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THE NEED

All families deserve to be empowered with readily available, accurate, and appropriate information to help them navigate the newborn screening system. The Newborn Screening Family Education Program is dedicated to developing opportunities for **all families to learn about newborn screening** and to creating educational and training resources that build confidence in families to become leaders in the newborn screening system.

PROGRAM GOALS

- Develop an **online educational module (Navigate Newborn Screening)** designed to deliver training and education about newborn screening (NBS) to a wide audience of parents and families.
- Expand **learning and engagement opportunities** to meet the diverse needs of families, specifically medically underserved.

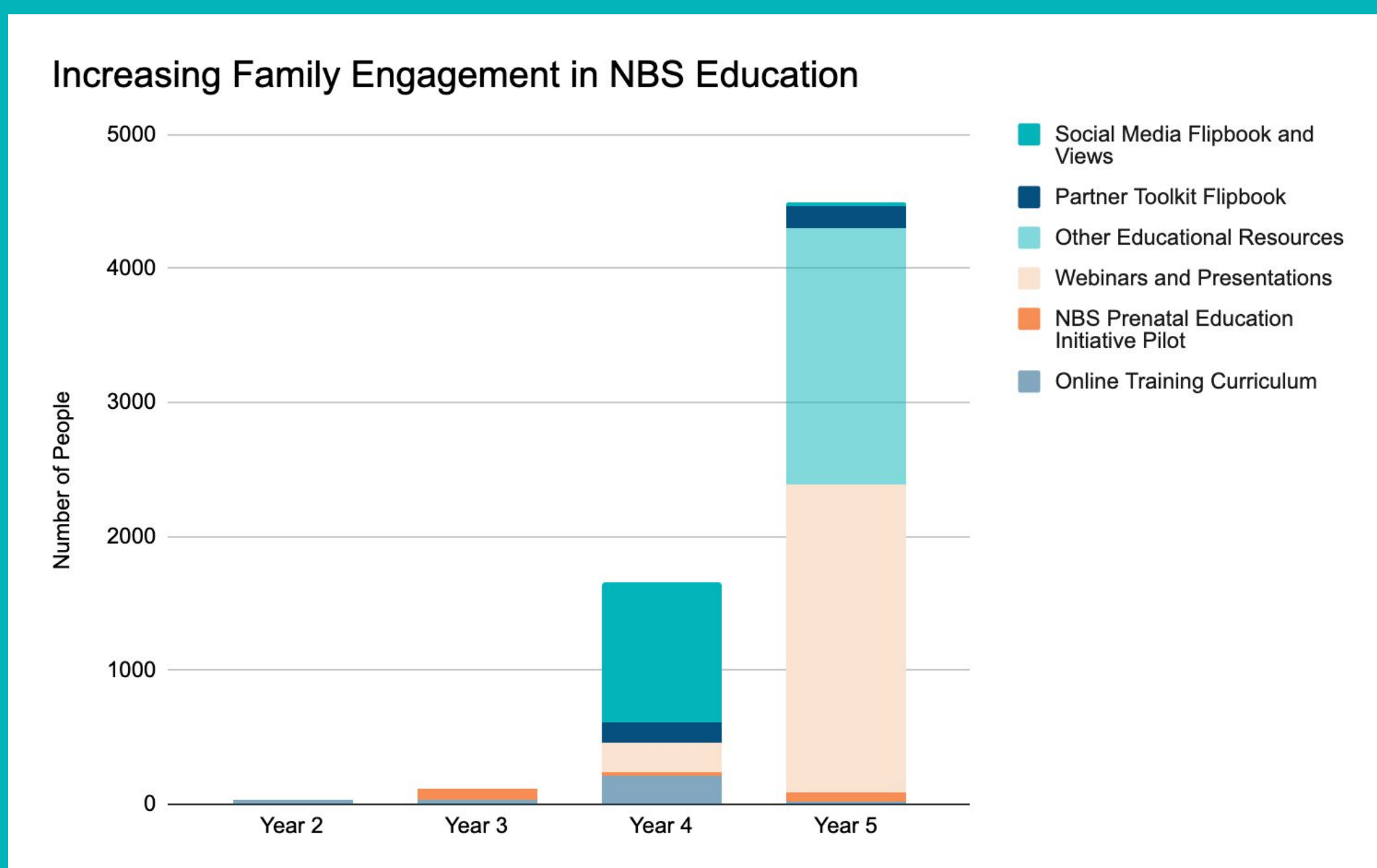
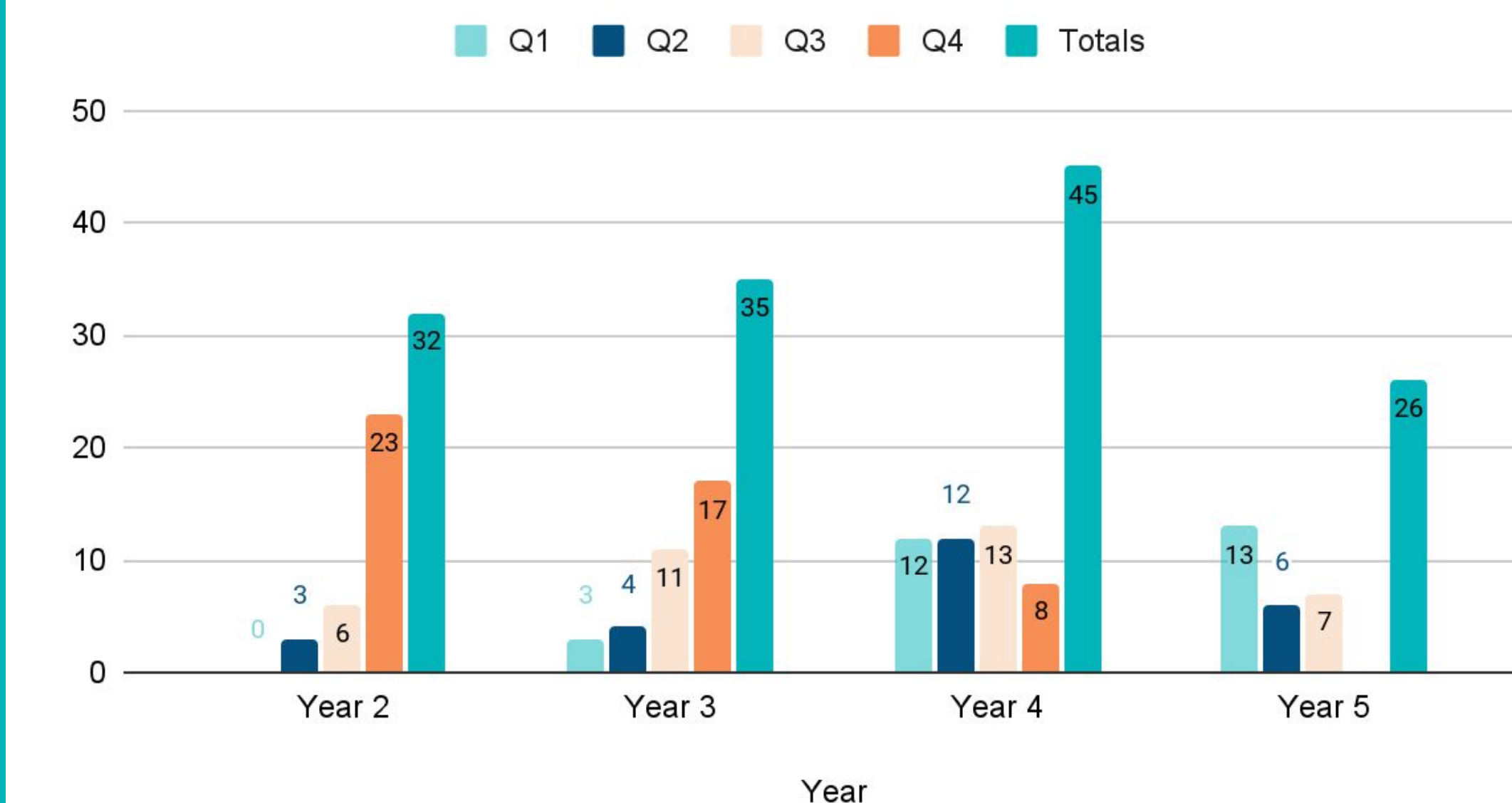
METHODS

- The program recruited families to complete the online training through a **variety of strategies** including: social media channels, dissemination partnerships, newsletters, as well as conferences at the national, regional and local levels.
- The **online training modules were hosted by a learning management platform**, Absorb LMS, which collects a broad array of metrics and reporting.
- The primary metric used to measure progress towards the objectives **were the number of participants who completed the module in either the English or Spanish versions of Navigate Newborn Screening**.
- An **evaluation form** was used to collect information about self-reported increases in knowledge, skill, ability, and self-efficacy related to NBS based on participation in the educational module.
- **Quality Improvement strategies including Plan, Do, Study, Act (PDSA) cycles were implemented** throughout the project time period to increase course engagement.
- **Additional learning opportunities and program activities were implemented in years 3-5** to expand outreach, education and engagement with families.

Navigate Newborn Screening: Results from an Online Training Module

- 138 families completed the online training module
- Each year, the curriculum saw increased enrollment from both parents, family members and health professionals interested in learning more about the newborn screening system.
- 90% of participants indicated the training was a good use of their time.
- Approximately 28% of total course enrollment was from health care providers.

Course Completions from February 2020-May 2023



Multiple strategies were implemented over the 5 year program to expand outreach and engagement **resulting in the training of 6,301 families**.

- Prenatal education pilots **trained 79 expecting mothers in year 3 and 27 in year 4**.
- A Facebook Awareness Campaign facilitated in year 4 successfully engaged over 1 million individuals and **trained 1,041 families through an online learning flipbook**.
- Additional methods such as webinars, learning collaboratives and educational videos were developed to train over **4,200 families in year 5**.

CONCLUSIONS

- As a result of expanded and targeted educational efforts, the number of parents and families trained and educated on the NBS system substantially increased from year to year.
- Building a range of partnerships that serve as trusted organizations in the community can help reach and recruit families, particularly in medically underserved communities
- Families who completed the online training provided a foundation of interested family leaders who also participated in additional training and leadership opportunities such as community discussion groups and the Navigate NBS Ambassador Program.
- The higher rate of enrollment of providers suggests an interest and need for more training and education opportunities.

Looking to the Future: At the conclusion of the 5 year program, the *Navigate Newborn Screening* module was transitioned to an educational video series now available on YouTube.



Year 1: Development

Facilitated family and provider needs assessment.
Developed framework for online training module: *Navigate Newborn Screening*

Year 2: Launch

Launch *Navigate Newborn Screening* Online Module
Establish Partnership Network to support outreach and dissemination.

Year 3: Growth

Launch *Navegando por la Evaluación del Recién Nacido: An Online Training Module* for Spanish speaking families to learn more about NBS
Launch *Navigate Newborn Screening Quick Bites: An abbreviated version of Navigate NBS* based on family feedback and requests for a shorter training module.
Launch Prenatal NBS Education Pilot Programs in Texas and Indiana

Year 4: Growth

Expand Prenatal Education Initiatives
Launch Social Media Awareness Campaign
Launch *Navigate NBS Ambassador Program* (a leadership training program for families)

Year 5: Sustainability

Expand *Navigate NBS Ambassador Program*
Develop resource and dissemination toolkits for families, partners and state NBS programs.

- **View and share** our FREE online video education series for families, scan the QR code.
- For questions or additional resources, contact mraia@expectinghealth.org

