

Education of children with Sanfilippo syndrome: Identification of needs, challenges, and services required for children with Sanfilippo syndrome by their parents

Lauren Gotsell, Stephanie Harris, MaryAnn Campion, Laurel Calderwood
Boston University School of Medicine, Boston, Massachusetts

Mucopolysaccharidosis type III (Sanfilippo syndrome) is a progressive, life-limiting, inherited metabolic disease characterized by severe behavioral manifestations and medical complications. Sanfilippo syndrome is often categorized into three stages of disease progression: the first stage is characterized by developmental delay, after a period of seemingly normal development. The second stage begins in early childhood and includes severe behavior problems and progressive mental deterioration. Specifically, children with Sanfilippo syndrome struggle with destructive, impulsive, and aggressive behaviors. The third stage is defined by motor deterioration and further neurological decline, ultimately leading to death. The behavioral manifestations and progressive nature of Sanfilippo syndrome are unique, thus traditional educational models for children with special needs may not be applicable. This study investigated the educational needs of children with Sanfilippo syndrome through parent interviews. Our results showed the difficulties parents of children with Sanfilippo syndrome face when choosing a school setting, and the need for an educational setting where the professionals have knowledge of the disease. The trajectory for developmental regression was also noted as a major challenge; however, participants spoke of the positive impact of traditional services like physical, occupational, and speech therapy, as well as alternative therapies. Our results provide educators with a better understanding of the needs and services for children with Sanfilippo syndrome, as well as other children with behavior manifestations and developmental regression.