

AN UPDATE ON AUTISM SPECTRUM DISORDER PART 2: THROUGH AN INSURANCE LENS

Abstract

During the past 30 years, autism spectrum disorder (ASD) has emerged as one of the faster-growing diagnosed disorders of childhood. Its growth in prevalence among children has led to the need for a much greater focus on this area from not only a clinical lens, but also an insurance one.

Autism is also not just a disorder of children. According to the CDC, more than 5.4 million adults (>2% of the population) in the U.S. alone have ASD. In addition, a 2022 study found that adults with autism comprise 0.6% of the world's adult population.

An additional concern with ASD is the many comorbidities linked to it that are known to impact the health and wellbeing of those with the disorder.

Assessing risk for ASD, however, is still inherently difficult due to the heterogeneity of its manifestations, as well as gaps in the clinical understanding of its pathogenicity, its potential comorbidities, and its variable long-term prognosis. This usually means that in addition to clinical information, social, educational, and behavioral information is routinely required in order to develop a comprehensive assessment when reviewing applications indicating ASD in the medical history.

This article, the second of two parts, provides a comprehensive review of the insurance medicine view of ASD and issues around its assessment when underwriting. To read Part I, please [click here](#).

Applications to Insurance

As Autism Spectrum Disorder (ASD) prevalence, awareness, and research have grown over the past 15 years, so have the juvenile insurance market. In the last five years, this segment has been a leading growth sector, with annual global growth forecasted at approximately 10% to 15%.¹ This growth partly reflects increasing awareness of and knowledge about juvenile diseases in general (and ASD in particular) among insurers and the buying public, greater growth in disposable income, more options available for healthcare and therapies for younger ASD individuals, and rising healthcare costs.

Coverage needs for juveniles overall are growing quickly. Awareness and understanding are increasing of ASD as well as other chronic neurodevelopmental disorders, and of the fact that ASD's physical and economic outcomes are similar to those of adults with critical illnesses.

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This is generating rising demand for products for this age group – particularly for juveniles with special needs. Families of children with such needs are seeking insurance products that will provide appropriate and supportive treatment and management benefits. A large number of products now specifically target this demographic, and more are on the way, as families with a child who has had an ASD diagnosis may be motivated early to purchase insurance coverage for their child to guard against long-term health implications.

Understanding ASD Applicant Risk

With ASD prevalence on the rise and greater diversification of juvenile insurance products, more families are seeking long-term life and living benefits insurance options for their affected children.

Insurance companies will need to know how to stratify the risk properly for life, total and permanent disability (TPD), and critical illness coverage options.

- **Mortality Risk.** Overall, mortality risk for children and young adults in the general population is very low, and for children and young adults with ASD, also very low in absolute numbers. However, when compared with the non-affected segment of this demographic, the overall risk is higher.² A long-term longitudinal study following an ASD cohort found the absolute risk was about double that of the general population in the younger age group.³ Causes are often linked to injuries and accidents sustained through misadventure, or due to comorbid psychiatric, neurological, or developmental disorders.⁴

With associated comorbidities, the mortality risk rises even further. Psychiatric disorders affecting mood

or anxiety, for example, increases ASD mortality risk slightly,^{5,7} but epilepsy approximately triples the risk⁶. Evidence also shows that younger adults with ASD have higher rates of suicide attempts later in life, independent of any associated psychiatric illness.⁸

- **Morbidity Risk.** Many comorbid conditions occur with ASD, or ASD is a part of the wider spectrum of symptoms found in developmental situations. For example, about 40% to 50% of individuals with Tuberous Sclerosis Complex, a genetic condition where benign tumors develop in major organs such as the brain, heart, lung, and kidney, leading to potential serious effects on organ function, also have ASD.

Commonly occurring comorbid conditions of ASD include:⁹

- Neurodevelopmental disorders
 - ADHD
 - Intellectual disability
- Psychiatric disorders
 - Anxiety and mood disorders (often worsen in adolescence and adulthood)
 - Severe aggression
 - Self-harm behaviors
- Medical conditions
 - Epilepsy
 - Tuberous Sclerosis Complex
 - Feeding and gastrointestinal difficulties
 - Weight extremes
 - Sleep difficulties
 - Self-care challenges (e.g., dental or skin care), which can lead to hygiene-related problems





Prognosis

The natural progression of ASD generally leads to poorer outcomes for social, psychological and physical wellbeing. In some cases, through early intervention and ongoing care strategies, some with mild ASD are able to live and function a close to normal life. In others, however, the individual with ASD is unable to function independently, requires higher levels of general and mental care, and finds it difficult to obtain and maintain employment.¹⁰

Severity of outcomes can be difficult to predict accurately, especially for children under three years of age. As firm evidence suggesting clear predictive signs and symptoms is lacking, future long-term mortality, morbidity, and functional capabilities need to be extrapolated from current states of function and interventions being undertaken. Even though great improvements are possible in cases where symptoms are or become mild or may be non-impactful, a person with ASD is still likely to retain some features of the disorder as they grow into adulthood.¹¹

Prognostic Factors^{12, 13, 14}

Prognostic factors for children with ASD indicating more favorable outcomes include:

- Early intervention
- Active participation in therapies
- Higher cognitive abilities

- Ability to play
- Better verbal communication abilities
- Attempts to socialize, share, show interest in others
- Fewer or less severe comorbid conditions (e.g., less severe ADHD)
- Lack of hospitalizations related to ASD and its associated comorbidities
- Able to participate in certain mainstream activities (e.g., school)

Conversely, prognostic factors that may indicate less favorable outcomes include:

- Lack of socialization, sharing, or interest in others by age 4
- Limited verbal vocabulary by age 5
- Severe ASD symptoms
- Lower cognitive abilities (such as IQ <70)
- Comorbid conditions, genetic conditions
- More frequent hospitalizations related to ASD and associate comorbidities
- Less access to therapies / lack of therapeutic interventions
- Older age at diagnosis
- High level of care requirements

As children grow older, the focus of the above factors will evolve into areas such as schooling, independent living and function, employment, and serious co-morbid complications.

Assessment of ASD underwriting cases, both for juveniles and adults, will likely need closer and more careful review. When assessing the risk, it may be prudent to account for both baseline risk and age-appropriate prognostic markers. This more individualized approach may be more nuanced and balanced, and could increase risk assessment accuracy, especially for very young patients.

In understanding the disease, it also indicates that how a child with ASD is assessed for cover is likely to differ depending on the product. Risk appetite for traditional life and critical illness (CI) products, for example, might be different from that for TPD and CI products that include specific neurodevelopmental and juvenile benefits.

Case Studies: Case 1

Applicant information

- Application for a 3-year-old male for a traditional life/CI/TPD bundled product
- Diagnosed with ASD at age 2½ (six months prior)
- Therapy begun upon diagnosis and monitored by developmental pediatrician
- No other medical history items noted on application form
- No current medications

In many instances, limited information may be presented upon first application and will require additional information to assess correctly, such as:

- Developmental history – cognitive function, milestones
- Verbal communication capabilities
- Social function capabilities
- Severity level
- Any schooling, whether mainstream or not
- What therapies have been undertaken and their results
- Comorbidities, any underlying related disorders

Discussion

The additional information can help stratify the likely risk into mild, moderate, and severe cases. Depending on the type of coverage, risk appetite of the product, and also underwriting guidelines in place, there may be different outcomes for this case.

In the case of a toddler-age child only recently diagnosed, it may be prudent to postpone writing cover until the child is older in order to enable a more comprehensive assessment. Many insurers may choose to postpone consideration until the child is in school and has had longer duration of therapy and/or treatments to see if functional capabilities and symptoms have stabilized in order to assess and stratify risk with more accuracy.

In cases involving very young applicants with ASD, underwriting frameworks may be in place to utilize available information and extrapolate into the different categories. In such cases, where a decision on long-term outcomes is made within the limits to be placed on very young applicants, it is important to weigh any factors that may predict a better outcome (such as early diagnosis or early intervention) versus less favorable factors (such as low cognitive functioning and associated comorbidities).

In general, for living benefits cover such as CI and TPD for very young ASD-diagnosed applicants, appropriate exclusions for ASD disease management and complications will often be warranted.

Case Studies: Case 2

- Application for a 16-year-old male traditional life/TPD/CI bundled product
- Diagnosed with ASD at age 5
- Initial symptoms: speech delay, reduced social interaction, repetitive behaviors
- ASD managed by pediatrician and psychiatrist
- Underwent behavioral therapy regularly
- No medications for ASD prescribed to date
- Currently in mainstream school with additional support
- Able to function well and independently both in and outside of school
- Still has some trouble socializing and making friends, but does attempt
- No comorbid disorders
- Only biannual follow-ups

Discussion

This case is that of an older adolescent with a longer history of ASD.

The history provided has more detail, enabling a clearer and more precise overall picture of the applicant's ASD history, treatments over time, disease progression, and current severity level.

Although more information was provided for this individual than for the individual in Case 1, it still may be prudent to request additional complementary material, such as school reports, recent psychiatrist/treating physician reports, and cognitive or behavioral testing outcomes, so as to corroborate the available history.

This case has several indicators of potentially positive outcomes, as his symptoms have been shown to have diminished over time due to long-term interventions and therapy. Based on this history, he may have a milder form of ASD and so is likely to have a more favorable prognosis in terms of mortality and morbidity. He therefore may be a candidate for the insurance.

Still, as per the previous case, appropriate exclusions for living benefits coverage for ASD and its complications may be warranted.

Product Development

Development of products that cover ASD, especially as part of CI plans, has been rising. It is mainly being driven by customer demand and awareness of this population's healthcare issues and needs.

Like mental health, neurodevelopmental disorders were traditionally on the exclusions list. Newer product designs,

however, are recognizing that the burden of disorders such as ASD may be similarly impactful to traditional CI diagnoses.

When formulating benefits for ASD cover, it is essential that critical disease factors be incorporated to ensure benefit appropriateness as well as cost and utilization risk containment.




Considerations around factors such as anti-selection, appropriate levels of monetary coverage that reflect the longer term, chronic, and costly nature of ASD, and the likelihood of high utilization of additional benefits, should be taken into account. The difficulty in long-term prognostication for very young ages as well as certain aspects of disease pathophysiology, progression, and impact on mortality and morbidity, can impact decisions on cost, pricing, and segmentation. Despite these challenges, it is worthwhile to consider expanding coverages to include ASD and provide benefits to a vulnerable population in need.

Conclusion

ASD is a chronic condition with increasing prevalence, mainly due to better screening and caregiver awareness. Over the past decade, improvements in understanding and treating the disease have seen better outcomes in prognosis. However, the potential comorbid disease associations and other genetic factors still predispose a child with ASD to higher mortality risk, morbidity complications, and in most cases a lower quality of life compared to the general population.

As prevalence of ASD is expected to continue rising among juveniles, people with this disorder are likely to be encountered more frequently by insurers. While the

disorder itself is multifaceted and individual cases can vary substantially, some general principles can guide risk assessments.

- Understand the disease afresh: spend time learning about its issues, including pathogenesis, symptoms, diagnosis, treatment and prognosis; and ask for information from a broad range of diagnostic, therapeutic, and functional information sources, such as:
 - Doctors (pediatricians, psychiatrists)
 - Clinical psychologists
 - Therapists
 - School reports
 - Educational
 - Counselors
 - Therapists
 - Social workers
 - Assess each case on its own merit
 - Every case will involve a complex assessment of potential current and future risk.
 - Not all cases will fit neatly into existing underwriting guidelines.
 - Multiple subject matter experts may be needed to analyze the information and determine possible outcomes.
 - When in doubt, ask for help (e.g., medical officers) and get to a solution together. 

References

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