Module 3: Working with Parents & Caregivers
Learning Objectives

- Describe 2 frameworks for working with families during health care transition

- Name at least one strategy to engage caregivers in health care transition

- Apply concepts from previous modules
Working with Parents & Caregivers: Evidence Base
Developmental Model of Child-Family-Professional Partnership
The Shared Management Model

- Lifespan approach
- Competent and confident
- Interdependence
Shared Management Roles

**Shared Management Overview**

**Role of Parent**
- Parent is **provider** of care → Youth **receives** care
- Parent becomes **manager** of care → Youth **provides** some self-care
- Parent becomes **supervisor** of care → Youth becomes **manager** of care
- Parent becomes **consultant** to youth → Youth becomes **supervisor** of care
- Parent becomes **consultant** to youth → Youth becomes **CEO** of care
Stage 1 – Provider Focus

- Educate caregiver
- Build a working alliance
- Manage patient’s condition
Stage 2 – Caregiver Focus

- Caregivers - greater level of responsibility
- Providers support parents
- Child is active participant
Stage 3 – Patient Focus

- Adolescent increases level of responsibility
- Caregivers provide oversight and support
- Providers support health care transition
Stage 4 - Interdependence

- Caregivers - advise and support

- Patients - health care supervisor
Shared Management Model in Action
Barriers for Caregivers

- Fear child will be overwhelmed
- Consequences of potential failure
- Likelihood of emergencies
Barriers for Patients

- Genuinely overwhelmed
- Prefer to rely on parent
- Boredom
Working with Parents & Caregivers: In Practice
Transferring Expertise

- Patient must acquire knowledge
- Parents are experts
- Physician encourages transfer of expertise
Ways to Transfer Expertise

- Create an emergency plan
- Preventing an emergency
- Condition monitoring and management
Practice for Big Decisions

- Encourage independent decision-making
  - School activities
  - Appearance
How Do You Get to Carnegie Hall?

Practice:

- Make doctor’s appointment
- Fill out health history form
- Call pharmacy for prescription refill
During Appointments…

- Rehearsing to go solo
  - Managing a visit
  - Asking questions
  - Speaking up when they don’t understand
Working with Parents & Caregivers: Using Tools & Resources
Encourage Family
INTRODUCTION: While all children are born being totally dependent on their parents for their every need, we expect them as they grow and develop to learn how to care for themselves and become independent adults. Children are expected to gradually master the necessary skills and to be increasingly responsible for self-management of their own needs and care. Children with developmental disabilities, chronic illness, or other disabilities may be delayed or limited in reaching this independence in daily self-management due to medical problems, physical restrictions, or cognitive limitations. Sometimes parents are hesitant or uncertain about how to encourage independence in children who have special needs.

_SHARED MANAGEMENT_ by parent and child is a model suggested by Dr. Gail Kieckhefer and Cristine Trahms, in which business labels are used to express the changing dynamics in the parent-child relationship as the child/youth grows and develops. The parent’s role changes over the years from the Provider of care to the Manager to the Supervisor and finally to the Consultant for the youth. The management of the child’s
Using Shared Management Theory

**Role of Parent**
- Parent is **PROVIDER** of care
- Parent becomes **MANAGER** of care
- Parent becomes **SUPERVISOR** of care
- Parent becomes **CONSULTANT** to youth

**Youth Role**
- Youth **receives** care
- Youth **provides** some self-care
- Youth becomes **manager** of care
- Youth becomes **supervisor** of care
- Youth becomes **CEO** of care
Teach Your Parents Well

- Support independence and self-reliance
- These are necessary steps and missteps
- Healthy and inevitable
Interactive Question

Think of one YSHCN in your practice and his/her family.

How could they benefit from the Shared Management Model?

What barriers might you encounter to using the Model with this specific patient and family?

Slide will automatically advance in 1 minute!
Shared Management

What is shared management?

Shared management is a helpful model for navigating transition. It values the key role you play in your child's health care and how your role shifts over time. Gail Keickhefer and Cris Trahms, leaders in shared management, borrow from the business world as a way to describe the changes parents go through. For example, in the beginning, you were the CEO of your child's care and, over time moved to manager, then supervisor, and eventually to consultant. This is a shift from total responsibility to shared responsibility. It happens as you guide and coach your child to develop skills, assume more responsibility and build confidence to more actively participate in their own care.

The goal is for your child to take an active role in their own health care. Each person's maximum potential to do this will be uniquely their own. Shared management holds the view that...
Reminder: When to Discuss

- When health -- and family life -- are stable
- Start early!
- Transition is normal part of growing up
Up Next: Video Clip!

- Video interview with patient
- Jeff, first met in Module 1
Transferring Expertise: Patient Experience
Working with Parents & Caregivers: Resources
Key Points

- Independence in self-care is building block
- Build gradually
- Practice
Summary of Tools

Health Care Transition Training for Health Care Professionals
2014 Course Release

Course Toolkit

Module 3. Working with Parents, Caregivers, and Guardians

1. Path to Independence

2. Seattle Children’s Hospital: Center for Children with Special Needs
   http://cshcn.org/planning-record-keeping/teen-transition-parents/shared-management
Citations

