Mass-STEP

Massachusetts Strategic Plan for Early Psychosis

ACKNOWLEDGEMENTS

In this document, we use the term "early-course psychosis" to encompass a range of populations and experiences, including individuals with a recent onset of psychosis, those at clinical high risk to develop psychosis, and the families that support these individuals and are themselves impacted by their loved ones' experience of psychosis. Although early intervention is the priority and focus of this plan, we recognize that a lifespan approach is necessary to support lifelong wellbeing among those experiencing psychosis and their families. We also refer to the BIPOC (black, indigenous, and other people of color) and LGBTQ (lesbian, gay, bisexual, transgender, nonbinary and queer or questioning) communities as key intersecting groups for whom unique considerations may be needed. Our goal in this document (as clinicians, researchers, public health professionals, and government stakeholders) is to partner with these communities to define priorities for improving statewide resources and services for early-course psychosis.

I. INTRODUCTION

The prevention and early intervention of psychotic disorders has emerged as a key public health mandate for local, national, and global mental health authorities. Early intervention in psychosis is both effective and necessary. The World Health Organization recommends a delay of no more than 90 days between symptom presentation and specialized early-course psychosis treatment (Bertolote & McGorry, 2005); however, estimates across the US place the average delay in accessing treatment between one to three years (Marshall et al., 2005; Srihari et al., 2009). The first two years of a psychotic illness in particular are a critical period for intervention, in which cognitive declines, grey matter loss, and suicide risk are highest. Rapid identification and access to specialized early psychosis services are associated with improved quality of life, cognitive functioning, participation in work and school, and treatment engagement, as well as reduced symptom severity, substance use, and downstream healthcare costs and involvement among individuals served (Breitborde et al., 2015; Correll et al., 2018; Kane et al., 2015, Randall et al., 2015; Goldberg et al., 2006). Simply put, intervention in this critical window is not only life-changing, but life-saving.

Epidemiological research has established a stark need for wide-spread easy access to evidence based early-course psychosis services. Each year, roughly 100,000 people across the US will experience a first episode of a psychotic disorder, with peak onset between the ages of 15 and 25 (Heinssen, Goldstein, & Azrin, 2014). In Massachusetts alone, this amounts to approximately 2,000 new cases annually. If each early intervention program can meet the ambitious goal of admitting one patient per week, or 52 patients per year, then we will need 39 programs minimally to meet this need. Currently, Massachusetts has approximately 20 specialty clinics for early-course psychosis including 12 Coordinated Specialty Care (CSC) programs for first-episode psychosis (FEP)— less than one third of the minimum number required ("First Episode Psychosis Programs", n.d.). Even these available clinics vary in their ability to deliver the standard of care for treatment in early-course psychosis, as essential elements of CSC are not currently supported through 3rd party reimbursement payment models.

In addition to the scarcity of clinics and clinicians specializing in early psychosis treatment, many individuals face barriers in accessing specialized mental health services. Factors including out of pocket costs, transportation, protected time to attend appointments, stable housing, affordable childcare, stigma, and more contribute to disparities in access to mental health care. These factors are compounded by a lack of public knowledge about the early signs of psychosis and resources available to youth and families. While stigma is a powerful factor known to deter individuals from understanding and identifying their symptoms, managing symptoms, connecting with others in the community, and seeking formal care, those experiencing stigma and discrimination associated with intersecting aspects of their identity such as race, sexual and gender minority status, or immigration status may be even more hesitant to seek help for emerging mental illness. One study conducted by Schoenbaum et al. (2017) found that, of individuals aged 16 to 30 in the US who received an index diagnosis of a psychotic disorder, 61% did not fill an antipsychotic prescription and 41% did not receive individual therapy in the year following this diagnosis. Further research suggests that access to care is particularly limited for Black and Hispanic individuals, for whom there are significant reductions in outpatient mental health service use within a year of diagnosis compared to non-Hispanic white individuals (van der Ven et al. 2020).

With the clear evidence that early intervention is critical to the health and wellbeing of people living with psychosis and their families, the well-established evidence-based standards of care for early intervention, and the mental health parity laws, now is the time to address the challenges necessary to assure wide-spread availability of specialized services for individuals in the early course of psychosis. Insufficient numbers of programs, limited geographic availability, insufficient funding, and other access barriers to early-course psychosis services constitute an issue of equity both for individuals affected by psychosis who themselves represent an underserved subset of the community living with mental illness, and for intersecting BIPOC, LGBTQ, and low-income communities who shoulder a disproportionate burden of serious mental illness while simultaneously experiencing disparities in access to and quality of care.

With guidance from community members who have first-hand experience with psychosis and other expert stakeholders, the Massachusetts DMH has partnered with the Laboratory for Early Psychosis (LEAP) Center, the Massachusetts Psychosis Network for Early Treatment (MAPNET), and the Northeastern University Institute for Health Equity and Social Justice Research (IHESJR) to develop the Massachusetts Strategic Plan for Early Psychosis (Mass STEP). The Mass STEP outlines priorities for mobilizing actions centered around prevention efforts, treatment services, and the system-level coordination needed to build up an adequate system of care for individuals living with psychosis in Massachusetts. Mass STEP acknowledges the difficult history of psychiatry and the racialization of psychotic disorders which continues to serve as a barrier to trust and engagement with some BIPOC communities. Mass STEP includes attention to diversity in religion and spirituality, familial culture, language barriers, gender and sexuality, and youth culture. It also prioritizes attention to the needs of BIPOC communities experiencing and managing discrimination, racially motivated violence, marginalization, and exclusion. All of these factors impact mental health and well-being, including experiences of psychotic symptoms and disorders. Mass STEP advocates for the development and implementation of early-course psychosis services informed by the principles of cultural sensitivity and humility.

The following sections of this report describe the mixed-methods approach used to identify priorities for the Mass STEP (Section II), the framework used to conceptualize these priorities (Section III), and a list of overarching goals and recommendations to promote and advance early intervention in psychosis across Massachusetts (Section IV).

II. A COMMUNITY-ENGAGED STRATEGIC PLANNING PROCESS

A. Feedback and Recommendations from People with Early-Course Psychosis and their Families

A mixed methods approach was used to gather information from people receiving services from early psychosis programs in Massachusetts and their family members. First, in the summer and fall of 2020, a survey was disseminated to assess patients' and caregivers' experiences with treatment services and resources, as well as suggestions for activities to improve or expand early psychosis programming across the state. Results from the survey informed the content of focus groups and individual interviews with a subset of survey respondents in order to gain a deeper understanding of consumers' needs and challenges, and to gather their input on the strategic plan. A detailed description of this mixed-methods data collection process is included in Appendix A.

B. Feedback and Recommendations from Expert Stakeholders in Early-Course Psychosis

Following the consumer and caregiver survey, a conference was held on November 5th, 2020 to further develop priorities for the strategic plan with experts in the field, titled "Early Intervention in Psychosis: A Strategic Roadmap for Massachusetts." Sessions included presentations from national and international experts in early intervention for psychosis, as well as panel discussions with clients, families, and clinicians involved with early psychosis treatment programs across Massachusetts. Discussion and brainstorming sessions were held using Zoom breakout groups to solicit feedback from all attendees. Over 200 participants registered for the conference, representing policy makers, clinicians, researchers, community advocates, and individuals and family members with lived experience of psychosis. Eighty-four perecent of registered attendees indicated that they lived, worked, or received mental health services in the state of Massachusetts. A full summary of proceedings from this symposium was published in March 2021 through Schizophrenia Research (Johnson et al., 2021).

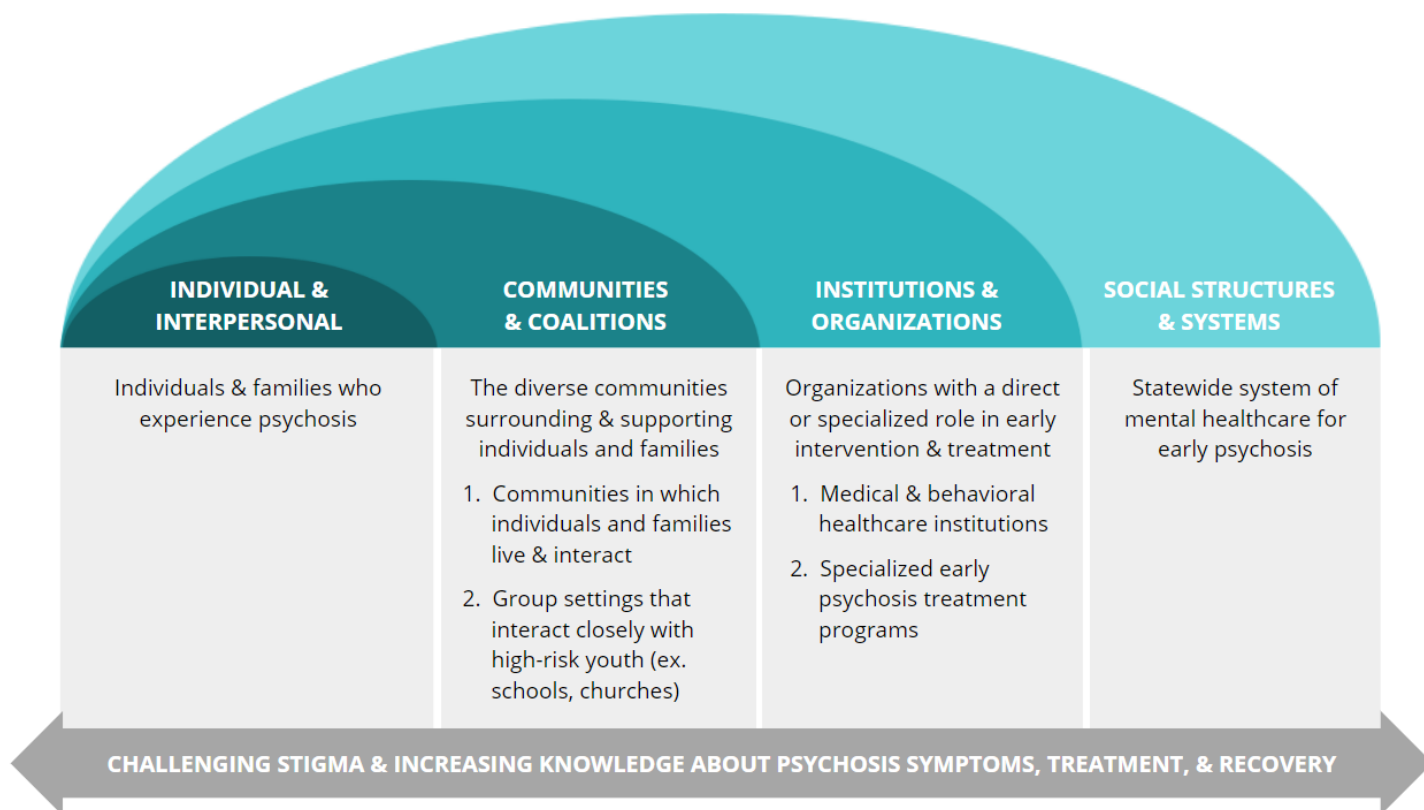**III. FRAMEWORK (THE SOCIO-ECOLOGICAL FRAMEWORK)**

The Mass STEP understands mental health and illness through the lens of a socio-ecological model of health. The overarching goal of early intervention and prevention in psychosis is to reduce suffering caused by these disorders and promote the overall health and wellbeing of individuals and their families; however, the actions taken to achieve this goal must acknowledge the context within which psychosis occurs. This framework identifies *Communities*, *Organizations*, and *Systems* as important contributors to an *Individual's* health and wellbeing. The model allows for a comprehensive look at mental health, providing insight into the specific challenges and needs of clients experiencing early-course psychosis.

As an example, consider a young person who begins to experience auditory hallucinations in school, which impede greatly on their ability to focus. They may disclose this to a trusted teacher in their school's network (*Communities*), who might suggest the need for further assessment. The student may then talk to their primary care clinician, who could refer them to a specialty psychosis program (*Organizations*). This program would provide high-quality evidence-based treatment thanks to collaborations with other specialists across the state and support from insurance (*Systems*). If any piece of this pathway were to be interrupted— for example, a teacher ignoring warning signs, a provider unsure of available treatment options, or insurance unable to cover the student's treatment needs— the end result would likely be the same. All levels of intervention must receive adequate support to make a difference for the individual seeking care.

This is just one situation in which the socio-ecological model may be applied to examine early intervention and prevention strategies. *Community* connections such as peer and social groups are known to enhance treatment and recovery outcomes in psychosis. In contrast, barriers to care are frequently contextualized on the *Systems* level through structural inequalities by race, ethnicity, gender, sexuality, and socio-economic status. With this knowledge, the Mass STEP aims to intervene at each level of the socio-ecological model to improve early psychosis services.

Lastly, the Mass STEP recognizes a need to create environments that minimize suffering and promote wellbeing by addressing stigma at every level of the model. Stigma, a devaluation of individuals resulting from negative beliefs and attitudes, can have a devastating impact on those with mental illness and is particularly salient for individuals experiencing psychosis. Internalized stigma (*Individual*) and *Community*-wide beliefs often deter people from disclosing symptoms and seeking support for psychosis. When individuals do choose to access services, medical and behavioral healthcare *Organizations* can perpetuate stigma by communicating in a paternalistic, demeaning, or pessimistic manner. At the *Systems* level, laws and policies can hinder pathways to recovery by restricting access to employment, education, and housing. To acknowledge the critical impact of stigma in psychosis— from internalized stigma to institutional bias— "Challenging Stigma" is noted as a core overarching theme that must be acted upon at every level. The following figure illustrates the priority populations identified through this model and the six primary goals resulting from these categories. In Section IV, we provide a detailed assessment of each goal and their potential action items, which are all informed by the stakeholder discussions described in Section II.

Socio-Ecological Model of Priority Populations for Early Intervention in Psychosis
Adapted from the Massachusetts Strategic Plan for Suicide Prevention

INDIVIDUAL & INTERPERSONAL	COMMUNITIES & COALITIONS	INSTITUTIONS & ORGANIZATIONS	SOCIAL STRUCTURES & SYSTEMS
Individuals & families who experience psychosis	The diverse communities surrounding & supporting individuals and families 1. Communities in which individuals and families live & interact 2. Group settings that interact closely with high-risk youth (ex. schools, churches)	Organizations with a direct or specialized role in early intervention & treatment 1. Medical & behavioral healthcare institutions 2. Specialized early psychosis treatment programs	Statewide system of mental healthcare for early psychosis

CHALLENGING STIGMA & INCREASING KNOWLEDGE ABOUT PSYCHOSIS SYMPTOMS, TREATMENT, & RECOVERY

Following this framework, the six primary goals of this plan are as follows:

1. Assure support for **individuals who experience psychosis and their families** through individual advocacy opportunities, community-building, and specialized early psychosis services.

2. Promote early identification and intervention for psychosis through community education and awareness efforts across the **diverse communities of Massachusetts**, particularly among underserved groups who face multiple barriers in accessing mental healthcare.

3. Promote early identification and intervention for psychosis through specialized supports for **community members who are likely to interact with those experiencing psychosis** (e.g. schools, faith leaders, law enforcement, EMTs).

4. Provide specialized support to **medical and behavioral healthcare professionals** in competencies related to early psychosis.

5. Support **specialized early psychosis treatment teams** in delivering high-quality, evidence-based care in a stepped framework that is culturally and linguistically appropriate, person centered, trauma informed, and recovery focused for people experiencing psychosis and their families.

6. Support and develop the **statewide system of services for early psychosis** by fostering communication across programs and integrating systemic supports for early intervention and prevention.

IV. STRATEGIC PLAN GOALS

Goal & Population	Examples of Possible Actions *(as identified in Symposium and Interviews/Focus Groups)*
1. Assure support for **individuals who experience psychosis and their families** through individual advocacy opportunities, community-building, and specialized early psychosis services.	1.1 Include stakeholders who experience psychosis on committees that make decisions about early psychosis resources, services and research (ex. DMH IRB, DMH, research advisory boards) 1.2 Increase resources for peer specialist roles on early psychosis teams; provide avenues for peer specialists to collaborate across programs and to advocate for needs in these roles. 1.3 Expand the reach of early psychosis support groups for individuals and families; for example, developing peer- and clinician-led support groups available regardless of program enrollment (see Wellspace groups at McLean, McFarlane multi-family groups, Australia's Headspace model), or utilizing virtual spaces for community-building and outreach (ex. apps & social media) 1.4 Provide specialized services to support individuals in achieving goals related to education and employment 1.5 Develop and strengthen supports for families & caregivers of individuals experiencing psychosis (Examples: In-Reach approach to teach motivational interviewing for caregivers) 1.6 Provide assistance with housing and food insecurity for individuals experiencing psychosis **CHALLENGING STIGMA**: Expand informational resources and programs for individuals and families who experience psychosis; Promote avenues for peer-led interpersonal support for individuals and families (ex. Hearing Voices groups); Implement evidence-based treatment approaches to address internalized stigma within the context of early-course psychosis treatment programs.
2. Promote early identification and intervention for psychosis through community education and awareness efforts across the **diverse communities of Massachusetts**, particularly among underserved groups who face multiple barriers in accessing mental healthcare.	2.1 Identify communities that are underserved by existing treatment programs and develop specialized approaches to outreach and support in these communities (ex. through churches or tribal governments) 2.2 Implement a public awareness campaign regarding signs and symptoms of psychosis, screening tools, etc. (see Yale MindMap campaign, https://mindmapct.org/about/) 2.3 Increase visibility of available resources and improve online information; for example, funding a marketing & media coordinator for early psychosis services or reassessing resources on the DMH website **CHALLENGING STIGMA**: Implement evidence-based anti-stigma programs to reduce community-level stigma associated with psychotic symptoms and increase hope for recovery.
3. Promote early identification and intervention for psychosis through specialized supports for **community members who are likely to interact with those experiencing psychosis** (e.g. schools, faith leaders, law enforcement, EMTs).	3.1 Develop a statewide centralized triage and navigation service to provide quick access to consultation & support in early psychosis and facilitate rapid connection of individuals and their families with care (ie. "MCPAP for psychosis" model) 3.2 Train community leaders & programs in the early signs, symptoms, and referral options for early psychosis (ex. schools, religious communities, youth programs, law enforcement/forensic programs, EMTs) 3.3 Create collaborative relationships between community organizations (emergency service providers, schools, etc.) and early psychosis assessment and treatment resources 3.4 Support local law enforcement in developing organizational procedures and culture that promote safe and compassionate interactions with people in crisis, including the provision of Mental Health First Aid and Crisis Intervention trainings (see IACP One Mind Campaign & Police-Mental Health Collaboration Toolkit). **CHALLENGING STIGMA**: Integrate anti-stigma and recovery-oriented content into trainings for community programs

4.	Provide specialized support to **medical and behavioral healthcare professionals** in competencies related to early psychosis.	4.1 Improve psychosis-specific resources in psychiatric inpatient units & strengthen connections to community programs; for example, developing a FEP-specific inpatient unit, supporting structure and psychosis competency in existing units, promoting continuity of care and discharge planning for transitions between inpatient and outpatient settings, and developing peer support/peer navigator programs within hospitals 4.2 Assist family members and practitioners in acute care settings in connecting to early psychosis treatment services (See description of centralized triage and navigation service in goal 3.1) 4.3 Create collaborative/integrated relationships between medical/behavioral health providers and specialized early psychosis teams 4.4 Educate behavioral health providers to, at a minimum, screen, detect, and refer to specialized services for psychotic symptoms (inpatient, ESP, and outpatient services) 4.5 Increase psychosis competency among community and private practice mental health providers for those who are being discharged from an early psychosis program or who may not need the level of support offered by specialty programs
		CHALLENGING STIGMA: Implement anti-stigma training for medical and behavioral healthcare professionals
5.	Support **specialized early psychosis treatment teams** in delivering high-quality, evidence-based care in a stepped framework that is culturally and linguistically appropriate, person centered, trauma informed, and recovery focused for people experiencing psychosis and their families.	5.1 Promote the development of new early psychosis coordinated specialty care (CSC) treatment programs in underserved areas across the state and support high-quality, whole-person, and recovery-oriented care initiatives across new and existing programs. Using a stepped-care framework, these programs should have capacity to adjust the intensity of the intervention based on the fluctuating needs of individuals and families over time 5.2 Maintain capacity to provide intensive outpatient service for those needing a higher level of care (ex. PREP) 5.3 Maintain the infrastructure necessary to provide expert training and consultation in the implementation of evidence-based practices to providers in early psychosis programs (ex. MAPNET) 5.4 Address issues of accessibility for telehealth and in-person services among clients & families; for example, using telehealth and mobile teams to increase access in communities far from urban academic medical centers, providing laptops/broadband for clients & families to address accessibility needs related to telehealth, and supporting access to in-person treatment through transportation programs and geographic flexibility 5.5 Support community programs within treatment settings such as cooking classes, exercise/sports groups, special interest groups, etc. that help clients to live healthy and active lives 5.6 Adapt engagement and treatment models to best meet the needs of culturally and linguistically diverse communities; for example, building a diverse workforce and increasing access to interpreter services 5.7 Invest in building a racially, linguistically and culturally diverse early psychosis workforce by providing paid mentorship and training opportunities for students, clinical trainees and residents from under-represented minority groups to learn to specialize in treating early psychosis 5.8 Support CSC programs in addressing comorbid substance use in treatment
		CHALLENGING STIGMA: Survey knowledge & beliefs about recovery among early psychosis treatment providers; Standardize the inclusion of recovery orientation in the training process for early psychosis treatment providers

6. Support and develop the **statewide system of services for early psychosis** by fostering communication across programs and integrating systemic supports for early intervention and prevention.	6.1 Assess and address issues related to capacity in the early psychosis care system; for example, addressing clinician burnout and turnover, utilizing community-level interventions (ex. Horyzons platform in Australia), and assuring that graduate programs and training sites are training future behavioral workforce members in recognizing the signs of early & emerging psychosis 6.2 Expand and diversify the workforce of trained staff across early psychosis services; for example, providing intensive training in psychosis for graduate & undergraduate students, developing incentives to reduce staff turnover, and increasing racial diversity in the mental health workforce (see 5.7) 6.3 Implement evidence-based strategies to monitor and address the mental health impact of marijuana legislation; for example, promoting evidence-based legal regulations for THC content and labelling of cannabis products, developing a community education campaign, or considering a "sin tax" wherein tax dollars generated by marijuana sales are allocated to support early psychosis services 6.4 Enhance sustainability in billing practices by creating a standardized program-level day-rate for early psychosis treatment reimbursable by third-party insurance payers. Formalize billing structures for services that are not currently 3rd party billable, e.g. peer support, psychoeducation, employment/education support, team meetings, coordination of care between acute & outpatient services, community education and outreach. Ensure that treatment is available in some form to everyone regardless of insurance coverage. 6.5 Evaluate implementation strategies that support the translation of innovative evidence-based practices in non-research settings 6.6 Utilize data to monitor needs in early psychosis services, capacity of the behavioral health system to address service needs, quality of services provided, and to evaluate impact of services received (via standardized systems for outcome evaluations & regular assessments of fidelity across teams implementing CSC or other EBPs)
	CHALLENGING STIGMA: Identify employer practices and policies that exemplify best practices in inclusion and stigma reduction for psychosis, and promote the use of these practices in new and existing systems/policies

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Appendix A
Data Collection Methods for Client & Family Stakeholder Feedback

Three phases of data collection were used to gather input from people experiencing early psychosis and their caregivers. First, in the Fall of 2020, a survey was disseminated to young adults and their caregivers through Massachusetts's network of early psychosis programs. The survey was developed by the research team at Northeastern University Institute for Health Equity and Social Justice Research in collaboration with the Massachusetts Department of Mental Health. In our survey, both people impacted by psychosis and caregivers were asked demographic questions concerning race, ethnicity, gender, sexual orientation, place of living, education, and employment status. Questions were developed to understand the experiences individuals and their caregivers had with treatment services, and to gain a deeper understanding of the lived experiences of those involved with early psychosis services. The data from the survey were analyzed using Statistical Package for the Social Sciences (IBM Corp, 2017) and open ended responses were approached as a thematic analysis to identify themes for focus groups and interviews (Braun & Clarke, 2007).

Following the completion of this survey participants were asked whether they were interested in participating in a follow-up focus group or interview concerning early psychosis services. In December 2020, we carried out two focus group interviews and four individual interviews over HIPAA-compliant Zoom calls. The two focus groups each consisted of three and four caregivers for an individual receiving early psychosis services. Individual interviews were conducted with those who were unable to participate in the focus groups. These included two additional caregivers, and two young adults receiving early psychosis services.

During the focus groups, we asked a series of questions to both individuals and caregivers. These questions were developed using information gathered from our patient survey and included questions to gage what would improve services (lists of questions asked for young adults and caregivers are included in the following pages). Questions encouraged participants to discuss their experiences receiving early psychosis services, and potential concerns where treatment could be improved. Audio recordings of all focus groups and interviews were transcribed and anonymized prior to analysis.

Interview Questions with Young Adults

1. When did you come in contact with treatment or services?
    a. How did you find out about services or how was your first contact with services?

2. Is there something that could have been done differently for you to better find out about services, treatment, and/or resources?
    a. What were some barriers to you getting into services?
    b. What were some things that helped you to access services?

3. What type of information was provided to you when entering into services?
    a. What would you have liked provided in terms of information when you first started services?

4. What types of services, treatment, resources were offered to you and your family?
    a. What did you like about what was available to you and your family?
    b. What do you wish was available to you and your family that wasn't?
    c. What would you have liked to be done differently for you and for your family?
    d. What types of resources, services, treatment would you like offered that weren't?

5. Now, I would like you to think about the current services, treatment, resources you receive.
    a. What services, treatment, resources that are available to you and your family now that are different than when you first came into services?
    b. What services, treatment, resources, do you wish were available to you and your family now that are different than when you first started using services?

6. I have one final question before we wrap up. What else would you like us to know as the Department of Mental Health (DMH) plans services, treatment, resources for youth who are experiencing psychosis. What do you want DMH to know?

Focus Group Interview Guide For Individuals and Caregivers

1. Would you share with us what has worked well or has been helpful for your child/family member?

2. What has been challenging in accessing support needed for your child/family?

3. We would like to share some pieces and goals of the draft on the roadmap:

Increase the competence of first responders who are more likely to encounter people at high risk and recent onset of psychosis. (such as law enforcement, forensic services; EMT'S and schools)
- Training in early signs, symptoms, screening
- Increased collaboration between emergency service providers, early psychosis assessment, and treatment resources
- Quick access to phone consultation/support regarding recognizing and responding to concerns for emerging symptoms

Partner with the diverse communities of Massachusetts to increase awareness and ability to identify individuals experiencing recent onset of psychosis
- Conduct public awareness campaigns regarding signs and symptoms, screening tools, etc.
- Reduce stigma associated with psychotic symptoms and increase hope for recovery
- Consider use of telehealth and mobile teams for increasing access to care for communities far from urban academic medical centers
- Adapt engagement and treatment models to best meet the needs of culturally and linguistically diverse communities

Would you share your reactions?

Would you like to add anything that you think might be important and helpful that we might have missed?

4. We value your experience as a caregiver/parent. We believe that you as a caregiver/parent have experiences that inform you to think about what could be helpful for your child/family member and other young people with psychosis. We ask you to imagine a world without any constraints such as funding. What would you like to add to the roadmap?

5. Is there anything else that you would like us to communicate with the Department of Mental Health as they plan for the roadmap?