NEWBORN AND DEVELOPMENTAL SCREENING:
STATE AND FEDERAL ACTION

MATERNAL AND CHILD HEALTH FELLOWS
NOVEMBER 12, 2020

Khanh Nguyen
Senior Policy Specialist
NCSL Health Program
AGENDA

- Federal action
- State trends and examples
  - Newborn screening
  - Developmental screening
- Resources
FEDERAL ACTION


- **H.R. 1058** (2019, enacted) - Amends the Public Health Service Act to enhance activities of the National Institutes of Health with respect to research on autism spectrum disorder; enhances programs relating to autism.
STATE ACTION AND EXAMPLES

- Newborn Screening
  - Addressing funding or coverage
  - Requiring screening of specific conditions
  - Increasing awareness for specific conditions

- Developmental Screening
  - Requiring specific providers to screen
  - Tying screening to quality measures linked to reimbursement
NEWBORN SCREENING

- **Coverage and funding**
  - **Colorado HB 1006** (2018, enacted) - Updates the current newborn screening program to require more timely newborn hearing screenings, authorizes the health department to assess a fee for newborn screening and necessary follow-up services, creates the newborn hearing screening cash fund for the purpose of covering the costs of the program.
  
  - **District of Columbia B23-0416** (2020, enacted) - Requires health benefit plans to provide coverage for newborn screenings and authorizes certain civil fines and penalties. Clarifies insurance companies must cover the cost of newborn screening.

- **Adding conditions**
  - **Kentucky SB 60** (2020, enacted) – Adds spinal muscular atrophy to the list of heritable conditions tested at birth.
  
  - **South Carolina HB 3036** (2019, enacted) - Adds Krabbe disease, Pompe disease and Hurler syndrome to state neonatal testing and establishes the Newborn Screening Advisory Committee.
NEWBORN SCREENING

- **Awareness**
  - *Pennsylvania HR 480* (2019, enacted) – Designates the month of September 2019 as Krabbe Disease Awareness Month, a condition on the Recommended Uniform Screening Panel (RUSP).

- **Other actions**
  - *Indiana HB 1210* (2020, enacted) - Authorizes blood lead screening and newborn screening information to be entered into the state immunization data registry, so providers and the individual may access the health information.
  - *Oregon HB 2563* (2019, enacted) - Establishes the Newborn Bloodspot Screening Advisory Board, provides for the Board's membership, duties, and powers.
DEVELOPMENTAL SCREENING

- **California AB 1004** (2019, enacted) - Requires MediCal Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) screening services to include developmental screening for ages 0 – 3.

- Georgia Medicaid requires reporting of developmental screening rates as a quality measure and provides incentives for providers with high screening rates. Medicaid covers autism spectrum disorder services.

- **Maine SP 524** (2019, enacted) – Resolves that the Department of Health and Human Services shall convene a stakeholder group to determine the capacity of the State to provide early and periodic screening, diagnostic and treatment services to children from birth to 8 years of age, the gaps in services and the costs of addressing those gaps.

- North Carolina Medicaid/CHIP has a special demonstration project to improve quality measures and community-based medical home models, including to identify children with developmental disorders.
DEVELOPMENTAL SCREENING

### Provider screening
- **Maryland HB 396** (2020, *introduced*) - Requires certain child care centers to offer early childhood screening for developmental disabilities for each child under a certain age in a certain manner.

### Treatment
- **Oklahoma SB 1034** (2019, *introduced*) – Requires insurance coverage for screening, diagnosis, and treatment of individuals less than 18 years of age with autism.
- **Michigan SB 552** (2019, *introduced*) – Restores funding for a pilot program to train providers on models of intervention for autism.
Resources

NCSL Resources
- NCSL Legislative Database, Maternal and Child Health Database
- NCSL LegisBrief, State Newborn Health Screening Policies

Additional Resources
- Advisory Committee on Heritable Disorders in Newborns and Children, Health Resources and Services Administration
- State Profiles, Association of Public Health Laboratories
- State Profiles, Baby’s First Test
- Developmental Screening Resource Center, American Academy of Pediatrics
- Medicaid Developmental Screening Policies by State, National Academy for State Health Policy
Thank you!

Contact:
Khanh Nguyen, MSW, MPH
Senior Policy Specialist, Health Program
khanh.nguyen@ncsl.org  |  303.856.1417