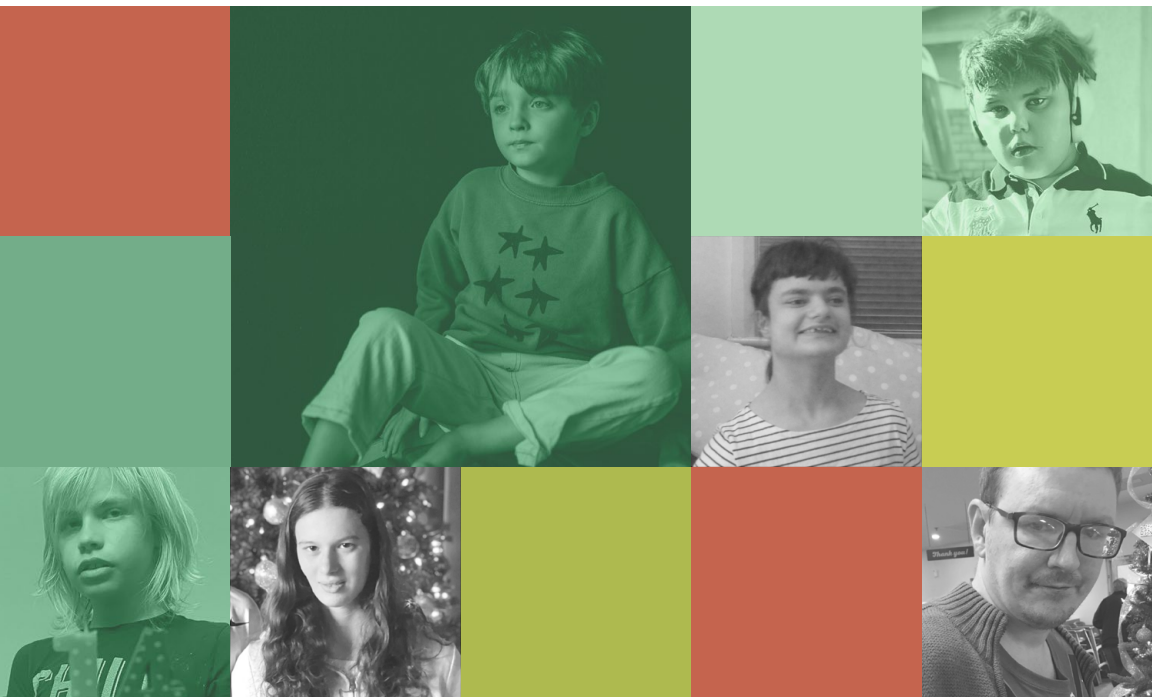


THIS IS PROFOUND AUTISM





Alison and Jodie Singer

Foreword by
ALISON SINGER,
 President of the Autism
 Science Foundation

In December 2021, The *Lancet* Commission on the Future of Care and Clinical Research in Autism, of which I was a member, published a special report that introduced the term “profound autism” to highlight the needs of people who cannot speak for themselves.

The term **profound autism** is intended to describe autistic people who have a substantial intellectual disability, have very limited language, are unable to advocate for themselves, and are likely to need 24-hour support throughout their lives. The goal of introducing this designation is to provide more specificity to the extremely broad autism spectrum and to equip parents, service providers and the public with the language necessary to ensure that all individuals with autism receive the accommodations and interventions they need. Concise, meaningful terms like “profound autism” simplify the process of determining appropriate care, leading to quicker and more targeted interventions.

As both an autism advocate and mother of a 25-year-old daughter with profound autism, I am confident that applying this term appropriately will make a positive difference in many lives. No two diagnoses of autism look the same. Some of those living with autism engage in destructive or self-injurious behavior; others do not. Some have intellectual disabilities; others are star students. Some are unable to perform basic tasks like brushing their teeth and getting dressed; others can live fully independent lives.



My daughter Jodie resides in a group living facility that offers medical and special education services for people who require a very intensive level of support. She often has seizures and struggles to perform everyday tasks like talking, expressing her needs and wants, and adjusting to even the slightest changes in her routine—a reality that made the pandemic especially challenging for her. Growing up, I also witnessed the many challenges my parents faced while trying to help my brother Steven, who also has what would now be called profound autism.

Jodie's long road to receiving the right interventions is a prime example of why specific language is needed to describe autism. For years, she had a miserable experience in mainstreaming programs that sought to give her the same school experience as higher-functioning special needs students. It wasn't until we found the live-in program that she began to thrive. I am grateful that after many difficult years I no longer must constantly fight to make it known that Jodie's needs are far different from those of individuals on the high-functioning end of the spectrum.

While my family's day-to-day struggles have lessened, that hasn't happened for many others who are suffering because so many people in society fail to understand how the needs and abilities of people with autism can vary so widely. This was illustrated to me in 2021 when a 4-year-old nonverbal autistic boy was kicked off a Spirit Airlines flight for not wearing a mask, despite having a doctor's note exempting him due to his condition. In advocating for his son, the father was told that his son's autism was "not a disability."

Anyone who thinks autism is not a disability should spend a day with my daughter.

Those who eschew labels and instead proffer the notion that autism is just an alternative way of being have created a world in which it is increasingly difficult to communicate the needs of individuals who require substantial

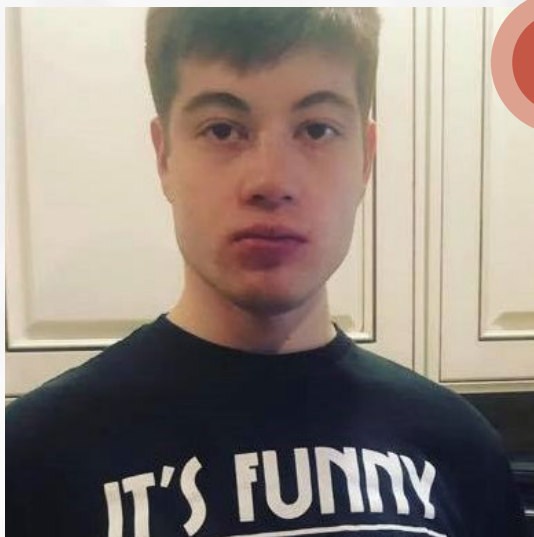
support to thrive—or even just survive. Mainstream autism advocacy is increasingly focused on more independent individuals, which leaves people at the more profound end of the spectrum forgotten and misunderstood. High-functioning autistics are more commonly depicted in the media (think of characters on shows including *The Good Doctor* and *Atypical*). The dominant presence of this type of autism in the media—which is often amplified on social media by higher-functioning individuals with autism—has led to a widespread misunderstanding about what having autism even means.

The *Lancet* Commission analyzed three international databases and determined that approximately 30% of people with diagnosed autism qualify for the new diagnosis of "profound." The term "profound autism" does not seek to demean individuals in this group, nor does it seek to invalidate the experiences of those not in it. Instead, "profound autism" is meant to call attention to the unique needs of this large, vulnerable and underserved community. Normalizing the term "profound autism" will help families more efficiently access the supports and services they need, giving people the best chance to live fulfilling lives with dignity.

The accounts you are about to read reflect the real lives of real people with profound autism. Their families chose to tell their stories because they are eager—and in many cases desperate—for public policy to catch up with the tremendous needs their family members face. We hope that after reading these moving profiles, you too will understand the need to utilize the term "profound autism" to give these individuals a real voice by listening to those who best understand their needs: their loving and exhausted parents. We hope you will support policy and legislation that recognize their needs as being very different from the needs of people with high-functioning autism.

Thank you for your attention and interest.

LEARN THEIR STORIES



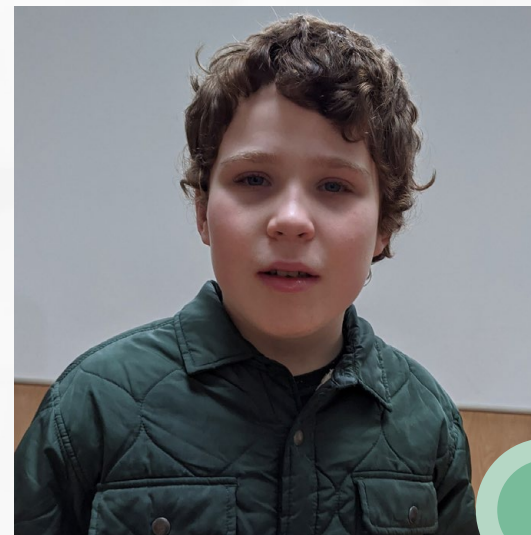
ZACHARY, 26

Zachary is "sweet, curious and loving," says mom Michelle. "Zach is intuitive and knows when people care about him. He can spot a 'fake' a mile away. Zach has an infectious smile, and nothing makes him smile bigger than his favorite people or his favorite music. He has taught us many lessons in humility, compassion, and patience, and most importantly he has shown us what is important in life and how not to sweat the small stuff."

Zach is also nonverbal, and has Phelan-McDermid syndrome and ring chromosome 22 disorder.

"His lack of functional communication via expressive speech, sign language or AAC devices makes it challenging for him to get his wants and needs met consistently," says Michelle. "We wish he could let us know why he is upset or what is bothering him when he is angry or not feeling well. Zach requires assistance with all activities of daily living, and his propensity for elopement and lack of understanding danger require his caregivers to remain in a state of hypervigilance. Fear of not being here to be his advocate and champions so that he has a safe and happy life in the future keeps us up at night."

"We will forever fight for our son," Michelle adds. "He is worthy and deserving of a safe, happy and fulfilling life!"



WESLEY, 15

Wesley loves swimming and is "quite a foodie," says mom Jennifer. "Nothing melts my heart more than when he takes my hand and stares deep into my eyes. Wesley has a remarkable way of connecting with people, despite being entirely nonverbal."

"We constantly worry about Wesley," Jennifer adds. "At home, he'd often not sleep much, or at all, and can be aggressive and quite self-injurious. We made the heartbreaking decision to move him to residential care, and after two of his group homes in California closed, he now lives out of state."

"We miss him terribly, and COVID has made it hard to visit as often as we'd like. We're angry and frustrated at the lack of quality services for kids and adults like Wesley, especially in our home state of California."



SETH, 48

Seth "likes being a helper," says mom Martha. He also likes playing pinball and laughing and following along while listening to books on CD. "Since communication is quite limited, I see him smile when he is able to say some new word or phrase."

Seth is prone to tantrums when his routine changes, and in addition to autism he also has IDD, bipolar disorder, OCD and megacolon.

"COVID changes have made him a worse person because his severe behaviors have gotten worse," says Martha, 83. "He is known as the most difficult person by everyone who works with him. He often wakes at night and stomps on the floor and listens to his radio and dances. He lived in his own place with a caregiver through a home and a community-based agency since age 22, and I became an administrator of his program. But in May I got cancer and decided it was time to call it quits. He is in a group home now, and I don't like the lack of individual attention, but they do provide good structure."



MYA, 20

Mya loves going for car rides, riding horses, and dancing and laughing with her family. She can also be very violent and gets frustrated and triggered easily, says mom Shauna.

"We walk on eggshells every day not knowing what behavior we are going to get from her," says Shauna. "It's not easy to talk about, which leaves us isolated a lot. Trying to get services and filling out paperwork is like a full-time job. I would do absolutely anything for my daughter, but I am completely exhausted."



SEBASTIAN, 12

Sebastian "has a sense of humor and a smile that lights up the room," says mom Arika. He also plays piano "beautifully" and loves to swim, often staying in the water "for hours."

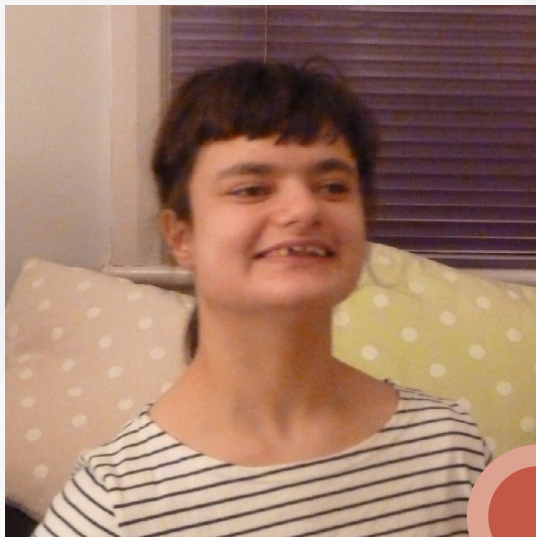
But Arika says he is also still in diapers, has no verbal language whatsoever and must be supervised at all times.

"He has episodes of self-injury throughout the day," says Arika. "When his behaviors are bad, he's extremely dangerous and has injured his caregivers multiple times. I don't know what I'll do if he becomes too much for them to handle. I fear being able to not afford enough care one day. I fear him becoming too strong for all of us to manage. His twin sister is neurotypical, and her dream is to become a neuroscientist and figure out the causes of autism. I still hope for him to overcome his challenges and change the world, but some days that hope reduces to just being able to keep him at home. Some days my entire hope is for him to just stop screaming."



JONATHAN, 23

Jonathan "Jonny" is a very strong, handsome and affectionate young man who loves listening to music, hiking and swinging, says mom Jill. He also cannot speak, read, write or even follow simple directions. "Jonny has no ability to care for himself and will require intensive 24/7 care for the entirety of his life," says Jill. "As much as we adore him, we should never sugarcoat this dire reality."

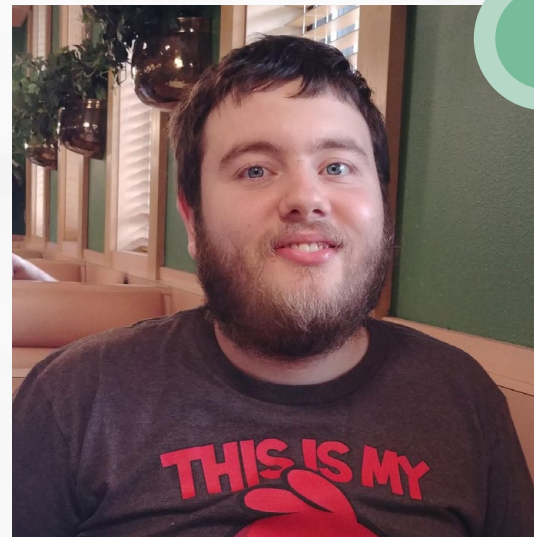


MIA, 15

Mia of the U.K. cannot speak and has limited communication skills, "but her smile says it all," says mom Maddy. "She loves pushing buttons and musical toys and also swimming."

Mia is also epileptic, and cannot wash or dress herself or use a knife and fork.

"She has no understanding of the world beyond her own," says Maddy. "I worry constantly about her future and who will look after her as well as we do when we are gone. Having no communication skills, she sometimes resorts to self-injuring (biting her hands) in sheer frustration, and this can be misunderstood as a negative behavior. Mia will need 24-hour care for the rest of her life."



JAMIE, 26

Jamie loves "walking, swinging and just being outside," says mom Donna. "He remembers every tune he hears, even though he can't sing the words. He is funny and likes being silly!"

Jamie is also nonverbal and suffers from chronic gastrointestinal issues, epilepsy, sensory issues and hypotonia.

"He is mostly incontinent and needs help with personal care. He has frequent meltdowns that can include self-abuse, aggressive and/or destructive behaviors. I worry about what will happen to him when my husband and I are no longer able to care for him. (We are in our 60s.) He deserves to be cared for and treated with respect, just like any other human being. He deserves the very best quality of life that we can give him!"



JONAH, 23

Jonah learned to read and write before he could talk, loves finding his favorite *Sesame Street* videos on YouTube and eating "ketchup and hamburger and French fries." He also has a history of very aggressive and self-injurious behavior that necessitated an almost yearlong hospitalization at age 9.

"My greatest fear is that once he moves into a residential setting, no one will care enough to find out what he means when he asks for a 'fun list' or 'white chips,' or know that he needs to sleep with the light on," says mom Amy.



GRACE, 15

Grace loves music, says mom Shannon. "She is definitely our pop music-loving child, but really loves anything with a good beat! If she's having a bad moment, we can turn on music and she calms down. Grace's laughter and smile can change the entire feeling of a room, it's so genuine and full of joy."

Although Grace is nonverbal, Shannon says her daughter "wants to be included and involved in daily activities just like any 15-year-old girl."

Shannon also worries about Grace's future. "What will her adult life look like? Who will care for her when my husband and I are gone? Will she always have self-injurious behaviors? Is she safe with her caregivers during the day? Can they predict her behaviors and needs when we aren't around?"



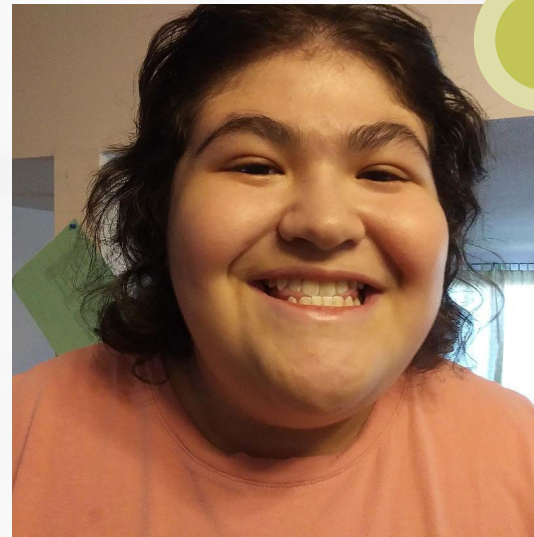


JAMES, 19

James has benefited "tremendously from ABA," says mom Amy. His many hobbies include finding locations on Google Maps. "I love that I often see him find remote places like the restaurant we ate at two years ago at the beach or the building we just visited on a trip to Houston." He was able to learn to ride a two-wheel bike, and Amy calls the 5- to 10-mile bike rides they take together "our most special mom/son activity."

Amy says James also has "significant problem behavior in the form of aggression toward others. Because James has access to a strong ABA team, we are able to keep the number of these aggressive episodes at low rates. However, he needs significant ongoing behavioral expertise and behavioral supports in place in all his environments to keep his problem behavior at a minimum and allow him to use the many skills he has acquired to maintain a meaningful quality of life.

"One of my biggest fears is that I will not be able to find any programs or residential situations that will support his behavioral needs. As all parents do in this category, I fear the unknown of what will happen to him when my husband and I are no longer able to take care of him or have passed away. I fear that he will be abused or treated cruelly. I fear that when he graduates from high school, there will be no meaningful, enriching programs available that can support his behavior needs. Despite that reality, James lives a life worth living—filled with joy, security and people who love him and cherish him. He deserves the chance to be in future environments capable of maintaining and advancing his quality of life. The chance at a decent life should not end at the age of 22."



ELENA, 13

Elena is "very loving," says mom Mel. "When I go to pick her up at school, she hugs both the teacher and me at the same time and says 'group hug' just like the *Trolls* movie. She is a little jokester doing cute little pranks all the time."

But Mel also worries about what will happen to Elena when her parents are no longer able to care for her. "She takes a pill smooshed into a gummy candy to keep her from having periods because she can't manage either the pads or the pain. Who will prepare it for her every day? Who will know that she eats only one brand and flavor of popsicle every day? Who will know that she only eats a handful of foods so I give her ground-up vitamins and minerals so she doesn't have deficiencies? Who will care enough to learn these things so she doesn't get sick and can be nourished?"



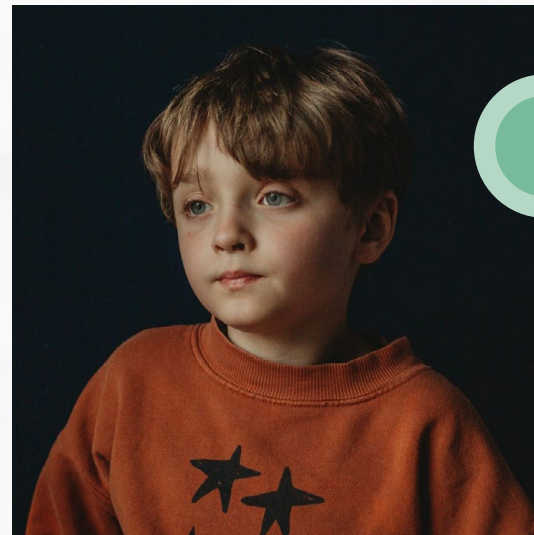
ELIJAH, 12

Elijah "gives the best hugs," says mom Rebecca. "He loves being tickled and cuddled. Elijah's laugh is infectious. He loves watching 'fail' videos on YouTube and loves watching people fall! My heart melts when he smiles. I think he is just about the handsomest boy in the whole world."

Elijah is also completely nonverbal, sometimes runs away and has pica disorder.

"We have locks and cameras all over our house to try to keep him safe. Elijah loves smelling and eating lotions, soaps, shampoo and other aromatic stuff. We're concerned he might ingest something very harmful. Elijah can be aggressive when his routine is changed. He hits, scratches and chokes others. He destroys property, kicks holes in walls, etc. He also has severe ADHD and anxiety."

Despite his difficulties, Rebecca says Elijah "is loving and sweet. He is more than a list of difficult behaviors, but those behaviors govern his and our lives."



CHARLIE, 9

Charlie finds joy in the simplest things, including chicken nuggets and kinetic sand. He is also nonverbal and engages in aggression, self-harm and destruction.

"There's nothing to celebrate about seeing your child have self-injurious and aggressive behaviors," says mom Eileen of The Autism Cafe. "It breaks my heart when I see him hit his little brother, who keeps asking me why Charlie doesn't love him."





CLAYTON, 21

Clayton loves *VeggieTales*, Pixar movies and riding in the car, says mom Erika. "He loves to watch videos with the audio from other languages—I think that if he could speak, he would be fluent in about 10 languages!"

He is also epileptic, mostly nonverbal and requires constant assistance and supervision.

"His father is his daytime caregiver while I teach school, then I take over on evenings and weekends," says Erika. "Clayton is very sweet and content most of the time, but between his seizures and occasionally violent, aggressive meltdowns, we don't dare to ask anyone else to care for him. One of his meltdowns last spring resulted in an injury to his dad, which required surgery. Since we can't leave him with anyone else, we don't do anything as a family—if one of the other kids has an event, we take turns going to watch/participate. One of us always has to be here with him. Family outings, vacations, dinner together in a restaurant—not possible.

"Despite the impact on our family, I absolutely cannot bear the thought of him living anywhere but home," she adds. "But I refuse to burden his siblings with the possibility of eventually caring for him, so I am willing myself to live forever (or at least long enough...)."



CHAUNCEY, 10

Chauncey "thrives on routine," says mom Amanda. "He loves school. He attends a special autism-based school and loves to run, hike and play. He loves to jump and swing and also loves water. He is happy with the smallest things."

He is also nonverbal and has severe intellectual disability.

"He is unable to communicate his wants and needs correctly. He cannot tell me when he hurts or where, what he's thinking. I worry for his safety. He doesn't understand danger. I worry who will care for him when I'm not here. I worry about his health and happiness and if he is going to have a good day of no harming.

"He is a happy boy who loves to be free," adds Amanda. "He just needs extra care and sensory breaks. He doesn't mean to hurt anyone. He just can't communicate."

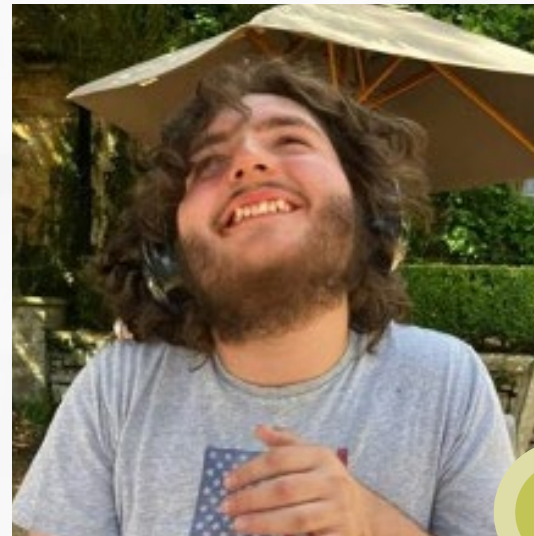


CASH, 14

Cash "loves hugs and jumping on his trampoline," says mom Stephanie.

She says he is also nonverbal (limited use of AAC), is not toilet trained and "has violent outbursts where he attacks his parents and cannot keep himself safe. He is mostly stable right now on the right combination of medications, but it does not eliminate violent outbursts that become more dangerous the bigger he gets. His autism and inability to communicate make medical care very difficult—he has to be put under general anesthesia for dental work and restrained for immunizations. I can't even cut his hair while he is awake because of the sound and his sensory issues, and he wakes up if I try to cut it while he is asleep.

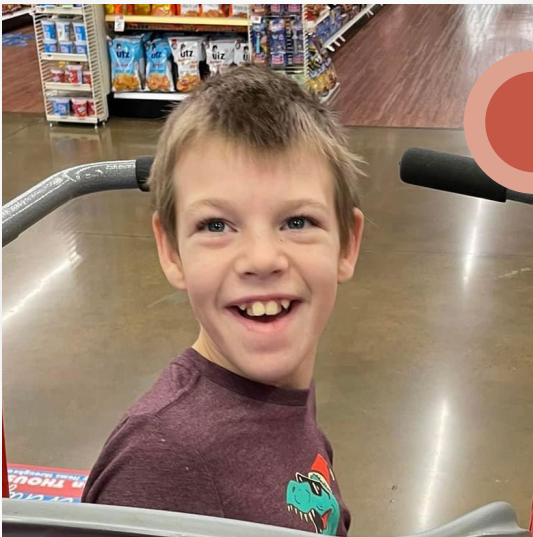
"He is worthy of living a life where he is safe and protected," Stephanie adds. "I love my son like every other mother loves her child, and I want to make sure he is taken care of after my husband and I are no longer living. I don't see what our options are at this point."



DECLAN, 14

Declan "has a very cheeky sense of humor and really enjoys having a good laugh," says mom Meredith. "He loves rollercoasters, and he loves swimming too, although he sometimes struggles in public pools, due to the noise and the acoustics."

He is also nonverbal and struggles to use his communication tools effectively. "Unfortunately, much of my son's communication is through his behavior, and if he's frustrated or in pain he can become very aggressive. Much of his aggression is self-directed in the form of self-injurious behaviors, which can be very dangerous. I worry for my son all the time, particularly as he finds it so hard to communicate his needs."



OWEN, 12

Owen "loves people," says mom Allison. "He's deaf, so just seeing their faces, engaging with them through different facial expressions, smiles and funny faces makes him so happy. He loves driving in the car and looking out the window. His smile grows even wider when he gets to stop at McDonald's or have a lollipop."

Because Owen's mood can change quickly, "our house is like Fort Knox, locked down from the inside, pictures off the wall, no doors on most rooms, every cabinet and drawer shut tight, locked up, all for his safety," says Allison. "Chairs line the wall so they're less likely to be thrown down. At night we are always listening for an escape from his bed, on guard, ready for action 24x7. I worry who will ever love him as much as we do, the burden that may be placed on our older child, who will understand that when he gazes at the top of the fridge he wants a snack, that when he lays in the doorway of Target he just needs a minute to get over the thrill of possibly being able to slam a door, that he doesn't want hugs when he's hurt, that just sitting with him on the floor and passing a lanyard back and forth can bring him immense joy."

Allison adds that Owen "may not be able to communicate in a traditional way, he can't hear when you speak, but he can pick up on subtle cues most people don't notice."



JOHNNY, 19

Johnny "is loved beyond all by his entire family," says mum Jane of the U.K., who notes that "his capacity for sheer joy in simple things like bouncing, swimming and a Maccy D's meal is unrivaled."

She also says he has little to no understanding of danger and will require 24-hour care for the rest of his life. "What happens after we, his parents, are gone is something I think about all the time. He is as vulnerable as a toddler out in the world."





BEN, 17

Ben "is full of energy and love," says mom Lauren. "He gives the best hugs and has the most contagious giggle. He loves being around people he knows—the more the merrier! He's our nature lover too and has taught us all to appreciate the beauty all around us!"

Ben also has many needs. "He requires help with all daily living skills, and we worry no one will love or care for him like we, his parents, do. We will have to rely on grace and compassion from complete strangers (making minimum wage) to care for him when we are gone.

"Ben has such a beautiful soul. He is so deserving," adds Lauren. "Like anyone else, he too deserves to live a happy and fulfilling life."



