

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, MALAGARI, KORTZ, DELLOSO AND RYAN, MAY 6, 2019

SENATOR BROOKS, HEALTH AND HUMAN SERVICES, IN SENATE, AS AMENDED, OCTOBER 6, 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~~ PROVIDING FOR WAITING LISTS <--
4 FOR INTELLECTUAL DISABILITY OR AUTISM SERVICES AND REPORT.

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

7 ~~Section 1. Short title.~~ <--

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

10 ~~Section 2. Findings.~~

11 ~~The General Assembly finds and declares as follows:~~

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

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

1 ~~(ii) make choices and decisions;~~

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

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

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

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

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

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

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

1 ~~affirmed. The General Assembly encourages individuals with~~
2 ~~intellectual disabilities or autism to remain in their homes~~
3 ~~or community to the maximum extent possible.~~

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

7 ~~(8) As of March 31, 2020, there are approximately 9,982~~
8 ~~people with intellectual disabilities or autism with~~
9 ~~emergency and critical needs waiting for home based and~~
10 ~~community based services. As of March 30, 2020, there are~~
11 ~~approximately 2,244 individuals on the autism home based and~~
12 ~~community based services waiting list, or interest list. The~~
13 ~~waiting lists for these persons are expected to grow~~
14 ~~substantially 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.~~

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

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

27 ~~(i) Make informed choices and decisions.~~

28 ~~(ii) Pursue meaningful and productive lives.~~

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

30 ~~(iv) Achieve full integration and inclusion in~~

1 ~~society in an individualized manner consistent with the~~
2 ~~unique strengths, resources, priorities, concerns,~~
3 ~~abilities and capabilities of each individual.~~

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

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

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

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

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

1 ~~receive and inform policies and programs which affect the~~
2 ~~lives of the individuals and their families.~~

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

9 ~~Section 3. Definitions.~~

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

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

19 ~~"Department." The Department of Human Services of the~~
20 ~~Commonwealth.~~

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

25 ~~(1) Communication.~~

26 ~~(2) Self care.~~

27 ~~(3) Home living.~~

28 ~~(4) Social and interpersonal skills.~~

29 ~~(5) Use of community resources.~~

30 ~~(6) Self direction.~~

1 ~~(7) Functional academic skills.~~

2 ~~(8) Work.~~

3 ~~(9) Health.~~

4 ~~(10) Safety.~~

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

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

16 Section 4. Choice.

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

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

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

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

1 ~~by the individual, the individual's guardian and advocate.~~

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

9 ~~(1) Assert the rights and interests of the individual.~~

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

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

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

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

1 ~~also continue to apply for each individual.~~

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

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

13 ~~(b) Waiting list plan. Within one year of the effective~~
14 ~~date of this section, the department shall, as part of a~~
15 ~~stakeholder process with participation by individuals with~~
16 ~~intellectual disabilities or autism and their family members,~~
17 ~~develop a five year plan to eliminate the current and any future~~
18 ~~additions to the critical and emergency waiting list for~~
19 ~~individuals with intellectual disabilities or autism who are in~~
20 ~~need of supports and services. The department shall submit the~~
21 ~~plans to the Governor, the General Assembly and the county~~
22 ~~intellectual disability program administrators.~~

23 ~~(c) Contents of plan. The plans required by subsection (b)~~
24 ~~shall include:~~

25 ~~(1) Statistical information on the current and projected~~
26 ~~annual increase in the waiting lists on a county basis. The~~
27 ~~department shall develop a Statewide standardized form to~~
28 ~~collect the information from the counties and the~~
29 ~~department's Bureau of Autism Services.~~

30 ~~(2) Budget projections taking into consideration the~~

1 ~~department's current budget year, projected annual costs~~
2 ~~associated with the elimination of the waiting lists,~~
3 ~~financial information on the amount of additional Federal,~~
4 ~~State or other funds in each county and with the department's~~
5 ~~Bureau of Autism Services which may be required annually for~~
6 ~~the operational costs associated with the elimination of the~~
7 ~~waiting list in each county and of the waiting list with the~~
8 ~~department's Bureau of Autism Services and the projected~~
9 ~~annual waiting lists in each annual plan update.~~

10 ~~(d) Public hearings and comment. In the development of the~~
11 ~~plans required by subsection (b), the department shall conduct~~
12 ~~public hearings and obtain public comment from individuals with~~
13 ~~disabilities, including those with intellectual disabilities or~~
14 ~~autism, their families and guardians and providers of services~~
15 ~~to the disability community, including the intellectual~~
16 ~~disabilities and autism community.~~

17 ~~(e) Annual submission of updated plan. The department shall~~
18 ~~update the budget, statistical and financial data to the plans~~
19 ~~required by subsection (b) annually and submit updated plans to~~
20 ~~the Governor, the General Assembly and the county intellectual~~
21 ~~disability program administrators on the anniversary date of the~~
22 ~~department's original submission of the plans.~~

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. Report.~~

1 ~~(a) General rule. The department shall submit a written~~
2 ~~report within nine months after the effective date of this~~
3 ~~section, and every four months thereafter, to the following:~~

4 ~~(1) The Governor.~~

5 ~~(2) The chairperson and minority chairperson of the~~
6 ~~Public Health and Welfare Committee of the Senate.~~

7 ~~(3) The chairperson and minority chairperson of the~~
8 ~~Health Committee of the House of Representatives.~~

9 ~~(4) The chairperson and minority chairperson of the~~
10 ~~Human Services Committee of the House of Representatives.~~

11 ~~(5) The chairperson and minority chairperson of the~~
12 ~~Appropriations Committee of the Senate.~~

13 ~~(6) The chairperson and minority chairperson of the~~
14 ~~Appropriations Committee of the House of Representatives.~~

15 ~~(7) The department's Medical Assistance Advisory~~
16 ~~Committee.~~

17 ~~(b) Posting of report. The report shall be posted on the~~
18 ~~department's publicly accessible Internet website in an~~
19 ~~accessible format.~~

20 ~~(c) Contents of report. The report shall include the~~
21 ~~following:~~

22 ~~(1) 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 for~~
25 ~~supports and services for individuals with intellectual~~
26 ~~disabilities or autism.~~

27 ~~(2) The number and age ranges, including under 18 years~~
28 ~~of age, 18 to 21 years of age and over 21 years of age, of~~
29 ~~individuals currently on the department's waiting list for~~
30 ~~supports and services for individuals with intellectual~~

1 ~~disabilities or autism:~~

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 ~~(3) The number of individuals added to the department's~~
7 ~~waiting list for supports and services for individuals with~~
8 ~~intellectual disabilities or autism in the last four months.~~

9 ~~(4) The number of individuals removed from the~~
10 ~~department's waiting list for supports and services for~~
11 ~~individuals with intellectual disabilities or autism in the~~
12 ~~last four months.~~

13 ~~(5) The number and age ranges, including under 18 years~~
14 ~~of age, 18 to 21 years of age and over 21 years of age, of~~
15 ~~individuals currently on the department's waiting list for~~
16 ~~supports and services for individuals with intellectual~~
17 ~~disabilities or autism who are in:~~

18 ~~(i) a State center;~~

19 ~~(ii) a private intermediate care facility for~~
20 ~~individuals with intellectual disabilities or persons~~
21 ~~with other related conditions;~~

22 ~~(iii) a State hospital;~~

23 ~~(iv) a private psychiatric hospital;~~

24 ~~(v) a residential treatment facility; or~~

25 ~~(vi) any other public or private facility or other~~
26 ~~institutional setting.~~

27 ~~(6) 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 ~~(7) The total number and age ranges, including under 18-~~
3 ~~years of age, 18 to 21 years of age and over 21 years of age,~~
4 ~~of individuals currently on the department's waiting list or~~
5 ~~interest list for the adult community autism program and the~~
6 ~~adult autism waiver:~~

7 ~~(i) with emergency needs;~~

8 ~~(ii) with critical needs; and~~

9 ~~(iii) the combined number of those with emergency-~~
10 ~~needs and critical needs.~~

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

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

20 ~~(i) a State center;~~

21 ~~(ii) a private intermediate care facility for~~
22 ~~individuals with intellectual disabilities or persons~~
23 ~~with other related conditions;~~

24 ~~(iii) a State hospital;~~

25 ~~(iv) a private psychiatric hospital;~~

26 ~~(v) a residential treatment facility; or~~

27 ~~(vi) any other public or private facility or other~~
28 ~~institutional setting.~~

29 ~~(10) The estimated per person cost to serve an eligible~~
30 ~~individual on the waiting list under paragraph (1).~~

1 ~~(11) The estimated per person cost to serve an eligible~~
2 ~~individual on the waiting list or interest list under~~
3 ~~paragraph (6).~~

4 ~~(12) The total estimated cost to serve all eligible~~
5 ~~individuals on the waiting list under paragraph (1) and the~~
6 ~~estimated cost to serve all eligible individuals in each~~
7 ~~category listed under paragraph (2).~~

8 ~~(13) The total estimated cost to serve all eligible~~
9 ~~individuals on the waiting list or interest list under~~
10 ~~paragraph (6) and the estimated cost to serve all eligible~~
11 ~~individuals in each category listed under paragraph (7).~~

12 ~~Section 8. Effective date.~~

13 ~~This act shall take effect immediately.~~

14 SECTION 1. SHORT TITLE.

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15 THIS ACT SHALL BE KNOWN AND MAY BE CITED AS THE INDIVIDUALS
16 WITH INTELLECTUAL DISABILITIES OR AUTISM BILL OF RIGHTS ACT.

17 SECTION 2. FINDINGS.

18 THE GENERAL ASSEMBLY FINDS AND DECLARES AS FOLLOWS:

19 (1) DISABILITY IS A NATURAL PART OF THE HUMAN
20 EXPERIENCE, WHICH DOES NOT DIMINISH THE RIGHT OF INDIVIDUALS
21 WITH INTELLECTUAL DISABILITIES OR AUTISM TO:

22 (I) ENJOY THE OPPORTUNITY TO LIVE INDEPENDENTLY, TO
23 THE MAXIMUM EXTENT POSSIBLE;

24 (II) MAKE CHOICES AND DECISIONS;

25 (III) CONTRIBUTE TO SOCIETY AND PARTICIPATE IN THE
26 COMMUNITY; AND

27 (IV) EXPERIENCE FULL INTEGRATION AND INCLUSION IN
28 THE ECONOMIC, POLITICAL, SOCIAL, CULTURAL, EDUCATIONAL
29 AND ALL OTHER ASPECTS OF SOCIETY IN THIS COMMONWEALTH.

30 (2) INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR AUTISM

1 CONTINUALLY ENCOUNTER VARIOUS FORMS OF DISCRIMINATION IN ALL
2 AREAS.

3 (3) THERE IS A LACK OF PUBLIC AWARENESS OF THE
4 CAPABILITIES AND COMPETENCIES OF INDIVIDUALS WITH
5 INTELLECTUAL DISABILITIES OR AUTISM.

6 (4) A SUBSTANTIAL NUMBER OF INDIVIDUALS WITH
7 INTELLECTUAL DISABILITIES OR AUTISM DO NOT HAVE ACCESS TO
8 APPROPRIATE SUPPORTS AND SERVICES FROM GENERIC AND
9 SPECIALIZED SERVICE SYSTEMS AND REMAIN UNSERVED OR
10 UNDERSERVED.

11 (5) COMMUNITIES CAN BE ENRICHED BY THE FULL AND ACTIVE
12 PARTICIPATION AND THE CONTRIBUTIONS BY INDIVIDUALS WITH
13 INTELLECTUAL DISABILITIES OR AUTISM AND THEIR FAMILIES OR
14 LEGAL GUARDIANS.

15 (6) THE LONG-TIME COMMITMENT OF THE GENERAL ASSEMBLY TO
16 SECURE FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR
17 AUTISM IN PARTNERSHIP WITH THEIR FAMILIES OR LEGAL GUARDIANS
18 THE OPPORTUNITY TO CHOOSE WHERE THEY LIVE IS AFFIRMED.

19 (7) 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 (8) 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 OF THEIR CHOICE; AND

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 (9) IT IS THE POLICY OF THE GENERAL ASSEMBLY THAT ALL
4 PROGRAMS, PROJECTS AND ACTIVITIES OPERATING IN THIS
5 COMMONWEALTH BE CARRIED OUT IN A MANNER CONSISTENT WITH THE
6 FOLLOWING PRINCIPLES:

7 (I) INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR
8 AUTISM ARE CAPABLE OF PURSUING INDEPENDENCE, PRODUCTIVITY
9 AND INTEGRATION AND INCLUSION INTO THE COMMUNITY AND
10 OFTEN REQUIRE THE PROVISION OF SERVICES, SUPPORTS AND
11 OTHER ASSISTANCE TO ACHIEVE INDEPENDENCE, PRODUCTIVITY
12 AND INTEGRATION AND INCLUSION.

13 (II) INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR
14 AUTISM HAVE COMPETENCIES, CAPABILITIES AND PERSONAL GOALS
15 WHICH SHALL BE RECOGNIZED, SUPPORTED AND ENCOURAGED, AND
16 ANY ASSISTANCE TO THE INDIVIDUALS SHALL BE PROVIDED IN AN
17 INDIVIDUALIZED MANNER CONSISTENT WITH THE UNIQUE
18 STRENGTHS, RESOURCES, PRIORITIES, CONCERNS, ABILITIES AND
19 CAPABILITIES OF THE INDIVIDUALS.

20 (III) INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR
21 AUTISM AND THEIR FAMILIES OR LEGAL GUARDIANS ARE
22 INSTRUMENTAL DECISION MAKERS REGARDING THE SERVICES AND
23 SUPPORTS THE INDIVIDUALS RECEIVE AND INFORM POLICIES AND
24 PROGRAMS WHICH AFFECT THE LIVES OF THE INDIVIDUALS AND
25 THEIR FAMILIES.

26 (IV) THE COMMONWEALTH SHALL, WITHIN BUDGETARY
27 ACCOUNTABILITY AND FEDERAL FUNDING AVAILABILITY, PROVIDE
28 SERVICES, SUPPORTS AND OTHER ASSISTANCE WHICH REFLECT THE
29 PRINCIPLES OF EVERYDAY LIFE AND SELF-DETERMINATION THAT
30 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).

1 "WAITING LIST." A LIST MAINTAINED BY THE DEPARTMENT WITH THE
2 INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR AUTISM WHO ARE
3 WAITING FOR SUPPORTS AND SERVICES TO MEET THEIR NEEDS.

4 SECTION 4. INDIVIDUALIZED SUPPORTS AND SERVICES.

5 (A) COMMUNITY-BASED SERVICES.--THE COMMONWEALTH SHALL, BASED
6 ON AVAILABLE FUNDING, PROVIDE INDIVIDUALIZED SUPPORTS AND
7 SERVICES FOR AN INDIVIDUAL WITH INTELLECTUAL DISABILITIES OR
8 AUTISM IF ALL OF THE FOLLOWING APPLY:

9 (1) THE INDIVIDUAL HAS INTELLECTUAL DISABILITIES OR
10 AUTISM.

11 (2) THE INDIVIDUAL CHOOSES CERTAIN SUPPORTS AND SERVICES
12 OR DOES NOT OPPOSE THE SUPPORTS AND SERVICES.

13 (3) THE SUPPORTS AND SERVICES ARE INCLUDED IN AN
14 APPROVED INDIVIDUALIZED SERVICES PLAN DEVELOPED IN ACCORDANCE
15 WITH THE PERSON-CENTERED PLANNING REQUIREMENTS UNDER 42 CFR
16 441.301(C)(1), (2) AND (3) (RELATING TO CONTENTS OF REQUEST
17 FOR A WAIVER) BY AN AUTHORIZED STATE OR COUNTY SUPPORTS
18 COORDINATOR WITH THE INPUT OF THE INDIVIDUAL AND THE
19 INDIVIDUAL'S GUARDIAN AND ADVOCATE.

20 (B) FAMILY.--

21 (1) IF THE INDIVIDUAL SO CHOOSES, FAMILY MEMBERS OF AN
22 INDIVIDUAL WITH INTELLECTUAL DISABILITIES OR AUTISM SHALL BE
23 INVOLVED IN MEETINGS REGARDING THE PLANNING FOR AND
24 ARRANGEMENT OF SUPPORTS AND SERVICES OR OTHER ALLOWABLE
25 SERVICES. LEGAL GUARDIANS SHALL, IN ACCORDANCE WITH 20
26 PA.C.S. § 5521(A) (RELATING TO PROVISIONS CONCERNING POWERS,
27 DUTIES AND LIABILITIES), HAVE ALL OF THE FOLLOWING DUTIES:

28 (I) ASSERTING THE RIGHTS AND INTERESTS OF THE
29 INDIVIDUAL.

30 (II) RESPECTING THE WISHES AND PREFERENCES OF THE

1 INDIVIDUAL TO THE GREATEST EXTENT POSSIBLE.

2 (III) ENCOURAGING THE INDIVIDUAL TO PARTICIPATE TO
3 THE MAXIMUM EXTENT OF THE INDIVIDUAL'S ABILITIES IN ALL
4 DECISIONS THAT AFFECT THE INDIVIDUAL, TO ACT ON THE
5 INDIVIDUAL'S OWN BEHALF WHEN THE INDIVIDUAL IS ABLE TO DO
6 SO AND TO DEVELOP OR REGAIN THE INDIVIDUAL'S CAPACITY TO
7 MANAGE THE INDIVIDUAL'S PERSONAL AFFAIRS TO THE MAXIMUM
8 EXTENT FEASIBLE.

9 (2) NOTHING IN THIS ACT SHALL BE CONSTRUED TO PROHIBIT A
10 LEGAL GUARDIAN FROM EXERCISING THE LEGAL GUARDIAN'S DUTIES
11 AND LIABILITIES ON BEHALF OF THE INDIVIDUAL.

12 (C) CONTACT.--NOTHING IN THIS ACT SHALL BE CONSTRUED TO
13 PROHIBIT AN INDIVIDUAL WITH INTELLECTUAL DISABILITIES OR AUTISM
14 FROM MAINTAINING CONTACT WITH FAMILY AND FRIENDS. THE INDIVIDUAL
15 SHALL ALSO HAVE THE CHOICE TO NOT HAVE CONTACT WITH FAMILY AND
16 FRIENDS.

17 (D) COMPLAINTS.--AN INDIVIDUAL WITH INTELLECTUAL
18 DISABILITIES OR AUTISM OR A FAMILY MEMBER OR LEGAL GUARDIAN OF
19 THE INDIVIDUAL WHO BELIEVES THAT THE NEEDS AS IDENTIFIED OR AS
20 DETAILED IN THE INDIVIDUALIZED SERVICE PLAN ARE NOT BEING MET
21 MAY PROVIDE THE STATE OR COUNTY A LETTER EXPRESSING CONCERNS.
22 THE STATE OR COUNTY SHALL, WITHIN 30 DAYS, ADDRESS THE CONCERNS
23 AND, IF NECESSARY, TAKE CORRECTIVE ACTION. ALL FEDERAL AND STATE
24 DUE PROCESS RIGHTS, INCLUDING WRITTEN NOTICE AND A FAIR HEARING,
25 ALSO CONTINUE TO APPLY FOR EACH INDIVIDUAL.

26 SECTION 5. WAITING LISTS FOR INTELLECTUAL DISABILITY OR AUTISM
27 SERVICES AND REPORT.

28 (A) WAITING LIST.--THE DEPARTMENT SHALL, WITHIN SIX MONTHS
29 OF THE EFFECTIVE DATE OF THIS SECTION, REORGANIZE ITS WAITING
30 LIST OR INTEREST LIST FOR INDIVIDUALS WITH INTELLECTUAL

1 DISABILITIES OR AUTISM INTO A WAITING LIST THAT UTILIZES PUNS.
2 THIS DATA SHALL NOT LIMIT ASSESSMENT DATA COLLECTION BASED ON
3 THE GEOGRAPHIC AREA WHERE INTELLECTUAL DISABILITIES OR AUTISM
4 SERVICES ARE PROVIDED IN THIS COMMONWEALTH. THE DEPARTMENT SHALL
5 MAKE THIS DATA AVAILABLE TO THE LEGISLATIVE BUDGET AND FINANCE
6 COMMITTEE FOR THE PURPOSE OF THE REPORT REQUIRED UNDER
7 SUBSECTION (B).

8 (B) REPORT.--WITHIN ONE YEAR OF THE EFFECTIVE DATE OF THIS
9 SECTION, THE LEGISLATIVE BUDGET AND FINANCE COMMITTEE SHALL
10 SUBMIT A REPORT ON THE DEPARTMENT'S WAITING LIST OR INTEREST
11 LIST SPECIFIED UNDER SUBSECTION (A) TO THE GOVERNOR, THE GENERAL
12 ASSEMBLY AND THE COUNTY INTELLECTUAL DISABILITY PROGRAM
13 ADMINISTRATORS.

14 (C) CONTENTS OF REPORT.--THE REPORT REQUIRED UNDER
15 SUBSECTION (B) SHALL INCLUDE ALL OF THE FOLLOWING INFORMATION:

16 (1) STATISTICAL INFORMATION ON THE CURRENT AND PROJECTED
17 ANNUAL INCREASE IN THE WAITING LISTS ON A COUNTY BASIS. THE
18 DEPARTMENT SHALL DEVELOP A STATEWIDE STANDARDIZED FORM TO
19 COLLECT THE INFORMATION FROM THE COUNTIES AND THE
20 DEPARTMENT'S BUREAU OF AUTISM SERVICES.

21 (2) BUDGET PROJECTIONS TAKING INTO CONSIDERATION THE
22 DEPARTMENT'S CURRENT BUDGET YEAR, PROJECTED ANNUAL COSTS
23 ASSOCIATED WITH THE ELIMINATION OF THE WAITING LISTS,
24 FINANCIAL INFORMATION ON THE AMOUNT OF ADDITIONAL FEDERAL,
25 STATE OR OTHER FUNDS IN EACH COUNTY AND WITH THE DEPARTMENT'S
26 BUREAU OF AUTISM SERVICES WHICH MAY BE REQUIRED ANNUALLY FOR
27 THE OPERATIONAL COSTS ASSOCIATED WITH THE ELIMINATION OF THE
28 WAITING LIST IN EACH COUNTY AND OF THE WAITING LIST WITH THE
29 DEPARTMENT'S BUREAU OF AUTISM SERVICES AND THE PROJECTED
30 ANNUAL WAITING LISTS IN EACH ANNUAL REPORT.

1 (3) THE TOTAL NUMBER OF INDIVIDUALS WITH INTELLECTUAL
2 DISABILITIES OR AUTISM ON THE DEPARTMENT'S WAITING LIST FOR
3 SUPPORTS AND SERVICES ON THE EFFECTIVE DATE OF THIS SECTION,
4 ORGANIZED AS FOLLOWS:

5 (I) BY AGE RANGE, AS FOLLOWS:

6 (A) UNDER 18 YEARS OF AGE.

7 (B) 18 TO 21 YEARS OF AGE.

8 (C) OVER 21 YEARS OF AGE.

9 (II) BY EMERGENCY NEED, CRITICAL NEED OR PLANNING
10 FOR NEED, AS ORGANIZED IN PUNS.

11 (III) BY THEIR HOME, INCLUDING ANY OF THE FOLLOWING
12 SETTINGS FOR SUPPORTS AND SERVICES:

13 (A) A STATE CENTER.

14 (B) A PRIVATE INTERMEDIATE CARE FACILITY FOR
15 INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR PERSONS
16 WITH OTHER RELATED CONDITIONS.

17 (C) A STATE HOSPITAL.

18 (D) A PRIVATE PSYCHIATRIC HOSPITAL.

19 (E) A RESIDENTIAL TREATMENT FACILITY.

20 (F) ANY OTHER PUBLIC OR PRIVATE FACILITY OR
21 OTHER INSTITUTIONAL SETTING.

22 (4) THE NUMBER OF INDIVIDUALS REMOVED FROM THE
23 DEPARTMENT'S WAITING LIST IN THE LAST YEAR.

24 (5) THE TOTAL ESTIMATED COST AND PER-INDIVIDUAL COST TO
25 SERVE ELIGIBLE INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR
26 AUTISM ON THE WAITING LIST.

27 (D) PUBLIC HEARINGS AND COMMENT.--IN THE DEVELOPMENT OF THE
28 REPORT REQUIRED UNDER SUBSECTION (B), THE LEGISLATIVE BUDGET AND
29 FINANCE COMMITTEE SHALL CONDUCT PUBLIC HEARINGS AND OBTAIN
30 PUBLIC COMMENT FROM INDIVIDUALS WITH DISABILITIES, INCLUDING

1 THOSE WITH INTELLECTUAL DISABILITIES OR AUTISM, THEIR FAMILIES
2 AND LEGAL GUARDIANS AND PROVIDERS OF SERVICES TO THE DISABILITY
3 COMMUNITY, INCLUDING THE INTELLECTUAL DISABILITIES AND AUTISM
4 COMMUNITY.

5 (E) ANNUAL SUBMISSION OF UPDATED REPORT.--THE LEGISLATIVE
6 BUDGET AND FINANCE COMMITTEE SHALL UPDATE THE BUDGET,
7 STATISTICAL AND FINANCIAL DATA IN THE REPORT REQUIRED UNDER
8 SUBSECTION (B) ANNUALLY AND SUBMIT AN UPDATED REPORT TO ALL OF
9 THE FOLLOWING:

10 (1) THE GOVERNOR.

11 (2) THE CHAIR AND MINORITY CHAIR OF THE APPROPRIATIONS
12 COMMITTEE OF THE SENATE.

13 (3) THE CHAIR AND MINORITY CHAIR OF THE APPROPRIATIONS
14 COMMITTEE OF THE HOUSE OF REPRESENTATIVES.

15 (4) THE CHAIR AND MINORITY CHAIR OF THE HEALTH AND HUMAN
16 SERVICES COMMITTEE OF THE SENATE.

17 (5) THE CHAIR AND MINORITY CHAIR OF THE HEALTH COMMITTEE
18 OF THE HOUSE OF REPRESENTATIVES.

19 (6) THE CHAIR AND MINORITY CHAIR OF THE HUMAN SERVICES
20 COMMITTEE OF THE HOUSE OF REPRESENTATIVES.

21 (7) THE MEDICAL ASSISTANCE ADVISORY COMMITTEE WITHIN THE
22 DEPARTMENT.

23 (F) POSTING OF REPORT.--THE DEPARTMENT SHALL POST THE REPORT
24 REQUIRED UNDER SUBSECTION (B) ON THE DEPARTMENT'S PUBLICLY
25 ACCESSIBLE INTERNET WEBSITE IN AN ACCESSIBLE FORMAT.

26 SECTION 6. FUNDING.

27 SERVICES UNDER THIS ACT SHALL BE MADE AVAILABLE ACROSS THIS
28 COMMONWEALTH, TAKING INTO ACCOUNT THE BUDGET CONSTRAINTS AND
29 FINANCIAL RESOURCES AVAILABLE TO THE COMMONWEALTH AND THE NEEDS
30 OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR AUTISM. NOTHING

1 UNDER THIS ACT SHALL CONSTITUTE AN ENTITLEMENT DERIVED FROM THE
2 COMMONWEALTH OR A CLAIM ON ANY FUNDS OF THE COMMONWEALTH.

3 SECTION 7. CHOICE OF CARE OPTIONS.

4 THE DEPARTMENT SHALL REVIEW THE REPORT REQUIRED UNDER SECTION
5 5(B) ANNUALLY AND WORK TO IDENTIFY INDIVIDUALS WITH INTELLECTUAL
6 DISABILITIES OR AUTISM ON THE WAITING LIST OR INTERESTED IN
7 RECEIVING SUPPORTS AND SERVICES THROUGH A PUBLIC INTERMEDIATE
8 CARE FACILITY. THE DEPARTMENT SHALL COLLABORATE WITH COUNTY
9 INTELLECTUAL DISABILITY PROGRAM ADMINISTRATORS TO CONTACT
10 INDIVIDUALS WITH INTELLECTUAL DISABILITIES OR AUTISM ON THE
11 WAITING LIST OR THEIR LEGAL GUARDIANS TO PROVIDE THE OPTION OF
12 RECEIVING CARE AT A PUBLIC INTERMEDIATE CARE FACILITY OR
13 REMAINING ON THE WAITING LIST FOR HOME AND COMMUNITY-BASED
14 WAIVER ENROLLMENT. THE DEPARTMENT SHALL DISCLOSE TO INDIVIDUALS
15 WITH INTELLECTUAL DISABILITIES OR AUTISM OR THEIR LEGAL
16 GUARDIANS ANY PLANS THAT MAY RESULT IN THE CHANGE OR ELIMINATION
17 OF THEIR SERVICES.

18 SECTION 8. EFFECTIVE DATE.

19 THIS ACT SHALL TAKE EFFECT IMMEDIATELY.