

# Resources for Children with Special Health Care Needs



# What Kind of Services Are Needed?

## 3 Groups of Children with Special Health Care Needs:

- Children with developmental delays or disabilities, such as learning disabilities, sensory impairment, and mental retardation
- Children with ongoing medical disorders, such as diabetes, asthma, chronic renal disease, CF, congenital heart disease
- Children with emotional or behavioral problems such as ADHD and psychiatric disorders

# Resources for Medical Care for Children with Complex Medical Needs

## *First Resource*

### Primary Care Provider

- Preventive care(WCC)
- Developmental evaluation
- Anticipatory Guidance
- Coordination of Services
- Referral to subspecialist  
when needed



# Pediatric Subspecialists

Definition: A subspecialist is a medical doctor who has had at least 4 years of medical school; Three years of pediatric training in an approved residency program; Two or three years of training in area of specialty



## Subspecialty Services cont...

### Principles:

- Children are not just small adults. They cannot always say what is bothering them. Sometimes they can't answer medical questions. They are not always able to be patient and cooperative.
- Choose your subspecialist with care.
- Subspecialists usually provide care in conjunction with other subspecialists—interdisciplinary approach
- For detailed information about Pediatric Subspecialty Services, go to [www.AmericanAcademyofPediatrics](http://www.AmericanAcademyofPediatrics) and search with: What is a Pediatric Subspecialist?

# Genetics Services

- Some children are born with differences in body structure, brain development, or body chemistry that can lead to problems with health, development, school performance, and/or social interaction.
- Pediatric Geneticists are trained to identify the causes and natural history of these disorders.

## Genetic Services cont.

Diagnosis, counseling, and treatment for families with:

- Birth defects (physical differences present at birth causing a health problem)
- Conditions with one or more birth defects (Down syndrome, achondroplasia) to find the right diagnosis along with expertise in dealing with children and treating children's genetic conditions.
- Conditions that can cause disabilities (fetal alcohol syndrome, or fragile X syndrome)
- Inborn errors of metabolism (cystic fibrosis, PKU)
- Familial or hereditary problems (congenital heart dis.)
- Short or tall stature (height below/above normal)

# Montana's Medical Resources for Children with Special Health Care Needs

- Better than you may think—  
Regional clinic sites
- Good availability of specialty providers:
  - Cardiology
  - Craniofacial
  - Developmental Pediatrics
  - Endocrinology
  - Genetics
  - Gastrointestinal
  - Hematology



## Subspecialty providers cont...

- Metabolic
- Neonatology
- Nephrology
- Neurology
- Ophthalmology
- Pediatric Neurosurgery
- Pediatric Surgery
- Plastic Surgery
- Psychiatry
- Pulmonology
- Rheumatology
- Urology

# Additional Resources

Part C (Early Intervention)  
PLUK  
Physical Therapy  
Occupational Therapy  
Speech Pathology  
Public Health Nursing/Public  
Health Departments  
School Counselors and  
Psychologists



## Additional Resources cont....

- Pharmaceutical Parent/child Programs
- Community Health Centers
- Disease specific organizations, i.e., Cystic Fibrosis Foundations
- NORD-National organization of rare disorders

What have you found in your  
community?



# Making it Work Together

The child with special health care needs primary resource—the parent

