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Walking tall: Born with developmental disabilities, this 21-year-old has a can-do spirit

by Anna Haigh, Sentinel Staff

At first glance, Jason S. Spengeman looks like a child. He's 4 feet 2 inches, 49 pounds — smaller than an average 4th-grader — with spindly limbs and a toothy smile.

Yet he moves with confidence as he walks into the Keene Beauty Academy, greeting all of the young female students with smiles, thumbs-ups and playful jokes. They flock around him, joking back and laughing. Later, he might pick one he likes best to give his hair a quick buzz before he starts his job there.

Jason is 21 years old, and like many others his age, he's a big flirt. But he isn't just like other adults. Jason loves model cars and cartoons, wears kid-size Velcro-fastened shoes and has a mother who still makes his lunch. These are the complexities of Jason's adult life.

He could seem limited by his disabilities. After all, those around him are the ones who help interpret what he feels and wants through his sign language and limited vocal sounds.

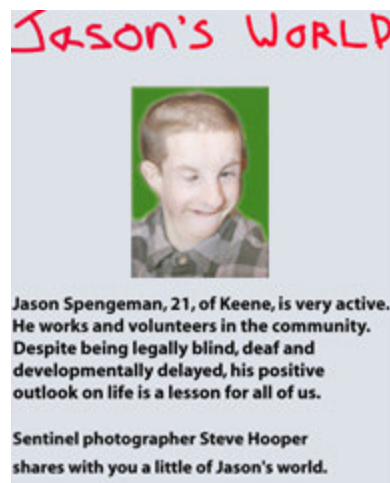
Jason is completely deaf, legally blind with limited vision, diabetic, and developmentally delayed, all due to a recessive genetic defect that caused almost identical developmental abnormalities in both Jason and his sister, Megan, 25. Megan, just short of 3 feet, 3 inches tall, weighs 43 pounds and has more severe disabilities than Jason. She attends an adult care program, while Jason needs 24-hour supervision.

"There aren't any other children out there like this," their mother, Emily Harper Scott, said.

But Jason hasn't let his disabilities define him. Although he can't express himself like other people, Jason has done the defining. He is the one who changes people — challenging them to rethink what they know about people with disabilities, and what it is to lead a meaningful life. Now, as a 21-year-old with state-funded services, Jason has overcome his severe physical and developmental disabilities to flourish as an adult, becoming a part of the community and working a job at the beauty academy.

But many adults in the state with developmental disabilities aren't so lucky — statewide, 254 adults were waiting for services at the end of last year, and 38 of them live in the Monadnock Region. Adults who receive state-funded services, such as Jason, have help developing life and career goals, growing as community members, and finding educational opportunities, residences and jobs, or joining a residential program. They can start living an adult life. And for Jason, who would otherwise be sitting at home in Keene, cared for by his mother, that funding means everything.

Jason and Megan deserve "the freedom to make choices and live as full a life as anybody else," Scott said.



Over the years, she said, she has worked to teach others to look past a disability to the person underneath. And she has learned to look at challenges as blessings. She speaks of all the things she doesn't have to worry about as a mother — her now-adult children doing drugs, causing trouble.

“Granted,” she said, “I will never be a grandmother. I will never walk my daughter down the aisle. But I'm grateful for other things.

“I love them to death and I wouldn't have it any other way ... I think they're here to teach the world. They have more gifts to offer than other people”

Jason is ready for his mother to leave. He's supposed to be fishing in the pond with friends at Robin Hood Park, but his mom is still hanging around with Megan. He tells her what he thinks — signing to his mom to take his sister and leave. Scott laughs, and lifts Megan up to put her into the car. Megan is the mellow one, so quiet she has a bell tied to her shoelace. Jason opens the door for Megan, kisses her, scoots her into the seat, and makes sure she has her seatbelt on. He always does this, Scott says, ever the gentleman. And with that, his mom is gone. Jason's day out on his own has finally started.

“He knows what he wants when he wants it,” Scott said earlier. “He'd rather be out than at home. ... Is that typical or what?”

Much of Scott's life has been determined by Megan and Jason. She has become an advocate for people with disabilities and has fought for funding for her children, learning more compassion and perseverance as she went along. She's had to see other children afraid of her own. And even now, Scott is still fighting for people to see her family the same as they do any other.

Dark-haired Megan was born in Unionville, Conn., in 1981, right on schedule, but she was far smaller than she was supposed to be at just 2 pounds, 13 inches.

Scott, who was raised in the region and graduated from Keene High School in 1972 before moving to Connecticut, stayed by Megan's side for four months in the neo-natal intensive care unit at Hartford Hospital, at times falling asleep as she leaned over her daughter's incubator.

Despite Megan's disabilities, Scott said she always knew she wanted Megan to have a sibling. Doctors didn't know whether Megan, and later Jason, would ever walk. But Scott reasoned that if she had a second child who was better off than Megan, that child could help.

“If the child is worse, at least she won't be the only one,” Scott recalled thinking at the time. “They'll have each other.”

When Megan came home from the hospital, she weighed only 3 pounds, 15 ounces, and a pair of hand-knitted yellow booties still went up to her knees. She had numerous medical conditions — some symptoms of Pierre Robin syndrome, which include a small jaw set unusually far back in the throat; short stature; cleft palate; developmental delays; and hearing and vision problems.

Scott said doctors told her that the rare set of conditions was caused by a recessive gene shared by Scott and her now ex-husband. Doctors gave Scott a 50-50 chance that her second child would be born just like Megan, and she was monitored closely throughout her second pregnancy.

Jason was born March 11, 1985, at exactly 2 pounds, 13 inches long, with medical conditions that were identical to Megan's, though less severe. His tiny footprint was barely larger than a quarter. Jason was in intensive care for three months, until he went home at 2 pounds.

Years passed, and Scott said she prayed for her children to grow. Finally, both children walked. Megan took her first steps at 6 years old, on Christmas day. For Jason, it was Easter Sunday the year he was 5.

Scott started work as an advocate early on, serving on a committee created by the commission of education in Connecticut when Megan was 4 years old. In 1993, Scott remarried, and her advocacy continued as she moved her family — including husband Dean S. Scott — to Keene in 2001 to be closer to her extended family. Scott is currently a member of Monadnock Developmental Services' board of directors and teaches sign language at the Castle Center, the Keene medical adult health program that Megan attends daily.

“I can be a voice for them,” she said of her children.

“I hate that word — handicapped. I think it should be handi-capable. They have more gifts to offer than other people.”

Both Megan and Jason attended Keene High School. Jason graduated at age 18 with his class in 2003, but the school system was required by law to continue educating him until he turned 21 in March 2006. Scott successfully advocated for Jason to stay in school until June 2006, she said, because state funding for services wasn’t available in March.

She’s worked to make sure the community knows more about her children ever since the family arrived in Keene.

“Fate has brought us here for a reason,” Scott said. “I think it’s so Megan and Jason can make a difference here.”

She points to the photographs proudly — Jason dancing with girls twice his size at prom, posing in a too-big cap and gown at graduation.

“The entire class gave him a standing ovation,” Scott said. “I cried.”

She said she wasn’t sure what Jason thought of it all.

“I think he knew it was a big night for everybody.”

Over the years, her mission as a mother and advocate — that her children lead a meaningful life in the community — has never changed.

“Not just them, anyone with a disability in this community,” she said. “That’s my mission in life.

Waiting for the day to start; finding commonalities

Jason lifts the white lace curtains to peer outside. He paces. He hums. And lifts the curtain again. Jason will do this once, twice, countless times, at each of the windows in his house, every weekday morning as he waits for his aide to arrive. Finally, at 10 a.m., 24-year-old Ben J. Gropp pulls up, and Jason’s day out and about can begin.

Ben is at the wheel and Jason points right, left, and then they’re driving along the back roads of Marlborough past hayfields and barns. Like every other day, there’s music playing and Jason makes his humming sound off and on again, watching the road go by out the window. An American Sign Language book sits on the floor of the car. It has been just a month since Ben began working as Jason’s aide, so he’s still learning more signs. Today, the pair is driving to Robin Hood Park.

As soon as they’re out of the car, Jason makes the sign for driving.

“You want to go driving, don’t you?” Ben asks.

They start walking, slowly, on the path around the pond, Jason’s thin fingers clutching Ben’s hand, his tiny shoes stumbling over exposed tree branches and wet leaves. Ben is close to twice as tall as Jason. If he wanted to, Ben could pick him up and spin him around like a child.

Just five minutes into the walk, Jason makes the driving sign again. There’s nothing he loves more than driving, but if Ben started the car every time Jason wanted to go for a spin, they would never do anything else. So, the pair keeps walking, and then turns around less than halfway around the pond. Once they’re back on firm ground in the parking lot, Jason lets go of Ben’s hand and Ben buckles him into his seatbelt.

Though Jason is legally blind — doctors have a hard time determining what he can see since Jason can’t talk — he sees well enough to understand sign language, and to get around on his own. Scott said he knows around 1,500 signs, but is short of fluency. Jason tells Ben if he doesn’t want to go somewhere with the sign for “finished” or “no,” Ben said.

Ben, a Swanzey resident, has a social psychology degree from Keene State College and previously worked with other adults with disabilities. He plans to go into advertising or marketing, but said he finds it more rewarding, for now, to help those with disabilities.

“Even though we’re not completely able to communicate yet, he’s 21, I’m 24, and I feel like with certain things, at least, we can certainly relate,” Ben said.

Jason already has a sign for Ben — a “B” and the sign for “beard,” which adorns Ben’s face.

After Jason’s services at Keene High School ended in June 2006, he was placed on the state’s wait list for funded services, Scott said. He only had to wait a few weeks to receive funding for an aide through Monadnock Developmental Services — thanks to a sudden increase in state funding at that time, she said. Scott said it has always been hard, however, to find teachers and aides who know sign language. In September 2006, Jason was matched up with his two current aides — Ben, and Fitzwilliam resident Linda Farnum — through Chesco Inc. in Keene, a non-profit agency.

Now, Jason goes out into the community for seven hours each weekday with one of his aides, stopping by his job at the Keene Beauty Academy a few hours each week, spending time on projects at LifeArt Community Resource Center in Keene, tossing a ball at Wheelock Park, or doing community service work.

“What they need now is far different than what they needed in school,” Scott said of her two children.

For Jason to be cared for as an adult, aides need to have an understanding that despite his size, “he is a man of 21 years,” she said. “Jason is a pretty independent young man. He’s not shy about telling you.”

On average, those who apply for state funded developmental services in New Hampshire wait around 200 days, though the length can vary depending on the severity of their needs, according to Matthew Ertas, director of the state’s Health and Human Services Bureau of Developmental Services. And the lengthy wait can be detrimental for many, he said. The gains made by many students through the school system are in jeopardy when those students graduate at 21 and have to wait for services, sitting at home, Ertas said.

A Statehouse bill proposed for the 2007 session would change that, by trimming the wait time for developmental services down to 90 days with \$16 million more in funding for the department of health and human services over the next two years. (See related story.)

Since Jason has been out of the school system, Scott said she’s noticed her son maturing. He has trouble with some situations — when the family had to euthanize their dog last year, she said, Jason didn’t realize what had happened. But sometimes, Scott said, his depth of understanding surprises even her.

At a visit to a cousin’s house, he responded to his cousin’s military uniform by saluting him, though Scott said she had never told him that was the right thing to do. And Ben said he knows Jason wants to feel just like other guys his age, even with little things. Ben remembered a time when Jason saw him shaving with an electric razor.

Jason signed “I want,” Ben said.

So, they shaved off the soft peach fuzz on Jason’s face together.

“For the next three days he told everyone he knew that he shaved,” Ben said.

Asked about it, Jason points at his chin and his upper lip. He signs “shave.” Then, “me,” looking satisfied with himself.

‘People who meet him will never forget him’

Jason’s brown hair is always neatly trimmed. That’s because there’s no shortage of young women at the Keene Beauty Academy eager to give him a haircut. He has been paid to work there a few hours a week folding towels, arranging magazines and sorting hair rollers, since late 2004. Before he starts his 11 a.m. shift, he picks out a hairstylist with a long, dark ponytail — he always plays favorites — and climbs into the barber’s chair. He waits patiently, jiggling his feet, which dangle far above the foot rest on the chair. Once the haircut is done,

he feels the top of his head, and cleans himself off with a towel. With a quick thumbs-up to his stylist, Jason is off to do his work folding towels by the dryer.

“He’s not too hard to fall in love with,” academy co-owner Cara D. Down said. “His outgoing personality. His sense of humor. He’s always smiling.”

“He’s just Jason,” co-owner Kathy L. Hammond said.

Down said Jason’s presence “has opened a whole new world” for her students, who learn that people with disabilities “are just people.” Now, when children with more severe handicaps come in for haircuts, Down’s students are less afraid to help them and more willing to accept them, she said.

“Seeing the way students react to (Jason) has been just so enlightening,” she said.

The beauty academy students even fight over who will cut Jason’s hair, Down said.

Because of his disabilities, Jason can’t have a regular 9 to 5 job, Scott, his mother, said — he can’t sit down and stay focused for long periods of time. She said it’s a challenge to find activities that Jason is interested in doing. But if there’s anything Jason loves more than driving, it’s his weekly paycheck from the beauty academy, which he uses to buy toy cars.

“That paycheck means so much to him,” Scott said. “He loves his work there.”

Jason’s regular job and other activities help him become a part of the community. And for many, his influence has left a lasting impression.

“Everybody in town knows him by now,” Scott said. “People who meet him will never forget him.”

A big day to end the week; the best parts of life

Today is the day. It’s Thursday. And Jason is already talking about his paycheck, though he and Ben have yet to arrive at the beauty academy.

Jason makes the sign for money, points to himself, and laughs.

“Point away,” Ben says, laughing.

They’re sitting in a coffee shop, so Jason understands enough to sit still, his legs crossed, hands folded, until it’s time to go. It’s two months into their relationship, but already, Ben and Jason seem to understand each other. There will always be complexities unique to their relationship.

“I wish he could hear so he could listen to my music,” Ben said of his hobby as a guitarist, though he thinks Jason can feel the vibrations of a drum beat. But, above all, their time together will help Jason experience the best parts of life, Ben said — friendship, laughter, fun.

“I think I’ve really tried to make it so we have this friendship more than anything else,” he said. “He deserves just as good of a life as anyone else.”

It’s finally time to go. Ben leads Jason across the street. Cars stop. Jason puts his hand up to thank a driver. At the Keene Beauty Academy, Jason grabs his paycheck out of the hands of one of the co-owners.

“Say ‘thank you,’” Ben reminds him.

Jason signs “thank you.”

Two young stylists surround him, offering high-fives and jokes. He smiles up at all of them, points to himself, and then makes the sign for “money.” Then he sticks out his tongue. And makes the “let’s go” sign to Ben. With that, they’re off. It’s raining outside but Jason’s humming again and he’s holding that check tightly — all \$9 worth.

It’s a good day.