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Beginning the Dialogue:
The Importance of Partnering.
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Today's Overview
Why: Prepare for transition
What: Transition? Meaning?
Who: Youth/Family/Medical & Behavioral Health Professionals
When: Transition from the Children's system to the Adult system
How: Policy & Implementation
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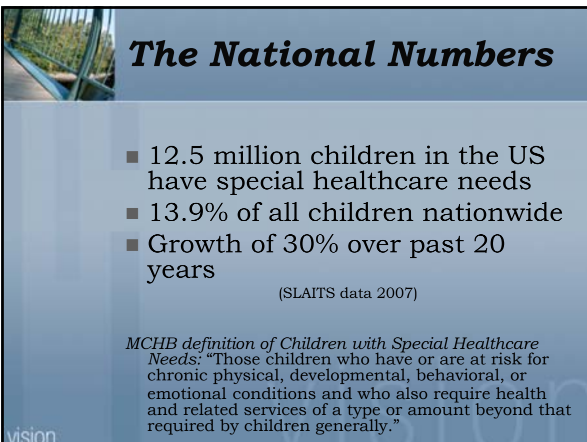
The National Numbers
12.5 million children in the US have special healthcare needs
13.9% of all children nationwide
Growth of 30% over past 20 years
(SLAITS data 2007)
MCHB definition of Children with Special Healthcare Needs: "Those children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."
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Arizona's Numbers

- OCSHN
  - **201,608** children/youth with special needs in AZ (age 0-17)
  - **12.5%** of all AZ's children
  - **13%** of these families have income levels 200%-399% below federal poverty level
  - **13%** of these families have income levels 400% or more below federal poverty level
  - **11.3%** of families spent 11 hours or more per week providing or coordinating their child's care
  - **20.2%** of families faced financial problems due to youth's condition
  - **23.1%** of families either had to reduce work hours or stop working due to their youth's condition

(SLAITS data 2007)

- DBHS
  - **38,442** children enrolled
  - **25%** of Latinos living in poverty
  - **25%** of the population is Latino
  - **6,329,482** population of Arizona
    - **1,732,204** Under the age of 20

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What does transition mean?

- Deliberate guidance with a formalized plan
- Inclusive of both the youth and their parent
- Holistic in nature and emphasizes both medical and non-medical aspects of a youth's life
- For the youth, the family, and the clinic and medical staff?

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Transition questions

When does it begin?

Who is involved?

How is it guided?

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Children's system to Adult System

Transition dialogue: What needs to occur?

- Financial
- Transportation
- Medical
- Housing
- Educational & Vocational
- Social
- The What ifs*

Financial Transition

- Is the youth aware of which health care benefits end at age 18 and age 21?
- Does the youth and family have a plan for continued dental, vision and health care coverage?
- Does the parent need to consult with their employer for continued health care coverage for youth (dependent disabled adult status)?
- Has the youth and family applied for Social Security benefits at age 18?
- Has the parent established a special needs will or trust to cover the youth's future medical care?
- Will the youth need a public fiduciary to handle his finances?

Transportation Transition

- Does the youth want to be independently mobile in their community?
- Does he have access to the community services/supports needed to increase/improve community participation (i.e. public transportation, adaptive vehicles, other specialized transportation services)?
- In what areas will the youth need assistance with transportation (i.e. shopping, school, medical appointments, etc)?

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Medical Transition I

- What is the youth's understanding of his/her medical condition?
- Can the youth take independent responsibility for medications, understand the reasons for them and know how to refill them?
- Can the youth identify signs/symptoms of his medical condition and the need for medical attention?
- How familiar is the youth with his medical supplies and how to obtain repairs and additional supplies?
- Can the youth communicate directly with his healthcare providers by scheduling his own appointments?
- Can the youth consent to his own medical care if over age 18?

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Medical Transition II

- What are the long-term plans to prepare for adult medical care?
- Has the youth and family identified any adult providers?
- Does the youth have a portable medical summary for the new adult provider?
- Is a formal plan being developed that would address these questions?
- Does the plan include specific goals and objectives?
- Does the youth and family receive a copy of this plan?

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Housing Transition

- Who will the youth live with and what living arrangements are being considered (i.e. independent, with a friend, in a dormitory on a college campus, in a group home, at home with his family or other family members, in a specialized care facility)?
- What supports will be needed for any of these living arrangements to be successful for both the youth and the parents?

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Educational & Vocational Transition I

- Has the IEP team begun to discuss transition out of the school environment?
- Have transition goals been added to the IEP or 504 Plan?
- What assistive technology is needed to make transition successful?
- If the youth plans to attend post-secondary education, have their options been discussed? (4-year college, community college, or vocational training program)
- What services are available on the college campus to assist a person with disabilities?

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Educational & Vocational Transition II

- Has the IEP team begun to discuss plans for employment and what setting would be most appropriate for the youth (i.e. independent, supported, or sheltered employment)?
- If the youth plans to work after high school, has he identified a career of interest and how will the IEP goals support pursuit of this career?
- If the youth does not plan to work or pursue employment, has the family identified alternative settings such as a day treatment or habilitative program?

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Social and Recreational Issues

- Has the youth identified specific recreational or social activities of interest?
- What supports are needed to assist the youth in participating in these activities?

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The What If's?

- Is legal guardianship needed and does the parent know when and how to complete the process?
- Is a medical power of attorney needed?
- Who will take responsibility for the youth's medical condition if the parent dies or becomes incapacitated? Has this person been identified in legal documents?

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Special Health Care Needs Case Example

- 14 year-old female with spina bifida and shunt
- Uses manual wheelchair as sole source of mobility
- Caths 4 times/day
- Not affected cognitively by diagnosis
- Lives with both parents and one younger sibling

WHAT WILL TRANSITION LOOK LIKE FOR THIS YOUTH?

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Special Health Care Needs Case Example

- 17 ½ year-old male with spastic quadriplegia, epilepsy, severe cognitive disability
- Requires total care (feeding, bathing, dressing, decision-making)
- Lives with single mother and 3 younger siblings

WHAT WILL TRANSITION LOOK LIKE FOR THIS YOUTH?

Behavioral Health Example

- 17 year-old with co-occurring substance abuse and recently diagnosed with schizophrenia
- Placed on "JIPs" (Juvenile Intensive Probation) until 18th birthday
- Removed from home and placed with relatives
- Has a CFT (Child and Family Team) in place
- Attending alternative high school

WHAT WILL TRANSITION LOOK LIKE FOR THIS YOUTH?

Principles of Youth & Family-Centered Care

- Recognize the family is the constant in the youth's life. Health care providers may change over time
- Facilitate youth/family and professional collaboration at all levels in health care
- Honor the diversity of youth and their families
- Recognize youth/family strengths
- Share complete and unbiased information
- Promote youth-to-youth and family-to-family support and networking
- Implement comprehensive policies and programs
- Design accessible health care systems that are flexible, culturally competent, and responsive to youth/family needs

~The 12 Principles~ Providing a Guide through the Children's System of Care

- 1.Collaboration with the Child and Family
- 2. Functional Outcomes
- 3. Collaboration with others
- 4. Accessible Services
- 5. Best Practices
- 6. Most Appropriate Setting
- 7. Timeliness
- 8. Services tailored to the Child & Family
- 9. Stability
- 10. Respect for the Child and Family's Unique Cultural Heritage
- 11. Independence
- 12. Connections to Natural Supports

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Partnering in practical Terms

- Family centered care means really listening
- Validating and acknowledging
- Being proactive
- Using people first language
- Involving other team members
- Going above and beyond
- Partnership

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Youth & Family Partnership

- Youth Voice
- Family Voice
- Impact of Culture
  - Different views of independence
  - Role of family after 18
- Reassuring family of their role after young adult turns 18

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What are we doing now

- OCSHCN
- DBHS
- Protocols
- Training
- National Conferences
- Statewide Transition
- System of Care Plans

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Many Thanks for your attendance today

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