



Dylan Bryson, 7, of Etters, having fun while comfortable at home.

Selective Mutism:

Dylan's Story

ANNE BURKLEY

While writing this article, I had the privilege of hearing something that few people have heard:

Dylan's voice. It's something that his teachers, friends and even some of his relatives don't hear often. Dylan has selective mutism which, according to the Selective Mutism Group, is a childhood anxiety disorder characterized by the inability to speak in one or more social settings, despite being able to speak comfortably in others.

It is estimated by the American Academy of Child and Adolescent Psychiatry that 7 in 1,000 children have selective mutism. It isn't commonly diagnosed because many children are often misdiagnosed with autism or labeled as extremely shy or even defiant. To be diagnosed with selective mutism, a child must consistently not speak in a social situation where speak-

ing is expected for more than one month. Selective mutism is believed to be genetic. It is not caused by tragedy or trauma.

Many professionals, from teachers to pediatricians, have little understanding of the condition. Carrie Bryson of Etters, mother to 7-year-old Dylan and author of the book *Why Dylan Doesn't Talk: A Real-Life Look at Selective Mutism Through the Eyes of a Child* (www.SelectiveMutismBook.com), searched for answers for months before she even heard of selective mutism.

Dylan was originally diagnosed with autism because of his lack of social skills in the clinical setting. Although Bryson was quick to point out that Dylan *did* make eye contact, engage in imaginary play and talk at home, a clinician can't measure what happens outside his or her office or diagnose a condition they have never heard of.

Much of the time, Bryson wondered whether or not doctors and other professionals even believed her. Frustrated, she did what many parents do, went to the library and turned to the Internet. "I started to read everything that I could about children being shy or introverted," she says. But the characteristics of these children didn't quite match those of her son.

Dylan is typical in many respects. He likes to talk, tell jokes and play with his two brothers. He collects coins as a hobby, gets good grades and likes to have his friends over. On the other hand, "He has never spoken to any of the children at school — ever," says Bryson. He may come off as lacking manners or aloof, but Bryson says what Dylan is actually feeling is intense fear. "It's like stage fright," she says, "without the stage."

Dylan wants very much to talk to his friends at school and talk with his teachers or even just say "Hi" back to a cashier or acquaintance. In almost all social situations, he shuts down, Bryson explains. His face goes blank; he becomes stiff and appears completely disengaged. He's always been like this.

In order to interview Dylan, I wrote questions and had his mother ask them to him while recording the interview. Had I been there, it is unlikely that Dylan would have talked. Had I asked the questions, he certainly would not have been comfortable enough to answer. Dylan was very aware that he was being recorded and, since he was at home, hammed it up like only a 7-year-old boy can. He listened intently, smiled often, joked around, bounced on the sofa and was a goofball. In his home, Dylan talks with ease to his brothers and even with his friends — the same ones that he can't speak with at school. "It's like there's a thousand kids at school," explains Dylan. "I only [talk] when there are one or two kids at our house." He admits that he does sometimes wish that he could talk at school, Cub Scouts or birthday parties like the other kids.

When asked why he doesn't talk at school, he jokes that he has to be three

“It’s like stage fright,” Bryson says, “without the stage.”

miles away from school to talk. Bryson says that there is some truth to his jest. She’s watched Dylan’s friends in the morning before school and has seen Dylan go from a chatty grade-schooler to completely mute as they approach school.

Talking to a Child about Selective Mutism

After Dylan was diagnosed with selective mutism by his pediatrician at age 5, Bryson was relieved. It opened up a new world of treatment, a network of other parents who also have children with selective mutism, and allowed her to explain to others why Dylan didn’t talk. But how should she tell him? She looked for a book, but she couldn’t find one that explained it through the eyes of a child experiencing selective mutism. So she wrote one herself. One that would let Dylan know that there is a reason why he doesn’t talk, that it is OK that he sometimes doesn’t say anything, and that other children suffer from the same condition. Bryson waited to read the book with Dylan. She feared that having a book about his life and his selective mutism would put pressure on him that would cause more anxiety.

It didn’t. After she read it to him, Dylan



Dylan and his brothers, Cameron and Gabriel.

asked her if she could give copies to his school and to other kids who didn’t talk. She handed out copies to his school and his former preschool to help raise awareness and so that teachers and students could get a better understanding of Dylan’s condition.

Slow and Steady

Over the last three years, Dylan has made marked improvements. In preschool, Dylan had severe separation anxiety for the first few months; he didn’t talk, and it was hard for him to follow directions (not because he meant to be disobedient, but because he froze when the expectation was upon him). In kindergarten, Dylan began to follow directions. In first grade, he started to respond to his teacher with limited speech, and now, in second grade, he will answer another student’s question with a head nod or shake. He even took his coin collection to school once and was able to talk about it, though he admits that was hard.

Bryson, like all parents, worries about the future. Will he regress over the summer? Will a move to a new grade and new part of the school building throw off his progress next year? In the distant future, when games of freeze tag at recess turn into tweenage conversation in middle school, she knows that Dylan’s social circle may shrink. It worries her.

But with Dylan’s progress and successful therapy techniques borrowed from selective mutism expert Dr. Elisa Shipon-Blum, whose daughter has selective mutism and is now able to talk in most social situations, Bryson is hopeful that Dylan’s future will be anything but silent.

Does Dylan think that he’ll ever be able to talk in school? “Maybe, like in fifth grade... fifth or sixth grade,” he says. Why then? Simple, he explains, “I’ll be older.”

Be Proactive

Bryson advises any parent who thinks that their child may have selective mutism to do their research. Print out the description and take it to your child’s pediatri-

cian or therapist. Take video of your child at home so that teachers, doctors and therapists see how the child behaves at home. Go online. There are very few local resources for parents, says Bryson. The closest expert is Shipon-Blum (of the SM Anxiety Research & Treatment Center located near Philadelphia). It can be frustrating, but you can find the support of other parents in selective mutism forums.

CHILDREN WITH SELECTIVE MUTISM:

- Find it difficult to look at you when they are anxious. They may turn their heads away and seem to ignore you. You might think that they are being unfriendly, but they are not. They just do not know how to respond.
- May not smile, or they may look blank or expressionless when anxious. In school, they will be feeling anxious most of the time, and this is why it is hard for them to smile, laugh or show their true feelings.
- Move stiffly or awkwardly when anxious, or if they think that they are being watched.
- Find it difficult to say hello, goodbye or thank-you. This can seem rude, but it is not intentional.
- May be slow to respond — in any way — to a question.
- Worry more than other people
- May be intelligent, perceptive and inquisitive
- Have good powers of concentration.

source: www.selectivemutism.org



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Louie Castriota Jr. and his daughter Brooke at Leg Up Farm. Castriota founded Leg Up to help children with disabilities.