

'Wait list' ... four letter words for families caring for children with Down Syndrome

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REGION — Hurry up and wait could describe life for people caring for family members with Down Syndrome.

From initial diagnosis of their intellectual handicap, to education to transition from minor child to adulthood, there are always forms to file in duplicate over time, agency officials in need of repeat information, medical providers to monitor and treat health conditions, and educators for individual learning plans.

Then comes the need to plan for life in adulthood. Families can spend years on waiting lists for any or all of the services their children need.



Austin Cochran, a 19-year-old in his final year of school, plays on Windham High School's unified basketball team. Once he crosses the bureaucratic line into adulthood, he may have to wait years to participate in community events, due to lack of programming and long wait lists. *Supplied photo*

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

Terry Lord of West Paris spent the first six months of his son Seth's life working to officially prove that Seth had Down Syndrome. Without confirmation, as a baby Seth (now 33) was ineligible to receive support and care from the Department of Health and Human Services.

"Six months," Lord said during a recent round table with the Advertiser Democrat in October, during National Down Syndrome Awareness Month. "I (finally) had to drive to Bangor to get him a chromosome test to be qualified."

Aranka Matolcsy of South Paris and mother to a 10-year-old with Down Syndrome said it took only five days before her son was diagnosed, granting him access to services as a newborn.

"But we have to requalify on a regular basis, at least every two years with Social Security, that he still has a disability. It's an absolute asinine expense for Social Security or MaineCare to have to reassess whether our children still have a disability or not."

Lord acknowledged that he had never been required to that for Seth while he was growing up during 1990s. Matolcsy estimates that in the first three years of her son's life she met with different medical and other providers at least 300 times.

"They've talked about a 'lifespan' program for all people with disabilities," she said. "A cloud [that] can follow a person from birth through their lives. There should be integration of HIPAA. I spend hours every six months with case management people to go over evaluations, do more goal-setting, sign more releases.

"If there was a cloud [system], all the people who work with this person could be part of their cloud, a hub."

Crystal Cochran, mother to 19-year-old Austin agreed, noting that electronic health records maintained by her family's providers make the job of doctor's visits much smoother.

"When we go to the geneticist her notes are right in the system," Cochran said. "It's nice for the doctors to pull up his record and see them. Currently we see, with the eye doctor, heart, pacemaker, behavior, geneticist and pediatrician, six doctors.

"Outside the doctor's office you have to relay all of the same information over and over again."

With no technological solution available, once a person with Down Syndrome becomes an adult, their guardians must start the process all over again: new case workers, new agencies, new rules and new review procedures. And more waiting.

Among the services available to children and adults with Down Syndrome is in-home care. The concept is sensible but the reality is that few families are able to rely on it.

Before the pandemic, good behavioral health professionals were hard to find. In the current environment of unfilled positions and unvaccinated workers walking away from their careers it has become close to impossible to bring qualified, trustworthy help inside the home.

"For most of our service providers, it is not possible to make a living in the state of Maine," Matolcsy declared. "If they're given the appearance of a livable wage than they are not able to work the hours to get there."

The parents all shared that more often than not the tenure of a BHP working in a private home lasts about a week. According to Matolcsy, the title is a pseudonym that belies the nature of the work expected to make up for low wages and little training.

"We bring them into our home and spent tremendous amounts of energy to train them and it's hard for all of us," Matolcsy said. "On the adult side, workforce behavioral health professionals can help people earn a living."

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Daniel Twitchell of South Paris is 30 and has Down Syndrome. He lives with his parents Deb and Arnold. After graduation, with the assistance of a BHP, Daniel went to work at Tambrands, a Procter & Gamble plant in Auburn.

“Working gave Daniel a sense of accomplishment,” explained Deb Twitchell. “And the people at Tambrands bent over backwards to work with him.”

For a time Daniel’s employment went well with assistance from his support person. But when that person moved onto another job it became difficult for Daniel to remain focused on the tasks he did. Tambrands eventually told the Twitchells that without a dedicated BHP they could no longer employ him.

Seth Lord worked at several, mostly seasonal jobs over the years. His father, who at 72 is mostly retired, is able to work alongside him.



Crystal Cochran, a special education teacher in Oxford Hills, worries that her son Austin will struggle once he graduates from high school next June. *Supplied photo*

Cochran caught a lucky break just as the pandemic hit, hiring a BHP who was wonderful with Austin.

“She worked with Austin for about 18 months,” Cochran said. “Just before everything locked down. He had a lot of growth with her, he was challenged by her and they really bonded.”

But this fall that worker left for another better-paying job. Rather than put energy and expense into finding a replacement, Cochran’s family has decided to make do without help for the time being. In his last year of high school, and able to attend in-person, Daniel participates in a STRIVE program and attends Portland Arts & Technology High School.

But even though she has already started the paper trail for Austin’s disability services when he enters adulthood, Cochran worries about life for him when he is out of school.

“We have to find a program for him” during the day she said, for social enrichment and to safeguard his well being. “Some people with Down Syndrome can function without supervision. Austin cannot be left alone. He can’t make his own decisions to care care of himself.”

Seth Lord and Daniel Twitchell attend the Casco Momentum Community Support Program during the day. They participate in Special Olympics through Momentum, take part in social and health-based activities and continue working on their life skills.

The Cochrans have yet to choose, or be accepted, by an adult program for Austin to attend once he turns 20.

Continuing his education, therapies and opportunities for social and community inclusion will be a matter of hurry and wait. Unfortunately for Austin, the wait could be a matter of years.

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Daniel Twitchell, 30, of South Paris, participates in Special Olympics through Momentum, an organization that serves adults with developmental disabilities. After Daniel graduated from high school it was five years before he was able to get into the support program.

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