Planning Transition from Pediatric to Adult Providers for the Fully-Dependent Child

INTRODUCTION

A shift that requires advance thinking and planning

All healthcare focuses on maximizing our lifelong wellbeing and functioning. As a child with significant health challenges matures into adulthood, there are many considerations that require advance planning. This Guide focuses on the process of providing for a child with significant health care needs, who is unable to be an active participant in their care and decision-making.

What is Health Care Transition?

The process of transferring healthcare from the primary responsibility of a pediatrician and a team of pediatric specialists whose focus is care and treatment from infancy through childhood, to a team with expertise in the healthcare issues of adulthood, is referred to as “transition.” It is the effort to find and engage high-quality, developmentally-appropriate services, ideally provided without notable interruption as the child moves from adolescence to adulthood.

As children with complex medical issues live longer and into adulthood, adult providers may not be prepared to handle the medical needs exhibited as a result of those pediatric conditions. What is the difference between pediatric and adult care? What do parents need to be aware of as their child grows and ages into adulthood?

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Comparing Pediatric Care to Adult Care

Pediatric Care	Adult Care
Family-centered model (discussions with family are integral, valued).	Patient-centered model (family members generally considered "back seat").
Assistance with coordination of care.	Independent coordination of care is expected.
Knowledgeable about childhood health conditions.	Limited experience with pediatric-onset diseases.
Link to social services.	Limited knowledge of community resources, actual limited community resources.
Facilities and staff are pediatric friendly but facilities, equipment and accommodations may not easily address the needs of adult sized patient (inpatient and outpatient).	Facilities and staff may not accommodate needs of developmentally delayed/ incapacitated adult, especially one with a pediatric cognitive baseline.
Pediatric palliative care services, if available, may include integrative therapies (such as music, massage and pet therapy) and psychosocial sup-port for the child and the entire family.	Adult palliative care may be offered in the hospital and/or in a community palliative program. Rarely includes integrative therapies, although some adult hospice care does.

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Working with Your Care Team to Plan the Transition

- When, ideally, should this transition process begin?
- Will care really be transferred to providers who will know how to care for your adult/child?
- Who sets the rules as to when this must happen?
- How will you, the parent, identify and learn to trust new providers?

As there may be some services tied to age, **most experts recommend starting discussions with your child's primary team when your child is between 14 and 16 years old.** The planning process should coincide with the transition planning that occurs at your child's IEP meeting.

Sometimes this process happens slowly and organically—one provider at a time. You may be referred to a new specialist in a different hospital, which leads to new connections, and may accelerate the transition.

Some of the questions to explore are:

- Is there an upper age limit for your child to be cared for by the pediatric medical practice?
- Is the pediatrician/provider willing to continue treating your child beyond the normal age limit? Is that a good idea?
- Does your hospital or clinic continue to provide visits for adult patients, and does this practice differ from specialist to specialist?
- Are there written rules limiting the age an adult is accepted for specific treatments and/or procedures. Who are the adult providers who may have the expertise in the comorbidities your child experiences but not necessarily the expertise of the underlying disease?
- Does the medical office provide assistance for the transition? Of what type?
- Will your child's pediatrician and/or specialists recommend providers and perhaps call prospective providers and/or stay involved for a time after transfer of care, and/or answer questions or confer with the new provider?
- Can there be overlap between pediatric and adult providers for any period of time?
- How will you help the new provider keep your adult/child front and center for research opportunities and/or new treatments that might become available to alleviate chronic symptoms?

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Ask your child's pediatrician to prepare a portable health summary and/or emergency care plan that can be shared with new providers.

Some examples:

- American College of Emergency Physicians Emergency Information Form for Children with Special Needs: https://www.acep.org/by-medical-focus/pediatrics/medical-forms/emergency-information-form-for-children-with-special-health-care-needs
- University of Southern Florida My Health Passport: https://flfcic.cbcs.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
- Emergency Planning Guide (CPN): https://courageousparentsnetwork.org/guides/in-case-of-an-emergency-here-is-what-others-need-to-know-about-my-childs-care/

Remember to also investigate medical transition resources; for example, a transition to adulthood program at a local children's hospital *that is inclusive of the needs of an incapacitated child/adult.* If there is no resource available locally, see if the nearest one would do a telehealth visit or be willing to answer questions by phone.

How Palliative Care Can Help

Involving the palliative care team in transition planning can be very helpful. Discussions about what you value in a provider, your child's health trajectory, quality of life, and any hopes and concerns you have as you acknowledge this life change will impact your entire family. Palliative care specialists are trained to listen and to help you clarify and express your goals. They understand that these discussions take time, and they will take that time with you.

Anticipating the Challenges

In addition to working with new providers, you will undoubtedly encounter other changes. Any or all of these may lead to discontinuity in care as well as anxiety and stress at this vulnerable time. Some examples:

- Loss of therapies provided through educational entitlement. If the need for the therapies persists, you will need to find resources and funding.
- Transition to another home care company and/or nursing staff/agency.
- The natural attrition of providers. They, too, age and change roles and retire, leaving families and patients to start over time and again.

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- Possible loss of insurance coverage/restricted options based on insurance.
- Possible loss or changes in services due to age, insurance coverage and legislation, once transition to adult palliative care and/or adult hospice is initiated (between the ages of 18 and 22).
- Initial lapses in communication and potential misunderstandings as to provider and/or family responsibilities; i.e., for instance: will the provider keep track of the timely renewal of long standing prescriptions or will the family need to reach out each month.
- Possible loss of opportunities for your child as they age out, at age 18, of pediatric services, state funding opportunities, enrollment in clinical trials or experiences like Make A Wish.
- Physical and emotional challenges as your adult/child may exhibit increased comorbidi-ties of the disease or a decline in baseline, resulting in behavioral changes or difficulty accomplishing activities of daily living (ADLs).

Understanding the Benefits of Transition to Adult Providers

As the parent you may feel an emotional attachment to your child's providers. There is shared history and, hopefully, a sense of trust. You may therefore feel skeptical about finding and having access to new capable, compassionate providers who will understand and support your adult/child's medical, emotional and physical needs. You may have fears of not achieving mutual trust, respect and credibility with these new providers. And, in fact, new providers may not appreciate the complexity of your child's past history, or your knowledge and expertise gained over years of caring for them.

Simply put, it will likely take time for you to teach new providers how to communicate and connect with your adult/child and understand your family's philosophy of care.

However, here are some of the positive aspects to transitioning to adult health care:

- There are medical and logistical risks of having an adult patient stay in a pediatric setting. For example, there can be adult-onset health and hygiene issues that may not be recognized or addressed by a pediatric provider.
- Establishing a relationship with new providers can offer a different perspective on your child's condition and therapeutic options.
- There are treatment options for adults that are not offered in pediatrics, and physicians who treat adults are experts in adult health and relevant treatments and interventions.

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Acknowledging the Family System

This transition happens within the context of your family system, which is likely changing along with the transition. These changes may contribute to feelings of loss and of being overwhelmed.

Siblings may be moving out of the home, impacting the family dynamic. Their absence may deepen the parents' sense of isolation. Some children have helped in the care of their sibling, but are no longer present to assist and offer respite. There may be fewer social contacts with others in the community; for example, limited opportunity to participate in activities with the healthy sibling and to interact with other families. It may be difficult to explain the sibling's absence to the adult/child who has limited understanding of these events.

As your child ages you, too, are aging. You may be facing your own emerging health concerns, with realistic views of time passing. You may have questions about whether you can physically continue to care for your child who is physically mature and/or has a changing baseline that includes progression of symptoms and complications, both behavioral and physical. You may be reaching the prospect of retirement age, possibly bringing up financial concerns. You may feel sad, or angry, that unlike your peers, you will never fully experience the freedom of having an empty nest.

If they are living, your parents—your child's grandparents—are also aging. They may be less able to offer support and in fact may need more help themselves.

All of these concerns, taken together or separately, may prompt the question of how to increase in-home support, and/or whether it would be beneficial to consider out of home placement or programs for the adult/child. If appropriate, identify and evaluate sustainable living situations in your region, such as residential or medical homes, and/or consider home modifications for the adult/child and/or caregivers.

The Courageous Parents Network Guide "Exploring Out-of-Home Placement" may be a helpful resource: https://courageousparentsnetwork.org/guides/exploring-out-of-home-placement/.

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“Checking the Boxes” of Transition Planning

In addition to finding new providers, here are some of the practical matters to be aware of, and act on, many before your child turns 18:

- Have legal capacity assessed, so that legal authority can be established and legal and estate planning documents can be updated.
- Secure the most beneficial insurance coverage and enroll your adult/child in adult benefits for government assistance/social service plans even if already enrolled in pediatric programs. Your state may have a dual eligibility model for an adult/child, typically Medicaid based (so you have to give up private insurance) but as the primary insurer they offer home-based care.
- Identify and secure social, emotional and recreational programming and activities for the adult/child and the necessary funding for them.
- Create a “letter of intent” for future caregivers, guardians and trustees so that they can best care for your adult/child. Here is a downloadable example: *www.specialneedsplanning.com/download-a-special-needs-letter-of-intent*.

Finding a New Primary Care Provider

As you likely have done in other circumstances, seeking recommendations from other families and from your current medical providers is a good place to start. You may contact the local chapter of a disability organization (e.g. ***The Arc,*** *https://thearc.org/*) or disease-specific organizations, or a national group specializing in the care of your child’s illness, disease or disability. Perhaps your own primary medical team will be willing to accept your adult/child as a patient, or the medical staff at a residential home may accept primary responsibility. There are also medical concierge services that charge a monthly fee above any primary insurance.

- In general, a family medicine provider may be preferred, as they are trained in both pediatric and adult care. Even though this adult provider may not be familiar with your child’s diagnosis, you can suggest they have an ongoing collaboration with your adult/child’s disease specialists.
- If your adult/child becomes more difficult to transport and/or care for, consider if the new provider can offer flexibility in ways to communicate and in scheduling consultations; i.e., in person or telehealth visits, email, cell, patient portal.
- There may be advantages to having a provider who is affiliated with a larger health care system. These systems may allow providers to electronically share records, be involved in hospital admissions and provide you a care coordinator, case manager or social worker.
- Adult facilities may be more accessible.

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CONCLUSION

Knowledge and preparation will ease this process

As your child ages out of the pediatric health care system, you will likely experience both logistical and emotional challenges. You will likely need time and multiple conversations with your child's care team, and with new potential providers, to decide what is in your child's and family's best interest.

For most families, the more knowledge and understanding they have, the more equipped they feel to cope with all of the changes involved. Talking with clinicians and other families, and doing your own research, will support you to do the best you can for your child.