

Newborn Screening Education Best Practices Framework: Real Life Examples

Baby's First Test partnered with experts in health education, ethics, policy, and public health systems to create the Newborn Screening Education Best Practices Framework. The framework has two parts: guiding questions and a flowchart. The framework is designed to help educators 1) identify an appropriate education approach to implement and 2) assess whether this approach can be considered a best practice.

TEXAS DEPARTMENT OF STATE HEALTH SERVICES

Planning for the Addition of X-ALD Screening

When Texas planned to add X-Linked Adrenoleukodystrophy (X-ALD) to their newborn screening panel, the Newborn Screening and Genetics Unit knew they had a lot of work ahead of them. When a condition is added to a panel, newborn screening programs need to consider how the addition will impact processes, resources, staffing, and of course, education.

The Texas team used the *Newborn Screening Education Best Practices Framework* to evaluate the decisions they made in designing an education approach for this new condition.

While the addition of a new condition gave Texas a clear idea of the goals and issues they were trying to address, **the framework highlighted the importance of researching existing practices and tailoring approaches to an audience.**

Ultimately, the Texas team synthesized several evidence-based approaches from other states and tailored them to the many diverse audiences impacted by Texas newborn screening. Texas intends to return to the framework when designing an initial evaluation of their education program.

NEW YORK STATE DEPARTMENT OF HEALTH

Implementation of Changes in Statewide Regulations

Recently, New York had the opportunity to update their newborn screening regulations for the first time since 1990. Similar to the implementation of a new condition, implementing new regulations requires a lot of work, particularly around educating staff about changes to programs, resources, and processes.

During this process, New York's Newborn Screening Education Working Group convened to discuss education around the regulation change. They began their discussion by using the *Newborn Screening Education Best Practices Framework*.

They talked through the guiding questions to define the characteristics of the issue they were trying to address. Then, they used the highly structured framework flowchart to focus their conversation on education strategies.

The framework provided a clear, step-by-step guide for their planning and helped them stay goal-oriented. The New York team plans to use this guide throughout their implementation process to check their work as well as for other education projects.

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We are always looking for models and this is a nice guide and roadmap. Why would we not use a well-developed model?

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Texas Newborn Screening Program

TECHNICAL SUPPORT

How Baby's First Test Can Help

Are you launching a new educational initiative, or do you need assistance on a current approach? The Baby's First Test team has more than a decade of experience in newborn screening education – everything from program development to evaluation. Specifically, we can help your program:

- **design** and tailor plain language education materials;
- **engage** communities and professionals;
- **build** strategic education and training plans; and
- **support** implementation of best practices.