

Hope lives here.



## 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 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



# Insurance

- ❖ Carry a copy of your medical insurance card
- ❖ Continue or know how to apply for health insurance
- ❖ Use community support services and advocacy services (legal services – Disability Rights Network, insurance - MAWD), when needed



# 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) *ask**jan**.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



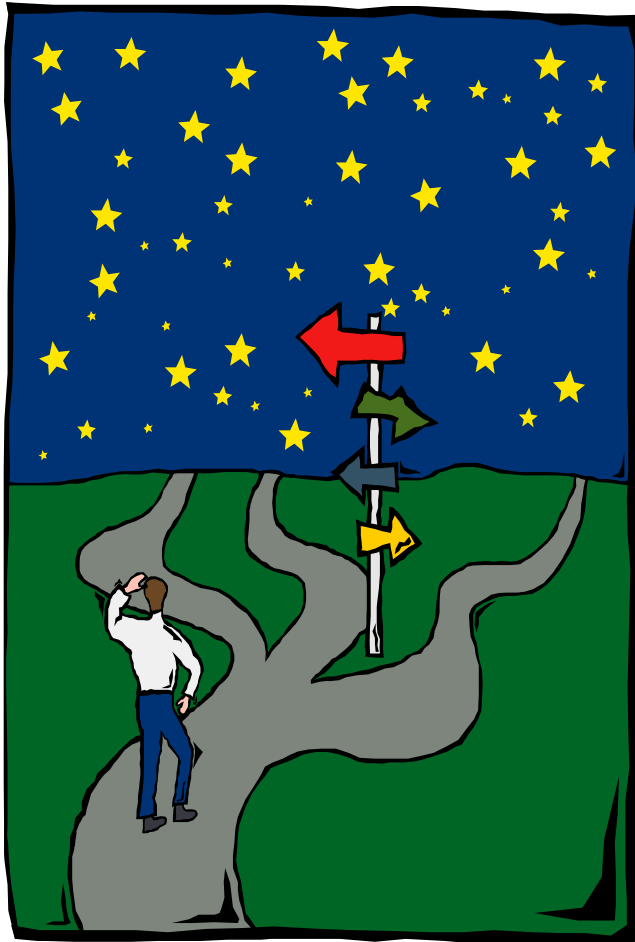
# REACH

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 Materials

[www.chop.edu/transitiontoadulthood](http://www.chop.edu/transitiontoadulthood)

## 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.



*Downloadable brochures are available to help guide parents through transition.*



*Youth brochures also available.*

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.

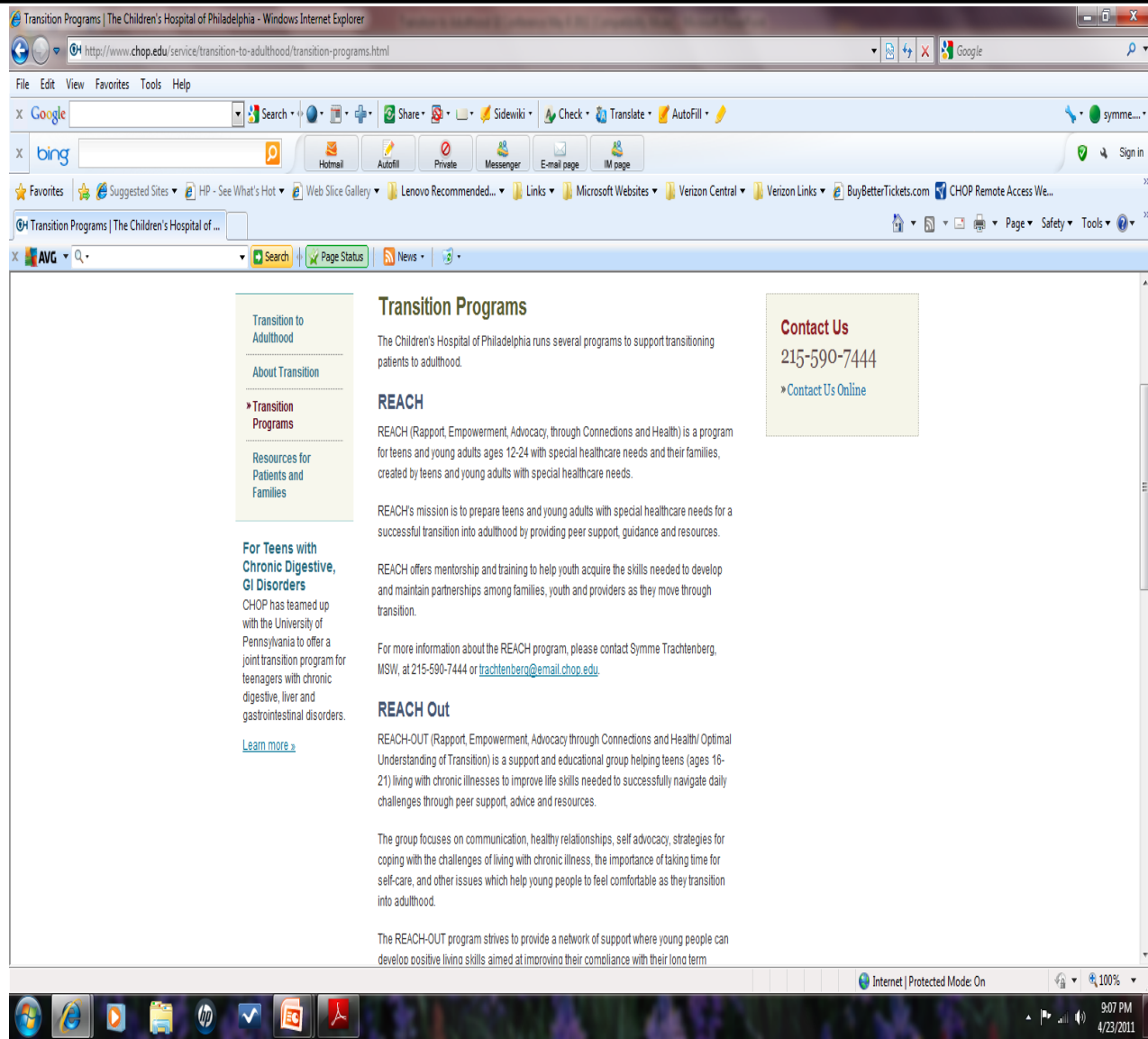
For more information:

[www.chop.edu/transitiontoadulthood](http://www.chop.edu/transitiontoadulthood)

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# Transition to Adulthood Website



# Community Resources for Families

[www.chop.edu/crf](http://www.chop.edu/crf)

The screenshot displays the 'Community Resources for Families' page on the CHOP website. The browser window shows the URL <http://www.chop.edu/about/chop-in-the-community/community-resources/community-resources-for-families.html>. The page features the CHOP logo and tagline 'Hope lives here.' at the top. A navigation bar includes links for 'Give to CHOP', 'Research', 'For Healthcare Professionals', 'Press Room', and 'Careers'. Below this is a secondary navigation bar with 'Health Information', 'For Patients and Visitors', 'Specialties and Services', 'Locations', 'Find a Doctor', and 'About Us'. The main content area is titled 'About Us' and includes a section for 'Community Resources for Families' which describes the database's purpose and provides a search link. To the right, there is a 'Contact Us' section with the phone number 215-590-1000 and links for 'Contact Us Online' and 'Request an Appointment'. Below the contact section is a 'Get Driving Directions' form with a 'Starting Address' field, a 'Your Destination' dropdown, and a 'Get Directions' button. The footer contains various links such as 'Web Accessibility', 'Short Cuts', 'Our Philosophy of Care', 'Sign Up for Newsletters', 'Awards and Honors', and 'Fellowships at The Children's Hospital of Philadelphia'. The Windows taskbar at the bottom shows the Start button and several open applications including Internet Explorer, Microsoft Word, and various folders.



# 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



# CHOP Career Path

- ❖ 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



# For More Information

Symme Trachtenberg, MSW, LSW

Director, Community Education

The Children's Hospital of Philadelphia

CHOP Leadership Education in Neuro-developmental Disabilities

Clinical Associate in Pediatrics

University of PA School of Medicine

Part-time Lecturer, University of PA

School of Social Policy and Practice

[trachtenberg@email.chop.edu](mailto:trachtenberg@email.chop.edu)

215-590-7444

Skills for Transition adapted from: Sawicki, et al, Measuring the Transition Readiness of Youth with Special Healthcare Needs: Validation of the TRAQ-Transition Readiness Assessment Questionnaire, Journal of Psychology, pp.1-12, 2009.

