Consumer Council System of Maine

A Voice for Consumers of Mental Health Services

Orientation to the Health & Human Services Committee

February 3, 2021

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Greetings:

The Consumer Council System of Maine greatly appreciates this opportunity to provide you with information about our organization, and we look forward to working with you to enhance and improve Maine's system of mental health care.

Mission Statement

The Consumer Council System of Maine represents fellow consumers with an effective, organized voice in shaping public policy and mental health services. We hold as essential the participation of all consumers and look to collaborate with allies to find realistic solutions to local and statewide issues and to advance recovery-oriented, consumer-driven mental health care and peer-run recovery opportunities.

Vision Statement

The Consumer Council System of Maine leads the way as a well-established cornerstone of a recovery-oriented system of mental health care, moving forward with courage and creativity, directed by an informed, diverse grassroots consumer network.

Values Statement

- We believe inclusion of all consumers/peers is essential to the success of our mission and honors the diversity of our community.
- We believe in a recovery-oriented, peer-led system of care guided by resiliency and hope.
- We believe in building collaborative relationships to find realistic solutions to local and statewide issues.
- We believe in moving forward with creativity and innovation to bring about systemic change to mental health care.
- We believe in listening and supporting one another with compassion, equality, dignity, and respect.
- We believe in open, honest communication, conducting ourselves with integrity and transparency, to encourage collective accountability.
- We believe in acting wisely and deliberately, informing ourselves and others, to advocate effectively for quality services and preservation of rights.

What is the Consumer Council System of Maine?

1. Established…
    a. by the 123rd Legislature as an independent public instrumentality (Title 34B, §3611)
    b. to provide an effective, independent consumer voice in an advisory capacity in the development of public policy, resource allocation, the delivery of effective and appropriate adult mental health services

2. Structured…
    a. to gather input from consumers of mental health services from the grassroots level, through Local Councils in Maine communities
    b. to elect representatives to the Statewide Consumer Council to decide collectively how best to advocate and advise state government on various issues/various settings

3. Motivated…
    a. by clear mission and values statements, created by members of the Statewide Consumer Council
    b. to advance recovery-based services for people with mental health challenges
    c. to promote the value and necessity of peer support as a vital component to an effective system of mental health care

Function and Focus of the Consumer Council System

- The main focus of the CCSM is Adult Mental Health Services. However, there will be times when the CCSM focuses on issues (i.e. Co-Occurring Disorders, Dual-Diagnosis MH/DD, etc.) that call for collaboration with other programs and groups.
- The function of the CCSM is to have an independent voice in the development of public policy and funding decisions.

Getting Involved

- People are encouraged to attend and participate in a Local Council closest to their home. Local Councils meet monthly to discuss and respond to local and statewide issues.
- The voice of Local Council members is brought to the Statewide Consumer Council (SCC) by representatives they elect to the SCC. SCC Members decide collectively on clear messages to send to state government. SCC members bring information back to the Local Councils to keep communication flowing back and forth.
- Any community member is invited to attend Statewide Consumer Council meetings. All meetings are open to the public Guests do not have voting rights at an SCC meeting, but anyone who self-identifies as a present/past recipient of mental health services may vote at Local Councils.

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES
HEADING: PL 1995, c. 560, Pt. K, §7 (rpr); 2001, c. 354, §3 (amd)

Chapter 3: MENTAL HEALTH

§3611. CONSUMER COUNCIL SYSTEM OF MAINE

In order to promote high-quality adult mental health services, the Consumer Council System of Maine, established in Title 5, section 12004-I, subsection 60-B and referred to in this section as "the council system," is established to provide an effective, independent consumer voice in an advisory capacity in the development of public policy and resource allocation. The council system consists of the Statewide Consumer Council established in subsection 6 and local councils. [2007, c. 592, §2 (NEW).]

1. Independent public instrumentality. The council system exists as an independent public instrumentality of the State to provide guidance and advice from consumers of adult mental health services provided or funded by the State regarding the delivery of effective and appropriate adult mental health services consistent with the State's comprehensive mental health services plan and to comply with the consent decree and incorporated settlement agreement in the case of Paul Bates, et al. v. Robert Glover, et al., Kennebec County Superior Court, Civil Action Docket No. CV-89-88 dated August 2, 1990.

[2007, c. 592, §2 (NEW) .]

2. Governmental functions; tort claims. Exercise of the powers conferred by this section is the performance of an essential governmental function. The council system must be considered as within the definition of "State" for the purposes of Title 14, section 8102, subsection 4. The council system is not considered an agency of the State for the purposes of budgeting, accounts and control, auditing, contracting and purchasing.

[2007, c. 592, §2 (NEW) .]

3. Duties. As pertains to the delivery of mental health services for adults, the council system shall:

A. Advise the department, the Governor and other state agencies. This duty includes advising the department on the review, analysis and evaluation of adult mental health programs, policies, procedures and service delivery systems administered or funded by the State and the hiring of personnel when appropriate; [2007, c. 592, §2 (NEW).]

B. Assist the department in program design and implementation, including assessment of the quality of services and delivery systems and prioritization of programming; [2007, c. 592, §2 (NEW).]

C. Provide consumers with a recognized mechanism for collaboration with State Government, including addressing issues with persons and entities that provide services through contracts with the department; [2007, c. 592, §2 (NEW).]

D. Provide input regarding programs, evaluation, public policy and resource allocation and address issues and concerns that arise at the local level; [2007, c. 592, §2 (NEW).]

E. Identify, research and respond to issues of importance to consumers, including requesting information and data to facilitate informed decision making; [2007, c. 592, §2 (NEW).]

F. Interact with state agencies, community entities and other organizations; [2007, c. 592, §2 (NEW).]

G. Provide budget requests to fund the council system to the department for each biennial budget and each supplemental budget; and [2007, c. 592, §2 (NEW).]

H. Make annual and interim recommendations to State Government and provide by May 31st of each year a report to the Governor and the Legislature. The report must include analysis of state programs, policies and procedures, legislative and regulatory proposals and recommendations for action by the State. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

4. Powers. The council system may:

A. Contract for staff assistance or hire employees, including an executive director or project manager and such other staff as necessary, to conduct the activities of and support the duties of the council system. Employees of the council system are not state employees; however, they are immune from civil liability for acts that they perform in good faith within the scope of their duties for the council system; [2007, c. 592, §2 (NEW).]

B. Reimburse members of the Statewide Consumer Council established in subsection 6 and local council members who are not otherwise fully reimbursed for expenses of participating in council system meetings from the council system budget in an amount up to the legislative per diem rate for participation in Statewide Consumer Council and local council meetings, plus reimbursement for reasonable and necessary expenses actually incurred, including but not limited to costs incurred for travel, child care for the member's child and substitute care for dependent adults. A standard statewide rate of reimbursement, including reduced reimbursement for a member entitled to partial reimbursement from any other source, must be approved by the Statewide Consumer Council. To the extent allowable under federal law, reimbursement under this paragraph may not be counted as income, resources or assets for the purposes of determining eligibility for benefits under any state or municipal program of assistance or health coverage for which a council member may be eligible; [2007, c. 592, §2 (NEW).]

C. Engage in advocacy regarding legislative and regulatory initiatives; and [2007, c. 592, §2 (NEW).]

D. Provide interim reports to the Governor and the Legislature and respond to written responses from the department under subsection 5. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

5. Written response. No later than September 30th of each year, the commissioner shall provide a written response to the council system's annual report under subsection 3, paragraph H to the chair of the Statewide Consumer Council, the Governor and the Legislature. The response must:

A. Address the actions that the department plans to take or proposes to implement with regard to the recommendations contained in the council system's annual report and any interim reports or the reasons for declining to take or propose action; and [2007, c. 592, §2 (NEW).]

B. Include a report on progress in implementing actions detailed in prior department written reports under this subsection. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

6. Statewide Consumer Council. The provisions of this subsection govern the membership, duties and operation of the Statewide Consumer Council, as established in Title 5, section 12004-I, subsection 60-B.

A. The Statewide Consumer Council consists of 16 to 30 members who represent the local councils, described in subsection 7, after being elected at local council meetings on a schedule established by the Statewide Consumer Council. [2007, c. 592, §2 (NEW).]

B. Members of the Statewide Consumer Council shall annually elect a coordinating committee consisting of a chair, vice-chair, secretary and treasurer. Officers serve for terms of one year and are eligible for reelection. [2007, c. 592, §2 (NEW).]

C. The Statewide Consumer Council shall:

(1) Convene at least 4 regular meetings per year and special meetings as the Statewide Consumer Council determines necessary;

(2) Establish an application procedure by which the Statewide Consumer Council may recognize a local council;

(3) Determine the timing of and procedures for elections by local councils to elect representatives to the Statewide Consumer Council;

(4) Apportion the number of representatives each local council will have on the Statewide Consumer Council; and

(5) Adopt policies and procedures regarding removal for good cause of a Statewide Consumer Council member. [2007, c. 592, §2 (NEW).]

D. Meetings of the Statewide Consumer Council or such subcommittees as may be formed from the council membership may be held to perform the duties listed in subsection 3 and:

(1) To receive, review and distribute the recommendations of the local councils and prepare the council system's annual report and any interim reports;

(2) To develop a mechanism for communication with department personnel that ensures timely responses to issues and concerns identified by the council system and that provides a formal means of communication with the commissioner and high-level department personnel;

(3) To advise and engage in dialogue with the department concerning oversight, evaluation, unmet needs, quality assurance and quality improvement, design of new program initiatives and prioritization of programming; and

(4) To oversee and manage the council system, including assumption of responsibility for the development of local councils in unrepresented areas. [2007, c. 592, §2 (NEW).]

E. The Statewide Consumer Council shall adopt policies and procedures for the operation of the Statewide Consumer Council and the local councils. The policies must:

(1) Require that local councils file with the Statewide Consumer Council periodic reports and maintain records of meetings and business conducted, a list of members elected to the Statewide Consumer Council and leadership and financial records; and

(2) Require that the Statewide Consumer Council file with the department periodic reports and maintain records of meetings and business conducted, policies and procedures adopted and financial records as required by contract with the department. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

7. Local councils. The provisions of this subsection govern the membership, duties and operation of the local councils.

A. Each local council shall follow the policies and procedures for local councils adopted by the Statewide Consumer Council pursuant to subsection 6. [2007, c. 592, §2 (NEW).]

B. Each local council shall hold regular meetings, at least 4 per year and more if determined necessary by the local council, for the purpose of discussing and reviewing the delivery of adult mental health services to consumers and shall engage in other activities:

(1) To reach out to all persons in the surrounding community to encourage participation in the local council, to stimulate and receive local consumer advice and to gain awareness of local concerns, needs and ideas, including identifying concerns of persons who do not usually participate in the local council meetings;

(2) To advocate for and provide advice regarding local response to local issues;

(3) To advise the department, State Government and independent contractors on local responses to local issues through communication with the Statewide Consumer Council;

(4) To elect representatives to the Statewide Consumer Council; and

(5) To communicate with the Statewide Consumer Council via elected members and reports regarding issues of concern identified by the local council. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

8. Funding. Funding for the council system must be included as part of the Governor's proposed budget for the department. The council system may accept gifts, grants and other funds and contributions for use in performing the duties of the council system as long as such gifts, grants, funds and contributions are in accordance with state laws prohibiting conflicts of interest.

[2007, c. 592, §2 (NEW) .]

9. General provisions. The provisions of this subsection apply to the council system.

A. A Statewide Consumer Council member or elected local council member may not cast a vote on any matter that would provide any direct or indirect financial benefit to that member or otherwise give the appearance of a conflict of interest under state law. [2007, c. 592, §2 (NEW).]

B. A person may not be excluded from the council system or discriminated against within the council system by reason of race, creed, color, gender, sexual orientation, age, marital status, homelessness, national origin, disability or status as a consumer of mental health services. [2007, c. 592, §2 (NEW).]

C. Meetings of the Statewide Consumer Council and local councils are public proceedings and their records are public records for the purposes of Title 1, chapter 13. [2007, c. 592, §2 (NEW).]

[2007, c. 592, §2 (NEW) .]

SECTION HISTORY
2007, c. 592, §2 (NEW).

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

[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).

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CCSM Issue Statements from Mental Health Forums May 2020

****We began the Augusta Forum by asking those in attendance the following question:**

"What is going well with mental health services and systems in your community or area?"

1) The current expansion of telehealth services for medication management & therapy.
2) Using Zoom/Telehealth for BHH & OHH.
   a. Was not sure it was going to go well at first but getting more results than expected.
   b. No show rates have gone down due to using telehealth.
   c. Able to still do groups and meet with people through Zoom and other digital platforms.

****We then moved on to the main topic of discussion and asked the following question:**

"What are the mental health issues that you are currently hearing about or seeing in your surrounding community?"

Augusta

Title: Police using punishment vs. treatment for mental health and substance use disorders.

Experience: Skowhegan Incident (naked driver apprehended in church)

Recommendations: None Given

Outcomes: None Given

Title: Correctional system not conducive for successful reintegration into society based on the current programs available.

Experience: None Given

Recommendations: None Given

Outcomes: None Given

Title: Lack of community acceptance outside of major metropolitan areas for treatment as opposed to punitive action.

Experience: None Given

Recommendations: None Given

Outcomes: None Given

Title: Lack of understanding and compassion for those with lived experience of substance use and mental health challenges throughout the state with a noticeable increase in rural areas due to the unavailability of services.

Experience: None Given

Recommendations: None Given

Outcomes: None Given

Title: Waiting lists continue to be an issue for medication management.

Experience: None Given

Recommendations: None Given

Outcomes: None Given

Title: Lack of safe and affordable housing stock.

Experience: Out of state developers have been coming in and buying up properties in some areas then jacking up the rent.

Recommendations: None Given

Outcomes: None Given

Title: Lack of housing voucher availability.

Experience: None Given

Recommendations: Would combine all housing voucher programs into one program with one priority list where literal homeless people and those with mental health and substance use disorder are the top priority.

Outcomes: None Given

Title: Lack of landlords that will work with tenants with known mental health and/or substance use disorders.

Experience: Landlords have learned to spot when people are coming to look at apartments with case managers and other "staff".

Recommendations: None Given

Outcomes: None Given

Title: Mid-Coast Connector is horrible!

Experience: Always late, often cancels, not reliable. Easy to schedule a ride but they will cancel on the consumers last minute causing them to miss their appointments. Also not sending accessible vehicles when the consumer requests it.

Recommendations: Confirm the ride before arrival, change brokers, new system.

Outcomes: None Given

Title: **KVCAP Transportation is unreliable and just awful.**

Experience: Always late, often cancels, not reliable. Easy to schedule a ride but they will cancel on the consumers last minute causing them to miss their appointments. Also not sending accessible vehicles when the consumer requests it.

Recommendations: Confirm the ride before arrival, change brokers, new system.

Outcomes: None Given

Title: **The way in which the BHH and OHH is set up are not efficient with the way they are designed. Some consumers may not be getting the case management they are entitled to.**

Experience: The OHH does not have case management. The BHH team model has all the parts but the case managers are overloaded with clients which at times can be up to 40 or more clients. According to KEPRO they can have case management, but it is a different code that not all providers know that there are two codes. Members call up because they want case management. They must end the OHH with case management and then the new case manager and new provider can open new case management and then the former OHH provider can open it back up for OHH without case management. The consumer then needs to tell their former OHH provider to reopen them for services.

Recommendations: Combine both the programs together so that everyone could get access to whatever services that the consumers need regardless of diagnosis. Since Substance Use disorders are in the DSM, they should be considered Behavioral Health since they are the same. This would make everything SO much simpler for all parties involved.

Outcomes: None Given

Title: It seems that Peer Support specialists are being paid through Medicaid dollars but the category that it is being placed under is case management. The agency is being reimbursed for the BHH by Medicaid/MaineCare.

Experience: None Given

Recommendations: None Given

Outcomes: None Given

Title: Consumers are unable to get transportation scheduled for medical appointments without prior authorizations through LogistiCare.

Experience: Spoke with Jen at KEPRO who shared her experiences of consumers calling up asking for them to give the prior authorization so they can get a ride to their appointment. The PA (prior authorization) is not something that KEPRO can do and is not required by some other transportation agencies. Why does LogistiCare need it?

Recommendations: For everyone to get their facts in order and be on the same page.

Outcomes: None Given

Bangor Area

Title: Increase in Isolation Since COVID19.

Experiences:

1. Increase in reported feelings of isolation.
2. Concerned about being able to get out into the community.
3. When is it going to be "normal" again?
4. What will "normal" look like?
5. The Unlimited Solutions Club House in Bangor is trying to mirror the physical meetings by doing them via Zoom such as "fun at four" and a social activity on Friday via Zoom. They are figuring out who needs to be reached out to. Just started to allow 6 members at a time with no more than 10 people into the clubhouse by appointment only when wearing a mask after clearing the CDC Health Questionnaire.

Recommendations: None Given

Outcomes: None Given

Title: Telehealth for Children vs. In Person Treatments.

Experiences:

1. Speech, PT, OT have been getting done through telehealth but would prefer in person at school.
2. Therapy also done by telehealth, but children not as engaged during treatment sessions as in person.

Recommendations:

1. Go back to school where the child had previously received treatment and services.
2. Resume in person therapy sessions.
3. Is it possible to do some treatment sessions in person and some via telehealth? Example: Meeting A held in the office while Meeting B held via telehealth, etc.

Outcomes: None Given

Title: Telehealth for Adult Services.

Experiences:

1. Many people can attend their appointments this way now.
2. Most providers are offering it.
3. Some consumers are concerned that it will go away or not be used as often after COVID19 passes and as the state opens more.
4. Feedback from all sides is that it is liked.
5. People are attending more appointments and not missing them.

6. Often gives the provider or the other person (during peer supports) the chance to see into the other person's "world" in a new light.
7. Not everyone has the device needed or even the high-speed internet connection required.
8. In the ID/DD world some providers are purchasing iPads and other technological devices for their clients to use.

Recommendations:

1. Continued use of Telehealth Services after COVID19 passes.
2. Expansion of high-speed internet services into more rural areas.
3. Expansion of access to technological devices to those who need them and do not have them for Telehealth purposes.

Outcomes: None given

Title: Limited Choice of Services in Rural Areas.

Experiences:

1. Appears like there are not a lot of options when it comes to behavioral health services.
2. There may be a variety of options available, but they are not always known to everyone.
3. More information is needed on what is out there and what types of services are offered by which place, privacy policies, who you may be working with, what insurances are accepted, etc.

Recommendations: None Given

Outcomes: None Given

Title: Supply of Food.

Experiences:

1. It was said by a CCSM member that there is an oversupply of USDA food that is often in bulk sizes and sometimes frozen.
2. It appears that the challenge may be in the distribution of the food and not the lack of supply. Children are still able to access food through food pick up from their local schools.

Recommendations:

Outcomes: None given

Title: Lack of Substance Use Services.

Experiences:

1. In the Bangor area there is a lack of providers and services.
2. Primarily given hospital-based services.
3. Sometimes people who experience addiction are also consumers of mental health services.

Recommendations:

1. More Peer Recovery Orientated Services
2. More research done on what type of services could serve the most amount of people in the area.

Outcomes: None Given

Title: Lack of Available Treatment Options for Consumers who experience an Addiction to Stimulants.

Experiences:

1. In the Bangor Area and possibly the state there are no known providers who offer specific treatment options for the addiction to stimulants.
2. This type of addiction can require different types of treatment than what it traditionally offered in the regular setting.
3. Sometimes people who experience addiction to stimulants are consumers of mental health services.
4. It was shared by a CCSM member at the forum that it is frustrating and discouraging to want treatment but for none to be available or for none to help no matter how hard you try because it is not designed for the type of addiction and mental health needs that you are battling.

Recommendations:

1. Available treatment options for consumers who experience an addiction to stimulants.
2. Peer Oriented Recovery Services for consumers who experience an addiction to stimulants.

Outcomes: None Given

Title: Homelessness

Experiences:

1. The Bangor Area Homeless Shelter has empty beds, but some do not feel it is safe to go there due to COVID19 and other concerns.
2. The Bangor Area Homeless Shelter is a dry shelter with rules and often people are not able to follow them for various reasons.
3. Some people are not able to follow them due to addiction, having pets, employment needs, etc.

4. There are other shelters in the Bangor area that have different rules however not everyone may know what rules are at each shelter or that the other shelters even exist.

Recommendations: None Given

Outcomes: None Given

Title: Housing Supports for People to Purchase Homes vs. Renting Apartments.

Experiences:

1. There are supports and programs to help people rent an apartment but there are limited programs to help someone purchase a home.
2. An apartment gives housing with a lease and potentially month to month basis whereas a home can offer more permanency and deeper roots for people.
3. There ARE some programs out there BUT they have a lot of barriers and hoops to climb and jump through.
4. Credit checks are often done to check for apartment renting and tend to be a barrier for many people.

Recommendations:

1. “Put the jobs where the people are & relocate the people to where the houses are for ownership.”

Outcomes: None Given

Title: Redo the “Rights of Recipients Training”.

Experiences:

1. Have consumer input on the training that is given that goes along with this.

2. There are a lot of rights in the mental health section that some people think that other people should not have.
3. Judgements can form.
4. More training needs to be done.
5. Training done with consumer input by those who have had rights taken away from them in the past.

Recommendations:

1. Training for "boots on the ground" providers filled with examples done by the people who know what it is like to be denied their rights.

Outcomes: None Given

Title: Basic Income for All

Experiences:

1. People who have not experienced unemployment in a while have recently found out how "close to the bottom they really are".
2. Both sides of the isle are sharing ideas.
3. A grassroots organization formed a committee to discuss this further.
4. Shenna Bellows is on this committee.

Recommendations: None Given

Outcomes: None Given

Title: Transportation

Experiences:

1. Lynx transportation is still taking those who have appointments to them and to other places that they need to go.
2. Need to call and set up transportation in advance.
3. Does cancel in the wintertime due to weather.
4. Currently requires riders to wear a mask.
5. Extremely strict on the time frame. If you have an appointment and you tell them it will last 60 minutes, and you run longer than 60 minutes and you are not ready they will leave you.
6. Currently down several drivers due to the COVID19.
7. It was shared by multiple CCSM Members that some drivers have been known, in the past and currently, to display unethical and unprofessional behaviors such as:
8. Refusing to transport consumers to/from medical offices that are known to provide Recovery Services or Substance Use Treatment.
    a. Post rude comments and personal information about consumers they do not like on social media.
    b. Display stereotyping and stigmatizing behaviors through their actions, looks, or gestures to their consumer/passenger.
9. Complaints have been filed by consumers about this unethical and unprofessional behavior but little to nothing has been done.

Recommendations: None Given

Outcomes: None Given

Title: Community Supports & Integrations

Experiences:

1. One CCSM member shared that someone they know is still able to get out into the community to do what is needed to be done.
2. Some case managers and community support workers are helping with this.
3. Based on the input from everyone, it appears that this is happening on an agency-by-agency basis.

Recommendations: None Given

Outcomes: None Given

Farmington

Title: Lack of Peer Center in the Farmington Area Experience.

1. Used to have peer center in Jay/Livermore Falls to attend.
2. Hearing that other peer centers are using phone contact with members during COVID-19.
3. Limited socialization- Suffer not having a way to connect with others.
4. No place for peers to gather. (social, support, education, etc.)
5. Need to be under an "umbrella agency".
6. Lack of knowledge of how to start a peer center -who would we communicate with.
7. Have to know and follow the COSP model- RFP process.
8. Need a place to go and talk to people.

Recommendations: None Given

Outcomes: None Given

1. Would like to see a peer center open in the area.
2. Would like to see center offer socialization, education, resource education/outlet.

Miscellaneous Comments:

Do you have to involve the state? Can you just start with a place to hang out, socialize and chat then build on to that?

Maybe get a church or something to sponsor and give a place to be.

Title: Knowing how to get assistance/what is available/how to access resources during COVID-19 and beyond.

Experience:

1. Lack of resource outreach.
2. Hard to reach DHHS.
3. Common source for resources.

Recommendations: None Given

Outcomes: None Given

Title: Transportation

Experience: None Given

1. Commissioners refused to release money.
2. Franklin county cut transportation Budget.
3. Franklin county Cut monies to social services.
4. Cut in county funds and federal funds that go with it.

5. Some people are able to hire personal worker to take them to places. (state gives funds)
6. People do not know the alternatives to get what they need. (i.e.: pharmacy delivery, etc.)

Recommendations:

1. MaineCare can send out informational letters/newsletter quarterly.
2. Add summary to review process.

Outcomes: None Given

Title: Housing

Experience:

1. Accessible Housing- Person living in subsidized hours (3 level)- wheelchair bound and struggling to get another apartment that is accessible.
2. Lack of affordable housing.
3. Section 8 waitlist is too long.
4. Lack of knowing about resources.
5. Sometimes have to be on the Maine state waitlist which is longer.
6. Not being able to afford deposit and first, last month's rent.
7. There are resources to help with deposit, etc, however, people don't know where to find them and their processes very from each agency and the waiting list is long.

Recommendations:

1. Use empty buildings for housing.
2. Use common application-one application to apply in multiple towns.

Outcomes: None Given

Other Comments:

Create a resource committee in each community.

Lack of transportation, housing, etc. for those being released from jail/prison.

No case management for people being released.

Lack of appropriate community integration- no community supports.

Lewiston

Title: Transportation

Experiences:

1. Either not coming at all or coming late. (LogistiCare in Lewiston/Auburn area).
2. Took person to an appointment but could not bring them back. This has stranded consumers forcing them to walk home or find their own transportation.
3. The transportation company does not connect with consumers to confirm rides. This causes additional stress and worry for people wondering if they will have a return ride at all.
4. The transportation company sometimes sends the wrong type of transportation (meaning a taxi when a wheelchair accessible van is needed or even requested in advance).
5. Consumers are not permitted to talk to the driver to check on the wait times for rides.
6. People are often late for their appointments causing them to miss their appointments.
7. Access to the information of where to and how to file a complaint/grievance is often a problem and non-existent.

Recommendations:

1. If there was a way for the consumers to talk to the drivers that could help with expected pick up and drop off times.
2. Is there was an easier way to immediately file complaints?

3. Could such complaints possibly go to an outside person/agency?

Outcomes: None Given

Title: Lack of a Public Homeless Shelter/Transitional Housing.

Experiences:

1. Temporary shelter was built at the Lewiston Armory to help with homelessness. Can something permanent be built?
2. The shelters in the L/A area are primarily religious based. They appear to be conservative based and we have gotten reports that people are being turned away.
3. Lack of transitional housing for Adults.
4. New housing is coming but how much of that will help people?

Recommendations:

1. Equal access/low barrier shelters are needed in the L/A area to help all people.
2. Transitional Housing is needed in the area for Adults.

Outcomes:

1. More Transitional Housing Programs.
2. Public Adult Homeless Shelter.

Title: Concerns with Telehealth ending or not being offered as frequently after COVID19.

Experiences:

1. People are having success with attending their appointments through telehealth.
2. Less people can miss appointments if they are done at home.
3. People who have challenges with transportation can access their providers.

Recommendations:

1. Push for continued use of telehealth after COVID19.

Outcomes: None Given

Title: Lack of Peer Center in the Lewiston/Auburn Area.

Experiences:

1. The Lewiston/Auburn Area does not have a Peer Center anymore since the closure of 100 Pine Street Wellness and Recovery Center in December 2017.
2. When it closed items were not allocated out to other Peer Centers for use or purchase.
3. Common Ties used to be the umbrella agency for it.
4. Common Ties did not complete the RFP paperwork to keep the peer center open.

Recommendations:

1. Future one would need to be recovery and wellness based with programs, groups, and activities.

Outcomes:

Would like to see a community stakeholder group between peers, providers, municipal people, OBH people to explore the potential creation of a new Peer Center and that it entails. (Funding, Etc.)

Title: During the time of COVID19 some DLS, PSS, Case Manager, and BHH services have been suspended by certain agencies.

Experiences: None Given

1. Some agencies are short staffed and do not have enough trained staff able to work out in the community with people. This means that some are unable to get to appointments and access other services.
2. Some are fearful of working in the Lewiston/Auburn area due to community violence.

Recommendations:

1. More workforce development.
2. More peer development for training to become PSS, DLS, and Advocates.

Outcomes:

1. Money savings by keeping people healthy and those who can stay in their own communities. Also, will lead to self-sufficiency.

Title: We Need a Stronger Statewide Grass Roots Peer Organization.

Experiences:

1. Would like to see a stronger presence within the peer community.
2. People are currently busy surviving and taking care of themselves.
3. Some consumers feel like that they do not have anyone to listen to them and do not know where to turn.
4. Some feel like the CCSM is not well known and that most people do not know that it exists and possibly needs rebranding.

Recommendations:

1. Consistent direct invitations (send a memo out to the director of every mental health agency, every clubhouse).
2. Build a network so that people know who we are and what we are doing.

Outcomes:

1. If we could welcome more people into an active organization than we would build it amazingly both in size and leadership.

Title: Continued need to expand outreach to grow the CCSM and all Local Councils.

Experiences:

1. Attendance at most local councils has been declining.

Recommendations:

1. Need to make it easier to become and stay involved at all levels and find a way that everyone can participate.
2. Keep people involved at whatever level they can participate.
3. Stronger, larger, and more powerful organization with more leadership development.

Outcomes: None Given

Title: Lack of a complete/comprehensive Resource Guide for the Lewiston/Auburn Area.

Experience:

1. Information is not getting out to consumers.
2. Who would keep this resource guide up to date & what's in it?

Recommendations:

1. Community Concepts should be contacted to see if they would be interested in a resource guide service and finding out what their customers' needs are.

Outcomes:

Ken will investigate how to become a community representative on the Board of Directors at Community Concepts.

Title: 211 does not always give the most accurate or clear information.

Experiences:

1. Sometimes their website is hard to navigate.
2. Hard to find what you are looking for.
3. Some do not have a lot of experience with it.

Recommendations:

1. More research is needed to gather information.

Outcomes:

1. Vicky M. will investigate how 211 works by calling it and asking it questions to see if she is able to get the information that she is looking for.
2. Ken will investigate how the 211 website works to see if he is able to get the information that he is looking for. Both will report back results.

Portland

Title: None Given

Experience: Telehealth is ok for some things but not all the time. I developed Tardive Dyskinesia. It is important to see someone in person to be able to see potential issues that may occur. I was offered video chat but lack of technology.

Recommendations: None Given

Outcomes: While telehealth is an important part of the continuum of care, we want options for in person as well as telephonically and video.

Title: None Given

Experience: People not wearing masks and going out constantly without them. (during the Covid-19 crisis)

Recommendations: We need to have the availability of PPE for everyone who needs it.

Outcomes: We need some clear guidance from the State and its entities so that it is clear for everyone.

Title: None Given

Experience: 211 does not have all the information on the Covid-19 and cannot direct me to information I need for traveling out of state.

Recommendations: None Given

Outcomes: None Given

Title: None Given

Experience: People with dementia do not have a voice at the systemic level.

Recommendations:

Outcomes: There needs to be a systemic vehicle for people with specific needs with dementia and cognitive issues.

Title: None Given

Experience: Maine Human Rights Commission (MHC) not recognizing the invisible disabilities. They do not have the same approach as other disabilities which in and of itself is another form of discrimination. If you need to file a case with the MHC they are not required to give you an attorney for free.

Recommendations: Dedicate some funds that will provide for free legal representation if someone

needs to file a case through the MHC.

Outcomes: We need a Human Rights Commission that is fair and equitable to people with all types of disabilities.

Title: None Given

Experience: Group Homes are tightly controlled during Covid-19 crisis. Would not take a resident to the bank but took others to the store.

Recommendations: None Given

Outcomes: None Given

Title: Lack of a true mental health peer recovery center in Portland.

Experience: Amistad Peer Recovery Center in Portland they are seemed to mostly be doing food/personal care package deliveries to peers in need. No recovery groups happening currently. More focus on homelessness and homeless outreach and not on the mental health recovery aspects desperately needed at this time, which is their mandate and what they are funded for.

Recommendations: None Given

Outcomes: None Given

Title: None Given

Experience: Concerns with Shalom House as a Community Provider. Residential services are allowing unethical and unprofessional things to happen to the people their serve. They used to have their own niche. Their agency model has changed including closing peer support programs.

Recommendations: None Given

Outcomes: None Given

Title: None Given

Experience: Action Program in Portland has been eliminated

Recommendations: None Given

Outcomes: None Given

Title: None Given

Experience: Alumni program. We need a flexible person-centered service system that allows for the flexibility that most need and want. We should focus on helping people to “graduate” from services or use it sporadically as needed. People feel like they must stay in services even when they don’t need it for fear of not having access when they truly need it.

Recommendations: None Given

Outcomes: None Given

Title: Emergency Planning

Experience: During the COVID-19 Pandemic, no plan was in place for peer support staff in regard to helping peers within their respective communities. People are finding it difficult to remain connected to services and their peers. Some peer support centers had different interpretations of the stay-at-home plans and there was no cohesiveness within Maine’s peer support community. Peer Support staff feels undervalued at times but are a valuable resource for agencies. They have been frustrated with their lack of ability to help as needed (i.e. Layoffs, ect.) Peer Support Specialist just want to be able to help as they care about their fellow peers.

Recommendations:

1. Offer remote supports right from the beginning.
2. Increase communications between management and Peer support staff.
3. Increase of education to providers about the value of peer support and can be offered.

Outcomes:

1. Peers will be able to help other peers to have a plan and stay connected to services and not being isolating.
2. Increase in perceived value of peer support- important to utilize supports available.
3. Peer Support Staff should be included in future emergency planning.

Title: Transportation Inconsistencies

Experience: Inconsistency within transportation services. before and with the onsite of COVID-19 pandemic, there have been several instances where people need to get prior authorization for a ride to doctors via the approved MaineCare reimbursable transportation services. Continued issues around scheduling, pick-ups, drop-offs, confidentiality, safety, honoring requested accommodations.

Recommendations:

1. Get clarity on needing prior authorizations for transportation services.
2. Check on outcome from Transportation Forums held by the state in 2019.

Outcomes: None Given

Title: Access to Technology

Experience: Not everyone is technologically connected. Do not have broadband services in the rural areas or the price is too expensive.

Recommendations: None Given

Outcomes: None Given

Rumford

Title: Emergency Planning

Experience: During the COVID-19 Pandemic, no plan was in place for peer support staff in regard to helping peers within their respective communities. People are finding it difficult to remain connected to services and their peers. Some peer support centers had different interpretations of the stay at home plans and there was no cohesiveness within Maine's peer support community. Peer Support staff feels undervalued at times but are a valuable resource for agencies. They have been frustrated with their lack of ability to help as needed (i.e. layoffs, ect.) Peer Support Specialist just want to be able to help as they care about their fellow peers.

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Recommendations:

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2. Check on outcome from Transportation Forums held by the state in 2019.

Outcomes: None Given

Title: Access to Technology

Experience: Not everyone is technologically connected. Don't have broadband services in the rural areas or the price is too expensive.

Recommendations: None Given

Outcomes: None Given

Open Forum

Title: Lack of in-home supports for the elderly and those with disabilities.

Experiences:

1. Seeing a great push to put people in institutions versus providing the supports they need to stay home successfully. Whether that is a nursing home or group home.
2. The workforce is struggling to keep up with pay for workers.

Recommendations: None Given

Outcomes: We would be able to successfully support anyone who is need of services to stay successfully in their home would be able to receive the services they need to accomplish this.

Title: There is a lack of telehealth available because of lack of access to technology. People do not have access to internet to utilize these important services.

Experiences: Most folks do just phone calls, many do not have internet services, and some do not have access to phones. They cannot afford the internet or data plans on their phones. This is a reality of living in poverty.

Recommendations: None Given

Outcomes: We would love to see that if we are moving to telehealth services, we need to make sure that people have the resources to have these services.

Title: Lack of consumer input into their plans of care.

Experiences: People's wishes are not being listened to. It has a major negative impact into people's lives. I have seen it just mailed to a client and he was asked to sign and send it back.

Recommendations: None Given

Outcomes: None Given

Title: There is a lack of coordination between organizations that work with the same individual.

Experiences: Every agency has a different plan of care and they are not shared, and the services are not coordinated.

Recommendations: None Given

Outcomes: None Given

Title: If someone has a guardian or POA, they should still be listened to and be involved in their own care.

Experiences: People should be listened to… what they want and need and respect their choices and desires.

Recommendations: None Given

Outcomes: None Given

Title: Transportation LogistiCare is a very challenging provider of Maine's public medical transportation system.

Experiences: People are missing appointments because their drivers showed up late. They are not picking people up. Example of a winter appointment with two toddlers and they had to wait hours at the police station until a family member could come get them. People have been brought to wrong places. People

Recommendations: There needs to be alternative ways to give rides to others. There is a ton of barriers and paperwork (LogistiCare has to a complicated system to be approved)

Outcomes: There are better systems of using volunteer drivers and reimbursing them adequately for their mileage.

Title: Lack of transportation to peer centers because it is not a MaineCare reimbursable program and this is prohibited by Federal Rule.

Experiences: None Given

Recommendations: None Given

Outcomes: We need to use DOT grant funds to support important State funded programs that are not eligible for funding.

Title: Lack of access to masks and education about how to social distance and how to protect themselves.

Experiences: 23 positive cases at 100 State St. Anxiety, lack of access to care

Recommendations: None Given

Outcomes: None Given

Title: Loosing healthcare due to job loss.

Experiences: None Given

Recommendations: None Given

Outcomes: None Given

Title: How to access services if you have never needed them before.

Experiences: None Given

Recommendations: None Given

Outcomes: None Given

Title: **We need to help behavioral health professionals with student loan debt and work on credit for service, we need to value the profession. It would be a huge help to help with the workforce shortages we have in Maine.**

Experiences: None Given

Recommendations: Debt forgiveness programs

Outcomes: None Given

Consumer Council System of Maine

A Voice for Consumers of Mental Health Services

Issue Statement Process: Starting from a Local Council

1 Brainstorming

The Local Council generates a list of issues that pertain to Maine's mental health system.

2 Identify & Define Issue

Using the generated list of issues, the local council, through group consensus, picks an issue from the the list to work on and then determines if it fits into the CCSM mission and identifies it is a local, regional or statewide issue.

3 Create First Draft

Using the CCSM Issue Statement template, a first draft is created by the Local Council.

4 First Draft Review by the Issue Statement Development Committee

All Issue statement drafts must be sent to the Issues Development Subcommittee for review and approval. They will determine if the statement should move forward and will make any needed revisions before sending it back out to local councils and the public for feedback.

5 Local Council & Public Feedback

The revised draft goes out to all local councils and is posted to the CCSM website, social media sites and sent out via email for public feedback. The deadline for feedback is the date of the next scheduled Issues Development Committee meeting.

6 Final Draft

All feedback received from the local councils and the general public are sent back to the Issues Development Subcommittee and the group will incorporate any feedback, as they deem fit, into a final issue statement draft.

7 Approval by the Statewide Consumer Council

The final draft is presented at the next Statewide Consumer Council (SCC) meeting for a vote of approval.

8 Approved?

Statement is archived; can be revisited at a later time, if appropriate. The full issue statement process must be followed again.

No

Yes

Sent out to the appropriate entity

Created by: The CCSM Issues Development Subcommittee 2018

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

Issue Statement Process: Starting from the Issue Development Subcommittee

1 Brainstorming

The subcommittee generates a list of issues that pertain to Maine's mental health system.

2 Identify & Define Issue

Using the generated list of issues, the subcommittee, through group consensus, picks an issue from the the list to work on and then determines if it fits into the CCSM mission and identifies it as either a local, regional or statewide issue.

3 Create Concept Draft

A concept draft, which clarifies the idea, is written. The issue is summed up in a paragraph yet gives enough detail to provide a comprehensive understanding of the idea.

4 Local Council & Public Feedback

The concept draft, which introduces the issue, is sent out to all local councils and posted to the CCSM website, social media sites and sent out via email for feedback along with a deadline to respond. Comments received will be used in creating the first draft.

5 Create First Draft

Once feedback from the concept draft is received, a first draft is created by the subcommittee using the CCSM Issue Statement template.

6 Local Council & Public Feedback

The first draft is sent out to all local councils and is posted to the CCSM website, social media sites and sent out via email for public feedback along with a deadline to respond.

7 Final Draft

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The final draft is presented at the next Statewide Consumer Council (SCC) meeting for a vote of approval.

9 Approved?

Yes

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No

Statement is archived; can be revisited at a later time, if appropriate

Created by: The CCSM Issues Development Subcommittee 2018

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www.maineccsm.org

Sample of Cover Letter

Date

DHHS Commissioner
Jeanne Lambrew
109 Capital Street
Augusta, Me 04330

Please find enclosed an Issue Statement regarding **Issue Statement that** has been written by our Issue Subcommittee and approved by the Consumer Council System of Maine Board of Directors.
Below you will find a description of the process the CCSM uses.

Issues, Assessment and Recommendations for Issue Statements

As directed in Title 34-B, §3611(6)(D)(2), the Consumer Council System of Maine (CCSM) has established a mechanism for formally communicating issues and concerns with the DHHS Commissioner and high-level department personnel. After the prescribed Statewide Consumer Council (SCC) process, the SCC may approve the presentation of an issue through a formal "Issue Statement." Issue Statements may originate from the community, Local Councils, or the SCC, and follow a format that includes stating 1) the issue, 2) the recommendation, and 3) the proposed outcome. Issue Statements are submitted primarily to the Commissioner and copied to the Director of the Office of Behavioral Health, Court Master, and other personnel as appropriate. We usually see a response from the party(s) addressed within 30 days.
If you have any questions about this issue statement, please contact us. We look forward to hearing from you on this issue and to moving ahead in a positive way.

Respectfully submitted,

Simonne Maline
Executive Director

Simonne M Maline

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CCSM Issue Subcommittee
Consumers not being consistently included in setting ISP/ITP goals and plans
Board Approved 8/28/2020

The Issue:

Consumers of mental health services often are not being included in setting their own Individual Service Plans (ISP)/Individualized Treatment Plans (ITP). Oftentimes providers, whether it be case managers or mental health providers will fill out all goals in domain areas such as transportation, spirituality, housing, finance, education, peer services etc. without the input of the consumers. They will have all these areas filled in on their plans before a person even shows up for their appointments/reviews. Consumers must sign these plans to indicate agreement without having much, if any, input at all. This can undermine an individual's confidence and stunts recovery in that consumers are not encouraged to think for themselves. Experience has taught us that people have great insight when it comes to knowing their own minds and bodies. When encouraged to be independent and think for themselves, individuals will improve much faster and even can recover completely from what distresses them. Consumers should determine how many goals they have, when they have accomplished their goals, when new goals may be considered or when they feel ready to leave services. All these things should include shared decision making that encourages an individual to apply what they have learned and mature.

Recommendations:

1. Train/retrain providers of mental health services about the importance of encouraging peers to be individuals to give them back the voice they may have lost in life due to trauma or other circumstances.

2. Included in that provider training would be for peers to describe their own goals. Ideally providers should support their clients in achieving their treatment goals by teaching them how use the ISP/ITP on their own. Peers should be able to seek help as needed instead of receiving ongoing/lifelong treatment. **Otherwise the system creates dependency**

on mental health services. Peers should always be encouraged to move forward and reach their full individual potential.

3. Both peers and providers alike need to know that people with mental health challenges no matter how severe, can and do recover. We need to promote any and all informed choices of action that a consumer wants to use to achieve maximum recovery opportunities.

4. People should always be offered a copy of their current and/or prior ISPs/ITPs once completed so that peers can always refer to their plans in their recovery work.

5. Make sure that peers have a chance to add comments about what they need at the end of the plan and always encourage them to be clear and direct about their needs.

Expected Outcomes:

Individuals will have the opportunity to be fully included in their treatment plan and also take charge of their own ISP/ITP. This will empower them in their endeavor to heal, change as a person and get to a positive place in their journey through life. **If they need treatment in the future it will be to maintain their recovery, not because they have severe and persistent mental illness.**
Then, they can be considered a person in recovery until they are fully recovered.

There is a body of research readily available that supports this concept.

Shared Decision-Making in Mental Health Care
https://store.samhsa.gov/sites/default/files/d7/priv/sma09-4371.pdf

"If people have a greater opportunity to participate fully then we all have a better chance at being successful." **~Quote from Consumer Council System of Maine**

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CCSM Issue Subcommittee
Section 17 Flexibility of Care Revisited
Board Approved 8/28/2020

The Issue:

Five years ago, the CCSM Issues Subcommittee submitted an issue statement to the Commissioner of DHHS addressing the need to look at case management and community integration eligibility rules. These rules do not provide an opportunity for people to move in and out of this service as needed. Since then nothing has been done to address this issue, thus we are bringing it to the forefront again.

Currently, the rules regarding Section 17 do not allow for the flexibility of case management and community integration services to work well together to meet the needs of individuals in these services. Many get to a point where they no longer need case management services as frequently, when they are forced by an inflexible system to continue regular contact or else be required to jump through challenging hoops to continue services. **This often leaves people trapped in services, sometimes for years when they do not need them. However, when individuals do need to engage in services they should not have to reapply and wait to gain access to such services. If the agency is full, the person should have a choice of waiting (we recommend they are on a priority waitlist) or going to another provider.** This would more effectively utilize tax dollars and better use the time and efforts of all those who are working in the case management system.

Some of us experienced a different model years ago that was offered by Catholic Charities in Portland known as the Alumni

Program. This offered people case management as needed, as well as, various skills groups. One could access this program when necessary and if there were months that went by, they did not have go in for 90-day reviews etc. It was on their terms based on their own needs. This model worked well but did not survive because it was grant funded with no other funding mechanisms available. In this program, there was a seamless transition back to traditional case management if needed, as well as, allowing people to graduate from the program when they did not need the service anymore.

Recommendations:

1. Explore models that move people towards what they need rather than what MaineCare rules dictate.

2. The Office of Behavioral Health (OBH) and MaineCare must research ways to implement flexibility in the continuum of services. Not only, is this what individuals need, it would be cost effective for the State of Maine.

3. We recommend that there is a way to "pause" a person's services in the system instead of completely ending services. This way, when/if a person needs to come back, you hit the pause button to reinstate them. We realize this may need a waiver from CMS but we feel this would make it easier for everyone to come and go as needed.

Expected Outcomes:

The goal of these changes would move Maine's service system to one that truly meets the needs of the individual and supports a person-centered recovery***** focused model of care. This would allow people to drive their own service needs without the same obstacles that exist in the current service structure. In doing so, the State would save funds and our peers could access services as needed and not based on the fear of not being able to access programs when necessary. This empowers consumers as well as providers to move the system forward in a positive way, thus improving individual recovery outcomes.

"If people have a greater opportunity to participate fully then we all have a better chance at being successful." **~Quote from Consumer Council System of Maine**

***Definition of Recovery by SAMSHA**: A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.

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January 6, 2021

STATEWIDE CONSUMER COUNCIL

CCSM Issue Subcommittee
Telehealth
Board Approved 12/18/2020

The Issue:

Telehealth has been inconsistent across the State and varies greatly within provider agencies. We feel that video telehealth is an important tool to offer for appointments, especially in the areas of mental health. Per Maine Care rule, video should be the top option and phone should only be used if no other resource is available. We often hear that people get phone calls and not the option of video due to either consumer/provider lack of technology or due to the provider preference. For example, within the same agency counseling is offered by video, and medication management appointments are only offered via phone. Clients' needs should be considered first and foremost.

Recommendations:

1. All providers should be offering their clients the option of HIPPA compliant video conferencing first and the clients should decide if that is what they want versus the provider deciding for the client.
2. We absolutely need to make sure that all peers have equal opportunity to access technology.
3. When possible, people should be given the choice to use technology rather than being forced to go into the office which is based on office policy. There needs to be a focus on the person's needs and safety first and foremost!
4. If providers are on video, they need to be seen and not keep their cameras off. This can create mistrust for the person.
5. Telehealth needs to be considered as part of our continuum of care as we move towards post Covid-19. It really is a great resource for people who lack access to transportation and live far away from service centers. It saves time, money, protects the environment and dramatically reduces the no-show rate for providers. This is a win/win for everyone!
6. DHHS should work with all providers to provide technical assistance when and if needed to make sure that everyone has access to telehealth options no matter which provider they use.
7. DHHS should work with all providers, nonprofit organizations and adult education providers to provide free training for their clients on how to use technology.
8. We recommend that Maine 211 have a live chat feature that could be another resource for people who may be struggling with access to information and technology.

Please note: Individuals should have the option of in person if that is what they choose. We are not saying that telehealth is perfect choice for everyone all the time.

Expected Outcomes:

Telehealth needs to be a viable alternative for every consumer/peer in the State of Maine. Working together, telehealth provides huge savings, quality client care and a more efficient system for all!

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

www.maineccsm.org

CCSM Issue Subcommittee
Office of Consumer Affairs
Board Approved 4/24/2020

The Issue:

In the past Maine historically had an Office of Consumer Affairs (OCA) and at various times it represented different disability groups. In the 1990's there was a cross disabilities OCA that worked under the DHHS Commissioner. In the 2000's there was a specific OCA office that was under the umbrella of the Office of Adult Mental Health Services (OAMHS). When the CCSM came into being, the State said that we would be the go-to-organization that would advise OAMHS as it was called at that time so there would be no need for an Office of Consumer Affairs.

What we know now through experience, is that because the CCSM is outside of State Government, we cannot be part of advising them on certain aspects of the work they do. For instance, we cannot help them write RFPs' (Request for Proposals) for services. This is not a good use of the State's time and our taxpayer dollars as demonstrated by the RFP that went out for the Intentional Warm Line program. This proposal would have reduced the operational hours of the Warm Line limiting peer access across Maine. We had to mobilize our peers who depend on this very valuable service to let the state, legislators, and governor know how detrimental this change would be to all concerned. The RFP was pulled, but a lot of time and money went into writing something that had peers been at the table through OCA representation, this extremely harmful action could have been prevented. It is because of examples like this we are asking DHHS to bring back an office of Consumer Affairs.

Recommendations:

1. A four staff peer member team, one of whom would be the peer director, who would be part of the Office of Behavioral Health Senior Management Team.
2. The OCA should work closely with the CCSM and the broader peer community and act as a liaison to the wider community at large.
3. We would want the OCA staff to gather input before writing RFPs or other initiatives by SAMHS so that our voice could be part of the process internally.

4. The recommendation of an OCA is also reflected in the final report from LD 1602 the Adult Mental Health Commission to bring back the OCA. See link below:
   https://legislature.maine.gov/doc/3874

Outcomes:

We would hope with the re-establishment of the Office of Consumer Affairs that there would be increased communication between the broader peer community the Office of Behavioral Health (OBH). Thus, with significant consumer voice and input, decisions made about our services could be enhanced. We also expect this would help eliminate the need for pulling RFPs in the future, which would save OBH time and taxpayers' money. This would also create less trauma in the peer community. Advisory capacity would increase and thus be more beneficial to the work done by consumers. It would also help the CCSM to fulfill our mandate in a much more effective manner. Ultimately, we realize DHHS is committed to exemplary customer service, so it makes perfect sense to have we the customers represented in DHHS. Our voices matter.

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

DATE: December 27, 2019

GROUP NAME: THE STATEWIDE CONSUMER COUNCIL OF MAINE

THE ISSUE STATEMENT:

Challenges to employment for people with mental health issues and have criminal backgrounds.

THE ISSUE:

The problem, not just in Maine but also in other states is that those with a criminal history are having a hard time getting hired for a job. This affects the mental health community disproportionally. Once most potential employers see on an application that you've been in trouble with the law, they often disregard your resume. In Maine it is a real problem because the State is a hire/fire at will state. Most of the employers in Maine have questions about felony convictions on their applications.

RECOMMENDATIONS:

1. Provide a job coach/mentoring program for people who are leaving or have left the correctional system.

2. Provide supports for high school equivalency programs and post-secondary education in correctional settings.

3. Create a clear path for expunging criminal records where applicable and appropriate.

4. Recommend to the Maine Legislature's tax subcommittee to create tax incentives to businesses for hiring people with correctional histories, like the WOTC Federal program: https://www.doleta.gov/business/incentives/opptax/

5. Amend the criteria for obtaining a contract waiver from DHHS for direct service professionals, when appropriate.

6. Assist individuals with felony backgrounds to find meaningful career paths and not just get them “employed”.
7. Engage DHHS with the CCSM and other stakeholders to gain a better understanding of the challenges people are facing and make constructive recommendations.
8. Add a resource page or additional chapter to the Maine Can Work Criteria/Book that discusses the topic of people with criminal backgrounds facing challenges with finding employment.

EXPECTED OUTCOMES:

Individuals with criminal backgrounds should be recognized as “people too”. They are redeemable and shouldn’t have to settle for a mediocre occupation when they may be capable and even in some cases are trained for so much more. Maine needs every person possible to be engaged in the workforce. This supports those with mental health challenges and criminal backgrounds to find meaningful employment and helps Maine struggling workforce. Maine has a history of ranking at or near the bottom percentile of employing people with disabilities and this is one path to achieving better employment outcomes.

Consumer Council System of Maine
A Voice for Consumers of Mental Health Services
www.maineccsm.org

GROUP NAME: **THE STATEWIDE CONSUMER COUNCIL OF MAINE**

Date: **June 28, 2019**

THE ISSUE STATEMENT: **Person first language: reducing stigma and focusing on a strength-based approach to care**

THE ISSUE:

The language a society uses to refer to persons with disabilities shapes its beliefs and ideas about them. Person-First Language is an objective way of acknowledging, communicating, and reporting on disabilities. It eliminates generalizations and stereotypes, by focusing on the person rather than the disability.

Person first language is not a new concept. It began in the 1970's within the larger Disability Rights Movement. Unfortunately, it has not had much work in the mental health disability community. We have been preceded by the ID/DD community in Maine. To this end, we want to make sure all, laws, contracts and statutes reflect person first language.

RECOMMENDATIONS:

1. SAMHS will add PFL requirements in all mental health provider contracts.
2. DHHS/SAMHS will provide statewide training on PFL with providers including all peer support programs.
3. SAMHS and CCSM will partner together on a work plan for potential legislative action that may be needed to update mental health statutes.
4. DHHS/ MaineCare to make needed changes to MaineCare rules and communications to members to make sure they are consistent with PFL.

EXPECTED OUTCOMES

By fixing outdated language, we hope that we can affect change in the way people see people with disabilities and see them as a person, not a diagnosis.

Consumer Council System of Maine
A Voice for Consumers of Mental Health Services
www.maineccsm.org

February 22, 2019

The Issue Statement: Trauma informed approaches to mental health treatment in emergency departments

The Issue:

Many peers who go into any of Maine's emergency departments in need of crisis mental health services often report traumatic experiences when they go there. People go to the emergency departments often as a last resort to having no other avenues available to them. Numerous people report that they leave the emergency department in worse shape than when they went in. Trauma is often experienced through interactions with various emergency department staff in the form of strip searches, restraints or forced medication etc (See attached examples of personal stories).

The Recommendation(s):

1. Trauma informed curriculum to be recommended for hospitals' personnel.

2. Explore the possibility of offering Emotional CPR (eCPR) Training to hospital personnel: Below is a link to their website. https://www.emotional-cpr.org/about-ecpr.htm

3. Suggest more open access hours in behavioral health practices that way more people could avoid the emergency department.

4. The 211 Phone Helpline is a very good resource to find support. Individuals often find their website difficult to navigate. Suggest that the United Way look at making the 211 website more user friendly. In an effort to avoid going to the emergency department, access to services might be an alternative used by peers.

5. Set up a stakeholders group made up of interested peers, SAMHS staff, providers and ED personnel to explore ways to bring trauma informed care best practices into all hospital emergency departments.

Expected Outcome(s):

It is our expectation, that all emergency department staff are trained and supported to use evidence-based trauma informed practices. Treatment at the emergency departments could be a more beneficial and a less traumatic experience for people needing crisis support. We also want to support a robust community support system that keeps individuals out of emergency departments whenever possible.

Janet T. Mills
Governor

Jeanne M. Lambrew, Ph.D.
Commissioner

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September 10, 2019

Simonne Maline, Executive Director
Consumer Council System of Maine
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Thank you for your letter (dated 3/26/19) regarding "Trauma informed approaches to mental health treatment in emergency departments," as well as the supportive documentation provided. The Department recognizes and agrees with the importance of trauma-informed care for individuals visiting the emergency department. The Department is interested in collaborating with the Consumer Council System of Maine to address your concerns in this domain, but notes that unlike past Issue Statements, this did not include a discussion of expected outcomes. We would value further discussion with the Council on this matter. We note that your recommendations include multiple mentions of helping individuals in mental health crisis avoid going to the emergency department. This is a major focus of SAMHS at this time, and is a central tenet of several Department projects and programs, including but not limited to the Crisis System; the Warmline; Medical Assisted Recovery Program; and First Episodic Psychosis. The Department is committed to traditional and innovative practices that may facilitate access to the most appropriate and helpful level of care possible.

Below you will find a direct response to each of the recommendations made in your letter:

1. Trauma-informed curriculum to be recommended for hospitals' personnel: The Department agrees that this may be a valuable intervention, and would value input on applicable curricula that could be leveraged.
2. Explore the possibility of offering Emotional CPR (eCPR) training to hospital personnel: The Department will conduct internal research into this model and follow-up.
3. Suggest more open access hours in behavioral health practices [so] more people could avoid the emergency department: The Department will engage with providers to assess the viability of this practice. We recognize that Mental Illness does not always present itself Monday-Friday from 9am-5pm.
4. The 211 Phone Helpline is a very good resource to find support. Individuals often find their website difficult to navigate. Suggest that the United Way look at making the 211 website more user-friendly we agree. In an effort to avoid going to the emergency department, access to services might be an alternative used by peers: The Department is working with 211 on a

continuous basis to formulate and implement improvements to web and phone services, including a full site redesign in 2017, an upgraded database system in 2018, and other smaller, modular alterations. The Department may recommend using the Search Tips function (https://211maine.org/2018/10/18/online-search-tips/) and using the site's feedback function (https://211maine.org/contact/) for specific issues of note, so that they may be avoided or rectified if necessary.

Thank you for providing this Issue Statement. We look forward to additional dialogue with the Council regarding solutions to the issues raised.

Sincerely,

Sheldon Wheeler, Director

Office of Substance Abuse and Mental Health Services

Cc: Commissioner Lambrew
Deputy Commissioner Hamm

Recovery Reference Guide & Glossary

Choice: a key concept in recovery-oriented care, choice refers to the central role people in recovery play in their own treatment, rehabilitation, recovery, and life. Within the health care system, people in recovery need to be able to select services and supports from among an array of meaningful options based on what they will find most responsive to their condition and effective in promoting their recovery. Both inside and outside of the health care system, people in recovery have the right and responsibility for self-determination and making their own decisions, except for those rare circumstances in which the impact of the condition contributes to their posing imminent risks to others or to themselves.

Consumer: Widely used to denote a person receiving mental health services. Historically has been used in mental health advocacy to offer a more active and empowered status to people who otherwise were being described as "clients" or "patients." Though intended to better describe people as consumers in the traditional sense of being able to make informed choices, that connotation is not often understood by either the consumer or provider community. Rather it can tend to imply someone who "consumes" more than he/she contributes, and as such is a point of controversy in the mental health system. It is however widely used.

Lived Experience: refers to a representation of the experiences and choices of a person who lives with mental health challenges, and the knowledge that they gain from these experiences and choices.

Natural Support: technical term used to refer to people in a variety of roles who are engaged in supportive relationships with people in recovery outside of health care settings. Examples of natural supports include family, friends, and other loved ones, landlords, employers, neighbors, or any other person who plays a positive, but non-professional, role in someone's recovery.

Peer: within mental health and/or substance use, this term is used to refer to someone else who has experienced first-hand, and is now in recovery from, a mental health and/or substance use condition.

Peer Support: mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery. Consumers encourage and engage other peers in recovery and provide each other with a sense of belonging, supportive relationships, valued roles, and community. Peer support happens in a variety of settings: individual to individual, in self-help and support groups, within peer centers and social clubs, both formally and informally, and in connection with various services offered by a well-developed system of mental health care, e.g. hospitals, phone support, and crisis alternatives.

Peer Support, Intentional: Intentional peer support attempts to actively use reciprocal relationships to redefine help, with a goal of building community oriented (natural) help rather than simply creating another formal service. It involves training, certification, and ongoing education, which provides the peer support specialist with a well-defined framework within which to engage meaningfully with others in a peer support role.

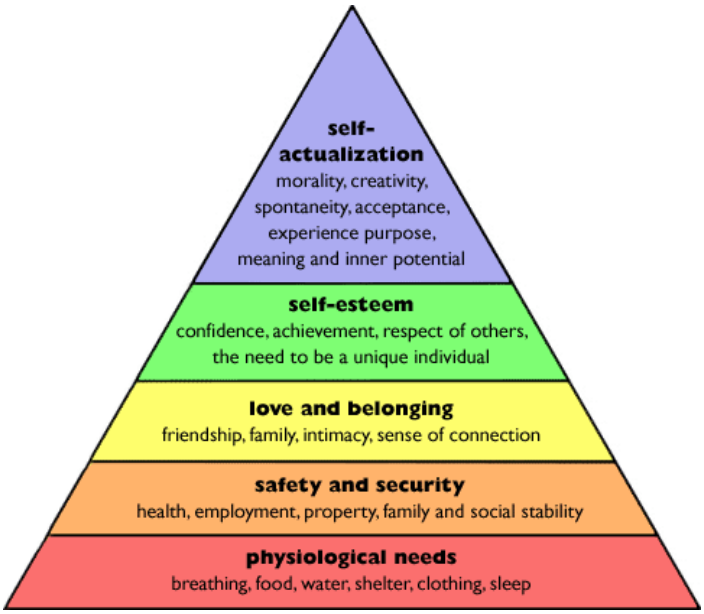
Person-Centered Care: care that is based on the person's and/or family's self-identified hopes, aspirations, and goals, which build on the person's and/or family's own assets, interests, and strengths, and which is carried out collaboratively with a broadly-defined recovery management team that includes formal care providers as well as others who support the person's or family's own recovery efforts and processes, such as employers, landlords, teachers, and neighbors.

Recovery: Definitions may vary, but all include key elements: 1) it is a journey or process; 2) involving healing, change, growth, transformation; 3) living a meaningful/productive life as defined by the individual; 4) realizing more and more of his/her full potential; 5) participating fully in the community of his/her choice.

> *"Recovery is a journey of change and growth toward realizing one's full potential, through meeting needs common to all humankind and inspired by personal dreams, goals, and hope, amid life challenges that include mental and emotional health."*

Recovery-initiating factors can exist within the person and/or within the person's family and social environment as well as in the health care system. These factors can include pain-based experiences, e.g., anguish, exhaustion; death of someone close; experiences of feeling humiliated; increased health problems; failures or rejections; or suicidal thoughts. **Less well-recognized and appreciated, however, are the hope- and pleasure-based experiences that appear to be even more effective in promoting recovery: pursuing interests and experiencing enjoyment and success; exposure to recovery role models; new intimate relationships; marriage, parenthood, or other major positive life change; a religious experience; or new opportunities.**

(See National Consensus Statement on Mental Health Recovery)



Maslow's Hierarchy of Needs

"Recovery is a journey of change and growth toward realizing one's full potential, through meeting needs common to all humankind and inspired by personal dreams, goals, and hope, amid life challenges that include mental and emotional health."

Policies, services, and resource allocation should be determined by how they address human needs, starting with the most basic.