



WHITE PAPER

Lasting Lessons from the Pandemic:

Advancing the Understanding of Special Education and Therapeutic Needs of Children with Neurodegenerative Disorders



PROJECT/
/ALIVE



OUR PURPOSE

The challenges of the pandemic shined a light on the critical role of special educators and rehabilitative therapists to protect these children's skills.

As we move forward, these lessons serve as a guide for educational priorities and service delivery to children with neurodegenerative disorders.

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This project was an initiative of Cure Sanfilippo Foundation, the National MPS Society, and Project Alive, together with the expert clinicians and researchers at the University of Minnesota Neurodevelopmental Program in Rare Disease (NPRD).



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SUMMARY

When the COVID-19 pandemic halted in-person instruction, educators, therapists, and parents faced unprecedented challenges as they sought to maintain the delivery of educational and therapeutic services. Without any kind of model, new methods of delivering special education and therapeutic services arose out of necessity: Educators and therapists faced the burden of learning in the moment. The abrupt transition to distance delivery presented a unique challenge for children with neurodegenerative conditions who require consistent and intensive instruction and treatment to maintain their fragile skills.

This brief is designed for educators and therapists who play a critical role in protecting the neurocognitive function and quality of life of children with neurodegenerative conditions.

Anticipating continued pandemic-related or other unforeseen disruptions, this material serves to advance the understanding of the unique needs of children with neurodegenerative disorders and highlights educational and therapeutic service considerations.

While the focus of this initiative was neuronopathic mucopolysaccharidosis (MPS), MPS is not the only rare disease involving neurodegeneration, sometimes known as childhood dementia. This brief can serve as a guide for making educational and care decisions for the larger community of children impacted by neurodegenerative diseases when in-school teaching or in-clinic treatment is compromised.



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Childhood Dementia

The array of pediatric neurodegenerative conditions are collectively considered a form of childhood dementia. These children develop, but then unbeknownst to many, they reach a developmental peak and tragically begin to lose skills. These losses in cognitive skills, motor ability, social skills, and behavior may be fast, but they can also be subtle, inconsistently expressed, and hard to notice or measure. Like in Alzheimer’s in adults, once truly lost, these skills are not recovered. However, because it is often hard to determine if the skills are completely gone, every effort must be made to stimulate the skills’ use and protect them.

Time is the most critical factor; these children need consistent and individualized services in order to build skills as much as possible during windows of opportunity, as well as maintain those skills or slow their losses. While the devastating and unexpected path of these rare disorders make it difficult to adapt to the disease’s challenges, interventions play an essential role in how long children retain these valuable cognitive abilities.

Pandemic Findings

Throughout the period in 2020 and 2021, when in-person educational delivery was suspended:

- Children with neuronopathic MPS and other forms of progressive neurological disease had an increased loss of potentially unrecoverable skills due to barriers to adequate education and specialized therapy.
- Distance learning included screen instruction which many children with special needs could not learn from; out of this situation arose an inappropriate need for constant parent involvement to moderate, focus, and re-teach information to their child.
- Parental delivery of therapies under virtual consultation resulted in significant loss of therapeutic benefit.
- Parents saw an increase in behavioral challenges due to reduced understanding of sudden changes.
- 24-hour supervision and social isolation significantly increased caregiver burden

The Value of Education

Educators play a crucial role in protecting these vulnerable children's skills by implementing student specific educational activities that with consistent practice and positive reinforcement, help to slow the loss of abilities in such devastating neurologic disorders. Critically, they also support these children's quality of life and provide opportunities for joy, stimulation, and inclusion.

Special educators are frequently the greatest advocates for the right to a Free and Appropriate Public Education (FAPE), one that addresses and serves a child's specific needs. By law, this education must include goals based on the child's current level of academic or functional skills.

For children with cognitive decline, educational programming must be designed with the child's highly specialized needs in mind. Interventions must be flexible and meet the child where they are at that moment. The declining nature of their conditions should be fought with energy and stimulation. Children must not be excluded by the nature of their very low or worsening functioning. A purpose-built learning environment, social opportunities not available outside of school, and consistency allow these children to experience aspects of education and childhood that all children deserve.

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Educational Recommendations Moving Forward

With new COVID-19 variants, pandemic-related challenges to education are likely to persist into the next few years. As a result, school districts may be faced with a delayed return to "normal."

These guidelines review factors to consider as parents and educators plan for the academic year ahead and determine how to provide for children with neurodegenerative disorders in circumstances where in-school teaching or in-clinic treatment is compromised.

- It is critical that educators and therapists have the necessary information and training to understand these highly unusual diseases. They need to collaborate with the families and disease specialists to understand what approaches are appropriate to develop, maintain, and measure skills in neurocognitively-fragile children.
- Children with neurodegenerative disorders require the expertise and support of multiple domains of special education, and rehabilitative intervention and/or supportive therapies at a high level of service intensity (i.e., full-time or maximal frequency feasible for the family).
- In-person speech-language therapy needs to support communication abilities.

- In-person occupational and physical therapies can help alleviate the physical impact of the disease on learning and daily function.
- It is important that children are evaluated regularly by practitioners familiar with both the individual patient and neurodegenerative diseases in general, so that neurocognitive, communication, daily living, and motor skills changes can be recognized and that both clinical and educational interventions can be adapted accordingly.
- Alternative therapies such as music therapy, adapted swimming, art, and sensory rooms can allow the child to work on maintaining skills while also enjoying the time spent doing it. The relief these supports offer from the unrelenting disease burden translates to more days with better function and should be tailored to meet the needs of the children.
- Given the documented decline, consider whether a deviation from these supports, such as during the COVID-19 pandemic, is ethical or unavoidable. Prioritize strategies to safely resume this fragile community's access to in-person education and supportive care whenever possible.
- Advocate for resources to support appropriate in-home teaching and supportive care when necessary or desired by families to address a child's higher risk for adverse outcomes associated with infection during public health emergencies on an individual basis.

KEY TAKEAWAYS

Teachers and therapists play a crucial role in helping a child with a neurodegenerative condition develop and sustain skills for as long as possible.

Regardless of the academic or global situation, children with neurodegenerative conditions require multiple domains of special education, and rehabilitative intervention and/or supportive therapies at a high level of service intensity.

In-person education and supportive care, whether at school or in the child's home, is the best method for meeting the needs of children with neurodegenerative disorders.

This white paper summarizes the findings in Eisengart J, Esler A, Ellinwood N, Hudock R, King K, Klein K, Lee C, Morton J, Stephens K, Ziegler R, O'Neill C. Issues of COVID-19-related distance learning for children with neuronopathic mucopolysaccharidoses, *Molecular Genetics and Metabolism*, 2021, ISSN 1096-7192, <https://doi.org/10.1016/j.ymgme.2021.06.012>.

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