

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 1363 Session of 2019

INTRODUCED BY MURT, DONATUCCI, STEPHENS, MARKOSEK, A. DAVIS, CALTAGIRONE, ROZZI, SCHLOSSBERG, HOHENSTEIN, NEILSON, McNEILL, FRANKEL, FREEMAN, CIRESI, WARREN, YOUNGBLOOD, MOUL, SHUSTERMAN, McCLINTON, READSHAW, KAUFER, STURLA, KENYATTA, GILLEN, SOLOMON, THOMAS AND MALAGARI, MAY 6, 2019

AS REPORTED FROM COMMITTEE ON HUMAN SERVICES, HOUSE OF REPRESENTATIVES, AS AMENDED, MAY 19, 2020

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;

1           (iii) contribute to society and participate in the  
2 community; and

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

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

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

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

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

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

1 intellectual disabilities or autism to remain in their homes  
2 or community to the maximum extent possible.

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

6 (8) As of ~~April 30, 2015~~ MARCH 31, 2020, there are <--  
7 approximately ~~10,234~~ 9,982 people with intellectual <--  
8 disabilities or autism with emergency and critical needs  
9 waiting for home-based and community-based services. As of  
10 ~~June 3, 2015~~ MARCH 30, 2020, there are approximately ~~1,675~~ <--  
11 2,244 individuals on the autism home-based and community- <--  
12 based services waiting list, or interest list. The waiting  
13 lists for these persons are expected to grow substantially  
14 into the foreseeable future.

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

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

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

- 28 (i) Make informed choices and decisions.
- 29 (ii) Pursue meaningful and productive lives.
- 30 (iii) Live in a home and community of their choice.

1 (iv) Achieve full integration and inclusion in  
2 society in an individualized manner consistent with the  
3 unique strengths, resources, priorities, concerns,  
4 abilities and capabilities of each individual.

5 (12) The purpose of this act is to reflect the United  
6 States Supreme Court decision of *Olmstead v. L.C.*, 119 S.Ct.  
7 2176 (1999) (No.98-536 U.S. 1999) and the integration  
8 mandates of the Americans with Disabilities Act of 1990  
9 (P.L.101-336, 104 Stat. 347) and the Rehabilitation Act of  
10 1973 (P.L.93-112, 29 U.S.C. § 701 et seq.).

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

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

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

28 (iii) Individuals with intellectual disabilities or  
29 autism and, if chosen by the individual, their families  
30 or legal guardians are instrumental decision makers

1           regarding the services and supports the individuals  
2           receive and inform policies and programs which affect the  
3           lives of the individuals and their families.

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

10 Section 3. Definitions.

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

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

20           "Department." The Department of Human Services of the  
21           Commonwealth.

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

- 26           (1) Communication.
- 27           (2) Self-care.
- 28           (3) Home living.
- 29           (4) Social and interpersonal skills.
- 30           (5) Use of community resources.

- 1 (6) Self-direction.
- 2 (7) Functional academic skills.
- 3 (8) Work.
- 4 (9) Health.
- 5 (10) Safety.

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

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

18 (a) Community-based services.--The Commonwealth shall, based  
19 on available funding, provide individualized supports and  
20 services for an individual with intellectual disabilities or  
21 autism if all of the following 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 supports and 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 the individual's abilities in all decisions  
15 that affect the individual, to act on the individual's own  
16 behalf when the individual is able to do so and to develop or  
17 regain the individual's capacity to manage the individual's  
18 personal affairs to the maximum extent 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 to not have contact with family and  
23 friends.

24 (d) Complaints.--An individual with intellectual  
25 disabilities or autism, or a family member or legal guardian of  
26 the individual who believes that the needs as identified or as  
27 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 written notice and a fair hearing,  
2 also continue to apply for each individual.

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

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

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



1 General Assembly and the county intellectual disability program  
2 administrators.

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

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

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

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

27 (e) Annual submission of updated plan.--The department shall  
28 update the budget, statistical and financial data to the plans  
29 required by subsection (b) annually and submit updated plans to  
30 the Governor, the General Assembly and the county intellectual

1 disability program administrators on the anniversary date of the  
2 department's original submission of the plans.

3 Section 6. Funding.

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

10 Section 7. Report.

11 (a) General rule.--The department shall submit a written  
12 report ~~by September 30, 2019~~ WITHIN NINE MONTHS AFTER THE <--  
13 EFFECTIVE DATE OF THIS SECTION, and every four months  
14 thereafter, to the following:

15 (1) The Governor.

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

18 (3) The chairperson and minority chairperson of the  
19 Health Committee of the House of Representatives.

20 (4) The chairperson and minority chairperson of the  
21 Human Services Committee of the House of Representatives.

22 (5) The chairperson and minority chairperson of the  
23 Appropriations Committee of the Senate.

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

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

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

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

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

8 (2) 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 supports and services for individuals with intellectual  
12 disabilities or autism:

13 (i) with emergency needs;

14 (ii) with critical needs; and

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

17 (3) The number of individuals added to the department's  
18 waiting list for supports and services for individuals with  
19 intellectual disabilities or autism in the last four months  
20 ~~and the reasons that the individuals were added to the~~ <--  
21 ~~waiting list.~~

22 (4) The number of individuals removed from the  
23 department's waiting list for supports and services for  
24 individuals with intellectual disabilities or autism in the  
25 last four months. ~~and the reasons that the individuals were~~ <--  
26 ~~removed from the waiting list.~~

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

1           ~~(6) The number of months or years that individuals with~~  
2 ~~critical needs currently on the department's waiting list for~~  
3 ~~supports and services for individuals with intellectual~~  
4 ~~disabilities or autism have been on the waiting list.~~

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

10           (i) a State center;

11           (ii) a private intermediate care facility for  
12 individuals with intellectual disabilities or persons  
13 with other related conditions;

14           (iii) a State hospital;

15           (iv) a private psychiatric hospital;

16           (v) a residential treatment facility; or

17           (vi) any other public or private facility or other  
18 institutional setting.

19           ~~(8)~~ (6) The total number and age ranges, including under <--  
20 18 years of age, 18 to 21 years of age and over 21 years of  
21 age, of individuals currently on the department's waiting  
22 list or interest list for the adult community autism program  
23 and the adult autism waiver.

24           ~~(9)~~ (7) The total number and age ranges, including under <--  
25 18 years of age, 18 to 21 years of age and over 21 years of  
26 age, of individuals currently on the department's waiting  
27 list or interest list for the adult community autism program  
28 and the adult autism waiver:

29           (i) with emergency needs;

30           (ii) with critical needs; and

1 (iii) the combined number of those with emergency  
2 needs and critical needs.

3 ~~(10) The number of individuals added to the department's <--  
4 waiting list or interest list for the adult community autism  
5 program and the adult autism waiver in the last four months  
6 and the reasons that the individuals were added to the  
7 waiting list.~~

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

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

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

21 ~~(14) (9) The total number and age ranges, including <--  
22 under 18 years of age, 18 to 21 years of age and over 21  
23 years of age, of individuals currently on the department's  
24 waiting list or interest list for the adult community autism  
25 program and the adult autism waiver who are in:~~

26 (i) a State center;

27 (ii) a private intermediate care facility for  
28 individuals with intellectual disabilities or persons  
29 with other related conditions;

30 (iii) a State hospital;

1 (iv) a private psychiatric hospital;  
2 (v) a residential treatment facility; or  
3 (vi) any other public or private facility or other  
4 institutional setting.

5 ~~(15)~~ (10) The estimated per-person cost to serve an <--  
6 eligible individual on the waiting list under paragraph (1).

7 ~~(16)~~ (11) The estimated per-person cost to serve an <--  
8 eligible individual on the waiting list or interest list  
9 under paragraph ~~(8)~~ (6). <--

10 ~~(17)~~ (12) The total estimated cost to serve all eligible <--  
11 individuals on the waiting list under paragraph (1) and the  
12 estimated cost to serve all eligible individuals in each  
13 category listed under paragraph (2).

14 ~~(18)~~ (13) The total estimated cost to serve all eligible <--  
15 individuals on the waiting list or interest list under  
16 paragraph ~~(8)~~ (6) and the estimated cost to serve all <--  
17 eligible individuals in each category listed under paragraph  
18 ~~(9)~~ (7). <--

19 Section 8. Effective date.

20 This act shall take effect immediately.