MinneStories: The Importance of Newborn Screening Storytelling

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What is MinneStories and Why is it Important?

- Inspired by StoryCorps Legacy, which can be heard on National Public Radio (NPR)
- Project to record and preserve the stories of MN families with conditions that can be identified by newborn screening.
- Storytelling is one of the most powerful forms of communication.
Training from the Professionals

- Paid for training from StoryCorps
- Multiple teleconferences with co-coordinators and associate manager of StoryCorps Legacy to prepare for on-site training
- Identified program staff to be trained as facilitators
- Purchased audio equipment
- Two-day training with StoryCorps Legacy
Internal Preparation

• Material creation:
  • Recruitment materials
  • Participant packet
  • Participant data sheet
  • Question list
  • Interview keywords form
  • Facilitator cheat sheet

• Practice, practice, practice
Recruitment

• Started with families known to our program
• Reached out to external partners for help
• Advertised the project at our booth at the MN State Fair

MinneStories

MinneStories is a project, inspired by StoryCorps, to record and preserve the stories of Minnesota families with conditions that can be identified by newborn screening.

MinneStories interviews are conversations between two people who knew one another. Participants talk about how newborn screening impacted their lives by asking one another open-ended questions.

When did you first realize that you had this condition?
What can doctors do to make your life better?
What about your child makes you smile?
What do you remember about the day your child was diagnosed?

A few weeks after your conversation, you’ll receive a free copy of the recording to share with family and friends. With your permission, the program will share your story on their website and seek other avenues to share your story about the importance of newborn screening.

How do I learn more or sign up to participate?
Contact Maggie Drex at Maggie.Drex@state.mn.us and/or (651) 291-6370 to schedule your interview today!

To listen to MinneStories, visit: minnestories.mn.gov
Day of Recording

• Introductions

• Logistics

• Recording:
  - In pairs, participants have a free-flowing conversation (i.e., non-scripted)
  - 40 minutes long
  - Facilitator may ask clarifying questions

• Debrief

• Consent
Post Recording

- Determine if recording warrants immediate review or not
- Share recording highlights with the team
- Facilitator meets with two other team members to review the recording and determine the story to share
- Send ideas to the audio and sound production engineer/student who does the audio editing
- Add to the database
Finished Product

- Participants receive the full, unedited recording as a thank you.
- Participants get to review the edited clip to make sure they feel it is an accurate representation.
- Distribution of edited clip:
  - Uploaded to our website with text transcript
  - Notification is sent to subscribers
  - Shared on social media platforms
  - Parents notified, so they can share with their network of family and friends

Like Lions

Shortly after she was born, a simple pulse oximetry screen prompted doctors to check Aria for a heart defect. Listen to her mother, Melia, and grandmother, Julie, talk about the strength Aria has shown and everything they went through as she fought for her life.

Minnesotastories is a project to record and preserve the stories of Minnesota families with conditions that can be identified by newborn screening. These stories of

Carrie, a lab technician in our newborn screening program, shares what she loves about her job.

And there’s a baby behind every single card that we get in. And there’s a family
• Backstage Pass

  • Rachel and Marsha discuss Rachel’s son, Cooper, and his diagnosis of MCAD deficiency found through newborn screening. Rachel shares her story of learning about her son’s diagnosis, a visit to the ER, and the opportunities that exist for him in spite of his diagnosis.
Participant Feedback

• Look forward to having their memories and experiences preserved

• Plan to share it with their children and other family members

• Have found this experience to be almost therapeutic
“We have never made the time to sit and talk about [our son’s] hearing loss the way we did yesterday so it was actually a great experience and pretty eye opening for us.”

- Mother of child with confirmed hearing loss
Current State

- 18 interviews have been recorded
- CCHD, hearing loss, CF, MCAD, and CAH just to name a few.
- All participants have given permission for us to share their story.
- 8 have been shared publicly
- 373 individuals have subscribed to receive notifications when new stories are added.
- Ongoing public health initiative – recordings continue to be collected and published.

Every family has a unique story to tell
Take a moment to listen to a story from a Minnesota family at MinneStories.mn.gov
Future Possibilities?

- Formal contract with professional audio editors
- Expand recruitment and distribution
- Train other interested newborn screening programs
- Develop or partner to develop a site for programs across the nation to upload to
- Create a podcast
Special Thanks

• Children’s Hospitals and Clinics of Minnesota - Hematology
• StoryCorps Legacy – Eddie Gonzalez
• Sudden Media

ALL of the families who have participated!!!

• Mark McCann