

Growing Up Is Hard, Especially For Young People With Disabilities

by Nadra Nittle, California Health Report | August 26, 2021

LOS ANGELES — The way 25-year-old Essence Guss of Pomona describes growing up captures the way many young people feel about the transition.

“Being an adult is hard,” she said.

But along with the typical challenges of “adulting,” as millennials often call it, like working and paying rent, Guss has cerebral palsy and related conditions including an intellectual delay, seizures and deafness in her left ear. She also has PTSD and severe anxiety.

Through it all, she’s held onto her job at a 99 Cents Only Store near the home she shares with her family and pays her mother \$100 per week to cover rent. But Guss’ health problems — and a dearth of services to support her transition to living independently — has made growing up especially difficult, her mother Tracy Evanson said.

Guss’ intellectual disability makes taking public transit confusing, so Evanson is trying to get the nearest regional center to provide her with transportation to and from work and occupational therapy appointments. So far, she’s had no luck. Evanson has also tried unsuccessfully to enroll Guss in California’s Supported Living Services program that helps adults with developmental disabilities live independently. It took Evanson months to book Guss a psychotherapy appointment, which became an urgent need after Guss’ mental health deteriorated following a bout with COVID-19. And while the mother is grateful for the vocational and daily living skills her daughter learned through high school and regional center training programs, she worries that Guss has not had the opportunity to develop interests that could lead to a more fulfilling life.

“(The) primary focus was her being able to cook and clean and manage her money and getting a job,” said Evanson. “It’s not looking beyond her disability.”

These experiences are not unusual. In interviews with the California Health Report, young adults with serious disabilities and their families pointed out that the transition to adulthood is filled with challenges. Accessing the medical care and transportation that would allow these young people to live more independently can be difficult. So can getting help with issues like socializing and pursuing hobbies because adult transition programs for youth with disabilities heavily focus on life skills, leaving little room for activities they enjoy, caregivers said.

Meanwhile, high-functioning young adults with disabilities who've made it to college said trying to balance the demands of higher education and coordinate their own health care for the first time outside a pediatric setting can feel overwhelming. Preparation and education from staff at pediatric hospitals could ease the transition for youth, as could greater disability awareness on college campuses.

Overall, young adults with disabilities and their parents argued that health care officials, regional centers, and school districts need to foster more awareness about what it's like for youth with disabilities to transition to adulthood. Far too many families don't know what to expect, they said, or how to get the services they need.

A handbook that doesn't exist

As the popular adage goes, parenting doesn't come with an instruction manual. But sometimes Whittier resident Sherri Brady wishes she could have consulted a guide when her 24-year-old daughter Lauren Brady, who has the neurological disorder Rett syndrome, transitioned into adulthood. It felt like California Children's Services (CCS), which selects and covers care for youth under age 21 with qualifying health conditions, simply told Lauren to "have a nice life" once she aged out, Brady recalled.

"When your child gets diagnosed with (a condition), there are handbooks and trainings and services," said Brady, Southern California representative for the Rett Syndrome Foundation and a California Health Report board member. "When they become an adult, where's the training for that?"

Even if parents know what to do, a lot of the support their children need when they become adults just isn't there, Brady said.

For example, Brady is struggling to obtain physical and speech therapy for her daughter. Rett syndrome, which causes severe physical impairments, has resulted in Lauren losing her ability to walk or speak. She also suffers from seizures, scoliosis, gastrointestinal difficulties, and breathing problems, among other health issues.

The physical therapy offerings Brady has encountered almost exclusively focus on helping otherwise healthy people recover from car accidents, strokes, or broken bones. It's short-term and not geared toward people like her daughter, who have chronic conditions but want to avoid losing muscle tone and other complications. Because Lauren wasn't progressing in traditional physical therapy, Medi-Cal stopped covering the service, Brady said.

Then there's the adult transitional program Lauren enrolled in after high school. The learning focused heavily on jobs, like stocking store shelves, that Lauren can't perform, Brady said. At one point, program officials sent Lauren to Whittier City Hall, where she had the responsibility of turning a radio switch on and off, work she found neither meaningful nor enjoyable.

Brady emphasized that she does not object to adult transitional programs focusing on job training. She would just like them to broaden their focus to include community engagement and unconventional work, such as micro enterprises, for people with severe disabilities.

“Is there a job that Lauren could do? Absolutely,” Brady said. “Creating something art-wise that she could sell on a website or on Etsy. ... We did talk about those kinds of things throughout her time in transition; they just never really materialized.”

Evanson, meanwhile, wants her daughter Guss to be able to pursue her own desires and goals, beyond menial employment. Guss is also artistically inclined and would like to launch her own T-shirt design company. And she enjoys singing, so Evanson wants to explore providing singing lessons for her.

Amy Westling, executive director of the Association of Regional Center Agencies in Sacramento, said that about 12 years ago, regional centers in California could purchase “social recreation services” that were designed to help individuals with disabilities enhance their social skills, but these services ended in the wake of budget cuts. In the 2021-22 fiscal year, they will be restored.

“We’re just beyond excited,” she said. “I think we all know that there’s more to life than just work and meeting your basic needs. There’s also a sense of community, and social interaction is a big part of that. We really look forward to (bringing those services back) because that has been a huge hole.”

Pandemic interruptions

For José Reyes, 19, the transition to adulthood got off to a rocky start. Before the pandemic, Reyes was learning to count change as part of a special education program at the Academic Leadership Community (ALC) of Miguel Contreras Learning Complex in Los Angeles. A year of virtual schooling cost him that skill, much to the disappointment of his mother, Mayra De Leon.

“He doesn’t understand how much change he should get or how much change he’s been given when he goes to the store,” De Leon said in Spanish through an interpreter. “That’s something he needs for his future.”

Reyes has DiGeorge syndrome, a rare condition caused by a chromosomal abnormality. Because of the syndrome, he has an intellectual disability and must track the amount of calcium he consumes to avoid falling seriously or deathly ill.

De Leon said her son didn’t get much life skills training until his junior year. She credits his special education teacher, Karina Pérez, with helping him make the shift. Under her watch, Reyes got a part-time job on campus cleaning teachers’ desks and the school gym, and started paying more attention to his schoolwork.

Pérez said she made a concerted effort to instill confidence into Reyes, her goal for every student. Over the past two years, she’s seen his English improve and his belief in himself grow. He’s no longer afraid to ask for help when he needs it, she said.

“For me, that’s a beautiful thing because I know that even if he has a hard time making changes ... he will be able to advocate for himself,” she said. “He does experience an intellectual disability, but he’s a brilliant kid, and he has a lot to offer.”

Despite the pandemic, Reyes did earn a certificate of completion from ALC in June. He's currently enrolled in Widney Career Preparatory & Transition Center, which prepares young adults with disabilities for life after high school.

As Reyes transitions to young adulthood, De Leon still worries about her son's health. But along with the fear, she has faith in her son, who is interested in an entertainment career. He's appeared as an extra in a Guatemalan film and is interested in music.

"We're just supporting him in his dream to be a DJ and an actor," De Leon said. "Some people don't get to the age that my son has. I thank God that he's gotten to this age."

Managing medical care and higher education

On Aug. 26, Iris vanDalen began graduate school at the University of San Francisco (USF), where she hopes to earn a master's degree in marriage and family therapy (MFT). From observing or interacting with the 23-year-old, it's not always possible to tell that she has a chronic illness, which is why vanDalen refers to her Crohn's disease as "an invisible disability."

An inflammatory bowel disease that disrupts the digestive tract, Crohn's disease can have life-threatening complications. In 2011, just before she was supposed to start high school, VanDalen first experienced Crohn's symptoms, which include malnutrition, diarrhea, weight loss, and abdominal pain. Her case was so severe it required her to receive blood transfusions and injectable medications, so vanDalen opted for independent study instead of traditional high school.

Today, vanDalen still receives bimonthly injections to suppress her immune system and keep her out of the hospital. To manage her pain, she has a service dog who can retrieve medications for her, remind her when it's time to take them, and pull her along when vanDalen feels fatigued. The yellow lab can also perform deep pressure therapy that entails putting the force of her body weight on vanDalen.

Transitioning into higher education has been challenging, vanDalen said. While completing her undergraduate degree in psychology at USF, she often felt overwhelmed managing her Crohn's disease, schoolwork, and social life. Adjusting to adult rather than pediatric care, dealing with her health insurance company and staying on top of her prescriptions was particularly difficult, she said.

You're "having to make all of these executive decisions and sign all the paperwork," she said. "That can be a big burden, especially for young people who are trying to live their lives and go to college."

Pip Marks, project director of Family Voices of California, a statewide collaborative of parent-run centers that advocates for youth with special health care needs, said she routinely hears from families that young people lack support when they shift to adult care. No longer cute and cuddly, teens don't elicit the same concern from medical staff that children do, Marks said.

"The doctors are just like, 'You're on your own. Now, you're an adult,'" she said. "We have this idea in our society that once you're 18 or 21, you're supposed to go off and fend for yourself,

but that's not really what happens for kids with severe medical conditions.”

VanDalen doesn't think the transition into adult care has to be such a trying time. She's a founding member of the University of California — San Francisco Medical Center's youth advisory council. The group advises hospital staff on ways to center the perspectives of young people as they provide care. VanDalen thinks health providers should educate youth about what they can expect as they age out of pediatric care.

Marks agreed. Pediatric physicians should continue to treat their newly adult patients until these young people have a better understanding of how to coordinate their own health care, she said. During the transition, young people could gradually be exposed to adult providers to learn the differences between pediatric and adult care.

Outside the hospital setting, college faculty should also be informed of the needs and rights of students with disabilities, vanDalen said. Although most faculty members were understanding about her Crohn's disease, some objected when the illness forced her to take days off from class or take longer on an assignment, she explained.

VanDalen teamed up with the disability services department at her university to inform these professors of her rights. But she said self-advocacy can be scary, especially for new college students who don't want to be perceived as difficult. Her advice to other young people with disabilities adjusting to life as an adult? Don't put too much pressure on yourself.

“When I started college, I had to reset what my expectations should be — my expectations of myself and my abilities,” vanDalen said. “I've learned to just let my body do whatever it needs to do and to make the best out of that amidst all of my circumstances.”

Claudia Boyd-Barrett contributed to this report.

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