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Healthcare Transition from the Family Perspective

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Hearing About Health Care Transition (HCT)

Many family members report first learning about HCT when their child becomes "of age."

Vignette

18-year-old Amanda and her mother, Leslie, come for Amanda's annual checkup. The office is a multi-specialty clinic, and Amanda has been receiving services there with several providers for most of her childhood and adolescence. After so many years of these regular visits, mother and daughter enjoy comfortable relationships with the doctors, nurses, and support staff and converse easily with them as they move through Amanda's routine appointments. Upon completion of her annual checkup, Amanda and her mother approach the front desk to set up Amanda's next appointment. There they are told Amanda has aged out: this was her last appointment.

Leslie is surprised but recovers quickly and says, "Oh, OK. Who do we need to see from now on?" She is met by blank looks. Leslie is an experienced mom who has encountered many medical concerns with her daughter, and she faces those blank looks with great aplomb. It's only later, after consulting by phone with Amanda's primary clinic physician, she is dismayed and panicked to learn there is no recommendation for Amanda's healthcare transition. The situation becomes more serious when they are unable to get new prescriptions for Amanda's medications because they do not yet have an adult provider for Amanda. Leslie posts a message to an online support group for advice and learns many other families are reporting similar experiences. Few can offer any helpful advice.

Leslie reaches out to her personal networks and finds a primary care physician willing to take Amanda into her practice, despite her lack of knowledge or experience with Amanda's conditions. It takes months to find

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and establish relationships with the specialists Amanda requires. The applications for Social Security and vocational rehabilitation services stall. A medical emergency in the midst of this lengthy transition could be devastating. Amanda and her parents experience tremendous anxiety in the interim.

The pediatric provider is troubled when Leslie calls and asks, "Why didn't you tell us she would have to leave your clinic at the age of 18?" The reality, as the pediatric provider knows, is there are no adult providers with the knowledge, skill set, and willingness to accept young adults with childhood-onset conditions that she is aware of. The pediatrician realizes it's time to develop an intentional process of preparing patients and their families for HCT.

Why HCT Is Important

The transition from pediatric to adult-based healthcare seems simple, from the eyes of the parent whose child has no significant healthcare issues. Initially, the typically developing and healthy young adult might obtain healthcare through the college health clinic, an urgent care clinic, or the emergency room. They likely begin engaging adult healthcare providers as the need emerges; for example, a young woman needing birth control might select a gynecologist. These adult patients make their medical decisions and maintain the privacy of those decisions. Typically developing young adults and their families often address the transition to adult-based care as the need arises. Teaching them to take on the responsibilities of setting and keeping appointments, asking questions, managing prescription medications, and taking care of any annual medical exams is a natural and collaborative experience.

But for adolescents and young adults with special healthcare needs (AYASHCN), the transition is not simple. A well-planned and well-executed transition to adult-based care is essential. The disease or disorder already compromises their health and places them at increased risk of developing more significant health concerns in adulthood. That risk rises dramatically when knowledgeable adult providers are not available. For many such patients, the family is faced with replacing many pediatric specialists, a daunting and—for some—near impossible process.

Vignette

Gabe's mom, Cristin Lind, struggled to explain this complicated network and came up with "Gabe's Care Map©" (see Fig. 5.1) [1]. She shared it with a group of primary care physicians and says, "They got it." There was a multitude of providers and organizations involved in Gabe's life, and his family was juggling them all! In 2012, the Huffington Post published an article about Gabe's Care Map, and Cristin's simple attempt to explain the complexity of her son's support needs took on a life of its own. Today, Ms. Lind and her pediatrician are further developing the practice of care mapping. More information is on Ms. Lind's website (https://durgastoolbox.com/caremapping/). Care mapping can be a useful tool in the transition process for families, young adults, and their providers.

Transition isn't a new concept, and it occurs elsewhere besides the healthcare system. Federal special education law requires public schools to address a student's transition from public school during the student's annual Individualized Education Program (IEP) meetings. The transition planning must begin before the age of 16 (some states begin as early as age 14). Remarkably, many families

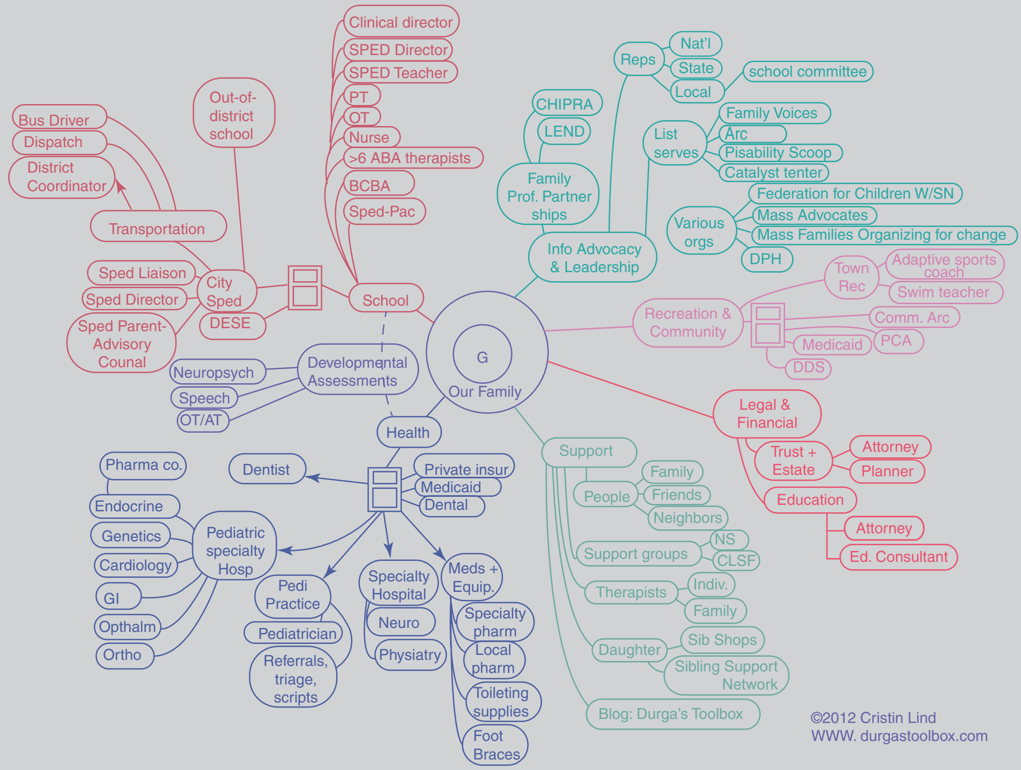

Fig. 5.1 Gabe's Care Map

are uninformed about the next steps when their student ages out of special education services (somewhere between the ages of 18 and 22, depending on the IEP). How can they be so unprepared? Explanations include families are overwhelmed by the daily needs of their loved one, the network of services and providers they are managing, and fears for their child's future. Families are trying to survive, to get through today. The necessary preparations for the future end up on their back burners, until the day arrives and no preparations are in place. They have reached the cliff.

As unprepared as families often are for the transition from public school services, they are equally unprepared for the changes occurring as their young adult transitions from pediatric to adult-based healthcare. Parents think doctors will prepare us parents and lead the way. We don't know to initiate the conversation about the transition, and even if we did, we are too terrified to ask. We count on our providers to guide and support us through.

Families address multiple transitions simultaneously for their AYASHCN, listed in Table 5.1, below.

While some young adults will experience changes in their healthcare at age 18, changes can occur again at the age of 21–22. For some, they will no longer be able to receive services at their pediatric hospital. Depending on the state's Medicaid system, some Medicaid benefits become limited after the age of 21. Consider Norah, who needed her wisdom teeth removed at the age of 22. Norah was receiving Medicaid care, which had always been sufficient for her needs. They were dismayed to learn Norah's Medicaid benefits excluded dental care at the age of 22. Had they removed her wisdom teeth before her 22nd birthday, Medicaid would have covered the costs.

Table 5.1 Multiple transitions that families are undergoing during HCT

- Departing public school special education services (an entitlement)
- Applying for state vocational rehabilitation services (eligibility-based)
- Applying for Medicaid (eligibility-based) (see Chaps. 8 and 25)
- Researching and meeting new health insurance eligibility requirements (see Chap. 8)
- Dealing with managed care, PPO, or HMO (finding approved providers, checking the prescription formulary, etc.)
- Filing an initial application (or redetermination) for the Social Security Administration’s supplemental security income (eligibility-based) (see Chap. 8)
- Addressing legal protections (possible guardianship, medical power of attorney, supported decision-making, HIPAA release, living will) (see Chap. 30)
- Obtaining long-term services and supports for those with significant support needs (eligibility-based and often wait-listed, sometimes for years)

We want these AYASHCN to manage their own healthcare to the greatest extent possible. But building self-management skills takes time. Developmental readiness must be considered. For example, adolescence probably isn’t the best time to suddenly turn over medication management. A measured, methodical approach to teaching self-management skills, as the patient is ready, is vital. Helping parents understand what they can do to assist in the process is invaluable.

Transition planning is a process, not an event. Good transition planning—in the school, the home, and the doctor’s office—requires significant time, intentional planning, development of self-management and self-advocacy skills, and clear, honest communication. Without it, AYASHCN can face potentially dire consequences to their health and well-being.

Special Considerations for AYASHCN with Cognitive Delay

Patients with intellectual disabilities are going to require more time and preparation on the part of the medical team and the family. Understanding how the individual communicates, what kinds of support they need in the medical environment, and ways to ease anxieties goes a long way toward a successful clinic visit. Are there specific parts of an exam that are troublesome for the patient? What helps? How can the practice accommodate those needs? For patients who don’t use words, what do their behaviors communicate? Some families are prepared to provide this information; others may need prompting questions or conversations to help the healthcare provider uncover these details. Taking the time to discover those details is crucial to the eventual transition to adult-based healthcare (see Chaps 17, 22, and 32).

Presume competence! We may never know what some individuals with intellectual disabilities understand due to their inability to express themselves verbally. The provider may need to look to family member(s) to help communicate, yet providers should address the patient directly, as they would any other patient, and include them in all conversations about their health concerns. A danger for people with intellectual disabilities is others’ misperceptions about their ability to speak for themselves with support. A presumption of incompetence or lack of capacity can result in preventing the patient from developing skills necessary for managing their personal health. Knowledge of their condition, understanding its issues, self-management skills, self-advocacy, and self-efficacy are at risk, and the danger for poor health outcomes escalates.

One example of underestimating individuals with intellectual disabilities is the perception of guardianship as the only option (see Chap. 30). Guardianship is a critical support for some, but it should be the last option rather than the first (and only) option. It is an expensive process, requiring the assistance of an attorney and a court. Although courts are instructed to design guardianships to encourage the development or maintenance of maximum self-reliance and independence of the incapacitated person, it's not uncommon for courts to create full guardianships. Full guardianship removes the rights of the individual to make even the simplest of decisions for themselves, such as the right to decide where they want to live and work and how they want to spend their days. Families think their only option is guardianship (it's the one option they hear about from education and medical professionals, among others) and end up spending money and removing their young adult's personal and civil rights unnecessarily. Reversing guardianship can be a challenging and costly process.

Alternatives to guardianship include durable power of attorney, medical power of attorney, and HIPPA release. A new and practical solution available to some individuals and their families is supported decision-making. This measure provides a legal means for an individual to choose a trusted individual or team of people who can provide support to the person without taking over their right(s) to decision-making. Guardianship is substituted decision-making: the guardian makes decisions for the individual. Supported decision-making provides for autonomy and self-direction while offering necessary guidance and support. Supported decision-making is not yet a legally available option in every state; more information on supported decision-making (including states in which it is an option) can be found online at http://supporteddecisionmaking.org/.

Look to the family to support their emerging young adult with an intellectual disability—they have valuable knowledge and experience—but not at the expense of ignoring the patient.

Vignette

A neurologist was explaining the results of a sleep study showing sleep apnea to my son, David (who can present as competent but has significant intellectual disabilities). He explained that airways become constricted during sleep. I could see the information was going over my son's head. I stopped the doctor and said to David, "David, when you are using the water hose at home, what happens if it gets kinked?" David explained how the water starts trickling from the hose or even stops completely. I told David, "That's what the doctor is saying is happening to the 'hose' in your nose and throat, the hose that carries oxygen to your lungs and helps you breathe while you're sleeping." "Oh!" David said. He asked "So there's a kink in my air hose? That's why I'm not sleeping like I'm supposed to?" The doctor said, "That's brilliant. Mind if I steal it?" Family members are well-versed in what their young adult understands and how they communicate. Direct your communication to the patient, but invite the family to assist if needed. Other forms of assistance from the physician's office are listed in Table 5.2, below.

Some parents hold high expectations for their child despite the intellectual disability. They will welcome conversations about transition and efforts to encourage self-efficacy and self-advocacy, despite their reasonable anxieties and concerns.

Others, being cautious and protective, will find your efforts harder to understand and support. They've spent years advocating for their child's services, often with a multitude of providers. They're aware of their child's vulnerabilities, and the future is frightening. Their protectiveness can negatively affect their and the providers' perception of their child's abilities.

Table 5.2 Other forms of assistance that the physician's office could provide to assist with HCT

• Translating or helping to explain medical information
• Clarifying treatment options as they relate to the individual's personal preferences and needs
• Taking extra time for discussion, questions, and decision-making
• Assisting with setting up and keeping appointments
• Helping with managing medications (refills, dosing) or other treatment regimens
• Easing fears or anxieties in the healthcare environment
• Assisting with decision-making
• Assisting with documentation for insurance claims, medical records

Well-meaning families can limit their young adult's autonomy and privacy by speaking for them, making all their healthcare and other service decisions, and assuming their child is incapable of assisting or of having an opinion. This scenario happens for AYASHCN without cognitive delay, but it is more frequent for those with intellectual disabilities.

Cultural understandings and expectations can complicate HCT. Healthcare providers should familiarize themselves with and be respectful of cultural norms around chronic illness and disability, self-efficacy, and self-advocacy. A conversation about the family's expectations for their young adult's life beyond childhood can help healthcare professionals provide culturally competent HCT guidance.

When family members take charge of all their young adult's decisions, without consulting them or encouraging their autonomy or self-advocacy, the healthcare provider(s) may follow the parents' lead, further disempowering the patient. Physicians have an opportunity to present an expectation of autonomy, self-advocacy, and self-efficacy, by looking to the adolescent or young adult first and consulting family members secondarily. Meeting with the adolescent alone for some part of the visit helps set that expectation. Letting the parent(s) know the provider is following standard clinical practice should help the parents understand this as part of the HCT process.

Whether they see their young adult as competent and capable of making decisions or not, their child will legally be considered an adult at age 18. Providers should help family members prepare for this reality. The family will need to put legal protections in place if their young adult needs support for decision-making and consent. The provider will need to have this conversation more than once and ask questions about the patient's and the family's plans.

Transition Planning in a Clinical Setting

A parent may say "He's going to live with us for the rest of his life" and consider the matter of transition to adulthood settled. The sad secret many parents harbor but will never say aloud is their hope the child will die before they do. This thought can be paralyzing. Rather than taking a proactive approach by teaching self-advocacy skills and building strong circles of support, some families simply ignore the inevitability of not being able to care for their AYASHCN. What's a healthcare provider to do in the face of such resistance? Begin the conversation early and revisit it annually. Families need a road map (see Chaps. 4, 16, and 26). Having a transition policy for your practice, posting it in a visible space, and reviewing it together with families will help keep HCT a priority. Physicians should provide timelines and assure patients and their family members they will be supported through the process. But there's more to your role.

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine state, "After the age of majority, all youth deserve to be treated as adults and to experience an adult model of care," even when they require decision-making support or are under legal guardianship.

Your patient's experience of being treated as an adult and experiencing an adult model of care requires preparation. Adult care assumes that the patient knows how to set and keep appointments, understands their health condition(s), is experienced in managing their health condition(s) including any medication or other necessary regimens, and is prepared to discuss their health management with the adult provider. The necessary knowledge and skills must be taught, practiced, and experienced before they enter adult care. Show them small steps they can take toward transition, e.g., having their child introduce themselves and present their health insurance card when checking in for an appointment or having the young person write their name and address on the check-in forms. The provider taking the lead at every opportunity, and beginning early, can help patients learn self-advocacy and self-efficacy.

Person Centered Thinking© [2] offers a model which proposes the difference between what is important to the person and what's important for them (see Table 5.3). Because of their training, health care professionals (and often family members as well), tend to focus on what's important for the person (health and safety), and pay less or no attention to what's important to them (the things that bring the person happiness, contentment, satisfaction, fulfillment or comfort). Nobody wants to live a life focused on their health and safety only, even when there are significant health concerns. We know people are more likely to do what's important for them (things related to their health and safety) when they can see a connection between that and something that's important to them. For example, David is more likely to pay attention to his low-sodium diet and kidney health if he can see its connection to his love of running. He is more inclined to use his CPAP machine when he understands how it impacts his ability to get a good night's sleep and wake up on time for work. Patients often do what's important for their health and safety if these behaviors improve or are connected to the things that matter most (important to them). Patient's self-efficacy and adherence to their treatment can be improved by hooking it to what's important to them. Training for healthcare providers in eliciting important information is needed. More information about person-centered practices can be found here: http://tlcpcp.com.

Table 5.3 Person-centered thinking—the balance of health and safety with quality of life

- Developed and taught by the learning community for person-centered practices [2]
- Defines health and safety as "important for" the person
- Defines anything that helps the person feel satisfied, content, happy, fulfilled, or comforted as "important to" the person
- AYASHCN often experience lives focused on what's important for them, without enough consideration for what's important to them
- People naturally desire balance between doing what's important for them and having what's important to them
- People are more likely to do what's important for them when they can connect it to what's important to them
- Patient self-efficacy and adherence to treatment increase when what's important for them is "hooked" or connected to something important to them
- http://www.tlcpcp.com/

Patients and families who have undergone an organized, well-defined transition process report better outcomes in their adult-based healthcare experiences. They express gratitude for well-written care summaries, referrals to knowledgeable adult providers when possible, time spent ensuring as much stability as possible before ending the relationship, and a warm sense of closure between the patient, family, and provider. The time taken for these measures may mean the difference between the patient successfully navigating the transition to adult-based care and having a poor health outcome. The website—www.gottransition.org—provides one resource for patients, families, and healthcare providers to organize the process. Their resources specific to healthcare professionals include six core elements of transition:

1. Transition policy
2. Transition tracking and monitoring

3. Transition readiness
4. Transition planning
5. Transfer of care
6. Transfer completion

Unfortunately, most AYASHCN and their families report seeing none of these elements before leaving their pediatric-based care. It's no wonder so many find themselves facing an abyss!

Promoting Self-Efficacy

Self-efficacy is essential for young patients to succeed in managing their health problems as they transition. The concept of self-efficacy theorizes that people must believe in their capacity to achieve their goals before they can work toward those goals. In terms of healthcare, patients must first have confidence in their ability to manage their health. Confidence comes from gaining knowledge and skills, having repeated opportunities for practice, and experiencing success. These points are summarized in Table 5.4.

Learning from others in a similar situation can aid in attaining self-efficacy, for the patient and family member(s). As young parents, we knew our son would need a lot of help to get through school, and we wanted him to have an inclusive education with his non-disabled peers (not the usual route for students with intellectual disabilities). Although I have a degree in special education, I doubted my ability to be his advocate for a different educational path. I associated myself with other parents whose kids were older than mine and who were successfully navigating the path I wanted to take. They supported and encouraged me and walked alongside me providing resources, knowledge, experience, and insight. They built my self-efficacy, and soon I was not only successfully teaming with my son's school professionals to create an inclusive education program for him but mentoring others to do the same. Years after his graduation, one of my mentors told me "You know, I wasn't sure it would work for your son." I was floored. "I believed you!" I said. "And that's why it worked for you and your son," she replied. "It worked because you believed you could make it work." I had gained confidence and self-efficacy followed.

Table 5.4 Promoting self-efficacy

• Patients must believe in their capacity to achieve their goals before they can work toward those goals
• Confidence in one's ability to manage their own health is critical
• Confidence is built through gained knowledge, practiced skills, and experienced success

Associating with people on a similar journey, others who have navigated various systems and gained hands-on expertise can be an empowering experience. Can your practice help patients and their families link with others? Family members and individuals involved in support organizations are quick to share their learning, offer support, and are eager to learn from others on the same path. One caution: If there is a significant difference between the families in terms of the HCT outcomes, these efforts can backfire. The person who is experiencing success may feel guilty or uncomfortable with the person who is having more difficulty. On the other hand, the person experiencing less success may feel the more successful person sets an expectation they can't reach. When my son was small, our neurologist gave my name (with my permission) to another parent whose son (several years older than mine) was diagnosed with the same disease as my son. The conversation started out fine. The other mom asked if my son was talking yet. "Yes, he's begun using some words," I said. "What about your boy?" I asked. A silence ensued on the other end of the phone until she finally choked out, "No, he can't talk at all." We never spoke again, despite living 15 minutes apart. I felt sad and a little guilty. I can't imagine what she felt.

Some parent support organizations provide a parent-matching program in which they connect families dealing with similar circumstances. A critical component of an effective matching program is training for the families engaged in the match, better preparing them to answer questions and provide support without falling into the kind of situation I found myself described above. Another underutilized but valuable resource can be adults living with similar conditions or concerns.

There are other methods to build patient self-efficacy into your practice, and they are discussed in other sections of this book (see Chaps. 5, 13, 19, and 20). Assessing self-efficacy skills, and encouraging patient and family to practice the undeveloped ones, builds capacity and confidence. One doctor routinely assigns homework to his patients based on this assessment, attempting to build the patient's skills throughout their adolescent years in his care.

Technology

Technology may help AYASHCN and families improve their self-efficacy. Apps on our phones, iPads, smart watches, and computers may provide ways to manage details of daily living. For example, a patient who cannot tell time can set timed reminders on his phone for medication reminders or appointment alerts on his calendar. The Medical ID app (available for IOS and Android platforms) provides readily accessible medical ID information on the patient's cell phone, especially in an emergency. Apps for tracking blood glucose levels, carbohydrate intake, and medication doses can assist with diabetes management. Many healthcare providers and clinics have moved to electronic communication, permitting patients to access records and communicate with their physician(s) electronically. Creative families have assisted a loved one in their home via the computer, providing everything from medication and schedule reminders to walking their adult child through a recipe.

Our son has intellectual disabilities as well as significant medical issues including kidney disease. He was a competitive varsity-level distance runner in high school and still enjoys running today. His nephrologist and dietitian talked with him about the importance of a low-sodium diet. But when we showed him a fitness and diet tracking app on his phone and helped him understand what his target sodium numbers should be, the sodium in his diet took on a new level of importance. The app also tracked his distance running, connecting what is important for him (low-sodium diet) to what's important to him (his love of running).

Promoting Self-Advocacy

Teaching self-advocacy skills—the practice of speaking for oneself, asking questions, making one's decisions, understanding one's rights and responsibilities, and asking for help and support—is crucial to successful transition. Self-advocacy is not an all-or-nothing practice. Family members and others in their circle of support can help the young adult to apply self-advocacy skills. Parents who work to support and empower their young adult's self-advocacy often report surprise at their child's growth and capabilities as they have an opportunity to do so.

Some families will resist promoting self-advocacy skills, whether it be from their fears, misperceptions of their child's capacity, or their own poor self-advocacy skills. Cultural norms and expectations can contribute to the resistance.

Most family members will view you, the patient's healthcare provider, as the expert. The provider can present self-advocacy opportunities and model family members' roles. Addressing yourself to your patient before the family member is a great start. Speaking to the patient—asking questions of the patient and giving time for the answer—sets the expectation of self-advocacy. Patients and their family members will come to expect it and prepare for it.

The same goes for making choices and decisions. First, ask open-ended questions to the patient. What do they think about the medication they are taking? Is it helping? How do they know it is helping? What are they pleased about in terms of their health and healthcare? What concerns do they have? Avoid closed-ended questions: those that can be answered with a "yes" or "no." Ask open-ended questions that open the door to conversation. And then listen. The provider's actions are as much about modeling the presumption of the patient's competence and self-advocacy as they are about hearing what the patient says.

Talking with your patient(s) about their health condition(s), answering their questions, and asking them what they understand about it prepare them to have those same conversations with adult care providers who will expect those kinds of discussions.

The Role of Parents in Preparing for HCT

Parents' roles and responsibilities begin years before the subject of transition is broached. Transition planning begins at birth. Parenting is all about preparing our kids for what life will throw their way, from disagreements on the kindergarten playground to the drama of junior high and the rigors of high school. Our child's health concerns and disabilities complicate our task.

Honest discussions about the child's diagnosis and medical condition, adapted for the child's age and ability to comprehend, create an essential foundation. Making the diagnosis and medical concerns an ongoing conversation provides the opportunity for the young person to learn important details about their condition, the necessary measures to manage the condition, and provides the opportunity to ask questions or address concerns. These kinds of conversations through the years can serve as a basis for the later development of more advanced self-efficacy and self-advocacy skills. In hindsight, the 27 years we've spent talking openly about David's condition, cursing it at times, shedding tears, and teaching him to address his concerns head on, have resulted in a young man who faces significant health problems with optimism, courage, and hope.

For some parents, however, this kind of conversation is too uncomfortable. Parents naturally want to protect their children, and shielding them from the painful truths of their condition(s) may seem easier in the short run. Unfortunately, our failures to honestly address the issues set the young person up for discomfort and avoidance in later years, potentially leading to serious health consequences. As parents, we must provide models of courage, competency, and honesty as we help our children face the realities of their medical concerns or disabilities and prepare them to manage the resulting issues. Don't underestimate the value of your support. Our kids tend to rise to the level of our expectations.

Transition readiness assessment tools used in the clinic can provide the patient, parents, and provider with an assessment of transition readiness (see Chap. 13). Transition planning tools can then be used over time to improve self-efficacy in tasks for adolescents and young adults to practice and gain competency as they prepare for the transition. Parents can use transition planning tools as a series of steps, tackling the tasks and providing instruction and encouragement, while gently encouraging their young person to take on more responsibility. Parents may be surprised at how competent their child can be with the right opportunity and support.

Finding an Adult Provider

It's happened; the time has come to leave the safety and security of the pediatrician's office and move into the world of adult-based care. Where to begin?

Parents say getting a referral from their pediatric-based care providers—who they have come to know, rely upon, and even love—is golden. We trust pediatric providers' recommendations.

Unfortunately, many family members report getting no such help. Whether it's a lack of time, knowledge, resources, or connections, families find themselves out there on the bridge to nowhere, trying to create their own bridges. They make call after call, only to learn the provider they're calling doesn't take their insurance, doesn't take Medicaid, isn't taking new patients, or doesn't feel he has the necessary knowledge or experience to treat their child. Without proper transition planning, this exercise in frustration can happen while there is a high need for continued medical care. The young adult has "aged out" of the pediatric clinic and must find adult-based care in a hurry. The risk of time lost, money wasted, and mistakes made is high.

Parents' Recommendations

A mom whose daughter has multiple physical health issues and developmental disabilities offered this recommendation to other families:

> Figure out what is your child's most critical medical need or what medical specialty is most important and find that physician first. It's preferable if you can find one already in a medical home system or electronic records system. Then build relationships with the other specialists you need who are already involved in that system if possible. If that's not feasible, find your most important specialist first and then try to find a network that includes the other providers you need in one system, so you only deal with one specialist out of the system.

The only danger with this strategy is if, for some reason, the patient can no longer access the medical home or networked system (e.g., change in insurance), they run the risk of losing the entire network. It's important to pay attention to coverage that can change at 18, 21, and again at 26 or even with PPO or MCO provider lists.

Another parent suggests: "Identify your current providers. Create a list of potential adult providers for each specialty. Ask each current provider 'If this were your child, who would you seek out for adult care?'" Other recommendations from parents are listed in Table 5.5.

How can the healthcare professional help? Get networked. Know who can do what you do in the adult system, develop a relationship with the person/clinic, and offer your referrals and recommendations.

Terminating the Relationship with the Pediatrician

For many of us, the child's pediatrician has been a constant in a sea of change, through the ups and downs of our lives. He/she has helped us through crisis. It's possible they have been there since our child was diagnosed. They have been our rock. For us—patient and family—ending our relationship with the pediatrician is hard.

Make our goodbyes easier by making sure everyone knows it's coming well in advance. Having a plan and clear timelines ensures nobody is surprised when the last appointment comes. Knowing where we will go for our young adult's health care, and having a thorough medical summary to take with us, eases our anxiety. Assuring us the pediatrician is still there if the adult provider needs a consult is comforting.

Lastly, pediatricians, give us time to thank you for the role you've played in our lives and to say goodbye. We're eternally grateful and will never forget you and what you've done for us. Thanks. A summary of parents' wishes for assistance from their pediatric provider is presented in Table 5.6.

Table 5.5 Other recommendations from parents of AYASHCN who have transitioned their AYASHCN to adult care

• "Network with other parents of individuals with special healthcare needs"
• "Get as much help from the pediatric doctor as possible"
• "Make an appointment to get to know the new doctor and for them to get to know your child. If you don't like the doctor, keep looking"
• "Do your own research. Ask questions!"
• "Start early!"

Table 5.6 Parents' HCT wish list

• Inform us about transition and then ask the question "What can we do to help you and your son/daughter make a successful transition?"
• Recognize it's one of the more stressful times for us as family members
• Help me by sharing what you know about my child with a medical summary, prepared for the new doctors
• Give me timelines, give me recommendations, and give me referrals
• We always hear the term "talk with your doctor," but sometimes it takes a lot for families to ask their questions
• Work with us as a team instead of leaving it all up to the parent
• Have patience with us. None of this is easy
• Show interest
• Give parents information on networking
• Prepare to work with the increasing population of special needs of young adults
• Be willing to consult with the new provider if necessary
• Support family through the transition to help make sure adult physicians are acutely aware of child/adult needs. It can be overwhelming for parents to change doctors for medically complex children. We are fearful that child's medical history won't be fully reviewed or understood. Communication and support are critical.
• The hardest thing was leaving our pediatric providers because of our emotional connection to them. They had been with us for 22 years!

References

1. "Gabe's Care Map" used with permission from author Cristin Lind.
2. Establishing a Healthcare Transition program for Adolescents and Young Adults with Chronic Illness and Disability includes person-centered concepts, principles, and materials used with permission from The Learning Community for Person Centered Practices. Find out more at http://tlcpcp.com.