THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 133

Session of 2015

INTRODUCED BY MURT, ACOSTA, BARRAR, BOYLE, V. BROWN, BROWNLEE, CALTAGIRONE, COHEN, D. COSTA, DAVIS, DeLUCA, FRANKEL, GOODMAN, KAVULICH, MILLARD, O'NEILL, C. PARKER, SCHLOSSBERG AND STURLA, JANUARY 21, 2015

REFERRED TO COMMITTEE ON HUMAN SERVICES, JANUARY 21, 2015

AN ACT

Establishing a bill of rights for individuals with intellectual 1 and developmental disabilities; and conferring powers and 2 duties on the Department of Human Services. 3 4 The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows: Section 1. Short title. 6 7 This act shall be known and may be cited as the Individuals with Intellectual and Developmental Disabilities Bill of Rights 9 Act. 10 Section 2. Findings. The General Assembly finds and declares as follows: 11 12 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 enjoy the opportunity to live, to the extent 16 possible, independently;

(ii) make choices;

- 1 (iii) contribute to society; and
- 2 experience full integration and inclusion in 3 the economic, political, social, cultural and educational mainstream of society in this Commonwealth.
 - Individuals with intellectual and developmental (2) disabilities continually encounter various forms of discrimination in critical areas.
 - There is a lack of public awareness of the capabilities and competencies of individuals with intellectual and developmental disabilities.
 - A substantial number of individuals with intellectual and developmental disabilities and their families or legal quardians do not have access to appropriate support and services from generic and specialized service systems and remain unserved or underserved.
 - Communities can be enriched by the full and active participation and the contributions by individuals with intellectual and developmental disabilities and their families; and there is a need to ensure that, within this Commonwealth, there is the availability and equitable provision of necessary services for individuals with intellectual and developmental disabilities, regardless of religion, race, color, national origin, economic or social status and degree or type of disability.
 - The long-time commitment of the General Assembly to secure for individuals with intellectual and developmental disabilities in partnership with their families or legal guardians the opportunity to choose where they live is affirmed. The choice of service options must be supported by State policy. The choice of service options is to be ensured

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- 1 to individuals with intellectual and developmental
- disabilities, encouraging that they not leave their homes or
- 3 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 September 30, 2014, there are approximately
 8 13,987 individuals in this Commonwealth with intellectual
 9 disabilities who are waiting for services and programs. There
 10 are more than 10,314 people with emergency and critical
 11 needs. The waiting list for these persons is expected to grow
 12 substantially into the foreseeable future.
 - (9) The Department of Human Services needs to develop an adequate plan to address the needs and services for the individuals on the waiting list for intellectual disability services.
 - (10) For true choice to exist, individuals with intellectual and developmental disabilities and their families or legal guardians must be provided with information about their options for services.
 - (11) The goals of the Commonwealth properly include the goal of providing individuals with intellectual and developmental disabilities and their families or legal guardians with the opportunities and support to:
 - (i) Make informed choices and decisions.
- 26 (ii) Pursue meaningful and productive lives.
- 27 (iii) Live in a home and community of their choice.
- 28 (iv) Achieve full integration and inclusion in
 29 society, in an individualized manner, consistent with the
 30 unique strengths, resources, priorities, concerns,

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abilities and capabilities of the individual.

(12) The purpose of this act is to reflect the United States Supreme Court decision of Olmstead v. L.C. (No.98-536 U.S. 1999) and the Commonwealth desires to assure individuals with intellectual and developmental disabilities and their families or legal guardians full and complete participation in the design of and access to services, supports and other assistance and opportunities which promote independence, productivity and choice of living arrangement.

- (13) It is the policy of the Commonwealth that all programs, projects and activities operating in this Commonwealth be carried out in a manner consistent with the following principles:
 - (i) Individuals with intellectual and developmental disabilities are capable of pursuing independence, productivity and integration and inclusion into the community and often require the provision of services, supports and other assistance to achieve independence, productivity and integration and inclusion.
 - (ii) Individuals with intellectual and developmental disabilities and their families or legal guardians have competencies, capabilities and personal goals which shall be recognized, supported and encouraged; and any assistance to such individuals shall be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities and capabilities of the individuals.
 - (iii) Individuals with intellectual and developmental disabilities and their families or legal guardians are the primary decision makers regarding the

- 1 services and supports such individuals and their families
- 2 receive and play significant decision-making roles in
- 3 policies and programs which affect the lives of such
- 4 individuals and their families.
- 5 (iv) Individuals with intellectual and developmental
- 6 disabilities and their families or legal guardians have
- 7 varying goals and needs, and, therefore, this act does
- 8 not support one specific service system or setting over
- 9 another so long as it is within the parameters of
- 10 applicable reported judicial decisions.
- 11 (v) The Commonwealth shall, within budgetary
- 12 accountability, provide services, supports and other
- assistance which reflect the principles of everyday life
- 14 that have been the cornerstone of the Commonwealth's
- 15 human services for people with intellectual and
- developmental disabilities.
- 17 Section 3. Definitions.
- 18 The following words and phrases when used in this act shall
- 19 have the meanings given to them in this section unless the
- 20 context clearly indicates otherwise:
- 21 "Department." The Department of Human Services of the
- 22 Commonwealth.
- 23 Section 4. Choice.
- 24 (a) Community-based service. -- The Commonwealth shall provide
- 25 individualized community-integrated supports and services for an
- 26 individual with intellectual and developmental disabilities if
- 27 all of the following apply:
- 28 (1) The individual has an intellectual or developmental
- 29 disability.
- 30 (2) The individual chooses certain supports and services

- or does not oppose the supports and services.
- 2 (3) The supports and services are included in an
- 3 individualized services plan developed by an authorized State
- 4 or county supports coordinator with the input of the
- 5 individual and the individual's quardian and advocate.
- 6 (b) Family. -- Unless the individual determines otherwise,
- 7 family members and legal guardians of an individual with
- 8 intellectual and developmental disabilities shall be involved in
- 9 meetings regarding the planning for and arrangement of
- 10 community-based services or other allowable services.
- 11 (c) Contact. -- Nothing in this act shall be construed to
- 12 prohibit an individual with intellectual and developmental
- 13 disabilities from maintaining contact with family and friends at
- 14 an intermediate care facility, a community living arrangement or
- 15 a day program.
- 16 (d) Complaints. -- An individual with intellectual and
- 17 developmental disabilities, a family member or a legal guardian
- 18 of such individual who believes that the needs as detailed in
- 19 the individualized service plan are not being met may provide
- 20 the State or county a letter expressing concerns. The State or
- 21 county shall, within 30 days, address the concerns and, if
- 22 necessary, take corrective action.
- 23 Section 5. Waiting list for intellectual disability services.
- 24 (a) Waiting list plan. -- Within one year of the effective
- 25 date of this section, the department shall develop a five-year
- 26 plan to eliminate the current as well as any future additions to
- 27 the critical and emergency waiting list for individuals with
- 28 intellectual disabilities who are in need of allowable supports
- 29 and services and shall submit the plan to the Governor, the
- 30 General Assembly and the county intellectual disability program

- 1 administrators.
- 2 (b) Contents of plan. -- The plan required by subsection (a)
- 3 shall include:
- 4 (1) Statistical information on the current and projected
- 5 annual increase in the waiting list on a county basis. The
- 6 department shall develop a Statewide standardized form to
- 7 collect the information from the counties.
- 8 (2) Budget projections taking into consideration the
- 9 department's current budget year, projected annual costs
- 10 associated with the elimination of the waiting list,
- financial information on the amount of additional Federal,
- 12 State or other funds in each county which may be required
- annually for the operational costs associated with the
- 14 elimination of the waiting list in each county and the
- projected annual waiting list in each annual plan update.
- 16 (c) Public hearings and comment. -- In the development of the
- 17 plan required by subsection (a), the department shall conduct
- 18 public hearings and obtain public comment from individuals with
- 19 intellectual disabilities, their families and guardians and
- 20 providers of services to the intellectual disability community.
- 21 (d) Annual submission of updated plan. -- The department shall
- 22 update the budget, statistical and financial data to the plan
- 23 required by subsection (a) annually and submit an updated plan
- 24 to the Governor, the General Assembly and the county
- 25 intellectual disability program administrators on the
- 26 anniversary date of the department's original submission of the
- 27 plan.
- 28 Section 6. Funding.
- 29 Services under this act shall be made available across this
- 30 Commonwealth, taking into account the budget constraints and

- 1 financial resources available to the Commonwealth and the needs
- 2 of individuals with intellectual and developmental disabilities.
- 3 Section 7. Effective date.
- 4 This act shall take effect in 60 days.