



Transition programs help young people take responsibility for their own health care and provide tools for identifying adult care resources.

Transition from Pediatric to Adult Care

Introduction

The teen years are a time of transition. This is especially true for young people with OI. Although formal "Transition Programs," are available for teens in many cities, this article points out how the process really starts before the teen years.

What are transition programs and why are they important?

Young adults with OI who have received all or most of their health care through a children's hospital are faced with many challenges when they no longer qualify for care through a pediatric facility. In recent years, the Shriners Hospitals and other children's hospitals that see children with life long medical conditions have begun offering programs to prepare young people and their families to make this transition.

What should you look for in a Transition to Adult Healthcare Program?

First, the program should be designed to help young people take responsibility for their own health care. This involves becoming knowledgeable about OI, being able to communicate confidently with physicians and being capable of making care decisions. Second, the program should provide tools to identify adult care resources before losing eligibility for care in the pediatric facility. This involves finding OI specialists, primary care physicians, and working within insurance limits.

What skills are important to making a smooth transition?

- Having an age appropriate understanding of what OI is and the medical and life style issues involved.
- Being comfortable speaking directly to doctors and other health care professionals about OI and other health topics.
- Being able to explain symptoms, ask questions, and understand instructions.
- Knowing how to make medical appointments.
- Knowing what to do if an injury occurs.
- Knowing how to take medication.
- Knowing how to keep medical records.
- Knowing how to submit bills to an insurance company.
- Understanding the adult healthcare system and finding doctors in different specialties.

Besides handling medical appointments, are there other issues involved in the transition to adulthood?

- Preparing for employment
- Living as independently as possible
- Sexuality and relationships
- Finding and attending a college
- Being a self-advocate
- Finding transportation in the community
- Participating in community activities
- Developing adult-level recreation and leisure interests

When should a child start the Transition Process?

While most formal programs are aimed at young people of high school age, the real process happens gradually beginning in childhood. For example, preparing for adult employment begins with the process of learning responsibility by doing chores and helping at home. As the child grows, the next step may be

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doing neighborhood jobs and then in the teen years, having a part-time job. Often children and adolescents growing up with disabilities have fewer of these experiences than their peers, and therefore reach adulthood less prepared for employment. The challenge is to be aware of the need to develop work experience and to creatively find opportunities that suit the young person's abilities.

Similarly, developing satisfying adult relationships is a gradual process that begins with learning to make friends as preschoolers and having age-appropriate social experiences in school and throughout adolescence. Some of the activities that are developmentally appropriate for teaching independence to children who have OI (and their siblings) are listed below.

Are there any resources available to families who do not have access to a formal transition program?

Local community colleges, community hospitals, banks and school systems often offer courses on different transition to adulthood topics. Money management, cooking, and college and career exploration are popular. Some high school guidance departments maintain lists of these courses. Organizations that offer information helpful to families facing transition include the following.

Centers for Independent Living

Centers for Independent Living (CIL) are programs of services for individuals with disabilities that promote self-sufficiency, advocacy, and life opportunities. They are funded by the Rehabilitation Services Administration of the U.S. Department of Education. The objectives and philosophy of CIL's may vary from state to state, however, the overall goal is to empower people with disabilities to live as independently as possible and take responsibility for their lives. For more information: www.abledata.com or www.ILUSA.com.

Vocational Rehabilitation

Each state has a Department or Division of Vocational Rehabilitation that assists people with disabilities to prepare for employment and career goals. Any person with a disability may apply if he or she feels that the disability will interfere with work or career plans. One's eligibility will depend on the disability and if it is considered an obstacle to employment. Services may include evaluation and guidance, skills testing, job development, placement, college assistance, and adaptive equipment. The National Center for Children and Youth with Disabilities can provide you with contact information in your state. 1-800-695-0285 or www.nichcy.org.

Post-secondary education

The HEATH Resource Center of George Washington University, Graduate School of Education and Human Development, is the national clearinghouse on postsecondary education for individuals with disabilities. Support from the U. S. Department of Education enables the clearinghouse to serve as an information exchange for educational support services, scholarships, policies, procedures, adaptations, and opportunities at American campuses, vocational-technical schools, and other postsecondary training entities. www.heath.gwu.edu.

How can young people locate health care providers in the adult system?

An important part of making a successful transition out of pediatric care is to locate new doctors and establish a relationship with the primary care physician and the orthopedist **before there is an emergency**.

There are three sources of information:

- Referrals from the pediatrician or pediatric specialist
- Guides from your insurance company
- Suggestions from other people, including the OI Foundation.

The young adult with OI may need to put together his/her own team of health care providers. Doctors to include on an adult's health care team include a primary care physician, orthopedist, endocrinologist, and, for women a gynecologist.

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Other specialists may be needed depending on the severity of the OI and on the person's other health needs.

Some pediatric specialists, including pediatric orthopedists, continue to treat their OI patients for specific OI related health problems, but usually not as a primary care physician.

There are a few OI clinics in different parts of the United States that offer services to adults with OI. Occasional visits to a specialty clinic is one way to manage OI during the adult years especially if there is good communication between the center and the hometown primary care physician. Insurance coverage may be an issue in some cases. The OI Foundation's Clinic Directory and the Talking with Your Doctor fact sheets have additional information on this topic.

Activities that Encourage Independence

Birth-3 years old

- Encourage your child to assist with activities
- Allow your child time to complete tasks
- Talk with your child about his/her OI

3-5 years old

- Teach your child about his/her special needs related to OI
- Encourage your child to participate in self-care
- Help your child to interact socially in various settings
- Assign household chores or responsibilities

6-12 years old

- Allow your child to relate his/her experiences and concerns about OI
- Help your child interact appropriately with healthcare providers
- Talk about career options, interests, and abilities
- Encourage your child to participate in organized activities that build social skills and confidence
- Allow your child to participate in making choices

13-18 years old

- Continue to assess your teen's knowledge and perception of OI and provide additional information as appropriate
- Encourage teens to gradually be responsible for making medical appointments and take responsibility for own healthcare decisions
- Discuss options for transitioning to adult healthcare
- Discuss sexuality, marriage, parenting. Assure that teens have an opportunity to discuss these topics with physicians, mentors with OI, and other teens
- Continue planning for postsecondary education, career, and independent living
- Talk about community transportation. Will the teen drive? Will they need adapted vehicles and/or public transportation?

19-21 years old

- Identify an adult healthcare provider
- Transfer medical records
- Determine financing and insurance options
- Continue transition to career and financial independence
- Plan for adult social, leisure, and recreational opportunities

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