

Wrongly Confined

A Disability Rights Vermont Report
in Consultation with Melodie Peet, M.P.H.
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Why are Vermonters with Disabilities Stuck in Hospital Emergency Departments and Psychiatric Units?

The State has Failed to Provide Adequate Community Supports and Resources.

The Solution is NOT to Build More Inpatient Hospital Beds but to Invest in Sufficient Community Capacity.

“I came into the hospital to get back on my medications and now [my outpatient providers] won’t allow me return to independent living. Four months after my hospital psychiatrist said I could be discharged, I’m still stuck here. In the community I am on an Order of Non-Hospitalization that requires me to live in housing approved by my outpatient team. They say I need a specialized residential program due to my mental illness and traumatic brain injury but the few ones in Vermont are either full or won’t accept me.

I just want to move on with my life.”¹

One patient who had been confined unnecessarily in a psychiatric unit for nearly a year due to the lack of sufficient community capacity expressed his hopelessness about this issue, stating he felt “stuck [there] until [he] dies.”²

I. Executive Summary

Over twenty years ago the U.S. Supreme Court issued the landmark decision in *Olmstead v. L.C.*³ affirming that people with disabilities have a right to live in the most integrated setting appropriate to their needs, and that the failure to realize such integration is a violation of the Americans with Disabilities Act⁴. Yet still today many Vermonters with disabilities are harmed by being held in hospitals, especially psychiatric units, long after their doctors say it is safe and appropriate for them to be discharged.

¹ DRVT client quote

² DRVT client quote

³ 527 U.S. 581 (1999)

⁴ 42 U.S.C §12101.

Vermont was a national leader in community reintegration with the closing of the Weeks School in 1979 and the Brandon Training Center in 1993. In response to Tropical Storm Irene, in 2011 Vermont shuttered its large, aged State Hospital in favor of building a smaller, state-of-the-art State Hospital, and in having private hospitals increase their inpatient bed capacity. And the promise was made to augment community mental health supports. But that momentum floundered in terms of adequate planning and funding for our community-based support system. Today Vermont is failing to honor the *Olmstead* mandate.

Confining people with mental health conditions in hospitals when they no longer need to be there is unjust, discriminatory, and harmful. It is also an enormous expense and creates a lack of available inpatient bed space for those who are in need of that level of care. This results in emergency departments around the state boarding people with disabilities for days, sometimes weeks at a time, as they await access to an appropriate level of care.

Over the last six months, Disability Rights Vermont (DRVT), Vermont's designated Protection and Advocacy System⁵ and Mental Healthcare Ombudsman,⁶ has worked along with Melodie Peet, M.P.H., a nationally-recognized expert on State mental healthcare systems, to identify the scope of Vermont's *Olmstead* problems, primarily in inpatient psychiatric units around the state. DRVT also sought input from Vermont Psychiatric Survivors, Inc., a statewide Peer advocacy organization, and mental health care providers around the state. Through outreach and monitoring efforts, DRVT received referrals for twenty-seven patients who had mental health conditions and were deemed by their treatment team no longer to require inpatient level of care, but were stuck in the hospital due to the unavailability of an appropriate community placement. DRVT understands from discussions with other stakeholders in our mental healthcare system that over these last six months there were many other patients who experienced similar unnecessary delays in community reintegration.

This report highlights that Vermont's governmental entities responsible for our system of care, specifically the Agency of Human Services, including the Department of Mental Health and the Department of Disabilities, Aging and Independent Living, have been aware for years that Vermonters' *Olmstead* rights are being violated. While the State asserts that they have increased capacity for mental health care over the last several years, their focus remains on building more inpatient psychiatric capacity - more hospital beds – rather than investing our limited resources to fill the huge gaps currently existing in community services. Building more psychiatric hospital beds without fixing the system's inadequate capacity and lack of available, less restrictive, community-based alternatives will result in even more people with disabilities being wrongfully confined to the most restrictive settings.

⁵ See Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15001 *et seq.*; Protection and Advocacy for Individuals with Mental Illness Act, 42 U.S.C. § 10801 *et seq.*; Protection and Advocacy of Individual Rights Act, 29 U.S.C. § 794e (2006); 42 C.F.R. Part 51 *et seq.*

⁶ 18 V.S.A. §7259

This report concludes with specific recommendations for our state government and stakeholders to fix our healthcare system and prevent ongoing and harmful *Olmstead* violations.

Recommendations include:

- (1) acknowledging and emphasizing the existence of, and the harm caused by, the ongoing *Olmstead* violations we are aware of in order to rally sufficient resources to adequately fund our community mental health system;
- (2) postponing investment in expensive, restrictive inpatient hospital beds until sufficient funding is allocated to less expensive, but proven effective, community-based capacities;
- (3) expanding who is eligible to benefit from intensive community-based services;
- (4) implementing payment structures that more effectively incentivize healthcare providers to effectively limit and reduce the amount of expensive, restrictive high-end placements for their clients with mental health conditions;
- (5) formalize and centralize discharge planning procedures and resource augmentation options needed to reduce and end unnecessary hospitalizations; and
- (6) effectively enforce anti-discrimination laws against care providers who refuse service to people with mental health conditions based on illegal discrimination that results in unnecessary institutionalization.

Now is the time for the State of Vermont to finally stop the ongoing unnecessary institutionalization of people with psychiatric disabilities.

II. Introduction

Julie Smith⁷, a woman in her late 50's, was admitted to an inpatient psychiatric unit. She was receiving psychiatric treatment pursuant to a Court Order when it was discovered that she also had cancer. She was transferred to an oncology unit for cancer treatment and continued to receive psychiatric treatment. About three months after her initial admission to the hospital, Julie was deemed clinically ready for discharge. Her treatment team advised that she should be discharged to a nursing home because of physical impairments resulting from her cancer. She agreed. Julie's hospital-based treatment team contacted nursing homes throughout the state and all of them refused to take her, primarily because of her history of mental illness. So she waited. And waited. She waited nearly a full year after being deemed appropriate to leave the hospital before her treatment team secured an out-of-state nursing home and Julie was finally

⁷ All names in this report are pseudonyms

discharged. Julie died shortly afterwards. Her hospital-based treatment team asserted that her extended, unnecessary stay in the hospital was inappropriate and harmful to her.

Julie's experience is not unique in Vermont. Many patients in Vermont hospitals regularly experience similar harmful delays in being reintegrated into their communities. In February 2020 the Vermont Department of Mental Health (DMH) identified that 36% of the inpatient patients they track who were receiving psychiatric treatment⁸ were being held in hospital settings after no longer needing that high-level of care. These patients are referred to as "sub-acute."⁹ That percentage equated to approximately 19 people confined to hospital psychiatric units when they are deemed no longer to be in need of inpatient care. That figure does not include those patients in similar circumstances who are not tracked by DMH.

In the past six months Disability Rights Vermont (DRVT), Vermont's designated Protection & Advocacy System and Mental Healthcare Ombudsman, has received requests for help regarding more than twenty-seven people who, like Julie and the other DRVT clients quoted above, were stuck in inpatient hospital units after no longer needing that expensive and restrictive level of care. In each individual's situation, Vermont's insufficient community mental health treatment and support capacity was central to the harm suffered by those involved.

Lisa Johnson remains hospitalized, where she has been for over a year since being identified by her doctors as not benefitting from inpatient treatment. She has complex behaviors related to her mental health condition and the clinical recommendation is that she be discharged to intensive residential treatment. The very few programs of that sort available in Vermont have not accepted her.

John Kennedy, a young man with significant behavioral problems related to his mental health condition, was identified by his inpatient treatment team as appropriate for a more residential, less restrictive, setting than the hospital he was detained in. He, too, spent more than year in the hospital waiting for a bed to open up in an appropriate community-based program.

Being confined to a psychiatric or other hospital unit when that level of care and restriction is not clinically necessary is harmful and discriminatory. This sad state of affairs still exists in Vermont despite the United States Supreme Court ruling more than 20 years ago in *Olmstead v. L.C.*¹⁰ that the unnecessary institutionalization of people with disabilities is a violation of the Americans with Disabilities Act. After the *Olmstead* decision, states were mandated to develop community programming sufficient to avoid the unnecessary use of psychiatric hospitals and other institutions.¹¹

⁸ DMH tracks involuntary patients in Level 1 beds, involuntary patient who receive Medicaid funding, and patients (voluntary or involuntary) who receive Community Rehabilitation and Treatment (CRT) services.

⁹ Email from Jennifer Rowell, DMH Executive Staff Assistant to DRVT received on 2/21/2020.

¹⁰ *Olmstead v. L.C.*, 527 U.S. 581 (1999).

¹¹ https://www.ada.gov/olmstead/q&a_olmstead.htm, at 12.

Vermont has historically been a national leader in community reintegration. Vermont closed the Weeks School in 1979, the Brandon Training Center in 1993, and the Vermont State Hospital in 2011. But that momentum floundered in terms of adequate planning and funding for our community-based support system. Vermont is now failing to comply with the *Olmstead* mandate. While our State Government acknowledges the ADA and its *Olmstead* requirement for community integration,¹² there is much that remains undone in the effort to develop an effective system of community supports.

The Legislature has provided that “Vermont’s mental health system shall provide a coordinated continuum of care by the Departments of Mental Health and of Corrections, designated hospitals, designated agencies, and community and peer partners to ensure that individuals with a mental condition or psychiatric disability receive care *in the most integrated and least restrictive settings available.*”¹³ Despite this clear legislative mandate, Vermont’s Agency of Human Services (AHS) has, at times, simply denied responsibility to assure that Vermonter’s *Olmstead* rights are honored and protected. In Motions to Dismiss before the Vermont Human Rights Commission in 2017 and again in 2018, AHS asserted that it was simply not responsible to assure that patients were discharged to a setting that was less restrictive than an inpatient psychiatric unit. Their rationale was that the State did not admit patients, did not run the hospital, and did not deny the patients admission to any community settings. See www.disabilityrightsvt.org/HRC-Decision.pdf and <http://www.disabilityrightsvt.org/HRC-Order.pdf>. This position is a startling abdication of Vermont Government’s responsibilities as the State Mental Health Authority and most certainly is an underlying cause of Vermonters suffering the consequences of current *Olmstead* violations.

The State, as manager of the healthcare system, is responsible when there is a systemic failure resulting in harm and unnecessary institutionalization of people with disabilities.¹⁴ Vermont’s *Olmstead* plan has not been updated since 2006.¹⁵ Our state is experiencing an *Olmstead* crisis. Vermont is lacking a current coordinated and effective *Olmstead* plan, including policies and procedures to systematically prevent unnecessary institutionalization, and the creation of an adequate community-based system of care. Our leaders are failing to act effectively to acknowledge and remedy this *Olmstead* crisis.

¹² The State has expressed a goal of having a holistic system of care: “It is the intent of the general assembly to strengthen Vermont’s existing mental health care system by offering a continuum of community and peer services, as well as a range of acute inpatient beds throughout the state. This system of care shall be designed to provide flexible and recovery oriented treatment opportunities and to ensure that the mental health needs of Vermonters are served.” Act 79. An act relating to reforming Vermont’s mental health system. (H.630), sec. 1.

¹³ 18 V.S.A. §7251 (3) (emphasis added)

¹⁴ 18 V.S.A. §7251

¹⁵ http://www.advancingstates.org/sites/nasquad/files/hcbs/files/143/7145/VT_Works_Strategic_Plan.pdf

III. Vermont has a systemic *Olmstead* problem and our State Government knows it.

For many years AHS and the Legislature have been aware that Vermonters' *Olmstead* rights are being violated. DMH reported to the Legislature in December 2017 that there existed:

*limited availability of appropriate discharge placements based on an individual's specific needs (an example of this is people who no longer require inpatient level of care and require long term care with skilled nursing but due to their mental health symptoms or history of aggression, [they] are not considered for admission by these facilities) and long wait lists for virtually all group homes and Intensive Residential Recovery programs.*¹⁶

This problem has not improved. The same report bluntly noted that:

*[c]urrent delays in transfer to the right level of care are often viewed as the result of a system that does not have the right amounts of treatment resources available, adequate numbers of well compensated treatment providers available, and services that people need and want to access.*¹⁷

DMH does not currently track delayed discharge data for *all* patients receiving psychiatric care in Vermont hospitals, but DMH and other departments of AHS have reported on some data highlighting the prevalence of this issue. AHS reported to the Legislature that in 2017, out of a total of 341 youth psychiatric admissions paid for by Medicaid, 26% (87) youth had either "awaiting placement" or sub-acute days, and out of a total of 1,633 adult psychiatric admissions paid for by Medicaid, 9% (149) adults also experienced "awaiting placement" or sub-acute days.¹⁸

In 2019 DMH reported to the Legislature that there were 6-10 involuntary patients in Vermont inpatient psychiatric units at the time of their survey who could be discharged to a secure residential program that has the capacity to perform occasional emergency involuntary procedures.¹⁹ DMH recently reported that they are aware of at least 19 patients who are currently sub-acute and "awaiting placement."²⁰

In addition to the injustice experienced by these individuals due to their delayed discharges, it is expensive. The enormous cost of unnecessary hospitalization to our system, to our State, and to the taxpayers of Vermont is also understood by our State Government. Data indicates that the average cost per individual per day hospitalized at our state-operated inpatient psychiatric hospital is \$2,537; the average daily costs for psychiatric patients in the privately-run

¹⁶ <https://legislature.vermont.gov/assets/Legislative-Reports/Act-82-Sections-3-and-4-12-15-17.pdf> at *19-20.

¹⁷ VERMONT2017 Reforming Vermont's Mental Health System. Report to the Legislature on the Implementation of Act 82, Sections 3 and 4. December 15, 2017 p.27

¹⁸ https://mentalhealth.vermont.gov/sites/mhnew/files/documents/Reports/Act_82_Facilities_QA_responses_2018-02-21.pdf (pp. 75-190)

¹⁹ https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/Act_26_Section_2_Report_Analysis_of_Need_FINAL_01152020.pdf (p. 9) This data does not include people that are clinically ready for discharge to a level of care lower than secure residential.

²⁰ See footnote 9 above, Rowell email 2/2020.

designated hospitals is \$1,425. Placement in an Intensive Residential Recovery Residence is approximately \$790 per day, in a Crisis Bed (either Designated Agency or Peer Run) approximately \$664 per day, and those individuals with mental illness being served in their own homes in the community cost approximately \$64 per day.²¹

A study conducted by University of Vermont Medical Center (UVMCC) from October 2014 through March 2017 analyzed this issue of delayed discharge for UVMCC's voluntary and involuntary psychiatric patients.²² The study found that "delays in discharge contribute to the utilization of 2 inpatient beds for non-medically necessary reasons or the lost opportunity to treat 57 patients annually (estimated ALOS [average length of stay] 14 days)." The UVMCC study found that during the 30 months studied 62% of patients that stayed more than 30 days (112 patients) experienced barriers to discharge, mostly due to not finding a placement in supervised or supported setting.²³ The UVMCC study estimated the cost of those "barrier days" to be over \$1.8 million dollars during the 30 month study period.²⁴

DMH has acknowledged that Vermont lacks sufficient community care service capacity. A 2019 DMH report acknowledged that the clinically preferred discharge option for many patients is often not readily available.²⁵ DMH reported that there is a lack of Group Home and Community Care Home capacity.²⁶ Group homes throughout Vermont are mostly operating at 95-100% capacity while private community care homes are closing due to low reimbursement rates.²⁷ Data further suggests that the number of residential beds has not increased significantly over the past three years. See Ward Nial Chart, Appendix A. This stagnation in residential

²¹ These figures are estimated from the following data sources: Vermont Care Partners 2018 "FY 2018 Outcomes and Data Report"; "Narrowing the Gap in Recovery-Oriented Community Services: A presentation by Alyssum, Another Way Community Center, Pathways Vermont, and Vermont Psychiatric Survivors" October 22, 2019; Vermont Department of Mental Health FY2018 Budget Presentation Melissa Bailey, Commissioner.

²² Inpatient Psychiatry Barrier Days Analysis, prepared by Eve Hoar, MBA. May 31, 2017, Network Director, Strategic and Business Planning In Collaboration with Jeffords Institute for Quality, with Isabelle Desjardins, MD Vice-Chair of Clinical Affairs Psychiatry Department and Eileen Whalen, MHA, RN, President and COO of UVM Medical Center as Executive Sponsors
https://mentalhealth.vermont.gov/sites/mhnew/files/documents/News/82/Inpatient_Psychiatry_Barrier_Days_Analysis.pdf

²³ *Id.* at p. 1

https://mentalhealth.vermont.gov/sites/mhnew/files/documents/News/82/Inpatient_Psychiatry_Barrier_Days_Analysis.pdf

²⁴ *Id.* at p.4

²⁵ DMH bed report powerpoint 2019 slide 6 identified 56 people that were involuntary adult patients and where their treatment teams thought was the best discharge option for those patients. Of those 56, the highest scoring option, with 17, was discharge to independent housing, followed by "other", secure residential and intensive residential; *see also*

https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/Act_26_Section_2_Report_Analysis_of_Need_FINAL_01152020.pdf

²⁶https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/Act_26_Section_2_Report_Analysis_of_Need_FINAL_01152020.pdf at p. 10

²⁷ *Id.*

placements is troublesome given the consensus that augmenting this capacity would positively impact unnecessary inpatient stays.

Also troubling is the DMH's use of the term "outliers" to describe people who are often harmed by the lack of fidelity to the *Olmstead* mandate. DMH identifies over 10 "outliers" per year on average, and 18 "outliers" for 2019, referring to people in their custody that "require unique living arrangements and an enhanced service delivery model in order to live safely and successfully in the community."²⁸ Use of the term "outlier" to describe people's needs is problematic because every Vermont citizen who is served in our mental health system deserves to be seen as an individual, with their needs addressed accordingly. The term "outlier" reflects that the current system's failures are being blamed on the individuals whose needs do not fit neatly into pre-existing or generally-applicable programs. Community resources regularly fail to provide services to patients with these intense individual needs because of stereotyping, prejudice, discrimination or ignorance. The use of this language by our State Government does not help to mitigate this problem.

Our State Government is also well aware that older Vermonters with psychiatric disabilities face significant barriers to finding a community treatment provider that will agree to work with them. Meeting notes of a 2017 DMH subgroup focused on older people with mental health conditions noted that although Vermont has a number skilled nursing facilities, none of them at the time provided a "specialty" program to manage individuals with behavioral needs. This includes behaviors related to psychiatric illness, dementia, traumatic brain injury, developmental/intellectual disability (or combination) making this population at risk for delayed hospital discharge.²⁹ In 2017 there were a few skilled nursing facilities (SNFs) in Vermont interested in having a certain number of beds available under State Regulation for specialized programming for individuals with behavioral needs, but it was not clear to the subgroup how or if those facilities were able to provide these augmented services.³⁰ The impact of an aging population on the work of Vermont's community mental health service system, known as Designated Agencies (DAs), has also been widely acknowledged. The percentage of people ages 56 and up receiving the highest level of community support (Community Rehabilitation and Treatment [CRT] and Community Support Programs [CSP] operated by DAs throughout Vermont) has increased from 42% to 47% from FY15 to FY18.³¹ "An older client population means that more and more clients have medical and nursing needs, and as a result have elevated service coordination needs associated with transportation, access to community, primary and emergency medical care. As a result, CRT/CSP programs are trying to meet client physical/medical/nursing needs through CRT/CSP services, provided by staff who do not

²⁸https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/Act_26_Section_2_Report_Analysis_of_Need_FINAL_01152020.pdf at p.11

²⁹ Geri psychiatric Subgroup Meeting Notes 3/22/17. Present: Deb Coutu, Michael Hartman, Sara Lane.

³⁰ *Id.*

³¹ Email from Dillon Burns, Mental Health Services Director, Vermont Care Partners, to DRVT, February 21, 2020.

necessarily have training or expertise in physical health supports and by nursing staff who can't be reimbursed for providing nursing services."³²

Vermonters rely on our State Government to design, obtain, implement and maintain services that are flexible and sufficient to meet the healthcare, including mental healthcare, needs of all citizens. A systemic lack of adequate placements, community supports, community-based alternatives to emergency departments, and supportive housing have all been universally acknowledged as barriers to timely and appropriate discharge.³³ Yet, still in 2020 the problem of a lack of adequate community placement capacity remains for people unnecessarily detained in hospitals.

IV. The State is investing in plans that are contrary to the data and will not solve the problem.

The solutions to our *Olmstead* problems are widely known. Our State Government has studied and reported on aspects of the problem for years, issuing various recommendations that, if prioritized correctly and pursued diligently, would have resulted in needed improvement already.

In a 2012 report to the Legislature the Behavioral Health Policy Collaborative, LLC³⁴ issued recommendations to improve Vermont's mental health system of care, including several suggestions to remedy the problem of delayed discharges to less restrictive placements.³⁵ This report was in response to Act 79, "An Act Relating to Reforming Vermont's Mental Health System", a comprehensive piece of legislation designed to significantly improve the delivery of mental health services. Act 79 included numerous provisions ranging from the temporary and long-term replacement of inpatient capacity previously provided at the Vermont State Hospital to the expansion of peer support programs. The report identified that "Vermont's systems change and redesign must remain cognizant of federal ADA (Americans with Disabilities Act) laws and the Supreme Court's *Olmstead* decision regarding community inclusion. Ignoring these will thwart development of a state-of-the-art system of care and could result in wasted time and resources..."³⁶ Unfortunately, Vermont failed to heed this warning.

Specific recommendations in 2012 included:

- a) Hire staff to monitor the mental health system including outpatient and CRT services (p 2);
- b) Develop inpatient and community services so that they align, with clearly defined clinical expectations relative to admission, discharge and continuity of care (p 2);

³² *Id.*

³³ VERMONT2017 Reforming Vermont's Mental Health System. Report to the Legislature on the Implementation of Act 82, Sections 3 and 4. December 15, 2017 p.19-20

³⁴ an independent consultant agency

³⁵ https://lifo.vermont.gov/assets/docs/jfc/2012/2012_07_20/44976e86d9/2012_07_20_BHPC_VT-Act-79-Report-FINAL-7-18-2012_2.pdf

³⁶ *Id.* at p. 2

- c) Establish a workgroup to develop appropriate policies and procedures for the operation of the Vermont state psychiatric hospital that meet federal standards of care and are directed by the ADA and the *Olmstead* Decision in terms of discharge planning, including prioritizing the development of new services that will prevent people from entering the inpatient care system, and providing intensive services and supports to those being discharged from care to help them become integrated in their communities (p 6);
- d) Establish a single point of clinical responsibility and authority within the State’s mental health system in response to confusion as to who has ultimate clinical authority for managing the system (p 6);
- e) Employ case managers to work specifically with the people who end up in hospital beds experiencing a personal or domestic crisis not related to a serious mental condition so as to prevent future involvement in deep end services and prevent the system from backing up (p 21-22);
- f) Improve alignment with Inpatient and Outpatient providers by having DMH ensure that all providers (inpatient and outpatient) work in tandem, and to remove any and all barriers that stand in the way of a unified system of care, with performance measures for both inpatient and outpatient providers regarding their mutual responsibilities to decrease length of stays and avoid unnecessary hospitalizations (p 25); and
- g) Expand the capacity of CRT so that more people can benefit from those services. (p 31-32).

The independent consultant’s report further emphasized that “[t]hroughout our visit, we heard the need for enhanced outpatient capacity, crisis stabilization and mobile crisis capacity and peer support... As current system pressures focus on inpatient capacity, investment of new state dollars or reinvestment of dollars from the Vermont State Hospital should be directed to those community services that will have the highest impact on hospital utilization...” (p 31).

Similar to the 2012 independent consultant recommendations stakeholders recently, including the VT Association of Hospitals and Health Systems, agree that to improve the current mental health system the following should be high priorities:

- Developing geriatric psych capacity and specialized treatment in the state;
- Creating more step-down beds to serve more people with mental health needs within the community;
- Creating more temporary crisis beds as an alternative to Emergency Departments;
- Creating well-targeted supportive housing programs;
- Better coordination between hospitals and state agencies including DMH, DCF, and DVHA to reduce barriers to care and actively assist in directing and providing patients with the appropriate level of care within the community.³⁷

³⁷See

<https://legislature.vermont.gov/Documents/2018/WorkGroups/Senate%20Health%20and%20Welfare/Mental%20Health/W~Devon%20Green~Mental%20Health%20Paper%20-%20VAHHS~2-10-2017.pdf>

These recommendations, and others like them, have not been fully or effectively implemented by our State Government. As a result, our mental health care system remains fragmented, inadequate, and at times harmful to the people it serves.

Key services that reduce the need for hospitalizations include (1) crisis services, (2) Assertive Community Treatment (also called ACT or PACT), (3) intensive case management, (4) peer support, (5) supported employment, and (6) permanent supported housing. These services can be provided in conjunction with traditional office-based therapy and medication management. In many studies over long periods of time, the findings have been consistent: Former hospital patients can transition to successful community living with the support of community-based services. See Key Community-Based Services Can Reduce Reliance on Hospital Admissions and Length of Stay, Melodie Peet, M.P.H., Appendix B).

Over the past 25 years, multiple studies in the U.S. and abroad have validated the significant impact that PACT teams have had on reducing hospital admissions and overall bed days.³⁸ Similarly, strong research over the last three decades chronicles the ways that mental health systems around the world have implemented crisis response programs that are ever more adept at resolving psychiatric emergencies without resorting to hospital admissions.³⁹ More recent research also identifies the beneficial impact of supported employment and peer support services in allowing people to live stable lives in their communities.⁴⁰

Currently, our State Government is planning on investing even more money on the high end of the continuum of care, including more inpatient beds, despite the data making it clear that more community resources would prevent inpatient admissions all together and facilitate timely discharges from hospitals and from Intensive Recovery Residences (IRRs).⁴¹ In 2018 Vermont's Legislature appropriated \$5.5 million dollars for the development of an additional 12 inpatient Level 1 beds at the Brattleboro Retreat⁴², while the University of Vermont Health Network has requested approval from the Green Mountain Care Board to build 29 – 34 additional adult inpatient beds.⁴³

DMH's most recent report on Residential Bed Capacity erroneously asserts—without adequate foundation—that what is needed to address the problem of delayed discharges from inpatient units is more highly secure Intensive Recovery Residences (IRRs), with the additional ability to

³⁸ McGraw, J., Bond, G., Dretan, L., et al (2006) "A multisite study of Client Outcomes in Assertive Community Treatment", *Psychiatric Services*, 1995, 46:696-701; Olfson, M. (1990) Assertive Community Treatment: An Evaluation of the Experimental Evidence", *Hospital and Community Psychiatry*, 1999, 41:634-641; Bond, G., Miller, L., Krumwred, R., et al, "Assertive Case Management in Three CMHCS: A controlled Study", *Hospital and Community Psychiatry*, 1988, 39:422-418; See also Appendix B.

³⁹ *Id.*

⁴⁰ *Id.*

⁴¹ <https://vtdigger.org/2020/02/17/150-million-price-tag-sets-back-new-psychiatric-facility/>.

⁴² Act 190 (2018)

⁴³ University of Health Network Psychiatric Inpatient Stakeholders Meeting, February 11, 2020

use emergency involuntary procedures.⁴⁴ DMH's focus on, and prioritization of, coercive treatments undervalues the fact that DMH acknowledges that people are often stuck in IRRs due to a lack of adequate and available community resources and lower-level beds.⁴⁵ Barriers to discharge from IRRs identified by DMH include:

- No group home/Community Care Home availability;
- lack of nursing home availability;
- first floor apartments to accommodate for mobility issues;
- housing availability with or without a voucher;
- client's choice is to remain in IRR;
- concern from Designated Agency (community mental health agency) to provide appropriate level of care in the community.⁴⁶

Absent from their list, but equally important, is the unavailability of intensive case management or ACT capacity. ACT is an Evidence Based Program that has demonstrated its efficacy at reducing rates of hospitalization for over 30 years,⁴⁷ yet Vermont has still not committed to fully implementing this important part of the service continuum.

In its January 15, 2020 Report to the Legislature on the Implementation of Act 79, DMH asserted that Vermont has increased its capacity for mental health care over the last several years in many ways. DMH reports that since 2011, and Tropical Storm Irene, they have added 60 inpatient psychiatric beds (and as noted above are planning even more), have increased crisis and intensive residential beds from 49 to 87, have provided additional funding to support the expansion of crisis beds so that they are now available in each Designated Agency's catchment area, and have increased the availability of peer-support services throughout Vermont.⁴⁸ Yet that growth, particularly of community-based services, was, and continues to be, insufficient to meet the identified needs. Now DMH is proposing a 10-year plan that has many of the same goals as have been previously identified, but implementation concerns remain.⁴⁹

Building more high-end, restrictive beds, where people are already stuck, and hoping that will result in people being served in the community is illogical. **Without addressing the gaps in**

⁴⁴ <https://legislature.vermont.gov/assets/Legislative-Reports/2019-12-16-Act-42-Sec.-30-Replacement-of-MTCR-Negotiation-Status-Update.pdf>

⁴⁵ https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/Act_26_Section_2_Report_Analysis_of_Need_FINAL_01152020.pdf

⁴⁶ *Id.* at P.17.

⁴⁷ McGraw, J., Bond, G., Dretan, L., et al (2006) "A multisite study of Client Outcomes in Assertive Community Treatment", *Psychiatric Services*, 1995, 46:696-701; Olfson, M. (1990) Assertive Community Treatment: An Evaluation of the Experimental Evidence", *Hospital and Community Psychiatry*, 1999, 41:634-641; Bond, G., Miller, L., Krumwred, R., et al, "Assertive Case Management in Three CMHCS: A controlled Study", *Hospital and Community Psychiatry*, 1988, 39:422-418; See also Appendix B.

⁴⁸ https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Leg/2020-ACT_79_REPORT_011520_FINAL_Corrected.pdf

⁴⁹ https://mentalhealth.vermont.gov/sites/mhnew/files/documents/AboutUs/Vision_2030_FINAL.pdf

community services, and creating better mechanisms for creating continuity of care between hospitals and community services, building more hospital beds will not solve the problem. Beds will fill up in short order, leaving even more of Vermont's citizens facing unnecessary delays in discharge and avoidable *Olmstead* violations. New resources should be targeted to services that prevent the need for hospitalization and those that provide opportunities for rapid return to community living post hospitalization.

V. DRVT's Initiative to Assess and Respond to Vermont's Current *Olmstead* Crisis

DRVT has conducted regular outreach and monitoring in each of the state's psychiatric inpatient units since being designated Vermont's Protection and Advocacy System in 1991. In August 2019, DRVT began a concerted effort to identify individuals experiencing *Olmstead* violations. With the consent of individual patients, DRVT staff helped to facilitate structured and regular multi-stakeholder meetings for each person with the goal of achieving prompt and appropriate placement in less restrictive settings. See http://www.disabilityrightsvt.org/pdfs/Press_releases/Olmstead-Init-PR-8-15-19.pdf.

Individual cases were identified through outreach and monitoring of psychiatric facilities, and referrals from hospital staff. DRVT has been contacted by, or on behalf of, at least 27 people requesting assistance to end their unnecessary inpatient stays since August 2019. Some were voluntary and others were involuntary patients. For each individual, DRVT identified key data points such as the reason for admission, housing at the time of admission, services at time of admission, date deemed sub-acute, discharge recommendations, and barriers to discharge. See DRVT *Olmstead* Initiative Charts 2/2020, Appendix C. For each individual requesting DRVT assistance, DRVT became involved in their discharge planning process by attending, and at times requesting, regular meetings of stakeholders (including inpatient and outpatient providers, and DMH and DAIL Care Managers) and advocating for effective work plans to obtain prompt and appropriate placements. DRVT then worked to hold stakeholders accountable by documenting the agreements and commitments made at the stakeholder meetings, noting who took individual responsibility to accomplish which tasks, and requesting prompt and continuing follow up meetings where progress was assessed and appropriate additional actions taken.

Over half of the 27 patients DRVT served experienced 30 days or more of unnecessary hospitalization before they were appropriately discharged. Often the person spent more time in the hospital after being deemed clinically ready for discharge than they did when they were actually receiving necessary inpatient level treatment.

The majority of people had been receiving mental health services in the community prior to their inpatient admission. Many (9) were CRT/CSP clients and had been living in supported community settings, not independently, at the time of their hospitalization. Four were homeless upon admission. The majority had characteristics that could have been identifiable early into their admission as likely barriers to timely discharge. These known barriers include behaviors related to their mental health condition (e.g. history of aggression, non-compliance with medications) and non-mental health-related medical conditions requiring specialized care.

Conceivably, if these individuals had the appropriate levels of community support, they could have avoided hospitalization altogether.

DRVT identified that the overwhelming barrier to timely discharge faced by the majority of people was the lack of adequate capacity in the community to appropriately support them, both in terms of funding and staffing. This is evidenced by community placements lacking open beds and having long waitlists. In addition, a number of community treatment options would often reject mental health patients asserting that they ‘lack necessary resources.’

VI. CONCLUSIONS and RECOMMENDATIONS

DRVT’s conclusions and recommendations for preventing ongoing and future *Olmstead* violations are based on the review of prior recommendations and available data, our work with patients and providers over many years, specifically through our *Olmstead* Initiative since August 2019, and consultation with Melodie Peet, a national expert on community mental health systems, and other stakeholders.

Systemic Capacity Issues:

Vermont’s mental health system is top heavy. Our State Government has become over reliant on expensive inpatient for people with severe mental illness. All the accumulated evidence and expertise supports investing in community supports instead. A recent report by the National Association of State Mental Health Program Directors showed that Vermont is out of step with the rest of the country in this regard. Between 1980 and 2010, the number of inpatient and residential beds in Vermont climbed from 602 to 737, an increase of 31%. During the same period, the trend in other states was to decrease reliance on these high end services. The data shows that while other states reduced their use of residential and inpatient beds by 34%, Vermont’s bed capacity was growing.⁵⁰

Rather than prioritizing and focusing on preventative care, due to lack of resources our system often waits for people to decline and become so ill they require residential or inpatient treatment. Furthermore, expensive high intensity services on the mental health continuum are currently not being managed effectively. Lengths of stays at the State-operated Vermont Psychiatric Care Hospital (VPCH) and the privately run Designated Hospitals are much higher than national averages.⁵¹

⁵⁰ National Association of State Mental Health Program Directors, "Assessment #10: Trends in Psychiatric Capacity, United States and Each State, 1970-2014", August, 2017, p. 45.

⁵¹ <https://embed.resultsscorecard.com/Scorecard/Embed/9939>; National Association of State Mental Health Program Directors, "Assessment #10: Trends in Psychiatric Capacity, United States and Each State, 1970-2014, August, 2017, pg. 23.

Unfortunately, recent efforts to build more inpatient beds and other locked facilities demonstrate that the commitment needed to create a community mental health capacity that will satisfy the *Olmstead* integration mandate is still lacking. There remains no consensus at the State Government level that there is an *Olmstead* crisis now, that it is harmful and unnecessary, and that it can be solved with focus, resolve and commitment to the values of inclusivity, autonomy and reducing unnecessary institutionalization.

Recommendation: Our State Government, both AHS and the Legislature, should explicitly acknowledge that we as a State are failing in our responsibility to maintain the capacity to provide services to people with psychiatric disabilities in the least restrictive, appropriate setting, both in terms of staffing and infrastructure. A call to action is necessary to produce the political will needed to effectively increase capacity for non-restrictive, supportive, community placements.

What will it take to confront our *Olmstead* problem and free our fellow citizens from unnecessary institutionalization?

- (1) Increasing the number of mental health professionals in Vermont, including peer advocates, support workers for independent living, Shared Living placements, Adult Family Care placements, Residential Care placements, and Group Homes;
- (2) initiating and augmenting programs like ACT and intensive case management;
- (3) increasing the availability of supported living options and housing vouchers;
- (4) adding sufficient police social workers, mobile crisis workers, and especially community-based peer advocates; and
- (5) continually assessing progress in this effort.

Until community-based services are adequately funded, staffed and implemented, creating more expensive, restrictive inpatient hospital beds should be postponed because those additional inpatient beds may not be necessary with a well-functioning community mental health system. The current plan to increase the State's most restrictive and segregated inpatient capacity is taking us in the wrong policy direction, especially for a state that historically has led the nation in decreasing institutionalization and providing state-of-the-art community services.

AHS should also promptly implement payment structures that incentivize community placements in order to retain, and quickly reaccept, clients so as to avoid unnecessary inpatient stays, or limit their durations. Suggestions include:

- bonuses for keeping CRT/CSP clients out of hospitals and/or penalties for failing to reintegrate clients once they are deemed subacute by hospital providers;

- use of performance contracts that set targets for use of hospital days and other high end services and for numbers of hospital diversions;
- enabling DAs to provide case management and other supports to more people, especially people who are homeless.

System Process and Policy Issues:

Planning Process Not Effective

Once a patient is hospitalized discharge planning should begin immediately. In practice opportunities for optimal outcomes are often missed. For example, DRVT identified that patients with certain co-occurring characteristics in psychiatric units were likely to experience more difficulty and delay in their discharge than those without those characteristics, but no effective augmentation in discharge planning efforts occurred until DRVT's intervention. Patients with dementia, autism spectrum disorders, behaviors that were violent or aggressive, geriatric patients, and patients who had made allegations of sexual assault in prior placements were all found to have a longer delay in being returned to the community. Identifying people with these characteristics promptly, and effectively organizing additional resources early in their stay will enable timely discharge.

The current system puts the burden of identifying and implementing a discharge plan mainly on the hospital staff, specifically the social worker. Regularly hospital social workers attempted to find placements for difficult-to-place patients by utilizing general practices of contacting facilities or entities that would be appropriate to support the person and awaiting follow up and records exchanges. In many of the situations DRVT reviewed, it was foreseeable that this generally effective effort by the social worker would not work for these specific patients due to their special characteristics. Often times even the social worker knew such efforts were futile, but due to policy and practice requirements valuable time was wasted. After dozens or more placements refused to accept the patient using this system, months had often gone by with the patient not being any closer to an actual appropriate discharge.

DRVT also identified that conflicts between inpatient medical providers and community-based providers regarding appropriate discharge plans for patients created additional, unnecessary discharge delays. All too often there was no immediate or effective intervention by any authority, such as AHS, to mediate and resolve these conflicts promptly, resulting in unnecessary delays. In some cases, due to long delays that were harmful to the patient, the patient was eventually discharged to services less robust than those recommended by either the inpatient or outpatient team, raising the risk of readmission or undue hardship in the community.

Recommendation:

Empower one entity to assure timely and appropriate discharges occur. Well-functioning mental health systems around the country place responsibility for discharge planning with a local entity (the local mental health authority model) that has prospective responsibility for a person's care whether they are in the community or temporarily being treated elsewhere. The current Designated Agency system in Vermont should be modified to address the need for a clear point of accountability for discharge planning, with the requisite funding and authority to implement State-wide *Olmstead* priorities.

Absent the assignment of authority for discharge planning at the local level, State Government should implement an effective system whereby specified AHS-level staff will be informed promptly (preferably within 24 hours) of the admission of a person who meets the profile of an individual with discharge challenges. AHS must then lead the discharge planning process to ensure that the person has a transition to an appropriate community setting within reasonable time parameters. Procedures should be put in place for (1) assessing barriers to discharge, (2) assigning responsibility for identifying supports and services to mitigate those barriers, (3) creating ever smaller timeframes between discharge planning meetings or deadlines to respond to continuing delays in discharge, (4) identifying how, what and when additional funds/staffing/resources will be allocated to end unnecessary inpatient or restrictive placements, and (5) establishing a system for referrals or complaints for inappropriate denials of service should be created with stakeholder input and implemented promptly.

State Government should institute more effective Utilization Management Practices for VPCCH and all DMH funded residential programs whereby the payor for care determines, and reports on, the extent to which the services delivered to a particular patient are provided in the least restrictive environment, are appropriate to the person's needs, and are of good quality. Importantly, augmenting and strengthening this practice will help determine if Vermont is making progress towards assuring that people stay in these intense, expensive and more restrictive settings no longer than is clinically necessary.

Lack of State Enforcement of Anti-Discrimination Laws

Often people with mental health conditions who also required nursing assistance or other non-mental health-related services are denied admission by privately run facilities based on the person's mental health condition. State Government has the duty and the ability to engage with those facilities to assure that they are not violating the ADA and Vermont's counterpart, the Fair Housing and Public Accommodations Act.⁵² To date DRVT is not aware of any effective effort in this regard by our State Government.

⁵² 9 V.S.A. §4500 *et. seq.*

Recommendation:

State Government should require the creation of a task force within the Attorney General's Office and in collaboration with AHS to promptly review complaints about denial of service decisions by community service providers based on disability discrimination. Timely review of such complaints by the Attorney General's Office and AHS is critical to having a useful impact on the alleged illegal act, and to cause systemic improvement. The Attorney General should be required to routinely report on the status of *Olmstead* compliance. The report should include efforts to educate the public on this *Olmstead* issue, facilitate filing complaints of possible discrimination for community placements, and provision of statistics and outcomes of reports made to the Attorney General's Office regarding the *Olmstead* mandate.

VII. Call to Action:

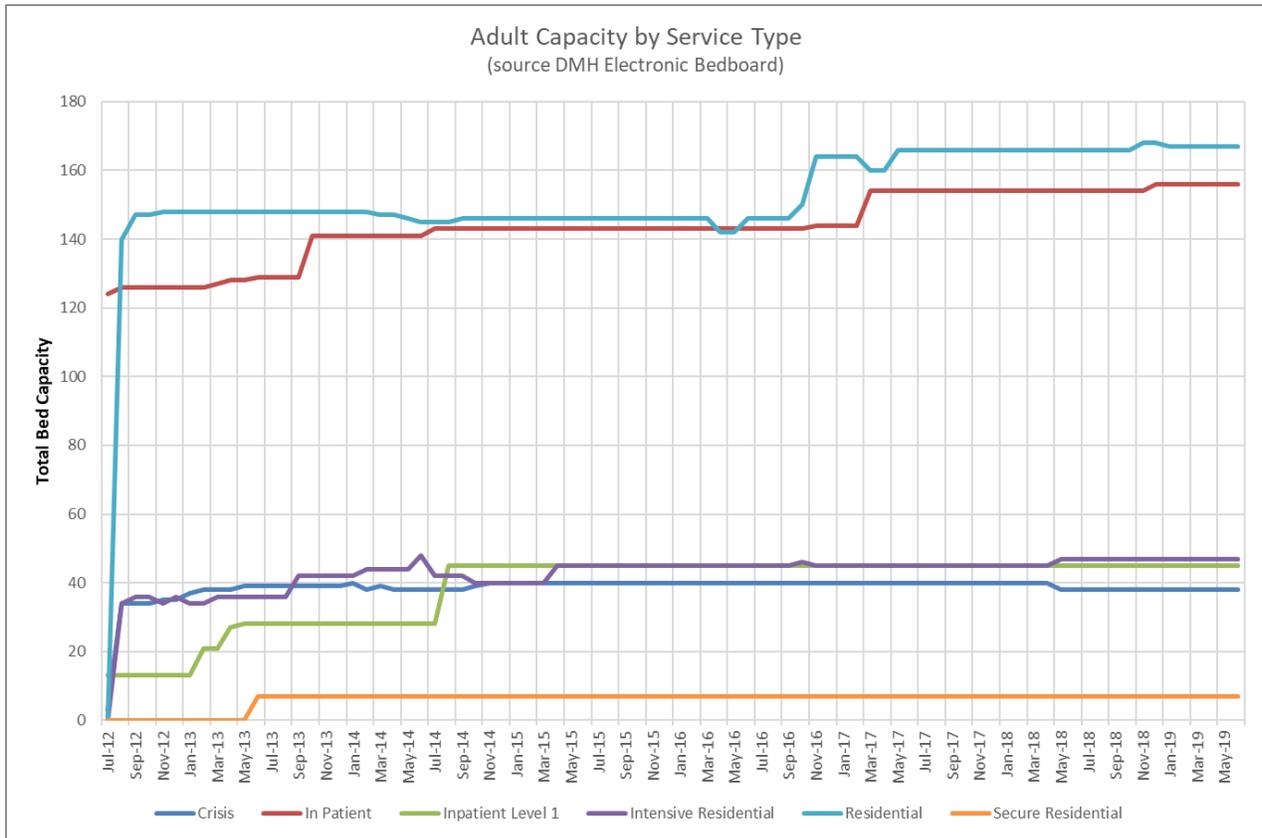
Thank you for reading this report on DRVT's 2020 *Olmstead* Initiative. Please talk to your friends, family, neighbors, and your elected representatives about your thoughts on the information put forth herein. Engage with your local peer advocacy and mental health service organizations to find out more about their specific local needs and how you can be more involved in supporting people with mental health conditions and those that work with them.

Together we can fix Vermont's *Olmstead* problem and prevent the harm that comes from unnecessary segregation and confinement in hospitals and other restrictive settings. When we pay attention to the life experiences of people involved and the available data, and focus our attention on getting the resources necessary to make living free from unnecessary institutionalization happen, we all win! Full integration of people with mental health disabilities matters!

Appendix A

Ward Nial Review of DMH Electronic Bed Board System

The data that I am sharing comes from the DMH Electronic Bed Board system. This is point in time data regarding bed capacity, beds used and beds closed. The bed board is a tool used by professionals in the system to help them find a place for people to transition to.



Notes:

- 1) The inpatient bed increase in March 2017 represents the VA hospital being included in the bedboard. These are not actually beds being added to the system.
- 2) The increase in residential beds in November 2016 is due to CMC Safe Haven, CSAC Hill House, CSAC Robinson House being reported on the bedboard. CMC Safe Haven (4 beds) have existed for many years, no confirmation if the same is true for the CSAC beds.

Key Community-Based Services Can Reduce Reliance on Hospital Admissions and Length of Stay

By Melodie Peet, M.P.H.

Extensive research demonstrated that persons who have been patients at psychiatric hospitals can be effectively served in the community. Virtually all individuals once served in hospitals can be served in the community when: (1) comprehensive services are available; (2) there is a public health approach to managing care across all locations of service; and (3) there is a recovery framework in the system of care.

Key services that reduce the need for hospitalizations include (1) crisis services, (2) Assertive Community Treatment (also called ACT or PACT), (3) intensive case management, (4) peer support, (5) supported employment, and (6) permanent supported housing. These services can be provided in conjunction with traditional office-based therapy and medication management. In many studies over long periods of time, the findings have been consistent: former hospital patients can transition to successful community living with the support of community-based services. ¹ Over the past 25 years, multiple studies in the U.S. and abroad have validated the significant impact that PACT teams have had on reducing hospital admissions and overall bed days. ² Similarly, strong research over the last three decades chronicles the ways that mental health systems around the world have implemented crisis response programs that are ever more adept at resolving psychiatric emergencies without resorting to hospital admissions. ³ More recent research also identifies the beneficial impact of supported employment and peer support services in allowing people to live stable lives in their communities.

Crisis Services

Even with effective ongoing supports, crises will arise that require an immediate, intensive response to help individuals stabilize in their communities and avoid hospitalizations. A comprehensive crisis response system that diverts people from hospitalizations includes crisis hotlines, walk-in crisis services, mobile crisis teams, and crisis stabilization beds.

Crisis hotlines often provide the first point of contact with the mental health system for individuals experiencing a psychiatric emergency. Emergency hotlines should operate 24 hours a day, 365 days a year and provide screening, triage, assessment, and information and referral services. Warm lines are intended to provide social support to persons who are not in crisis. They are often staffed by peer workers who can make access to care less daunting for people who need assistance. ⁵

Walk-in crisis services operate on the “urgent care” model that is prevalent in medical care settings. People can come to a center without an appointment and be seen quickly. Typically, they provide screening and assessment, brief treatment, and linkage to ongoing services. ⁶

Mobile crisis teams have been an essential anchor of psychiatric emergency systems for over 40 years. Typically, they are available 24 hours a day to respond to people in their communities. Team members go to homes, schools, emergency rooms, or wherever a person is in crisis.

Usually, these teams are staffed by licensed clinicians, with physician backup, and they may also include a peer support specialist. They are skilled at de-escalating crises and making clinical determinations regarding the need for hospital admission. Once the presenting incident is resolved, the teams play an important role in connecting people to ongoing services.⁷

Crisis residential, crisis apartments, or respites services provide a structured, safe environment where individuals may go to recover from a psychiatric emergency if they need to be out of their home environment for a short period of time, but do not meet clinical criteria for hospitalization. Depending on the model, staffing can include clinicians, paraprofessionals, peer support staff, or a mix of all three. After resolution of the crisis, staff connect the individual to ongoing services.⁸

Crisis Stabilization Units (CSUs) serve people who are experiencing an acute crisis and need 24-hour supervision and treatment for a brief period. While similar to traditional inpatient care, these programs are focused on crisis resolution and rapid return home.⁹ The typical length of stay in CSUs is less than 5 days.¹⁰ As with mobile crisis and crisis respite services, connecting individuals with ongoing support is a key element of crisis stabilization unit operations.

PACT and Intensive Case Management

PACT and Intensive Case Management are also core elements of the program array that minimizes or eliminates the need for hospitalization. PACT services are provided by a multi-disciplinary treatment team that has near daily contact with those receiving its services. It is an evidence-based practice (i.e. a practice that has been extensively studied and whose results have been demonstrated) that is used to support people who have not been successful using traditional services. Teams include psychiatrists, nurses, peers with lived experience, employment support specialists, and clinicians, so that they can address all aspects of a client's life.¹¹ Some areas of the country have also established specialized PACT teams to serve rural regions.¹²

Having a consistent connection with an individual or a team provides essential relational attachment for the persons trying to break a crisis driven pattern of repeated hospitalizations and brief community stays. Because of the frequency of their contracts, PACT team members have opportunities to de-escalate crises and avoid disruptive inpatient stays. As people learn more about the cycles of their illness through psychoeducation, they are better able to predict when they will need intensified supports and can communicate this to their PACT Team or case manager. PACT services are provided at an as-needed level of intensity. Generally, people require more intensive services when initially discharged, but less so over time (with increases to correspond with acute need), often transitioning from PACT to a different, less intensive, model of service delivery.¹³

Intensive case management provides varying levels of support over time to individuals who need assistance building skills to manage the challenges of life. A provider comes to the person's home and works with the individual to address needs and develop skills. With regular support, people are often able to maintain stability and integrate into their communities, identifying meaningful activities and natural supports. While some people may need only intermittent or monthly contact, others, particularly those with a history of hospitalization, likely need more frequent support.

Peer Support

Peer support is another important element that yields successful outcomes in community living.¹⁴ Peer specialists are people with lived experience of mental illness and recovery who can offer support from a position of empathy and understanding. They give hope to people who are struggling with developing better responses to the challenge of living with a serious mental illness. Peers are often included as members of mobile crisis teams and can also be paired with an Intensive Case Manager to increase the support for an individual. Peer drop-in centers that offer more informal opportunities to engage with peers, receive support, and build community are another way to use the skills and wisdom that peers afford.

Supported Employment

Supported Employment is an evidence-based practice that provides the services and supports necessary to help individuals with serious mental illness gain the necessary skills to find employment in integrated and competitive work environments. Additionally, staff work with the individuals and employers to sustain job tenure over time.¹⁵

Permanent Supported Housing

Permanent supported housing, consisting of safe and affordable housing and the support services that enable people to remain stable in those homes, is the foundation to successful community living for many individuals living with a psychiatric disability. Permanent supported housing providers assist people with a range of activities such as locating housing, working with landlords, supporting employment or obtaining benefits, and facilitating connections with clinicians and other services. People in permanent supported housing choose their own roommates, or choose not to have a roommate.¹⁶ Having a stable living situation that is not tied to compliance with a proscribed treatment regime is a key precursor to recovery and often eliminates crises that result in hospitalizations.¹⁷

Impact of Prolonged Hospital Stays

Psychiatric inpatient hospitalization can provide necessary therapeutic support under limited circumstances, but these benefits come with considerable risks that include:

- Loss of control over one's own life
- Stigma
- Loss of basic human rights
- Physical injury
- Psychological trauma
- Potential retraumatization
- Segregation away from one's family, home, social network, and source of income

The potential for these consequences varies depending on the person's underlying condition, the environment on the hospital unit; the degree to which the individual is involved in his or her treatment decisions; the training and attitudes of staff; and the degree to which a person remains connected to his

or her prior life while hospitalized. The potential for negative consequences from these risks increases with the duration of hospital stays.

Authorities in the field since the 1960s have confirmed the above. In Erving Goffman's seminal work on institutions and their impact on people, he identifies disabilities as "attributes that are deeply discrediting" and further notes that because of this, people with disabilities are marginalized, mistreated, and stigmatized by society.¹⁸ The harms caused by institutional settings are collectively known as "institutionalization syndrome," which is now used to describe a set of maladaptive behaviors that are evoked from the pressures of living in any institutionalized setting."¹⁹ Patients become habituated to the routines, structures, and lack of control that are central to life in hospitals. They become deskilled and fearful about resuming their lives in the community.

As our understanding has grown regarding the impact of traumatic events on an individual's well-being, there has been a parallel rise in awareness of the importance of listening to the voices of mental health consumers regarding what they experience as helpful versus harmful in their interface with the treatment system.²⁰ The experiences that people receiving services have shared with me over the years evoke the concept of "sanctuary trauma" a term coined to define the experience of individuals who turn to social systems for help, only to find themselves traumatized or retraumatized by those very institutions.²¹

In an important study of consumer self-reports about their experiences on inpatient units, Karen J. Cusack, et al, interviewed 57 individuals who had used the public psychiatric hospitals that were part of the South Carolina DMH system.²² Forty-seven percent reported experiencing a DSM IV-defined traumatic event while in the hospital. The most frequent events were witnessing physical assaults (22%) and experiencing a physical assault (18%).²³ Summarizing the results of the study, the authors stated, "this study provides initial empirical support for concerns raised by consumer and advocacy groups that the psychiatric setting can be a frightening and/or dangerous environment. In general, the results of this study indicate that mental health consumers have experienced a number of traumatic, humiliating, or distressing events during their hospitalization. In addition, results indicate that consumers are adversely affected by these experiences."²⁴

People with Mental Illness, Like People without Disabilities, Prefer to Live in the Community

Available studies show that people with mental illness nearly universally prefer to live in integrated community settings rather than in institutions. One article reviewed the findings of eight studies that surveyed consumers about their experience of community re-entry following inpatient care and their preferences for hospital versus community living.²⁵

The reviewed studies surveyed a total of 415 clients with severe disabilities and extended periods of hospitalization. They lived in the U.S., the United Kingdom, and Canada. When asked about their preference for community versus hospital living, 98% stated a clear preference for the community. Reasons for this choice included the freedom, autonomy, mobility, privacy safety, and proximity to friends and family that community living afforded. Conversely, participants identified the disadvantages of hospitalization as becoming stigmatized and rejected, and the loss of autonomy, privacy and dignity. Given choice, people want to live in communities, surrounded by people that they choose, engaging in activities that are gratifying to them.

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- 1 McGraw, J., Bond, G., Dretan, L., et al (2006) "A multisite study of Client Outcomes in Assertive Community Treatment", *Psychiatric Services*, 1995, 46:696-701; Olfson, M. (1990) Assertive Community Treatment: An Evaluation of the Experimental Evidence", *Hospital and Community Psychiatry*, 1999, 41:634-641; Bond, G., Miller, L., Krumwred, R., et al, "Assertive Case Management in Three CMHCS: A controlled Study", *Hospital and Community Psychiatry*, 1988, 39:422-418
- 2 Clausen, et al. (2016) "Hospitalization of Severely Mentally Ill Patients With and Without Problematic Substance Use before and During Assertive Community Treatment: An Observational Cohort Study," *MC Psychiatry* 16:125
- 3 See NASMHPD, Assessment #3: Crisis Services' Role in Reducing Avoidable Hospitalization (2017); Substance Abuse and Mental Health Services Administration, "Crisis Services: Effectiveness, Cost Effectiveness, and Funding Strategies," HHS Publication No. (SMA)-14-4848
- 4 Luciano, A. et al, (October 2016) "Hospitalization Risk Before and After Employment Among Adults with TS., Mueser, K.T., & Kupper, Z. (2014), "Long-term effectiveness of supported employment: 5-year follow-up of a randomized controlled trial," *Am J Psychiatry*, 171(11), 1183-1190; Chien, W.T., & Thompson, D.R. (2013) "An RCT With Three-Year Follow-Up of Peer Support Groups for Chinese Families of Persons With Schizophrenia," *Psychiatric Services*, 64 (10), 997-1005; Dixon, L. B., Holoshitz, Y., & Nossel I. (2016), Treatment engagement of Individuals experiencing mental illness; review and update," *World Psychiatry*, 15 (1), 13-20.
- 5 See Substance Abuse and Mental Health Services Administration, *supra* note 43 at 11.
- 6 Technical Assistance Collaborative, A community-Based Comprehensive Psychiatric Crisis Response Services: An Informational and Instructional Monograph, April 2005, 9.
- 7 *Id.* At 9-10
- 8 Technical Assistance Collaborative, *supra* note 48 at 10.11
- 9 See Technical Assistance Collaborative, *supra* note 48 at 11: Substance Abuse and Mental Health Services Administration, *supra* note 43 at 9-10
- 10 Technical Assistance Collaborative, *supra* note 48 at 11. .
- 11 Substance Abuse and Mental Health Services Administration, *supra* note 43 at 5-6, 14
- 12 Huz, S., et al. (June 2017) "Time in Assertive Community Treatment: A Statewide Quality Improvement Initiative to Reduce Length of Participation," *Psychiatric Services* 68:6.
- 13 *Id.*
- 14 See HHS, Office of Disability, Aging and Long-Term Policy (2015), An Assessment of Innovative Models of Peer Support Services in Behavioral Health to Reduce Preventable Acute Hospitalization and Readmission; Chien, W.T., *supra* note 44 at 997-1005; Dixon, L.B., *supra* note 44 at 13-20.
- 15 See Drake, R. et al. (2016) "Individual Placement and Support Services Boost Employment for People With Serious Mental Illnesses, But Funding is Lacking," *Health Aff (Millwood)*, 35 (6), 1098-1105; Hoffmann, H. *supra* note 44 at 1183-1190.
- 16 See Rog, D. et al. (2014) "Permanent Supportive Housing: Assessing the Evidence," *Psychiatric Services*, 65(3), 287-294
- 17 See NASMHPD, Assessment #4: The Role of Permanent Supportive Housing in Determining Psychiatric Inpatient Bed Capacity (2017).
- 18 Goffman, E., *Notes on the Management of Spoiled Identity*, (1963), 3. See also Chow, W. & Priebe, S. (2013) "Understanding Psychiatric Institutionalization: A Conceptual Review," *BMC Psychiatry*, 13:169, 9-10.
- 19 Johnson, M. and Rhodes, R., (Spring 2007) "Institutionalization: A Theory of Human Behavior and the Social Environment," *Advances in Social Work*, Vol. 8 No. 1, 219.
- 20 Cusak, K., et al., (May 2003) "Trauma Within the Psychiatric Setting: A Preliminary Empirical Report." *Administration and Policy in Mental Health*, Vol. 30:5, 454 (<http://psychrights.org/articles/psychiatrictrauma.pdf>).
- 21 *Id.*
- 22 *Id.* at 455.
- 23 *Id.* at 457
- 24 *Id.* at 458
- 25 Davidson, L. et al., (1996) "Hospital or Community Living? Examining Consumer Perspectives on Deinstitutionalization," *Psychiatric Rehabilitation Journal*, Vol. 19:3, 52-55.

Appendix C

DRVT *Olmstead* Initiative Charts 2/2020

In the past six months Disability Rights Vermont (DRVT), Vermont's designated Protection & Advocacy System and Mental Health Ombudsman, has received requests for help regarding more than twenty-seven people who were stuck in inpatient hospital units after no longer needing that expensive, restrictive level of care, but had no appropriate community based placement options due to Vermont's insufficient community mental health treatment and support capacity.

Individual cases were identified through regular outreach and monitoring of psychiatric facilities, and referrals from hospital staff. For each of the 27 individuals, DRVT identified the reason for admission, diagnoses, housing at the time of admission, services at time of admission, date deemed sub-acute, length of stay after no longer needing inpatient level of care, discharge recommendations, and barriers to discharge.

