

RULEMAKING NOTICE FORM

Notice Number _____

Rule Number He-M 501

1. Agency Name & Address:

**Dept. of Health & Human Services
Office of Client Services
Bureau of Developmental Services
109 Pleasant Street-Main Building
Concord, NH 03301**

2. RSA Authority: RSA 171-A:31

3. Federal Authority: _____

4. Type of Action:

Adoption _____

Amendment _____

Repeal _____

Readoption _____

Readoption w/amendment X

5. Short Title: **Autism Registry**

6. (a) Summary of what the rule says and of any proposed amendments:

The Department of Health and Human Services (Department) is proposing to re-adopt with amendment He-M 501, entitled “Autism Registry.” He-M 501 is in interim status and is scheduled to expire on November 21, 2016.

He-M 501 establishes an autism registry to define terms, list demographic and diagnostic information to be reported, and describe access to the registry by third parties. The Department proposes to readopt He-M 501 amending the definition of “autism spectrum disorder” in He-M 501.02(b) to align with other parts of He-M 500. The proposal also amends He-M 501.04(b)(8) to provide the most current diagnoses taken from the “Diagnostic and Statistical Manual of Mental Health Disorders”, fifth edition (DSM-V) and the “International Classification of Diseases”, tenth edition (ICD 10).

6. (b) Brief description of the groups affected:

Those affected by the rule include providers, insurers researchers and governmental agencies. Those affected by the rule include those who conduct and complete epidemiologic surveys and make reports to the Department and those who use information in the registry to facilitate planning for services to children and adults with ASD and their families.

6. (c) Specific section or sections of state statute or federal statute or regulation which the rule is intended to implement:

RULE	Specific State Statute Which The Rule Implements
He-M 501.01	RSA 171-A:30, 31
He-M 501.02	RSA 171-A:30, 31
He-M 501.03	RSA 171-A:30, 31
He-M 501.04	RSA 171-A:30, 31
He-M 501.05	RSA 171-A:30, 31
He-M 501.06	RSA 171-A:30, 31

7. Contact person for copies and questions including requests to accommodate persons with disabilities:

Name: **Catherine Bernhard** Title: **Rules Coordinator**
 Address: **Dept. of Health and Human Services** Phone #: **271-9374**
Administrative Rules Unit Fax#: **271-5590**
129 Pleasant St. E-mail: catherine.bernhard@dhhs.nh.us
Concord, NH 03301

TTY/TDD Access: Relay NH 1-800-735-2964 or dial 711 (in NH)

The proposed rules may be viewed and downloaded at:
<http://www.dhhs.nh.gov/oos/aru/comment.htm>

8. Deadline for submission of materials in writing or, if practicable for the agency, in the electronic format specified: **Thursday, October 20, 2016**

Fax

E-mail

Other format (specify):

9. Public hearing scheduled for:

Date and Time: **Thursday, October 13, 2016**

9:00 a.m.

Place: **DHHS Brown Bldg., Room 232, 129 Pleasant St., Concord, NH**

10. Fiscal Impact Statement (Prepared by Legislative Budget Assistant)

FIS # 16:184 , dated 09/09/16

1. Comparison of the costs of the proposed rule(s) to the existing rule(s):

There is no difference in cost when comparing the proposed rule to the existing rule.

2. Cite the Federal mandate. Identify the impact of state funds:

There is no federal mandate and no impact on state funds.

3. Cost and benefits of the proposed rule(s):

A. To State general or State special funds:

None.

B. To State citizens and political subdivisions:

None.

C. To Independently owned businesses:

None.

11. Statement Relative to Part I, Article 28-a of the N.H. Constitution:

The proposal modifies an existing program or responsibility, but does not mandate any fees, duties or expenditures on the political subdivisions of the state, and therefore does not violate Part I, Article 28-a of the N.H. Constitution.

Readopt with amendment He-M 501, effective 5-25-16 (Document #11103 Interim), to read as follows:

PART He-M 501 AUTISM REGISTRY

Statutory Authority: RSA 171-A:31

He-M 501.01 Purpose. The purpose of these rules is to establish and implement a state autism registry and thereby improve current knowledge and understanding of autism spectrum disorder (ASD), allow the conducting of thorough and complete epidemiologic surveys of the disorder, enable analysis of the problem, and facilitate planning for services to children and adults with ASD and their families.

He-M 501.02 Definitions. The words and phrases used in these rules shall mean the following, except where a different meaning is clearly intended from the context:

(a) “Autism registry” means the system established under RSA 171-A:30, I for reporting and recording new instances of autism spectrum disorder.

(b) “Autism spectrum disorder” (ASD) means a developmental disorder of brain function that presents with:

(1) Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

a. Deficits in social-emotional reciprocity;

b. Deficits in nonverbal communicative behaviors used for social interaction; and

c. Deficits in developing, maintaining, and understanding relationships;

(2) Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least 2 of the following, currently or by history:

a. Stereotyped or repetitive motor movements, use of objects, or speech;

b. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior;

c. Highly restricted, fixated interests that are abnormal in intensity or focus; or

d. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment;

(3) Symptoms that are present in the early developmental period, but might not become fully manifest until social demands exceed limited capacities, or might be masked by learned strategies in later life;

(4) Symptoms that cause clinically significant impairment in social, occupational, or other important areas of current functioning; and

(5) Disturbances that are not better explained by intellectual disability or global developmental delay.

~~(1) Is typically manifested in:~~

~~a. Impaired social interaction;~~

~~b. Problems with verbal and nonverbal communication and imagination; and~~

~~c. Unusual or severely limited activities and interests;~~

~~(2) Has symptoms that generally appear during the first 3 years of childhood and continue throughout life; and~~

~~(3) Includes:~~

~~a. Autistic disorder;~~

~~b. Pervasive developmental disorder — not otherwise specified;~~

~~c. Asperger's syndrome;~~

~~d. Rett's syndrome; and~~

~~e. Childhood disintegrative disorder.~~

(c) “Bureau” means the bureau of developmental services of the department of health and human services.

(d) “Commissioner” means the commissioner of the department of health and human services or his or her designee.

(e) “Patient” means a person diagnosed as having ASD.

(f) “Reporter” means any physician, psychologist, or other licensed or certified health care provider who is qualified by training to make the diagnosis of ASD.

He-M 501.03 Establishment of the Autism Registry. The commissioner shall implement and maintain a computerized autism registry as established in RSA 171-A:30, I.

He-M 501.04 Methods of Submission and Content of Records.

(a) Reporters shall submit to the bureau demographic and diagnostic information pertaining to each patient newly diagnosed as having ASD. Such records shall be submitted via:

- (1) An electronic interface provided by the bureau; or
 - (2) Written records.
- (b) Demographic and diagnostic information submitted regarding each patient shall include the patient's:

- (1) First initial of last name;
- (2) Last 4 digits of social security number, if applicable;
- (3) Date of birth;
- (4) Gender;
- (5) City, county, state and zip code of birth residence;
- (6) Residence, including city or town and zip code, at time of diagnosis;
- (7) Ethnicity, identified as either:
 - a. American Indian or Alaskan Native;
 - b. Asian;
 - c. Hispanic;
 - d. Non-Hispanic Black;
 - e. Non-Hispanic White;
 - f. Native Hawaiian or other Pacific Islander;
 - g. Not reported; or
 - h. Other, specified;
- (8) Specific diagnosis, identified as either:
 - a. Autism spectrum disorder;
 - b. Asperger's syndrome;
 - c. Pervasive developmental disorder, not otherwise specified (PDD-NOS);
 - d. Rett's syndrome or other PDD;
 - e. Atypical Autism; or

e. Childhood ~~autismdisintegrative disorder~~; and

(9) Date of diagnosis.

(c) Reporters submitting records to the autism registry shall include the reporter's:

(1) Full name;

(2) Address, including:

a. Street or P.O. box;

b. City or town;

c. State; and

d. Zip code;

(3) Phone number;

(4) E-mail address;

(5) Licensure type;

(6) Highest educational degree attained;

(7) Specialty and subspecialty, if applicable; and

(8) Signature and date signed.

(d) The bureau shall assign a unique identifying code to each patient. The code shall not include the patient's name or address.

(e) The bureau shall supply to reporters an informational notice describing the purposes of the autism registry and the name, phone number and e-mail address of a contact person for questions.

(f) Each reporter shall:

(1) Post the informational notice described in (e) above conspicuously in his or her place of practice; and

(2) Inform each patient, parent of a patient who is a minor child, or guardian, as applicable, of the reporting requirements under the registry law, RSA 171-A:30.

He-M 501.05 Security Regarding the Autism Registry. To ensure confidentiality, all information submitted to the registry shall be stored in a secure file and database.

He-M 501.06 Access to the Autism Registry By Third Parties. Upon request, the commissioner shall release analyses and compilations of demographic and diagnostic records that do not disclose the identity of the registrants to:

- ~~(1)~~(a) Providers;
- ~~(2)~~(b) Insurers;
- ~~(3)~~(c) Managed care organizations;
- ~~(4)~~(d) Researchers; and
- ~~(5)~~(e) Governmental agencies.

Appendix

RULE	Specific State Statute Which The Rule Implements
He-M 501.01	RSA 171-A:30, 31
He-M 501.02	RSA 171-A:30, 31
He-M 501.03	RSA 171-A:30, 31
He-M 501.04	RSA 171-A:30, 31
He-M 501.05	RSA 171-A:30, 31
He-M 501.06	RSA 171-A:30, 31