DEPARTMENT
OF HEALTH

Newborn Screening Compass: Mapping Access

Health Equity Showcase, August 2019

What's the project?

Aim: Assure timely and easy access to health care and services for infants with MN blood spot newborn screening (NBS) results in need of follow-up, and their families.

Initial focus: Engage with health care providers & teams to hear their perspective on:

- experiences,
- strengths,
- priorities,
- concerns,
- and factors associated with access to care and services during the MN blood spot NBS follow-up process.

Why is it important?

Barriers to accessing health care and services can delay or prevent timely diagnosis (or ruled-out diagnosis) and interventions for infants with a NBS result in need of follow-up. Timeliness of NBS activities is an important Newborn Screening Quality Indicator. Delays in these activities can have negative effects on the NBS system, including for children and their families.

More work is needed to understand stakeholder views and experiences with access to needed care and interventions in order to assure timely NBS follow-up of infants.

How did you accomplish it? Who were your partners?

In joint effort with colleagues across MDH, we visited primary and specialty health care teams to hear their points of view on access to care and services during the initial NBS follow-up period.

We then did extensive process mapping to help us see where delays in follow-up may happen. The process mapping also helped us know where authentic engagement with various stakeholders is needed to clarify unknowns and assumptions in our follow-up processes.

Lessons Learned

Stakeholders should have been included earlier, in the project design phase. Stakeholder engagement should have been ongoing, throughout the project.

Partially influenced by the scale of unmet needs identified, project scope changed. When the scope grew beyond dedicated project resources, the project came to a standstill.

More work with stakeholders is needed to develop short-term solutions to overcome unmet needs in a timely way. Longer-term solutions are also needed to prevent these barriers from happening in the first place. Both approaches are needed to reach the project aim.

Results and Next Steps

Initial stakeholder engagement identified several unmet needs thought to delay or prevent timely access to care and services for at least some infants with MN NBS results in need of further follow-up, including:

- family awareness of the newborn's health insurance status,
- access to transportation,
- access to appropriate language assistance,
- access to recommended infant nutrition and supplies,
- access to care coordination, and
- education about barriers faced.

Later, changes were made to MDH NBS follow-up documentation processes. Now we can more easily identify data on barriers to care and services for children with conditions detected by MN NBS, from their family's perspective. Data collected from families includes the unmet needs learned through this project, and the associated public health interventions provided to families to help meet the individually-identified needs. Systematic analysis of this data should more readily find gaps in access to care and resources at the population level. More work with stakeholders is important to strategize, prioritize, and carry out efforts to promote timely and easy access to care and services for infants with NBS results in need of further follow-up.

Team Members

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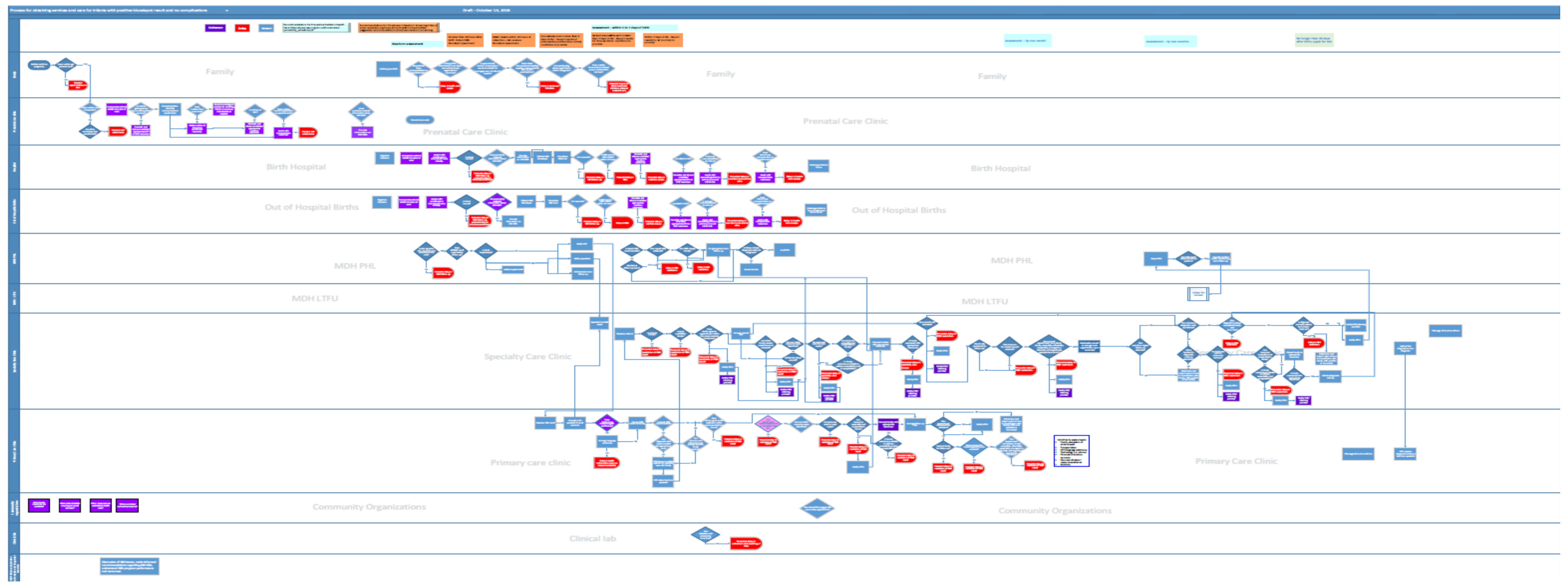

Process Mapping: Newborn Screening Access to Care and Services