Blazing the Trail of Reform for Children and Youth with Special Health Care Needs

Objectives

• Why care coordination (CC) for Children and Youth who have Special Health Care Needs is Family Centered Care
  – for children and families
  – for professionals
  – for health care systems

• Describe a Family Perspective

• Detail lessons from CC implementation in Indiana

• Opportunities to Impact & Access Care Coordination via Policy
Family Centered Care

“Family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children, with children gradually taking on more and more of this decision-making themselves.”

Information Sharing
Care in Context of Family and Community
Respect and Honoring Differences
Partnership and Collaboration
Negotiation

AAP Policy Statement

Fragmentation

Physician Team
- Primary care
- Neurology
- Metabolic
- Pulmonology
- Cardiology
- Neurology
- ENT
- Podiatry
- Gastroenterology
- Rheumatology
- Dental
- Orthodontics
- Vision

Life
- School
- OT
- PT
- Teacher of Record
- Teacher of Services
- Gifted and Talented Coordinator
- Outpatient
- OT
- PT
- Durable Medical
- Oxygen
- Wheelchair
- Assistive Technology
- Home Healthcare

Health Care Financing
- Employer Sponsored
- Private Insurance
- Health Savings Account
- Medicaid Disability
- Medicaid Waivers
- Out of Pocket Expenses

Children with Special Needs Whose Families Spend 11 Hours or More a Week on the Child’s Health Care

Mom
- Full-time Job
- 50 min commute
- NFP Board Director

Dad
- Senior in High School
- 50 minutes from MD
- Extracurriculars
- 4 H
- Part time Job

Daughter
- Sophomore in High School
- 50 minutes from MD
- Weekly 4-hour infusion
- Extracurriculars
- 4 H

Son
- Full-time Job
- 30 min commute
- Part time job
- 15 min commute
- NFP Board Director
Why Care Coordination

This is the Moment

Indiana efforts
How Care Coordination

- Team Based
  - Family, clinician, care coordinator
- Shared Plan of Care
  - Medical Summary
  - Negotiated Goals
- Time

It's all a work in progress.

Don't let the perfect be the enemy of the good.

One step forward, two steps back.

I'm just trying to achieve the impossible.
Themes of Family Goals

- Safety
- Treatment
- Skill building
- Adequate coverage
- Treatment
- Transportation
- Medicaid transportation
- Translation
- Diapers
- Diagnostic clarity
- Medical needs
- Who helps with what?

Have fun together as family
Get past road blocks
Untapped
Coordination

Where Care Coordination

- Not separate from care
- Able to talk to all providers
- Able to communicate with family

Primary Care
Tertiary Care
Specialty Care
Make it Real

1. Don’t pay for Fragmentation
2. Same definition in ALL Policy
3. Invest in team-based Coordination
4. Hire, Train and Develop Care Coordination Skills

Care Coordination is a patient & family-centered, assessment driven, continuous, team-based activity designed to: meet the bio-psychosocial needs of children and youth, while enhancing person & family caregiving skills and capabilities.