Summary of Proposal:

Section 1. Incorporate Federal Recommended Uniform Screening Panel into Newborn Screening Program. This section authorizes the Commissioner of Public Health, subject to the approval of the Secretary of the Office of Policy and Management, to add any disorder to Connecticut’s newborn screening testing panel that has been included on the federal recommended uniform screening panel (RUSP) by the U.S. Department of Health and Human Services. This will enhance the department’s ability to identify possibly affected infants for necessary and beneficial follow-up and treatment.

The following disorders will be added to the screening panel, commencing in FY 2020:

- **Pompe disease** caused by the buildup of glycogen in the body’s cells. The accumulation of glycogen in certain organs and tissues, especially muscles, impairs the ability to function normally. The classic form of infantile-onset Pompe disease, if untreated, leads to death from heart failure in the first year of life. Pompe disease affects about 1 in 40,000 people in the United States.

- **Mucopolysaccharidosis type I (MPS I)** affects many parts of the body. The more common form of MPS I, which occurs in approximately 1 in 100,000 newborns, is typically related to developmental delay by age one and usually a shortened lifespan.

- **Spinal muscular atrophy (SMA)** a genetic disorder characterized by weakness and wasting in muscles used for movement. The most common form of the disorder is evidenced by muscle weakness at birth or within the first few months of life. This disorder affects 1 per 8,000 to 10,000 people worldwide.

Sections 2 - 3. Adjust Local Health Department and District Grants. These sections implement a proportional reduction imposed upon each grant to a local health department and district in any fiscal year in which the amount appropriated for such grants is insufficient to meet the statutory formula amounts (CGS Sec. 19a-202 and 245 are modified).

Section 4. Establish Permanent Methodology for Safe Drinking Water Primacy Assessment. This section codifies the safe drinking water primacy assessment that supports the Department of Public Health’s regulation of high quality drinking water. First implemented in FY 2019, the assessment, which is based upon the classification and size of the owned public water system, supports the department’s ability to maintain primacy under the federal Safe Drinking Water Act.
Primacy is delegated by the U.S. Environmental Protection Agency and includes the responsibility to implement and enforce the SDWA. Under the Governor’s proposal, the assessment will be equitably imposed on all public water systems.

Specific requirements include:

- By 10/1/19 and annually thereafter, DPH, in consultation with OPM, shall post its costs to support maintaining EPA primacy designation. This cost shall constitute the assessment for the current fiscal year.
- Small water systems shall be assessed based on fixed fee amounts that are equivalent to amounts collected in FY 2019, as follows:
  - Community Water Systems (CWS) having less than 50 service connections - $125
  - Non-Transient Non-Community Water Systems - $125
  - CWS’s having at least 50 but less than 100 service connections - $150
  Starting in FY 2022:
    - Transient Non-Community Water Systems having had a sanitary survey conducted in the prior year - $150
- Community Water Systems having 100 or more service connections shall pay a per service connection fee, not to exceed $5.00. The actual fee will be dictated by the cost projection.
- Should DPH lose its EPA primacy designation, the assessment mandate shall immediately terminate.
- By 12/1/19, and annually thereafter, DPH shall be required to issue a report detailing resources dedicated to maintaining primacy in the prior fiscal year, positions performing these duties, and quality improvement strategies that have been deployed to improve operational effectiveness.

The following shows the approximate number of water systems, by type:
- CWS, 0-49 service connections: 288
- CWS, 50-99 service connections: 73
- CWS, ≥ 100 service connections: 152
- NTNC: 522
- TNC: 1,435, of which about 280 (or one-fifth) have a sanitary survey conducted each year.

**Section 5:** Repeals CGS Sec. 19a-202b, an obsolete statute that established a funding distribution methodology applicable to local health departments and districts specific to FY 2000.

**Reason for Proposal:**

Legislation is required to implement the Governor’s proposed budget.

**Significant Impacts:**

**Section 1:** The budget adds $0.1 million under DPH’s budget in each of FY 2020 and FY 2021 to support the purchase of testing supplies necessary to add three disorders to the newborn screening panel. It is expected that the Commissioner of Public Health will exercise his statutory
discretion to adjust the newborn screening fee from the current $110 to approximately $113 per infant to make this change budget neutral. The fee is charged to hospital birthing centers.

Sections 2 - 3: The budget provides eighty percent ($3,742,666) of the funding that would be required to fully fund statutory per capita grants to eligible full-time local health departments and health districts in each of FY 2020 and FY 2021 ($4,678,332).

Section 4: The budget reflects estimated revenues of $1.7 million in FY 2020 and $2.0 million in FY 2021 from the safe drinking water primacy assessment within consensus revenue estimates. State-operated public water systems shall not be subject to the assessment.

Section 5: Technical change having no impact.