



A transitional care program

# Timeline

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**KOSAIR  
CHILDREN'S  
HOSPITAL**  
*A Part of Norton Healthcare*



# Timeline

## Transition to adult care

As the survival rate of pediatric patients with congenital abnormalities, developmental disabilities and chronic health issues continues to improve, the need to transition these patients to adult-service providers becomes more acute. Ninety percent of children with chronic illnesses or disabilities survive to adulthood, and most want to live full, productive lives.

Pediatricians can play a critical role in helping patients and families make appropriate transitions to adult care by preparing the patient and family and by knowing which practitioners have the clinical skills needed and which have an interest in working with adults with disabilities. Young adults may stay with pediatricians who are comfortable with adult health and sexuality issues if the patient and family agree. The process of transitioning to adult care should begin as soon as the medical condition is established and should be phased in gradually, according to the patient's developmental ability.

## *Timeline suggestions for physicians*

### **12 to 14 years**

- Begin a discussion and education about the transition process with the patient and his or her parents.
- Begin seeing the patient without the parents in the room.
- Discuss assessment and management issues with the patient and parent.
- Complete first transition checklist.

### **15 to 16 years**

- Continue discussion and education about the transition process.
- Arrange for a visit from or to an adult-service provider.
- Complete second transition checklist.

### **17 to 21 years**

- Complete third transition checklist.
- Alternate pediatric and adult-service office visits.
- Establish timeline for final family transfer.

## *Timeline suggestions for parents*

### **Birth to age 3, or according to your child's developmental ability:**

- Reassure your infant that the world is a good place in which to live.
- The development of a sense of trust is vital to the development of a healthy personality.
- Allow your child to develop at his or her own individual pace.
- As a parent it is important to take short breaks from your child to renew energy with which to enjoy him or her.
- Begin keeping a record of your child's educational and medical history, including immunizations.
- Contact the First Steps Program for services/programs to help you and your child. If you are eligible, a First Steps service coordinator will be assigned to you. Contact the First Steps Program in your state for information regarding the First Steps Program in your community.
  - Kentucky – **(800) 442-0087**
  - Indiana – **(800) 412-STEP**
- The HANDS program is available for first-time parents and includes programs that span the prenatal period to 3 months old. If you are eligible, a case worker will be assigned and can provide assistance with referrals to other programs in your community. They also offer parenting tips and advice. The local number is (502) **574-5243**.
- The Family Resource and Youth Services Center (FRYSC) through your local public school can also help with referrals for services and programs. It can assist with your child's transition to the school setting.
- A transition plan meeting must be held at least three months before your child's third birthday and a written plan developed.
- If your child is eligible for Early Childhood Special Education Services, an Individualized Education Program (IEP) must be in place by your child's third birthday or the FRYSC coordinator will work with you to identify other programs/services.
- Seek a parent program for emotional support and networking.
- Involve your child and family in community and recreational activities that include children with and without special needs.

# Timeline *(continued)*

## **By ages 6 to 11, or according to your child's developmental ability:**

- Continue assigning your child chores appropriate for his or her ability level.
- Continue teaching your child normal self-care skills as well as skills related to his or her special health care needs.
- Begin helping your child interact directly with doctors, nurses, therapists and teachers.
- Assess your child's perception and basic knowledge of his or her special health care needs and build on his or her understanding.
- Encourage hobbies and leisure activities; include exploring community and recreational activities, clubs, 4-H, scouts, Camp Fire USA, YMCA, sports, etc.
- Continue to encourage decision-making skills by offering choices to your child.
- Take your child shopping whenever possible. Ask him or her to help choose purchases.
- Let your child choose how to spend some or all of his or her allowance.
- Teach your child that his or her behaviors and choices have consequences.
- Allow your child to experience the consequences of poor choices as well as good ones.
- Begin teaching your child self-advocacy skills.
- Take your child to visit your place of work.
- Continue asking your child, "What do you want to do when you grow up?"

## **By ages 12 to 18, or according to your child's developmental ability:**

- Continue to allow your teen to help with family chores.
- Continue teaching your teen normal self-care skills as well as skills related to his or her special health care needs.
- Continue to encourage hobbies and leisure activities.
- Assess your teen's perception and basic knowledge of his or her special health care needs and fill in gaps in his or her understanding.
- Begin helping your teen keep a record of his or her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and Individualized Education Program (IEP) if on an IEP.

- If on an IEP, encourage your teen to participate in IEP meetings.
- Begin helping your teen take responsibility for making and keeping his or her own medical appointments and ordering supplies.
- Begin exploring health care financing for your soon-to-be young adult.
- Discuss sexuality with your teen.
- Help your teen identify and build on his or her strengths.
- If your teen is interested, explore support groups.
- Begin to talk about and explore career interests with your teen.
- Help your teen find work and volunteer activities.
- Help your teen identify and be involved with adult or older teen role models.
- With your teen, encourage age-appropriate care from his or her family practitioner or pediatrician.
- With your teen, begin to identify with whom he or she will eventually be receiving health care as an adult.

## **By ages 18 to 21, or according to your child's developmental ability:**

- If on an IEP, you may want to encourage your young adult to stay in a school program until age 21.
- If on an IEP, continue to encourage your young adult to participate in IEP meetings and continue transition planning with the young adult and the IEP team, including employment and adult-life activities.
- Act as a resource and support for your young adult.
- Encourage your young adult to participate in support groups and/or organizations relevant to his or her special health care needs.
- Finalize health care financing with your young adult.
- With your young adult, finalize age-appropriate medical care from his or her family practitioner or transfer to an adult provider.

## Support services to consider

### **By age 14**

Transition plan from school to post-school options begins for teens on IEPs. They must be invited to participate in their IEP meeting.

### **By age 17**

- Begin exploring health care financing for your young adult.
- Notify Division of Vocational Rehabilitation (DVR) for a teen with or without an IEP by fall of the year before he or she graduates.
- If appropriate, begin guardianship procedures two months before the teen turns 18. Guardianship may be full or limited.
- Notify student of rights that will transfer to him or her on reaching the age of majority at least one year before the student reaches the age of majority.

### **By age 18**

- Check eligibility for SSI the month the teen turns 18.
- Investigate SSI work incentives, such as Plan for Achieving Self-Support (PASS).
- Contact campus student disability services to request accommodations for youth attending college.

### **By age 21**

- For a young adult with developmental disabilities, notify the Division of Developmental Disabilities (DDD) for adult services.
- A young adult can sign up for DDD at any age – the earlier the better.