

## **Community Health Needs Assessment 2019**

### **Cooley Dickinson**

#### *Appendices*

- Appendix I. Stakeholders Engaged in the 2019 CHNA Process
- Appendix II. Glossary
- Appendix III. Focus Group Summaries
- Appendix IV. Key Informant Interview Summaries (including Public Health Officials)
- Appendix V. Community Conversation Summaries
- Appendix VI. Community Chat Summary
- Appendix VII. Notes from Cooley Dickinson Community Benefits Advisory Council

## Appendix I. Stakeholders Engaged in the 2019 CHNA Process

### Regional Advisory Committee (RAC)

Name (Last, First)	Title	Organization	Organization Serves Broad Interests of Community	Organization Serves Low-Income, Minority, & Medically Underserved Populations	State, Local, Tribal, Regional, or Other Health Department Staff
Bankert, Sarah	Program Manager, Healthy Hampshire	Collaborative for Educational Services	X	X	
Bruno, Kathleen*	Health Management Program Manager	Health New England	X	X	
Cardillo, Beth	Executive Director	Armbrook Village	X	X	
Darling, Ann	Director of Planning and Resource Development	Community Action Pioneer Valley	X	X	
Douglas, Henry Jr.	Recruitment & Retention Specialist	Men of Color Health Awareness (MOCHA), MLK Family Services	X	X	
Fallon, Sean*	Manager of Community Benefits and Health	Mercy Medical Center; Trinity Health of New England	X	X	
Frutkin, Jim	Senior Vice President Business IFU	ServiceNet; Western MA Veterans Outreach	X	X	
Golden, Annamarie*	Director, Community Relations	Baystate Health	X	X	
Goldman, Doron	Freelance baseball researcher/historia n	Cooley Dickinson Hospital Patient Family Advisory Council	X	X	

Gonzalez, Brittney*	Community Benefits Specialist	Baystate Health	X	X	
Gorton, George*	Director of Research, Planning & Business Development	Shriners Hospital for Children - Springfield	X	X	
Harris, Aumani	Project Manager	Springfield Department of Health & Human Services	X	X	X
Harness, Jeff*	Director, Community Health and Government Relations	Cooley Dickinson Health Care	X	X	
Kaufmann, Sally*	Director, Post Acute Business Integration and Development	Baystate Health	X	X	
Knapik, Michael*	Vice President, Government and Community Relations	Baystate Health	X	X	
Lake, Eliza	Chief Executive Officer	Hilltown Community Health Center	X	X	
Lamas, Kelly	Project Coordinator	Baystate Springfield Educational Partnership	X	X	
Landrau, Madeline	Senior Relationship Manager	Mass Mutual	X		
Lee, Jennifer	Systems Advocate	Stavros Center for Independent Living	X	X	
Lopez, Luz	Executive Director	Metrocare of Springfield	X	X	
Patrissi, JAC	Director of Domestic Violence & PATCH Services	Behavioral Health Network, Inc.	X	X	
Perez-McAdoo, Sarah	Board of Health Member	East Longmeadow Board of Health	X	X	X

Pluguez-Moldavskiy, Melissa	President	National Association of Hispanic Nurses of Western MA	X	X	
Puleo, Elaine	Community Member	Town of Shutesbury Baystate Franklin Medical Center Community Action Council	X		
Reed-McNally, Maureen	Director	Mass Mutual	X		
Robinson, Frank*	Vice President, Public Health	Baystate Health	X	X	
Rosenthal, Sarah*	Administrative Coordinator	Shriners Hospital for Children - Springfield	X	X	
Silverman, Risa	Outreach Director	Western MA Health Equity Network, University of Massachusetts - Amherst School of Public Health & Health Sciences	X	X	
Stevens, David P.	Executive Director	Massachusetts Councils on Aging	X	X	
Walker, Phoebe	Director of Community Services	Franklin Regional Council of Governments	X	X	
Wilson, Gloria M.	ACO Care Manager MSC, RN	Western MA Black Nurses Association	X	X	

\*Coalition of Western Massachusetts Hospitals/Insurer member

## Focus Group Participants

Findings from four focus groups conducted in Hampshire County and ten focus groups from other Western Massachusetts counties informed this CHNA. In total, 14 focus groups were conducted for the full Coalition CHNA effort, and unique perspectives that were appropriate to this CHNA from different geographic areas informed this CHNA. Each focus group had a specific topic, and participants represented a range of age, gender, and race/ethnicity. Focus groups included:

### Hampden County

#### ***Shriners Hospitals for Children – Springfield: Parents of Children with Neuromuscular Diseases***

- 11 participants
- 10 women and 1 man
- All participants were parents of children ages 5-18
- Two participants required Spanish translation, provided by a fellow participant

#### ***Mercy Medical Center: Cancer Support Group Participants***

- 10 participants
- 5 women and 5 men
- 6 people were between the ages of 51-70; 1 person was under 50, 1 person was between 71-80, and two people were over 80
- All 10 people identified as White

#### ***Baystate Noble Hospital: Service Providers and Family Members of People with Substance Use Disorder***

- 8 participants
- 5 women and 3 men
- 6 were over age 40; 2 were between 20-40
- 6 people were White and 2 were Latino

### Hampshire County

#### ***Cooley Dickinson Hospital: Community forum with Older Adults - Northampton***

- 47 participants
- Mostly women
- All participants were older adults, mostly age 60+
- Roughly 90% White, 10% People of Color

#### ***Cooley Dickinson Hospital: Community Forum with Older Adults - Amherst***

- 40 participants
- Mostly women
- All participants were older adults, mostly age 60+
- Roughly 90% White, 10% People of Color

## Franklin County

### ***Baystate Franklin Medical Center: People Experiencing Homelessness***

- 9 participants
- 4 women and 5 men
- 3 age 31-40; 4 age 41-50; 1 age 51-60
- 7 White, 1 Black Latina, 1 American Indian

### ***Baystate Franklin Medical Center: People Who Use a Rural Food Pantry***

- 13 participants
- 10 women and 3 men
- 1 age 22-30; 1 age 31-40; 2 age 41-50; 5 age 51-60; 3 age 61-70; 1 age 71-80
- 10 White; 2 American Indian; 1 Bi-Racial (White/American Indian)

### ***Baystate Franklin Medical Center: Youth of Color***

- 11 participants
- 5 women, 4 men, 2 no gender selected
- 10 under 18 years; 1 age 18-21
- 5 Latinx; 2 Black; 2 Asian; 2 Bi-Racial (Black/American Indian and Asian/Other)

### ***Baystate Franklin Medical Center: People who are Transgender, Non-Binary, and/or Gender Non-Conforming***

- 5 participants
- People identified as unmanifested genderless/manifested female, transgender (1); female, male, & nonbinary, prefer not to say whether transgender (1); male, transgender (1); nonbinary transgender (2)
- 4 age 22-30; 1 51-60
- 4 White, 1 Semitic

## Hampden, Hampshire, Franklin, Berkshire, and Worcester Counties

### ***Health New England: Adults Living with Disabilities***

- 7 participants who were patients or clients of Caring Health Center
- 4 women, 3 men
- All People of Color
- All spoke English

## Key Informant Interviewees

Findings from interviews with individuals conducted in Hampshire County and from other Western Massachusetts counties informed this CHNA. Interviewees from Hampshire County were the primary data sources; however, unique perspectives that were appropriate to this CHNA from different geographic areas also informed this CHNA. Key informants were health care providers, health care administrators, local and regional public health officials, local leaders that represent the interests of the community or serve people who are medically underserved, have low incomes, or are people of color. Key informants were:

Name (Last, First)	Title	Organization	Organization Serves Broad Interests of Community	Organization Serves Low- Income, Minority, & Medically Underserved Populations	State, Local, Tribal, Regional, or Other Health Department Staff
<b><i>Shriners Hospitals for Children - Springfield</i></b>					
Adamopolous, Ava	Program Director	Boys and Girls Club of Springfield	X	X	
Bakowski, Lisa	Principal	Edward P. Boland School, Springfield	X	X	
Kaplan, Lawrence	Developmental Pediatrician	Shriners Hospitals for Children – Springfield		X	
Phillips, Kelly	Founder and Director	KP Fit		X	
<b><i>Mercy Medical Center</i></b>					
LeBlanc, Ashley	Nurse Navigator	Thoracic Surgery – Mercy Hospital Cancer Center		X	
Nash, Shirin	Pathologist and Cancer Committee Outreach Coordinator	Mercy Medical Center's Cancer Center		X	
Velis, Stephanie	Oncology Program Coordinator	Mercy Medical Center's Cancer Center		X	

<b>Cooley Dickinson Hospital</b>					
Nurse care managers, social workers, project specialist, director of clinical operations	7 Integrated Care Management Program Staff	Cooley Dickinson Physician Hospital Organization	X	X	
Tartakov, Carlie	Community member, retired university professor				
<b>Baystate Franklin Medical Center</b>					
Calabrese, Jessica	Chief Operating Officer	Community Health Center of Franklin County	X	X	
Carey, Cameron	Development Director	Community Health Center of Franklin County	X	X	
Ewart, Jared	Accountant	Community Health Center of Franklin County	X	X	
Hamilton, Wes	Chief Information Officer	Community Health Center of Franklin County	X	X	
Heidenreich, Maria	Medical Director	Community Health Center of Franklin County	X	X	
Hoynoski, Arley	Chief Financial Officer	Community Health Center of Franklin County	X	X	
Jacobson, Allie	Information Officer	Community Health Center of Franklin County	X	X	
Luippold, Susan	Human Resources	Community Health Center of Franklin County	X	X	
Petrie, Maegan	Accountant	Community Health Center of Franklin County	X	X	
Sayer, Ed	Chief Executive Officer	Community Health Center of Franklin County	X	X	
Van der Velden, Allison	Dental Director	Community Health Center of Franklin County	X	X	
Welenc, Susan	Population Health	Community Health Center of	X	X	



		Franklin County			
<b>Public Health Personnel</b>					
Caulton-Harris, Helen	Commissioner of Public Health	City of Springfield, Public Health Department			X
Cluff, Ben	Veterans' Services Coordinator	MA Department of Public Health, Bureau of Substance Use Services			X
Federman, Julie	Health Director	Town of Amherst			X
Hyry-Dermith, Dalila	Supervisor	MA Department of Public Health, Division for Perinatal, Early Childhood and Special Needs, Care Coordination Unit			X
Walker, Phoebe	Director of Community Services	Franklin Regional Council of Governments			X

## Community Chats

Regional Advisory Committee (RAC) members and Baystate Health Community Benefits Advisory Committee members identified existing community or provider meetings to bring information about the CHNA and gather priorities. Findings informed prioritization of CHNA health needs.

Organization (12)	Population	Location	# of Participants (total: 89)
<b>Hampshire County (10)</b> <b>N = 77</b>			
Community Benefits Advisory Council Baystate Wing	Community Leaders	Ware	15
Hampshire Regional YMCA	Non-Profit Staff	Northampton	7
Ware Senior Center	Older Adult Community Member	Ware	8
Common Goals –E2E	Non-Profit Staff	Ware	9
Hillside/Highland Community Center	Community Members	Ware	6
Healing Alliance Support Group	Community Members	Ware	5
Treehouse Community	Non-Profit Staff	Easthampton	6
Treehouse Community - Youth	Youth Community Members	Easthampton	8
UMass Public Health Graduate Students	UMass Graduate Students	Amherst	5

It Takes a Village	Community Members	Cummington	8
<b>Franklin County (2)</b> <b>N = 12</b>			
Baystate Franklin Medical Center Social Workers	Social Workers	Greenfield	9
Baystate Franklin Medical Center Emergency Department	Emergency Department Staff	Greenfield	3

## Appendix II. Glossary of Terms

- **Built Environment** – Man-made structures, features, and facilities viewed collectively as an environment in which people live, work, pray, and play. The built environment includes not only the structures but the planning process wherein decisions are made.
- **Community** – Can be defined in many ways, but for the purposes of the CHNA we are defining it as anyone outside of the Western MA Coalition of Hospitals/Insurer, which could be community organizations, community representatives, local businesses, public health departments, community health centers, and other community representatives.
- **Community Benefits (hospitals)** – Services, initiatives, and activities provided by nonprofit hospitals that address the cause and impact of health-related needs and work to improve health in the communities they serve.
  - **Community Health Needs Assessment (CHNA) and Implementation Plan** – An assessment of the needs in a defined community. A CHNA and a hospital implementation plan are required by the Internal Revenue Service in order for nonprofit hospitals/insurers to maintain their nonprofit status. The implementation plan uses the results of the CHNA to prioritize investments and services of the hospital or insurer's community benefits strategy.
- **Community Health Improvement Plan (CHIP)** – Long-term, systematic county-wide plans to improve population health. Hospitals likely participate, but the CHIPs are not defined by hospital service areas and typically engage a broad network of stakeholders. CHIPs prioritize strategies to improve health and collaborate with organizations and individuals in counties to move strategies forward.
- **Cultural humility** – An approach to engagement across differences that acknowledges systems of oppression and embodies the following key practices: (1) a lifelong commitment to self-evaluation and self-critique, (2) a desire to fix power imbalances where none ought to exist, and (3) aspiring to develop partnerships with people and groups who advocate for others on a systemic level.
- **Data Collection**
  - **Quantitative data** – Information about quantities; information that can be measured and written down with numbers (e.g., height, rates of physical activity, number of people incarcerated). You can apply arithmetic or statistical manipulation to the numbers.
  - **Qualitative data** – Information about qualities; information that cannot usually be measured (e.g., softness of your skin, perception of safety); examples include themed focus groups and key informant interview data.
  - **Primary data** – Collected by the researcher her/himself for a specific purpose (e.g., surveys, focus groups, interviews that are completed for the CHNA).
  - **Secondary data** – Data that has been collected by someone else for one purpose, but is being used by the researcher for another purpose (e.g. rates of disease compiled by the MA Dept. of Public Health).
- **Determination of Need (DoN) application** – Proposals by hospitals for substantial capital expenditures, changes in services, changes in licensure and transfer of ownership by hospitals must be reviewed and approved by the Massachusetts Dept. of Public Health. The goal of the DoN process is to promote population health and increased public health value by guiding hospitals to focus on the social determinants of health with a proportion of funds allocated for the proposed changes.

- **Ethnicity** – Shared cultural practices, perspectives, and distinctions that set apart one group of people from another; a shared cultural heritage.
- **Food insecure** – Lacking reliable access to sufficient quantity of affordable, nutritious food.
- **Health** – A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO).
- **Health equity** – The highest standards of health should be within reach of all, without distinction of race, religion, political belief, economic or social condition (WHO)
  - Health equity is concerned with creating better opportunities for health and gives special attention to the needs of those at the greatest risk for poor health
  - Health equity is when everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstance.
- **Housing insecurity** – The lack of security about housing that is the result of high housing costs relative to income, poor housing quality, unstable neighborhoods, overcrowding, and/or homelessness. A common measure of housing insecurity is paying more than 30% of income toward rent or mortgage.
- **LBGTQ+** – Lesbian, bisexual, gay, transgender, queer or questioning, and all other people who identify within this community.
  - **Transgender** – Refers to anyone whose gender identity does not align with their assigned sex and gender at birth.
  - **Non-Binary** – People whose gender is not male or female.
  - **Gender-Nonconforming** – A person who has, or is perceived to have, gender characteristics that do not conform to traditional or societal expectations.
- **Race** – Groups of people who have differences and similarities in biological traits deemed by society to be socially significant, meaning that people treat other people differently because of them, e.g., differences in eye color have not been treated as socially significant but differences in skin color have. Race is a socially created construct as opposed to true categorization.
  - **Black** – We use the term “Black” instead of African American in this report in reference to the many cultures with darker skin, noting that not all people who identify as Black descend from Africa.
  - **Latino/a** – We use the term “Latino” or “Latina” in this report in reference to the many cultures who identify as Latin or Spanish-speaking. We chose to use Latino/a instead of Hispanic or Latinx, noting that there is a current discussion on how people identify. Latinx is a gender-neutral term, a non-binary alternative to Latino/a.
- **Social determinants of health** – The social, economic, and physical conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power, and resources at global, national and local levels. (WHO)
- **Social justice** – Justice in terms of the distribution of wealth, opportunities, and privileges within a society.

## Appendix III. Focus Group Summaries

### Coalition of Western Massachusetts Hospitals 2019 Community Health Needs Assessment

#### Focus Group Report: Substance Use

**Primary Hospital/Insurer:** Baystate Noble

**Topic of Focus Group:** Substance use

**Date of Focus Group:** 3/11/2019

**Facilitator:** Gail Gramarossa

**Note Taker:** Karen Auerbach

#### **Executive Summary**

##### A. Participant Demographics:

- Middle-aged adults with substance use issues, or with adult children with substance use issues
- Eight people
- Five women, three men
- Six people were White, two were Hispanic/Latino
- Six people seemed to be over age 45, and two seemed to be in their early 30's
- One man who was Latino and in his early 30's did not talk at all

##### B. Areas of Consensus:

- People who are receiving treatment for substance use disorders need housing for treatment to be effective, but it is often very difficult for them to get affordable housing.
- Not having adequate transportation from a treatment/recovery center to home or work can be a big barrier to receiving effective treatment.
- There aren't enough beds in hospitals and inpatient substance use treatment centers. Even if someone does get a bed, the length of stay is very short.
- There is stigma around receiving addiction support, so typically people who live in Westfield go outside Westfield for addiction treatment and recovery, and people who live outside Westfield go to Westfield for these services.
- There is typically little to no follow-up for people who are discharged from medically assisted treatment programs.
- Grandparents who are raising grandchildren because their children are addicts need more support.

##### C. Key Recommendations:

- There should be more recovery options, like sober houses and recovery coaches, in Westfield.
- Addiction treatment and recovery programs should include mental health services and support because most people who are addicted to drugs also have mental health issues, which if untreated can lead to relapse.

- There need to be therapists in Westfield who are trained in addiction. There aren't any currently.

D. Quotes:

- "You can't do treatment without a place to live. Can't do it if you're living on the street."
- "Some people might be stable in transitional housing their whole lives, some may be able to move on to independent living. Everyone's unique, their bodies are different, need different types of treatment and housing."

## Key Issues

Question	Synthesis of Responses
1. What are the most serious barriers or service gaps that consumers face in accessing mental health and substance use care?	<ul style="list-style-type: none"> <li>• There are very few beds in hospitals and other inpatient substance use treatment centers that are available when they are needed (without a long wait time) for people without private insurance. Even if someone does get a bed, the length of stay is very short.</li> <li>• There aren't enough options in Westfield for post-inpatient treatment and recovery. There are options in Holyoke and Springfield, but these places may be too far away from Westfield (especially if people don't have adequate access to transportation) to be realistic options. As a result, it can be difficult for parents who live in Westfield to support their children's recovery in Holyoke or Springfield.</li> <li>• People who need or are receiving treatment for a substance use disorder need a place to live for treatment to be effective, but it's often very difficult for people in treatment to find and get affordable housing, especially people with CORI issues. Background checks and credit checks that are done when people apply for housing can be a barrier.</li> <li>• Inadequate transportation to or from treatment and recovery locations to home, family, or work can also be a big barrier to recovery.</li> <li>• Judges may not understand the substance use treatment and recovery process. People who are convicted of drug offenses and are in drug treatment don't get access to methadone or suboxone when in pretrial. If they go to jail or the street, they also won't get access to this treatment.</li> <li>• Judges and others may not understand what drug addiction is. One judge said an addicted person can't be addicted if he's working full time and has a car and place to live. Another didn't believe someone's son who was a great athlete with an injury could be addicted to heroin. Some believe that if a drug is a prescription drug, there can't be addiction.</li> </ul>

	<ul style="list-style-type: none"> <li>• Probation should be integrated with the legal system and hospitals, but it is not. Recovering addicts on probation are made to jump through hoops, like call in every day or go to court by 4 pm even if they have no transportation. There should be a separate probation for drug issues - currently they're all for crime.</li> <li>• Most addicts have mental health issues as well, but typically addiction treatment and recovery programs only address addiction issues. As a result, recovery may not last very long.</li> <li>• Most clinics help with addiction and provide counseling and women's support groups, but they don't provide the other services and support that people in recovery need to become financially self sufficient, be better parents, and so on.</li> <li>• There are no therapists in Westfield who are trained in treating addiction. Patients are usually just treated by interns at the hospital who are in training. But these interns typically leave for other, better paying jobs when they're done with their internships.</li> <li>• The whole system needs a group of people who know what's going on and understand the system who can help people seeking or receiving treatment to navigate it and coordinate all the different parts.</li> </ul>
2. Are there specific vulnerable populations that you are most concerned about in relation to addiction and substance use? Who are they and why?	<ul style="list-style-type: none"> <li>• It's hard to help high schoolers deal with anxiety and depression with meds effectively, so they often turn to drugs.</li> <li>• Some high schoolers with learning disabilities can have lots of trouble with anxiety, and take drugs to help with the anxiety.</li> </ul>
3. What about mental health care and substance use/addiction care for people who have young children? What are the major needs and issues for those age groups?	<ul style="list-style-type: none"> <li>• Getting affordable housing can be very difficult for mothers in recovery whose children were taken away from them. They often cannot get their children back without having housing, but may need to have their children living with them to obtain affordable housing.</li> <li>• Often grandparents are raising their grandchildren because their children are addicted to drugs or are in treatment and recovery. There is not enough support for these grandparents to raise their grandchildren and deal with their children's addiction and recovery.</li> <li>• Some addiction recovery support groups don't allow children to be present or don't provide child care, so some parents can't attend these support groups.</li> <li>• Because most state services can only be accessed in Springfield (like applying for MassHealth), it can be very hard for</li> </ul>



	grandparents to access these services for their grandchildren.
4. Are there enough providers who can prescribe Medication Assisted Treatment (MAT) such as suboxone? Is there a methadone clinic in Westfield? If not, should there be?	<ul style="list-style-type: none"> <li>• There are two providers for medically-assisted recovery in Westfield– 1 doctor who can prescribe suboxone and one methadone recovery center.</li> <li>• There is a lot of stigma around receiving this treatment, so people who live in Westfield tend to get MAT outside of Westfield (like Riverbend and Clean Slate), and people who get MAT in Westfield tend to live elsewhere. There is community pushback and stigma against having more services available in Westfield.</li> <li>• The protocol for MAT is often not effective, especially when therapy is not provided at the same time, which can lead patients to relapse.</li> <li>• When most people are discharged from an MAT program at a hospital or clinic, they are itching to get out and don't use other services available to continue their recovery, and often relapse. There is typically no follow-up 24-48 hours after discharge.</li> <li>• One place had a grant for two years to follow-up with people who were discharged. After they lost grant funding, follow-up was just a phone call. People were just cut off after discharge.</li> <li>• Sometimes the police were sent to find people after they were discharged from Noble hospital, but there wasn't enough money and training to support police to keep doing that.</li> </ul>
5. What about long-term substance use and recovery care needs? What are the needs for such services?	Recovery coaches can help people recover from having a substance use disorder, but there are very few recovery coaches in Massachusetts. Gándara, the Behavioral Health Network, and Caring Center provide recovery coach training. People with lived experiences, who have overcome their mental health or addiction issues, can be effective coaches and help addicts throughout their recovery process. They can help with the spiritual and emotional aspects of recovery and can be there every step of the way for a recovering addict. But there isn't much training for them, they're not paid very much, and may not get paid if they don't meet some requirements (like meeting with a client 5 times or more in a month).
6. In relation to opioid use, what are the most pressing issues and needs around prevention, intervention and access to care? How about	<ul style="list-style-type: none"> <li>• The Westfield task force can't do a Narcan training. Only the police can, so they have done a couple trainings. But this isn't enough.</li> <li>• The police force is having some issues with getting Narcan –</li> </ul>

overdose issues such as prevention and who carries Narcan?	sometimes it's because of unions, and sometimes police officers don't want to carry Narcan. Sometimes officers get ill from fentanyl and need treatment.
7. What is happening in this area related to substance use prevention? Should there be more prevention efforts and what would that look like?	<ul style="list-style-type: none"> <li>• There is proper education for HIV and free condoms are available everywhere. But there isn't very much around drug use. One program is just starting in Westfield for 6<sup>th</sup>, 8<sup>th</sup>, and 10<sup>th</sup> graders, which will integrate drug addiction education.</li> </ul>
8. How do substance use disorders and addiction impact overall community health and stability?	<ul style="list-style-type: none"> <li>• The police force often have to diagnose and place people with addiction issues, but they're not trained and equipped to handle things like this.</li> <li>• The Westfield community seems economically and socially divided by neighborhoods. People think drug problems exist in other neighborhoods, but not theirs.</li> <li>• There is a huge impact of young adults dying from overdoses on other young adults and their families, and the community in general. Grief is often not recognized or dealt with. "It's like a lost generation." There is sadness and weariness in the community as a result. There is an impact on businesses, faith leaders, and family-owned funeral homes as well.</li> </ul>

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Transgender, Non-Binary, and Gender Nonconforming (GNC) People**

**Primary Hospital/Insurer:** Baystate Franklin Medical Center

**Topic of Focus Group:** Transgender, non-binary, and gender nonconforming (GNC) people

**Date of Focus Group:** 2/19/2019

**Facilitator:** Kat Allen

**Note Taker:** Jeanette Voas

**Executive Summary**

**A. Participant Demographics:**

- Five participants
- Four participants were between the ages of 22 and 30. One was between the ages of 51 and 60
- Four were White, one was Semitic
- One Unmanifested genderless, manifested female, transgender; one Female, male, & nonbinary, prefer not to say whether transgender; one Male, transgender; two Nonbinary transgender

**B. Areas of Consensus:**

- “Transgender, non-binary, and gender nonconforming” works as an acceptable set of labels. There are many other culturally specific identities like “two-spirit.” [In this report “trans” – the word the participants used most often – is used as short hand to cover a range of identities.]
- The health care system needs to be more trans-friendly and trans-knowledgeable at all levels. There are a few good PCPs that trans/GNC people go to, but not enough, and sometimes other providers use the fact that someone else is trans-friendly as an excuse to *not* need to become more informed. And most specialists do not have the needed sensitivity and knowledge.
- There are not enough behavioral health care providers who are transgender (the ideal situation) or trans-friendly and trans-competent.
- Medical providers should be expected to meet a higher bar for trans-competence than the general public does. Patients should not need to be in the position of educating their medical providers.
- The administrative level of health care does not feel trans-friendly, e.g. forms and protocol disregarding information provided about preferred names, asking patients to fill out forms with inscrutable questions about transgender status.
- The lack of coordination among agencies can make it difficult to find trans-friendly care and services.
- There’s a general lack of sensitivity in the community, which can be socially isolating, especially for transgender people who don’t “pass.”

- All of the participants agreed that they felt uncomfortable or afraid going to any of the gyms in town.
- C. Areas of Disagreement:
- D. Recommendations:
  - Recruit trans-friendly and trans-knowledgeable providers (including and especially behavioral health specialists), and providers who are themselves transgender. Involve trans people in the hiring/interviewing process.
  - Train everyone in the hospital or medical practice in trans issues to build competence throughout the organization.
  - Provide training to community organizations to make them trans-friendly and motivate them to involve transgender people. Gyms are a good place to start.
  - Create a single LGBTQIA+ hub that people know about and can go to for information about providers, resources, events, etc. (Cooley Dickinson just hired someone for a similar role.)
- E. Quotes:
  - "I need Baystate to understand that people are falling through the cracks. We're *not* healthy, we're *not* doing great, we're suicidal, struggling to maintain employment and paying all the bills, so it's so difficult to do self-care. There's a lot of personal responsibility on me taking care of myself, but also I need those resources to be there and available and accessible, and to be treated like a human being."
  - "I have never been in a gym where I have not felt terrified 100% of the time I was there. I just want to exercise!"
  - "I can't go to the gym and do the things I want to do, be with people in that setting, and maybe develop a friendship. I can't have that because I don't think they're ready for it. And specifically in my case, it's because I do not pass."
  - "Not passing is a huge barrier to everything."
  - "When I feel like I am expressing myself in a way that's true to myself, most people in society don't know how to read that or be with it."
  - "There's this idea that you're moving from one side of the binary to the other, you're in transition, and you're always trying to get somewhere. I'm non-binary but that doesn't mean I'm trying to find a means to an end. I hope that health care can get used to the idea of people just being people and identifying as themselves without having to reach some gender identity. This idea that people have to look at you and have to diagnose you as something is really frustrating."
  - "Even the hormones they put trans people on were usually designed for cis people. So much of what happens with trans people, there's no research, there's no knowledge."
  - "Before coming here I went to Fenway Health in Boston, which is specifically for LGBTQIA+ community. Here I feel like providers lack interest in becoming well-read and accepting and caring. It feels like they're doing it because they're being mandated to, or because people are reacting against the things that they're not doing."

- "I swear medical school steals people's souls. Every time I deal with a medical assistant or nurse practitioner, they're so great...doctors terrify me."
- "I seek out only trans-friendly physicians. I go to people I trust."
- "If they're taking new patients."
- "There's no network. Coming here and finding a therapist who's trans-friendly... In Boston, there's a network you can go to and there's actual information about the providers and what their experiences are with trans people. Here I have no idea."
- "Resources are so fragmented. I've seen at least 3 separately compiled documents made by different groups that list all the trans-friendly providers in the area, with 90% overlap, but people at three different organizations had to painstakingly put these together separately and then give them to like the five people they interact with."
- "In this area, people think, 'everyone's queer,' so we don't need queer-specific resources, we don't need a LGBT center like Fenway."
- "Some weeks what I do to stay healthy is I eat well and I exercise and some weeks what I do to stay healthy is I eat McDonalds and I sleep for 15 hours and I try again the next week. I don't want a health care system that's going to shame me because I have to do that sometimes."

## Key Issues

Question	Synthesis of Responses
1. Obstacles to being healthy	<p>Lack of awareness, sensitivity, and competence around trans issues in the health care system</p> <ul style="list-style-type: none"> <li>• Providers need to be better educated about trans issues. Otherwise the burden falls on the patients to teach the providers.</li> <li>• Ideally, there would be good providers who are themselves transgender. Second choice: loving, caring providers who have the knowledge and understanding.</li> <li>• There are not enough mental health providers who are transgender themselves or trans-friendly and trans-competent. And mental health support is a big need for trans people.</li> <li>• It's difficult to seek behavioral health. Five years ago I knew I'd be approached a certain way, asked to do certain tests. Now I get a lot of apologies. It's just too much.</li> <li>• Some providers lack sensitivity, and others will say, "I treat transgender people like everyone else." But there are extra issues with being transgender. The providers need to be knowledgeable about that.</li> <li>• There are a few providers who are known to be trans-friendly, and everyone goes to them. Because those few providers are out there, other providers, especially specialists, seem to feel they don't need to become trans-knowledgeable themselves.</li> <li>• I have health issues that have nothing to do with being trans,</li> </ul>

	<p>but when I go to a specialist, all they want to know is whether I'm on testosterone.</p> <ul style="list-style-type: none"> <li>• The administrative level needs training as well. They're the first line. They don't use your preferred name and they give you forms with questions that are not helpful and hard to answer.</li> </ul> <p>Lack of sensitivity in the community, no welcome feeling</p> <ul style="list-style-type: none"> <li>• The gyms in town do not feel welcoming. Fear that someone will freak out in the locker room and call 911. Gyms aren't ready for us. "I have never been in a gym when I have not felt terrified."</li> </ul> <p>Social isolation if you don't fit in</p> <ul style="list-style-type: none"> <li>• If you don't pass, you're a provoker. Not passing is a huge barrier to everything. There are lots of nonpassing transgender women who don't leave the house.</li> <li>• People don't see us as we are.</li> </ul> <p>Capitalism</p> <ul style="list-style-type: none"> <li>• We live in a system that funnels power and wealth to people who don't tend to be transgender or care about transgender people.</li> </ul>
<p>2. Health challenges unique to transgender people &amp; how well are they being addressed</p>	<ul style="list-style-type: none"> <li>• Not enough research on health issues for transgender people. <ul style="list-style-type: none"> <li>○ What are long-term effects of hormones?</li> <li>○ What about interaction of hormones and other medications?</li> <li>○ How best to deal with other health issues that are different for transgender people?</li> <li>○ It's like we're being experimented on.</li> </ul> </li> <li>• There are not many providers who are themselves transgender. Getting into those fields can be hostile to transgender people.</li> <li>• A lot of trans-specific health care happens to people before they're 18, when they can't speak or decide for themselves. <ul style="list-style-type: none"> <li>○ One participant reported medical abuse as a child, including having medications and treatments that weren't explained to them, perhaps because of their gender nonconformity.</li> </ul> </li> <li>• I worry that if you have a history in the mental health system, as many transgender people have, that can affect how you're treated in the medical system. You say something's going on and they say, "It's just in your head."</li> <li>• Trans people don't all want the same things, the same combination of hormones &amp; surgery. <ul style="list-style-type: none"> <li>○ One participant said: Insurance has had restrictive rules, e.g. you can't get top surgery unless you're on hormones</li> <li>○ Another said: rules have changed in MA, so that's no</li> </ul> </li> </ul>

	<p>longer the case</p> <ul style="list-style-type: none"> <li>○ Another said: providers need to be able to educate patients about things like that</li> <li>• At times, there have been shortages of HRT meds and I have been unable to get them at the pharmacy. It's awful.</li> </ul>
3. Where do you get medical care & do you get the care you need?	<ul style="list-style-type: none"> <li>• CHC, Baystate, VMG, CSO, alternative providers</li> <li>• Mix of satisfaction with providers: I'm comfortable, I'm ready to move, I don't talk with my doc about anything</li> <li>• Dental is awesome at CHC!</li> <li>• Bad experiences: <ul style="list-style-type: none"> <li>○ Hole in the system: I hit my head at work, I have symptoms that prevent me from working, but I don't have a diagnosis and without a diagnosis, I can't get disability or any kind of assistance.</li> <li>○ In CT, when I was suicidal I was admitted to hospital into awful conditions, with people freaking out all around and guards. There was no trans support, no recognition. You've got to make accommodations and be trans knowledgeable. I was ready for help and that's how I got treated.</li> <li>○ I've been in Baystate psych ward. They're not trans knowledgeable. And the reason why is that they send trans people up to Brattleboro Retreat, but that unit is poorly resourced, as compared to other units.</li> </ul> </li> </ul>
4. Local resources that have helped you be healthier	<ul style="list-style-type: none"> <li>• Recovery Learning Center, for community and mental health support</li> </ul>
5. What else/what other services would be helpful?	<ul style="list-style-type: none"> <li>• A central go-to place for trans people to find out where to get trans-friendly services. An LGBTQI+ resource center. A hub that people know about, one entry point. <ul style="list-style-type: none"> <li>○ There's word of mouth, and everyone says to go to the same provider and that provider is booked solid</li> <li>○ For someone new in town, it's hard to navigate</li> </ul> </li> <li>• When people go into crisis here, they often get sent to respite. But respite sucks for trans people. Their policies make no sense, so they usually don't accept trans people. Trans people who could be in a less locked-down situation end up getting pushed into the hospital.</li> <li>• Opportunities for improving health &amp; talks about health resources that don't all go back to exercise and eating well. Some of us can't exercise, and the healthy food is the most expensive food.</li> </ul>
6. What do you do to stay healthy?	<ul style="list-style-type: none"> <li>• Exercise, take care of yourself be fit &amp; active, mentally healthy and happy</li> <li>• Dance, as often as possible</li> </ul>

	<ul style="list-style-type: none"> <li>• I need Baystate to understand that people are falling through the cracks</li> <li>• Marijuana has been helpful. Looking for increased accessibility and lower price.</li> </ul>
7. Recommendations from one participant who wrote up her thoughts for us	<ul style="list-style-type: none"> <li>• Remove gender-specific signage</li> <li>• Stockpile and make available HRT meds when supplies become low</li> <li>• Set a gift fund for transgender surgical procedures for those who cannot afford them</li> <li>• Hire health care providers - especially mental health providers -who are themselves trans or GNC</li> <li>• Recruit medical professionals with specific training with trans people</li> <li>• Conduct mandatory training of all health care employees for trans-friendly environment</li> <li>• Involve trans people in provider hiring &amp; interviewing process</li> <li>• Get involved in retraining influential people and the community at large to create a more inclusive environment</li> </ul>



**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Youth of Color**

**Primary Hospital/Insurer:** Baystate Franklin Medical Center

**Topic of Focus Group:** Youth of Color

**Date of Focus Group:** 2/19/2019

**Facilitator:** Kat Allen

**Note Taker:** Jeanette Voas

**Executive Summary**

- A. Participant Demographics: Eight participants
  - Five women, three men
  - Six people seemed to be over age 45, and two seemed to be in their early 30's
  - Six people were white, two were Latino
- B. Areas of Consensus:
  - Life is stressful, with multiple demands of school, homework, chores at home, and for many, work
  - School can be a stressful environment, with social expectations, cliques, unnecessary drama, and a school environment that doesn't help young people deal with the emotions and the stress
  - The students said they see a lot of anxiety, eating disorders, and depression among their peers
  - They report instances of being stereotyped by their peers, being treated unfairly at school because of race, or being less likely to be hired because of race
  - Young people need a place to hang out that's not school
- C. Key Recommendations:
  - Support social emotional learning in schools
  - Work to destigmatize mental health issues
  - Provide lots of support for students transferring into a school
  - Train students and staff in diversity/cultural humility
  - Continue support for programs like CAYP Shout Out group
  - Consistently and fairly apply school discipline policies and school dress code across gender, race, ethnicity, class, and appearance
  - Incidents of teachers and school staff not respecting students' physical space (i.e. dress code violations) are not uncommon and should be avoided
  - Community activities and resources such as "lightskating" and a skate park and greater access to the YMCA would provide healthy ways for youth to feel more connected and engaged
- D. Quotes:

- "School's supposed to be a learning environment, but it stresses you out. There's not enough time to socialize, time to learn social skills."
- "There aren't enough hours in the day to get everything done in a way that's acceptable to your peers and your parents."
- "When I get angry, I don't show my emotions for nothing. People can use it against you. I feel bottled up by too much emotion. Sometimes I don't pay attention because I'm so stressed, it slows me down."
- "It's not good for your body to be so stressed out. You get panic attacks, anxiety. We see lots of it. I know so many people at school who have eating disorders or anxiety."
- "If you transfer in to our school, it's not easy to integrate in. Everyone stays with their own friend group."
- "Teachers care about the work, not the student – well, not every teacher. I can stay after to talk about school work, but I can't stay after to talk with a teacher about emotional problems."
- "In school they don't teach you how to deal with emotional stress. You can end up being depressed about it."
- "There's a lot of stigma against mental health. I know a girl who's depressed and her friends told her, 'I don't get it, just be happy.' She's afraid to go to therapy because people don't understand."

## Key Issues

Question	Synthesis of Responses
1. Things that get in the way of being healthy	<ul style="list-style-type: none"> <li>• Financial issues               <ul style="list-style-type: none"> <li>○ Expense of health insurance and health care</li> <li>○ Some people don't have enough money to go to the doctor and doctors shame and threaten parents that they should take better care of their kids.</li> <li>○ It's too expensive to go to the Y or to have exercise equipment</li> </ul> </li> <li>• Family has moved a lot, and that makes it hard to be healthy. You have to adjust to everything, to new schools.</li> <li>• No rides; it takes a long time to get places</li> <li>• Lack of a healthy social environment in school               <ul style="list-style-type: none"> <li>○ It's hard to transfer into a new school and fit in</li> <li>○ Peer pressure to spend money and have certain clothes, shoes, technology. It makes people stressed out.</li> </ul> </li> <li>• Stressors               <ul style="list-style-type: none"> <li>○ People compare their body types to others. I know a lot of people with eating disorders.</li> <li>○ School + work + homework + chores + sports is exhausting. It's hard to stay awake during the day.</li> <li>○ We see lots of anxiety, panic attacks, depression</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• JUULing, including in school</li> <li>• Some parents are against vaccination; kids can't decide on their own to get vaccinated</li> </ul>
2. Health issues unique to young people of color?	<ul style="list-style-type: none"> <li>• It's harder to get hired.</li> <li>• There are social expectations – people expect you to be something you're not, and that adds to stress.</li> <li>• Because of Asian stereotype, everyone wants to be in a group with me and make me do all the work.</li> <li>• People get labeled for how they look or act.</li> <li>• People get called messed up names.</li> <li>• There's drama that's unnecessary and so common.</li> <li>• There's unequal treatment, for example in dress code violations. It doesn't happen to white girls like it does to me.</li> </ul>
3. How well are those challenges addressed	<ul style="list-style-type: none"> <li>• Some teachers care about school work, not about the students.</li> <li>• We complain, for example about school food, and nothing is done about it.</li> <li>• Teachers can be disrespectful, for example, yanking off a hood instead of asking you to take it off.</li> </ul>
4. Discrimination that impacts health	<ul style="list-style-type: none"> <li>• A guy told me I was unattractive because I'm Black. It took a toll on me.</li> <li>• I keep my emotions bottled up.</li> <li>• In school they don't teach you how to deal with emotional stress. You can end up being depressed about it.</li> <li>• There's a stigma against mental health. Someone might not go to therapy because people don't understand.</li> </ul>
5. Local resources that contribute to health	<ul style="list-style-type: none"> <li>• CAYP, Family Center</li> <li>• The Shout Out advisor bought me a planner and helped me plan</li> <li>• Therapy</li> <li>• Friends can be therapists, too</li> <li>• Family members</li> <li>• It's good to have someone you can trust</li> <li>• Being alone</li> </ul>
6. What else is needed	<ul style="list-style-type: none"> <li>• A place for youth to go hang out <ul style="list-style-type: none"> <li>○ Friday night "Lightskating" with lights and DJ was good, but they don't do it anymore</li> <li>○ Skatepark is gone and Turners is so far</li> <li>○ Boredom makes kids do crazy things</li> </ul> </li> <li>• Transportation – Leyden Woods is so far from</li> </ul>

	everything
7. How do you stay healthy	<ul style="list-style-type: none"> <li>• Sports</li> <li>• Spending time alone</li> <li>• Hike to Sachem's Head – it's so peaceful</li> <li>• Dance when I clean</li> <li>• Go to the Y</li> <li>• Have pets</li> </ul>

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: People Living Unsheltered in Greenfield, MA**

**Primary Hospital/Insurer:** Baystate Franklin Medical Center

**Topic of Focus Group:** People living unsheltered in Greenfield, MA

**Date of Focus Group:** 1/23/2019

**Facilitator:** Kat Allen

**Note Taker:** Jeanette Voas

**Executive Summary**

- A. Participant Demographics:
  - Nine participants: four women, five men
  - Seven non-Hispanic white, one Black Latina, one American Indian
  - Three age 31-40; four age 41-50; one age 51-60
- B. Areas of Consensus:
  - Shortage of mental health/substance use care
  - Problems with coordination of care and continuity of care
  - There's a shortage of shelter space and a need for warm places to go during the day
  - Transportation can be a barrier to accessing services; lack of transportation on evenings & weekends
  - Shelter residents have good access to healthy food
- C. Key Recommendations:
  - Identify warm places to be during the day, with volunteer opportunities for shelter residents
  - Weekend bus service is needed
  - More shelter beds are needed
  - Increased access to MAT is needed
- D. Quotes:
  - "There's not enough follow up to mental health and substance use care. When you're discharged from a program, it's hard to get the meds you need."
  - "Trying to get a provider and get prescriptions after you've been discharged from a program is a huge challenge."
  - "There's a stigma about being homeless. They assume we're just trying to get a free ride. I don't have a home, no car. Sometimes you have to rely on people in the community."
  - "There are plenty of meals. Food is not hard to find, if you can get there."
  - "FRTA promises new bus stops, and then cuts back. There's no weekend or evening bus. This town needs weekend bus service."

## Key Issues

Question	Synthesis of Responses
<p>1. Biggest things that make it hard for you to be as healthy as you would like to be</p>	<ul style="list-style-type: none"> <li>• Inadequate mental health care, especially for those with dual diagnoses               <ul style="list-style-type: none"> <li>○ Not enough beds</li> <li>○ Not enough capacity at Greenfield methadone clinic</li> <li>○ Nursing homes don't take people on methadone</li> <li>○ Not enough follow up, continuity of care when you leave a program</li> <li>○ It's taken a long time to get an accurate diagnosis</li> <li>○ DMH beds for respite are taken up by people who don't want to be there and aren't taking advantage of services; and there are others who need higher level of care</li> </ul> </li> <li>• People with substance use disorders and mental health diagnoses are not listened to and face discrimination in medical system               <ul style="list-style-type: none"> <li>○ Long waits for appointments, can't get in to see my own doctor, communication problems with provider organizations</li> </ul> </li> </ul>
<p>2. Services currently available to people experiencing homeless in Franklin County</p>	<ul style="list-style-type: none"> <li>• In Greenfield, excellent resources for a small town</li> <li>• We need more shelters</li> <li>• Here it's a transportation issue               <ul style="list-style-type: none"> <li>○ Sometimes you have to travel a ways for care (e.g. to methadone clinic in Springfield)</li> <li>○ If you're in any kind of treatment you can get a free bus pass</li> <li>○ Greenfield needs weekend and evening bus service</li> </ul> </li> <li>• We have to leave the shelter at 8:00am and there's nowhere to go</li> <li>• Breakfast and lunch at Salvation Army &amp; you can shower there</li> <li>• Plenty of meals offered, if you can get there</li> </ul>
<p>3. Barriers for people experiencing homelessness to accessing these services</p>	<ul style="list-style-type: none"> <li>• Transportation               <ul style="list-style-type: none"> <li>○ No weekend service</li> <li>○ If you don't have a stable address, you don't get PT1 (transportation voucher)</li> </ul> </li> <li>• Have to be sober to access many services</li> </ul>

	<ul style="list-style-type: none"> <li>• Long waits to get into shelters</li> </ul>
4. What else is needed to help people experiencing homelessness be healthier	<ul style="list-style-type: none"> <li>• Warm places to be during the day</li> <li>• Productive things to do during the day <ul style="list-style-type: none"> <li>○ We could volunteer to help out, to make things</li> <li>○ Keep old buildings and let the homeless people who want to better themselves get to work on them</li> </ul> </li> </ul>
5. Source/availability of medical care	<ul style="list-style-type: none"> <li>• Have used many medical resources in town – Baystate, Valley Medical, CHCFC, Health Care for the Homeless (Springfield) – and have moved among them</li> <li>• Have had both positive and negative experiences with medical system</li> <li>• Are able to get preventive care if they choose to</li> <li>• Limited availability of dental care – only a certain number of patients on certain days</li> </ul>
6. Measures to stay as healthy as you can while experiencing homelessness	<ul style="list-style-type: none"> <li>• Eat healthy food <ul style="list-style-type: none"> <li>○ Ready availability of food</li> <li>○ Plenty of fruits and vegetables</li> <li>○ A lot of options at shelter; can cook own food</li> <li>○ Shout out to Stone Soup!</li> </ul> </li> <li>• Rest</li> <li>• Walk</li> <li>• Garlic/herbs/other personal remedies and habits</li> </ul>

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Users of a Rural Food Pantry**

**Primary Hospital/Insurer:** Baystate Franklin Medical Center

**Topic of Focus Group:** Users of a Rural Food Pantry

**Date of Focus Group:** 1/31/2019

**Facilitator:** Kat Allen

**Note Taker:** Jeanette Voas

**Executive Summary**

- A. Participant Demographics: 13 participants
  - Ten women, three men
  - Ten non-Hispanic White; two American Indian; one White/American Indian
  - One age 22-30; one age 31-40; two age 41-50; five age 51-60; three age 61-70; one age 71-80
- B. Areas of Consensus:
  - Transportation is the #1 issue
  - Shortage of good primary care physicians, mental health providers, and participants often have to go to Springfield for specialists
  - Insurance doesn't cover things the participants feel they need, and trying to get referrals or deal with insurance is frustrating
  - Social networks among neighbors are recognized as an asset
  - Pretty good access to healthy food; participants said the Charlemont Federated Church food pantry was the best. HIP at farmers' markets is a plus
- C. Key Recommendations:
  - Satellite or mobile clinics would be very useful for rural residents
  - Telehealth and telemental health services would be very useful
  - Pharmacy delivery services (which used to exist) would be very useful
  - A clothing closet (perhaps mobile, perhaps paired with other mobile services) would be very useful
  - Expand community health nursing programs
- D. Quotes:
  - "Some places you get frowned on because you get food stamps whether you live in the Hilltowns or in the city."
  - "If you get together with your neighbors, you will always have something to eat."
  - "Transportation is the ultimate question. It's a big trip to Greenfield. You ask the neighbors, 'Who's going in today?'"
  - "What is needed? *Anything* mobile."
  - "Because our population is small, our priorities get kicked down the road."



## Key Issues

Question	Synthesis of Responses
1. Biggest things that make it hard for you to be as healthy as you would like to be	<ul style="list-style-type: none"> <li>• Transportation! <ul style="list-style-type: none"> <li>○ Bus comes through 2-3 times a day. Some people can't get down to the bus. If you go into Greenfield you have to wait around to catch a bus back.</li> <li>○ People can get PT-1, but people not on MassHealth need rides, too.</li> </ul> </li> <li>• Shortage of primary care physicians, not enough mental health care, providers not accepting new patients. No ENT, No rheumatology. You get sent to Springfield.</li> <li>• Referrals get complicated confusing. You get frustrated and you go without care.</li> </ul>
2. Sources of food, and access to healthy food	<ul style="list-style-type: none"> <li>• Charlemont Federated Church food pantry is the best. Difference of opinion about others (from "food pantries and offerings are good" to "they ask you lots of questions and the food is not very good.")</li> <li>• Farmers' markets and HIP are good. Several in the group had used HIP; not everyone knew about it.</li> </ul>
3. What you do if you run out of food	<ul style="list-style-type: none"> <li>• Go hunting</li> <li>• Turn to family and neighbors ("Stone Soup")</li> </ul>
4. Source and adequacy of medical care	<ul style="list-style-type: none"> <li>• Various, mostly in Greenfield, including Valley Medical, CHCFC, Franklin Adult Medical, Shelburne Family Practice, CHD, and Minute Clinic (participant says she has been unable to get her own doc)</li> <li>• Had to go to Orange for dental care because it's easier to get in there</li> <li>• Medication can be hard to get; insurance doesn't cover supplements and some tests we need</li> <li>• Walk-in clinics at the church are helpful</li> </ul>
5. Transportation	<ul style="list-style-type: none"> <li>• The ultimate question!</li> <li>• There's a bus in the morning, and 11:20, and then you're stuck all day</li> <li>• I've hitchhiked</li> <li>• People who have bicycles use them</li> </ul>
6. Missing services, other things that would help	<ul style="list-style-type: none"> <li>• Sidewalks. To get to the bus I have to walk ¼ mile in the road.</li> <li>• The town plans a bicycle trail and sidewalks, with construction to begin in the spring</li> </ul>

	<ul style="list-style-type: none"> <li>• Even two more buses would help</li> <li>• A rural clinic for all the towns around here</li> <li>• Anything mobile, e.g. a mobile unit from Baystate or CHCFC that would do lab draws, prescriptions</li> <li>• Pharmacies that deliver up here</li> <li>• Ambulance could take people to appointments when it's not on call</li> <li>• Telehealth</li> <li>• Group exercise classes</li> <li>• Clothing closet (there's one in Colrain at First Baptist)</li> </ul>
7. What you do to stay healthy, despite the challenges	<ul style="list-style-type: none"> <li>• I don't smoke or drink</li> <li>• I go to bed at a reasonable hour</li> <li>• I walk my dog</li> <li>• I garden</li> <li>• We have a strong social network</li> </ul>

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report (based on Two Community Forums)**

**Primary Hospital/Insurer:** Cooley Dickinson Health Care, but the focus group results are applicable to:

- Baystate Franklin Medical Center
- Possibly Baystate Eastern Region for rural similarities
- Health New England for needs of older adult members across western Massachusetts

**Topic of Focus Group:** Older Adults

**Date of Focus Group:** February 26, 2019 in Northampton and March 4, 2019 in Amherst

**Facilitator:** Jeff Harness

**Note Taker:** Gail Gramarossa

**Executive Summary**

**A. Participant Demographics:**

- 47 participants in Northampton, 40 participants in Amherst
- Mostly women
- Roughly 90% white, 10% people of color at both sessions
- Older adults, mostly age 60+

**B. Areas of Consensus:**

- Older adults want to stay as independent and safely live in their own homes/apartments as long as possible.
- Social connections and networks for social activities and support are as important as medical and mental health care. Older adults want to feel valued and involved in the community.
- Having access to health care provides a sense of safety and security.
- Reliable and accessible transportation to and from appointments and other activities is still a huge barrier to services, especially during winter.
- Managing chronic diseases requires that there be adequate education, support, and ability to navigate the complexities of the medical care system.
- Older adults want their providers to discuss alternative treatments and end-of-life care issues more openly and frequently.
- Knowing how to access mental health care is a challenge and there are too few providers with expertise in older adults' mental health care needs.

**C. Key Recommendations:**

- Need more home-based services
- Need more "elder friendly" affordable housing options.
- Need more congregate housing options that allow people to keep their pets, such as assisted living
- Need more specialty providers with expertise in geriatrics

- Primary care and behavioral health care need to be more integrated and providers need to communicate with each other more consistently
- Need more deliberate and direct outreach to older adults, rather than waiting for them to come to you as health care providers

D. Quotes:

- "We are not our mothers – our health and social needs are very different from our parents' generation."
- "We want to make new 'families' and create our own supportive communities, especially if our children/grandchildren live far away from us."
- "We need help to manage the mental aspects of having a chronic disease such as stress, depression, and anxiety."
- "Our needs really vary by decade – what I need in my 60s may not be what I need in my 70s or 80s or 90s, so tailor services to my changing needs."
- "Be sure that providers and patients are 'tapping the resources', for example, the Diabetes Education Center at CDH. Many primary care doctors do not refer to the Center; I learned so much from the Step Up program and was able to avoid going on medication for 15 years based on diet and exercise. Diabetes is an illness that people feel guilty about, they feel they brought it on themselves, but I have learned to manage it well. No primary care doc can give me what I received from the Center."

E. Was there anything that could be relevant to another hospital service area? If so, which geographic area and describe:

- This information could be useful for other hospitals that serve a suburban and rural community with many retirees and older adults. This audience was also fairly well-educated and aware of services in the region.

## Key Issues

Question	Synthesis of Responses
1. What makes life fulfilling as you grow older? What is important to aging successfully?	<ul style="list-style-type: none"> <li>• Social connections and people you can call upon for help</li> <li>• Feeling valued and involved</li> <li>• Sense of safety and capacity to get health care when you need it</li> <li>• Quality of life, control over your life, having a say in your life</li> </ul>
2. What supports and services do you or other older adults in our community need to support good health? Where are there gaps in services, and how do these gaps impact	<ul style="list-style-type: none"> <li>• Transportation</li> <li>• Affordable housing, down-sized and smaller</li> <li>• Provider with expertise in elder care issues/needs</li> <li>• Financial advice and information to avoid financial "scams"</li> <li>• Home-based services</li> <li>• Day programs for frail elders</li> </ul>

<p>older adults? Think about older adults with limited English, or who are people of color, or live in a rural area, identify as LGBTQ, or from other underrepresented groups.</p>	<ul style="list-style-type: none"> <li>• Care coordination services to integrate care more seamlessly</li> </ul>
<p>3. Most older adults in our community have at least 1 chronic or serious illness. What helps older adults manage chronic disease?</p>	<ul style="list-style-type: none"> <li>• Behavioral health support to manage the psychological impact/stress and anxiety of having a chronic disease</li> <li>• Help with managing and following a medication regimen</li> <li>• Case management services</li> <li>• Pharmacy home delivery</li> <li>• Help with navigating insurance and Medicare issues</li> <li>• More follow-up and "check-ins" from my primary care provider</li> <li>• Health education for managing chronic illness provided in a non-hospital setting</li> <li>• Be sure that providers and patients are aware of and referred to key health education and support programs that help with managing chronic disease such as the Diabetes Education Center at CDH; too many primary care doctors do not refer to the Center or other similar supports</li> <li>• It is important for CDH to let the community know about all of the resources that are available to help older adults manage chronic illnesses</li> <li>• Primary care needs to be better integrated with the other resources within the community</li> <li>• For someone who is not able to get themselves there, perhaps a coach or someone to help people get to outside resources</li> <li>• Could each office have 1 nurse who works specifically on integrating the office with other resources in the area? They could work with primary care around how to link the patients with those resources, using resources guides and websites about local services</li> <li>• CDH should make sure that their primary care doctors/office staff are fully knowledgeable about what is out there in terms of other local resources and support services to manage chronic illness</li> </ul>
<p>4. What would you like to see in your community that would make it a better place for older adults to live?</p>	<ul style="list-style-type: none"> <li>• More support for "aging in place"</li> <li>• Better sidewalks and recreation areas</li> <li>• Home visiting</li> <li>• More entertainment and social activities</li> </ul>

<p>5. <i>Optional if time allows:</i> Do you have adequate access to health care services, including mental health care? Is it working for you? Is it easy to get a qualified provider?</p>	<ul style="list-style-type: none"> <li>• Need more elder-friendly psychiatric services with expertise in older adults' needs, but it's hard to find a good therapist</li> <li>• There are insurance barriers to ongoing care</li> <li>• When you are new to the area, hard to find a primary care provider, need a navigator</li> </ul>
---	---

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Experience with Healthcare and Basic Needs for Disabled Adults**

**Primary Hospital/Insurer:** Health New England

**Topic of Focus Group:** Experience with healthcare and basic needs for disabled adults

**Date of Focus Group:** 3/5/2019

**Facilitator:** Gail Gramarossa

**Note Taker:** Caitlin Marquis

**Executive Summary**

**A. Participant Demographics:**

- Seven participants who were patients or clients of Caring Health Center
- Four women, three men
- All People of Color
- All spoke English

**B. Areas of Consensus:**

- Caring Health Center provides several services to help patients understand and carry out the roles they play in maintaining their own health, such as cooking classes, exercise classes, crocheting circles, etc.
- MassHealth-provided transportation is unreliable and drivers tend to be disrespectful or apathetic toward patients. A great deal of the conversation was dedicated to this topic.
- Supplemental and emergency food resources are inadequate and difficult to access. SNAP benefits awarded sometimes do not feel worth the invasive application process, and food pantries in Springfield can be chaotic and difficult to make use of without transportation home from the pantries. The latter problem is exacerbated by poorly maintained housing with elevators in disrepair.
- Participants had experienced instances of both targeted and structural racism that discouraged them from using emergency and support services.
- For a variety of reasons, accessing services to address basic needs can be a highly stressful experience that causes participants to question whether accessing those services is worth the stress.
- The healthcare system comes across to many of the participants as hasty, uncoordinated, and emotionally apathetic. There were accounts of pharmacists, doctors, and homecare providers all lacking the time and information required to help patients understand and receive the care they need.

**C. Recommendations:**

- Doctors, nurses, or staff in the doctor's office should do the work of arranging transportation and billing MassHealth
- Eliminate Yellow Cab as a Provider Requested Transportation (PT-1) provider

- Instead of trying to arrange a pick-up time with transportation ahead of time, patients should be able to call transportation when they are done with their appointments (however, doing this now gets the transportation providers off schedule)
- Drivers should escort patients from their doors to the van to ensure their safety
- Drivers should be trained to treat people with respect, empathy, and concern
- Make grocery carts available in housing developments to help people go get food and carry it home
- Records should be centralized with the primary care provider and easy for other doctors and specialists to access on demand
- Update the phone lines so that patients can actually reach someone
- Follow up on complaints that are filed about things like unreliable transportation
- Politicians should be coming to cities and knocking on the doors of people who use all these services to talk to them about their experiences
- Look to states that are doing a good job of delivering healthcare as an example for what we should be doing in Massachusetts
- Cultural education for people in the medical field

#### D. Quotes:

- Transportation:
  - “She waited for an hour and it was like 0 degrees outside and she was waiting and we wasn’t gonna leave her so we ended up waiting with her, but God forbid if she was by herself. You’re relying on someone to give you a ride and then you call but nobody answers so what do you do? Do you wait around or do you leave?”
  - “I’ve watched [name redacted] stand out there four two hours waiting for a driver, and then the driver comes up with only attitude. My brother, that woman lives all the way out in Timbuktu. She travels out here on a bus sometimes, and then to leave her here to have her family come all the way out here to drive her home—ridiculous. Nevermind she has emotional issues. We all have emotional issues.”
  - “In 2015, I got sick and went to Baystate. 9:30 at night, no bus to come back from Baystate to King Street, snow to my knee. I walked from Baystate to King Street [about 3 miles], snow to my knee. Nobody at the hospital asked ‘how are you getting home?’”
- Food
  - “I did the groceries but the elevator wasn’t working and I live on the fourth floor. I went in one trip with all my groceries and when I got to the last floor, I had a heart attack. I stood there; nobody was around. So, I said, ‘I have to bring this home,’ so I crawled over, and brought my groceries to the house... The elevator was out for like two weeks.”
  - “If you’re going in to apply [for SNAP], it’s because you need it. So, if I’m telling you I’m coming here and I’m degrading myself, giving you all my business, and then you want to tell me ‘okay, we can only give you \$15,’ I’m like ‘uh, what is \$15 gonna do?’ You’d be lucky if you can get some eggs, some milk, some bread and that’s it.”



- Health care
  - “I watched a video on Facebook... saying that there is a separation of how black people are treated in emergency rooms versus other nationalities of people... I have noticed myself, whether it’s Baystate, Mercy, Noble, or any other hospital, when I [a black man] have an issue, I have to wait an hour or two just to get a doctor to come see me, and then for somebody to tell me, ‘Oh, we don’t have enough doctors,’ that makes no sense to me. You’re a hospital. Baystate is one of the top five hospitals in America. You have a helipad, and you’re telling me there’s not enough doctors in here?”
  - “My biggest issue is respect. I feel like a paycheck; I don’t feel like a person. I feel like a docket number; I don’t feel like a person. You don’t even know my name.”

## Key Issues

Question	Synthesis of Responses
1. How do you see your own role in taking care of your health? What do you see as your responsibilities to help yourself stay healthy?	<ul style="list-style-type: none"> <li>• Eating healthy</li> <li>• Exercising</li> <li>• Getting out and socializing with others</li> <li>• Taking advantage of the cooking, exercise, crocheting, etc. classes offered by Caring Health Center</li> <li>• Being an advocate for myself--actively participating in activities and my primary care</li> <li>• Understanding the choices I have, speaking up when I don’t want something, and getting help somewhere else when I need it</li> <li>• Working with an advocate provided by the healthcare system</li> <li>• Calling my care coordinator when I need something</li> </ul>
2. Let’s talk about some day-to-day issues that can affect health. Are there services to meet basic needs such as food, housing, and transportation that you have had trouble accessing or getting enrolled into? What has been your experience trying to use such services? Do you feel that you are aware of the wide range of such services that you could use and be eligible for? What services would you like to	<ul style="list-style-type: none"> <li>• Having to make repeated calls to schedule transportation for regularly scheduled appointments</li> <li>• Elderly people and people with limited mental capacity have to call back to arrange transportation over and over again, and this can create serious consequences for someone who needs urgent or steady care</li> <li>• Transportation works well less than half the time</li> <li>• Worrying about transportation being reliable for family members or loved ones</li> <li>• Sometimes rides don’t show up for people who scheduled them and those people don’t have anyone else to call for rides, and there is no number to call if the ride doesn’t show up</li> <li>• The people who come to pick up patients are rude, disrespectful, and treat people very poorly. They don’t talk to or treat the people they are picking up as if they know they are physically and/or mentally disabled.</li> </ul>

know more about?	<ul style="list-style-type: none"> <li>• There is a lack of empathy and understanding among drivers of all types of transportation.</li> <li>• When Yellow Cab is called for transportation, they don't call the riders and sometimes they leave if the rider is not looking in the right place for them and doesn't come out in time. Yellow Cab gets paid regardless of whether they actually pick up a patient or not.</li> </ul>
3. Which of the basic needs we talked about - food, housing, and transportation, for example - pose the greatest problem for you? What happens when you can't get access to food, housing or transportation? What are some of the social, emotional, mental, physical or financial impacts?	<ul style="list-style-type: none"> <li>• Transportation is among the top five hardest basic needs to access</li> <li>• If walking or taking the bus is an option, that is preferable to the provider-scheduled transportation</li> <li>• When scheduling transportation, providers ask if people have mobility impairments, but then drivers say that it is not their job to accommodate those mobility impairments.</li> <li>• The transportation providers don't answer the phone at busy times</li> <li>• Even if it is not a problem to walk to pantries, it is a challenge to walk home with all the groceries. There used to be workers who would help with this at Caring Health Center, but they shut that program down.</li> <li>• SNAP benefits are not enough to sustain someone with all the nutrients they need for a whole month</li> <li>• Some buildings don't have elevators and people have to carry loads of groceries from the food pantries up the stairs</li> <li>• The DTA requires a ton of information in order to just get someone \$15 a month in SNAP benefits, causing clients to wonder if it's worth it</li> <li>• The SNAP benefits the DTA gives out have gone down, but the cost of food has gone up</li> <li>• The lines at food pantries are aggressive and cause participants to question whether it is worth it to go to food pantries</li> <li>• The wait at a pantry can be as long as two hours and some pantries have let certain people jump the line</li> <li>• One participant experienced another pantry-goer making degrading comments about Puerto Ricans</li> </ul>
4. What has been your experience when you try get health care? What has worked well? What has not worked well or has been a real problem in getting the health care you need?	<ul style="list-style-type: none"> <li>• Hospitals engage in practices that appear racist to one of the participants</li> <li>• Emergency rooms say that they don't have enough doctors to treat all the patients in the emergency room</li> <li>• Emergency rooms don't have the specialists or equipment needed to test people for all the issues they come in with</li> <li>• It is very expensive to have even a short visit with an emergency room doctor</li> <li>• Doctors in emergency rooms and specialists aren't getting records from primary care providers with enough timeliness to</li> </ul>

	<p>have a complete understanding of a patient's health issues within a visit</p> <ul style="list-style-type: none"> <li>Doctors prescribe medications that have side effects that force patients to choose between the lesser of two evils, and patients may not have the capacity or resources to treat the side effects as a separate issue. Doctors don't take the time to determine if patients might be susceptible to the side effects.</li> </ul>
5. What happens when you are not able to get the health care that you need? What are some of the social, emotional, mental, physical or financial impacts?	This question was not explicitly asked or answered.
6. How does managing your disability fit into the overall picture of trying to get health care services when you need them? What would help your living with a disability?	This question was not explicitly asked or answered.
7. When you get health care services, how much do you think the doctors, nurse, therapists or other healthcare providers really understand what you experience from your disability? How would you rate them in terms of that understanding?	<ul style="list-style-type: none"> <li>Caring Health Center understands mental disabilities but only provides limited care on the physical disability side</li> <li>Doctors only treat patients for one issue at a time and don't take a holistic view of dealing with physical disabilities</li> <li>Doctors don't always treat patients with respect and empathy, and don't take the time required to get to know patients' names or really understand their issues</li> <li>Caring Health Center has too many clients and makes patients feel like they are just getting dealt with as quickly as possible</li> <li>There is too much of a separation in treatment between physical and mental health</li> <li>The pharmacy isn't giving out enough doses of insulin to get one participant through more than two or three days</li> </ul>
8. Let's talk about home care services. What has worked well in any home care services you have had? What has not worked well? What do you see as lacking in home care services? What would make home care services better?	<ul style="list-style-type: none"> <li>The doctor asks at every visit if patients need care at home</li> <li>Help with eating and cooking more nutritiously</li> <li>Providing an in-home nutritionist</li> <li>Better background checks and oversight for home care providers</li> <li>Home care providers aren't necessarily always doing the work they are getting paid to do</li> <li>Aligning diagnoses for home care because the doctors and the home care providers don't always agree that home care is required</li> </ul>

	<ul style="list-style-type: none"> <li>• Home care available around the clock for surgery recovery</li> </ul>
<p>9. Is there anything else you think we need to know about what it is like living with a disability? What would help? Everyone go around and say one thing that we maybe haven't said yet.</p>	<ul style="list-style-type: none"> <li>• Better housing</li> <li>• Getting a call from my doctor to check-in every six months or so</li> <li>• Nothing, everything is good</li> <li>• More accessible housing for a wheelchair or for other disabilities</li> <li>• Assisted living for people with disabilities</li> <li>• Empathy, less focus on statistics and working "by-the-book"</li> <li>• Individualized care</li> <li>• For doctors to make sure that patients are okay when they are leaving, and then conduct a follow-up call to make sure patients have what they need</li> <li>• Doctors being on time and taking more time with patients</li> <li>• Doctors getting to know patients on a personal level</li> <li>• More coordination between emergency care and primary care</li> <li>• Reducing the wait time between emergency room visits and follow-up treatment</li> <li>• Getting enough doses of insulin from the pharmacy to get through more than a few days before coming back</li> </ul>

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Cancer**

**Primary Hospital/Insurer:** Mercy Medical Center

**Topic of Focus Group:** Cancer

**Date of Focus Group:** 3/4/2019

**Facilitator:** Kim Gilhuly

**Note Taker:** Eve Sullivan

**Executive Summary**

**A. Participant Demographics:**

- Ten participants - five women and five men.
- One person was aged 41 – 50, three people were aged 51 – 60, three people were aged 61-70, one person was aged 71 – 80, and two people were over age 80.
- All participants were White

**B. Areas of Consensus:**

- Mercy's Cancer Support Group has been an incredible and vital source of assistance, advocacy, support and love for people in treatment, their caregivers, and after cancer. People were effusive about the Support Group and most were long-time participants.
- The position of Nurse Navigator or Social Worker to help people and families navigate the cancer care, medical, support services, and insurance systems is incredibly important.
- People appreciated doctors and other staff who are dedicated, seem to go the extra mile, and are truly caring. The cancer care at Mercy was very appreciated.
- Impacts of cancer are grief, the difficulty of dealing with uncertainty, whole-family impacts (ranging from family members not wanting to talk about it to divorce), and the ongoing nature of cancer – "it never ends".

**C. Key Recommendations:**

- Need a Children/Youth Cancer Support group for children or grandchildren of people who have cancer.
- Make sure other hospitals (such as Baystate) have Cancer Support Groups that meet every week and are for all cancer types.
- Make sure other hospitals (such as Baystate) have a nurse or social worker navigator to help patients and their families navigate the medical, support services, and insurance systems.

- Assistance and guidance and support is especially needed in times when a patient is near death but it's not entirely clear. If some kind of person or program could be created for those patients and those times, it would be helpful.
- All patients who have completed treatment for cancer should leave with a Survivor Care Plan

D. Quotes:

- "These support groups (cancer support and grief) have made a huge difference for me, learning to be a self-advocate, becoming more informed as patients and family member."
- "My mom was diagnosed with 3-6 months to live, and I think if she weren't in a pancreatic support group, she wouldn't be alive. Support group makes her have hope and want to live."
- "The devotion of the staff here is one of the most loving and embracing care environments I have ever encountered. I felt when I was a patient here that I had extended family."
- "My doctor stretched to try to get my husband into a trial; he did what he had to do. It was too late for my husband but I recognize that the doctor tried."
- "When my mom had cancer it was worse than having cancer myself."
- "That feeling (*survivor's guilt*) is real."
- "No one else understands. That's why the Support Group is so important."
- "Last year my insurance changed. Now I have a high deductible, but the hospital helped me through a social worker. So I experience no barriers with the hospital."

## Key Issues

Question	Synthesis of Responses
1. Strengths of Mercy's cancer treatment and support	<ul style="list-style-type: none"> <li>• Every single person mentioned the cancer support group, and couldn't say enough about it. They liked that it was a single group for people with any kind of cancer, rather than type-specific support groups. They also liked that the group meets once a week (instead of once a month or less frequently).</li> <li>• Having all services and treatment in one place. "I had to leapfrog from one place to another before but now it is much nicer to have all care together."</li> <li>• Devotion, kindness, and commitment from all staff (doctors, nurses, navigators, etc.). There were several stories of incredible devotion and follow up by doctors and other staff.</li> <li>• Having a nurse navigator or social worker to help coordinate care, navigate insurance, and advocate for you and your family.</li> <li>• One person called out the importance of the spiritual aspect of Mercy as a Catholic hospital.</li> </ul>

2. Suggestions/ recommendations	<ul style="list-style-type: none"> <li>• Doctors and staff on the care team need to educate all cancer patients that the support group exists.</li> <li>• Other hospitals should have Cancer Support Groups modeled after Mercy's.</li> <li>• The nurse navigator position is key to being able to navigate your services and get the services and treatment you need. One person mentioned that Baystate doesn't have this position.</li> <li>• Wish there was a Cancer Support group for children and youth.</li> <li>• Help and guidance in those times when it's not clear what to do because it seems like the end (see Question 4).</li> </ul>
3. Impacts of going through cancer	<ul style="list-style-type: none"> <li>• Not knowing how much to tell children, and seeing the impact on children and younger family members.</li> <li>• Cancer affects everyone in the family.</li> <li>• Sometimes cancer tears families apart due to grief and reactions to grief. Some never get through their grief.</li> <li>• Some family members just will not talk about the cancer.</li> <li>• There is survivor's guilt.</li> <li>• Cancer is frightening.</li> <li>• The ongoing nature of cancer, that it often returns, and the uncertainty can wear on people. "Cancer never ends".</li> <li>• One couple didn't have kids because of the cancer.</li> <li>• One person mentioned losing their job because of the cancer, and ending up divorced.</li> </ul>
4. Barriers to treatment or support services	<ul style="list-style-type: none"> <li>• Navigating the medical and insurance system can be a challenge</li> <li>• High deductibles and copays, but there are individuals (social workers, pharmacists) that can help get these costs down</li> <li>• One heartfelt barrier people mentioned is that it's difficult to know what to do when the outcome is unclear – mentioned by a couple of people about when is best to end treatment, start hospice, give up hope for healing. A guide around that uncertainty would be helpful.</li> </ul>
5. Have you seen inequities in treatment by race, sex, income, sexual preference, or other?	<ul style="list-style-type: none"> <li>• Participants had not experienced inequity. They hypothesized that people might experience "barriers" (not inequities) due to financial issues, bad insurance mostly. But several with public insurance felt that they were treated well at Mercy.</li> </ul>
6. Policy or practice suggestions that Mercy could support to decrease risk of cancer	<ul style="list-style-type: none"> <li>• Laws, regulations, and more education about e-cigarettes and the risks of smoking in general</li> <li>• One person was against regulation and in favor of education</li> <li>• Practice suggestion: Hospital should make sure every patient has a survivor care plan when they are through with their treatment. Now when people are done they are just sent out on their own to "deal." Everyone should have something written down about what to do after they are no longer receiving</li> </ul>

	treatment, whether it's a pamphlet, a business card with a phone number, or something else. This plan would be something that patients could also take to any future doctor they need to see as part of their history.
--	--



**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Focus Group Report: Parents of Children with Neuromuscular Diseases**

**Primary Hospital/Insurer:** Shriners Hospital for Children - Springfield

**Topic of Focus Group:** Parents of Children with Neuromuscular Diseases

**Date of Focus Group:** 1/30/2019

**Facilitator:** Gail Gramarossa

**Note Taker:** Caitlin Marquis

**Executive Summary**

**A. Participant Demographics:**

- 11 participants who were parents of children in the BFit program, a power-based exercise program designed to aid children with neuromuscular diseases.
- Ten women, one man.
- All participants were parents of children ages 5 - 18.
- At least two participants required Spanish translation, which was provided by a fellow participant.

**B. Areas of Consensus:**

- When children of the parents in the group are the targets of bullying, school authorities do not respond in a satisfactory way that includes repercussions for the bullies or safeguards for the bullied children.
- It is hard to find the necessary doctors, specialists, urgent care, and consistent care in Western Massachusetts. Parents sometimes have to find the time and resources to go to Boston in order to get the care their children need.
- Many challenges that the parents in the group reported revolve around navigating insurance coverage and other spheres in which their children needed to qualify for treatment or support. For example, sometimes the diagnosis that merits insurance coverage for treatment is not the same diagnosis that merits support in school.
- It is important to be connected to other parents of children with disabilities in order to find out about helpful resources and programs for the children.
- The BFit program has helped both children--by empowering them to engage in socialization and physical activity--and parents, by giving them a sphere in which to connect with one another about challenges and resources.

**C. Recommendations:**

- Leverage gatherings of parents: Parents named several programs and services that support children with neuromuscular differences, including the BFit program, and each of these is an opportunity to catch parents while they are waiting for their children to complete a class or session. These opportunities could be leveraged to check in with parents about their support needs, share information

about available programs and resources, and encourage parents to support and network with one another.

- Find funding for the 4C program or a similar intervention: The Collaborative Consultative Care Coordination Program was a federally funded program that provided teams of professionals to support pediatric patients who required many different specialists and types of support. Federal funding for the program was cut, but parents in the group remarked on how helpful the program was for navigating a complicated landscape of providers and services.
- Increase support for children with disabilities in schools: Many parents felt that schools were not sufficiently acting on their responsibility to support children with disabilities. Areas where schools were perceived to be falling short include:
  - Swift and satisfactory response to bullying incidents where children with disabilities are the targets.
  - Providing therapies and supports that were perceived by parents to be necessary to their children's success, but that insurance companies will not cover because they expect schools to provide them.
  - Creating accurate assessments that would qualify students for services that the parents perceived to be necessary for their children's success.
  - Advocating for students with disabilities.
- Expand the umbrella of children who qualify for the BFit program: Many parents noted how essential the BFit program was to their children's physical and social success, but some parents noted that they had to fight or have advocates fight to get their kids into the program because their children did not technically qualify.
- Streamline diagnoses: Create broader categories of diagnoses to increase access to services without having to have kids misdiagnosed. Provide consistency in support for the same diagnosis across healthcare and school environments.
- Consolidate information about support for children with disabilities: Make information about specialists more readily available and easy to access, particularly by empowering specialists and healthcare providers with knowledge about other specialists in the area. Make information about physical activity opportunities available at Shriners and other healthcare providers' offices.
- Employ adult and therapeutic mentors, psychologists, therapists, etc. to help kids cope with bullying.
- Use advocacy groups, such as the Special Education Parent Advisory Council (SEPAC or SpedPAC), as a vehicle to identify issues that many students with disabilities are facing and elevate them to the attention of higher authorities in the school department.
- Make exercise and durable equipment more available and affordable for increasing physical activity opportunities and capacity in the home.

D. Quotes:

- Bullying:

- [Translating for Spanish speaker] “When [some kids at school] poured juice on her daughter she went to the school department and put in a complaint. They told her that they cannot move her from that school because it has to be three incidents back-to back... When she brought it to the attention of the principal in [the middle school], they just moved her into another school in the same building as where the bullying was occurring.”
- “My son...told me... he was being assaulted... in every class and every day.... They started a bullying investigation and they asked me for his statement and we wrote out the statement, but before I could drop off his statement they closed the investigation and they told me that they didn’t find that any bullying had happened. When I asked them how they could conclude the investigation without my son’s statement, they said they just used some information that I mentioned in an email. They said that none of the students witnessed it.”
- “Living in Holyoke or Springfield, you cannot ignore the racial difference... If you are a Hispanic parent, particularly if your English isn’t what they think it should be, there is a huge gap and a much different response. There is also a large group of kids who are labeled special ed who are really just English Language Learners”
- Access to specialty medical services:
  - “My daughter was seeing a physiatrist in West Springfield who was great... but then she left the practice and was no help in terms of telling us where to go next. She suggested that we try Boston... I did try Boston, but it was a 3-month process to even get her in there. We finally got her in there and I like it, but four or five times a year, we’re driving to Boston, and she’s four, so it’s not fun.”
  - “Some of the specialists that we do see... they’re not helpful in expediting the process or making referrals, or sending her where she needs to go.... That information is not out there.”
  - “My daughter’s doctor in Boston told me she needed therapies for two years... I have so much difficulty, struggle, and pressure on me, on my husband, on my family.... Every night I have to cry. I went to Baystate [for my daughter’s recommended treatment] and after a while they said that the insurance wouldn’t cover it, and I had to call many people and after a gap [in her treatment] they sent me to [another hospital], and then after a while, they told me the insurance wouldn’t pay again. Then, finally, they sent me here to Shriners and the same thing happened. I said ‘no! I am done with this. My daughter needs these therapies. When she is making gains and progress, why do you want to stop it?’... This is the end of her therapies now, and again, I’m scared they are going to put gaps in between. This is my nightmare I have every day.”
- Physical Activity Opportunities:
  - “BFit has helped my daughter from being the most uncoordinated kid to being able to ride a bike last year.”

- “[My son’s high school] just started Special Olympics two years ago and [my son] was afraid to do it, but we have a competition in two weeks and [my son] is doing real good... he was literally afraid to walk off the bus [before] because he was afraid people were going to make fun of him.”
- “I asked one of the physical therapists for swimming opportunities for my daughter because swimming is very good for relieving neuromuscular pain and she said we used to have [a pool] at Shriners but they closed it for financial reasons, and I would like them to open it again because a pool is actually a treatment for our children.”

## Key Issues

Question	Synthesis of Responses
1. What do you know about the frequency or type of bullying that occurs towards youth with disabilities in the local schools?	<ul style="list-style-type: none"> <li>• A bully hit one woman’s son the morning of the focus group</li> <li>• One woman’s daughter had juice poured on her, had insults written on her shirt, and had other students tell her that kids were only friends with her because they felt bad for her</li> <li>• One woman’s son told her that kids were taking opportunities when the teachers weren’t looking to hit him in every class, and it was happening every day</li> <li>• One woman said that she homeschools because one of her kids is terrified that he would be bullied if he went to school outside the home</li> <li>• One woman said that her son was lucky and hadn’t experienced any bullying at his current school, but that she took him out of his elementary school because how poor the school condition was</li> </ul>
2. When you or someone else reports the bullying to the school, how do they respond?	<ul style="list-style-type: none"> <li>• The school called the mother and asked her to take her son to the ER</li> <li>• The school gave the bully a verbal warning</li> <li>• The school said they cannot move the child who was bullied to another school because that would require three incidents back-to-back</li> <li>• The school moved the child to another school, but in the same building as the school where the bullying occurred</li> <li>• The school said they conducted an investigation but didn’t collect a statement from the bullied child and said that they concluded the investigation and didn’t find any bullying because there were no witnesses</li> <li>• The school said that, in order to determine bullying had occurred, incidents had to be ongoing and repetitive over the course of 3-4 weeks</li> </ul>

	<ul style="list-style-type: none"> <li>The school has repeatedly ruled incidents “not bullying” for a variety of reasons</li> </ul>
2a. Is their response effective?	<ul style="list-style-type: none"> <li>One woman reported that the school discourages bullying by asking students to be careful because they might hurt her son; no other effective responses were reported</li> </ul>
3. If your child has been bullied, what strategies do you use with your child to help them cope with and respond to the bullying?	<ul style="list-style-type: none"> <li>Recruiting a mentor through a family member who works on a military base</li> <li>Therapeutic mentorship</li> <li>In-home therapy</li> <li>Outpatient therapy</li> <li>Working with Special Education Parent Advisory Council (SPEDPAC) to get the attention of school authorities</li> <li>Seeing a therapist and psychologist</li> </ul>
3a. Are they effective?	This question was not specifically answered, but one woman was successful in reaching school authorities through SPEDPAC
4. How does bullying affect the physical and mental health of youth with disabilities?	<ul style="list-style-type: none"> <li>One child has gotten very tough and tried to hurt other kids before they could hurt her because she is constantly being hurt. She is seeing a therapist and a psychologist.</li> <li>Feeling unsafe</li> <li>Feeling terrified of potential bullying</li> </ul>
5. Where do you receive help obtaining specialty medical services (Shriners, other organizations, other hospitals)?	<ul style="list-style-type: none"> <li>Referrals from other specialists</li> <li>Formerly, the 4C program</li> <li>Shriners</li> </ul>
5a. What services do you access while at the hospital?	<ul style="list-style-type: none"> <li>BFit</li> <li>Physical therapy</li> <li>Diagnoses for services and treatment outside of the hospital</li> <li>Neurological/psychological evaluation and testing</li> <li>Bike camp</li> </ul>
5b. What services do you access while at school, if applicable?	<ul style="list-style-type: none"> <li>Occupational Therapy</li> <li>Physical Therapy</li> <li>Speech Therapy</li> <li>Neurological/psychological evaluation and testing</li> </ul>
5c. What services do you access in the community?	This question was only answered with regards to services that support physical activity. See question 8.
6. What specialty care services does your child need, that you lack access to (at Shriners or in the	<ul style="list-style-type: none"> <li>Physiatrists</li> <li>Child psychiatrists</li> <li>Neuropsychologists</li> </ul>

area)?	
6a. What is not offered here in Western MA?	<ul style="list-style-type: none"> <li>Physiatrists</li> </ul>
7. What are some of the barriers you face in obtaining access to the types of specialty medical services that your child needs? (awareness, availability/waitlists, insurance/cost, travel, etc)	<ul style="list-style-type: none"> <li>Lack or dearth of certain specialists in Western MA</li> <li>Treatments not recognized or covered by insurance</li> <li>Insurance won't cover services that they pay the schools to provide, but the school won't qualify the students for the services because they're not "bad enough"</li> <li>Insurance companies refusing to pay for services that the school is supposed to pay for, but doesn't</li> <li>Lack of readily available information about who providers are and where to find them</li> <li>Failure to diagnose children in ways that qualify them for the services they need</li> <li>Long waitlists</li> <li>Deciding which diagnosis to pursue in order to get necessary services</li> <li>Highly specific diagnostic categories that block patients from qualifying for necessary services</li> </ul>
8. Where do you receive help with your child's access to physical activity opportunities (Shriners, other organizations, other hospitals)?	<ul style="list-style-type: none"> <li>BFit</li> <li>BFit cycling club</li> <li>The Kehila Program at the Springfield Jewish Community Center</li> <li>Whole Children</li> <li>Ultimate Sports Program, particularly rock climbing</li> <li>Children's Miracle Network</li> <li>Project Splash swim lessons at Mount Holyoke College</li> <li>Spedchildmass.com has a listing of programs</li> <li>Miracle League adaptive baseball</li> <li>Special Olympics</li> <li>Hippotherapy (horseback riding)</li> <li>Easter Seals</li> <li>Facebook groups for parents of children with disabilities</li> <li>Center for Human Development</li> <li>Willpower Foundation to help pay for programs</li> <li>getATstuff.com [currently inactive]</li> <li>Our Lady of Guadalupe CYO Basketball for ages K - 2</li> <li>Family Scouts</li> <li>Federation for Children with Special Needs listserv</li> <li>Family TIES of Massachusetts</li> </ul>
8a. Which organizations do you access for services?	<ul style="list-style-type: none"> <li>Shriners</li> <li>Springfield Jewish Community Center</li> <li>Whole Children</li> </ul>

	<ul style="list-style-type: none"> <li>• Ultimate Sports Program</li> <li>• Children's Miracle Network</li> <li>• Baystate Hospital</li> <li>• Mount Holyoke College</li> <li>• Miracle League</li> <li>• Special Olympics</li> <li>• Easter Seals</li> <li>• Department of Developmental Services</li> <li>• Center for Human Development</li> <li>• Federation for Children with Special Needs</li> </ul>
9. What do you need to help your child gain greater access to physical activity opportunities, that you currently lack access to (at Shriners or in the area)?	<ul style="list-style-type: none"> <li>• Help with renting or buying indoor exercise equipment</li> <li>• The opportunity to exchange information and resources with other parents of children with disabilities</li> </ul>
9a. What is not offered here in western MA?	This question was not specifically answered
10. What are some of the barriers you or your child face in obtaining access to physical activity opportunities? (equipment, accessibility, awareness, availability/waitlists, insurance/cost, travel, etc.)	<ul style="list-style-type: none"> <li>• Cost of programs or equipment</li> <li>• Not knowing about the opportunities</li> <li>• Some volunteer-run recreational and physical activity opportunities will not accept children with disabilities because volunteers are not willing to take them on (cub scouts, youth sports leagues, etc.)</li> </ul>
11. Do you have ideas for other ways that Shriners or other hospitals could be helpful to you around access to physical activity opportunities? If so, what are they?	<ul style="list-style-type: none"> <li>• A swimming pool at Shriners</li> <li>• A list of physical activity resources, at Shriners or at primary care doctors' offices</li> <li>• Encourage the sharing of information and resources among parents of children in BFit and other similar programs</li> </ul>
11a. Speaking generally, and thinking back over our discussion so far, what is the most important service you need for your child?	<ul style="list-style-type: none"> <li>• Therapies--speech, OT, and PT</li> <li>• Neuropsychologists</li> <li>• Consistency of services</li> <li>• Access</li> <li>• Continuum of care</li> <li>• Continuous therapies</li> <li>• Fun physical therapy like the BFit program</li> <li>• Easier access to durable equipment--fixing used equipment and getting it into the marketplace (insurance sometimes</li> </ul>

	<p>won't cover this equipment and it can be expensive)</p> <ul style="list-style-type: none"> <li>• The right placement in school (this was said twice)</li> <li>• A ramp for the home because some homes will not qualify for this</li> <li>• Attentive housing management that will ensure ongoing ADA accessibility</li> <li>• Lists of services that the child may qualify for other than BFit and Shriners services</li> <li>• More advocates for kids with disabilities in schools</li> <li>• Continuation of Applied Behavioral Analysis services</li> </ul>
11b. Is there anything you would like Shriners to know about your needs around any of these issues?	<ul style="list-style-type: none"> <li>• It would be helpful to get grants for parents of children with disabilities to take classes at community colleges and educate themselves about how to take care of their children at home</li> <li>• Schools seem to be using the excuse that there are a lot of kids fighting for services and this is why they will not give kids the services they need</li> <li>• Because of several fires in public housing, the housing authority is addressing the needs of those who were affected by the fires before the needs of those with disabilities</li> </ul>



## Appendix IV. Key Informant Interview Summaries

### Coalition of Western Massachusetts Hospitals 2019 Community Health Needs Assessment

#### Key Informant Interview Report

**Hospital/Insurer:** Baystate Franklin Medical Center

**Interviewer:** Kat Allen, with Jeanette Voas taking notes

**Interview Format:** In person interview, 1 hour

#### **Participants:**

Community Health Center of Franklin County Leadership Team of:

- Ed Sayer (CEO)
- Jared Ewart (Accountant)
- Arcey Hoynoski (CFO)
- Maria Heidenreich (Medical Director)
- Cameron Carey (Development Director)
- Maegan Petrie (Accountant)
- Allison van der Velden (Dental Director)
- Allie Jacobson (Information)
- Jessica Calabrese (COO)
- Susan Welenc (Population Health)
- Susan Luippold (Human Resources)
- Wes Hamilton (CIO)

Question	Synthesis of Responses
1. Three most urgent health needs/problems	<ul style="list-style-type: none"><li>• Homelessness</li><li>• Access issues (including # providers, transportation, social determinants, expenses), e.g. for oral health – urgency because of lack of access</li><li>• Behavioral health; too few psych prescribers, so primary care providers end up prescribing outside their comfort zones</li><li>• Shortage of dental specialists, so dental providers work outside their comfort zones</li></ul>
2. Health issues that have emerged and/or dramatically increased in prevalence in the last 1-2 years	<ul style="list-style-type: none"><li>• Opioid crisis isn't new but it's gotten more visible in past couple of years</li><li>• Anxiety and depression – everyone has some psych diagnosis that needs managing</li><li>• Obesity continues to mount, and that causes other health problems</li><li>• New diagnoses of PTSD including from dysfunctional families. We may be identifying it more than before. People see a behaviorist and things start to come out.</li></ul>

3. Specific vulnerable populations of concern	<ul style="list-style-type: none"> <li>• Migrant seasonal agricultural workers (we take care of about 300 – there are close to 2,000 in FC) with usual problems plus language, cultural barriers, insurance. They are unfamiliar with our system &amp; don't advocate for themselves. CHC doesn't have enough bilingual staff</li> <li>• Pediatric population: <ul style="list-style-type: none"> <li>○ More kids with anxiety, OCD, ADD</li> <li>○ When our dental providers see kids, they're often well down the path of oral disease</li> <li>○ Behavioral health issues affect school attendance, health regimes &amp; take a toll on families</li> </ul> </li> <li>• LGBTQ – we're trying to get better at providing services for them</li> <li>• Elderly – we don't tend to their needs specifically, e.g. no fall risk screening</li> </ul>
4. Gaps to health care of most concern	<ul style="list-style-type: none"> <li>• Transportation</li> <li>• Gaps in reimbursement structure, e.g. telehealth, community health workers</li> <li>• When people shift to high deductible plans, docs will wait until the end of the year to see them when deductible is paid</li> <li>• Lack of coordinated care (primary care, oral health, behavioral health)</li> </ul>
5. Barriers	<ul style="list-style-type: none"> <li>• Transportation</li> <li>• Language</li> <li>• Psychiatric services</li> <li>• Housing</li> <li>• Food insecurity – has gotten worse</li> <li>• Poverty</li> <li>• Illiteracy</li> </ul>
6. What's missing that we're not seeing in the data	<ul style="list-style-type: none"> <li>• Just starting to capture social determinants</li> <li>• We have data on those who are using the system; we don't know about those who are not.</li> </ul>
7. Opportunities for prevention to keep people out of hospital	<ul style="list-style-type: none"> <li>• Transitions of care: we contact discharged patient within 48 hours and follow up on meds, questions, services, appointments. It's reimbursed through CMS (Centers for Medicare &amp; Medicaid Services) if patient not readmitted within 30 days.</li> <li>• Complex case management is not reimbursable or sustainable</li> <li>• Work on getting patient buy-in, holding patients accountable, responsible for self-care</li> <li>• More oral health providers and space where people can get regular restorative care. ER visits for dental issues are a waste of \$\$.</li> </ul>
8. What's needed apart from more funding	<ul style="list-style-type: none"> <li>• Access to healthy food</li> <li>• Healthy social support systems to address loneliness, isolation,</li> </ul>

	lack of transportation <ul style="list-style-type: none"> <li>• Places to congregate</li> <li>• Exercise opportunities and associated social connections</li> <li>• More community health workers</li> </ul>
9. Resources to refer people to from the CHC	<ul style="list-style-type: none"> <li>• Dental specialists (oral surgeons, periodontists, orthodontists). We have regional shortages, and it's even worse in the public service sector.</li> <li>• Groups for social support, weight loss, etc</li> <li>• Psychiatry for ongoing care</li> </ul>
10. Recommendations for connections between hospitals and public health	<ul style="list-style-type: none"> <li>• This is important. Now we have a Balkanization of health services.</li> <li>• Hospitals can:             <ul style="list-style-type: none"> <li>○ Attract and recruit specialists</li> <li>○ Fund common electronic health record</li> <li>○ Provide clearinghouse for best practices</li> <li>○ Legal services to help people navigate issues, e.g. with landlords</li> </ul> </li> </ul>
11. How to support such a partnership	<ul style="list-style-type: none"> <li>• Subscription. CHCFC would be ready to pay into a menu of services.</li> </ul>
12. Other	<ul style="list-style-type: none"> <li>• It's shocking how weak the connection is between the hospital and the CHCFC.</li> <li>• More than 80% of our patients are below 200% poverty. There needs to be a lot more cooperation. CHC has the most comprehensive picture of the low income population.</li> <li>• It's a struggle to recruit and staff the health center. Loan reimbursement can help attract doctors, but not nurses, dental assistants, etc. What can we do to make this a destination career?</li> </ul>

### Quotes:

- "There are too few psychiatric prescribers, so primary care providers end up prescribing outside their comfort zones."
- "There are too few dental specialists, so dental providers have to work outside their comfort zones, too."
- "Anxiety and depression have increased. It seems like everyone has some psychiatric diagnosis that needs managing."
- "I'm concerned about migrant seasonal agricultural workers. We take care of about 300 of them and there are close to 2000 in Franklin County. Apart from the usual problems, they have barriers of language, culture, insurance. They are unfamiliar with our system and don't advocate for themselves. The Community Health Center doesn't have enough bilingual staff."
- "When we see children in the dental clinic, they're often well down the path of oral disease."
- "We are seeing more kids with anxiety, OCD, ADD. Behavioral health issues impact school attendance and health regimes, and they take a toll on families."

- "It's a struggle to recruit and staff the health center. Loan reimbursement can help attract doctors, but not nurses, dental assistants, etc. What can we do to make this a destination career?"
- "Hospitals are the hub of the healthcare system. It's shocking how weak the connection is between the hospital and the CHCFC. More than 80% of our patients are below 200% poverty. CHC has the most comprehensive picture of the low income population. There needs to be a lot more cooperation."

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Key Informant Interview Report**

**Hospital/Insurer:** Cooley Dickinson Health Care

**Interviewer:** Catherine Brooks

**Interview Format:** One group interview (7 participants), approximately 60 minutes, with the Cooley Dickinson Physician Hospital Organization (CDPHO) integrated care management program staff. One 45-minute telephone interview.

**Participants:**

- Group interview: nurse care managers, social workers, project specialist, and the director of clinical operations
- Carlie Tartakov, professor emerita, University of Massachusetts

Question	Synthesis of Responses
<p>1. What makes life fulfilling as you grow older? What supports exist in our community to help older adults find joy and meaning in their lives?</p>	<p>People noted the following ways in which life remains fulfilling for older adults:</p> <ul style="list-style-type: none"> <li>• Interaction with others and with the community</li> <li>• Making a contribution to the community</li> <li>• Being able to continue to live independently and access needed services</li> <li>• Participating in social and cultural activities</li> </ul> <p>Supports mentioned included:</p> <ul style="list-style-type: none"> <li>• Senior centers</li> <li>• College and university lifelong learning programs</li> <li>• Transportation provided through some senior centers</li> <li>• Aging Services Access Points (ASAPs)</li> <li>• The Hilltown Elder Network</li> <li>• The Food Bank of Western Massachusetts</li> <li>• The MassHealth Frail Elder Waiver Program</li> </ul>
<p>2. What supports and services do older adults in our community need to support good health? Where are there gaps in services, and how do these gaps impact older adults? Think about older adults with limited English,</p>	<p>Supports and services needed by older adults include transportation, help with medicine, help with household tasks, healthy food, and opportunities for exercise.</p> <p>Gaps include a lack of people who provide support services, and a lack of people of color providing these services.</p> <p>When service providers do not reflect the demographics of their clientele, they don't understand their specific cultural needs, and it is difficult for people receiving services to feel comfortable with them. In addition, people who do not speak English or Spanish</p>

<p>or who are people of color, or live in a rural area, identify as LGBTQ, or from other underrepresented groups.</p>	<p>sometimes have trouble accessing services, because of a lack of translated materials or people who can interpret for them. Immigrants may have limited health insurance coverage that does not allow them to access non-emergency services.</p> <p>Transportation was mentioned repeatedly as a significant gap in services. In some communities, there are vans run by senior centers, but even there people usually have to schedule their transportation in advance and they may not be able to make multiple stops. In more rural areas, transportation may not be available at all.</p>
<p>3. Older adults can feel isolated, lonely, or depressed. How does the community help older adults with these feelings? What are the barriers, if any, to receiving or accessing help with mental or emotional health?</p>	<p>Many elders have experienced loss as people close to them die. They also may perceive their neighborhoods changing around them and feel unable to connect with the people around them. Some also do not want to participate in senior center activities; they see the senior centers as cliquish or otherwise not suiting their needs. The issues older adults experience with hearing, vision, or eating (dental needs) can also lead to isolation.</p> <p>An additional problem is that people of color sometimes come from communities that encourage them to be outwardly strong and not ask for help. They might also lack trust in service providers who do not reflect their cultural heritage.</p> <p>Senior centers attempt to address these needs, but they are only able to reach the people who are willing to engage with their services, and they have limited budgets. Some communities have strong support networks, but this is highly variable among towns and neighborhoods. There are some library programs and “meet-ups,” but these are limited.</p>
<p>4. What supports and services do elders in our community need but have a hard time accessing? What are the barriers they face? (Probe for housing, transportation, ability to afford prescriptions, and healthy food.)</p>	<p>As noted above, transportation is a necessary support but is sometimes difficult to access. Eligibility is limited and the service must be scheduled in advance. Some older adults need services but do not qualify based on their age or income levels.</p>
<p>5. What needs do elders have for social services? (Probe: Food Pantry, Weatherization and Heating)</p>	<p>Some needed social services noted included:</p> <ul style="list-style-type: none"> <li>• Behavioral health counseling</li> <li>• Assistance with medication</li> <li>• Subsidized or free heating, food, and housing</li> </ul>

Assistance, Exercise classes, Help with bills, Help with taxes, Home Health Care, Housekeeping Support) What are the barriers they face in accessing these services?	<ul style="list-style-type: none"> <li>• Personal care</li> <li>• Housekeeping</li> </ul> <p>The primary barrier faced in accessing needed services is financial. ASAPs provide home-based care and other services on a sliding scale, but this can still be expensive. There are many living communities for older adults that provide services, but they also are expensive. People have to spend down all of their assets before they can qualify for support.</p> <p>Other barriers include the logistics of having to interview home health care providers, and a lack of knowledge about available resources. Some people think that Medicare will pay for nursing homes and any other needed services, which is not the case.</p>
6. What would you like to see in your community that would make it a better place for older adults to live?	<p>Needs mentioned included transportation, affordable housing, walkable sidewalks, a nearby grocery store, and someone to provide the services noted above. People also noted the need to listen to elders, treat them with respect, and honor their stories. There needs to be positive, proactive outreach, and maybe a rebranding of senior centers, with access to different services and providing more of a connection to the community.</p> <p>In addition, Cooley Dickinson Health Care is no longer providing home draw services, which makes it difficult for some seniors to keep up with their health. There is a need to make this and other home-based medical services available to seniors.</p>
7. Which skilled nursing facilities do you work with most frequently and are there any systems concerns – communication, hand-offs, medical records, medications, etc.	<p>The CDPHO staff reported that they work with three different skilled nursing facilities, and have not encountered any systems concerns.</p>

#### Quotes:

- “The general attitude toward elders in our society is a problem. They are not just people to be cared for.”
- “The hospital sees episodes of care, but doesn’t see the full picture”

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Key Informant Interview Report**

**Hospital/Insurer:** Mercy Hospital

**Interviewer:** Kim Gilhuly

**Interview Format:** Phone interviews, from 30 to 45 minutes in length.

**Participants:**

- Dr. Shirin Nash, pathologist, physician liaison with community, Cancer Committee outreach coordinator.
- Ashley LeBlanc, thoracic surgery nurse navigator. Provides education and helps people with expectations and navigating through cancer, the hospital system, and can get people connected
- Stephanie Velis, oncology program coordinator.

Question	Synthesis of Responses
1. Strengths of Mercy's Cancer care and support services.	<ul style="list-style-type: none"> <li>• Get patients in very quickly – important for the stage of cancer and getting treatment. Much quicker in comparison to other places.</li> <li>• Very committed, responsive, and talented doctors and staff</li> <li>• Treat all kinds of cancer – breast, colorectal, prostate, other – but specialty is lung cancer – have specialized surgeons and services.</li> <li>• Have a robust support team – two nurse navigators, two social workers and one patient advocate dedicated to the Cancer Center. Have amazing spiritual counseling.</li> <li>• Also have lung cancer screening program – the earlier you detect the better the outcomes are.</li> <li>• Have an amazing Cancer Support group.</li> <li>• We have a Patient Fund here that people contribute to.</li> </ul>
2. Services and supports that you wish Mercy had.	<ul style="list-style-type: none"> <li>• Better programs to treat the psychological side of things. "The C word is a really scary thing."</li> <li>• Services to help people feel emotionally well, such as massage, reiki, pet therapy, acupuncture, meditation, hypnosis. Classes in how to do make-up, moisturizer to use for your skin, sleeping changes. "Things that help people feel their best when they are feeling their worst." Almost impossible to get reimbursed for these things.</li> <li>• Clinical trials – have to send to Boston or Hartford</li> <li>• Cancer survivorship support – more people are surviving (great!) but need guidance, support, mental health services during survivorship</li> <li>• Education for patients – what is cancer, how do you access care, etc.</li> </ul>



	<ul style="list-style-type: none"> <li>Smoking cessation for oncology patients (not just lung cancer)</li> </ul>
3. Barriers people face that it would be helpful to address (or address more)	<ul style="list-style-type: none"> <li>Transportation – shuttle, better taxi service, make sure taxi voucher program through the Patient Fund is still running, that cancer patients are accessing Mercy Hospital Uber services, even some sort of valet parking services and help getting exhausted and nauseous patients through the parking lot and the hospital</li> <li>Co-pay assistance – can be very large and we don't have assistance</li> <li>Financial counseling – have support from social workers if people need help w/ their insurance companies, but having someone in the Cancer Center to think through the cost of their treatment (which can be huge) would be helpful. Can access financial counseling for all of Mercy, but would be good to have in Cancer Center</li> <li>Bilingual assistance</li> <li>Mental health needs</li> <li>More community outreach so people know about the Cancer Center. We have amazing services here and many people don't even know we're here.</li> </ul>
4. Models for care in other places that would be good at Mercy	<ul style="list-style-type: none"> <li>Genetic counseling and genetic lab services to enable targeted therapies (if a tumor has a specific genetic makeup there may be specific drugs). Must have ability to identify the problem, counsel, provide therapy for that problem, and then counsel families as to what it might mean for them.</li> <li>Breast cancer screening that is more immediately responsive. Would mean having a standby radiologist do a "wet read", if something is suspicious get immediate same-day appointment for ultrasound or biopsy. Now Mercy has a primary care model, PCP order mammogram, it's read in a day or so, results back to PCP. It's just slower. Our breast cancer screening to treatment should mirror how fast and responsive our lung cancer screening to treatment is.</li> <li>Palliative care team inside the Cancer Center. Mercy has a palliative care service just for inpatient, we would like to have an outpatient service. We have a pharmacist pain specialist we can access, but would be good to have palliative care at the Cancer Center.</li> </ul>
5. Impacts of cancer diagnosis	<ul style="list-style-type: none"> <li>Devastating</li> <li>Scary, anxiety-provoking, general emotional distress</li> <li>Impacts not just the person with cancer but caregivers</li> <li>People need to know – I have cancer, what does it mean for me, my family, will I work again. It would be great if we could explain to every cancer patient their prognosis, therapy, how to survive cancer. Just not sure if any of our first line clinicians, primary care docs, have the time.</li> </ul>
6. Cancer prevention	<ul style="list-style-type: none"> <li>Lung cancer screening at the hospital. If you can identify lung</li> </ul>

efforts that Mercy is doing	<p>cancer early on, you can treat it early and prognosis is much better.</p> <ul style="list-style-type: none"> <li>• We did one free lung cancer screening day last year and will do one this year</li> <li>• Did some work through Transforming Communities Initiative educating adolescents about the harms of smoking</li> <li>• Helped pass Tobacco 21 in Springfield and the state. Some of those same youth in the education sessions were able to talk to legislators.</li> <li>• Work with Tobacco Free Springfield – meet to see who is selling tobacco to whom</li> <li>• Education about cervical cancer screening for Healthcare for the Homeless</li> </ul>
7. Cancer prevention efforts that would be good to do	<ul style="list-style-type: none"> <li>• Continue lung cancer screening</li> <li>• Mobile CT scan so lung cancer screening doesn't NEED to be done at the hospital</li> <li>• HPV vaccination outreach and education – the Cancer Committee is planning on doing some of this in the coming year</li> <li>• Do HPV screening event and a prevention/education program</li> </ul>
8. Policy or practice change that Mercy could support that would decrease risk of or reduce cancer (like Mercy supported Tobacco 21 law last year)	<ul style="list-style-type: none"> <li>• Lung cancer is the deadliest cancer (only about 17% of people are alive 5 years after diagnosis). Outcomes are much better if caught earlier.</li> <li>• Push the U.S. Preventative Services Task Force to incorporate lung cancer screening into doctors' computer programs so they are prompted to ask patients if they fit the criteria.</li> <li>• Insurance companies should expand the criteria for lung cancer screening – it is very narrow now (age 55-77, former smokers within 15 years, family history) and many more people would benefit.</li> <li>• Expand awareness in 1) health care community and 2) general public of importance of lung cancer screening</li> <li>• Address the barrier that regulatory and compliance puts on hospitals setting up ancillary services (massage, meditation, acupuncture, etc.). Now it's very hard to bring in outside services because of laws and rules that implicate that hospitals are trying to coerce patients to come.</li> <li>• Resources for HPV education and screening</li> </ul>
9. Have you witnessed any inequities in cancer treatment or services by race, income, gender, sexual preference, or in any other way?	<ul style="list-style-type: none"> <li>• No</li> </ul>
10. Anything else?	<ul style="list-style-type: none"> <li>• Would like to see cancer rates for different types of cancer in the hospital service area incorporated into the CHNA.</li> </ul>

	<ul style="list-style-type: none"> <li>• Mercy does some amazing stuff, would be great if the larger community knew about it. Healthcare for the Homeless, community work through Transforming Communities Initiative, other. This all should be publicized!</li> <li>• Heresy, but would be great if we could have ONE cancer center in the Springfield area and everyone get treated there rather than duplicating services. Not sure everyone would agree.</li> </ul>
--	--

#### Quotes:

- The Mercy Hospital Caritas Cancer Center is “not just competent cancer care but compassionate cancer care.”
- “We get patients in very quickly, and are very responsive to patients. Doctors and the whole team are very available. We get patients in appointments in 24 – 48 hours; other facilities might not even answer the call in that amount of time. Mercy tracks patients from our lung cancer screening; where other hospitals’ time between initial scan and surgery is 4 to 6 months, ours is less than 30 days.”
- “The “C” word is a really scary thing, and people don’t often know how to handle or understand the diagnosis or what it means for them. Support systems, how are people going to get the kids on the bus. I wish we had a program to assist this side – it’s usually simple things.”
- The survival rate for lung cancer is lower than any other cancer. Only 17% - 18% are living 5 years after their diagnosis, compared to breast cancer where 90% are. That’s why screening and immediate treatment are so important.
- “People in the world don’t understand that HPV vaccination is prevention – of cervical, penile, others cancers, and if you can vaccinate kids while they are still developing you can be protected for life. But there is this strange thought out there that having child vaccinated at 10 or 11 will make them promiscuous. My subcommittee [of Mercy’s Cancer Committee] is going to find ways to talk to parents about this.”

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Key Informant Interview Report**

**Hospital/Insurer:** Shriners Hospital

**Interviewer:** Catherine Brooks

**Interview Format:** Phone interviews, approximately 30 minutes - 1 hour in length.

**Participants:**

- Ava Adamopolous, Program Director, Boys and Girls Club of Springfield
- Kelly Phillips, Founder and Director, KP Fit
- Lawrence Kaplan, Developmental Pediatrician, Shriners Hospitals for Children
- Lisa Bakowski, Principal, Edward P. Boland School, Springfield

Question	Synthesis of Responses
1. What specialty medical services for children are needed that are not offered in western Massachusetts?	There is a lack of pediatric subspecialties – neurology, neuropsychology, neurosurgery neurodevelopmental pediatrics. There are also no autism clinics. Western Massachusetts needs occupational therapy that is appropriate for children with sensory issues. There are very few providers – it’s a chronic problem; it’s very difficult to attract people to work in the Springfield area.
2. What barriers do families face in obtaining access to specialty medical services for their children in western Massachusetts (i.e., awareness, availability/wait lists, insurance/cost, transportation, distance to travel)?	The major issue is access, waitlists – there is a waitlist of over a year for Dr. Kaplan’s program. There is also lack of awareness among parents about what services are available, and what developmental delays look like. Many parents don’t understand the system, how to use it, or how to get the care their children need.
3. Do you have ideas for ways that Shriners or other hospitals could be helpful to families with a child with disabilities around access to specialty medical services? If so, what are they?	<p>Dr. Kaplan is working collaboratively with Northampton Area Pediatrics, based on Collaborative Office Rounds. He is in direct communication with care providers and has the opportunity to follow up on referrals. This could also be done with Holyoke Pediatrics – they are interested in starting the process.</p> <p>Shriners offers BFit, a new cerebral palsy clinic. Shriners could do something similar for children with behavioral issues, pairing children with tutors/mentors, using the Basketball Hall of Fame resources for rewards.</p> <p>Shriners could offer educational materials aimed at parents, such as descriptions of the typical ranges of development, a list of what resources there are for children not meeting these targets,</p>

	<p>descriptions of how to access these resources. This could be disseminated through schools.</p> <p>In an ideal world, Shriners and other hospitals would provide a crisis response team, evaluate a child who needs help, and connect them with services.</p>
<p>4. What types of supports or resources do families and children with disabilities need to gain greater access to physical activity opportunities? What is not offered here in western Massachusetts?</p>	<p>Services in western Massachusetts are very limited – it's especially difficult to find services for children with autism. We need access to swimming pools for swimming lessons and Hubbard tanks for warm water therapy. There is no gym at Shriners. We need more opportunities for kids in wheelchairs to be mobile.</p>
<p>5. What are some of the barriers that families face in obtaining access to physical activity opportunities for their children with disabilities? (e.g., equipment, accessibility, awareness, availability/ waitlists, insurance/cost, travel, etc.)</p>	<p>The biggest barrier is lack of information about what is out there. Other issues include cost (insurance does not usually cover these types of opportunities), transportation, the need for venues that won't provide sensory overload, and the need for venues that are barrier-free.</p>
<p>6. Do you have ideas for ways that Shriners or other hospitals could be helpful around access to physical activity opportunities for children with disabilities? If so, what are they?</p>	<p>Someone needs to put together information about what is available and distribute it to families and schools. This has been done in Connecticut and could be done here – someone needs to keep on top of this information, make sure the programs are effective, and make sure the information gets out to families (could be distributed through schools). There are a lot of grassroots organizations out there, but no one is gathering all of the information. This could be a task, not for Shriners Hospital, but for the local Shriners members and women's auxiliary members in the area. They are willing to roll up their sleeves and get to work, looking for projects. The hospital could disseminate the information they collect.</p> <p>Shriners also has vans that can support transportation to programs. Shriners could also partner with community organizations, churches with space, YMCA, colleges, to offer programs throughout the city. People are more likely to go to programs if they are nearby.</p>
<p>7. What do you know about the frequency or type of bullying that occurs</p>	<p>It's definitely a big issue. There are estimates that 70% of children with disabilities are bullied at school. It's usually verbal abuse, taunting, and staring. Schools can combat this with integrating</p>

towards youth with disabilities in the local schools?	children, lunch groups, model play.
8. How does bullying affect the physical and mental health of youth with disabilities? In what ways does bullying impact them differently than youth without disabilities?	Bullying diminishes self-confidence, which is already low for these children – they cower down, withdraw. They sometimes exhibit selective mutism. It can lead to physical issues – for example, a child who won't use a walker for fear of being singled out could fall more often and get hurt. The impact varies – some students aren't aware of it, because their disability impedes their perception, but others range the gamut from being bothered by it to being acutely aware. It makes their disability even more traumatic for them. It can be hard to know what is bothering them and how to address it.
9. What types of bullying prevention education would be helpful for children with disabilities and their families? Who do you think should do it?	<p>Kids get a lot of general, schoolwide messages, but they don't internalize them. There needs to be more of a connection. Kids need to express how the bullying makes them feel, in encounter groups mediated by adults, or the parents of bullied children could do this. Maybe bring bullies and victims together to work on projects, again with adult supervision.</p> <p>Difference of opinion over doing it in school vs. in outside groups. One respondent thinks that kids are more receptive to messages that they get in fun, social settings. Another talked about the need to do it in school so that they don't have to transfer skills learned in an outside setting to the school setting.</p>
10. If resources were available to spend on initiatives that might address the problem of bullying and children with disabilities, what types of things do you think should be done? What should we consider... educational programs, public campaigns to promote inclusion/integration and acceptance? Who should we target for these initiatives... the individuals with disabilities themselves, families, caregivers, schools... etc.?	<p>Exercise programs that are adapted for people with disabilities – builds self-confidence, self-worth, makes them less vulnerable to bullying. Currently there is a lack of quality fitness programs for people with disabilities – a lot of the organized activities for them are around food.</p> <p>It's best to start with young children, and use school settings to build awareness, provide information. You can use spaces and events where parents and families gather. It's important to start in elementary school - begin the work of building decent people who appreciate each other.</p>
11. Is there anything we	There should be an educational health collaborative, modeled after

haven't discussed that you'd like to mention before we finish the interview?	<p>the program in Connecticut, established here – it brings people together, and provides momentum and continuity for goals.</p> <p>Professionals need to underscore the importance of using schools as a conduit for providing information to families.</p>
--	--

#### Quotes:

- “The clock is ticking . . . we’re missing opportunities to provide services to these kids”  
Lisa Bakowski
- “A good part of disabilities care isn’t medical care” Larry Kaplan
- “Shriners can be a hub for information” Kelly Phillips
- “People with disabilities are perfect victims for bullying and abuse” Kelly Phillips
- “If kids are uncomfortable or if something is unfamiliar, they make light of it” Ava Adamopolous

NOTE: Kelly Phillips mentioned that her church, [St. Paul Lutheran](#) in East Longmeadow, would be interested in partnering with Shriners to offer space for programs for children with disabilities. Anne Strickert is the pastor.

**Coalition of Western Massachusetts Hospitals  
2019 Community Health Needs Assessment**

**Public Health Interview Summary Report**

**Interviewer:** Catherine Brooks

**Interview Format:** Phone interviews, approximately 30-45 minutes in length.

**Participants:**

- Helen Caulton, Commissioner of Public Health, City of Springfield
- Ben Cluff, Massachusetts Department of Public Health, Bureau of Substance Use Services
- Julie Federman, Health Director, Town of Amherst
- Dalila Hyry-Dermith, Supervisor, Massachusetts Department of Public Health, Division for Perinatal, Early Childhood and Special Needs, Care Coordination Unit
- Phoebe Walker, Director of Community Services, Franklin Regional Council of Governments

Question	Synthesis of Responses
1. What local policies and social conditions predispose people in your community/ service area to good health and mental wellness?	Some of the conditions and policies mentioned included schools, education around prevention issues, nutrition, and health. In more rural areas, there are farms that have farm stands and Community Supported Agriculture programs, and institutional support for local healthy food. In urban areas, there is good access to services. The hospitals do a good job with outreach to communities in general and to people of color. Communities in this area are attuned to wellness and health in implementing policies throughout local government.
1a. Are there groups of people who benefit from these policies/social conditions more than others?	The people who benefit most are white people and people with higher levels of education. The system is oriented toward prevention, so people who are able to hear and incorporate that message are better served. Implementation takes more time and money than prevention does. There is a lack of cultural competence in provider community – it is difficult for people of color to access mental health supports from people who understand their culture.
2. What kind of structural and social changes are needed to tackle health inequities in your community/service area?	There is a need to integrate services that are provided from different organizations. We need an integrated approach to health care, removing structures that get in the way of collaboration. Physician training should include racial equity, family-centered care. We need a graduated income tax, and greater investment in education, child care, transportation, and community health workers. We need one-stop shopping with health care services under one roof. We need cultural humility, diversified offices and staff, public schools with staff who look like the students.
3. What are the 3 most urgent health needs/problems in your service area?	The issues most frequently named were mental health, substance use, obesity, chronic diseases.
4. In the last 1-2 years what	Public health officials in Hampshire and Franklin counties



health issues have emerged or increased dramatically in prevalence in your area? What evidence or data do you have to illustrate this increase?	mentioned tick-borne diseases. These are tracked through the University of Massachusetts, which tracks ticks sent in for testing, and through the Massachusetts Virtual Epidemiologic Network, which tracks diagnoses. Other health issues mentioned include pertussis being spread through unvaccinated people, and influenza. Health departments are facing bigger issues, such as mental health, substance use, and opioids, but these have been around longer.
5. What gaps in services exist in addressing these needs? What are barriers to filling these gaps?	We need a coordinated system of roles, the widespread use of Community Health Workers, and recovery coaches. Public health professionals need to be out in the community, and value community voices. We need a centralized public health system – some small towns do not have services. We need better transportation in rural areas – I would love it if hospitals would buy vans. Emergency Medical Technicians can provide wellness checks and preventive services. This would be especially important for mental health – there are not enough providers, people have to travel to find them. We need more racial and cultural competence, especially for mental health providers. The current education system for health providers lacks this.
6. In addition to more funding, what resources do you need to better address these emerging or increasing health concerns?	We need policy changes at the state level – established minimal expectations for public health services at the town level. We need a good public health response and resources around marijuana legalization. We need culturally sensitive practices in health care, which includes providers who look like and are from the community, who understand the culture, and who understand the history of racism. Hospitals need to develop a transportation infrastructure, and to develop the workforce to provide mobile health care (Boston is making a start with this). There needs to be outreach to mental health patients and an increase in prescribers for mental health issues, especially those who accept MassHealth health insurance.
7. What specific vulnerable populations are you most concerned about? And why?	<p>Populations mentioned included:</p> <ul style="list-style-type: none"> <li>• People with mental health issues</li> <li>• People coming out of jail</li> <li>• African-Americans</li> <li>• Transgender population</li> <li>• Isolated elders</li> <li>• New Americans, from specific communities that lack established outreach</li> <li>• Homeless</li> <li>• Residents of rural communities</li> <li>• Inner city residents</li> </ul> <p>All of these communities lack resources, access, culturally sensitive providers.</p>
8. Externally, what resources/services do you wish people in your area had access to?	<p>Resources and services mentioned included:</p> <ul style="list-style-type: none"> <li>• Transportation</li> <li>• Better pain management services (Stanford has a course about</li> </ul>

	<p>creative, non-medical approaches to pain management)</p> <ul style="list-style-type: none"> <li>• Housing for people coming out of jail</li> <li>• Supports for new Americans</li> <li>• Funding for social determinants of health</li> <li>• Workforce issues – recruiting and retaining physicians</li> <li>• Drop-in day services for people with mental health issues and people experiencing homelessness</li> <li>• Easy-to-navigate public health insurance accepted by most providers</li> </ul>
<p>9. How would you recommend that your local hospitals/insurers and/or Western Massachusetts Hospital Coalition work in closer partnership with local and regional municipal public health entities after the CHNA is completed? What specific ways can such a partnership be supported and sustained?</p>	<p>Hospitals are the big organization in any partnership. They need to step back and not always take a leadership role, let smaller community-based organizations lead at times. There is a need to clarify roles and responsibilities within partnerships.</p> <p>Some suggestions for what hospitals can do include:</p> <ul style="list-style-type: none"> <li>• Working with public health nurses on readmission prevention and discharge planning</li> <li>• Partnering with local health departments for workshops on pain management</li> <li>• Putting pressure on the state to provide public health, put political power behind the need for a better system</li> <li>• Providing Community Health Needs Assessment data for their communities to local health agents</li> <li>• Providing forums for community people to come together and talk</li> <li>• Supporting partnerships between public health nurses and community liaisons from hospitals. Jeff Harness does this very well, but he is one person</li> </ul> <p>Sustainability suggestions include:</p> <ul style="list-style-type: none"> <li>• Using community benefits funding to support and sustain the partnership</li> <li>• Working from a project list to sustain momentum</li> <li>• The Massachusetts Department of Public Health can provide financial support for forums</li> </ul>
<p>10. What issues do you see emerging in the next 5 years?</p>	<p>Issues mentioned included:</p> <ul style="list-style-type: none"> <li>• The opioid crisis will keep evolving, with new types of drugs</li> <li>• The warming climate will lead to an increase in tick-borne diseases, mold, respiratory ailments</li> <li>• Youth marijuana and vaping</li> <li>• Pertussis</li> <li>• Child and maternal health</li> <li>• Obesity</li> <li>• Aging population, especially veterans</li> <li>• The rising cost of health insurance</li> <li>• The immigrant community being afraid to access health insurance and health services</li> </ul>

**Quotes:**

- "We're too often talking about people, not with people." Helen Caulton
- "Hospitals see themselves as taking leadership roles in places where they should be taking supportive roles, especially in public health." Helen Caulton
- "Health disparities are seriously affected by where you live, your race, your income." Ben Cluff
- "We consider health in all our policies - we look at impact on health, not just on traffic, finances" Julie Federman
- "People whose mental health needs are not met become poorer in physical health" Julie Federman
- "Mental health has a social component - it's hard to treat people who don't look like you" Dalila Hyry-Dermith

## Appendix V. Community Conversation Summaries

### Coalition of Western Massachusetts Hospitals 2019 Community Health Needs Assessment

#### Community Conversation Summary Report

**Primary Hospital/Insurer:** Baystate Medical Center

**Topic of Focus Group:** Health needs and social determinants of health/ Spanish

**Date of Focus Group:** 2/08/2019

**Facilitator:** Melissa Pluguez-Moldavskiy NAHN-WMass

**Note Taker:** Brittney Gonzalez

**Location:** Riverview Senior Center, Springfield, MA

#### **Executive Summary**

##### A. Participant Demographics:

- 45 people
- Brightwood neighborhood/ Clyde Street in Springfield
- Primarily Hispanic/Latino attendees
- Majority elderly and mixed gender

##### B. Areas of Agreement (top health needs and related issues):

- Transportation: length wait times, delayed arrival or none at all causing missed appointments
- Access in Spanish to services
- Nutrition services in Spanish, diabetic education
- Food insecurity
- Day resources for the elderly

##### C. Recommendations:

- Need more dialogue and mutual conversation with health care providers, phone resources available in Spanish in the offices.
- Need more resources to address social needs in a culturally competent manner for the Spanish community. Senior centers are a good resource for resources, but underlying social/economic needs require more attention.
- Need more community involvement
- Stay focused on key needs
- Need more time to talk and to talk more frequently, not just every 3 years, include more Spanish-speaking communities.
- Want to know more about when the report and CHNA findings will be available - what will be done with this information to make improvements?
- Do more advertising for future meetings to get more people

D. Participant Quotes:

- "Transportation: Hospitals don't provide enough, Public is cheaper but riskier."
- "Education is not culturally sensitive; diet medical, lack of cultural knowledge in the medical community."
- "Advisar de recursos que hay para la comunidad hispana (advertise about resources available to the Latino community)"

Question	Synthesis of Table Discussions
1. What are the top 3 most pressing health needs in your community?	<ul style="list-style-type: none"> <li>• Transportation</li> <li>• Culturally competent care with Spanish speaking translators</li> <li>• Food Securities</li> </ul>
2. Who is disproportionately impacted by these problems? How?	<ul style="list-style-type: none"> <li>• People without transportation</li> <li>• Non-English speaking</li> <li>• Undereducated</li> <li>• Speakers of other languages</li> <li>• Homeless/at risk for homelessness</li> <li>• People living with substance use disorders</li> <li>• Older adults</li> </ul> <p>These groups lack access to services, encounter stigmas that pose barriers to getting services, lack the means to get to and from appointments, do not understand how to navigate through the health care system, are just trying to survive "day-to-day", and tend to feel that health care is not necessarily a top priority.</p>
3. Who do you think is being missed in the CHNA process?	<ul style="list-style-type: none"> <li>• Media</li> <li>• Elderly/older adults</li> <li>• Barber shops and beauty salons</li> <li>• Men</li> <li>• Government officials</li> <li>• Grandparents who are raising their grandchildren</li> <li>• Youth and young adults</li> <li>• Single parents</li> <li>• Clergy</li> </ul>

## Appendix VI. Community Chat Summary

### Community and Stakeholder Engagement

The Western Massachusetts Coalition of Hospitals/Insurer prioritized the input of the community and other regional stakeholders as an important part of the CHNA process. In an effort to increase community engagement, the CHNA Regional Advisory Committee (RAC) brought information about the CHNA and gathered priorities at the regular meetings of service providers, community-based organizations, support groups and hospital-based groups in the form of Community Chats.

### Methodology

From January 2019 to April 2019, the RAC held 60 Chats throughout Hampden (46), Hampshire (10), Franklin (2), and Worcester (2) counties. The Chats were a convenience sample selected by Baystate Health through the input of RAC members, Community Benefits Advisory Council (CBAC) members, and through leveraging existing community relationships. Participation snowballed throughout the process with the assistance of Chat participants suggesting other community groups to include in the process. In total, the RAC reached 838 people through these Chats. Figure 1 shows the role participants identified with during the Chats.

Figure 1: Chat Participants

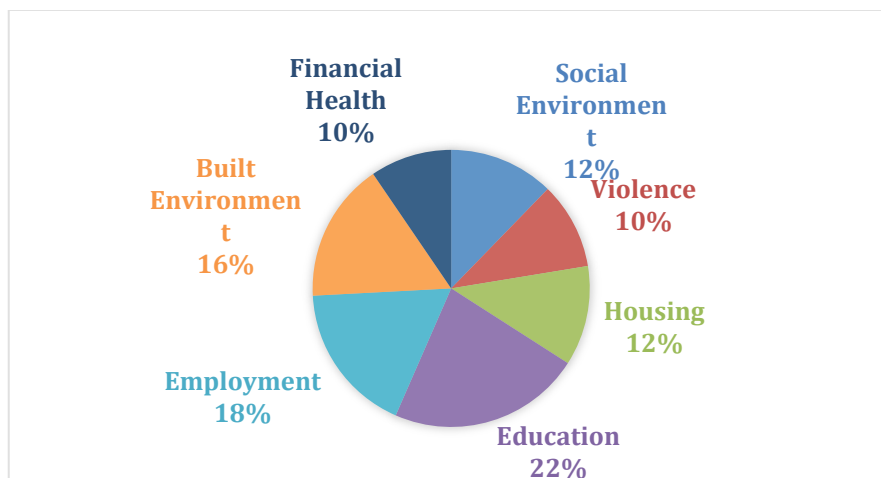
Nonprofit Staff	23%
Health Care Professionals	21%
Community Members	19%
Youth	13%
Older Adults	8%
Municipal Staff	5%
Community Leaders	5%
Individuals with Disabilities	3%
Transgender and LGBTQ+	2%
Faith Leaders	1%

### Health Needs, Issues and Concerns:

In 42 of the 60 Chats conducted, participants were given two sticker dots and asked to mark on a poster what they believed were the two most pressing health issues in their communities. Facilitators presented options organized by the Massachusetts Department of Public Health Social Determinants of Health Framework, which included: social environment, violence,

education, employment, housing, built environment, financial health, as well as more specific subsets of each topic listed. Figure 2 lists how Chat participants voted.

Figure 2: Social Determinants of Health Priorities 2019



### **Priorities from Chat Participants**

**Education:** Education was the top priority of Chat participants throughout Western Massachusetts. Resources and opportunities for education were identified as the most pressing issues, followed by social and psychological education, and knowledge and behavior. A lack of health literacy was a common issue for communities as well. Participants identified limited knowledge of available services, and the need for a reference list of all available services and resources within their communities.

**Employment:** Employment was also identified as a top priority in Western Massachusetts. Within the category of employment, Chat participants specifically elevated the issue of income and poverty over some of the other options, such as benefits and resources, employer policies, and physical workspace.

**Built Environment:** Built environment top priorities included transportation, health care access, and food access, respectively. Many Chat participants reported living in transportation deserts or reported inadequate transportation services. Participants also mentioned a lack of sidewalks and sidewalk upkeep. Community members reported issues such as food deserts, unaffordable healthy food, lack of fast-food zoning laws, and stigma around food pantries as challenges. Additionally, lack of health care access was indicated in many Chats. This includes: inability to pay for services, difficulty navigating healthcare and health insurance systems, long wait times in the ER and to see a health care specialist, and limited service providers. Overwhelmingly, participants reported a lack of mental health and substance use disorder treatment as an issue.

**Social Environment:** The social environment encompasses factors as such language isolation, racism, poverty, gender discrimination, immigration status, ageism and more. Through the Chats, challenges with the social environment were found at the individual, community and

societal (systems and policies) level. Increased cultural humility among providers, as well as a need for bilingual providers, were areas where participants identified needs. Institutionalized racism was consistently mentioned as a significant contributor to poor health in Western Massachusetts. Community members also identified a lack of community engagement and specifically requested more after-school programs and mentoring programs for youth.

**Housing:** Participants named homelessness as the top issue within the housing category, with some participants also reporting housing stability and quality as an area of concern. Chat participants specified that affordable housing was low quality and aging, but also limited, leading to long waitlists.

**Financial Health:** Financial health is built through having access to safe, high-quality financial products and services that help people save, spend, borrow, and plan. Financial health not only improves a person's life today, but it also creates opportunity for their future generations. Overall, Chat participants reported financial health as a general problem.

**Violence:** Violence was most frequently reported as a problem at the interpersonal level (such as domestic violence, bullying, and homicide). Self-directed violence, including self-harm and suicide, was also reported as a community concern.

### **Vulnerable Populations**

Commonly cited vulnerable populations and common challenges include:

- Immigrants, refugees, and non-English speakers – Lack of access to care, low health literacy, and lack of cultural humility from providers
- Older adults – Isolation, loneliness, unaffordable care, and lack of transportation
- Youth – Substance use (vaping, alcohol, and marijuana), limited school resources, poor mental health
- LGBTQ+ – Stigma, lack of family and community support, untreated mental health, and lack of LGBTQ+ knowledgeable providers
- Low-income people and People of Color – adversely impacted by all the challenges and lack of resources stated above in prioritized health challenges
- People with disabilities – lack of transportation, lack of health care providers

### **Community Assets**

Community assets were often very specific to the community where the chat was held. However, some consistent community assets included: community centers, local hospitals, schools, support groups, faith communities, libraries, and community colleges.

### **Limitations and Recommendations**

The Chat data have some limitations. Many of the Chats were clustered within Hampden County, particularly within Springfield and Westfield. Additionally, older adults, people with disabilities, and youth participated less in the quantitative assessment (voting on social determinants of health) due to the nature of the activity, leading to the potential that this may have skewed the data. Additionally, Chats were facilitated by approximately ten different RAC



members; questions may have been asked or framed differently depending on who facilitated the conversation. In the future, we hope to select a more geographically diverse population, capture the demographic make-up of the Chat participants, and begin the Chats earlier in the CHNA process to better guide CHNA priorities.

## **Appendix VII. Notes from Cooley Dickinson Community Benefits Advisory Council**

Notes from the Community Benefit Advisory Council that were incorporated into the 2019 Cooley Dickinson Health Center CHNA.

### **Data suggestions:**

- Population-based initiatives in discrete census tracts (i.e. Meadowbrook apartments)
- Convenings of at least Western Mass coalitions that operate in Hampshire County (Western Massachusetts Network to End Homelessness, Coalition to End Hunger, health providers network, PVTa)

### **Older adults:**

- Home remodeling help
- Transportation
- Avoiding social isolation
- Hire geriatricians
- Alzheimer's

### **Health system:**

- Need for referrals/connection between providers
- Physical access to health facilities
- Interest in evidence-based data collection
- Increase attention to family-patient-medical system collaboration
- Neighborhood markets
- SNAP matching programs
- Food access programs
- Mental health
- Opioid crisis
- Substance use disorder
- Homelessness
- Trauma as a lens for looking at SDOH for ALL ages, understanding that kids are most vulnerable
- Trauma sensitivity training for all social service providers
- Children and foster care
- Trauma – affected children generally
- Children and mental health/internal stressors – trauma free communities
- Housing and homelessness effect on children
- Health disparities
- Chronic disease programs

- Cancer survivors (LiveStrong at the YMCA)
- Both cultural sensitivity in relation to access and understanding of cultural frames to managing health situations
- Legal connections/coordination