
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 414 Session of
2017

INTRODUCED BY MURT, D. MILLER, BARRAR, BOBACK, R. BROWN,
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ROZZI, SCHLOSSBERG, SOLOMON, STURLA AND WARD,
FEBRUARY 8, 2017

REFERRED TO COMMITTEE ON HUMAN SERVICES, FEBRUARY 8, 2017

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 individuals' 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 the 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 and the
7 Rehabilitation Act.

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

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

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

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

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

7 Section 3. Definitions.

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

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

17 "Community-integrated supports and services options," "home
18 and community-based services" or "supports and services."
19 Integrated services in the home and community, including the
20 integrated settings where such services are provided, as defined
21 by Federal regulations at 42 CFR §§ 440.180 (relating to home
22 and community-based waiver services) and 441.301(c)(4) and (5)
23 (relating to contents of request for a waiver), which are
24 developed in accordance with the person-centered planning
25 requirements of 42 CFR § 441.301(c)(1), (2) and (3).

26 "Department." The Department of Human Services of the
27 Commonwealth.

28 "Intellectual disability." Significantly subaverage general
29 intellectual functioning that is accompanied by significant
30 limitations in adaptive functioning in at least two of the

1 following skill areas:

- 2 (1) Communication.
- 3 (2) Self-care.
- 4 (3) Home living.
- 5 (4) Social and interpersonal skills.
- 6 (5) Use of community resources.
- 7 (6) Self-direction.
- 8 (7) Functional academic skills.
- 9 (8) Work.
- 10 (9) Health.
- 11 (10) Safety.

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

16 Section 4. Choice.

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

22 (1) The individual has intellectual disabilities or
23 autism.

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

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

1 coordinator with the input of the individual and, if chosen
2 by the individual, the individual's guardian and advocate.

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

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

11 (2) Respect the wishes and preferences of the individual
12 to the greatest extent possible.

13 (3) Encourage the individual to participate to the
14 maximum extent of his or her abilities in all decisions that
15 affect him or her, to act on his or her behalf when he or she
16 is able to do so and to develop or regain his or her capacity
17 to manage his or her personal affairs to the maximum extent
18 feasible.

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

24 (d) Complaints.--An individual with intellectual
25 disabilities or autism, or a family member or a legal guardian
26 of such individual who believes that the needs as identified or
27 as detailed in the individualized service plan are not being met
28 may provide the State or county a letter expressing concerns.
29 The State or county shall, within 30 days, address the concerns
30 and, if necessary, take corrective action. All Federal and State

1 due process rights, including, but not limited to, written
2 notice and a fair hearing, also continue to apply for each
3 individual.

4 Section 5. Waiting lists for intellectual disability or autism
5 services.

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

17 (b) Waiting list plan.--Within one year of the effective
18 date of this section, the department shall, as part of a
19 stakeholder process with participation by individuals with
20 disabilities or autism and their family members, develop a five-
21 year plan to eliminate the current as well as any future
22 additions to the critical and emergency waiting list for
23 individuals with intellectual disabilities or autism who are in
24 need of home-based and community-based supports and services.
25 Within one year of the effective date of this section, the
26 department shall develop a two-year plan to eliminate the
27 current as well as any future additions to the home-based and
28 community-based services waiting list for individuals with
29 autism and to prevent future home-based and community-based
30 services waiting lists for all other persons with disabilities,

1 including those with physical and developmental disabilities,
2 including brain injury. The department shall submit the plans to
3 the Governor, the General Assembly and the county intellectual
4 disability program administrators.

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

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

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

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

29 (e) Annual submission of updated plan.--The department shall
30 update the budget, statistical and financial data to the plans

1 required by subsection (b) annually and submit updated plans to
2 the Governor, the General Assembly and the county intellectual
3 disability program administrators on the anniversary date of the
4 department's original submission of the plans.

5 Section 6. Funding.

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

12 Section 7. Report.

13 (a) General rule.--The department shall submit a written
14 report by September 30, 2017, and every four months thereafter,
15 to the following:

16 (1) The Governor.

17 (2) The chairperson and minority chairperson of the
18 Public Health and Welfare Committee of the Senate.

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

21 (4) The chairperson and minority chairperson of the
22 Health Committee of the House of Representatives.

23 (5) The chairperson and minority chairperson of the
24 Human Services Committee of the House of Representatives.

25 (6) The chairperson and minority chairperson of the
26 Appropriations Committee of the House of Representatives.

27 (7) The department's Medical Assistance Advisory
28 Committee.

29 (b) Posting of report.--The report shall be posted on the
30 department's publicly accessible Internet website in an

1 accessible format.

2 (c) Contents of report.--The report shall include the
3 following:

4 (1) The total number and age ranges, including under 18
5 years of age, 18 to 21 years of age and over 21 years of age,
6 of individuals currently on the department's waiting list for
7 home-based and community-based services for individuals with
8 intellectual disabilities or autism.

9 (2) The number and age ranges, including under 18 years
10 of age, 18 to 21 years of age and over 21 years of age, of
11 individuals currently on the department's waiting list for
12 home-based and community-based services for individuals with
13 intellectual disabilities or autism:

14 (i) with emergency needs;

15 (ii) with critical needs; and

16 (iii) the combined number of those with emergency
17 needs and critical needs.

18 (3) The number of individuals added to the department's
19 waiting list for home-based and community-based services for
20 individuals with intellectual disabilities or autism in the
21 last four months and the reasons they were added to the
22 waiting list.

23 (4) The number of individuals removed from the
24 department's waiting list for home-based and community-based
25 services for individuals with intellectual disabilities or
26 autism in the last four months and the reasons they were
27 removed from the waiting list.

28 (5) The number of months or years that individuals with
29 emergency needs currently on the department's waiting list
30 for home-based and community-based services for individuals

1 with intellectual disabilities or autism have been on the
2 waiting list.

3 (6) The number of months or years that individuals with
4 critical needs currently on the department's waiting list for
5 home-based and community-based services for individuals with
6 intellectual disabilities or autism have been on the waiting
7 list.

8 (7) The number and age ranges, including under 18 years
9 of age, 18 to 21 years of age and over 21 years of age, of
10 individuals currently on the department's waiting list for
11 home-based and community-based services for individuals with
12 intellectual disabilities or autism who are in:

13 (i) a State center;

14 (ii) a private intermediate care facility for
15 individuals with intellectual disabilities (ICF/IID) or
16 persons with other related conditions (ICF/ORC);

17 (iii) a State hospital;

18 (iv) a private psychiatric hospital;

19 (v) a residential treatment facility; or

20 (vi) any other public or private facility or other
21 institutional setting.

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

27 (9) The total number and age ranges, including under 18
28 years of age, 18 to 21 years of age and over 21 years of age,
29 of individuals currently on the department's waiting list or
30 interest list for the adult community autism program and the

1 adult autism waiver:

2 (i) with emergency needs;

3 (ii) with critical needs; and

4 (iii) the combined number of those with emergency
5 needs and critical needs.

6 (10) The number of individuals added to the department's
7 waiting list or interest list for the adult community autism
8 program and the adult autism waiver in the last four months
9 and the reasons they were added to the waiting list.

10 (11) The number of individuals removed from the
11 department's waiting list or interest list for the adult
12 community autism program and the adult autism waiver in the
13 last four months and the reasons they were removed from the
14 waiting list.

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

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

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

28 (i) a State center;

29 (ii) a private intermediate care facility for
30 individuals with intellectual disabilities (ICF/IID) or

1 persons with other related conditions (ICF/ORC);
2 (iii) a State hospital;
3 (iv) a private psychiatric hospital;
4 (v) a residential treatment facility; or
5 (vi) any other public or private facility or other
6 institutional setting.

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

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

12 (17) The total estimated cost to serve all eligible
13 individuals on the waiting list under paragraph (1) and the
14 estimated cost to serve all eligible individuals in each
15 category listed under paragraph (2).

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

20 Section 8. Effective date.

21 This act shall take effect immediately.