



# Module 3: Working with Parents & Caregivers

# Learning Objectives

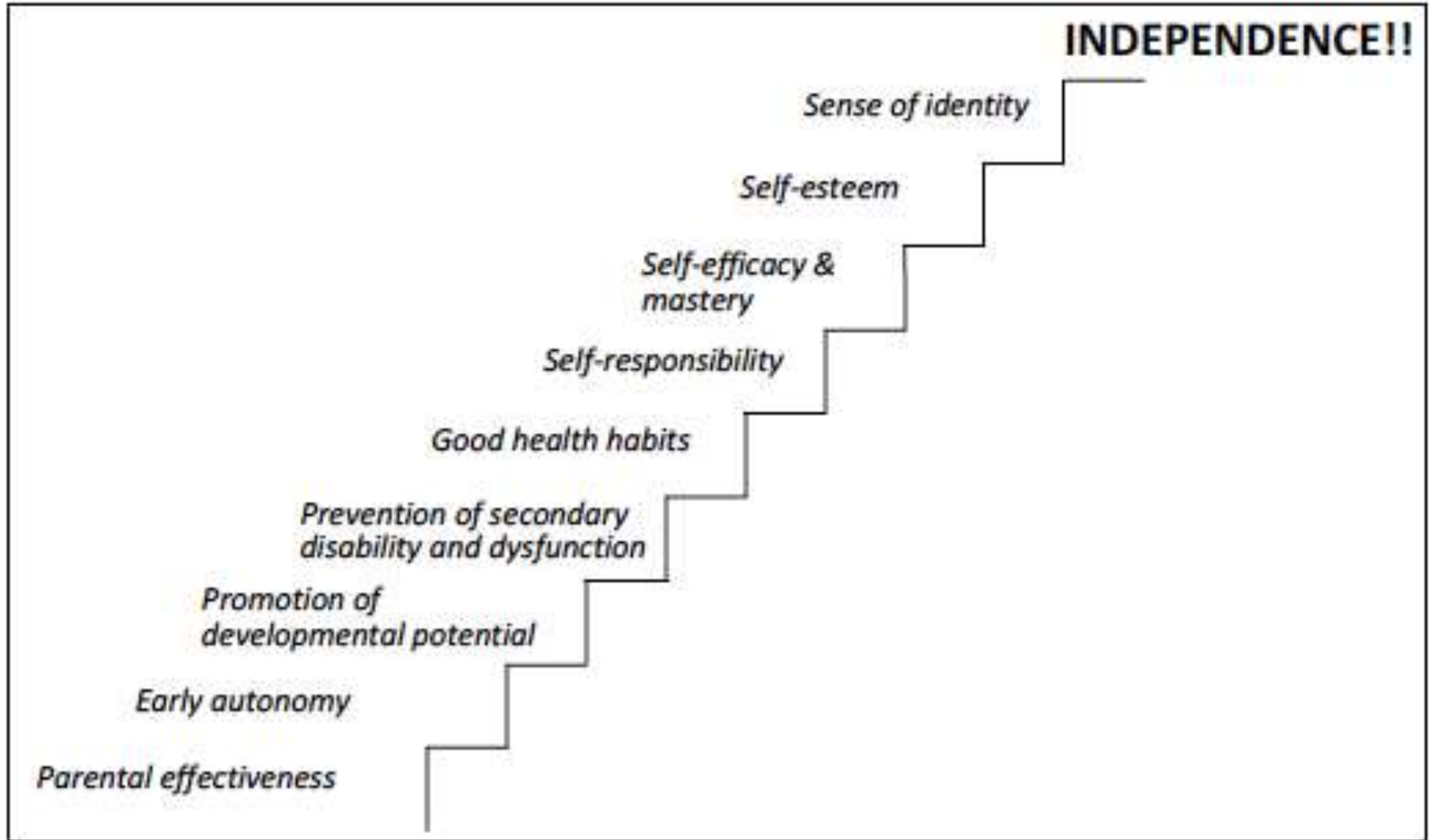
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- ▶ Describe 2 frameworks for working with families during health care transition
- ▶ Name at least one strategy to engage caregivers in health care transition
- ▶ Apply concepts from previous modules

# Working with Parents & Caregivers: Evidence Base

# Developmental Model of Child-Family-Professional Partnership

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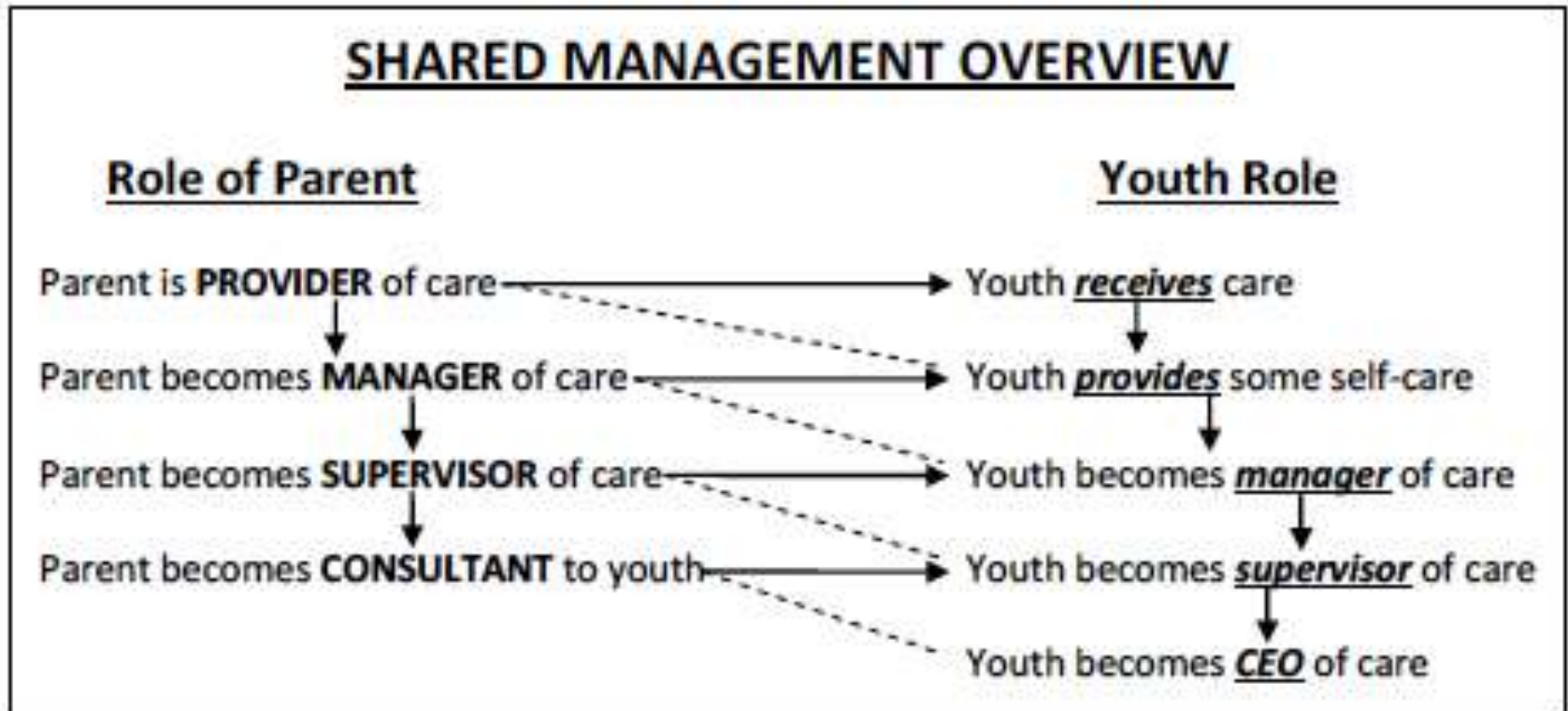
# The Shared Management Model

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- ▶ Lifespan approach
- ▶ Competent and confident
- ▶ Interdependence

# Shared Management Roles

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# Stage 1 – Provider Focus

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- ▶ Educate caregiver
- ▶ Build a working alliance
- ▶ Manage patient's condition

## Stage 2 – Caregiver Focus

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- ▶ Caregivers - greater level of responsibility
- ▶ Providers support parents
- ▶ Child is active participant



## Stage 3 – Patient Focus

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- ▶ Adolescent increases level of responsibility
- ▶ Caregivers provide oversight and support
- ▶ Providers support health care transition

# Stage 4 - Interdependence

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- ▶ Caregivers - advise and support
- ▶ Patients - health care supervisor

# Up Next: Video Clip!

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- ▶ Interviews with Jim, his parents, and providers
- ▶ First of 2 video clips



# Shared Management Model in Action

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# Barriers for Caregivers

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- ▶ Fear child will be overwhelmed
- ▶ Consequences of potential failure
- ▶ Likelihood of emergencies

# Barriers for Patients

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- ▶ Genuinely overwhelmed
- ▶ Prefer to rely on parent
- ▶ Boredom



# Working with Parents & Caregivers: In Practice

# Transferring Expertise

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- ▶ Patient must acquire knowledge
- ▶ Parents are experts
- ▶ Physician encourages transfer of expertise



# Ways to Transfer Expertise

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- ▶ Create an emergency plan
- ▶ Preventing an emergency
- ▶ Condition monitoring and management

# Practice for Big Decisions

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- ▶ Encourage independent decision-making
  - ▶ School activities
  - ▶ Appearance

# How Do You Get to Carnegie Hall?

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- ▶ Practice:
  - ▶ Make doctor's appointment
  - ▶ Fill out health history form
  - ▶ Call pharmacy for prescription refill

# During Appointments...

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- ▶ 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

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# Provider Resource!

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## PARENT-CHILD SHARED MANAGEMENT Path to Independence

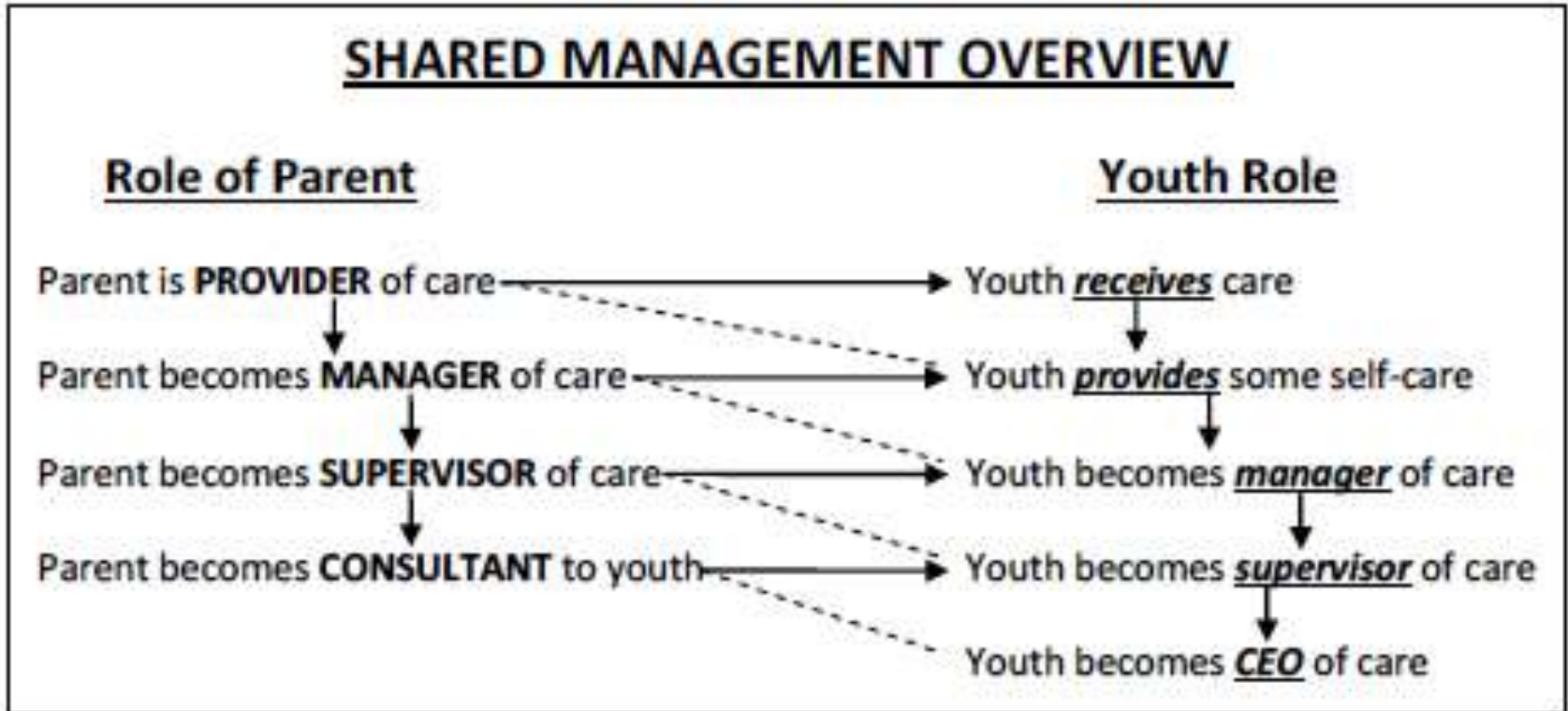
**Introduction:** While all children are born being totally dependent on their parents for their every need, we expect them as they grow and develop to learn how to care for themselves and become independent adults. Children are expected to gradually master the necessary skills and to be increasingly 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

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# Teach Your Parents Well

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

# Interactive Question

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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!



# Caregiver Resource! Transfer Expertise

The Center for  
**Children with  
Special Needs**



Click and type...

SEARCH

## CHOOSE A CATEGORY

- About Us
- Diagnosis Information
- Resources & Contacts
- Planning & Record Keeping
- Childcare, Schools, & Community
- Finding Support & Making Connections
- News

## ACTION ITEMS

*New Diagnosis?  
Get Started*

*Download Forms  
and Documents*

Parents & Caregivers

Teens

Professionals

[Home](#) > [Planning & Record Keeping](#) > [Teen Transition: A Parent's Important and Changing Role](#) > Shared Management

## 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

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*Learn more about shared management from Gail Keickhefer, PhD, Pediatric Nurse Practitioner, University of Washington, School of Nursing.*

# Reminder: When to Discuss

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- ▶ When health -- and family life -- are stable
- ▶ Start early!
- ▶ Transition is normal part of growing up

## Up Next: Video Clip!

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- ▶ Video interview with patient
  
- ▶ Jeff, first met in Module 1

# Transferring Expertise: Patient Experience

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# Working with Parents & Caregivers: Resources

# Key Points

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- ▶ Independence in self-care is building block
- ▶ Build gradually
- ▶ Practice



# Summary of Tools

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## 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](#)

<https://depts.washington.edu/healthtr/documents/sharedmanage.pdf>

2. [Seattle Children's Hospital: Center for Children with Special Needs](#)

<http://cshcn.org/planning-record-keeping/teen-transition-parents/shared-management>



# Citations

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1. Parent-child shared management: The path to independence. 2010. University of Washington adolescent health transition project.
2. Bright futures guidelines for health supervision of infants, children, and adolescents: Adolescence – 11 – 21 years. 2008. American Academy of Pediatrics.
3. Seattle Children's Hospital – Center for Children with Special Needs.  
<http://cshcn.org/planning-record-keeping/teen-transition-parents/shared-management>.  
Accessed 5/24/2014.

