Promoting Health Care Transitions for Adolescents with Special Health Care Needs and Disabilities

edited by

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number of initial medical tests and procedures, not making disparaging remarks about pediatric providers, and asking youth what worked and what did not work for them in their pediatric care. The leadership of pediatric and adult health care organizations also has a critical role to play in making transition a priority and in addressing the financial, procedural, and inter-professional issues that can impede the smooth transfer of youth with special health care needs and disabilities to the adult health care system.

**SUMMARY**

This chapter has discussed the multiple participants and their roles in the health care transition planning process. Every young adult and their family will face unique hurdles in the transition process. For some, transition may be relatively smooth and trouble free. For others, health care transition will be time consuming and present seemingly insurmountable obstacles. Regardless of how health care transition unfolds, asking questions about the future in general and health care specifically lays the foundation for planning and anticipating future health care needs. Transition planning tools and activities have been suggested to help make the process of HCT more manageable and organized. The longest journey always begins with one step—health care transition planning is that step.

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**My Story**

Joy and John Ryan Mudry

An important aspect of health care transition planning and independence is its perception. The following vignette demonstrates that even within one family there are both shared and unique understandings of the transition process. In this vignette John Ryan and his mother share their perspective on health care transition and John Ryan’s future.

**John Ryan**

We’re all in a card game called Life. God is the dealer. You keep what is dealt. Some hands are good, some bad. You just keep playing ’til you cash out.

That is a pretty good way to look at it I think. It is really not what you have; it’s how you look at it. Take me and my family, for instance. Dad sees mostly negative; Mom sees mostly positive. You’re either living in a dark, gothic castle, or you’re living in Disney World. Me, I’m a realist. I look at both positive and negative aspects of life and then base my judgments, views, and predictions on what things really are. Yes, I have several chronic illnesses, yes I will have a shorter life, but I can still have fun, go out with friends and all that. I just have to make choices like having a regular soda versus having a dessert. That extra piece of pie or more insulin. In economics that’s called an opportunity cost. What you give up for something else. I think I manage my health affairs pretty reasonably, but shush! Don’t let my parents know! They still think I can’t handle it just because I do things a little late or change the order around a bit.

What can I say? Parents, oh bless them! I reason that they did a pretty decent job of transitioning me from pediatrics to adult medical care. I mean, as long as I’m still conscious I can handle any problem that should arise. I make decisions even when my nurses are not sure. I’ve been handling all my own insulin and medicines since I was 12. At first Mom did everything, then I started injecting the needle myself, then I would draw up what my mom would tell me to do, and finally I can make all the decisions for myself. In fact, Mom doesn’t do anything in that area anymore. I can talk to doctors, ex-
plain what is going down and decide what medicines I need and when to take them. I've learned how to read my pulmonary function tests numbers well enough to know whether I'm sick or not. Mom used to check all my meds to see if I was running low, and now I check them and send the order into the pharmacy myself. About the only thing I can't handle yet is the dollar end of it. Those prices are really high and I don't even have a job yet. But I could handle the numbers if need be. I have three bank accounts and I can balance a checkbook. So all in all I reckon I came out all right. Thanks most in part to my parents.

Joy: John Ryan's Mother

I believe that I have been transitioning John Ryan since he was born. Going from a crib to a “big boy” bed, then lately into a queen size. Moving from pre-K into regular school, then middle school, then high school, and now looking into colleges. The medical aspect is just one more transition that must be made.

I first started the transition process by never allowing John to make excuses for his illnesses. He has always been expected to do well in school, to do his chores at home, and take part in physical education classes. We have helped him learn his limitations and when to give in to them. His dad and I determined early on that he would be treated just like any other kid. Today you would never know he had problems to look at him or talk to him.

John has numerous health issues. He has cystic fibrosis, Type I diabetes (not related to the cystic fibrosis), hypothyroidism, short-gut syndrome, asthma, sporadic croup, and nasal polyps. He has had eight surgeries in the last 18 years. Before he went to kindergarten, he could do all his own finger-sticks for blood glucose monitoring, and take all his enzymes at meals. I met with every kindergarten teacher, the resource teachers, the nurse, all office staff, and all of the administrators before he went to school. They worked with me to keep him as independent as possible at school. I stayed in constant touch with a beeper and frequent meetings. Every year in elementary school I would go and talk to his teachers and anyone new that would have contact with him. We were very blessed with a wonderful school and very caring people who helped us make the transition from home to school a smooth one.

John started learning to draw up his own insulin and inject himself when he was around 9. He learned to keep good records and start recording events that affected his health and/or his blood glucose. I went back to work teaching when he was in third grade, and was able to work at the same school where he was until eighth grade, so contact was easily made when a problem came up. However, he did a very good job of talking to the teachers about his health and of keeping up with his work when he had to be out. I'm very proud to say that he has maintained honor roll status through out his entire 12 years in school.

Cystic fibrosis means frequent stays in the hospital. I learned to question everything and ask lots of questions when he was very young. Without even realizing it, John has learned to mimic me and he does the same. We used to stay with him all the time when he was in the hospital, then gradually leave him at night. His last stay he was able to sign himself in, talk to the doctors and nurses, get his percutaneous intravenous catheter line in, and get his room set up before I even got there from work. He checks everyone's badges when they come in, keeps his own records, and handles all of the hospital stay like a pro.

Toward the end of middle school, I started making John responsible for keeping track of his medicines, keeping them well stocked and calling for refills when they would get low. I also had him start calling the nurses at Pulmonary and Endocrine to report any problems or concerns. They would talk to him first, then to me for my input. He has gradually taken over all of the calls to the specialists, and all of the medicine orders. He goes to the pharmacy to pick them up, and writes the check to pay for them. By the
time he started high school, he could rattle off the names, doses, and costs of all of his medicines. I wrote a letter to his teachers introducing him during preplanning and he went to them to talk about his health issues and how they could help. He also started talking directly to his doctors during clinic visits at that time. He would look to me for some assistance. Now, just this past December he went to several clinic visits alone. He discussed everything with the doctors and made return appointments.

We still have a long ways to go to move him to total independence. He recently brought home a brochure about a college in Miami. I must confess that I laughed and thought he was kidding. He wasn’t, and we had to have big discussion about his readiness to move that far away from the doctors, nurses, hospital, and parents who know him inside out. Transition has been a work in progress from the time he was born. As a parent and full-time caregiver, it has been difficult in some ways, and easy in others. John is a great kid, who, for the most part, handles his illnesses well. My goal throughout his life has been to make him as healthy and happy as possible, so that eventually he could be an independent adult with as great a life as possible.

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