

The background of the slide is a photograph of the North Dakota State University gate. The gate is a black wrought-iron archway with the words "NORTH DAKOTA STATE UNIVERSITY" in white capital letters. To the right of the gate is a brick pillar topped with a white sphere. In the foreground, there is a paved walkway with a brick pattern, flanked by flower beds containing pink, yellow, and white flowers. Two people are walking on the path. The sky is blue and there are trees in the background.

NORTH DAKOTA STATE UNIVERSITY

Review of Best Practices in Documenting Newborn Screening Refusals for States

October, 2014

Supported in part by a grant from HRSA H46MC24089

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	Number of States	Percent of States
Refusal for any reason	15	29%
Refusal for religious reasons	33	65%
No provision for refusals	3	6%



	No State Form		Optional State Form		Required State Form	
	n	%	n	%	n	%
Refusal provision						
Refusal for any reason	5	10%	6	12%	4	8%
Refusal for religious reason	12	24%	6	12%	15	29%
No provision for refusals	3	6%	0	0%	0	0%
Total:	20	39%	12	24%	19	37%

Purpose of Project

- Documentation of refusals is considered good practice for state programs and supports the goals of newborn screening programs
- Wide variation in what states do to document refusals
- Little information available on how to effectively document refusals

Methods

- Survey of state newborn screening coordinators
 - 82% response rate
 - \$5 gift card offered
- Collected newborn screening refusal forms
 - 93% of optional or required forms gathered
- In-depth interviews with five states
 - \$10 gift card offered
- Focus group with parent advocates on refusal forms



Results

- Highlighted the value of documenting refusals at the program level

All newborn screening programs should require program-level documentation of newborn screening refusals

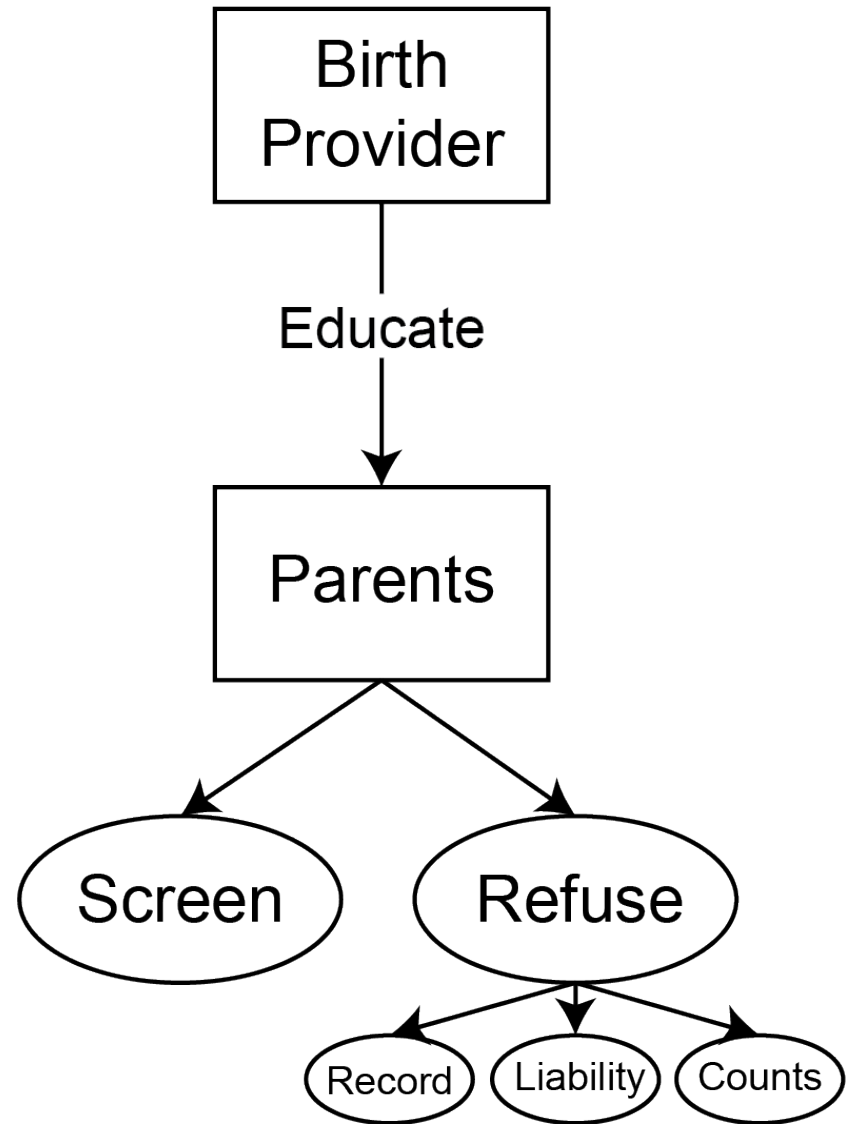
(States without a provision for refusals should document refusals so information is available for appropriate follow-up)



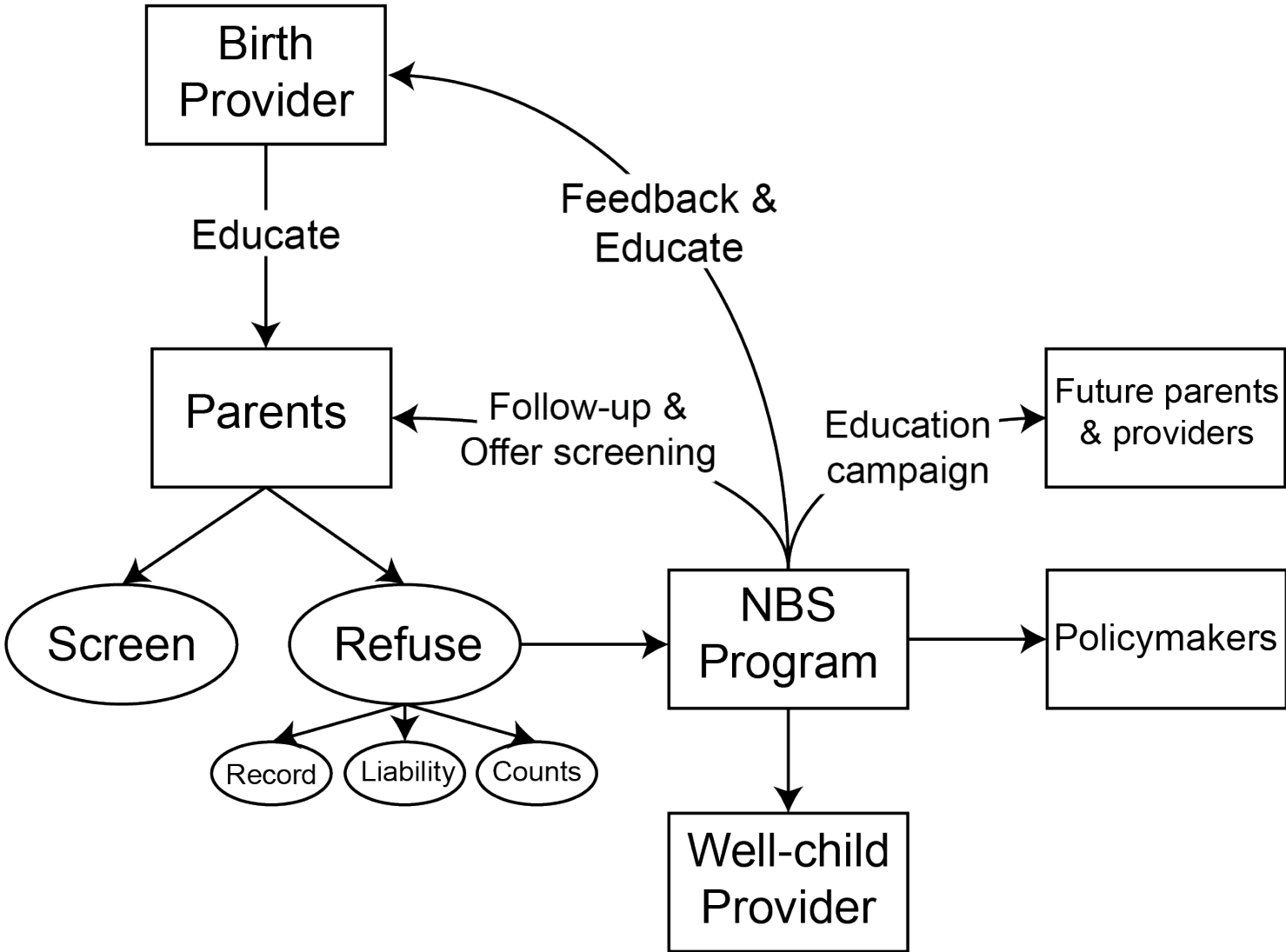
Basic model for documenting refusals

Challenges:

- Cost / benefit ratio seems high
- Emphasis on counting and protection from liability
- Can be easy to see why some programs wouldn't want to bother with this



Enhanced Model for Documenting Newborn Screening



The most important purpose for documenting newborn screening refusals is to facilitate communication between the many stakeholders while record-keeping, liability protection, and counting serve a secondary role.

Well-child
Provider



Gathering accurate data regarding newborn screening refusals allows newborn screening programs to follow-up with parents, hospitals, birth providers, and well-child providers, and **reduces the number of babies who are not screened**

What to Include on the Form

- Contact information for:
 - Parents
 - Birth center / hospital
 - Birth provider
 - Well-baby provider
- Make the form available in multiple languages
- Ask for the reason for refusal
- Educate about screening – might be the only NBS document a parent sees
 - Summary of conditions screened

What to Include on the Form

- Include website and phone number for additional information about screening
- Clear instructions on the form
- Separate refusal for screening with refusal for storage / research of bloodspot cards
- Have separate options for metabolic / genetic, CCHD, hearing
- Use a paper form (or require a portion be printed and given to the parents)
- Do not rely on bloodspot card (insufficient space for all of the information needed and parents do not usually see the bloodspot card)

Linking Records

- Link laboratory records, birth certificate records, and refusals to ensure all babies are accounted for
- Some smaller states did this by hand
- Integrated electronic data systems would be best
- Want to avoid “misses”

Next Steps

- Find out what your state's NBS program does to document refusals (and your state's policy on refusals!)
- Update your state's refusal documentation form
- You can request specific feedback from the authors: jeremy.penn@ndsu.edu
- Communicate the change with key stakeholders
- Support additional research on educating providers, follow-up with patients, reasons parents refuse, and using information on refusal to inform policy decisions

Note: statements in this presentation are those of the authors and not necessarily those of NDSU or HRSA