

For parents of children with Down Syndrome, respite is elusive but joy is not

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By Nicole Carter

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REGION — Families raising children and caring for adults with Down Syndrome find themselves in a never-ending cycle of red tape for resources but also with children who enrich their lives with love and joy.

The Advertiser Democrat recently held a round table interview with parents and guardians of people with Down Syndrome as part of October's Down Syndrome Awareness Month to learn more about the everyday challenges and joys their families experience. Life for a caregiver is a continuous bureaucratic battle but also filled with love and celebrations of personal achievements.

The battle

At one point Terry Lord of West Paris was penalized for \$5,000 by the Social Security Administration when he traded heavy equipment for real estate to use as part of his business operation.

Aranka Matolcsy, who lives in South Paris with her son Colby, was told to pay a \$20,000 penalty for operating an off-grid cabin in Franklin County as a vacation rental.

What Lord and Matolcsy have in common is the struggle for single parents to earn a living while caring for children with Down Syndrome. Through the lens of health agencies, their properties were personal assets that disqualified their kids from receiving support services, not business investments that helped them put food on the table.

"I fought and fought and fought to keep my property, without a lawyer," Matolcsy said. "Then they slapped me with the over payment (penalty)."

Matolcsy was informed by three different lawyers that the only way to move forward and hold onto the services her son Colby had received up until then was to sell the property.



Aranka Matolcsy's son Colby, who has Down Syndrome and other health conditions. Fighting for the services he needs is a full time job for the single mother from South Paris. *Supplied photo*

“People verified that as long I took the proceeds from that sale and left it in my bank account for 30 days, as long as it wasn’t in my account for 32 days there would be no disruption in qualification for Colby,” she said.

But Matolcsy appealed her case, citing exceptions allowed by Program Operations Manual System (POMS) guidelines that the Social Security Administration uses for day-to-day operations. Eventually she was granted the exception and held on to the business property that provides income to pay her home mortgage. But her long fight, just one example of what parents have to go through to care for special needs children, left her traumatized and drained.

Listening to Lord, 72, talk about the obstacles and restrictions he faces caring for his son Seth, 33, Matolcsy is getting a preview of what life will be like as Colby, 10, matures into adulthood.

“Seth has done very well,” Lord explained. “His mother and I were divorced in ‘96. Our communication wasn’t always good. Now, I take care of him full time. He still sees her once in a while.”

After graduating from high school, Seth went to work and has had several jobs. He worked at Camp Acadia as a barn helper, at Aubuchon Hardware, seasonally at Pie Tree Orchards and for a few years at the Fryeburg Fair.

But for every dollar Seth makes at a low-paying job, 50 cents is taken away from his social security allowance. That puts his aging father in a bind to provide for both of them since Seth moved in with him five years ago.

Getting approved into Maine’s Shared Living Program has helped stabilize the Lords’ living situation to a degree.

“Shared living provides a stipend for care for people with special needs,” Lord said. “It’s very hard to get it as a family, but for a single parent it’s a little more common. Seth was approved for Shared Living Section 29. He’s been on the Section 21 waiting list forever.”

Crystal Cochran from Windham, mother of a 19-year-old son with Down Syndrome, Austin, will soon embark on the application process for adult services and Shared Living, which is a program for people 21 and older with development disabilities.



Seth Lord, 33, of West Paris, participates in a tennis match during the Special Olympics.

Supplied photo

“We’re just getting into that,” said Cochran, who works in Norway as a special education teacher. “Twenty-nine is where there is one pot and if you take shared living you’re allocated x-amount of funds. And it takes most of the funds out and you can’t then do other programs.

“Twenty-one is a bigger pot, more for kids with higher needs. A bigger allocation where you can do something like shared living and other programs or in-home support. With my son, we [would] qualify for 21 but we’ll never get there. My son needs constant support and supervision. He has other health things besides Down Syndrome.”

Cochran said that the only way her son’s support care can be approved under Section 21 is if someone already receiving it passes away or if there is a drastic change to his life like losing his primary care-giver, which is her.

Deb and Arnold Twitchell of South Paris have two adult sons, Joshua who is 34, and Daniel, who is 30 and has Down Syndrome. Deb Twitchell says that her family has been fortunate in that they have not had to heavily rely on support services in raising and caring for Daniel.

“We’ve been able to access an integrated education for Daniel,” she said. “He has no serious health issues and my husband’s job allowed me to be with him full time.”

Twitchell and her husband Arnold both have backgrounds in elementary and special education and had a general idea of what to expect for their son’s future after he was diagnosed with Down Syndrome at birth.

His education began early – starting at a preschool program at the age of 18 months with other special needs children. During his three years there Daniel did well, socializing and forming friendships. But when Twitchell asked his teachers when Daniel would begin to interact with normal kids the answer was that available programming did not extend to that level.

That was not what she and her husband wanted for him so when he was old enough to start kindergarten, they enrolled him at Guy E. Rowe School in Norway and she returned to work so the her work matched his school schedule.

The Twitchell’s first challenges with the education system for children with Down Syndrome and other intellectual handicaps began in earnest when Daniel began seventh grade.

“Daniel is non-verbal,” Twitchell said. “He has a vocabulary of about 30 words but he is just the best at charades.”



Daniel Twitchel, 30, of West Paris competes in several Special Olympics events, including equestrian driving. *Supplied photo*

She and Daniel's elementary teachers were able to help him communicate through gestures by asking questions that allowed him to get his points across his way. However, when he began junior high school he was no longer able to do that.

"People would guess what he was trying to say," Twitchell said. "He grew frustrated with not being understood and started to lash out."

Cochran and Austin said their sons experienced the same obstacles while attending junior high.

Louisa Westleigh of West Paris is the guardian of her late sister's son Xander, who is 15. Middle school was so difficult for Xander that she now sends him all the way to Portland to attend an outreach program through Baxter School for the Deaf at Lyman Middle School.

"He came to live with me when he was six. He has situational deafness and limited verbal skills but he wants to talk, in his way," Westleigh, Coordinator for Club Rowe childcare in Norway, explained. "The elementary school was amazing. But when he got to middle school it all fell apart. He was becoming frustrated and angry because he could not communicate what was going on.

"It was difficult and I had to make the choice to move him. Now that he's at a new school and having people know how to communicate with him and know how to ask him questions to get answers (his way), I've got my happy boy back. This kid is the happiest you'll ever meet. But for a year it was hard. Supports for kids with Down Syndrome, or any disability, lack transition from elementary to junior high."

Lord, too, fought for more education in communication when Seth was in middle school.

"He had speech therapy for a short time and I wanted to get him more," Lord recalled. "Their response was that they (special needs students) get plenty of speech from each other. To me, there was not one kid in the class who did not need more speech therapy. It was not appropriate what they were getting."

"It was as if they've learned everything they need to by middle school," added Wesleigh. "That's not true. A lot of children with Down Syndrome, and actually all kids I've worked with with special needs, they want to communicate like everyone else does and they never stop wanting to learn."

While Matolcsy, Wesleigh and Cochran navigate state agencies and SSA to get their minor children the support they need, Seth Lord and Daniel Twitchell receive adult services that engages them with the community. The two are good friends, attending the Casco Momentum Community Support Program together. Through Momentum they participate in Special Olympics and other enrichment activities.

Seth was once engaged, although it didn't work out.

“I met her at my day program at Casco,” Seth said. “She said, she asked me to marry her.”

Seth said that his girlfriend’s father and his had conversations about ways to make that possible, but the romance petered out.

“Sometimes a relationship between two people like Seth and his fiance is more platonic,” Lord said. “He did not respond to the relationship as well as he could have. They’d go to a dance and instead of spending his time with her, he’d be talking with his friends. She wanted more out of it, and she actually is married to someone else now.”

The Twitchells built Daniel a basement apartment that gives him a degree of independence. He is responsible for his own breakfast and joins the family for dinner meals. He maintains an active life, having worked for a period at Tambrands, swimming, playing tennis, learning karate and competing in equestrian events at the Special Olympics.

“Every day Daniel brings a whole lot of fun to our family,” Twitchell said. When people ask about him, her answer is that, “there is not one thing I would change about him because then he would no longer be the same.”

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