### **Model Legislation – An Act to Create a Transparent Waiting List for Those with Intellectual and Developmental Disabilities in Need**

*[To amend State statute delineating the duties of the Department serving those with intellectual and developmental disabilities]*

When State funding is not adequate to meet service needs, the department shall establish a waiting list, to be called the registry, for persons with developmental disabilities who would be eligible to receive State-funded services under [reference relevant statute] if adequate State funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the House and Senate finance committees and the persons chairing the House and Senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators. The report must:

1. describe the purpose for the waiting list and the strategies used to notify persons about the waiting list, and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [relevant section of State law];
2. explain how an individual is placed on the waiting list, what criteria determine rank on the list, with at least quarterly updates to such assessments, and how the waiting list is used to select individuals equitably and fairly across the State;
3. give the basic demographic information across all regions about the age (under 22 years old, from 23 to 39 years old, from 40 to 59 years old and more than 59 years old), gender, and racial and ethnic background of the individuals on the waiting list;
4. identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need and show these costs by age and length of time the individual has remained on the waiting list;
5. identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list, shown by age;
6. list the number of individuals who have been on the waiting list for 6 months, 12 months, 24 months, 36 months, 48 months, or more by age and with an account of the department's steps to regularly review each individual's status while waiting for services or supports;
7. report annual data from the [education department] about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school.