03

# Medical Comorbidities

ASD AND GASTROINTESTINAL DISORDERS

ASD AND SLEEP DISORDERS

ASD AND ANXIETY, ASD AND ATTENTION DEFICIT HYPERACTIVITY DISORDER

ASD AND SEIZURE DISORDERS

Because children with developmental disabilities (DD) will often meet the diagnostic criteria for more than one DD, making a definitive diagnosis can be challenging. Further, children with DDs, including ASD, frequently have co-occurring medical conditions that complicate the delivery of treatment and necessary interventions. Several studies have examined the link between ASD and comorbidities and have found varying prevalence estimates, but significant impacts.[32] [33]

At the time of initial diagnosis of ASD, children should be screened for comorbid medical conditions and referred to a specialist for a full evaluation and treatment. The importance of identifying comorbid, health-related conditions associated with ASD are multiple. Many of the conditions can be treated, and if identified and managed, can result in an improved sense of well-being, more effective participation in educational and therapeutic programs, and improved quality of life for the child and the child's family. In addition, identification of specific medical disorders may help physicians and researchers better understand medical conditions associated with ASD and develop more detailed protocols for assessment and treatment.[34]

Several of the most common and significant comorbid medical conditions are described in detail below. However, there are numerous other comorbidities that also add to the complexity of caring for a child with autism.

32 "Concurrent Medical Conditions and Health Care Use and Need among Children with Learning and Behavioral Developmental Disabilities," *National Health Interview Survey*, 2006-2010.

33 Bauman, Margaret L., "Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment," 2010.

34 ibid

According to a report completed by researchers at the CDC,[35] after adjusting for a child's sex, age, race/ethnicity, and mother's education, children with autism were found to be:

- 1.6 times more likely than children without developmental disabilities to have asthma,
- 1.7 times more likely to have eczema or skin allergies,
- 2.4 times more likely to have food allergies,
- 17.8 times more likely to experience stuttering,
- 2.4 times more likely to have had more than three ear infections in the last 12 months, and
- 1.8 times more likely to have chronic severe headaches.

35 "Concurrent Medical Conditions and Health Care Use and Need among Children with Learning and Behavioral Developmental Disabilities," *National Health Interview Survey*, 2006-2010.

# ASD AND GASTROINTESTINAL DISORDERS

The exact prevalence estimate of ASD and gastrointestinal disorders, including gastroesophageal reflux disease (GERD), chronic constipation, diarrhea, celiac disease, or inflammatory bowel conditions is largely unknown, but estimates range from between 9% and 70% or higher.[36] A National Health Interview Survey from 2006-2010 showed that children with ASD were 7.1 times more likely to have had frequent diarrhea or colitis within the last 12 months and 2.6 times more likely to have stomach or intestinal illness with vomiting or diarrhea within the past two weeks than children without any developmental delay.[37] At present, the prevalence of gastrointestinal abnormalities in individuals with ASD is not fully understood.

Part of the difficulty of identifying comorbid medical conditions is that children with ASD may not exhibit symptoms in an easily recognizable manner. For example, children with gastrointestinal distress may tap their chest, apply pressure to their stomach, or act out in school. Diagnostic evaluations for patients with ASD and gastrointestinal symptoms therefore can be complex, especially when the patient presents with behavioral manifestations.

An expert panel convened in 2010 identified key guidelines regarding ASD and gastrointestinal distress and how care providers should approach treatment delivery.[38] According to this panel, pediatricians and other primary care providers should be alert to potential nutritional problems in patients with ASD and should refer the patient for an evaluation by a nutritionist and/or dietician who is familiar with nutrition support for individuals with ASD to the extent that caregivers raise concerns about the patient's diet. Children with ASD should be referred for consultation with a gastroenterologist specialist.

Anecdotal reports suggest there may be a subgroup of individuals with ASD who respond to dietary interventions, although additional data are needed before pediatricians and other professionals can recommend specific dietary modifications.

As noted above, children with ASD are 2.4 times more likely to have food allergies. As such, pediatricians and other primary caregivers should obtain a detailed history (including personal history of allergic disease, dietary history, and family history) to identify any potential associations between allergen exposure and gastrointestinal and/or behavioral symptoms. Involvement of specialists such as allergists and feeding therapists may be beneficial.

Clear guidelines for the management and treatment of ASD and gastrointestinal disorders are not universally accepted. However, the wide variation in prevalence rates of co-occurring gastrointestinal disorders in children with ASD and the vast array of research studies conducted to date suggest that caregivers and health care providers should be educated and trained on how to recognize both typical and atypical signs and symptoms of gastrointestinal disorders in individuals with ASD and that diagnosticians and primary medical providers should refer the patient to specialists if symptoms are identified. Our Lady of the Lake Children's Hospital has a pediatric gastroenterology medical group in Baton Rouge.

36 Bauman, Margaret L., "Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment," 2010.
37 "Concurrent Medical Conditions and Health Care Use and Need among Children with Learning and Behavioral Developmental Disabilities," National Health Interview Survey, 2006-2010.
38 Buie, Timothy; Campbell, Daniel B.; et al, "Evaluation, Diagnosis, and Treatment of Gastrointestinal Disorders in Individuals With ASDs: A Consensus Report," 2010, http://pediatrics.aappublications.org/content/125/Supplement_1/S1.

# ASD AND SLEEP DISORDERS

Sleep disorders are one of the most prevalent co-occurring conditions for children with ASD. Often, sleep disorders manifest in children having difficulty falling asleep or staying asleep through the night, with some children experiencing nightmares, and other sleep disorders. The prevalence of sleep disorders varies from 40% to 80% of all children with ASD as compared to 30% of children without a developmental disability.[39]

Without appropriate intervention, sleep disorders can result in daytime drowsiness which affects overall health and well-being. In addition, without proper sleep, children cannot focus to benefit from therapeutic interventions, may become hyperactive, or struggle with maintaining attention. Studies have suggested that aggression, hyperactivity, emotional reactivity, and anxiety were exacerbated in children with ASD who also struggled from sleep disorders.[40]

All children with ASD should be screened for a potential sleep disturbance and pending the results of the screening, should be referred to a sleep specialist or neurologist. Currently, Our Lady of the Lake employs one pediatric trained sleep specialist and a second has recently been hired. Research related to the specific recommended treatment for sleep disorders shows varying levels of efficacy. Establishing a sleep program, using behavior interventions, and using pharmacologic interventions may be indicated depending on the child.[41]

39 Bauman, Margaret L., "Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment," 2010.
40 Sikora, Darryn M.; Johnson, Kyle; et al, "The Relationship Between Sleep Problems and Daytime Behavior in Children of Different Ages With Autism Spectrum Disorders," 2012, http://pediatrics.aappublications.org/content/130/Supplement_2/S83.
41 Bauman, Margaret L., "Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment," 2010.

# ASD AND ANXIETY, ASD AND ATTENTION DEFICIT HYPERACTIVITY DISORDER

At least 30% of people with ASD also have an anxiety disorder which can include social phobia, separation anxiety, excessive worry, and obsessive compulsive disorder. Children with ASD and anxiety disorders should receive treatment like behavioral intervention and pharmaceutics.

The prevalence of attention deficit hyperactivity disorder (ADHD) in children with ASD is reported between 30% and 50%. Similarly, approximately 2/3 of children with ADHD show features of ASD.[42]

Recent research suggests that the "co-occurrence of ADHD and ASD is associated with a lower quality of life and poorer adaptive function than in any one of these conditions. Both disorders often include difficulties in attention, communication with peers, impulsivity, and various degrees of restlessness or hyperactivity. Both are more common in boys than in girls..."[43] Children with ASD and ADHD are frequently treated with pharmaceuticals and behavioral intervention focused on social learning theory.

42 Leitner, Yael, "The Co-Occurrence of Autism and Attention Deficit Hyperactivity Disorder in Children – What Do We Know?," 2014.
43 ibid

# ASD AND SEIZURE DISORDERS

Children and adults with ASD experience seizures more frequently than their typically developing peers – 20 times more frequently, as reported by the National Health Interview Survey.[44] Prevalence estimates of seizures in children with ASD range from 7% to 14% and in adults with ASD from 20% to 35%.[45] All types of seizures – major motor, myoclonic, febrile, and complex partial – have been reported in association with ASD.

Challenges in identifying seizures in children with ASD abound, as atypical movements that would typically suggest the clinical manifestation of a seizure can be found in many children with ASD without seizures or with another co-occurring condition, such as gastrointestinal distress. Any child with ASD who exhibits behavior such as "staring spells, cessation of activity, eye fluttering, or eye deviation to one side, as well as behavioral changes associated with confusion or followed by fatigue or sleep should raise the suspicion of complex partial seizures, and should lead to further investigation."[46]

Although the research is not clear-cut in terms of the prevalence of the multiple medical comorbid conditions, evidence is clear that there are numerous medical conditions that present more often in children with ASD than they do in children without any developmental disability.

The identification and treatment of comorbid conditions is critical to the well-being of children with ASD, since the earlier these co-occurring diseases are diagnosed and treated, the more effectively a child with ASD can participate in educational and therapeutic interventions. Unfortunately, many of these comorbid conditions are often more difficult to recognize and diagnose in a child with ASD due to an inability to communicate discomfort and relay symptoms effectively.

Regardless of which type of specialist makes an initial ASD diagnosis for a child, all children should undergo a comprehensive diagnostic evaluation by a medical specialist such as a neurologist or developmental pediatrician trained to recognize medical comorbidities such as the ones described above. To the extent co-occurring conditions are identified, the child should be referred to additional specialists for further evaluation and treatment. Today, in the Capital Region, this process involves parents visiting and coordinating among numerous physicians and providers, which is not only time-consuming and confusing, but can also lead to inconsistent information and treatments. There is a lack of coordination among the initial diagnostician, a child's primary treatment physician, specialists treating various comorbid medical conditions and a child's therapists. Ideally, a child's behavioral treatment plan should be developed, implemented, and changed as needed *in collaboration* with the child's medical caregivers to ensure each of the treatment plans complement each other and to ensure there is open communication about how changes to one treatment plan may affect the child's behavior or response to other types of treatments.

44 "Concurrent Medical Conditions and Health Care Use and Need among Children with Learning and Behavioral Developmental Disabilities," *National Health Interview* Survey, 2006-2010.
45 Bauman, Margaret L., "Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment," 2010.
46 ibid

# SPOTLIGHT: **A NEURODEVELOPMENTAL THERAPY CENTER & AUTISM TREATMENT CLINIC FOR BATON ROUGE, LA**

The Our Lady of the Lake Pediatric Development & Treatment Center (PDTC) is leading an effort to open a Neurodevelopmental Therapy Center & Autism Treatment Clinic in Baton Rouge.

The goal is to develop a state-of-the-art, stand-alone pediatric neurodevelopmental and behavior diagnostic and treatment facility designed to assess the comprehensive health needs of children with behavior issues and neurodevelopmental disabilities, including ASD, by addressing their underlying co-morbid physical health conditions as a component in the overall diagnosis and treatment plan. This facility would focus on neurodevelopmental disabilities as an anchor for diagnosis, teaching, research, and multi-disciplinary assessments including social work, behavioral intervention, genetics testing, nutritional counseling, physical assessments for co-morbid physical and metabolic dysfunction, and therapeutic delivery (speech therapy, occupational therapy, and physical therapy).

This proposed center will provide outpatient, inpatient, and critical care services for the developmentally and intellectually disabled, as well as children with significant co-morbid health issues. The facility would be placed directly adjacent to the new Children's Hospital so that services could be more easily integrated and to save operational costs, as well as reduce replication in services. The proposed facility would include six branches of operation:

- An Autism Center that would be a separate dedicated clinic focused on improving early diagnosis and treatment plans. The center will include parent education, as well as parent liaison/lay worker to assist with services and adult care transition. This center will also draw from clinics defined below, including hosting gastrointestinal and sleep medicine specialists to be integrally involved in care of patients on the autism spectrum.

- A Developmental Pediatrics/Rehabilitation Clinic to address developmental pediatrics, psychology services, and physiatry-physical medicine and rehabilitation physicians.

- A Neurology and Neurosurgery Clinic.

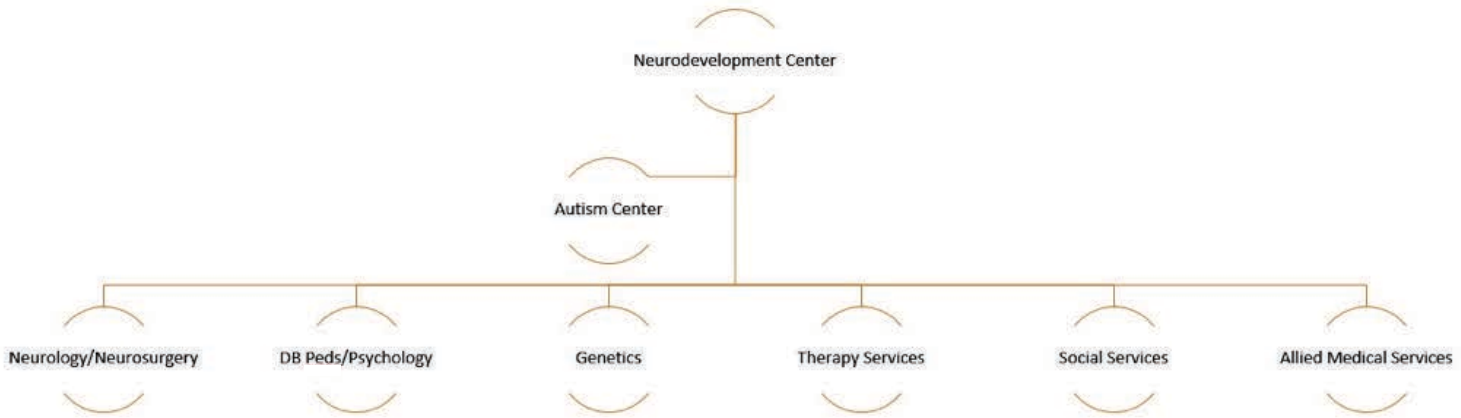
- A Genetics Clinic with a focus on personalized medical treatment plans and integrative health care.

- Pediatric Therapy Services, including therapeutic delivery of occupational, speech, and physical therapy.

- A Social Work and Community Liaison Division which will focus on educating parents and leading them through social services for which the child might be eligible. This division would assist with directing parents through paperwork and case management, as well as develop educational programming to enhance a continuum of care and provide marital and financial counseling so that families have an improved chance of retaining their nuclear function.

- Allied Medical Services to integrate with the existing Children's Hospital services and provide necessary medical treatments for co-morbid health conditions present in the developmentally/intellectually delayed and behaviorally disturbed population.

## Proposed Clinical Organizational Structure:




The Our Lady of the Lake Pediatric Development & Treatment Center envisions that this clinic would become a National Institute of Health Center of Excellence in this region in order to collaborate with entities like Pennington Biomedical Research Center and become a part of the Autism Treatment Network (ATN) system throughout the United States. As a recognized facility within this network, the center will more readily be able to access federal funds to support their ATN research and service activities. More information about NIH Centers of Excellence and the ATN can be found in the **ASD Research and National Center of Excellence Recognition** section of this report. Ultimately, this center would allow multiple care delivery models to occur under one roof and support families in seeking care for a child with comorbid medical conditions.

# 03 RECOMMENDATION

# MEDICAL COMORBIDITIES

Children with ASD will frequently be diagnosed with comorbid medical conditions that will affect the child's well-being and the efficacy of typical therapeutic interventions.

1. All children with ASD who present with symptoms of potential comorbid medical conditions should be referred to a physician specialist who can best determine the treatment regimen necessary.

   The Baton Rouge community should support the creation of a designated neurodevelopmental center, like Our Lady of the Lake's Pediatric Development and Therapy Center, that focuses on the treatment of medical comorbidities within an integrated developmental and behavioral care facility.