

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 1. Short title. This Act shall be cited as the
5 Autism Spectrum Disorders Reporting Act.

6 Section 5. Legislative findings and purpose.

7 (a) The General Assembly finds that:

8 (1) the incidence of autism spectrum disorders has
9 increased significantly in Illinois, as in other states;

10 (2) the Centers for Disease Control and Prevention
11 estimates that autism spectrum disorders affects 1 in 166
12 children;

13 (3) autism spectrum disorders affect children of every
14 racial, ethnic, and socioeconomic background, and occurs
15 in every part of Illinois;

16 (4) little is known about causes of autism, although
17 research has indicated that autism is due to an abnormality
18 of brain development that may be related to environmental
19 factors, pharmacological agents, and other prenatal or
20 early childhood exposures, genetics or a combination
21 thereof;

22 (5) because there is no biologic marker for autism,
23 surveillance for this disability presents several
24 technical and logistic challenges that must be overcome;

25 (6) families of children with autism experience
26 tremendous psychological and financial stress related to
27 their child's disability;

28 (7) children with autism require long-term care and
29 services; special education costs for a child with autism
30 average more than \$19,000 per year nationwide, more than 3
31 times the cost of the average student and more than any
32 other special education category; some specially

1 structured programs cost over \$40,000 per year, and care in
2 a residential school costs between \$80,000 and \$100,000 per
3 year; these costs continue as children become adults, which
4 can be more than \$50,000 per person;

5 (8) genetic and environmental factors have been
6 suggested;

7 (9) there is no known cure for autism, although some
8 available therapies, treatments, and medicines may relieve
9 the severity and symptoms associated with the disorders;

10 (10) there exists no unified effort to collect and
11 analyze information on autism spectrum disorders and their
12 potential effects on public health, families, schools, and
13 the economy in Illinois;

14 (11) the lack of comprehensive information has caused
15 concern on the part of Illinois citizens and a lack of
16 effective control by the State;

17 (12) it is the obligation of the State to inform and
18 protect the citizens of Illinois by developing a
19 comprehensive and integrated data system on autism
20 spectrum disorders and public health; and

21 (13) the establishment of an Autism Spectrum Disorder
22 Registry will help better define who is affected by autism
23 and the impact of autism; define the range of impairments
24 and disability associated with autism; identify better
25 mechanisms to refer persons with autism to available
26 services; and provide a research tool for universities,
27 physicians, and policymakers to conduct studies in
28 Illinois.

29 (b) It is the purpose of this Act to establish a unified
30 statewide project to collect, compile, and correlate
31 information on public health and autism spectrum disorders, to
32 be known as the Autism Spectrum Disorders Registry. The
33 information is to be used to assist in the determination of
34 public policy and to provide a source of information for
35 researchers and the public, except when public disclosure of
36 the information would violate the provisions of this Act and

1 other applicable laws concerning confidentiality.

2 (c) In particular, the purpose of the collection of autism
3 spectrum disorder incidence information is to:

4 (1) monitor incidence trends of autism spectrum
5 disorders to detect potential public health problems,
6 predict risks, and assist in investigating clusters;

7 (2) more accurately target intervention resources for
8 communities and patients and their families;

9 (3) inform health professionals and citizens about
10 risks, early detection, and treatment of autism spectrum
11 disorders;

12 (4) promote high quality research to provide better
13 information for the study of autism spectrum disorders,
14 treatment, interventions, and services, and the impact of
15 autism spectrum disorders on families, schools, public
16 health, and the economy; and

17 (5) promote Illinois as a national leader in research
18 into the causes, effects, and treatment of autism spectrum
19 disorders.

20 Section 10. Definitions. In this Act:

21 "Autism spectrum disorder" means a pervasive developmental
22 disorder described by the American Psychiatric Association or
23 the World Health Organization diagnostic manuals as an autistic
24 disorder, atypical autism, Asperger Syndrome, Rett Syndrome,
25 childhood disintegrative disorder, or pervasive developmental
26 disorder not otherwise specified; or a special education
27 classification for autism or other disabilities related to
28 autism.

29 "Department" means the Department of Public Health.

30 "Director" means the Director of the Department of Public
31 Health.

32 "Facility" means a governmental or private agency,
33 department, institution, clinic, laboratory, hospital, or a
34 health maintenance organization, association, or other similar
35 unit designated by the Director.

1 "Qualified professional" means a medical, clinical or
2 educational professional in a position to observe children with
3 developmental disabilities, including, psychologists,
4 physicians, teachers, speech and language pathologists,
5 occupational therapists, physical therapists, nurses, and
6 social workers.

7 Section 15. Reporting autism spectrum disorders. A
8 qualified professional who diagnoses any individual that
9 resides in the State with an autism spectrum disorder shall
10 report within 30 days the existence of an autism spectrum
11 disorder diagnosis along with all such additional information
12 as determined in rules promulgated pursuant to this Act. On or
13 before September 1, 2005, the Department of Human Services,
14 Department of Public Aid, and the State Board of Education
15 shall report the existence and content of data compiled by them
16 in the course of their duties pertaining to individuals with
17 autism spectrum disorders. The annual reports shall be filed on
18 January 1 of each year. The Director shall also promulgate
19 rules and procedures allowing for individuals with autism
20 spectrum disorder and their parents or guardians to voluntarily
21 report their own diagnosis and information.

22 Section 20. Reports; contents, filing, availability for
23 research and public inspection.

24 (a) The reports prescribed in Section 15 of this Act shall
25 be designated an autism spectrum disorder report and shall
26 contain information that the Director considers necessary to
27 identify, locate, and investigate the occurrence, frequency,
28 incidence, cause, effect, and prognosis of autism spectrum
29 disorder and other relevant data and findings.

30 (b) The Director shall promulgate rules regarding the form,
31 content, and manner of filing the report prescribed in Section
32 15 of this Act, which shall be submitted to the Department
33 unless otherwise prescribed by the Director. Any rules
34 promulgated by the Director shall contain a specific provision

1 guaranteeing the maintenance of the physician-patient
2 privilege and compliance with all provisions of the Genetic
3 Information Privacy Act.

4 (c) Autism spectrum disorder reports and data shall be
5 maintained by the Department in a manner suitable for use for
6 research purposes and shall be made available to persons as
7 prescribed in Section 25 of this Act.

8 (d) A report or other data relating to autism spectrum
9 disorder that discloses the identity of an individual that was
10 reported as having autism spectrum disorder shall be made
11 available only to persons that demonstrate a need for the
12 report or other data that is essential to health related
13 research. No report or data or portion of the data that
14 discloses the identity of the individual shall be made
15 available to the public.

16 (e) Nothing in this Section shall mandate the Department to
17 investigate or otherwise follow-up any reported incidence of
18 autism spectrum disorder.

19 Section 25. Contracts; Autism Spectrum Disorder Registry.
20 The Department may enter into contracts with individuals,
21 corporations, hospitals, universities, not-for-profit
22 corporations, governmental entities, or other organizations
23 whereby such individuals, organizations, or agencies agree to
24 provide assistance in the compilation of the Autism Spectrum
25 Disorder Registry or to conduct research on behalf of the
26 Department consistent with the purposes of this Act. The
27 Director shall adopt rules governing such contracts, which
28 shall include: (i) requirements for a written protocol
29 outlining the purpose and public benefit of the research; (ii)
30 the description, methods, and projected results of the
31 research; (iii) peer review by other scientists; (iv) the
32 methods and facilities to protect the confidentiality of the
33 data; and (v) the qualifications of the researcher proposing to
34 undertake the research.

1 Section 30. Annual progress reports. The Department shall
2 annually report to the General Assembly beginning September 1,
3 2005. Beginning January 1, 2006, the Department shall provide
4 annual progress reports to the Governor and the General
5 Assembly by January 1 of each year. The annual report shall
6 include information on the progress of the Autism Spectrum
7 Disorder Registry, as well as descriptions of any studies which
8 are underway or have been completed, including those performed
9 to determine the potential public health significance of an
10 increase in autism incidence, together with any findings and
11 recommendations. The annual report shall also include a list of
12 those persons, organizations, and agencies which have refused
13 to cooperate with the Department in the collection or
14 transmission of information under this Act.

15 Section 35. Implementation. The Director shall promulgate
16 rules to implement this Act which fosters the study, research,
17 diminution, and control of autism spectrum disorders in this
18 State.

19 Section 99. Effective date. This Act takes effect upon
20 becoming law.