

Education and Training Workgroup



Beth Tarini, Chair
Cynthia Powell, CO-Chair

ACHDNC MEETING
APRIL 24, 2019

Members



- Joseph Bocchini
- Natasha Bonhomme
- Jane DeLuca (NEW)
- Siobhan Dolan
- Barbara Ferreira
- Amy Gaviglio
- Aaron Goldenberg
- Joyce Graff
- Stacy Hines-Dowell
- Yvonne Kellar-Guenther
- Mary Klein

- Keri LeBlanc
- Sylvia Mann (NEW)
- Jeremy Penn
- Cynthia Powell
- Maa-Ohui Quarmyne (NEW)
- Britton Rink
- Beth Tarini
- Samantha Vergano (NEW)
- Sarah Viall
- Cate Walsh Vockley

Current Member Activities



- **Natasha Bonhomme**
 - NBS Family Education Project – nearing completion of needs assessment of 500 parents regarding health information preferences/usage
- **Aaron Goldenberg & Keri LeBlanc**
 - Education best practices framework to facilitate development of resources
 - <https://www.babysfirsttest.org/newborn-screening/resources/newborn-screening-education-best-practice-framework>

GUIDING QUESTIONS

1. WHAT/WHY

What is the overall goal of the education?
What is the issue that needs to be addressed?
Are the plans people and purpose driven?
What type of information dissemination will meet the goal?

Why does the issue need to be addressed?
What is the cause of the issue?
What is the motivation to address the issue now?
How high is the priority?

2. WHO

Who is the target audience?
What is the geographical target area?
What special considerations are necessary for the target population?

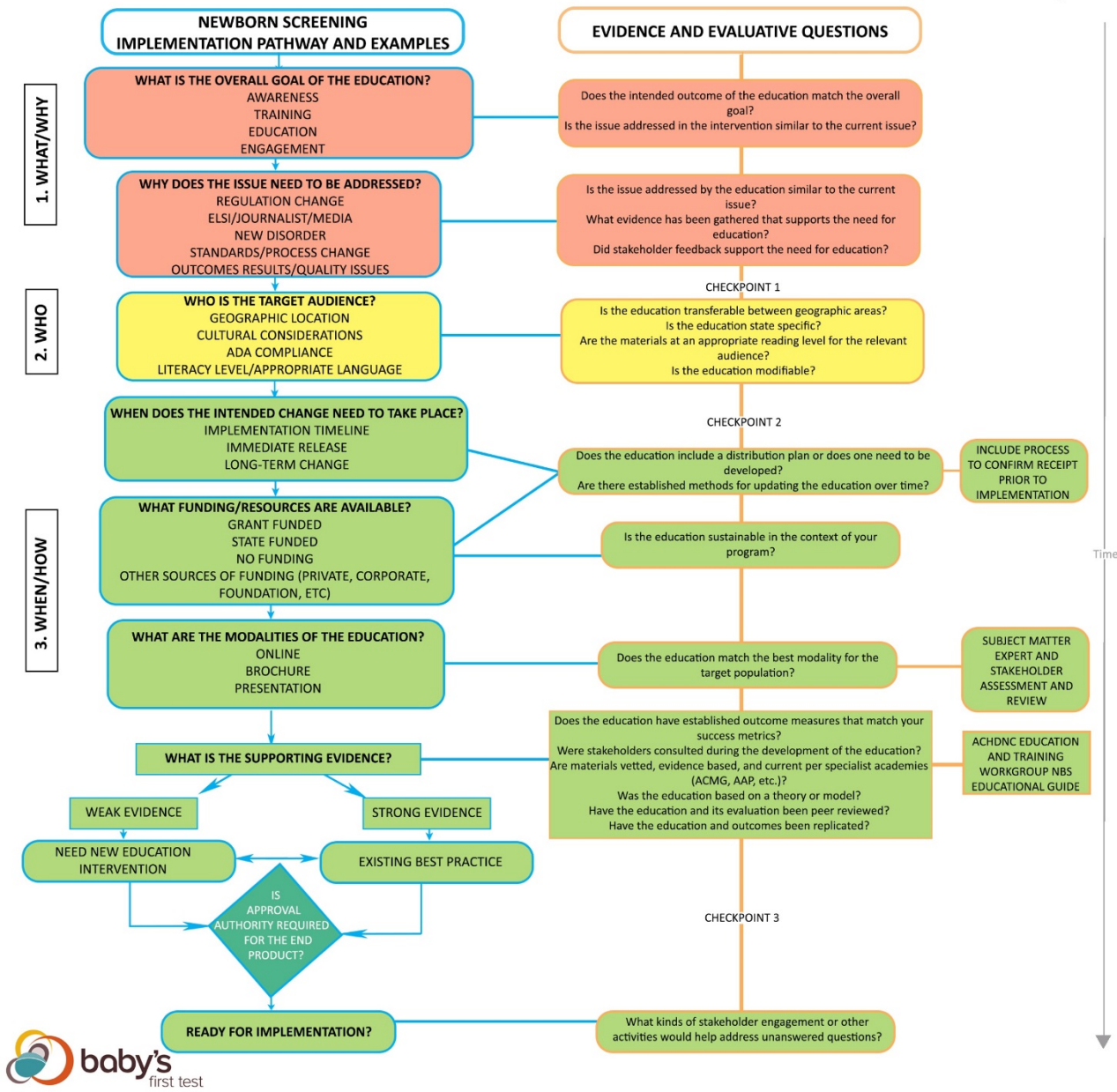
When does the intended change need to take place?
Is there an urgent need to address the issue? Provider needs, family needs etc.

3. WHEN/HOW

What modalities and distribution strategies are planned?
What resources are available for developing new materials or modifying existing materials?
What other barriers exist in developing/implementing?
What is the best modality for the target population?

Is the need, desired outcome, or audience unprecedented?
Are there existing education materials available to meet this need?

Read from left to right



Current Member Activities



- **Yvonne Kellar-Guenther, NewSteps**
 - Video tutorial, midwife-client discussions about NBS – expected summer/fall
- **Cate Walsh Vockley**
 - Training programs for midwives, CCHD screening for CCHD & donated pulse oximeters for full coverage

Michigan NBS: General Information Sheet for Parents Following Positive Screen



- **Mary Kleyn (MI NBS Program Manager) presented**
- **In-development information sheet that PCPs would provide to parents following a strong positive screen**
 - Would accompany a disease-specific fact sheet that is already provided.
- **Contains...**
 - A resources area to direct them to websites that provide helpful information regarding NBS and disorders
 - An area where families could write down questions to bring to their confirmatory appointment with the specialist
 - Information about public insurance program for children that could be used to cover confirmatory testing

RUSP Condition Nomination & Evidence Review Process



- Debriefed and discussed through lens of E&T Workgroup charge
- Main focus of discussion -- terminology
 - Shared and consistent terminology is bedrock of educational efforts
 - Members echoed concerns about use of “target” to describe identification of unintended conditions (e.g., secondary targets)

Ad-Hoc WG NBS Results Education



- **Issues for Ad-hoc group to consider:**
 - Borrowing from existing efforts – e.g., CLSI Workgroup
 - Potential future value - Development of templates that could be used across NBS stakeholders

Specific Projects



- We have completed our projects (Education & Communication Guides) and working to disseminate
- We are “off-cycle” - we will work with Committee and HRSA on new initiatives/next steps

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Questions?