

AMENDMENTS TO HOUSE BILL NO. 1363

Sponsor: SENATOR BROOKS

Printer's No. 3796

1 Amend Bill, page 1, lines 2 and 3, by striking out
2 "conferring powers and duties on the Department of Human
3 Services" and inserting
4 providing for waiting lists for intellectual disability or
5 autism services and report

6 Amend Bill, page 1, lines 6 through 16; pages 2 through 13,
7 lines 1 through 30; page 14, lines 1 through 20; by striking out
8 all of said lines on said pages and inserting

9 Section 1. Short title.
10 This act shall be known and may be cited as the Individuals
11 with Intellectual Disabilities or Autism Bill of Rights Act.

12 Section 2. Findings.
13 The General Assembly finds and declares as follows:
14 (1) Disability is a natural part of the human
15 experience, which does not diminish the right of individuals
16 with intellectual disabilities or autism to:
17 (i) enjoy the opportunity to live independently, to
18 the maximum extent possible;
19 (ii) make choices and decisions;
20 (iii) contribute to society and participate in the
21 community; and
22 (iv) experience full integration and inclusion in
23 the economic, political, social, cultural, educational
24 and all other aspects of society in this Commonwealth.
25 (2) Individuals with intellectual disabilities or autism
26 continually encounter various forms of discrimination in all
27 areas.
28 (3) There is a lack of public awareness of the
29 capabilities and competencies of individuals with
30 intellectual disabilities or autism.
31 (4) A substantial number of individuals with
32 intellectual disabilities or autism do not have access to
33 appropriate supports and services from generic and
34 specialized service systems and remain unserved or

1 underserved.

2 (5) Communities can be enriched by the full and active
3 participation and the contributions by individuals with
4 intellectual disabilities or autism and their families or
5 legal guardians.

6 (6) The long-time commitment of the General Assembly to
7 secure for individuals with intellectual disabilities or
8 autism in partnership with their families or legal guardians
9 the opportunity to choose where they live is affirmed.

10 (7) For true choice to exist, individuals with
11 intellectual disabilities or autism and their families or
12 legal guardians must be provided with information about
13 options for supports and services.

14 (8) The goals of the General Assembly properly include
15 the goal of providing individuals with intellectual
16 disabilities or autism with the opportunities and support to:

17 (i) make informed choices and decisions;

18 (ii) pursue meaningful and productive lives;

19 (iii) live in a home of their choice; and

20 (iv) achieve full integration and inclusion in
21 society in an individualized manner consistent with the
22 unique strengths, resources, priorities, concerns,
23 abilities and capabilities of each individual.

24 (9) It is the policy of the General Assembly that all
25 programs, projects and activities operating in this
26 Commonwealth be carried out in a manner consistent with the
27 following principles:

28 (i) Individuals with intellectual disabilities or
29 autism are capable of pursuing independence, productivity
30 and integration and inclusion into the community and
31 often require the provision of services, supports and
32 other assistance to achieve independence, productivity
33 and integration and inclusion.

34 (ii) Individuals with intellectual disabilities or
35 autism have competencies, capabilities and personal goals
36 which shall be recognized, supported and encouraged, and
37 any assistance to the individuals shall be provided in an
38 individualized manner consistent with the unique
39 strengths, resources, priorities, concerns, abilities and
40 capabilities of the individuals.

41 (iii) Individuals with intellectual disabilities or
42 autism and their families or legal guardians are
43 instrumental decision makers regarding the services and
44 supports the individuals receive and inform policies and
45 programs which affect the lives of the individuals and
46 their families.

47 (iv) The Commonwealth shall, within budgetary
48 accountability and Federal funding availability, provide
49 services, supports and other assistance which reflect the
50 principles of everyday life and self-determination that
51 have been the cornerstone of this Commonwealth's human

1 services for people with intellectual disabilities or
2 autism.

3 Section 3. Definitions.

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

7 "Autism" or "autism spectrum disorder." Any of the pervasive
8 developmental disorders defined by the Diagnostic and
9 Statistical Manual of Mental Disorders, 5th Edition (DSM-5),
10 including autistic disorder, Asperger's syndrome and pervasive
11 developmental disorder not otherwise specified.

12 "Department." The Department of Human Services of the
13 Commonwealth.

14 "Home." The community or facility in which individuals with
15 intellectual disabilities or autism reside.

16 "Intellectual disability." As defined in section 102 of the
17 act of October 20, 1966 (3rd Sp.Sess., P.L.96, No.6), known as
18 the Mental Health and Intellectual Disability Act of 1966.

19 "Intermediate care facility." A facility for individuals
20 with intellectual disabilities as defined in section 1396d(d) of
21 the Social Security Act (49 Stat. 620, 42 U.S.C. § 1396d(d)).

22 "PUNS." The prioritization of urgency of need for services
23 tool.

24 "Supports and services." Integrated services in the home,
25 including the integrated settings where the services are
26 provided, as defined in 42 CFR 440.180 (relating to home and
27 community-based waiver services) and 441.301(c)(4) and (5)
28 (relating to contents of request for a waiver), which are
29 developed in accordance with the person-centered planning
30 requirements of 42 CFR 441.301(c)(1), (2) and (3).

31 "Waiting list." A list maintained by the department with the
32 individuals with intellectual disabilities or autism who are
33 waiting for supports and services to meet their needs.

34 Section 4. Individualized supports and services.

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

39 (1) The individual has intellectual disabilities or
40 autism.

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

43 (3) The supports and services are included in an
44 approved individualized services plan developed in accordance
45 with the person-centered planning requirements under 42 CFR
46 441.301(c)(1), (2) and (3) (relating to contents of request
47 for a waiver) by an authorized State or county supports
48 coordinator with the input of the individual and the
49 individual's guardian and advocate.

50 (b) Family.--

51 (1) If the individual so chooses, family members of an

1 individual with intellectual disabilities or autism shall be
2 involved in meetings regarding the planning for and
3 arrangement of supports and services or other allowable
4 services. Legal guardians shall, in accordance with 20
5 Pa.C.S. § 5521(a) (relating to provisions concerning powers,
6 duties and liabilities), have all of the following duties:

7 (i) Asserting the rights and interests of the
8 individual.

9 (ii) Respecting the wishes and preferences of the
10 individual to the greatest extent possible.

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

18 (2) Nothing in this act shall be construed to prohibit a
19 legal guardian from exercising the legal guardian's duties
20 and liabilities on behalf of the individual.

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

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

35 Section 5. Waiting lists for intellectual disability or autism
36 services and report.

37 (a) Waiting list.--The department shall, within six months
38 of the effective date of this section, reorganize its waiting
39 list or interest list for individuals with intellectual
40 disabilities or autism into a waiting list that utilizes PUNS.
41 This data shall not limit assessment data collection based on
42 the geographic area where intellectual disabilities or autism
43 services are provided in this Commonwealth. The department shall
44 make this data available to the Legislative Budget and Finance
45 Committee for the purpose of the report required under
46 subsection (b).

47 (b) Report.--Within one year of the effective date of this
48 section, the Legislative Budget and Finance Committee shall
49 submit a report on the department's waiting list or interest
50 list specified under subsection (a) to the Governor, the General
51 Assembly and the county intellectual disability program

1 administrators.

2 (c) Contents of report.--The report required under
3 subsection (b) shall include all of the following information:

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

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

19 (3) The total number of individuals with intellectual
20 disabilities or autism on the department's waiting list for
21 supports and services on the effective date of this section,
22 organized as follows:

23 (i) By age range, as follows:

24 (A) Under 18 years of age.

25 (B) 18 to 21 years of age.

26 (C) Over 21 years of age.

27 (ii) By emergency need, critical need or planning
28 for need, as organized in PUNS.

29 (iii) By their home, including any of the following
30 settings for supports and services:

31 (A) A State center.

32 (B) A private intermediate care facility for
33 individuals with intellectual disabilities or persons
34 with other related conditions.

35 (C) A State hospital.

36 (D) A private psychiatric hospital.

37 (E) A residential treatment facility.

38 (F) Any other public or private facility or
39 other institutional setting.

40 (4) The number of individuals removed from the
41 department's waiting list in the last year.

42 (5) The total estimated cost and per-individual cost to
43 serve eligible individuals with intellectual disabilities or
44 autism on the waiting list.

45 (d) Public hearings and comment.--In the development of the
46 report required under subsection (b), the Legislative Budget and
47 Finance Committee shall conduct public hearings and obtain
48 public comment from individuals with disabilities, including
49 those with intellectual disabilities or autism, their families
50 and legal guardians and providers of services to the disability
51 community, including the intellectual disabilities and autism

1 community.

2 (e) Annual submission of updated report.--The Legislative
3 Budget and Finance Committee shall update the budget,
4 statistical and financial data in the report required under
5 subsection (b) annually and submit an updated report to all of
6 the following:

7 (1) The Governor.

8 (2) The chair and minority chair of the Appropriations
9 Committee of the Senate.

10 (3) The chair and minority chair of the Appropriations
11 Committee of the House of Representatives.

12 (4) The chair and minority chair of the Health and Human
13 Services Committee of the Senate.

14 (5) The chair and minority chair of the Health Committee
15 of the House of Representatives.

16 (6) The chair and minority chair of the Human Services
17 Committee of the House of Representatives.

18 (7) The Medical Assistance Advisory Committee within the
19 department.

20 (f) Posting of report.--The department shall post the report
21 required under subsection (b) on the department's publicly
22 accessible Internet website in an accessible format.

23 Section 6. Funding.

24 Services under this act shall be made available across this
25 Commonwealth, taking into account the budget constraints and
26 financial resources available to the Commonwealth and the needs
27 of individuals with intellectual disabilities or autism. Nothing
28 under this act shall constitute an entitlement derived from the
29 Commonwealth or a claim on any funds of the Commonwealth.

30 Section 7. Choice of care options.

31 The department shall review the report required under section
32 5(b) annually and work to identify individuals with intellectual
33 disabilities or autism on the waiting list or interested in
34 receiving supports and services through a public intermediate
35 care facility. The department shall collaborate with county
36 intellectual disability program administrators to contact
37 individuals with intellectual disabilities or autism on the
38 waiting list or their legal guardians to provide the option of
39 receiving care at a public intermediate care facility or
40 remaining on the waiting list for home and community-based
41 waiver enrollment. The department shall disclose to individuals
42 with intellectual disabilities or autism or their legal
43 guardians any plans that may result in the change or elimination
44 of their services.

45 Section 8. Effective date.

46 This act shall take effect immediately.