

“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 3 - Company

During our Statewide EHDI Meeting (February 2, 2024) we will have time for discussion, in smaller groups, around Part 3 “Company” 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. On page 125, Megan writes, “But I don’t feel like there’s any centralization of Anna’s information among all the specialists we’ve seen.” As early interventionists what systems do we have in place (or strive to have in place) that support the centralization of information?
2. Reflect on ableism themes that emerged in this section. Discuss wows, wonders, wishes and worries that resulted from the reading. A few examples:
 - a. Page 170: I decide I’ll never subtract from where Anna is, in her moment again.
 - b. Page 169: After Anna’s activation I am ready to get rid of the ableist equations.
 - c. Page 169: The Anat Baniel Method rejects the idea that all children would be held accountable to a typical timeline. Children who develop differently are not objects to be fixed but works in progress to whom we can play close attention and deeply connect.
3. On page 122, Megan writes, “I can see Luke filling the freezers in our garage with fish, and I envy him the ability to manage tasks without being destroyed, as I am, by the inexorable changes of our lives.” This is an opportunity to reflect on how different family members process information, change, and uncertainty in different ways at different speeds and with different types of support. How might we individualize strategies and interventions so that they meet the unique needs of fathers, siblings, and other family members?
4. On page 134 Karina talks about Jayden saying, “We took him everywhere and did everything with him whether or not he could fully participate. The point was to build an experience and memory.” What implications does this have for EI providers and programs? How does this perspective reflect the importance of following DEC Recommended Practices? What might these practices have looked like in action with Jayden’s family?
 - a. DEC RP E1: Practitioners provide services and supports in natural and inclusive

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- environments during daily routines and activities to promote the child’s access to and participation in learning experiences.
- b. DEC RP F3: Practitioners are responsive to the family’s concerns, priorities and changing life circumstances.
 - c. DEC RP F4: Practitioners and the family work together to create outcomes or goals, develop individualized plans and implement practices that address the family’s priorities and concerns and the child’s strengths and needs.
5. Reflect on the impact of her informal support network that emerged in this section. Her friends helped with Zaley, learned sign language, fashioned a headband to solve a problem and brought her breakfast sandwiches. What does the DEC Recommended Practice (RP) F7 look like in your program? What conversations do you have with families that might help them identify the informal resources and supports they have and might access?
- a. DEC Recommended Practice F7: Practitioners work with the family to identify, access and use formal and informal resources and supports to achieve family-identified outcomes or goals.
6. On page 143, Megan writes the following about her new friend Lee’s daughter, “But Anna’s challenges are the kind you can’t see: she’s had to battle the tease of a seemingly typical body that isn’t actually typical when it applies itself to the things she wants to do.” How often does this happen in educational settings when a child’s body appears ‘typical’? As an educator, reflect on how you might place expectations on the students you work with? How might the student’s physical body characteristics impact the expectations you set?

Resources:

Which resources have you utilized before?

How was a resource helpful?

Which resources do you plan to explore more?

- ★ [Listen Foundation](#) - funded Anna’s expensive speech therapies for three years. (page 142)
- ★ [Minnesota Deaf Mentor Program](#)
- ★ Ableism
 - [PBS Wisconsin Education Ableism](#) Video 6 minutes
 - Access Living [Ableism 101](#)
- ★ [National CMV Foundation](#)
- ★ [National CMV Foundation Registries](#)

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- ★ Warrior Beads: [Beads of Courage](#)

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?

- ★ Per 1,000 live births, 3 white infants are infected with CMV versus 9.5 Black infants. And Black children are up to twice as likely to die from CMV-related complications than white children. (page 130)
- ★ CMV can lie dormant in the cells of the body, waiting for an opportunity to reactivate, similar to the herpes virus. (page 138)
- ★ “I just remember in the beginning, I was so angry,” Lee says, “I was so mad that no one had told me about CMV.” Staying silent does not help people to process what is happening and what has happened and the impact on the family and child. (page 143)
- ★ Watching your child alter course due to any inability will heavy the heart. (page 143)
- ★ Congenital does not just mean “from birth;” it means CMV will impact children until their deaths. (page 145)
- ★ “And their excitement about her makes me so excited, too.” (page 170)

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.