

“Sensing a Problem”

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Karen Winkler's newborn daughter took fussing and picky eating to the extreme. At one-month old, Susannah screamed constantly and refused to eat anything. Dozens of tests and a stay in the hospital turned up nothing, and doctors puzzled over what to do as Susannah rapidly lost weight.

"My husband and I were at a loss as to what was happening to our daughter at the time," Winkler said. "She was practically starving herself."

As a last resort, Winkler turned to Littleton resident Dr. Lucy Jane Miller. And after treatment at Miller's STAR Center, Susannah is a different child, Winkler says. "After a couple of weeks, we started to see a difference," she said. "And, now, you wouldn't be able to pick her out of a crowd. She's in no way at the point she was then." Miller's magic diagnosis? Sensory Processing Disorder, or SPD, a disease Miller has been studying and treating for more than three decades. Miller runs the nonprofit KID Foundation, the world's largest research organization dedicated to the study of SPD, and the STAR Center, which treats SPD sufferers from infants to adults.

Last April, she released her first book, "Sensational Kids: Hope and Help for Children with Sensory Processing Disorder," a reader-friendly manual intended to make it easier for parents to understand SPD and its effects. At first glance, the symptoms of SPD seem like normal, childlike behavior < picky about food, difficulty paying attention, a penchant for roughhousing. But children with SPD can't control their behavior, and it can lead to problems everywhere from the classroom to the home to the playground.

SPD sufferers have trouble dealing with everyday sensory stimulation, such as touch, sound and movement. Some are over-responsive, bothered by things as small as the tags on their clothing or the feel of food in their mouths. Others are under-responsive, not feeling things such as heat, pain or even the need to use the bathroom. Clumsiness and slow motor skills can also accompany SPD. Treatment for the disorder is available, but because SPD is relatively new to the medical world and is similar to Attention Deficit Disorder, its often years before patients are diagnosed correctly.

"Parents know that their kid has a problem, but they don't know what it is," Miller said. "And that's frustrating."

At the STAR Center, Miller treats patients using short bursts of therapy over a period of 20 weeks. Therapists use a combination of occupational and listening therapies during the sessions. Usually, patients perform tasks such as building up and knocking down foam blocks while listening to a variety of sounds on headphones to stimulate brain activity.

Parents are also given activities and tips to take home so they can work with their children on their own time.

"We try to teach them everything we know about it, so they can go home and make this a part of their life," Miller said.

So far, the approach seems to be working. In the last year alone, the STAR Center has served about 1,500 patients, some from as far away as Mexico. And the center recently expanded to a new location at the Denver Tech Center in order to have more room.

"The kids are happier after treatment," Miller said. "They have better self-esteem, and that's such a key to whether you're a winner or a loser."

But there's still a lot of work to be done, Miller says. Despite efforts by the KID Foundation, SPD has yet to be acknowledged by the Diagnostic and Statistical Manual of Mental Disorders, considered the premier source of information for mental problems in the medical world, and is still not covered by many insurance companies. Funding for research is also scarce, and Miller says many people are still not aware that SPD exists, something that can delay diagnosis and treatment for children in need. Through her work with the foundation and the center as well as other medical organizations studying the disorder, Miller hopes to move that effort along as quickly as possible.

"I believe so much that these kids deserve to have a normal life, and that's what we want to help them do," she said.