Promoting Family Understanding of Care Coordination

2019 QI Projects Summit
Presenter: Brigit Frank

Each family has a voice • Together, our voices will be heard
familyvoiceswi.org
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Family Voices of Wisconsin

We’re a network of families who have children and youth with disabilities and/or special health care needs. Our work focuses on health care and community supports, education and information.

Newsletters

Trainings

Fact Sheets

Listserv
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Overview of this Session

- Wisconsin Data
- Available Tools
- Including Families in the Care Team through Advocacy
- Lessons Learned in Pilot Program
- Final Thoughts and Questions
• 91.5% of Wisconsin children were in excellent or very good health

• Wisconsin ranked 14th overall based on 30 measures of physical and social determinants of health

• Wisconsin ranked 12th overall for child well being
• Children in minority populations and those with special health care needs are at higher risk of not having a medical home

• Wisconsin ranks 44th in adequate health insurance for children, 39th in well-baby checks, and 50th in excessive drinking among women ages 18-44

• Black/white infant mortality ratio of 3.0 is one of the largest disparities in the nation
## Care Coordination: Why do we want it for Wisconsin Children?

<table>
<thead>
<tr>
<th>Measure</th>
<th>Wisconsin %</th>
<th>Nation %</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN with 11 or more days of school absences due to illness:</td>
<td>16.5</td>
<td>15.5</td>
</tr>
<tr>
<td>CSHCN with any unmet need for specific health care services:</td>
<td>24.5</td>
<td>23.6</td>
</tr>
<tr>
<td>CSHCN with any unmet need for family support services</td>
<td>8.0</td>
<td>7.2</td>
</tr>
<tr>
<td>CSHCN without a usual source of care when sick (or who rely on the emergency room):</td>
<td>11.2</td>
<td>9.5</td>
</tr>
<tr>
<td>CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child:</td>
<td>24.4</td>
<td>22.1</td>
</tr>
<tr>
<td>CSHCN whose families spend 11 or more hours per week providing or coordinating child’s health care:</td>
<td>11.0</td>
<td>13.1</td>
</tr>
</tbody>
</table>
Why Build this Home?

Families that have a Medical Home have:

• Children who get a higher quality care overall
• Greater access to community services
• Understanding of how to navigate the medical system
• Improved self-advocacy skills
• The opportunity to connect with other families
• Knowledge to maintain health and living

This content has been adapted from:
Comprehensive Care Coordination in a Medical Home Leads to:

- Greater access to community services
- Improved skills for self-advocacy
- Opportunity to connect with other families
- Knowledge to maintain health and living
- Greater capacity to navigate the system

This content has been adapted from:
Using Tools to Engage Families
We Have the Tools to Engage Families

Coordinating Your Child’s Healthcare

- 40-minute online training
- On the Family Voices of Wisconsin website, familyvoiceswi.org
- Spanish language available
  - Old version
  - Written materials will be translated soon
  - Contact Family Voices for Spanish language materials
Our Team
The Need for a Care Notebook

- Definitions
- Care Mapping Directions and Template
- Start Building a Medical Home Materials
- Creating a Shared Plan of Care Directions and Example
- Wisconsin Resources for CYSHCN
- Health Care Provider Contact Information Form
- FDA’s My Medicine Record
- Insurance Company Contact Information Form
- Medical Equipment Supply Information Form
- Agencies to Support my Family Form
- Family Voices of Wisconsin Fact Sheets
- A Navigation Guide for Families who have CYSHCN and Disabilities
Facilitators’ Guide

- Training Overview Preparedness
- Tips for Facilitators—Before, During and After
- Discussion Questions
- Training Flyer
- Potential Community Partners for Outreach
- Evaluation Form
- Materials Needed Check List
- Training Sign-In Sheet
Mental Health and Behavioral Health Services for My Child

Treatment and Program Options for My Child

What Treatment Programs Are Available?

There are many programs and treatment options for children and teens who struggle with mental health challenges. Parents and caregivers should work closely with their child’s primary care provider to find the best fit for a child.

Types of Mental Health Services

- Talk to your child’s teacher.
- Talk to your child’s school counselor.
- Talk to Family Support Agency coordinators.

Consulting with family support agencies may lead to the development of treatment plans. For example, clinics in your area may provide counseling services for your child. In addition, the school counselors may be able to help your child with their school work.

Two things you should know about these resources are:

- They are available for children and teens aged 0 to 26.
- They are available for children and teens who are currently enrolled in school.

In addition, the school counselors may be able to help your child with their school work.

If you have any questions about your child’s mental health needs, please contact your Local Mental Health Authority.

Mental Health Fact Sheet Series

Waiting for Services

Many families wait for services while they work through the system. Your child’s primary care provider or counselor may be able to help you find the right services for your child.

Mental Health and Behavioral Health Services for My Child

When to Get Help

If you are concerned about your child’s behavior or emotions, it is important to seek help early. When to Get Help is designed to help parents and caregivers understand when and how to seek help for their child.

What can you do to help your child when they are in need?

- Share your concerns with your child’s primary care provider.
- Talk to your child’s school counselor.
- Talk to the school principal or other staff member.

Mental Health and Behavioral Health Services for My Child

Pay for Mental Health Care

If you have health insurance through your employer, you may be able to get mental health services covered by your insurance. If you do not have health insurance, you may be able to get help from local organizations that provide mental health services.

Private Pay

If you do not have health insurance, you can pay for mental health services out of pocket. You can also see if your local government or non-profit organization provides mental health services for free or at a reduced cost.

Mental Health and Behavioral Health Services for My Child

Who can help my child?

If you are concerned about your child’s behavior or emotions, it is important to seek help early. When to Get Help is designed to help parents and caregivers understand when and how to seek help for their child.治疗和计划选项是可用的，对于儿童和青少年，这些计划可能包括医疗、心理和社交支持。

- 联系儿童的精神健康顾问或家庭支持机构，了解有关精神健康服务的信息。
- 与学校辅导员或学校管理人员讨论您的孩子。

Mental Health and Behavioral Health Services for My Child

Waiting for Services

许多家庭在等待服务时会感到焦虑，尤其是对于儿童和青少年。您可以通过与孩子的主要护理提供者或辅导员联系来寻找适合您孩子的服务。

Mental Health and Behavioral Health Services for My Child

Pay for Mental Health Care

如果您需要帮助支付精神健康服务的费用，请联系您的雇主的福利部门。

私人支付

如果您没有雇主提供的健康保险，您可能需要自己支付精神健康服务的费用。您还可以查看您所在地区的非盈利组织提供的精神健康服务。

Mental Health and Behavioral Health Services for My Child

寻求帮助的时机

如果您对孩子的行为或情绪感到担忧，重要的是尽早寻求帮助。寻求帮助的时间表旨在帮助父母和监护人了解何时何地寻求帮助。

Mental Health and Behavioral Health Services for My Child

治疗选择

这里有三种主要的治疗方式：心理治疗、药物治疗和心理咨询。

- 心理治疗，也称为“谈话疗法”，是在一个安全的环境中与一位专业的治疗师进行一对一的治疗。
- 药物治疗，是在一个安全的环境中与一位专业的治疗师进行一对一的治疗。

Mental Health and Behavioral Health Services for My Child

药物治疗

药物治疗是治疗精神健康问题的一种方式。药物可能会被用于提高患者的情绪或改善患者的认知。

- 您可以与儿童的精神健康顾问或家庭支持机构联系，了解有关服务的信息。
- 与学校辅导员或学校管理人员讨论您的孩子。

Mental Health and Behavioral Health Services for My Child

计划和治疗设置

精神健康和行为健康服务可以提供一系列的计划和治疗，包括心理治疗、药物治疗和社交支持。

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Mental Health and Behavioral Health Services for My Child

付费方

私人支付

您可以通过与您的雇主福利部门联系来了解您是否有资格获得精神健康服务的私人支付。

Mental Health and Behavioral Health Services for My Child

需要帮助的时机

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Family advocacy driving care coordination for children in a state where the concept is in its infancy.
“Hello, I don't want to be the one who is negative but I wanted to mention that I have taken the training which has great information but unfortunately there is nothing in place to support it. My husband and I, at the end of the day, are the coordinators/managers and it's exhausting even when dealing with a rather large hospital as Children's and having social workers to support us. Hoping the providers will get on board some day! —Thank you!”
Advocacy Grows One Family at a Time

Knowledge is power. Information is liberating. Education is the premise of progress, in every society, in every family.

(Kofi Annan)
Educate and Empower
Introducing the Amazingly Convenient Medical Home. Now Available with Care Coordination!

✓ It organizes your entire family!
✓ It’s a time saver!
✓ It’s a memory booster!
✓ It lets you see the whole picture!
✓ It helps you predict the future!
See the Whole Picture!
<table>
<thead>
<tr>
<th><strong>Important Family Members</strong></th>
<th><strong>Recreation/Community/Social</strong></th>
<th><strong>Legal/Financial</strong></th>
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</thead>
<tbody>
<tr>
<td>Immediate family</td>
<td>Special Olympics</td>
<td>Trust/Estate</td>
</tr>
<tr>
<td>Extended family</td>
<td>After School Program/Clubs</td>
<td>Attorney</td>
</tr>
<tr>
<td>Friends like family</td>
<td>Adaptive Classes</td>
<td>Economic Services</td>
</tr>
<tr>
<td></td>
<td>Summer Camps</td>
<td>Social Security</td>
</tr>
<tr>
<td></td>
<td>Hippo Therapy</td>
<td>Employment</td>
</tr>
</tbody>
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<thead>
<tr>
<th><strong>Health</strong></th>
<th><strong>Education</strong></th>
<th><strong>Home Care</strong></th>
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</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>School</td>
<td>Respite</td>
</tr>
<tr>
<td>Insurance/Medicaid</td>
<td>Transportation</td>
<td>Private Duty Nurse</td>
</tr>
<tr>
<td>Dentist</td>
<td>Special Education</td>
<td>Personal Care Worker</td>
</tr>
<tr>
<td>Hospital</td>
<td>Regular Education</td>
<td>Home Health Services</td>
</tr>
<tr>
<td>Pharmacy/Medications</td>
<td>School District</td>
<td>Guide Dog</td>
</tr>
<tr>
<td>Specialists</td>
<td>Nurse</td>
<td>Child Care</td>
</tr>
<tr>
<td>OT/PT/Speech</td>
<td>Case Manager</td>
<td>Vacation</td>
</tr>
<tr>
<td>Equipment</td>
<td>Lunch / Recess</td>
<td></td>
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<thead>
<tr>
<th><strong>Social Services</strong></th>
<th><strong>Advocacy and Information</strong></th>
<th><strong>Support</strong></th>
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<tbody>
<tr>
<td>Case Manager</td>
<td>Children &amp; Youth with Special Health Care Needs</td>
<td>Spiritual Community</td>
</tr>
<tr>
<td>Programs</td>
<td>ABC for Health</td>
<td>Parent to Parent</td>
</tr>
<tr>
<td>WIC</td>
<td>Family Voices of WI</td>
<td>Parent Support Groups</td>
</tr>
<tr>
<td>Birth to Three</td>
<td>Representatives – local, state, national</td>
<td>SIBShops</td>
</tr>
<tr>
<td>Early Intervention</td>
<td></td>
<td>Blogs</td>
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<tr>
<td>Waiver Programs</td>
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</tbody>
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Solve a Problem
People Learn Differently

**Learning Styles**

- **Visual** (special): Learn best by seeing
- **Auditory** (aural): Learn best by hearing
- **Reading/Writing**: Learn best by reading and writing
- **Kinesthetic** (physical): Learn best by moving and doing
It’s a Time Saver!
The Importance of Constant Feedback
Lessons Learned:
Target Audience
Lessons Learned: Outreach
Engaging Families in Care Coordination

- Be aware of different reading levels
- Think about issues with technology
- Try to be flexible in partnering with families
Questions
Contact Information

Family Voices of Wisconsin
familyvoiceswi.org

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References:

1. Annie E. Casey Foundation’s KIDS COUNT Project, 2018 KIDS COUNT Data Book.
5. SAMHSA, Substance Abuse and Mental Health Services Administration.
6. Wisconsin DHS, Maternal Child Health Block Grant: 5 Year Needs Assessment Summary.