

Identifying Resources For Children/Youth and Families

Appreciating the big picture, making a unique journey



Kristin Aasen-Gowan, MSSW
Resource Specialist
Southern Regional Center for CYSHCN,
Waisman Center

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



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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

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Wisconsin Regional Centers


Children and Youth with Special Health Care Needs



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Examples of Family Supports

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



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Learning/Training Opportunities

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


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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

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Caring for Health



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Partnering with Doctors

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

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Medical Home

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



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Getting an Education



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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



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Early Intervention

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

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Early Intervention

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

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Special Education

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

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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



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Supporting Development





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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

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Examples of Interventions and Supports

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

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Examples of Interventions and Supports

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



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Paying for What You Need



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Paying for What You Need


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



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Paying for What You Need

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



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When You Have Questions or Need Some Help. . .



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Wisconsin Regional Centers

Children and Youth with Special Health Care Needs




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Ask a Question

 **Viewing online?**

- o Click on the chat icon above
- o Question emailed to Training Team
- o Questions answered by expert on topic
 - o Response within 2-3 weeks


 **Viewing at a live training?**


- o Organizer shares questions with Training Team

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 Children and Youth with
Special Health Care Needs

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