

AN ACT concerning health.

**Be it enacted by the People of the State of Illinois,
represented in the General Assembly:**

Section 5. The Protection and Advocacy for Persons with Developmental Disabilities Act is amended by changing Section 1 as follows:

(405 ILCS 40/1) (from Ch. 91 1/2, par. 1151)

Sec. 1. The Governor may designate a private not-for-profit corporation as the agency to administer a State plan to protect and advocate the rights of persons with developmental disabilities pursuant to the requirements of the federal Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 6001 to 6081, as now or hereafter amended. The designated agency may pursue legal, administrative, and other appropriate remedies to ensure the protection of the rights of such persons who are receiving treatment, services or habilitation within this State. The agency designated by the Governor shall be independent of any agency which provides treatment, services, guardianship, or habilitation to persons with developmental disabilities, and such agency shall not be administered by the Governor's Planning Council on Developmental Disabilities or any successor State Planning Council organized pursuant to federal law.

The designated agency may receive and expend funds to protect and advocate the rights of persons with developmental disabilities. In order to properly exercise its powers and duties, such agency shall have access to developmental disability facilities and mental health facilities, as defined under Sections 1-107 and 1-114 of the Mental Health and Developmental Disabilities Code, ~~and~~ facilities as defined in Section 1-113 of the Nursing Home Care Act, Section 1-113 of the ID/DD Community Care Act, or Section 1-113 of the MC/DD Act, and community-integrated living arrangements as defined in Section 3 of the Community-Integrated Living Arrangements Licensure and Certification Act. Such access shall be granted for the purposes of meeting with residents and staff, informing them of services available from the agency, distributing written information about the agency and the rights of persons with developmental disabilities, conducting scheduled and unscheduled visits, and performing other activities designed to protect the rights of persons with developmental disabilities. The agency also shall have access, for the purpose of inspection and copying, to the records of a person with developmental disabilities who resides in any such facility subject to the limitations of this Act, the Mental Health and Developmental Disabilities Confidentiality Act, the Nursing Home Care Act, the ID/DD Community Care Act, and the MC/DD Act. The agency also shall have access, for the purpose of inspection and copying, to the records of a person with

developmental disabilities who resides in any such facility if (1) a complaint is received by the agency from or on behalf of the person with a developmental disability, and (2) such person does not have a legal guardian or the State or the designee of the State is the legal guardian of such person. The designated agency shall provide written notice to the person with developmental disabilities and the State guardian of the nature of the complaint based upon which the designated agency has gained access to the records. No record or the contents of any record shall be redisclosed by the designated agency unless the person with developmental disabilities and the State guardian are provided 7 days advance written notice, except in emergency situations, of the designated agency's intent to redisclose such record, during which time the person with developmental disabilities or the State guardian may seek to judicially enjoin the designated agency's redisclosure of such record on the grounds that such redisclosure is contrary to the interests of the person with developmental disabilities. Any person who in good faith complains to the designated agency on behalf of a person with developmental disabilities, or provides information or participates in the investigation of any such complaint shall have immunity from any liability, civil, criminal or otherwise, and shall not be subject to any penalties, sanctions, restrictions or retaliation as a consequence of making such complaint, providing such information or participating in such investigation.

Upon request, the designated agency shall be entitled to inspect and copy any records or other materials which may further the agency's investigation of problems affecting numbers of persons with developmental disabilities. When required by law any personally identifiable information of persons with developmental disabilities shall be removed from the records. However, the designated agency may not inspect or copy any records or other materials when the removal of personally identifiable information imposes an unreasonable burden on mental health and developmental disabilities facilities pursuant to the Mental Health and Developmental Disabilities Code or facilities as defined in the Nursing Home Care Act, the ID/DD Community Care Act, or the MC/DD Act.

The Governor shall not redesignate the agency to administer the State plan to protect and advocate the rights of persons with developmental disabilities unless there is good cause for the redesignation and unless notice of the intent to make such redesignation is given to persons with developmental disabilities or their representatives, the federal Secretary of Health and Human Services, and the General Assembly at least 60 days prior thereto.

The designated agency shall submit to the Department of Human Services an annual report to be made available to the public. The annual report shall include, but is not limited to:

(1) how many visits were made by the designated agency to developmental disability facilities in the year

preceding the report;

(2) which community provider agencies or State-operated developmental centers were visited in the year preceding the report; and

(3) the nature of each visit, such as meeting with residents and staff of the developmental disability facility, distributing written information to the developmental disability facility, or whether the visit was scheduled or unscheduled.

As used in this Act, the term "developmental disability" means a severe, chronic disability of a person which:

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is manifested before the person attains age 22;

(C) is likely to continue indefinitely;

(D) results in substantial functional limitations in 3 or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and

(E) reflects the person's need for combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

Public Act 100-0694

HB5636 Enrolled

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(Source: P.A. 99-180, eff. 7-29-15.)

Section 99. Effective date. This Act takes effect January 1, 2019.