

## **4100 Family Health Services**

### **4109 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

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- 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 Exemption Based on Religious Grounds**

- 5.1 The provisions of these regulations shall not apply to any person or private institution that, as an exercise of religious freedom, treats the sick or suffering by spiritual means through prayer alone.
- 5.2 A parent, custodian or guardian of an infant having autism may refuse disclosure to surveillance system and registry of the infant's name and identifying information on the grounds that such autism identification is contrary to the religious tenets and practices of the infant's parent, custodian or guardian.]

#### **6.0 Confidentiality of Reports**

- 6.1 No report of a diagnosis or treatment of confirmed autism received by the Division 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.
- 6.2 No individual or organization providing information pursuant to these regulations shall be held liable for divulging such information to the Division.
- 6.3 Inclusion on the registry does not determine the eligibility for services through any state agency.

#### **7.0 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.** 226. Justices of the Peace Courts have jurisdiction over such violations.

#### **8.0 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**

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<b>Broad Categories</b>	<b>Specific Categories</b>	<b>Codes</b>
Autism spectrum disorder (ASD)	<b>ICD-9</b>	
	Infantile autism	299.0
	Infantile autism, active state	299.00
	Infantile autism, residual state	299.01
	<b>DSM-IV</b>	
	Autistic disorder	299
	Childhood disintegrative disorder	299.1
	Rett's Disorder	299.8
	Asperger's Disorder	299.8
	Pervasive developmental disorder NOS	299.8

**8 DE Reg. 1481 (4/1/05)**