SERGG SICKLE CELL INITIATIVES

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SERGG SICKLE CELL HISTORY

- Sickle Workshop focused on newborn screening
- TASCS Force helps four states start newborn screening
- CORN working group outlines program designs
- TASCS Force helps Region and six other states start programs
COMMON OPPORTUNITIES FOR IMPROVEMENT IN ADULT CARE

• Sickle cell disease exacerbates in late teens and twenties
• Lack of independence - Learned helpless
• Chronic illness behavior
• Transfusion related problems
  – Venous access
  – Alloimmunization
  – Iron overload
• Chronic pain states
POTENTIAL SOLUTIONS

- Early intervention using newborn screening as an opportunity to educate the parents and family
- Improve the adult medical home
- Develop effective transition programs to establish an effective adult medical home
EARLY FAMILY INTERVENTION

- Address medical issues
- Provide parent education
- Provide extended family education
- Improve social support
- Increase psychological functioning
- Address financial functioning
Nurse Home Visitor Program

David Olds: Elmira, Memphis, Denver

- Prenatal and two year postnatal intervention
- Treatment effects up to 15 years
  - Mother and child show reduced substance abuse, legal problems, dependence on welfare, risky sexual behavior
- Positive effects only in high risk mothers
- Nurses appear to be necessary
- Rigorous protocol and training
LIMITATIONS OF OLDS’ MODEL

- Expensive
- Requires highly trained professionals
- Prenatal initiation of intervention
- Effects in high risk mothers and normal infants
- No sickle specific elements to guide parent and family education
TRANSITION

WHO, TO WHERE, WHEN, and HOW?
WHO NEEDS TRANSITIONING

- Individual with sickle cell disease
- Primary care givers and family
- Pediatric health care team
• To No Where!

• Lack of knowledgeable health care providers for adults
WHO REALLY CARES FOR ADULTS WITH SICKLE CELL DISEASE?

- Emergency Room Physicians
- Hospitalists
- General Internal Medicine and Family Medicine Physicians
- Oncologists/Hematologists
SUPPORT A SYSTEM OF PRIMARY CARE WITH BACKUP

- Adequate funding for primary care
- Protocols for primary health maintenance developed for and with generalists and physician extenders
- Protocols for and with Emergency Room Physicians
- Protocols for and with Hospitalists
- Support for Centers of excellence that know the disease and the patients
SERGG INITIATIVE IN PRIMARY CARE BACKUP

• Develop protocols with the two HRSA funded projects in our region
• Focus on protocols for pain management
• Develop protocols for home management, emergency rooms, and inpatients
• Assessment tools for management and outcomes assessment
WHEN

Eckman

- Starts early
  - Transition truly must begin at birth
- Based on developmental stages not age
- Never transfer, especially with crisis
- Formal celebration of the event near natural transitions
The family, young adult, and provider have a future orientation.

Transition is started early.

Family members and health care providers foster personal and medical independence.

Planning occurs for all future material needs.

The youth verbalizes the desire to function in the adult medical world.

Reimbursement for services is not interrupted and comparable.

If pediatric providers continue care, it is shifted to adult care systems.

Individuals are able to continue to receive services from the same health system.
TRANSITIONS IN PARALLEL UNIVERSES  

- Transition clinics for affected individuals – Pilot New Models
- Parallel educational activities for family and care providers
- Pre- and post- clinic meetings of the providers of pediatric and adult medical care
ASSESSMENT OF OUTCOME

- Database established by newborns screening results & annual update
- Similar networks of outreach clinics in Alabama, Georgia, and North Carolina
- Include two HSRA Sickle demonstration projects
- Explore NIH C-data or CDC hemophilia clinical database as models
THANK YOU!!
WWW.SCINFO.ORG