

The Data Bill (A2028) P.L.2011, c.163
Requires DHS to collect and disseminate data about persons with developmental disabilities

- DDD shall collect, and when practical maintain a database of, information about eligible persons with developmental disabilities.
- The data to be collected, and when practical maintained, for each eligible person shall include:
 - The person's name and contact information, guardian, if applicable, and any primary caregivers
 - The person's age, gender, race or ethnicity, and disability or diagnosis, as applicable
 - A needs assessment categorized, at a minimum, by the person's need for residential services, employment or day support services, family support services, medical support services, and behavioral support services
 - A list of services that the person or his/her parent or guardian has indicated that the person would like to receive, including residential and day support services
- DDD shall ensure that eligible persons are reassessed as to their needs and services as needed
- DDD shall annually notify, in writing, persons receiving services of the following:
 - The services the person is currently receiving from DDD and, in the case of an individual budget to purchase services, the amount of that budget and the services that are being purchased with the funds from that budget
 - The person's status on a waiting list, if any, and how many persons with developmental disabilities on the list are expected to be served in the next 12 months.
 - The manner in which the person can easily correct or update, as applicable:
 - The person's contact information
 - Information concerning how the person is spending funds in an individual budget, if any
 - The person's expected future service needs
 - Any other relevant information that requires updating
 - Information about where the person with a developmental disability or a family member or guardian can find information about services for persons with developmental disabilities, including the link to the department's official website.
- DDD shall annually publish a report, to be made available on the department's website, containing non-identifying aggregate data about eligible persons. The report shall, at a minimum, include:
 - The number of eligible persons, tabulated by county and other demographic information, including, but not limited to, age, gender, race or ethnicity, and disability or diagnosis, as applicable
 - For each developmental center:
 - The number of person with developmental disabilities residing in the developmental center who have expressed to DDD a desire to reside in the community but are still awaiting such placement

- The number of persons who require behavioral supports to reside in the community
 - The number of persons who are currently residing in a developmental center because they have mobility impairments and have been unable to find accessible housing
- An explanation of how DDD determines to place an eligible person on a waiting list maintained by DDD, what criteria determine a person's priority level and ranking within that priority level on the list, and how a person is selected from the list to receive services
- For each waiting list maintained by the division, within each county:
 - The number of people who are waiting for: residential services, employment or day support services, family support services and, if so, which supports
 - The year in which persons requested placement on any DDD-maintained waiting list.
- The number of eligible persons served in each residential setting during the preceding 12 months, including, but not limited to, a developmental center, family member's home, group home, supervised apartment, community care residence, nursing home, or out-of-State placement
- Tabulated by county:
 - the number of eligible persons who are expected to transition from receiving services from a school district to receiving services from DDD for each year
 - the expected service needs of these persons
 - the total projected cost of services for these persons
- During the preceding 12 months, tabulated by county:
 - The number of eligible persons who were removed from any DDD-maintained waiting list
 - The reason each person was removed from the list
 - How long each person had been waiting for services of supports before being removed from the list
 - The number of eligible persons who were classified as an "emergency"
 - For those persons who received residential services, the percentage who received such services in a developmental center, group home, supervised apartment, community care residence, nursing home, out-of-State placement, or any other residential setting
 - The number of eligible persons who were placed in a nursing home and their age when placed, categorized by the reason for such placement
 - The number of eligible persons who were placed in a developmental center, categorized by the reason for such placement
 - The number of eligible persons who previously but no longer received services from DDD
- An explanation of the current procedures and criteria used to admit an eligible person into a developmental center

- DHS shall report to the Governor, and to the Legislature two years after the effective date of this act as to:
 - The progress of the data collection and reporting required
 - The viability of including additional data within its data collection and reporting practices
- The Commissioner shall adopt rules and regulations to effectuate the purposes of this act
- This act shall take effect on the first day of the 13th month next following the date of enactment, except that the Commissioner may take such anticipatory administrative action in advance thereof as shall be necessary for the implementation of this act.