
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 1363 Session of
2019

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GILLEN AND SOLOMON, MAY 6, 2019

REFERRED TO COMMITTEE ON HUMAN SERVICES, MAY 6, 2019

AN ACT

1 Establishing a bill of rights for individuals with intellectual
2 disabilities or autism; and conferring powers and duties on
3 the Department of Human Services.

4 The General Assembly of the Commonwealth of Pennsylvania
5 hereby enacts as follows:

6 Section 1. Short title.

7 This act shall be known and may be cited as the Individuals
8 with Intellectual Disabilities or Autism Bill of Rights Act.

9 Section 2. Findings.

10 The General Assembly finds and declares as follows:

11 (1) Disability is a natural part of the human
12 experience, which does not diminish the right of individuals
13 with intellectual disabilities or autism to:

14 (i) enjoy the opportunity to live, to the maximum
15 extent possible, independently and in the community;

16 (ii) make choices and decisions;

17 (iii) contribute to society and participate in the

1 community; and

2 (iv) experience full integration and inclusion in
3 the economic, political, social, cultural, educational
4 and all other aspects of society in this Commonwealth.

5 (2) Individuals with intellectual disabilities or autism
6 continually encounter various forms of discrimination in all
7 areas.

8 (3) There is a lack of public awareness of the
9 capabilities and competencies of individuals with
10 intellectual disabilities or autism.

11 (4) A substantial number of individuals with
12 intellectual disabilities or autism do not have access to
13 appropriate community-integrated supports and services from
14 generic and specialized service systems and remain unserved
15 or underserved.

16 (5) Communities can be enriched by the full and active
17 participation and the contributions by individuals with
18 intellectual disabilities or autism and their families, and
19 there is a need to ensure that, within this Commonwealth,
20 there is the availability and equitable provision of
21 necessary community-integrated supports and services for
22 individuals with intellectual disabilities or autism,
23 regardless of religion, race, color, national origin,
24 economic or social status and degree or type of disability.

25 (6) The long-time commitment of the General Assembly to
26 secure for individuals with intellectual disabilities or
27 autism in partnership with their families or legal guardians
28 the opportunity to choose where they live in the community is
29 affirmed. The General Assembly encourages individuals with
30 intellectual disabilities or autism to remain in their homes

1 or community to the maximum extent possible.

2 (7) Services must ensure accountability, credibility,
3 responsiveness and quality assurance, whether the funding is
4 Federal, State, local or community.

5 (8) As of April 30, 2015, there are approximately 10,234
6 people with intellectual disabilities or autism with
7 emergency and critical needs waiting for home-based and
8 community-based services. As of June 3, 2015, there are
9 approximately 1,675 individuals on the autism home-based and
10 community-based services waiting list, or interest list. The
11 waiting lists for these persons are expected to grow
12 substantially into the foreseeable future.

13 (9) The Department of Human Services needs to develop an
14 adequate plan to address the needs and services for the
15 individuals on the waiting list for intellectual disability
16 services, for the individuals on the waiting list or interest
17 list for autism services and for all individuals with
18 disabilities to prevent institutionalization.

19 (10) For true choice to exist, individuals with
20 intellectual disabilities or autism and their families or
21 legal guardians must be provided with information about
22 options for supports and services.

23 (11) The goals of the General Assembly properly include
24 the goal of providing individuals with intellectual
25 disabilities or autism with the opportunities and support to:

26 (i) Make informed choices and decisions.

27 (ii) Pursue meaningful and productive lives.

28 (iii) Live in a home and community of their choice.

29 (iv) Achieve full integration and inclusion in

30 society in an individualized manner consistent with the

1 unique strengths, resources, priorities, concerns,
2 abilities and capabilities of each individual.

3 (12) The purpose of this act is to reflect the United
4 States Supreme Court decision of *Olmstead v. L.C.*, 119 S.Ct.
5 2176 (1999) (No.98-536 U.S. 1999) and the integration
6 mandates of the Americans with Disabilities Act of 1990
7 (P.L.101-336, 104 Stat. 347) and the Rehabilitation Act of
8 1973 (P.L.93-112, 29 U.S.C. § 701 et seq.).

9 (13) It is the policy of the General Assembly that all
10 programs, projects and activities operating in this
11 Commonwealth be carried out in a manner consistent with the
12 following principles:

13 (i) Individuals with intellectual disabilities or
14 autism are capable of pursuing independence, productivity
15 and integration and inclusion into the community and
16 often require the provision of services, supports and
17 other assistance to achieve independence, productivity
18 and integration and inclusion.

19 (ii) Individuals with intellectual disabilities or
20 autism have competencies, capabilities and personal goals
21 which shall be recognized, supported and encouraged, and
22 any assistance to the individuals shall be provided in an
23 individualized manner consistent with the unique
24 strengths, resources, priorities, concerns, abilities and
25 capabilities of the individuals.

26 (iii) Individuals with intellectual disabilities or
27 autism and, if chosen by the individual, their families
28 or legal guardians are instrumental decision makers
29 regarding the services and supports the individuals
30 receive and inform policies and programs which affect the

1 lives of the individuals and their families.

2 (iv) The Commonwealth shall, within budgetary
3 accountability, provide services, supports and other
4 assistance which reflect the principles of everyday life
5 and self-determination that have been the cornerstone of
6 this Commonwealth's human services for people with
7 intellectual disabilities or autism.

8 Section 3. Definitions.

9 The following words and phrases when used in this act shall
10 have the meanings given to them in this section unless the
11 context clearly indicates otherwise:

12 "Autism" or "autism spectrum disorder." Any of the pervasive
13 developmental disorders defined by the most recent edition of
14 the Diagnostic and Statistical Manual of Mental Disorders (DSM),
15 or its successor, including autistic disorder, Asperger's
16 syndrome and pervasive developmental disorder not otherwise
17 specified.

18 "Department." The Department of Human Services of the
19 Commonwealth.

20 "Intellectual disability." Significantly subaverage general
21 intellectual functioning that is accompanied by significant
22 limitations in adaptive functioning in at least two of the
23 following skill areas:

- 24 (1) Communication.
- 25 (2) Self-care.
- 26 (3) Home living.
- 27 (4) Social and interpersonal skills.
- 28 (5) Use of community resources.
- 29 (6) Self-direction.
- 30 (7) Functional academic skills.

- 1 (8) Work.
- 2 (9) Health.
- 3 (10) Safety.

4 The onset must occur before the individual reaches 22 years of
5 age, as defined by the act of October 20, 1966 (3rd Sp.Sess.,
6 P.L.96, No.6), known as the Mental Health and Intellectual
7 Disability Act of 1966.

8 "Supports and services." Integrated services in the home and
9 community, including the integrated settings where the services
10 are provided, as defined under 42 CFR §§ 440.180 (relating to
11 home and community-based waiver services) and 441.301(c)(4) and
12 (5) (relating to contents of request for a waiver), which are
13 developed in accordance with the person-centered planning
14 requirements of 42 CFR § 441.301(c)(1), (2) and (3).

15 Section 4. Choice.

16 (a) Community-based services.--The Commonwealth shall, based
17 on available funding, provide individualized supports and
18 services for an individual with intellectual disabilities or
19 autism if all of the following apply:

20 (1) The individual has intellectual disabilities or
21 autism.

22 (2) The individual chooses certain supports and services
23 or does not oppose the supports and services.

24 (3) The supports and services are included in an
25 approved individualized services plan developed in accordance
26 with the person-centered planning requirements of 42 CFR §
27 441.301(c)(1), (2) and (3) (relating to contents of request
28 for a waiver) by an authorized State or county supports
29 coordinator with the input of the individual and, if chosen
30 by the individual, the individual's guardian and advocate.

1 (b) Family.--If the individual so chooses, family members
2 and legal guardians of an individual with intellectual
3 disabilities or autism shall be involved in meetings regarding
4 the planning for and arrangement of supports and services or
5 other allowable services. Legal guardians shall, under 20
6 Pa.C.S. § 5521(a) (relating to provisions concerning powers,
7 duties and liabilities):

8 (1) Assert the rights and interests of the individual.

9 (2) Respect the wishes and preferences of the individual
10 to the greatest extent possible.

11 (3) Encourage the individual to participate to the
12 maximum extent of the individual's abilities in all decisions
13 that affect the individual, to act on the individual's own
14 behalf when the individual is able to do so and to develop or
15 regain the individual's capacity to manage the individual's
16 personal affairs to the maximum extent feasible.

17 (c) Contact.--Nothing in this act shall be construed to
18 prohibit an individual with intellectual disabilities or autism
19 from maintaining contact with family and friends. The individual
20 shall also have the choice to not have contact with family and
21 friends.

22 (d) Complaints.--An individual with intellectual
23 disabilities or autism, or a family member or legal guardian of
24 the individual who believes that the needs as identified or as
25 detailed in the individualized service plan are not being met
26 may provide the State or county a letter expressing concerns.
27 The State or county shall, within 30 days, address the concerns
28 and, if necessary, take corrective action. All Federal and State
29 due process rights, including written notice and a fair hearing,
30 also continue to apply for each individual.

1 Section 5. Waiting lists for intellectual disability or autism
2 services.

3 (a) General rule.--The department shall, within four months
4 of the effective date of this act, reorganize its waiting list
5 or interest list for individuals with autism into a waiting list
6 that prioritizes individuals according to the categories of
7 emergency needs, critical needs and planning needs. This data
8 shall be collected using a tool that measures the level of care
9 needed and that does not limit assessment data collection based
10 on the geographic area where autism services are provided in
11 this Commonwealth. Additionally, the prioritization of need may
12 not include consideration of services that the individual with
13 autism currently receives.

14 (b) Waiting list plan.--Within one year of the effective
15 date of this section, the department shall, as part of a
16 stakeholder process with participation by individuals with
17 intellectual disabilities or autism and their family members,
18 develop a five-year plan to eliminate the current and any future
19 additions to the critical and emergency waiting list for
20 individuals with intellectual disabilities or autism who are in
21 need of supports and services. Within one year of the effective
22 date of this section, the department shall develop a two-year
23 plan to eliminate the current as well as any future additions to
24 the supports and services waiting list for individuals with
25 autism and to prevent future supports and services waiting lists
26 for all other persons with disabilities, including those with
27 physical and developmental disabilities, including brain injury.
28 The department shall submit the plans to the Governor, the
29 General Assembly and the county intellectual disability program
30 administrators.

1 (c) Contents of plan.--The plans required by subsection (b)
2 shall include:

3 (1) Statistical information on the current and projected
4 annual increase in the waiting lists on a county basis. The
5 department shall develop a Statewide standardized form to
6 collect the information from the counties and the
7 department's Bureau of Autism Services.

8 (2) Budget projections taking into consideration the
9 department's current budget year, projected annual costs
10 associated with the elimination of the waiting lists,
11 financial information on the amount of additional Federal,
12 State or other funds in each county and with the department's
13 Bureau of Autism Services which may be required annually for
14 the operational costs associated with the elimination of the
15 waiting list in each county and of the waiting list with the
16 department's Bureau of Autism Services and the projected
17 annual waiting lists in each annual plan update.

18 (d) Public hearings and comment.--In the development of the
19 plans required by subsection (b), the department shall conduct
20 public hearings and obtain public comment from individuals with
21 disabilities, including those with intellectual disabilities or
22 autism, their families and guardians and providers of services
23 to the disability community, including the intellectual
24 disabilities and autism community.

25 (e) Annual submission of updated plan.--The department shall
26 update the budget, statistical and financial data to the plans
27 required by subsection (b) annually and submit updated plans to
28 the Governor, the General Assembly and the county intellectual
29 disability program administrators on the anniversary date of the
30 department's original submission of the plans.

1 Section 6. Funding.

2 Services under this act shall be made available across this
3 Commonwealth, taking into account the budget constraints and
4 financial resources available to the Commonwealth and the needs
5 of individuals with intellectual disabilities or autism. Nothing
6 under this act shall constitute an entitlement derived from the
7 Commonwealth or a claim on any funds of the Commonwealth.

8 Section 7. Report.

9 (a) General rule.--The department shall submit a written
10 report by September 30, 2019, and every four months thereafter,
11 to the following:

12 (1) The Governor.

13 (2) The chairperson and minority chairperson of the
14 Public Health and Welfare Committee of the Senate.

15 (3) The chairperson and minority chairperson of the
16 Health Committee of the House of Representatives.

17 (4) The chairperson and minority chairperson of the
18 Human Services Committee of the House of Representatives.

19 (5) The chairperson and minority chairperson of the
20 Appropriations Committee of the Senate.

21 (6) The chairperson and minority chairperson of the
22 Appropriations Committee of the House of Representatives.

23 (7) The department's Medical Assistance Advisory
24 Committee.

25 (b) Posting of report.--The report shall be posted on the
26 department's publicly accessible Internet website in an
27 accessible format.

28 (c) Contents of report.--The report shall include the
29 following:

30 (1) The total number and age ranges, including under 18

1 years of age, 18 to 21 years of age and over 21 years of age,
2 of individuals currently on the department's waiting list for
3 supports and services for individuals with intellectual
4 disabilities or autism.

5 (2) The number and age ranges, including under 18 years
6 of age, 18 to 21 years of age and over 21 years of age, of
7 individuals currently on the department's waiting list for
8 supports and services for individuals with intellectual
9 disabilities or autism:

10 (i) with emergency needs;

11 (ii) with critical needs; and

12 (iii) the combined number of those with emergency
13 needs and critical needs.

14 (3) The number of individuals added to the department's
15 waiting list for supports and services for individuals with
16 intellectual disabilities or autism in the last four months
17 and the reasons that the individuals were added to the
18 waiting list.

19 (4) The number of individuals removed from the
20 department's waiting list for supports and services for
21 individuals with intellectual disabilities or autism in the
22 last four months and the reasons that the individuals were
23 removed from the waiting list.

24 (5) The number of months or years that individuals with
25 emergency needs currently on the department's waiting list
26 for supports and services for individuals with intellectual
27 disabilities or autism have been on the waiting list.

28 (6) The number of months or years that individuals with
29 critical needs currently on the department's waiting list for
30 supports and services for individuals with intellectual

1 disabilities or autism have been on the waiting list.

2 (7) The number and age ranges, including under 18 years
3 of age, 18 to 21 years of age and over 21 years of age, of
4 individuals currently on the department's waiting list for
5 supports and services for individuals with intellectual
6 disabilities or autism who are in:

7 (i) a State center;

8 (ii) a private intermediate care facility for
9 individuals with intellectual disabilities or persons
10 with other related conditions;

11 (iii) a State hospital;

12 (iv) a private psychiatric hospital;

13 (v) a residential treatment facility; or

14 (vi) any other public or private facility or other
15 institutional setting.

16 (8) The total number and age ranges, including under 18
17 years of age, 18 to 21 years of age and over 21 years of age,
18 of individuals currently on the department's waiting list or
19 interest list for the adult community autism program and the
20 adult autism waiver.

21 (9) The total number and age ranges, including under 18
22 years of age, 18 to 21 years of age and over 21 years of age,
23 of individuals currently on the department's waiting list or
24 interest list for the adult community autism program and the
25 adult autism waiver:

26 (i) with emergency needs;

27 (ii) with critical needs; and

28 (iii) the combined number of those with emergency
29 needs and critical needs.

30 (10) The number of individuals added to the department's

1 waiting list or interest list for the adult community autism
2 program and the adult autism waiver in the last four months
3 and the reasons that the individuals were added to the
4 waiting list.

5 (11) The number of individuals removed from the
6 department's waiting list or interest list for the adult
7 community autism program and the adult autism waiver in the
8 last four months and the reasons that the individuals were
9 removed from the waiting list.

10 (12) The number of months or years that individuals with
11 emergency needs currently on the department's waiting list or
12 interest list for the adult community autism program and the
13 adult autism waiver have been on the waiting list.

14 (13) The number of months or years that individuals with
15 critical needs currently on the department's waiting list or
16 interest list for the adult community autism program and the
17 adult autism waiver have been on the waiting list.

18 (14) The total number and age ranges, including under 18
19 years of age, 18 to 21 years of age and over 21 years of age,
20 of individuals currently on the department's waiting list or
21 interest list for the adult community autism program and the
22 adult autism waiver who are in:

23 (i) a State center;

24 (ii) a private intermediate care facility for
25 individuals with intellectual disabilities or persons
26 with other related conditions;

27 (iii) a State hospital;

28 (iv) a private psychiatric hospital;

29 (v) a residential treatment facility; or

30 (vi) any other public or private facility or other

1 institutional setting.

2 (15) The estimated per-person cost to serve an eligible
3 individual on the waiting list under paragraph (1).

4 (16) The estimated per-person cost to serve an eligible
5 individual on the waiting list or interest list under
6 paragraph (8).

7 (17) The total estimated cost to serve all eligible
8 individuals on the waiting list under paragraph (1) and the
9 estimated cost to serve all eligible individuals in each
10 category listed under paragraph (2).

11 (18) The total estimated cost to serve all eligible
12 individuals on the waiting list or interest list under
13 paragraph (8) and the estimated cost to serve all eligible
14 individuals in each category listed under paragraph (9).

15 Section 8. Effective date.

16 This act shall take effect immediately.