



# Engaging Family Leaders in the NBS system

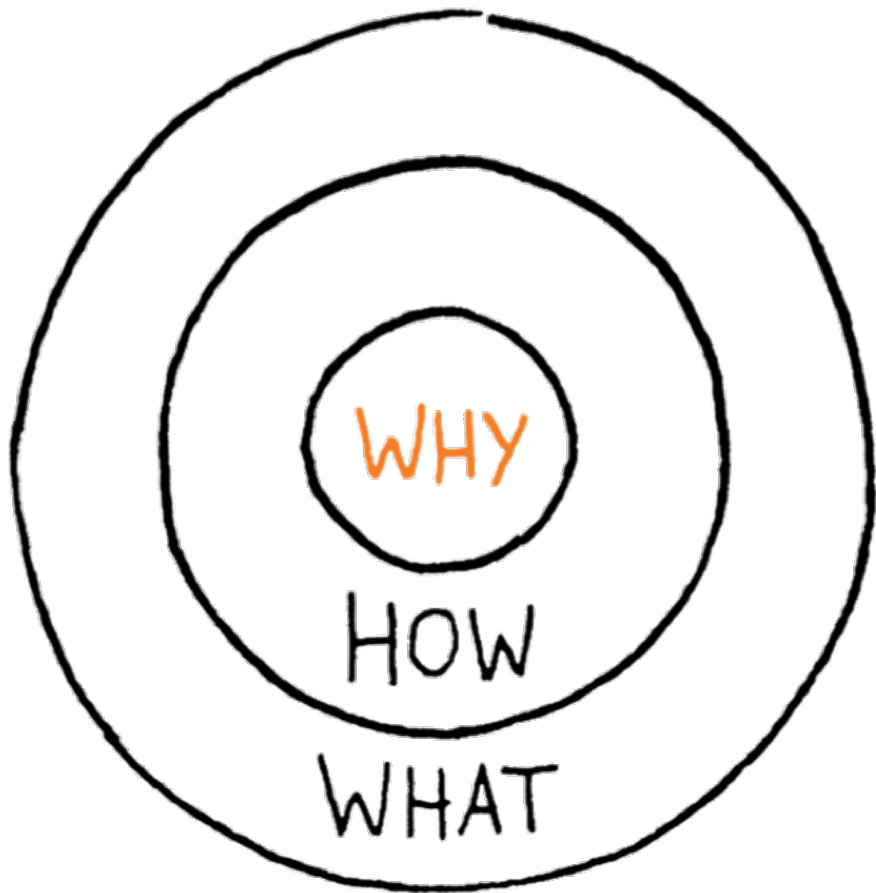
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On behalf of the many families who have engaged, shared their stories  
and changed the newborn screening system.



# THANK YOU

*This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$400,000 with 0 percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.*



- *How can we improve communication in newborn screening?*
- *How do we coordinate efforts across the newborn screening system?*
- *How do we educate the general public about newborn screening?*

# Plan for Action:

- **Build KNOWLEDGE.** *Provide an overview of the Navigate NBS Ambassador Program*
- **REFLECT** *Learn from families and their lived experiences in newborn screening*
- **Generate ACTION** *Share what you can do to get involved and engage families in the newborn screening system.*



# What do **Navigate NBS Ambassadors** Do?



## CONNECT

*Build community by connecting with other families and developing relationships with local, regional and national NBS stakeholders.*



## BUILD

*Participate in online and live training sessions, discussion groups and program activities to build leadership and advocacy skills.*



## LEAD

*Serve as leaders in the newborn screening system by raising awareness for newborn screening and supporting systems change.*



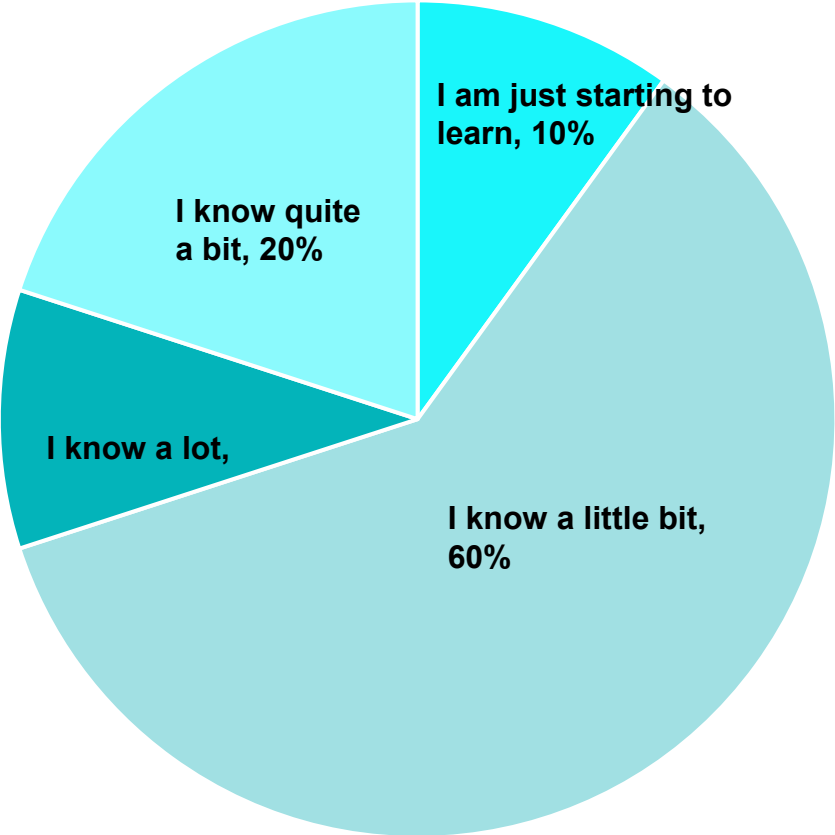
# What Training Is Provided?

- Connecting with Others
- Quality Improvement Process
- Sharing Your Story in Varied Settings
- Newborn Screening Resources
- Self Care

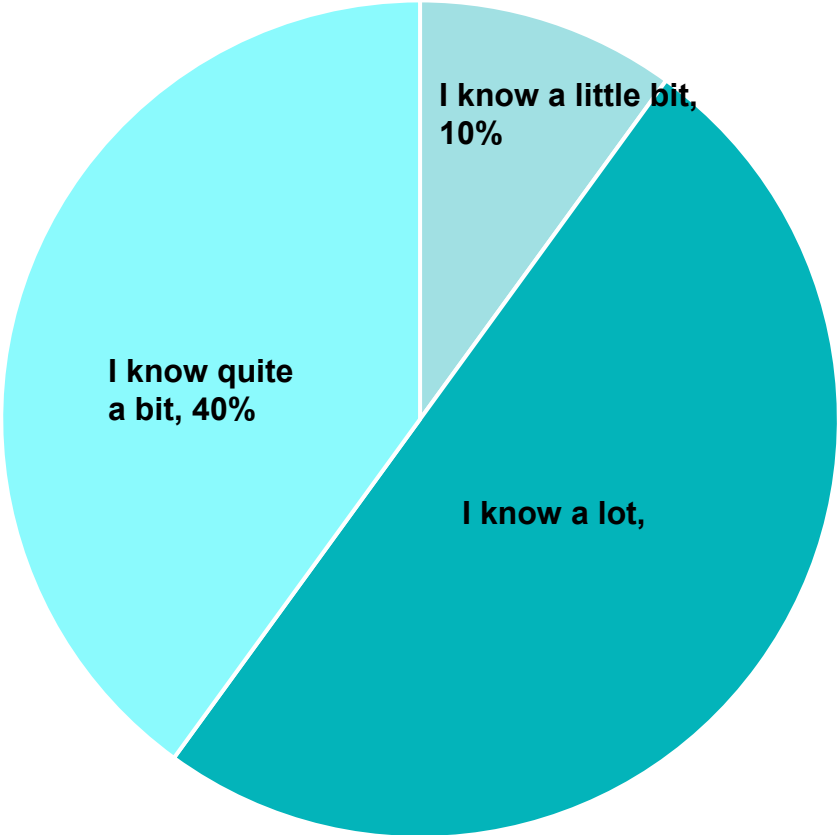


# Ambassadors know more about NBS after completing the program

Baseline



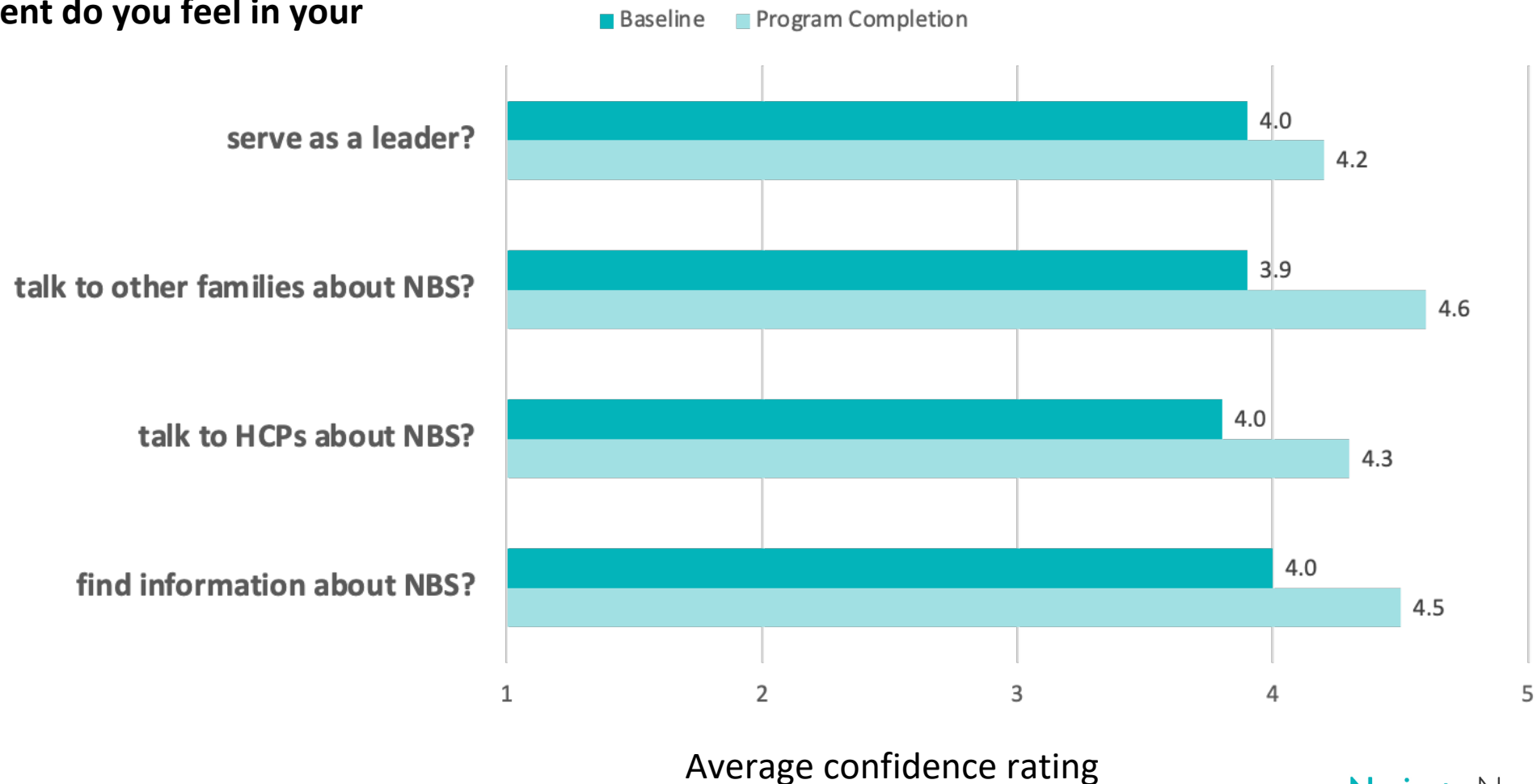
Program Completion





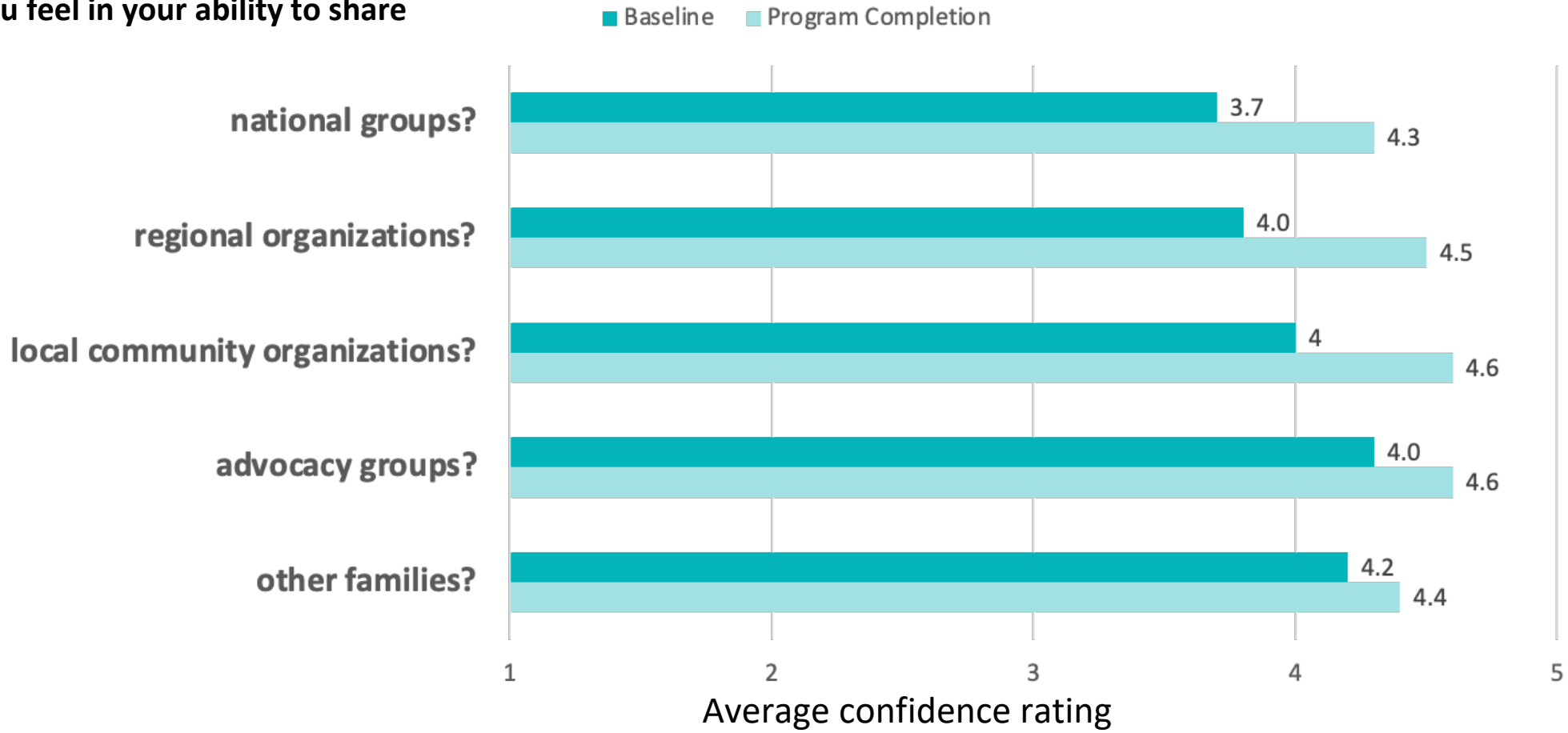
# Ambassadors have more confidence in their leadership skills after completing the program

How confident do you feel in your ability to...



# Ambassadors have more confidence to share their story

How confident do you feel in your ability to share your story with ...



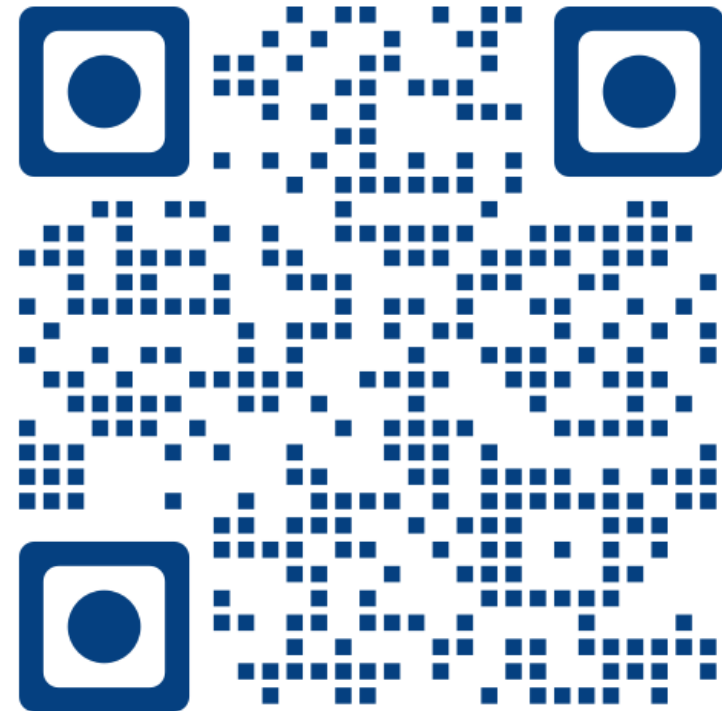
# Stories Help Us: Connect, Learn and Improve Systems

Newborn screening family leaders

who are building community

and changing the system.

At the Heart of Newborn Screening:  
Families Making Change



<https://www.youtube.com/watch?v=nniHSCPL09k&list=PL6M2gEwQoV25pYKKTwN7GnK1cf1kiDL40&index=2>

**WHAT CAN YOU DO  
TO ENGAGE FAMILIES  
IN YOUR  
COMMUNITIES?**

# REFLECT: What can we learn from what's been done?

- Education & Engagement needs to **meet families where they are.**
  - *How are you collecting and sharing family stories?*
  - *Where can you GO to meet families in their comfort zones?*
- Education & Engagement **is not one way.**
  - *How are you including families in your educational activities?*
  - *What training are you giving WITH families?*
- Education & Engagement relies on **trusted relationships.**  
**Families are key connectors.**
  - *What opportunities are you creating for families to lead program improvements?*

# **ACTION:** What Can **YOU** Do?

- 1 Share Family Stories:** Share family stories and allow those stories to change your programs.
- 2 Ask Questions, then listen:** Go to where families are having discussions.
- 3 Build Capacity:** Utilize the existing resources, toolkits and frameworks to help you



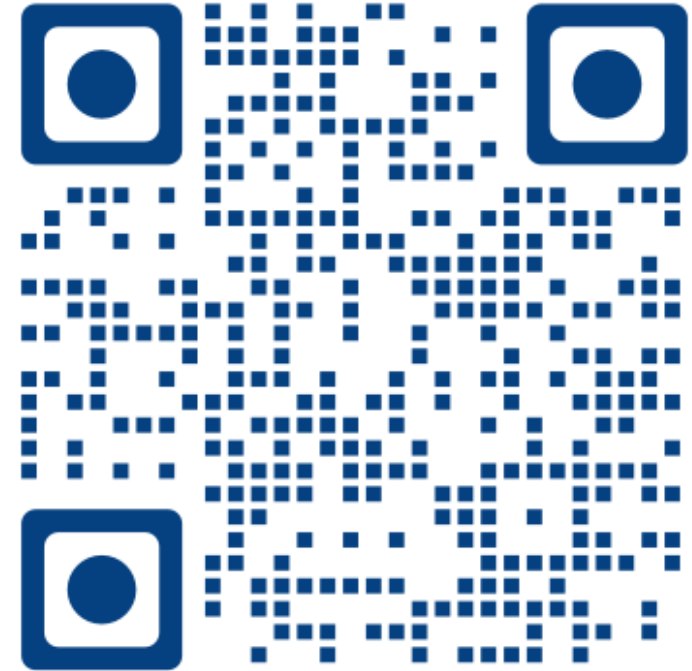


# You Are Not Alone

Navigate Newborn  
Screening: A  
Resource Sharing  
Toolkit



Navigate Newborn Screening  
An Expecting Health Program



SCAN ME

# Thank You!



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