



Engaging Family Leaders in the NBS system

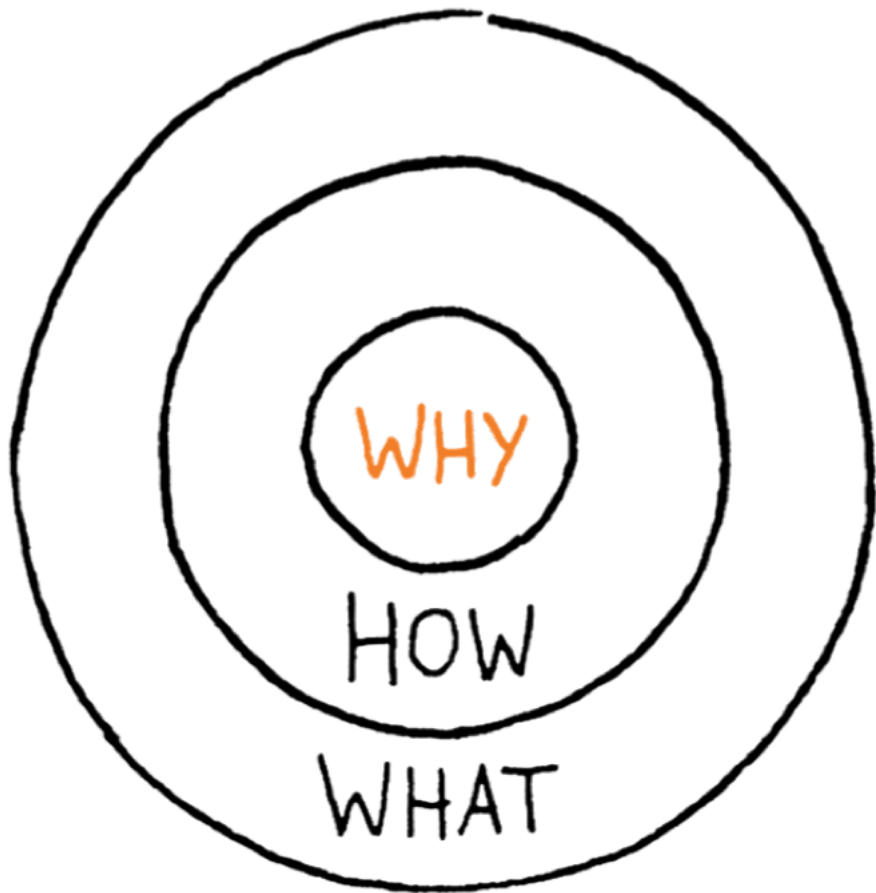
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On behalf of the many families who have engaged, shared their stories and changed the newborn screening system.



THANK YOU

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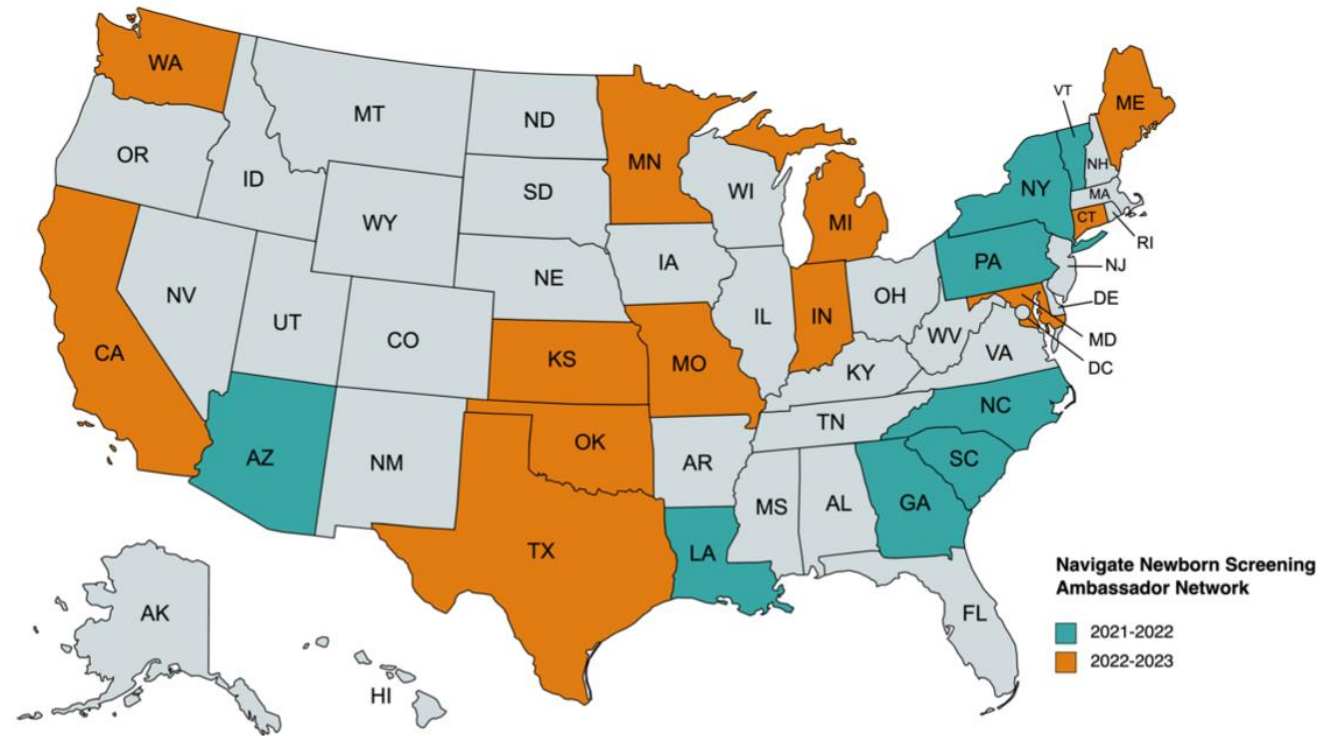
- *How can we improve communication in newborn screening?*
- *How do we coordinate efforts across the newborn screening system?*
- *How do we educate the general public about newborn screening?*

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 is the **Navigate NBS Ambassador Program**?

- A **network** of family leaders representing diverse perspectives and family experiences in newborn screening
- Annual program consisting of **online & live training sessions**, quarterly **discussion groups**, and **leadership activities**



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.

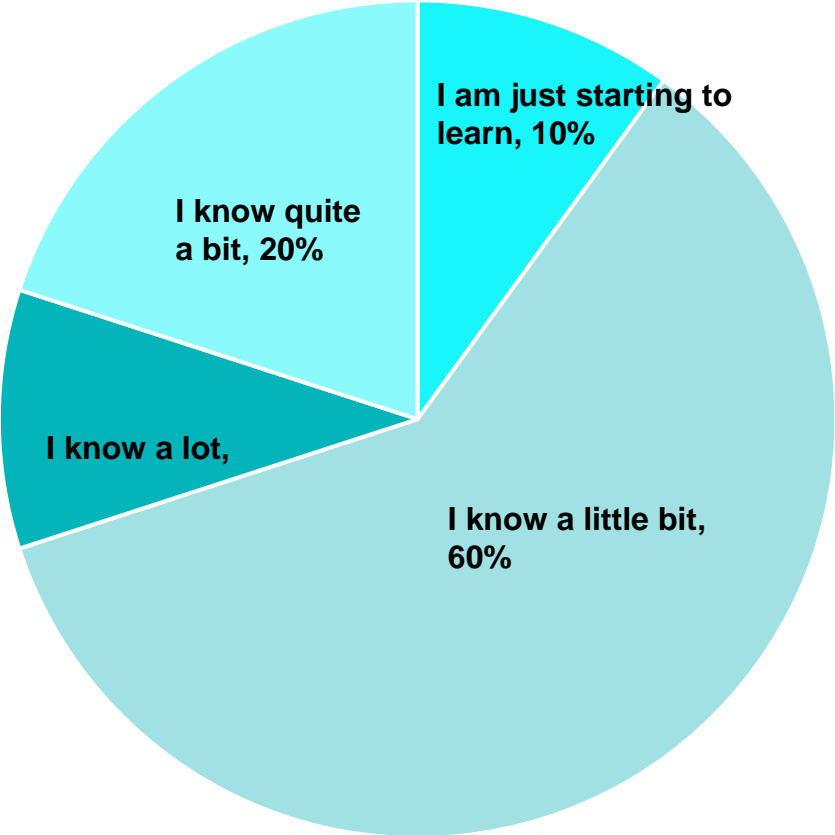
What Training Is Provided?

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

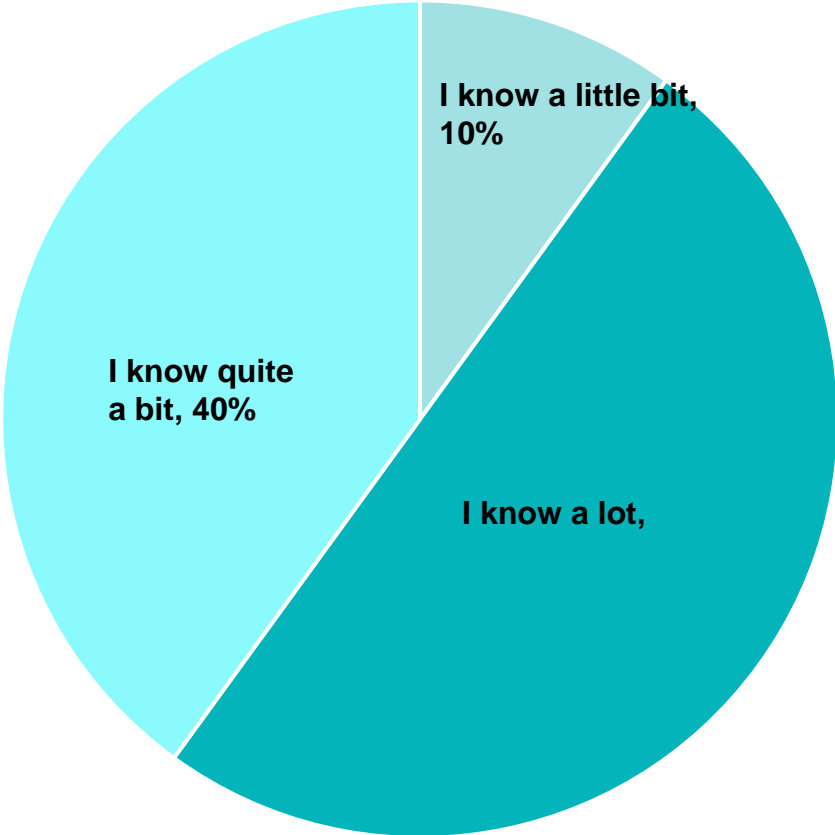


Ambassadors know more about NBS after completing the program

Baseline

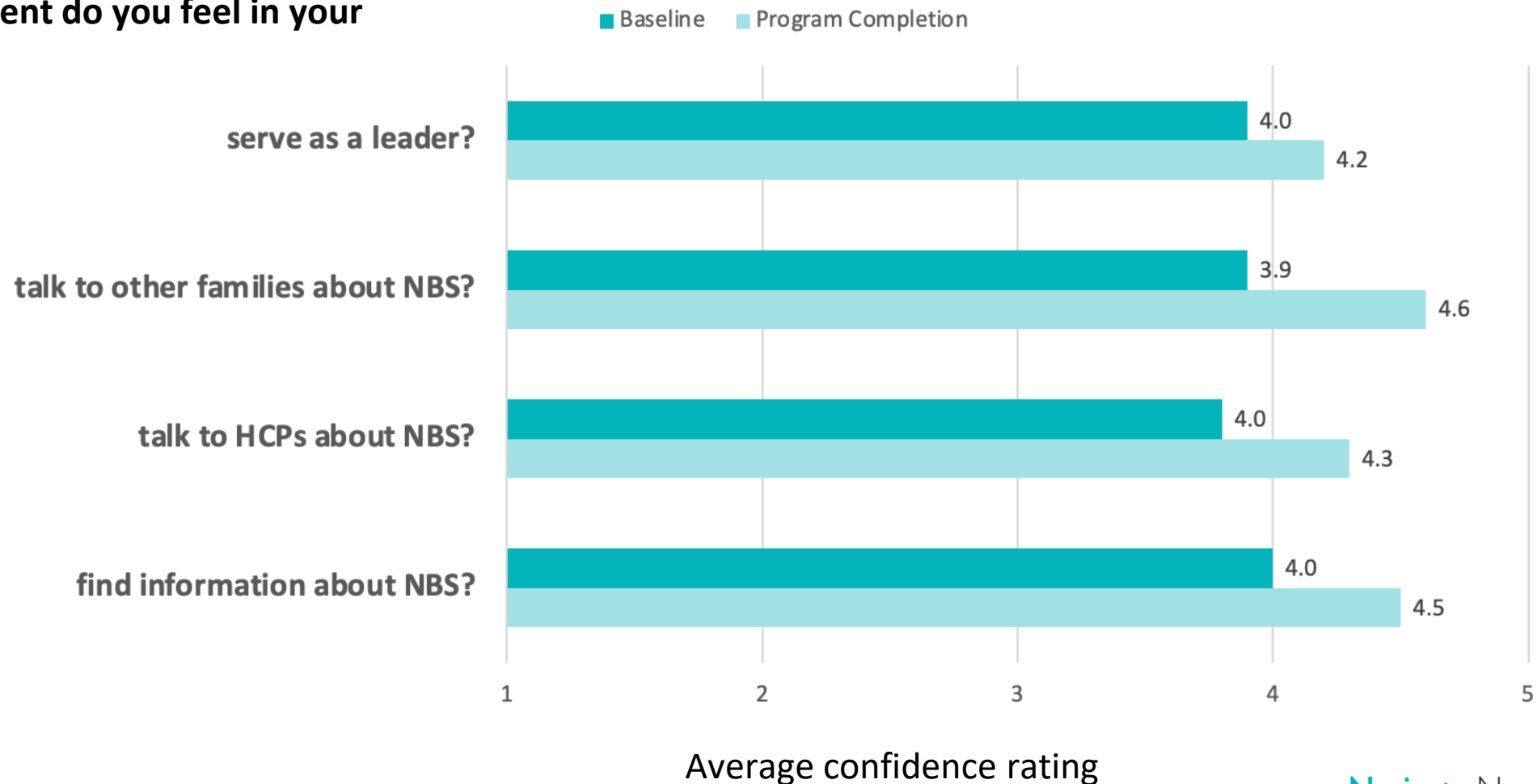


Program Completion



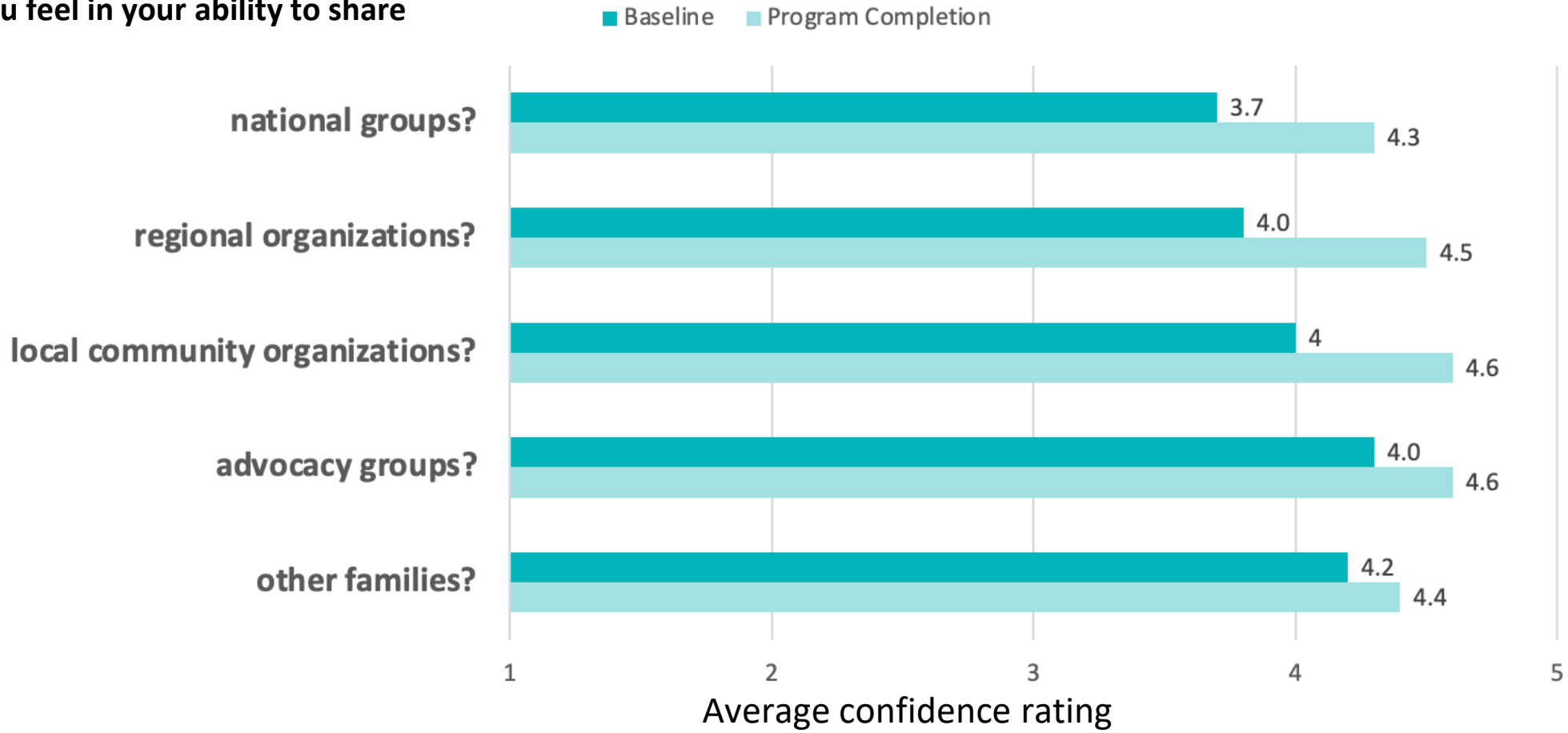
Ambassadors have more confidence in their leadership skills after completing the program

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 ...



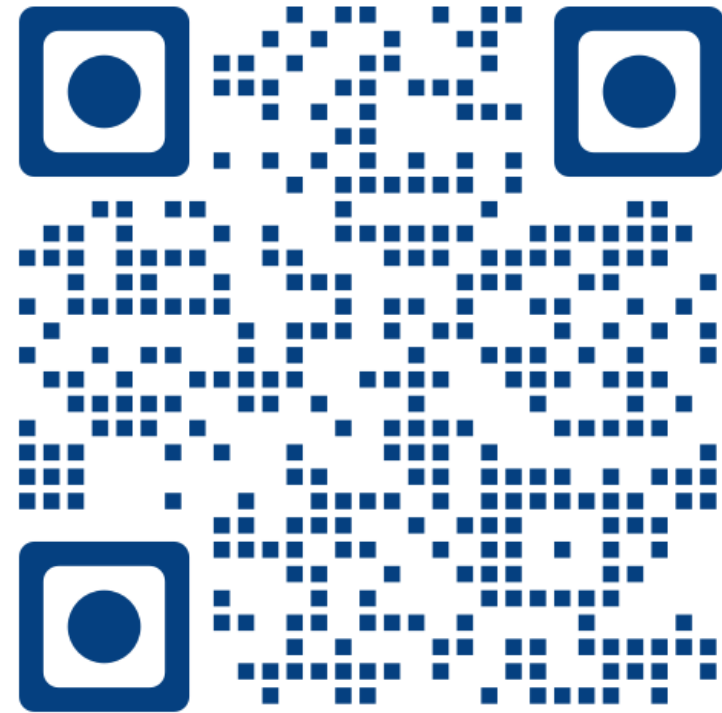
Stories Help Us: Connect, Learn and Improve Systems

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=P L6M2gEwQoV25pYKKTWn7GnK1cf1kiDL40&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

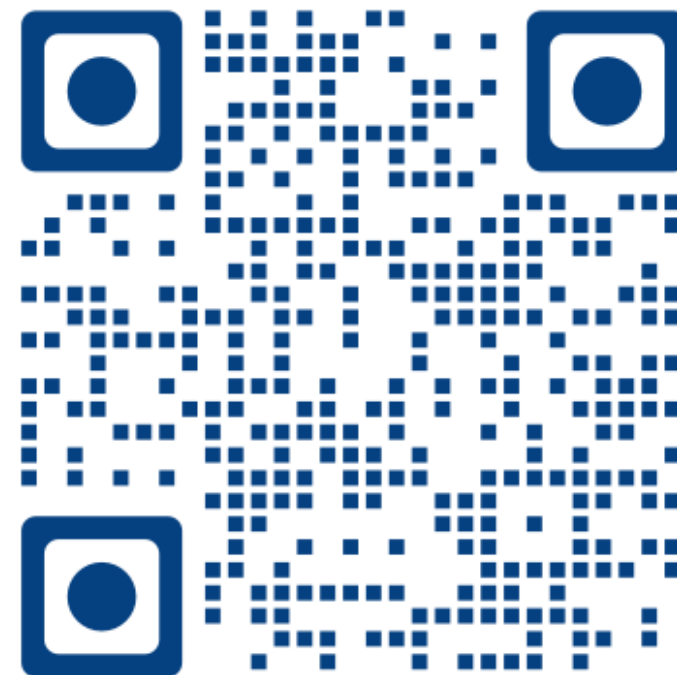


You Are Not Alone

Navigate Newborn
Screening: A
Resource Sharing
Toolkit



Navigate Newborn Screening
An Expecting Health Program



SCAN ME

Thank You!



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