WI Children & Youth with Special Health Care Needs: Supporting Families & Providers Who Support Them

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June 2, 2021
Guiding Principles

- Children are best served within their families.
- Children, youth, and families are best supported within the context of their community.
- Families will have convenient access to care planning.
- Collaboration is the best way to provide comprehensive services.
- Family perspective and presence must be included in all aspects of the system.
Wisconsin uses the federal definition as:

"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."
Wisconsin Title V Children and Youth with Special Health Care Needs Program
Five Regional Centers

Northern Region
866-640-4106

Northeast Region
877-568-5205

Western Region
800-400-3678

Southern Region
800-532-3321

Southeast Region
800-234-KIDS (5437)
Themes from Regional Centers

• “Our work is diving in, being with, walking along the side of parents.”

• “We spend as much time as needed, as often as needed and as long as needed.”

• Families tell us:
  - You listened.
  - You helped me with what I thought was important.
  - You helped me find my next step.
Why Families Call

- Access to Information
- Health Benefits Questions
- Care Coordination Needs
- Education Related Concerns
- Parent Support
- Family and Youth Leadership
- Transportation
- Help with Transition and Medical Home
WI Youth Health Transition

• Health care transition is the process of changing from a pediatric to an adult model of health care

• Supports youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without a disruption in care.

• Six Core Elements

• healthtransitionwi.org
A medical home is a trusting partnership between your child, and your pediatric primary health care team.

Key components:
- Care Coordination
- Shared Plan of Care
- Care Mapping

wismhi.org
• Statewide non-profit focused on supporting the voice of families in decision-making, leadership, and systems change roles.
• Provides information, training, and support around health care and community services.
• [familyvoicesofwisconsin.com](http://familyvoicesofwisconsin.com)
• Fact Sheets
• Advocacy for Change
• Provides parent support to parents of children with special needs.
• One-to-one connection with another parent who knows firsthand about the feelings and realities that come with having a child with special needs.
• Support Parent Training
• 715-361-2934 / 888-266-0028
• Get-Connected@p2pwi.org
• p2pwi.org
• Nonprofit public-interest law firm
• Dedicated to ensuring health care access for children and families, particularly those with special needs or who are at risk.
• Provides information, advocacy tools, legal services, and expert support.
• 608-261-6939 / 800-585-4222
• safetyweb.org
• Statewide Information and Referral hotline
• Serves families with children who have special health care needs and professionals.
• A health and human services database of disability-related resources has been developed and is regularly updated.
• 1-800-642-7837
• https://wellbadger.org/
Training Opportunities
Youth Health Transition

- Build Your Bridge; Moving From Child to Adult Health Care
- Dreaming Differently
- Bridging the Gap
- Closing the Gap
- What’s After High School?

Contact your CYSHCN Regional Center
Training Opportunities
Medical Home

• Did You Know? Now You Know!
• C.A.R.E. Medical Home Series for Families
  o Caring for the Whole Family
  o Assembling a Care Notebook
  o Requesting a Shared Plan of Care
  o Exploring Care Mapping
• Medicaid Made Easy

Contact your CYSHCN Regional Center
Acknowledgement

Funded in part by the MCH Title V Services Block Grant, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services.
Children and Youth with Special Health Care Needs

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