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Office of Aging & Disability Services

Task Force Recommendations on Rules and Procedures Regarding the Rights and Basic Protections of Persons with Acquired Brain Injuries

In response to P.L. 2021, ch. 284

January 2022



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Executive Summary

The 130th Maine Legislature directed the Commissioner of Health and Human Services to convene a task force to develop and make recommendations on rules and procedures regarding the rights and basic protections of persons with acquired brain injuries pursuant to P.L. 2021, ch. 284. The task force included experts in the field of acquired brain injury, providers of services to persons with acquired brain injuries, persons with acquired brain injuries, advocates for persons with acquired brain injuries and representatives of the Acquired Brain Injury Advisory Council established pursuant to 34-B M.R.S. § 19001.

P.L. 2021, ch. 284 directed the task force to recommend rules regarding the rights and basic protections of persons with acquired brain injuries and procedures for the annual instruction for persons receiving brain injury services on their rights. In addition, the task force was tasked with recommending procedures for hearing and resolving grievances and complaints made by persons with acquired brain injuries.

The task force developed its recommendations over the course of five (5) meetings. The task force made the recommendations for consideration as the Department adopts rules to ensure that individuals receiving brain injury services in Maine are informed of their rights using easily understood methods and language. It is important to note that inclusion in this report does not indicate support from the Department for a recommendation.

Introduction

P.L. 2021, ch. 284 (formerly [LD 559](#)) added persons with acquired brain injuries to laws providing rights and basic protections to persons with intellectual disabilities or autism, including laws governing grievance procedures. In addition, it directed the Commissioner of Human Services to convene a task force to develop and make recommendations on rules and procedures regarding the rights and basic protections of persons with acquired brain injuries. It also required the Commissioner to report the findings and recommendations of the task force to the Joint Standing Committee on Health and Human Services.

The task force included experts in the field of acquired brain injury, providers of services to persons with acquired brain injuries, persons with acquired brain injuries, advocates for persons with acquired brain injuries and representatives of the Acquired Brain Injury Advisory Council established pursuant to 34-B M.R.S. § 19001. A list of the membership of the task force is included in the Appendix.

P.L. 2021, ch. 284 directed the task force to recommend:

- Rules regarding the rights and basic protections of persons with acquired brain injuries;
- Procedures for the annual instruction for persons receiving brain injuries services, provider staff and others on the rights and basic protections of persons with acquired brain injuries;
- Procedures for hearing grievances of persons with acquired brain injuries; and
- Procedures for filing and resolution of complaints regarding the brain injury service system for persons with acquired brain injuries.

The task force met five (5) times during the fall of 2021 and created these recommendations on the rights and basic protections of persons with acquired brain injuries. The Department will consider and evaluate the recommendations of the task force in its adoption of rules regarding the rights and basic protections of persons with acquired brain injuries subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

Recommendations

Definitions

The task force recommended that the Department, whenever possible, define the following terms in rule using plain language while maintaining understanding and clarity:

- A. **Acquired Brain Injury** means an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which is not of a degenerative or congenital nature; can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning; can result in the disturbance of behavioral or emotional functioning; can be either temporary or permanent; and can cause partial or total functional disability of psychosocial maladjustment.
- B. **Chemical Restraint** means a psychoactive drug administered for purposes of punishment for certain behaviors or to accommodate the needs of the staff and is not required to treat the Recipient's specific condition.
- C. **Complaint** means a formal expression of dissatisfaction by a Recipient with the provision of services or the performance of an entity in conducting other activities associated with the operation of a service. A complaint can be a written or spoken statement in which a Recipient says that somebody has done something wrong or that something is not satisfactory.
- D. **Grievance** means a formal, Recipient complaint about the way a service provider is furnishing a service or about the conduct of a service administration process. Grievance means an allegation by a Recipient of a violation of basic rights, including those enumerated in this rule.
- E. **Person Centered Planning Process** means an ongoing problem-solving process used to help a person with disabilities plan for their future. In person centered planning, support and rehabilitation team members, the person's friends and family focus on the person and their vision of what they would like to do in the future.
- F. **Positive Behavioral Support** means a set of strategies used to increase quality of life and decrease problem behavior by teaching new skills and making changes in a person's environment.
- G. **Recipient** means an individual with an acquired brain injury who is receiving brain injury services, pursuant to 22 M.R.S. § 3089, at any agency, facility or program licensed, funded and/or under contract with the Department of Health and Human Services in the State of Maine.

Notice of Rights

The task force recommended that the Department include the following language regarding notice of rights in rule:

All Provider agencies, facilities and/or programs, funded in whole or in part by the Department, will inform Recipients of their rights. Recipients of services will be provided these rights both in writing and verbally, in clear, understandable language and form. Complete copies of the rules and regulations must be posted in each agency, facility and/or program.

A. Procedure for Notification and Documentation

The Recipients will be informed of and must be offered a copy of their rights by the agency, facility, or program at the time of admission, intake, transfer or as soon afterwards as is reasonable feasible, and then annually thereafter. This notification must be provided to the Recipient using plain language. In the cases where the Recipient does not understand English or is Deaf or hard of hearing, the notification must be given in an accessible format and/or interpreted for the Recipient. If the Recipient's conditions at admission or intake precludes understanding of their rights, additional attempts to provide information about rights shall occur and be documented.

Recipients shall be advised of their right to name a supported decision maker or representative of choice to assist them to receive notices of meetings and to participate at meetings. Recipients shall additionally be given information regarding available advocacy and peer programs as available.

All provider agencies must document that each Recipient was notified of these Rights in the Recipient's record. Documentation of the results of the discussion about rights shall be noted in the Recipient's permanent treatment record. Documentation required under this Section shall be made available to the Department upon request.

B. Posting of Rights

Copies of these rights shall be posted conspicuously in all agencies, facilities and or programs. Complete copies of these rights and accompanying rules and regulations must be made available upon request.

The following must also be posted alongside these Rights:

1. Contact information for the Department of Health & Human Services, Office of Aging and Disability Services 11 Statehouse Station Augusta, Maine 04333-0011;
2. Contact information for advocacy services available through the protection and advocacy agency designated pursuant to 5 M.R.S. § 19502.
3. Contact information for the Long-Term Care Ombudsman Program established pursuant to 22 M.R.S. § 5107-A; and

4. Contact information for the Americans with Disabilities Act/Civil Rights Office within the Department of Health and Human Services.

C. Provider Training and Documentation Requirements

All provider agencies, facilities and/or programs will train all program staff serving individuals with an acquired brain injury on the application of these Rights in delivering care, support and services to this population on an annual basis. Documentation of the training required under this Section shall be made available to the Department upon request and placed and maintained in each staff person's personnel file. This documentation may be required to be electronic.

Basic Rights of All Recipients

The task force recommended that the Department include the rights listed below in rule. The Department will consider and evaluate these rights in its adoption of rules subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

- A. You have the same human rights and civil rights that apply to all citizens.
- B. You have the right to be treated with courtesy and dignity.
- C. You are at all times entitled to respect for your individuality and recognition that your personality, abilities, needs, and aspirations are not determinable on the basis of disability.
- D. You have the right to dignity of risk, autonomy, and choice
- E. You have the right to be treated with respect, acknowledging diversity of culture, beliefs, gender, sexuality, and lifestyle choices.
- F. You have the right to self-determination in aspirations, goals, and lifestyle.
- G. You have the right to evidence based medical treatment and brain injury rehabilitation.
- H. You have the right to reasonable accommodations to engage in the same life activities as all citizens.
- I. You have the right to be free from abuse, neglect, or exploitation of any kind and to not be subjected to humiliation or corporal punishment.
- J. You have the right to be treated as an individual.
- K. You have the right to vote subject to the rules that apply to all citizens.
- L. You have the right to practice your religion.
- M. You have the right to receive information in a way that is understandable to you.
- N. You have the right to privacy which includes time alone and/or with people you choose to be with without another person monitoring.
- O. You have the right to send and receive mail, phone calls, and other forms or electronic communications without another person interfering, delaying, or monitoring your communication.
- P. You have the right to communication that is equally effective as communication for people without disabilities, including the right to communicate with, receive information from, and convey information to providers of services.
- Q. You have the right to consensual intimate contact and consensual sexual relationships.

- R. You have the right to access information and receive guidance on sexual expression and contraceptive services.
- S. You have the right to be free from discrimination because of your race, gender, sexual orientation, nationality, religion, age, or because you have a disability.
- T. You have the right to assert your rights without someone retaliating against you or punishing you in response.
- U. You have the right to advocacy and representation to assist you in the protection of your rights.
- V. You have the right to confidentiality regarding your personal support needs, rehabilitation, and medical information.
- W. You have a right to access copies of your care, rehabilitation, and medical records. (Title II of the Americans with Disabilities Act prohibits discrimination against qualified individuals with disabilities in the services, programs, and activities of public entities, 42 U.S.C. § 12132; 28 C.F.R § 35.130.)
- X. In order to benefit from the service, benefit, or program the individual has the right to a reasonable accommodation or modification of policies, practices or procedures, unless the accommodation or modification would fundamentally alter the nature of the service or program, or pose an undue burden.

Rights Related to Participation in Support and Treatment

The task force recommended that the Department include the rights related to participation in support and treatment listed below in rule. The Department will consider and evaluate these rights in its adoption of rules subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

- A. You have the right to a comprehensive array of medically eligible services to meet your assessed needs within the limits of available resources.
- B. You have the right to maintain your natural support systems, such as family and friends including with, individual, formal and informal networks of people who were involved in supporting you over time.
- C. You have the right to receive individualized support and treatment in the least restrictive environment and to understand the risks and benefits of that support and treatment.
- D. You have the right to have an individual service plan that is developed using a person-centered planning process.
- E. You have the right to have your individual service plan be understandable to you and to those individuals who support you. Services delivered to you shall be based on your identified individual needs. The plan must be written in plain language and in a manner that responds to your disabilities and/or any language limitations.
- F. You have the right to have access to supports to develop your skills and abilities and to receive services in a way that accommodates changes in your needs and the variations in the intensity of your needs in a culturally sensitive manner and the right to refuse all or some of the services offered.
- G. You have the right to include people you choose to help develop your individual service plan and coordination of all components of the service system.
- H. You have the right to participate whenever your individual service plan is reviewed and updated.

- I. You have the right at any time to request that your individual service plan be reviewed and updated.
- J. You have the right to receive services that are based on your individual needs when those services are available (limited only by state laws/rules and/or admissions, eligibility, policies and standards of the service provider).
- K. You have the right to refuse the services offered to you and be informed of the risks and benefits of refusing that service.
- L. You have the right to positive behavioral supports to assist you in overcoming any behavioral challenges. Those challenges and the positive approaches are outlined in your individual service plan.
- M. You have the right to trained and educated service providers who understand how a brain injury may affect your response and functioning and will adapt treatment and support approaches to your individualized needs.
- N. You have the right to be free from behavioral treatments that include coercion, punishment, segregation, seclusion, negative reinforcement, and delayed access to basic needs. Interventions and supports will cause no harm to the individual (for example, being told “when you must get dressed for or what you may have for breakfast”).
- O. You have the right to be free from chemical restraints as defined in this Section.

Rights Related to Community Residential Services

The task force recommended that the Department include the rights related to community residential services listed below in rule. The Department will consider and evaluate these rights in its adoption of rules subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

- A. You have the right to the greatest degree of independence possible.
- B. You have the right to live in a community of your choice.
- C. You have the right to assemble a resident group and as a group provide input on menus, activities, and daily schedules,
- D. You have the right to have visitors and to withdraw someone's permission to visit you.
- E. You have the right to food and drink that is readily accessible.
- F. You have the right to independence in the performance of hygiene and grooming.
- G. You have the right to use and keep personal property if using and keeping the personal property aligns with the goals of your service plan, the requirements of your agreement, and the Department’s licensing requirements.
- H. You have the right to personal space and privacy, including a bedroom with a door that locks from the inside of the room.
- I. You have the right to manage your own personal financial affairs unless you are found to need help through guardianship, conservatorship, or other court order.
- J. You have the right to the opportunity for physical exercise and recreation, including access to the outdoors.
- K. You have the right to information and materials of community activities and to be involved in those community activities, including who facilitates your access to the community.

Rights Related to Employment

The task force recommended that the Department include the rights related to employment listed below in rule. The Department will consider and evaluate these rights in its adoption of rules subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

- A. You do not have to inform an employer of your disability when you apply for a job or when you are hired, even if later you need a reasonable accommodation.
- B. If you are employed, you have the right to competitive integrated employment and to work at a job that pays you at least minimum wage, in a place that has people with and without disabilities working together, and provides opportunities for advancement.
- C. You have the right to ask for and receive reasonable accommodations that allow you to have an equal chance to succeed.
- D. If you meet your job's requirements, your employer cannot refuse to hire or promote you; fire or demote you; harass you; or pay you less because of your disability.
- E. You have the right to services even if you choose to not be employed pursuant to 26 M.R.S. § 3403(4).

Due Process

The task force recommended that the Department include the rights related to due process listed below in rule. The Department will consider and evaluate these rights in its adoption of rules subject to the formal rulemaking process required by the Maine Administrative Procedure Act, 5 M.R.S. §§ 8001-11008.

A. Due Process Rights of Recipients

- 1. You have the right to file a grievance or complaint against the Department and providers.
- 2. Your rights cannot be waived or restricted if you are under court ordered guardianship.
- 3. You have the right to raise objections to decisions made about your care through complaints and appeals.
- 4. You have the right to ongoing education and guidance on your rights and how to exercise your rights.
- 5. You have the right to ask your case manager, a family member, or friend to help you make a complaint or raise a concern and then to have those complaints or concerns addressed.
- 6. You have the right to appeal decisions made about your Medicaid funded services by provider organizations or the Department through direct appeal to the Office of MaineCare Services.
- 7. You have the right to contact any advocacy service and request assistance in advocating for your rights including the state protection and advocacy agency, the Long-Term Care Ombudsman, the Department's ADA/Civil Rights office or legal services providers.

8. You have the right to report any violation of your rights to the Department without fear of reprisal.

B. Provider Responsibilities Related to Due Process

1. Program providers will have a complaint resolution process and a grievance process in place that is approved by the Department.
2. Program providers will give every opportunity for resolution of concerns, grievances, or complaints.
3. Each provider will provide training to all staff to ensure understanding and prompt response by all staff to its complaint resolution process and grievance process.
4. All complaints, grievances and resolutions will be documented and summary data provided to the Department upon request.

Appendix

Task Force Member List

*These individuals are also representatives on the Maine Acquired Brain Injury Advisory Committee

Expert in the Field of Acquired Brain Injury

Cara Orton, Psy.D., Clinical Psychologist Specialist

Providers of Services for Individuals with Acquired Brain Injury

Sharlene Adams, GT Independence*

Survivors of Acquired Brain Injury

Anthony Barresi*

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Advocates for Individuals with Acquired Brain Injury

Sarah Gaffney, Brain Injury Association of America, Maine Chapter*

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Peter Rice, Disability Rights Maine*

Representative of the Maine Acquired Brain Injury Advisory Council

Gary Wolcott*