The Urgency of Early Engagement:
Five Persistent Barriers to Mental Health Treatment, Care and Recovery in Massachusetts and the Search for Solutions

A Report by Health Care For All

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I. Overview

The Purpose of this Report

This report has three goals:

(1) to present the results of a year-long study of on going barriers to early mental health treatment, care, and recovery based on the insights from people in Massachusetts

(2) to explore how to overcome these barriers, using the most practical, concrete and cost-effective tools possible;

(3) to propose next steps.

Health Care For All (HCFA) began its work when The Peter and Elizabeth C. Tower Foundation funded a broad overview of the behavioral health barriers that people face when trying to get care, particularly for individuals attempting to cope with mental illness as well as their families, providers and other allies. The research initially focused on insurance barriers, mostly relating to mental health parity. However, the information coming back took us in a less obvious but no less significant direction: early barriers to getting care can have a significant impact on a person’s potential for recovery.

The Lasting Costs of Barriers to Early Engagement

Substance use, homelessness, and incarceration are three well-documented, devastating consequences of failures at the early stages of the mental health system. The opportunity for individuals to get early and possibly lasting support for their mental health care needs can be lost when important information about treatment options is not readily available, when early symptoms of mental illness foster isolation and stigma, when insurance coverage proves hard to navigate, when costs of treatment discourage or limit access, and when effective providers are seemingly impossible to find. As a result, many individuals face an increased likelihood of months and more often years of untreated or inadequately treated mental illness. The resulting life disasters become immoveable problems in and of themselves. This makes it difficult — and sometimes impossible — for individuals to regain precious ground and access the treatment and supportive services that make recovery an achievable goal.

Too often circumstances prevent people from getting the care they need.

An Overview of Five Persistent Barriers

This report has three sections: this overview, findings, and recommendations. In the findings section, we identify five themes. These themes represent our effort to summarize the wide variety of responses used to identify the primary barriers individuals encountered as mental illness came to occupy their lives.

1. Knowledge Barriers: A significant lack of knowledge about mental illness and the resources available for treatment and support pervade every step of the overwhelming journey to recovery. For many individuals, a lack...
KEY ADVISERS

In doing this work, HCFA was blessed with dozens of advisers listed in the Acknowledgments section. We wish to recognize here several advisers whose knowledge and experience guided the project in pivotal ways. Despite their valuable help, any errors are the sole responsibility of the authors. Moreover, their participation in its preparation does not imply endorsement of its content.

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✔ Christopher Gordon, M.D., Medical Director and Senior Vice President of Clinical Services, Advocates, Inc.;
✔ Kaitlyn Kenney Walsh, Senior Director of Policy and Research, Blue Cross Blue Shield of Massachusetts Foundation (BCBSMA Foundation);
✔ Lisa Lambert, Executive Director, P/PAL
✔ Danna Mauch, Ph.D., President/CEO, Massachusetts Association for Mental Health (MAMH); former Assistant Commissioner, Massachusetts Department of Mental Health (DMH);
✔ Ewa Pytowska, President, NAMI Mass. Greater Boston Consumer Action Network (GBCAN);
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✔ Megan Wiechnik, Director, NAMI Mass. Compass.

Due to external prejudices and internal shame, individuals will often delay, avoid and even dislike the help they need.

2. Attitude Barriers: Due to external prejudices and internal shame, individuals will often delay, avoid and even dislike the help they need. The name usually given to this debilitating prejudice and shame is stigma, but using that label often ends rather than starts a conversation. When fully unpacked, the phenomenon of stigma reveals deep and varied barriers to engagement.

3. Insurance Barriers: The difficulties people face in navigating the complexities of insurance coverage – including mental health coverage – are particularly unfortunate despite Massachusetts’ gains as a state with near universal coverage. Consumers inevitably reach out to insurance companies upfront as an important point of contact. They could, therefore, serve as allies and guides to their members. Instead, most respondents viewed their insurers as adversaries. This adversarial relationship is compounded by the failure to fully implement mental health parity.


5. Delivery Barriers: Even when insurance coverage applies, finding effective treatment rather than treatment in name only is much more difficult than it should be. Moreover, current commercial insurance coverage leaves out treatments critical to early treatments.
Overcoming Barriers to Early Engagement

In Section III, the report turns to the question of what to do. These barriers are not new; they have been explored before. Efforts to address them also have been made before. And yet they persist.

At the same time, first-hand observers described programs and policies in Massachusetts working effectively to overcome some of these barriers, at least for the people fortunate enough to have access to them. What made these reports so important is the fact that these programs already exist – that there is evidence, although often anecdotal, that these programs actually help. How excellent would it be if overcoming these distressing barriers did not require us to start from scratch, particularly given the urgency of making a difference in the lives of the thousands of people struggling right now?

Summary of Recommendations

- To overcome barriers, Massachusetts should help promising programs grow to scale. Two immediate candidates are the INTERFACE referral service (INTERFACE) and Bridge for Resilient Youth in Transition (BRYT). Other programs deserving consideration are described in Section III, and still others are waiting to be discovered.  
- Massachusetts should commit to closing the knowledge gap by creating a state-of-the-art resource helpline and promoting its use statewide. A promising project with that goal is now underway. 
- Massachusetts should expand the training and employment of people in peer support roles. One major step in that direction would be MassHealth payment for Certified Peer Specialists. 
- Massachusetts should require increased transparency of insurance, improved customer relations, and safeguards to guarantee that people receive the full measure of the mental health coverage to which they are entitled by their insurance policies. 
- The services of Emergency Services Programs (ESPs) should be available to all. To that end, all commercial insurers should include ESPs as an essential part of their behavioral health coverage. 
- The comprehensive approach to children’s mental health, embodied by the Children’s Behavioral Health Initiative (CBHI), should become a universal feature of commercial insurance.

The Photographs—Faces of Recovery

Appearing throughout this report are photographic portraits of people in recovery from mental illness. These individuals are participants in the 99 Faces Project, an artistic work conceived and created by Massachusetts artist Lynda Michaud Cutrell. The goal of 99 Faces is to portray, in the words of Cutrell, “individuals whose lives are remarkable for their recovery, not their illness.” As such, they exemplify and reflect the promise that timely and effective access to treatment for mental health conditions holds. As we state in our conclusion, this report takes an optimistic approach to our collective ability to reduce the barriers to delivery of effective mental health treatment in Massachusetts, because optimism supplies essential energy to the effort. The photographs we have included speak eloquently to why this matters.
II. Five Persistent Barriers to Treatment, Care, and Recovery in Massachusetts

This section presents a summary of information collected by HCFA during the research phase of this project from August 2016 through August 2017. We conducted our research in the following ways:

(1) HCFA staff held twenty-five initial interviews with providers, advocates, public officials, nonprofit leaders and other knowledgeable individuals;

(2) The staff convened four focus groups of people with lived experience and their family members, and two of providers;

(3) HCFA distributed a statewide survey through several online channels and websites, seeking input from individuals and families who had sought mental health treatment in the previous three years. 476 surveys were completed and returned;

(4) Staff of HCFA and NAMI Compass, the resource helpline of NAMI Mass., combed through 2,000 logs of callers seeking mental health resources in the previous year, and culled out forty-six logs representative of the difficulties that callers were encountering;

(5) HCFA staff also reviewed 300 logs of calls and emails recorded by the Massachusetts Attorney General's Office (AGO) that raised complaints about some aspect of mental health care;

(6) Finally, in February 2017, HCFA staff hosted an expert discussion group with nine individuals; included in the group were peers, family members, clinicians, advocates, and former public officials with decades of mental health experience. Fifteen one-on-one follow up discussions were held with members of this group and with six other experts unable to attend the February meeting.


Knowledge Barriers

Across all sectors, we found broad consensus that a lack of basic knowledge about mental illness is an overarching barrier to treatment, care and recovery. Respondents in every group — peers, family members, providers and other professionals — repeatedly emphasized that a lack of knowledge about the symptoms of mental illness and where to turn for help takes a toll at the onset of an episode. The recollection of bewilderment when faced with inexplicable and often frightening behaviors defined our conversations with peers and in particular their families. Thereafter, as the respondents also emphasized, lack of knowledge creates an obstacle that reinforces every barrier documented in this report.

In a one year period beginning on March 1, 2016, NAMI Compass responded to over 2,200 calls and emails from across the Commonwealth requesting assistance in finding, understanding, and navigating available mental health resources. The questions spanned dozens of issues, but the most frequent concerned (a) housing and homelessness, (b) frustration finding a treatment provider or a program covered by insurance, (c) requests for legal assistance on a wide variety of problems triggered by crisis, and (d) confusion about insurance coverage.

"I am in desperate need of guidance to assist my twenty year old son,” one woman wrote in a recent email to NAMI Compass. She described circumstances in which the son and his eighteen year old brother came to live with their grandmother as a result of what the mother had considered "normal disrespectful teenage behavior” in her home. “At the time,” she wrote, “it wasn't understood that my twenty year old son was developing schizophrenia and obsessive-compulsive disorder.” Now, armed with the knowledge that her son's behavior is a result of mental illness, she wrote that the current situation had become further complicated by the fact that her son was “too old to help without personal consent.”
When confronted with the strange and unfamiliar symptoms that often define the onset of mental illness... neither the individual nor the family knows where to turn for the immediate help that is essential.

Illuminating the anguish of a family in crisis, she writes, “My heart breaks for my kids, especially when I can’t give my mentally suffering child a stable environment. . . . I’m at a loss in more ways than I can explain.”

Lack of knowledge fosters isolation, which makes recovery harder. When confronted with the strange and unfamiliar symptoms that often define the onset of mental illness — excessive and uncontrollable crying, self-injury, or days without sleep – neither the individual nor the family knows where to turn for the immediate help that is essential. Frightened and worried that something bad is happening, an individual’s or the family’s first impulse often is to hide the behavior from others. The lack of knowledge about symptoms of and treatment for mental illnesses tends to instill fear and a sense of shame that discourage people from seeking treatment immediately. Sadly, the very fact of delay may compromise the efficacy of the treatment they do receive later on.16

Joan Mikula, Massachusetts Commissioner of Mental Health, considers the social isolation of an individual affected by mental illness to be “at the heart” of existing barriers to recovery. To an individual first experiencing the symptoms of mental illness, it is usually far from self-evident that, as Commissioner Mikula asserted, “you can lead a full and active and productive life even with a serious mental illness.” She emphasized the importance of people realizing that “they’re not the only ones, that there are other folks in the same boat, facing the same challenges,” and that many of these individuals are today on a path to recovery, with housing and jobs.

Nevertheless, faced with a situation unexplainable by past experience, families often flail about in turmoil. Sometimes, families don’t even know what mental illness looks like. Lisa Lambert, the executive director of the Parent/Professional Advocacy League (P/PAL), said, “I think that on the kid side psychiatry in mental health does a very poor job of talking . . . about what mental health issues can look like in children . . . it contributes to the lag of about four years from the first signs until a parent gets them to treatment. . . . And by then, it’s [because] the school is calling you, ‘come and get him.’”

The bewilderment that comes from not knowing where to start turns one problem into many, creating a “problem pileup” that reinforces the chaos of mental illness.
The bewilderment that comes from not knowing where to start turns one problem into many, creating a “problem pileup” that reinforces the chaos of mental illness. The case logs we collected from NAMI Compass illustrate the interconnected nature of the barriers as they show up in the lives of individuals and families. Many callers have one basic, often unspoken question: “Where do I start?”

Surrounded by problems flowing from the initial symptoms, however, a caller may fixate on one thread in an interwoven and confounding fabric. For example, a mother who was distraught watching her son lie around the house in emotional pain after he had abruptly left college, called for advice about how to avoid a default on his student loans, not aware that immediate help might be available for his suffering. In this case, in fact, an immediate in-home intervention by the Emergency Services Program (ESP)\(^1\) covering her community was far more important than a loan obligation. The Compass navigator persuaded the mother to first address her son’s suffering and defer ancillary issues, a key step in plying apart the pileup.

Lack of knowledge is aggravated by a system that expects individuals and families to know what they need, putting the burden on them to ask the right question. Without accurate, timely information, it is impossible to understand insurance coverage, access treatment, coordinate services and navigate the complexities and inevitable setbacks in each. Lisa Lambert of P/PAL compared the lack of knowledge about mental illness in the general population to the abundance of knowledge that people have about certain physical diseases and the treatments available for them. “I look at the television commercials about . . . treatment and cancer … they’re really good at talking about what cancer treatment can be: ‘It can be tailored to you. You can find it right here. If you have any questions, call this number. ’ We’re really bad [in mental health] . . . at doing that.” Instead, it falls on often unknowing consumers to determine exactly what they need.

Megan Wiechnik identifies herself as someone with lived experience of serious mental illness. She serves as the director of NAMI Compass. She described a system of care and services in which “we have to know exactly what we’re asking for in order to receive the good fit.” Despite her expertise in both the resources that exist and in guiding others to find them, Wiechnik said she, too, has encountered this knowledge barrier. “I’ve experienced that even though I work in mental health. . . . You have to know exactly what the solution is, and ask for it directly, and many, many people don’t have that education.”

While knowledge itself does not ensure recovery, without knowledge the barriers to recovery can be insurmountable. Lack of knowledge aggravates the other persistent barriers. Knowledge is central to effective use of health insurance benefits and access to experienced caregivers. Without knowledge of price such as insurance co-payments and services not covered by insurance, people can quickly find themselves in an unsustainable financial situation. Knowledge also is an essential ingredient in making the right choice from among the confusing array of available treatments and services.

### Attitude Barriers

Fear of the humiliation often experienced as a result of prejudice and outright discrimination discourages individuals from seeking mental health care and poses an intimidating barrier to recovery. Despite increasing public attempts to create a supportive environment for individuals struggling with mental health conditions, from formal public policy discussions to daily blog posts, these individuals still often find themselves assaulted by persistently negative stereotypes and low expectations.\(^1\)

Such negativity is reflected in the disparaging lexicon many of us employ so casually and without fear of reproach: “That’s insane;” “She’s so schizo;” “He’s a nut case.” These attitudes are manifested in the backlash experienced by the Department of Mental Health (DMH) as well as providers of community-based services as they work to expand group housing for individuals with psychiatric conditions.\(^2\) Mental
health disorders are widely seen as dangerous, to be feared and avoided. Whether born of malice, ignorance or simply thoughtlessness, demeaning attitudes create an environment that reinforces the tendency of many individuals and families to deny symptoms, avoid treatment and suffer in isolation to avoid shame and disrespect.

The fact that individuals and their families internalize the prejudice they observe only worsens its impact and reinforces the tendency toward isolation. DMH Commissioner Mikula pointed out that individuals have a “personal fear about opening up and ‘putting your stuff on the table.’” In the context of mental health, she said, before seeking treatment people often ask, “What are others going to think of me? How will I perceive myself?” Family members, too, can be resistant to seeking care for a loved one. A participant in our consumer focus group recalled the difficulty he encountered with his own parents: “My high school guidance counselor . . . got my parents involved, who were very reluctant to seek care . . . . My main difficulty there was just getting my parents to realize that there was an actual problem that needed addressing.”

The negative effects of stigmatizing attitudes continue once an individual or family has decided to seek treatment. Advocates described an environment in which it is not uncommon for providers to assume character flaws in an individual with symptoms of mental illness, or for primary care providers to be poorly trained in and unwilling to “step out of their silo” to address mental health issues.

Christopher Gordon, a psychiatrist and the medical director of Advocates, Inc., a community social services provider located in Framingham, spoke to the enormous impact of an individual’s first interaction with the world of mental health — a person’s first attempt to “seek some kind of help”—and the lasting effects of that experience, especially if it is negative. “Very often, the help they receive is awful . . . and people [thereafter] are trying to recover partly from the bad experiences they’ve had as well as whatever the turbulence was caused by in the first place. . . . They receive ghastly messages that define them as a patient, as a person with an illness, as a person with a broken brain. . . . We need to find a way to greet people in distress in the very beginning that would enable people to embark on an entirely different journey.”

A participant in the provider focus group discussed the experience of her clients, saying, “I [hear about] the disrespect that my clients have [received] . . . going through the system — most of whom have been through other small outpatient counseling programs, and have been double-booked or their counselor just disappears and no one does follow up — and it all feeds into the stigma.” Programs designed to help people with mental illness can also be treated as less legitimate than programs designed to serve those with physical health problems. Another provider commented that “it’s subtle sometimes but
in places that I work . . . we're not included in a lot of decisions and sometimes somebody needs our room, ‘well, you're not a real program.’ I've had people say that: ‘You're . . . not a real program.’”

Having begun treatment, individuals and families often feel the need to keep this part of their lives secret for fear of negative judgments from others. As one individual said, "I can't explain it but it's . . . I'm like even embarrassed to turn into this . . . office in case people will see me on the street going there.” Reflecting on his own experience, a participant in the consumer focus group said, “even among people at work . . . [there were] just a few of my friends I actually told about my condition because there's a huge stigma because in the news, people with bipolar go nuts and have terror rampages.”

In our consumer focus groups, participants also discussed their approaches to disclosing behavioral health diagnoses and treatment to primary care providers. While a few noted that it was important for primary care providers to know about mental health treatment they were receiving, respondents also expressed a generalized fear that sharing this information could cause problems and indicated that was discouragement enough. One participant said that “[stigma] is the reason I never talked about [my mental health diagnosis] with my primary care physician. And I’ve tried to seek treatment on my own.”

Given attitudes about mental illness, the mental health of children carries a particularly fearsome connotation. To begin with, fear of “branding”—affixing a diagnosis to a child that will always define the child going forward—poses a major barrier to recovery because it deters parents from seeking care for children with mental health needs. A provider who participated in our focus group describes parents’ reluctance to seek mental health care for their children. He stated that “although often psychiatric illnesses can be much more treatable and can often have a much better prognosis [than physical illnesses], I’ve seen parents go through extensive demands of trying to find some clinical, medical explanation for why the child is having panic attacks as opposed to the fact that the child may have an anxiety disorder.”

Mathieu Bermingham, a child psychiatrist, described the apprehension that parents often feel about seeking treatment for the mental health needs of their children because acknowledgment and documentation of mental health challenges could adversely affect the child’s future and potential opportunities: “They’re worried that . . . occupational choices may be diminished by having a depression diagnosis in the record.”
Parents, teachers and other adults in positions of authority can often easily mistake the manifestation of symptoms of mental illness in children to be simply “bad behavior.” As a result, it is not uncommon for children who could benefit from mental health treatment to be punished instead. Depending on their training, providers are not immune from making such assumptions either. “When they see a child who is explosive, they see a child who punches holes in walls, overturns desks. . . . Providers judge children by their behavior, not by a symptom of their illness,” said Lisa Lambert of P/PAL. She added that the problem is exacerbated by a related and common theory that children who exhibit explosive behaviors are “hard to treat.”

There is a widespread assumption that parenting is at fault when children’s mental health issues arise. Nancy Scannell, the director of external affairs at the Massachusetts Society for the Prevention of Cruelty to Children (MSPCC), highlights the fact that children rely on caregivers to get them help. “If an adult’s feeling like something is happening, they have a much greater capacity to say something feels wrong,” she said. With children, “[t]he person in charge of getting resources is often getting blamed for it happening. It’s not a warm and fuzzy environment for a parent to seek behavioral health services for a kid.”

Implicit bias in public systems more readily attributes child misbehavior to parenting failure in families that are different racially or culturally from the mainstream. For certain populations, particularly poorer families of color, the anxiety about entering into a system where there may be an encounter with the Department of Children and Families is even greater. “They want to get care for their kid,” said Kate Ginnis, the director of behavioral health advocacy and policy at Boston Children’s Hospital, “but [they feel] like they’re going to be judged, that the providers look more like us than like them.” This dynamic leads to delays in treatment and to laying blame on the parent.
Respondents’ reticence to share their behavioral health information is reflected in concerns that advocates have about the use and storage of electronic health records. The Parent/Professional Advocacy League (P/PAL) recently conducted a survey on the topic of electronic health records. Lisa Lambert explained that the survey found “…the younger the child is (and that would mean the younger the parents are), the more worried they are about putting all of their child’s mental health information in there. . . . I thought they would be more comfortable but they’re worried . . . [that] there’s nobody who will explain to [them], essentially, how this information is protected in a security way, not in a psychiatry confidential way. [This new role of technology is] . . . a new barrier that we’re just hearing about more and more . . . how vulnerable technology can be. People tell us they simply don’t tell everything anymore.”

Insurance Barriers

Despite the fact that ninety-seven percent of Massachusetts residents have mental health insurance coverage, translating coverage into actual treatment remains elusive. Insurance coverage is a vital component of recovery because, for all but the wealthiest of families, the reality is that no insurance means no care. This is why it is so upsetting for families who have surmounted the knowledge and attitude barriers to encounter a new round of frustrations in finding and paying for the instruments of recovery.

The complexity and obscurity of mental health insurance benefits pose a major barrier to treatment. An insurance helpline navigator at HCFA put it this way: “Comparing health plans for behavioral health needs can be extremely difficult because you must anticipate what services you may use and where you would receive them.” Describing the difficulty of anticipating the mental health needs of his son, who is a disabled adult dependent, one participant in our consumer focus group recalled, “[a crystal ball] was probably the primary way I chose which plan we were going to go on.” Giving voice to a frustration probably familiar to anyone who has attempted to navigate health insurance coverage generally, another consumer focus group participant said, “You can read the [materials], but that doesn’t mean you can understand them. . . . Every time you have to pick your health insurance, I read them as carefully as possible, and I find that I’m still surprised at some of the things that aren’t covered.”

Once enrolled in a plan, the difficulties in determining the details of coverage, obtaining referrals for treatment providers who take insurance, and, where required, seeking prior authorizations hinder necessary care. The illness’ onset – once the illness is recognized — is often the first time most families have occasion to examine the details of their insurance policy’s coverage. At precisely the moment where informed action and early intervention have the greatest potential to avert a downward spiral and hasten recovery, the role of insurers is all-important. As the HCFA insurance helpline navigator said, “When a patient is in behavioral health crisis the last thing they need to worry about is insurance network issues and referrals. It adds an additional burden that can prevent people from receiving timely and adequate care.”

In search of clarification about their insurance coverage, eighty-three percent of all respondents to our statewide online survey had turned to their insurers. As the most common reasons for contacting their insurance companies, respondents cited seeking pre-approval, finding a provider who took their insurance, finding out why a plan didn’t pay for care, and general confusion around benefits. And when asked to rank satisfaction with this contact, more than half of those seeking mental health care were dissatisfied with their plan’s response to their inquiry.

“Jumping through hoops”: Participants in our consumer focus groups and advocates in the field separately, repeatedly, and remarkably often, characterized this process of seeking coverage and reimbursement from an insurance company with the
We found a strong consensus that individuals with commercial insurance face greater barriers to treatment, care and recovery than participants in MassHealth, the Commonwealth’s Medicaid program.

same phrase: “jumping through hoops.” “It takes a lot of energy,” a participant said, “and a lot of people are not going to do it, and that’s what the insurance companies are probably [counting] on. That people will not jump through the hoops to do it or they can’t jump through the hoops to do it ‘cause they don’t know which hoops to jump through or they don’t have the resources.” Determining what these hoops are and how to jump through them is a role often assumed by family members — if family members are available and willing – and one that Janice Peters, the manager of healthcare policy at the Massachusetts Health and Hospital Association (MHA) describes as invariably “time consuming and arduous.”

Complaints to the Attorney General repeatedly cited difficulties accessing insurance and emphasized the detrimental effects of delay and denial of care. Complaints logged by the Health Care Division of the Massachusetts Attorney General’s Office reflect the challenges people have seeking coverage and reimbursement, the difficulty of communicating with their insurers, and the resulting negative effects on their treatment and recovery. One complainant described a situation in which she was owed reimbursements from her insurer for outpatient mental health visits with an out-of-network provider. She explained that three separate cases had been opened by the claims department at [insurer], but that each time a case was closed, the insurer failed to make the reimbursement. “I believe [insurer] required an inordinate amount of communication and documentation from me,” she wrote.

Another complainant to the Massachusetts Attorney General’s Office arrived at the pharmacy to pick up his prescription medication only to be told a prior authorization was required. At the time he made the complaint, this issue had yet to be resolved. “I have been without my medication for a SOLID MONTH,” he wrote. “I have spent countless hours during work time on the phone with this office, and at this point it is just BEYOND ridiculous. Because I’ve been without necessary medication to manage my ADHD symptoms for so long, I am probably close to losing my job...At this point, I am desperate.”

“With respect to insurance coverage and access to care, what I see is that those who have MassHealth, have an array of services that help to keep them afloat.”

We found a strong consensus that individuals with commercial insurance face greater barriers to treatment, care and recovery than participants in MassHealth, the Commonwealth’s Medicaid program. Recovery depends on the availability of a robust, comprehensive, and diverse set of services, and these necessary services extend beyond the medical services covered by commercial insurers. Participants in the expert discussion group spoke at length and from direct experience about the deficiencies of private insurance as opposed to public insurance in accessing the services that facilitate recovery from serious mental illness. In her role as president of the NAMI Mass. Greater Boston Consumer Action Network (GBCAN), Ewa Pytowska works with individuals with private insurance as well as those who have public insurance. She said, “With respect to insurance coverage and access to care, what I see is that those who have MassHealth have an array of services that help to keep them afloat. They have case managers, they have homemaker services, people who come to the house and help them clean and help them do laundry, and manage their daily lives, etc.” She added that usually none of these services are available to those with private insurance plans.
Assembling what Parent/Professional Advocacy League (P/PAL) executive director Lisa Lambert calls a “constellation of services” requires both coordination and advocacy. Individuals and families who are covered by private insurance not only have fewer options in terms of services available but because they generally lack a case manager to search for these services and then advocate for them, they have to advocate with their insurer directly. For this reason, Lambert said, “We teach parents how to advocate with their insurer. Otherwise, we tell them how to [add MassHealth as a secondary insurer].”

The failure of commercial insurance to foster or provide access to effective, broad-based and community-based services results in health declines and expanded use of emergency departments. The difference in coverage is further reflected in the experiences reported to NAMI Compass. For example, the Massachusetts Emergency Services Programs (ESPs) are widely lauded as an effective and cost-efficient option to divert individuals in crisis away from both the emergency room and the criminal justice system and into appropriate stabilization and treatment. ESPs are covered for all MassHealth members, people with Medicare, and people without health insurance, but uncovered for the most part by commercial insurance.

In a scenario echoed in many NAMI Compass calls, a mother named Paulette emailed the resource line looking for assistance for her son Tom, who had recently been hospitalized for first episode psychosis. Discharged with medication, but no treatment plan, Tom soon stopped taking his medication. In crisis once again, Paulette contacted her local ESP but was told Tom was not eligible for services because of his commercial insurance. A mere five days after his discharge, Tom was re-hospitalized.

Advocates, Inc. runs the ESP for the Metrowest area of the state. Although, according to Christopher Gordon, the Advocates medical director, the Advocates ESP is insurance-blind — the only such ESP that we found to be so — Dr. Gordon corroborated that service options are more limited for those covered by private insurance. “If we respond to somebody and they have MassHealth, then the team has a broad array of options to work with,” he said. “If it’s so-called ‘good insurance?’ Nada. You’ve got a . . . private policy, but you got nada.”

Child psychiatrist Mathieu Bermingham spoke of the success MassHealth has seen in its implementation of “wraparound services” for children. “At its core,” he said, is “the understanding that you need to take care of ‘everything else.’ For the
young people, what they love most is a good Therapeutic Mentor." He pointed out that a “Family Partner” may be the least expensive of services offered but is the most appreciated by young patients. “They hang with you...They remind [the young people] of themselves,” Dr. Bermingham reflected.

The inadequacy of insurer “provider directories” is a major barrier to treatment, care and recovery. In turning to their insurance carrier for assistance in finding a provider, individuals are often given the insurer's directory or list of eligible network providers. They report that these lists, referred to by advocates as “ghost networks” or “phantom panels,” are often out of date, guaranteeing frustration and delay when members discover still-listed providers are in fact not currently accepting new patients, have moved away, are no longer accepting insurance, or are deceased.

In search of a provider for his partner who needed care for depression and anxiety, one NAMI Compass caller said that he had been depending on spreadsheets supplied by the insurance company. For over a year, he had gone down the lists and researched each provider but was unable to find one who accepted his partner’s insurance and had availability during evening or weekend hours. Overwhelmed, he called Compass seeking ideas.

Discouraged in a long search for a therapist specializing in post-traumatic stress disorder, one person contacted the Health Care Division of the Massachusetts Attorney General’s Office. She, too, had first turned to her insurer for recommendations. Told to select a provider from a list on the insurer’s website, she was unable to find one currently accepting new patients and was denied out of network approval by the insurer. “I called nearly thirty people from their list and none of them were accepting new patients,” she recalled. “I have done my best to work with [the insurer] and do things the way they have told me, but have had no positive outcome... This stress is causing increased PTSD triggers, which is the very reason I am undergoing treatment.”

Providers report that unreimbursed administrative time demands discourage them from accepting insurance. Jennifer Warkentin, the director of professional affairs at the Massachusetts Psychological Association, labels “insurance complexity...the biggest barrier for providers.” Providers describe a landscape riddled with unreimbursable time spent on the phone and computer attempting to get on insurance [networks], determining exactly what insurance benefits their patients have, requesting prior authorizations for prescription medication and seeking approval for additional treatment sessions. Often, they report, foregoing participation in insurance panels altogether appears to be the better option. A participant in the provider focus group said, “I've spent half an hour, thirty-five minutes talking to one person after another trying to get a prior authorization for a needed medication. And... there's no reimbursement whatsoever for this. So, it feels ... like they're actually just driving people right out of accepting insurance.”

While nationally the number of psychiatrists who accept commercial insurance is greater than the number who accept Medicaid, indirect evidence indicates that the largest cohort of psychiatrists in the Commonwealth are those who accept no insurance coverage at all. Many private practitioners find that the reimbursement rates offered by insurance, both MassHealth and commercial, make insurance participation unattractive. As stated by one provider, “the reimbursement is a [huge] problem. ... It is difficult to recruit psychiatrists and nurse clinical practitioners because of the reimbursement but the people that I think are really suffering are the fee-for-service clinicians. It's a terribly bad business model for them because not only are they on fee-for-service, [but] at least at [the place where I work], we can't afford to pay people for no shows.” The same provider explained that her own practice is fee-for-service, reimbursed at a gross rate of thirty dollars per session. When she calculates the time she spends doing paperwork, attending meetings and not getting reimbursed for “no shows,” that number becomes closer to fifteen dollars an hour. “I’m not going to be able to continue,” she said, “and I feel really sad that it won't make sense for me to continue to stay there to provide care for the clients but it’s just not a sustainable model.”
Providers report frustration and concern with the influence that insurers wield over clinical decisions, creating another disincentive to insurance participation. Kate Ginnis of Boston Children's Hospital described the process providers must pursue to get sessions authorized and the amount of clinical information they must share as “onerous.” In addition, she said, there is a lack of transparency surrounding the criteria to prove medical necessity. As stated by one participant in the provider focus group, “[the insurers have] so much power in influencing how healthcare and medicine is practiced with very little reliability involved[.] . . . [T]heir response often is ‘we don’t tell you what to do, we only agree to pay or not pay.’ But I think their de facto ability . . . to pay or not pay for care is almost as if [the patient] can either get it or not get it. With some of the cost of the medications, if an insurance company decides not to pay for the medication that we’ve prescribed, they’re basically limiting access to that treatment.”

There are state and federal laws mandating mental health insurance parity that have been in effect for several years. Unfortunately, there is a widespread lack of understanding on the part of consumers, providers and all but a few specialty health care lawyers about what the parity laws require. “I’ve been practicing for forty years and I’m a medical director so I really should know more than I do,” said one provider on the subject of parity laws. “But the issue of parity doesn’t really come up very much for me. I’m sort of embarrassed to acknowledge it but it’s true. . . . I feel deficient in not being able to advise clients but I don’t know what I don’t know. I’m not sure what I would even advise them about.”

As examples of the confusion surrounding the term parity, there are barriers to mental health treatment that sound like violations of the parity principle which are not, however, violations of the parity laws. For example:

- It is not a violation of the parity laws for psychiatrists to refuse to accept insurance altogether, despite the disparity it causes in access to psychiatric care as opposed to other medical care. Data show that a far lower percentage of psychiatrists as compared with other specialists accept insurance.\(^41\)

- There is no parity violation in charging a co-pay for outpatient mental health visits as long as the same co-pay amount applies to other types of visits, despite the practical fact that mental health therapy often includes repeated visits over the long term, resulting in a significantly higher mental health annual co-pay as compared with other types of care.\(^42\)

Additionally, recognition of a parity violation requires a thorough understanding of all the provisions of an insurance policy, both mental health and otherwise. This is a painstaking process. Quantitative comparisons are at the simple end of the spectrum and easily detected, which is why differential annual
and lifetime benefit caps, co-pays, and deductibles have become largely obsolete. As Henry White, a psychiatrist who serves as the clinical director of the Brookline Center for Community Mental Health (The Brookline Center) stated, "'nickel and diming' type practices [by insurance companies] such as capping the number of visits allowed per year ‘hasn't gone away, but the intensity has decreased.’ However, qualitative differences, e.g., differences in the scope of coverage as opposed to costs, are much harder to measure, particularly because such differences are typically subject to prior authorization, which put the policyholder in the position of having to go well beyond the words of the policy and extract data comparing prior authorization experience across treatment categories. The complexity and expense of such inquiries place them beyond the reach of most people.  

People experience inequities in how mental health problems are treated as compared to physical health conditions, whether illegal under the parity laws or not. Respondents' experiences suggest that, despite the parity laws, it is still more difficult to access mental health treatment than other types of health care. Don Condie, the medical director at Vinfen, described a common scenario: if an individual presents at an emergency room with symptoms of a heart attack, he would be admitted 'straightaway,' but if the precipitating medical issue is psychiatric, '[ER's are] questioned by all of the insurance plans.'

Another example is rehabilitative care following an inpatient stay. Current parity laws may prohibit qualitative differences in coverage, such as refusing to cover residential rehabilitation following a mental health hospital inpatient stay as compared to covering rehabilitation following an inpatient medical stay, but insurers appear far more likely to refuse the first than the second despite the medical necessity of both. To the degree such coverage disparity exists, it is going largely unchallenged because of the difficulties of proof. A plethora of anecdotal evidence and complaints to the Massachusetts Attorney General's Office suggest that such differential coverage practices hinder the ability of people to access these medically necessary mental health services. Absent an effective mechanism to compel insurance payment, this type of rehabilitative treatment will remain financially prohibitive for all but the most wealthy.  

In a case reminiscent of many others we reviewed, a woman's email complaint to the Massachusetts Attorney General's Office centered on the insurer's denial of coverage for a dual diagnosis rehabilitative facility recommended by her husband's doctors to follow his hospitalization. "As you know,” she wrote, “if he was suffering from cancer, he of course would be treated right away.”

Price Barriers

The price of mental health care, despite insurance, poses a major barrier to recovery. Despite the fact that 98% of respondents to our survey were insured, approximately one quarter of those who had sought mental health care reported that they could not afford to get that care. Of the respondents who indicated that they had problems receiving needed care, more than half reported that affordability of care has had negative effects on their recovery.

Consumers struggle to meet the disproportionate impact of co-pays on mental health care. “Consider co-payments: a $20 co-pay to see a primary care physician and a $20 co-pay to see a mental health provider are, at face value, ‘on par.’ [However], you may see your PCP once per year, whereas you may see your therapist once per week. That $20 per week adds up over time,” explained Jonas Goldenberg of the National Association of Social Workers, Massachusetts Chapter.
Health Care For All

(NAWMA). A participant in the consumer focus group struggling to afford those co-pays, told us, “I live on a very fixed income, like a lot of people, so the cost of getting to the therapist on a regular basis might seem minimal to somebody but to me adds up at the end of the month.”

Health insurance plans with high co-pays can also contain high deductibles, which force people to make costly out-of-pocket payments for significant periods of time. Jonas Goldenberg said that he sees this happening with outpatient visits to clinical social workers whose individual charges for therapy are relatively moderate. “As [people] get new policies with significant deductibles, they are for all intents and purposes, self-pay now. If someone is in weekly or bi-weekly outpatient therapy and has a $3,000 or $5,000 deductible, they are unlikely to reach that threshold for at least a year. Plans with high deductibles are getting out of paying for services.” Consumers agreed. “You just pay, pay, pay out of pocket. Most people don’t even meet their deductible. . . . We’re going broke,” said one consumer focus group participant.

The high price of residential treatment is unaffordable for most people, which often prevents early rehabilitation after hospitalization for a severe episode. As stated earlier, insurer resistance to coverage of mental health residential rehabilitative care is a serious barrier. A separate aggravating factor is the unwillingness of some residential facilities to accept any insurance at all. Even the best theoretical coverage proves irrelevant, frequently in pivotal moments such as a hospital discharge to a residential facility that most families cannot afford.

Others find themselves in situations in which insurance stops covering facilities in which they are already being treated and they must decide between paying out of pocket or being discharged: One respondent said, “The social worker said my son was ready to leave the hospital. He clearly wasn’t. When I pressed, it came out that the insurance company was calling the shots.” Another said, “[I’ve had] a fear that I won’t be ready to leave [the facility when the insurance company mandates] and I’m going to wind up having to pay-of-pocket for expensive treatment.”

Despite insurance coverage, the high price of out-of-network services heightens the price barrier. Complaints to the Massachusetts Attorney General’s Office reflected the prevalence of these practices and the ways in which difficulty communicating with insurance companies contributes to costs piling up. One log described the process through which an insurer authorized temporary services at an in-network rate. The insurer, however, failed to determine the status of the provider by the end of the temporary service period. The consumer reported, “[The provider] charged me as if they were in-network during this [later] time period with the good-faith expectation they would be reimbursed appropriately by [the insurer] after approval . . . . [The provider] has now been informed that . . . . until a determination of their status has been made, they will be reimbursed only as an out-of-network provider.” The result is that the person’s out-of-pocket costs unexpectedly shot up. Another consumer reported that her “mental health costs more than doubled” when her insurer significantly reduced out-of-network reimbursement for mental health providers without sufficiently communicating about the change.

The recurring refrain is: “It all adds up.” One respondent said, “by the time . . . your deductible is met if you’re lucky, you still owe 20% and you still have to pay a co-pay for the visit and then you have the medicine [co-pay].” Co-pays for every visit to a provider, the costs of each prescription filled at the pharmacy, essential but often out-of-reach post-acute step-down and residential treatment settings, rising deductibles, out-of-network surprises — respondents across the spectrum agree that “it all adds up.”
Delivery Barriers

In mental health care, “finding a provider” can be a Herculean task that encompasses many components: tangible—location, availability, insurance coverage, specialty knowledge, and language; and intangible—the necessary “fit” between patient and provider. Survey respondents consistently ranked “help identifying providers” in the top three most needed systemic improvements. They expressed, repeatedly and emphatically, that “making a match” or “finding a fit” with a provider is essential to the formation of a treatment relationship that will foster necessary trust, continuation of treatment through difficult times, eventual improvement and, in time, recovery. The near nonexistence of resources to guide individuals in their search for this “fit,” constitutes a major barrier to recovery.

Finding a provider who is needed to launch a journey to recovery is a puzzle that is often over-reliant on luck and happenstance. Henry White, who has developed a school-based program to help students transition back to school following a mental health crisis, said outright that “the pathways to getting help are completely obscure.”

Many respondents found it difficult to articulate the exact qualities they seek in a mental health provider but used words such as “fit” and “match” to describe what they look for. Several discussed the need for a connection, or “click.” Of survey respondents who reported problems receiving mental health care, approximately half could not find a provider who felt “right.”

One participant in a consumer focus group said, “They have to connect with you on a more personal level than, say, your primary care which is mechanical. You go in, they take your blood pressure, you take your shot or whatever. But you have to really open up to your psychiatrist, and so it has to be someone that you relate to on a certain level. I kind of said ‘ineffable,’ because it’s hard to sort of put your finger on it exactly what makes a good match.”

Respondents described a complex interpersonal process. A respondent explained that “the first match might not be the right match, and it might take a couple of different trials with different therapists, but that doesn’t seem to be an option in the greater Boston area. It’s just like, this is who you’re assigned to, this is when you’re going to show up, and that’s the end of the story. And if not, then find another agency.”

In attempting to define the essential ingredients of a “therapeutic relationship,” respondents discussed the importance of: feeling respected; being recognized as an expert in one’s own behavioral health care; provider recognition of one’s personal treatment preferences; and shared decision-making between client and provider.

A participant in a consumer focus group described the partnership he has created with his provider that incorporates both clinical expertise and personal rapport. The participant said, “One of my favorite things about my psychopharmacologist is that he does research, and he works in a clinical setting. . . . I never questioned how much he knows and his level of expertise, but also [I do] not feel disconnected from [him]. . . . [He’s] just someone who sort of has a similar life view...and similar sense of humor, and it doesn’t feel like . . . it feels more like we’re partners in figuring out what’s going on with me rather than doctor/patient, somebody’s in charge and somebody’s not.”

“If you are cognitively compromised ...if you’re living with major depression and...if you’re struggling to function,” said one provider, “it’s really hard to retain this information or to even think about [self-advocacy] because your brain just isn’t in that place, you’re not able to think as clearly.”
The emotional and cognitive aspects of the conditions for which people are seeking care inhibit their ability to navigate the road to treatment. Several providers discussed how people — especially those already struggling with a mental health issue — are overwhelmed by both finding and accessing care. One provider said, "some of my people who have multiple problems and no access to media or they don’t have a smartphone. . . . I mean they could go to the library to get some information but it’s very difficult to find reliable information to get hooked up with medical services even with MassHealth. And so, I spent some fair amount of time supporting people in . . . in trying to make those connections. It’s been extraordinarily difficult." “If we think about the people who are most likely seeking these services . . . if you are cognitively compromised . . . if you’re living with major depression and . . . if you’re struggling to function,” said one provider, "it’s really hard to retain this information or to even think about [self-advocacy] because your brain just isn’t in that place, you’re not able to think as clearly.”

Ewa Pytowska, president of the NAMI Mass. Greater Boston Consumer Action Network (GBCAN), shared another example: "I show up in the waiting room, and I’m given an iPad and am told that I have to fill out this iPad survey before I see my clinician . . . and the questions on that iPad build from simple to the most intrusive, intrusive, intrusive questions . . . including one question after another about suicide. And, you know, I certainly didn’t walk in there even remotely thinking about suicide, but the triggering of memory through that survey on the iPad . . . almost induc[es] a psychotic experience. . . . I was mostly okay when I walked into that waiting room but in pretty bad shape by the time my therapist was ready to see me.”

Sometimes “fit” refers to the compatible match between a client and an individual provider, while other times the “fit” is broader in nature, referring to the identification and provision of appropriate services. Danna Mauch, the President/CEO of the Massachusetts Association for Mental Health (MAMH), said, “We fail far too often to achieve any goodness of fit between what it is people really need and what it is we provide them. . . . That lack of fit is a barrier to recovery. . . . One size does not fit all in the behavioral health and disability service world.”

Lisa Lambert of the Parent/Professional Advocacy League (P/PAL) also emphasized that services in general are not good enough—they must be matched to the needs of the consumer. “A family will call, said and they have had services, but they’re describing a crisis, the child is being sent home from school, difficult to manage in the home (hurting siblings), or something [else] that is alarming, and they’ve had services but they’re all the wrong services.” Families themselves are not usually looking for specific services, she said, they are looking “for the expertise to get the service that meets the needs of children.”

Finding an adequate “fit” is made harder by a behavioral health workforce that lacks the cultural and linguistic competency to meet the needs of a diverse population. Participants in the provider focus groups agreed that the behavioral health workforce is primarily white and female, lacking both equal gender and diverse racial and ethnic representation. In immigrant and non-English speaking communities, people “bring their cultural perceptions about what mental health is,” Lisa Lambert explained. Without culturally competent providers, it is difficult to bridge that gap. However, as stated by Amanda Gilman of the Association for Behavioral Healthcare (ABH), licensing levels create barriers. She continued: “Commercial insurers are strict and make it difficult to find culturally competent providers or providers who speak the same language as the consumer.”
A participant in a provider focus group said, "a number of my clients of color and immigrant clients, where you’re throwing in maybe a language issue . . . they’re just not getting the same level of care. And so . . . they just don’t put the effort in following up or following through because they’re going to assume everywhere else is the same. . . . By the time people get to us, they really are quite jaded with the system so I think an overall disrespect — especially with people who have co-occurring disorders or substance is one of the issues — is a significant barrier.”

The high number of mental health specialists, particularly psychiatrists, who refuse insurance – the “private pay” cohort – conflates the barriers of insurance, price, and delivery to impair the process of recovery. Of survey respondents who reported problems receiving mental health care, approximately half had problems finding a provider who accepts insurance.53

This report has discussed how low reimbursement rates, unreimbursable administrative burdens, and the influence of insurance companies on clinical decision-making deter providers from accepting insurance. These disincentives are a clear example of how an insurance barrier translates into a treatment delivery barrier. Department of Mental Health Commissioner Joan Mikula stated, “Massachusetts has the highest percentage of licensed mental health clinicians of any state in the country, and we have the lowest percentage of licensed mental health professionals who will take insurance of any kind. . . . We have 1900 psychiatrists in Massachusetts [the actual number is closer to 2900]. Nine hundred of them operate outside the insurance system.”54 The result, observed Jennifer Warkentin of the Massachusetts Psychological Association, is that “people are paying premiums for care but cannot actually get services.”

Participants in the consumer focus groups discussed numerous challenges in finding an available provider who accepts their insurance. One person said, “[I had a list of] some really great therapists, both private practice and community based, and of course the almighty first question is what type of insurance do you have. And despite the fact that I have insurance, I was told 100% of the time, ‘we don’t take YOUR insurance.’” This process discourages people from seeking care. “I recently relocated . . . and actually found great difficulty in trying to find a therapist who would accept my insurance, which discouraged me from trying to find a therapist — it was a nightmare,” said a consumer, who also compared his search for a mental health provider to finding a provider for physical health care: “I’ve found that it’s much easier to find providers who take my insurance for physical stuff, that generally it’ll be the first place I call and they’ll take my insurance, versus calling around [for mental health care].”

Consumers and providers agreed that the increasing incidence of waitlists discourages and delays access to mental health treatment. Participants in our provider focus groups discussed the growing prevalence of waitlists, especially for people insured by MassHealth. One provider described the detrimental effects of this “waiting game”: “It’s very difficult because we do see people with such complex trauma and undiagnosed everything, which is probably why a lot of people
self-medicate, and so you want to get people a psych eval, and if [they] have MassHealth, it’s just not going to happen right away, at all . . . . You have to get them an appointment to get an intake, which can take a while. Then they do the intake, then they’re assigned to a therapist who has to see them three to four to five times before then they’re . . . referred to the psychiatrist, which can take months. So you have someone drowning, who would probably really benefit from that type of treatment, and they can’t [get it]: the waiting game. And bad things happen during those waits sometimes.”

Jonas Goldenberg of the National Association of Social Workers, Massachusetts Chapter said that his group’s “social work therapy referral service” receives 3000 calls per year, and he added that members across the Commonwealth are saying there exists a two-to four-month wait in organizations that are approved for Medicare and Medicaid. “Members cannot see them if they are in private practice or solo practice because only agencies and facilities can get contracts with MassHealth, unless you’re in an HMO or PPO that is contracted but those networks are all closed.” As a result, Goldenberg’s service is receiving “frequent anecdotal reports of networks that are full and clients that are waiting months for an open spot.”

From calls to NAMI Compass to complaints made to the Massachusetts Attorney General’s Office, we have learned that such waits and the accompanying desperation of people in need are nearly ubiquitous. A 62 year old woman covered by MassHealth who has experienced depression disorder and anxiety disorder throughout her life called NAMI for assistance after a community mental health center informed her of a six-month waiting list to see a therapist. A participant in the provider focus groups separately reflected on the reality of waitlists for people at his clinic: “some have tried for months to find someone who will take MassHealth where there isn’t, you know, a wait for months and months. . . . If they have MassHealth, they’re looking at between six and twelve weeks’ wait . . . . We get a lot of court-mandated folks who need like an appointment like yesterday.”

In a complaint to the Massachusetts Attorney General’s Office, a consumer described her own situation in which she was prescribed medication, experienced an increase in symptoms and was told by the facility where she was being treated that “they could not fit me in for a whole month and offered me no advice on what to do about my current condition.” She eventually sought care in her local hospital emergency department.

The lack of availability of care undermines people’s motivation to seek care and their trust in the care they ultimately receive. Providers highlight the detrimental effects of missed opportunities on long-term recovery when people perceive they have been poorly treated in the past, even when they finally do connect. A participant in the provider focus group said: “First of all, there’s such a huge distrust of psychiatry. A lot of the people I see have had terrible experiences. And to even get them so that they’re willing to see somebody is very hard. And then if they can’t actually get there or it takes so long, they become very discouraged with the whole process.”

When people are able to access care, experts and advocates emphasized that inexperience is a defining feature of the behavioral health workforce. As a result of low insurance rates, Marie Hobart of Community Healthlink said that it is “difficult for publicly-funded clinics to be able to retain staff, to have salaries that are reasonable and competitive.” Entry level positions in psychosocial and residential services are poorly paid, thus attracting individuals who lack the education, training, and experience to address the most complex issues.

Lisa Lambert of the Parent/Professional Advocacy League (P/PAL) recounted that she had “always thought the number one issue was access,” but now, she said, “if you [do] get access, inexperience is the issue . . . . Someone will see a child with two diagnoses who has failed out of three medications, and the provider will say ‘I’ve never seen this before.’ You want to hear that

[I] had “always thought the number one issue was access, [but now] if you [do] get access, inexperience is the issue . . . . Someone will see a child with two diagnoses who has failed out of three medications, and the provider will say ‘I’ve never seen this before.’ You want to hear that providers have seen it before, and have a plan.”
providers have seen it before, and have a plan.” Vic DiGravio, the president and CEO of the Association for Behavioral Healthcare (ABH), said that his organizational members struggle to recruit and retain qualified individuals, often hiring social workers right out of graduate school who work at an organization until they are licensed, and then leave for private practice or hospital employment. Such turnover forces people, essentially, to “start over” with a new provider. “If someone announces they’re leaving,” he said, “they stop taking new patients, they wind down caseload. Someone replaces them and inherits some cases, but getting up to speed takes time.”

In the inpatient setting, psychiatry units utilize “mental health techs” or “mental health counselors” to work directly with patients. As described by Gaurav Chawla of Mercy Behavioral Health Care, these individuals have “very little training in mental health.” He explained that “when hospitals are reimbursed at such a low rate, we as a medical specialty end up using people who are not as skilled to take care of our patients and carry out the treatment that requires specialized skills.” Dr. Chawla compared this phenomenon to an inpatient orthopedic floor where, he said, they “will not have people with little training taking care of patients.”

HCFA data confirm that a shortage of inpatient beds has constituted a major barrier to treatment delivery. Recently, Larry, a grandfather, contacted NAMI Compass through Facebook about his six-year-old granddaughter, Emily. When Larry contacted Compass, Emily had already been held in a psychiatric holding room at his local hospital emergency department for five days because there was no available bed on the children’s unit. “My fear,” Larry said, “is that after her stay in the holding room, she is going to end up with more mental health issues than when she went in.”

Participants in the provider focus group discussed their frustration with, and reliance on, hospital emergency departments for their patients. One provider said, “it feels very frustrating not only for you as the clinician or provider, but also for the patient to have them sitting there and [to have to say] [to them], “I can’t get you a bed, I can’t find a place for you to go,” even when they’re at that critical moment where they said they want help. And that’s just really, really hard.”

Data collected by DMH document a total of 8,115 discharges made to homeless shelters from private psychiatric hospitals licensed by DMH between 2005 and 2010.

Failure on the part of hospitals to identify appropriate aftercare following an acute inpatient hospital stay poses a major barrier to recovery. We found a broad consensus that discharge from both brief and longer-stay psychiatric hospitalization presents a complex array of medical, social and logistical challenges. Calls to NAMI Compass document a pattern of inadequate discharge planning that leaves patients in limbo and undercuts progress toward recovery during the inpatient stay. Recently, a mother emailed NAMI Compass in search of resources for her son, Adam, who had been hospitalized within the previous three weeks for first episode psychosis. After being discharged with medication and no discharge plan, Adam stopped taking his medication and was re-hospitalized within five days. Another parent called about his daughter who had been discharged without a permanent address in the state. Data collected by DMH document a total of 8,115 discharges made to shelters from private psychiatric hospitals licensed by DMH between 2005 and 2010.

When children are released from the hospital, too few resources exist to assist their integration back into school and the larger community. Without adequate supports, children are likely to end up right back in the emergency room. Upon discharge from an inpatient hospitalization, children and adolescents, still managing the symptoms of acute mental illness, return home to face missed school work and social isolation. Because of the lack of coordination between inpatient and community care, coupled with long waits for outpatient care, psychiatrists and neuropsychiatrists, families often feel left to “fend for themselves,” once again encountering the barriers they thought they had overcome. Nancy Scannell of MSPCC said,
“when [children] come out [of the hospital], the supports to integrate back into community or school are inadequate, Recent budget cuts have further limited wraparound services to keep children in the community, according to Gaurav Chawla of Mercy Behavioral Health Care.

This was the case for the son of a recent NAMI Compass caller. Faith called for guidance about her son, recently discharged from an inpatient hospital stay for depression and anxiety. Covered by commercial health insurance and assigned both a psychiatrist and a therapist, Faith still felt unable to help her son successfully reintegrate into the community and transition him back into the school where he had been a strong student in the past. With the child limited to commercial insurance and therefore ineligible for Children's Behavioral Health Initiative services, the wraparound non-medical services like a Family Partner and Therapeutic Mentoring were unavailable.

The five barriers covered here—knowledge, attitudes, insurance, price, and delivery—cover a great deal of ground, and together they can seem overpowering and intractable. This is why the search for solutions carries such urgency. Our initial expeditions into this territory appear in Section III.
III. The Search for Solutions

Making Connections Between Barriers and Possible Solutions

As HCFA staff members consulted with advocates, public officials, and peers to examine early barriers to recovery, these advisers began to infuse our conversations with their knowledge of relevant programs in Massachusetts. The shift from identifying problems to finding ways to solve them shed new light on a variety of programs, some of which are well-known and some little-known. These programs share the avowed purpose of overcoming one or more of the barriers we document.

We also heard and read heartfelt testimonials from people who spoke of their own successful engagement with these programs: individuals who had been guided to a mental health provider at a critical moment by the INTERFACE Referral Service; parents whose children had been successfully reintegrated into school after a prolonged absence due to a mental health crisis through the Bridge for Resilient Youth in Transition (BRYT) program; family members who recalled the relief they felt when they discovered they could access the resources of an Emergency Services Program (ESP) instead of calling the police. Advisers shared a common thought about these programs: “when they can be made to happen statewide, it not only makes a difference in people’s lives, it changes the system itself.”

This section seeks to explore what this kind of changed system would look like: effective programs operating statewide to overcome early barriers to treatment, care and recovery. To pursue this path, we asked advisers for additional examples. It became clear that no one expert, organization, or database purported to have an exhaustive inventory of programs recognized as effective. It also became increasingly clear that the furthest this project could go in the time allotted was to highlight a handful of programs identified by one or more experts as the kind that, if brought to scale, hold the potential to improve the mental health system statewide.

Programs, however, are not the whole story. Vital as they are to treatment, care and recovery, programs alone cannot address, much less solve, all problems. Our system of care is an intersection of public policy — statutes and regulations giving directions — and on-the-ground programs carrying them out. For example, health insurance reform legislation enacted in 2006 transformed access to health care in Massachusetts, but what translates that policy into health and wellness are effective programs financed by insurance that improve the lives of their clients. Conversely, ESPs began decades ago in the form of a few stand-alone pilots created by communities to respond to mental health crises without the necessity of hospitalization. Today, although there is more work to be done in relation to private insurance, ESPs amount to a public policy codified and built into our public mental health system.

Public policy can enable or mandate programs, and programs can evolve into public policy. This latter process of change arises most often from the ground up: small programs, trial and error, and a natural evolution over time, to the tipping point of system change. Consequently, in the search for solutions to persistent barriers, focusing on promising programs, while keeping an eye out for policy opportunities to accelerate and codify them, offers a reliable and valuable approach.

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We present below examples of promising Massachusetts programs and policy proposals targeting barriers to early engagement. Three of these programs — INTERFACE, BRYT, and Recovery Learning Communities (RLCs) — are described in fuller detail than others, to illustrate some of the salient features that set programs apart as offering hope for broader system impact. As far as promising policies are concerned, we present pieces of legislation that directly address various identified barriers, all of which have been proposed but not yet acted upon. For programs and public policy both we have chosen to emphasize what already exists.

**Overcoming Knowledge Barriers: The Role of Helplines**

Dozens of helplines exist in Massachusetts that attack the knowledge barrier from a variety of angles. They share a common mission to connect callers with the information with which any journey to recovery must begin. Described here are two well-respected examples and a promising project underway to create a statewide resource database. As a matter of policy, Massachusetts should promote and support a state-of-the-art resource helpline.

**INTERFACE Referral Service**

INTERFACE began in 2003. Its initial purpose was to address the challenges parents and community personnel faced in finding mental health providers for children within the Newton Public Schools. Today, as part of William James College of Psychology, the INTERFACE Referral Service matches callers of all ages using a statewide database of 7,000 licensed providers. This service is free and confidential for individuals living in the 58 subscribing communities.

Defined by its practice of “holding the caller” and by maintaining communication until a satisfactory therapeutic match is established, INTERFACE assists callers in accessing treatment that can prevent the escalation of symptoms and maximize the opportunity for recovery. The database has been built by incorporating provider lists compiled by schools, online list-serves, insurance companies, and outreach efforts by community providers in contracting and surrounding communities. INTERFACE also conducts an “environmental scan” of each contracting community to identify additional providers and resources for the database.

The referral service is staffed by a group of 24 mental health professionals and advanced trained psychology graduate students from William James College. Each caller participates in a 20-45 minute intake process during which a resource and referral counselor assesses the caller’s needs, determines the caller’s insurance status, principal language, time constraints, transportation limitations, and any other relevant information. The counselor then searches the database for providers who meet the caller’s requirements. Only when a caller indicates that a therapeutic relationship has been established, or decides not to pursue treatment, does INTERFACE consider the referral completed.

INTERFACE is free to the caller, but callers are eligible for INTERFACE services only if they live in a community that has made a contract with INTERFACE. A city or town must sign a two-year contract with INTERFACE with an annual fee of $12,500.

**NAMI Compass**

NAMI Compass is a statewide database operated by people with experience dealing with the mental health system, for themselves or a loved one. These trained navigators are available by phone, email, and through online contact to answer a wide range of questions and refer people to direct services. As mentioned, common topics include social supports, access to treatment, housing resources, police and legal issues, substance use, and hospital discharge rights. Compass currently operates on a modest annual budget, but its mission in every respect is to overcome lack of knowledge and its damaging consequences.

NAMI Compass is free to all callers. It is part of the NAMI Mass. annual budget. DMH also supports a portion of Compass through a contract with NAMI Mass. Compass receives more than 2,000 calls for help each year.
A Comprehensive Statewide Database of Community-based Services

Several months ago, an “action team” was created as part of an initiative titled Behavioral Health, the Unfinished Agenda of Reform (BHUAR), the brainchild of the Massachusetts Health & Hospital Association (MHA). This action team is one of several BHUAR projects. Fortuitously, it is focusing on the need for a comprehensive database of community-based services, and therefore offers a significant opportunity for directly addressing the knowledge barrier documented in Section II. Organizations leading the project include the Blue Cross Blue Shield of Massachusetts Foundation, Massachusetts Association for Mental Health, NAMI Mass. and the Brookline Center for Community Mental Health.

The action team’s work plan offers a model for the process of scaling up from smaller programs — like INTERFACE and NAMI Compass, both of which have been studied by the team — to a state-of-the-art, comprehensive database designed to facilitate statewide access to community-based services. By the end of 2017, the MHA action team will have drawn from the information it is collecting and lessons learned to make a recommendation about how to implement a comprehensive database for 2018 and beyond.

Another distinct advantage of a comprehensive database is its potential for addressing the sometimes huge knowledge gap about the basics of mental illness that was documented in Section II. There are statewide databases in other states that have been able to integrate basic information with resource assistance.69
Overcoming Attitude Barriers: The Role of Peer Programs

There is no panacea for the age-old prejudice against people with mental illness. Deeply engrained in the public consciousness, negative stereotypes, low expectations and outright discrimination conspire to create a barrier to recovery that, as Section II describes, is both external and internal. It is well documented, however, that the increase in peer programs is contributing both to a shift in the public perceptions of mental illness and to empowering individuals to overcome stigma in their own lives.70 The following programs are examples of peer programs that demystify mental illness and set an example of the realities and possibilities of treatment, care and recovery. To overcome attitude barriers, Massachusetts should widen its support of the peer movement and join other states that include Certified Peer Specialists among the services covered by Medicaid.

✔ NAMI In Our Own Voice Program

NAMI In Our Own Voice (IOOV) is a program created by the national NAMI organization and offered in many states, including Massachusetts. It is a free presentation given by two trained individuals about their difficult journeys toward recovery while living with mental illness. The 60-90 minute talk has a mission of changing attitudes towards people with mental illness and is presented to widely diverse groups: students, law enforcement officials, educators, providers, faith community members, politicians, professionals, incarcerated individuals, and interested civic groups. The presentation includes personal testimony and discussion, and seeks to expand the audience's understanding of how individuals cope with the reality of their illness while recovering and achieving productive lives. More than 400 IOOV presentations were given throughout Massachusetts in the past year, double the previous year. NAMI IOOV has been judged among the most effective established programs for overcoming stigma.71

The increase in peer programs is contributing both to a shift in the public perceptions of mental illness and to empowering individuals to overcome stigma in their own lives.

✔ Recovery Learning Communities

In 2008, DMH developed a plan to establish local peer-operated programs that would build upon established partnerships. Called Recovery Learning Communities, or RLCs, these communities of support and education are now operating in all five DMH Areas: Metro Boston, Western Massachusetts, Central Massachusetts, Northeast, and Southeast. At the time, RLCs represented a new model, one that relies on the momentum of the peer movement and the commitment of DMH to partner with that community to foster recovery.

RLCs are peer-run networks of self-help/peer support, information and referral, advocacy and training activities. Training in wellness concepts and tools, advocacy forums, and social and recreational events are integral components of each community. RLCs seek to create significant culture change, one that shifts the focus from symptom management to promotion of recovery, resilience and wellness. RLCs support and encourage people to take charge of their own recovery process, for example by advocating for themselves in seeking needed services, and be a part of a greater supportive community. Certified Peer Specialists are a key component of RLCs.

Eligibility for RLC services is universal, and services are free. The doors are open to anyone who wants to participate. RLCs work collaboratively with mental health providers, other human service agencies and the community at large to forward the mission of community integration and respect for people with mental health conditions. RLC activities are designed to appeal to the full range of people in the community, including people of all racial and ethnic backgrounds and people of all co-occurring disabilities.

Metro Boston Recovery Learning Community (MBRLC) is one of the five Massachusetts RLCs; we describe it briefly here as an illustration. MBRLC serves the Metro Boston area, providing group and one-on-one peer support, education, employment readiness, advocacy, and friendship. Boston Medical Center oversees MBRLC.
To overcome attitude barriers, Massachusetts should widen its support of the peer movement and join other states that include Certified Peer Specialists among the services covered by Medicaid.

financially, with funds from a five-year DMH grant. Membership is free and requires no commitment. To become a member of MBRLC, one need only present his or her first name.

The day-to-day activities of the MBRLC are peer-run, that is, everyone who works at MBRLC has his or her own lived experience with mental health challenges. The staff does outreach in inpatient units, stabilization units, and homeless shelters in the Metro Boston area to let people struggling with mental health issues know that MBRLC exists and is available to them.

The MBRLC Peer Bridger program, like those in other RLCs, provides support to people in transition — people who are coming out of inpatient facilities, crisis stabilization units and transitional homeless shelter programs, and entering back into natural community support environments. Peer Bridgers help people in transition lay a foundation for recovery by assisting them in finding a place to stay, clothing, food, a T-pass, and a primary care physician. People in transition may neglect other health conditions or lack access to a phone or computer. Peer Bridgers help navigate these issues. A Peer Bridger may also assist individuals to apply for food stamps, navigate public transportation, and fill out complex medical forms.

The MBRLC Peer Support Line is another MBRLC program that offers support, compassion, and validation to callers. Calls are answered by operators, many of whom are Certified Peer Specialists, with specialized training to refer callers to local, state, or national programs and services, depending on the need of the caller. The Peer Support Line is open seven days a week, from 4 p.m. to 8 p.m.

MBRLC is both a program and a community. Members learn that recovery from mental illness is not only possible but probable and that they can create their own path towards recovery. Having an emotionally-safe physical space, people to talk to and receive support from, creates a structure that fosters optimism. MBRLC values each individual’s voice and unique path, and that is reflected in the way the program is run: with changing group and individual offerings, and with regular open meetings.

There are no membership fees or dues associated with membership an RLC. Most funding comes from DMH and a handful of small grants and private contracts for providing services. RLCs must stay within their budget when organizing activities; expansion will require increased funding to pay Certified Peer Specialists for travel time and the valuable work that they do.

RLCs in Massachusetts are not yet at scale. Being regionally-based, they can be hard to reach, particularly for the many people without access to an automobile. An increase in the funding of the existing RLC structure is necessary to allow the programs to reach more people.

✔ Certified Peer Specialists
Certified Peer Specialists are individuals with personal experience of recovery from mental health conditions, substance use, or trauma who receive specialized training to guide and support others toward recovery. Because of their own lived experience, they offer a degree of empathy and expertise that professional training cannot replicate. A large part of that empathy derives from understanding and having overcome the stigma that discourages engagement.

A Certified Peer Specialist training program (CPS training program) was established in Massachusetts in 2006. DMH funds the program, which is run by the Transformation Center, a statewide nonprofit organization governed and staffed by people in recovery.
Peer support programs have been recognized (with some qualifications) as effective in enhancing the principles of self-direction and mental health recovery, and have helped to improve the quality of life for the thousands of people who use their services. The support offered by Certified Peer Specialists is proving to be a valuable resource in improving an individual’s ability to remain within the community. The most recent evaluation of Certified Peer Specialist services in Massachusetts was published in 2011.

Legislation mandating MassHealth payment of peer specialist services

“An Act Relative to Mental Health Certified Peer Specialists” was filed in Massachusetts in 2015. The first state to include Certified Peer Specialists as a covered Medicaid Service was Georgia, in 1999. In 2007, the Centers for Medicare & Medicaid Services (CMS), the federal Medicaid agency, released a "Guidance to States” endorsing the provision of peer support as an optional covered service, and recommending that the states include such services in their state plans. Among the many conditions laid out by CMS for acceptance of a state’s plan, the most important was that “peer support practitioners complete training and certification as defined by the State.” Despite the fact that Massachusetts established its CPS training program is 2006, it has not followed Georgia’s lead, or the lead of 34 other states that also created such training programs and now pay for Certified Peer Services. Legislation has been pending for several years that would require MassHealth to take advantage of the federal decision to subsidize peer support services with federal financial support. Here is an issue on which a broader coalition of health care and mental health care organizations should join together to advocate for change.

If the percentage of psychiatrists accepting insurance [now 55% nationally] were equal to other medical specialties, which stands at 88.7% nationally, the private pay phenomenon would decline and access would increase.

Overcoming Insurance And Price Barriers: Helplines and Policy Change

Certain barriers arising out of insurance coverage are clearly the responsibility of the insurance companies themselves. Confusing policy language, poor customer service, outdated lists of covered providers, and resistance to paying for expensive covered services — there is no ambiguity that these are insurance company barriers. When the terms of an insurance policy cover a treatment and nonetheless a person is left with the choice of paying out-of-pocket or foregoing the treatment altogether, that is also a problem of insurance. But insurance and price barriers clearly overlap and are often interconnected. Is the fact that Massachusetts is a high-income state a factor in shrinking insurance provider lists, because providers believe, correctly, that enough patients are willing to pay privately and pay well, rather than depend on insurance? This is an important question because psychiatrists who refuse insurance account for approximately half the psychiatrist population. When psychiatrists opt out, the large consumer population who cannot afford private payment must depend on the fifty percent of psychiatrists who do accept insurance. To put this in perspective, it is worth noting that if the percentage of psychiatrists accepting insurance were equal to that of other medical specialties, which stands at 88.7 % nationally, the private pay phenomenon would decline and access would increase.

In this section, we explore a program and a policy that can help minimize unnecessary barriers created by insurers. We also attempt to begin the process of identifying problems where insurance and price barriers are intertwined.

The HCFA HelpLine

The HCFA HelpLine is the only statewide, multilingual phone service that helps Massachusetts residents at all income levels with enrollment into health insurance coverage, including mental health coverage. Experienced counselors answer questions and troubleshoot cases. The counselors form relationships with callers in their native
languages and hear from them whenever they need help. Complex mental health issues can be addressed with the help of policy specialists at HCFA and Health Law Advocates (HLA).82

Because so many of the questions of mental health insurance coverage involve not only enrollment complexities but denials of coverage, legal help is often required to gain access to treatment. In such instances, the availability of HLA to advise and even represent HelpLine callers expands the HelpLine's effectiveness.

✓ Legislation to increase transparency

The proposed legislation is 2017 House Bill No. 2947 and Senate Bill No. 528, entitled, “An Act to Increase Consumer Transparency About Insurance Provider Networks.” This legislation would force changes to insurer practices that would address the lack of transparency and related insurance barriers described in Section II. The principal goals of the legislation are:83

- To require insurers to update their online network provider directory within a week of learning that a provider is not accepting new patients, changing location or populations served, or otherwise taking actions that would require revision of the directory in order to maintain its accuracy;
- To establish a dedicated customer service email address and telephone number or electronic link that plan members, providers and the general public may use to notify the carrier of inaccurate provider directory information;
- To ensure that out-of-network care is adequately and promptly covered when medically necessary without interrupting the continuity of care, for as long as the carrier lacks in-network providers able to provide the service.

As reported in Section II, the fact that the person seeking information has symptoms that affect mood and cognition makes the need for attentive customer service even more urgent.

✓ Addressing recurring co-pays

A second price problem inherent in outpatient mental health care is the recurrent burden of co-pays, coupled with high deductibles.84 Despite the fact that recurring treatment visits have been deemed medically necessary in order to be covered by one's policy at all, the expense of co-pays can reach into the hundreds or even thousands of dollars, capped only by the deductible limit. The more limited a person's means, the more likely he or she will engage in the outpatient version of "pill-splitting," i.e., reducing treatment to afford the co-pays.

We have found no legislative or policy proposal advanced in Massachusetts to ease the burden of recurring co-pays for long-term outpatient treatment.85 One avenue worth investigating would be to cap co-pays at a reasonable dollar level. Co-pay relief has been discussed, and legislation offered, in connection with other illness categories, and applying the same form of relief to mental health outpatient services would assist in making this form of treatment more affordable.86
Nationally, the dropout rate for high schoolers who suffer an extended break from school caused by an acute mental health episode is 50%, far higher than the rate for students with other medical issues.

**Overcoming Delivery Barriers: Early Engagement Programs**

This section examines early treatment delivery barriers in two categories: delays in access to treatment and the lack of resources available to assist individuals and families to identify the necessary “fit” in services and providers.

✔ **Bridge for Resilient Youth in Transition (BRYT)**

The Brookline Center for Community Mental Health (The Brookline Center) first launched BRYT at Brookline High School in collaboration with a group of parents and administrators. With support from the Brookline Center, Wellesley High School opened its own program in 2006, and since that time the Center’s BRYT Network Team has supported a growing number of schools across Massachusetts in starting and continuously improving programs modeled on BRYT.

BRYT-model programs support students in their social and academic re-integration into school after extended absence due to mental illness. By assisting students in overcoming isolation and re-engaging with school life at a moment that is critical for both academic success and personal health, BRYT helps overcome a critical barrier to recovery. The program operates at no cost to the students’ families.

Nationally, the dropout rate for high schoolers who suffer an extended break from school caused by an acute mental health episode is 50%, far higher than the rate for students with other medical issues. In the first ten years of operation in Brookline High School, the graduation rate for 600 BRYT participants was 95%. Recently, a formal program evaluation documented the efficacy of BRYT’s transition programs in improving student outcomes. Of several hundred program participants, 85% graduated or finished the school year fully caught up and on track for the next grade level. In 2014, BRYT was awarded the American Psychiatric Association’s Gold Achievement Award for innovative community based programs.

The BRYT transition model has four key elements: (1) an individualized transition process; (2) four types of support services: clinical, care coordination, academic, and family support; (3) a dedicated classroom in the school, open and staffed every day, every period; and (4) dedicated clinical and academic support staff.

The student and his or her parents meet with the program coordinator to begin the transition process before the student returns to school. During the initial days back at school, students typically spend most of their time in the
BRYT classroom. As students’ conditions improve, they spend more time in their regular classrooms and class attendance gradually increases to 100 percent. With this support, most student participants are able to reintegrate fully into the classroom in four to twelve weeks; average program participation is eight to ten weeks.

Schools pay for the staffing and related costs of their BRYT programs. Average cost per participating student, about $2,500 per year, is substantially less than the $50,000 or higher cost of an out-of-district placement and has an incalculable value in its effect on dropout rates. In Brookline, staff estimate that the program has reduced out-of-district placements by four or five students a year, saving as much as $200,000, which compares favorably to the $130,000 overall cost of the BRYT program at the high school. The BRYT Network Team, which is based at the Brookline Center, provides schools with consultation to help get programs started at no cost, and charges very modest technical assistance and membership fees once schools have their programs up and running.

As of fall 2017, the BRYT model has been implemented in 71 schools in Massachusetts, which collectively serve 79,000 secondary school students, including nearly 25% of all public high school students across the Commonwealth. Students who might otherwise have left school after an acute mental health crisis are returning to their classrooms with the support of these programs. The BRYT Network's target is to make the program available to all Massachusetts public high school students over the next five to ten years.

As it pursues opportunities for expansion and replication, BRYT will need to address some critical questions. For example, how will all schools be able to fund a BRYT program? Will the BRYT Network be sustainable via its current combination of private foundation funding and modest fees from participating schools? Does the scaling process in itself require a more wholesale funding source? How does replication of the BRYT model effectively respond to the racial, ethnic, socioeconomic and geographic diversity of Massachusetts’ public high schools?

INTERFACE Referral Service

Introduced earlier as one promising program to overcome the knowledge barrier, the special value of INTERFACE lies in its commitment to “hold the caller” by maintaining communication until the caller signals that a satisfactory therapeutic match has been established. The process may take several days or weeks. The willingness of navigators to maintain communication with a caller seeking help plays a major role in achieving the early engagement that prevents dropout and withdrawal from the course of recovery.

Like BRYT, expansion of INTERFACE to operate on a larger basis raises some significant questions. With over 350 communities in Massachusetts, expanding INTERFACE statewide in its current community-by-community model would be prohibitively complex. To deal with this problem, the executive director (and founder) of the organization, Margaret Hannah, envisions an approach to growth based on a regional “hubs” model across the Commonwealth. Trained counselors would oversee each regional hub, perhaps located in a school, town agency or medical practice, but serving the entire region. It is an approach worth serious exploration.

The special value of INTERFACE lies in its commitment to ‘hold the caller’ by maintaining communication until the caller signals that a satisfactory therapeutic match has been established.
System impact: what do the program examples have in common?

Focusing just on the programs described above, HCFA staff sought to understand what features they share that make them good candidates for "scaling up" to achieve system impact. We searched but were unable to locate a set of criteria in the research literature that appeared specifically to identify the readiness of programs to scale up—in essence to become part of the system itself. To fill the gap, with the help of our advisers, we created a set of informal criteria that are listed immediately below. Clearly, these criteria, which are qualitative, do not approximate the precision reflected in the evaluation process of the Substance Abuse and Mental Health Services Administration (SAMHSA). But it is worth questioning whether that degree of quantitative detail is necessary in every case or whether a more qualitative approach is appropriate, due to the nature of the programs we examine. Moreover, how much "proof" is needed to justify strategic support for a program to enable it to grow remains a question for discussion.
**We offer these common elements as proposed criteria for identifying promising programs:**

1. **The program addresses one or more documented early barriers.**
   In our discussions, we attempted to focus on programs whose express mission addresses at least one barrier our information search had identified and documented.

2. **The program provides direct services.**
   While there are many worthwhile programs that address vital systemic issues, HCFA decided to focus on existing programs that directly serve individuals and families, and could therefore have the greatest impact on their engagement in the recovery process.

3. **There are credible reports of the program’s success.**
   There are programs working effectively that have not yet accumulated the rigorous, evidence-based evaluations of the type emphasized by SAMHSA. In these instances, we believe that consideration of anecdotal evidence, particularly when reported consistently from diverse sources, is a valuable foundation on which to begin.

4. **The program is capable of growth.**
   We encountered programs that are working well but are acknowledged by their founders and administrators to have structural impediments that make them unlikely candidates for growth and system-wide adoption. Potential for growth is a vital aspect of any small program that hopes to contribute to system change.

5. **The program is affordable and universally available.**
   Every program we encountered has the important feature of being available free to everyone within the area covered by the program, regardless of insurance status or scope of insurance coverage. The absence of a price tag is a critical difference from many expensive programs, not covered by insurance, whose services benefit only those people fortunate enough to have the resources to pay for them.

It is essential that, as a program scales up, it remain affordable. However, for some programs, one of the ironic byproducts of scaling up to become part of the public system of care, characterized by public financial support, is that those with private insurance are left behind, creating a different type of inequity.
IV. The Benefits and Challenges of Growth: Two Examples

To examine the implications of scaling up, we decided it would be useful to examine two programs already operating as part of the statewide system. When we did that, we discovered that success in scaling up geographically can introduce new challenges. For example, because the commercial insurance industry in Massachusetts is lagging behind the state’s progress in mental health innovation, people on MassHealth have access to critical programs not available to those with private coverage. Therefore, to achieve universal access to early engagement programs, we must not only "scale up" some programs geographically, we must at the same time "scale out" some programs to reach populations excluded by their insurance.

Emergency Services Programs (ESPs)

ESPs exist throughout Massachusetts and represent a program that is at scale geographically. ESPs have existed in Massachusetts for over 30 years. This statewide approach evolved from locally-based crisis response programs, which sprang up in the latter part of the twentieth century in a few Massachusetts cities and towns, and in other communities throughout the country. As with every program responding to complex problems, it has its challenges. Nonetheless, its track record is positive, its role essential, and its success in achieving and maintaining a statewide reach over several years makes it a primary model for improvement.

There are 21 separate private nonprofit ESPs operating under contract with the state, each covering a different region. Each contract requires a common set of operating procedures, including behavioral health crisis assessment, intervention, and stabilization services on a 24-hour, 365 days a year basis to individuals of all ages who are experiencing a behavioral health crisis.

Because the commercial insurance industry in Massachusetts is lagging behind the state’s progress in mental health innovation, people on MassHealth have access to critical programs not available to those with private coverage.

ESPs also maintain Adult Community Crisis Stabilization (CCS) beds, often called respite beds. They provide staff-secure, safe, and structured crisis treatment services in a community-based program that serves as a less-restrictive and voluntary alternative to inpatient care. CCS serves adults ages 18 and older. It is used primarily as a diversion from inpatient hospitalization and has a current capacity of 153 CCS beds statewide.

ESPs are required to emphasize peer supports and a recovery orientation in program design and operation. This means emphasizing the use of Certified Peer Specialists, Family Partners, and programs with recovery-oriented and consumer-operated resources, such as RLCs.

ESPs, unfortunately, present a "scale-out" challenge. ESP contracts are administered by the MassHealth behavioral health manager, Massachusetts Behavioral Health Partnership (MBHP), which pays ESPs using federal-state matched Medicaid funding. As a result, to be entitled to the early crisis engagement provided by ESPs, individuals must either be uninsured or MassHealth members. The overwhelming majority of Massachusetts residents, however, are insured by commercial insurance companies and therefore have no guarantee of emergency services when in crisis. The only way a person insured commercially can qualify for ESP services is through a separate contract between that person’s commercial insurer and the ESP serving the region in which the person lives. Very few such contracts exist. This insufficient arrangement results in the vast majority of people with commercial insurance being unable to access ESP services.
The overwhelming majority of Massachusetts residents . . . are insured by commercial insurance companies and therefore have no guarantee of emergency services when in crisis.

Legislation mandating commercial coverage of ESP services

Behavioral health organizations have sought for years to extend the availability of ESP services to the seventy percent of Massachusetts residents who have commercial insurance rather than MassHealth. The two most recently filed bills are 2017 Senate Bill No. 525, “An Act Requiring Insurance Coverage for Emergency Psychiatric Services” and 2017 House Bill No. 486, “An Act to Require Health Care Coverage for the Emergency Psychiatric Services.” Passage is long overdue.

Children’s Behavioral Health Initiative (CBHI)98

CBHI has operated statewide for several years. Its mission is to engage children and families at as early a stage in life as possible. It is firmly embedded in the Massachusetts public mental health system and has been documented as effective in overcoming barriers to treatment, care and recovery. Evaluations of CBHI do show that the services provided vary in quality, but overall the level of quality is high, and the evaluations offer solid advice about addressing problems.99 Unfortunately, the services of CBHI are not available to children covered by commercial insurance.

The origins of CBHI can be traced to the remedial stages of a class action lawsuit, Rosie D. v. Patrick, which sought to revamp the mental health services provided to children with severe emotional disturbance (SED) insured by MassHealth.100 Because the judge found that the state's system of mental health care for children on MassHealth violated federal law, the remedy was dictated by the judge's determination of which changes were necessary to bring the state into compliance. Fortunately, the state ultimately embraced the need for change, and what has proved a successful reform process was underway.

To achieve early engagement, CBHI requires primary care physicians treating MassHealth patients to provide standardized behavioral health screenings at each well-child visit. In any follow-up examination, behavioral health clinicians must use a standardized assessment tool. If services are called for, the Commonwealth must provide new or enhanced community-based behavioral health services. These services include: (1) intensive care coordination; (2) in-home therapy; (3) in-home behavioral services; (4) family support and training; (5) therapeutic mentors; and (6) mobile crisis intervention.

In concept, CBHI places the family and child at the center of the MassHealth service delivery system, and seeks to build an integrated system of behavioral health services101 that meets the individual needs of the child and family. Working as designed, the policies, financing, management, and delivery of publicly-funded behavioral health services combine to make it easier for families to find and access appropriate services, and to ensure that families feel respected and receive services that meet their needs, as defined by the family.
In many ways, CBHI offers a useful model to smaller early engagement programs for defining what geographical scale looks like. In one serious aspect, however, CBHI falls short. It is offered at no cost to families on MassHealth and is financed by state and federal dollars. Unfortunately, with narrow exceptions, it is not available to children covered exclusively by commercial insurance. This is another example of public policy outstripping private coverage, raising the question of the state’s responsibility to ensure that all children have the benefit of a system of early engagement, regardless of whether they are publicly or commercially insured.

**Legislation Mandating Coverage of “Wraparound Care” by Commercial Insurers**

The proposed legislation is 2017 House Bill No. 488 and Senate Bill No. 547, entitled, “An Act to Increase Access to Children’s Mental Health Services in the Community.” Currently, coverage for community and home-based behavioral health care services (“wraparound care”) is available only to children with MassHealth. Children and families covered by commercial insurance must either go without these services or, if the child qualifies as disabled, obtain “secondary MassHealth” to access these services. This legislation would require coverage for “wraparound care” for all children and adolescents who are covered by commercial insurance.

[CBHI] is another example of public policy outstripping private coverage, raising the question of the state’s responsibility to ensure that all children have the benefit of a system of early engagement, regardless of whether they are publicly or commercially insured.
V. Recommended First Steps

The suggestions offered in this section are a beginning. Eradicating these persistent barriers will require work in many directions. As the work takes place, it is a source of strength, however, to know that we are not compelled to start from scratch. Existing programs hold promise for significant improvement, and existing policy proposals address several of the documented barriers.

Here is a summary of the recommendations that emerge from our examination of existing programs and current policy proposals:

- To overcome barriers, Massachusetts should help promising programs grow to scale. Two immediate candidates are INTERFACE and BRYT. Other programs deserving consideration are described in Section III, and still others are waiting to be discovered.

- Massachusetts should require increased transparency of insurance, improved customer relations, and safeguards to guarantee that people receive the full measure of the mental health coverage to which they are entitled by their insurance policies.

- Massachusetts should commit to closing the knowledge gap by creating a state-of-the-art resource helpline and promoting its use statewide. A promising project with that goal is now underway.\(^{104}\)

- The services of ESPs should be available to all. To that end, all commercial insurers should include ESPs as an essential part of their behavioral health coverage.

- Massachusetts should expand the training and employment of people in peer support roles. One major step in that direction would be MassHealth payment for Certified Peer Specialists.

- The comprehensive approach to children's mental health, embodied by CBHI, should become a universal feature of commercial insurance.

VI. Conclusion

There are two crosscurrents at work in the mental health system. One current drives us toward the system's failures and deficiencies. It begins with an undeniable truth about the system -- large numbers of people with serious mental illness are failing to gain access to the medical treatment, supportive care, and opportunities for recovery that make life meaningful and productive. Many families and advocates living with this reality understandably see little or nothing positive about either our private or public systems of care.\(^{105}\)

The optimists, who drive the system's countercurrent, do not dispute these deficiencies. In fact, most of them have endured a great deal of hardship over the years, either as people with lived experience of mental illness, their family members, or their professional caregivers. What distinguishes these optimists is hope, the steadfast belief that the system can improve. They set out to prove it can happen by starting programs and offering public policy proposals that reverse the failures and overcome the barriers standing in the way of both personal recovery and improvement of the system as a whole.

HCFA is firmly on the side of the optimists. We hope that this report contributes to the achievement of the system they and we envision.
Acknowledgments

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The contributions of all interviewees, focus group participants and survey respondents made this report possible.
Endnotes

1 This report was prepared by Natalie Litton and Stephen Rosenfeld.


3 These three terms – “treatment,” “care,” and “recovery” – in this report connote three different, complementary goals of the mental health system:

   (1) “Treatment” refers to the medical dimension including, among other things: (a) psychiatric medications (i.e., psychoactive drugs used in psychiatry) such as anti-anxiety drugs, antipsychotic drugs, and mood stabilizers; (b) convulsive therapies, including electroconvulsive therapy (ECT); (c) psychosurgery, including bilateral cingulotomy and deep brain stimulation; (d) psychotherapy, including cognitive behavior therapy; psychoanalysis, gestalt therapy, interpersonal psychotherapy, eye movement desensitization and reprocessing (EMDR), and behavior therapy; 

   (2) “Care” is a shorthand reference to supportive care beyond the medical dimension, including, e.g., housing assistance, case or care management, employment training and transitional employment assistance, education, and other supports. For young people, support services often involve a “wraparound service” process. For adults with serious mental illnesses, wraparound services are often called assertive community treatment (ACT).

   (3) “Recovery” refers to the process whereby a person takes control of his or her own life; it reflects the first-person aspect of treatment. An often-quoted description of recovery states: “Recovery is the reawakening of hope after despair. Recovery is breaking through denial and achieving understanding and acceptance. Recovery is moving from withdrawal to engagement and active participation in life. Recovery is active coping rather than passive adjustment. Recovery means no longer viewing oneself primarily as a person with a psychiatric disorder and reclaiming a positive sense of self. Recovery is moving from alienation to a sense of meaning and purpose. Recovery is a complex and nonlinear journey. Recovery is not accomplished alone—the journey involves support and partnership.” Craig Winston LeCroy and Jane Holschuh, eds., *First Person Accounts of Mental Illness and Recovery* (Hoboken, N.J.: Wiley Publishing, 2012) quoted material.

4 Throughout this report, the term “mental health” is used rather than “behavioral health.” Although in common usage the terms are used interchangeably, they have taken on distinct meanings in the world of policymakers and advocates. Use of the term “behavioral health” usually signals that the speaker is referencing not only mental illness but also substance use. Because the information gathered from all sources was largely focused on mental illness alone, this report avoids the term “behavioral health,” to prevent misunderstanding.


9 A description of INTERFACE appears on p. 28 and p. 35 A description of BRYT appears on pp. 34-35.

10 The treatment of helplines, including the project now underway, appears on pp. 28-29.

11 A description of Certified Peer Specialists and proposed legislation appears on pp. 31-32.

12 Proposed legislation to achieve these goals appears on p. 33.


14 CBHI is described on pp. 40-41. Proposed legislation to expand its availability appears on p. 41.

15 To protect the confidentiality of NAMI Compass communications, we have changed all names used in presenting Compass case logs in this report.
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17 Emergency Service Programs (ESPs) provide community-based assessment, intervention, and stabilization services for individuals experiencing a mental health or substance use crisis. Services may include short-term counseling and medication management, access to peer support, and respite as an alternative to hospitalization. ESPs also help connect individuals with appropriate long-term services. ESPs seek to keep people out of the hospital and in the community whenever possible. See Section III of this report, pp. 39-40.


19 Bruce L. Bird, President and Chief Executive Officer, Vinfen, and Don Condie, Medical Director, Vinfen, joint interview with Health Care for All (HCFA) staff, September 22, 2016; Joseph Valley, Housing and Homelessness Specialist, Massachusetts Department of Mental Health (DMH), conversation with HCFA staff, March 28, 2017.

20 Pete Earley, author of Crazy: A Father’s Search Through America’s Mental Health Madness (2006), writes the leading blog on mental illness, www.petearley.com. He described his son’s early engagement as follows: “My son’s first break was when he was most open to the idea of engagement. He was scared and didn’t know what was going on. He voluntarily went to see a psychiatrist, but the manner in which he was treated really closed the door at that opportune moment. The psychiatrist was proud of being the kind of doctor who tells it like it is. He told my son, 'you have a mental illness and are going to be on medications for the rest of your life. They’ll probably cause you to gain significant weight, and you probably won’t be able to work in a regular job. If you don’t take the medications, you are going to end up homeless, in jail or dead.’ My son’s reaction was to reject that and to close the door on treatment,” quoted in NAMI Engagement, p. 2.


23 The HCFA HelpLine is a statewide multilingual telephone service that assists Massachusetts residents at all income levels to enroll in health insurance coverage. HelpLine counselors partner with the HCFA policy department to understand health insurance policy changes as they happen and the impact of policy on the HelpLine’s clients.

24 There appears to be a gradual shift away from prior authorizations on the part of some insurers. For example, Blue Cross Blue Shield of Massachusetts (BCBSMA), as of July 1, 2014, eliminated all prior authorization and notification requirements for all hospital emergency departments seeking inpatient psychiatric and detox admissions. BCBSMA pays for 48 hours of care and then begins a review process. This shift in approach reflected the insurer's interpretation of the parity laws’ requirements, as BCRSMA had implemented a similar approach to emergency department admissions on the medical-surgical side. In June of 2016, BCBSMA also removed all co-pays and deductibles for methadone, and prior authorization for suboxone prescriptions in therapeutic ranges in May 2017. (Conversation with Kenneth Duckworth, M.D., Medical Director of Behavioral Health, BCBSMA, August 19, 2017).


26 HCFA Survey Report, p. 17.

27 HCFA Survey Report, p. 18.

28 The deficiencies in the scope of services covered by commercial insurance as compared with MassHealth is sometimes obscured by the fact that more mental health providers accept commercial insurance than they do MassHealth. The reality, however, is that services covered only by MassHealth – i.e., not by commercial insurers -- are pivotal. See n. 93, and accompanying text. Moreover, the percentage of providers accepting MassHealth is not dramatically lower than those accepting both MassHealth and private insurance. See n. 39, and accompanying text.

29 It is generally acknowledged that most states’ Medicaid coverage of mental health benefits are typically more generous than private insurance coverage. See, e.g., Julia Zur, MaryBeth Musumeci, Rachel Garfield, “Medicaid’s Role in Financing Behavioral Health Services for Low-Income Individuals” (Menlo Park, CA: Kaiser Family Foundation, June 29, 2017), http://www.kff.org/medicaid/issue-brief/medicaides-role-in-financing-behavioral-health-services-for-low-income-individuals/ (“While many insurance plans cover psychiatric hospital visits, in some states, Medicaid is more likely than many private insurance plans to cover additional services, such as case management, individual and group therapy, detoxification, and medication management, in addition to psychiatric hospital visits; behavioral health services for children are particularly comprehensive due to Medicaid’s Early, Periodic Screening, Diagnosis, and Treatment [EPSDT] benefit for children. EPSDT includes all medically necessary Medicaid services permitted under federal law and is required for children from birth to age twenty-one. Under this benefit, states must provide access to behavioral health care, including screenings and assessments. Children diagnosed with behavioral health conditions receive any service available under federal Medicaid law necessary to correct or ameliorate the condition, even if the state does not cover the service for adults”) (last visited 9/7/17). See also “How Medicaid Enrollees Fare Compared with Privately Insured and Uninsured Adults: Findings from the Commonwealth Fund Biennial Health Insurance Survey, 2016,” available at http://www.commonwealthfund.org/publications/issue-briefs/2017/apr/how-medicaid-enrollees-fare-in-comparison-to-adults-with-private-coverage (“Medicaid enrollees have nearly equivalent access to care based on many important measures. Medicaid coverage also appears to offer better financial protection than private insurance against the cost of treating illness, a possible reflection of steady increases in private plan deductibles and copayments in recent years”) (last visited 8 27/17).

30 MassHealth CommonHealth is a program available to, among others, children and adolescents with a mental health disability whose commercial insurance does not cover all their medical needs. For a comprehensive description, see http://www.mass.gov/eohhs/docs/masshealth/membappforms/aca-1-english-mb-mh-commonhealth.pdf.

31 See n.93, and accompanying text.
In all the case logs from NAMI Compass, names and other possible identifiers have been changed to protect the privacy of the callers seeking help.

“Wraparound services” is a name commonly used for the intensive and individualized care planning and management process utilized by the Children’s Behavioral Health Initiative (CBHI) in which a child or youth under the age of 21 and his or her family work with professionals to create an individualized set of community services and supports. See n. 98, and accompanying text.

A therapeutic mentor works individually with a child or youth to support and improve social and communication skills and specifically to achieve the goals articulated a structured plan written by an outpatient therapist, in-home therapy provider or intensive care coordination (ICC) team. Therapeutic mentoring services are delivered in the home, school or community settings.

The MassHealth CBHI Guide describes a Family Partner as “an individual with lived experience as the caregiver of a child or youth with behavioral health or special health care needs. Family Partners are trained to assist families in either of two MassHealth services—Family Support and Training, or Mobile Crisis Intervention. The Family Partner provides emotional support for the caregiver, fosters empowerment, and encourages the expression of family voice. Family Partners often share parts of their own stories with the intention of helping caregivers develop insight and the motivation to act on their child’s and family’s behalf.” http://www.mass.gov/eh/bh/docs/masshealth/cbhi/cbhi-guide.pdf.

“Provider directories,” supplied by insurers, contain information about providers whose services are covered by that insurer. Often available online, provider directories are intended to assist people in choosing a provider who fits their particular insurance, location and special needs.

People have found that deceased providers remain listed in insurer-supplied provider directories, leading to the term “ghost networks.”

People also find that providers who are no longer accepting insurance (generally or a particular insurance company’s policies), as well as those who are no longer accepting new patients, nonetheless remain listed in insurer-supplied provider directories, leading to the term “phantom panels.”

The leading article on this topic is Tara F. Bishop, et al., “Acceptance of Insurance by Psychiatrists and the Implications for Access to Mental Health Care,” JAMA Psychiatry 71: 2 (2014): 176-181 (National statistics show 55.3% of psychiatrists take at least one form of insurance, and 43% take both private and public (Medicaid) insurance; of psychiatrists taking private insurance, geographic breakdown shows higher rates of acceptance in the Midwest (85.1%) and lowest rates of acceptance in Northeast (48.5%); acceptance of any insurance by psychiatrists (55.3%) is far lower than other types of M.D.s (88.7%).)

A comprehensive description of federal and Massachusetts laws mandating mental health insurance parity may be found in the Mental Health Parity Toolkit prepared by Health Law Advocates (HLA), available at http://www.healthlawadvocates.org/get-legal-help/resources/document/HLA-MentalHealthParityToolkit_6_pub-3.15.17.pdf (hereafter, HLA Toolkit).

The parity laws apply only to insurance companies, not to providers of medical care.

The full extent of the parity laws’ regulation of co-pays is described in the HLA Toolkit: (“Under the Federal Parity Law, financial requirements for MH/SUD [mental health/substance use disorders] benefits must be no more restrictive than financial requirements for medical and surgical benefits. Financial requirements are defined as deductibles, co-payments, coinsurance and out-of-pocket maximums. A health plan is not allowed to apply a particular financial requirement only to MH/SUD benefits. So, for example, a health plan could not require only co-payments for medical/surgical benefits and impose coinsurance on MH/SUD benefits. Some health plans used to have separate deductibles for medical/surgical benefits and mental health/substance use disorder benefits. This is no longer allowed. Now health plans may have only one combined deductible for all benefits”).


To further widen the gulf between the way these two types of residential treatment are handled by insurers, there persists a widespread misunderstanding among providers that “post acute care” (PAC) is a term reserved for medical-surgical conditions, and does not include medically necessary care after discharge from an acute inpatient psychiatric bed. It is hard to conceive of achieving parity when post-acute mental health care is not even included in PAC statistical analysis. See, e.g., Massachusetts Health and Hospital Association, “Overview of Post-Acute Care Hospitals/Units in Massachusetts,” https://www.mhalink.org/AM/Template.cfm?Section=Newsroom&Template=/CM/ContentDisplay.cfm&ContentID=17260 (last visited 8/20/17). See also Wen Tian, “An All-Payer View of Hospital Discharge to Postacute Care” (U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, Statistical Brief #205, 2013).


One need only examine the descriptions of residential facilities contained in the member directory of the American Residential Treatment Association (ARTA) to appreciate the intensiveness of state-of-the-art residential care on the one hand, and the prohibitive, usually private payment requirements on the other. See http://www.artausa.org/#directory (last visited 9/9/17).


SAMHSA defines “cultural competence” as “the ability to interact effectively with people of different cultures by being respectful and responsive to the health beliefs and practices of diverse population groups in order to ensure the needs of all community members are met.” See https://www.samhsa.gov/cap/apply-strategic-prevention-cultural-competence (last visited 8/27/17); Neel Krishan Aggarwal, et al., “The Meanings of Cultural Competence in Mental Health: An Exploratory Focus Group Study with Patients, Clinicians, and Administrators.” SpringerPlus, 5 (Published online March 31, 2016), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4814393/ (last visited 9/10/17).


The damage that waiting for care does to college students is particularly troublesome. See Megan Thielking, “A dangerous wait: Colleges can't meet soaring student needs for mental health care,” STAT News, February 6, 2017, https://www.statnews.com/2017/02/06/mental-health-college-students/(last visited 9/10/17).

Unfortunately, the waiting continues in the emergency room, a barrier to treatment for both adults and children experiencing a mental health crisis. A recent Boston Globe article highlighted a study finding that patients with mental illness waited an average of sixteen to twenty-one hours for a bed in a psychiatric hospital or unit while patients who arrived with a “medical issue” and then required admission to the hospital waited approximately four hours. The Baker administration has identified reduction of emergency room boarding for both children and adults as a top priority, and in early 2015 established an emergency boarding working group under the leadership of the Executive Office of Health and Human Services. In addition, the Children’s Mental Health Campaign (CMHC) is in the midst of a three-year project to understand and reduce pediatric psychiatric boarding. Both groups represent the ongoing efforts of healthcare providers, insurance companies, consumers, advocates and policymakers to overcome the barrier of delays in treatment.

For more information on CMHC, go to https://childrensmentalhealthcampaign.org/.


This chart was prepared in August 2011 and is titled “Discharges to Shelter from Private Psychiatric Hospitals Licensed by DMH (2005-2010).” Of the 53 hospitals included in the report, one facility, Bournewood Hospital, located in Brookline, Massachusetts, discharged 723 of the 8115 patients statewide. Of the 48 shelters listed in the report, four, located respectively in Boston, Quincy, Brockton, and Springfield, reported more than 25% of all people discharged to shelters. The hospital discharge records were kept by hospitals pursuant to 104 C.M.R. § 27:09(1) (b), which states as follows: “A facility shall make every effort to avoid discharge to a shelter or the street. The facility shall take steps to identify and offer alternative options by a patient, document such measures, including the competent refusal of alternative options by a patient in the medical record. In the case of such discharge, the facility shall nonetheless arrange for, in the case of a competent refusal, identify post-discharge support and clinical services. The facility shall keep a record of all discharges to a shelter or the street in a form approved by the Department [DMH] and submit such information to the Department on a quarterly basis.” The authors were not able to find any information about the enforcement of this regulation. The Massachusetts Housing and Shelter Alliance has long decried such discharges: “Discharges into the shelter system are a costly and ineffective way to address the unique needs of mentally ill and other persons in the community and contributes to, rather than prevents, homelessness.” http://www.mhsha.net/about-us/discharge-planning (last visited 9/11/17).

See pp. 40-41 for a description of CBHI.


See description of INTERFACE, p. 28 and p. 35.

See description of Bridge for Resilient Youth in Transition (BRYT), pp. 34-35.

See description of ESPs, p. 39.


For example, a database company that includes basic information on mental illness is Network for Care, which operates in many states, and provides database services through public contracts. For this and related information, see http://nhnetworkofcare.org/ (last visited 9/10/17).

For a recent thorough study on stigma and the role of peers, see National Academies of Sciences, Engineering, and Medicine, Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change (Washington, D.C.: The National Academies Press 2016). The pre-publication version can be viewed online at https://www.beaconhealthoptions.com/wp-content/uploads/2016/11/National-Academy-of-Science-The-Evidence-for-Stigma-Change.pdf (“Peers play an essential role in combatting stigma, in part because they model personal recovery. Their role is critical in helping individuals to overcome the debilitating forces of self-stigma. Peer support programs and services include social and emotional support, as well as practical support related to quality-of-life decisions, delivered by people with mental and substance use disorders. . . . [T]he research suggests that people who use peer support services are more likely to use other behavioral health services of all kinds, including professional services and prescription drugs, which may lead to improved outcomes” [page 9]).


Tiegreen, “Maximizing Medicaid Coverage for Peer Support Services.”

Mental Health America, Peer Services, http://www.mentalhealthamerica.net/peer-services (last visited 9/6/17).

See n. 39, and accompanying text.

Id.


See section II, pp. 18-19.


A related approach is taken in 2017 House Bill No. 522, sponsored by Rep. Tricia Farley-Bouvier, and 2017 Senate Bill No. 546, sponsored by Sen. Jason Lewis, both titled “An Act to Promote Value-Based Insurance Design in the Commonwealth.” The legislation seeks to encourage a preference for treatments proved to have high value. Currently, many patients avoid recommended treatments because of high out-of-pocket costs. This leads to declines in patients’ health and increases the cost to the system due to patient non-adherence. The legislation proposes a process for certifying a list of high-value medications that would be available without co-pays.


See p. 28 for a fuller description.


Information about the rigorous process of establishing programs as evidence-based under SAMHSA’s approach can be found at the National Registry of Evidence-based Programs and Practices (NREPP) website: [https://www.samhsa.gov/nrepp](https://www.samhsa.gov/nrepp) (last visited 9/10/17).

Id.

Elsewhere referenced in this report at p.15.


Id., at 15.

The B.E.S.T. program is an example. B.E.S.T., which stands for the Boston Emergency Services Team, is the ESP for Dorchester, South Boston, Roxbury, West Roxbury, Jamaica Plain, Mattapan, Roslindale, Hyde Park, Lower Mills, Brighton, Brookline, Charlestown, Chelsea, East Boston, Revere, and Winthrop. It has contracts with Harvard Pilgrim Health Care, Unicare, and those commercial insurers whose behavioral health benefits are managed by Beacon Health Options. All other commercial insureds are ineligible for B.E.S.T. services.


Children who have commercial insurance as their primary coverage but have secondary coverage with MassHealth are eligible for CBHI services. This is a feature of the Commonwealth program, which offers health care benefits similar to MassHealth Standard to disabled adults and disabled children who cannot get MassHealth Standard because they have commercial insurance as their primary coverage. [https://www.masspartnership.com/member/CoveredServices.aspx](https://www.masspartnership.com/member/CoveredServices.aspx) (last visited 8/20/17). However, Commonwealth services are not available to children with mental illness who have not been certified as disabled. An explanation of Commonwealth can also be found, among other places, at [http://www.mass.gov/eohhs/docs/masshealth/membappforms/aca-1-english-mb-mh-commonhealth.pdf](http://www.mass.gov/eohhs/docs/masshealth/membappforms/aca-1-english-mb-mh-commonhealth.pdf) (last visited on 8/20/17)


See p. 29 for a description of this project.

For a scathingly negative description, see, e.g., D.J. Jaffe, *Insane Consequences: How the Mental Health Industry Fails the Mentally Ill* (Amherst, N.Y.: Prometheus Books, 2017).
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The Urgency of Early Engagement:
Five Persistent Barriers to Mental Health Treatment, Care and Recovery in Massachusetts and the Search for Solutions