Identifying Resources For Children/Youth and Families

Appreciating the big picture, making a unique journey

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Learning Objectives

- Be familiar with the broad range of options and resources
- Identify individual child/youth and family priorities
- Know how to identify resources to match unique needs and goals

Defining CYSHCN

- Children/Youth 0 - 21 years of age with a long term, chronic illness or condition that is:
  - Physical
  - Developmental
  - Behavioral
  - Emotional

Navigating Options and Making Decisions

- Range of options and resources
- Identify unique needs
- Match options to needs
- Formal and informal supports

Appreciating the Big Picture

Making a Unique Journey
Supporting the Family

- Where to go with questions
  - Wisconsin First Step
  - Regional Centers for CYSHCN (0-21 yrs)
  - Aging & Disability Resource Centers (18+ yrs)
- Service coordinators and teams
- Family to family supports
- Natural supports

Wisconsin Regional Centers

Examples of Family Supports

- Respite
- Learning/Training
- Childcare
- Legal assistance
- Summer Camps
- Sibshops
- Family/Friends/Neighbors

Learning/Training Opportunities

- Statewide conferences
- Disability specific organizations
- Online learning modules
- Statewide Trainings
- Leadership Trainings (parents/youth)
- Professional Organizations

Family to Family Resources

- Non profit / Not-for-profit
- Staffed by family members
- Each with a specific focus including:
  - Working with schools
  - Mental health supports
  - Public policy advocacy
Caring for Health

- Developmental screening
- Diagnostic assessment
- Medications
- Ongoing basic health care
- Specialty care
- Transition to adult health care

Partnering with Doctors

Medical Home

- Family-centered
- Accessible
- Coordinated
- Comprehensive
- Partnership

Getting an Education

- Early intervention—Birth to 3 program
  - Ages Birth to 3 years
- Special Education
  - Individualized Education Program (IEP)
    - Ages 3-21 years
  - Transition to adulthood
    - Starting at age 14 years

Early Intervention

- Federally-mandated program
- Service coordination and services
- Individualized Family Service Plan (IFSP)
Early Intervention

- Eligibility criteria
  - At least 25% delay in one area of development, or atypical development
  - Diagnosis with high probability of resulting in developmental delays

Special Education

- Specially designed instruction
- Related to learning
- Coordination between educationally and medically necessary services
- Individualized Education Program (IEP)

Transition Planning

- Start early!
- IEP transition plan at age 14
- Programming possible up to age 21
- Preparing for post-high school life
- Transition to the adult services

Supporting Development

- No cookie cutter
- Which interventions and supports can help with your child's unique needs?
- Range of evidence-based interventions
- Match options to needs

Examples of Interventions and Supports

- Community-based SLP, OT, PT
- Equipment / Supplies
- Social groups
- Medications
- Communication aids and systems
Examples of Interventions and Supports

- Play groups
- Clubs/Sports at school
- YMCA
- Faith-based community
- 4-H
- Friends/Neighbors

Paying for What You Need

- Private health insurance
- Wisconsin Medicaid
  - Katie Beckett
  - Supplemental Security Income (SSI)
  - Children’s Long-Term Support (CLTS) Waivers

Paying for What You Need

- Family Support Program
- Informal options
  - Grants/ scholarships
  - Civic organizations
  - Lending closets

When You Have Questions or Need Some Help . . .

Wisconsin Regional Centers
Children and Youth with Special Health Care Needs