

INSIGHTS *from* LIVED EXPERIENCE

Raising Children with Special Health Care Needs

With one in five Wisconsin children having at least one special health care need, there are countless parents in our state navigating resources to help these children.

The work can be challenging and leave parents weary. But these parents can't quit as their child's well-being and mental health depends on it.

Four parents of children with special health care needs share parts of their experience in hopes to create understanding and awareness.



children.wi.gov

Parents of kids with special health care needs share from their experiences what they'd like others to know:



Heather Birk, OCMH Lived Experience Partner, is the parent of two neurodivergent children. She sees the **challenges her children face that other kids don't** and the strain it places on families.

"Our children with disabilities often face barriers to accessing the care and support they need to thrive. While we often talk about formal supports for our children, the informal supports we receive through everyday connections with family, friends, teachers, peers at school, work colleagues, and our community as a whole go unmentioned. Having people in your life who see and accept you as you truly are is vital to long term, positive outcomes. Children with disabilities often face bullying, harassment, exclusion, and isolation at significantly higher rates than their nondisabled peers. This, compounded with the additional barriers they already face with their disability, leads to increased risks of anxiety, depression, suicide, and more. Unfortunately, many mental health care providers and facilities do not have the knowledge or capacity to help kids with disabilities, leaving families struggling to care for their children at home."



Tracey Stanislawski, OCMH Lived Experience Partner, is the parent of a child with autism, ADD, and anxiety. She wants schools and systems to understand that **children communicate through their behavior**.

"Behavior is communication. All children do well if they can – If they are struggling to communicate, that results in behaviors that are often viewed as negative. They are not giving us a hard time, instead they are having a hard time. Before my son was diagnosed, he was not willing to participate in most family activities and was almost despondent. He refused anything to do with school. His only outlet was baseball, which he found success in. We were scared to see where his life was headed. With help navigating the mental health system we got a diagnosis and were referred to occupational therapy and speech and language pathology. Without these resources I don't know what would have happened to my son."

(continued)

INSIGHTS *from* LIVED EXPERIENCE

Raising Children with Special Health Care Needs (continued)



20%
of all kids have special health care needs

such as autism, learning disabilities, speech or language impairments, or intellectual & developmental disabilities.



Laina Hartenstein, Department of Children and Families Parent Leader in Child Welfare, is the parent of a child with ADHD, anxiety, depression, and autism. She sees the important **connector mental health is to the overall well-being of children with disabilities.**

"With my kids and others I know, their mental health directly affects their ability to work through the other symptoms of their disabilities. When their mental health is good, they seem to cruise through life with minimal issues from their other diagnoses. However, when their mental health is poor, everything is so much harder to deal with in everyday situations."



Robert Kaminski, OCMH Lived Experience Partner, is the parent of children with cognitive and mental health challenges. One of his children is able to hold a job and owns a car and home whereas the other cannot hold a job and will not be able to live on their own. He sees how **the systems shame children with disabilities.**

"The system is constantly shaming our children by consistently reminding them that they are different and do not belong. Students with disabilities are being secluded and restrained in our schools at far higher percentages than other students. As a parent I have to figure out how to handle a situation without rejecting the child whereas our systems and schools all too often just give up. The message that sends to our kids is 'I don't want you here.' I ask adults to reflect on their adolescent years in school and how difficult it was to find their place as a healthy child. Then consider how this is for our kids with disabilities who are way too often being separated and alone from classmates and adults."



56% of CHILDREN/YOUTH WITH SPECIAL HEALTH CARE NEEDS have a **MENTAL HEALTH CONDITION**

