

# Tompkins County Community Health Assessment

# FOCUS GROUP SUMMARY REPORT

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### Introduction

Four focus groups were held with Tompkins County residents during the month of July, 2019. The groups were targeted to include: low-to-moderate income mothers, African-American residents, low-income college students, and low-income rural residents. A total of 32 residents participated in a group. Each participant received a \$30 VISA gift card in appreciation for their assistance.

The focus groups were conducted using a focus group guide (Appendix A.) intended to generate feedback on challenges related to and ideas to address:

- healthy eating
- physical activity
- disease screening
- prenatal care
- mental health
- school-based health options

### **Access to Healthy Food**

### Challenges to Healthy Eating

Focus group participants were asked describe what kinds of challenges people face in accessing healthier foods. By far, the most commonly noted challenge was transportation.

"The transportation or means to get to the store is the hardest."

"Without access to sidewalks, it's wheelchair inaccessible – so some people can't even leave their home for food if need be. Which is messed up because getting food should be accessible to people. It's a necessity."

"I had 6 months of being in a walker. You can't carry groceries that way. And even with Gadabout it was double fair, and it had to be arranged 24 hours in advance, so it was \$7 one way just to go to Ithaca."

"There's buses but it's not enough. even with that, I'm going to pay \$2 and get off 3 minutes away?"

"One nice thing about Trumansburg, there are sidewalks. Even to the grocery store which is a little out of town, but when you start looking at TC3 and other towns around here like Newfield and Dryden, access to grocery stores by walking is very tough."

"I know folks who are my age or older with physical limitations, and now for them to be able to go and get a substantial amount of food, they need to find a way to Ithaca. It makes it entirely impossible."

"I know our (pantry) delivery is up. I must deliver to 60-70 households every month. Seniors take a big chunk of that because I deliver to the nursing home, and I deliver to the school house, and an additional 25 deliveries to people who can't make it to the pantry because they work or have physical ailments and can't make it."

"The weekend is the worst. The [cafeteria] closes at 3pm I think. It's very annoying then you have to make yourself dinner in the middle of the weekend and buses are very scarce on the weekend on the TCAT. There's like 3 buses in and out and they're far apart so it's harder."

Focus group participants also noted that the quality of food available in rural areas is often poor and does not include fresh produce. In some locations, participants said they only had access to a dollar store for food. Some participants said the food at their local pantry was not healthy while others noted the pantry was the only place they could get fresh produce.

"The only way I get produce is from the food pantry or here (the Groton library). In fact, ...where I get most of my produce is from the library on Tuesdays."

"I walked always to Dollar General, that's as far as I could get. So, Dollar General was the only place I could get food. They don't have any produce. They have a decent amount of food, but it's microwaveable garbage. It's not very good for you."

"And there were other basic things, staple foods I was looking for, and they didn't have them. They don't even have whole wheat bread a lot of the time, no produce whatsoever, no meat."

"The problem is, I'm going back to the things that were donated [to the pantries], the things donated are nothing healthy – the cakes, the donuts, muffins. I know our meat department puts aside meat for the pantries, but when it comes to the vegetables, they're so far gone, you can't donate them. One thing I do on Monday and Tuesday is to go through the vegetables – if you've got lettuce that's good for 3 days, they're going to keep it on the shelves until the day before because that's the rules and regulations. So, it makes it difficult for them to pull something off the floor for donations because when they send it to us, the lead time is so short. But even the food pantries talk to these companies to try to get them to donate more healthier foods, but they're only going to donate what's getting ready to go out. I asked one of the managers if they were going to eat it? I said, if you won't eat it, then don't donate it."

"... a lot of places like Spencer or more rural towns, they have one store and access to good produce and health foods is scarcer. There are a lot of places across the county that have mom and pop shops that don't have any produce at all. Access is really important. Even if it's food banks and grocery stores. Having access in general is really important."

Participants also noted that the high cost of food made it difficult to eat healthier foods.

"For a lot of things, the dollar store prices are more expensive."

"Strawberries - \$6 for a (pint). I always see what fruits Aldi's has on sale. Those fresh things that are healthier are the most expensive things."

"The farmers' market is nice, but some people charge way too much. The only way you get good deals is if you bring kids with you."

"I do think there's a problem with how far you have to walk for actual produce. Like Clarks, when you get there, they overprice things. They purposely overprice things because they know it's the only grocery store in this town."

"I got a salad at Wegmans and it was almost \$7. I was like I could get five sandwiches at McDonald's for that."

"Ramen and hot dogs – not nutritious, [but it's the] least expensive. You have to have some nutrition. [They] don't make it easy."

"We go through a lot of ramen. With 6-7 people in a household, you do what you have to do."

Other challenges to healthy eating included a lack of knowledge and a lack of cooking and storage facilities.

"I'm 40 and I've talked to some of my peers and some of the younger ones don't know how to cook if it's not right on the box."

"A lot of them are scared and they think cooking is something that can only be done on the food channel. I've talked to a couple of people and said 'if you can read you can cook'. [One person] was 30 and said it never occurred to her."

"The one thing I see at the pantry is we have so many folks who do not have the means to store or cook the food. For example, I keep can openers on hand for people who don't have a way to open their own cans. In certain residences in town you may have only access to a room, not even a kitchen or microwave, so they can only take food that is simple."

### Ideas to Support Healthy Eating

When asked what ideas they had for supporting healthy eating in their community, participants most frequently said creating opportunities for people to gain more knowledge and skills was important, particularly when being offered unfamiliar healthy foods.

"I notice that CMC came down and brought smoothies. I don't like them, but I tried it and they told people how to make it. And now I've noticed in the neighborhood everyone is talking about smoothies. And Southside has on occasion has brought people to come in and do a lunch, and then afterwards have a bunch of food like collard greens and said this is what you just ate."

"I've been to some [pantries] and they have boxes and boxes of collard greens. I don't know if it's a mind thing, but people will not take collard greens. They won't take carrots, cucumbers, but they'll take silly things like grapes, but leave all the vegetables behind... They need to learn how to cook them. Also, the white bread, they won't take the wheat bread. All the whole grains, all the organic food, they'll leave it there. [Someone] needs to teach it."

"That may be where canning or freezing classes would be helpful. If people can learn how to can or freeze that may be helpful. Just to teach people how to store food."

"I think there definitely could be some help with ideas, recipes, learning how to have a better idea. Even me, I love to cook and be creative, and I found it helpful to have an example."

"I think it should be a school thing. They should give classes about how to cook in the dorms or show recipes."

"I think that's a great idea that schools should be able to provide easy recipes, healthy recipes for students to make. Other options than the meal plan because all people who live on campus have to have the meal plan, and while there are some healthy options sometimes the salad bar isn't open, and sometimes all your options are deep fried."

"I give away vegetable plants at the library that anyone can take. I'd like to get it to where people realize that if you get a 5 gallon bucket you can grow a tomato plant in that on your balcony or porch."

Participants also noted that improving the food offered through pantries and expanding pantry hours would be beneficial in terms of healthy eating for low-income residents.

"More food pantries that's available for people like myself that work five days a week. Because a lot of times the food pantries are not available for us. Because they have them at times we're not able to come to them."

"One of the biggest problems too is that most pantries don't operate every day. It would be great if they did because they could do that every day — but if they only operate once a month or twice a month — whatever is left on that day is what they get. If they could schedule it a little bit different, so you could go to a pantry every day and not buy groceries. They tend to not have so much perishable, because they don't know who's going to show up."

"The farmers too – maybe the collective of the farmers' market to get the excess produce from the end of the weekend and donate that. I don't know how you do that, but getting people to at least think about donating fresh fruits and vegetables."

"It'd be nice if the food pantries and if the stores could be a little bit more generous with what they gave. An intermediary that was between the stores and food pantries that could fund or supply fresh fruits and vegetables – even frozen fruits and vegetables to pantries. A lot of times what you see in the pantries is not fresh and you get maybe a day or two before you have to throw it out, lots of breads or pasta. Even the pantries aren't necessarily giving out good, nutritious food as the type we're discussing. If there was somebody between that would mediate that better."

"More farmers' market and food banks and they [should] actually give you food that's going to be good for a while."

"About the type of food that ends up in the pantries: analytics can tell you how much supermarkets and the restaurants waste and it would seem like if you knew that — if you know you waste this much lettuce each week, set aside that much and give it away while it's fresh to the pantries [...] instead of getting to the point where you've only got two days left [before it goes bad]. If you had 10 heads of lettuce and you know you throw 2 away every week. Then take those 2 at the beginning of the week and donate them."

Participants also said expanding eligibility for SNAP and WIC would be useful.

"My husband and I are starting a business so we have pretty much no income, so we are on SNAP, WIC, and we are also part of the healthy food for all where we get a discounted CSA share. I've lived in Tompkins County for nine years, the first four years as a student. This is the first time that I've ever felt like I have food security with \$505 in food stamp money. It's so ironic, I'm on benefits right now, but I'm actually able to buy the food I want or need instead of in past when I had to have a budget for food and get cheapest meat that we can. I thought this was so ironic, that I'm now on benefits and actually can secure food and have access that my family needs."

"WIC being more accessible would be better. I know a woman who I used to work with who made less than \$100 a week when I worked at 7-11. She ended up pregnant, then found out she had cancer and couldn't go to work because the doctor wanted to start treatments. She applied for WIC and they said she made too much. She also has no insurance and had to pay for everything out of pocket. I think she might have just now been able to get WIC after going through a bunch of crap and her child has a lot of special needs because of the treatment. Someone like her shouldn't have had to go through everything she had to go through just to get WIC – and her daughter is almost a year now."

"My boyfriend and I cook for ourselves, but we live with my parents and they denied us [for SNAP] even though we purchase and cook food for ourselves. I am hoping that they will take that into consideration. People might live with other people, but you're purchasing food for your own person. We got denied because they make too much, they took my mother-in-law's SSI and her husband and my boyfriend's work income. And he's barely making over \$1,200 a month, not including what we were paying for rent, internet, electric bill, but they didn't take that into consideration."

Participants remarked on the value of community gardens in terms of providing both knowledge and skills as well as access to fresh produce.

"One of the things I noticed when I was walking down the street was [...] CFCU had a community garden. Wouldn't it be nice to have more neighborhood gardens in areas of public spaces and public parks [...] the local government and community could set up those gardens and teach people how to grow stuff."

"It's very difficult because one of the things that the produce manager was telling me over at Wegman's is sometimes lettuce only has a shelf life of three days. The hat's the reality of it. Even in fridge, you should eat it within three days or it becomes less healthy for you. That's why neighborhood gardens are good because people can pick it at will and eat it."

"A friend of mine... gets this box of vegetables and fruits that aren't perfect looking, but they don't like to throw away just because they don't look perfect. She gets this box every couple of days in the mail and says 'what can I cook with it'. We have so many local farmers that have these[items] that aren't perfect. Can't they make those available?"

Participants also noted a need for a store in their community, opportunities for more communication, and ideas for carpooling to stores.

"I know the one thing, and I think every single person in this room would agree, that would really help Groton, and I don't think it'll ever happen, is a grocery store. Everyone knows Groton does not have one. When we lost Family Dollar for two months, if you didn't have a car, or know anyone with a car, or have money for the bus, you were up the creek. You were stuck shopping at a gas station."

"If there was an Aldi's right here in Dryden, that would be nice. I like getting groceries from there. It's cost efficient there."

"I think a lot of it is publicity and communication and I was thinking about the whole supermarket thing, if we had some way to get people together. I wouldn't mind taking someone to the market but they don't know who I am or when I'm going. So maybe having that option of carpooling, even for medical appointments. Do you know how many times I go to Cortland to medical appointments? I'd be glad to drive people to the grocery store."

### **Physical Activity**

### Challenges to Physical Activity

Participants were asked to identify some of the primary challenges to engaging in physical activity. Participants most frequently mentioned cost, lack of options, time, child care and transportation as barriers.

"Gyms are expensive."

"I wish there was an option that didn't cost money. For example, I wish there was a league such as softball."

"People cannot afford to go to a gym. Planet Fitness is probably the cheapest, but people still have to get there."

"We struggle in the winter to find free stuff, even if it's \$5, it's a lot of money. We went to the toy library and the library. We ended up buying a Sciencenter membership."

"There's not a lot of options for adults, there's the gym and trail system, that's something new."

"And the only two places that offer child care is Island and the Y. And Island is very expensive and you have to pay to use the child care. The Y offers an assisted rate."

"Also for summer, there's a lot of summer camps, but they want ridiculous amounts of money. Even with scholarships they are unaffordable."

"My main concern is having two kids, working full time – when am I going to [exercise]? I used to walk all the time. In the summer time, for free exercise, you can just go for walks. But it's either 5 in the morning or 8 at night. That's challenging with kids. I think it's tied to the work schedule. My husband stays at home with the kids, so he's on a full-time schedule, so I try to help him. Nobody has free time."

### Ideas to Support Physical Activity

Participants had several suggestions to support physical activity including creating community and neighborhood groups to exercise and motivate each other, encouraging gyms to be more inclusive, and letting people know about free, outdoor exercise options.

"It'd be great if there was a way to get people together to exercise like a group of moms."

"Exercise is free. I'm 66 years old. I grew up when you stayed outside until the porch lights went on and played jacks, I was all around the neighborhood. And now I hardly see any kids playing outdoors. [...] I think that's something CMC could do monthly – a community 'let's move' day – GIAC, Southside, even this church, where you can get water, get some health stuff, a triage thing and people walking. That's free."

"Neighborhood competitions."

"I have a health plan that says I can go to the Y in Cortland. I have one right down the street. And I can't go there. I don't understand what's causing that type of thing. So, in terms of having those services — unify — so we can be successful."

"One of the other things we need to do is we need to take that stereotype and change it. When I first was thinking about a gym, I said I'm not going to no gym. All them people are young and got their figures and my stuff ain't there no more. Once you get past that mindset and get in there and you know you're doing it because you have to get healthier. You have to make sure you're doing the right thing. We need to teach people, especially black women, to get into the gym, go to the mall and walk around. Walking is a good form of exercise if you can't get to a gym. And we didn't grow up with a mindset of going to a gym — only rich people go to gyms. So you do something else."

"With the trails, I was talking to someone about the possibility to create a Food Forest as well. If we can plant things like fruit trees or berries or nut bushes along the trails, you could get exercise and food."

"Ithaca High School has a beautiful fitness facility. And a rock climbing wall. And so, it's partnering with the already existing entities. Some of them are really underutilized."

"You have to be inclusive and make people feel included. I imagine someone who has limited resources, might not be comfortable going into a place like Island. Their perception might be that they don't belong. It'd be nice if it was a goal of Cayuga Medical, for every 50 memberships, let's give one membership to somebody who can't afford it."

"I found out that if you have a library card for any library in county, you can go check out a[n Empire] park pass for a week, and that's free."

"There's spaces downtown. Some churches have nice places where they could host classes. There's the Henry St. John building that has a beautiful gym where classes could be held, but [there is] no person to help organize and get something running. There are spaces to run exercise classes for different people, but we would need someone to organize that."

### **Disease Screening & Preventive Care**

### Challenges Preventing Disease Screening

Participants were asked identify reasons why county residents might not choose to be screened for diseases such as breast and cervical cancer. Participants noted that cost and lack of insurance coverage were main barriers to accessing screening.

"One of the biggest issues is that you pay all this money every week for your insurance, lots of money, and you go see a specialist and it's \$45. So why am I paying all this insurance and I have this high co-pay and that will deter you from going to all these specialists. My mammogram, thank the lord, is free, but when you go to see the doctor to get the results of it, that's \$35. It's like, ok, I don't have that kind of money, I'm a single woman trying to do the best with the little bit I get paid."

"One of the things [is] cost. I went for an annual check-up, the nurse practitioner said you might want to have a shingles vaccination. While I wasn't opposed, [but] she said, you'll have to sign this first, your insurance might not cover it and it's going to cost \$375. Did I want it? Yes. Did I want to pay it? No. I've been coming to the same place for over 20 years, I'm sure I'm not the only person with that same insurance that had that issue. At least say, if you have this insurance it is covered by this, we've already billed it and [insurance] covered it. At least give them an opportunity."

"Until this year I didn't have health insurance."

"A lot of people can't even get a physical every year. I personally haven't met my primary care doctor in two years. I've only gone to the OB/GYN because I had a daughter a year and half ago, and am now expecting again in September. I've had physical therapy, but never met my PCP. Also, their office doesn't take Medicaid anyways."

Participants said that the information on whether and when to get screenings was confusing or that they were lacking information to help them make a good choice.

"I think another reason, my own personal experience, is Ithaca is so organic. We are so crunchy here that we have doctors that don't believe in mammograms. I've been scolded by a doctor that it's not important to have them done every so often. I've been informed by doctors that I really don't need this vaccine or I should think about these vaccines. This is a huge thing around Ithaca with vaccines and screenings. And then people who only understand half of it, we don't know who to believe. We really don't know. It would be great if there was some teaching. Some of us go get our mammograms and the rest don't because doctors say don't bother. I had one doctor tell me it doesn't really catch most cancers."

"I won't get a mammogram because from what I read it leads to over treatment. If you know how to do a self exam, you are good enough."

"I think there's no information either. I'm listening to this information and I'm wondering have I done these things? And I haven't."

"I have a 3-month-old and you're supposed to have a mammogram when you're 40 and I'm a year over that and even my OB and midwife didn't say anything about it. They didn't say, you're breastfeeding and you might want to have a mammogram because you're going to have lumps and bumps and that might worry you. You just reminded me – no one mentioned it – they just said come back next year."

"We are coming out of a generation of women not doing those things for themselves, and now their kids aren't doing it either."

Participants also noted issues with providers that prevented them from accessing screening and preventive care services. Some participants said services were unavailable locally while others commented on the quality of communication between providers and a lack of diversity in the provider network.

"What I really don't like about that though is Planned Parenthood is only in Ithaca. Why is that the only place? In the city, there's a Planned Parenthood in every borough and even with that there are others in between. When I came up here I really had to get used to everything being so far out and in my experience, the schools don't even do regular STD testing on campus. It's just pregnancy tests. I think STD testing on a college campus is so important. Nobody is taking a cab to Planned Parenthood to get tested so I think that should be on every college campus."

"I think and feel the lack of women of color and men of color who are health care providers [is an issue]. Particularly around mental health issues, but I think everything else too. I know going in and bringing in certain things, I feel and believe I'd get a different response from a woman of color."

"I called the Cancer Resource Center once to get a mammogram, she put me through this whole battery of questions. When I said I didn't have insurance, she asked why [...] why should I have to explain this? I said I couldn't afford it and she wanted to know why. That's irrelevant. I need the test. If you said the service is free, don't badger me. You won't get that same thing at Planned Parenthood, they say come on in – if I call the Cancer Resource Center, it's a whole thing. Maybe they think people are trying to abuse the system, I get it, but if I need the test, I need it."

"It's about communication. I found the CT scan upstate did in 2017 never got reported to my doctor here. I've been going in and they did a bypass and I kept going in for the follow up and they say I'm doing just wonderfully, but I still can't walk. They also found a lump on my gallbladder that should be investigated, but nobody ever did anything about it, and they never told my PCP, so now I'm not inclined to do anything like that again. Why bother?

Participants also said that fear was a big deterrent to accessing screenings.

"I think fear contributes a lot. I was just talking to a woman a few days ago whose husband is having a lot of bad symptoms but he's too afraid to go. Sometimes fear plays a huge piece of it."

"Guys don't like to face the fact that you have it, but if you don't go, you may not have to face it until the last moment."

"People think they're ok and nothing is going to happen."

"[Black men do not go to the doctor] unless it's absolutely necessary. Especially, black men are scared to stiff to go to the doctor for prostate examinations and a colorectal exam. The word cancer is a red flag to a bull."

"I think it's cultural. Black men have been so marginalized, their self worth and value is so low – they don't want to come in acting weak."

Time and transportation were also noted as issues related to not accessing disease screening.

"For women specifically, we are too busy taking care of other people that we don't take care of ourselves. There's not enough hours in the day. We tend to just take care of our kids and make sure the house is done."

"They offer a lot of free screenings in other towns, but again, transportation is an issue."

Participants noted that systemic racism was a significant barrier to accessing adequate disease screening for African-Americans.

"There's the perception of black men [as not needing medical care]. My brother-in-law died at 51 of pancreatic cancer. He was 6'2", 175 pounds, [and in] excellent shape. He was having problems with his foot, had a blood clot. He was healthy, ate right, had the same job for years, kept going, kept going, all of a sudden, his back hurts and they give him some more blood thinners. Finally, my sister took him in to the doctor, he died the next day. He had blood clots all over the place because they never checked for pancreatic cancer because he did not hit the profile."

"The racism in medicine [is a problem], there is a perception we can take more pain, there is evidence from studies and tests that we continue to be subject to that. It's racist."

"[...] when we do go to the doctors, instead of giving us 20 or 30 pills, take a few extra minutes and talk to us about lifestyle. That makes all the difference. That's a big part of it. The extra time to talk to people. When we do show up, educate us. And not in a demeaning way."

### Ideas for Increasing Disease Screening

Participants said they thought mobile opportunities for screening would be useful, but it is important to ensure information is available to residents in advance.

"I know my mother said one time they had a truck there [in Newfield] for a mammogram. I forget who did it, but I know she went."

"I think it's a good idea [...] accessibility is great, but people need to know about it. I don't even know who my primary care physician is."

"I think if it was advertised ahead of time, I think people would come."

"[Share the information on the] Ithaca Gift Economy Facebook."

### **Prenatal Care**

### Challenges to Early Prenatal Care

Participants were asked to describe the main barriers to prenatal care as well as the types of solutions that would be most effective in ensuring women receive early prenatal care. The most frequently noted issues regarding prenatal care were a lack of access to providers due to wait times for appointments due to full OB/GYN practices and a need for transportation support.

"Sometimes I think it's just hard to access services. My sister is pregnant now and is trying to work, and she's trying to not take time off so she can save her time off for when the baby comes. She was able to find a Saturday appointment but there aren't a lot of options like that. [...] I think if they had clinics similar to what they were doing at the church, like a clinic that came in once per month. If they offered some of that women would come."

"I think by the time they make an appointment, the offices are booking up too far."

"I was 10 weeks when I got onto [the MOMs program]. And they had to get me into TP3 before I could get into doctor so I was already 12-16 weeks before I could go into see the doctor for the first appointment."

"Offices are full."

"With my first son, I'm a permanent resident, I'm a Latino and finding out where I could get health care, it was a hassle. When we moved to Ithaca, I found out I was pregnant two days before we moved. Nothing was in place. I was calling OB/GYNs, but they don't have appointments and [I was] trying to figure out insurance."

"I've heard a student say 'I might be pregnant' and we're like 'how are we going to get you to Planned Parenthood?' And she says 'I don't know, I guess I'm just not going to. I guess I'll just figure it out.' How is no one going to help her? It's crazy. This happens all the time. I might be pregnant, but I don't have the ability to go somewhere to find out, to even get a pregnancy test. That's super messed up."

Participants also noted there seems to be a "standard of care" in the community where OB/GYN offices will not schedule appointments before 10 weeks of pregnancy. In addition, participants said there may be different cultural perceptions of whether pre-natal care is necessary.

"The first time [I was pregnant], I called up Ithaca OB/GYN as soon as my period was late and I did a home test, but they said wouldn't see me until I was 10-12 weeks."

"I've only done Ithaca OB/GYN for the two pregnancies. I called as soon as I found out, but the first time I think I was seen around 10-11 weeks and the second time around 12 weeks. I just thought it was the norm. I don't know if this is a US thing or a Tompkins County thing. I thought you weren't seen during the first part of pregnancy because anything can happen."

"The first trimester is three months. If you know you're pregnant, two months are already gone. I remember when I was pregnant, when I went to the doctor, there's not a lot they do anyway. They don't even give you the ultrasound in the first trimester. Culturally, women have been having babies since the dawn of time..."

"If you feel fine and nothing's wrong, there doesn't seem to be a pressing need of going to the doctor outside of seeing general practitioners."

Participants said that some women may have a lack of knowledge about what to do or a fear about dealing with a pregnancy.

"Also, a lot of women don't know they're pregnant until their second trimester. A lot of people don't think about it. Being pregnant in the first trimester can look like a stomach bug and ... it's very different woman to woman."

"I had a kid at 17 and thank god I got connected to resources early. But other women just don't know. People don't talk about it. And a lot of times the resources are out there, but people don't know what questions to ask to learn about resources."

"I'm thinking that younger women will not necessarily have the means of guidance to seek assistance or preventive care quick or soon or right away."

"Some of it has to do with education, especially when you deal with younger people, [or] their first child. I'm sure in school they still educate young people, but maybe they don't. If you miss your period, there's a possibility you could become a mom. I think education is a big piece of it. If you missed your period, you need to go to a doctor, and you can deal with the prenatal thing."

"There's a stigma attached to being pregnant when you're young."

"They might still be trying to hide it."

Participants also noted that costs for prenatal care can be an issue for some mothers.

"You have to pay out of pocket if you don't have health insurance. They don't give that [prenatal care] away for free."

"No health insurance is a barrier. Or [some women might not] realize they have access to health insurance, especially if you are a new mom and you don't know about the MOMS program."

### Ideas for Supporting Early Prenatal Care

For the most part, participants recommended the Ithaca Pregnancy Center as a place where women can get early ultrasounds. Participants suggested making information on prenatal care more available and better access to providers.

### **Mental Health**

### Challenges to Mental Health Care

Participants were asked to describe whether there has been an increase in emotional and mental health issues in their community and why they thought that might be the case. They were also asked to describe how both adults and children have been impacted by mental health and emotional issues and potential solutions for addressing those challenges.

Participants commented most frequently on the lack of providers as a primary challenge to mental health care in the county. Some participants said a lack of culturally appropriate providers was of particular concern. Others noted that insurance often doesn't cover mental health care and presents a substantial barrier to care.

"I'm struggling with post-partum. I have a history of depression and anxiety. It's hard to pick up the phone and the road blocks [make it harder]. I called everybody and I still haven't been able to get in anywhere because of wait lists. At the hospital, they said they would have a new [appointment available] in June, but then they said they had to cancel because they needed my past medical history and because I needed to sign releases, so I gave up."

"I've noticed there's not a lot of available counselors or places you can go in this area. [...] I have to go all the way to Binghamton to get counseling because they're booked or they don't take my insurance and that's just crazy."

"There's no one in Groton. You have to go to Ithaca."

"There's also the increase in need goes hand in hand with the decrease in providers. It started when I was in Ithaca College years ago. The college was cutting their counseling center so that put a lot of burden on the rest of the community. A lot of students have to use counselors that are in Ithaca as opposed to being able to get help on campus. I have depression and post-partum depression and have gone through a few counselors in past years and a lot of them had said they mostly see students."

"What's important is that mental health [care is available] in the school system. [There is a] need for properly trained and racially sensitive counselors."

"If we had any doctor that we could identify with based on culture or belief, [they would] have a full practice."

"Most quality therapists don't take the kind of insurance most of us have."

Participants also noted that stigma and discomfort with talking about mental health issues is a barrier to care.

"So many males aren't going to express themselves. It happens with females, but more so with males. You're raised to not cry. You have to hide your emotions. I'm confused on why that's even a thing. I feel so bad for guys that still feel like that in their mid-30's, 40's."

"It's not ok to have feelings basically. If you're a man."

"A lot of people are afraid to get the help they need. My significant other has schizophrenia. He is afraid of mercury, doesn't trust medical system, refuses to take meds. It's kind of hard."

"I think there's a lot of personal stuff with that too. Some people are in the mindset of 'I know what they're going to say and it's not going to help me, so why go'. And that's the first block you have to get over, taking the chance and going. Even if you know what they're going to say, it still might help you nonetheless."

"I have a son in high school. This year they had two former students who committed suicide. [...] I think that whole teenage angst, high school is that time. My son is more in touch, I talk to my husband all the time – he says he's too emotional. I say, no it's ok for boys to have feelings and express themselves. My husband is ex-military and was raised in a military home, so he's like no, but I think sometimes actually kids don't always have an outlet to talk, or express their feelings and sometimes internalize more and don't really know what to do with it until it gets to be too much."

"I think also a lot of single parent households or households where both parents work, there's less access for those children ... less time with their parents, that causes a lot of challenges with communication and learning. And school, especially for me, elementary or middle school where you learn some of those habits, didn't really foster a good environment for me to communicate with people or show my emotions."

"We don't air our dirty laundry."

"No one wants to be seen walking out of the school psychologist's office."

Participants said there with issues with the quality of mental health support that's available and poor referral to resources from providers.

"My midwife told me to fake it til you make it. I've had depression for 25 years, fake it? I left angry."

"It takes so much courage already to start calling and when you call and they don't call you back. I reached out my midwife when I was at a point that I have to get help and she sent me a list that basically said 'here is everyone's name'. You have to find out if they take your insurance, if they actually specialize in post-partum. I think I called a couple of people on the list, but never heard back from any of them. Eventually I talked to my physical therapist and she recommended someone and that's who I'm seeing right now. It's so hard to start the first step."

"I had someone who went to [the counselors at school] and who was helped a lot and someone who got terrible advice about something very important. I guess it's hit or miss with whatever your issues are. If they're more extreme, seeing an actual licensed therapist and psychiatrist is a better option, but whether you have access to that is the problem."

"I think it's different when you're talking to our community. We are very aware that when our child does something slightly outside the rules, we have a black child. So, we have that issue and we also have the issue [that we are] a group of people that are believers. [So, you're] dealing with the idea of cultural sensitivity, but also being sensitive to the fact that we believe there's space and room for secular counseling [that] can help in ways [others] cannot. We need to have therapists that understand that there's a place and opportunity for other belief. There needs to be space for people to get their help and still be ok believing what they believe."

"I'm going through post-partum depression and [...] a lack of support. I have two kids and a job, and nothing is falling in place and I'm exhausted and it was so hard to reach out and there's a huge stigma. I don't even mention it to people any more. I've had so many moms look at me with panic. There's not enough information. Now I feel even worse. Just finding a counselor [was hard], which I did, but the other day I had to pay the copay. It's not in my

budget to pay \$20 every week. How long will I be able to this? Hopefully I will be able to, but there's the medication and you have to pay. And it's a lot on top of the stress that it is already."

"I don't think the people who go to this school even know that there's a place that they can go to talk to [somebody]. Last semester I was having some emotional issues and I wanted to talk to a psychiatrist so I asked my friends and coworkers if there was a psychiatrist on campus and no one knew. One person told me that there is someone you can talk to if you want to, but it's not heavily advertised who they are and what they are. We have one, but people just don't know."

Participants said social media and challenges with parenting were key challenges related to child mental health.

"Most parents who have kids [with] mental health issues probably have mental health issues themselves. If they're not getting help themselves, they're going to feel awkward taking their kids."

"It used to be that if you were bullied, your parents would call their parents. Now parents might be working more and unable to deal with it or unaware."

"[There is] more pressure on kids to figure it out on their own."

"One of the things I see is they just plop their kids in front of a screen instead of spending time with them. I've seen so many kids in [the library] who are here for hours as soon as school is out. I see a lot of that at the park. [They] just drop their kids off. They are there from 7am to 8pm."

"This is my opinion, we got social media, got kids bullying each other. I had one of my staff members tell me she was being bullied, I tried not to chuckle because I thought it was funny. There's a way to stop that, unfriend her, quit following her, end it. That's the easy fix. But these kids nowadays, they're so attached to these things, they don't know how to communicate to anybody what is going on in their lives. They get bullied and talked about and taken down [and] they feel the only solution they have is so permanent. I just think social media has done a whole lot. When I was growing up, you didn't hear of people killing themselves."

"[There is] no privacy, more social pressure, anonymous bullying, cyber bullying. It's a lot worse out there now."

"I think the climate, the culture of our country, whether we recognize it or not, there is a weight. I do feel like there is an overall, cultural weight."

### **Ideas for Addressing Mental Health**

Participants offered several ideas for increasing awareness and offering information on resources in a variety of venues. They also suggested providing more emotional communication skills training to residents.

"If you all have not read Beverly Tatum's book, you really should. It gives great insight to the need for affirming identity for our children in our schools."

"It starts with you. Understanding your own emotions, but going forth and encouraging your [male] friends [...] that are having a hard time. You can talk to me, you can be as real and emotional, you should feel what you're feeling. Encouraging those in your life that are internalizing their pain to not. Be an example, I guess. Being there for them is really important. A lot of people don't have it. A lot of families are like if you don't talk about the problem, there's no problem. My family [believed] if there's a problem, we're just going to ignore it and that's not a good way to do things and creates unhealthy communication skills. Unlearning that is very difficult, but once you do, you want to spread that information and kindness. It really does help and makes a difference in your lives and other people's lives."

"Giving [parents] tools on how to help [children] when you need the help yourself."

"Start with colleges [offering] programming [about] how to communicate your emotions. Not even with therapy, but in general and making it ok. A lot of people don't know how to communicate in general with their friends, their family, their teacher. They don't have that outlet. I feel like it starts at home, and then going to a therapist office if it gets to that point. I think people think they need something wrong to go to therapy. I just feel like therapy is a practice of maintaining that healthy communication of getting things out. I feel like expressing myself can be hard. It can get built up. I feel like you need a practice communicating emotion. More programming. More free advertising. That's the whole conversation of social media that everybody else is saying it's not cool to be out front with your emotions, that you have to hide it."

"I'm more reserved with my emotions. I grew up with only my mother and she's always nagging me. I'm of the mindset that I'm not going to tell you about an issue if you worry about something you can't solve. So, I do keep a lot of my personal stuff to myself when it comes to my emotions. But I'm not afraid to vent that online. If I have a way to express myself, I'm ok. So, if I talk to people I play games with, I tell them how I'm feeling and ... it's kind of like, how some people have a stress pillow. I have a place to dump my negative emotions."

"That's what I like about the anonymous part of online. There's a bad part too, but I do like that for people who don't want to be face to face, but want to be able to talk."

"Having a central thing – 211 is great – but they don't know all information. I don't leave my house a lot. I just go to the playground with the kids and sometimes I don't want to talk to everyone there. I get anxious. [For] people who have social anxiety, maybe to have a central location or a website [to look things up]"

"There's not a whole lot of connectedness in medical arenas between doctors. I's so nice to have a trainer, therapist, nutritionist to work together to make that person whole. Even if therapists made themselves available to churches. Show up at a service. If you ask a pastor, they'll often let you introduce yourself. Show up and talk about whatever it is you do. We see politicians are smart enough to do that. We don't see medical professionals showing up and saying this is what I can offer."

"I feel like general Facebook, like some of the Ithaca mom's groups or family's economy groups – posting there. Everybody's got Facebook. That's one way to advertise all that stuff."

"Any public place putting up flyers. This place [Jillian's Drawers] has a lot of flyers, but only pregnant people and people with kids are going to see that. I think grocery stores or in the library. So, you can take them and not being judged. I know CARS has some things like that. It's more around addiction, but they do have some about dealing with your kids and stuff like that. I think DSS having stuff, grocery stores."

"I don't have TV. I have mobile data. I don't have internet. One phone, one car so it would be awesome to have a flyer. I don't go on the internet much because I run out of mobile data [...] so would be really great to have it seen where I go to a store (Aldi's), or on a bus."

"Putting it on the fridge, advertising it on the banners. They have that big campaign on alcohol and weed, I think it'd be much more efficient and helpful to have something on mental health and access to it. Those big posters are actually going to be read and looked at it."

"If therapists came to the school or offered it after school, families would do it. If they could stay after school and see someone on their own. Like maybe if they are having an issue and don't want to tell us parents, they could stay after school and see someone."

"Maybe if there was a group set up at school."

### **School-Based Health Services**

Participants were asked what kinds of health services they thought could be located at schools. Participants had both positive and negative views related to school-based health services. While participants said that having health services at school could overcome some insurance barriers and create consistency, they had concerns about confidentiality and stigma. Participants generally expressed approval of a mobile health care option that home-schooled students and adults could also access.

"[It] goes hand in hand with schools trying to push people toward healthier options. [They] give people healthy options to eat, but health [care], in general, is still not provided. I think that would help."

"I think it would be interesting for the lower schools. A lot of families don't have the best insurance. It's right there and kids could have access to it even if it's not available through their parents. I think vaccines and like that [...] I'd be ok with them doing that, the dental, the counseling services, I think it would be good. I would like him to be able to come to me, but if there's someone he could go to, I'd like that."

"I would prefer all kids would get shots at school. That's what they did in China, but the US is not ready for that."

"With mental health services for elementary and middle schools, I have a lot of concerns about confidentiality and access for younger kids [at school]. I think that's definitely a responsibility of the parent at their age. But for high schoolers or adults, I think that'd be much more important to have those services [at school]."

"I don't let my kid do them because I have a son who is black. My child is not going to be a statistic for anybody. When we did the fluoride in our class, it was clear that those of us participating were the kids who did not have. It didn't feel good. Because you grow up, you know you don't have enough, you go to school and your peers, there's all us black kids and a few white kids and all of us are getting those free services and all of our other friends, who aren't taking the services, know we are taking them because we don't have the money. That's why I don't want my kid to do it."

"The only thing I would say is, don't throw out the baby with the bathwater. Because there are kids, if it were not provided for at schools, would not get them. So, change the stigma. Change the way it's structured or the system so stigma isn't there."

"If they're going to be offered at school, it should be after school. Parents should have to bring them at another time and sign up. There should be days when kids can be seen when all the other kids who aren't participating aren't around. I don't like it. Clearly, I had a bad experience. It's fine — my experience isn't everybody's. I think kids have so much pressure right now in how they live — bullying, kids are so tuned into what other kids are doing. Two months ago, there was a 10-year-old that committed suicide. Clearly, we don't know what our kids are experiencing. I don't want to do anything that will contribute to that."

"What they had at BJM was a health fair kind of thing. Black teachers would incorporate it into a health fair kind of week. One teacher had a terrarium in the classroom where kids grew vegetables which culminated in the kids making gazpacho. Each kid in kindergarten got a toothbrush so it's incorporated, not isolated. This [could be] part of our educational process. You'll get a health screening, you'll get fluoride."

"Like mobile clinics - I'd like that."

"It would be good to have even for adults. Opening it up to the community, not just the kids. Have the parents get checked too and show the kids how it can be done."

Participants described positive experiences with school-based health services and also difficulty with school-based health options that provide minimal services.

"TCA Head Start has a dentist come a few times a year. My kids don't have a dentist because they go there."

"I remember taking advantage of [a school-based health clinic] when I was in elementary school in Washington DC and I think my mom appreciated that service a lot."

"When I was in school, the nurse had a doctor that did physicals. In high school, they had somebody who would come and check to make sure nothing was broken at sports practices and then refer to a doctor outside of school. But I feel like with diabetes and asthma, your stuff was always in the nurse's office and you weren't able to carry it with you. There was one girl, she actually died on the soccer field. She had asthma. The nurse wasn't there to get into the office during after school hours. Having a school nurse or having a doctor that volunteers every day – not just certain days – and school counselors being more willing to do something rather than thinking kids will be kids, would be good."

"I went through school where there was no real physical help for me and grew up with a genetic disorder no one knew about. They didn't get it, so medical access was not available unless I went to an outside doctor. The school nurse could never help me. And even in high school and college, people don't know what to do with you and don't know how to help you. I probably would have known I was sick earlier if there had been people at elementary or middle school who were medical people and knew what they were doing. Most of the time they were like I can put a Band-aid on this – the end. They can't even distribute Advil. They can't do any of that. They're so limited, it's almost pointless to have a school nurse. It's so bizarre."

### **Appendix A. Focus Group Guide**

Over the course of the past few months, the health department and hospital have been looking at data, getting feedback from the community through a survey, and talking with different stakeholders in the county with the goal of identifying the most pressing health issues in the community and developing or expanding efforts to address those issues. There have been a few areas that have risen to the top in terms of importance and prevalence and we'd like to get your feedback on what you see as the primary challenges related to these issues and what kinds of solutions you'd like to see implemented to address them.

1. Let's start with food. One of the things we've seen in the data is that there is a significant number of county residents (14%) that don't have consistent access to enough nutritious food to support a healthy, active lifestyle. In addition, there are big differences in the rate of nutrition related diseases between people based on their income and where they live in the county. When we asked survey respondents what kinds of barriers they faced in being able to eat a healthy diet, cost was the most commonly mentioned challenge.

What kinds of effort do you think would be most effective in ensuring people in your community have access to healthier foods?

Beyond expense, the other challenges people identified were: lack of time, insufficient cooking skills and a lack of motivation. What kinds of efforts or programs do you think would be most effective in helping to inspire people to prioritize eating healthy foods?

We saw much the same responses for physical activity – with cost, time and motivation being the biggest barriers. What kinds of efforts or programs do you think would be most effective in helping to inspire people to prioritize exercising and engaging in physical activity?

2. Another issue we've noticed is that a lower percentage of people in Tompkins County are receiving screening for diseases that are most effectively treated in early stages such as cancer. For example, only 3/4 of women in the county were screened for cervical cancer and just over half of women had received a mammogram in the past 2 years. Breast cancer screening has declined in recent years as well.

What do you think are the reasons women in your community don't access these screenings and tests?

What do you think would be effective interventions to increase testing and screening? (location? Mobile van?)

3. Data has also shown that over one-quarter of pregnant women in the county do not receive pre-natal care in their first trimester and when you break that down by race, even fewer women who are African-American/Black receive early pre-natal care.

What do you think are the main barriers to women receiving early pre-natal care?

What kinds of solutions do you think would be most effective in ensuring that women receive early pre-natal care?

4. There has been a lot of information and data indicating that people in the county, both children and adults, are experiencing more emotional and mental health issues and are unable to access mental health services.

First, can you tell me why you think there has been an increase in emotional and mental health issues in the community? Is this something you've seen within your community?

How do you think *children* in your community are impacted by the increase in emotional and mental health issues? What do you think we should do about it (home visits, clinics, social events, other?)? Are there things we can do that would be helpful in preventing emotional and mental health issues for kids?

What kinds of challenges have you or your family or friends experienced in addressing children's emotional or mental health problems?

What kinds of solutions do you think would be most effective in addressing the emotional and mental health challenges for *adults* in the county (this can include anything from anxiety and depression to more severe mental health issues)? What do you think we should do about it? Are there things we can do that would be helpful in preventing emotional and mental health issues in adults?

What kinds of challenges have you or your family or friends experienced in addressing adult emotional or mental health problems?

5. And finally, I'd like to find out what you think about what kinds of health service opportunities you think would be good for kids to receive at school? (Some ideas could include having a wellness clinic onsite at the school where kids can get their physicals, care for acute medical needs such as flu or chronic conditions such as asthma and diabetes, dental screenings and care, mental or behavioral care, nutrition education, etc.)

What do you think would work best? What are the pros and cons of offering health services at school?