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LAW/KR

P.L.2011, CHAPTER 163, *approved January 5, 2012*
Assembly, No. 2878 (*First Reprint*)

1 **AN ACT** concerning persons with developmental disabilities and
2 supplementing chapter 6D of Title 30 of the Revised Statutes.

3
4 **BE IT ENACTED** by the Senate and General Assembly of the State
5 of New Jersey:

- 6
7 1. The Legislature finds and declares that:
- 8 a. Reliable and current data about the service needs of persons
9 with developmental disabilities who are eligible for services from
10 the Division of Developmental Disabilities in the Department of
11 Human Services is fundamental to the division's ability to plan
12 effectively to meet those needs;
 - 13 b. Similarly, in order to make appropriate decisions about State
14 funding for these services, it is important to understand the needs of
15 persons with developmental disabilities served by the division;
 - 16 c. Information about service needs is also essential for service
17 providers as they seek to expand services, acquire or build
18 infrastructure where needed, make services available at the time
19 they are needed, and ensure that the services they provide are
20 compatible with the needs of persons with developmental
21 disabilities residing in their particular service areas;
 - 22 d. Additionally, persons with developmental disabilities and
23 their family members and guardians need access to current data so
24 that they can develop informed expectations about the system that
25 provides services for persons with developmental disabilities;
 - 26 e. As this system evolves into one in which more persons with
27 developmental disabilities and their family members and guardians
28 play a larger role in obtaining necessary support services in the
29 community, it is critical to create a truly transparent system on
30 which persons with developmental disabilities and their family
31 members and guardians can rely, and which they can trust; and
 - 32 f. In order to ensure that the State and persons with
33 developmental disabilities and their family members and guardians
34 have reliable data about the service needs of persons with
35 developmental disabilities and that such data can be made available
36 to those who need to factor that information into their decision-
37 making, planning, funding, and expectations for services, it is the

EXPLANATION – Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted in the law.

Matter underlined thus is new matter.

Matter enclosed in superscript numerals has been adopted as follows:

¹Assembly AAP committee amendments adopted June 13, 2011.

1 policy of the State to provide for the collection and dissemination of
2 data on persons with developmental disabilities.

3

4 2. As used in this act:

5 "Department" means the Department of Human Services.

6 "Division" means the Division of Developmental Disabilities in
7 the Department of Human Services.

8 "Eligible person with a developmental disability" or "eligible
9 person" means an eligible **1** [developmentally disabled] **1** person
10 1with a developmental disability¹ as defined in section 3 of
11 P.L.1985, c.145 (C.30:6D-25).

12 "Services" means services as defined in section 3 of P.L.1985,
13 c.145 (C.30:6D-25).

14

15 3. a. The Division of Developmental Disabilities shall collect
16 1 and 1when practical¹ maintain a database of 1 information
17 about eligible persons with developmental disabilities pursuant to
18 this section.

19 b. The division shall, within 12 months of the effective date of
20 this act, collect and maintain data as specified in this section on
21 persons declared eligible persons as of the effective date of this act.
22 In the case of a person with a developmental disability who
23 becomes eligible for services after the effective date of this act, the
24 division shall collect the data no later than 60 days after the person
25 is determined eligible for services by the division.

26 The data to be collected 1 and 1when practical¹ maintained 1
27 for each eligible person shall include:

28 (1) the person's name and contact information, guardian, if
29 applicable, and any primary caregivers;

30 (2) the person's age, gender, race or ethnicity, and disability or
31 diagnosis, as applicable;

32 (3) a needs assessment categorized, at a minimum, by the
33 person's need for residential services, employment or day support
34 services, family support services, medical support services, and
35 behavioral support services; 1and¹

36 (4) **1** [a description of the services the person is currently
37 receiving, including: in the case of residential services, whether
38 those services are provided in a developmental center, group home,
39 supervised apartment, community care residence, nursing home, or
40 out-of-State placement; in the case of day support services, the type
41 of day support service; and in the case of an individual budget to
42 purchase services, the amount of that budget and the services that
43 are being purchased with the funds from that budget;

44 (5) a list of all services from the division for which the person is
45 currently eligible;

46 (6) **1** a list of services that the person or his parent or guardian
47 has indicated the person would like to receive **1** [but cannot

- 1 access¹, including residential and day support services ¹[], and an
2 explanation of the reason the person cannot access the service;
- 3 (7) an anticipated change in the level of need of the person over
4 the next 10 years and an anticipated date when those changes can be
5 expected to occur; and
- 6 (8) the age and overall health status of any primary caregivers of
7 the person, and the length of time a caregiver anticipates being able
8 to continue to provide services to the person¹.
- 9 c. The division shall ensure that eligible persons are re-
10 assessed as to their needs and services ¹[at least every five years]
11 as needed¹.
- 12
- 13 4. The division shall annually notify ¹[an eligible person by
14 mail] , in writing, persons receiving services¹ of the following:
- 15 a. the services the person is currently receiving from the
16 division and, in the case of an individual budget to purchase
17 services, the amount of that budget and the services that are being
18 purchased with the funds from that budget;
- 19 b. the person's status on a waiting list, if any, and how many
20 persons with developmental disabilities on the list are expected to
21 be served in the next 12 months;
- 22 c. ¹[the projected needs of the person over the next 10 years,
23 as stated in the most recent assessment of the person;
- 24 d.]¹the manner in which the person can easily correct or update,
25 as applicable: the person's contact information; information
26 concerning how the person is spending funds in an individual
27 budget, if any; the person's expected future service needs; and any
28 other relevant information that requires updating; and
- 29 ¹[e.] d.¹ information about where the person with a
30 developmental disability or family member or guardian can find
31 information about services for persons with developmental
32 disabilities, including the link to the department's official website.
- 33
- 34 5. The division shall annually publish a report, to be made
35 available on the department's website, containing non-identifying
36 aggregate data about eligible persons. The report shall, at a
37 minimum, include:
- 38 a. the number of eligible persons, tabulated by county and
39 other demographic information, including, but not limited to, age,
40 gender, race or ethnicity, and disability or diagnosis, as applicable;
- 41 b. for each developmental center: the number of persons with
42 developmental disabilities residing in the developmental center who
43 have expressed ¹to the division¹ a desire to reside in the community
44 but are still awaiting such placement; the ¹number of persons who
45 require ¹[medical or]¹ behavioral supports ¹[], or both,¹ to reside
46 in the community; and the number of persons who are currently

- 1 residing in a developmental center because they have mobility
2 impairments and have been unable to find accessible housing;
- 3 c. an explanation of how the division determines to place an
4 eligible person on a waiting list maintained by the division, what
5 criteria determine a person's priority level and ranking within that
6 priority level on the list, and how a person is selected from the list
7 to receive services;
- 8 d. for each waiting list maintained by the division, within each
9 county:
- 10 (1) the number of people who are waiting for: residential
11 services; employment or day support services; family support
12 services and, if so, which supports; ¹["medical support services;"]¹
13 and behavioral support services; and
- 14 (2) the ¹["median length of time that persons with developmental
15 disabilities have been waiting for services; the percentage of
16 persons with developmental disabilities who are assigned to the
17 different priority levels of all applicable waiting lists; and the
18 number of persons added to the lists in the preceding 12 months]
19 year in which persons requested placement on any division-
20 maintained waiting list¹;
- 21 e. the number of eligible persons served in each residential
22 setting during the preceding 12 months, including, but not limited
23 to, a developmental center, family member's home, group home,
24 supervised apartment, community care residence, nursing home, or
25 out-of-State placement ¹["], and the number of persons with
26 developmental disabilities who moved from one setting to another,
27 tabulated by setting and the reason for the move]¹;
- 28 f. tabulated by county: the number of eligible persons who are
29 expected to transition from receiving services from a school district
30 to receiving services from the division for each ¹["of the three
31 subsequent years] year¹; the expected service needs of these
32 persons; and the total projected cost of services for these persons
33 ¹["], including those persons who are in out-of-State placements
34 through a school district and the number of persons in such
35 placements]¹;
- 36 g. during the preceding 12 months, tabulated by county:
- 37 (1) the number of eligible persons who were removed from ¹["a
38 division] any division-maintained¹ waiting list; ¹["the services for
39 which each person was waiting;"]¹ the reason each person was
40 removed from the list; ¹["the services each person had been
41 receiving, including placement in a developmental center; the
42 services the person is now receiving;"]¹ and how long each person
43 had been waiting for services or supports before being removed
44 from the list;
- 45 (2) the number of eligible persons who were classified as an
46 ¹["emergency," the amount of time it took to provide them with

1 services, and the percentage who received certain services,
2 including, but not limited to, residential services, in-home
3 behavioral support services, and medical support services]
4 "emergency"¹;

5 (3) for those persons who received residential services, the
6 percentage who received such services in a developmental center,
7 group home, supervised apartment, community care residence,
8 nursing home, out-of-State placement, or any other residential
9 setting;

10 (4) the number of eligible persons who were placed in a nursing
11 home and their age when placed, categorized by the reason for such
12 placement;

13 (5) the number of eligible persons who were placed in a
14 developmental center, categorized by the reason for such
15 placement; ¹and¹

16 (6) the number of eligible persons who previously but no longer
17 receive services from the division¹ [, and the reason for no longer
18 receiving such services, categorized by event, including, but not
19 limited to, relocation out-of-State or death, or by some other reason;

20 (7) the number of eligible persons who reported to the division
21 that they were unable to access needed services and the reason,
22 including, but not limited to, lack of funding, unavailability of
23 services in the person's community, and lack of transportation]¹;
24 and

25 h. an explanation of the current procedures and criteria used to
26 admit an eligible person into a ¹[nursing home or]¹ developmental
27 center.

28

29 ¹6. The department shall report to the Governor, and to the
30 Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1),
31 two years after the effective date of this act as to: the progress of
32 the data collection and reporting required pursuant to this act; and
33 the viability of including additional data within its data collection
34 and reporting practices.¹

35

36 ¹7. The Commissioner of Human Services, pursuant to the
37 "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et
38 seq.), shall adopt rules and regulations to effectuate the purposes of
39 sections 3 and 4 of this act.¹

40

41 ¹[6.] 8.¹ This act shall take effect on the first day of the
42 ¹[seventh] 13th¹ month next following the date of enactment ¹,
43 except that the Commissioner of Human Services may take such
44 anticipatory administrative action in advance thereof as shall be
45 necessary for the implementation of this act¹.

1

2

3

Requires DHS to collect and disseminate data about persons with

4

developmental disabilities.

ASSEMBLY, No. 2878

STATE OF NEW JERSEY 214th LEGISLATURE

INTRODUCED JUNE 14, 2010

Sponsored by:

Assemblywoman VALERIE VAINIERI HUTTLE

District 37 (Bergen)

Assemblyman UPENDRA J. CHIVUKULA

District 17 (Middlesex and Somerset)

Assemblyman RUBEN J. RAMOS, JR.

District 33 (Hudson)

Co-Sponsored by:

Assemblywoman Rodriguez

SYNOPSIS

Requires DHS to collect and disseminate data about persons with developmental disabilities.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 6/14/2011)

1 AN ACT concerning persons with developmental disabilities and
2 supplementing chapter 6D of Title 30 of the Revised Statutes.

3

4 **BE IT ENACTED** *by the Senate and General Assembly of the State*
5 *of New Jersey:*

6

7 1. The Legislature finds and declares that:

8 a. Reliable and current data about the service needs of persons
9 with developmental disabilities who are eligible for services from
10 the Division of Developmental Disabilities in the Department of
11 Human Services is fundamental to the division's ability to plan
12 effectively to meet those needs;

13 b. Similarly, in order to make appropriate decisions about State
14 funding for these services, it is important to understand the needs of
15 persons with developmental disabilities served by the division;

16 c. Information about service needs is also essential for service
17 providers as they seek to expand services, acquire or build
18 infrastructure where needed, make services available at the time
19 they are needed, and ensure that the services they provide are
20 compatible with the needs of persons with developmental
21 disabilities residing in their particular service areas;

22 d. Additionally, persons with developmental disabilities and
23 their family members and guardians need access to current data so
24 that they can develop informed expectations about the system that
25 provides services for persons with developmental disabilities;

26 e. As this system evolves into one in which more persons with
27 developmental disabilities and their family members and guardians
28 play a larger role in obtaining necessary support services in the
29 community, it is critical to create a truly transparent system on
30 which persons with developmental disabilities and their family
31 members and guardians can rely, and which they can trust; and

32 f. In order to ensure that the State and persons with
33 developmental disabilities and their family members and guardians
34 have reliable data about the service needs of persons with
35 developmental disabilities and that such data can be made available
36 to those who need to factor that information into their decision-
37 making, planning, funding, and expectations for services, it is the
38 policy of the State to provide for the collection and dissemination of
39 data on persons with developmental disabilities.

40

41 2. As used in this act:

42 "Department" means the Department of Human Services.

43 "Division" means the Division of Developmental Disabilities in
44 the Department of Human Services.

45 "Eligible person with a developmental disability" or "eligible
46 person" means an eligible developmentally disabled person as
47 defined in section 3 of P.L.1985, c.145 (C.30:6D-25).

1 "Services" means services as defined in section 3 of P.L.1985,
2 c.145 (C.30:6D-25).

3

4 3. a. The Division of Developmental Disabilities shall collect
5 and maintain a database of information about eligible persons with
6 developmental disabilities pursuant to this section.

7 b. The division shall, within 12 months of the effective date of
8 this act, collect and maintain data as specified in this section on
9 persons declared eligible persons as of the effective date of this act.
10 In the case of a person with a developmental disability who
11 becomes eligible for services after the effective date of this act, the
12 division shall collect the data no later than 60 days after the person
13 is determined eligible for services by the division.

14 The data to be collected and maintained for each eligible person
15 shall include:

16 (1) the person's name and contact information, guardian, if
17 applicable, and any primary caregivers;

18 (2) the person's age, gender, race or ethnicity, and disability or
19 diagnosis, as applicable;

20 (3) a needs assessment categorized, at a minimum, by the
21 person's need for residential services, employment or day support
22 services, family support services, medical support services, and
23 behavioral support services;

24 (4) a description of the services the person is currently
25 receiving, including: in the case of residential services, whether
26 those services are provided in a developmental center, group home,
27 supervised apartment, community care residence, nursing home, or
28 out-of-State placement; in the case of day support services, the type
29 of day support service; and in the case of an individual budget to
30 purchase services, the amount of that budget and the services that
31 are being purchased with the funds from that budget;

32 (5) a list of all services from the division for which the person is
33 currently eligible;

34 (6) a list of services that the person or his parent or guardian has
35 indicated the person would like to receive but cannot access,
36 including residential and day support services, and an explanation
37 of the reason the person cannot access the service;

38 (7) an anticipated change in the level of need of the person over
39 the next 10 years and an anticipated date when those changes can be
40 expected to occur; and

41 (8) the age and overall health status of any primary caregivers of
42 the person, and the length of time a caregiver anticipates being able
43 to continue to provide services to the person.

44 c. The division shall ensure that eligible persons are re-
45 assessed as to their needs and services at least every five years.

46

47 4. The division shall annually notify an eligible person by mail
48 of the following:

- 1 a. the services the person is currently receiving from the
2 division and, in the case of an individual budget to purchase
3 services, the amount of that budget and the services that are being
4 purchased with the funds from that budget;
- 5 b. the person's status on a waiting list, if any, and how many
6 persons with developmental disabilities on the list are expected to
7 be served in the next 12 months;
- 8 c. the projected needs of the person over the next 10 years, as
9 stated in the most recent assessment of the person;
- 10 d. the manner in which the person can easily correct or update,
11 as applicable: the person's contact information; information
12 concerning how the person is spending funds in an individual
13 budget, if any; the person's expected future service needs; and any
14 other relevant information that requires updating; and
- 15 e. information about where the person with a developmental
16 disability or family member or guardian can find information about
17 services for persons with developmental disabilities, including the
18 link to the department's official website.

19

20 5. The division shall annually publish a report, to be made
21 available on the department's website, containing non-identifying
22 aggregate data about eligible persons. The report shall, at a
23 minimum, include:

- 24 a. the number of eligible persons, tabulated by county and
25 other demographic information, including, but not limited to, age,
26 gender, race or ethnicity, and disability or diagnosis, as applicable;
- 27 b. for each developmental center: the number of persons with
28 developmental disabilities residing in the developmental center who
29 have expressed a desire to reside in the community but are still
30 awaiting such placement; the number of persons who require
31 medical or behavioral supports, or both, to reside in the community;
32 and the number of persons who are currently residing in a
33 developmental center because they have mobility impairments and
34 have been unable to find accessible housing;
- 35 c. an explanation of how the division determines to place an
36 eligible person on a waiting list maintained by the division, what
37 criteria determine a person's priority level and ranking within that
38 priority level on the list, and how a person is selected from the list
39 to receive services;
- 40 d. for each waiting list maintained by the division, within each
41 county:
 - 42 (1) the number of people who are waiting for: residential
43 services; employment or day support services; family support
44 services and, if so, which supports; medical support services; and
45 behavioral support services; and
 - 46 (2) the median length of time that persons with developmental
47 disabilities have been waiting for services; the percentage of
48 persons with developmental disabilities who are assigned to the

- 1 different priority levels of all applicable waiting lists; and the
2 number of persons added to the lists in the preceding 12 months;
- 3 e. the number of eligible persons served in each residential
4 setting during the preceding 12 months, including, but not limited
5 to, a developmental center, family member's home, group home,
6 supervised apartment, community care residence, nursing home, or
7 out-of-State placement, and the number of persons with
8 developmental disabilities who moved from one setting to another,
9 tabulated by setting and the reason for the move;
- 10 f. tabulated by county: the number of eligible persons who are
11 expected to transition from receiving services from a school district
12 to receiving services from the division for each of the three
13 subsequent years; the expected service needs of these persons; and
14 the total projected cost of services for these persons, including those
15 persons who are in out-of-State placements through a school district
16 and the number of persons in such placements;
- 17 g. during the preceding 12 months, tabulated by county:
- 18 (1) the number of eligible persons who were removed from a
19 division waiting list; the services for which each person was
20 waiting; the reason each person was removed from the list; the
21 services each person had been receiving, including placement in a
22 developmental center; the services the person is now receiving; and
23 how long each person had been waiting for services or supports
24 before being removed from the list;
- 25 (2) the number of eligible persons who were classified as an
26 "emergency," the amount of time it took to provide them with
27 services, and the percentage who received certain services,
28 including, but not limited to, residential services, in-home
29 behavioral support services, and medical support services;
- 30 (3) for those persons who received residential services, the
31 percentage who received such services in a developmental center,
32 group home, supervised apartment, community care residence,
33 nursing home, out-of-State placement, or any other residential
34 setting;
- 35 (4) the number of eligible persons who were placed in a nursing
36 home and their age when placed, categorized by the reason for such
37 placement;
- 38 (5) the number of eligible persons who were placed in a
39 developmental center, categorized by the reason for such
40 placement;
- 41 (6) the number of eligible persons who previously but no longer
42 receive services from the division, and the reason for no longer
43 receiving such services, categorized by event, including, but not
44 limited to, relocation out-of-State or death, or by some other reason;
- 45 (7) the number of eligible persons who reported to the division
46 that they were unable to access needed services and the reason,
47 including, but not limited to, lack of funding, unavailability of
48 services in the person's community, and lack of transportation; and

1 h. an explanation of the current procedures and criteria used to
2 admit an eligible person into a nursing home or developmental
3 center.

4
5 6. This act shall take effect on the first day of the seventh
6 month next following the date of enactment.

7
8
9 STATEMENT

10
11 This bill requires the Division of Developmental Disabilities in
12 the Department of Human Services to: collect and maintain a
13 database of information about persons with developmental
14 disabilities who are eligible for services from the division; annually
15 provide certain information to eligible persons with developmental
16 disabilities; and publish an annual report containing non-identifying
17 aggregate data about eligible persons with developmental
18 disabilities.

19 Specifically, the bill provides that:

- 20 • The data to be collected and maintained for eligible persons with
21 developmental disabilities would include:
22 -- the person's name and contact information, guardian, if
23 applicable, and any primary caregivers;
24 -- the person's age, gender, race or ethnicity, and disability or
25 diagnosis, as applicable;
26 -- a needs assessment categorized, at a minimum, by the person's
27 need for residential services, employment or day support
28 services, family support services, medical support services, and
29 behavioral support services;
30 -- a description of the services the person is currently receiving,
31 including: in the case of residential services, whether those
32 services are provided in a developmental center, group home,
33 supervised apartment, community care residence, nursing home,
34 or out-of-State placement; in the case of day support services,
35 the type of day support service; and in the case of an individual
36 budget to purchase services, the amount of that budget and the
37 services that are being purchased with the funds from that
38 budget;
39 -- a list of all services from the division for which the person is
40 currently eligible;
41 -- a list of services that the person or his parent or guardian has
42 indicated the person would like to receive but cannot access,
43 including residential and day support services, and an
44 explanation of the reason the person cannot access the service;
45 -- an anticipated change in the level of need of the person over
46 the next 10 years and an anticipated date when those changes can
47 be expected to occur;

1 -- the age and overall health status of any primary caregivers of
2 the person; and

3 -- the length of time a caregiver anticipates being able to
4 continue to provide services to the person.

5 The division would collect the data specified above, within 12
6 months of the bill's effective date, in the case of persons with
7 developmental disabilities declared eligible for services as of the
8 bill's effective date. For those who become eligible for services
9 after the effective date, the data would be collected no later than 60
10 days after the person is determined eligible for services by the
11 division.

12 The division also would ensure that eligible persons are re-
13 assessed as to their needs and services at least every five years.

14 • The division shall annually notify an eligible person by mail of
15 the following:

16 -- the services the person is currently receiving from the division
17 and, in the case of an individual budget to purchase services, the
18 amount of that budget and the services that are being purchased
19 with the funds from that budget;

20 -- the person's status on a waiting list, if any, and how many
21 persons with developmental disabilities on the list are expected
22 to be served in the next 12 months;

23 -- the projected needs of the person over the next 10 years, as
24 stated in the most recent assessment of the person;

25 -- the manner in which the person can easily correct or update, as
26 applicable: the person's contact information; information
27 concerning how the person is spending funds in an individual
28 budget, if any; the person's expected future service needs; and
29 any other relevant information that requires updating; and

30 -- information about where the person with a developmental
31 disability or family member or guardian can find information
32 about services for persons with developmental disabilities,
33 including the link to the department's official website.

34 • The division would annually publish a report, to be made
35 available on the department's website, containing non-
36 identifying aggregate data about eligible persons with
37 developmental disabilities. The report, at a minimum, would
38 include:

39 -- the number of eligible persons, tabulated by county and other
40 demographic information, including, but not limited to, age,
41 gender, race or ethnicity, and disability or diagnosis, as
42 applicable;

43 -- for each developmental center: the number of persons with
44 developmental disabilities residing in a developmental center
45 who have expressed a desire to reside in the community but are
46 still awaiting such placement; the number of persons who require
47 medical or behavioral supports, or both, to reside in the
48 community; and the number of persons who are currently

1 residing in a developmental center because they have mobility
2 impairments and have been unable to find accessible housing;
3 -- an explanation of how the division determines to place an
4 eligible person on a waiting list maintained by the division, what
5 criteria determine a person's priority level and ranking within
6 that priority level on the list, and how a person is selected from
7 the list to receive services;
8 -- for each waiting list maintained by the division, within each
9 county:
10 -the number of people who are waiting for: residential
11 services; employment or day support services; family
12 support services and, if so, which supports; medical support
13 services; and behavioral support services; and
14 - the median length of time that persons with developmental
15 disabilities have been waiting for services; the percentage of
16 persons who are assigned to the different priority levels of
17 all applicable waiting lists; and the number of persons added
18 to the lists in the preceding 12 months;
19 -- the number of eligible persons served in each residential
20 setting during the preceding 12 months, including, but not
21 limited to, a developmental center, family member's home, group
22 home, supervised apartment, community care residence, nursing
23 home, or out-of-State placement, and the number of persons who
24 moved from one setting to another, tabulated by setting and the
25 reason for the move;
26 -- tabulated by county, the number of eligible persons who are
27 expected to transition from receiving services from a school
28 district to receiving services from the division for each of the
29 three subsequent years, the expected service needs of these
30 persons, and the total projected cost of services for these persons,
31 including those persons who are in out-of-State placements
32 through a school district and the number of persons in such
33 placements;
34 -- during the preceding 12 months, tabulated by county:
35 -the number of eligible persons who were removed from a
36 division waiting list; the services for which each person was
37 waiting; the reason each person was removed from the list;
38 the services each person had been receiving, including
39 placement in a developmental center; the services the person
40 is now receiving; and how long each person had been
41 waiting for services or supports before being removed from
42 the list;
43 - the number of eligible persons who were classified as an
44 "emergency," the amount of time it took to provide them
45 with services, and the percentage who received certain
46 services, including, but not limited to, residential services,
47 in-home behavioral support services, and medical support
48 services;

- 1 - for those eligible persons who received residential services,
 - 2 the percentage who received such services in a
 - 3 developmental center, group home, supervised apartment,
 - 4 community care residence, nursing home, out-of-State
 - 5 placement, or any other residential setting;
 - 6 - the number of eligible persons who were placed in a
 - 7 nursing home and their age when placed, categorized by the
 - 8 reason for such placement; and the number of eligible
 - 9 persons who were placed in a developmental center,
 - 10 categorized by the reason for such placement;
 - 11 - the number of eligible persons who previously but no
 - 12 longer receive services from the division, and the reason for
 - 13 no longer receiving such services, categorized by event,
 - 14 including, but not limited to, relocation out-of-State or
 - 15 death, or by some other reason;
 - 16 - the number of eligible persons who reported to the division
 - 17 that they were unable to access needed services and the
 - 18 reason, including, but not limited to, lack of funding,
 - 19 unavailability of services in the person's community, and
 - 20 lack of transportation; and
 - 21 - an explanation of the current procedures and criteria used
 - 22 to admit an eligible person into a nursing home or
 - 23 developmental center.
- 24 The bill takes effect on the first day of the seventh month
- 25 following its enactment.

ASSEMBLY HUMAN SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 2878

STATE OF NEW JERSEY

DATED: NOVEMBER 15, 2010

The Assembly Human Services Committee reports favorably Assembly Bill No. 2878.

This bill requires the Division of Developmental Disabilities in the Department of Human Services to: collect and maintain a database of information about persons with developmental disabilities who are eligible for services from the division; annually provide certain information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

Specifically, the bill provides that:

- The data to be collected and maintained for eligible persons with developmental disabilities would 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 description of the services the person is currently receiving, including: in the case of residential services, whether those services are provided in a developmental center, group home, supervised apartment, community care residence, nursing home, or out-of-State placement; in the case of day support services, the type of day support service; 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;
 - a list of all services from the division for which the person is currently eligible;
 - a list of services that the person or his parent or guardian has indicated the person would like to receive but cannot access, including residential and day support services, and an explanation of the reason the person cannot access the service;
 - an anticipated change in the level of need of the person over the next 10 years and an anticipated date when those changes can be expected to occur;

- the age and overall health status of any primary caregivers of the person; and
- the length of time a caregiver anticipates being able to continue to provide services to the person.

The division would collect the data specified above, within 12 months of the bill's effective date, in the case of persons with developmental disabilities declared eligible for services as of the bill's effective date. For those who become eligible for services after the effective date, the data would be collected no later than 60 days after the person is determined eligible for services by the division.

The division also would ensure that eligible persons are re-assessed as to their needs and services at least every five years.

- The division shall annually notify an eligible person by mail of the following:
 - the services the person is currently receiving from the division 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 projected needs of the person over the next 10 years, as stated in the most recent assessment of the person;
 - 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; and any other relevant information that requires updating; and
 - information about where the person with a developmental disability or family member or guardian can find information about services for persons with developmental disabilities, including the link to the department's official website.
- The division would annually publish a report, to be made available on the department's website, containing non-identifying aggregate data about eligible persons with developmental disabilities. The report, at a minimum, would 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 persons with developmental disabilities residing in a developmental center who have expressed a desire to reside in the community but are still awaiting such placement; the number of persons who require medical or behavioral supports, or both, to reside in the community; and 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 the division determines to place an eligible person on a waiting list maintained by the division, 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; medical support services; and behavioral support services; and
 - the median length of time that persons with developmental disabilities have been waiting for services; the percentage of persons who are assigned to the different priority levels of all applicable waiting lists; and the number of persons added to the lists in the preceding 12 months;
- 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, and the number of persons who moved from one setting to another, tabulated by setting and the reason for the move;
- tabulated by county, the number of eligible persons who are expected to transition from receiving services from a school district to receiving services from the division for each of the three subsequent years, the expected service needs of these persons, and the total projected cost of services for these persons, including those persons who are in out-of-State placements through a school district and the number of persons in such placements;
- during the preceding 12 months, tabulated by county:
 - the number of eligible persons who were removed from a division waiting list; the services for which each person was waiting; the reason each person was removed from the list; the services each person had been receiving, including placement in a developmental center; the services the person is now receiving; and how long each person had been waiting for services or supports before being removed from the list;
 - the number of eligible persons who were classified as an "emergency," the amount of time it took to provide them with services, and the percentage who received certain services, including, but not limited to, residential services, in-home behavioral support services, and medical support services;
 - for those eligible 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; and 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 receive services from the division, and the reason for no longer receiving such services, categorized by event, including, but not limited to, relocation out-of-State or death, or by some other reason;

- the number of eligible persons who reported to the division that they were unable to access needed services and the reason, including, but not limited to, lack of funding, unavailability of services in the person's community, and lack of transportation; and

- an explanation of the current procedures and criteria used to admit an eligible person into a nursing home or developmental center.

The bill takes effect on the first day of the seventh month following its enactment.

This bill is identical to Senate Bill No. 2028 (Gordon), which is currently pending in the Senate Budget and Appropriations Committee.

FISCAL NOTE
ASSEMBLY, No. 2878
STATE OF NEW JERSEY
214th LEGISLATURE

DATED: JANUARY 7, 2011

SUMMARY

Synopsis: Requires DHS to collect and disseminate data about persons with developmental disabilities.

Type of Impact: An expenditure increase that cannot be determined.

Agencies Affected: Department of Human Services (DHS), Division of Developmental Disabilities (DDD).

Executive Estimate

Fiscal Impact	<u>Year 1</u>	<u>Year 2</u>	<u>Year 3</u>
State Cost (\$000)	\$7,387	\$29,427	\$29,427

Office of Legislative Services Estimate

Fiscal Impact	<u>Year 1 -3</u>
State Cost	Unable to determine.

- The Executive Estimate does not identify any federal funding to offset a portion of the State's cost.
- The DDD will likely have to issue a Request for Proposals to upgrade its Management Information System (MIS). Until bids are received back from vendors, projected MIS costs cannot be determined.

BILL DESCRIPTION

Assembly Bill No. 2878 of 2010 requires the DDD to: collect and maintain a database of information about persons with developmental disabilities who are eligible for services from the DDD; annually provide information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with

developmental disabilities. In addition to basic demographic information on each client, the type of information to be collected shall include: a needs assessment, services the person currently receives, services the person would like to receive, the person's needs over the next ten years, etc.

FISCAL ANALYSIS

EXECUTIVE BRANCH

The DHS and the Office of Management and Budget (OMB) have indicated that the legislation would cost approximately \$7.4 million during the first year and approximately \$29.4 million in the second and third years. Fifteen new staff would need to be hired at an initial cost of about \$0.3 million, increasing to about \$1.1 million in each of the second and third years. During the first year, MIS costs would total over \$7.0 million and would increase to \$28.3 million in subsequent years.

No information is provided as to how it was determined that 15 new staff would need to be hired or that it would cost upwards of \$28.3 million in MIS costs.

The DHS and OMB do not identify any federal reimbursement of these costs.

OFFICE OF LEGISLATIVE SERVICES

As the DHS and the OMB have not provided any information as to how the Executive Branch estimates were developed, the Office of Legislative Services can neither verify or refute those estimates.

While there are additional costs associated with the legislation, the Office of Legislative Services is unable to determine what these costs may be.

Federal reimbursement should be available for some portion of these costs, as many of the persons who receive services from the DDD are Medicaid eligible and the additional administrative costs associated with the legislation should qualify for federal administrative reimbursement.

Much of the information to be collected is already available in the case records the DDD and private agencies maintain on the over 40,000 persons who receive services. Unfortunately, much of the requested information is either on internal forms that have not been computerized or is in the form of handwritten notes. Personnel would either have to be reassigned, new part-time or full-time personnel would have to be hired, or a private vendor could be hired to review the 40,000+ case records to extract the required information. The amount of time required to review the case records cannot be determined as the volume of materials to be reviewed will vary depending on how long a person has received services from the DDD. There are many DDD clients who have received services through the DDD for decades and who would have voluminous case files that would have to be reviewed. The information from the case files would then have to be entered into the DDD's MIS in order to be retrieved and updated. As much of the information being requested is new, existing computer programs would have to be modified or enhanced to accept this new information.

The DDD's current MIS may be inadequate to handle the additional volume of information required to be collected and processed. The DDD (through the Division of Purchase and Property) would likely issue a RFP to upgrade and enhance its MIS. Until a RFP is issued and bids are received from vendors, the cost to enhance and upgrade the DDD's MIS to accommodate the additional data collection and reporting requirements cannot be determined.

It is also noted that many of the 40,000+ persons who receive services from the DDD are eligible for Medicaid, and at least 10,000 persons participate in the Medicaid Community Care Waiver program, in addition to their being on the regular Medicaid program. The Medicaid MIS has significant amounts of health care related data available with respect to the health care services utilized by specific individuals and significant amounts or aggregate data on various eligibility groups including persons with developmental disabilities. It is possible that the Medicaid MIS also may have to be modified to collect additional data elements and to create new reports as a result of this legislation. Such costs cannot be determined at the present time.

Section: Human Services

*Analyst: Jay Hershberg
Principal Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This fiscal note has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

ASSEMBLY APPROPRIATIONS COMMITTEE

STATEMENT TO ASSEMBLY, No. 2878

with committee amendments

STATE OF NEW JERSEY

DATED: JUNE 13, 2011

The Assembly Appropriations Committee reports favorably Assembly Bill No. 2878, with committee amendments.

Assembly Bill No. 2878, as amended, requires the Division of Developmental Disabilities in the Department of Human Services (DHS) to: collect, and when practical maintain a database of, information about persons with developmental disabilities who are eligible for services from the division; annually provide written notification of certain information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

THE DATA TO BE COLLECTED and, when practical maintained for eligible persons with developmental disabilities, includes:

- 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; and
- a list of services that the person or his parent or guardian has indicated the person would like to receive, including residential and day support services.

The bill requires the division to collect the data specified above, within 12 months of the bill's effective date, in the case of persons with developmental disabilities declared eligible for services as of the bill's effective date. For those who become eligible after the effective date, the data will be collected no later than 60 days after the person is determined eligible for services by the division.

The bill directs the division to ensure that eligible persons are re-assessed as to their needs and services as needed.

THE DIVISION SHALL ANNUALLY NOTIFY, IN WRITING, PERSONS RECEIVING SERVICES of the following:

- the services the person is currently receiving from the division 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; and any other relevant information that requires updating; and
- information about where the person with a developmental disability or family member or guardian can find information about services for persons with developmental disabilities, including the link to the DHS website.

THE DIVISION SHALL ANNUALLY PUBLISH A REPORT, to be made available on the DHS website, containing non-identifying aggregate data about eligible persons with developmental disabilities. The report, at a minimum, will 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 persons with developmental disabilities residing in a developmental center who have expressed to the division 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; and 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 the division determines to place an eligible person on a waiting list maintained by the division, 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; and behavioral support services; and
 - the year in which persons requested placement on any division-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 the division for each year, the expected service needs of these persons, and 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 division-maintained waiting list; the reason each person was removed from the list; and how long each person had been waiting for services or supports before being removed from the list;
- the number of eligible persons who were classified as an "emergency";
- for those eligible 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; and the number of eligible persons who were placed in a developmental center, categorized by the reason for such placement; and
- the number of eligible persons who previously but no longer receive services from the division; and
- an explanation of the current procedures and criteria used to admit an eligible person into a developmental center.

The bill requires DHS to report to the Governor and to the Legislature, two years after the effective date of the bill, as to: the progress of the data collection and reporting required pursuant to the bill; and the viability of including additional data within its data collection and reporting practices.

The bill provides for rulemaking, and has a delayed effective date of the first day of the 13th month following enactment, except that the Commissioner of Human Services may take anticipatory administrative action in advance as necessary for implementation of the bill.

FISCAL IMPACT:

It is the understanding of the committee that the Division of Developmental Disabilities in the Department of Human Services is of the opinion that the bill, with the committee amendments adopted today, can be implemented by the division at no additional cost to the State.

COMMITTEE AMENDMENTS:

The amendments make changes with regard to:

- Data collection and maintenance. The division must collect, and when practical maintain a database of, information about eligible persons with developmental disabilities. Certain data are deleted from the collection and maintenance requirements of the bill (a description of the services an eligible person receives, a list of the services for which the person is currently eligible, services that cannot be accessed and an explanation of the reason for lack of accessibility; anticipated changes in needs; and age and health status of primary caregivers). In addition, the division will ensure that eligible persons are re-assessed as needed, rather than at least every five years;
- Notification to persons receiving services. The division will annually notify person receiving services in writing, rather than by mail. Additionally, the notification will not include information about the projected needs of the person;
- The annual report to be published by DHS: The amendments:
 - delete the requirement that the report include the number of persons who require medical supports and the number waiting for these supports;
 - provide that the report include the year in which persons requested placement on any division-maintained waiting list, rather than the median length of time on waiting lists, the percentages of persons on the levels of the lists, and the number of persons added to the lists;
 - delete the requirements that the report provide: the number of persons with developmental disabilities who moved from one setting to another; the total projected costs for out-of-State placements through a school district and the number of such placements; and the number of persons expected to transition from a school district for the three subsequent years and, instead, require an annual number for transitions; and
 - delete the requirement to specify: the services for which the person was waiting, had been receiving, and is currently receiving; the amount of time to provide emergency services; the reason persons are no longer receiving services; the number of persons who reported inability to access services;

and the current procedure to admit eligible persons to nursing homes;

- Reporting to the Governor and the Legislature. Two years after the bill's effective date, DHS is required to report on its progress on data collection, and also on the viability of including additional data within its data collection and reporting practices; and
- Rulemaking and delayed effective date. The bill provides for rulemaking, and has an effective date delayed until the first day of the 13th month following enactment, except that the Commissioner of Human Services may take anticipatory administrative action in advance.
- The amendments also include a technical amendment that revises the definition of "eligible person with a developmental disability" to conform with the enactment of P.L.2010, c.50, which provides for person-first language when describing a person with a developmental disability.

FISCAL NOTE
[First Reprint]
ASSEMBLY, No. 2878
STATE OF NEW JERSEY
214th LEGISLATURE

DATED: JUNE 30, 2011

SUMMARY

Synopsis: Requires DHS to collect and disseminate data about persons with developmental disabilities.

Type of Impact: An expenditure increase that cannot be determined.

Agencies Affected: Department of Human Services (DHS).

Executive Estimate Revised

Fiscal Impact	<u>Years 1 -3</u>
State Cost	DHS indicates that any additional costs will be absorbed within funds already available to the Division of Developmental Disabilities (DDD). The Office of Management and Budget (OMB) questions whether the DHS assessment is “realistic.”

Office of Legislative Services Estimate

Fiscal Impact	<u>Year 1 -3</u>
State Cost	An expenditure increase that cannot be determined.

- DDD’s Management Information System (MIS) may not be capable of handling the additional data required to be collected, stored and processed.

BILL DESCRIPTION

Assembly Bill No. 2878 (1R) of 2010 requires DDD to:

- collect and, when practical, maintain a database of information about persons with developmental disabilities who are eligible for services from DDD;
- annually provide written notification of certain information to eligible persons with developmental disabilities; and

- publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

For persons who are eligible for services from DDD on the effective date of the legislation, the data is to be collected within 12 months. For those persons who are determined eligible for services after the effective date of the legislation, the information is to be collected within 60 days of eligibility.

FISCAL ANALYSIS

EXECUTIVE BRANCH

The DHS has indicated that costs associated with the revised legislation “could be absorbed within existing DHS resources.”

The OMB has questioned whether the DHS assessment is “realistic,” and indicates that “further analysis is required” particularly given DDD’s “significant existing needs in the area of information technology.”

OFFICE OF LEGISLATIVE SERVICES

There are additional costs associated with the legislation that the Office of Legislative Services (OLS) is unable to determine. Federal reimbursement should be available to offset a portion of any costs that may be incurred, as many of the persons who receive services from DDD are Medicaid-eligible and the additional administrative costs associated with the legislation should qualify for federal administrative reimbursement.

Much, if not all, of the required information to be collected is already available in case records maintained by DDD and private agencies on the over 40,000 persons eligible for services. However, much of the requested information is either on internal forms that have not been computerized or is in the form of handwritten notes. In addition to information contained in DDD’s files, the Medicaid MIS maintains data on DDD clients who are eligible for the Medicaid program, including the Community Care Waiver program. This additional data may have to be reviewed.

The overall number of staff at DDD’s central office operations has decreased due to retirements and the inability to fill most non-direct care positions. As such, while it is possible for existing staff to compile the additional information required by the legislation, existing staff may have to curtail their other duties and responsibilities, which may impact other DDD operations.

The DDD would have to develop new forms or modify existing forms to maintain the additional information to be entered into DDD’s MIS for subsequent use and analysis. The DDD existing computer hardware and software systems may have to be modified or enhanced to accept these new or modified forms. The OLS has no information as to whether the hardware and software currently used by DDD is capable of handling the additional volume of information required to be collected and processed. As DDD’s MIS was developed in the late 1980s/early 1990s, the MIS is not considered “state of the art.”

Section: Human Services

*Analyst: Jay Hershberg
Principal Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This fiscal note has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

SENATE BUDGET AND APPROPRIATIONS COMMITTEE

STATEMENT TO

[First Reprint]

ASSEMBLY, No. 2878

STATE OF NEW JERSEY

DATED: SEPTEMBER 22, 2011

The Senate Budget and Appropriations Committee reports favorably Senate Bill No. 2878 (1R).

This bill requires the Division of Developmental Disabilities in the Department of Human Services (DHS) to: collect, and when practical maintain a database of, information about persons with developmental disabilities who are eligible for services from the division; annually provide written notification of certain information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

THE DATA TO BE COLLECTED and, when practical maintained for eligible persons with developmental disabilities, includes:

- 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; and
- a list of services that the person or his parent or guardian has indicated the person would like to receive, including residential and day support services.

The bill requires the division to collect the data specified above, within 12 months of the bill's effective date, in the case of persons with developmental disabilities declared eligible for services as of the bill's effective date. For those who become eligible after the effective date, the data will be collected no later than 60 days after the person is determined eligible for services by the division.

The bill directs the division to ensure that eligible persons are re-assessed as to their needs and services as needed.

THE DIVISION SHALL ANNUALLY NOTIFY, IN WRITING, PERSONS RECEIVING SERVICES of the following:

- the services the person is currently receiving from the division 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; and any other relevant information that requires updating; and

information about where the person with a developmental disability or family member or guardian can find information about services for persons with developmental disabilities, including the link to the DHS website.

THE DIVISION SHALL ANNUALLY PUBLISH A REPORT, to be made available on the DHS website, containing non-identifying aggregate data about eligible persons with developmental disabilities. The report, at a minimum, will 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 persons with developmental disabilities residing in a developmental center who have expressed to the division 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; and 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 the division determines to place an eligible person on a waiting list maintained by the division, 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; and behavioral support services; and
 - the year in which persons requested placement on any division-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 the division for each year, the expected service needs of these persons, and 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 division-maintained waiting list; the reason each person was removed from the list; and how long each person had been waiting for services or supports before being removed from the list;
- the number of eligible persons who were classified as an "emergency";
- for those eligible 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; and the number of eligible persons who were placed in a developmental center, categorized by the reason for such placement; and
- the number of eligible persons who previously but no longer receive services from the division; and
- an explanation of the current procedures and criteria used to admit an eligible person into a developmental center.

The bill requires DHS to report to the Governor and to the Legislature, two years after the effective date of the bill, as to: the progress of the data collection and reporting required pursuant to the bill; and the viability of including additional data within its data collection and reporting practices.

The bill provides for rulemaking, and has a delayed effective date of the first day of the 13th month following enactment, except that the Commissioner of Human Services may take anticipatory administrative action in advance as necessary for implementation of the bill.

As reported, this bill is identical to Senate Bill No. 2028, as amended and reported by the committee

FISCAL IMPACT:

In the Fiscal Note to the bill, the DHS has indicated that costs associated with the revised legislation “could be absorbed within existing DHS resources.” The Office of Management and Budget in the Department of the Treasury has questioned whether the DHS assessment is “realistic,” and indicates that “further analysis is required” particularly given the DDD’s “significant existing needs in

the area of information technology.” The Office of Legislative Services (OLS) indicates in the Fiscal Note that there are additional costs that will be incurred under the bill that it is unable to determine.

Federal reimbursement should be available to offset a portion of any costs that may be incurred, as many of the persons who receive services from DDD are Medicaid-eligible and the additional administrative costs associated with the legislation should qualify for federal administrative reimbursement.

Much, if not all, of the required information to be collected is already available in case records maintained by DDD and private agencies on the over 40,000 persons eligible for services. However, much of the requested information is either on internal forms that have not been computerized or is in the form of handwritten notes. In addition to information contained in DDD’s files, the Medicaid Management Information System (MMIS) maintains data on DDD clients who are eligible for the Medicaid program, including the Community Care Waiver program. This additional data may have to be reviewed.

The overall number of staff at DDD’s central office operations has decreased due to retirements and the inability to fill most non-direct care positions. As such, while it is possible for existing staff to compile the additional information required by the legislation, existing staff may have to curtail their other duties and responsibilities, which may impact other DDD operations.

The DDD would have to develop new forms or modify existing forms to maintain the additional information to be entered into DDD’s MMIS for subsequent use and analysis. The DDD existing computer hardware and software systems may have to be modified or enhanced to accept these new or modified forms. The OLS has no information as to whether the hardware and software currently used by DDD is capable of handling the additional volume of information required to be collected and processed. As DDD’s MMIS was developed in the late 1980s/early 1990s, the MMIS is not considered “state of the art.”

SENATE, No. 2028

STATE OF NEW JERSEY
214th LEGISLATURE

INTRODUCED JUNE 3, 2010

Sponsored by:

Senator ROBERT M. GORDON

District 38 (Bergen)

Senator LINDA R. GREENSTEIN

District 14 (Mercer and Middlesex)

SYNOPSIS

Requires DHS to collect and disseminate data about persons with developmental disabilities.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 9/23/2011)

1 AN ACT concerning persons with developmental disabilities and
2 supplementing chapter 6D of Title 30 of the Revised Statutes.

3

4 **BE IT ENACTED** *by the Senate and General Assembly of the State*
5 *of New Jersey:*

6

7 1. The Legislature finds and declares that:

8 a. Reliable and current data about the service needs of persons
9 with developmental disabilities who are eligible for services from
10 the Division of Developmental Disabilities in the Department of
11 Human Services is fundamental to the division's ability to plan
12 effectively to meet those needs;

13 b. Similarly, in order to make appropriate decisions about State
14 funding for these services, it is important to understand the needs of
15 persons with developmental disabilities served by the division;

16 c. Information about service needs is also essential for service
17 providers as they seek to expand services, acquire or build
18 infrastructure where needed, make services available at the time
19 they are needed, and ensure that the services they provide are
20 compatible with the needs of persons with developmental
21 disabilities residing in their particular service areas;

22 d. Additionally, persons with developmental disabilities and
23 their family members and guardians need access to current data so
24 that they can develop informed expectations about the system that
25 provides services for persons with developmental disabilities;

26 e. As this system evolves into one in which more persons with
27 developmental disabilities and their family members and guardians
28 play a larger role in obtaining necessary support services in the
29 community, it is critical to create a truly transparent system on
30 which persons with developmental disabilities and their family
31 members and guardians can rely, and which they can trust; and

32 f. In order to ensure that the State and persons with
33 developmental disabilities and their family members and guardians
34 have reliable data about the service needs of persons with
35 developmental disabilities and that such data can be made available
36 to those who need to factor that information into their decision-
37 making, planning, funding, and expectations for services, it is the
38 policy of the State to provide for the collection and dissemination of
39 data on persons with developmental disabilities.

40

41 2. As used in this act:

42 "Department" means the Department of Human Services.

43 "Division" means the Division of Developmental Disabilities in
44 the Department of Human Services.

45 "Eligible person with a developmental disability" or "eligible
46 person" means an eligible developmentally disabled person as
47 defined in section 3 of P.L.1985, c.145 (C.30:6D-25).

1 "Services" means services as defined in section 3 of P.L.1985,
2 c.145 (C.30:6D-25).

3

4 3. a. The Division of Developmental Disabilities shall collect
5 and maintain a database of information about eligible persons with
6 developmental disabilities pursuant to this section.

7 b. The division shall, within 12 months of the effective date of
8 this act, collect and maintain data as specified in this section on
9 persons declared eligible persons as of the effective date of this act.
10 In the case of a person with a developmental disability who
11 becomes eligible for services after the effective date of this act, the
12 division shall collect the data no later than 60 days after the person
13 is determined eligible for services by the division.

14 The data to be collected and maintained for each eligible person
15 shall include:

16 (1) the person's name and contact information, guardian, if
17 applicable, and any primary caregivers;

18 (2) the person's age, gender, race or ethnicity, and disability or
19 diagnosis, as applicable;

20 (3) a needs assessment categorized, at a minimum, by the
21 person's need for residential services, employment or day support
22 services, family support services, medical support services, and
23 behavioral support services;

24 (4) a description of the services the person is currently
25 receiving, including: in the case of residential services, whether
26 those services are provided in a developmental center, group home,
27 supervised apartment, community care residence, nursing home, or
28 out-of-State placement; in the case of day support services, the type
29 of day support service; and in the case of an individual budget to
30 purchase services, the amount of that budget and the services that
31 are being purchased with the funds from that budget;

32 (5) a list of all services from the division for which the person is
33 currently eligible;

34 (6) a list of services that the person or his parent or guardian has
35 indicated the person would like to receive but cannot access,
36 including residential and day support services, and an explanation
37 of the reason the person cannot access the service;

38 (7) an anticipated change in the level of need of the person over
39 the next 10 years and an anticipated date when those changes can be
40 expected to occur; and

41 (8) the age and overall health status of any primary caregivers of
42 the person, and the length of time a caregiver anticipates being able
43 to continue to provide services to the person.

44 c. The division shall ensure that eligible persons are re-
45 assessed as to their needs and services at least every five years.

46

47 4. The division shall annually notify an eligible person by mail
48 of the following:

- 1 a. the services the person is currently receiving from the
2 division and, in the case of an individual budget to purchase
3 services, the amount of that budget and the services that are being
4 purchased with the funds from that budget;
- 5 b. the person's status on a waiting list, if any, and how many
6 persons with developmental disabilities on the list are expected to
7 be served in the next 12 months;
- 8 c. the projected needs of the person over the next 10 years, as
9 stated in the most recent assessment of the person;
- 10 d. the manner in which the person can easily correct or update,
11 as applicable: the person's contact information; information
12 concerning how the person is spending funds in an individual
13 budget, if any; the person's expected future service needs; and any
14 other relevant information that requires updating; and
- 15 e. information about where the person with a developmental
16 disability or family member or guardian can find information about
17 services for persons with developmental disabilities, including the
18 link to the department's official website.

19

20 5. The division shall annually publish a report, to be made
21 available on the department's website, containing non-identifying
22 aggregate data about eligible persons. The report shall, at a
23 minimum, include:

- 24 a. the number of eligible persons, tabulated by county and
25 other demographic information, including, but not limited to, age,
26 gender, race or ethnicity, and disability or diagnosis, as applicable;
- 27 b. for each developmental center: the number of persons with
28 developmental disabilities residing in the developmental center who
29 have expressed a desire to reside in the community but are still
30 awaiting such placement; the number of persons who require
31 medical or behavioral supports, or both, to reside in the community;
32 and the number of persons who are currently residing in a
33 developmental center because they have mobility impairments and
34 have been unable to find accessible housing;
- 35 c. an explanation of how the division determines to place an
36 eligible person on a waiting list maintained by the division, what
37 criteria determine a person's priority level and ranking within that
38 priority level on the list, and how a person is selected from the list
39 to receive services;
- 40 d. for each waiting list maintained by the division, within each
41 county:
 - 42 (1) the number of people who are waiting for: residential
43 services; employment or day support services; family support
44 services and, if so, which supports; medical support services; and
45 behavioral support services; and
 - 46 (2) the median length of time that persons with developmental
47 disabilities have been waiting for services; the percentage of
48 persons with developmental disabilities who are assigned to the

- 1 different priority levels of all applicable waiting lists; and the
2 number of persons added to the lists in the preceding 12 months;
- 3 e. the number of eligible persons served in each residential
4 setting during the preceding 12 months, including, but not limited
5 to, a developmental center, family member's home, group home,
6 supervised apartment, community care residence, nursing home, or
7 out-of-State placement, and the number of persons with
8 developmental disabilities who moved from one setting to another,
9 tabulated by setting and the reason for the move;
- 10 f. tabulated by county: the number of eligible persons who are
11 expected to transition from receiving services from a school district
12 to receiving services from the division for each of the three
13 subsequent years; the expected service needs of these persons; and
14 the total projected cost of services for these persons, including those
15 persons who are in out-of-State placements through a school district
16 and the number of persons in such placements;
- 17 g. during the preceding 12 months, tabulated by county:
- 18 (1) the number of eligible persons who were removed from a
19 division waiting list; the services for which each person was
20 waiting; the reason each person was removed from the list; the
21 services each person had been receiving, including placement in a
22 developmental center; the services the person is now receiving; and
23 how long each person had been waiting for services or supports
24 before being removed from the list;
- 25 (2) the number of eligible persons who were classified as an
26 "emergency," the amount of time it took to provide them with
27 services, and the percentage who received certain services,
28 including, but not limited to, residential services, in-home
29 behavioral support services, and medical support services;
- 30 (3) for those persons who received residential services, the
31 percentage who received such services in a developmental center,
32 group home, supervised apartment, community care residence,
33 nursing home, out-of-State placement, or any other residential
34 setting;
- 35 (4) the number of eligible persons who were placed in a nursing
36 home and their age when placed, categorized by the reason for such
37 placement;
- 38 (5) the number of eligible persons who were placed in a
39 developmental center, categorized by the reason for such
40 placement;
- 41 (6) the number of eligible persons who previously but no longer
42 receive services from the division, and the reason for no longer
43 receiving such services, categorized by event, including, but not
44 limited to, relocation out-of-State or death, or by some other reason;
- 45 (7) the number of eligible persons who reported to the division
46 that they were unable to access needed services and the reason,
47 including, but not limited to, lack of funding, unavailability of
48 services in the person's community, and lack of transportation; and

1 h. an explanation of the current procedures and criteria used to
2 admit an eligible person into a nursing home or developmental
3 center.

4
5 6. This act shall take effect on the first day of the seventh
6 month next following the date of enactment.

7
8
9 STATEMENT

10
11 This bill requires the Division of Developmental Disabilities in
12 the Department of Human Services to: collect and maintain a
13 database of information about persons with developmental
14 disabilities who are eligible for services from the division; annually
15 provide certain information to eligible persons with developmental
16 disabilities; and publish an annual report containing non-identifying
17 aggregate data about eligible persons with developmental
18 disabilities.

19 Specifically, the bill provides that:

- 20 • The data to be collected and maintained for eligible persons with
21 developmental disabilities would include:
22 -- the person's name and contact information, guardian, if
23 applicable, and any primary caregivers;
24 -- the person's age, gender, race or ethnicity, and disability or
25 diagnosis, as applicable;
26 -- a needs assessment categorized, at a minimum, by the person's
27 need for residential services, employment or day support
28 services, family support services, medical support services, and
29 behavioral support services;
30 -- a description of the services the person is currently receiving,
31 including: in the case of residential services, whether those
32 services are provided in a developmental center, group home,
33 supervised apartment, community care residence, nursing home,
34 or out-of-State placement; in the case of day support services,
35 the type of day support service; and in the case of an individual
36 budget to purchase services, the amount of that budget and the
37 services that are being purchased with the funds from that
38 budget;
39 -- a list of all services from the division for which the person is
40 currently eligible;
41 -- a list of services that the person or his parent or guardian has
42 indicated the person would like to receive but cannot access,
43 including residential and day support services, and an
44 explanation of the reason the person cannot access the service;
45 -- an anticipated change in the level of need of the person over
46 the next 10 years and an anticipated date when those changes can
47 be expected to occur;

1 -- the age and overall health status of any primary caregivers of
2 the person; and

3 -- the length of time a caregiver anticipates being able to
4 continue to provide services to the person.

5 The division would collect the data specified above, within 12
6 months of the bill's effective date, in the case of persons with
7 developmental disabilities declared eligible for services as of the
8 bill's effective date. For those who become eligible for services
9 after the effective date, the data would be collected no later than 60
10 days after the person is determined eligible for services by the
11 division.

12 The division also would ensure that eligible persons are re-
13 assessed as to their needs and services at least every five years.

14 • The division shall annually notify an eligible person by mail of
15 the following:

16 -- the services the person is currently receiving from the division
17 and, in the case of an individual budget to purchase services, the
18 amount of that budget and the services that are being purchased
19 with the funds from that budget;

20 -- the person's status on a waiting list, if any, and how many
21 persons with developmental disabilities on the list are expected
22 to be served in the next 12 months;

23 -- the projected needs of the person over the next 10 years, as
24 stated in the most recent assessment of the person;

25 -- the manner in which the person can easily correct or update, as
26 applicable: the person's contact information; information
27 concerning how the person is spending funds in an individual
28 budget, if any; the person's expected future service needs; and
29 any other relevant information that requires updating; and

30 -- information about where the person with a developmental
31 disability or family member or guardian can find information
32 about services for persons with developmental disabilities,
33 including the link to the department's official website.

34 • The division would annually publish a report, to be made
35 available on the department's website, containing non-
36 identifying aggregate data about eligible persons with
37 developmental disabilities. The report, at a minimum, would
38 include:

39 -- the number of eligible persons, tabulated by county and other
40 demographic information, including, but not limited to, age,
41 gender, race or ethnicity, and disability or diagnosis, as
42 applicable;

43 -- for each developmental center: the number of persons with
44 developmental disabilities residing in a developmental center
45 who have expressed a desire to reside in the community but are
46 still awaiting such placement; the number of persons who require
47 medical or behavioral supports, or both, to reside in the
48 community; and the number of persons who are currently

1 residing in a developmental center because they have mobility
2 impairments and have been unable to find accessible housing;
3 -- an explanation of how the division determines to place an
4 eligible person on a waiting list maintained by the division, what
5 criteria determine a person's priority level and ranking within
6 that priority level on the list, and how a person is selected from
7 the list to receive services;
8 -- for each waiting list maintained by the division, within each
9 county:
10 -the number of people who are waiting for: residential
11 services; employment or day support services; family
12 support services and, if so, which supports; medical support
13 services; and behavioral support services; and
14 - the median length of time that persons with developmental
15 disabilities have been waiting for services; the percentage of
16 persons who are assigned to the different priority levels of
17 all applicable waiting lists; and the number of persons added
18 to the lists in the preceding 12 months;
19 -- the number of eligible persons served in each residential
20 setting during the preceding 12 months, including, but not
21 limited to, a developmental center, family member's home, group
22 home, supervised apartment, community care residence, nursing
23 home, or out-of-State placement, and the number of persons who
24 moved from one setting to another, tabulated by setting and the
25 reason for the move;
26 -- tabulated by county, the number of eligible persons who are
27 expected to transition from receiving services from a school
28 district to receiving services from the division for each of the
29 three subsequent years, the expected service needs of these
30 persons, and the total projected cost of services for these persons,
31 including those persons who are in out-of-State placements
32 through a school district and the number of persons in such
33 placements;
34 -- during the preceding 12 months, tabulated by county:
35 -the number of eligible persons who were removed from a
36 division waiting list; the services for which each person was
37 waiting; the reason each person was removed from the list;
38 the services each person had been receiving, including
39 placement in a developmental center; the services the person
40 is now receiving; and how long each person had been
41 waiting for services or supports before being removed from
42 the list;
43 - the number of eligible persons who were classified as an
44 "emergency," the amount of time it took to provide them
45 with services, and the percentage who received certain
46 services, including, but not limited to, residential services,
47 in-home behavioral support services, and medical support
48 services;

- 1 - for those eligible persons who received residential services,
2 the percentage who received such services in a
3 developmental center, group home, supervised apartment,
4 community care residence, nursing home, out-of-State
5 placement, or any other residential setting;
 - 6 - the number of eligible persons who were placed in a
7 nursing home and their age when placed, categorized by the
8 reason for such placement; and the number of eligible
9 persons who were placed in a developmental center,
10 categorized by the reason for such placement;
 - 11 - the number of eligible persons who previously but no
12 longer receive services from the division, and the reason for
13 no longer receiving such services, categorized by event,
14 including, but not limited to, relocation out-of-State or
15 death, or by some other reason;
 - 16 - the number of eligible persons who reported to the division
17 that they were unable to access needed services and the
18 reason, including, but not limited to, lack of funding,
19 unavailability of services in the person's community, and
20 lack of transportation; and
 - 21 - an explanation of the current procedures and criteria used
22 to admit an eligible person into a nursing home or
23 developmental center.
- 24 The bill takes effect on the first day of the seventh month
25 following its enactment.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE, No. 2028

STATE OF NEW JERSEY

DATED: JUNE 7, 2010

The Senate Health, Human Services and Senior Citizens Committee reports favorably Senate Bill No. 2028.

This bill requires the Division of Developmental Disabilities in the Department of Human Services to: collect and maintain a database of information about persons with developmental disabilities who are eligible for services from the division; annually provide certain information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

Specifically, the bill provides that:

- The data to be collected and maintained for eligible persons with developmental disabilities would 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 description of the services the person is currently receiving, including: in the case of residential services, whether those services are provided in a developmental center, group home, supervised apartment, community care residence, nursing home, or out-of-State placement; in the case of day support services, the type of day support service; 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;
 - a list of all services from the division for which the person is currently eligible;
 - a list of services that the person or his parent or guardian has indicated the person would like to receive but cannot access, including residential and day support services, and an explanation of the reason the person cannot access the service;

- an anticipated change in the level of need of the person over the next 10 years and an anticipated date when those changes can be expected to occur;
- the age and overall health status of any primary caregivers of the person; and
- the length of time a caregiver anticipates being able to continue to provide services to the person.

The division would collect the data specified above, within 12 months of the bill's effective date, in the case of persons with developmental disabilities declared eligible for services as of the bill's effective date. For those who become eligible for services after the effective date, the data would be collected no later than 60 days after the person is determined eligible for services by the division.

The division also would ensure that eligible persons are re-assessed as to their needs and services at least every five years.

- The division shall annually notify an eligible person by mail of the following:
 - the services the person is currently receiving from the division 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 projected needs of the person over the next 10 years, as stated in the most recent assessment of the person;
 - 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; and any other relevant information that requires updating; and
 - information about where the person with a developmental disability or family member or guardian can find information about services for persons with developmental disabilities, including the link to the department's official website.
- The division shall annually publish a report, to be made available on the department's website, containing non-identifying aggregate data about eligible persons with developmental disabilities. The report, at a minimum, would 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 persons with developmental disabilities residing in a developmental center who have expressed a desire to reside in the community but are still awaiting such placement; the number of persons who require medical or behavioral supports, or both, to reside in the community;

and 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 the division determines to place an eligible person on a waiting list maintained by the division, 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; medical support services; and behavioral support services; and

- the median length of time that persons with developmental disabilities have been waiting for services; the percentage of persons who are assigned to the different priority levels of all applicable waiting lists; and the number of persons added to the lists in the preceding 12 months;

-- 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, and the number of persons who moved from one setting to another, tabulated by setting and the reason for the move;

-- tabulated by county, the number of eligible persons who are expected to transition from receiving services from a school district to receiving services from the division for each of the three subsequent years, the expected service needs of these persons, and the total projected cost of services for these persons, including those persons who are in out-of-State placements through a school district and the number of persons in such placements;

-- during the preceding 12 months, tabulated by county:

- the number of eligible persons who were removed from a division waiting list; the services for which each person was waiting; the reason each person was removed from the list; the services each person had been receiving, including placement in a developmental center; the services the person is now receiving; and how long each person had been waiting for services or supports before being removed from the list;

- the number of eligible persons who were classified as an "emergency," the amount of time it took to provide them with services, and the percentage of such eligible persons who received certain services, including, but not limited to, residential services, in-home behavioral support services, and medical support services;

- for those eligible persons who received residential services, the percentage of persons 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 receive services from the division, and the reason for no longer receiving such services, categorized by event, including, but not limited to, relocation out-of-State or death, or by some other reason;
- the number of eligible persons who reported to the division that they were unable to access needed services and the reason, including, but not limited to, lack of funding, unavailability of services in the person's community, and lack of transportation; and
- an explanation of the current procedures and criteria used to admit an eligible person into a nursing home or developmental center.

The bill takes effect on the first day of the seventh month following its enactment.

FISCAL NOTE
SENATE, No. 2028
STATE OF NEW JERSEY
214th LEGISLATURE

DATED: JANUARY 7, 2011

SUMMARY

Synopsis: Requires DHS to collect and disseminate data about persons with developmental disabilities.

Type of Impact: An expenditure increase that cannot be determined.

Agencies Affected: Department of Human Services (DHS), Division of Developmental Disabilities (DDD).

Executive Estimate

Fiscal Impact	<u>Year 1</u>	<u>Year 2</u>	<u>Year 3</u>
State Cost (\$000)	\$7,387	\$29,427	\$29,427

Office of Legislative Services Estimate

Fiscal Impact	<u>Year 1 -3</u>
State Cost	Unable to determine.

- The Executive Estimate does not identify any federal funding to offset a portion of the State's cost.
- The DDD will likely have to issue a Request for Proposals to upgrade its Management Information System (MIS). Until bids are received back from vendors, projected MIS costs cannot be determined.

BILL DESCRIPTION

Senate Bill No. 2028 of 2010 requires the DDD to: collect and maintain a database of information about persons with developmental disabilities who are eligible for services from the DDD; annually provide information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities. In addition to basic demographic information on each client, the type

of information to be collected shall include: a needs assessment, services the person currently receives, services the person would like to receive, the person's needs over the next ten years, etc.

FISCAL ANALYSIS

EXECUTIVE BRANCH

The DHS and the Office of Management and Budget (OMB) have indicated that the legislation would cost approximately \$7.4 million during the first year and approximately \$29.4 million in the second and third years. Fifteen new staff would need to be hired at an initial cost of about \$0.3 million, increasing to about \$1.1 million in each of the second and third years. During the first year, MIS costs would total over \$7.0 million and would increase to \$28.3 million in subsequent years.

No information is provided as to how it was determined that 15 new staff would need to be hired or that it would cost upwards of \$28.3 million in MIS costs.

The DHS and OMB do not identify any federal reimbursement of these costs.

OFFICE OF LEGISLATIVE SERVICES

As the DHS and the OMB have not provided any information as to how the Executive Branch estimates were developed, the Office of Legislative Services can neither verify or refute those estimates.

While there are additional costs associated with the legislation, the Office of Legislative Services is unable to determine what these costs may be.

Federal reimbursement should be available for some portion of these costs, as many of the persons who receive services from the DDD are Medicaid eligible and the additional administrative costs associated with the legislation should qualify for federal administrative reimbursement.

Much of the information to be collected is already available in the case records the DDD and private agencies maintain on the over 40,000 persons who receive services. Unfortunately, much of the requested information is either on internal forms that have not been computerized or is in the form of handwritten notes. Personnel would either have to be reassigned, new part-time or full-time personnel would have to be hired, or a private vendor could be hired to review the 40,000+ case records to extract the required information. The amount of time required to review the case records cannot be determined as the volume of materials to be reviewed will vary depending on how long a person has received services from the DDD. There are many DDD clients who have received services through the DDD for decades and who would have voluminous case files that would have to be reviewed. The information from the case files would then have to be entered into the DDD's MIS in order to be retrieved and updated. As much of the information being requested is new, existing computer programs would have to be modified or enhanced to accept this new information.

The DDD's current MIS may be inadequate to handle the additional volume of information required to be collected and processed. The DDD (through the Division of Purchase and Property) would likely issue a RFP to upgrade and enhance its MIS. Until a RFP is issued and bids are received from vendors, the cost to enhance and upgrade the DDD's MIS to accommodate the additional data collection and reporting requirements cannot be determined.

It is also noted that many of the 40,000+ persons who receive services from the DDD are eligible for Medicaid, and at least 10,000 persons participate in the Medicaid Community Care

Waiver program, in addition to their being on the regular Medicaid program. The Medicaid MIS has significant amounts of health care related data available with respect to the health care services utilized by specific individuals and significant amounts or aggregate data on various eligibility groups including persons with developmental disabilities. It is possible that the Medicaid MIS also may have to be modified to collect additional data elements and to create new reports as a result of this legislation. Such costs cannot be determined at the present time.

Section: Human Services

*Analyst: Jay Hershberg
Principal Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This fiscal note has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

SENATE BUDGET AND APPROPRIATIONS COMMITTEE

STATEMENT TO

SENATE, No. 2028

with committee amendments

STATE OF NEW JERSEY

DATED: SEPTEMBER 22, 2011

The Senate Budget and Appropriations Committee reports favorably Senate Bill No. 2028, with committee amendments.

As amended, this bill requires the Division of Developmental Disabilities (DDD) in the Department of Human Services (DHS) to: collect, and when practical maintain a database of, information about persons with developmental disabilities who are eligible for services from the division; annually provide written notification of certain information to eligible persons with developmental disabilities; and publish an annual report containing non-identifying aggregate data about eligible persons with developmental disabilities.

THE DATA TO BE COLLECTED and, when practical maintained for eligible persons with developmental disabilities, includes:

- 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; and
- a list of services that the person or his parent or guardian has indicated the person would like to receive, including residential and day support services.

The bill requires the division to collect the data specified above, within 12 months of the bill's effective date, in the case of persons with developmental disabilities declared eligible for services as of the bill's effective date. For those who become eligible after the effective date, the data will be collected no later than 60 days after the person is determined eligible for services by the division.

The bill directs the division to ensure that eligible persons are re-assessed as to their needs and services as needed.

THE DIVISION SHALL ANNUALLY NOTIFY, IN WRITING, PERSONS RECEIVING SERVICES of the following:

- the services the person is currently receiving from the division 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; and any other relevant information that requires updating; and
- information about where the person with a developmental disability or family member or guardian can find information about services for persons with developmental disabilities, including the link to the DHS website.

THE DIVISION SHALL ANNUALLY PUBLISH A REPORT, to be made available on the DHS website, containing non-identifying aggregate data about eligible persons with developmental disabilities. The report, at a minimum, will 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 persons with developmental disabilities residing in a developmental center who have expressed to the division 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; and 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 the division determines to place an eligible person on a waiting list maintained by the division, 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; and behavioral support services; and
 - the year in which persons requested placement on any division-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 the division for each year, the expected service needs of these persons, and 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 division-maintained waiting list; the reason each person was removed from the list; and how long each person had been waiting for services or supports before being removed from the list;
- the number of eligible persons who were classified as an "emergency";
- for those eligible 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; and the number of eligible persons who were placed in a developmental center, categorized by the reason for such placement; and
- the number of eligible persons who previously but no longer receive services from the division; and
- an explanation of the current procedures and criteria used to admit an eligible person into a developmental center.

The bill requires DHS to report to the Governor and to the Legislature, two years after the effective date of the bill, as to: the progress of the data collection and reporting required pursuant to the bill; and the viability of including additional data within its data collection and reporting practices.

The bill provides for rulemaking, and has a delayed effective date of the first day of the 13th month following enactment, except that the Commissioner of Human Services may take anticipatory administrative action in advance as necessary for implementation of the bill.

As amended and reported, this bill is identical to Assembly Bill No. 2878 (1R), as also reported by the committee.

COMMITTEE AMENDMENTS:

The committee amendments make changes with regard to:

- Data collection and maintenance. The division must collect, and when practical maintain a database of, information about eligible persons with developmental disabilities. Certain data are deleted from the collection and maintenance requirements of the bill (a description of the services an eligible person receives, a list of the services for which the person is currently eligible, services that cannot be accessed and an explanation of the reason for lack of accessibility; anticipated changes in needs; and age and health status of primary caregivers). In addition, the division will ensure that eligible persons are re-assessed as needed, rather than at least every five years;
- Notification to persons receiving services. The division will annually notify person receiving services in writing, rather than by mail. Additionally, the notification will not include information about the projected needs of the person;
- The annual report to be published by DHS: The amendments:
 - delete the requirement that the report include the number of persons who require medical supports and the number waiting for these supports;
 - provide that the report include the year in which persons requested placement on any division-maintained waiting list, rather than the median length of time on waiting lists, the percentages of persons on the levels of the lists, and the number of persons added to the lists;
 - delete the requirements that the report provide: the number of persons with developmental disabilities who moved from one setting to another; the total projected costs for out-of-State placements through a school district and the number of such placements; and the number of persons expected to transition from a school district for the three subsequent years and, instead, require an annual number for transitions; and
 - delete the requirement to specify: the services for which the person was waiting, had been receiving, and is currently receiving; the amount of time to provide emergency services; the reason persons are no longer receiving services; the number of persons who reported inability to access services; and the current procedure to admit eligible persons to nursing homes;
- Reporting to the Governor and the Legislature. Two years after the bill's effective date, DHS is required to report on its progress on data collection, and also on the viability of including additional data within its data collection and reporting practices; and
- Rulemaking and delayed effective date. The bill provides for rulemaking, and has an effective date delayed until the first day of the 13th month following enactment, except that the Commissioner

of Human Services may take anticipatory administrative action in advance.

- The amendments also include a technical amendment that revises the definition of "eligible person with a developmental disability" to conform with the enactment of P.L.2010, c.50, which provides for person-first language when describing a person with a developmental disability.

FISCAL IMPACT:

In the Fiscal Note to the identical Assembly, No. 2878 (1R), the DHS has indicated that costs associated with the revised legislation "could be absorbed within existing DHS resources." The Office of Management and Budget in the Department of the Treasury has questioned whether the DHS assessment is "realistic," and indicates that "further analysis is required" particularly given the DDD's "significant existing needs in the area of information technology." The Office of Legislative Services (OLS) indicates in the Fiscal Note that there are additional costs that will be incurred under the bill that it is unable to determine.

Federal reimbursement should be available to offset a portion of any costs that may be incurred, as many of the persons who receive services from DDD are Medicaid-eligible and the additional administrative costs associated with the legislation should qualify for federal administrative reimbursement.

Much, if not all, of the required information to be collected is already available in case records maintained by DDD and private agencies on the over 40,000 persons eligible for services. However, much of the requested information is either on internal forms that have not been computerized or is in the form of handwritten notes. In addition to information contained in DDD's files, the Medicaid Management Information System (MMIS) maintains data on DDD clients who are eligible for the Medicaid program, including the Community Care Waiver program. This additional data may have to be reviewed.

The overall number of staff at DDD's central office operations has decreased due to retirements and the inability to fill most non-direct care positions. As such, while it is possible for existing staff to compile the additional information required by the legislation, existing staff may have to curtail their other duties and responsibilities, which may impact other DDD operations.

The DDD would have to develop new forms or modify existing forms to maintain the additional information to be entered into DDD's MMIS for subsequent use and analysis. The DDD existing computer hardware and software systems may have to be modified or enhanced to accept these new or modified forms. The OLS has no information as to whether the hardware and software currently used by DDD is capable of handling the additional volume of information required to

be collected and processed. As DDD's MMIS was developed in the late 1980s/early 1990s, the MMIS is not considered "state of the art."