CARE Series Feedback and Recommendation Report

Children's Health Alliance of Wisconsin
Medical Home Initiative
December 2025

Executive summary

Over the past year, Children's Health Alliance of Wisconsin's (the Alliance) medical home initiative gathered feedback from professionals and families to explore potential new learning options and determine the future of the CARE Series:

- **C**aring for the whole family
- **A**ssembling a care notebook
- **R**equesting a Shared Plan of Care (SPOC)
- **E**xploring care mapping

In total, 13 professionals from parent organizations, Children's Resource Centers (CRC) and clinics took part in interviews, and two focus groups were held with parents and guardians.

Feedback highlights that the CARE Series is valuable, particularly for its in-person care mapping activities and opportunities for families to connect. However, there are opportunities to test new approaches to engage the audience, make learning sessions easier to access and make content clearer. Families shared a need for simpler language, more practical resources, multiple learning formats and adjusted topics.

This report shares key findings about the health information that families and professionals want. It also provides recommendations to improve the CARE Series so we can better support families as they navigate their children's care.

Background

The CARE Series is a set of four learning sessions. It supports families who have children or youth with special health care needs (CYSHCN). It also builds awareness and informs professionals.

We designed the series with CYSHCN partners in 2019. Topics include: Caring for the Whole Family, Assembling a Care Notebook, Requesting a SPOC and Care Mapping. The five CRCs for CYSHCN deliver learning sessions statewide. The sessions aim to provide tools, knowledge, resources and support networks.

Our goals:

- Gather family and professional views on content, format and delivery.

- Understand what is working well in the CARE Series.
- Identify challenges and areas to improve.
- Create recommendations for future learning sessions and potential new topics.

How we collected data:

- Professional interviews
    - We talked with 13 professionals who directly serve families.
    - They work at: Children's Wisconsin, CRCs, Family Voices, Parent to Parent and University of Wisconsin Pediatric Complex Care Program.
- Family focus groups
    - We held two family focus groups.
    - Gathered feedback from 11 families total.
        - Six families in person at the Family Voices' Circles of Life Conference.
        - Five families virtually from Children's Wisconsin Family Advisory (they reviewed SPOC and Caring for the Whole Family learning sessions).
- Survey
    - We created a survey for families and professionals.
    - Shared it at the Family Voices Circles of Life Conference.
    - Received 21 responses.
        - 12 families
        - Eight professionals
        - One child/youth

What to keep in mind:

- The families and professionals we talked with are not representative of all Wisconsin communities where kids learn, live and play.
- Children's Wisconsin Family Advisory focus group: We reviewed two of the four CARE Series learning sessions with families. We focused on the SPOC and Caring for the Whole Family learning sessions because we heard that the Care Notebook and Care Mapping sessions are more interactive and better attended.
- Survey gaps: The survey was only available at the Family Voices' Circles of Life Conference for people who stopped at our exhibitor table.

Key findings from professionals

We had many conversations with professionals who serve families. Below are some key themes and takeaways shared when asked about the CARE Series.

Strengths of the CARE Series

- Virtual access: Allows participants to join learning sessions without having to travel or arrange childcare.
- Presentation style: Provides information directly and efficiently.
- Care mapping in person:
    - Care notebooks and care mapping bring meaningful conversations.
    - Engages families in hands-on activities.
    - Families have shared that having printed slides and walking through them is helpful.
- Opportunities for connection in person:
    - Participants can network and share experiences and resources with one another.
    - Parents have shared that having a weekend option is appreciated. Friday nights and Saturday afternoons work well for some families.
    - Providing meals, respite care and comfortable spaces enhances engagement.
- Caring for the Whole Family training: Appreciation expressed for addressing emotional layers and feelings.

Challenges of the CARE Series

- Attendance and engagement:
    - Average attendance is around 50% of registration.
    - Attendance typically improves when paired with other workshops or events.
    - Marketing and outreach: CRCs use multiple outlets (including social media platforms, trusted organizations, their network and word of mouth) to reach families since each family finds information in different ways. Professionals expressed difficulty in reaching families, especially for Caring for the Whole Family sessions.
- Limited interaction among participants, especially in virtual sessions.
- Need for content clarity:
    - Current language is often academic or complex. We need to use plain language and improve slide visuals with less words.
        - For example, the terms “medical home” and “shared plan of care” are not health literate.

Feedback methods: Post-event feedback can be difficult to collect, and response rates are low. Follow-up resources are sent via email. We need to consider how to gather feedback as surveys might not be the best method.

Current promotion strategies

- Encourage families to invite others and leverage word of mouth promotion.
- Flyers shared with schools, agencies and public health organizations.
- Partner with other agencies and Neonatal Intensive Care Unit (NICU) to reach families.
- Use social media and email (email alone may not be enough).

Suggestions for format and delivery

- A variety of formats are necessary to reach different audiences: in-person, virtual, short videos, flyers and recordings.
- Timing should be flexible (weekdays, weekends, lunch hours, evenings, etc.) to accommodate schedules.
- Short video snippets (2 minutes) could relay key information effectively.
    - These could live on an online resource or webpage.
- Advance notice, calendar invites and reminders are helpful.
    - This has been successful for University of Wisconsin Pediatric Complex Care Program’s trainings.

Key findings from families

Family Voice’s Circles of Life focus group feedback

The medical home initiative held an in-person focus group at the Family Voice’s Circles of Life conference. The goal was to learn what health information families would value and how they want to receive it. Families were engaged (even staying longer and setting up another meeting) and eager to share their experiences, frustrations and recommendations. Below are some of the key themes and takeaways we heard about what is most important while navigating their child’s health journey.

Health information needs

Gaps in information and desire clear guidance on:

- Brief, actionable information rather than large packets.
- Individualized Education Program (IEP) trainings, including rights and processes.
- Support for sibling needs and family-wide coping strategies.
- Tools for child safety and independence outside of health care settings.
- Understanding available services by county and navigating blocks in getting those services.

The most trusted sources of health information for their children include caseworkers, health care teams, hospital social workers and family networks.

Learning session format preferences

- In-person sessions allow for deeper connection, networking and engagement.
- Virtual options are great for convenience, but content should be recorded and shared for later access.
- Timing should be flexible. Some families are able and willing to adjust schedules for high-quality sessions.
- Content should be delivered in small, digestible segments with follow-up.

Statewide Children’s Wisconsin Family Advisory focus group feedback

Our team had the chance to have a more focused discussion about specific learning sessions. The group watched a recording of the SPOC, Care Mapping and Caring for the Whole Family learning sessions, followed by a conversation. Below are some of the key themes and takeaways from these discussions.

SPOC and Care Mapping sessions

Most helpful:

- Appreciated recommendations on who to give the SPOC to.

- Slide showing different categories of the SPOC was helpful (see slide 1). More time should be spent on this slide.

- Shared that care mapping bridges the gap between the care team and "organizes the chaos." Families appreciated the suggestion of taking a picture of the care map so it's portable.

Goal Cards for Families

- 5 Categories of Cards
  - Communication
  - Community, Social and School
  - Home and Family
  - Independence
  - Medical and Health
- Available in English
  https://healthtransitionwi.org/wp-content/uploads/sites/178/2020/05/Goal-Cards-for-Families_final.pdf
- Available in Spanish
  https://healthtransitionwi.org/wp-content/uploads/sites/178/2020/05/Goal-Cards-for-Families-Spanish.pdf

Have others listen and understand me

Experience my community

Have someone help find and coordinate community services

Be more independent

Access more therapy opportunities

Slide 1

Least helpful:

- Slides are distracting in current form. Need consistency in structure and font, more simple language and updated clip art.
- SPOC content placement was confusing and overwhelming. The SPOC should be discussed fully before other plans of care are discussed.
- The different categories of the SPOC went too fast (see slide 1). Spend more time here.
- There is a lack of explanation and understanding of why care mapping is critical. Share examples of how to use it and its impact.
  - Build a shared understanding of its benefit and take time to create together.

Feedback on Caring for the Whole Family session

Most helpful and top slides:

- Had a lot of takeaways that could be expanded on (see slide 2).
- Liked the part about teachable moments (see
- slide 3).
- Reputable sites for information (see slide 4).

Parenting as a Whitewater Rafting Experience

Good times and bad
- Health
- School
- Family

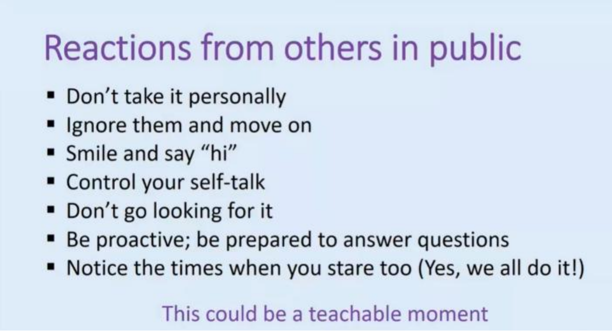
Don't do it alone
- Other parents
- Programs and resources

Need some guidance
- Doctors
- Teachers
- New language

Benefit from protective gear
- Advocacy skills
- Sometimes a thicker skin

Beautiful and rewarding
- Accomplishments
- Pride in your child

Slide 2



Reactions from others in public

- Don't take it personally
- Ignore them and move on
- Smile and say "hi"
- Control your self-talk
- Don't go looking for it
- Be proactive; be prepared to answer questions
- Notice the times when you stare too (Yes, we all do it!)

This could be a teachable moment

Slide 3

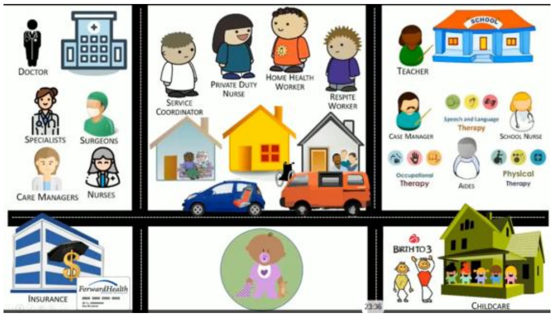
Learn about the diagnosis

- Ask your child's doctor
- Centers for Disease Control and Prevention
  https://www.cdc.gov/DiseasesConditions/
- National Organization for Rare Disorders
  https://rarediseases.org/for-patients-and-families/information-resources/rare-disease-information/
- Mayo Clinic
  https://www.mayoclinic.org/diseases-conditions

Slide 3

Least helpful:

- While information was presented in a positive way, parents want professionals to communicate honestly and directly. Don't sugarcoat the reality of a care journey or diagnosis for a family.
    - In the whitewater rafting example (slide 2 above), parents didn't like to hear the message "you won't drown." Parents could lose their kids and that is like drowning. That doesn't need to be called out directly, but it can't be ignored.
- Clip art and slide formatting is outdated and lacks emotions (see examples below).




Telling family members and friends

We found out the gender of our baby and it's another boy!!

He has a condition called ____________.

Additional recommendations and comments about learning sessions

Professional comments:

- Encourage staff to ask all colleagues and parents about support or diagnosis groups. Inform families and send information by email. They might not be ready now but will be able to look back when they are ready.

Family comments:

- Encourage families to ask other professionals if they have suggestions. Don't just hear "no" once and think it's the end and there is nothing out there. Be persistent and talk to multiple professionals.
- Remind parents it's ok not to do everything. Some families go years without having all the information about their child. It can be a long process.
    - For example, for foster families, one family might get the information, but that same information isn't passed on to other families.
- Remind families that when they are talking to others about their child's diagnosis, it is ok to say, "we are navigating this, and I don't know that information yet."
- Remember your primary role is being your child's parent. Make sure to make room for joy, love and connection.
- Mention that you will need to be your child's advocate sometimes. Remind parents that they must be an advocate for their child, and they are not annoying for continuing to advocate for their child.

Training comments:

- More family perspectives are wanted in the trainings. For example, have an interview with families.
- Add a disclaimer that says something like, "your child may not fit all of the information shared in the training," and something else about talking to your doctor.
- It’s hard when dealing with a wide spectrum of illnesses that kids experience. Perhaps offer some guidance in the training to encourage families to seek out other families or others who may be seeking support, or even reference disability groups.
  - Share some support group options for parents.
  - Kids don't fit one group or another. Sometimes kids fit into a gray area.
- It could touch on more nontraditional groups (e.g., learning how to be a sibling’s advocate).

Overall recommendations for CARE Series improvements

Through focus groups and conversations with professionals, we learned that the CARE Series is a valuable resource for families navigating complex health care journeys. Families find the most benefit from clear, purposeful information, opportunities to connect with others and flexible learning formats.

We did not review all four components of the CARE Series trainings. The questions were broader about the trainings. When we met with families from the Children's Wisconsin Family Advisory focus group to review specific trainings, two of the four trainings were chosen. We chose to focus on the SPOC and Caring for the Whole Family learning sessions because we have heard that the Care Notebook and Care Mapping learnings sessions are more interactive and better attended.

Below are the recommendations and adaptations.

- Content:
    - Include disclaimers emphasizing individual differences and differences in provider expertise. One provider may not have all the answers. Some training information may not be applicable to a family's individual and family experience and/or understanding.
    - Provide physical and digital resources.
    - Simplify language and clarify complex topics like SPOC and medical home.
    - Update slides for consistent formatting, clear visuals and practical examples.
- Format and delivery:
    - Incorporate breakout discussions or "speed dating" sessions to foster peer connection.
    - Offer multiple formats: in-person, virtual and recorded sessions.
    - Pair with another workshop or learning session to improve attendance.
    - Utilize short videos and communications/social media platforms to highlight key messages from trainings (concrete takeaways and /practical skills).
    - Vary session timing to increase accessibility.
- Engagement and outreach:
    - Partner with schools, NICUs and community organizations for promotion.
    - Leverage social media, word of mouth and trusted family networks.
    - Send reminders and calendar invites well in advance.
- Feedback methods:
    - Revise survey process and test new ways to get feedback. Implement a new standard process for feedback after each session to capture participant input.
    - Follow up with resources and optional check-ins for families who request additional support.

Broader learning session topics and changes for consideration:

- Provider education on culturally competent care and navigating complex family needs.
- Supporting families in understanding their child’s rights and navigating IEPs.
- Coordination between health care teams, schools and community providers.
- Guidance for families on care transitions, including moving from pediatric to adult care.
- Training on building resilience, mental health support and managing sibling needs.

Test new topics and directly ask families in specific communities what topics are most relevant and beneficial to them. There are a broad range of topics and questions that families may have, and it’s important to recognize that the interests will look different depending on the family’s situation (e.g., a family with a child who has a new diagnosis may need different resources than one that has been navigating services for some time). While the CARE Series is helpful for some, it may not meet the needs of all families.

Implementing the recommendations above could help improve accessibility, clarity and engagement of the CARE Series. Future trainings can also explore broader topics to better support both families and providers.