

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 133 Session of 2015

INTRODUCED BY MURT, ACOSTA, BARRAR, BOYLE, V. BROWN, BROWNLIE, CALTAGIRONE, COHEN, D. COSTA, DAVIS, DeLUCA, FRANKEL, GOODMAN, KAVULICH, MILLARD, O'NEILL, C. PARKER, SCHLOSSBERG, STURLA, GIBBONS, SAMUELSON, MOUL, R. BROWN, BIZZARRO, FLYNN, SCHWEYER, KILLION AND TOOHIL, JANUARY 21, 2015

AS REPORTED FROM COMMITTEE ON HUMAN SERVICES, HOUSE OF REPRESENTATIVES, AS AMENDED, JUNE 9, 2015

AN ACT

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

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

6 ~~Section 1. Short title.~~

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7 ~~This act shall be known and may be cited as the Individuals-~~
8 ~~with Intellectual and Developmental Disabilities Bill of Rights-~~
9 ~~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 and developmental disabilities to:~~

15 ~~(i) enjoy the opportunity to live, to the extent-~~
16 ~~possible, independently;~~

1 ~~(ii) make choices;~~
2 ~~(iii) contribute to society; and~~
3 ~~(iv) experience full integration and inclusion in~~
4 ~~the economic, political, social, cultural and educational~~
5 ~~mainstream of society in this Commonwealth.~~

6 ~~(2) Individuals with intellectual and developmental~~
7 ~~disabilities continually encounter various forms of~~
8 ~~discrimination in critical areas.~~

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

12 ~~(4) A substantial number of individuals with~~
13 ~~intellectual and developmental disabilities and their~~
14 ~~families or legal guardians do not have access to appropriate~~
15 ~~support and services from generic and specialized service~~
16 ~~systems and remain unserved or underserved.~~

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

26 ~~(6) The long time commitment of the General Assembly to~~
27 ~~secure for individuals with intellectual and developmental~~
28 ~~disabilities in partnership with their families or legal~~
29 ~~guardians the opportunity to choose where they live is~~
30 ~~affirmed. The choice of service options must be supported by~~

1 ~~State policy. The choice of service options is to be ensured~~
2 ~~to individuals with intellectual and developmental~~
3 ~~disabilities, encouraging that they not leave their homes or~~
4 ~~community to the maximum extent possible.~~

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

8 ~~(8) As of September 30, 2014, there are approximately~~
9 ~~13,987 individuals in this Commonwealth with intellectual~~
10 ~~disabilities who are waiting for services and programs. There~~
11 ~~are more than 10,314 people with emergency and critical~~
12 ~~needs. The waiting list for these persons is expected to grow~~
13 ~~substantially into the foreseeable future.~~

14 ~~(9) The Department of Human Services needs to develop an~~
15 ~~adequate plan to address the needs and services for the~~
16 ~~individuals on the waiting list for intellectual disability~~
17 ~~services.~~

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

22 ~~(11) The goals of the Commonwealth properly include the~~
23 ~~goal of providing individuals with intellectual and~~
24 ~~developmental disabilities and their families or legal~~
25 ~~guardians 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. (No.98 536-~~
5 ~~U.S. 1999) and the Commonwealth desires to assure individuals~~
6 ~~with intellectual and developmental disabilities and their~~
7 ~~families or legal guardians full and complete participation~~
8 ~~in the design of and access to services, supports and other~~
9 ~~assistance and opportunities which promote independence,~~
10 ~~productivity and choice of living arrangement.~~

11 ~~(13) It is the policy of the Commonwealth 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 and developmental~~
16 ~~disabilities are capable of pursuing independence,~~
17 ~~productivity and integration and inclusion into the~~
18 ~~community and often require the provision of services,~~
19 ~~supports and other assistance to achieve independence,~~
20 ~~productivity and integration and inclusion.~~

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

29 ~~(iii) Individuals with intellectual and~~
30 ~~developmental disabilities and their families or legal~~

1 ~~guardians are the primary decision makers regarding the~~
2 ~~services and supports such individuals and their families~~
3 ~~receive and play significant decision making roles in~~
4 ~~policies and programs which affect the lives of such~~
5 ~~individuals and their families.~~

6 ~~(iv) Individuals with intellectual and developmental~~
7 ~~disabilities and their families or legal guardians have~~
8 ~~varying goals and needs, and, therefore, this act does~~
9 ~~not support one specific service system or setting over~~
10 ~~another so long as it is within the parameters of~~
11 ~~applicable reported judicial decisions.~~

12 ~~(v) The Commonwealth shall, within budgetary~~
13 ~~accountability, provide services, supports and other~~
14 ~~assistance which reflect the principles of everyday life~~
15 ~~that have been the cornerstone of the Commonwealth's~~
16 ~~human services for people with intellectual and~~
17 ~~developmental disabilities.~~

18 ~~Section 3. Definitions.~~

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

22 ~~"Department." The Department of Human Services of the~~
23 ~~Commonwealth.~~

24 ~~Section 4. Choice.~~

25 ~~(a) Community based service. The Commonwealth shall provide~~
26 ~~individualized community integrated supports and services for an~~
27 ~~individual with intellectual and developmental disabilities if~~
28 ~~all of the following apply:~~

29 ~~(1) The individual has an intellectual or developmental~~
30 ~~disability.~~

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

3 ~~(3) The supports and services are included in an~~
4 ~~individualized services plan developed by an authorized State~~
5 ~~or county supports coordinator with the input of the~~
6 ~~individual and the individual's guardian and advocate.~~

7 ~~(b) Family. Unless the individual determines otherwise,~~
8 ~~family members and legal guardians of an individual with~~
9 ~~intellectual and developmental disabilities shall be involved in~~
10 ~~meetings regarding the planning for and arrangement of~~
11 ~~community based services or other allowable services.~~

12 ~~(c) Contact. Nothing in this act shall be construed to~~
13 ~~prohibit an individual with intellectual and developmental~~
14 ~~disabilities from maintaining contact with family and friends at~~
15 ~~an intermediate care facility, a community living arrangement or~~
16 ~~a day program.~~

17 ~~(d) Complaints. An individual with intellectual and~~
18 ~~developmental disabilities, a family member or a legal guardian~~
19 ~~of such individual who believes that the needs as detailed in~~
20 ~~the individualized service plan are not being met may provide~~
21 ~~the State or county a letter expressing concerns. The State or~~
22 ~~county shall, within 30 days, address the concerns and, if~~
23 ~~necessary, take corrective action.~~

24 ~~Section 5. Waiting list for intellectual disability services.~~

25 ~~(a) Waiting list plan. Within one year of the effective~~
26 ~~date of this section, the department shall develop a five year~~
27 ~~plan to eliminate the current as well as any future additions to~~
28 ~~the critical and emergency waiting list for individuals with~~
29 ~~intellectual disabilities who are in need of allowable supports~~
30 ~~and services and shall submit the plan to the Governor, the~~

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

3 ~~(b) Contents of plan. The plan required by subsection (a)~~
4 ~~shall include:~~

5 ~~(1) Statistical information on the current and projected~~
6 ~~annual increase in the waiting list on a county basis. The~~
7 ~~department shall develop a Statewide standardized form to~~
8 ~~collect the information from the counties.~~

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 list,~~
12 ~~financial information on the amount of additional Federal,~~
13 ~~State or other funds in each county which may be required~~
14 ~~annually for the operational costs associated with the~~
15 ~~elimination of the waiting list in each county and the~~
16 ~~projected annual waiting list in each annual plan update.~~

17 ~~(c) Public hearings and comment. In the development of the~~
18 ~~plan required by subsection (a), the department shall conduct~~
19 ~~public hearings and obtain public comment from individuals with~~
20 ~~intellectual disabilities, their families and guardians and~~
21 ~~providers of services to the intellectual disability community.~~

22 ~~(d) Annual submission of updated plan. The department shall~~
23 ~~update the budget, statistical and financial data to the plan~~
24 ~~required by subsection (a) annually and submit an updated plan~~
25 ~~to the Governor, the General Assembly and the county~~
26 ~~intellectual disability program administrators on the~~
27 ~~anniversary date of the department's original submission of the~~
28 ~~plan.~~

29 ~~Section 6. Funding.~~

30 ~~Services under this act shall be made available across this~~

1 ~~Commonwealth, taking into account the budget constraints and~~
2 ~~financial resources available to the Commonwealth and the needs~~
3 ~~of individuals with intellectual and developmental disabilities.~~

4 ~~Section 7. Effective date.~~

5 ~~This act shall take effect in 60 days.~~

6 SECTION 1. SHORT TITLE.

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7 THIS ACT SHALL BE KNOWN AND MAY BE CITED AS THE INDIVIDUALS
8 WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BILL OF RIGHTS
9 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 AND DEVELOPMENTAL DISABILITIES TO:

15 (I) ENJOY THE OPPORTUNITY TO LIVE, TO THE MAXIMUM
16 EXTENT POSSIBLE, INDEPENDENTLY AND IN THE COMMUNITY;

17 (II) MAKE CHOICES AND DECISIONS;

18 (III) CONTRIBUTE TO SOCIETY AND PARTICIPATE IN THE
19 COMMUNITY; AND

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

23 (2) INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL
24 DISABILITIES CONTINUALLY ENCOUNTER VARIOUS FORMS OF
25 DISCRIMINATION IN ALL AREAS.

26 (3) THERE IS A LACK OF PUBLIC AWARENESS OF THE
27 CAPABILITIES AND COMPETENCIES OF INDIVIDUALS WITH
28 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES.

29 (4) A SUBSTANTIAL NUMBER OF INDIVIDUALS WITH
30 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THEIR

1 FAMILIES OR LEGAL GUARDIANS DO NOT HAVE ACCESS TO APPROPRIATE
2 COMMUNITY-INTEGRATED SUPPORT AND SERVICES FROM GENERIC AND
3 SPECIALIZED SERVICE SYSTEMS AND REMAIN UNSERVED OR
4 UNDERSERVED.

5 (5) COMMUNITIES CAN BE ENRICHED BY THE FULL AND ACTIVE
6 PARTICIPATION AND THE CONTRIBUTIONS BY INDIVIDUALS WITH
7 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THEIR
8 FAMILIES; AND THERE IS A NEED TO ENSURE THAT, WITHIN THIS
9 COMMONWEALTH, THERE IS THE AVAILABILITY AND EQUITABLE
10 PROVISION OF NECESSARY COMMUNITY-INTEGRATED SERVICES FOR
11 INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES,
12 REGARDLESS OF RELIGION, RACE, COLOR, NATIONAL ORIGIN,
13 ECONOMIC OR SOCIAL STATUS AND DEGREE OR TYPE OF DISABILITY.

14 (6) THE LONG-TIME COMMITMENT OF THE GENERAL ASSEMBLY TO
15 SECURE FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL
16 DISABILITIES IN PARTNERSHIP WITH THEIR FAMILIES OR LEGAL
17 GUARDIANS THE OPPORTUNITY TO CHOOSE WHERE THEY LIVE IN THE
18 COMMUNITY IS AFFIRMED. THE CHOICE OF SERVICE OPTIONS SHALL BE
19 SUPPORTED BY STATE POLICY. THE CHOICE OF COMMUNITY-INTEGRATED
20 SERVICE OPTIONS IS TO BE ENSURED TO INDIVIDUALS WITH
21 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, ENCOURAGING THAT
22 THEY STAY IN THEIR HOMES OR COMMUNITY TO THE MAXIMUM EXTENT
23 POSSIBLE.

24 (7) SERVICES MUST ENSURE ACCOUNTABILITY, CREDIBILITY,
25 RESPONSIVENESS AND QUALITY ASSURANCE, WHETHER THE FUNDING IS
26 FEDERAL, STATE, LOCAL OR COMMUNITY.

27 (8) AS OF MARCH 31, 2015, THERE ARE APPROXIMATELY 13,971
28 INDIVIDUALS IN THIS COMMONWEALTH WITH INTELLECTUAL
29 DISABILITIES WHO ARE WAITING FOR HOME-BASED AND COMMUNITY-
30 BASED SERVICES AND PROGRAMS. THERE ARE MORE THAN 10,323

1 PEOPLE WITH EMERGENCY AND CRITICAL NEEDS. AS OF JANUARY 31,
2 2015, THERE ARE MORE THAN 1,400 INDIVIDUALS ON THE AUTISM
3 HOME-BASED AND COMMUNITY-BASED SERVICES WAITING LIST, OR
4 INTEREST LIST. THE WAITING LIST FOR THESE PERSONS IS EXPECTED
5 TO GROW SUBSTANTIALLY INTO THE FORESEEABLE FUTURE.

6 (9) THE DEPARTMENT OF HUMAN SERVICES NEEDS TO DEVELOP AN
7 ADEQUATE PLAN TO ADDRESS THE NEEDS AND SERVICES FOR THE
8 INDIVIDUALS ON THE WAITING LIST FOR INTELLECTUAL DISABILITY
9 SERVICES, FOR THE INDIVIDUALS ON THE WAITING LIST FOR AUTISM
10 SERVICES, AND FOR ALL INDIVIDUALS WITH DISABILITIES TO
11 PREVENT UNNECESSARY INSTITUTIONALIZATION.

12 (10) FOR TRUE CHOICE TO EXIST, INDIVIDUALS WITH
13 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THEIR
14 FAMILIES OR LEGAL GUARDIANS MUST BE PROVIDED WITH INFORMATION
15 ABOUT THEIR OPTIONS FOR COMMUNITY-INTEGRATED SERVICES.

16 (11) THE GOALS OF THE COMMONWEALTH PROPERLY INCLUDE THE
17 GOAL OF PROVIDING INDIVIDUALS WITH INTELLECTUAL AND
18 DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES OR LEGAL
19 GUARDIANS WITH THE OPPORTUNITIES AND SUPPORT TO:

20 (I) MAKE INFORMED CHOICES AND DECISIONS.

21 (II) PURSUE MEANINGFUL AND PRODUCTIVE LIVES.

22 (III) LIVE IN A HOME AND COMMUNITY OF THEIR CHOICE.

23 (IV) ACHIEVE FULL INTEGRATION AND INCLUSION IN
24 SOCIETY, IN AN INDIVIDUALIZED MANNER, CONSISTENT WITH THE
25 UNIQUE STRENGTHS, RESOURCES, PRIORITIES, CONCERNS,
26 ABILITIES AND CAPABILITIES OF THE INDIVIDUAL.

27 (12) THE PURPOSE OF THIS ACT IS TO REFLECT THE UNITED
28 STATES SUPREME COURT DECISION OF OLMSTEAD V. L.C., 119 S.CT.
29 2176 (1999) (NO.98-536 U.S. 1999) AND THE COMMONWEALTH
30 OBLIGATION TO ASSURE INDIVIDUALS WITH INTELLECTUAL AND

1 DEVELOPMENTAL DISABILITIES AND, IF CHOSEN BY THE INDIVIDUAL,
2 THEIR FAMILIES OR LEGAL GUARDIANS, FULL AND COMPLETE
3 PARTICIPATION IN THE DESIGN OF AND ACCESS TO SERVICES,
4 SUPPORTS AND OTHER ASSISTANCE AND OPPORTUNITIES WHICH PROMOTE
5 INDEPENDENCE, PRODUCTIVITY AND CHOICE OF COMMUNITY LIVING
6 ARRANGEMENT.

7 (13) IT IS THE POLICY OF THE COMMONWEALTH THAT ALL
8 PROGRAMS, PROJECTS AND ACTIVITIES OPERATING IN THIS
9 COMMONWEALTH BE CARRIED OUT IN A MANNER CONSISTENT WITH THE
10 FOLLOWING PRINCIPLES:

11 (I) INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL
12 DISABILITIES ARE CAPABLE OF PURSUING INDEPENDENCE,
13 PRODUCTIVITY AND INTEGRATION AND INCLUSION INTO THE
14 COMMUNITY AND OFTEN REQUIRE THE PROVISION OF SERVICES,
15 SUPPORTS AND OTHER ASSISTANCE TO ACHIEVE INDEPENDENCE,
16 PRODUCTIVITY AND INTEGRATION AND INCLUSION.

17 (II) INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL
18 DISABILITIES HAVE COMPETENCIES, CAPABILITIES AND PERSONAL
19 GOALS WHICH SHALL BE RECOGNIZED, SUPPORTED AND
20 ENCOURAGED; AND ANY ASSISTANCE TO SUCH INDIVIDUALS SHALL
21 BE PROVIDED IN AN INDIVIDUALIZED MANNER, CONSISTENT WITH
22 THE UNIQUE STRENGTHS, RESOURCES, PRIORITIES, CONCERNS,
23 ABILITIES AND CAPABILITIES OF THE INDIVIDUALS.

24 (III) INDIVIDUALS WITH INTELLECTUAL AND
25 DEVELOPMENTAL DISABILITIES AND, IF CHOSEN BY THE
26 INDIVIDUAL, THEIR FAMILIES OR LEGAL GUARDIANS ARE THE
27 PRIMARY DECISION MAKERS REGARDING THE SERVICES AND
28 SUPPORTS SUCH INDIVIDUALS AND THEIR FAMILIES RECEIVE AND
29 PLAY SIGNIFICANT DECISION-MAKING ROLES IN POLICIES AND
30 PROGRAMS WHICH AFFECT THE LIVES OF SUCH INDIVIDUALS AND

1 THEIR FAMILIES.

2 (IV) INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL
3 DISABILITIES AND THEIR FAMILIES OR LEGAL GUARDIANS HAVE
4 VARYING GOALS AND NEEDS, AND THEREFORE, THIS ACT DOES NOT
5 SUPPORT ONE SPECIFIC SERVICE SYSTEM OR SETTING OVER
6 ANOTHER SO LONG AS THE CHOICE AS TO HOW AND WHERE TO
7 RECEIVE SERVICES REMAINS WITH THE INDIVIDUAL.

8 (V) THE COMMONWEALTH SHALL, WITHIN BUDGETARY
9 ACCOUNTABILITY, PROVIDE SERVICES, SUPPORTS AND OTHER
10 ASSISTANCE WHICH REFLECT THE PRINCIPLES OF EVERYDAY LIFE
11 AND SELF-DETERMINATION THAT HAVE BEEN THE CORNERSTONE OF
12 THE COMMONWEALTH'S HUMAN SERVICES FOR PEOPLE WITH
13 INTELLECTUAL AND DEVELOPMENTAL DISABILITIES.

14 SECTION 3. DEFINITIONS.

15 THE FOLLOWING WORDS AND PHRASES WHEN USED IN THIS ACT SHALL
16 HAVE THE MEANINGS GIVEN TO THEM IN THIS SECTION UNLESS THE
17 CONTEXT CLEARLY INDICATES OTHERWISE:

18 "COMMUNITY-INTEGRATED SUPPORTS AND SERVICES OPTIONS," "HOME
19 AND COMMUNITY-BASED SERVICES" OR "SUPPORTS AND SERVICES."
20 INTEGRATED SERVICES IN THE HOME AND COMMUNITY, INCLUDING THE
21 INTEGRATED SETTINGS WHERE SUCH SERVICES ARE PROVIDED, AS DEFINED
22 BY FEDERAL REGULATIONS AT 42 CFR §§ 440.180 (RELATING TO HOME
23 AND COMMUNITY-BASED WAIVER SERVICES) AND 441.301(C)(4) AND (5)
24 (RELATING TO CONTENTS OF REQUEST FOR A WAIVER), WHICH ARE
25 DEVELOPED IN ACCORDANCE WITH THE PERSON-CENTERED PLANNING
26 REQUIREMENTS OF 42 CFR § 441.301(C)(1), (2) AND (3).

27 "DEPARTMENT." THE DEPARTMENT OF HUMAN SERVICES OF THE
28 COMMONWEALTH.

29 "DEVELOPMENTAL DISABILITY." A SEVERE, CHRONIC DISABILITY OF
30 AN INDIVIDUAL THAT CONSISTS OF THE FOLLOWING:

1 (1) IS ATTRIBUTABLE TO A MENTAL OR PHYSICAL IMPAIRMENT
2 OR COMBINATION OF MENTAL AND PHYSICAL IMPAIRMENTS.

3 (2) IS MANIFESTED BEFORE THE INDIVIDUAL ATTAINS 22 YEARS
4 OF AGE.

5 (3) IS LIKELY TO CONTINUE INDEFINITELY.

6 (4) RESULTS IN SUBSTANTIAL FUNCTIONAL LIMITATIONS IN
7 THREE OR MORE OF THE FOLLOWING AREAS OF MAJOR LIFE ACTIVITY:

8 (I) SELF-CARE.

9 (II) RECEPTIVE AND EXPRESSIVE LANGUAGE.

10 (III) LEARNING.

11 (IV) MOBILITY.

12 (V) SELF-DIRECTION.

13 (VI) CAPACITY FOR INDEPENDENT LIVING.

14 (VII) ECONOMIC SELF-SUFFICIENCY.

15 (5) REFLECTS THE INDIVIDUAL'S NEED FOR A COMBINATION AND
16 SEQUENCE OF SPECIAL, INTERDISCIPLINARY OR GENERIC SERVICES,
17 INDIVIDUALIZED SUPPORTS OR OTHER FORMS OF ASSISTANCE THAT ARE
18 OF LIFELONG OR EXTENDED DURATION AND ARE INDIVIDUALLY PLANNED
19 AND COORDINATED, AS DEFINED BY SECTION 102(8) OF THE
20 DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT
21 OF 2000 (PUBLIC LAW 106-402, 42 U.S.C. § 15002(8)). THE TERM
22 SHALL ALSO INCLUDE INDIVIDUALS DIAGNOSED WITH AUTISM SPECTRUM
23 DISORDER.

24 "INTELLECTUAL DISABILITY." SIGNIFICANTLY SUBAVERAGE GENERAL
25 INTELLECTUAL FUNCTIONING THAT IS ACCOMPANIED BY SIGNIFICANT
26 LIMITATIONS IN ADAPTIVE FUNCTIONING IN AT LEAST TWO OF THE
27 FOLLOWING SKILL AREAS:

28 (1) COMMUNICATION.

29 (2) SELF-CARE.

30 (3) HOME LIVING.

- 1 (4) SOCIAL AND INTERPERSONAL SKILLS.
- 2 (5) USE OF COMMUNITY RESOURCES.
- 3 (6) SELF-DIRECTION.
- 4 (7) FUNCTIONAL ACADEMIC SKILLS.
- 5 (8) WORK.
- 6 (9) HEALTH.
- 7 (10) SAFETY.

8 THE ONSET MUST OCCUR BEFORE THE INDIVIDUAL REACHES 22 YEARS OF
9 AGE, AS DEFINED BY THE ACT OF OCTOBER 20, 1966 (3RD SP.SESS.,
10 P.L.96, NO.6), KNOWN AS THE MENTAL HEALTH AND INTELLECTUAL
11 DISABILITY ACT OF 1966.

12 SECTION 4. CHOICE.

13 (A) COMMUNITY-BASED SERVICES.--THE COMMONWEALTH SHALL
14 PROVIDE INDIVIDUALIZED COMMUNITY-INTEGRATED SUPPORTS AND
15 SERVICES FOR AN INDIVIDUAL WITH INTELLECTUAL AND DEVELOPMENTAL
16 DISABILITIES IF ALL OF THE FOLLOWING APPLY:

17 (1) THE INDIVIDUAL HAS AN INTELLECTUAL OR DEVELOPMENTAL
18 DISABILITY.

19 (2) THE INDIVIDUAL CHOOSES CERTAIN SUPPORTS AND SERVICES
20 OR DOES NOT OPPOSE THE SUPPORTS AND SERVICES.

21 (3) THE SUPPORTS AND SERVICES ARE INCLUDED IN AN
22 INDIVIDUALIZED SERVICES PLAN DEVELOPED IN ACCORDANCE WITH THE
23 PERSON-CENTERED PLANNING REQUIREMENTS OF 42 CFR § 441.301(C)
24 (1), (2) AND (3) (RELATING TO CONTENTS OF REQUEST FOR A
25 WAIVER) BY AN AUTHORIZED STATE OR COUNTY SUPPORTS COORDINATOR
26 WITH THE INPUT OF THE INDIVIDUAL AND, IF CHOSEN BY THE
27 INDIVIDUAL, THE INDIVIDUAL'S GUARDIAN AND ADVOCATE.

28 (B) FAMILY.--IF THE INDIVIDUAL SO CHOOSES, FAMILY MEMBERS
29 AND LEGAL GUARDIANS OF AN INDIVIDUAL WITH INTELLECTUAL AND
30 DEVELOPMENTAL DISABILITIES SHALL BE INVOLVED IN MEETINGS

1 REGARDING THE PLANNING FOR AND ARRANGEMENT OF COMMUNITY-BASED
2 SERVICES OR OTHER ALLOWABLE SERVICES. LEGAL GUARDIANS SHALL,
3 UNDER 20 PA.C.S. § 5521(A) (RELATING TO PROVISIONS CONCERNING
4 POWERS, DUTIES AND LIABILITIES):

5 (1) ASSERT THE RIGHTS AND INTERESTS OF THE INDIVIDUAL.

6 (2) RESPECT THE WISHES AND PREFERENCES OF THE INDIVIDUAL
7 TO THE GREATEST EXTENT POSSIBLE.

8 (3) ENCOURAGE THE INDIVIDUAL TO PARTICIPATE TO THE
9 MAXIMUM EXTENT OF HIS OR HER ABILITIES IN ALL DECISIONS THAT
10 AFFECT HIM OR HER, TO ACT ON HIS OR HER BEHALF WHEN HE OR SHE
11 IS ABLE TO DO SO AND TO DEVELOP OR REGAIN HIS OR HER CAPACITY
12 TO MANAGE HIS OR HER PERSONAL AFFAIRS TO THE MAXIMUM EXTENT
13 FEASIBLE.

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

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

29 SECTION 5. WAITING LIST FOR INTELLECTUAL DISABILITY SERVICES.

30 (A) WAITING LIST PLAN.--WITHIN ONE YEAR OF THE EFFECTIVE

1 DATE OF THIS SECTION, THE DEPARTMENT SHALL, AS PART OF A
2 STAKEHOLDER PROCESS WITH PARTICIPATION BY INDIVIDUALS WITH
3 DISABILITIES AND THEIR FAMILY MEMBERS, DEVELOP A FIVE-YEAR PLAN
4 TO ELIMINATE THE CURRENT AS WELL AS ANY FUTURE ADDITIONS TO THE
5 CRITICAL AND EMERGENCY WAITING LIST FOR INDIVIDUALS WITH
6 INTELLECTUAL DISABILITIES WHO ARE IN NEED OF ALLOWABLE HOME-
7 BASED AND COMMUNITY-BASED SUPPORTS AND SERVICES. WITHIN ONE YEAR
8 OF THE EFFECTIVE DATE OF THIS SECTION, THE DEPARTMENT SHALL
9 DEVELOP A TWO-YEAR PLAN TO ELIMINATE THE CURRENT AS WELL AS ANY
10 FUTURE ADDITIONS TO THE HOME-BASED AND COMMUNITY-BASED SERVICES
11 WAITING LIST FOR INDIVIDUALS WITH AUTISM AND TO PREVENT FUTURE
12 HOME-BASED AND COMMUNITY-BASED SERVICES WAITING LISTS FOR ALL
13 OTHER PERSONS WITH DISABILITIES, INCLUDING THOSE WITH PHYSICAL
14 AND DEVELOPMENTAL DISABILITIES, INCLUDING BRAIN INJURY. THE
15 DEPARTMENT SHALL SUBMIT THE PLANS TO THE GOVERNOR, THE GENERAL
16 ASSEMBLY AND THE COUNTY INTELLECTUAL DISABILITY PROGRAM
17 ADMINISTRATORS.

18 (B) CONTENTS OF PLAN.--THE PLAN REQUIRED BY SUBSECTION (A)
19 SHALL INCLUDE:

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

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

1 THE OPERATIONAL COSTS ASSOCIATED WITH THE ELIMINATION OF THE
2 WAITING LIST IN EACH COUNTY AND OF THE WAITING LIST WITH THE
3 DEPARTMENT'S BUREAU OF AUTISM SERVICES AND THE PROJECTED
4 ANNUAL WAITING LISTS IN EACH ANNUAL PLAN UPDATE.

5 (C) PUBLIC HEARINGS AND COMMENT.--IN THE DEVELOPMENT OF THE
6 PLAN REQUIRED BY SUBSECTION (A), THE DEPARTMENT SHALL CONDUCT
7 PUBLIC HEARINGS AND OBTAIN PUBLIC COMMENT FROM INDIVIDUALS WITH
8 DISABILITIES, INCLUDING THOSE WITH INTELLECTUAL AND
9 DEVELOPMENTAL DISABILITIES, THEIR FAMILIES AND GUARDIANS AND
10 PROVIDERS OF SERVICES TO THE DISABILITY COMMUNITY, INCLUDING THE
11 INTELLECTUAL AND DEVELOPMENTAL DISABILITY COMMUNITY.

12 (D) ANNUAL SUBMISSION OF UPDATED PLAN.--THE DEPARTMENT SHALL
13 UPDATE THE BUDGET, STATISTICAL AND FINANCIAL DATA TO THE PLAN
14 REQUIRED BY SUBSECTION (A) ANNUALLY AND SUBMIT AN UPDATED PLAN
15 TO THE GOVERNOR, THE GENERAL ASSEMBLY AND THE COUNTY
16 INTELLECTUAL DISABILITY PROGRAM ADMINISTRATORS ON THE
17 ANNIVERSARY DATE OF THE DEPARTMENT'S ORIGINAL SUBMISSION OF THE
18 PLAN.

19 SECTION 6. FUNDING.

20 SERVICES UNDER THIS ACT SHALL BE MADE AVAILABLE ACROSS THIS
21 COMMONWEALTH, TAKING INTO ACCOUNT THE BUDGET CONSTRAINTS AND
22 FINANCIAL RESOURCES AVAILABLE TO THE COMMONWEALTH AND THE NEEDS
23 OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES.

24 SECTION 7. EFFECTIVE DATE.

25 THIS ACT SHALL TAKE EFFECT IN 60 DAYS.