Expanding Follow-up System Capacity Through New Partnerships

"Trying Times Call for Trying New Approaches!
Expanding Follow -up -System Capacity
With Existing Resources,
Through New Partnerships and Collaborations,
to Reduce Lost -to -Follow -up"

2019 APHL NEWBORN SCREENING AND GENETIC TESTING SYMPOSIUM

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Disclaimer

No Conflicts of Interest to Disclose

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Objectives

- Demonstrate need for expanding resources for newborn screening follow-up.
- Identify resources external to the program who can become partners.
- Provide examples implementing new collaborative relationships to achieve successful follow-up.
- Consider action steps needed to establish formal procedures.

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Identifying the need

Some observations in recent years:

- ✓ **States adding more conditions to the panel, often without adding more follow-up personnel**
- ✓ **States losing personnel, and some having difficulty filling positions with qualified personnel at the salaries offered.**
- ✓ **Huge learning curve for everyone, so proficiency becomes delayed.**
- ✓ **Pediatric practice has evolved:**
  - ✓ **In 1950's/early 60's they still made house calls (at least in some places)**
  - ✓ **By the 1980's no house calls but did visit baby in hospital after delivery**
  - ✓ **In the last decade the PCP often doesn't see the baby in hospital (hospitalists or the on-call partner might)**
  - ✓ **In the last few years we even have post-discharge physician office's not acknowledging the patient until they've been in for a patient visit (often at 2 weeks of age)**

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Identifying the need (cont'd)

- **Nebraska specific issues amplifying the need:**

  - ✓ **Mandatory screen with enforcement requirement in the law.**

  - ✓ **Experiencing more situations with passive refusal / or inability to follow through by parents. (Homelessness, lack of transportation, low socio-economic status, transient living situations, frequent phone limitations, trauma/abuse experienced, human trafficking, language barriers *).**

***These family situations are not likely just Nebraska-specific, but addressing this for other jurisdictions is beyond the scope of this presentation.**

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Other attempts to ensure follow-up occurs:

- **Hospitals**: Will sometimes send phlebotomist out to collect repeat (especially if prior specimen was unacceptable or they discharged the patient without a screen.)
- We formerly contracted with a **private organization** **to collect in-home specimens** on our request, which was especially helpful for out-of-hospital births. (Problem with getting acceptable sample
- If there is clear refusal, and education has not succeeded, **report to** **County Attorney**.

- **But…what about situations in which we don't get a clear refusal, and parents are just not responding?**

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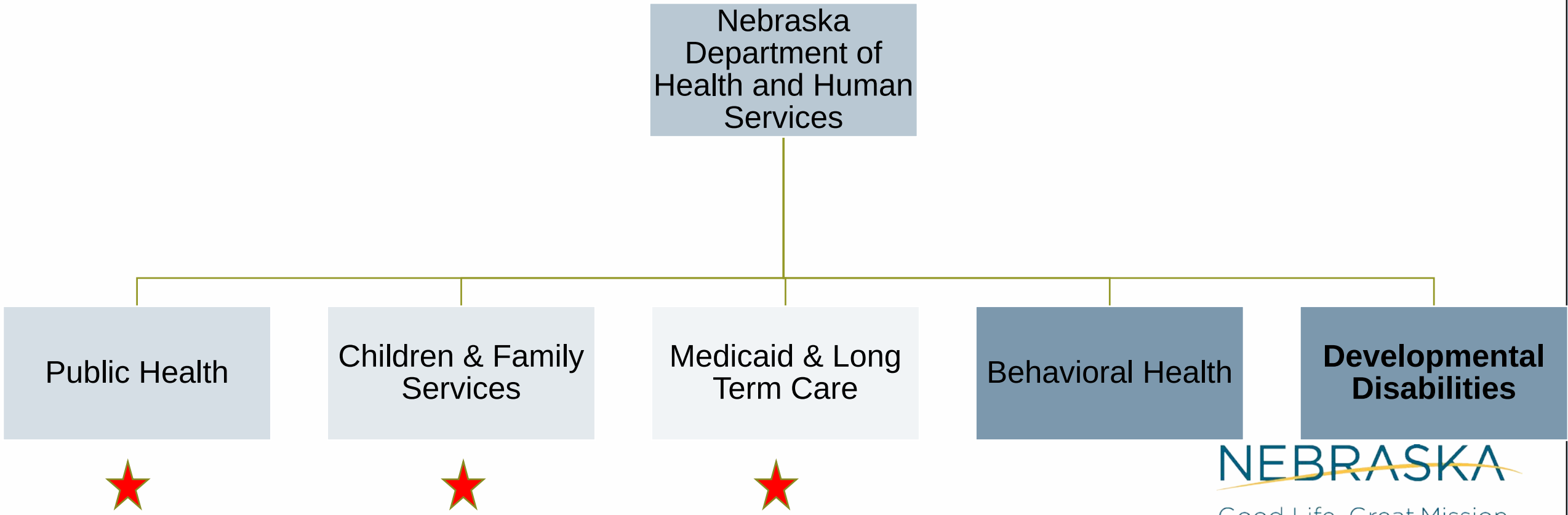
Possible partners (within the agency)



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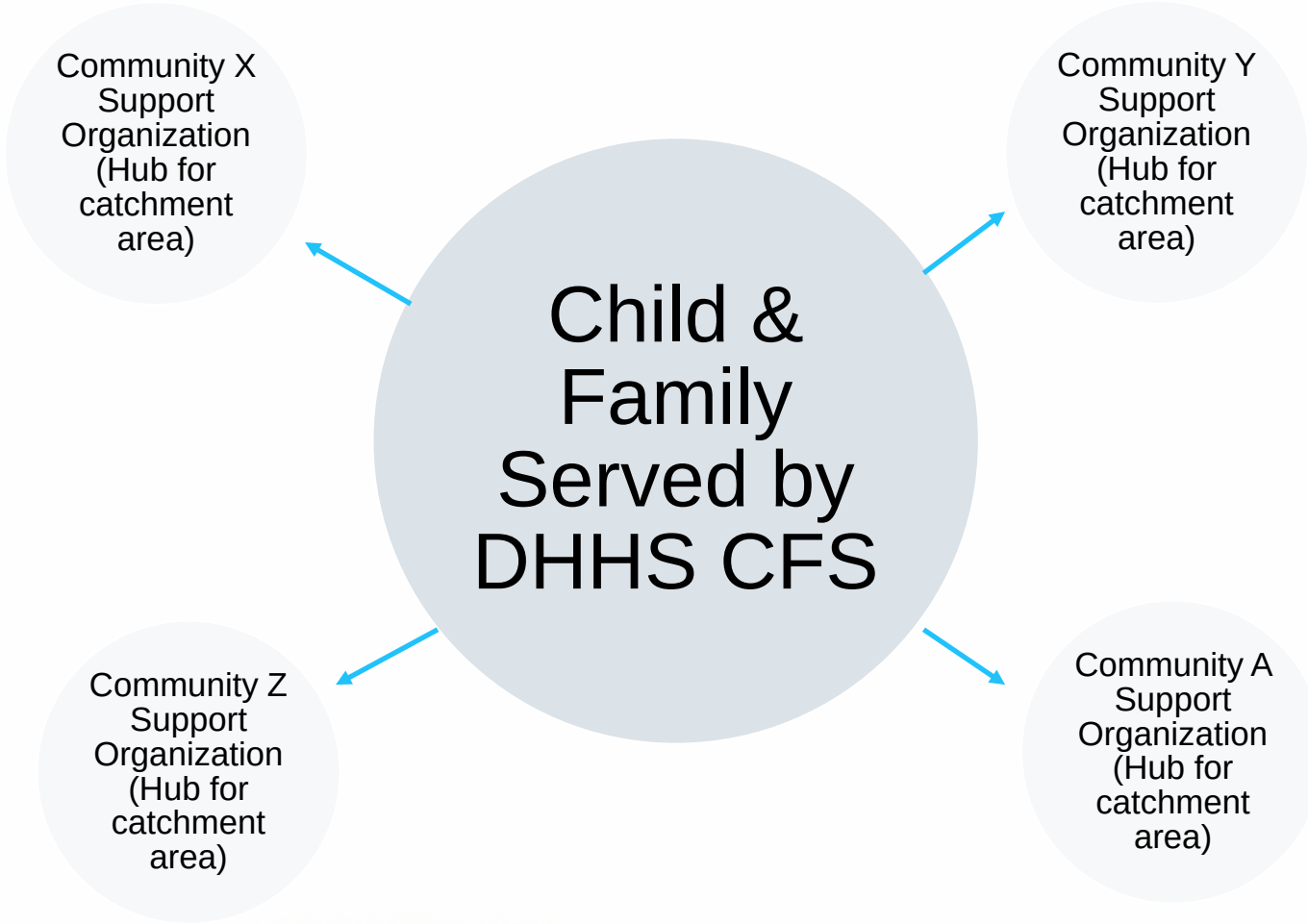
Organizations outside of DHHS



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Story 1: (Communication barriers)

- Unacceptable specimen (could not test for all conditions - CF). Reported on day 4.

- Hospital Social Worker offering transportation but communication road blocks.
- NBS follow-up and CPS multiple calls and emails, but NBS had difficulty getting timely responses back.
- Needed to understand model of Family Preservation for Protection vs. Child Protection.
- Took some convincing that coordination and sharing of information was essential to the baby's health.

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Needed to break down situations for CFS and help them understand the various levels of urgency/need for action.

Scenario I

Parent(s) refusing newborn screen or needed follow-up testing

Notify County Attorney of County where newborn resides

Scenario II

1) Parent(s) not refusing newborn screen or needed follow-up testing, but not complying with the law despite efforts to notify and educate by phone and letter including certified letter. AND:
2) The reason a repeat screen is needed is due to <u>hospital error</u> (unacceptable specimen or discharged without a screen).

Hospital is responsible to arrange for repeat screen. Contact Hospital Social Worker and determine what barriers there are. Facilitate communication between any DHHS resource that may be of assistance(Medicaid MCO, CFS services or Home Health in that order).

Scenario III

Parent(s) not refusing newborn screen or needed follow-up testing, but not complying with the law despite efforts to notify and educate by phone and letter including certified letter.

What other questions should we ask to determine what is the best path to achieve screening or follow-up? ...and where do we get the answers...whom do we ask or can we get N-focus access.

What about baby's with an alternate caretaker as part of a "safety plan". What rules apply and what resources come to bear? Can those be treated the same as if a Ward of the State?

A. Baby is at increased risk for immediate jeopardy. Determined based on positive screen results for CAH, GAL, MCAD, MSUD, PA, Pompe (2nd inconclusive for Pompe), SCID, list other FAO/OA's

B. Baby at very high risk for serious harm from early onset neurological damage. Determined based on very abnormal screen result. (CPH, BIO, PKU,...list other AA's,. OR at risk of serious harm due to a positive screen result received later than optimal (after 1st 10 days of life).

Contact CFS. Baby is a Ward of the State under Protective Custody? *

YES → CFS confirms custody arrangement and provides contact information to NNSP to work with foster care provider to complete follow-up.

NO → Baby 's Insurance Coverage is Medicaid?

NO → Welfare check. Priority 1 CFS Site visit occurs same day and ensures custodial parent takes baby in same day. (Hospital or Doctor per NNSP instruction).

YES → Determine which MCO and contact MCO Care Coordinator. MCO arranges to get baby in for repeat or confirmatory testing the same day notified. (e.g. Transportation or in home specimen collection by trained phlebotomist or nurse, or hospital admission.) MCO Communicates status back to NNSP.

MCO immediately notifies NNSP unable to complete follow-up.

NNSP notifies CFS that MCO was unsuccessful, request Welfare Check/Priority 1 site visit and ensure same day follow-up (Hospital or Doctor per NNSP instruction).

C. Baby at very high risk for serious harm from complications of the screened disease (less urgent but treatment in first month to two months critical) Determined based on positive screen result not confirmed by 4 weeks of age for CF, clinically significant hemoglobinopathies or, MPS I and X-ALD confirmation and referral appointment not kept.

D. Baby is at increased risk for any unscreened condition because a complete screening was not done. (Determined via Vital records/NNSP records match, or due to unacceptable specimen that could not be tested for the full panel.

*Exception if in Douglas County. Kristin Lynch County Attny will send someone out.

Contact CFS. Baby is a Ward of the State under Protective Custody? *

YES → CFS confirms custody arrangement and provides contact information to NNSP to work with foster care provider to complete follow-up.

NO → Baby 's Insurance Coverage is Medicaid?

NO → Contact CFS to determine if baby/family receiving any other DHHS services (AABD, ADC, Child care support, Energy assistance, SSI, SNAP, MHCP, WIC?

Caseworker assigned who can help? If yes, contact family within 48 hours to assist.

Community Resources available to help?

If MHCP only, contact them first for service coordinator to assist.

If no to all above, is MIECH-V available in the community?

If no, report to the CFS intake/ hotline request welfare check within 48-72 hours.

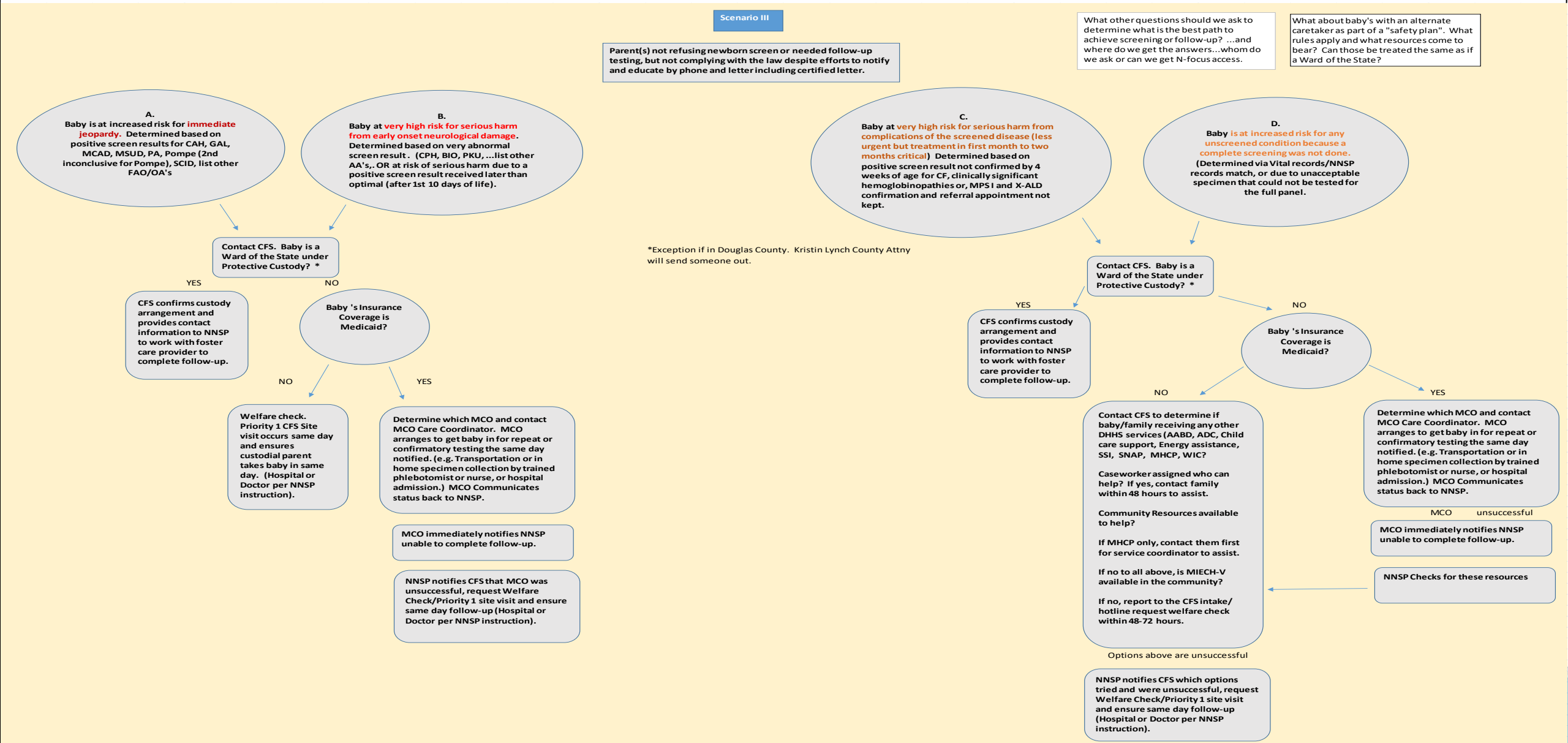
Options above are unsuccessful → NNSP notifies CFS which options tried and were unsuccessful, request Welfare Check/Priority 1 site visit and ensure same day follow-up (Hospital or Doctor per NNSP instruction).

YES → Determine which MCO and contact MCO Care Coordinator. MCO arranges to get baby in for repeat or confirmatory testing the same day notified. (e.g. Transportation or in home specimen collection by trained phlebotomist or nurse, or hospital admission.) MCO Communicates status back to NNSP.

MCO unsuccessful → MCO immediately notifies NNSP unable to complete follow-up.

NNSP Checks for these resources

CFS Referral: Level of Urgency



Story 2: (One thing after another!)

- Inconclusive Galactosemia Screen (Elevated Galactose/*in-range UT* -Classical GAL not likely)
- Reported on a Saturday (baby age 3 days). Primary care physician on call was notified and repeat screen requested.
- Multiple letters, calls, faxes to/with baby's physician, nurses, baby's mom, CFS, (and even County Attorney since we weren't getting anywhere with mom - and this Cnty Attorney will send an investigator out). CFS reached out to Community Health Worker at day 25 for assistance.
- It appeared mom understood, but was just not showing up for agreed upon appointments. Medicaid had a different address for mom than we did, but noted ours was correct physical address for mailing.
- Ineligible for Medicaid transportation as Mom had a working car (no gas).
- Finally SSW obtained a gas card from a volunteer organization. But mom could only reach out to obtain it via email, and the person who had it didn't have email access over the weekend.
- Finally repeat screen obtained at 33 days of age.

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Story 3: (several months into the collaborative practice)

- Baby with concentrations of C3, C3:C2 and C3:C16 slightly elevated. Repeat needed. Reported @ day 4.
- Second requests, multiple calls and letters to mom. Baby had been no-show for appointments.
- Baby covered by Medicaid so reached out to MCO. They sent worker out who said address did not exist, but knocked on neighboring trailers. MCO worker also left voice mail for mom.
- Next step reported to CPS. When NBS checked back with them were told case not accepted. NBS then reached out to administrators of CFS and hotline to get this resolved. NBS was given case workers name as family was known to system, and thorough explanation was given to them before they went to the home.
- Finally on day 58 baby got repeat and fortunately was within normal limits.
  - These demonstrated we still weren't there, and needed a more direct and simplified approach.

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After 3-4 meetings, and experience with 4-5 cases, we were able to simplify the algorithm, and process.

Scenario III

Parent(s) not refusing newborn screen or needed follow-up testing, but not complying with the law despite efforts to notify and educate by phone and letter including certified letter.

A.
Baby is at increased risk for immediate jeopardy. Determined based on positive screen results for CAH, GAL, MCAD, PA, Pompe (2nd inconclusive for Pompe), SCID, (and less commonly ASA, BKT, CIT, GA-I, HMG, IVA, LCHAD, MCD, MMA (two types), MSUD.

PRIORITY 1

B.
Baby at very high risk for serious harm from early onset neurological damage. Determined based on very abnormal screen result. (CPH, BIO, PKU, .other AA's,. OR at risk of serious harm due to a positive screen result received later than optimal (after 1st 10 days of life) or other delay has already occurred.

PRIORITY I

C.
Baby at very high risk for serious harm from complications of the screened disease (less urgent but treatment in first month to two months critical, Or at high risk risk for serious harm from early onset neurological damage but screen result is not in the critical range (e.g. inconclusive biotinidase, possibly a partial, or likely Duarte Galactosemia). Determined based on positive screen result not confirmed by 4 weeks of age for CF, clinically significant hemoglobinopathies or, CUD, TFP, TYR, 3-MCC, MPS-I and X-ALD and, confirmation and referral appointment not kept.

PRIORITY II OR IF AGE AT TIME OF NOTICE PUTS INFANT IN HIGHER RISK GROUP PRIORITY I

D.
Baby is at increased risk for any unscreened condition because a complete screening was not done. (Determined via Vital records/NNSP records match, or due to unacceptable specimen that could not be tested for the full panel.

PRIORITY II OR I IF AGE AT TIME OF NOTICE PUTS INFANT IN HIGHER RISK GROUP

BABY IS ON MEDICAID and MCO has been unsuccessful in getting caregiver to take baby in for testing* (See * below) OR BABY IS NOT ON MEDICAID.

NNSP emails hotline @ DHHS.ChildAdultANHotline@nebraska.gov and CC:'s Program Coordinator (Mikayla Wicks) who will reachout to the assigned CFS case worker specialist to ensure they understand need and it is classified appropriately (e.g. level one reach out w/ law enforcement in next hours vs. level 2 reach out in next day or so, to family, alternate care provider or foster care provider to complete follow-up.

CFS case worker (if an open voluntary placement) will request permission from care provider to provide phone contact to NNSP, and if no phone, will place the call to NNSP for them. If permission is received, phone contact information is immediately relayed to the NNSP. NNSP immediately contacts alternate care provider. If not answered NNSP contacts CFS case worker to escalate assistance while on-site.

If baby is in involuntary placement with other than the parents, Program Coordinator explains provides care provider's contact information directly to the alternate care provider if not previously known/attempted by NNSP.

*

NNSP Notifies Medicaid MCO Care Coordinator of circumstances and known contact information and efforts to contact. MCO Care Coordinator works with parent/caregiver to get baby in for repeat or confirmatory testing the sdame day notified (i.e. transportation or in-home specimen collection by trained phlebotomist or nurse, or hospital admission.) MCO communicates status back to NNSP within 24 hours. If unsuccessful notifies NNSP immediately.

MCO's

Contacts:	Melanie Surber	Wellcare RN Supervisor	384-3033
	Sharon Whitman	United Health Care HSS Mngr	445-5445
	Ellen McElderry	Ne Total Care Dir Clin Ops	531-329-8475

CFS

Contacts:	Emily Kluver	CFS	471-1791
	Mikayla Wicks	Program Coordinator	471-8438
	Darla Berger	SW. Nebr. Community Support Specialist	402 595-3314
	Shelly Witt	West/Central Nebr. Community Support Specialist	402 984-9905
	Stacy Schenk	Northeast Nebr. Community Support Specialist	402 375-7055
	Darniece Amos	Douglas County Community Support Specialist	402 595-3369

NNSP

Contacts:	Julie Luedtke	Program Manager	471-6733
	Krystal Baumert	Follow-up Coordinator	471-0374 24/7 link to pager from this line
	Karen Eveans	Follow-up Coordinator	471-6558
	Sarah Seberger	QA/Follow-up Specialist	471-6759

Communication Feedback loops. Throughout each cycle the CFS and NNSP will report back to each other whenever new information or action is taken.
Communication Feedback loops. Through each cycle in which MCO is involved, the NNSP and MCO will report back to each other whenever new information or action is taken.
***Exception if in Douglas County. Kristin Lynch County Attny will send someone out to house if CFS can't. All screening refusals in Douglas County are reported to her.**

Formalizing procedures and communication tools

Baby's Name:
Date of Birth:
Place of Birth:

Mother's Name:
Mother's address information: (all known from NBS records and other sources)

Mother's phone contact information: (all known including emergency contacts)

Baby's Medicaid status if known: (and siblings if known)

What baby needs (e.g. initial screen, repeat screen, confirmatory testing)

Why baby needs it (e.g. prior unsat/not screened, inconclusive CF, substantial elev C3). (Explain implications)

Note: Neb.Rev.Stat.§§71-519 through 71-524 requires every newborn born in Nebraska to be screened for certain conditions. As of 7/1/2018 this includes screening for 30 rare but serious and some life threatening diseases that without complete screening, cannot be detected clinically until damage or death has occurred.

Implications of not having completed it yet. Communicate assessment of relative risk of harm to the baby (effects of the diseases) and (age of onset of symptoms/irreversible damage relative to age of baby now and efforts described below) to justify implications for urgency of CPS/law enforcement action (e.g. within 2 hours, within 24 hours, in the next few days):

Describe efforts made thus far to communicate with parent(s) and/or other contacts including any Medicaid Managed Care outreach that may have been done.

Other relevant information: (e.g. mother's primary language, transient or homeless status, place of work, anything of relevance).

Name, phone and email of newborn screening (NBS) contact person to obtain more information (to connect with assigned CFS worker).CFS worker and NBS will communicate directly once intake is assigned.

Note: Feedback Loop

Requested time frame for feedback from CFS:

When successfully getting baby to hospital for further testing CFS worker will contact NBS program contact so program can assure physician's orders are faxed to the appropriate hospital laboratory for

Note further instructions/feedback

Other possible partner entities to pursue:

- MIECH-V Nebraska's voluntary Maternal Infant Early Childhood Home Visiting Program
- Title V CYSHCN – In Nebraska it is the MHCP program (Workers are not in all parts of the State)
- Early Head Start
- Community Collaboratives
  - (If external to your agency consider contracts/ MOA's / BAA's)

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Collaboration takes work:

- Meet with the probable partners to explain the situations, and risks of not getting the screen or screening follow-up (you may need multiple meetings!).
- Develop a streamlined but detailed procedure and get agreement from partners.
- Make sure you have a list of primary contacts who understand the procedure and have authority to direct action.
- Make sure the contacts understand the urgency to be able to properly prioritize/classify how they will respond.
- Create a template so all essential information is shared when reporting the problem and requesting help.
- Offer to educate the outreach worker whether that be a home health worker, CFS, Medicaid MCO worker or other.
- Insist on feedback loops. (Get exemption from non-disclosure policies).
- Revisit the procedure and discuss with partners how to improve it.

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Thank you!

To receive a copy of procedures or templates, or discuss further.

Julie Luedtke, Program Manger

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dhhs.ne.gov

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Mia and I Thank you!

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