autism Spectrum Disorder/Developmental Disability (ASD/DD), they also report training and knowledge gaps as significant barriers to making these improvements.<sup>9</sup> Primary care providers reported having little confidence managing sleep problems, anxiety, depression, and aggression in particular for ASD, and also reported limited knowledge of community supports, services, and therapies for ASD.<sup>10</sup>

A 2019 Minnesota Department of Human Services report of Managed Care Organizations listed their top barriers to ASD screening, diagnosis and initiation of services as:

- Families struggle to identify the early signs of ASD.
- Families may be reluctant to follow-up on referrals or accept their children are experiencing developmental delays.
- Families who do not speak English as a first language may have difficulty understanding the tools because they are not adapted to their language, values, and customs.
- High costs of purchasing and training staff on ASD-specific screening and diagnostic tools.
- Lack of coordination between service providers.
- Shortage of qualified providers in the state who are trained to provide screening, diagnosis, and treatment.

Even after a child finally receives a diagnosis for ASD/DD, there are still challenges in the management and ongoing care. The combination of complex developmental and other co-occurring medical conditions has proved difficult for both primary and specialty clinicians to provide quality care.

*“I have had a child on my caseload wait in a pediatric hospital for eight days for an available bed. There were available beds, but he was turned away due to having autism and the facility not being able to meet their needs or the individual would not ‘fit’ into their programming due to the autism.” – Needs Assessment Discovery Survey Respondent*

## Financial Barriers

Therapies and other services can help mitigate symptoms and reduce the long-term need for significant supports, families often experience barriers in knowing about and accessing these services. Many parents report having to stop work to care for their child with ASD.<sup>11</sup> Annual medical expenditures per child with an ASD range from \$2,100 to \$11,200. Additionally, intensive behavioral interventions for a child with an ASD can cost from \$40,000 to \$60,000 per year and nonmedical costs of special education for a child with an ASD are about \$13,000 per year.<sup>12</sup> According to the Minnesota ASD Qualitative Study, families reported that insurance does not cover adequate ASD services (e.g., specialized services not covered, caps on the number of covered services, providers not accepting more Medicaid patients, etc.).

## Focus on Health Equity

In the Minnesota ASD Qualitative Study examining the experience of culturally diverse families with a child/youth with ASD, parents reported experiencing multiple challenges as they tried to access ASD-related services. Family-level challenges included stress of caring for a child with ASD and fear for their safety, competing work and family demands, impact on parents’ and family health as well as financial

wellbeing, and lack of knowledge about available resources. Provider-level challenges included language barriers, concerns providers held back information about services, and lack of follow-up. Systems-level challenges included long waitlists for services, the complexity of navigation, lack of support services for parents and other family members, language and cultural barriers, and transportation issues. Concerns about unauthorized immigrant status among Latino parents (whose children are likely US-born) intensified challenges to accessing services.<sup>13</sup> Families highlighted a need for services for young adults with autism to help fill the current void when the young adult is transitioning from school to the adult world – this includes housing and job training for young adults with ASD. Finally, respite care provided by members of one’s own cultural community was expressed as a significant need.<sup>13</sup>

## Resources for Families and Providers related to ASD

[Minnesota Autism Resource Portal \(https://mn.gov/autism/\)](https://mn.gov/autism/): Website that provides the Minnesota Autism community up-to-date information and resources related to ASD. Created as a result of a joint state agency effort, including the Minnesota Departments of Education, Health, Human Services, and Employment and Economic Development.

[Minnesota Early Intensive Developmental and Behavioral Intervention \(EIDBI\) Benefit \(https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/eidbi/eidbi.jsp\)](https://mn.gov/dhs/partners-and-providers/news-initiatives-reports-workgroups/long-term-services-and-supports/eidbi/eidbi.jsp): The EIDBI Benefit provides medically-necessary early intensive intervention for people with ASD and related conditions.

[Pathway to Services and Supports for ASD \(https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751-ENG\)](https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6751-ENG): Informational flyer that provides information resources available for families. Flyer is geared toward staff from lead agencies, providers, health care professionals, educators, and other stakeholders.

[Cultural Responsiveness in ASD Services \(https://www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_DYNAMIC\\_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs-319148#\)](https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs-319148#): Introductory level course gives an overview of and provides strategies for culturally responsive practices when providing services to people with ASD and related conditions.

## Important Note on Equity and Intersectionality

The Minnesota Department of Health’s Title V Needs Assessment team acknowledges that structural (social, economic, political and environmental) inequities can result in poor health outcomes across generations. They have a greater influence on health outcomes than individual choices or a person’s ability to access health care, and not all communities are impacted in the same way.

**All people living in Minnesota benefit when we reduce health disparities.**

We also acknowledge that the topic addressed in this data story does not exist in isolation– which is important to remember as we do needs assessments and as we start thinking about how we approach solutions. In addition to the needs themselves being intersectional, there are also intersecting processes and systems through which power and inequity are produced, reproduced, and actively resisted.

## Citations

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