

Equality and Equity in Newborn Screening

Amy Gaviglio, MS, CGC

Aaron Goldenberg, PhD, MPH

Universality of Newborn Screening

“... newborn screening is universally available in varying forms to all infants born in the United States, regardless of ability to pay or other familial factors (e.g., ethnicity, area of residence, literacy level, or language). It is important that universal access to this screening and its central public health focus are maintained, while efforts move forward to bring uniformity and equity to State screening efforts.”

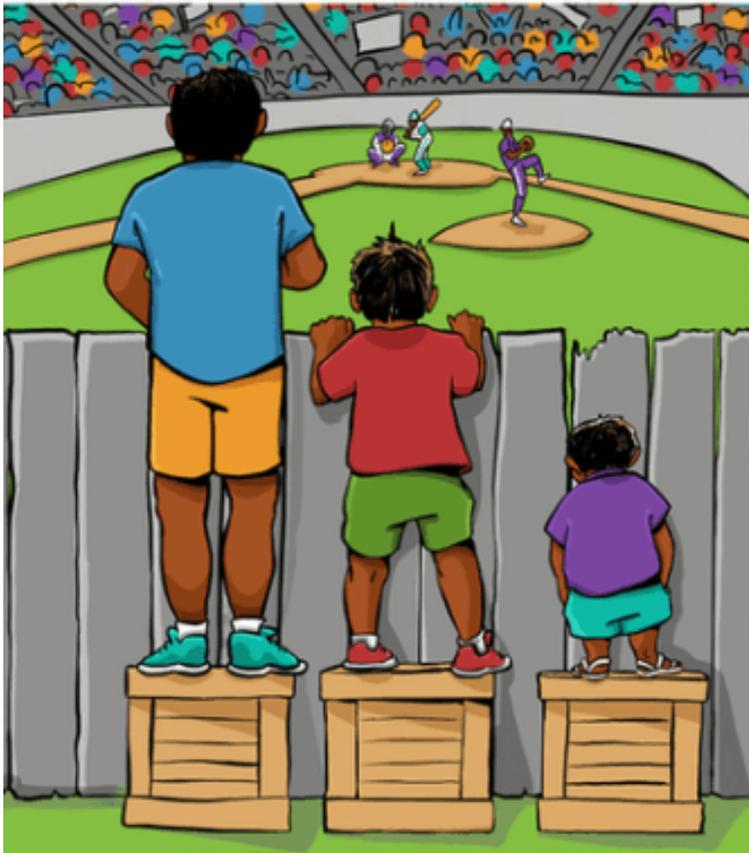
- Discovering a condition in the newborn period is not sufficient to eliminate disparities in outcomes:
 - Adherence to follow-up and management
 - Underlying social and environmental factors
- “More important, NBS programs need to maintain their universal nature and public health follow-up structure to maximize their role in reducing population-based health disparities.”

DOES THE UNIVERSALITY IN SCREENING ITSELF
GUARANTEE UNIVERSALITY IN DIAGNOSTIC ACCESS,
QUALITY OF MEDICAL CARE, AND ACCESS TO
TREATMENT?

HAVE WE MAXIMIZED OUR ROLE IN IMPROVING
OUTCOMES?

Equality versus Equity versus Justice

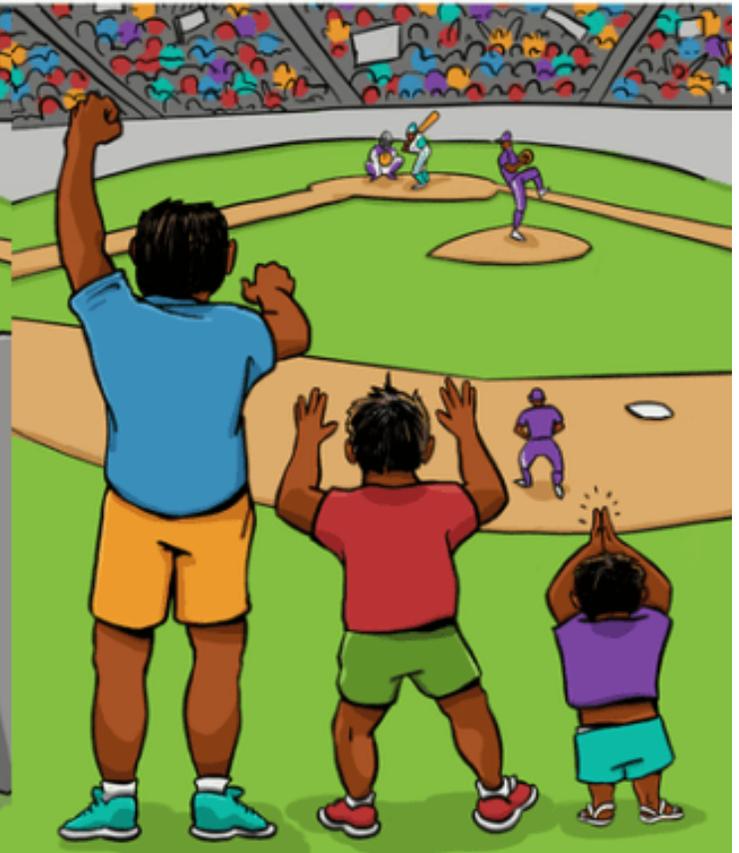
Equality



Equity



Justice



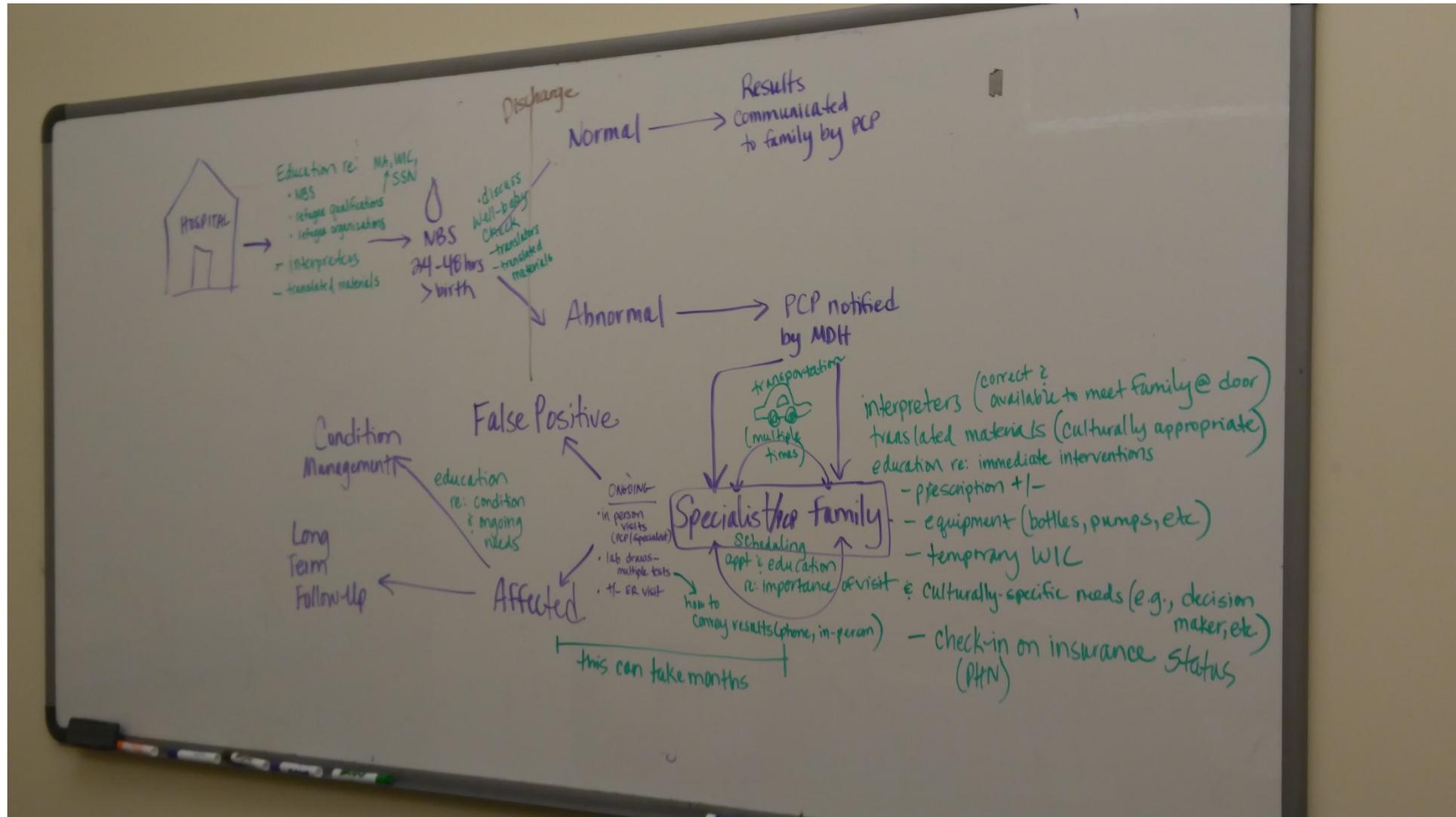
Adapted from Original Image created by Craig Froehle

Is the Totality of Newborn Screening Universal?

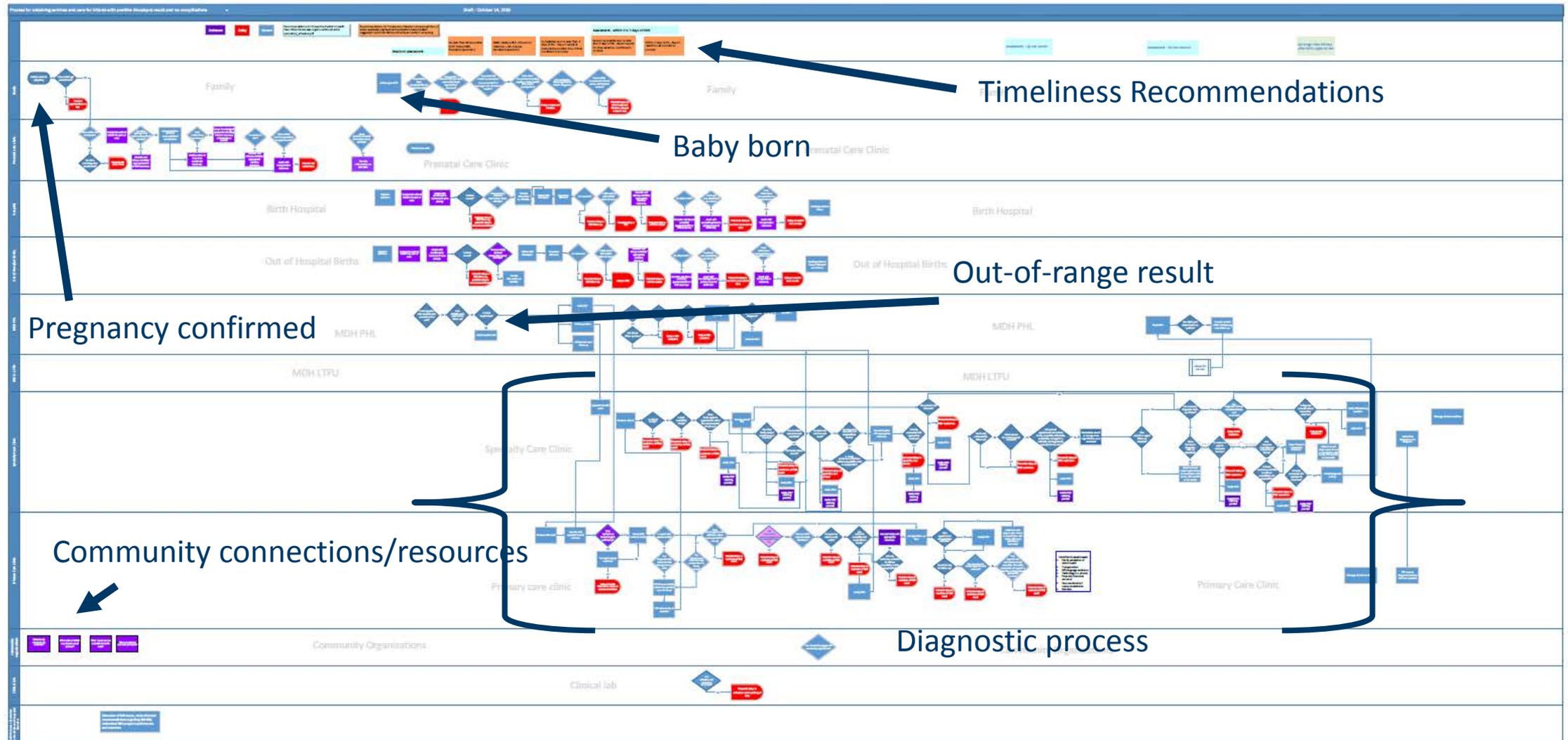
NBS Condition Category	Access to...	Proximate Cause(s)
All	Education (about NBS, clinical management, etc.)	Language, culture, literacy
CF	Screening benefits	Panel not inclusive
All	Care (diagnostic, therapeutic)	Language, culture, financing, transportation, literacy, etc.
IBEMs	Medical foods/formula	Financing
Hemoglobinopathies	Pain management	Structural racism
SCID/LSDs	Monitoring and transplantation	Financing, geography
All	Pediatric-to-adult transition	Workforce
All	Genetic services (sequencing, etc.)	Financing, geography, culture

Adapted from Anthony Steyermark, PhD

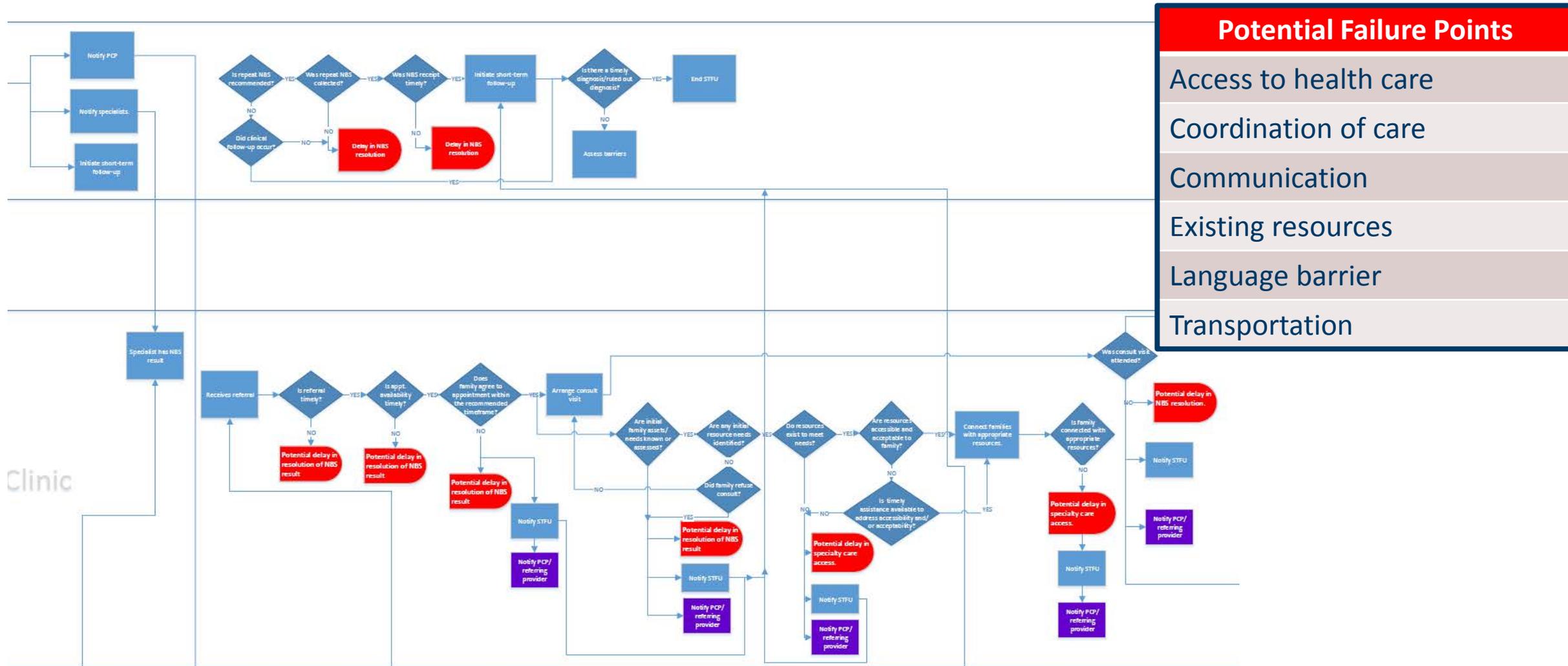
Mapping the Process. Version 1



Mapping the Process. *Version 1000*



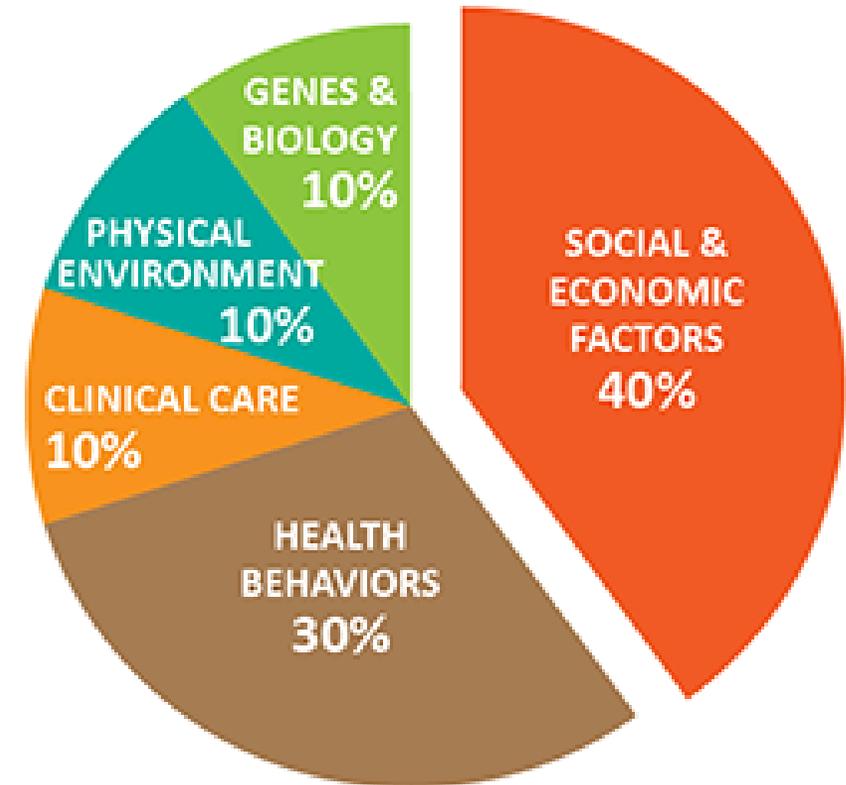
Potential “Failure Points”



- Continue the mapping process
 - Assess what we know versus what we think we know
- Address each potential failure point looking for short- and long-term solutions
 - **EXAMPLE:** TRANSPORTATION
 - **SHORT TERM:** NBS program subsidizes taxi transportation through existing MDH programs (e.g, Refugee Health and Infectious Disease)
 - **LONG TERM:** Engage DHS to understand transportation voucher system, identify system gaps, and work towards state-wide policy solution

Considerations

- **Renewed focus on quality versus quantity**
 - Newborn screening is a *system*
 - Mandatory screening ≠ same outcomes for all
 - Mandatory screening = more responsibility
- **The entire screening and clinical infrastructure needs to be able to support the best outcomes for ALL infants and families impacted by screening**
 - False Positives/Negatives
 - Families without means for diagnosis/treatment/monitoring



DETERMINANTS OF HEALTH

Equity, Newborn Screening, and Genomics: New Challenges

- The expense of genomic technology
 - Sequencing, follow-up services, data storage and management
 - Impact on programs and families
- Even if sequencing is cheaper, would underserved communities have access to “genomic services”
- Genomics may make the equity/access focus of NBS services more challenging

On the other hand....

- NBS is one of the only public health or medical systems facing the genomic era with “universality” as a foundational starting place
- NBS may represent the most equitable way to integrate genomics into population health
- Or..at least the larger genomics community could learn from NBS

Project: Genomics and the Newborn Screening System

- Project Goal: To identify and begin addressing the programmatic and policy challenges raised by the integration of NGS technology into State NBS programs.
 - HRSA Child and Maternal Health Bureau (R40MC268050102)
 - Co-PI's: Aaron Goldenberg and Beth Tarini (working with Amy Gaviglio)
 - Worked with the 7 HRSA Regional Genomics Collaboratives
- 12 Focus Groups/Discussions with State NBS programs

Results Related to Equity

- “I think the universality is really a baseline value that I think most Newborn Screening people share”
- “it’s one of the only places in life where there’s not healthcare [disparities]... that’s our mantra, right, is universal health? The only time in your life you really could get it [genomics], and so where can we fit in there to benefit our population?”
- It’s equitable. A limited next-generation sequencing, newborn screening panel would be equitable so that every child in the state would be on equal platform for finding out as a second tier, not as a first tier, as a second tier. It would be equitable for to be able to say ‘Here it is. We’ve confirmed it. We’ve got it, and we can then make it available to other adverse family members, regardless of your insurance,’
- But I think that the backbone of this whole thing is missing, ‘cause we don’t have socialized medicine in the country. So you have this patchwork of healthcare, and we’re on the front end giving, if we gave results out, even if we could have people to interpret it, families don’t have equal resources to be able to treat, manage or get whatever services they need, so we don’t have the backbone in our country to serve our families well.

Disparities in Education: Conveying Complex Information

- Newborn Screening is becoming increasingly complex
 - More rare disorders; ability to detect carriers; late-onset disorders; parental options
- At the same time...
 - Only 12% of adults have proficient health literacy¹
 - Almost 10% of the US Population is considered Limited English Proficient²
 - Medicaid covers ~50% of births (25% Hawaii -70% Louisiana)

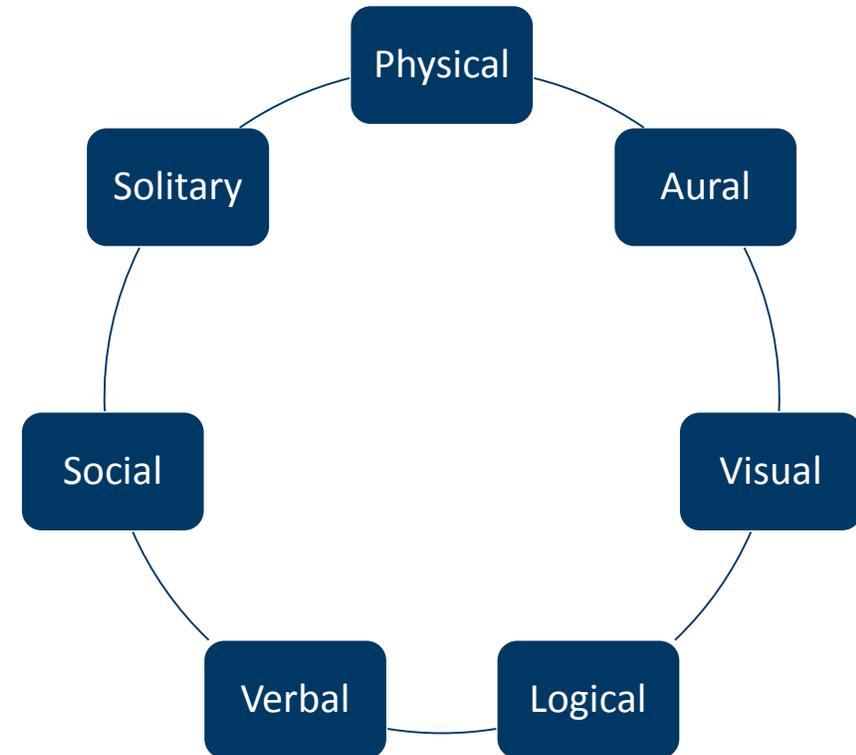
¹ National Assessment of Adult Literacy; ² Migration Policy Institute, ³ plainlanguage.gov

Other Known Challenges in Education

- Limited shared best practices
- Not a one and done process/ needs long term sustainability
- Competing priorities and messages – Hard to distinguish what is needed and what is noise
 - Messages need to seem relevant to audience
 - Messages need to be presented in more than one situation – multiple touchpoints
- Channels where people get information can change overtime
- Time consuming and often not prioritized

Addressing these Challenges

- Most information is provided in text form though people understand information through other means
- Plain Language Initiative: Communication your audience can understand the first time they read or hear it³
- 64% of pregnant women access info from smartphone
- Have to take into account
 - How to keep information simple
 - Understand audience so your efforts match what they are ready to understand
 - What are the cultural norms as well as what is day to day life entail



Modified from <http://www.learning-styles-online.com/overview/>

Acknowledgements

- MN Dept of Health
 - Kristi Bentler
 - Tony Steyermark
 - Judy Bifulk
 - Maggie Dreon
- University of Iowa Hospitals & Clinics
 - Beth Tarini
- Baby's First Test
 - Natasha Bonhomme