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An Act To Improve the Authority of Guardians of Persons with Intellectual Disabilities or Autism

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 34-B MRSA §5604, 2nd ¶, as amended by PL 2011, c. 542, Pt. A, §127, is further amended to read:

The rights and basic protections of a person with an intellectual disability or autism under section 5605, subsection 1 may not be restricted or waived by that person's guardian, except as permitted by rules adopted pursuant to this section or by order of the Probate Court.

Sec. 2. 34-B MRSA §5604, last ¶, as enacted by PL 2011, c. 186, Pt. A, §17, is amended to read:

The department has authority to adopt rules to implement this section except that the rules do not govern probate court proceedings. Rules adopted pursuant to this paragraph are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

Sec. 3. 34-B MRSA §5604, as amended by PL 2011, c. 657, Pt. EE, §7, is further amended by adding at the end 2 new paragraphs to read:

Nothing in this section may be interpreted to limit the Probate Court's authority and jurisdiction to determine if an action taken or not taken by a guardian is within the permissible powers of the guardian, as limited by the rights established in section 5605, subsection 1.

Nothing in this section may be interpreted to limit the Probate Court's authority and jurisdiction to expand the powers of a guardian to permit the restriction or waiver of the rights of a person with an intellectual disability or autism as outlined in section 5605, subsection 1.

Sec. 4. 34-B MRSA §5604-A, sub-§5 is enacted to read:

5. Probate Court authority not limited. Nothing in this section limits the Probate Court's authority pursuant to section 5604.

Sec. 5. 34-B MRSA §5605, as amended by PL 2013, c. 500, §1, is repealed and the following enacted in its place:

§ 5605. Rights and basic protections of a person with an intellectual disability or autism

1. Rights and basic protections. A person with an intellectual disability or autism is entitled to the following rights and basic protections. These rights and protections may be waived or limited only in compliance with section 5604.

A. A person with an intellectual disability or autism is entitled to dignity, privacy and humane treatment.

B. A person with an intellectual disability or autism is entitled to religious freedom and practice without any restriction or forced infringement on that person's right to religious preference and practice.

C. A person with an intellectual disability or autism is entitled to private communications.

(1) A person with an intellectual disability or autism is entitled to receive, send and mail sealed, unopened correspondence. A person who is a provider may not delay, hold or censor any incoming or outgoing correspondence of a person with an intellectual disability or autism, nor may any such correspondence be opened without the consent of the person or the person's legal guardian.

(2) A person with an intellectual disability or autism is entitled to reasonable opportunities for telephone and Internet communication.

(3) A person with an intellectual disability or autism is entitled to reasonable visitations during reasonable hours.

D. A person with an intellectual disability or autism engaged in a work program that requires compliance with state and federal wage and hour laws is entitled to fair compensation for labor in compliance with regulations of the United States Department of Labor.

E. A person with an intellectual disability or autism may not be denied the right to vote.

F. A person with an intellectual disability or autism is entitled to the possession and use of that person's own clothing, personal effects and money, except when temporary custody of clothing or personal effects by a provider is necessary to protect the person or others from imminent injury.

G. A person with an intellectual disability or autism is entitled to nutritious food in adequate quantities, and meals may not be withheld for disciplinary reasons.

H. A person with an intellectual disability or autism is entitled to receive prompt and appropriate medical and dental treatment and care for physical and mental ailments and for the prevention of any illness or disability, and medical treatment must be consistent with the accepted standards of medical practice in the community, unless the religion of the person with an intellectual disability or autism so prohibits.

(1) A person with an intellectual disability or autism may not be subject to the use of medication as punishment, for the convenience of staff, as a substitute for habilitation or in unnecessary or excessive quantities.

(2) For a person with an intellectual disability or autism who resides in an institutional setting and who does not have a guardian or who has the State as a guardian:

(a) Medication may be administered only at the written order of a physician;

(b) Daily notation of medication received by a person with an intellectual disability or autism must be kept in the records of that person;

(c) Periodically, but no less frequently than every 6 months, the drug regimen of each person with an intellectual disability or autism must be reviewed by a physician or other appropriate monitoring body, consistent with appropriate standards of medical practice; and

(d) All prescriptions must have a termination date.

(3) Prior to instituting a plan of experimental medical treatment or carrying out any surgical procedure, express and informed consent must be obtained from the person with an intellectual disability or autism, unless the person has been found to be legally incompetent, in which case the person's guardian may consent.

(4) Before making a treatment or surgical decision, the person with an intellectual disability or autism must be given information, including, but not limited to, the nature and consequences of the procedure, the risks, benefits and purposes of the procedure and the availability of alternate procedures, unless the person has been found to be legally incompetent, in which case the person's guardian must be given such information.

(5) The person with an intellectual disability or autism or, if legally incompetent, that person's guardian may withdraw express and informed consent at any time, with or without cause, before treatment or surgery.

(6) Notwithstanding the absence of express and informed consent, emergency medical care or treatment may be provided to a person with an intellectual disability or autism who has been injured or who is suffering from an acute illness, disease or condition if delay in initiation of emergency medical care or treatment would endanger the health of the person.

(7) Notwithstanding the absence of express and informed consent, emergency surgical procedures may be provided to a person with an intellectual disability or autism who has been injured or who is suffering from an acute illness, disease or condition if delay in initiation of emergency surgery would substantially endanger the health of the person.

I. A person with an intellectual disability or autism may not be sterilized, except in accordance with chapter 7.

J. A person with an intellectual disability or autism is entitled to reasonable opportunities for behavioral and leisure time activities that include social interaction in the community, as set out in section 5610.

K. A person with an intellectual disability or autism is entitled to reasonable opportunities for appropriate physical exercise, including the reasonable use of available indoor and outdoor facilities and equipment.

L. A person with an intellectual disability or autism may not be subject to corporal punishment or any form of inhumane discipline or seclusion as a form of discipline.

M. A provider of residential services may establish house rules in a residential unit owned or operated by the provider. A person with an intellectual disability or autism receiving services who resides in the residential unit is entitled to participate, as appropriate, in the formulation of the house rules. A house rule must be uniformly applied to all residents of the residential unit where the rules apply. A copy of the house rules must be posted in a residential unit where the rules apply and a copy of the rules must be given to all residents who receive services and, if any resident is under guardianship, to the guardian of the resident receiving services.

N. A person with an intellectual disability or autism who is not a patient in a psychiatric unit of an acute hospital or a psychiatric hospital as defined in section 3801, subsection 7-B is entitled to behavior modification and management and supports that comply with the following.

(1) A person with an intellectual disability or autism may not be subjected to a behavior modification or behavior management program to eliminate dangerous or maladaptive behavior without first being assessed by a physician to determine if the proposed program is medically contraindicated and that the dangerous or maladaptive behavior could not be better treated medically.

(2) Support programs may contain both behavior modification and behavior management components.

(3) The following practices are prohibited as elements of behavior modification or behavior management programs:

(a) Seclusion;

(b) Corporal punishment;

(c) Actions or language intended to humble, dehumanize or degrade the person;

(d) Restraints that do not conform to rules adopted pursuant to this section;

(e) Totally enclosed cribs or beds; and

(f) Painful stimuli.

(4) Behavior modification and behavior management programs may be used only to correct behavior more harmful to the person than the behavior modification and behavior management program.

(5) If the State is the person's guardian or if no guardian has been appointed for the person, then behavior modification and behavior management may be used only:

(a) On the recommendation of the person's personal planning team;

(b) For an adult 18 years of age or older, with the approval, following a case-by-case review, of a review team composed of a representative from the department, a representative from the advocacy agency designated pursuant to Title 5, section 19502 and a representative designated by the Maine Developmental Services Oversight and Advisory Board. The advocacy agency representative serves as a nonvoting member of the review team and shall be present to advocate on behalf of the person. The department shall provide sufficient advance notice of all scheduled review team meetings to the advocacy agency and provide the advocacy agency with any plans for which approval is sought along with any supporting documentation; and

(c) For a child under 18 years of age, with the approval, following a case-by-case review, of a review team composed of a representative from the advocacy agency designated pursuant to Title 5, section 19502, a team leader of the department's children's services division and the children's services medical director or the director's designee. The advocacy agency representative serves as a nonvoting member of the review team and shall be present to advocate on behalf of the person. The department shall provide sufficient advance notice of all scheduled review team meetings to the advocacy agency and provide the

advocacy agency with any plans for which approval is sought along with any supporting documentation. Until rules are adopted by the department to govern behavioral treatment reviews for children, the team may not approve techniques any more aversive or intrusive than are permitted in rules adopted by the Secretary of the United States Department of Health and Human Services regarding treatment of children and youth in nonmedical community-based facilities funded under the Medicaid program.

2. Restraints. A person with an intellectual disability or autism is entitled to the following basic rights and protections. These rights may be waived or limited only in compliance with department rules. The Probate Court may not limit or waive these rights even if a guardian has been appointed.

A person with an intellectual disability or autism is entitled to be free from restraint unless:

- A. The restraint is a short-term step to protect the person from imminent injury to that person or others; or
- B. The restraint has been approved as a behavior management program in accordance with this section.

A restraint may not be used as punishment, for the convenience of the staff or a guardian or as a substitute for habilitative services. A restraint may impose only the least possible restriction consistent with its purpose and must be removed as soon as the threat of imminent injury ends. A restraint may not cause physical injury to the person receiving habilitative services and must be designed to allow the greatest possible comfort and safety.

Daily records of the use of restraints pursuant to paragraph A must be kept, which may be accomplished by meeting reportable event requirements.

Daily records of the use of restraints pursuant to paragraph B must be kept, and a summary of the daily records pertaining to the person must be made available for review by the person's planning team, as defined in section 5461, subsection 8-C, on a schedule determined by the team. The review by the personal planning team may occur no less frequently than quarterly. The summary of the daily records must state the type of restraint used, the duration of the use and the reasons for the use. A monthly summary of all daily records pertaining to all uses of restraints must be relayed to the advocacy agency designated pursuant to Title 5, section 19502.

3. Reimbursement provided. Notwithstanding any other provision of law, the department shall provide reimbursement within available resources for durable medical equipment that provides a safe sleeping environment for persons with intellectual disabilities or autism under 16 years of age if:

- A. The durable medical equipment is necessary to correct or ameliorate a behavioral health condition;

B. The durable medical equipment is the least restrictive alternative for the treatment of the behavioral health condition;

C. The durable medical equipment is approved on a case-by-case basis by a review team composed of the same representatives as the team conducting children's behavioral treatment reviews under subsection 1, paragraph N, subparagraph (5), division (c); and

D. The department determines that the durable medical equipment is cost-effective in comparison to the provision of other covered services or equipment that can sufficiently correct or ameliorate the behavioral health condition.

4. Records. All records of persons with intellectual disabilities or autism receiving services must remain confidential as provided in section 1207.

A. A person with an intellectual disability or autism or, if the person is incompetent, a parent or guardian is entitled to have access to the records upon request.

B. The commissioner is entitled to have access to the records of a provider if necessary to carry out the statutory functions of the commissioner's office.

5. Therapeutic devices or interventions. Therapeutic devices or interventions must be prescriptively designed by a qualified professional and applied with concern for principles of good body alignment and circulation and allowance for change of position.

6. Safety devices and practices. A safety device or practice must be prescribed by a physician. A safety device must be designed and applied with concern for principles of good body alignment and circulation and allowance for change of position.

7. Rules. The department may adopt rules as necessary to implement the provisions of subsections 2 to 6. Rules adopted pursuant to this subsection are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

SUMMARY

This bill addresses several ambiguities with regard to the powers of guardians of persons with intellectual disabilities or autism.

Currently, the Probate Code provides no clear restrictions on how far the court may expand the guardian's powers. This bill resolves the ambiguity by clearly allowing probate courts to continue to use the broad powers granted by the guardianship statute. It also provides a 2nd avenue through which a right may be waived or restricted. This is consistent with the historical role of the probate court in administering guardianships.

This bill also clarifies the rights of persons with intellectual disabilities or autism, as well as provides that, although the Department of Health and Human Services has authority to oversee certain types of behavioral interventions and related actions, that authority may not be used to limit the authority of guardians.