

From Emergency to Everyday:

Lessons Learned from Provider Reflections on a Year of COVID-19 in Newborn Screening

March 2021

The Newborn Screening Family Education Program hosted a webinar series convening key newborn screening (NBS) stakeholders including providers, NBS program representatives, parents, and advocates, to learn how state newborn screening laboratories supported families during the COVID-19 pandemic. This resource reflects the perspectives of webinar attendees and shares strategies to support families through future health emergencies.

- **40% of respondents** indicated that COVID-19 negatively impacted NBS.
- **38% of respondents** indicated that they're not sure how COVID-19 impacted NBS.
- **17% of respondents** indicated that NBS has stayed the same.
- **5% of respondents** indicated that COVID-19 has positively impacted NBS.

KEY TAKEAWAYS

- The need to support families without interruption to services, support, and available resources is paramount.
- Timely communication and connection in a digital world, including virtual and online groups are essential to meet the needs of parents' informational and emotional support.

CHALLENGES AND STRATEGIES

Lack of information for parents during the newborn screening process pre- and post-screening

Provide contact, scheduling, and information to equip parents to feel confident to address any concerns about how baby will be kept safe at visit

Hesitation to bring newborns to appointments due to fear of exposure to COVID-19

Ensure parents understand the importance of timely follow-up after initial screening

Geographic distance from health services affected access to in-person care and available resources

Support telemedicine services for non-urgent NBS cases to reduce exposure to COVID-19 and alleviate childcare challenges

Interruptions in essential laboratory services for follow-up testing

Advocate for continuation of essential services during emergencies including prioritization of older babies

BEST PRACTICES IN SUPPORTING FAMILIES



SLOW

- Minimize delays in communication to families regarding follow-up and next steps



START

- Identify barriers and reasonable solutions
- Develop tools to guide decision and triage points
- Increase communication of follow-up steps to parents



CONTINUE

- Utilize telemedicine to maintain access to services
- Track trends on the impact to long-term follow-up and implement strategies

Watch the full webinar on [Expecting Health's YouTube Channel](#)

*This data represents individual data from 111 webinar registrants and does not represent all webinar attendees.

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