

INTERIM RULEMAKING NOTICE FORM

Proposed Interim Rule Number 2016-12 Rule Number He-M 501

<p>1. Agency Name & Address:</p> <p>Department of Health & Human Services Bureau of Developmental Services 105 Pleasant Street Concord, NH 03301</p> <p>5. Filing Date: May 5, 2016</p>	<p>2. RSA Authority: <u>RSA 171-A:31</u></p> <p>3. Federal Authority: _____</p> <p>4. Type of Action:</p> <p>Adoption _____</p> <p>Amendment _____</p> <p>Repeal _____</p> <p>Readoption <u>X</u></p> <p>Readoption w/amendment _____</p>
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6. Short Title: **Autism Registry**

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

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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. Summary explaining the effect of the rule:

He-M 501 is scheduled to expire on May 17, 2016. The interim rule is being proposed to readopt the rule unchanged in accordance with RSA 541-A:19, I(e) in order to minimize the time between the expiration of the rule and its readoption.

He-M 501 creates an autism registry, as required by RSA 171-A:30 to record all reported cases of autism spectrum disorder (ASD) that occur in NH in order to improve current knowledge and understanding of 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.

9. Listing of people, enterprises, and government agencies affected by the rule:

Those affected by the rule include children with ASD and their families and physicians, psychologists, and other licensed or certified health care providers who are qualified by training to make the diagnosis of ASD.

10. Specific section or sections of state statute or federal statute or regulation which the rule is intended to implement.

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

11. Summary of the effect upon the state if the rule were not adopted:

If the rule were not readopted as an interim rule, physicians, psychologists, or other licensed or certified health care providers qualified by training to make the diagnosis of ASD might not continue to provide information to the registry, which would be contrary to the purpose for which it was established and contrary to RSA 171-A:30.

12. Proposed date of review by the Joint Legislative Committee on Administrative Rules:

May 20, 2016.

13. The fiscal impact statement prepared by the Legislative Budget Assistant, if applicable.

A fiscal impact statement is not required for this interim rule.

Readopt He-M 501, effective 5-17-08 (Document #9161), cited to and to read as follows:

CHAPTER He-M 500 DEVELOPMENTAL SERVICES

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:

(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. Autistic disorder;

- b. Asperger's syndrome;
- c. Pervasive developmental disorder, not otherwise specified (PDD-NOS);
- d. Rett's syndrome; or
- e. Childhood disintegrative 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) Providers;
- (2) Insurers;
- (3) Managed care organizations;
- (4) Researchers; and
- (5) 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
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