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Invisible Disabilities: Should You Hide Them?

Katherine Hightet, 28, plays the harp magnificently and is quick to volunteer her musical talents for charity events. She works diligently on her Rider University coursework and enjoys Friday pizza nights with a group of friends.

When Katherine was 2½, the pretty blonde from Voorhees, NJ, was diagnosed with PPD-NOS (pervasive developmental disorder, not otherwise specified), a classification on the autism spectrum. Katherine's family was open about the diagnosis from the onset. "It was important for us that people understood her and her disability," recalls her mom, Danuta. "You can't have acceptance without understanding. The more others knew about her, the more they tried to interact with her."

Yet not all parents of children with invisible or hidden disabilities — diagnoses not obvious by looking at a person, including autism, learning disabilities, language and mental health disorders — choose to be so open.

"Sometimes families don't want [to hear] a diagnosis because they feel it will be a diagnosis for life," says Nancy Allard, director of the Luma Center, a Valley Forge Educational Services program. "At 2, 3 or 4 years old, families are not sure they want to give the child a diagnosis or share it, particularly in a preschool program. As kids get older and the diagnosis becomes clearer to families, they know they need to get their child into the proper school program, and that [attitude] changes."

The stigma of an invisible disability diagnosis

When behaviors associated with hidden disabilities surface — kids acting out, having tantrums, not wanting to be touched or behaving inappropriately — onlookers often chalk it up to bad parenting. "That's our culture; we're used to looking at the physical piece," says Allard. However, "If a behavior is not understood, we might respond in a way that sets the child off more."

For example, if a child is hypersensitive to touch and someone who doesn't know that tries to soothe him by patting his arm, the gesture may upset him further. "That touch might actually be painful to the child, but we think 'That child's acting out,'" says Allard.

The importance of early intervention

The knowledge a diagnosis provides is power; the earlier you know what you're dealing with, the more time you have to address it. "Learning starts at birth," says Rosanne Griff-Cabelli, who manages early intervention up to age 3 for Delaware Health and Social Services. "Research shows through brain development that the earlier we can intervene, the better the outcomes for children."

An early diagnosis allows for access to services, and it's a crucial step even if a family is not yet ready to accept that diagnosis or share the information with others. Early intervention services can be provided in the home, especially for a young child not yet in school. The most important thing is building on the child and family's routine, says Griff-Cabelli, as providers "work with you and respect your privacy wherever you want intervention."

Support is crucial for invisible disabilities

Even at the early stages of a diagnosis, Allard urges parents to inform a child's preschool about any concerns or challenges, so teachers can better help understand and help. A child may need extra time to complete a task or require direct eye contact while getting instructions.

"Teachers don't have to have all the jargon and language — or even the diagnosis — but you want a partner," says Allard. "You want the first school experience to be a success."

"Everything Katherine does today is possible because of the support of all of those who helped her along the way: her classmates, teachers, children in our community theater and dance classes," insists Danuta Hightet. "I don't believe that she would get this support if we did not do our part in helping everyone understand and get to know Katherine and her disability."

Terri Akman is a contributing writer to MetroKids.

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