Practical Steps to Help Transition Pediatric Patients to Adult Care
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The transition from pediatric to adult care is a complicated process for many patients and families. For adolescents and young adults with a chronic condition, in which gaps in care can lead to significant health consequences, the transition to adult care can be especially problematic. Patients with intellectual and developmental disabilities (IDDs) and their families face additional challenges during the transition because the patients may not be fully independent as adults and families need to account for this during the transition.1

More providers are working with families before they leave pediatric care, but the transition process does not end with a patient’s first appointment in adult care. Patients and families need to get comfortable with new doctors and get established with new services. Recently published guidelines on transition highlight the importance of supporting transition for patients and families after their transfer to adult care.1

Marie Crawford is a mother of 2 sons with IDDs: Peter and Patrick. Peter has Down syndrome and a colostomy from surgery to repair his Hirschsprung disease. Patrick has autism and communicates nonverbally. They are in their 20s and have transferred to adult providers. Through her work with the state- and county-level service providers for adults with disabilities, Mrs Crawford has also helped other families navigate the transition. Her experience helping her sons and other families navigate the transition to adult care provides some important insights into life after transfer to adult care for patients with IDDs and their families. Peter, as the person experiencing transition to new providers, also has important insights to provide. Dr Garey Noritz is a complex care physician who does primary care for children with disabilities and worked with Marie and her sons during their transition. Dr Laura Hart, a researcher with an interest in transition, spoke with Mrs Crawford, Peter, and Dr Noritz about their transition experience and their advice for patients with IDDs, their families, and providers during the young adult years.

INTERVIEW

Change to a New Doctor

Dr Hart
Had you thought much about changing to an adult doctor before your sons had to do so?

Mrs Crawford
Honestly, no. Our sons’ doctor decided that his patients with IDDs needed to stay in his care into adulthood. So we weren’t thinking that we would need to transition to an adult doctor. Until he decided it was time to retire. I knew at that point all of their care would change, and it has.

Peter Crawford
I liked Drs Dawdy and King (Peter’s pediatric primary care doctor and pediatric surgeon). But Dr Noritz is pretty good too.
Dr Hart
What has it been like to see new doctors in adult care?

Mrs Crawford
So, with any new person my sons meet, there is a “getting-to-know-you” period just like dating someone. We try to get to know the nurses and the front desk staff just as much as the doctor.

Peter Crawford
I don’t mind meeting new doctors or nurses, and they treat me like a grown-up. I like that. It is hard sometimes when they go very fast or ask questions that I am not sure about. And sometimes I answer a question, but the doctor doesn’t know what I mean. It helps to have my mom there to help with the questions and explain to the doctors when they don’t understand.

Mrs Crawford
We end up retraining new providers and staff on what to expect with my guys. I am also prepping my sons for this new experience. It takes some work. I find going through everything one more time can be overwhelming. For many families, the fact that you have to engage with one more person about your sons’ or daughters’ medical issues and/or deficits can be daunting.

Dr Noritz
As a provider, I try to get examples of what makes the getting-to-know-you period easier. For example, how have families navigated changes to new teachers at school? These parallel experiences provide insights that I use to smooth over the change within my practice.

During or even before the first visit, I ask about patient and family expectations, such as what is likely to make a patient upset, what parts of the physical examination are easier or harder to do, and if adjustments to the usual clinic routine might help the patient adjust to the visit.

I know parents are apprehensive of having to recreate a health care team from scratch in the adult world. I think parents feel pressure to recreate the adult team quickly. I remind parents that the pediatric team evolved with time and that the adult team can, as well. I think that takes some of the pressure off.

Dr Hart
What has helped you navigate new doctor’s visits?

Mrs Crawford
Well, there’s no single perfect solution. In my case, Peter doesn’t mind going to the doctor, but Patrick does. And Peter can speak for himself to some extent, but Patrick is nonverbal. We have to adapt differently for each one.

That being said, a few things have helped us when we have changed to a new doctor:
1. a parent or guardian going in for a getting-to-know-you visit with or without the patient;
2. practice visits in which my sons could see the waiting room, tour the office, meet the staff, and maybe even have blood pressure taken without actually seeing the doctor;
3. asking the front desk to text us when they are ready so we can wait outside in the car;
4. being scheduled as the first appointment or last appointment of the day; and
5. establishing with the new doctor mutually realistic appointment times for well and illness care.

Dr Noritz
I have some additions to Marie’s excellent list to help with the visit:
1. bring a favorite book or toy;
2. iPads are great for distraction;
3. the following Web sites have great resources for patients and families:
   - vkc.mc.vanderbilt.edu/etoolkit/
   - www.aane.org/resources/adults/
   - www.cdc.gov/ncbddd/disabilityandhealth/index.html, and
   - www.autismandhealth.org; and
4. if long visits are difficult, having several shorter visits initially is another alternative to address patient and family needs.

I also want to add that providers should be thinking about both medical (history, surgeries, medications, etc) and nonmedical (work or school setup, guardianship, estate planning, etc) needs, which is another reason to plan for longer initial visits and/or frequent follow-up.

Dr Hart
It seems like some of these changes might be hard to implement in a busy clinic day.

Dr Noritz
Yes, some are easier than others, particularly when time is tight. In that case, I would encourage providers to do their best and get creative. Although a visit with just the parents may not be feasible, perhaps the doctor and parent (or staff member, such as a nurse) could talk by phone in advance. If frequent visits are logistically difficult, a patient portal can help facilitate intervisit communication.

Handling Other Life Transitions and Obtaining Services After School Is Over

Dr Hart
How have you been able to navigate the other transitions your sons have been through (school to work, etc)?
**Mrs Crawford**

Preparation for those other transitions was key. Peter had Hirschsprung disease as an infant and still has a colostomy. Part of his individualized education plan (IEP) in school included teaching him to ask for help with his bag when he needed it.

**Peter Crawford**

Yeah. I would tell my teacher that my bag needed to be changed, and she would make sure I got to the school nurse. Now, I tell my aid or the staff at my job that I need help, and they help me.

**Mrs Crawford**

Without the time to practice those self-advocacy skills in school, I think managing the bag would be much more difficult now.

With that in mind, it is important to remember that once school is finished at age 22 (for patients with IDDs), there are no mandated services. The Individuals with Disabilities Education Act mandates that schools provide services for children and adolescents in school to address their disabilities, but there is no equivalent legislation for adults.²

The key steps for us were enrolling the boys in Social Security Disability Income, which could be done after they turned 18, and enrolling them in Medicaid before leaving school. There are certain community services available, but you need to be enrolled in the County Board of Developmental Disabilities (in Ohio) to access these. The process to get enrolled can be time-consuming and overwhelming for families, so they should ideally start this before the young person leaves school.

**Dr Noritz**

As Marie mentioned, there are no mandated services after individuals with disabilities leave school, but a patchwork of services are available, such as vocational training, supported work environments, and adult activity centers. Families have to navigate this patchwork more or less on their own, which is a barrier to participation in society after school for many adults with IDDs.

Marie described the process here in Ohio very well. I want to mention that although the process details may vary geographically, every county has a county board of developmental disabilities to support individuals with disabilities and their families.

I think it’s also important to state that, in theory, the IEP that adolescents with IDDs have in school can and should include supports for getting adolescents and young adults enrolled in services they will use after school is over,² but this is not always done.

**Dr Hart**

What happens after the process with the county board gets going?

**Mrs Crawford**

Once they (the young person and their family) receive a case manager or service and support administrator from the county board, that case manager or service and support administrator helps the individual find the appropriate supports and services. Each individual agency and/or provider will need different documentation that usually involves having a physician writing for these services. This is another reason to start the process early, so that the new services are at least somewhat established before patients and families meet a new doctor. Even with help from these services, we often rely on what we hear from other parents and our own observations.

Of course, that process assumes the individual qualifies for services through the county board. In some cases the individual has improved and may not be eligible for services, which takes the individual down a different path.

**Dr Hart**

We will have to save that for another time, I think. Thank you all for sharing your experiences.

**DISCUSSION**

The Crawfords’ story highlights some important lessons for pediatricians about the transition to adult care for pediatric providers’ patients with complex medical conditions, such as IDDs.

Most importantly, life for these families does not end with the transfer to adult care. Although it is the end of the relationship between the pediatrician and the patient and family, it is a whole new, often stressful, beginning in other ways. Even if young adults stay with the same doctor, there are other life transitions that occur, such as leaving high school and moving to college or work or, as described here, to services for adults with disabilities. If a patient is seeing a pediatric provider and transfer is necessary, ideally, the transfer should be done during a period of stability when the adolescent or young adult is well.

We need to remember that meeting new doctors is tough for these families. Patients are often uncomfortable in a new environment, and parents have to try to go over everything all over again. This is why the transition guidelines recommend a transfer letter with a succinct summary of the patient in advance, the first visit is often easier for the new doctor and the family. So, although finding the time to write a transfer letter is hard, a good transfer letter may be the best gift you can give to your patients as they graduate from pediatric care, especially for patients with IDDs and their families. We recommend that pediatricians write the transfer letter that they would want to read, which is thorough, but not exhaustive, and...
includes an accurate medication list, current problem list, and up-to-date vaccine list. Keep in mind that guidelines also recommend following up with the receiving provider to ensure that transfer is complete.

Guidelines recommend starting a conversation about transition when a patient is 12 to 14 years old. Many pediatricians feel that is too early, but as shown in the interview, connecting to services is time-consuming. Starting a transition conversation early allows families to consider and plan for a health care transition as well as transitions in other life domains. Although starting early may feel uncomfortable, it is an important facet of good transitional care. Early on, it may consist of encouraging families to find other families with children of similar ages so they have a network to work through concerns with as they arise.

Providers may also encourage families to investigate the community supports that are available in their area for adults with their child’s condition, such as the resources for adults with IDDs described in this article. As doctors, we can be mindful of making sure that the school IEP is addressing transition. Specific conversations about finding a new doctor may not come until later but will go over easier if they are not a surprise.

With this story, we highlight the reasons why the guidelines on transition have been structured the way they are. We hope that by sharing their story, Mrs Crawford and Peter can help pediatric providers think about the whole expanse of transition, both before and after the transfer to adult care.

**ABBREVIATIONS**

IDD: intellectual and developmental disability

IEP: individualized education plan

**REFERENCES**


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