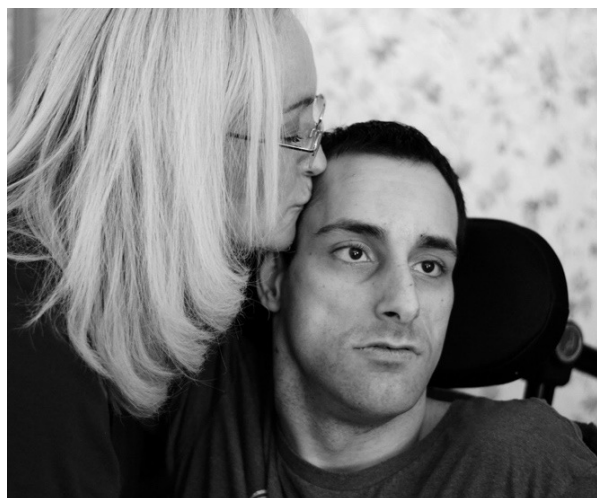


# Real Lives, Real Impact: Stories from the WVU Center for Excellence in Disabilities (CED)

## Tony and Bonnie



My son Tony was born a preemie at 27 weeks. He was 2lbs. 13 oz. He was my first child. He was eventually diagnosed with cerebral palsy (CP) and profound deafness. He had many complex medical needs. Despite that, he progressed well with early intervention and special education through the county schools.

Tony learned how to use a communication device. He was also taught that he could use sign language to communicate. Even though Tony was in a wheelchair, I took him everywhere. We attended family gatherings, went to the movies, went shopping, went to parks and community events. We were not wealthy, but we had a good family and friends who invited us to stay and have

fun with them. Tony and our family were able to visit the beaches, amusement parks, and zoos. Tony lived a full and rich life! Tony was an amazing person with a great personality. He touched so many people's lives. Many people said he was such a happy person, and his smile could light up a room.

I heard about the WVU Center for Excellence in Disabilities through a social worker at the Children with Special Healthcare Needs organization that Tony was enrolled in. Tony attended the WVU CED Feeding & Swallowing Clinic, where they helped him with swallowing issues and gave me strategies to help him eat better. He could eventually eat table foods and drink from a cup he held and a straw, which was amazing for someone with severe CP. Then, we were able to access the Loan Library at the West Virginia Assistive Technology System (WVATS) program at the WVU CED. We were able to borrow communication devices, adaptive toys, switches, and adaptive equipment throughout his life. All for free for 30 days through WVATS. All the programs we accessed were free. They also helped me find the support and many resources we needed for Tony even as an adult.

When I began working as a service coordinator with the WV Birth to Three early intervention program several years ago, I recommended the WVU CED many times to families that I served. They reported back to me how helpful it was for their children and their families.

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My son passed away about three years ago at the age of 37. I began my job at the WVU CED over a year ago with the Paths for Parents/Family to Family program. I have since helped many caregivers, parents and families that have children with disabilities. Our staff are parents that have children with disabilities, and we are trained to help those families find resources, mentorship and support, the same way they helped my son and my family. Many families that I serve have friends and family, but no one can connect and relate to them like other parents and caregivers of children and adults with disabilities.

The proposed federal budget wrongly lumps University Centers for Excellence in Developmental Disabilities (UCEDDs) like the WVU CED in with DEI programs. If the budget is not changed, all UCEDDs will be eliminated, removing millions of free services for people with disabilities and their families. I will also lose my job at age 61 after dedicating most of my life to helping others along with 95 other co-workers who serve families in West Virginia. Last year the WVU CED provided services to over 400,000 people. These services reduce reliance on public aid, fill critical provider shortages, and provide a strong return on every public dollar. Please save them!

Sincerely,  
Bonnie Shannon  
Parent Network Specialist  
Paths for Parents/Family to Family program

[www.cedwvu.org](http://www.cedwvu.org)

 West Virginia University  
CENTER FOR EXCELLENCE IN DISABILITIES