The Honorable Representative Patricia A. Serpa
Chair of the House Oversight Committee
82 Smith Street
Providence, RI 02903

March 30, 2021

Re: Eleanor Slater Hospital

Dear Chairwoman Serpa and Members of the Committee:

Thank you for holding this special hearing. And thank you for the opportunity to express our concerns about the proposal to close the civil commitment facilities at Eleanor Slater Hospital (ESH). ESH is an important and necessary part of Rhode Island's continuum of care for patients with disabilities. The Mental Health Association of Rhode Island (MHARI) is particularly troubled by the recent reports that patients are being discharged against the advice of their treating physicians. We must ensure the safety of these patients. **First and foremost, we respectfully request a moratorium on disputed discharges.**

Just as mental health and serious persistent mental illness fall on the opposite ends of a spectrum, the phrase "continuum of care" describes the full range of settings and services from the outpatient level to the inpatient level and everything in between. People with disabilities often "step up" and "step down" to settings and services across the spectrum as their condition improves or worsens over a lifespan. ESH is considered a "placement of last resort" for patients with complicated co-occurring behavioral health and medical disabilities. It falls on the farthest end of the "continuum of care" and is the most restrictive. The fact that it is so restrictive does not make it an illegitimate option for the patients who need the most intensive level of care.
We appreciate the State's intention to discharge patients to less restrictive settings. However, Rhode Island currently lacks a suitable alternative to ESH, and patients in

ESH have nowhere else to go. Many of them have already tried and failed at lower levels of care like nursing homes and assisted living facilities. Even a nursing home with behavioral health “enhancements” would not meet the needs of many of these vulnerable patients. Deinstitutionalization works only when there is an appropriate alternative.[1] Discharging patients in ESH’s civil commitment facilities puts them at risk of homelessness and incarceration. In essence, they trade the institution of a hospital setting for a prison setting.

It must also be noted that in the *Olmstead v. L.C.* ruling, the United States Supreme Court held that individuals have the right to receive treatment in the least restrictive placement available when:

1. Such services are appropriate
2. **The affected persons do not oppose community-based treatment** and
3. Community based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs or others who are receiving disability services from the public entity.

Therefore, patients and their guardians who feel that community-based treatment is not appropriate for their loved one should be allowed to remain in ESH.

We also appreciate the State’s desire to cut costs, but rather than gutting our already inadequate “continuum of care,” we respectfully encourage the State to establish a "living" Olmstead Plan to (1) assess current and future supply and demand (2) coordinate and (3) fund the full continuum of care for Rhode Islanders with disabilities. We have to spend money to save money. Without permanent supportive housing and services, people with disabilities cycle in and out of emergency departments, hospitals, shelters and prison. **Doing nothing is not free.**

With creativity and the will to succeed, we can fund the full “continuum of care” in Rhode Island. For example, we can follow suit with Massachusetts and strategically utilize the Affordable Care Act’s “community benefit” provision by requiring nonprofit hospitals to fund supportive housing for people with disabilities. We can use federal relief dollars to support ESH’s renovations and other gaps in our continuum of care. Lastly, if the proposed merger between Lifespan and Care New England is approved, we can explore the possibility of requiring funding for Rhode Island’s continuum of care as a precondition of the merger.

[1] https://www.pbs.org/wgbh/pages/frontline/shows/asylums/special/excerpt.html

In addition to the moratorium on discharges, we respectfully request that the General Assembly:

- Form a permanent Joint Legislative Commission on Rhode Island's Continuum of Care
- Work with community advocates to create a transparent patient evaluation process at Eleanor Slater Hospital (ESH)
- Cease discharging ESH patients against the advice of their physicians or wishes of their legal guardians
- Increase transparency, due process and accountability in ESH's appeal process

The State must ensure that a hospital-like setting continues to exist now and for future generations of patients who will come to need it.

Attached to this letter is a proposal for Eleanor Slater Hospital authored by MHARI in collaboration with other community advocates. We hope to partner with the State to find solutions to this crisis. We are at your service and ready to roll up our sleeves and get to work. I look forward to hearing about next steps.

Thank you for your consideration.

Respectfully submitted,

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Policy Proposal
for the
Reorganization of Eleanor Slater Hospital

Submission Date: March 15, 2021

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Background: Per direction from the Raimondo Administration, the Department of Behavioral Health, Developmental Disabilities, and Hospitals (BHDDH) is proposing to reorganize Eleanor Slater Hospital, including closing its civil psychiatric facilities (Adloph Meyer and Regan Buildings). BHDDH's proposal includes plans to move patients currently residing at ESH with co-occurring serious and persistent mental illness (SPMI) and complicated medical conditions and/or developmental disabilities into nursing homes, assisted living facilities, or the proposed

re-purposed Zambarano facility. We applaud the State's initiative to discharge patients who could have a better quality of life in the community. This is an important step toward achieving the civil rights afforded by the Americans with Disabilities Act (ADA), which requires that states help people with disabilities live in the least restrictive setting permitted by their disabilities. It should also be noted that the U.S. Supreme Court stipulated in the Olmstead decision that the "least restrictive setting" is appropriate if:

1. Such services are **appropriate**
2. The affected persons do not **oppose** community-based treatment and
3. Community based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs or others who are receiving disability services from the public entity.

BHDDH's proposal estimates that closing the Regan and Adolph Meyer facilities and relicensing the Zambarano Unit to become a "step down receiving facility" would save Rhode Island $62,000,000 in FY 2022 and ultimately a total of $788,000,000 over the next ten years.

We recognize the State's need to cut costs, but we believe this proposal to reorganize ESH will not accomplish that objective. Closing the civil psychiatric facility at ESH will cost more in the end. There are and will always be a number of patients who have complicated co-occurring behavioral health and medical conditions that necessitate living in a hospital-like setting. In recent history, the State has not invested in or maintained the full continuum of care for Rhode Islanders, including a hospital-like "placement of last resort" like ESH, residential treatment facilities, psychiatric nursing homes, and all the other less restrictive levels of care. Patients who are inappropriately discharged will ultimately "fail" and be forced to leave lower levels of care, utilize emergency department services and inpatient hospitalization, and be at risk for homelessness and incarceration. Doing nothing is not free; it is usually more expensive.

History

Up until 1991, Rhode Island had one of the best mental healthcare systems in the country. It was publicly funded with a statutory scheme at its foundation. In the 1990's, Rhode Island's leadership shut down ESH to long term admissions, which created a bottleneck of long term patients lingering in acute care beds. As public money got tighter, MHRH (that is, BHDDH of today) terminated all emergency admissions and resisted the transfer of inmates with mental illness. These actions resulted in bringing MHRH closer to its budget targets, but at a heavy cost. It shifted the burden of long term care onto acute care facilities. It shifted the burden of emergency care onto hospital emergency departments. It shifted the care of prisoners with mental illness onto the prison. Staying within the dwindling budget that was afforded to BHDDH was placed at a premium, and the coordinated continuum of care suffered. Tens of millions of private sector funds (supported by insurance premiums) have been spent to cobble together a disjointed system with gaping holes.

Currently, Rhode Island does not have a stand-alone state psychiatric hospital. Instead, the State of Rhode Island employs a federal Medicaid/Medicare shared funding arrangement, which allows it to receive almost 50% federal funding for long-term psychiatric patients in ESH. Given

that the federal Institutions for Mental Disease (IMD) Rule prohibits Medicaid from paying for patients in an institution housing more than 50% psychiatric patients in its census, the State has consistently remained below that 50% census threshold. As such, ESH has been able to care for some of our most vulnerable Rhode Islanders, but it is not enough to meet the demand for all who need this level of care. We need more options. We need to build a robust continuum of care.

Over the past two decades, the State of Rhode Island has not funded or ensured the full continuum of mental healthcare for its residents. A Pew Charitable Trust report noted in Fiscal Year 2012 Rhode Island spent only 9.1% of its general fund on its state mental health agency, which placed us in the third-to-last lowest funding level behind Arizona and Vermont.[2] State mental health agencies "directly operate mental health care programs or fund and oversee publicly or privately operated programs or hospitals." According to Mental Health America, "A state's role in funding mental health services varies greatly across the U.S. While all states receive federal support via Mental Health Block Grants and partial funding of services provided through Medicaid and CHIP (Children's Health Insurance Program), each has freedom in designing and funding its mental health system. In addition to funding state hospitals, state funding is typically funneled to county and local levels where services are offered." Shifting the burden of long term care and emergency crisis intervention away from public sector (state funded) management onto the private sector and the market economy results in an "every man for himself" approach to mental healthcare that sets us back more than a century. The State must invest in its mental healthcare system. There is no health without mental health.

Problem/Need: We applaud the State's efforts to deinstitutionalize those who can "step down" to a lower level of care. However, in order to fully comply with the ADA, states must provide the full continuum of care, which enables people with disabilities to "step up" or "step down" to the most appropriate level of care as needed. This includes a "placement of last resort" hospital setting like ESH on the far end of the spectrum for people with the most severe disabilities who need constant care. Furthermore, Rhode Island's mental health law provides that a person receiving treatment in a facility as defined in said law has the "right to receive the care and treatment....necessary for and appropriate to the condition for which he or she was admitted and from which he or she can reasonably be expected to benefit." We submit to you that ESH is a designated "facility" under said law and is therefore required to provide the appropriate level of care for people with disabilities. Lastly, as noted above, the Olmstead v. L.C. ruling placed a premium on patient choice. Patients and their legal proxies have the right to choose the level of care they feel is best.

It should also be noted that some of the patients at ESH who are being discharged have already had unsuccessful attempts at living in nursing homes and other community based settings. Because of the complexity of their co-occurring medical and mental health conditions, they and/or their family members believe that a "placement of last resort" like ESH is the most appropriate level of care to keep these patients safe and stably housed. While patients in this

[2] https://www.pewtrusts.org/~/media/assets/2015/06/mentalhealthandroleofstatesreport.pdf

“placement of last resort” may eventually “step down” to a lower level of care or pass away, the State has an obligation to ensure that this level of care remains available in perpetuity as new generations of patients come to need it. This intensive level of care is one part of the full continuum of care.

Proposal: The Mental Health Association of Rhode Island and other community mental health advocates respectfully propose an alternative solution to meet the State’s interest in saving money while also meeting the State’s legal obligation to ensuring a robust and comprehensive continuum of care for people with disabilities, including “placements of last resort” like psychiatric hospitals for those with serious and persistent mental illness.

1. We request a moratorium on disputed discharges at Eleanor Slater Hospital until a transparent patient evaluation process can be developed.
2. We respectfully urge the State to commit to honoring patient choice, rather than subjecting patients and their family members to a stressful appeal process. If there must be an appeal process, then we ask for due process, transparency and accountability. We request that the appeal process and panel of reviewers be developed in collaboration with the Office of the Mental Health Advocate and the ESH Stakeholder Group described below.
3. We request that BHDDH work with community advocates to develop a more transparent patient evaluation process at ESH. Ideally, ESH patients would be evaluated by physicians outside of BHDDH or Eleanor Slater Hospital. We also request that the State develop and require the use of a standard checklist of patient needs to be used by physicians when evaluating patients for placement. Similarly, we should develop a comprehensive list of all facilities in all levels of care. Physicians evaluating patients should select the level of care that best meets the patient’s needs. If a patient needs a level of care currently unavailable in Rhode Island--either because there is a waitlist for it or it does not exist at all in the State, like psychiatric nursing homes--then the patient should not be discharged from ESH.
4. We respectfully request that the General Assembly form and maintain a permanent “Joint Commission on Rhode Island’s Continuum of Care.” This special commision will have oversight on ensuring that Rhode Islanders have access to all levels of care on the continuum. At public hearings, it should take testimony from patients’ family members, community advocates, and physicians/staff at Eleanor Slater Hospital and other facilities. Once per year, it will deliver a report to the General Assembly and Governor’s Office. The report should include but is not limited to: intake and discharge rates of all facilities; discharge planning and processes; readmission policies and processes; patient evaluation processes; the tracking of patient outcomes using de-identified aggregate data; environmental risk assessments; funds spent on staffing and transitional services; waitlists; steps taken to achieve accreditation; and placements of special populations (not eligible for Medicaid).
5. This Commission shall also assist in the development of a “living” Olmstead Plan, which is a renewable 5 year plan to achieve a comprehensive system of care that meets the

needs of our population. We respectfully request the Governor's Office to issue an Executive Order to establish a "living" Olmstead Plan to assess Rhode Island's supply and demand, coordinate, and fund the full continuum of care for people with disabilities.

6. We encourage the State to form an ESH Stakeholder Advisory Council comprised of family members of patients; the Department of Behavioral Health, Developmental Disabilities and Hospitals; the Executive Office of Health and Human Services; housing experts; community advocates like NAMI Rhode Island, Oasis Wellness and Recovery, and the Mental Health Association of Rhode Island; the Office of the Mental Health Advocate; the Attorney General's Office; the Department of Corrections, etc.. Having a diversity of perspectives, interests, and expertise will produce robust solutions to complicated problems with broad buy-in. Systems change requires that all stakeholders are at the table. Furthermore, we request regular Stakeholder meetings and reports.
7. We request that BHDDH track patients who discharge from ESH for two years. This will allow patients and their family members to have peace of mind that a lower level of care is appropriate for the patient.
8. We request that patients are allowed to readmit to ESH if they discharge to a lower level of care that ultimately does not meet their needs.
9. We request that BHDDH regain control over its own budget. BHDDH should also be empowered to collect data from EOHHS and Managed Care companies to inform decision-making and planning.
10. The Executive Office of Health and Human Services (EOHHS) should be required to be active members of the Governor's Council on Behavioral Health, as EOHHS has authority over all health and human service agencies in Rhode Island.
11. State and federal funding sources currently supporting patients in the State's care at ESH and in prison should follow these individuals into the community, rather than staying in the State's coffers. Additionally, the projected savings of $788,000,000 over the next ten years should be put toward developing a robust and comprehensive Olmstead Plan for people with all disabilities: serious persistent mental illness, intellectual/developmental, and physical disabilities.
12. The Zambarano facility and enhanced nursing homes are not appropriate settings for some of the patients currently residing in ESH who continue to need a hospital-like setting for their safety and care. Given that the Affordable Care Act requires nonprofit hospitals to provide benefits to the community, the State should explore requiring our hospitals to contribute toward an Olmstead Plan and supporting the full continuum of care in Rhode Island. The merger between Lifespan and Care New England might present another opportunity. Part of the conditions of the merger could be to help fund an Olmstead Plan.
13. If it is not financially feasible to renovate ESH's Regan or Adloph Meyer facilities or construct new facilities, then we propose that the State rent or purchase space at the Memorial Hospital campus or some other local hospital and continue to fund, staff, and care for ESH's most vulnerable patients in this setting. The savings afforded to the State from closing parts of ESH can be put toward transitioning part of Memorial Hospital into a long term care "placement of last resort" facility. The hospital has many large, sunny rooms and the parking lot can be turned into a lovely green space for the residents.

Under this proposal, the State would continue to fund the facility and staff the care of these residents. A similar arrangement currently exists with Fatima Hospital, wherein the State contracts with Famtima to take in permanent psychiatric patients discharged from ESH. However, this arrangement is not ideal for two reasons. (1) Fatima is not located in a place where patients who reside there can experience being outdoors because it is located on a busy street with no yard and (2) Because Fatima is a private hospital, there is less transparency and accountability for what happens to these patients. If and when Fatima Hospital decides to close its doors, there will be little oversight for ensuring that each patient is properly placed elsewhere or that alternative placements actually exist. Patients might end up living with family members who cannot properly care for them, or they may become homeless. The nature of these patients' complicated disabilities deserves the State's protection and care. These are our most vulnerable Rhode Islanders, after all.

Thank you for your consideration of our proposal. We look forward to hearing your feedback and working with you to provide the full continuum of care for Rhode Islanders with disabilities. Everyone deserves the chance to live their best life.

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