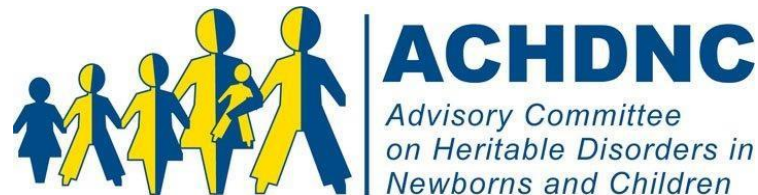


Education and Training Workgroup Meeting Report 11/3/2022

November 4, 2022



Education and Training Workgroup Members

ACHDNC MEMBERS

- Jane DeLuca, PhD, RN, CPNP (Chair)
- Melissa Parisi, MD, PhD
National Institutes of Health
- Jannine De Mars Cody, PhD

ORGANIZATIONAL REPRESENTATIVES

- Natasha Bonhomme
Genetic Alliance
- Siobhan Dolan, MD, MPH
March of Dimes
- Karin Downs, RN, MPH
Association of Maternal and Child Health Programs
- Shakira Henderson, PhD, DNP, MS, MPH, RNC-NIC, IBCLC
Association of Women's Health, Obstetric & Neonatal Nurses
- Steven Ralston, MD, MPH
American College of Obstetricians & Gynecologists
- Cate Walsh Vockley, MS, LCGC
National Society of Genetic Counselors

WORKGROUP MEMBERS

- Barbara Ferreira, RN, BSN
- Stacy Hines-Dowell, DNP, AGN-BC
- Yvonne Kellar-Guenther, PhD
- Mary Kleyn, MS
- Keri LeBlanc, NNP, MSN, CNS
- Sylvia Mann, MS, CGC
- Jeremy Penn, PhD
- Maa-Ohui Quarmyne, MBchB MS
- Lisa M. Shook, MA, MCHES
- Samantha Vergano, MD
- Sarah Viall, MSN, PPCNP-BC

MCHB

- Loraine Swanson, MPH
- Alaina Harris, MSW, MPH

What are the 3 top priority solutions the Committee can consider acting on to support state implementation of conditions added to the RUSP?

Solutions Generated by Workgroup

- Support use of existing good training programs and mentorship already available
- Creating standards for states to reach in screening education
- Focus on achievable health outcomes
- Develop evaluation methods to measure if people are using materials
- Assure diverse and culturally tailored materials are available to families; support fostering equity
- Seek more guidance and input from the public health perspective
- Develop and target discrete goals that can be targeted
- Partner with other governmental agencies working in similar spaces (e.g. preventive task forces, maternal-child commissions etc.)
- Develop discreet goals for education and training
- Consider basic genetic and NBS education

- ***A Rich Discussion Ensued...***

The How? Where is the information or training located?

- Gathering, organizing, creating
 - Use of templates that states could modify
 - Existing places to find education materials
 - Regional Genetics Network Coordinating Center, ACMG, APHL Bootcamp
 - Money is spent on good training programs and mentorship. Let's use it!
 - Can we collect information and highlight it for people?
- Centralizing resources; Repositories
- Core question: Are we speaking specifically about the newest disorders or also going back to some of the older conditions where education is still needed?
- Websites are great but what about social media since that's where a lot of families get information (at times misinformation- can we combat that?)

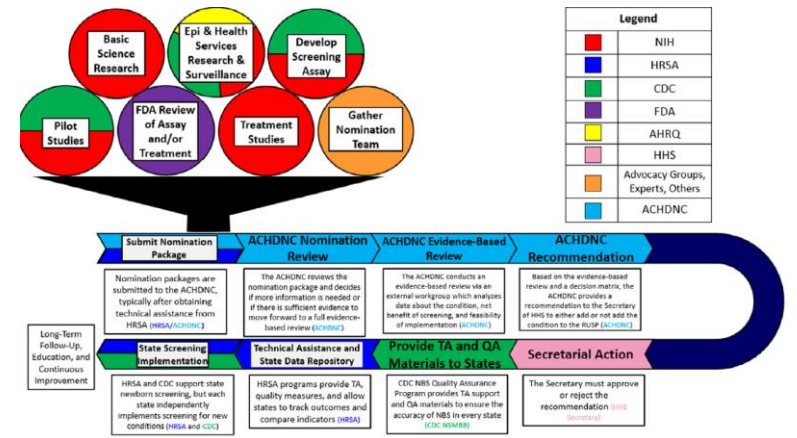
Screening is getting bigger (and not just NBS)

- Prenatal screening, bigger panels and more tests. There is a huge industry of influence. There is often misunderstanding.
- You often do not get to NBS without going through prenatal screening.
- Parents can be confused by the time they get to newborn screening and can have preconceived ideas about what screening is. Clinicians may be confused by it as well.
- More screening is better?
- We don't speak consistently about these concerns. (FDA/ NYT)
 - Screening vs. diagnostic testing poorly understood
- There is the potential for more confusion, not less.

Partnering with Government Agencies

- Identify sister gov agencies/departments, e.g. **preventive task forces, maternal-child commissions etc.** for potential collaborations (e.g. data linkages or trainings?)

- **The Road to the RUSP**, is a model in *Newborn screening research sponsored by the NIH: From diagnostic paradigms to precision therapeutics* (Minear et al, 2022), which depicts various federal agencies and their roles in advancing a disorder to the RUSP. This could serve as a starting point for illustrating relationships between federal organizations and E & T Work group goals.



- Federal agencies have different missions; identification of key individuals/groups will be essential.
- Connect with professional genetics groups for education and information resources

Prioritizing Culturally Appropriate Information, Education and Training

- We live in a diverse culture
- Do we have culturally appropriate materials for all? Can we create materials where the look and feel of a culture is there, not just the language?
- Newborn screening programs may differentially affect people from diverse cultures. We need to understand peoples' experiences of the healthcare system and address inequities.

Education and Training is everyone's responsibility!

- Education and training is the responsibility of every stakeholder.
- Everyone needs to continue learning and building their skills.
- We can find out who is doing what and what exists to create a blueprint!

What are the 3 top priority solutions the Committee can consider acting on to support state implementation of conditions added to the RUSP?

Priority Focus and Solutions

Partnering with governmental agencies and professional groups working in similar spaces, we will support development, distribution, and awareness of diverse and culturally focused new and existing newborn screening education programs and materials, ensuring coverage of basic genetics and newborn screening for all.