

Medical Home: Transitioning to Adult Care

Establishing a medical home in which your child's health care is coordinated, comprehensive, and continual is an ongoing effort. For a child with complex health care needs, building a quality pediatric care team comprised of providers across multiple medical specialty areas can be a years-long process. With few exceptions, pediatric providers generally do not see adult patients. So as your child approaches the age of 18, it is important to plan for ongoing medical needs and for transition into adult health care.

Getting Started: It's Never Too Late or Too Early

No matter how old your child is, you can begin planning for transition. Start slow. Start small. Start now. Take advantage of opportunities in daily life to prepare your child with special health care needs for greater involvement in taking care of his own needs.

- Build decision-making skills by offering choices.
- Teach self-care skills: both general and diagnosis-specific
- Help your child interact directly with doctors, nurses, therapists, and teachers.
- Teach your child about relationships, his body, sexuality, and personal space, as age-appropriate.
- Periodically assess your child's perception and knowledge of his diagnosis
- Help your child make and keep medical appointments, order supplies, etc.
- Help your child keep a record of medical history, conditions, procedures, treatments, etc.
- Plan for emergency situations, including advanced directives.
- Include health-related goals in the transition IEP.

Transition to Adult Care

During the ages from 18-21, there are several things to consider.

- Finalize the transfer of medical care to adult providers.
- Establish health insurance coverage. See details below.
- In accordance with your child's developmental ability, encourage participation in support groups specific to his special health care needs.
- Guardianship or Alternatives: Some individuals with special health care needs will eventually achieve complete independence, while others may require assistance throughout adulthood. As a parent, you may find it necessary to establish guardianship or power of attorney to continue being involved in your adult child's health care decisions. Family Voices Indiana offers fact sheets on guardianship and alternatives to guardianship.

For more
information,
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Health Insurance Options

Health coverage options changes as your child approaches the age of 18. Begin exploring future health care coverage for your child around age 17. Some options are outlined below:

- Hoosier Healthwise and CHIP eligibility change at age 19.
- Children's Special Health Care Services (CSHCS) coverage ends at age 21, except for individuals with Cystic Fibrosis.
- Private insurance under parent's plan may continue until age 26, or older for a child with disability.
- An adult child who is employed may have private insurance through an employer, or may qualify for MED Works.
- Long-term supports through Home and Community Based Services, i.e. Medicaid waivers. Family Voices offers fact sheets on waiver services.
- In the state of Indiana, qualifying for SSI at age 18 or over automatically qualifies the individual for Medicaid Disability coverage.
- Healthy Indiana Plan (HIP) for ages 19-64
- To access healthcare without insurance, visit community health centers, federally qualified health centers, community mental health centers, or free clinics.

Finding Adult Providers

- Involve your teen in looking for "good fit" adult care providers. At the first visit/new patient visit, you might even think of it as a "trial run" where you and your child are "interviewing" the doctor to evaluate whether he/she is suitable.
- Ask the current physician for possible references.
- Ask for recommendations from adults who have health needs similar to your child's needs.
- Keep in mind that if you or your adult child are not happy with the quality of care, you have the right to choose a different provider.
- Refer to the list of approved providers covered by your child's insurance.
- Consult a Vocational Rehabilitation or Independent Living counselor.

Resources

The Center for Youth and Adults with Conditions of Childhood (CYACC) can help you develop a portable medical summary and a transition plan. They can help you identify appropriate adult health care providers. To learn more, call (317) 948-0061.

Programs and systems change often. It is important to ensure that you are using the most current information. This Fact Sheet was updated on August 2021. Please check http://fvindiana.org/fact_sheets for the most recent edition.

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