

DEPARTMENT OF HEALTH AND SOCIAL SERVICES
DIVISION OF PUBLIC HEALTH
Statutory Authority: 16 Delaware Code, Section 223 (16 Del.C. §223) 16 DE Admin. Code
4108

PROPOSED

4108 Autism Surveillance and Registration Program

PUBLIC NOTICE

Nature of the Proceedings

Pursuant to 16 **Delaware Code**, Section 223, the Department of Health and Social Services is proposing “Autism Surveillance and Registration Program Regulations” that will require health care practitioners to report information on children under 18 years of age with autism to a central Autism Registry. The information collected in the Autism Registry will be used to track changes in prevalence of autism over time, to inform the planning of service delivery to children with autism and their families, and to facilitate autism research.

Notice of Public Hearing

The Division of Public Health, Department of Health and Social Services will hold a public hearing to discuss the proposed Autism Surveillance and Registration Program Regulations. The public hearing will be held on January 24, 2005 at 10:00 a.m., in the Third Floor Conference Room of the Jesse Cooper Building, Federal and Water Streets, Dover, Delaware.

Copies of the proposed regulations are available for review by calling the following location:

Community and Family Health (Rebecca Luis)
Blue Hen Corporate Center, Suite 206
655 S. Bay Road, Dover, Delaware
Telephone: (302) 741-2980

Anyone wishing to present his or her oral comments at this hearing should contact David Walton at (302) 744-4700 by January 21, 2005. Anyone wishing to submit written comments as a supplement to or in lieu of oral testimony should submit such comments by January 31, 2005 to:

David P. Walton
Division of Public Health
Jesse Cooper Building
P.O. Box 637
Dover, Delaware 19903-0637

4108 Autism Surveillance and Registration Program

1.0 Purpose

1.1 Autism is a severe neurodevelopmental disorder whose prevalence appears to be increasing in Delaware and across the United States. An Autism Surveillance and Registration, or an Autism Registry, will enable the Department of Health & Social Services (DHSS), Division of Public Health (DPH) to collect basic descriptive information on the individuals with autism, to track changes in prevalence over time, to inform the planning of service delivery to children with autism and their families, and to facilitate autism research.

1.2 The purpose of the Autism Registry is to provide an accurate and continuing source of data concerning autism to provide information to Public Health officials to help to ultimately decrease the autism morbidity burden associated with the disorder. The Autism Registry will gather data to assist with: prevalence estimation, cluster investigation, risk factor identification, and outcome assessment.

1.3 The usefulness of the data collected in the Autism Registry will depend upon the full and accurate reporting

of the confirmed diagnosis of autism by health care practitioners, hospitals, and clinical laboratories.

1.4 The Autism Registry will be a separate component of the Newborn Screening Management System.

2.0 Definitions

The following words shall have the meanings indicated:

"Autism" means any structural or biochemical abnormality, regardless of cause, diagnosed at any time before or after birth, that requires medical or surgical intervention or that interferes with normal growth or development. Reportable autism diagnoses are listed in Appendix A of these Regulations.

"Confirmed Autism Or Diagnosed Autism" means an abnormality characterized by each of the following symptoms:

- Impaired social behavior:
 - marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - failure to develop peer relationships appropriate to developmental level
 - a lack of spontaneous seeking to share enjoyment, interest, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - lack of social or emotional reciprocity
- Abnormal development of communication skills:
 - delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - stereotyped and repetitive use of language or idiosyncratic language
 - lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- Lack of awareness of the need for emotional support and little emotional response to family members:
 - encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - apparently inflexible adherence to specific, nonfunctional routines or rituals
 - stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
 - persistent preoccupation with parts of objects

"Division" refers to the Division of Public Health under the Department of Health and Social Services.

"Infant" refers to a newborn from birth to 1 year of age.

"Registry" means a central data bank containing collected, classified, coded, and sorted data relating to confirmed autism in children from birth through age 17, as reported by health care practitioners, hospitals and clinical laboratories.

"Surveillance" means the process of identifying and investigating confirmed autism in children under age 18.

"Suspected Autism" is a term used for an infant or young child who is showing some developmental variations that do not meet the criteria for autism but whose variations have been shown to be associated with a risk of eventually developing all of the traits of autism.

3.0 Reporting Requirements

The provisions of this section shall apply to the Delaware Health and Social Services, Division of Public Health, Autism Registry:

3.1 The registry shall collect information on any child under the age eighteen (18) who is a resident of the state of Delaware, or whose parent is a resident of Delaware, and who is diagnosed at any time prior to age eighteen (18) as having confirmed autism. For the purposes related to the registry the Department shall have access to any medical record of the child with confirmed autism.

3.2 The Department shall have access to information in the medical records of children with suspected autism. On request of the Department all mandated reporting sources should identify children who have suspected autism. The Department shall have access to records of such children.

3.3 Any diagnosis of confirmed autism shall be reported for all infants and children up to age 18, including those who have since died (if the data is still available).

3.4 For purposes of these reporting requirements, reportable diagnoses are those diagnoses, from the International Classification of Diseases (ICD) and DSM IV as listed in Appendix A of these regulations; as well as the 6-digit modified Pediatric Association system (BPA/ICD-9). The reportable diagnoses listed in Appendix A may be revised, upon notice, to reflect changes in publications accepted for use by the Centers for Disease Control and Prevention.

3.5 The following persons and organizations are required to report occurrences of autism within 30 days of diagnosis to the Division of Public Health.

3.5.1 Any physician, surgeon, dentist, podiatrist, or other health care practitioner who diagnoses a child with autism under age 18 who is not known to be previously reported. Other health care practitioners will include but not be limited to: psychiatrists, clinical and school psychologists, speech and language pathologists, licensed clinical social workers, and nurses including school nurses;

3.5.2 The designated representative of any clinical laboratory conducting assessment, evaluation or research that performs any test which identifies a child or children under age 18 with confirmed autism not known to be previously reported; and

3.5.3 The designated representative of any hospital that diagnoses a child or children under age 18 with confirmed autism.

3.6 The administrative officer of every health care facility shall be responsible for establishing reporting procedures at that facility, using the identified Autism Registry Reporting Form. Reporting procedures must ensure that, on the effective date of these regulations, each child up to the age of 18 diagnosed as having confirmed autism or currently under care with a diagnosis of confirmed autism must be reported to the Division.

3.7 Reporting sources shall complete the Division of Public Health Autism Surveillance Form for each reported case, and forward the completed form to the Division of Public Health Director or designee within 30 days of the diagnosis.

4.0 Follow-up Information from Reporting Sources

Any follow-up information, including family, physician, hospital or clinical laboratory contact deemed necessary by the Department, shall be submitted to the Department at least 1 time each year by those required to report occurrences of autism. The required follow-up information for the Autism Surveillance and Registry system will be sent to the same address as the Autism Registry Report Form.

5.0 Confidentiality of Reports

5.1 No report of a diagnosis or treatment of confirmed autism shall be disclosed in such a way as to identify the child who is the subject of the report, or as to identify the child's family. However, patient-identifying information may be exchanged among authorized entities as approved by the Department and upon receipt by the Department of satisfactory assurances by those entities of the preservation of the confidentiality of such information. Those entities will maintain the confidentiality of any information exchanged for the purpose of delivery of program services, evaluation, early intervention and epidemiological investigation.

5.2 No individual or organization providing information pursuant to these regulations shall be held liable for divulging such information to the Division.

5.3 Inclusion on the registry does not determine the eligibility for services through any state agency.

6.0 Penalties

Any person or organization required to report the diagnosis or treatment of confirmed autism pursuant to these regulations, and who violates these regulations, shall be subject to a fine of up to \$100 for each violation, pursuant to 16 Del.C. Sec. 226. Justices of the Peace Courts have jurisdiction over such violations.

7.0 Severability

In the event any particular clause or section of the regulations should be declared invalid or unconstitutional by any court of competent jurisdiction, the remaining portions shall remain in full force and effective.

APPENDIX A

DELAWARE AUTISM REGISTRY REPORTABLE DIAGNOSES

Broad Categories **Specific Categories** **Codes**

Autism spectrum **ICD-9**

<u>disorder (ASD)</u>	<u>Infantile autism</u>	<u>299.0</u>
	<u>Infantile autism, active state</u>	<u>299.00</u>
	<u>Infantile autism, residual state</u>	<u>299.01</u>
	<u>DSM-IV</u>	
	<u>Autistic disorder</u>	<u>299</u>
	<u>Childhood disintegrative</u>	
	<u>disorder</u>	<u>299.1</u>
	<u>Rett's Disorder</u>	<u>299.8</u>
	<u>Asperger's Disorder</u>	<u>299.8</u>
	<u>Pervasive developmental</u>	
	<u>disorder NOS</u>	<u>299.8</u>

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