Supporting Foster/Kinship/Adoptive Families and Children with Medically Fragile Health

Child Abuse Prevention Conference
July 18, 2014
Objectives

- Discuss foster/kinship/adoptive families
- Define children with medically fragile health
- Discuss unmet needs
- Capacity building
Children with Medically Fragile Health

• **Person First Language**
  – Brings the person to the forefront, not a case or a condition- a child.
  – Brings to mind other roles the child has: grandchild, sibling, cousin, play-mate, neighbor.

• **Medically Fragile Health**
  – A physical condition which may become unstable and change abruptly, resulting in a life-threatening situation.
Foster/Kinship/Adoptive Families

PreService Model Approach to Partnerships in Parenting (MAPP) training
  o Co-Parenting
  o Goal is reunification

Medically Fragile training

Additional training for therapeutic, leadership, etc. roles for families
Similar Experiences

- New Diagnosis
- A new routine or rhythm of life
- School/Childcare
- Parents and work
- Emergency department visits
Building Capacity

• Keep an open mind
• Encourage a sense of humor
  – Life can be tough, humor helps us manage
  – Finding fun in everyday challenges
• Look forward to learning new things
• Identify caregiver supports
Hospital to Home

• Name and contact information of person who can answer questions prior to first Primary Care Provider (PCP)/specialist visit.

• Plan for continuity of care after a hospital stay
  – Insurance: CMDP, what else is available
  – Elevated level of care coordination from insurance provider and PCP
  – Home Health in place before leaving hospital
  – 26.4%*

*National Survey for Children with Special Health Care Needs, 2009-10
Continuity of Care

• Identify PCP, Specialists, Labs, Radiology, Nutrition, Therapists, etc. in insurance plan

• Health Plan Member Handbook
  • Member Services
  • Benefits, what is covered
  • How to appeal a denial, what are patient’s rights
  • When is a prior authorization needed, referral or letter of medical necessity
Continuity of Care

- Define what “well” looks like for this child.
- Define the first signs of becoming unwell
  - Plan for that possibility
  - Describe steps, interventions
  - Care notebooks
  - In the ED
Ask for Instructions

• Using equipment
• Bathing
• Hospital Routine
• Medications
• Feeding
• Dietary Restrictions
Usual Childhood Health

• Colds, flu, stomach upset
  – How do these common illnesses affect this child’s underlying condition
  – minimizing contagion
  – mitigate effects

• Immunizations
  – Some health conditions preclude or postpone immunizations; talk with child’s pediatrician
Physical Abilities

• Everyone needs to move!!!!!
  – Repositioning
  – Time off
  – Movement/Physical Activity
Advocacy

This is one of a parent’s most important roles - until the child is able to advocate for him/herself a parent must speak up in their best interest

Parents and Healthcare providers working in partnership leads to

Shared decision making

and ultimately,

what’s best for the child
Advocacy

Parents become experts on their child

• Self-determination

Education

• Early Intervention
• Child Find
• Individualized Education Program (IEP)
• 504 Plan
• Individualized Healthcare Plans
Providers in the Home are Considered as Guests

• Honor family routine
• Include siblings in fun stuff
• Homework, PT, OT, etc
• Life happens....just because the family didn’t complete “homework” doesn’t mean they aren’t good parents
Medical Home

An approach to providing comprehensive primary care, that is:

• Accessible
• Continuous
• Family-Centered
• Coordinated
• Compassionate
• and Culturally Competent
Medical Home and Family-Centered Care

• Recognizing family as the constant in the child’s life.
• Including families in team discussion, decisions, plans and evaluation of treatment.
• Respecting the family’s expertise and culture.
Programs for Children with Special Health Care Needs (CSHCN)

**Arizona Early Intervention Program**
- Children birth to age three;
- Who do not meet at least half of their developmental milestones;
- AHCCCS eligible receive all services at no cost to the family.
- Others families will pay a percentage of the state cost of most services
  - this may change soon.
- Team-based model
Programs for CSHCN

Arizona Long Term Care System (ALTCS)

• For individuals of any age who require health related care at a level similar to that of a nursing facility.

• Medicaid waiver – individual income, not family income is considered for eligibility.

• Apply at any DES/ALTCS office.
Programs for CSHCN

Children’s Rehabilitative Services

• For children ages birth – 21 (new option)
• U S citizen or legal resident
• Has been diagnosed with a qualifying condition
• AHCCCS enrolled; carve-out
Programs for CSHCN

Department of Developmental Disabilities (DDD)

• Eligible diagnoses
  – Cognitive Disability, Autism, Epilepsy, Cerebral Palsy

• AHCCCS eligible to receive all services.

• Others may receive service coordination and referral to community resources only.
Programs for CSHCN

Supplemental Security Income (SSI)

Individuals of any age who are disabled, including children, may receive monthly cash benefits and in Arizona may be eligible for AHCCCS health care.

- Meet federal definition of permanently disabled, live in a household with little or no income.
- Have never been gainfully employed
Grief and Loss

• Parents
  – Loss of the child they imagined
  – In foster-care
    actual loss of custody of child
  – Self-blame; what I did or didn’t do
  – Having to break “bad” news over and over again
  – Cultural perspectives
Grief and Loss

• Children
  – Separation from Parent
  – Separation from sibs, home, friends, school
  – Guilt, responsibility
  – Being different, “wrong,” no control

• Parents
  – Separation from Child
  – Failure
Resources

• Arizona Early Intervention Program (AzEIP)
• Arizona Health Care Cost Containment System (AHCCCS)
  – http://www.azahcccs.gov/
• Arizona Long Term Care System (ALTCS)
• Care Notebooks
  – http://www.medicalhomeinfo.org/for_families/care_notebook/
• Children’s Rehabilitative Services (CRS)
• Comprehensive Medical and Dental Program (CMDP)
  – https://www.azdes.gov/cmdp/
Resources

• Department of Developmental Disabilities (DDD)
  – https://www.azdes.gov/developmental_disabilities/

• Hospice of the Valley, grief support, Phoenix metro area
  – http://www.hov.org/grief-support

• Living With Serious Illness, Pima County

• Office for Children with Special Health Care Needs

• Raising Special Kids
  – http://www.raisingspecialkids.org

• Tribal/Regional Behavioral Health Authorities (T/RBHA)
  – http://www.azdhs.gov/bhs
Questions?

Thank You!