RE-IMAGINING MAINE'S ADULT MENTAL HEALTH SYSTEM

Consumer Council System of Maine
A Voice for Consumers of Mental Health Services

October 2020

A. Executive Summary

The following report synthesizes key themes and takeaways from seven forums hosted by the Consumer Council System of Maine ("CCSM") as part of the series on "Re-inventing the Adult Mental Health System." Using the content from these forums, this report identifies and outlines nine major areas in need of improvement within the adult mental health system in Maine and proceeds to transform the themes into concrete recommendations that should serve as action items for the State of Maine. These recommendations include, if applicable, structural changes to the system.

Mental health systems reform cannot be based on cost containment. Such reform must be based on addressing the needs of the mental health community through sustainable, predictable, and standardized practices. Inconsistencies in the very access to services, ranging from housing to medication to acute services, stymies an individual's treatment and progress, and can often lead to worsening conditions and outcomes for the individual and greater costs for the State. Individuals require a mental health system that reliably provides them with the services they require regardless of where they live and the degree to which they are informed about the system and how it works. The nine key areas for improvement in the mental health system include:

1. Housing
2. Empowerment
3. Immediate Care and Medication
4. Support Systems
5. Alternative Therapy
6. Prisons and Jails
7. Systemization of Care
8. Consent Decree
9. Employment Opportunities

B. Areas for Improvement

1. Housing

The quality, stability, and affordability of housing is strongly correlated with health outcomes. Indeed, housing is one of the best researched social determinants of health, and the results of the research are clear: the more stable, safe, and affordable housing is and the more robust the neighborhood, the healthier the individual.[1] For individuals with mental illness, who are more likely than those without mental illness to suffer from loneliness[2] and other secondary illnesses[3], the need for quality housing is paramount.

The desire for independent living, in which individuals have the capacity and tools to cook, clean, and budget for themselves, is also clear. Individuals participating in the forums cited anecdotes of other individuals who, upon developing the skills necessary to live independently, experienced increased overall health and in fact, were more likely to decrease their use of and/or reliance on the mental health system. In the context of a federal housing certificate program, researchers found that participants in the program with "chronic mental illness" experienced positive mental health outcomes as a result of independent living gained through the program.[4]

The antithesis of independent living is constrained, dependent living which tends to deprive individuals of opportunities to gain skills that lead to independence. In Maine, dependent living for persons with mental illness, in large proportion, takes the form of Private Non-Medical Institutions ("PNMIs"). Although PNMIs provide housing stability, research shows that individuals strongly prefer supportive, transitional housing over segregated living in group or nursing homes.[5] Transitional housing is vital for homeless individuals, individuals desiring to

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[1] Taylor, Lauren, "Housing and Health: An Overview of the Literature," *Health Affairs*, June 2018.
[2] Mushtaq, Raheel et al., "Relationship Between Loneliness, Psychiatric Disorders and Physical Health: A Review of the Psychological Aspects of Loneliness," *Journal of Clinical and Diagnostic Research*, September 2014.
[3] "Chronic Illness and Mental Health: Recognizing and Treating Depression," *National Institute of Health*, available at https://www.nimh.nih.gov/health/publications/chronic-illness-mental-health/nih-15-mh-8015_151898.pdf.
[4] Newman, Sandra et al., "The Effects of Independent Living on Persons with Chronic Mental Illness: An Assessment of the Section 8 Certificate Program," *Milbank Quarterly*, 1994.
[5] Stephen H. Leff *et al.*, "Does One Size Fit All? What We Can and Can't Learn from a Meta-Analysis of Housing Models for Persons with Mental Illness," *Psychiatric Services*, April 2009, Vol. 60, No. 4, pp. 473-482.

escape substandard living conditions, individuals leaving state or private psychiatric institutions and individuals who are moving from community residential programs to more independent living arrangements. Research shows that transitional housing programs, through which individuals are provided with rental subsidies, assistance in paying rent, and guidance in understanding their rights and responsibilities under their leases, effectively help consumers of mental health services to maintain stable housing.[6]

In Maine, the Bridging Rental Assistance Program ("BRAP") operates as a facilitator of transitional housing by providing a rental subsidy and assisting consumers with finding independent housing throughout Maine. Recognizing the increasing difficulty of individuals to meet the requirement that they contribute 51% of their income toward their monthly rent, particularly in the wake of COVID-19, the State decreased this income contribution requirement to 40%. In addition to this prudent policy change, the State should consider re-allocating funds from PNMIs, which deprive individuals of independence, to BRAP. By doing so, the State could increase the total number of individuals it can support through BRAP and decrease the number of individuals on wait lists for the program.

Additionally, many individuals have reported that, while they have secured vouchers for housing through BRAP, there is no housing available. This may be due in part to landlords refusing to accept vouchers. In response to this issue, the State should educate landlords about the process of accepting certificates and the way in which billing and payments are handled following their acceptance. Furthermore, the State could increase the caps currently in place on rental prices to allow people to live where they want to live. For instance, an individual who works and/or who has developed a community in the Portland area would currently be unlikely to secure Portland-area housing given Portland rental prices and the caps. The BRAP program should work to allow people to live in the communities in which they have the greatest number of connections and thus the highest likelihood for well-being.

[6] Dohler, Ehren et al., "Supportive Housing Helps Vulnerable People Live and Thrive in the Community," *Center on Budget and Policy Priorities*, May 2016.

2. Empowerment

"Give a man a fish, and you feed him for a day. Teach a man to fish, and you feed him for a lifetime." - unknown

Feedback provided in the forums coupled with research indicates that empowerment, achieved by increasing an individuals' control over her health and lifestyle decisions, leads to greater life satisfaction among persons with diagnoses of mental illness.[7] In many cases, individuals, simply by being labeled with a mental illness, suffer chronic disempowerment in the form of institutionalization, segregation, and community ostracism. In general, consumers of mental health services in Maine should be involved in every decision that impacts their lives and should be involved in meaningful ways in the transformation of the mental health system. Stakeholder engagement is viewed as crucial to many areas of planning and development – school systems involve parents and students in planning events and budgeting, state licensing systems involve professionals in developing standards, among many other examples – and the situation should be no different for individuals whose lives are drastically impacted by the structure and functioning of the mental health system. Such individuals must be involved in designing and envisioning changes to the system that so greatly affects their day to day life. Since people best know what works for them and which services positively impact their lives, forum participants recommended that the State seek the opinions of people using the services, before funding those services.

Three specific areas (described below) in which the State should intervene to increase empowerment among people with mental illness include:

(a) transportation,

(b) technology access, and

[7] Kilian, Reinhold et al., "Indicators of empowerment and disempowerment in the subjective evaluation of the psychiatric treatment process by persons with severe and persistent mental illness: a qualitative and quantitative analysis," *Social Science & Medicine*, September 2003.

(c) seeking input from mental health consumers in meaningful and systematic ways.

(a) Transportation

The ability to secure safe, reliable transportation to medical appointments, social events, grocery stores, peer recovery centers, and other places, is essential to sustaining health and well-being. Research shows that individuals are less likely to access needed services when they face transportation difficulties[8]; indeed, transportation is often cited as a major barrier to health care access.[9] For people with mental illness, missing an appointment because of transportation problems could have long term disastrous impacts on mental health, and could potentially lead to a crisis. Additionally, as a consequence of missing an appointment due to transportation problems, an individual may have difficulty securing a replacement appointment, thereby causing potentially grave detriment to his or her health and treatment process.

Forum attendees reflected the widespread presence of transportation problems in Maine, specifically with regard to Logisticare. Attendees cited situations in which individuals were unable to secure a ride to an appointment, were dropped off at the wrong location, or were able to secure transportation *to* their desired location, but were not picked up and brought home. Attendees lamented that, upon providing Logisticare with feedback reflecting these problems, they were met with inadequate or no responses.

As a remedy to these persistent problems and the lack of attention to them, attendees suggested the implementation of an appeal/complaint process through which service recipients could submit formal complaints, perhaps directly to the Department of Health and Human Services. Currently, although Logisticare offers a complaint line, consumers complain that they do not receive call backs from the organization and are frustrated with the lack of response. If the State were to implement a formal complaint process, under which a State agency would receive

[8] "How Transportation Impacts Public Health," *The Sycamore Institute*, February 2017.
[9] "Healthcare Disparities & Barriers to Healthcare," *Stanford Medicine*, available at http://ruralhealth.stanford.edu/health-pros/factsheets/disparities-barriers.html.

and process the complaint, Logisticare would be held more accountable for issues related to the services they provide and the likelihood that complaints would be ignored would decrease.

In addition to the suggestion regarding an improved complaint process for Logisticare, attendees suggested a broader, state-wide implementation of Neighbors Driving Neighbors, or an equivalent program. Neighbors Driving Neighbors, which currently operates in Belgrade, Fayette, Mount Vernon, Rome, and Vienna, is a non-profit organization that provides free transportation for adults for grocery trips, errands, medical appointments and the like. The organization operates on a volunteer basis, wherein neighbors donate their time, vehicle, and gas. The State should expand this model to cover all rural areas, soliciting local volunteers and providing an organized internal network to ensure that individuals in rural areas could access a reliable database of willing and able drivers. The State should also incentivize local drivers to participate in the program by offering reimbursement for mileage.

(b) Technology Access

Similar to transportation, technology access is key for independence and empowerment. Forum attendees emphasized the need, particularly in the increasingly internet-based work and personal lives we will lead during and after COVID-19, for widespread, reliable access to technology. Of particular importance is access to telehealth, which allows individuals who are unable to attend in person-meetings with their doctors due to health or other reasons, to receive health advice from physicians remotely. The risks introduced by COVID-19 have increased the demand for telehealth precipitously. Before the start of the COVID-19 public health emergency, less than 0.1% of Medicare primary care visits were provided through telehealth. In April, only one month after the public health emergency began, nearly half (43.5%) of Medicare primary health visits were provided through telehealth.[10] Although providers in both rural and urban counties saw increases in telehealth adoption and utilization, the increase in rural areas was smaller. This disproportionate use of telehealth is likely due to barriers in rural areas, including

[10] "HHS Issues New Report Highlighting Dramatic Trends in Medicare Beneficiary Telehealth Utilization Amid COVID-19," *Department of Health and Human Services*, July 2020, available at https://www.hhs.gov/about/news/2020/07/28/hhs-issues-new-report-highlighting-dramatic-trends-in-medicare-beneficiary-telehealth-utilization-amid-covid-19.html.

limited access to high speed internet, which affects the ability of patients to participate in video consultations, monitor their health at home, and transmit health information to their physicians, and limited access to smartphones, which are required for many mobile health and patient monitoring systems, among others barriers.[11]

Maine should view this present increase in demand as an opportunity to expand telehealth access permanently, thereby increasing telehealth access among consumers of mental health services who, even in the absence of a global pandemic, often have difficulty securing transportation to in person meetings. Expanding telehealth in Maine could be achieved by increasing access to high speed internet among rural communities, improving access to cellular telephones, and providing training opportunities to ensure that individuals know how to access telehealth services. Importantly, even with training and access, many individuals will face economic barriers; namely, the high cost of broadband. To alleviate this problem, congregate living facilities should offer Wi-Fi access at no costs to their indigent residents, and potentially at a pro-rata, reduced cost to those who can afford to contribute. Residing in a congregate facility can be isolating, particularly if transportation is difficult to procure; access to a broader, online community would contribute to increased overall wellbeing.

(c) Consumer Input

In general, consumers of mental health services in Maine should be involved in every decision that impacts their lives and should be involved in meaningful ways in the transformation of the mental health system. Since people best know what works for them and which services positively impact their lives, forum participants recommended that the State seek the opinions of people using the services, before funding those services. The DHHS should hold focus groups with consumers of mental health services regarding what is funded within the mental health system. CCSM and others can assist in identifying experts who use the services and provide regular, digestible trainings on self-advocacy and grass-roots involvement.

[11] "Barriers to Telehealth in Rural Areas," *Rural Health Information Hub*, available at https://www.ruralhealthinfo.org/toolkits/telehealth/1/barriers.

3. Immediate Care and Medication

Findings from clinical research and accounts of forum attendees illustrate the importance of fast, convenient, and affordable access to medication and services for consumers of mental health services. Nearly six in ten Americans have sought or wanted to seek mental health treatment for themselves or a loved one, and over seventy-five percent of Americans believe mental health is just as important as physical health.[12] For many mental health consumers, access to health care services and medication is essential to their successful treatment and recovery. In contrast, limiting access to essential care and treatment can have detrimental effects. Indeed, research has shown that reducing access to medications results in treatment lapses or discontinuation by almost 30% of patients.[13] Consequently, ensuring continued access to medication and improving rapid access to care is an essential component of a successful mental health system, one that benefits mental health consumers and ultimately leads them toward healthy and productive lives in their communities.

Despite the importance of rapid, convenient, and affordable access to medication and services, there are numerous barriers to the ability to seek mental health treatment. First, high drug costs and insufficient insurance coverage are seen as the top barriers for accessing mental health care, with one in four Americans (25%) reporting having to choose between getting mental health treatment and paying for daily necessities.[14] The challenges associated with accessing mental health treatment due to cost manifest themselves in multiple ways for those using mental health services. People with diagnoses or labels of mental illness are less likely to have health insurance than those without mental health problems, and even those who do have health insurance have substantial out-of-pocket expenditures for medical care; approximately fourteen percent of working-age patients have out-of-pocket expenditures that exceed twenty

[12] "America's Mental Health 2018," *Cohen Veterans Network*, October 10, 2018.
[13] "Issue Brief: Access to Medications," *Mental Health America*, available at https://www.mhanational.org/issues/issue-brief-access-medications.
[14] Cohen Veterans Network, "New Study Reveals Lack of Access as Root Cause for Mental Health Crisis in America," *National Council for Behavioral Health*, December 10, 2018.

percent of their annual family income.[15] These factors severely impede access to care for those most in need.

Additionally, long wait times limit access to care and increase the perception that access is insufficient. The acute shortage of psychiatric services available is particularly problematic, especially for individuals with immediate need. Indeed, despite the fact that the vast majority of Americans believe that patients should not have to wait longer than a week to receive treatment, 38% of American adults report having had to wait longer than a week for mental health services.[16] This discrepancy between public opinion and reality highlights the clear gap between the need for fast, affordable care and the ability to access it. Lastly, access to mental health services is particularly challenging for those living in rural communities and low-income households.[17] This creates additional challenges for those with mental health issues living in Maine, where barriers to access are particularly pronounced, wait lists are long and there are not enough services.

Issues surrounding immediate and convenient access to care and medication were also recurring themes in the forums, with many participants expressing frustration and anxiety over both the complexity of accessing their medication, particularly when in immediate need; as well as the inequality in access to care. As discussed above in Section B.2 – Empowerment, access to reliable transportation and technology is fundamental to a person's ability to access the care that they need. However, despite its importance, many forum participants characterized their experience utilizing transportation and technology as a means to access care as "scarce and unreliable". For example, forum participants discussed their personal experiences being stranded far from home or missing important appointments or even losing their jobs, because their transportation did not show up at all. As a result, services that should be a bridge connecting people with the services and supports they need actually operates as a deterrent. Improving the reliability of transportation services and expanding programs such as Neighbors Driving

[15] Rowan, Kathleen, Donna McAlpine and Lynn Blewett, "Access and Cost Barriers to Mental Health Care by Insurance Status, 1999 to 2010," *Health Affairs*, October 2013; 32(10): 1723–1730.
[16] "America's Mental Health 2018," *Cohen Veterans Network*, October 10, 2018.
[17] "America's Mental Health 2018," *Cohen Veterans Network*, October 10, 2018.

Neighbors and offering technical support and equal access to online services will greatly improve access to care for those with mental health needs.

Improving other mechanisms of access, such as same day access and long term supply of medications, were also cited by forum participants as important changes that need to be made.

4. Support Systems

For consumers of mental health services, a strong support system is a multifaceted support system. Forum participants discussed the positive impact of having multiple options within a peer support network that foster independence, empowerment, community engagement, and understanding. Programs and organizations such as The Living Room Project, ADVANCE 7-Day (Veteran based), Western Mass Recovery Learning Community, Peer Respite, Peer Warm Lines, and other successful peer support projects offer incredibly helpful opportunities for people to connect with others experiencing life in similar ways and to deal with the trauma that is causing the thoughts and behaviors resulting in labels of mental illness and cycles of medication and hospitalization.

Forum participants were eager to see expanded access and improved quality of these programs, and made a number of suggestions on where Maine can improve on these fronts. For example, some forum participants discussed how helpful virtual support for veterans have been, especially during the pandemic. However, as discussed in Section B.2 – Empowerment, limited technology access is a serious barrier for many Maine people with mental illness, and as a result diminishes the benefit this resource provides. Addressing the limitations of technology access would foster greater participation in successful virtual programs, which participants are eager to utilize even post-pandemic.

Additionally, forum participants regularly cited peer support recovery centers ("PSRCs") as instrumental in improving their mental health. PSRCs provide a safe place for people to engage in one-on-one support, recovery classes, alternative therapy, and support groups. PSRCs also provide key opportunities for mental health consumers to connect with one another, and connect with their community. However, the number of PSRCs available is limited, and funding and transportation challenges stifle their ability to be fully utilized. Multiple forum participants

discussed the challenges they face with transportation, and many see MaineCare as an opportunity to address these challenges. For example, expanding MaineCare to include reimbursement for travel to and from peer support recovery centers would not only increase participation among Mainers who have already experienced its benefits, but also expand the reach of PSRCs to those who have not yet utilized its benefits.

Creating incentives to improve and expand programs for peer support specialists, such as helping to pay for education that would support training, would not only increase the breadth of the peer support network by encouraging vocational participation, but would also aid in the effectiveness of these positions. The better equipped the peer support system is, the more support it can offer those with mental illness in reaching their full potential.

Forum participants suggested that DHHS explore and then fund alternatives to traditional mental health treatment by incentivizing current mental health provider agencies to step up and offer innovative, yet proven to be successful, additions to their traditional approach. DHHS, in partnership with consumers of mental health services, should make decisions as to effective alternatives to fund, such as the Living Room Project, and then pilot them or put them out to bid or otherwise incorporate them into the existing system. Additionally, as a potential funding source for expanding access to transportation services to and from PRRCs (and other key community resources), the state could tap into Federal Department of Transportation grants.

5. Alternative Therapy

In addition to alternative models of service provision, forum participants felt strongly that the mental health system should be able to offer alternative and individualized therapy options. While traditional medical and therapeutic methods have improved over the years, they often do not completely lessen or eliminate the symptoms of mental illness or the side effects of medication. As a result, many people (over one-third of U.S. adults) turn to alternative therapies as complementary treatment to improve health and wellbeing.[18] For those with mental illness, alternative therapies also provide a substantial source of care, with a reported 35% of people with

[18] Clarke, Tainya et al., "Trends in the Use of Complementary Health Approaches Among Adults: United States, 2002-2012," *National Health Stat Report*, February 10, 2015: (79) 1-16.

a mood, anxiety, or substance abuse disorder using alternative therapies in response to their mental health problems.[19] Alternative therapies can include acupuncture, biofeedback, chiropractic, energy healing, exercise or movement therapy, herbal therapy, massage therapy, and relaxation and meditation techniques, among others.[20]

People often experience a variety of symptoms, including:[21]

- Feeling sad or down
- Confused thinking or reduced ability to concentrate
- Excessive fears or worries, or extreme feelings of guilt
- Extreme mood changes of highs and lows
- Withdrawal from friends and activities
- Significant tiredness, low energy or problems sleeping
- Detachment from reality (delusions), paranoia or hallucinations
- Inability to cope with daily problems or stress
- Trouble understanding and relating to situations and to people
- Problems with alcohol or drug use
- Major changes in eating habits
- Sex drive changes
- Excessive anger, hostility or violence
- Suicidal thinking

Importantly, research has shown that alternative therapies can be particularly beneficial for those with mental illness in that the reported benefits of alternative therapies typically help address many of these issues, as seen in the summary table below.

[19] Woodward, A.T. et al, "Use of complementary and alternative medicines for mental and substance use disorders: A comparison of African Americans, black Caribbeans, and non-Hispanic whites," *Psychiatric Services*, October 2009, 60(10): 1342-1349.
[20] Woodward, A.T. et al, "Use of complementary and alternative medicines for mental and substance use disorders: A comparison of African Americans, black Caribbeans, and non-Hispanic whites," *Psychiatric Services*, October 2009, 60(10): 1342-1349.
[21] "Mental illness," *MayoClinic*, available at https://www.mayoclinic.org/diseases-conditions/mental-illness/symptoms-causes/syc-20374968.

Select Symptoms of Mental Illness and Reported Benefits of Alternative Therapy[22]		
Symptom	**Frequently Reported Practice(s)**	**Reported Benefit**
Feeling sad or down	Meditation	Increased emotional calmness
Withdrawal from friends and activities	Yoga and Religious/Spiritual Activities	Decreased social isolation
Inability to cope with daily problems or stress	Meditation and Guided Imagery	Increased capacity to cope
Confused thinking or reduced ability to concentrate	Meditation	Improved concentration
Significant tiredness, low energy or problems sleeping	Herbal therapy and nutritional supplements	Improved sleep and increased energy
Extreme mood changes of highs and lows	Meditation, Massage, Yoga, and Guided Imagery	Increased emotional stability
Excessive fears or worries, or extreme feelings of guilt	Religious/Spiritual Activities, Meditation, Massage, Guided Imagery	Increased emotional calmness, increased self-esteem, and increased inner strength/empowerment

Participants in the forum discussed their personal experience with alternative therapies, and cited therapies such as equine therapy, art and music therapy, and reiki, among others, as having brought them peace and helped them address trauma. One forum participant noted that while "pills have a place," counseling offered through a referral by their primary care doctor was the blessing that they needed; "it made the difference in getting me out of crisis mode." Other forum participants agreed with this sentiment, and noted that funding for alternative therapy would be valuable because "having options instead of meds" felt important. Maine should consider expanding funding for and access to alternative therapies given the clear evidence of their potential to serve as an effective addition to or replacement for traditional mental health intervention.

[22] Russinova, Zlata et al., "Use of Alternative Health Care Practices by Persons with Serious Mental Illness: Perceieved Benefits," *American Journal of Public Health*, October 2002.

6. Prisons and Jails

People with diagnosed mental illness are disproportionately represented in prisons and jails, both nationally and in Maine. Individuals with diagnoses of mental illness are 4.5 times more likely to be arrested compared with those in the general population, and once incarcerated serve longer than persons without diagnosed mental illnesses who committed comparable crimes.[23] Moreover, incarcerated persons with mental health needs cost taxpayers more per day of incarceration than those without any mental health issues.[24]

The lack of support, treatment, and community-based resources for persons with mental illness or labels of mental illness have ultimately resulted in people with mental illness getting swept up in the criminal justice system, which is ill-equipped to provide an appropriate level of care and tends to engage in a "diagnosis game" in which responsibility for those with mental health needs shifts from one institution to another. In this way, consumers of mental health services have largely been "criminalized" in Maine, and often face discrimination, misunderstanding, victimization, lack of treatment, and violations of their civil rights and liberties by the criminal justice system.

Treatment is critical, but lacking within prisons and jails in the State of Maine. There is insufficient space to safely house persons with behaviors associated with a diagnosis of mental illness, and there are inadequate means to effectively treat and habilitate them.[25] Research shows that with effective treatment, people with serious mental illness are no more likely to commit violent acts than those without serious mental illness.[26] This underscores the importance of effective treatment and the positive impact of community-based resources and a sufficient

[23] "The Criminalization of People with Mental Illnesses in Maine," *United States Commission on Civil Rights*, May 2019, available at https://www.usccr.gov/pubs/2019/07-30-Maine-Criminalization-Mental-Health.pdf.
[24] "The Criminalization of People with Mental Illnesses in Maine," *United States Commission on Civil Rights*, May 2019, available at https://www.usccr.gov/pubs/2019/07-30-Maine-Criminalization-Mental-Health.pdf.
[25] "The Criminalization of People with Mental Illnesses in Maine," *United States Commission on Civil Rights*, May 2019, available at https://www.usccr.gov/pubs/2019/07-30-Maine-Criminalization-Mental-Health.pdf.
[26] "Risk Factors for Violence in Serious Mental Illness," *Treatment Advocacy Center*, June 2016, available at https://www.treatmentadvocacycenter.org/key-issues/violence/3633-risk-factors-for-violence-in-serious-mental-illness.

support system (see Section B.4 – Access to Support Systems). Given the lack of space and resources within jails and prisons to hold and provide adequate care for individuals, the State should consider providing more visibility into and trainings on alternative sentencing.

Additionally, although alternative sentencing is available for all Maine residents who meet certain defined eligibility criteria, there are barriers to the program that may be particularly acute for individuals in the mental health system. In particular, such individuals may not be aware of the program or of its requirements, and may not have adequate legal representation necessary to gain such insight. Furthermore, the fees associated with the program may be prohibitive for certain individuals. The State should consider fee waivers for individuals in the mental health system, as well as provide greater informational transparency about the contours and requirements of the program.

Importantly, there are opportunities before, during, and after incarceration to support those with mental health needs and enable such individuals to thrive in Maine's communities. Immediate access to care and medication (Section B.3), effective support systems (Section B.4), and a systemization of care (Section B.7) are examples of themes highlighted during the forums as important areas of improvement that would foster successful integration of people with mental illness into the community and limit the risk of their absorption into the criminal justice system. During incarceration, access to medication is essential – and yet, medication continuity in prison is seriously lacking. Indeed, research has found that 40-50% of inmates taking medication for a mental health condition at admission did not receive medication in prison.[27]

Participants in the forum discussed waiting days for their medications to arrive, and explained that having a liaison (e.g., a nurse) between the jail and their healthcare provider would help ensure those in need of medication do not fall through the cracks upon incarceration. Post incarceration, re-integration services were emphasized by participants in the forums as crucial to successful rehabilitation. This sentiment is supported by research, which finds that people with disabilities who lived in supportive housing after release from jail or prison were

[27] Gonzalez, Jennifer and Nadine Connell, "Mental Health of Prisoners: Identifying Barriers to Mental Health Treatment and Medication Continuity," *American Journal of Public Health*, December 2014, 104(12): 2328-2333.

61% less likely to be re-incarcerated one year later than those not offered supportive housing.[28] As such, Maine should implement and expand transitional plans on release and reintegration into the community in order to maintain a positive trajectory upon release from prison and reduce recidivism.

7. Systemization of Care

Forum attendees described problems with communication between and among health care providers statewide. Attendees discussed situations in which different providers have non-uniform access to patient information, which can result in consumers receiving contradictory information or inadequate or improper care. To alleviate this problem, attendees suggested that there should be more collaboration and communication between primary care physicians and specialists within and across facilities. Attendees also cited issues with regard to inconsistent standards for the provision of services across provider agencies. That is, consumers have found that the procedures for admissions, access to services, screenings for particular illnesses, and drug prescriptions are different depending on the agency. Discrepancies in care can cause providers to overlook illnesses and administer contradictory advice or treatment plans.

The need for integrated, systemic mental health care services is widely known. Indeed, in 2012 the World Health Organization published the "Mental Health Action Plan 2012-2020"[29], in which the Organization provided four major objectives for reducing morbidity among people using the mental health system. One of the four objectives was the provision of comprehensive, integrated mental health care services in community-based settings. The report outlined the need for information sharing and continuity of care between different providers and levels of the health system. The State could address the problem caused by the lack of integration in Maine by implementing a statewide computerized system for maintaining and sharing health records across provider agencies. Currently, each major health care provider agency utilizes distinct information systems, such that consumers have difficulty predicting which hospital has their records. In

[28] "Supportive Housing Helps Vulnerable People Live and Thrive in the Community," *Center on Budget and Policy Priorities*, May 31, 2016, available at https://www.cbpp.org/sites/default/files/atoms/files/5-31-16hous.pdf.
[29] "Mental Health Action Plan 2013-2020," *World Health Organization*, 2013, available at https://apps.who.int/iris/bitstream/handle/10665/89966/9789241506021_eng.pdf?sequence=1.

emergency situations, when a consumer is brought to a hospital outside of their regular network that does not have their records, this can lead to severe oversights in the administration of care that could be potentially life-threatening. The State could also propose incentives to providers for systemizing care so that consumers can reliably predict standard care across providers.

8. The Consent Decree

The Consent Decree tasked the DHHS with establishing and operating a comprehensive mental health system. In pursuit of this goal, DHHS was given the option of providing services either directly to Maine people, or through contracts with private agencies. DHHS chose the latter. Mental health consumers argue that this was not necessarily the right choice, for many of the reasons outlined above. The negative results of delegating control of the system to the private sector include: limited State oversight, inconsistent practices and standards across provider agencies, insufficient flexibility to meet unique individual needs and mental health providers controlling the narrative regarding the needs of the individuals served.

For example, because each private agency conducts its own assessments for service eligibility, a person could be found eligible by one agency, and ineligible by another. Such inconsistencies make it difficult for individuals to assess which agencies are appropriate for them. In order to navigate this complicated, disparate system, individuals rely heavily on case managers. However, the process of *finding* a case manager is, in and of itself, complicated; the gatekeepers to the system are themselves difficult to procure.

People receiving services from Maine's mental health system were initially concerned at the prospect of the Consent Decree going away but once people understood what the plaintiff's lawyers and the State had agreed to, consumers were pushing for passage of the bill to allow Disability Rights Maine to litigate providers directly when they violated people's rights. Consumers were excited that their individual rights would be better protected and that they would have greater access to legal assistance through increased staff at Disability Rights Maine. Given that this bill did not pass, mental health consumers do not want the Consent Decree to go

away. Rather, the Consent Decree should be used to make systemic change to improve the mental health system.

In order to begin solving these problems with the Consent Decree still in place, the State should adopt a more hands on approach to improving the mental health system. Such a process would include the following four steps: (1) centralizing initial access to community services, (2) providing a system for follow up, (3) creating a centralized dispute resolution process, and (4) creating a process for settling unresolved disputes. In addressing the first step, the State should create an office that provides:

a. Free assessments for clients to be pre-authorized for eligibility. Each person that gets assessed could be approved for a specified set of services, to be provided at *any* agency.
b. A "navigator" who would assist the client with linking the services they were approved for with agencies that have the capability to provide those services.
c. A centralized database that would connect the provider to the client and list the services the individual was approved to receive.
d. A network of State psychiatrists, psychologists and social workers who could provide direct, immediate assistance to clients in situations in which providers have waitlists and cannot provide immediate care.

In addressing the second step, the State should organize a staff to respond to point c. above by following up with clients in the database at regular intervals to determine whether their needs are being met. If the client reports a problem, the staff member would then refer the client back to the navigator discussed in point b. above, who could then direct them to the appropriate agency, individual, or information necessary to solve the issue.

In addressing step 3, a centralized dispute resolution process, the State should organize a central office capable of receiving client complaints. At this stage, state employees could act as informal dispute arbiters, providing support and assistance, and directing the client to the appropriate resources. Importantly, when the issue involves services provided solely through provider contracts, clients and advocates have observed that State assistance in such disputes

shifts in focus from serving the client to concern for adherence to process. For example, in certain MaineCare regulations, Assertive Community Treatment ("ACT") services have a twenty-five mile radius restriction for reimbursement. Of course, this does *not* mean that a client living more than twenty-five miles away from an ACT team does not clinically require the service. In such circumstances, a state employee not saddled by MaineCare regulations could provide the service.

In addressing step 4 - settling unresolved disputes - the State should take the position that clients can and should use the Grievance process.

9. Employment

Access to competitive employment for people with diagnoses or labels of mental illness is severely limited. Indeed, in the United States, such persons have an employment rate of about two thirds of the general population.[30] This disparity is in large part due to the misconception that people with mental illness do not want to work or are incapable of working. In Maine, while more than half of residents with a disability are of working age (18 to 64 years), only 33% of these individuals were employed between 2013 and 2017. This number is striking when compared with the fact that 80% of the working age population in Maine *without* a disability were employed during the same period.[31]

During and in the wake of the COVID-19 pandemic, unemployment in Maine and beyond is likely to increase. As such, the State of Maine should take concrete steps now to increase access to employment among those with mental illness before the situation worsens. Specifically, the Department of Health and Human Services should work closely and cooperatively with the Department of Labor to implement Employment First and to design and implement coherent, feasible best practices and policies for employment access and sustainability.

[30] Mechanic, David et al., "Employing Persons with Serious Mental Illness", *Health Affairs,* September 2002
[31] "Maine Workers with Disabilities 2019 Data Update", *Maine Department of Labor,* 2019.

Maine became an "Employment First State" when the statute was passed in 2013. This statute requires that persons with disabilities are offered, as the first and preferred service or support option, a choice of employment services. The act calls on state agencies to "coordinate [their] efforts with other state agencies to ensure that the programs directed, the funding managed, and the policies adopted by each state agency support the acquisition by persons with disabilities of integrated community-based employment or customized employment."[32] For people with mental illness who are stuck in the cycle of institutionalization and medication, and who are living in poverty, work is often recovery.

C. Conclusion

Every human being deserves unqualified, non-discriminatory access to services necessary to live a healthy, independent, and prosperous life. We believe that the State of Maine agrees that those who use the mental health system are entitled to the same standard of life available to Maine residents who do *not* use the system. A minimum standard of living requires not only access to the basic necessities – food, shelter, water, and medical care – but also to opportunities to become independent, self-sufficient, and engaged in community life. In order to better serve the mental health community in meeting this standard of life, we recommend that the State of Maine engage in a process of (1) increasing the availability of independent, stable, and safe housing, (2) providing opportunities for empowerment, (3) increasing access to immediate care and supports, (4) increasing access to support systems, (5) providing for alternative therapy options, (6) ensuring proper care and support in prisons and jails (7) systemizing standards of care and information sharing across healthcare providers in Maine, (8) implementing changes to the provision of services using the Consent Decree to ensure the flexibility required to meet individual needs, and (9) implementing Employment First to increase employment opportunities among Maine's residents with disabilities.

[32] M.R.S.A. Title 26, Chapter 26, §3403(3).