

1 AN ACT concerning health.

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

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

7 (405 ILCS 40/1) (from Ch. 91 1/2, par. 1151)

8 Sec. 1. The Governor may designate a private not-for-profit
9 corporation as the agency to administer a State plan to protect
10 and advocate the rights of persons with developmental
11 disabilities pursuant to the requirements of the federal
12 Developmental Disabilities Assistance and Bill of Rights Act,
13 42 U.S.C. 6001 to 6081, as now or hereafter amended. The
14 designated agency may pursue legal, administrative, and other
15 appropriate remedies to ensure the protection of the rights of
16 such persons who are receiving treatment, services or
17 habilitation within this State. The agency designated by the
18 Governor shall be independent of any agency which provides
19 treatment, services, guardianship, or habilitation to persons
20 with developmental disabilities, and such agency shall not be
21 administered by the Governor's Planning Council on
22 Developmental Disabilities or any successor State Planning
23 Council organized pursuant to federal law.

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

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

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

14 The Governor shall not redesignate the agency to administer
15 the State plan to protect and advocate the rights of persons
16 with developmental disabilities unless there is good cause for
17 the redesignation and unless notice of the intent to make such
18 redesignation is given to persons with developmental
19 disabilities or their representatives, the federal Secretary
20 of Health and Human Services, and the General Assembly at least
21 60 days prior thereto.

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

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

1 preceding the report;

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

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

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

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

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

15 (C) is likely to continue indefinitely;

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

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

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

2 Section 99. Effective date. This Act takes effect January
3 1, 2019.