

# Mental Health in Children With Neuromuscular Diseases

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Many discussions of pediatric neuromuscular diseases center around symptoms and physical disabilities. But what about mental health? [Studies have found](#) that disabilities that restrict mobility, self-care, leisure, and community activities in adolescents negatively impact mental health and well-being. For young people living with neuromuscular diseases and their caregivers, prioritizing mental health is crucial for overall well-being.

Kayla Richards, LCSW, a pediatric social worker for UT Health Austin Pediatric Neurosciences at Dell Children's, points out that kids with neuromuscular diseases can have comorbidities, such as autism or attention-deficit/hyperactivity disorder (ADHD), and a lot of children with these diseases experience anxiety and depression. Depression is also a particular concern as children enter adolescence, a developmental stage when comparisons with peers are common. The degree of mental health conditions may be influenced by factors such as the child's prognosis, stage of disease progression, and level of understanding of their condition.

"It isn't uncommon for me to make referrals for mental health support at the onset of a diagnosis either for a child or teenager," Kayla says. She recommends establishing mental health care early because many in-network therapists have waiting lists, and it may take time to start services.

"It is also more beneficial to learn coping strategies when a person is not in crisis, as it is easier to practice and retain skills," she says. "Establishing a therapeutic relationship early on helps create a supportive and foundational relationship potentially before there is significant distress."

Kayla explains that pediatric neuromuscular disease can make some protective factors for families — such as community or relational support — more difficult, as the diagnoses themselves can feel isolating. "Therapeutic support for the whole family can help each member navigate the complexities of living with a chronic illness," she says.

## Support through school and social life

Feeling different from their peers at school and being dependent on caregivers can hinder a child's social life, which is crucial for development. That's why Kayla believes mental health support is vital. For some children, the opportunity begins in school.

"Parents or caregivers may benefit from contacting their child's school counselor and inquiring about mental health services, as some districts offer partnerships with licensed community-based therapists who can offer sessions during school hours," Kayla says.

When children are young, adults exert more control over kids' social activities and can ensure children with disabilities are included. As kids grow and increase their independence, children with disabilities may feel left behind.

"If I'm not ambulatory and have to rely on my caregiver, who might have their own responsibilities, I may not have access to build relationships or be involved in things that otherwise might be available to me," Kayla says. "These gaps in access and available programming continue to widen with age."

The result may be isolation, which is a risk factor for depression and anxiety.

## **Preventive action from the start**

"There's been an intentional shift in reducing stigma for mental health and making it a part of the societal conversation, and that is beneficial," Kayla says.

It is essential to have an awareness of specific symptoms that may come with a mental health diagnosis, such as not sleeping well or not eating, as these symptoms may impact mood. Providers can help their patients make those connections on the overlaps between physiological experiences in the body, like sleep hygiene.

Providers can use mental health assessments, such as the PHQ-9 or GAD-7, to get a window into how a child is coping and better monitor for potential crises. It's crucial for providers to check in with their patients and proactively discuss observed risk factors and how families can make preventive changes.

Providers can encourage parents and caregivers to be mindful of multiple domains in the child's life, such as friendships, familial relationships, sleep, eating, school, engagement, and motivation, and how they overlap. If the child is struggling, it's helpful to start having those conversations early.

"Just because something is 'normal' or typical for a child or teen to experience doesn't mean it is not difficult or that they wouldn't benefit from additional support. We want to make sure we are not devaluing or dismissing what is hard for a child," Kayla says. "There's a spectrum of mental health support available. It is important that interventions be targeted to the level of need and that patients are appropriately referred. Referrals may depend on your child's current level of functioning, including current/past risk of harm and/or safety concerns. Mental health services include outpatient counseling on a weekly or biweekly basis, intensive outpatient programs with programming 3-5 days a week, and inpatient psychiatric hospital admissions."

## Finding the right fit

It's important to be aware that there are disparities in access to healthcare and mental healthcare. When assessing a child's mental health, providers should consider factors such as where the family lives and their primary insurance, as both could limit access to mental healthcare.

"I think we often have this great intention of providing someone with a therapist who knows all about the diagnosis of a particular child. A lack of knowledge about a specific diagnosis does not necessarily mean the provider will be a poor fit for your child," Kayla says.

When making a mental health referral, Kayla recommends:

- Seeking a practitioner who can navigate the complexities of chronic illness and is open to learning about a particular diagnosis.
- Having resources available to help therapists better understand a patient's disease.
- Collaborating with a child's therapist about how their diagnosis may impact their activity level and what is recommended.
- Encouraging patients to use initial consultations to find a good fit.

"In addition to partnering with their child or teen's school, parents may also explore their county's assigned mental health authority," Kayla adds. "Families can initiate an assessment with their local mental health authority without a provider's referral. Many providers continue to offer virtual appointments, which can be a good option for some children and teens."

## Mental Health Resources:

- Visit MDA's [Mental Health Hub](#).
- Share MDA's [K-12 Education Resources](#) with educators and families.
- Find a therapist with this search tool: [psychologytoday.com/us](https://www.psychologytoday.com/us).
- Consult your integrated behavioral health team regarding what is available for patients in your area.