



Join the Chain

Stop the Pain of Sickle Cell

Statewide Sickle Cell Conference
April 20, 2012



Pediatric Psychosocial Issues in Sickle Cell Disease Transitions of Care

- Andrew Harner, LCSW
- Riley Hospital for Children
- 2012 Statewide Sickle Cell Conference
- April 20, 2012

Ecological – Systems theory approach

- *An evolutionary, adaptive view of human beings in continuous interaction with their environment (Derauf, 2008)*
- Humans live in a state of homeostasis with their environments and develop a “niche” or “fit”

Cultural Competence

Process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic background's, religions and other diversity factors in a manner that recognizes, affirms and values the work of individuals, families and communities and protects and preserves the dignity of each

When Does Transitioning Start?



Session Three

Birth

Ten

Sixteen

Adult

Giving the authority to make decisions as the child/ parent is able to do so RESPONSIBLY

Empowerment

Teaching how to make decisions

Making it practical and easy to make decisions

Giving opportunities to make decisions

Developmental Tasks of Adolescence

- Developing a sense of identity
- Adjusting to body changes
- Developing abstract thought
- Acquiring interpersonal skills
- Establishing autonomy

Developmental Tasks of Adolescence continued...

- Acquiring a value system
- Establishing and negotiating a new relationship with family
- Setting goals for future achievement
- Choosing a vocation

Friedman, 1993

Transition Programs can:

1. Increase the likelihood for uninterrupted care
2. Reduce the inequalities of opportunities
3. Promote physical and psychosocial health

(MCHB, 1992)

Barriers to Transitioning Programs

- Families or patients who are dependent on pediatric care providers
- Pediatric providers who foster dependence and have difficulty letting go of their patients
- Young adults who lack advocacy skills
- Pediatricians who may not trust adult practitioners to manage childhood onset diseases

Barriers to Transitioning Programs continued...

- Professionals who lack the understanding of the developmental issues necessary to deal with these young adults
- Pediatric and adult healthcare systems that lack formal or informal structural mechanisms for communications among various groups of caregivers
- Economic concerns hospital programs have about the potential loss of a patient base that supports an on-going research

(blum, 1995; Rosen, 1995; Sawyer, Blair, and Sawyer, Blair, and Bowes, 1997)

Final Thought:

- “Nothing could be worse than the fear that one had given up too soon, and left one unexpended effort that might have saved the world.” -- Jane Addams

