Improving Timeliness in Newborn Screening: The Story Behind the Story

Marci Sontag, PhD
Project Director, NewSTEPs 360
Director, Center for Public Heath Innovation
CI International
Improving timeliness across the newborn screening (NBS) system to assure that more babies are saved. For more information, watch this video.
Timely newborn screening is critical
Funding Opportunity

• Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB), Genetic Services Branch
  – NBS Timeliness Mini CoIIN (Collaborative Improvement and Innovation Network)
  – Timeliness Quality Improvement Initiative
Timeliness Mini CoIN Overview

• Design
  – 2014-2015
  – Eight Programs Participated, 5 members on each team (including hospital representative)
  – No direct state funding
  – Continuous Quality Improvement (CQI) techniques and apply to local projects

• Connection
  • One in person-meeting,
  • Monthly coaching calls
  • Monthly webinars
  • Focus on virtual engagement

• Lessons learned that have broad applicability
Newborn Screening Mini CoILN - Lessons Learned

Video developed by programs participating in the CoILN Pilot Program
Following up on success...

- HRSA Newborn Screening Timeliness Quality Improvement Initiative
  - Three years of funding
    - CQI Training
    - State Based Projects
  - Twenty-four programs encompassing 28 states were funded
  - Collaboration
Each team chose their own focus area
Improvements in timeliness!

• November 2017 presentation to ACHDNC highlighted interim success

• It takes a village.... of unsung heroes
Unsung Superheroes
Timeliness Toolkit for Expanding Newborn Screening Services

Introduction

The toolkit for expanding newborn screening services was developed by NewSTEPs 360, a collaboration between the Colorado School of Public Health (CoSPH) and the Association of Public Health Laboratories to support states to make improvements in their courier and newborn screening (NBS) laboratory operations. It is designed to assist state NBS programs, advocates, legal, and public health professionals to shape appropriate policies and communicate the value of weekend and holiday courier and laboratory operations in order to improve timeliness in newborn screening.

https://www.newsteps.org/toolkits/timeliness-toolkit-expanding-newborn-screening-services
Final 360 in person meeting: April 2018

- Networking
- Sharing ideas and solutions
- Skill-building
  - Budgeting
  - Building process maps
  - Story-telling
Video production skill-building

• Dual purpose:
  – Inexpensive video production
  – Custom video to thank newborn screening professionals
Closing of meeting
Thank You
Acknowledgments

• Families involved in the video
  – Wilkerson
  – Kelly
  – Allen
  – Loukonen

• Denver Film and Digital
  – Steph and Chris Sealy

• NewSTEPs CoLinN Teams
• NewSTEPs 360 State and Regional Teams
• NewSTEPs 360 Teams
  – Colorado School of Public Health/Center for Public Health Innovation at CI International
  – Association of Public Health Laboratories

• MCHB Genetics Services Branch, HRSA