NEW YORK STATE MINORITY HEALTH COUNCIL

VOICE YOUR VISION

LISTENING TOUR 2016

REPORT AND POLICY RECOMMENDATIONS

September, 2016
“This is a living document and by no means does it represent a complete picture of the interests and concerns of the communities engaged. Rather, the Council believes that the content herein provides insight into the many challenges that influence the health and well-being of New York State residents, and opportunities to change that paradigm.”

- New York State Minority Health Council
# Contents

ABSTRACT  

I. REPORT ............................................................................................................................................. 1  
   A. Background.................................................................................................................................. 1  
   B. Conceptual Model....................................................................................................................... 4  
   C. Project Organization.................................................................................................................. 5  
   D. Design and Methodology............................................................................................................. 5  
   E. Description of Listening Sessions ............................................................................................... 7  
   F. Limitations.................................................................................................................................... 9  
   G. Results and Analysis.................................................................................................................. 9  

II. RECOMMENDATIONS ................................................................................................................. 12  
   A. Community Recommendations................................................................................................... 12  
   B. Council Recommendations ....................................................................................................... 17  

ACKNOWLEDGEMENTS ..................................................................................................................... 18  

APPENDICES........................................................................................................................................ 25  

REFERENCES......................................................................................................................................... 44
ABSTRACT

In response to a charge by New York State Commissioner of Health, Dr. Howard Zucker, the New York State Minority Health Council (MHC) and the Office of Minority Health and Health Disparities Prevention (OMH-HDP), coordinated a series of community-led listening forums in selected areas of the state with 40% or greater non-White population, defined as Minority Areas\(^1\). The goal was to engage community residents to hear their views on factors that influence their health and well-being, what works and what doesn’t in the health care delivery system, and what may be needed to enhance service delivery and utilization and improve the quality of their lives. The sessions were held in Buffalo, Rochester and Albany, New York in the Fall of 2015 and Spring 2016.

The theoretical underpinning for the sessions was based on the premise that reducing disparities in health and health care can yield substantial results when a collective impact approach that addresses the interplay between social, physical, cultural and organizational influences is applied\(^2\). The organizing strategy was guided by well recognized ecological public health models and published examples of place-based interventions. These interventions demonstrate the potential power and success of this approach\(^3\).\(^4\) and the key principle; that engagement and mobilization of community residents in realizing a shared vision are critical elements in community transformation.

The appeal of the community engagement effort was to change the mindset of communities that government is able to solve society’s problems, by encouraging community involvement, leadership, asset mapping and resource leveraging, as alternative models of sustainable change.

Outreach to participants was accomplished in collaboration with trusted community stakeholders from different neighborhoods and diverse socio-economic backgrounds. Their participation ensured that neighborhood associations, churches, block clubs, and other self-help groups were informed of the listening session purposes, dates and locations. Stakeholders also identified conversation topics of significant interest to the community, thereby attracting maximum participation. On average, 100-150 individuals participated in each of the sessions.

The sessions were held in a neutral space that was centrally located and accessible to community residents, such as a local school or armory. To foster a sense of community ownership, the all-day exercise was planned and led by community residents with technical assistance from the MHC. Local groups and artists added to the ambience and camaraderie by contributing their talent in music, poetry, food and relaxation techniques. The agenda consisted of group introductions and establishing safe space etiquette, followed by table top discussions moderated by community members. Topics ranged from life course health issues to violence and trauma, spirituality and health, access to services, taking charge of your health, and LGBTQ concerns. Transcripts were recorded and later analyzed and fed back to the community for validation.

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\(^1\) NYS Public Health Law Title L. 1993, c 443, “Minority Area “shall mean a county with a non-white population of forty percent or more........


\(^3\) Dahlgren and Whitehead, Social Ecological Model, 1991

While the sessions were convened in areas with a 40% or greater non-White population, the report reflects the thoughts and opinions of participants and may not provide a complete picture of the community’s concerns as a whole, nor of the multi-dimensional factors influencing health and well-being. Nevertheless, it represents a step towards a deeper understanding of some of the daily challenges facing community residents. This knowledge can then inform efforts regarding New York State’s ongoing health care transformation.

Key findings from the sessions included critical concerns around health care access; cultural and linguistic competence; stigma; violence; community empowerment and advocacy; social, economic and educational opportunities for upward mobility; and the importance of community-designed and community-led interventions that can contribute to improved health and socio-economic well-being. There was a clear call for the incorporation of public health and care management into a more holistic system of health care delivery, where community residents have a say about the quality of care and what kind of system would best serve them. These sentiments are consistent with quality-based care parameters espoused by health care and other accountable organizations.

This report provides a summary of three listening sessions that gave voice to disenfranchised communities across New York State and presents a set of recommendations intended to inform the implementation of health policies, strategies, programs, and activities across culturally, linguistically, racially diverse, and multi-ethnic communities.
I. REPORT

A. Background

Breakthrough medical advances and new technologies are providing greater options for health and wellness, and offering the potential for living longer, healthier lives – but these advances have not benefited all members of the population equally. There is an abundance of published data which demonstrate that poor health is not randomly distributed in our country or our state, but instead, the highest rates of disease are concentrated in communities with the highest proportion of racial minorities, poverty, unemployment and low educational attainment.

Disparities exist across a wide range of health outcomes including life expectancy, infant mortality, low birth weight deliveries, teen pregnancy, mental illness, drug and alcohol addiction, obesity, heart disease, cancer and homicide.\(^5\) The societal burden of health and health care disparities in the United States is a significant and powerful indicator that our goal of health equity is not yet being realized\(^6\). This is in large part due to the complex nature of health disparities, which require attention to several policy and practice areas all working together towards a collective goal.

First, from a demographic standpoint, national trends show an increasingly diverse population. According to the U.S. Census Bureau, approximately one-third of the population in the United States currently belongs to a racial or ethnic minority group, and by the year 2042, racial and ethnic minorities will become the majority\(^7\). In New York State in 2010, according to the U.S. Census, approximately 42% of the population was non-white and demographic projections for the State indicate that by 2025, racial and ethnic minorities will be the majority of the population in the State\(^8\). The demographic changes anticipated over the next decade magnify the importance of ensuring that health care organizations become culturally competent and equipped with the knowledge and skills necessary to facilitate and increase mutual understanding and acceptance of the many cultures served.

Hand in hand with demographic information is the need for both quantitative and qualitative data on the health status of the populations served; knowledge of the social, economic, and cultural factors influencing the delivery, and utilization of services; and effective evidence-based interventions to guide us in effectively eliminating disparate health outcomes. Communities are dynamic and the pace of new research is slow, lagging behind the increasing needs of the most vulnerable communities. There is a critical need for health disparities research in both the bio-medical arena, as well as practice-based research to test new models of care that engage patients, providers and communities.

Emerging literature and thought leaders point to social and structural factors as having the greatest influence on health inequality. In this context, opinion leaders including government agencies and community development advocates are calling for more connected and coordinated approaches for driving and sustaining change responsive to the nature of local communities and their role.\(^9\)

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\(^5\) NYSDOH. 2012 Minority Health Surveillance Report


\(^7\) U.S. census 2010

\(^8\) New York State Office of the Aging. New York State Plan on Aging 2011-2015

For the past decade there has been a resurgence of community-based and community-engaged efforts aimed at eliminating disparities and advancing health equity. For example, the CDC’s Racial and Ethnic Approaches to Community Health (REACH) program has empowered residents to seek better health, helped change local health care practices, and mobilized communities to implement evidence-based public health programs to reduce health disparities across a broad range of health conditions. The National Institutes for Health, and major philanthropic organizations such as the Kresge and Robert Wood Johnson Foundations, are now emphasizing the value of community engagement as a way of bringing about sustainable social change – change that resonates deeply with the vision and strategic direction of community-driven solutions.

Further, organizations of all types, acting in diverse settings, are implementing a collective impact approach to solving complex social problems, and there are now published examples of large-scale multi-dimensional place-based interventions and formal collaborative infrastructures and Community Based Participatory Research (CBPR)-style capacity building, which demonstrate the potential power and success of this approach.\(^{10,11}\)

Examples of these place-based initiatives are:

(a) **STRIVE Collaborative**: a collective impact initiative formed among 300 government, non-governmental organizations, academic, private and corporation foundation, school district and community stakeholders to address the student achievement crisis in Cincinnati and northern Kentucky.

(b) **Purpose built model of neighborhood transformation**: a 10 year collaboration among residents of the village of East Lake in Atlanta and Purpose Built Communities, an Atlanta-based not-for-profit community development corporation, which developed and implemented a multidimensional intervention (i.e., quality housing, educational attainment, workforce development, improved social services, and infrastructure improvements), which decreased crime by 70%, increased employment of low-income adults by 57%, and dramatically increased student performance in the local charter school.

(c) **The Dudley Street Neighborhood Initiative (DSNI)**: a resident-led community-based planning and organizing nonprofit organization rooted in the Roxbury/North Dorchester neighborhoods of Boston. It was formed in 1984 when residents and organizations in the Dudley Street area came together out of fear and anger to revive a neighborhood that was devastated by disinvestment, abandonment, redlining, arson and dumping, and to protect it from outside speculators, and

(d) **Magnolia Place Community Initiative (MPCI)** within the West Adams, Pico Union and North Figueroa Corridor neighborhoods of Los Angeles: MPCI is a community transformation initiative that brings together community residents and organizational partners to create a community culture to support and sustain health and well-being for everyone.

(e) **Community, Opportunity, Reinvestment (CORe)**: Governor Cuomo’s 2013 State of the State initiative to improve the well-being of New York’s most distressed communities. CORe, a neighborhood-based community change model to address disparities in employment, public safety,


education, health, and housing, used an innovative data tool (COReSTAT) to direct attention to the people and places that were most in need.

The key principal that underlies these placed-based initiatives is that priorities and action plans are determined by the communities directly impacted by health inequality, while the governmental agencies and service organizations serve as allies to a "bottom-up" process. Thus, the role of government and stakeholder organizations is to facilitate a process that creates the space for the community to identify and set priorities and to plan, implement, evaluate and sustain interventions that can achieve long-standing impact.

In October 2014, The Robert Wood Johnson Foundation launched its “Data for Health” initiative, which focused on community priorities using health information to build a culture of health, and hosted a series of “Learning What Works” events in five cities across the country, not including New York, to hear from local leaders, residents and professionals from a wide range of sectors on what information is important to them and how they might use it to help people lead healthier lives and improve health in their communities.

Similarly, in November 2014, the New York State West African Health Collaborative was established by the Office of Minority Health & Health Disparities Prevention with the central goal of working with leaders of West African communities to develop a community-led strategy and action plan to address their health needs and concerns around Ebola and other public health and social issues. Key components of this strategy were to create space for community residents to openly discuss their concerns and identify priority issues; align identified priority issues and needs with state and local resources; and provide technical assistance and support to help build community capacity, collaboration, mobilization and sustainability efforts around Ebola and other issues beyond Ebola.

In keeping with the need to establish and build upon models and frameworks (i.e., best practices, evidence based models) proven successful in engaging and involving minority populations as active participants in the planning, design, implementation and evaluation of health interventions, Commissioner Zucker charged the Minority Health Council to convene a minimum of three (3) listening sessions in areas defined as Minority Areas within New York State in 2015 and 2016.

Among the questions for which insight was sought were:

- What do you see as the challenges facing your community?
- What would your community look like if your hopes, aspirations and concerns were met?
- What assets does your community possess that would strengthen and transform your community?
- What are the identified gaps and resource needs?
- Who are the stakeholders for accountability?
- How would you know if your interventions are successful?

The expected outcomes included learning about local problems and added elements needed to strengthen, empower and sustain communities in order to ultimately improve health outcomes. These outcomes can foster greater understanding of the policies and resources needed to support communities across the state.
B. Conceptual Model

Persistent and well-documented health disparities continue to exist, and health equity remains elusive across the United States\(^1\). Health disparities — differences in health outcomes that are closely linked with social, economic, and environmental disadvantage — are often driven by the social conditions in which individuals live, learn, work and play. Traditional top-down research approaches have not resulted in the necessary changes for communities with the least access and power, and communities whose voices are often not heard.

The project was organized around the view of thought leaders and emerging literature that argue that if health is socially determined, then health issues are best addressed by engaging community partners who can bring their own perspectives and understandings of community life and health issues. Furthermore, if health inequalities are rooted in larger socioeconomic inequalities, then approaches to health improvement must take into account community concerns and be able to benefit diverse populations.\(^12\)

Thus, the project relied on public health ecological models (figure 1) that focus attention on the universe of biological and individual life style factors, social and community networks, and broader socio-economic, cultural and environmental conditions, which all intertwine to affect health outcomes. With this background, a community-led, bottom-up and holistic approach to obtain the views and insights of community residents around a range of topics chosen by community members, and likely to engender maximum engagement and participation was pursued, with the aim of developing interventions that address and cut across each domain and result in appropriate individual and community level change.

![Figure 1. Socioecological Model for Public Health](source: Dahlgren and Whitehead 1991)

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\(^{12}\) Centers for Disease Control and Prevention in: Community Engagement: Definitions and Organizing Concepts from the Literature Donna Jo McCloskey, RN, PhD, (Chair), Mary Anne McDonald, D.Ph., MA, Jennifer Cook, MPH, Suzanne Heurtin-Roberts, PhD, MSW, Stephen Updegrove, MD, MPH, Dana Sampson, MS, MBA, Sheila Gutter, PhD, Milton (Mickey) Eder, PhD, (2009).
C. Project Organization

The foundation for the organization of the listening sessions was based on the principles of empowerment, asset mapping, active participation, community ownership and meeting people where they are\textsuperscript{13}. The concept of social action\textsuperscript{14} is an employed method of engaging, mobilizing and empowering people in a community with a shared interest. It is used in order to develop solutions that will bring about positive changes in health and well-being, inspire community transformation, and sustain positive behaviors and was also used to inform the project development.

The project included five steps:

1. initial focus groups with neighborhood stakeholders with the purpose of advertising the listening sessions within their constituencies and turning out participants;
2. community listening sessions;
3. written and oral “reporting out” to the community to validate and update listening session findings;
4. modeling of projects for community review and approval; and
5. finalizing the project report and presenting it to resource holders.

An important feature of the project organization and design was to incorporate a place-based, self-help approach that strengthened the ability of community residents to identify and select issues they felt were most pressing for their community. This allowed them to generate ideas, contribute to decision making and share the responsibility of accountability.

Power was ceded to community residents in planning, outreach, organizing, and facilitating the sessions. This process engendered meaningful community participation and a heightened sense of community pride. An equally important component of the organizing process was creating a safe space for communities to dialogue and voice their vision without feeling intimidated. Thus, venue selection, rules of etiquette emphasizing mutual respect, trust, and a safe space for sharing were established at the beginning of the planning process, articulated at each session, and made visible throughout the process as a reminder.

D. Design and Methodology

The target population included community stakeholders who participated in initial focus groups for the purpose of maximizing community participation; and racial, ethnic and other underserved community members of all ages. On average 100-150 individuals participated in each session.

Stakeholders included individuals from the community and organizations such as faith institutions, schools, block and civic associations, community-based organizations, housing and social service advocates, local media, and other cultural brokers who knew their community well. These individuals were invited to help plan and advertise the sessions within their constituencies. While participants could

\textsuperscript{13} Beena Antony, Archana Kaushik Social Action: Concept and Principles *, University of Dehli
\textsuperscript{14} Ibid 12
be considered as representing the universe of the populations targeted, neighborhoods where health disparities are greatest, neighborhoods with large gang and drug use activities, racial and ethnic groups, homelessness, youth, and older adults were those most sought-after. Stakeholders were also instrumental in shaping the agenda for the meeting, selecting formats and identifying facilitators and speakers.

To reduce some of the barriers to participation, transportation and bus passes as well as babysitting services were available. In Albany, community residents from the local YWCA pooled their individual dollars to make the session possible. This was testament to the community’s hunger for this type of engagement.

The locations of the sessions were an important consideration. To ensure a centrally located, accessible, neutral and safe space which conveyed a sense of neighborhood, positively viewed schools were selected in Buffalo and Rochester which maximized youth participation and the Armory at SAGE College was selected in Albany. Below is a brief summary of each meeting:

**Buffalo: July 11, 2015—Buffalo School of Architecture and Planning**
Voice Your Vision Buffalo focused on health disparities and environmental concerns facing the residents of Western New York. Breakout session topics included but were not limited to housing, lack of resources, access to quality care, senior health, and men’s and children’s health. Voice Your Vision was a collaboration of the New York State Minority Council and Greater Buffalo United Accountable Healthcare Network (GBUAHN) Health Home of Buffalo, New York. The listening session aimed to create a safe space for community members to voice their opinions to the NYS Minority Health Council, health care professionals and public officials about how the health care industry can better assist in delivering better care. The breakout sessions were led by various members of community based organizations. Voice Your Vision Buffalo was free and open to the public. Also, a continental breakfast and lunch were included for all registrants.

**Rochester: October 3, 2015—Integrated Arts & Technology School**
Voice Your Vision Rochester was held at the Integrated Arts & Technology High School at Franklin Campus, a large school located in an area known as “The Crescent of Poverty” or the “Fatal Crescent.” The name refers to the five neighborhoods clustered around the northern border of Rochester’s downtown. These socioeconomically disadvantaged neighborhoods contain the region’s highest rates of health disparities, and are comprised of the City’s highest concentration of Hispanics/Latinos and African American residents, who are also very impoverished. There are approximately 143,000 neighbors who live in the “Crescent.”

An array of services, aimed at bringing in the population whose voice often goes unheard, were provided throughout the day. Door-to-door transportation was provided by a number of community partners to ensure that all who wanted to attend could do so. Childcare was also provided throughout the entire event. A hot, cooked breakfast, with a live steel pan band, started the day with a jovial and welcoming atmosphere. Other services offered throughout the day included a men’s barbershop area, and a host of other community health related services offered by community based organizations.

Community leaders shared their personal experiences with accessing health and their feeling of how important it is for the community to participate in this event, and others like it. With the honest voice of real community members sharing their problems with accessing and utilizing the health care system, a multifaceted approach to solving the problems that cause these huge disparities is possible.
The listening session then moved into World Café sessions, where the guests were able to move from table to table to participate in the various topics for discussion. With the help of a dedicated team of community volunteers and partners from the various community based organizations, each table had a facilitator and two scribes to ensure that all the information community residents shared was captured with detail.

After each table completed their overall discussions, scribes compiled the common themes gleaned from their conversations and presented them to the larger group. When listening to each table’s discussions there were a few common themes that emerged from the day.

One of the most significant stories of involved the “Man who received a haircut.” A few community members attending happened to be homeless. One gentleman who attended was in need of a haircut and a shave. It was noticeable that he wasn’t really participating in the discussion, but sitting on the periphery, just watching the other folks converse. He took part in the services available at the mens’ table, or “the barbershop” as many called it, and received a haircut. As he was receiving this haircut and shave, his whole demeanor opened up. He began to engage in each discussion he joined afterward. This was certainly a victory. If it was not for the services offered that day, his invaluable feedback, which represents some of the most underserved in our community, the homeless, would not have been captured.

**Capital District: Saturday 23, 2016 Sage College—Armory at Sage**

On January 23, 2016, the Sage Colleges and NYS Minority Health Council hosted Voice Your Vision: Capital Region at the Armory at Sage in Albany, NY. The day began with breakfast and a welcome. Unique to this community listening session, the opening and welcome were presented in three languages. Then, a reminder of the charge to the NYS Minority Health Council was provided, along with review of “safe space” etiquette, blessing, and a poem. Participants were then led through a “Stretch & Breathe” exercise session. Participants then had the opportunity to sit at various tables to voice their experiences on a variety of topics. Table topics included women’s health, taking charge of your health, violence and trauma, spirituality and health, seeking services in the community, youth and adolescent health, aging and elder care, people with disabilities, LGBTQ health, men’s health, and open topics. Volunteer table facilitators supported open, community discussions.

**E. Description of Listening Sessions**

To foster a sense of community ownership, the all-day exercises were planned and led by community residents with technical assistance from the MHC. Local groups and performers added to the ambience, culture, and camaraderie by contributing their talent in music, food, relaxation techniques and poetry. This set the tone for a cultural appreciation of the sessions. In addition, each session featured some form of spirituality and blessing. This was an important element given the role that faith and spiritual beliefs often play in community members lives. Attention to language was another key feature, and at the Albany session for example, greetings were extended in three different languages to embrace the diversity of participants.

Throughout the day, local programs disseminated health and related materials and a barber shop in Rochester was offered to target and encourage a dynamic discussion on men’s health. It also provided much needed services to the homeless creating a sense of well-being.
The format of each session consisted of a large group introduction and welcome, followed by table top discussions moderated by community members. In an iterative process, topics were selected from a standard list that was used across all sites, but each site varied their selection according to the needs of the community. Topics ran the gamut from taking charge of your health; to women’s health, men’s health; violence and trauma; spirituality and health; youth and adolescent; aging and eldercare; living with variable abilities; LGBTQ health; and seeking services in the community.

A safe space was ensured for dialogue and sharing, and rules of engagement as indicated below agreed upon by each participant. A video was prepared to capture the essence of these sessions and can be found at: https://www.youtube.com/watch?v=nozOyHFpG2w&feature=youtu.be. A poem, prepared and recited by Amen Imhotep Ptah, a community resident and participate in the Rochester listening session, was shared at both the Rochester and Albany sessions (see Appendix A).

VOICE YOUR VISION

Has been designated as a “Safe Space.”
A place where all voices hold value and all perspectives are seen as valid.

Below you will find a few house rules to help maintain the integrity and safety of this space.

NO RACISM
NO SEXISM
NO HOMOPHOBIA
NO TRANSPHOBIA
NO FATPHOBIA
NO ABLEISMS
NO AGEISMS
NO HATE

All guests are asked to practice “Active Listening” which is the art of listening to others with the intent to understand, instead of waiting for your turn to speak.

As previously noted, transcribers were present to document and record the discussions, keeping individual personal identities confidential.

Following the discussion, a description and analysis of topics discussed was done in three ways, by site, by topic and by cross-cutting themes. Two researchers performed the analysis reading each transcript six times: three times independently and three times where results were compared. In the first step, the data was read and coded by site. For example, all the Rochester transcripts were read together, all the Buffalo transcripts together and Capital District transcripts were read together. In the second step, transcripts were re-sorted by topic and materials from all three sites integrated. In the third step all the transcripts cross-cutting themes were identified.
The collective results were summarized and translated into recommended action steps. In the fourth step, the results of the analysis were returned in draft form to those who conducted the sessions as a form of ‘member-checking’ and to make sure the content and spirit of the deliberations was properly captured. Further, very often community members are “heard” but believe that their perspectives are ignored when no follow up or visible action transpires. Therefore, summaries of the discussion along with recommended action steps were returned to a sample of the community through follow-up meetings. The intent of this follow up was to assure that the right words and the proper spirit in which the discussions occurred were expressed were accurately captured.

F. Limitations

The limitations encountered revolved around outreach, collection of demographic data, financial support for the project, and comparing provider and community member perspectives.

**Outreach:** Although the sessions were open and accessible, outreach was difficult as some of the targeted populations are often outside the mainstream of community networks, such as the homeless and the uninsured. As an additional barrier, the sessions used only existing resources, and were carried out on a short timeline. Paid advertising in newspapers or on the radio, may have attracted more participants. Further, participation among the LGBTQ community was minimal. One site had no one who identified as LGBTQ, either because they were not contacted, or because they did not feel comfortable disclosing their status in the session. Greater emphasis on the participation of this underserved and often stigmatized group including engaging LGBTQ organizations that work with that population, would potentially yield better results.

**Collection of Demographic Data:** Although there was documentation of attendees, only Rochester provided a breakdown by race, ethnicity, age, and other demographic variables. Availability of this information would allow for more targeted outreach. Therefore, the extent listening session participants were demographically representative of the targeted communities was not documented.

**Project Financing:** The design of the project did not take into consideration project financing which, ultimately, was identified as a limitation.

**Comparing Provider and Community Member Perspectives:** Listening session participants included both providers and community members. Both voices were captured. There was no way to delineate perspectives and thereby compare them. Therefore, the relative contribution of provider and community perspectives to the collective voice captured could not be assessed.

G. Results and Analysis

**Summary of Key Issues:** The following is a summary of key points from the topics discussed. A more detailed description of the discussion by topic arranged by desired outcome, concerns voiced by community members, and solutions and action items is attached (Appendix B).

- **Taking Charge of Your Health:** Themes included empowerment; freedom and advocacy; taking charge of one's own health through exercise, healthier diets, and less stress; eliminating the fear of getting, or being diagnosed with a disease and realizing there is comfort in knowing one's health status; and becoming an expert in one's own health.
• **Women’s Health:** Discussions included the importance, or lack, of services related to regular or routine screenings and tests, such as mammograms and pap smears; childbearing resources and services; management of stress and depression; mental health counseling and care; insurance eligibility; access, and weight management.

• **Men’s Health:** Much discussion was about men acting tough and suffering in silence. Many men perceive the need for health care as a weakness as they are supposed to be providers and protectors. Medical issues such as diabetes and heart disease are likely to be discussed by men but mental health and prostate issues are often hidden.

• **Violence and Trauma:** The consensus of the discussion was a self-help approach. Participants stated that “we may not be able to change the nation, but we can do something local in our own neighborhoods and towns.” The need to envision a better future for themselves and successive generations was strongly emphasized, as was the need to find a way to make their communities safer. Solutions offered included strengthening vulnerable communities and creating a path out of poverty.

• **Spirituality and Health:** Suggestions included training of pastors and other church personnel to serve as referral and early intervention resources particularly around issues of mental health.

• **Youth and Adolescents:** In response to issues that affect youth and adolescents, participants expressed that health is less of a concern for them than living to see another day, because of violence and trauma. They want to feel safe emotionally and physically. Regarding health, there is a need for educational programs that address skills such as making appointments and engaging in dialogue with their provider.

• **Aging and Eldercare:** Major issues for elders and the aging were the need to stay connected with community members; become involved in programs that allow them to share their experiences and skills across generations; maintain their independence; have access to programs that explain Medicare, Medicaid, health, and long term care insurance; and access to training programs in web-based technology to help them stay current.

• **Living with Variable Abilities:** In response to ways in which living with a disability affected their health, participants expressed the desire to be seen as a whole person, not just a disability. They also indicated that providers often make assumptions about lifestyle and sexuality among individuals with disabilities and stressed the importance of routine screenings, information and supplies for birth control and sexually transmitted diseases. In addition, barriers such as inaccessible examination rooms, rushed providers, staff who are not accustomed to working with the differently-abled, stigma, and availability of transportation rated highly among their concerns.

• **LGBTQ Health:** In one of the listening sessions, no one identified as LGBTQ. In subsequent sessions the table topic was changed to indicate that this was a discussion of assumed beliefs, and not necessarily the voice of individuals who have the lived experience. The discussion then generated responses indicating that stigma around homosexuality was prevalent. Participants described observed and actual bullying and verbal abuse. Key areas
identified were physical abuse, verbal abuse, and suicide. They expressed the need for acceptance, respect for one another and freedom to feel comfortable with who they are.

- **Seeking Services in the Community.** A number of barriers to seeking services were articulated. Among them were cost, scheduling difficulties, transportation, child care issues related to keeping appointments, trust of the health care system, living conditions such as homelessness and isolation, and lack of health literacy and culturally competent care.

**Cross-Cutting Themes:** Several cross-cutting themes emerged from the sessions. If a theme was identified in three of more of the topical sections, it was considered a cross-cutting theme. While addressing these themes would not be a panacea for improved health and well-being, they provide insight that can inform a platform for approaches to improve health outcomes in underserved communities. Themes that cut across all the table discussions included:

- Providing culturally competent care;
- Connecting with people where they are: geographically, emotionally and educationally;
- Increased attention to the changing structure of families;
- Addressing issues of transportation and social isolation;
- Addressing cost of care;
- Improving the built environment;
- Eliminating stigma;
- Providing opportunities for ending poverty;
- Addressing the social determinants that influence health outcomes; and
- Re-inventing healthcare to encompass preventative health and wellness.

1) **Analysis of Transcripts:** All transcripts were analyzed by table topic and are attached in the appendix. For example, the transcripts from all three sites that reflected LGBTQ Health were combined, the transcripts from all three sites for Men’s Health were combined, the transcripts that described Taking Charge of Your Health from all three sites were combined, and so on. When topics were not discussed at all three sites, it is noted in the comments and the data reflects only the sites that held discussions on that topic. ‘Wordles’ were made from the unedited transcripts, where a larger word indicated a greater emphasis on that that it was mentioned more times. The results were then abstracted, and quotes from the listening sessions were provided when available. If a suggestion or solution was cited or proposed, it is reflected in the Solutions/Action Items column.
II. RECOMMENDATIONS

A. Community Recommendations
Participants in the community listening sessions made specific recommendations focused on improving health outcomes and transforming communities by addressing the social, economic, geographic, cultural and other related factors that influence utilization and delivery of health care. Their recommendations included specific actions for policy and practice and are presented by the topic areas discussed.

Recommendation #1: Taking Charge of Your Health
Empowerment, freedom and advocacy were the overarching themes in response to the question, “What comes to mind when you think of taking charge of your health?” More specifically, participants expressed that empowerment, freedom and advocacy can be achieved through exercise, healthier diets, reduced stress, eliminating the fear of having or being diagnosed with a disease, knowing one’s own health status and becoming an expert in one’s own health. Collectively, they recommended:

- Increasing health education in schools at all grade levels, especially around reproductive health and sexual education.
- Using the socio-ecological model (individual, interpersonal, community and societal levels) to allow providers to understand the connection between the patient, his/her environment and his/her health to coordinate a comprehensive care and prevention plan.
- Addressing issues of stigma, childhood experiences, sexual abuse and other kinds of trauma and their impact on physical and mental health.
- Providing care in a culturally competent manner.

Recommendation #2: Women’s Health
Ensuring regular and routine screenings such as mammograms and pap smears, issues related to childbearing and child-rearing, stress, depression and mental health issues, insurance access and obesity were the topics that emerged relevant to women’s health. Collectively, they recommended:

- Increasing the availability and accessibility of after-hours clinics for working women, with special attention to waiting time to address conflicting roles and responsibilities.
- Providing mental health and stress management services to assist women to cope with anxiety, work, family, self-care and caregiving.
- Improving provider communication to avoid judgmental attitudes.
- Addressing transportation and child care issues to make it easier for women to make and keep appointments.
- Being sensitive to family structures.
Recommendation #3: Men’s Health
Participants expressed the notion that men often act tough but suffer in silence because they perceive the need for health care as a weakness. They were comfortable discussing medical issues such as diabetes and heart disease. However, mental health and prostate problems are often hidden. In addition, prostate exams and colonoscopies invoke feelings of violation and homophobia. Collectively, they recommended:

- Using community leaders and public figures as ambassadors for promoting preventive health care to alter the perception, thereby “making it cool” to get preventive care.
- Launching public service campaigns by sports figures or celebrities that normalize colonoscopies and prostate exams.
- Increasing the number of male providers of color.
- Involving other family members in the discussion about men’s health.
- Promoting men’s preventive health care at barbershops and sports or car events.
- Involving faith leaders in men’s mental health issues.
- Developing interventions to encourage men to use preventive health care services taking into consideration the role they play as “protectors and providers”.
- Developing user-friendly websites targeted to men.

Recommendation #4: Violence and Trauma
In response to the question “What is the effect of violence and trauma in your neighborhood?” the collective response was “we may not be able to change the nation, but we can do something locally in our own neighborhoods and towns”. Participants articulated the desire to envision a better future for themselves and their children and attribute the problem, in large part, to poverty, lack of basic needs, and the feeling that they are seen as less than human. Collectively, they recommended:

- Investing in opportunities for the future including education, employment, youth opportunities, housing, school programs, mentorship programs, and creating a path out of poverty.
- Increasing in the number of available community resources.
- Increasing health literacy and financial literacy. For example, people who are not literate are unable to complete forms for benefits, jobs, or insurance. This presents a barrier in places such as doctor’s offices as they are embarrassed to tell anyone, thus shying away from needed care.
- Focusing on mental health issues as living among violence and in poverty affects mental health which in turn leads to violence. Clergy should be trained to help address mental health issues.
- Increasing funding to recognize and address the underlying social determinants of health, rather than only the medical manifestation of a disease.
- Increasing training for outreach workers to encourage people from the community who are compassionate and caring to serve those in their own communities.
Recommendation #5: Spirituality and Health
Relationship building, community conversations and trust were among the themes that came instantly to participants’ minds in response to the question “How are spirituality and health connected in your community?” Participants articulated the importance of the role of the church in bringing people together around issues of health, serving as a first responder for mental health issues and connecting people to resources. Collectively, they recommended:

- Providing training to religious personnel to act as a resource base with the ability to refer individuals for health care services.
- Working with churches to unify and collaborate to bridge gaps between and across denominations.
- Embedding health services (including mental health services) into the church.
- Using models of health improvement that incorporate faith- and community-based organizations.

Recommendation #6: Youth and Adolescent Health
The broader social determinants of health, in particular, safety and security were on the forefront of the minds of youth and adolescents when asked the question “What are the issues that affect youth and adolescent health in your community?” The collective response was “we need to feel safe, emotionally and physically. It’s not so much about health as it is about living to see another day. We do not worry about check-ups because our safety is more of a risk and more immediate”. Collectively, they recommended:

- Increasing educational programs that address skills, such as making appointments with health care providers and engaging in dialogue during exams.
- Offering health care services directly to adolescents in middle and high schools.
- Co-locating family clinics in elementary schools.
- Offering widely available family planning materials and supplies, and educate youth on becoming a parent, with the understanding that they are not ready to be parents.
- Offering parenting classes for kids who do become parents and providing programs that allow them to complete their high school education.
- Providing information and a pre-printed list of questions to ask at doctor’s visits to make the most of appointments with health care providers.
- Recognizing the use of technology and use texting and other media to disseminate reliable medical information.
- Developing teen empowerment programs that offer opportunities for success, connections, and mentorship programs that re-inforce individual value and self-worth.
Recommendation #7: Aging and Eldercare

The group articulated a number of desired outcomes regarding the issue of aging and eldercare in their community. Among them: better health outcomes, keeping families together, maintaining as much independence as possible, preparing for aging, caring for aging parents, managing their own homes, coping with new rules and regulations for Medicare and Medicaid, addressing their fears and achieving meaningful engagement. Collectively, they recommended:

- Training providers who are competent in working with the elderly to address their fears, help them plan for aging, connecting them to resources, and coordinate their health care.
- Supporting programs that increase individual awareness and knowledge of Medicare, Medicaid, health insurance and long term care.
- Exploring evidence-based models for community care and successful aging such as programs that pair youth with elders possibly coordinated by schools.
- Increasing and enhance basic services related to medication, transportation, safety, housing, therapists, nutritionists and life alert.
- Ensuring effective telecommunication methods for elders who may not be up to date, or have access to, new technology and offer classes on computer literacy and smart phones.
- Supporting training for the many family members who are unpaid caregivers.
- Reviewing and revise programs to ensure that inter-generational family structure is accounted for and supported.
- Increasing information provided about alternative living arrangements.
- Building a culture of valuing elders.

Recommendation #8: Health and Living with Variable Abilities

Participants in this group articulated their desire to be seen as a whole person, not just the disability. Providers often make assumptions about lifestyle and sexuality because a person is disabled they do not need routine screenings, evaluation, information and supplies for birth control and sexually transmitted diseases. Physical space, thoughtful discussions and tailored programs about prevention and wellness would benefit people with disabilities. Barriers include inaccessible examination rooms, rushed providers, staff who are not accustomed to working with differently-abled, stigma, and availability of transportation. Collectively, they recommended:

- Demonstrating cultural competence when seeing and treating patients living with disabilities, and modified options of the same advice on diet, exercise and good preventive care.
- Providing additional time with providers because their issues are more complicated and persons with disabilities need more time to dress, undress and maneuver the room.
- Improving compliance with the Federal Americans with Disabilities Act (ADA) by ensuring physical access at clinics for wheelchairs, use of bathrooms, etc.
Recommendation #9: LGBTQ Health
For one of the three listening sessions, no one identified as LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer or Questioning). To promote discussion, in subsequent sessions the labels were changed to reflect that this was a discussion of assumed beliefs and not necessarily the voice of individuals who have lived the experience. Stigma around homosexuality was assumed to be prevalent and participants described observed and actual bullying and verbal abuse. Key areas were identified such as physical abuse, verbal abuse and suicide. Collectively, they recommended:

- Promoting respect for, and acceptance of, each other with the understanding that we all want to be healthy, have freedom to be comfortable, and need to be respected.
- Increasing education about the availability of care.

Recommendation #10: Seeking Services in the Community
Participants articulated a number of barriers when seeking services in the community. Chief among them were cost, scheduling, transportation, childcare, trust, conditions of living such as homelessness and isolation. People voiced that being seen by clinic doctors and having to repeat their medical history many times, lack of health literacy (both their own and those of providers) and lack of cultural competence of providers were barriers to seeking care in the community. Collectively, they recommended:

- Increasing access to and helping with obtaining Medicare and Medicaid.
- Providing workshops on how to enroll in health insurance programs.
- Delivering healthcare in locations and at times that are convenient to patients to reduce the burden of transportation and time off from employment.
- Providing brochures and other informational materials in languages and at a literacy level to meet the needs of culturally diverse populations.
- Utilizing ethnically diverse print and electronic media outlets to disseminate information.
- Ensuring that services are provided in a culturally competent manner and raise providers' understanding about issues of privilege, structural racism and power.
- Restructuring the primary care visit to provide better linkages.
- Leveraging and improving academic and community partnerships.
- Improving opportunities for training the next generation of health care workers.
B. Council Recommendations

In addition to the Community Recommendations, the Minority Health Council further recommends the following:

1. Replicate Community Listening Sessions in Underserved Communities Across New York State

Very often community members believe that providers and others seek their assistance in articulating problems to support their research work, but believe their perspectives are ignored when no actions are taken. The Council recommends using the outcome of the community listening sessions to change this paradigm by providing financial support to contractors in selected §240 MA to host community engagement forums. Such contractors would be required to partner with community members and other key stakeholders to develop a community-based action and sustainability plan that uses community identified priorities as well as other quantitative and qualitative data as a framework for determining the most effective strategies and interventions to increase access to care and improve the health and well-being of the community.

2. Improve the Reliability and Granularity of Data as a Tool for Community Intervention

The Council recommends that the Department work to increase the granularity and availability of race and ethnicity data in Minority Areas across the state to serve as a tool for Health Department programs and community stakeholders to better assess, understand and communicate local health issues, target resources, and support local strategic health planning and prioritization, intervention design and evaluation efforts. Such data should include:

- Quantitative information but also qualitative narrative about the broader social determinants influencing health outcomes.
- Making available to consumers an action-oriented framework for addressing health disparities to serve as a resource and guide to community intervention efforts; and
- A more user-friendly, technologically advanced Health Equity Report.

3. Develop a Tool Kit for Planning, Implementing and Evaluating Community Engagement Sessions

The Council recommends that the Department make available a Toolkit that can serve as a guide for stakeholders to plan, implement and evaluate community engagement sessions.

4. Integrate the Community Listening Session Model into other Health Care Delivery Efforts

Medicaid Redesign, Delivery System Reform Incentive Payment (DSRIP), Prevention Agenda, Population Health Improvement Plan (PHIP) and other related programs are exciting opportunities for systems change and health improvement in New York State. All of these initiatives include the active participation of, and input from, communities throughout the state. While there are many mechanisms for acquiring insights from community residents, the Voice Your Vision community listening model, because of its community-led and bottom up approach, is capable of generating important information that adds real value in community assessment, design, implementation and evaluation of community interventions, as communities understand the association between chronic community development problems, and chronic public health and health systems problems. Thus, the Council recommends that the Department consider this model for use in its programs, initiatives, and agendas, and encourage health care providers to consider its use to engage communities in health care and public health transformation.
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- Excellus Bluecross Blueshield
- Finger Lakes Health System Agency
- Healthy Baby Network
- Ibero-American Action League, Inc.
- Jakababran Consulting Group
- Mental Health Association
- Monroe County Office of Mental Health
- Nathan Kline Center of Excellence in Culturally Competent Mental Health Care
- NY State of Health, Health Plan Marketplace
- CCSI’s Prevention, Access, Self-Empowerment, and Support (PASS) Program
- St. Joseph’s Neighborhood Center, Inc.
- Teen Empowerment, Inc.
- Trillium Health
- National Black Leadership Commission on AIDS, Inc.
- Interdenominational Health Ministry Coalition
- Grace Unity Fellowship Church
- We the People Community Group
- Rochester City School District Parent Advisory Council
- Greater Rochester Collaborative, MSW Program of Nazareth College

Community Groups
- Black Women’s Leadership Forum
- Conkey Cruisers
- Rochester Jamaican Organization, Inc.
- African American Health Coalition
- Latino Health Coalition
- Social Welfare Action Alliance
- Rochester-Monroe Anti-Poverty Initiative
- Building Leadership and Community Knowledge
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APPENDICES

Appendix A: Poem by Amen Imhotep Ptah, Rochester Participant
Appendix B: Analysis by Topic
“I’m Not Feeling Well” - Poem by Amen Imhotep Ptah
Community Listening Session Participant

<table>
<thead>
<tr>
<th>I’m not feeling well; my health is withering away</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sunny days got overcast now my casket is gray</td>
</tr>
<tr>
<td>I’m not feeling well; my health is withering away</td>
</tr>
<tr>
<td>After HIV aid the path that laid me in an early grave</td>
</tr>
<tr>
<td>I’m not feeling well; my health is counting on my cells</td>
</tr>
<tr>
<td>But my cells are locked behind cells, diseased jails</td>
</tr>
<tr>
<td>And as a Black male, sometimes I feel blackmailed</td>
</tr>
<tr>
<td>To trail behind in despair, low income no healthcare</td>
</tr>
<tr>
<td>I’m not feeling well, and I’m dying in a drought</td>
</tr>
<tr>
<td>No water in my well, got an empty bank account</td>
</tr>
<tr>
<td>And a high viral load with a low CD4 count</td>
</tr>
<tr>
<td>Below two hundred I’m biologically hunted</td>
</tr>
<tr>
<td>Blood pressure climbing, strokes on the horizon</td>
</tr>
<tr>
<td>Blood vessels clogging, my brain is getting no oxygen</td>
</tr>
<tr>
<td>Air supply is depleted, my spirit is feeling defeated</td>
</tr>
<tr>
<td>Failed by a country we all pledge our allegiance</td>
</tr>
<tr>
<td>Satan’s venom secreted in the veins from the fangs of a demon</td>
</tr>
<tr>
<td>Biting then binding in the bloodstream and semen</td>
</tr>
<tr>
<td>Infectious, contagious, and sex drive outrageous</td>
</tr>
<tr>
<td>Translates to an epidemic like Indiana’s new AIDS cases</td>
</tr>
<tr>
<td>Pardon me I meant HIV</td>
</tr>
<tr>
<td>I stand corrected medically, but psych metaphorically</td>
</tr>
<tr>
<td>Yes I can bring it scholarly, but I’m a bring it to your chest</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>It’s no conspiracy that Blacks lead the pack in cause of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart disease I believe that the leading cause is stress</td>
</tr>
<tr>
<td>And depression which then leads to other things like diabetes</td>
</tr>
<tr>
<td>Overeating and obesity, overstretching the flesh</td>
</tr>
<tr>
<td>John Henry was a Black who slaved himself until his last breath</td>
</tr>
<tr>
<td>And Blacks have prolonged exposure to stress</td>
</tr>
<tr>
<td>Due to Structural Racism our bodies are perplexed</td>
</tr>
<tr>
<td>Racial health disparities equates to race-based inequity</td>
</tr>
<tr>
<td>First from the rate of infant mortality</td>
</tr>
<tr>
<td>To the fact, that Blacks our last in any wealth capacity</td>
</tr>
<tr>
<td>And many pseudoscientists they say the cause is ethnicity</td>
</tr>
<tr>
<td>But in reality, who’s engineering that philosophy?</td>
</tr>
<tr>
<td>I’m not feeling well, and ditto says my sick society</td>
</tr>
<tr>
<td>That’s why we lack comradery, we’re troubled with disharmony</td>
</tr>
<tr>
<td>Post-traumatic slave blood clotting in our arteries</td>
</tr>
<tr>
<td>A massive heart attack is like the straw that broke the camel back</td>
</tr>
<tr>
<td>A human being issue, and you can’t deny the facts</td>
</tr>
<tr>
<td>If you’re Black say it with me: I’m not feeling well</td>
</tr>
<tr>
<td>You understand say it with me: I’m not feeling well</td>
</tr>
<tr>
<td>You overstand SCREAM it with me: I’m not feeling well</td>
</tr>
<tr>
<td>You innerstand whisper with me: I’m not feeling well</td>
</tr>
</tbody>
</table>
When we asked the question: What comes to mind when you think of taking charge of your health? We heard: comments about empowerment, freedom and advocacy, about taking charge of your own health through exercise, healthier diets, and less stress. Eliminating the fear of getting, having or being diagnosed with a disease, and realizing there is comfort in knowing your own health status, and becoming an expert in your own health.

<table>
<thead>
<tr>
<th>Desired Outcome</th>
<th>Concern Voiced by Community Members</th>
<th>Solutions and Action Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase healthy exercise and incorporate into lifestyle</td>
<td>Unsafe Streets</td>
<td>Exercise in pairs or inside your own home</td>
</tr>
<tr>
<td>Getting accurate age- and situation-appropriate health information</td>
<td>Doctor visits that are limited in time, and not knowing how to ask a question or what question to ask</td>
<td>Increase health education in schools at all grade levels. Especially around reproductive and sexual education. Providers should use the socioecological model (individual, interpersonal, community, society levels) when addressing a patient’s needs. Providers need to help patients ask the right questions and assure understanding</td>
</tr>
<tr>
<td>Information delivered in a culturally competent way</td>
<td>Nurse Bowick has an urban radio show on health that airs on a gospel radio station. We can find the natural pathways of communication and utilize those for accurate health information</td>
<td></td>
</tr>
<tr>
<td>Consider the context</td>
<td>Stigmatized issues are not addressed</td>
<td>Ask us about adverse childhood experiences, sexual abuse and trauma, and other key conditions</td>
</tr>
<tr>
<td>Time for Health Management</td>
<td>Don’t add to my To-Do list</td>
<td>How can it become part of what we do every day, take care of ourselves</td>
</tr>
<tr>
<td>Prevention</td>
<td>Go from fee-for-service to preventative care</td>
<td>We want to keep ourselves healthy</td>
</tr>
</tbody>
</table>
Women’s Health

When we asked the question: What comes to mind when you think of women’s health?
We heard: comments about annual screenings and tests such as mammograms and pap smears, childbearing, stress, depression and mental health issues, insurance eligibility and issues of access, weight and stress.

<table>
<thead>
<tr>
<th>Desired Outcome</th>
<th>Voiced Concern</th>
<th>Solutions and Action Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care in physical health</td>
<td>Conflicting roles and responsibilities</td>
<td>After-hours clinics and consider the competing priorities. If a woman comes in for care, take her seriously, it took a lot for her to come, and dismissing the complaints or the patient is devastating</td>
</tr>
<tr>
<td>Self-care in mental health</td>
<td>Anxiety and time management; work, family, care-giving and children all compete for time for appointments and health maintenance</td>
<td>Ask more questions about mental health and offer services or connection to services. “We are stressed in every way imaginable”</td>
</tr>
<tr>
<td>Provider communication</td>
<td>Disconnect between women and providers. Judgmental attitudes and lack of ‘believability’ about the issues</td>
<td>Take the time to ask better questions and to listen to the answers</td>
</tr>
<tr>
<td>Programs that have been helpful in my community for health maintenance and information</td>
<td>Lack of accurate and timely health information</td>
<td>The Library; our health center; local news; culturally tailored diabetes education programs; neighborhood Centers; mental health association; YMCA and hospital outreach efforts</td>
</tr>
<tr>
<td>Desired Outcome</td>
<td>Voiced Concern</td>
<td>Solutions and Action Items</td>
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<tr>
<td>Timely medical care</td>
<td>Delays from many aspects, individual, systems and access, long waits for providers, lack insurance or money to pay</td>
<td>Meet people where they are, both geographically, emotionally and educationally.</td>
</tr>
<tr>
<td>Women are disproportionately affected by family stress as they are the universal caregiver for families</td>
<td>“We are the dump truck” We nurture everyone else and not ourselves</td>
<td>Go to women, instead of having them come to you. Deliver care in the workplace or the woman’s home. Make sure that it is covered financially, that transportation is available, and childcare is on-site. Otherwise there are too many barriers to getting and receiving care and it is just not truly accessible</td>
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</table>
When we asked the question: What comes to mind when you think of men’s health? We heard: comments about acting tough and suffering in silence. Medical issues such as diabetes and heart attacks are ok to discuss, but mental health and prostate issues are often hidden. Men perceive the need for healthcare as a weakness and the ability to keep powering through as a strength.

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<tr>
<td>Preventative care for men</td>
<td>Men will be seen as weaker if they seek preventative care. “Men don’t go to the doctor”</td>
<td>Alter perceptions by “making it cool” to get preventative care. Publicize leaders in the community and famous people getting care</td>
</tr>
<tr>
<td>Routine screening especially colonoscopies and prostate exams</td>
<td>Invasive procedures evoke feelings of violation and homophobia</td>
<td>Public service campaigns by sports figures or celebrities that normalize colonoscopies and prostate exams. Men’s healthcare education starting earlier and talking about the importance of screening and prevention. Involve other family members so that it is being done for them. Advertise in Barber Shops, at Sports and car events. Provide services where men go.</td>
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<tr>
<td>Trust in medical providers especially in regards to mental health</td>
<td>Women have special doctors like OB/GYN --should men? Men tend to turn to faith-leaders for issues of mental health</td>
<td>Advertise and promote “Men’s Health” like we do Women’s Health. Increase the number of male providers of color that could understand and provide culturally competent care</td>
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<tr>
<td>Pride and identity.</td>
<td>Men are providers and protectors, and ill health may challenge that critical role If a physical is required by work or sports and is covered by insurance it will be done right away</td>
<td>By taking the responsibility off men to make a decision about the exam, and by making sure it is covered by insurance, we could increase preventative care and treatment for common diseases</td>
</tr>
<tr>
<td>Teach about health, health promotion and diseases prevention</td>
<td>Make it attractive to the youth, part of the new generation</td>
<td>By changing our attitudes about health, the next generation can be healthier.</td>
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<tr>
<td>Seek care when needed</td>
<td>Many told stories of trying to push through the pain of conditions. A patient being taken to the operating room for an appendix rupture and was rolled into surgery saying “I can probably just push through and handle this on my own”</td>
<td>Recognize that men are unlikely to seek care and by the time they come the situation is serious. Encourage men to seek care earlier and that taking care of yourself is a sign of strength, not a sign of weakness</td>
</tr>
<tr>
<td>Meet us where we are</td>
<td>Safe places to talk such as barber shops, gyms, sports events. Have forums on Men’s health in the community. Focus on prevention. Have a Man’s convention or piggy-back on events where men gather</td>
<td>Have a website that focuses on men’s health (the current website isn’t friendly for men)</td>
</tr>
<tr>
<td>Engage local and national heroes to help with marketing</td>
<td>Reggie Jackson on Prostate Cancer was extremely effective</td>
<td>Increase resources and attention specifically towards men’s issues</td>
</tr>
</tbody>
</table>
Violence and Trauma

When we asked the question: What is the effect of Violence and Trauma in your neighborhood? We heard: “We may not be able to change the nation, but we can do something” [local in our own neighborhoods and towns]. We need to be able to envision a better future for ourselves and our children. We need a way out or to make where we are safer and healthier. There is a subtle and insidious violence, a lack of basic needs and a feeling that we are seen as less than human. Violence moves in when people move out. We do not want to lose the voices of the most vulnerable to violence and trauma, we want to hear the voices of the homeless and those in need of help the most. The most important step we can take is to create a path out of poverty and towards a better future.

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| Increase connection to the community and to each other as a means to reduce violence | People are disconnected, from each other and from a productive future | Invest in opportunities for the future:  
  - Educational  
  - Employment  
  - Youth opportunities  
  - Jobs  
  - Housing  
  - School programs, Preschool/Head Start  
  - Arrangements with Colleges and Universities  
  - Mentor programs  
  - BOCES  
  - CREATE A PATH OUT OF POVERTY |
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| Increase number of resources and connection to resources | Community Center Resources Education for parents and kids | Community resources that are helpful:  
- RG & E (electric company) can help customers with paying off outstanding bills  
- Salvation Army  
- ARC (Center for Adult Rehabilitation)  
- Organizations that give food and counseling |
| Increase literacy, especially health literacy and financial literacy | There are people who can’t read, and so they can’t fill out the forms for benefits, jobs or insurance. It is a barrier in doctor’s offices because it is too shameful to tell anyone so they either don’t go or don’t understand the instructions or materials that are provided | Don’t assume everyone can read and write. Offer assistance to people until you know they are able to do so themselves.  
Increase opportunities for learning basic literacy, health literacy and financial literacy |
<p>| Focus on Mental Health Issues | Living in violence and poverty dramatically affects health, especially mental health. Unacknowledged, unaddressed and untreated mental health issues lie at the root of some of the violence | Recognize the health effects and mental health toll of living in violence and the circular nature of untreated mental health issues leading to violence leading to more mental health issues. Train clergy in dealing with mental health issues and make them aware of community services available |
| Dealing with the stress of living | The cause of death can be violence, and being underinsured. These are what is causing our death, even if the listed cause is ‘heart disease’. Some people self-medicate. It is the cause of high-blood pressure | Increase funding to recognize and address the underlying social determinants of health, rather than the medically-stated manifestation. Recognize the actual causes of stress, disease and death. |
| Living in danger, living in poverty | Living in the 19th Ward. Should people stay or go? Is there a way that the people perpetrating the violence can be moved? | Return decaying neighborhoods to their previous, safer states. Increase anti-gang and anti-drug programs; increase alternative pathways and opportunities such as BOCES, mentors, jobs and school support; programs that connect youth to opportunities |
| Find ways to connect with people and services in the communities | People feel forgotten, “less than”. It can make a big difference when staff people in these places go above and beyond to connect and to help. A staff member comforted a crying baby in the waiting room and it change the experience | Increase number and training of outreach workers. Fund pipeline programs that encourage people from the community who are compassionate and caring to get additional training and return to the community |
| Living without healthy nutritious food | “Our corner store, liquor stores, everywhere in the city, not giving them nutritious or affordable food” | Invest in programs that help supply nutritious food to low access, low income areas. Food trucks, community cooking classes, farmer’s markets, food stamp programs that double in value for fruit and vegetables, among others provisions. |
| Adverse Childhood Experiences (ACES) Studies show the long-term trauma of living in a violent neighborhood | Our stress is what is killing us. | Ask question and screen for ACE using evidence-based tools. |</p>
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<tr>
<td>Safer and less stressful neighborhoods</td>
<td>The violence and stress comes from the community being unsafe without good options to make it safer for all. We want better relationships with the police and law enforcement so our streets can be safer for our families. We want to join forces to improve our communities</td>
<td>Strengthen the relationship between the communities and the police. Investigate and implement evidence-based community policing programs</td>
</tr>
</tbody>
</table>
Spirituality and Health

When we asked the question: How are spirituality and health connected in your community? We heard: “Move out into the communities to increase opportunities to be present, create relationships, develop trust, start conversations, identify areas of need, and be proactive.”

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<tr>
<td>Redefine the role of the church</td>
<td>The church could be more proactive, more involved up-front</td>
<td>The church could bring people together around issues of health</td>
</tr>
<tr>
<td>Churches could serve as a resource</td>
<td>Need to train people in the church since they are a type of ‘first responder’</td>
<td>Increase training to pastors, ministers and staff. They could be the site of early intervention and also connect people to resources</td>
</tr>
<tr>
<td>Recognize mental, physical and reproductive health as a spiritual matter</td>
<td>Have health imbedded in the church. God desires that we prosper and be in health even as our soul prospers (I John 3:3) and also says our bodies are the temple of God, so we need to take care of our temples</td>
<td>Find more ways to embed mental health and health services into the church so that worshipers can heal their minds and bodies</td>
</tr>
<tr>
<td>Unity and Collaborate</td>
<td>Bridge gaps between and across denominations</td>
<td>We can improve the health of our communities, models like the Communities of Harlem Health Revival that focus on faith and community-based organizations may offer promising models. <a href="http://www.chhrinfo.org/">http://www.chhrinfo.org/</a></td>
</tr>
</tbody>
</table>
When we asked the question: What are the issues that affect youth and adolescent health in your neighborhood or community? We heard: “we need to feel safe, emotionally and physically. It’s not so much about health as living to see another day. I don’t worry about checkups because my safety is more at risk and more immediate. The things we choose not to say anything about are what affects us most.”

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<tr>
<td>Taking control of your</td>
<td>My mom used to make appointments for me; when is it appropriate for me to make</td>
<td>• Increase educational programs that address skills such as making an appointment with a</td>
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<tr>
<td>own health</td>
<td>them for myself?</td>
<td>practitioner and how to engage in a dialogue during an exam.</td>
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<td>• Offer health services directly to adolescents in Middle and High Schools.</td>
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<td>• Co-locate family clinics in Elementary Schools</td>
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<tr>
<td>Kids having kids</td>
<td>Young kids aren’t ready to be parents. “My parents didn’t get the support</td>
<td>• Offer and have widely available family planning material and supplies.</td>
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<td>they needed [growing up] and then my mom gets upset because she thinks she’s</td>
<td>• Discuss and educate youth on becoming a parent</td>
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<td></td>
<td>not enough”</td>
<td>• Offer parenting classes for youth who do become parents at an early age</td>
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<td>• Provide programs that allow young parents to complete their high school education</td>
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<tr>
<td>Comfort with healthcare providers</td>
<td>When I’m at the doctor it’s awkward. Why? Because he knew me as a baby, because he’s asking about my sexual orientation -- are these normal questions for him to ask? I want to talk about my health but not when it’s uncomfortable. Who should I be asking?</td>
<td>Increase classes and information on how to make the most of an appointment with a doctor or nurse. Have and provide a pre-printed list of questions that are asked at every appointment so that youth can see that it is part of a usual screening. Practitioners: explain more about why you are asking questions, provide context and have a discussion more than just asking and soliciting answers.</td>
</tr>
<tr>
<td>How technology affects our</td>
<td>We are in a technologic age so we might not know how to start the conversation</td>
<td>Use texting and other forms of technology to deliver reliable medical information. At the same time, realize that discussions with adults have declined and help start, guide and keep the discussion going.</td>
</tr>
<tr>
<td>Teen Empowerment programs are</td>
<td>Opportunities, internships, connections, communication, mentoring are all critical aspects</td>
<td>Significantly increase the number, funding and support to Teen Empowerment programs that offer opportunities, connections and mentorships.</td>
</tr>
<tr>
<td>Acceptance of who we really are</td>
<td>It’s exhausting, I don’t want to be tough all the time</td>
<td>Acknowledge that it is hard to grow up in this type of situation, and that it can become a childhood-interrupted. The youth are under pressure without having enough resources or guidance.</td>
</tr>
<tr>
<td>Envision what our future holds</td>
<td>Need to be acknowledged and given hope. We need optimism in our lives</td>
<td>Reinforce value and self-worth and increase opportunities for success</td>
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</tbody>
</table>
When we asked the question: What are the issues of aging and eldercare in your community or neighborhood? We heard: “find ways of being present”, such as sitting on the front porch, walking in the neighborhood and talking to people; volunteering to help others as needed; asking neighbors to provide the introductions. The goal is for people to really see each other, across the generations. The goal is to connect to one another, especially our seniors.

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<tr>
<td>Better health outcomes</td>
<td>Focus on prevention, what can be done to stay healthy</td>
<td>Healthcare providers should offer advice on prevention and address fears instead of just focusing on the medical problem at hand</td>
</tr>
<tr>
<td>Maintaining as much independence as possible</td>
<td>Our goal is to care for elders while allowing them to maintain independence</td>
<td>Survey to identify areas where seniors/elders can maintain their independence and those areas that present the greatest barriers to independence</td>
</tr>
<tr>
<td>How can we prepare for aging?</td>
<td>We don’t want to be a bother or burden</td>
<td>What should we put in place now to help our families and ourselves when we are older? What kind of planning is most helpful and what resources may be available to do so?</td>
</tr>
<tr>
<td>How can we prepare to care for our aging parents?</td>
<td>Education about the financial, medical, social and nutritional needs of our aging population</td>
<td>Increase number and access to programs that explain Medicare, Medicaid, health insurance and long term insurance</td>
</tr>
<tr>
<td>Managing in your own home</td>
<td>Shortage of in-home care</td>
<td>Explore evidence-based models for community care and successful aging. Explore programs that pair youth with elders, possibly coordinated by schools. Connect elders together to increase social support and assist with services</td>
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</table>
| Meeting the needs of the aging population | • Medication  
• Transportation  
• Insurance (Medicaid vs. Medicare vs. private insurance)  
• Social interaction  
• Safety  
• Housing  
• Connection to the community  
• Therapists  
• Nutritionists  
• Nurses  
• Life Alert Services | Increase and enhance basic services to seniors and elders. |
| There is a generational divide. | Web-based and automated phone services aren’t always helpful to the older generation | The move towards technology has left elders behind. Maintain a personal or phone pathway for elders. Offer classes on computer literacy and smart phone use for elders. Portals, insurance sign up and benefit review by computer may not be assessable to older generations without additional training. |
| Care for the caregiver | Support and education groups are needed for family members | 40 million families are unpaid caregivers in communities across the nation. Support and training are needed as family members assume this role. |
| The family structure is changing but this new structure is complicated by rules, regulations and eligibility requirements that don’t recognize how the family unit has evolved | Some of our community elders adopt a child from the family. When this is the case it complicates housing arrangements and housing options | Review and revise Medicare, Medicare, Section 8, WIC and other programs to ensure that this new intergenerational family structure is accounted for and supported. Keeping families together should be a top priority of our social service systems. Increase the attention to supporting, maintaining and enhancing the family connection. |
| What types of other arrangements are available, how would I know about them | Information on nursing home placement. When, how and in what ways would this be good for me? | Investigate and increase information about alternative living arrangements. Hold educational sessions about who is eligible and how nursing homes work. |
| Address our fears | We see death around us all the time from dialysis, Alzheimer’s, kidney failure, and social isolation | Reinforce that preventative care can reduce the incidence of these diseases. Address, correct and amend the cycle that has formed where people are afraid of getting a bad diagnosis, put off care, come late; and are given a poor prognosis. Stress wellness, early testing, early recognition and successful treatment and management. Break the cycle. |
| Respect for elders | Build a culture of valuing elders | Community organizations should adopt a community elder. |
| People need meaningful engagement | Provide a job or purpose to keep people healthy and alive | Connect to the neighborhood in a meaningful way. This would improve the neighborhood and the health of our residents at all ages. |
When we asked the question: What are the ways in which living with a disability affects your health? We heard: a desire to be seen as a whole person, not just the disability. Providers make assumptions about lifestyle and sexuality -- that because a person is disabled they don’t need routine screenings, evaluation for and providing information and supplies for birth control and sexually transmitted diseases. Physical space, thoughtful discussions about tailored programs of prevention and wellness would benefit patients living with disabilities. Barriers include inaccessible examination rooms, rushed providers, staff who are not accustomed to working with differently-abled, stigma, and availability of Access-a-ride.

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<tbody>
<tr>
<td>Prevention, health promotion and health maintenance</td>
<td>General health screenings are often not offered as they would be to others</td>
<td>Develop cultural competence in seeing and treating patients living with a disability. Offer modified options of the same advice on diet, exercise and good preventative care.</td>
</tr>
<tr>
<td>See me, not just my disability</td>
<td>Not screening or offering me information about sexually transmitted diseases or pregnancy, why is it assumed that I don’t have sex?</td>
<td>Healthcare providers should screen everyone for everything; don’t make assumptions about lifestyle just because the person is disabled.</td>
</tr>
<tr>
<td>Health information is not being communicated</td>
<td>Information underload or overload</td>
<td>Frequent checks for understanding and for how information is delivered.</td>
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<tr>
<td>Need additional time with practitioners</td>
<td>15-minute appointments are not enough</td>
<td>Schedule appointments for people with disabilities with double the amount of time. The issues are more complicated and those with physical disabilities may need addition time to dress, undress and maneuver in the room.</td>
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<tr>
<td>Physical access and transportation are complicated</td>
<td>Many places are not equipped for special equipment, wheelchairs and walkers</td>
<td>Survey and assess all clinics for accessibility. Modify those that are not accessible to people with mobility issues.</td>
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</table>
When we asked the question: What are the issues effecting LGBTQ health in your neighborhood or community? We heard: For one of the listening sessions, there were no people who identified as LGBTQ. In this table the labels have been changed to reflect that this was a discussion of assumed beliefs, and not necessarily the voice of individuals who have the lived experience. Stigma around homosexuality is assumed to be prevalent and participants described observed and actual bullying and verbal abuse. Key areas were identified such as physical abuse, verbal abuse, and suicide.

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<tr>
<th>Discussion Topic</th>
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<td>Religion</td>
<td>Provides a negative view of gays. May divide us.</td>
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<tr>
<td>Generational differences</td>
<td>Views change from generation to generation</td>
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<td>Acceptance</td>
<td>We should accept and respect one another</td>
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<td>What we all need to be</td>
<td>Freedom to be comfortable</td>
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<td>healthy.</td>
<td>To feel respected</td>
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<td>To be who you are</td>
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<td>To have courage</td>
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<td>To create a space to be brave</td>
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<td>Availability of care,</td>
<td>Be honest, and be an ally. You don’t have to be gay to be an ally to gays. Increase education.</td>
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When we asked the question: What should we know about seeking services in the community? We heard: About many barriers to affording and obtaining health services. Cost, scheduling, transportation, childcare, trust, conditions of living such as being homeless or isolated -- all these affected people’s ability to seek and obtain the care they needed. People voiced that being seen by clinic doctors and having to repeat their medical history many times, lack of health literacy (both their own and those of the providers) and cultural competence of providers were barriers to seeking care in the community.

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| Cost                             | Expense/Cost of Healthcare  
  Even with health insurance the co-pays may be too high.  
  Lack of health insurance and grateful for the small amount that health insurance pays | Better access to and help with obtaining Medicare and Medicaid  
  Workshop and enrollment under ACA  
  Access to free or sliding scale services |
| Time to attend the appointment/Scheduling issues | Challenges of finding time to tend to health: such as eating/cooking healthy foods, exercising, getting sufficient sleep.  
  Difficulty of taking time off of work to get to medical appointments | One individual’s solution to caring for her health is to schedule all of her medical appointments during the same couple of months every year, including annual checkups (i.e. mammogram).  
  Worksite program would help deliver health to where people are  
  Increase transportation or build clinics/offices with considerations of public accessibility. |
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<tr>
<td>Health Literacy</td>
<td>Medical terminology&lt;br&gt;Communities members who are non-English speaking or cannot read or write in English</td>
<td>Find other sources of communication; translate brochures and distribute Gospel and Latino radio stations Health Beats on WDKX is one example</td>
</tr>
<tr>
<td>Relationship and consistency of the healthcare providers.</td>
<td>There are issues of trust. I want to be heard</td>
<td>Cultural competence, compassion and understanding are necessary when administering care to this population. Raise the consciousness of providers about issues of privilege, structural racism, and power. Providers need to listen more to the concerns, the fears and the thoughts, and act accordingly. Treatment is not just medical, it's psychological and social.</td>
</tr>
<tr>
<td>Increase health promotion/disease prevention.</td>
<td>More information about preventative healthcare would be welcomed</td>
<td>Restructure the Primary Care visit to provide information about prevention. Provide better linkages to services through programs like New York Care Coordination, PASS (Prevention, Access, Self-Empowerment &amp; Support program)</td>
</tr>
<tr>
<td>Increase communication with healthcare providers</td>
<td>Empowering patients to ask questions would help</td>
<td>Use tools like Ten Questions You Should Ask Your Doctor&lt;br&gt;<a href="http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/10questions.html">http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/10questions.html</a></td>
</tr>
<tr>
<td>Leverage academic-community partnerships</td>
<td>Is there a way to partner with academic institutions to improve opportunities and community health at the same time?</td>
<td>Explore, fund and provide examples of successful community—academic partnerships, especially in training the next generation of health professionals.</td>
</tr>
</tbody>
</table>
REFERENCES

1. NYSDOH. 2012 Minority Health Surveillance Report


