2021 ABIAC Officers and Members – appointed by Commissioner of the Department of Health & Human Services

PROVIDERS
Scott Mayo, Co-Chair, Deer Isle
Matthew Hickey, Secretary, Yarmouth
Sharlene Adams, Manchester
Austin Er rico, Ph.D., Freeport
Jen Jello, West Ossipee N.H.

FAMILIES
Lewis Lamont, Mapleton
Suzanne Morneault, Eagle Lake
Ed Russell, Winterport
Gary Wolcott, Chesterville
Annmarie Albiston, Carrabassett Valley

ADVOCATE
Sarah Gaffney, Vassalboro
Catherine Slye, Augusta
Courtney Michalec, Brunswick
Trish Thorsen, Greene
Lee Glynn, Co-Chair, Skowhegan

SURVIVOR
Nitzana Aufiero, Newport
Ted Brackett, Westbrook
Anthony Barresi, Presque Isle

STATE LIASONS
Derek Fales, OADS Liaison
Jessica Gartland, Vocational Rehabilitation
Aaron Burke, Maine CDC Injury Prevention
Emily Poland, Maine DOE
Theresa Barrows, OCFS

PURPOSE & OVERVIEW

Every 9 seconds, someone in the United States sustains a brain injury.

An acquired brain injury (ABI) is a brain injury that occurs after birth and is not hereditary, congenital, degenerative, or induced by birth trauma. ABI is the umbrella term for all brain injuries, including traumatic and non-traumatic injuries (e.g., strokes, brain tumors, anoxic injuries). ABIs can affect every aspect of an individual’s being: physical, emotional, and cognitive impacts are common. More than 3.6 million children and adults sustain an ABI each year, but the total incidence is unknown (BIAA). It is estimated that 10,000 Mainers experience a brain injury every year.

ABIAC RESPONSIBILITIES AND HISTORY

• Formed in 2002 to support a federal grant
• Established in Statute in 2007 to provide oversight and advice to DHHS & Legislature
• Meets at least four times/year and holds at least two public hearings annually. Over the past 15 years, the ABIAC has held more than 50 public hearings throughout the state.
• Over the past 15 years, the ABIAC has served as the mandated Advisory Board for four Federal Traumatic Brain Injury (TBI) Partnership grants to improve the Maine’s system of care for persons living
with brain injuries and their families. As part of those grants, the Council has sponsored more than a
dozen statewide forums on critical issues and partnered with multiple provider organizations to provide
training for hundreds of professionals and paraprofessionals.

- In 2021 the Council met ten times and held two public hearings.

CURRENT SERVICE SYSTEMS

Operated by provider organizations under contract with Maine DHHS or Maine DOL.

Medicaid Funding:

Specialized Nursing Care (Section 67)
2 Specialized Skilled Nursing/Rehabilitation Facilities with 44 licensed specialized beds for persons with ABI

Brain Injury Home and Community Waiver – Section 18 MaineCare Benefits
202 Section 18 recipients, 48 Section 18 funded offers, 155 on Section 18 waitlist
37 Maine residents placed out-of-state due to lack of services. The current rates for skilled neurorehabilitation in
an “Out of State nursing facility” are up to $425 dollars per day. The current rate for community based
neurobehavioral treatment can start at around $750 per day and the rate for intensive neurobehavioral
treatment also in combination with complex medical needs can be up to $2,000 per day. (The 2021 rate for Level
3 neurobehavioral services in Maine was $489 per day).

Comparative Costs: In State versus Out of State

<table>
<thead>
<tr>
<th>In State Level 1</th>
<th>Out of State Nursing</th>
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<tbody>
<tr>
<td>$9.49 per hour</td>
<td>Up to $425 per day</td>
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<table>
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<tr>
<th>In State Level 2</th>
<th>Out of State Neurobehavioral</th>
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<tr>
<td>$301.39 per day</td>
<td>$750+ per day</td>
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<table>
<thead>
<tr>
<th>In State Level 3</th>
<th>Out of State Intensive Neurobehavioral/Complex Medical</th>
</tr>
</thead>
<tbody>
<tr>
<td>$489.61 per day</td>
<td>$2000 per day</td>
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Excludes related costs like air ambulance transport.
To help stabilize the workforce and improve an HCBS system that has been strained by the COVID-19 pandemic, effective retroactively to January 1, 2021, the Department will temporarily increase rates for certain Home Support Services (T2016) under Section 18 (Home and Community-Based Services for Adults with Brain Injury).

These changes are made pursuant to P.L. 2019, ch. 616, Part A, Sec. A-7, An Act Making Supplemental Appropriations and Allocations for the Expenditures of State Government, General Fund and Other Funds and Changing Certain Provisions of the Law Necessary to the Proper Operations of State Government for the Fiscal Years Ending June 30, 2020 and June 30, 2021, and have been approved by the federal Centers for Medicare & Medicaid Services (CMS) in Maine’s amended 1915(c) HCBS waivers with the Emergency Preparedness and Response Appendix Ks.

3 Providers of care coordination services with 201 individuals served in 2021
35 Community residential programs with 153 beds
2 In-home support programs
16 Section 18 recipients are receiving attendant care services, a new service offered in 2021.

**Comparative Landscape for Maine ABI Services**

<table>
<thead>
<tr>
<th>Time in Years</th>
<th>Number of Persons with ABI</th>
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<tbody>
<tr>
<td>2020</td>
<td>100</td>
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<tr>
<td>2021</td>
<td>155</td>
</tr>
<tr>
<td>2020</td>
<td>26</td>
</tr>
<tr>
<td>2021</td>
<td>37</td>
</tr>
</tbody>
</table>

**BI Outpatient Services**
8 Outpatient neurorehabilitation clinics served 464 individuals in 2021 with MaineCare funding, more individuals were served with a different payer.
1 Work-ordered day club house, serving 28. However, the club house was initially closed in 2021 due to the Governor’s indoor gathering limits, and remained temporarily closed due to workforce shortages.

**Vocational Rehabilitation Funding**
2 Vocational Rehabilitation providers served 202 individuals in 2021.
DHHS Contract Funding with the Brain Injury Association of America - Maine Chapter Providing Core State Brain Injury Supports (CSBIS) for vulnerable populations.

- Neuro-Resource Facilitation to ensure access to brain injury services in Maine for high-risk individuals and support for families
- Information & Resource services to assist at-risk individuals and their families to navigate the brain injury system of care, including access to joint state and national HELPLINE.
- **1758** Neuro-Resource Facilitation and Information & Resource communications in 2021
- Outreach to newly injured/diagnosed persons with ABI
- Education and training, including the annual state brain injury conference, a Maine brain injury resource fair, a Maine-based resource directory, and family caregiver training
- Support and education for hospitals and agencies working with at-risk ABI populations
- Support for **17** Support Groups for survivors and families that engaged more than **2000** participants in 2021

### CURRENT ACL FEDERAL PARTNERSHIP GRANT

In 2021, the Office of Aging & Disability Services (OADS) wrapped up a 2-year Federal TBI Partnership Grant through the Administration for Community Living (ACL) focused on addressing the intersection of the opioid crisis and brain injury. Accomplishments included webinars; a forum connecting the mental health, substance use disorder, and brain injury communities; and a statewide brain injury needs assessment. Additionally, in 2021, OADS received a new 5-year TBI Partnership Grant through the ACL. The focus of this new grant is to strengthen systems and services of support for Maine’s underserved brain injury populations.
ABIAC PRIORITIES FOR 2021 and OUTCOMES

- Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to ensure humane, cost-effective, evidenced-based treatment in Maine. Explore collaboration with New Hampshire and Vermont on development of mobile neurobehavioral team for assessment, treatment, and consultation for individuals served by community agencies. **Outcome - The ABIAC has created a subcommittee on policy and legislative initiatives. Committee members will provide recommendations for the full ABIAC to consider, review, and present to DHHS.**

- Advocate for a state law clearly describing the Rights of Service Recipients with ABI. **Outcome - LD 559 became law in 2021: An Act to Improve the Rights and Basic Protections of Persons with Acquired Brain Injury. The ABIAC had advocated for this action for more than a decade, and the ABIAC participated on the task force to develop recommendations on rules and procedures regarding the rights and basic protections of persons with acquired brain injury.**

- Advocate for ongoing coordination and funding for services to address the confluence of persons with substance use disorder and a brain injury. Support efforts to increase awareness, professional education, and treatment coordination. Advocate for MaineCare rule changes and funding for Substance Abuse Counseling as a billable service in the Neurorehabilitation Clinics in Section 102. **Outcome – The ABIAC supported the efforts of the recently completed Federal TBI Partnership Grant, which focused on the intersection of brain injury and substance use disorder. Next steps include finding a pathway to opening the Section 102 rules so Substance Abuse Counseling can once again be a billable service provided in the Section 102 Neurorehabilitation clinics.**

- Improve access and impact of Assistive Technologies/Telehealth for service recipients and providers through advocacy for DHHS rule changes that provide greater flexibility. Such changes can cause more efficient and effective use of funds and personnel to support service recipients. **Outcome - The ABIAC has created a subcommittee on policy and legislative initiatives. This sub-committee will participate in a work group that will provide assistance and advise DHHS regarding assistive technology policy.**

- Support the creation of an ABI trust fund to help Maine children and adults with ABI who lack financial resources/eligibility for timely, effective treatment. **Outcome- The brain injury trust fund subcommittee has demonstrated that there is a need in Maine for a funding source to support survivors through flexible, financial grants to obtain equipment and resources that may be beyond their means. The ABIAC has advocated for the formation of a group of individuals who will form a 501(c)(3) charitable trust to administer and assist the fund and to conduct fund raising on its behalf. The goal is to fund an initial round of modest grants in the spring of 2023.**

- Improve understanding and coordination of services for children with ABI through regular participation of a representative of OCFS on the ABIAC. **Outcome – In 2021, the ABIAC welcomed a representative from OCFS who is regularly participating in ABIAC meetings and activities.**

- Improve the effectiveness of the ABIAC through providing advanced, formal, quarterly status reports describing critical indicators of brain injury services from OADS, MaineCare, Maine CDC, and OCFS. **The ABIAC has created a subcommittee for efficacy and data collection. Committee members will provide recommendations for the full ABIAC to review, consider, and present to appropriate State of Maine departments.**
• Provide guidance to the ACL Partnership grant efforts including the statewide needs assessment to be conducted in 2021. **Outcome – Several members of the ABIAC participated as members of the steering committee for the statewide brain injury needs assessment conducted by OADS in 2021. In addition, several members provided testimony and interviews during the needs assessment, and the ABIAC helped distribute the provider and survivor/caregiver surveys to the Maine brain injury community.**

**ABIAC PRIORITIES FOR 2022**

• Advocate for development and funding of Neurobehavioral Treatment Services (24/7 care) to ensure humane, cost-effective, evidenced-based treatment in Maine. Explore collaboration with New Hampshire and Vermont on development of mobile neurobehavioral team for assessment, treatment, and consultation for individuals served by community agencies.
• Advocate for ongoing coordination and funding for services to address the confluence of persons with substance use disorder and a brain injury. Support efforts to increase awareness, professional education, and treatment coordination. Advocate for MaineCare rule changes and funding for Substance Abuse Counseling as a billable service in the Neurorehabilitation Clinics in Section 102.
• Improve the effectiveness of the ABIAC by acquiring from OADS, MaineCare, Maine CDC, and OCFS advanced formal quarterly status reports describing critical indicators of brain injury services.
• Revise by-laws, remote meeting procedures, and new member orientation and development.
• Through the needs and awareness subcommittee of the ABIAC, identify transportation barriers and make recommendations for improvements to DHHS.
• Participate in the Rights of Service Recipients with ABI task force.
• Improve access and impact of Assistive Technologies/Telehealth for service recipients and providers through advocacy for DHHS rule changes and practices that provide greater flexibility.
• Advocate/support legislation related to Stroke Response care in Maine.
• Advocate for plan and program design to increase member awareness of MaineCare benefits.
• Support Brain Injury prevention strategies and campaigns. Make recommendations to DHHS.

**REPORT SUMMARY**

The COVID-19 pandemic has greatly impacted Maine’s brain injury community: increased isolation and anxiety, difficulty accessing services, and the day-to-day obstacles of living through a global pandemic have been extremely challenging. The ABIAC commends the outstanding efforts of Maine’s brain injury providers, healthcare workers, advocates, and State service providers in their efforts to support and protect Maine’s brain injury survivors and their families during the ongoing pandemic.

Brain Injury is a significant, on-going public health issue that affects all communities in Maine. More than 10,000 Mainers will experience a brain injury in 2022. Falls, motor vehicle crashes, sports-related concussions, violence, combat-related injuries, opioid overdoses, strokes, brain tumors, infections, and other causes can result in ABIs. The Council is also concerned about brain injuries caused by emerging infectious diseases, including COVID-19, and the resultant impact on Maine citizens. ABIs are often accompanied by significant, long-term cognitive, emotional, behavioral, and physical changes that alter the lives of brain injury survivors and their families. In addition, brain injury survivors are at increased risk of experiencing social, mental health, and substance use disorder challenges.

The Federal Centers for Disease Control and Prevention (CDC) reports that traumatic brain injury (TBI) alone is the leading cause of death and disability in children and young adults in the United States. Overall, the number of persons currently living with disability due to acquired brain injury represents
4.5% of the U.S population (including stroke, TBI, and epilepsy combined). Many will make meaningful recoveries, especially if they get the needed rehabilitative care. Up to 15% of those who experience a brain injury will live with very difficult, life-altering disabilities. Immediate access to specialized neurorehabilitation treatment (including information and care coordination) is crucial for positive outcomes. Unfortunately, public and private health insurance continues to impose limits for rehabilitative care based solely on financial costs rather than based on functional goals or treatment outcomes.

Sometimes, the system of community care ends prematurely for individuals, condemning them to costly nursing homes or institutions and cutting off options for the person to return home and to a productive life. History shows that these individuals can live successfully outside of institutions when treatment and supports are available. In addition, some individuals appear physically uninjured, but have significant cognitive and behavioral disabilities, and struggle to access services and support.

Year after year, testimony in ABIAC public hearings in Maine has demonstrated that individuals continue to experience avoidable challenges related to their brain injuries. Their injuries are often dismissed or misdiagnosed, leading to the provision of ineffective treatment which creates a significant misdirection of valuable resources. Even worse are those who are turned away with no treatment at all.

Public hearing testimony and the recent needs assessment has also emphasized the need for greater geographic access to services, education for professionals, addressing workforce shortages, waitlist for services, expanded care coordination services, increased public awareness for prevention, increased family and peer supports, access to employment opportunities, improved children’s services, and addressing the complex needs of individuals with challenging behaviors.

The past year revealed alarming trends related to need and resources. The wait list for home and community-based services (MaineCare Section 18 waiver) increased 55% (from 100 in 2020 to 155 in 2021) and out-of-state placements due to lack of services climbed 42% (from 26 members in 2020 to 37 in 2021). In 2021, two home and community based group homes closed and two temporarily closed. By contrast, resource facilitation communications through the Brain Injury Association of America Maine Chapter more than doubled from the previous year.

The system in Maine must be about improving timely access to the right services and supports, thus creating efficiencies that allow our tax dollars to be used effectively. Effective utilization of resources includes evidence-based treatment approaches and a focus on positive behavioral supports to enhance the outcomes for the individual. By proper use of the tax dollars for treatment of individuals with brain injury, we also lower the burden on other support and service systems such as schools, hospitals, behavioral health services, and the criminal justice system.

**THE LEWIS AND CLARA LAMONT ADVOCACY AWARD**

In 2010 the ABIAC presented an Advocacy Award to Lewis and Clara Lamont for their amazing work with the Brain Injury Association of America’s Maine Chapter as well as their strong advocacy for individuals impacted by brain injury. The award is presented every year in their name to someone who has positively influenced the brain injury community.
Past Recipients:

2011-Dr. Berkner, Dr. Atkins, Dr. Heinz- Maine Concussion Management Initiative

2012-Beverly Bryant-Author and Advocate

2013-Marcia Cooper-Acquired Brain Injury Advisory Council and Brain Injury Information Network

2014-Kirsten Capeless-Brain Injury Services Manager DHHS

2015-Sarah Gaffney-Brain Injury Association of America-Maine Chapter

2016-Richard Brown-Family Member and Advocate

2017-Suzanne and Mindy Morneault- All Things Become New-Founder

2018-Gary Wolcott-Former State Service Leader, Family Member and Advocate

2019-Kelley Spencer-Maine A.T. Solutions

2020-Representative Allison Hepler

STATUTORY REQUIREMENTS

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES
Chapter 19: ADVISORY COUNCILS
§19001. Acquired Brain Injury Advisory Council

1. Council established. The Acquired Brain Injury Advisory Council, referred to in this section as "the council," is established to provide independent oversight and advice and to make recommendations to the commissioner. [PL 2011, c. 657, Pt. CC, §4 (AMD).]

2. Duties. The council shall:
   A. Identify issues related to brain injury, including prevention and the needs of individuals with disabilities due to brain injuries and the needs of their families; [PL 2007, c. 239, §2 (NEW).]
   B. Recommend methods that will enhance health and well-being, promote independence and self-sufficiency, protect and care for those at risk and provide effective and efficient methods of prevention, service and support; [PL 2007, c. 239, §2 (NEW).]
   C. Seek information from the broadest range of stakeholders, including persons with brain injuries, their families, rehabilitation experts, providers of services and the public, and hold at least 2 public hearings annually, in different regions of the State, to generate input on unmet needs; [PL 2007, c. 239, §2 (NEW).]
   D. Review the status and effectiveness of the array of brain injury programs, services and prevention efforts provided in this State and recommend to the commissioner priorities and criteria for disbursement of available appropriations; and [PL 2007, c. 239, §2 (NEW).]
   E. Meet at least 4 times per year and by January 15th of each year submit a report of its activities and recommendations to the commissioner and to the Legislature. [PL 2007, c. 239, §2 (NEW).]

3. Administrative support. The department shall provide administrative support to the council. [PL 2011, c. 657, Pt. CC, §4 (AMD).]
4. **Membership.** The commissioner shall appoint 25 persons to serve as members of the council and shall annually appoint one person to serve as chair. Members serve 2-year terms. Members must represent the following persons and interests:

A. Five members with acquired brain injuries must represent persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

B. Five members must represent families of persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

C. Two members must represent advocates for persons with acquired brain injuries; [PL 2007, c. 239, §2 (NEW).]

D. Five members must represent providers of services to persons with acquired brain injuries; [PL 2019, c. 566, §1 (AMD).]

E. Five members must represent state agencies with expertise in the areas of education, employment, prevention of brain injuries, homelessness, corrections and services to veterans. Members of the council who represent state agencies serve ex officio, without the right to vote, and shall provide data, information and expertise to the council; [PL 2019, c. 566, §1 (AMD).]

F. One member must represent an aging and disability resource center; [PL 2019, c. 566, §1 (NEW).]

G. One member must represent a center for independent living; and [PL 2019, c. 566, §1 (NEW).]

H. One member must be the long-term care ombudsman under Title 22, section 5107 A or a representative of the long-term care ombudsman. [PL 2019, c. 566, §1 (NEW).]

5. **Expenses.** Members of the council serve without compensation but are entitled to reimbursement of reasonable expenses for attending meetings of and serving on the council.

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**Title 22: HEALTH AND WELFARE**  
**Subtitle 2: HEALTH**  
**Part 7: PUBLIC REHABILITATION SERVICES**  
**Chapter 715-A: ASSISTANCE FOR SURVIVORS OF ACQUIRED BRAIN INJURY**

§3087

§3086. **Definitions**

As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings. [PL 1987, c. 494 (NEW).]

1. **Acquired brain injury.** "Acquired brain injury" means an insult to the brain resulting directly or indirectly from trauma, anoxia, vascular lesions or infection, which:

A. Is not of a degenerative or congenital nature; [PL 1989, c. 501, Pt. P, §26 (NEW).]

B. Can produce a diminished or altered state of consciousness resulting in impairment of cognitive abilities or physical functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]

C. Can result in the disturbance of behavioral or emotional functioning; [PL 1989, c. 501, Pt. P, §26 (NEW).]

D. Can be either temporary or permanent; and [PL 1989, c. 501, Pt. P, §26 (NEW).]

E. Can cause partial or total functional disability or psychosocial maladjustment. [PL 1989, c. 501, Pt. P, §26 (NEW).]

§3088. **Comprehensive neurorehabilitation service system**

The department shall, within the limits of its available resources, develop a comprehensive neurorehabilitation service system designed to assist, educate and rehabilitate the person with an acquired brain injury to attain and sustain the highest function and self-sufficiency possible using home-based and community-based treatments, services and resources to the greatest possible degree. The comprehensive neurorehabilitation service system must include, but is not limited to, care management and coordination, crisis stabilization services, physical
therapy, occupational therapy, speech therapy, neuropsychology, neurocognitive retraining, positive neurobehavioral supports and teaching, social skills retraining, counseling, vocational rehabilitation and independent living skills and supports. The comprehensive neurorehabilitation service system may include a posthospital system of nursing, community residential facilities and community residential support programs designed to meet the needs of persons who have sustained an acquired brain injury and assist in the reintegration of those persons into their communities. [PL 2011, c. 293, §3 (RPR).]

SECTION HISTORY

§3088-A. Support for underserved populations
Within the limits of its available resources, the department may enter into contracts with organizations representing individuals with a brain injury and their families, bringing together state and national expertise to provide core brain injury support for underserved populations of individuals with an acquired brain injury, including, but not limited to, individuals who experienced an opioid drug overdose resulting in anoxic or hypoxic brain injury, who are veterans, who are victims of domestic violence, who are experiencing homelessness, who are ineligible for MaineCare and who have a newly acquired brain injury. For the purposes of this section, "core brain injury support" includes, but is not limited to, resource facilitation, brain injury support groups, outreach designed for individuals who have a newly acquired brain injury, access to a joint state and national helpline, information and resource education and family caregiver training. The department may adopt rules to implement this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2 A. [PL 2019, c. 488, §1 (NEW).]

SECTION HISTORY
PL 2019, c. 488, §1 (NEW).

§3089. Acquired brain injury assessments and interventions; protection of rights
The department is designated as the official state agency responsible for acquired brain injury services and programs. [PL 2005, c. 229, §1 (NEW).]

1. Assessments and interventions. In addition to developing the comprehensive neurorehabilitation service system under section 3088, the department may undertake, within the limits of available resources, appropriate identification and medical and rehabilitative interventions for persons who sustain acquired brain injuries, including, but not limited to, establishing services:

A. To assess the needs of persons who sustain acquired brain injuries and to facilitate effective and efficient medical care, neurorehabilitation planning and reintegration; and [PL 2011, c. 293, §4 (NEW).]
B. To improve the knowledge and skills of the medical community, including, but not limited to, emergency room physicians, psychiatrists, neurologists, neurosurgeons, neuropsychologists and other professionals who diagnose, evaluate and treat acquired brain injuries. [PL 2011, c. 293, §4 (NEW).]

2. Rights of patients and responsibility of department to protect those rights. To the extent possible within the limits of available resources and except to the extent that a patient with an acquired brain injury's rights have been suspended as the result of court-ordered guardianship, the department shall:

A. Protect the health and safety of that patient; [PL 2011, c. 293, §4 (NEW).]
B. Ensure that the patient has access to treatment, individualized planning and services and positive behavioral interventions and protections; and [PL 2011, c. 293, §4 (NEW).]
C. Protect the patient's rights to appeal decisions regarding the person's treatment, access to advocacy services and service quality control standards, monitoring and reporting. [PL 2011, c. 293, §4 (NEW).]
3. **Rules.** The department shall establish rules under this section. Rules adopted pursuant to this section are routine technical rules as defined in Title 5, chapter 375, subchapter 2-A.

[PL 2011, c. 293, §4 (NEW).]

SECTION HISTORY