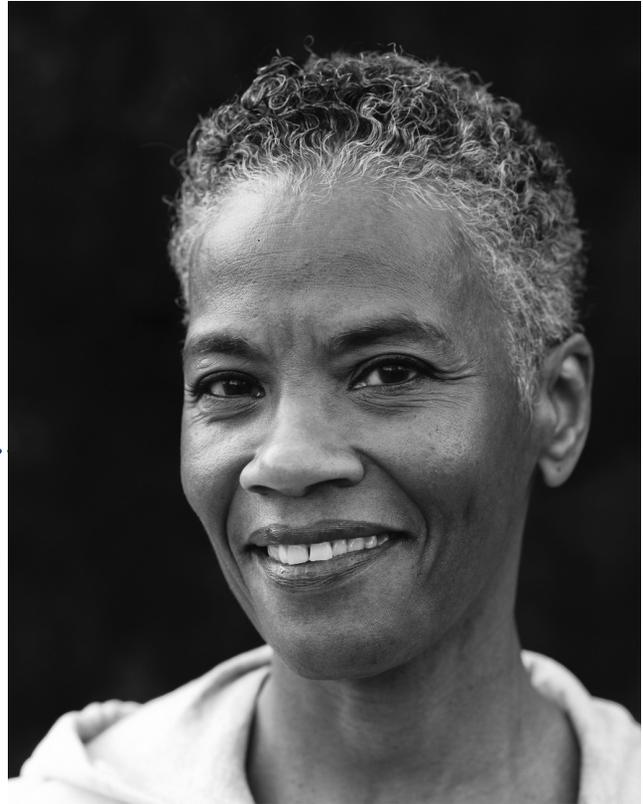


## Helping Youth Transition into Adulthood: A Parent's Perspective

**A**t the moment when that newborn baby is placed into a parent's arms, natural instincts cause us to do our first quick inspection. We want to see two soft cute arms and legs, two half open eyes, perky ears and a somewhat round head. We let out a sigh... all looks normal. As we watch them sleep, we start to dream about our future teacher, nurse, doctor, lawyer or the next President of the United States of America. After all, this baby is perfect, smart, and the sky is the limit. As time goes on, there will be many transitions in the life of this child; things from potty training to the first day of kindergarten, then middle school, and at last, high school graduation. As a parent, we strive to make these transitions as smooth and as positive as possible. While these transitions are a normal part of healthy development and growth, they are extraordinarily more difficult for the child who has a serious emotional, behavioral, or mental health disorder.

As a parent, I have grown accustomed to having to prepare in different ways for these transitions. My son was involved in multiple child-serving systems and transitions were a way of life for us. I remember my son asking the question at a child and family team meeting as we prepared to transition him back into his community school after 18 months in a residential treatment facility, "Where am I supposed to tell my friends I was for a year and a half?" This question was answered by the team in a way that, in hindsight, taught my son to be ashamed of and hide his need for mental health care and support. He was offered the following solutions: Tell them you went to stay with your grandmother in Virginia, tell them you were in boarding school, or tell them it's none of their business. I was not prepared for how this would shape the way my son handled these kinds of transitions right into adulthood.

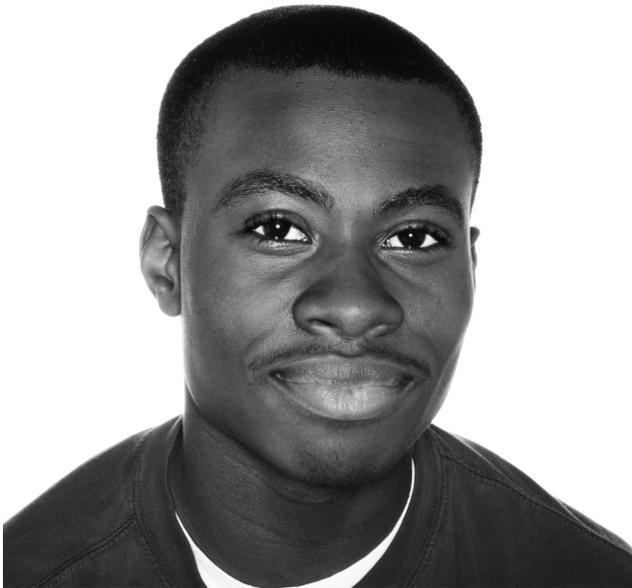
I had been my son's advocate since his first diagnosis at the age of four. I had learned to be open with people about his challenges and to ask for all the supports and services



I felt he would need to be successful. As he grew older, I often encouraged him to speak up for himself. I told him that we would need to know his hopes and dreams in order to support him in reaching them. The best thing I could do for my child was to not only be his greatest advocate, but to teach him to be his own advocate. What I was not prepared for was the anger, disappointment, and distrust he would develop for the systems he had been involved in and the amount of blame he would place on me allowing the system to "mess him up."

The Individuals with Disabilities Education Act (IDEA 1997) mandates transition planning. My son's school did a great job with this planning. What we realized is that the best made plans will not work without the support systems and services remaining in place. My son was placed in a charter school so that he could participate in the culinary arts program in order to fulfill his desire to become a chef. He was in his senior year in high school when he entered the two-year program. He completed the first year with much success. He also completed all of his high school graduation requirements. He was given the choice of graduating with only one year of the program completed or staying in high school another year to complete the two year program. IDEA says that a student's right to a Free Appropriate Public Education (FAPE) is terminated upon graduation with a

“regular” high school diploma, but not with any other kind of graduation certificate. My son was on track to get a full high school diploma. He worked hard to stay on the graduation track. As his mother, I wanted him to stay in high school another year and come out with a high school diploma as well as a two-year certificate in culinary arts. From my perspective, this was a win-win. He would continue to have the support of the school counselor and school psychologist and would be closer to reaching his goals. On the other hand, my son was angry with the choices; or in his words, the “lack of good choices.” He could stay in school and miss graduating with his class and be viewed by his peers as fail-



ing and not graduating on time, or he could graduate now and worry about school later. He chose to graduate. The school did not feel it was the right decision and tried multiple times to change his mind. I supported my son’s decision although I really wanted him to stay in high school. I was able to see my son’s point about the “lack of good choices.” He graduated, and none of his services and supports from school followed him. Although the planning process started off in a very family-driven, youth-guided way, the regulations did not allow the process of completing the culinary program to work for my son.

Transitioning from the children’s mental health system to the adult system was a lot more challenging for me as a parent than it was for my son. When he turned 18, I immediately realized that my role in his life would have to change even more. My son’s dream was to never go from the child system to the adult system, and he wanted my support in helping him reach that goal. He wanted to be weaned from his medication and taught to manage the symptoms of his disability. I did not think this was the best thing to do. My son’s psychiatrist was willing to try taking him off of his medication and again, I realized that my role was to be supportive. I had taught him to speak up for what he wanted, but I also taught him to understand the responsibility that came with decision making. It has been over a year, and while things have not been perfect, my son is proud of the decision he made.

My son had a setback a few months ago that caused him to be placed on probation with an assigned probation officer and a new therapist. My son chose not to disclose any prior involvement in the mental health system, because of his distrust and for what this disclosure could mean. I was very afraid that without this knowledge the court system would give him a harsh sentence and not meet his mental health needs. My son was willing to take that risk just to be “treated like a normal adult.” My attempts to call his probation officer and therapist were to no avail, because he was now over 18 and I could not speak to them without his permission. I felt completely shut out of his care and treatment, although I am still responsible for the expense of his health care. I wanted to tell them his history and help them with his treatment. I am sure any parent reading this will understand my view point, and any young adult reading this is saying, “He’s grown now mom, back off!” By making his own decision, my son stepped up, took responsibility for what he had done and explained to the judge that he should have made better choices. I am very proud of the young man he has become. He also has become his own advocate, being able to speak up for himself and his needs.

As a parent, I worked hard to get the best services and supports possible for my son; although at times, my best efforts did not get him the best treatments. My son now realizes that, just as he is not always given the best choices, he has to make the decision based on what he feels is best for him. He also understands now that as his mother, I too was not always given the best choices, and I did what I thought was best for him at that time. We both realize the importance of making sure that family and youth voices are heard and supported in the service delivery process. We both agree that these are a few keys to success in the transition to adulthood for youth with serious behavioral, emotional or mental health challenges:

- having a parent or other supportive adult who believes in the youth
- parents helping the youth build their own support network
- having excellent services and supports
- having a cadre of “good choices”
- parents teaching the youth to be a self advocate
- parents supporting the youth in the decision making process

It’s a challenge for parents to know when to step in and when to let go; we need to stay tuned to the development and maturity of our youth and listen to them. I could not have waited until my son was 18 and then say, “now that you are an adult, you drive your services.” I had to allow him all along the way to be involved in treatment and service decisions. This process allowed me to be better able to support him in his decisions as a young adult.

#### **AUTHOR**

*Sandra Spencer* is a parent and Executive Director of the National Federation of Families for Children’s Mental Health.