

# “REMEDIES FOR SORROW” Book Study

Author Megan Nix

Created 2023



This discussion guide is put together for the purpose of supporting the Minnesota Statewide Early Hearing Detection & Intervention (EHDI) Representatives as they participate in reading the book, “Remedies for Sorrow”.

## Part 2 - Contemplation

During our Statewide EHDI Meeting (February 2, 2024) we will have time for discussion, in smaller groups, around Part 2 “Contemplation” from the book. There are 4 sections in our discussion guide. Your group might choose to focus on one section, a few sections, or cover all the sections. Do whatever feels most helpful for your group. The sections are: [Reflections](#), [Resources](#), [Quotes and/or Facts](#), and [Actions Steps](#).

### Reflections:

**Pick 3-5 of the following questions to reflect.**

1. How did Zaley’s acceptance of Anna impact the author?
2. What was the author’s intended message about the medical culture and women as she described ACOG’s stance on counseling pregnant women about CMV?
  - a. On page 69 the author tells her OB/GYN that Anna has CMV and asks if he ever counsels his patients about CMV, he replies; ACOG doesn’t recommend it, plus women won’t want to worry about one more thing.
3. On page 63 the author talks about the stigma of the disease and being upset that she needs to educate every woman about it. Consider how EI providers can support families as they prepare to explain, advocate, and share information about their child’s diagnosis with family, friends and even other professionals.
4. “Who gets to decide what we can handle?” How do we make decisions on what information to share with parents/caregivers? In reference to the Abilene Complex described on page 67.
  - a. *The **Abilene paradox** is a collective fallacy, in which a group of people collectively decide on a course of action that is counter to the preferences of most or all individuals in the group, while each individual believes it to be aligned with the preferences of most of the others.*<sup>[1][2]</sup> (quote from Wikipedia)
5. On page 73, the author provides statistics regarding the number of infants with a CMV diagnosis compared to the prevalence of CMV. How might Minnesota change this narrative for our state because of the cCMV newborn testing we are doing? What does this potentially mean for Help Me Grow referrals? For early interventionists?

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6. On page 87, the author outlines the process for her to secure the medicine needed for Anna, to be transported to rural Alaska. She states she feels like James Bond in her effort to get what her daughter needs. How might this feeling parallel what families in Minnesota might experience who are striving for resources/services/supports in all areas of our state? How can we advocate for our education system to support families equitably, no matter where they live?
7. The author discusses the differences in how she and her husband respond to stressors, specifically navigating insurance. (page 89) What are your stress relievers?
8. On page 103, the author talks about her feelings and thoughts after receiving confirmation that Anna can't hear. She feels guilty for not using more signs, for not erring on the side of caution that Anna had always heard nothing. What do you think the author would change? What might she have wanted professionals to do differently?
9. Families seek to talk about profound matters and moments of exchange. (page 105) How are practitioners facilitating and participating in that?
10. This chapter included information about their decision to have the cochlear implant surgery. What can our field learn from this? What practices, skills and competencies does our field need to call upon to support families in making informed decisions? How did this broaden your perspective about the complexity of some of the decisions families encounter? What strong beliefs or biases might you have noticed emerging as you read about their decision making? How might these impact any future conversations you might have with families about this topic?
  - a. DEC Recommended Practice F2: Practitioners provide the family with up-to-date, comprehensive, and unbiased information in a way that the family can understand and use to make informed choices and decisions.

## Resources:

*Which resources have you utilized before?*

*How was a resource helpful?*

*Which resources do you plan to explore more?*

- ★ [Roadmaps for reflection-support series](#): The roadmaps serve as a tool for planning a conversation or as a “guide on the side” during conversations related to helping families meet their family outcomes. The roadmaps guide practitioners in using coaching interaction practices during these conversations. There are guides for 18 different topics.
- ★ [Do service coordinators coach?](#) -this tool is a one page infographic summarizing how coaching interaction practices might look during service coordination.

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- ★ [Supporting Family Member Informed Decision Making](#): Practice Guide from ECTA. This practice guide provides strategies for involving family members in informed decision making.
- ★ [Involving Families in Obtaining Supports and Resources](#)-Practice Guide from ECTA: This guide includes strategies for actively involving caregivers in accessing family identified supports and resources in ways that build on family strengths and interests.
- ★ “[Washing Our Hands of the Congenital Cytomegalovirus Disease Epidemic](#).” Mike Cannon, epidemiologist at the CDC, (referenced on page 86)
- ★ On page 93 Megan shares a conversation she has with Somer, audiologist, where Somer provides the information that two months of delay at such an early age could impact Anna’s language development noticeably. Watch the video by Dr. Rush and Dr. Shelden, “[Sharing My Expertise](#)” which discusses how early intervention specialists might consider providing families with information.

## Quotes and/or Facts from Part 1 Weeping:

*Which quotes really resonate with you? Why?*

*What additional quotes from the book were impactful for you as you were reading?*

- ★ “5 minutes of counseling might have saved us from everything we are experiencing and about to experience.” (page 66)
- ★ “The truth I am after is proof that women can handle the facts-no matter how inconvenient, no matter how complex.” (page 66)
- ★ “Our kids won’t live common lives, they’ll live extraordinary ones.” (page 117)

## Action Steps:

Take a few moments to reflect on any possible action steps you are considering. This might include your own personal growth, ideas for supporting children and families, and sharing back with your colleagues.