

AN ACT concerning health.

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

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

Section 5. Legislative findings and purpose.

(a) The General Assembly finds that:

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

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

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

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

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

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

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

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

(8) genetic and environmental factors have been suggested;

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

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

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

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

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

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

other applicable laws concerning confidentiality.

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

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

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

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

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

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

Section 10. Definitions. In this Act:

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

"Department" means the Department of Public Health.

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

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

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

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

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

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

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

Information Privacy Act.

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

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

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

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

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

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

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

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

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