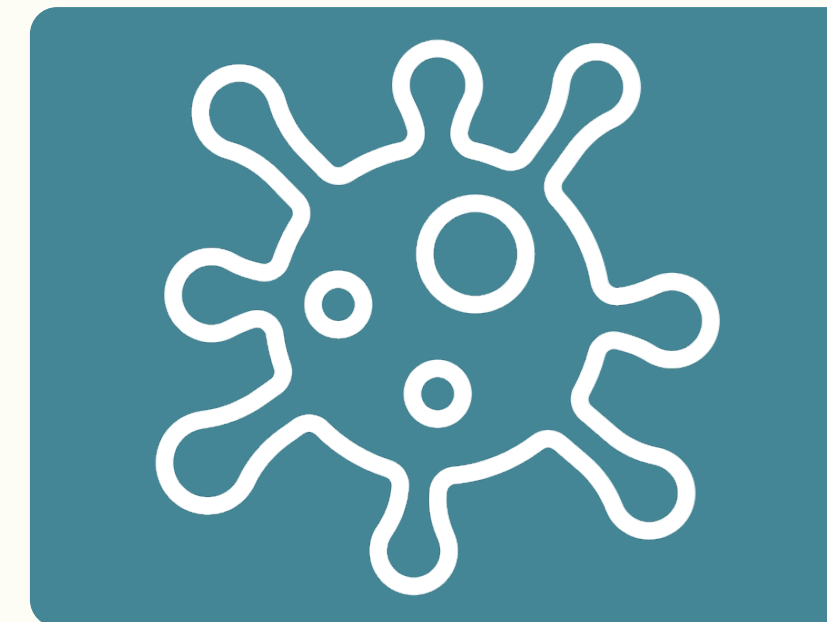
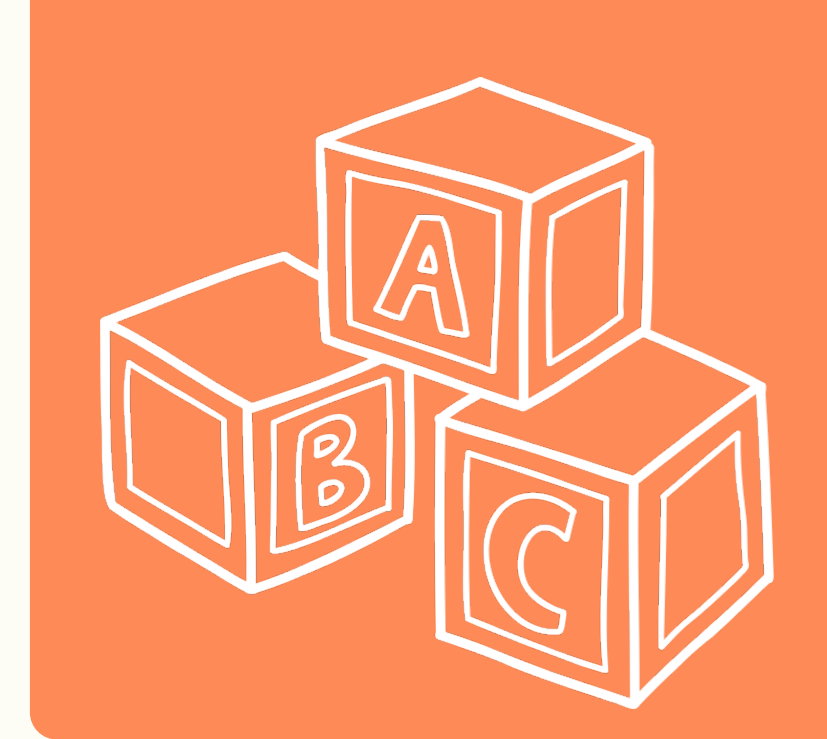


2026 EHDI Conference

# Beyond the Diagnosis

**Opportunities for Early Interventionists to  
Support Children with Congenital CMV  
and Their Families**

Jess Moen  
MN EHDI Statewide Specialist

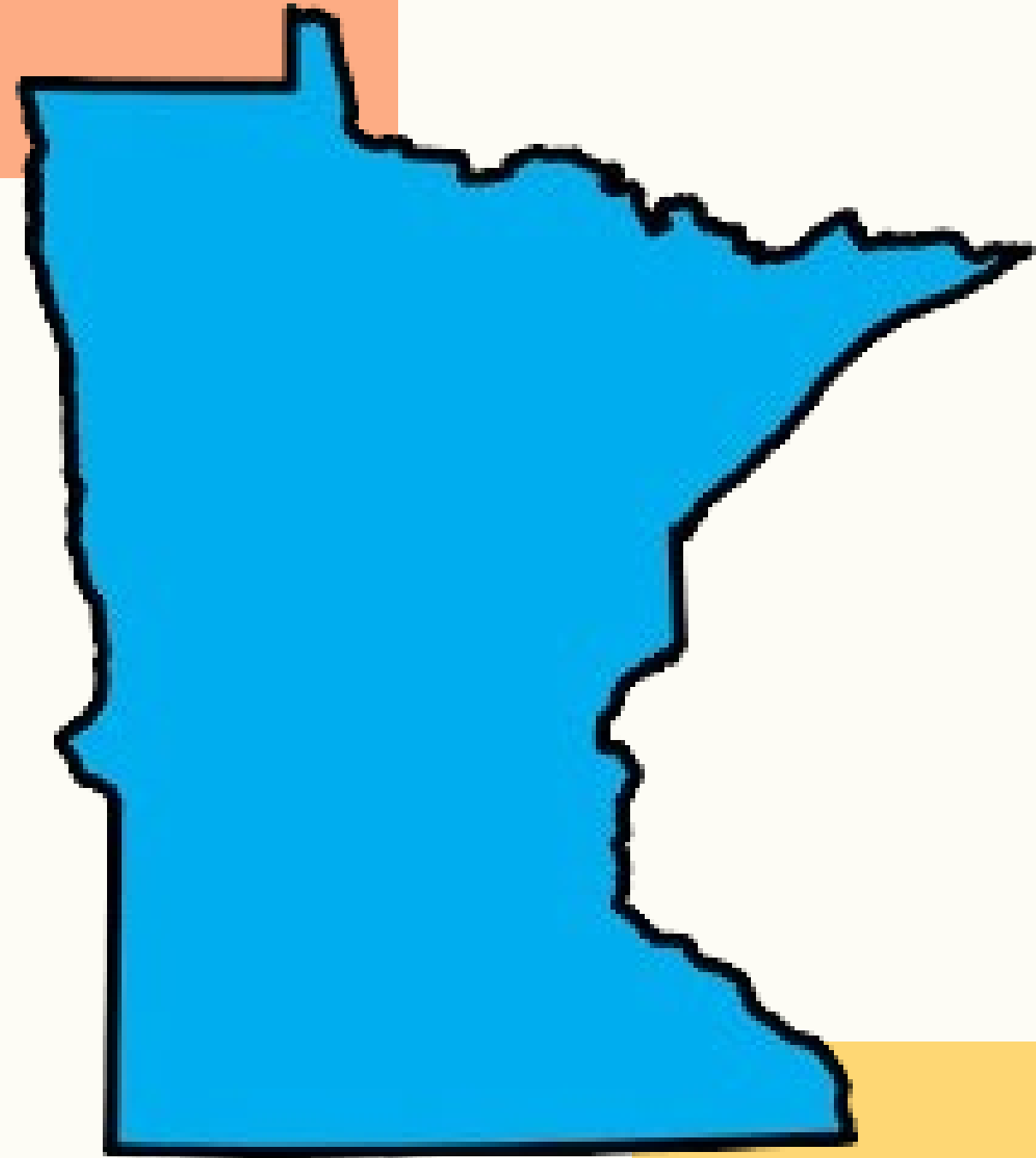


# Presentation Goals

- Highlight activities used in Minnesota to increase awareness and knowledge about congenital CMV with educators.
- Share practical strategies for incorporating information about congenital CMV in a child's Individualized Family Service Plan (IFSP) or Individualized Educational Plan (IEP).
- Showcase examples of Minnesota early intervention teams who are working to provide appropriate supports and service delivery to meet the unique needs of children with congenital CMV.



# **Screening and Part C Services in Minnesota**



# Learning Sprinkles

Activities Minnesota has used to increase educators' awareness and knowledge of congenital CMV.

<https://mnlowincidenceprojects.org/cCMV/index.html>

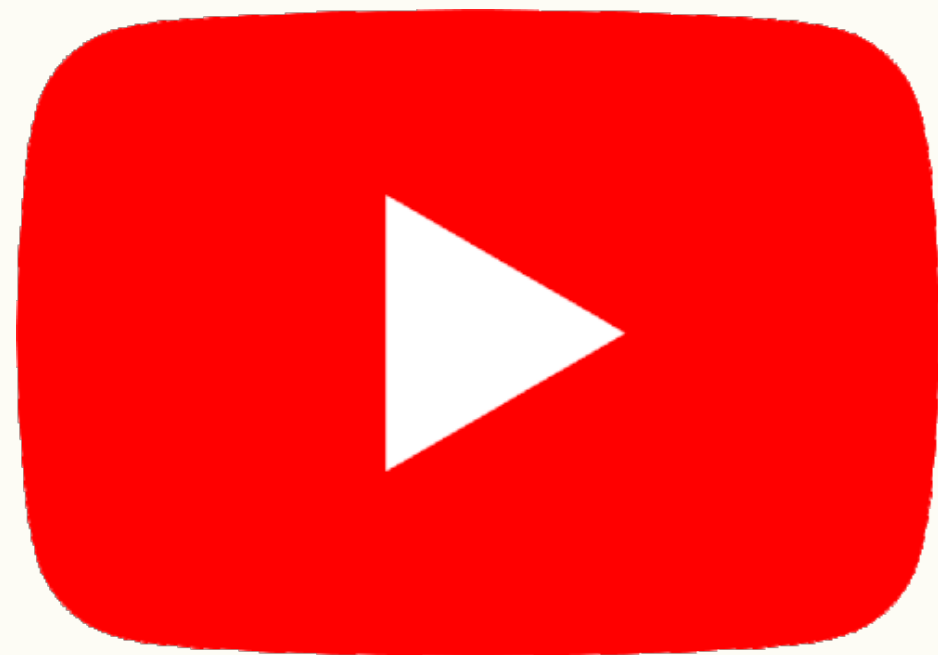
Variety of learning opportunities and styles

- Independent learning
- Large group learning
- Synchronous learning
- Asynchronous learning
- Sharing with colleagues
- Reading
- Videos/presentations





# Webinars

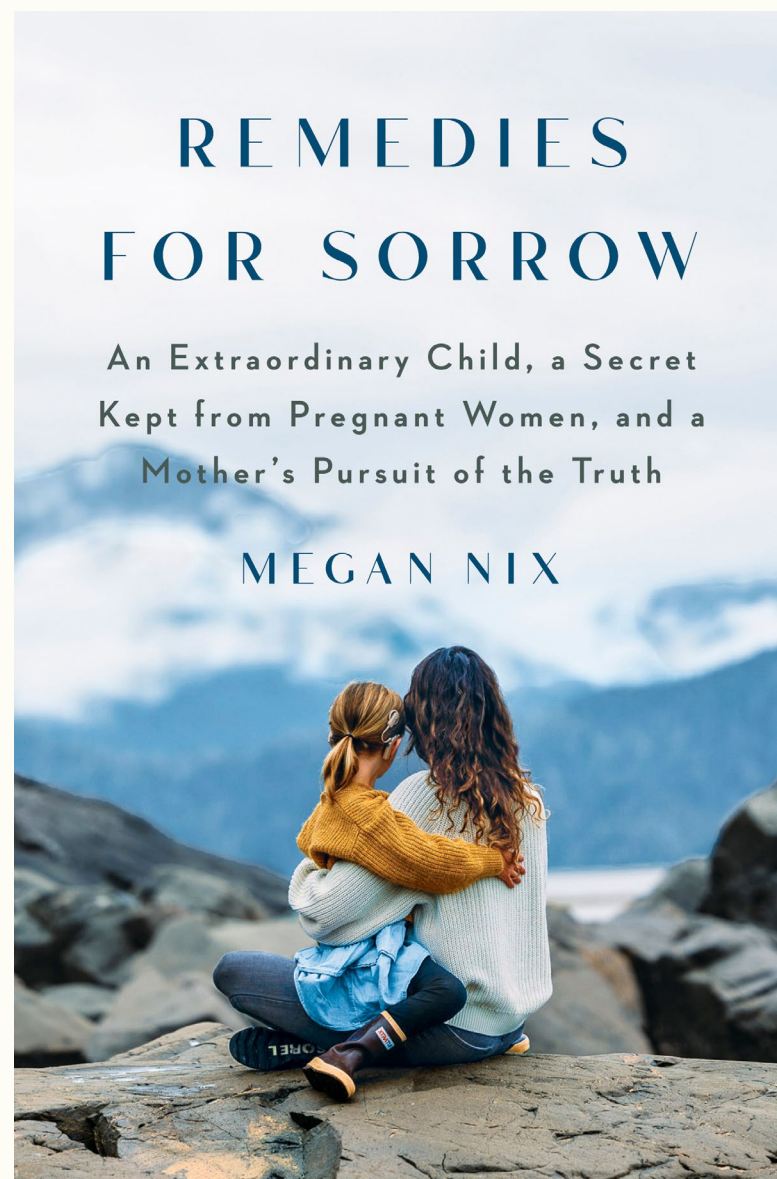


Two-part webinar series (1 hour each) which was offered live 2024 and is now available either as a recording or an online learning course.

- Webinar #1: All Hands on Deck! Supporting the Development of Children with Congenital CMV with Dr. Megan Pesch
- Webinar #2 All Aboard! Impacts of Congenital CMV in Early Childhood Special Education in Minnesota



# Remedies for Sorrow Book Study



**“Remedies for Sorrow An Extraordinary Child, A Secret Kept from Pregnant Women, and a Mother’s Pursuit of the Truth,” by Megan Nix**

Created with the purpose of supporting educational professionals in Minnesota to learn more about congenital CMV, its potential impact on children and families, and available resources.

- Book study guide
- Includes both Minnesota specific and National resources
- Asynchronous, online, course (offered three times)



# Congenital CMV 101 Packet

A presentation created for individuals to use to share awareness and information about Congenital Cytomegalovirus (cCMV) with educators. Includes:

- What is congenital CMV and why is it important
- Minnesota and congenital CMV
- Minnesota parent stories
- Inclusion
- Continued monitoring
- IFSP or IEP considerations, including an impact statement



# Bridging into Implementation

Strategies for IFSP/IEPs to document information of diagnosis and potential impact.

- Eligible for Part C Services in MN
- Continued developmental monitoring in Part C
- Consistently documenting Congenital CMV on every IFSP/IEP
- Impact statement in the IFSP/IEP
- Inclusion (not excluding children with congenital CMV from educational settings)



# Impact Statement

Importance for all Part C service providers to be aware of congenital CMV possible impacts:

- How cCMV might affect a child
- How cCMV might manifest over time
- How a cCMV diagnosis could be impacting the child's caregiver(s)
- Importance of quality monitoring of all areas of development to quickly address any areas of need if they arise
- Practitioners share relevant information in a timely manner with caregivers and connect to resource and other families



# Example:

# Impact Statement

[Name] was born with congenital cytomegalovirus (cCMV), which is a viral infection [he/she] caught in utero. Children with congenital CMV are at higher risk of developmental delays and differences due to the virus impacting their in - utero development. Some of the effects of congenital CMV on a child's development can be apparent early in infancy, whereas other impacts may appear later on in childhood. In [name] case, they have the following apparent impacts of congenital CMV: [list known impacts]. Children with congenital CMV are also at greater risk of developing new onset or progressive hearing loss, autism spectrum disorder, and learning difficulties that may not be apparent early in life. Of note, children with congenital CMV have lower rates of 'success' with using Listening and Spoken Language strategies only, therefore multimodal language learning strategies are paramount.



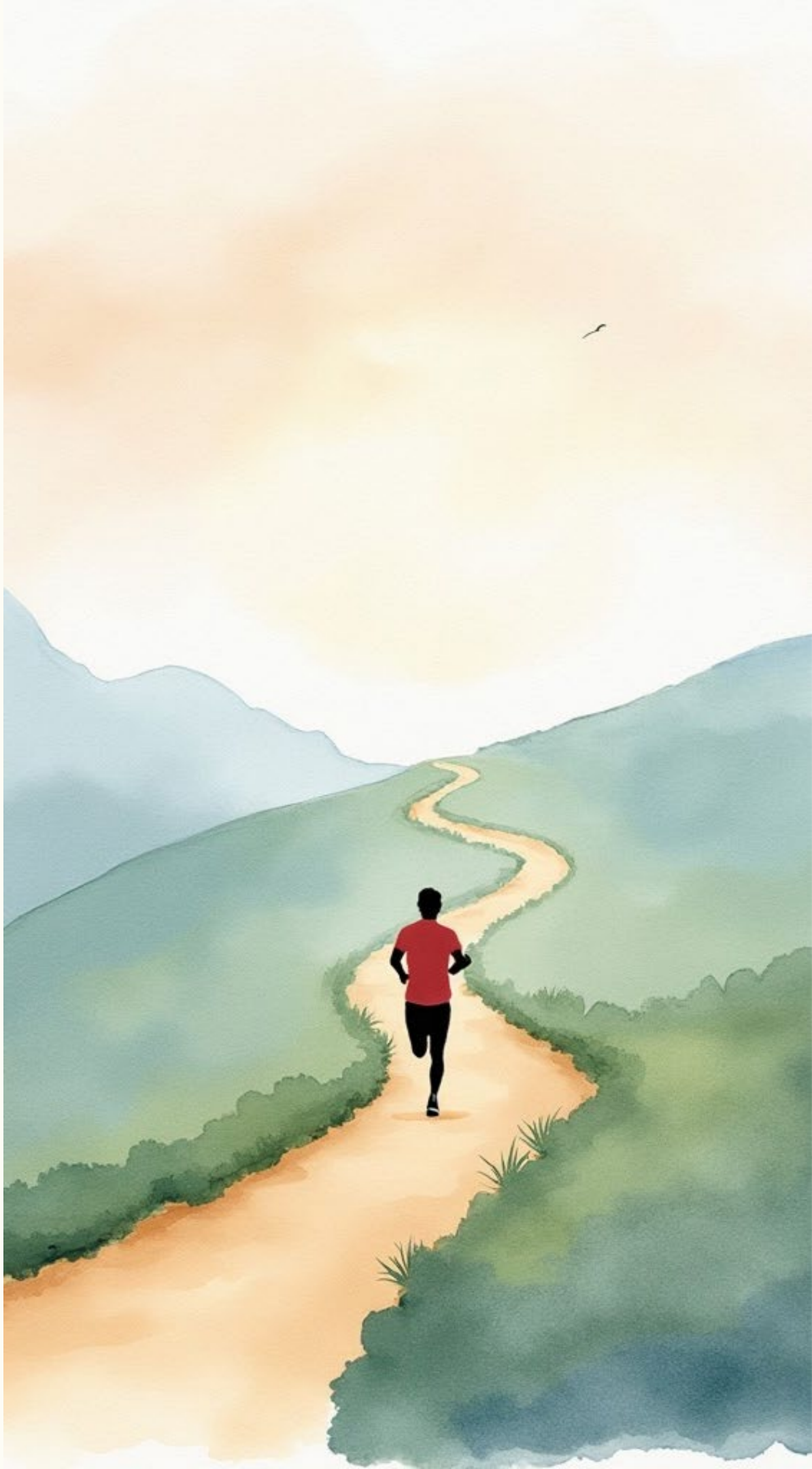
# Example:

## Impact Statement

### Listing Known Impacts

- [Name's] speech and language delays impact their ability to communicate and express themselves effectively.
- [Name's] hearing difference impacts their ability to understand and follow verbal instructions in the classroom.
- [Name's] hearing difference impacts their ability to naturally acquire language through implicit learning of what is happening around them.
- [Name's] vision loss impacts their ability to navigate within spaces.





# MN Educators In the Field

- Hearing screenings
- Services for asymptomatic children
- Exploring Communication Opportunities

# MN Educators In the Field

## Hearing Screening



“We had a clinical audiologist reach out to us regarding a parent who shared potential concerns about the frequency of going to the clinic for ongoing hearing monitoring for their baby who was recently identified with congenital CMV. We shared that we are able to provide hearing monitoring support if the family receives Part C, early intervention services. Support will be from the educational audiologist(s) who works with the early intervention team. If the family is not enrolled in Part C, then we suggest they connect with their Local Public Health agency to inquire about other possible supports, as well as talking to their clinical audiologist on their care plan.”

Dr. Mallory Salmon, Au.D., CCC-A

# MN Educators In the Field

## Services for Asymptomatic Children

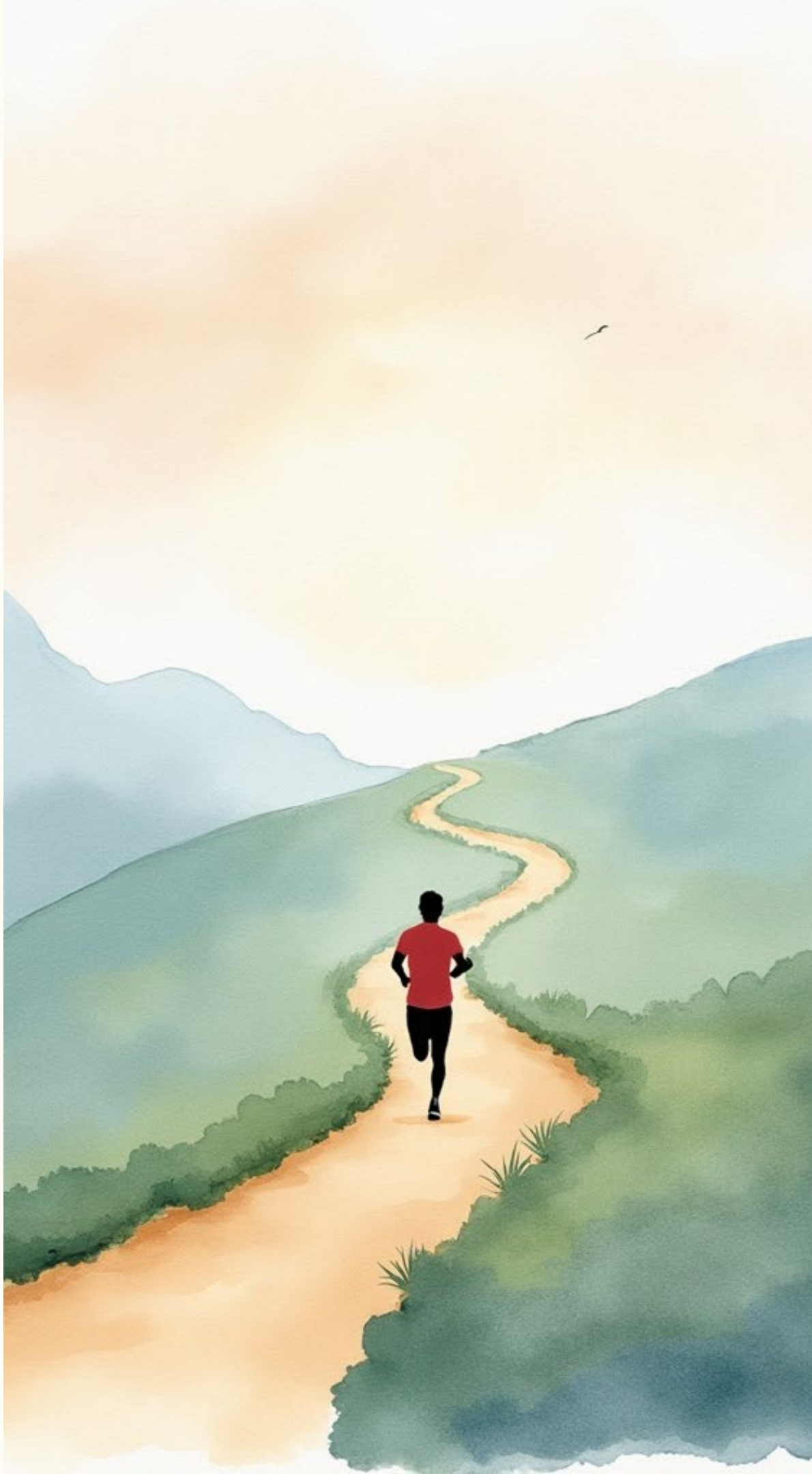


"For babies who are asymptomatic, because we know cCMV effects, especially hearing loss, can show up later or change over time, the focus is on monitoring development, checking in, and sharing information. Audiology and the Deaf and Hard of Hearing teacher step in as needed to talk with families about the importance of ongoing hearing testing and what signs of hearing changes to watch for. Our service is preventative and relationship-based, making sure families feel supported and know who to call if concerns come up."

Stephanie Alexander, Teacher Deaf/Hard of Hearing

# Family Story

## Services for Asymptomatic Children



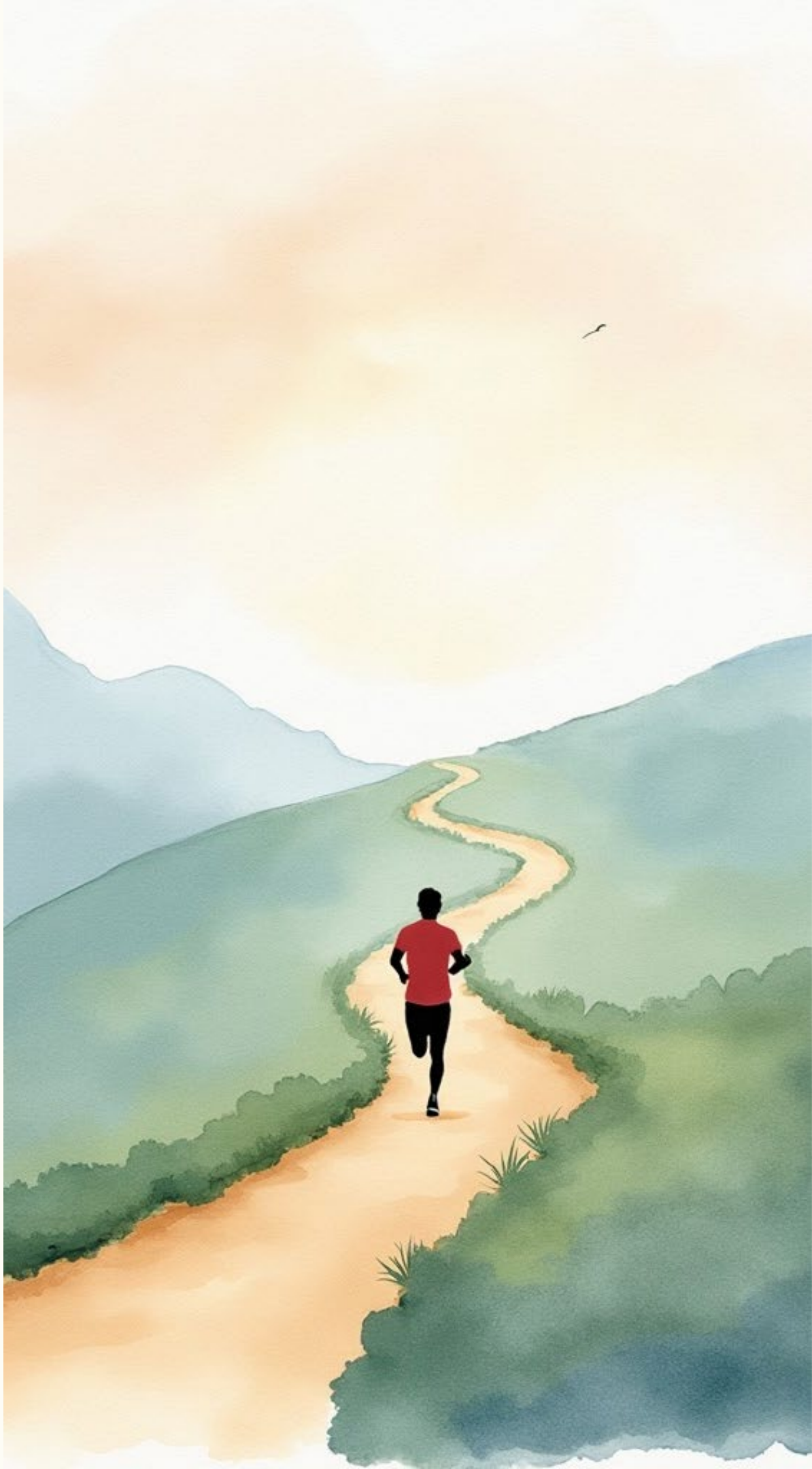
<https://youtu.be/gkBgi1Tp-JU>

# MN Educators In the Field

## Services for Symptomatic Children



“For symptomatic or medically complex infants, early intervention is team-based and designed to fit into everyday life, not to add another layer of therapy. Many families are overwhelmed as they try to process complex medical information, balance numerous appointments, care for other children, and grieve the child they thought they would have. We spend much of our time, especially in the early months, repeating and clarifying medical information and helping families carry over outside therapies into manageable steps that fit within their daily routines. Our goal is to reduce stress through consistent, relationship-based support while balancing meeting families where they are with helping them prepare for what lies ahead.” A Minnesota Early Intervention Team



# MN Educators in the Field Communication Opportunities



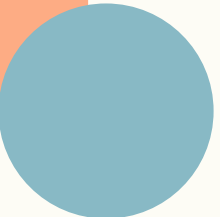
# Key TakeAways



**Sprinkle in  
Learning**  
about Congenital  
CMV to  
Educators

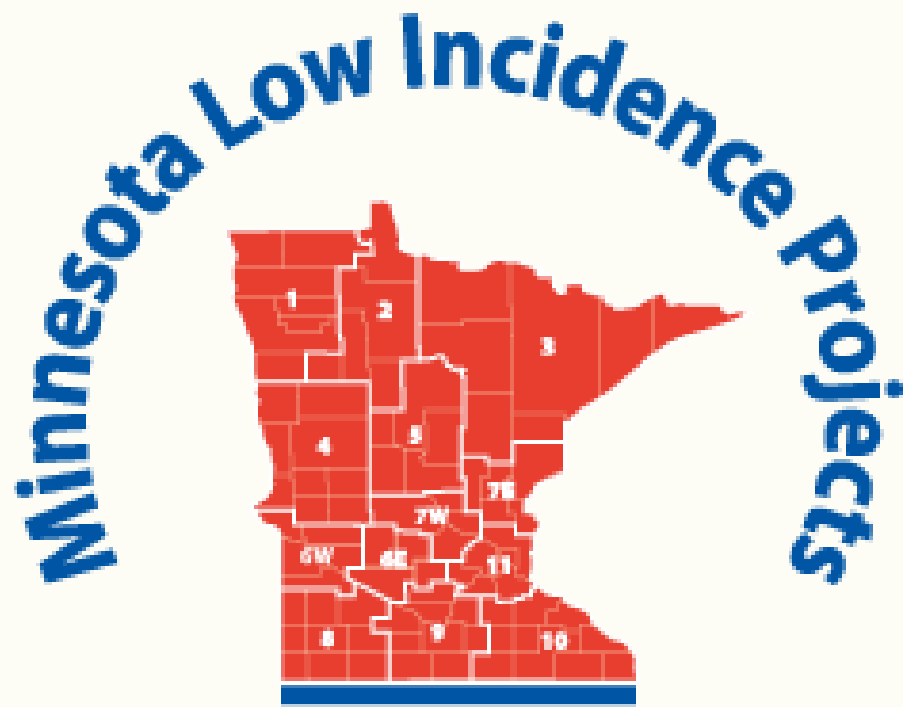
**Bridge into  
Implementation**  
Specific  
Practices

**In the Field,  
Support Children  
and Families**



# Questions





**Jess Moen**

MN Statewide Specialist Early Hearing  
Detection & Intervention (EHDI)

MN Low Incidence Projects

[jess.moen@brightworksmn.org](mailto:jess.moen@brightworksmn.org)



# Presentation Resources

**Webpage: Minnesota Low Incidence Projects: Congenital Cytomegalovirus**

<https://mnlowincidenceprojects.org/cCMV/index.html>

- Congenital CMV Packet 101
- Remedies for Sorrow Book Study Guide
- Webinars

**Webpage: Minnesota Low Incidence Projects: Exploring Communication Opportunities**

<https://mnlowincidenceprojects.org/Projects/ehdi/ehdiCommunicationOpp.html>

**Video: Parent Story - Part C Services Asymptomatic Congenital CMV (Jess)**

<https://youtu.be/gkBgi1Tp-JU>

# Presentation Resources continued

**Webpage: Minnesota Department of Health (MDH) Congenital Cytomegalovirus & Cytomegalovirus**

<https://www.health.state.mn.us/diseases/cytomegalovirus/index.html>

**Webpage: MDH Congenital Cytomegalovirus Public Health Data**

<https://www.health.state.mn.us/diseases/cytomegalovirus/congenital.html>

**Webpage: MDH Vivian Act Legislation**

<https://www.health.state.mn.us/diseases/cytomegalovirus/vivianact.html>