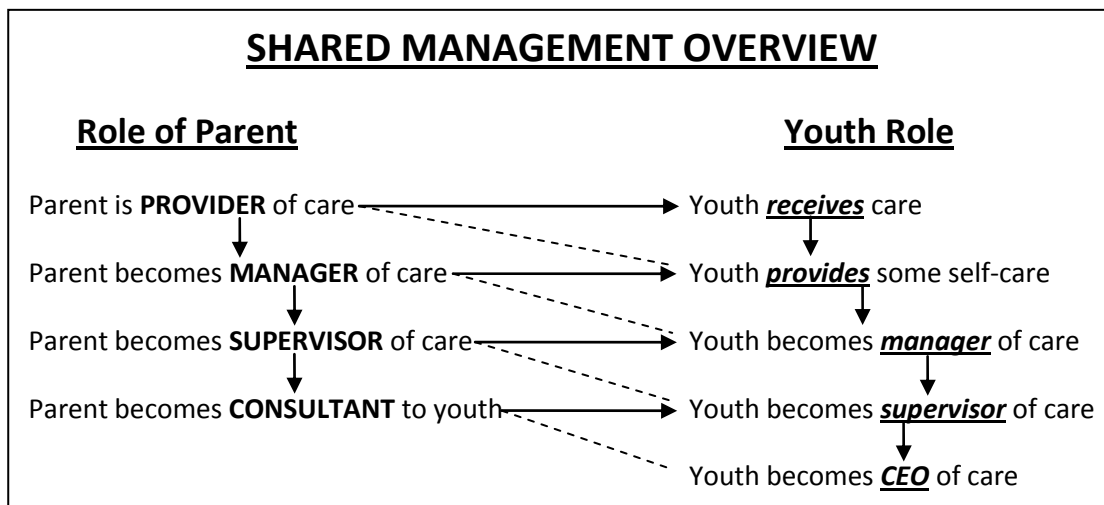


PARENT-CHILD SHARED MANAGEMENT

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 care gradually shifts from parents to child as the child's skills and responsibility increase even as the parents continue to have a supporting, consultative role.



Shifting Responsibility:

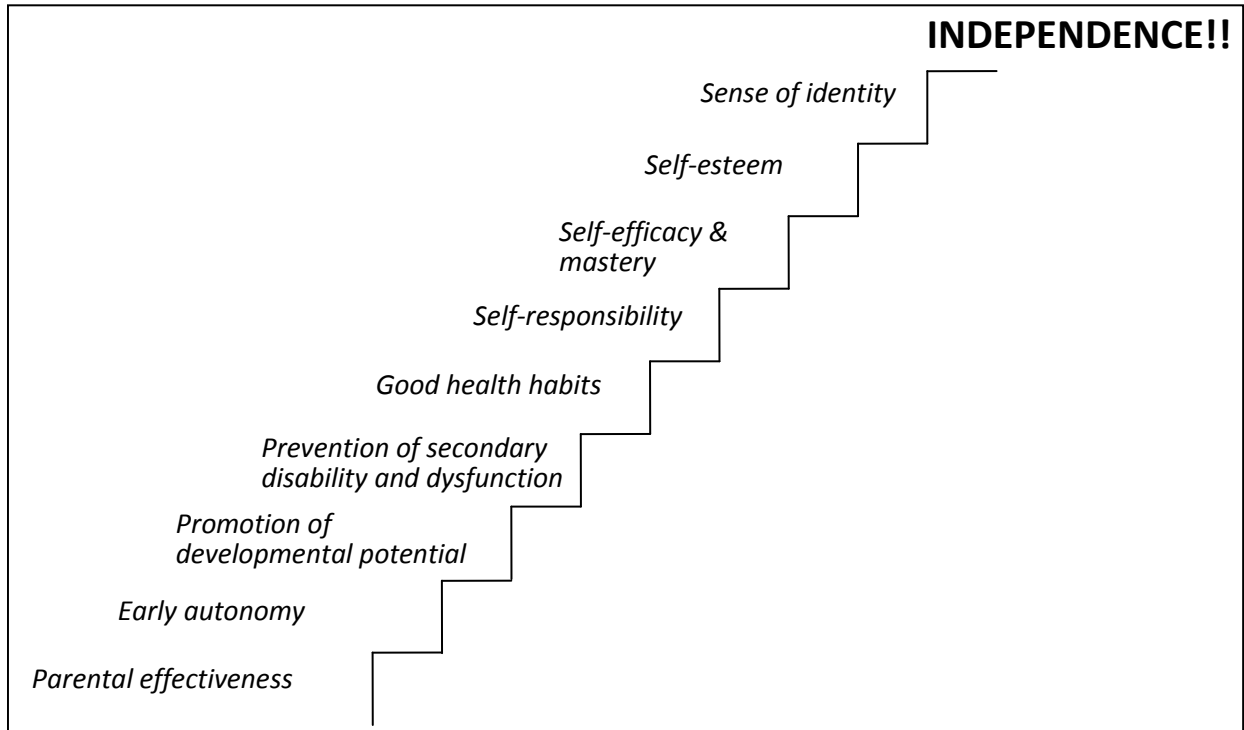
Initially, the youth receives care as a child, then begins to learn aspects of self-care. As the youth grows and develops she/he takes on the roles of Manager, then Supervisor and finally CEO of her/his own care. While the goal of this model is for the young adult to become the CEO of her/his own care and develop a set of independent self-management skills, parents are still involved in supporting roles of supervising and

consulting. Just as the CEO of a company has a board of directors and other executives and employees to assist, the young adult still interacts with and receives support from family and community, thus the concept of “shared management.”

Key Points:

- Parents guide youth’s forward movement of skills and responsibility
- Parents monitor youth’s progress, support efforts and negotiate changes in responsibility.
- Parents and youth both have central roles to play
- Learning is based on the cognitive and physical readiness of the youth

The model above was developed for youth with typically developing cognitive skills, but the approach can be modified with smaller steps and a final outcome anywhere along the continuum – still aiming for maximal self-management and independence.



Steps to Independence

In regard to Shared Management and working towards independence, youth and parents should remember:

1. It is never too early and never too late to begin!
2. No youth is too limited to participate – but age and developmental level both need to be considered.

3. Shared management supports movement up the stairway to maximal independence, *taking the next small step*, but allows for temporary regression.
4. Shared management requires of parents:
 - Parenting skills for typical challenges of growing up
 - Special skills related to the youth's disorder and its management
 - Aspirations for maintaining family life
 - Dedication to support current and future overall health outcomes

How To Start Taking the Next Small Step Towards Independence

- Identify areas in which progress needs to be made. Look at recent IEPs, the Health skills transition checklist, Bright Futures steps, etc. Consider youth and family needs, concerns, goals.
- Select a few specific goals to work toward, which are important to the youth and parents.
- Break these goals into small steps considering current skills and limitations and the tasks to be learned. Teachers and therapists may be helpful in doing this.
- Prepare a plan to learn/teach these skills with youth taking as much responsibility as possible. Parents may act as consultant, supervisor or manager.
- Review/reevaluate periodically.

Source: "Keeping the AFOs on: A Developmental Approach to Engaging Children and Families in Shared Management" a presentation on March 26 at the 2010 Duncan Seminar by Gail M Kieckhefer, PhD, PNP, ARNP, Family & Child Nursing and MCHB Pediatric Pulmonary Center, University of Washington.

This handout from the above presentation was developed with permission by Katherine TeKolste, MD and Sue Livingstone, MD, Adolescent Health Transition Project, Center on Human Development and Disability, University of Washington, June 2010.

