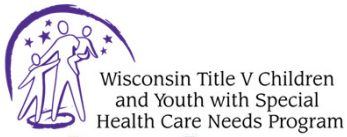
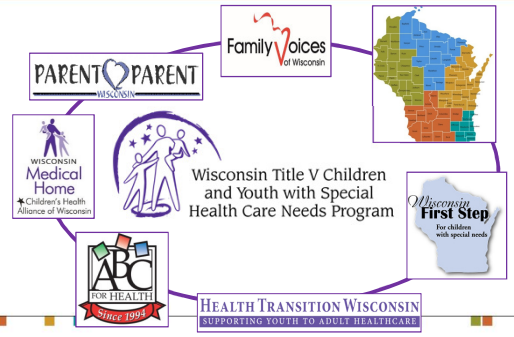
Children and Youth with Special Health Care Needs

Circles of Life 2017
Becky Burns
CYSHCN Statewide Coordinator



Our Primary Network

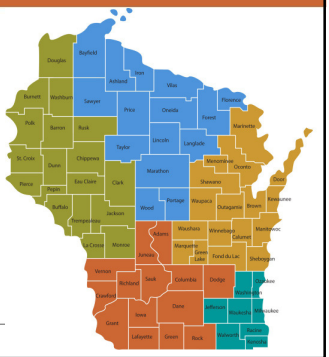


Who do we serve?

- 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."
- Children with <u>and without</u> Special Health Care Needs

Regional Centers

- Northern
- Northeast
- Southern
- Southeast
- Western



Wisconsin Regional Centers
Children and Youth with
Special Health Care Needs

Who do we serve?

Over 200,000 (or >15%) of Wisconsin children have a special health care need, of which:

- Over 1 in 6 children missed 11 or more days of school due to illness.
- Over 1 in 9 families reports spending 11 or more hours each week providing or coordinating their child's care.
- Over one third of families currently insured report their insurance is inadequate.
- Over 1 in 4 families reports spending $1,000 or more each year for out of pocket medical expenses.

- Source: Child and Adolescent Health Measurement Initiative. **2009/2010** National Survey of Children with Special Health Needs, Data Resource Center for Child and Adolescent Health website.

Themes from our 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."
- Parents say:
  - You listened
  - You helped me with what I thought was important
  - You helped me find my next step

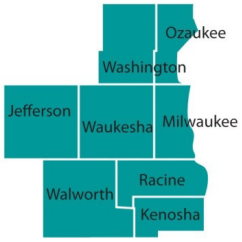
Northern

- Located in Wausau, WI
- 715-261-1906
- 866-640-4106
- Director: Julia Stavran
- julia.stavran@co.marathon.wi.us

northernregionalcenter.org

Southeastern

- Located at the Children's Hospital of WI in Milwaukee, WI
- 414-266-6333
- 800-234-KIDS (5437)
- Director: Katie Cavanaugh
- serc@chw.org



southeastregionalcenter.org

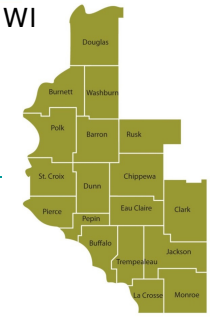
Northeastern

- Located in Neenah, WI
- 920-969-5325
- 877-568-5205
- Director: Tracey Ratzburg
- infonerc@chw.org

northeastregionalcenter.org

Western

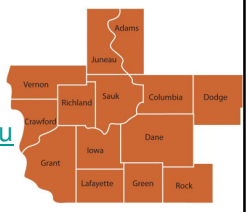
- Located in Chippewa Falls, WI
- 715-726-7907
- 800-400-3678
- Director: Dawn Stark
- cyshcn@co.chippewa.wi.us



co.chippewa.wi.us/CYSHCN

Southern

- Located at the Waisman Center in Madison, WI
- 608-265-8610
- 800-532-3321
- Director: Tim Markle
- cyshcn@waisman.wisc.edu



waisman.wisc.edu/cshcn

Why Families Call the Regional Center

- 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 Medical Home Initiative

- 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

WISCONSIN Medical Home
Children's Health Alliance of Wisconsin

wismhi.org

Parent 2 Parent of Wisconsin

...making connections statewide

- 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

Youth Health Transition Initiative

- 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

HEALTH TRANSITION WISCONSIN
SUPPORTING YOUTH TO ADULT HEALTHCARE

ABC for Health

Since 1994

- 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

Family Voices of Wisconsin

- 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

Wisconsin First Step

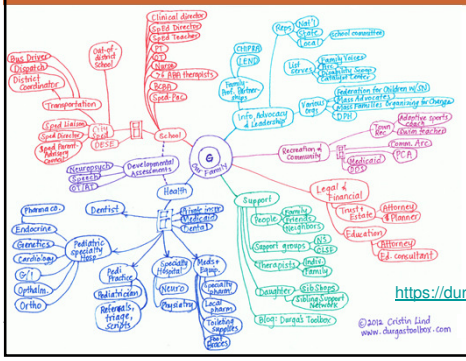
For children with special needs

- 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
- mch-hotlines.org/wisconsin-first-step

What is our Mission?

To assure that children and youth with special health care needs are identified early, receive coordinated care and that their families have access to the supports they need.

Care Mapping

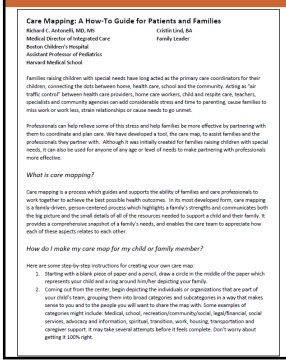


https://durgastoolbox.com

CYSHCN 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.

Next Steps



Care Mapping: A How-To Guide for Patients and Families

Richard C. Antonelli, MD, MS
Medical Director of Integrated Care
Boston Children's Hospital
Assistant Professor of Pediatrics
Harvard Medical School

Cristin Lind, RA
Family Leader

Families raising children with special needs have long acted as the primary care coordinators for their children, connecting the dots between home, health care, school and the community. Acting as "air traffic control" between health care providers, home care workers, child and respite care, teachers, specialists and community agencies can add considerable stress and time to parenting, cause families to miss work or work less, strain relationships or cause needs to go unmet.

Professionals can help relieve some of this stress and help families be more effective by partnering with them to coordinate and plan care. We have developed a tool, the care map, to assist families and the professionals they partner with. Although it was initially created for families raising children with special needs, it can also be used for anyone of any age or level of needs to make partnering with professionals more effective.

What is care mapping?

Care mapping is a process which guides and supports the ability of families and care professionals to work together to achieve the best possible health outcomes. In its most developed form, care mapping is a family-driven, person-centered process which highlights a family's strengths and communicates both the big picture and the small details of all of the resources needed to support a child and their family. It provides a comprehensive snapshot of a family's needs, and enables the care team to appreciate how each of these aspects relates to each other.

How do I make my care map for my child or family member?

Here are some step-by-step instructions for creating your own care map:

1. Starting with a blank piece of paper and a pencil, draw a circle in the middle of the paper which represents your child and a ring around him/her depicting your family.
2. Coming out from the center, begin depicting the individuals or organizations that are part of your child's team, grouping them into broad categories and subcategories in a way that makes sense to you and to the people you will want to share the map with. Some examples of categories might include: Medical, school, recreation/community/social, legal/financial, social services, advocacy and information, spiritual, transition, work, housing, transportation and caregiver support. It may take several attempts before it feels complete. Don't worry about getting it 100% right.

- Blank piece of paper
- Pencil or a pen
- Start in the center
- Brainstorm

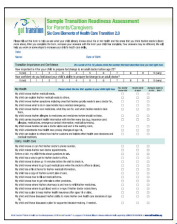
Medical Home

- Care Mapping
- A process which guides and supports the ability of families and care professionals to work together to achieve the best possible health outcomes.
- It provides a comprehensive snapshot of a family's needs, and enables the care team to appreciate how each of these aspects relates to each other.

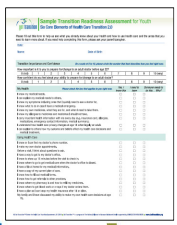
Youth Health Transition

Transition Readiness Assessments

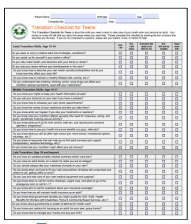
For Parents



For Teens



Teens' Checklist



Training Opportunities

- Build Your Bridge; Moving From Child to Adult Health Care
- Partnering with Your Child's Doctor
- Did You Know? Now You Know!
- What's After High School?

- Contact your local CYSHCN Regional Center

Acknowledgement

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