

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 "Health care professional" means a physician licensed to  
2 practice medicine in all of its branches under the Illinois  
3 Medical Practice Act of 1987 or a clinical psychologist  
4 licensed under the Clinical Psychologist Licensing Act.

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

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

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

28 (b) The Director shall promulgate rules regarding the form,  
29 content, and manner of filing the report prescribed in Section  
30 15 of this Act, which shall be submitted to the Department  
31 unless otherwise prescribed by the Director. Any rules  
32 promulgated by the Director shall contain a specific provision  
33 guaranteeing the maintenance of the physician-patient  
34 privilege and compliance with all provisions of the Genetic

1 Information Privacy Act.

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

6 (d) A report or other data relating to autism spectrum  
7 disorder that discloses the identity of an individual that was  
8 reported as having autism spectrum disorder shall be made  
9 available only to persons that demonstrate a need for the  
10 report or other data that is essential to health related  
11 research and complies with the Illinois Health Statistics Act.  
12 No report or data or portion of the data that discloses the  
13 identity of the individual or health care professional shall be  
14 made available to the public. This data shall be subject to the  
15 provisions of the Communicable Disease Report Act.

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 (f) Any person making a report under this Act shall have  
20 immunity from any liability, civil or criminal, that may result  
21 by reason of making the report, except for willful or wanton  
22 misconduct.

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

1 methods and facilities to protect the confidentiality of the  
2 data; and (v) the qualifications of the researcher proposing to  
3 undertake the research.

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

18       Section 35. Implementation. The Director shall promulgate  
19 rules to implement this Act which fosters the study, research,  
20 diminution, and control of autism spectrum disorders in this  
21 State. This Act shall be subject to appropriation.

22       Section 99. Effective date. This Act takes effect upon  
23 becoming law.