# Education and Training Workgroup

Tuesday 11/9/2021

Report to Advisory Committee on Heritable Disorders in Newborns and Children

Wednesday 11/10/2021

# Education and Training Workgroup Members

**ACHDNC MEMBERS**

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# Workgroup Discussion Questions

**Education and Training Workgroup:**

- Where are the major gaps in NBS workforce education? Do Education and Training Workgroup members have additional recommendations on resources or training opportunities that support addressing shortages in the NBS workforce? How could those resources be expanded to further strengthen the NBS system?

- **Clarification Question:** Does this question include people who work for newborn screening programs or clinicians and those who care for patients and those who support families? Are you focused on family? People who have newborn screening title in their job description?

- **Clarification Answer:** Includes everyone who is part of the NBS system - laboratory, public health practitioners involved in the short and long-term follow-up programs.

# Q: Where are the major gaps in NBS workforce education?

- Where to start? By defining approaching the different phases of NBS: preanalytical/provider-clinical/short and long term or by “chain of custody”,
  - Dr. Tarini and the steps of the NBS process, at the level of state programs, hospitals, couriers, identifying key structures and specifying gaps
  - Specific education needed in each phase of the screening process

- The NBS Educational Planning Guide identified stakeholders and what they needed to know about NBS programs, but not formal education for stakeholder groups to improve their knowledge or specified educational resources for https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/Resources/achdnc-educational-guide-newborn.pdf

- Expertise in NBS often begins from the workplace, within the laboratories, on the job training, New Steps and ad hoc mechanisms

# Do Education and Training Workgroup members have additional recommendations on resources or training opportunities that support addressing shortages in the NBS workforce?

- There is the LSD fellowship, NAMA
  - Can more professional organizations be charged with providing training?
- What are we educating for? There are all different types/levels of education needed for different roles and philosophies (public health, precision medicine, all interacting)
- **There is very limited time for educating the workforce**. Clinicians and staff are focusing on complicated tasks and issues in
- There are personnel shortages up and down the NBS workforce; how to appeal to keep people in NBS with a shrinking workforce and inability to compete?
  - More metabolic fellow slots are needed (15 in 2022)
  - Can more MPH student/ counselors be trained up in NBS- what can we give them, what kinds of incentives?
  - Personnel train up and leave (labortorians, GCs, nurses, others) attracted by other opportunities better lifestyle choices, pay or they are unaffordable (GC salaries)
- Note: other groups are in need of access to point of care education: Couriers, OBs, dieticians, social workers, technicians

# Staffing challenges/ workforce needs

- What are we looking for in personnel? Do we need a “match” and staff committed to the NBS program on all levels.
- APHL has workforce development, environmental project and looking into this.
- Public health personnel are holding on for now during the pandemic and committed to seeing this through, but may leave if they can, because the stress levels are immense.

- Shortages of lab workers and data managers
  - GIM articles on staff shortages: https://www.nature.com/articles/s41436-021-01162-5 ;
  - Current conditions in genetics practice https://www.nature.com/articles/s41436-018-0417-6

- Concern with adding more disorders to the RUSP if staff/states have difficulty keeping up with the current disorders.

# What is at the center of screening?

- **The at-risk infant and family**
- What is the purpose of education, and educating providers and families?
- Ideas for improving the ACT sheets and providing information to families
    - Links on the ACT sheets to communication guides
    - Some states link the communication guide to ACT sheets or directly to Baby's First Test
- Drill down: What are these interactions, the return of results, the moment a person conveys this information and family reactions, what metrics do we have to gauge the impact and effectiveness?
- There is a lot of factual information available, but families could go to the internet and find bad or old information. How do you keep information factual for them?

# What is at the center of screening? (con’t)

- Communicating factual information effectively
  - Matters of trusting providers. These are difficult times for establishing trust with medical providers and systems. Mistrust of governmental agencies.

- Can providers answer the questions? There can be direct harm to families due to poor communication, knowledge deficits
  - A communication guide for clinicians and providers to help frame the initial notification and discussion with parents about positive/abnormal/out-of-range newborn screening results.
    - https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/Resources/achdnc-communication-guide-newborn.pdf

- More complex disorders = more complex educational messages
  - more expensive treatments

# Do Education and Training Workgroup members have additional recommendations on resources or training opportunities that support addressing shortages in the NBS workforce? (con't)

- How can we pull people in and engage persons for NBS work, engage persons who have a passion for the work?
  - Target people in high school (this is done to attract students to genetics)
  - What about a NBS specialty? We don't speak in these terms
  - Patient navigators are needed, may be nurses or genetic counselors, midwives, doulas – goal is to build trust to deliver better education. If parents trust, they may be more open to learning.
  - Get creative on how to pull in professionals (i.e. nurse who has worked bedside for x amount of years, looking for a new opportunity and others to move into NBS roles)

# Educating parents

- What to expect when you are expecting
  - Providing education in doses and formats appropriate for today’s parents: apps, podcasts

- Great packages of information are available but often are not looked at beyond the first page.
- Targeting OBs/midwives and doulas. The mothers may discuss issue with them.
- A successful pilot was performed where researchers went into an OB office and set up an education program for women. The Obs were too busy to be part of it, they were champions of it. Results are pending
- Birthing groups/ classes are outdated. Videos in the waiting room could help with information delivery
- Prenatal GC educated attempted, but they were busy with NIPT/CVS. “Just in time” education may be effective.
- OB clinics are different from each other. What is needed? These clinics are teaching about SIDS
- What changes do we want to see, what do we what them to know, what is important?
- Prenatal check list for parents, developed through a grant, packets going to OBs, loaded videos to YouTube. Data forthcoming. Look at maternal behaviors before and after—parent behavior changes.
- Offer prizes for completing NBS education

# More of about the issues

- What change do we want to see?
- Small NBS programs cannot compete with larger, research- oriented organizations in personnel and resources
- Where does the federal/states money go for NBS? Where does the funding go and to what? Treatment centers used to recieve funding
- Need to think outside the box to address gaps. It may involve regional models or contracted services that can help (e.g., groups of Genetic Counselors to provide services/notification/answer questions?)?
- What other models besides trying to deal with this on a state-by-state basis might be needed?
- Regional NBS consultants

# Workgroup Discussion Questions

## All Workgroups:

- Should the Committee consider the availability of follow-up experts (clinical, follow-up, public health, laboratory, etc.) when reviewing a new condition nominated to the RUSP? How could that information be collected? What role could the Committee play in calling attention to identified shortages of follow-up experts?

# Should the Committee consider the availability of follow-up experts (clinical, follow-up, public health, laboratory, etc.) when reviewing a new condition nominated to the RUSP? How could that information be collected?

- A problem with question – no NBS program sitting around with extra capacity, waiting for new conditions.
- Availability needs to be taken into account when reviewing a new condition.
- NBS programs are very optimistic in wanting to care for all comers, but this needs to be a reality based.
- If the state is not thinking about disorders, then you don't have that information. It is in the research phase. Some states do not do research.
- Would like to see the professional groups looped in, what is possible in the systems and capacity on a national level. Who could have more insight?
- Would states make NBS a PH priority? If NBS is not a priority, it could be. You could raise taxes, find funding but there are other priorities the states will go with.
- What are the issues within the states? We know there is pressure with greater expansion.
- There are historical inequities, that persist across states
    - Why is this important issue left up to the states?
- Not enough specialists, limited resources for support.

# Con’t

- Outcomes can be different in different states/systems.
- Historically, PKU rolled out, states said, but do we make this more equitable? How can they still screen or in a regional level, can we still get access to regions.
- New England Region- how is that done, look closely at those systems?
- When reviewing a condition for the RUSP, how could this information be collected? Different aspects of payee information, different aspects, travel, funding experts, clinical FU, public health, laboratory.
- Clinical/PH-additional partners upfront, a big demand at first- but noted that operationalizing the process makes it easier over time.
- States that are screening for disorders already have information and can provide a mock- up for others. State feel they HAVE to screen, but are not ready. Check out states that are screening and understand their infrastructure. Make a road map (observe the road blocks).
    - Include a case study or two and a description of lessons learned.
    - Careful approach, this could influence whether a disorder goes up or not.

# How could that information be collected? What role could the Committee play in calling attention to identified shortages of follow-up experts?

- Very broad question, needs to be considered in depth in the future - How could the information be collected? Much is being asked at once - Availability of clinical specialists, hospital space, treatment capacity, maybe information in terms of Medicaid and other payers can cover this question.

# Summary

Many important issues put forth that need careful consideration

We need to think differently. We need to acknowledge that state-by-state might not work moving forward. New approaches are need

Consider regional approaches to newborn screening challenges

Development of white paper or article on workforce educational needs and NBS staffing needs/ shortages.