The Children’s Hospital of Philadelphia

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Transition to Adulthood

Symme Trachtenberg, MSW, LSW, Director, Community Education
The Children’s Hospital of Philadelphia
Plan for Today

- Skills for Transition
- Resources
- Programs
Skills for Transition

- Take charge of your health
- Have a person who will help with health care decisions, if a family member cannot
- Know who to call in case of an emergency
- Have a one page medical summary
  - Emergency Information sheet
- Learn how to coordinate your healthcare
- Describe medical condition and explain special health care needs to others
  - Friends, teachers, employers
Healthcare Collaboration

- Spend time alone with health care provider(s) at each visit
- Call the doctor’s office to make an appointment
- Call the doctor about unusual changes in your health (e.g., allergic reactions)
- Follow up on any referrals for tests or check-ups and labs
Healthcare Collaboration

- Make a list of questions before the doctor’s visit
- Answer questions that are asked by the doctor, nurse or clinic staff
- Tell the doctor or nurse what you are feeling
Healthcare Collaboration

- Discuss sexuality issues with your healthcare provider

- Know how to get birth control and protection from sexually transmitted infections

- Discuss how the use of tobacco, alcohol and drugs will impact your health with your healthcare provider
Healthcare Collaboration

- Know what your healthcare condition may bring in the future
- Have/find a doctor that can provide adult care
- Know the types of doctors needed to be seen as an adult
- Know about your right to control personal health care information (HIPAA)
Medications

- Take medications independently and correctly
- Know the names of medications and what they do
- Fill prescriptions when needed
- Reorder medications before they run out
- Know the side effects of each medication
- Know what to do if you are having a bad reaction
Supplies and Equipment

- Independently use and take care of medical equipment and supplies
- Order medical supplies before you run out, know how to pay for them
- Call the suppliers when there is a problem with your equipment
<table>
<thead>
<tr>
<th>Insurance</th>
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<tbody>
<tr>
<td>✷ Carry a copy of your medical insurance card</td>
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<tr>
<td>✷ Continue or know how to apply for health insurance</td>
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<tr>
<td>✷ Use community support services and advocacy services (legal services – Disability Rights Network, insurance - MAWD), when needed</td>
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School or Work

- Request and get the accommodations and support you need at school or work
  - Job Accommodation Network (800)526-7234 (Voice), (877)781-9403 (TTY)  askjan.org

- Get financial help with school, if needed
  - Find out if eligible for Vocational Rehabilitation

- Know how to apply for a job or vocational services
REACH

Rapport, Empowerment, Advocacy through Connections and Health

Transition to Adulthood Educational Program

REACH for College
REACH for Independence
A program **for** teens and young adults (ages 15 to 19) with special healthcare needs, created **by** teens and young adults with special healthcare needs.

Supported by a grant from the Dept. of Health & Human Services, Health Resources & Services Administration, Maternal Child Health Bureau, MCH Grant T73MC00051.
Vision - 2003

REACH will locate, help to develop, and establish comprehensive, collaborative adult-oriented healthcare and community services for young adults with special healthcare needs that encourages and supports independence and well-being.
REACH for Youth and Parents

Workshops
- Self Care
- Self Advocacy
- Care Coordination
- Wellness
- Relationships
- Eligibility for insurance and Federal programs
- Navigating the medical system
- Advocating for support services

Opportunity for youth and their parents to gather information, network and socialize.
Transition to Adulthood

Adolescents with chronic conditions, special healthcare needs and/or disabilities need support as they become adults. Transition encompasses healthcare and all facets of adult life. The goal: self-care and self-advocacy to the greatest extent possible.

Important points about transition:
- Transition is a process, not an event.
- Adolescents and their families should be involved in all healthcare decisions.
- Parents and caregivers can help facilitate change.
- Transition of care works best when pediatric providers prepare patients and families.

During transition, youth should learn to understand their health conditions, their health insurance and how to access care. Our family-focused materials can help and are easily available online.

For more information:
www.chop.edu/transitiontoadulthood

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Transition Programs
The Children’s Hospital of Philadelphia runs several programs to support transitioning patients to adulthood.

REACH
REACH (Rapport, Empowerment, Advocacy, through Connections and Health) is a program for teens and young adults ages 10-24 with special healthcare needs and their families, created by teens and young adults with special healthcare needs.

REACH’s mission is to prepare teens and young adults with special healthcare needs for a successful transition into adulthood by providing peer support, guidance, and resources.

REACH offers mentorship and training to help youth acquire the skills needed to develop and maintain partnerships among families, youth, and providers as they move through transition.

For more information about the REACH program, please contact Szymon Twadletborg, MSW, at 215-590-7444 or twadletborg@email.chop.edu.

REACH Out
REACH-OUT (Rapport, Empowerment, Advocacy through Connections and Health: Optimal Understanding of Transition) is a support and educational group helping teens (ages 15-21) living with chronic illnesses to improve life skills needed to successfully navigate daily challenges through peer support, advice, and resources.

The group focuses on communication, healthy relationships, self-advocacy, and strategies for coping with the challenges of living with chronic illnesses, the importance of taking time for self-care, and other issues that help young people feel comfortable as they transition into adulthood.

The REACH-OUT program strives to provide a network of support where young people can develop positive life skills aimed at improving their compliance with their treatment.
Care Binder
What is a Care Binder?

- Represents the whole person
- Developed through a partnership of patient families, youth and clinicians to make it convenient to use and carry to appointments
- Organizing tool for youth with special needs
- A place to keep track of important information about the health care, school records
- Flexible, so it can be organized in a way that works best for the person/family
What is a Care Binder?

- A way for family members to coordinate care

- A place to keep current medical information to share with healthcare teams, within CHOP, adult providers and with community based providers

- A tool to empower youth/parents/caregivers at school Individual Education Program (IEP) meetings to better communicate and advocate to get what is needed educationally for the youth

- A place to keep track names and contact information of significant professionals in the child’s life

- Not an official medical record – it is what the person/family chooses to carry
What is included in the Care Binder?

- **Medical tab**
  - Discharge instructions, medication log, appointment logs, immunization records, visit summaries, HIPAA/medical release forms, radiology test results, etc.

- **Family tab**
  - Family information and family health history

- **Education/Therapies/Community Resources tab**
  - Community Resources, Speech, Occupational Therapy and Physical Therapy, Audiology, etc. names and reports, Individualized Education Program (IEP/Special Education), 504 Plan
What is included in the Care Binder?

- **Daily Routines tab**
  - Daily care schedules, personal hygiene, social experiences, behavior management, child care service providers, respite care, transition planning

- **Insurance, Legal and Financial tab**
  - Insurance/financial information, life planning checklist, wills and estate plans, trusts

- **For pages in English and Spanish**
  - [www.chop.edu](http://www.chop.edu) Type in Care Binder

Acknowledgement: Care Notebook pages adapted with permission, Seattle Children’s and the Washington State Department of Health, 2009
Program Models

- CHOP Career Path
- REACH for Work
- REACH for College
Evaluates and trains students and young adults with disabilities

Transitions youth from a pediatric/school setting to an adult community setting

Develops the unique potential of each learner

Provides knowledge, skills and strategies needed to achieve personal, academic, vocational and civic goals
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