

# Meaningfully Engaging Families in Newborn Screening Education

May 8, 2019

**Adrianna (Annie) Evans, MPH**  
*Program Development Specialist*  
Genetic Alliance



# Who We Are

Expecting Health was founded by a group of women with a simple idea: families deserve and should *expect* more – *more* support, *more* guidance, *better* health.

**Born from Genetic Alliance, Expecting Health shares science-based and policy-informed information that reflects the lived experiences of individuals and their families.**

We know that education and support don't start or end at childbirth. Instead, a whole new set of shared support and needs emerge.

## VISION

At Expecting Health, we believe that **new and expecting families**, regardless of makeup, income, or background, **should and deserve to expect health**.

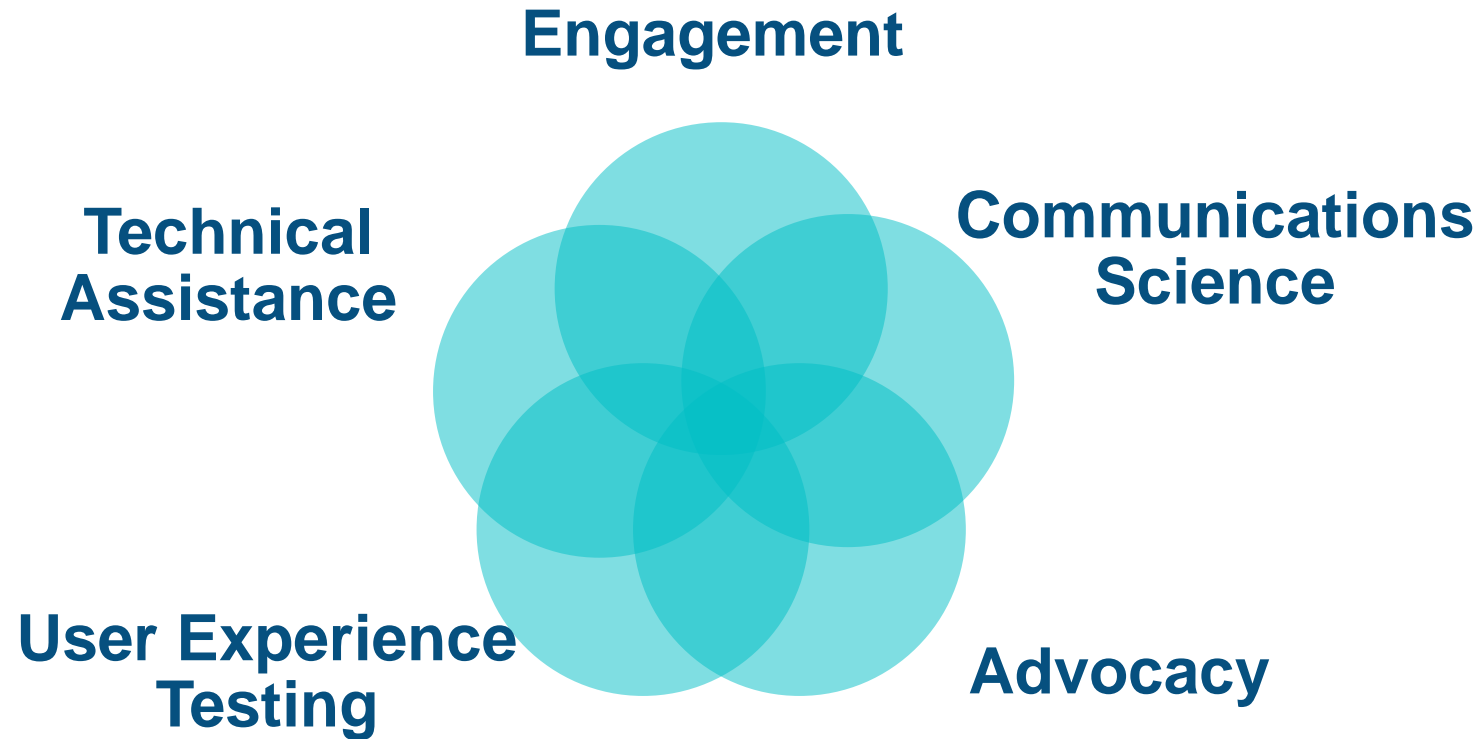
*We simply don't think it needs to be this hard.*



## GOAL

To bridge science-based information and real life strategies to help parents and parents-to-be make informed decisions.

# Our Approach



# Newborn Screening Background

# What is Newborn Screening?

- Newborn screening (NBS) is a state public health service that is performed soon after the birth of your baby (usually between 24-48 hours)
- While most babies are born healthy, some babies are born with serious, but treatable medical conditions. Newborn screening helps health professionals identify and treat these conditions before they make these babies sick.



**These conditions can be present in any family, even those without a family history of them.**

- To learn more about what to expect, check out our animated video on Baby's First Test's YouTube Channel:  
<https://www.youtube.com/watch?v=6skxqLUjFDg>



# Three Parts to Newborn Screening

1

**BLOOD TEST**



2

**PULSE OX**



3

**HEARING TEST**



## Who is screened?

- Newborn screening reaches nearly all of the 4 million babies born in the U.S. each year.
- **You do not need to request it.** It is standard across hospitals in the United States. If you're planning an out-of-hospital birth, families should ask their midwives about their newborn screening process to make sure they have proper equipment, etc.
- Most states only allow families to opt out for religious reasons.

## What conditions will be my baby be screened for?

- It's different in every state! Most states screen for **29 of the 35 conditions** recommended by the Secretary of Health and Human Services.

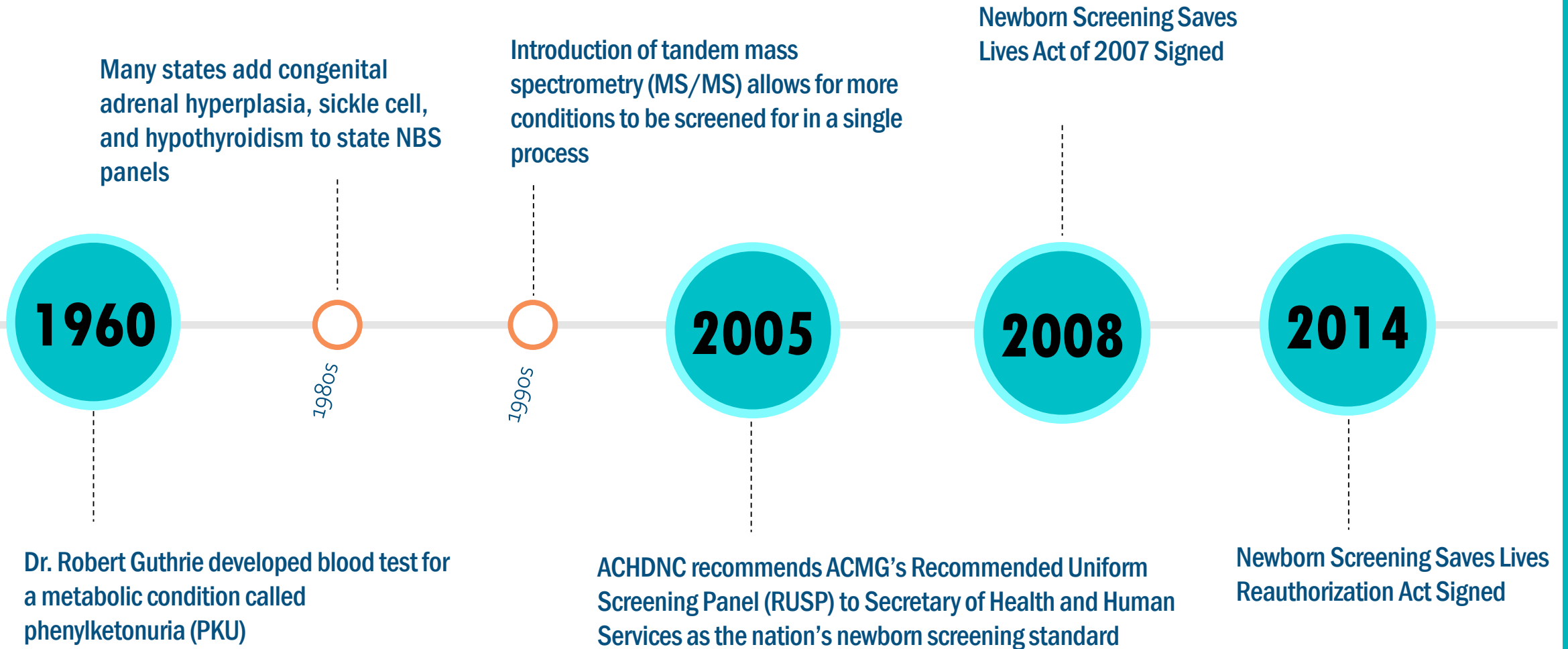
## How is newborn screening paid for?

- Newborn screening is typically covered by insurance, but some states pay in cases where families are unable to.
- If you're planning an out-of-hospital birth, ask your midwife. Some midwives offer it free within their packages.





# Important Milestones



# Introduction to the Newborn Screening Family Education Program



A photograph of a woman with dark hair, wearing a grey sweater, smiling warmly as she holds a newborn baby. The baby is wearing a white long-sleeved shirt and is looking towards the right. The background is softly blurred, suggesting an indoor setting like a home or a clinic.

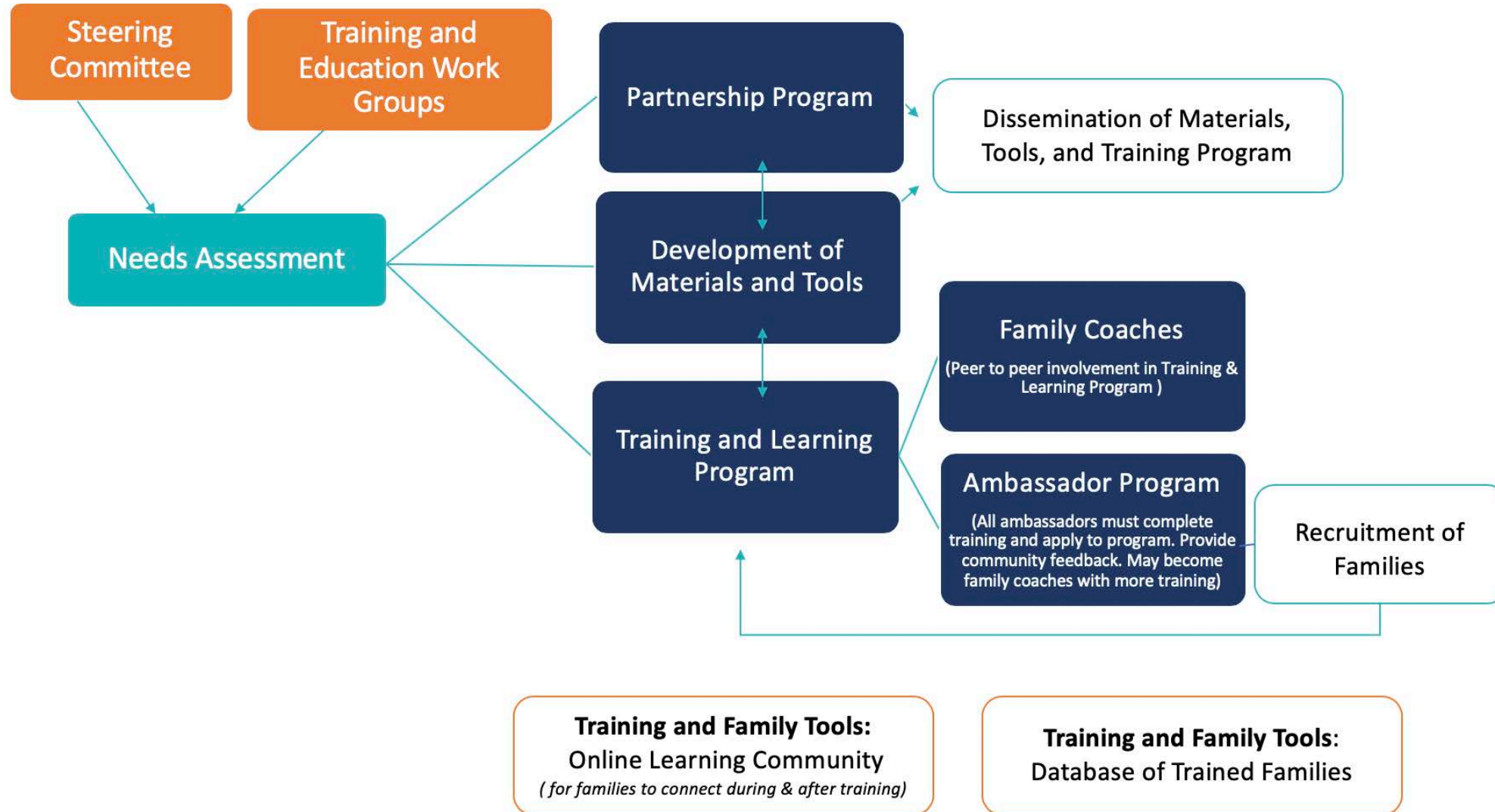
## VISION

All families have equitable access to newborn screening information and have confidence to participate in the newborn screening system.

## GOAL

Within 5 years, create a comprehensive newborn screening training program for families that provides them with the information they need to self advocate, discover resources, and serve as leaders in the newborn screening system.

# Program Overview

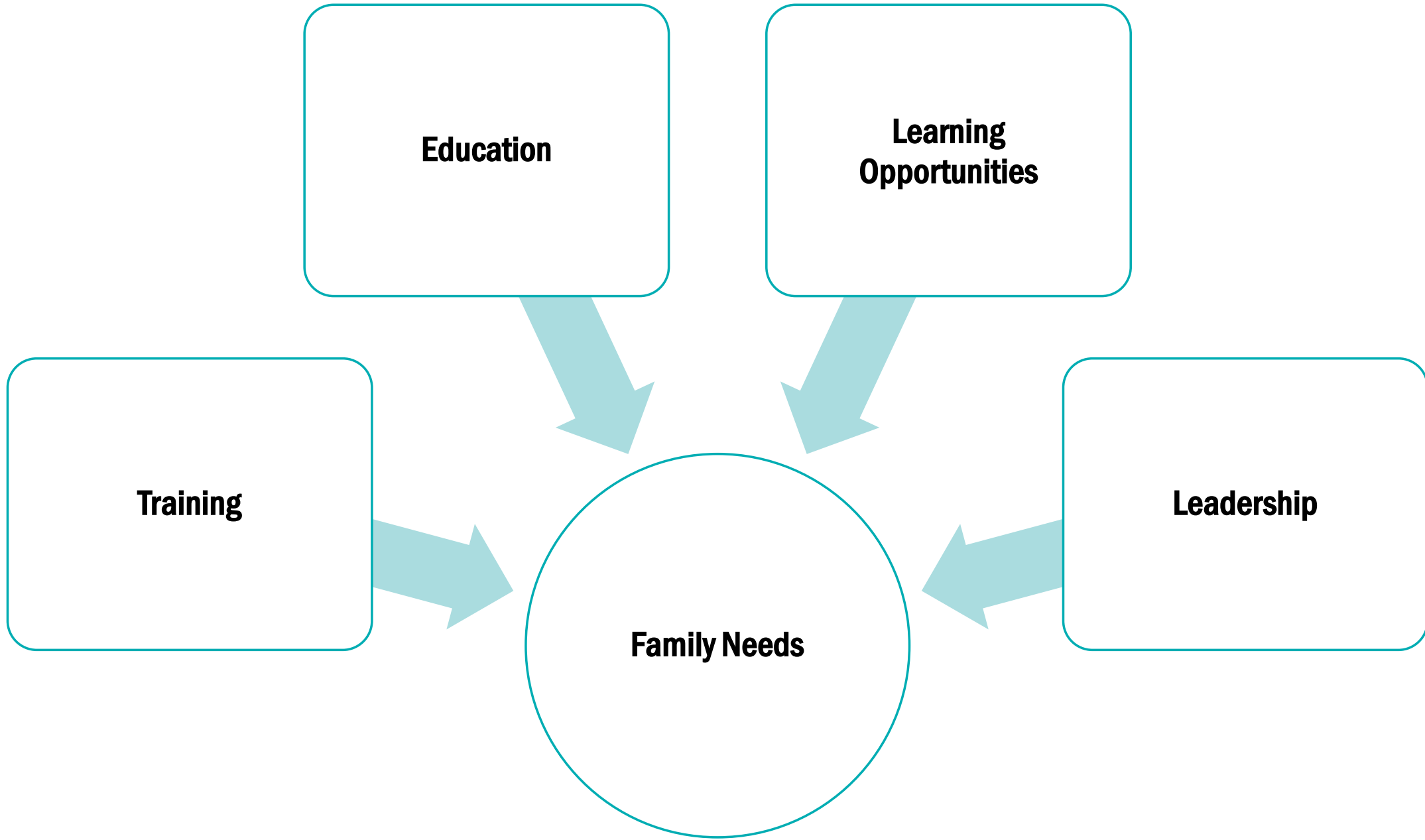


# Project Objectives

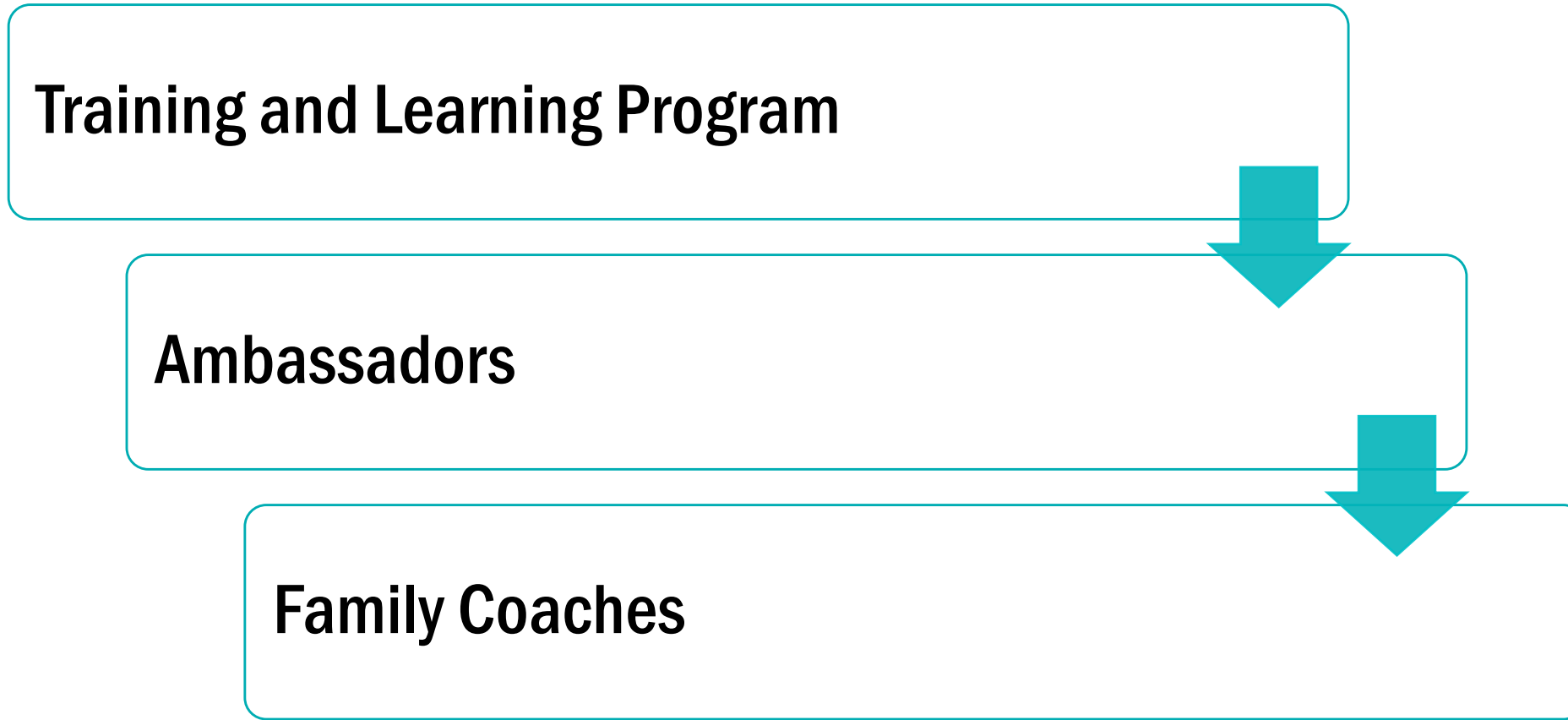
1. By 2023, increase by 20 percent from baseline, the **number of parents and families trained and educated** on the newborn screening system annually.
2. By 2023, increase by 15 percent from baseline, the **number of partnerships to increase awareness of newborn screening** and to facilitate the dissemination of materials to the target audiences.
3. By 2023, increase by 20 percent from baseline the number of families/parents trained that **report increased knowledge, skill, ability and self-efficacy** to serve as leaders on newborn screening systems-level teams.
4. By 2023, increase by 10 percent from baseline, the **outreach to medically underserved populations** and increase by 10 percent the **number of medically underserved individuals that are aware of newborn screening** and have access to information on the newborn screening system.

# Opportunities for Families





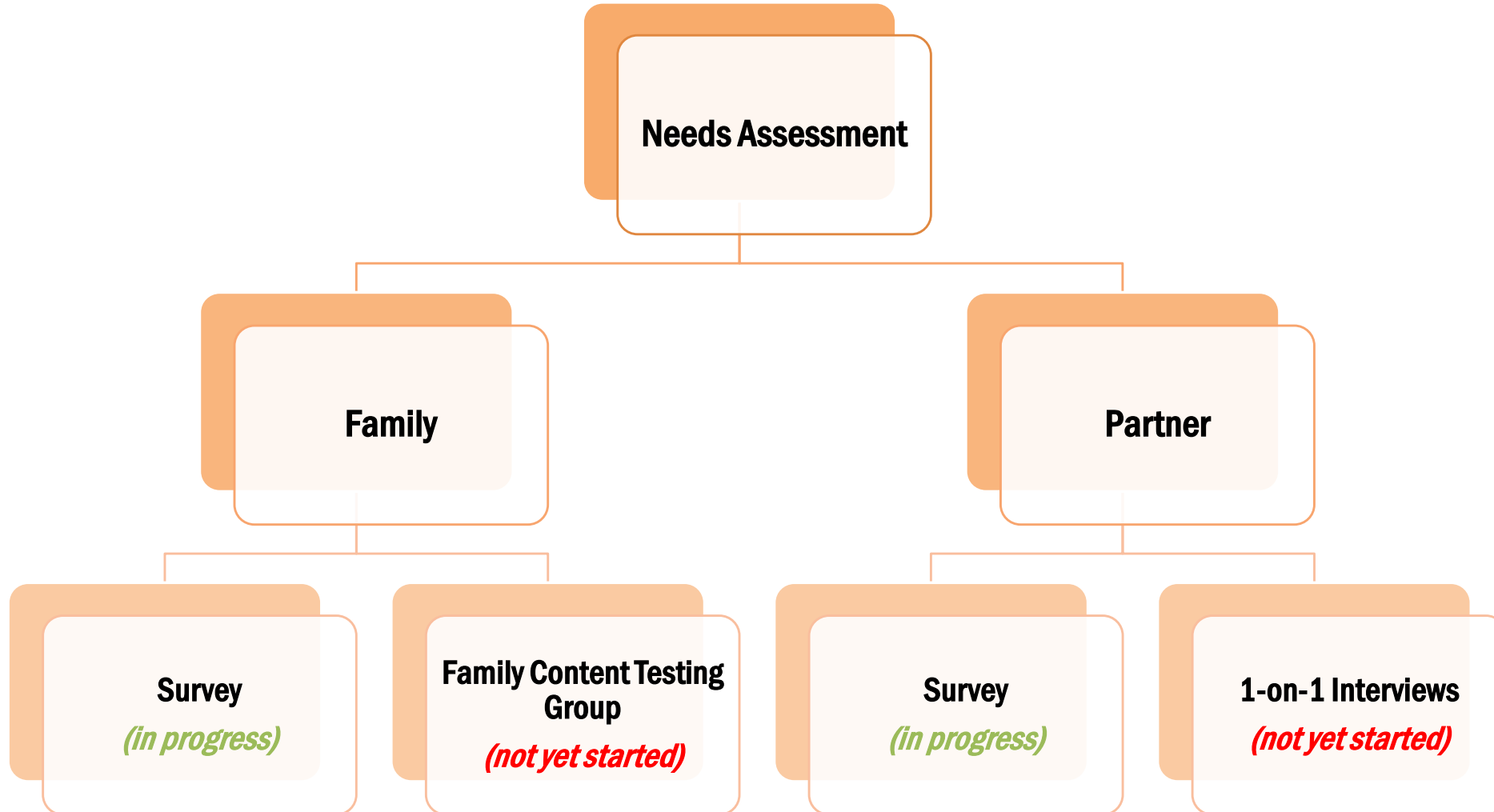
# Family Leadership in the Program





# Investigating the Educational Needs of Families and Organizations

# Methodology



# Reaching Families



# Communication & Dissemination Methods

## Trusted Community Leaders

Family leaders

Cultural brokers

Home visitors

## Media

- Social media

- Media campaigns

- Advertising

## Partnership Program

- Local and national organizations

- Healthcare professionals

# Partner With Us!

## We need help with:

- Family recruitment
- Dissemination of materials

## We can help you with:

- Family referrals
- Dissemination of your materials

# Table Discussion

1. What are your NBS education needs?
2. What training recruitment methods work best for families in your network?
3. Are we planning the most effective recruitment methods for families?
4. How can this program partner with you to add to your NBS education efforts?

# NBS Family Education Survey

*Share Your Voice and Enter to Win a \$75 Gift Card!*



<https://www.surveymonkey.com/r/GSF932T>







# Expecting Health

## Connect With Us

Annie Evans, MPH  
*Program Development Specialist*  
[aevans@geneticalliance.org](mailto:aevans@geneticalliance.org)

Natasha Bonhomme  
*Program Director*  
[nbonhomme@geneticalliance.org](mailto:nbonhomme@geneticalliance.org)

## Keep in Touch



[www.ExpectingHealth.org](http://www.ExpectingHealth.org)



@ExpectingHealth



@ExpectHealthOrg



@ExpectingHealth