



# Tompkins County Community Health Assessment

## KEY STAKEHOLDER QUALITATIVE INTERVIEWS SUMMARY REPORT

*PREPARED FOR: Tompkins County Health Department & Cayuga Medical Center  
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## Introduction

Twenty-six stakeholders representing various sectors participated in a qualitative telephone interview during March and April of 2019. Stakeholders were asked to complete a brief pre-interview survey to select the three most important: health issues facing the county, unmet needs, social determinants of health negatively impacting the county (Appendix A.) In addition, in the survey stakeholders were asked to select all the social determinants of health which positively impact the county.

<b>Most Important Health Issue</b>	<b>N</b>	<b>Top Unmet Health Needs</b>	<b>N</b>
Drug/Alcohol Misuse	17	Mental Health Care	15
Mental Health Issues	13	Dental/Pediatric Dental	14
Health disparities between populations	10	Long-term care/nursing homes	7
Nutrition-related diseases	8	Substance use/rehab/counseling/prevention	6
Child/adolescent developmental/emotional/mental health	8	Home health care	5
Poor disease self-management	5	Affordable health care/adequate insurance	5
Insufficient support for well-being and resilience	5	Health knowledge/skills	3
Adverse childhood experience	3	Trauma-informed care	3
Child dental health	2	Healthy Food	3
Tobacco-related diseases	1	Prescription medications	3
Poverty/lack of support	1	Respite care	2
		Specialist care	2
		Primary Care	1
		Apathy	1
		Vision Care	1
		Lack of child psychiatry	1

<b>Negative SDOH</b>	<b>N</b>	<b>Positive SDOH</b>	<b>N</b>
Poverty/Income insufficiency	15	Strong Network of Community-Based Services	15
Lack of transportation	11	Strong Economy	11
Housing instability	10	Green Spaces/Walkable Community	11
Food insecurity	8	High Quality Schools	10
Substandard housing	4	Arts/Cultural Events/Opportunities	10
Health illiteracy	4	Opportunities for Recreation/Physical Activity	10
Under/unemployment	3	Robust Civic Participation	8
Lack of social cohesion	3	Outdoor Air Quality	8
Lack of access to primary care	2	Sufficient Access to Healthy Foods	7
Racism/other oppression	1	Low Crime and Violence	7
Lack of comprehensive mental health services	1	Access to Religious/Spiritual Options	7
Underinsurance	1	Availability of Early Childhood Education	6
Stress	1	High Enrollment in Higher Education	5
Lack of access to healthy foods	1	High Graduation Rates	4
Lack of early childhood education	1	Sufficient Access to Primary Care	4
Lack of community based services	1	Water Quality	4
Lack of nutrition/exercise knowledge/skills	1	Social Cohesion	3
Discrimination	1	Access to Communication and Technology	3
Workforce issues	1	Health Literacy	2
Screens	1	Climate Conscious Design of the Built Environment	2
Desolation, Loneliness	1	Accessibility of Physical Spaces, especially for people with disabilities	2
Language/literacy issues	1	Sufficient, Affordable, Safe Housing	1
		Sufficient Transportation Options	1
		High employment	1
		High socio-economic status	1
		Sufficient Access to Specialty Care	0

In the follow-up qualitative interviews (Appendix B.), stakeholders were asked to describe the thinking behind their selections and their perception of the community's awareness of and willingness to address those issues. In addition, stakeholders were asked to identify areas where prevention programming has been successful and the types of programs and initiatives they would most like to see implemented.

## Drug/Alcohol Misuse

Key stakeholders ranked drug and alcohol misuse as the number one most important health related issue and the 4<sup>th</sup> most important unmet need.

### Prevalence

A number of stakeholders noted that drug and alcohol use is pervasive in the area.

*“As far as drug misuse, unfortunately, that’s the same thing other areas are dealing with. Opioids are happening all over the place and happening with siblings of my staff members. It’s pervasive, and we’re not taking any real measurable steps.”*

*“I see literally every day the results of people with alcohol and drug issues.”*

*“Of course, opioids are a big thing, though statistically our area is below the national average in individuals caught up in that.”*

*“We see drug misuse in our work. It crosses social classes [...] everyone here has been touched in some ways from overdoses that have occurred from the opioid crisis. Even my kids from Cornell knew someone who had a problem with heroin. I think the community is talking about it. I think that is over all [economic] classes. And then there’s just the drug use now generally. We’re a society that if you have a pill that will make it better. That’s a different type of misuse that is pervasive.”*

### Impact

Stakeholders also said the prevalence of substance use disorders combined with the severe impact of the disease was a key reason for selecting it as a top health priority.

*“I feel we are having an opioid and meth epidemic. At least that’s what I see and the people I’m in contact with see. It appears that heroin and meth have taken over families lives [...] people aren’t eating right, not sleeping, they don’t have housing. I think this creates an unhealthy situation for the total person. [...] I see people walking down the street that I can tell have just used meth and I’ve never seen that before.”*

*“We are also recognizing that many of these issues have changed grandparents into parenting grandchildren. The numbers are going to become greater – my own sister-in-law raises her grandkid because of an issue like this. [...] they are already limited with income and are not going to take their medicine and are going to use that money to take care of their grandchild. It’s going to impact in so many ways.”*

*“I think heroin is everywhere. I know people who have (overdosed). There’s data treatment models (abstinence only) that are more deadly for heroin addicts. We are pushing an evolution in how we think about that is a priority. The fire department said every other day they’re reviving someone in county – that’s off the cuff. It’s hard to get official data – REACH had some data, but it’s big. And the impact on kids.”*

## Awareness

Stakeholders noted that there is awareness of substance use disorders as an issue in the county, but there is a lack of agreement on the best way to address it.

*"I do think there's interest in addressing the issue, but there's a lot of discussion about how. We have leadership in Ithaca that's pushing for an injection site. Which nobody wants that in their neighborhood. I would rather have that than continue to find syringes outside our office in the playground."*

*"I think there's interest and I think there's probably some frustrations not knowing how [to address the issue]. People are interested in a wet shelter. There are recurring issues with the jungle and homeless population and people are recognizing that even if we had a great housing unit, especially if the program requires is that you can't use substances and have to be clean before/remain, it might not help. Those are real challenges. The interest in a wet shelter is just to meet people where they're at. I think there would be plenty of resistance in the community. There are folks on both sides of those issues."*

*"I think most people don't know how to address this stuff. I think the community is aware and to what detail depends on their sector and their stations and their income. It's easy to have "no idea." I think people self-isolate based on wealth and say 'I hear the mayor wants to do all this and doesn't know what he's talking about. And it's all the mayor and STAP's fault.' I think those two models [harm reduction versus abstinence] fight with each other. I think that makes everything more difficult. And so, we have factions and so people dig their heels into their group and I don't think people are very willing to listen to each in this county. We have lots of opinions here."*

*"With substance use, I think everybody ideally would like a solution to address it, but just nobody can agree on the right way to do it. I can understand not wanting their block turned into a testing ground. But at some point, that has to happen."*

Stakeholders also said they felt the county was at least trying to address the problem even with the disagreements on how best to address the issue.

*"I feel this community understands addiction and are at least trying to do something with the committees, and the mayor's pillars concept. There could be more tolerance. There are still some people in the community that think it's a bad character fault rather than a disease. But, again, our community offers stuff and understanding more than others."*

Substance use prevention and treatment was the fourth most commonly selected unmet need by key stakeholders. Stakeholders noted a lack of in-patient rehab options, the availability of safe, effective post-treatment sober housing, and prevention activities.

*"People who need the most crisis level of substance use prevention have to go to Syracuse, Rochester or Binghamton, so we've been heavily focused on getting that into the community as fast as possible. It's looking positive that it might be able to happen this year."*

*"It worries me that where the halfway houses are. Are they in locations where you can make healthy habits, or right next door to where they're getting their drugs from."*

*"[Prevention is] the most cost effective and best way to deal with any of these issues. There's not a lot of emphasis placed on that. And the different organizations within the NYS health care field don't define prevention the same way. So how we define prevention compared to physical health versus substance use versus mental health [is different]. The department of health calls Narcan prevention because it prevents death, but we see it as a treatment intervention."*

## **Mental Health**

Key stakeholders ranked mental health as the second most important health issue and the number one unmet need in the county.

Stakeholders indicated that the prevalence, impact, stigma, and the connection to social determinants of health were the primary reasons they selected mental health as an important health issue in the county.

### **Stigma**

*"I think there also remains a stigma around mental health and accessing resources. There are issues with people's understanding of how they manifest and what to do."*

*"It's obviously an issue that's been swept under table. People haven't wanted to talk about it or understand for a long time. Nationwide, statewide efforts are not enough. There are still a lot of people nervous about admitting they're on some medications, some anti-anxiety meds. There is still some stigma."*

*"...mental health has been something that people have not gotten the kind of assistance required. It's partly systemic, partly because insurance companies had to be legislated into providing support for it. It's better now because of advocacy, regulatory, and legislative changes. What I find that is that most people don't get help for the two most common mental health problems, anxiety and depression, until they are disabled from them. Once at a state of crisis, people start showing up at treatment providers, but most people don't seek help for these conditions until they absolutely have to...It's a combination of stigma, ignorance. We're experiencing an epidemic of mental health problems – both in the community and as well as at the universities. People are showing up as freshmen with mental health issues, and try as they can right now the system is overburdened. There is more need than there are counselors. That's a concern."*

*"I do think mental health is a huge issue and it's not something that we have in terms of available services. Particularly for folks who are low income. It impacts of people of all economic backgrounds, as does the stigma. And it impacts people's ability to live healthy lifestyles."*

*"We have a lot of rural poverty around us and there's both mental health and physical health challenges related to various stresses, and a lack of information and it can be a lot harder when you don't have resources in your household. [...] It's an interesting time we live in and how many young people coming to campus with various stresses in their life."*

### **Impact**

A stakeholder remarked on family systems issues which affect mental health treatment.

*“I work with a number of families with a parent with significant mental health issues who is caring for a child with mental health issues. They are in denial and not acknowledging their own problem and so don’t acknowledge the child’s. A lot is going on to lessen the stigma, but there is still stigma attached to mental health. And there is a lack of support from extended families around mental health. For example, I have a mom who wants help, but the grandmother may be saying there’s nothing wrong with that child. There is lack of generational support around mental health. And then also a lack of resources due to insurance and whatever transportation you may have. It takes a lot of work and a long time to build a positive supportive relationship where parents might trust you and trust that you have their child’s best interest at heart. So, some of our kids go year after year of not receiving any out of school mental health support and it gets deeper and harder for them. They not only don’t have coping skills, but continue their negative habitual responses. If a student gets upset, instead of using coping skills in classroom, they flee. That’s their way to escape. They do it enough and that’s what they do. And the longer you do that, the more ingrained it is to do that and it’s harder to change patterns of behavior.”*

### **SDOH Burden**

Stakeholders noted that while mental health issues cross demographic boundaries, specific groups may have additional challenges which may limit their access to mental health care.

*“It’s not that we don’t have the services to support people with mental health issues. And there’s more awareness and screening, but there seems to be some sort of gap in terms of people accessing care. I don’t necessarily think it’s awareness, it’s probably ongoing stigma. For [the older adult] population, we definitely see a lot of depression and anxiety. It might be history or adjustment to older age or a recent illness. They are appropriately screened, but access to care is different for different populations. We might screen them, but maybe they’re homebound. I know Family & Children’s has an in-home geriatric program, but they only can see so many people. Another example is young children with mental health issues who need psychiatry. There’s a limitation in what is available.”*

A stakeholder noted significant challenges for the immigrant and refugee communities in the county.

*“A fairly significant portion of the Cambodian population were so traumatized from the Pol Pot regime and as adults cry at the snap of finger at memories, say they have nightmares, and are still traumatized. A lot of Burmese villages were burned. We tried to get mental health services for someone, but she didn’t understand what I was taking about. She has two [family members] that are schizophrenic. One goes to a doctor to get medication, but can’t participate in a therapy program because of the language barrier. [Another family member] who had never been treated for psychosis and went three years without medicine wandered into the woods. That whole family has so much trauma in it. Racker goes in for some of kids, but she’s 22 and it seems there’s no program she could participate in because of the language barrier. How do you participate in a group setting? Same with an uncle who is an alcoholic. He got hospitalized with liver toxicity. They’re recommended group therapy, but it’s not going to work because he doesn’t speak a word of English. In our county, they are very isolated because of their inability to learn English. If they were in Rochester, there might be a group and some kind of social worker that could work with them.”*

A stakeholder noted that access may be dependent on financial status.

*“It’s hard for people to find mental health care, particularly if they don’t have the resources. You can pay to see a therapist, but if you’re on Medicaid, or have a crappy high deductible plan, you might think twice.”*

### **Lack of Providers**

Several stakeholders noted the lack of mental health providers is an issue in the county and a primary driver of identifying mental health as an unmet need.

*“We have a lot of students who have mental health issues or developmental issues that are not being diagnosed. So maybe a family – and this is across economics they’re going to pediatricians and they are giving a mental health diagnosis which is often just ADHD for all kids. It’s not what we think is going on and pediatricians are not the experts in mental health field. So, there’s a need for more diagnostic professionals in this area for child psychiatry. We only have one in Tompkins County that takes Medicaid and he’s spread through three different agencies he services. We have a lot of kids that are misdiagnosed and are not getting full evaluations. That’s an issue regardless of economics. They do have someone in Syracuse or Rochester, but the wait time is sometimes a year or a year and a half. Which creates transportation issues for people that don’t have the finances. It feels like it’s a one-shot opportunity. The doctor says this is what I think is going on, but there is no connection with resources in their own communities and there’s no follow through on the medical end of it. So, kids are really struggling at school because of the emotional and developmental issues they have. And schools are not a diagnostic place, it’s not our role. We’re trying to meet the needs of the kids, but don’t have a clear picture of what’s going on with them.”*

*“I know we need more child psychiatrists and psychologists. They’ve been recruiting people. Even getting prescribers, there aren’t enough in this county to get through all the kids. Your appts are five mins long if that. They read notes and then prescribe.”*

*“I know we have great services, but we know there is a gap. There are folks who aren’t getting the level of care they need such as affordable psychiatric care where they are being followed for medication management. There are primary care physicians being forced to follow patients that would benefit from something else. [...] They are screening more, but there are wait lists for things.”*

### **Awareness**

Stakeholders did not agree whether they believed the community is aware of the issues surrounding mental health in the county. Some stakeholders believe there is high awareness and a will to address the issues, while others said that there were only pockets of awareness and discussion is limited to service providers.

*“I do think there are a lot of conversations around mental health. I know the school district is keenly focused on it as well as other groups working to reduce barriers to access and reduce stigma. It’s not hard to convene a group of stakeholders around these topics, what is difficult is the best strategy or best resources.”*

*“[With respect to awareness] yes, the mental health subcommittee has been involved and is always looking to see what gaps in services exist and what can be done to respond to it. Some years ago, Ithaca did not have a board-certified child psychiatrist. Nobody could afford one and we*

*weren't going to get somebody to open a practice. A combination of the mental health department, Family & Children's Services and Cayuga Medical Center went to recruit a psychiatrist to meet the needs. [...] Between the Human Services Coalition and mental health subcommittee, I think there's a lot of awareness."*

*"I feel like it's not talked about. It's not normalized in my experience."*

### **Child Emotional Health**

A number of stakeholders said that the mental, emotional and developmental health of children specifically is a top health issue in the county. Several stakeholders remarked on the prevalence of mental and emotional health problems among children.

*"We're seeing that need is increasing [...] I think our more recent generations are more open to talking about emotional and mental health due to anti-stigma efforts for younger generations. [...] There is a lot of more recent evidence and reports, especially from school settings, that social media has negatively affected the emotional and mental health of youth – primarily bullying and feeling a discomfort with the future. [...] And I would say this is all age groups including transitional youth (18-26). That's trending up in the last 3 years."*

*"One of the things that's been front of mind for me is the fact that as we see in the general population, youth are seeing a rise in anxiety and depression. And having to navigate that as a school district is challenging. Because while we provide a significant amount of emotional support and do some emotional learning, that's not our primary mission. It has a significant impact on a child's ability to engage and learn."*

*"I'm in the schools a lot and talking with organizations who are working with school-age kids and it's everywhere. A lot of districts are talking about anxiety levels, and teachers are using instructional time to ensure kids are able to settle down and learn."*

### **Awareness/Interest**

A stakeholder suggested that there is high interest in addressing the mental, emotional and developmental health of children in the county through collaboration on anti-bullying and anti-bullying.

*"I don't think people are as alarmed about childhood issues as they should be. I think if some of the information were more public and known that would start a raging outcry, but I'm not sure people are seeing it as more than "my kid" or a kid in my kid's classroom. They don't see it as a public health issue."*

One stakeholder noted that the funding shifts for child mental health has been a difficult transition. Community-based organizations providing care had been regulated and funded through the Office of Mental Health which has been shifted to the Department of Health home care management model. The stakeholder noted that the payment model has resulted in fewer services being made available to children without Medicaid.

*"Care management agencies only get a little bit of reimbursement from the county and state because they figure there aren't that many non-Medicaid kids that need case management, but we don't have high Medicaid rates. Right now, we're getting close to having a waiting list for non-Medicaid care management."*

## **SDOH Burden**

Some stakeholders noted that social determinants of health such as housing and income insufficiency are tied to child emotional health.

*“There are a lot of children that are in insecure housing in this area and I think that insecurity is manifesting itself in kids having challenges that they shouldn’t have at that young of an age. I don’t know there are a lot of support systems for those kids to gain help.”*

## **Trauma/ACES**

A stakeholder noted that trauma is a key driver that must be addressed to help address child emotional health.

*“And the way schools are set up is to try to avoid conflict and to do whatever they can to “solve it” and move on. It’s not set up to actually view conflict as a natural part of human condition when we live in community and recognize those as opportunities for uncovering root causes and genuinely solving problems. If we could switch the paradigm and realize that we can actually proactively create environments that presume that all people have experienced trauma and actively teach people how to recognize when something is happening that’s moving them from a centered health place to an unhealthy place and how to communicate that and advocate for what they need. And create institutions where people recognize that’s happening to the other person. To me so many other issues would be resolved. Lack of academic success, discipline issues, all of these other pieces would work themselves out if we were starting from a foundation of creating a safe, healthy learning environment [...] we spend a lot of time dealing with other symptoms rather creating the foundation.”*

A handful of stakeholders said that adverse childhood experiences (ACES) are a top health related problem, but agreed that there is a significant amount of work to create awareness.

*“The research has over 30 years of support to show that the higher your ACES score, the more likely you’re going to have all sorts of issues as an adult. Just getting people to identify and address those early on in prevention and getting that word out to health providers [has been difficult] It’s been ignored, but has some of the most significant [proof] that if you address it you can really help with resiliency building.”*

A stakeholder said there are substantial emerging efforts locally to address ACES.

*“We’re part of the Compass Care Network and an ACES workgroup, started recently. A lot of agencies from Tompkins are part of that and we are hoping to bring something back to the community by the end of year to educate and to address ACES. [...] It crosses over so many different layers. It’s a score that helps inform and address care in a number of different environments including substance use.”*

## **Nutrition-Related Disease & Food Insecurity**

Nutrition related diseases and food insecurity was ranked as the fourth most important health issue and the fourth most important negative social determinant of health in the county.

### **Prevalence**

Stakeholders said the prevalence of nutrition-related diseases as well as the disproportionate incidence among specific populations were the reasons they selected it as a top health issue in the county.

*“It keeps coming up in community conversations, discussions about diabetes, obesity, heart disease, bad knees and other things that could relate to nutrition. I’ve come realize that a large amount of the population don’t take care of themselves. Part of that is because of money. Fast food is cheaper. It takes money and time to purchase, prepare and eat food.”*

*“I know the diabetes is probably one of the biggest problem that’s growing because of obesity in childhood. We see that with people who are getting prescriptions that have ill effects on the metabolic system. We’re definitely aware of that. OMH is telling us that more people have to be tested for diabetes, even children.”*

### **Health Disparities**

In addition to people with mental health disabilities, stakeholders remarked on the prevalence of nutrition-related disease among older adults, low income residents, and in the African-American community.

*“African Americans suffer more than other ethnicities with cardiovascular disease and diabetes [...] It is a long-standing issue in the community and continues to be.”*

*“What we’ve heard from our nutritionists at pantries, there are a significant number of clients who are suffering from nutrition related disease. There is a lot of diabetes, obesity, high blood pressure. Agencies are saying the same thing.”*

### **Food Insecurity**

Stakeholders remarked on the impact and persistence of food insecurity in the county.

*“I feel very strongly about food insecurity. You can’t be healthy if you don’t have food.”*

*“I think we are working really hard to address it. We have [...] great organizations that are on top of it. But it still exists.”*

A stakeholder noted that food insecurity is complicated by transportation challenges.

*“And if you live in any of the outlying areas, Enfield, Caroline, Groton, the outskirts of Dryden, Candor, Newfield - getting to a place that sells healthy food isn’t easy. I took TCAT and I had to take two buses to go to Wegmans or Greenstar. The places where people can buy fresh produce, non-highly processed foods is not easy or convenient. [And] one has to plan for it. Twenty minutes in and out so you have to plan more for an hour each round. And the bus doesn’t necessarily come super close. It may be a mile walk to a bus stop. It’s a complicated process.”*

## Health Disparities

Health disparities were ranked the 3<sup>rd</sup> most important health related issue in the county.

### Income/Age

Stakeholders noted health disparities primarily related to income and age.

*“[There is a] growing income disparity in the country and locally here in Ithaca, which is a unique place where you have rural, urban and suburban areas. It’s a lot less homogenous and you see those health disparities clearly manifest.”*

*“I think for me, personally, as someone who is interested not just as a psychologist, trying to understand the political economy of health. I do think many of the areas that are listed come under health disparities. We definitely see more ACES from trauma correlated with poverty. Clearly you have [health disparities associated with] access to food, prenatal care, and education. [...] There are probably correlations between tobacco and socio-economic status. Child dental, can’t get a dentist for anyone if you’re poor.”*

*“We see that the people we are serving are lower income and have less access to primary care and preventive care and are very much dependent on the emergency room. They have a reactive approach to health versus a proactive approach to health. A lot of that has to do with income.”*

*“Tompkins County sometimes gives an illusion that we don’t have some of the other problems that our surrounding communities have. We have higher income, Cornell, [...] but you drive 2 miles out and you have extreme poverty. [...] And for an older adult, those health disparities may look a little different. For an older adult, they might be food insecure or malnourished [...] because there are environmental challenges or metabolic challenges or access challenges because of an inability to transport. Or medical challenges like cognitive impairment, living alone, social isolation.”*

### SDOH Burden

A stakeholder said that social determinants of health can create additional burdens which make it difficult to access care.

One stakeholder described challenges with patients being discharged from care providers.

*“Patients get kicked out of a practice due to non-compliance with attendance or non-payment of bills. [They might] get a barrage of notices to what’s listed as their residence. But this is assuming the patient got that, could read it, and fully understood what it meant [...], but they often don’t realize they’ve been discharged until they try to make an appointment and then find out. Or an appointment gets made, but there is no follow-up or reminder or maybe the methodology for the reminder is phone and the patient doesn’t have working phone, then they’re missing the reminder.”*

A stakeholder said these challenges extend to mental health care.

*“I know for my family, if we needed to, we could seek out and get private care. We have money and insurance. I also know how challenging it is for young people and their families to get that care when they don’t have good insurance or the money. At least from my experience, it appears they*

*have to do a lot of work to get on [waiting] lists or on someone's caseload. There are a lot of hurdles along the way and it often seems that it just doesn't work out."*

## **Awareness**

Stakeholders had varying views on the awareness and will to address health disparities in the county.

*"I've worked in so many different communities and counties across western half of state and I've never seen a county so focused on gaps and a willingness of agencies to step up and try to fill it and the willingness of the county to spread resources to those efforts. An example is the re-entry coordinator for the county. The community did not want to incarcerate our population and that's a huge focus and especially incarcerating our behavioral health population. That was a huge disparity and not resiliency focused. The county literally gave us funding for a position. As far as I can find, no other community in the whole state is offering that."*

*"I think there's awareness in pockets. If you can identify those pockets and put them all in same room, would probably put a little more power behind it. We have access to payers to influence them, but having other community members input and how big of issues it is to persuade those people with power to change them. From a health care perspective, I see a lot inpatient and outpatient clients with health disparities that are labeled as non-compliant, but there's usually a reason behind that. In general, people are trying. They don't want to make their doctor angry, but they can't be expected to do what they don't know how or what to do. I think from a medical provider standpoint there is a disconnect with reality. They may not have communication from the patient."*

*"I don't think people give a shit enough about people of color to care about that."*

## **Poor Disease Self-Management/Health Literacy**

Poor disease self-management was ranked the 6<sup>th</sup> most important health issue and health literacy as the 5<sup>th</sup> most important negative social determinant of health.

## **Health Disparity**

Stakeholders noted that disease self-management is directly tied to health literacy especially among older adults, people with low incomes, and people with language barriers.

*"I think most of [poor disease self-management] is related to health literacy I think. People are not understanding what they're supposed to do, how they're supposed to manage their prescriptions. On discharge, they are confused and don't have support to manage that process. It's a gap and often what they end up doing is not getting prescriptions filled or following up on appointments. Eventually this will affect their health in general. Accessing transportation is an issue, [...] not having a person with them when they're going through the discharge process. I feel like it's a big issue for clients we serve. The people we see that require home care, aides, that access some of our services may be lower-income, needing more support and help. The clients we serve in general, it's pretty prevalent."*

*"Especially with the low-income people, they have a very hard time understanding their disease and how to manage their disease. I think we all have to remember to do our teaching with health literacy in mind. We're trying to include health literacy with the training of all our staff. The people*

*can't retain it if the teaching is done with medical jargon and it just goes over their heads. We all really have to tone it down. I think there's more awareness and some initiatives that bring more awareness."*

*"I think the health management skills that I'm seeing in the middle-aged to older immigrants and refugees [are a problem]. They don't know, don't take good care when have diabetes. They don't understand and rebound into the doctors' offices constantly. I have someone with asthma who is hospitalized a lot. Another who has wounds open up because he doesn't take care of it. They don't understand glucose and are not keeping up on reading [their blood sugar]. It usually takes a family member taking care of them. But if there's a language barrier, then it's even more difficult. There's more access to home health without as many regulations, but Visiting Nurse Services said they couldn't communicate and then just were done. There is a need to have language services on the phone or have it paid by government."*

A stakeholder noted that there are challenges with health literacy due to a lack of education.

*"I know there are programs at health department where they go into the community. I see the health department at street fairs and trying to educate people. I think it's a community that cares and tries to address the issues by education, but we haven't found the way to get people to find the action that's needed. Don't know if that's the people doing the education don't look like folks that they're trying to educate or not from the immediate community. In a lot of ways Ithaca is a small town and closed in some ways. So that if you don't know someone and therefore trust them, you're not likely to take the action they're urging you to than if it was if was someone you knew. Green star is a [good] example. They instituted the flower program and have done a good job with diversifying staff and putting programs in to reach out to diverse communities. Being out in communities, partnering with community agencies. The health department, we always see them out at the fairs, Southside, Juneteenth, I think there are efforts being made. But I think Greenstar has done a good job of getting folks of color involved as employees and involved."*

*"I think the ability to read is an issue, but then there's the ability to actually understand. There are multi-factorial issues related to diabetes. I don't think we do a good job as a health care community of displaying common disease pathways. [We do well with] tobacco, but diabetes – we're not advertising, highlighting the amputations, dialysis, blindness that's the eventual pathway for uncontrolled diabetes. [There's no] general knowledge about disease processes and how treatable they are and the importance of preventive care and screening. They don't know what they don't know and it's our job to teach them."*

*"For people with chronic conditions, I'm surprised the degree to which they don't understand their diagnosis and the inter-related nature of their behaviors and decisions and health outcomes. For example, with heart failure, there's no going back, there's no reversing like with type 2 diabetes. We had patients that thought it was an acute, not chronic condition that didn't appreciate that consuming a high amount of sodium would land them in the hospital. It's not limited to people of low income. We have really highly educated individuals that live in the anti-vaxxer camp. I think health illiteracy along with skepticism of science and well-established facts threaten all ends of the economic spectrum."*

*"There's a segment of population that may not be that savvy, but I would also put it to you as a physician, there are patients who are getting health information from the internet and that's [also]*

*illiteracy. A lot of it is not vetted or even validated by any medical standard. Patients who are taking their health care into their own hands and in a lot of cases making themselves worse. We see that in fad diets, CBD oil. People are taking their care into their own hands when they are getting information from non-medical sources.”*

## **Dental/Pediatric Dental**

Dental and pediatric dental were ranked the second most important unmet need by stakeholders.

### **Lack of Providers**

The most significant issue related to dental care in the county is the lack of Medicaid providers and funding for dental.

*“We just found out, one of our clients tried to make an appointment, but nobody takes Medicaid any more. Now you have to go to Binghamton, Cortland, or Lodi, if you have fee for service Medicaid.”*

*“Dental for elders is a big issue. I know hardly any dentist accept Medicaid, but most also don’t accept Medicare – same for eye care. When you’re older is when your teeth and eyes are at the worst point and there’s [no care available] so people don’t do it.”*

*“We see those dentition issues very significantly with the older adult population. More people are requesting please don’t send apples because they can’t chew them. They have no dental care, no access, and can’t afford it. And they don’t have teeth. I don’t know the level of challenge with kids. Cost and access to affordable dental care is probably the same for them. But it really impacts older adults and how it affects their nutrition.”*

*“On a committee about 5 years ago, we hosted nurses from all the schools in the county. They said was dental [is a problem]. Very few people have dental plans. It’s a flaw in the inadequate insurance system. Not covered for many people and so they don’t go to dentist. And who it hurts the most again, is low-income families. They only go when have a cavity and it hurts and by then probably compromising health. In schools, that’s what nurses told us, dental health is a huge problem.”*

*“There are not a lot of good dental providers that accept Medicaid. The population that I work with, I have a lot of kids that have Medicaid or have no insurance. They don’t get the traditional, every 6 months checkup. Parents can’t afford it and they can’t find anybody. By the time they get to dentists, their teeth are already so bad they can’t afford to fix them because it costs so much to fix them. There are not a lot of pediatric providers in area and none that take Medicaid. A lot of people have to travel to Binghamton. Then there is the waiting time and the issue of transportation and families not being able to get there. Same issues for parents and teeth. It’s just not taking care of and it’s not for lack of wanting to. I think dental takes a backseat in hierarchy of needs. It’s not a priority.”*

A stakeholder noted the lack of fluoridated water as a concern.

*“Our water isn’t fluoridated in the county so there’s that. One of the most effective public health activities is fluoridated water. Which is seemingly an easy fix, but is probably controversial. Outside of garnering enough political will to fluoridate our water, think that something that we could*

*influence is in terms of recruiting and retaining dentists. I don't know much about that or who's working on that or what resources exist."*

### **Awareness**

For the most part, stakeholders indicated that there was little awareness about the dental challenges.

*"I think the dental [issue] is not as known. I'm on the Medicaid Long-Term Care committee and we didn't find out until not too long ago. I think a lot of people don't understand. It feels like when people think medical, dental is not the first thing that comes to mind, but it can really change health outcomes. It's not on the radar or being addressed."*

*"I don't think there is a will or interest about dentistry. Don't think people see that as too high of a priority."*

One stakeholder noted that there is increasing interest and funding available but that there are a lot of challenges to overcome.

*"We're starting see some of the seed grants to think innovatively about mobile dental clinics. [My colleagues] see it a lot, this person needs a dentist, but they can't get there or can't sit in a dental chair. There's all sorts of added challenges, dentures broke, they're uncomfortable and don't want to wear them, because they don't have an appropriate fit, or can't get them serviced. There are just a million issues."*

### **Long-Term Care/Home Health Care**

Long term care was ranked #3 and home health care was ranked #5 as important unmet needs in the county.

### **Lack of Affordable, Quality Long-Term Care Options**

*"There are no Medicaid or affordable assisted living for older adults in TC. Longview takes a couple. They try, but can't afford to do that. What that means that [organizations are] trying to help people stay in the community living independently. But some really need that assisted living level of care, but can't afford it and that doesn't exist here. I know COFA has been working at that. That is definitely a very big problem for older adults in the community."*

*"Obviously we have quite a few nursing homes, but I would question the quality. Especially when they make it into a New York Times article. Affordable assisted living facilities, there are none here. Basically, when we talk to families about going, it's not a nursing home, but it's in Auburn or Montour Falls. They say 'My family is here' and we almost convince them, but they realize it's far away. To not have a single facility [is a problem]. I know Longview has some affordable beds through congregate care, but the two [primary options] are going to be in Montour Falls or Auburn. I think that is severely lacking."*

*"In the nursing home, they're really addressing rehabilitation. For somebody who needs rehabilitation, they get thrown into a setting that is for long-term patients. I don't think the two needs mix very well. I think people who only need rehab, get discouraged and depressed when see people who are there for the long haul. I wish we had more dedicated rehab services."*

*"I have multiple people myself, my dad is 100 years old, and finding care is just impossible. And as a society we're cruel with the elderly. We don't offer good care options unless you spend thousands of dollars a month. And then you can go to Kendall or Bridges. And since we don't live in a world of nuclear family units, we don't take generations very well. My wife is a nurse, I hear it all the time, elderly people being alone and don't have any where to go. They drop them off at the hospital and the nurses scrambling finding a place for them. Even here where we have facilities like Cayuga Ridge and Beechtree, this is pure gossip and hearsay, but these places are really not top notch. They could use some help. Even when you have the facilities, they are allowed to be run down or not run well. It's sad as hell. It's scary because I'm looking down the road and ending up somewhere. And of course, in writing a long-range plan, you see trends in demographics, the boomers are getting older. We're going to have a lot of elderly folks. Our population is getting older, we are losing the middle. We always have lots of young people because of the colleges, but the middle cohort is getting older. We're going to have a population curve that is a lot of young people and a lot of old people and less in the middle. And that population tends to cycle. That might change as millennials enter workforce and have families, but it isn't going to deal with the boomers. We're in for a period of high need and with elderly folks, more medical needs. I don't know that in the community we're really ready for that. I hear the hospital is jam packed these days and has been for months. Is it time for the hospital to grow? Possibly – but I don't know that they are in a position to do that."*

*"I think you can have great insurance and end up in a crummy place. Last year I ended up spending a week at Cayuga Ridge. It was a real eye opener. I had friends bringing me food, seeing me so I had no problems, but it wasn't very clean, terrible food. If you didn't have what I have, it was terrible. People in the hallway drooling, not enough staff. I was shocked by my experience. I happen to know someone who had Parkinson's with dementia. That person had some money and was going to use it all to stay in this sort of nice place and then he got so demented that they threw him out and now we don't know where he's going to go. What are we doing with people. We throw them away – when they're young, when they're old – if you're not rich, you end up in horrible places with people who are trying to care for you. They didn't feed me for two days. I didn't have a problem with that, but what if I didn't have people bringing me food. They are understaffed, overworked, and reimbursement is not enough."*

*That whole [long-term care/nursing home] model is just a mess. That's not just Tompkins County, that's federal policy and how they have to operate and run. Nursing homes are really struggling to stay alive financially because Medicaid reimbursements are so low for those services. And that obviously puts a strain. They operate with minimal staffing and have not great quality care. No one wants to go to a nursing home, they're becoming more like little hospitals. Hospitals have to discharge more quickly so they have high level need people, but do not have the staffing associated with that level. We might see them a little more significantly because we only have a couple of nursing homes in our community."*

*"As a 59-year-old who's healthy, I'm fortunate that I can see a positive future. I'm relatively healthy, have a house, don't have debt, have good kids and family, but long-term care is really in the forefront of people's lives and they can't afford it. I think it's a community issue. This community is trying to deal with it. [...] I think people are isolated and they don't have answers and haven't created source or the income to pay for that. There's part of me that strongly believes that*

*people are just people. I have a good buddy and asked him if he has a retirement plan. He says, no, I'm going to work until I die. You can't force a horse to drink water."*

*We have [home health] agencies in town, but I think they're all strapped. It seems like they all have very busy case loads and therefore limited time with patients, like half an hour a week when they can get there. And there's a tendency for them to get discharged and then they're hosed for the next time. The hospital gave VNS a referral, the hospital thought it was fine. The patient left the hospital, but VNS wouldn't open because the person was discharged before. We found out they were discharged because the person is unsafe and couldn't take their prescription. I think a lot of home health agencies have high caseloads, heavy turnover rates, the jobs are difficult to hire, and they are highly regulated and can be held liable. But they need to figure out why the person is not safe and figure out services to make safe rather than just discharge."*

*"[Home health workers are] paid poorly and often not the best people to work with a vulnerable population."*

### **Impact**

*"I do think it causes other health issues to have people staying in their homes who are really having trouble caring for themselves, but not going to a nursing home. Definitely an issue that leads to other stuff."*

### **Awareness**

*"The assisted living lens is something we've been talking about for years and trying to get NYS DOH on board. They are, but because of some of changes with skilled nursing homes in the area, things have fallen through the cracks. People applied for RFPs, but never followed through and it was dropped at the state level. I think people are very aware of the need and willing to work on that. Even legislators really want to know what's happening there and they're really focused on housing."*

*"People in the know are aware of the long-term problem. The problem is the state only allows so many licenses. There's only so much we can do, we can stay in touch with it. We can ask for permission to build and license for Tompkins County, but we also need a partner to build and make it happen. That should be in the works before a license or at the same time. I think the county could do more to move that along."*

*"I think that COFA is doing a great job with long-term care. I think they're trying."*

*"I think [awareness of home health issues] might be for people who have thought any of these things, don't think it's a community wide conversation. I think when I was first starting in my current job, the IC gerontology program had a lifespan housing group partly driven by older boomers who had retired who were shocked at the many things they need to remain here. There are pockets of realization. If somebody hasn't experienced it, probably not."*

*"I think home health is definitely a topic of conversation with all the agencies and the LTC committee. We have taken on subcommittee just focused on that to try to raise the level of show*

*the value of them. We had direct care worker programs that have tried to supplement some of the income of the aides because they are not paid enough. We try to address them in different ways – why don't aides stay at the job – retention, recruitment. I think that's been a topic for a little while. The general public, I'm not sure [of awareness], but service providers, most people are aware of that and willing to address it."*

## **Social Determinants of Health Negatively Impacting Community**

### **Poverty/Income Insufficiency**

Poverty and income insufficiency was ranked the top negative social determinant of health in the community.

Stakeholders noted that poverty underpins many of the other social determinants of health including transportation, education, access to health care, housing, and food security. They also noted impact of poverty on both mental and physical health.

*"Every group I deal with talks about eliminating or dealing with poverty, we're all about providing services in equitable manner. Low income families are more dependent on a variety of modes of transportation. If you think about it, they don't have enough money to own a car, are dependent on buses, walking, biking, sharing rides. So, it's important to provide and have those options available. If we let our transit system go to pot, it's not going to hurt well to do in Cayuga Heights, it's going to hurt low income families the most."*

*"Although I know Tompkins County is unique in terms of how our unemployment rates are, but poverty and income insufficiency still exist here. I think the county has made progress towards a living wage, but even with living wage, people still can't afford to live in Tompkins County."*

*"You can't separate poverty from all other social determinants of health."*

*"I feel sorry for kids who are living in a household that might have some challenges to it. Those are the ones we need to focus on, the kids who aren't eating well enough. See how many kids have to come to school to eat breakfast and lunch. How many kids who aren't exposed to regularly getting exercise and getting in shape. A lot of times they are single parent household and barely keeping it together themselves. It's the family unit, the cost of day care, the cost of camps – I think we get a little delusional about it."*

*"Poverty – I think that's one of the overarching issues. The stress of being poor."*

Stakeholders said that while there is awareness of the issues related to poverty, there hasn't been much progress in providing solutions.

*"This is a very caring community in many ways. There is a lot of work around trying to provide additional support for those experiencing poverty, but we haven't figured out how to get the roots to it. We are working on symptoms not root causes."*

*"As many good hearts we have in county, a lot of people don't get beyond writing a check and doing their part. We can be a have or have not county at times. The haves need to get a little more involved"*

*“I think that overall our community is pretty supportive. Because I work with children, I see people are more willing to help children or help people in poverty that have children. Kids are a draw for some folks. I do think as an overall community, people are pretty supportive and recognize as a community, the level of poverty we have here. [...] When we put out requests for help with different things, I feel like our community steps up and offers to help. Whether it’s time or talent or money.”*

## **Transportation**

Transportation was ranked second in the list of negative social determinants of health.

Stakeholders noted the prevalence of transportation issues as well as the high impact a lack of transportation can have. As with poverty, stakeholders noted that transportation can impact other social determinants of health.

*“Transportation infuses everything.”*

*“Lack of transportation is an issue particularly. We have the situation where the jobs are concentrated in the Ithaca area, but it’s expensive to live close to where those jobs are. Lower income people tend to live outside of the city and if they do not have access to reliable transportation, it is difficult to get and keep a job or access other services. The public transportation in the county is not awesome. It’s not practical for people to try to rely on public transportation to get from Groton to a job at Cornell.”*

*“Regardless of what services are available, if you don’t have transportation to get there back and again – you’re not going to access what’s available.”*

*“We have so many good things in this county and we really do have some transportation, but it’s still not enough. There are still those gaps that people need to get their doctor or out of county medical transportation. We have a pretty connected volunteer driver pool, but it’s still very limited and people aren’t able to access everything they need. Gadabout is awesome, but the way it functions, people can’t always get where they need to go at the time they need. Whether that’s an important appointment or going to church or the doctor, those social connections aren’t always available with a lack of transportation. That’s pretty huge for older people living in their own homes and socially isolated.”*

*“Although we are in much better shape with Gadabout and other programs than surrounding counties, there are still parts of the county where it’s still hard. In McLean, it’s almost an hour walk to the nearest bus stop. If you’re elderly dealing with health issues, it’s hard to get there. It makes it more difficult as people start losing the ability to drive. And you have people who are lower income and the only place they can afford is out of town. They certainly can’t afford a car and again, you have the domino effect of health care and taking care of themselves and being able to get to food. Food insecurity can happen where the only grocery store is a Dollar General.”*

*“We set up a lot of transportation for people. We’ve always been able to, but it’s tricky. People leaving on their own accord couldn’t pull it together in the same way [we can]. Particularly for Medicaid. The cab will take them from the doctor’s office to home, but won’t let them pick up medications.”*

*"[...] the reality is transportation doesn't exist in isolation. If we had everything needed in every community, we wouldn't need transportation. If everybody had a thriving primary care provider in their town, we wouldn't need as much transportation. If every town had a community center addressing youth and senior issues, we wouldn't need transportation. Transportation doesn't solve the issue in some ways. Even if we could miraculously transport people, it still wouldn't help people with social determinants of health. You've just momentarily transported them to those services. That's the social cohesion. Back in the day you had everything you needed in your community or neighboring community, food, things to do."*

*"In terms of connecting, the primary barrier once past the gauntlet of signing up and filling out all the forms is often transportation."*

*"Medical assisted transport is often difficult for individuals to access. It requires, for example, for reservations to be made a few days in advance and oftentimes you need support from the physician's office to confirm the appointment. As compared to other things (Uber, Lyft, on demand services) medical assisted transport is not consumer friendly in light of the persons they work with (disabled, lack ability to secure own transportation). People that are living day to day, to ask them to call and make arrangements 3 days in advance, it may as well be a month from now."*

*"Downtown in Ithaca, we hear about transportation and parking, can't get here, or can't park, or can't afford a parking spot. Medicaid cabs and all that are very problematic. You can get a Medicaid cab, but it can be so impossible to sign up with that."*

Stakeholders generally agreed that there is awareness of transportation as an issue in the county, but they also indicated that it is a difficult challenge to overcome.

*"I think with transportation there is a lot of interest. I think there's some frustration especially around public transportation because of the fiscal realities constraining things. There are some efforts trying to think outside box and working with what we've got. The movement is there, there's been effort, especially in the city, to try to work more on bike infrastructure and to give people more options. There's still a lot of work there."*

*"I think in the non-profit world, we're pretty aware because help may be available, just not for you. It's not enough to know there's counseling, addiction services, if you can't get there. I think people are cut off from solutions in many cases. If they're working Monday through Friday, 9-5, we don't have good options."*

### **Housing Instability/Substandard Housing**

Housing instability was ranked third and substandard housing was ranked fifth in the list of negative social determinants of health in the community.

Stakeholders noted the significant impact challenges with housing can have on people.

*"I know that safe affordable housing saves people's lives. The bedrock of your life is your house, whether you own it or not -if it's comfortable, clean, the temperature is appropriate, it's not leaking, where kids can do homework, you can relax. I've seen everything else change in a person's life because of a Section 8 voucher. For example, a woman was about to lose her child because of*

*neglect, the next thing I know she's a nurse and moving away for a better job and it only took about a couple years. And it took about a month for her to start thinking about the future and to be confident enough to go back to school and make a secure home for her child. I feel like nobody is going to get anywhere without housing. It doesn't have to be beautiful, it just has to be safe."*

*"Housing instability is a big one with the population we work with. When you're moving or living in the kind of place they have to live, you're just not going to focus as much on health. [...] Housing instability is still an issue and still a negative impact on our community."*

Generally, stakeholders believed there's an awareness of housing issues, but a lack of willingness in communities to address it creates challenges.

*"I think there has been increasing awareness that we have some issues there. The problem I have experienced is that it's one thing to get someone to acknowledge that we have a real housing problem, but that's different from getting people to say I want you to fix it on my block. People might say more housing is needed, but when you start to talk about specifics, that is where people are far less supportive. I think there is some movement, but a whole lot more that would need to happen. I think there is a broader conceptual willingness, but we are not quite at a point where the actual action is totally there."*

*"There's a lot going on in housing in this community – I think people recognize it's a bit of an Achilles heel and is causing a lot of problems. It's kind of driving a lot of people's life's decisions which affect their lifestyles and I mean everybody, not just low-income families. I'm 60, I'm starting to think about what retirement looks like and having a hard time justifying staying in my current house in Ithaca. Financial decisions may drive me out of here. A lot of people are in the same boat. They created a position related only to housing, TCAD is talking about housing, every development agency, Cornell developing housing. They're building 2,000 units of housing on north campus and trying to capture the value of all those rents. Most of them are living in apartments and slum houses in town and now those kids are going to have nice apartments at Cornell. If you create more supply, it brings down prices. We'll see how it plays out."*

*"Everybody thinks it's someone else's problem, but they don't want those people in their neighborhood."*

*"I think people are sick and tired about hearing about people's housing – so the word is out there. I think people have heard that there's a deficit of housing. I think our legislators know that. I don't know if that makes people behave differently or helps our cause at all. [A community member] said, 'there's all kinds of supportive housing in this town. There's 100s of units.' – I said what are you talking about? He said 'INHS, the Section 8 voucher. There's this discriminatory acknowledgement of a problem, but it's still pigeonholed and it's not my problem and I don't want to pay for this. The have's and have not's is excruciatingly in your face. A lot of liberal talk, but don't you touch my house."*

## Prevention Successes

When asked what prevention activities have been most successful in Tompkins County, stakeholders most frequently noted collaborative efforts, specific programs and providers.

*"I think all of the efforts and organizations in the county are trying to be inclusive, trying to get more voices in conversation, so for me – I consider that going well. I don't know how successful they are in achieving their result."*

*"And I'm part of discharge planning group. That's great to have so many community people together. When people get discharged from hospital they can fall through the cracks and end up in the hospital again so having people connected is great. Titus Towers has a couple of nurses that work there. There's no wound care, but when somebody comes out of hospital, they help them with health literacy and work through what their aftercare needs are. VNS has one too for people with Medicaid. Those are cutting edge efforts that are doing it the right away."*

*"I think one of the big strengths is that there's an inner connectedness. The hospital is talking with Alternatives, INHS, and other groups about how to work together and link between all of us. I think it's starting to come together and be more formal rather than informal so that people do have a safety net that goes across other services."*

*"I would say we have an active system of care, a collaborative system of care that is related to values. We have strong relationships there. There is ongoing energy around addressing concerns. If I don't know the answer, I know who to call. [It's a strength] having a strong network of relationships with people throughout the systems regardless of what it is. I find it valuable. Here's a specific example, Northeast Pediatrics has a behavioral health consultant as part of their practice who addresses mental health as it comes up. Every practice that sees kids should have that. I think it's great that we have a behavioral health unit that can serve teenagers at the hospital. It would be nice to serve younger kids, but OMH won't let it happen. That we have an adolescent unit is helpful and good. The fact that we have at least one child/adolescent psychiatrist in our county is good."*

Other programs, providers, and efforts that were noted:

CCE	Chronic Care Program
Child Development Council	MOMs Program
Using Cornell students as mentors	Home Visiting Program
Teachers incorporating volunteerism into their classrooms	SPCA
Falls prevention	Primary Care Provider Network
Healthy, local food initiatives	UrgentRx
Housing	STAP/syringe exchange
Trauma-informed training	Narcan distribution
Behavioral health programming	BASICS program (substance use prevention for college students)
Free clinic/Ithaca Health Alliance	Smoking laws/prevention efforts
Pregnancy prevention	Vaccination
Head Start	Youth programming
Healthy Neighborhood Program	

## Desired Program Changes/Improvements within Organization

Stakeholders, from all types of organizations including mental health, food, housing, and education, most frequently said they would like to be able to provide more case management services to their clients.

*“I wish we had more case managers to help people with needs that are great. At one point we had developed community support services [...] that included intensive case management, but the state made that go away and is not likely to start providing salary funding for individuals doing that work. The reality is that systems don’t help people. Human beings within systems help people. The more feet you have on the ground in the trenches, I find the better the result could be.”*

*“We wish we had more time and case workers to help out the community.”*

*“I think what we would like to be able to provide is a more effective case management program.”*

*“I would really like for us to be able to provide some sort of resident services to our tenants – a monthly rotation of healthy nutrition, having wellness programs in community rooms, providing safe space for someone to learn about something for an hour. That’s something that I’d like to be able to provide. I’m not ready to do this, but I am considering sometime over the next 5 years, we hire at least one full-time social worker to handle resident issues. A lot of people are not suffering from a serious mental health issue, but a lot of people are on the edge and sometimes I think that’s the most dangerous spot to be when you may not know that you need help. I really stress to my [staff], your good intentions are not good enough, it can lead to bad things happening, so I ask them not to [...] step in. The challenge is having a social worker on staff is going to require a lot more regulation, possibly changing some aspects of how our business is done. At this point, I know we need it, but am wondering if there’s a way to contract with local agencies to say can I have five or six people to refer to or do you have a social worker we can call and pay extra to have them on call. I know the challenges the social services organizations face. I see the turnover and burnout. My hope is that there is a way to come up with an interesting partnership so the social service agency can manage the staff and we’ll provide the clients.”*

*“We have geriatric mental health programs which means counseling and have access to psychiatry and help for caregivers, but what I really need is case manager. The care manager system is broken in the county. They can’t meet their demands. I would love to have some case managers who could follow-up with some of the families. Everything we have to do is a billable service and I can’t bill for that case management services. I would love that. For example, for an elderly person in their home, they don’t need a therapist every week, but needs someone to check to make sure they get their “x” today.”*

*“And with our young children’s program too. [...] we need more people to do [...] more home-based work like an early intervention for some families. They need somebody to come between 4:00pm and 7:00pm. DSS used to fund a parent aid program for high risk families. That’s the witching hour. If you have these small children, how do you feed them, give them a bath instead of sticking them in front of the TV if you’ve never had that model as a child. Those need grant funding and nobody wants to fund ongoing programs like that. They’re not sustainable.”*

*“I’d like to work in concert with families to address their concerns around students’ education. Help students that come from another country, to facilitate that transition and welcome them into the district and not overwhelm them with administrative burden.”*

*“I think [a PACE program] would be applicable in our county.”*

Stakeholders also noted they would like to expand programming to enhance coordination with other agencies, offer more mental health and emotional health programming, housing supports, dental care, transportation and substance use disorder programs.

### **Suggested Programs/Initiatives**

When asked what programs, initiatives or approaches they would most like to see enacted in the county, stakeholders most frequently suggested better coordination, more providers, enhanced focus on well-being and mental health, a dental van, and transportation related options.

#### **Coordination**

*“So, we have 15 zillion non-profits in Tompkins County, so I don’t think we need any more non-profits. But what I’d like to see, and I think this is what DSRIP and the healthy community alliance is trying to do which is to bring together community based organization with opportunities for funding to collaborate. For a “no wrong door approach”, I would like to see that happen more effectively. We need money to make that happen. I think our organizations make a deliberate effort to be referral partners, to communicate about shared clients, we work really hard to do that. But there needs to be some sort of sustained funding umbrella where community based organizations can more effectively work together for a continuum of care for people.”*

*“I would also like coordinated efforts. Which is not easy to do. It requires [organizations to have] a willingness to pool resources and, to the degree that they may or may not have stake in outcome, [...] support positive developments. There are those folks that are willing and interested in coming together on, [but I] can’t determine if that’s been effective. But funding or mandates can get people swimming in own lanes, right next to each other. [An example is] narrowly prescriptive funding or funds that come down from the state or federal government that are designated for activity X. Because there can be a lot of activity, it’s just ensuring we’re all rowing in the same boat instead of swimming in own lanes. I think it’s helpful to have awareness and coordination, even if we are not working jointly, where you might see where your work might overlap.”*

*“As difficult as it is to have another meeting in Ithaca, and I’ve been to these meetings with different organizations, what the mayor did I thought was great and brought things to the forefront. We need positive media making sure the every day folks who have these issues know how to get it. And sometimes you got to get into the trenches. I think about the people who work on the street – I don’t have staff to bring them in telling them they have to improve their life. It’s going to take a combination of media and that powerful group of leadership on the street. Those who are walking among those needs – it can be better done.”*

*“I think we try really hard. I think we have a lot of people with a lot of opinions. That’s great, but how do we move those ideas to action. Everyone has an idea and people are very happy to voice them here in this community. We have this strong network of community based organizations, but how do we work better together. There needs to be streamlined funding maybe merging some of the services together. No one ever wants to do that. Erie county in Buffalo, their food bank merged with the regional meals on wheels. Now they are one big umbrella called Feed More. It works well because they’re serving many counties. That’s like a perfect example of both organizations working hard to address food insecurity. We have awesome resources, why not pull them together and really effectively address the problem. Don’t know that regionalizing is very popular. [...] Is there a way to more effectively pool our resources, and maybe make a hard decision regarding regionalizing to better attack what’s happening.”*

*“My thought is that in Tompkins County one of the biggest issues is we have this disparate network of people doing their own thing and they’re not organized. If you were to do collective impact, there’s no feeling that they’re part of this larger kind of effort. That is the biggest opportunity to wrangle all these cats and figure out where there’s opportunity for partnership and leveraging resources effectively to have greatest impact rather than this little group doing this thing there and that one doing things there. That’s not sustainable. We need to be having a broader conversation about what does it mean to have a healthy thriving community.”*

## **Providers**

*“One would be an emphasis, which may be afoot that I’m not aware of, on the recruitment and retention of providers in the area. Physicians, mental health, dentists, and not just those individuals, but PAs and NPs as well.”*

*“I think health programs, clinics at community locations, like GIAC/Southside, something regular, in the community, where people are comfortable would go a long way to improving outcomes.”*

*[I would suggest] a more comprehensive palliative care service. When you think of end of life care, palliative care is so important to comfort, dignity. It has to be more than hospice so Hospicare could be a more far-reaching program.”*

*“There is no “respite” program. Kids can go to EPT crisis respite if they are 10 and older, but there is no hourly respite unless you’re involved in some high-level community program and have Medicaid. MHA has done as well as they can, but have limited funds. I’d like to see an expansion of their weekend Y program. We can’t get more psychiatrists because they can’t make them fast enough. It’s not really an approach, or even a specific program, [that I would suggest], but a more intensive home program, as an alternative to MST which requires an open case.”*

*“Medical stabilization detox is required. There is high demand from all our agencies/hospital and everyone in community.”*

*“I don’t know what goes on in the local school systems. To be honest, when you don’t have the kind of response when you’re doing community outreach/public health education and keeping people interested, folks really have to want to change and have to see the true importance of that. And the only way to help that happen is to start at a very early age and continually remind folks about the importance of preventive care, managing your health conditions. There are number of great programs that do that generally for a specific malady or disease, but I don’t know what goes on in schools in terms of reaching folks. It would probably be the most effective way to do it.”*

## **Mental Health/Well-Being Focus**

*“Anything related to mental health. If we had the ability, even telephonically or something like Skype to be able to have consultations with psychiatrists who are skilled with pharmacologic management like bipolar disorder and some of the various forms of schizophrenia, that would be an enormous benefit. PCPs are being psychiatrists by default. [Some patients] clearly need to be on some kind of medication, but how to do that is beyond us and there’s no resource to reach out.”*

*“Mental health care. I am especially concerned about making sure our students get better health care. Looking to expand school satellites. It’s a paperwork nightmare to get them approved, but it doesn’t cost*

*the school anything. They've been thrilled, the students are right there and during a break in school they can meet with clinician. It's been fantastic and we are seeing need increase significantly at all our schools and everyone is asking for more."*

*"Maybe a community awesomeness campaign: 'be grateful for what you have', [...] 'hey let's help people and be nice.' [...] I feel like everybody is 'I've got mine – you go away.' I don't think it matters what the issue is. I feel like in some ways that's what we're missing. It might be perception of resources. We should have lots of pie, more pie and not who gets what slice."*

*"There are two pieces that I've read that relate to this conversation. One piece that I've read, using an asset approach for positive mental well-being [where] they looked at the idea that mental health and well-being is an entire community's responsibility. Rather than looking at that from a deficit perspective, it was how can we look at this from an asset perspective. What are our skills and experiences, what do people bring with them that we can amplify and support. In order to do that, it takes, at an individual, organizational and financial level, complete commitment to want to approach the work that way. I don't think that's the typical way people approach [supporting others, instead] people, in well-intentioned ways, [think] how can we help the other people. So, on the most mundane level, we have a canned food drive, instead of eliminating the need for a canned food drive. If we're really going to eliminate the need for a canned food drive, we have to reorient people's priorities and some of those are going to be people from private industry around the profit motive. I don't know how you do that. It seems like a problem we've been working on forever."*

*"[I would suggest] in schools, teaching students how to relax, be quiet, mindfulness. Something as simple as Tai Chi can be relaxing. With a simple diagnosis of depression in the UK, if you go your clinic and get that diagnosis, the first thing they do is write a prescription to go to the health club and start exercising, but we don't do that. I imagine that could also be helpful with respect to anxiety. Reality is one out of five adults is going to experience disabling anxiety or disabling depression. Lifestyle training can help address that."*

*"[Something to] help people navigate something whatever it might be to go to doctor, help you if you don't understand, need a ride, it just might be a friendly visitor. But there are not enough people. Connecting people to services is one step, but a lot of older people need that hand holding. We're not case managers, but people need a companion, hand-holding to get through that."*

*"I think if you wanted to look at how you impact inter-generational health, if you look at health care, I guess there would be things that we would need to do for families that are struggling really early on. What do families need really early on to change the trajectory and I think that we've moved out of preventive services for funding streams right now. Twenty years ago, you saw more preventive programs, but now the money is only there for the most high-risk situations and they're about violence and foster care. Social services have less money to impact the lower risk issue, for example a. young mom with intergenerational poverty. We don't have much prevention. I think we need to go back to some of those things. We're seeing now is the number of 6 and 7-year olds referred to mental health services because they can't hold it together in school. The problem is so deep by the time the kids are coming to us. I think that is where we need to put more effort."*

*"I think opportunity to improve screening. Part of the spike in mental health concerns is not just because of an increase in rate. They are better at screening for it in primary care and at the hospital and the more people you ask these questions of, the more people are going to screen positive. I think continuing to do that in a sound fashion using rigorous evidence based screening tools [is important]. It reminds me a little of the ADHD thing, when it seemed like every kid had it. There's this increased sensitivity that's occurring and along with that I'd like to see increased specificity. Not just depression, but what degree of depression*

*are we talking about, chronic, bipolar, situational – so not every person we encounter has depression. It offers the ability to give the right resources and results for individual needs. What is the mental health crisis and how do we differentiate between a kid whose dog died and is sad versus the kid who is engaging in suicide ideation.”*

## **Dental**

*“We want a dental van, like the mammography bus, to bring to schools, laundromats. Most people’s insurance will cover it, but there’s not a place to treat them. A dental van is on our wish list.”*

*“One thing, I don’t know if it still happens, but there was a mobile dental that would come through and park at DSS. I don’t know if it still comes. I have not seen it in a very long time. It was positive because dental health is so important, but expensive.”*

*“I think a mobile dental program and a mobile mental health program would be wonderful. Something that would come to our community that people could access and was here on a regular basis to develop relationships with our families. I think that would be great.”*

## **Transportation**

*“How can we create a transportation system that would allow people to get back and forth from medical appointments when they need to. I think that’s very important. And I don’t know what the county could do in terms of funding for that kind of access.”*

*“I can look at the work I do and I can tell you from personal experience, living a more active lifestyle and transportation makes a gigantic difference. People by walking or biking more can alter their health profile. That’s something we do every day and we can do every day a little more.”*

*“I wouldn’t mind seeing more bike lanes around town.”*

In addition, stakeholders suggested more education on screen time and disease self-management, firearms prevention, improving access to healthy food, translation services, better outreach to rural areas, better leadership and positive media exposure, improved screening and differentiation for mental health, and more recreation options that are safe and winter friendly.

## **Other Comments**

### **Discrimination**

*“I want to really emphasize [that the way] racism, homophobia, genderism, and economic insecurity play out in people’s lives is profound and not understood and acknowledged as much as it needs to be acknowledged. [...] I think more and more people are experiencing microaggressions and they go about their day, deal with it and move on, but I think under the surface all those things are at play and aren’t brought up to surface and dealt with as well as they should. It doesn’t mean they aren’t trying, but the reality is that we don’t have as many people of color in administration or as teachers. It’s not necessarily for lack of trying, but doesn’t change that we just don’t. Therefore, we’re not as attentive as we would be. If we had more folks of color, we’d continually be pushed to unlearn things we don’t even realize we do.”*

*“I think racism and classism overlay all this as well. A lot of the people I worked with in Newfield and I think a lot of folks in the county may not say it out loud, but consider them poor white trash. And then for lots of folks of color, I think there are all these preconceived notions of about what they’re doing or not doing to contribute to their own problems. I think those are all interrelated.”*

*“We see a lot of discrimination in the housing choice voucher program. ‘This is where black people live and this is where white people live.’ Generally black people are being pushed into places that aren’t as decent, safe, sanitary as white people. We had a whole conversation on source of income. You can’t discriminate based on source of income, but they’ll just find another way to discriminate. People were discriminating before on other kinds of things – color, single mom. So, I think the discrimination pigeon-holes people and causes all those problems with mental health, drug abuse – those are kinds of coping things – using drugs to get through the day. And I think it hits people of color probably harder than poor whites.”*

*“I think we have some champions related to discrimination who are really good at keeping it at the front – like Kirby, Laura. I think there are some strong personalities here that are helping to change people’s minds about it. Although, I’m in this little tiny world – if I lived in Cayuga Heights, what would that be like? I doubt there’s very many people of color in Cayuga Heights.”*

## **System Design Challenges**

*“I think the insurance system is breaking the back of health care.”*

*“The reimbursement rates of the insurance companies, it’s the control the insurance companies have and the drug companies. They control health care. We haven’t listed that as a social determinant.”*

*“I think one of the barriers is that so much of health care is delivered through employers and it’s expensive if you’re purchasing through the exchange. So, people don’t access as often as needed for preventive care. And something like dental for a lot of people just doesn’t happen. And dental care is very important to overall health. It comes to lack of income which is tied to employment as well.”*

*“A significant portion of folks we encounter are often having to deal with staggering amounts of medical debt and not knowing how to manage that debt or even liquidate that. We provide some services here that teach them how to do it.”*

*“I think the people who are in-between, the working poor, who make too much to qualify for free health services, the health insurance they have is basically catastrophic. They can’t afford the copay for their visits and prescription and they don’t go and get taken things care of because they know they can’t afford it. That’s a huge issue.”*

*“I think frequency of appointments is an issue. People want to come more frequently than most are able to provide. How often I get to see a therapist or health care provider [is dictated by insurance]. I hear this constantly – someone wanted to stay in the hospital longer, but had to discharge because health insurance wouldn’t let me stay longer. I’d like to come weekly, but we give appointment two times a month and want you to go to a supportive group or therapist doesn’t have time. Or my insurance will only pay for two times a month. I think frequency or how long I get approval to stay are issues. Or I can’t see my physician, I always see the nurse practitioner, those kinds of things. I’m having to settle for something less because of insurance restrictions or availability restrictions.”*

*“Everyone wants evidence-based programming and funding is short.”*

*“The long-term strategy would be to invest in preventive health care practices. Let’s help somebody not become obese and then diabetic and then dealing with the host of issues that come from that. Let’s keep people from smoking. Help people to wear their seatbelt and don’t drive drunk. But we have a system that doesn’t address it from a preventive angle. The long-term return on investment is much higher if we focus earlier with preventive care. That’s a societal shift – we can do some things at the lower level and work with individuals, but would take a big shift on a national level to move in that direction.”*

*“You’re expected to do everything online and we have a huge elderly population that has no clue on how to do that.”*

## Appendix A. Pre-Interview Survey

Thank you for being willing to participate in a telephone interview for the Tompkins County Community Health Assessment. This short survey will help inform our conversation – please take a few minutes to fill it out prior to our interview. Please be assured that all the information you provide will be kept completely confidential. All responses will be reported in aggregate. You can either email your pre-interview survey back to me at [Lisa@HornResearch.com](mailto:Lisa@HornResearch.com), or we can go over your answers during the interview. Thank you!

**1. In the following list, what are the three most important health related problems currently impacting Tompkins County’s overall community health? Please check only three:**

- |   |   |
|---|---|
| <input type="checkbox"/> Nutrition-Related Disease (e.g. cardiovascular disease, diabetes)      | <input type="checkbox"/> Health Disparities between Populations             |
| <input type="checkbox"/> Tobacco-Related Disease (e.g. COPD, cancer)                            | <input type="checkbox"/> Insufficient Support for Well-Being and Resilience |
| <input type="checkbox"/> Late Disease Detection (e.g. cancer, diabetes, cardiovascular disease) | <input type="checkbox"/> Alcohol Misuse                                     |
| <input type="checkbox"/> Poor Disease Self-Management Skills                                    | <input type="checkbox"/> Drug Misuse  |
| <input type="checkbox"/> Injuries including Falls, Traffic Accidents                            | <input type="checkbox"/> Adverse Childhood Experiences                      |
| <input type="checkbox"/> Maternal Mortality/Morbidity   | <input type="checkbox"/> Mental Health Issues                               |
| <input type="checkbox"/> Teen Pregnancy   | <input type="checkbox"/> Vaccine-Preventable Diseases                       |
| <input type="checkbox"/> Infant Mortality/Morbidity   | <input type="checkbox"/> HIV/STIs   |
| <input type="checkbox"/> Child/Adolescent Developmental, Mental and Emotional Health            | <input type="checkbox"/> Hepatitis C  |
| <input type="checkbox"/> Child Dental Health  | <input type="checkbox"/> Antimicrobial Resistance                           |
|   | Other   |

**2. In the following list, what are the three most important Social Determinants of Health NEGATIVELY currently impacting Tompkins County’s overall community health? Please check only three:**

- |   |   |
|---|---|
| <input type="checkbox"/> Under/Unemployment                 | <input type="checkbox"/> Lack of Access to Healthy Foods                            |
| <input type="checkbox"/> Food Insecurity                    | <input type="checkbox"/> Crime and Violence   |
| <input type="checkbox"/> Housing Instability                | <input type="checkbox"/> Outdoor Air Quality  |
| <input type="checkbox"/> Poverty/Income Insufficiency       | <input type="checkbox"/> Climate Conscious Design of the Built Environment          |
| <input type="checkbox"/> Lack of Early Childhood Education  | <input type="checkbox"/> Water Quality  |
| <input type="checkbox"/> Low Enrollment in Higher Education | <input type="checkbox"/> Substandard Housing  |
| <input type="checkbox"/> Low High School Graduation Rates   | <input type="checkbox"/> Lack of Transportation                                     |
| <input type="checkbox"/> Language/Literacy Issues           | <input type="checkbox"/> Lack of Accessibility to Spaces for People with Disability |
| <input type="checkbox"/> Lack of Civic Participation        | <input type="checkbox"/> Lack of Community Based Services                           |
| <input type="checkbox"/> Discrimination                     | <input type="checkbox"/> Lack of Access to Communication/Technology                 |
| <input type="checkbox"/> Incarceration                      | <input type="checkbox"/> Other  |
| <input type="checkbox"/> Lack of Social Cohesion            |   |
| <input type="checkbox"/> Lack of Access to Primary Care     |   |
| <input type="checkbox"/> Lack of Access to Specialty Care   |   |
| <input type="checkbox"/> Health Illiteracy                  |   |

3. In the following list, what are the three top unmet health needs within the county? Please check only three:

- |  |   |
|--|---|
| <input type="checkbox"/> Dental/Pediatric Dental                   | <input type="checkbox"/> Respite Care             |
| <input type="checkbox"/> Mental Health Care                        | <input type="checkbox"/> Home Health Care         |
| <input type="checkbox"/> Vision Care                               | <input type="checkbox"/> Primary Care             |
| <input type="checkbox"/> Long-term Care/Nursing Homes              | <input type="checkbox"/> Specialist Care          |
| <input type="checkbox"/> Substance Use Rehab/Counseling/Prevention | <input type="checkbox"/> Prescription Medications |
| <input type="checkbox"/> Healthy Food                              | <input type="checkbox"/> Medical Supplies         |
| <input type="checkbox"/> Health Knowledge and Skills               | <input type="checkbox"/> Trauma-Informed Care     |
| <input type="checkbox"/> Affordable Health Care/Adequate Insurance | <input type="checkbox"/> Other                    |

4. In the following list, which Social Determinants of Health are POSITIVELY impacting Tompkins County's overall community health? Please check all that apply:

- |  |  |
|--|--|
| <input type="checkbox"/> Strong Economy                            | <input type="checkbox"/> Climate Conscious Design of the Built Environment                         |
| <input type="checkbox"/> Sufficient, Affordable, Safe Housing      | <input type="checkbox"/> Water Quality   |
| <input type="checkbox"/> Availability of Early Childhood Education | <input type="checkbox"/> Strong Network of Community-Based Services                                |
| <input type="checkbox"/> High Enrollment in Higher Education       | <input type="checkbox"/> Sufficient Transportation Options   |
| <input type="checkbox"/> High Quality Schools                      | <input type="checkbox"/> Access to Communication and Technology                                    |
| <input type="checkbox"/> High Graduation Rates                     | <input type="checkbox"/> Green Spaces/Walkable Community   |
| <input type="checkbox"/> Robust Civic Participation                | <input type="checkbox"/> Arts/Cultural Events/Opportunities  |
| <input type="checkbox"/> Social Cohesion                           | <input type="checkbox"/> Access to Religious/Spiritual Options                                     |
| <input type="checkbox"/> Sufficient Access to Primary Care         | <input type="checkbox"/> Accessibility of Physical Spaces, especially for people with disabilities |
| <input type="checkbox"/> Sufficient Access to Specialty Care       | <input type="checkbox"/> Opportunities for Recreation/Physical Activity                            |
| <input type="checkbox"/> Health Literacy                           | <input type="checkbox"/> Other   |
| <input type="checkbox"/> Sufficient Access to Healthy Foods        |  |
| <input type="checkbox"/> Low Crime and Violence                    |  |
| <input type="checkbox"/> Outdoor Air Quality                       |  |

## Appendix B. Key Stakeholder Qualitative Interview Guide

Thank you for your willingness to participate in this interview. Your feedback is very important and will help Tompkins County guide future public health planning and decision making. *I want to remind you that your participation will be kept completely confidential. We will not release your name or any other personal identifying information at any point. All information we gather will be aggregated and quotes will be anonymized.*

1. First, let's start with your responses to the pre-interview survey. *(Can you tell me which 3 health related problems you selected?)* What are the reasons you selected those health related problems? *(Data, indicators, organization wait lists, other?)* What do you think the level of interest is in the community for addressing those issues?
2. In your opinion, what are the primary drivers of the health related problems you identified? Are there underlying causes that are not being sufficiently addressed?
3. *(And what did you select for the social determinants negatively affecting community health?)* Why do you think those social determinants of health are the most important? Can you describe the community's perception of these issues? Do you feel like there is general awareness of the issue? Is there a "will" to address these issues?
4. Are there other kinds of challenges Tompkins County residents face in accessing needed health care services? Are there other barriers preventing people from getting needed care? *(e.g. not knowing where to go, wait lists, services not available)*
5. *(What did you select for question 3, the top unmet health needs in the county?)* Tell me why you select those unmet health needs as the most important. How would you describe the community's awareness of and interest/will to address these health needs?
6. Is there an action, service, program, or resource you would like to see initiated to help make Tompkins County a healthier community? Is there a particular approach that you would like to see implemented that would address the unmet needs you noted?
7. *(What did you select for question 4, the social determinants that are positively affecting community health?)* Are there other things you think Tompkins County has "going for it" with regard to having a healthy community? Is there an area that you think could be continued or expanded to have greater impact?
8. What do you think are the primary strengths of prevention efforts (e.g. health care services, public health initiatives and services, programs addressing social determinants of health) in Tompkins County? What is working well?
9. Are there services or programs that your organization would like to be able to provide residents, but aren't able to? What are they? Why aren't you able to?