

# State Coordinator Meeting 2015

## Utah

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# LTFU Definitions

• **“Parents / Family Contacted but Unresponsive”**= The EHDI program has contacted the family but there is no documentation of a response OR the family responds that they will bring the infant in for recommended screening / diagnostic testing but they did not show up for the appointment.

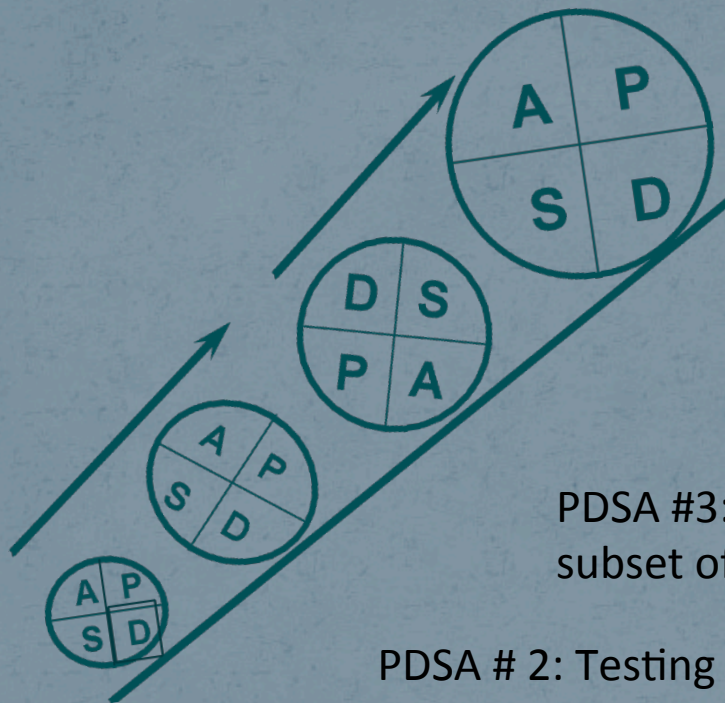
**This category is counted in LTFU.**

• following up with families who are unresponsive and could they at some point be considered passive declinations.

- **What is the potential for the strategy to improve LTFU/D?**
  - To make our follow-up protocol more efficient and easier to move babies into the most appropriate categories



# PDSA cycles



PDSA #4: Testing definitions with 2013 data

PDSA #3: Testing definitions with subset of 2012 data

PDSA # 2: Testing definitions with advisory council

PDSA # 1: Development of definitions

# PDSA #1

- **Utah EHDI Rules:** Hospital > 2 documented attempts to family and >1 to PCP prior to state EHDI follow-up.  
**Consideration:** A baby could be moved from *Contacted but Unresponsive* to *Declined Services* if the EHDI program utilizes **at least 2 methods** (e.g., phone calls, letters, emails) of contact with **accurate # and accurate address** (see definitions of accurate phone numbers and addresses below) and the family has not f/u'd within a 30 day timeframe.  
  
An *accurate phone number* is defined as a number where an EHDI staff can speak directly to the intended recipient or leave a message on a voicemail that explicitly states the name of the intended recipient.  
  
An *accurate physical or email address* is defined as a location (physical or virtual) where the letters and emails that the EHDI program sends are not returned as undeliverable and due process has been taken to assure validity.  
  
as the basis for our state EHDI f/u protocol.
- **Act:** Adapt- test the definitions with advisory group.



# PDSA #2

- **Plan:** Present definitions to advisory council.
- **Do:** The council was concerned about what is refusal and what is Contacted but Unresponsive. Several scenarios were presented that would differentiate a refusal “declination” vs Contacted but Unresponsive.
- **Study:** After gaining a better understanding of the categories all advisory member felt the new definitions helped better reflect Utah EHDI efforts.
- **Act:** Adapt- test the definitions on a data set.



# PDSA #3

- **Plan:** Test definitions with subset of 2012 data.
- **Do:** Review records of 20 babies for 2012 data that were reported as “Contacted but Unresponsive”. Using revised definitions, determine how many could be re-categorized.
- **Study:** Of 20 children, 8 could be re-categorized as Parent Declined (40%).
- **Act:** Review 2013 data with revised definitions.



# PDSA #4

- **Plan:** Test definitions with 2013 data.
- **Do:** With new definitions in place, review records of 20 babies for 2013 data that were reported as LTFU.
- **Study:** Of 20 children, 6 were Contacted but Unresponsive, 3 were Unable to Contact, 11 were “declined” (55%).
- **Act:** Implement revised definitions for future data.



# Moving Forward

- Next PDSA cycle?
  - Our plan is to test these new definitions with 2014 data. We predict that we might adopt the definitions after the 5<sup>th</sup> PDSA cycle.
- Overall what have you learned from testing this strategy?
  - By clearly pondering and defining our LTFU definitions we think we have been better able to categorize, improve our LTFU protocol, better represent Utah EHDI efforts, and determine when to stop state f/u.
- What advice would you give to other states who want to test this strategy?
  - We encourage you to examine LTFU definitions in your state.