

The Trouble in Texas: Nightmare, Dream, and New Vision



Ben Burns

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By Dan E. Burns, PhD



Dan E. Burns, PhD, is the author of *Saving Ben: A Father's Story of Autism*. He is a retired assistant professor from The University of Texas, where he taught communication courses.

Ben sprinted ahead of me on the Katy Trail, veered off onto Routh Street, and disappeared into the city. Fear, searching, squad cars, sirens, helicopter, night. His mother and I, exhausted, waited for the call from the police, the hospital, or the morgue. An hour and a half later, he came loping back down the Katy Trail, thirsty, exhausted, and brimming with pride. For the first time in his adult life, my 22-year-old son with severe autism was briefly on his own.

He had declared his independence. And survived.

But his disappearance touched a chord. “One of the biggest fears of parents of autistic children,” says Stephen M. Edelson, PhD, director of the Autism Research Institute, “is what will happen to their son or daughter when they are gone.”

Where will our adult children with autism live, learn, work, play, heal, and find friends after

the school bus stops coming and for the rest of their lives? “A worst-case scenario,” says Dr. Edelson, “is homelessness.”

As the parent of an adult child with autism, my fears are more graphic. Sleeping under a bridge. Abused, tormented. In jail. Those are my nightmares for my 23-year-old son with autism, Ben.

“If little or nothing is accomplished in the near future, for many people, as their children with autism graduate from high school and pour out onto the streets, those fears will become a reality,” Dr. Edelson says.

For the family of Adam Wilson, they certainly did.

Adam, diagnosed with autism spectrum disorder (ASD), had been sheltered, tutored, and loved by a large and loving extended family in and around his home town of Arp, a rural community nestled at the end of Farm Road 2089, deep in the piney woods of East Texas, where he worked on mission trips for his church and raised animals.

Adam Wilson's family had planned that he would always remain with them in the community where he was loved and respected. By August 2010, shortly after his 21st birthday his safe world began to come apart. After an incident at work, he abandoned his job as a grocery sacker and roamed the woods and county roads day and night, struggling with unexplained agitation and anxieties. Despite his father's repeated calls for help to his son's personal physician and Adam's own pleas for help—he chartered a cab to the emergency room and begged to be admitted to a psychiatric hospital for observation—no help was forthcoming, and the crisis escalated to a violent conclusion. By the middle of September he was sitting in jail, awaiting prosecution for killing his father.

What are the options for Adam, for my son Ben, and for the hundreds of thousands of young adults with autism who will come pouring out of the school system in the next 5 years?

Today I share two of them: the nightmare and the dream.

THE NIGHTMARE

If Adam stands before a judge, he may be headed for a Texas state hospital or for one of the state schools for people with mental health issues or intellectual disabilities (recently renamed state living centers). From that point on, his prospects are not good.

Texas has more institutions than any other state for people with intellectual disabilities, including autism. These institutions have a history of civil right violations. In 2005 and 2006, the U.S. Department of Justice investigated the Lubbock State School and other Texas residential treatment facilities for persons with developmental disabilities. They found gross abuse and neglect and violations of civil rights regarding the right to leave the facility. Seventeen people with significant medical and intellectual disabilities died in those facilities within a single year. Most died from neglect.

Jeff Garrison-Tate, founder of Community Now, witnessed the conditions in these institutions firsthand.

"I was a member of a team put together by Advocacy Incorporated with federal authority to go into the Lubbock State School and several other Texas state institutions to confirm DOJ findings," said Jeff. "I was stunned by what I saw."



Above and below: Adam Wilson



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"In Lubbock, I heard a young man screaming from another room. I saw him in a chokehold, held down by four people, squirming in his own blood. When the residents found I was from the outside, I was swarmed by people begging me to help get them out. Those voices and faces are in my dreams now."

Texas will soon experience a wave of children and young adults with autism exiting the public school system. "The potential consequences for communities and families are frightening," says Jeff. While there are programs for people with intellectual and physical disabilities and autism to stay in the community with support from community services—largely through Medicaid waivers administered through the Texas Department of Aging and Disability Services (DADS) program—the situation is far from ideal. "The waiting list now contains over 100,000 names," Jeff says. "There's an eight-to-ten-year wait, and it's getting longer. Many of those with disabilities who live in the community, like Adam, are struggling. In some cases their families are being destroyed because there's not enough community infrastructure to support them. State schools are the only entitlement."

I asked him what we must do.

"First," says Jeff, "we must realize it's a problem that belongs to everyone: you, me, and the community. We must strengthen the safety net. Adam is paying the dues for what, in my opinion, the State of Texas and our community lacked. He and his family should have had available services, including adequate support from the medical system and crisis counseling. We need, right now, to organize for change and make certain that our children, as adults, get the support they need in order to give back to the community and live a valued life," he says.

THE DREAM

What other options exist for adults with autism?

I put that question to Anna Hundley, executive director of the Autism Treatment Centers of Texas, a position she has held for the past 31 years. Anna is president of the National Association of Residential Providers for Adults with Autism, and she serves as the vice chair of the Texas Autism Council on Autism and Pervasive Developmental Disorders.

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“Tell me about small group homes as an option,” I asked. “How does that fit into the picture?”

“Small group homes are great,” said Anna, “if you can find one with an opening.” She explained that while some parents do get together and buy or lease a house for their adult children with autism, there is a learning curve. “If you have three individuals, three adults, who have HCS funding, you can get a house and a loan, possibly from the Federal Home Loan Bank. But that’s just the beginning,” she says. “You’re got to have some kind of funding and support to operate that home and staff it and maintain it.”

Some parents say, “As long as I draw breath, my disabled child will have a home with me. And when I’m gone, his brothers and sisters will take care of him.” Is that a viable option?

“It’s a viable option, a good option, and the right option for many people,” said Anna. “But the key is what you said: ‘What happens when I’m gone?’ You must have a guardianship plan in place so that when you are gone, your adult child has a safe place to live.”

I asked Anna if there were any other options.

“Foster care. State schools. Homeless shelters, jail, and prison,” she said. “That’s about it. We’ve got to have additional options so that our children can be contributing citizens and have the kind of adult life that they deserve. We have got to get to work and develop some other solutions, a new vision.”

Ben’s sprint for freedom, his declaration of independence, should be honored. How to reconcile safety and freedom, independence and community? That is the challenge we face.

The New Vision

In November of 2010, I met with other founders of The Autism Trust USA in Austin, Texas. We shared our vision of what such a life would look like.



Above: Danny Baker, Polly Tommey, Andy Wakefield, Carmel Wakefield, and Dan Burns

Here is my vision.

I see a small college-like campus, in or near a city, open and accessible, connected with fields and farmland extended into the surrounding country, where adults with autism spectrum disorder (ASD) and other different abilities can live, learn, work, play, grow, and use their extraordinary talents to give back to their communities and live safely into the bright and creative future with purpose they deserve.

I see residential facilities—small group homes and individual apartments under shared ownership—grouped on campus around a common area that encourages socialization, and other homes integrated within the larger community, where residents are offered as much or as little support as they need from fully trained, caring staff.

I see cafes and small shops selling products grown, created, and served by members where visitors can meet and mingle, communicate, and learn, connected by the Web to resources worldwide.

And a transportation system making the campus accessible to visitors, family, and members who choose to live or work in the broader community, with access to volunteer activities, church, movies, shopping, nature, and hiking.

And agricultural and horticultural

centers with gardens, orchards, landscaping and janitorial enclaves, barns and greenhouses, woodshops and studios.

And a business and banking center, fully equipped with digital technology, populated by entrepreneurs with autism and their families who start, nurture, and run their own small businesses.

I see a training and conference outreach center, open to members, visitors, families, and caregivers, where guest lecturers share the latest information on living, learning, healing, and thriving with autism.

I see a wellness center with a presence both on and off campus and where diet, biomedical, and behavioral therapies are taught and practiced. I see an outpatient resource center where doctors, nutritionists, and behavioral specialists offer their expertise to students and any member of the autism community who seeks wellness and wholeness.

Our adult children need a safe place, a campus, a parent-driven enterprise where they can have the future they deserve, a future with purpose. If you would like to be part of making this dream a reality, we are looking for \$500,000 to buy land near Austin. Donors should send checks made payable to “The Autism Trust USA” to Dan Burns at The Autism Trust USA, 3919 Holland Avenue, Dallas, TX 75219.