

Individualizing Healthcare for Patients with Developmental and Behavioral Challenges

“Drew hated to go to the doctor’s for anything. It would always be a battle between the two of us, and I would always get the raw end of the deal. I went to talk to Drew’s doctor at Cincinnati Children’s and they recommended I talk to the Adaptive Care Team coordinator. I felt more at ease knowing I had someone who knew my situation, and who was going to be there by my side. Everything went smoothly. I really don’t know what I would have done without their help.”

—Mandy (mother)

“I think whenever parents hear the word ‘surgery,’ they automatically tense up, and their mind explodes with hundreds of little worries. For us, those worries quickly piled up into the thousands. When your child has autism and even a haircut can provoke panic, the possibility of a ureteral reimplantation (a kidney surgery) just seems insurmountable. I am sure that the success of our experience was due to ACT’s involvement in preparing Tress and communicating the plan to the hospital staff. It was such a different experience than our fears had anticipated.

We are very appreciative of their advocacy and support.”

—Holly & Brad (mother & father)

“Joey is 20 years old with Fragile X Syndrome. He is nonverbal and has a very hard time with any healthcare visit. When his next surgery came, [the Adaptive Care Team] met us with a wheelchair at the entrance. We were taken back to the prep room with some of his favorite things already waiting. He cooperated with staff and woke up in a private recovery room with us already there.

Surgery is no longer a horrible experience. Joey trusts the staff now and likes seeing them.

What a difference for all of us.”

—Don & Ray (father & caregiver)

