"Assessing Mental Health Needs in the Community: Considerations for Care Coordination"

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Acknowledgements

Acknowledgements

Stakeholder Advisory Committee

Ascentria Care Alliance
Clark University
Center for Health Impact
Common Pathways
Community Legal Aid
Fallon Community Health Plan
Family Health Center of Worcester, Inc.
Pernet Family Health Service, Inc.
Latin American Health Alliance
The Hector Reyes House
Southeast Asian Coalition
Spectrum Health Systems, Inc.
The Bridge of Central Massachusetts, Inc.
Worcester Division of Public Health
UMass Memorial Medical Center
Worcester Police Department
Worcester Youth Center

Qualitative Interviews

Ascentria Care Alliance
Centro las Americas
Community Healthlink
Community Legal Aid
Edward M. Kennedy Community Health Center
Faith Tabernacle Church
Fallon Community Health Plan
Family Health Center of Worcester, Inc.
Genesis Club, Inc.
Hahnemann Family Health Center
Latin American Health Alliance
The Hector Reyes House
Multicultural Wellness Center
Pernet Family Health Service, Inc.
Pathways for Change, Inc.
Southeast Asian Coalition
The Bridge of Central Massachusetts, Inc.
Worcester Police Department
Worcester Refugee Assistance Project
VA Central Western Massachusetts HCS
UMass Memorial Medical Center

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- Despite the goals of Healthy People 2020 to improve the mental health of the U.S. population through prevention and access to appropriate, quality mental health services – the burden of mental disorders remains high and untreated.

  - In 2012, there were an estimated 43.7 million adults aged 18 or older in the U.S. with any mental disorder in the past year, representing approximately 18.6 percent of all U.S. adults (SAMHSA, 2012).

  - Despite the existence of numerous efficacious psychosocial and pharmacological treatments for mental disorders, many individuals in need do not receive adequate treatment (Wang, Demler and Kessler 2002).

  - In particular, racial and ethnic minorities (including immigrant and refugees), individuals from lower socioeconomic backgrounds, and men are less likely to receive adequate mental health care (Gonzales & Papadpoulos, 2008; Kessler et al., 2008; Snowden, 2012, Berdahl & Torres Stone, 2009).

Background

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- The purpose of this study is to increase our community's understanding of the perceived mental health experiences and issues faced by Worcester residents.

- The 2015 Worcester Community Mental Health Assessment is a community-based overview of the;

  - challenges Worcester residents, providers, and Executive Directors report seeing on a daily basis

  - different perspectives residents hold about mental health and treatment

  - various approaches to coping with stress that residents demonstrate

  - barriers and facilitators relevant to accessing mental health services.

Purpose of the Study

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Individuals participated in either a focus group or an individual interview with research staff

- 61 individuals who represented Worcester residents and/or consumers of mental health services, as well as providers of mental health and community-based services in Worcester.

The quantitative data for this mental health needs assessment were obtained from two primary sources: the Behavioral Risk Factor Surveillance System (BRFSS) from the Center for Disease Control (CDC) and the MassCHIP from the MA Department of Public Health please see full report http://www.umassmed.edu/sparc/about-our-center/featured-news/2015/November/worcester-county-mental-health-assessment/

Research Methods

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- Recruitment of service providers in Worcester was conducted with the help of our community stakeholder advisory board, comprised of a number of Executive/Program Directors of Worcester-based services.

  - These organizations included health and mental health centers, social services agencies, immigrant and refugee assistance programs, legal consultation services, faith-based organizations, and law enforcement. Inclusion criteria included experience as a service provider in Worcester; there were no exclusion criteria.

- Worcester residents and/or consumers of mental health services were recruited with the help of providers and Executive/Program Directors on our community stakeholder advisory board.

  - In addition to recruiting individuals via clinician referral, research staff posted flyers advertising the project at local community organizations and via online "listservs."
  - Inclusion criteria included being 18 years or older; no exclusion criteria applied. However, the research staff was only able to accommodate data collection in English, Spanish, and Vietnamese. Research staff utilized clinical judgment to determine individuals' current mental health status and capacity to give consent.

- All individuals provided informed consent prior to participating.

- Participants were paid $25 per completed interview or focus group.

Study Participants and Recruitment Strategy

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Table 1. Focus Group / Interview questions for Worcester residents

1. Let's talk about the common challenges people experience on a day to day basis – that you have experienced, your family and/or friends have experienced, or that you've heard other individuals in the community have experienced, and so on.

2. You've talked about your life stressors and challenges. As you can imagine, we think that these things are deeply connected to mental health. What do you think about mental health more generally?

3. What are the different ways in which you or other individuals in your community manage these stressors?

4. What have your experiences or others' experiences that you know been with trying to access mental health services in Worcester?

5. Do you have any recommendations about the provision of services in Worcester, or services that don't exist that you'd like to see exist, or additional social assistance programs?

Interview Questions for Worcester Residents

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Table 2: Focus Group / Interview questions for Providers and Executive Directors

1. What are the most common challenges you see people experiencing in the Worcester community?

2. How do you understand consumers' and residents' ideas and attitudes towards mental health? How do you see stigma interfering with help-seeking?

3. What are the most common ways you see people coping with their life stressors and mental health challenges?

4. What are your perceptions of individuals' experiences in trying to access mental health services in Worcester?

5. What gaps do you see in the system or in your particular organization? How could service provision in the Worcester community be improved?

Interview Questions for Worcester Providers and Executive Directors

- These participants ranged in age from 24 to 74, with a mean age of 56.6 years (SD = 13.4).

- The sample was racially and ethnically diverse, with 88% of the participants self-identifying as racial/ethnic minorities and just over two-thirds of the sample indicating they were U.S. immigrants.

- Slightly more than half the sample were men (58%), just under half were single (42%), and more than half of participants (77%) had less than a college degree.

- Participants were also predominantly from low-income backgrounds, with half of the sample reporting that they earned less than $10,000 per year.

Demographics

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1. Identifying the most common daily challenges facing Worcester residents, which included:

- Economic Difficulties: Poverty, work, safe and affordable housing
- Exposure to violence and trauma
- Substance use disorders
- Medical comorbidity

The Qualitative Findings

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A second important theme that emerged across the interviews and focus groups was the elevated rates of lifetime and current exposure to violence and trauma. For some immigrants who come from countries with extensive civil strife, the trauma can be extensive. As one non-mental health provider described:

- *"Immigrant and refugee families have seen lots of violence before coming to the United States. They come from war countries. Some have experienced genocide but are survivors. We have so much to learn about resilience from them."*

Exposure to Violence and Trauma

Unsurprisingly, military veterans were a group of individuals for whom experiences of trauma was a salient theme.

One provider who works with the veteran population said:

"*A lot of our clients through homeless Veterans program have multiple levels of trauma. There might be civilian trauma, childhood sexual trauma, to trauma when they were drinking and drugging and using on the streets, to trauma in the military. And the only one of those traumas that is honorable ... would be military trauma. So there's a whole harboring of secrets they endure, looking at someone who had a whole lot of trouble prior to entrance and it has not really been addressed due to the secretive nature, or their resistance, or shame and embarrassment by the veteran.*"

Exposure to Violence and Trauma

- Non-Western conceptions of mental health and treatment

- Stigma, especially for immigrant and refugee groups, as well as military veterans

Conceptualizations of Mental Health

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Several providers noted that community residents did not always recognize symptoms of stress as psychological in nature and possibly treatable.

For example, a religious pastor, in reference to experiences of trauma, said:

- *"They don't know that they have trauma. It's our responsibility to direct them to Worcester services but we have to be careful how we do it…we have to build trust with the mother and the child first."*

Similarly, a mental health provider who worked with immigrant and refugee populations noted that many of these individuals struggle with the effects of pre-immigration trauma, but are not familiar with Western notions of mental health and illness, and so focus on physical symptoms. He stated:

- *"So lots of people have come from civil war torn countries that have extensive traumatic experiences, and they are in a new country where they don't speak the language, they don't recognize the new faces around them, and it's unsafe to sleep. I would say so many of the clients that come in, one of their most salient needs is that 'I am not able sleep.'"*

Conceptualizations of mental health

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When asked about attitudes towards mental health, stigma emerged as a common theme across residents, providers, and executive directors. As one mental health consumer stated:

- "There is a lot of stigma in Worcester… Employers don't want to hire individuals with mental illness [because] they think we're crazies who won't be able to do the job right."

Of note, interviewees suggested that mental health stigma is much more pronounced in immigrant and refugee populations, many of whom equate mental illness with "being crazy" and as being inherently shameful. As one non-mental health provider described about some of her clients who are served by her organization:

- "There is a lot of stigma – once they are settled – they are still in contact with each other. They feel like they have worked so hard to get to the United States that they can't have a problem. They can't be looked down upon. They don't want to get help with any of their symptoms because they don't want to be labeled as mentally ill."

Negative attitudes and stigma

Military veterans were a group for whom stigma posed unique challenges. In addition to having the general stigma about mental health challenges, many veterans worry about the consequences to their military career if they were to seek help. One provider who works with military veterans noted:

- *"Veterans, particularly if they remain an active service member in the Guard or Reserves, are willing to tell us about their mental health issues but don't want us to document it on their records because the military has access to their medical records. You get mixed messages from the military: on the one hand, you are encouraged to disclose your mental health condition but everything changes after that. Sometimes disclosure limits their ability for promotion and changes their career path. "*

Negative Attitudes and Stigma

3. Learning about the common coping strategies used by Worcester residents.

- Some of the coping strategies were conceptualized as unhelpful and included alcohol and substance use/abuse, self-injury, and isolation.

- Many of the coping strategies were adaptive, however, and included a number of individually-oriented strategies (e.g., exercise, meditation, relaxation, religious and spiritual coping)

- as well as more socially-oriented approaches (e.g., support from friends and family, structured social activities).

Coping Strategies

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4. Identifying the barriers to utilization of mental health services. Findings demonstrated that commonly experienced barriers included:

* Long waiting lists
* Navigating the mental health system
* Patient engagement (e.g., perceptions of uncaring providers)
* Cultural competence
* Logistical barriers (i.e., hours of operation, transportation, and insurance copays)
* Dearth of providers
* Lack of coordinated care
* Transportation
* Language barriers

Barriers to Utilization of Mental Health Services

Many participants expressed frustration with the difficulties in scheduling appointments with mental health providers. This frustration was expressed regarding both psychiatric and psychotherapeutic services, and it was noted as particularly concerning for communities of color.

One mental health provider we interviewed stated:

- *"I think the most common challenge is, I think, lack of resources. When people decide – especially we see that in the public sector, psychiatry, definitely…When people decide they need services or they try to seek services, there's a number of waiting lists, you know. And people, sometimes – especially with the Latino community, which is the community that I work with, people sometimes look for services when they really needed it yesterday, so there is a certain urgency that goes with looking at, getting the services. And, what happens is that many times there are waiting lists among the providers in town, and then either the crisis gets resolved or they have to suffer through it, end up in the hospital. You know, that I think is, access, I think is one of the biggest challenges."*

Waiting Lists

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Participants consistently described the difficulties Worcester residents experience when attempting to navigate the complex health and mental health systems. This difficulty was often noted as particularly stark for immigrant and refugee populations, many of whom come from countries with very different healthcare systems.

- One Vietnamese resident stated:
- *"I have a doctor and Mass health insurance. When my doctor prescribed a medication, I took his prescription to everywhere, but no one had it. They kept telling me to go here and go there. This caused me so much stress that caused my nerves stretched thin. I came to this place that was supposed to sell the medication, but I was sent to another place and another place. I really need help to get my medical needs [met]."*

Many providers and Executive Directors expressed similar frustration with the complex systems. Concerns were expressed about the challenges of coordinating care across providers and between organizations. The absence of any system to facilitate coordination of care was noted expressly by many providers.

One Executive Director lamented the current state of affairs when she said:
- *"I think a lot of the agencies are so specialized in what they do, I think sometimes they are trying to fit a square peg into a round hole…and I think organizations need to be more client-centered, and really understand the client as a unique individual…I can't tell you how many times…the therapist will say, 'Oh, I don't work with that, you have to go here…clients are feeling abandoned, pushed-off.*

Navigating the Mental Health System

One mental health provider who works with military veterans acknowledged how complicated and daunting the system can be for patients. She yearned for a facilitator who could help patients with the inevitable challenges, stating:

- *"I crave for my clients a patient, experienced coordinator. Someone who is comparable and analogous to an articulate, well-educated person who has the time to help navigate what might feel like a daunting, complicated, intimidating system – private or VA. People do better with someone who is in the room, who [will] help them talk to their doctor when they're anxious about all the things that they're dealing with – to debrief after the appointment, follow up appointments, prepare for the next appointment. The experience would be much more productive."*

This desire for a facilitator or patient navigator was articulated by many providers in different ways. One non-mental health provider described this need for South Asian populations:

- *"We need more health navigators and outreach workers who are focused on specific populations like the Burmese and Vietnamese population. It's very hard to have different people come to their homes who don't understand their background situation. We need to include different agencies to help bridge the gap between primary care, housing and mental health."*

Patient Navigators

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A number of logistical barriers to engaging with services were noted by residents, providers, and Executive Directors. These logistical barriers were more salient for consumers from lower socioeconomic backgrounds and included issues with transportation, operating hours, and insurance co-pays.

With regard to transportation complications, one Worcester resident who was a consumer of mental health services stated:

- *"Transportation can be challenging. I have to take two buses to work and two buses back. I have to be at work at 11:15am, so I have to be at the bus stop by 9:45 to catch a 9:55am bus to the HUB and then catch a 10:30 bus to work."*
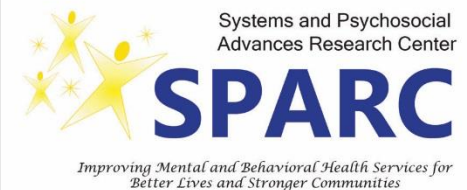
Logistical Barriers

- Worcester residents included economic challenges and elevated rates of lifetime and current exposure to violence and trauma. In addition, substance use and medical comorbidity also emerged as common themes.

- Many immigrant and refugee residents struggle with the effects of pre-immigration trauma, but are not familiar with Western notions of mental health and illness, and so focus on physical symptoms.

- Stigma emerged as a common theme across residents, providers, and Executive Directors. Of note, interviewees suggested that mental health stigma is more pronounced in immigrant and refugee populations, as well as among military veterans.

- Adaptive coping strategies included a number of individually-oriented strategies (e.g., exercise, meditation, relaxation) as well as more socially-oriented approaches (e.g., support from friends and family, structured social activities). Religious and spiritual coping emerged as particularly salient for racial and ethnic minority populations.

- Participants identified numerous barriers to utilizing mental health services, including long waiting lists, navigating the mental health system, language barriers, and several logistical barriers (i.e., hours of operation, transportation, and insurance copays).

Summary of Findings

Taken together, these results from the Worcester Community Assessment of Mental Health Needs led to the following **recommendations to improve the mental health needs of the Worcester community**:

- Greater and broader coordinated care
- Increased use of case managers, patient navigators/advocates, community health workers
- Greater network/community among providers
- Mental health literacy/more mental health education
- Culturally competent care
- Extended hours of operation and better transportation support
- More opportunities for social interactions

Recommendations

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Integrated care has been linked to improvements in clinical outcomes, compliance with medical regimes, lower total medical costs to patients, patient and provider satisfaction, and access to behavioral health care particularly for groups that are difficult to engage (Blount, 2003).

As one Executive Director noted:

- *"What seems to be working the most smoothly for us is when behavioral health and medical work together for a patient, whether that's an integrated or coordinated service…when we're both on the same page, that seems to work better for patients…so, our medical providers understand what the condition of access to behavioral health is in Worcester, so they are reasonable about distinguishing between those patients in dire need for it versus those for whom it'd be helpful…and behavioral health cooperates by finding appointments for patients who are higher priority of need."*

Coordinated Care

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- In addition to increased coordinated care, a strong desire was articulated for greater network and community among providers, both within and across agencies.

- Case studies have shown that inter-organizational networks are effective in responding to conflicting institutional pressures from the state and the profession particularly in major shifts in the state's funding mechanism from fee for service to managed care.

One mental health provider referenced the Worcester Latino Coalition as an example of a successful cross-agency networking alliance that helped improve the care of Latinos. She stated:

- *"In the past, many years ago, we had had the Worcester Latino Coalition, for example. And that was people from different worlds, you know. People who were either Latino or who were interested in making sure that the Latino community was served. And that was kind of like a networking place, where a lot of us used to come in ... and projects were born out of that. And I think the reason why 20 years later we are doing better, you know, and there is more access, is because of, partly because of, the Latino Coalition. For example, interpreter services and Language link were created through the Worcester Latino Coalition initially, like 20 something years ago. So it was kind of that networking, and I think that's missing now. And I wonder if that is something that would be helpful somehow. Not just with Latinos, but multicultural you could call it."*

Greater network/community among providers

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Patient navigation is emerging as an effective intervention to reduce health disparities, as it can identify and target specific barriers to treatment engagement (e.g., Druss et. al., 2010).

As one non-mental health provider articulated;

- *"The Burmese don't have the words in their own language to describe mental health…They have their own way of adapting to mental illness. They lack a Western understanding of how the body works in Western terms. Having someone advocate for them is helpful…sometimes it's someone who has had experience with the group who doesn't necessarily have to be of the same culture."*

Patient Navigators

Providers, mental health consumers, and residents felt that there is a need for more mental health literacy about both mental health conditions and services offered in Worcester. Mental health literacy is linked to increased willingness to seek help from a psychiatrist or counselor.

Yet, many people, especially recent immigrants and cultural minorities, lack knowledge of what mental illness is, how to recognize early signs, what treatments are available and how and when to seek professional help (Collier et al., 2012; Jorm, 2012).

As noted earlier, residents do not always recognize symptoms of stress as psychological in nature and as possibly treatable. One non-mental health provider noted:

- *"We need community education for those in crisis…We don't always know how to talk about it, mental health can range from bipolar to schizophrenia to hardly presenting at all….People think that mental health treatment is for people screaming in the street; crazy people."*

Mental Health Literacy

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Providers who worked with communities of color and special populations (veterans) consistently articulated the need to deliver services in a culturally responsive way.

This includes understanding the political histories and culture of immigrant and refugee populations, and ideally, being proficient in the language of the consumers.

A Vietnamese resident noted the difficulties inherent in trying to communicate with providers. He noted:

"My difficulties are in daily activities, especially as an elder. I find that because we are an Asian, as a Vietnamese, we speak Vietnamese only and now live in American society, the most difficult is the language barrier. When you go to agencies, some do provided translation but most of them do not. So that will create obstacles when you try to communicate. Even if they have translators, it's still difficult. But most places do not have translators."

Culturally Competent Care

Providers who worked with military veterans identified them as another group that has unique needs and preferences, and so acquiring understanding and skill in working with this population is essential. One provider noted that:

- *"There are veterans who don't want to get services in the community and prefer to be treated at the VA. The community providers don't understand veteran culture. They feel better understood around other veterans."*

Culturally Competent Care

Given the data suggesting that Worcester residents are experiencing numerous stressors, as well as substantive barriers to mental health care, it is imperative that the community come together to advance the cause of those most in need. As a pastor at a local church stated quite eloquently:

"We need organizations that serve as a bridge to create effective communication between services. Right now there is water, and our people can't swim. We need this bridge to be a strong bridge to connect services and get things done – a bridge that people can trust. People are accounted for and people are accountable. We have a lot of people in the community who help but don't have the funds to do it all. We are not asking for a hand out but a hand up!"

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Closing Remarks

Thank you for coming!

Primary Authors

Esteban Cardemil, Ph.D., Clark University: Dr. Cardemil's research focuses on understanding and addressing the mental healthcare disparities in the United States that continue to disproportionately affect individuals from low-income and racial/ethnic minority backgrounds. He has been closely involved in two prior mental health needs assessments in Worcester and in Framingham that focused primarily on the Latino community.

Rosalie Torres Stone, Ph.D., Clark University and University of Massachusetts, SPARC: Dr. Torres Stone's empirical work in mental health and health disparities extends existing conceptual frameworks by including socioeconomic and culture-specific factors in examining health outcomes and access to care for underserved populations.

Kristen Keefe, M.A., Clark University: Ms. Keefe's research focuses on mental health disparities and minority mental health. She is particularly interested in better understanding disparities affecting patients' engagement in aftercare following inpatient psychiatric hospitalization.