

Haredi Health Coalition
Initial Meeting
Monday, November 19, 2018, 10am-noon
Yeled V'Yalda, 1257 38 St., Brooklyn, NY, Room 431, 4th floor

Co-facilitators:

Alyssa Masor, PhD, New York City Department of Health and Mental Hygiene, amasor@health.nyc.gov
Zackary Sholem Berger, MD, PhD, Johns Hopkins School of Medicine and Johns Hopkins Berman Institute of Bioethics, zberger1@jhmi.edu

Agenda

- Introductions (10min)
- Discussion of meeting goals per email responses (10min)
 - Preventive health
 - Engagement
 - Health knowledge/education
- Chevruta (Pairwise) exercise (20min)
 - What should be the Chasidic community's healthcare goals?
 - Think about how we can advise, influence, and provide health education
 - Who are the authoritative/influential members of the community
 - Not doctors, Department of Health, scientists
 - No central rabbinic figure, however most do trust their rabbi
 - Linking to the yeshivas is helpful – ex. when child is unable to come to school due to vaccine non-compliance
 - Need to develop something within the community
 - How can we go about gaining trust?
 - Provide more opportunities for health education in central locations that are easy and convenient for parents and other members of the community to attend
 - Maybe Yeled v'Yalda could host for Borough Park
 - Get the idea that members of the community want to listen and learn, but are afraid
 - Important to understand cultural issues and the importance of convenience when planning to provide education
 - What are the Chasidic community's current healthcare objectives as practiced?
 - Everyone wants to improve the health of the community, despite different backgrounds, interests and focus
 - Usually only talking about health when someone is sick – works by putting out fires and not by preventing them
 - Successful programs are internally grown
 - Vaccination
 - Contributing factors to anti-vaccination
 - Mistrust of the system
 - Not based on religion
 - Comes from a group of anti-vaxxers with a united front; powered by propaganda

- Also stems from resistance to Big Pharma
 - Mothers have felt that physicians ignored anything that the parents brought up a possible side effect post vaccination; causes more distrust and prevents forward movement
 - Lack of internet access and insular nature of community limits access to educational material that refutes propaganda
- Taking the time to explain things like herd immunity can help
- Parents are more likely to listen to advice from nurses as they are seen as having less of an agenda and no relationship with Big Pharma
- Measles
 - Belief that the reason why it is worse to get it as an adult is because everyone is supposed to have it when they are younger
 - Some families are attempting to exposure their children when they are young to someone who has the infection, rather than vaccinating
- Strep
 - Many parents bring children to physicians requesting strep tests and refuse to accept negative results
 - Attribute symptoms not caused by strep infection to strep
 - Want antibiotics regardless of laboratory results
 - Requires providers to refuse antibiotics and explain why to the parents; some providers are treating anyways
 - Would it be more effective if nurses had these conversations?
- Group exercise (30min)
 - What different groups within the Chasidic community do you serve in your practices/organizations? What are their goals in healthcare? What are their barriers in meeting those goals?
 - Stigmatized health issues
 - Genetic disorders most highly stigmatized, due to impact on finding a husband/wife
 - Cancer
 - Mental health
 - Lack of education regarding mental health issues
 - Medicine adersion results in lack of treatment and improper management
 - Often there is a need for professional help/therapy – when this information is passed onto the affected individual, they will say that they're successful and do not need therapy
 - Sometimes parents will step in and say that treatment isn't needed
 - Could community health workers help? Who are the community health workers?
 - Ex. Baltimore African-American community
 - Similar in that there has been generational trauma leading to distrust

- Community health workers have been extremely useful in working with community to connect them with services and assess need
- DOH Nurse-Family Partnership
 - Program where nurses are matched with families and new mothers to provide guidance and support
 - Yeled v'Yalda provides something similar, paraprofessionals are matched with families and supervised by nurses
- WIC program could be a good fit for the community health worker role
- Who are the people in the community who aren't being served? What are their needs and how can they be reached?
 - People who have recently left the community
 - Being exposed to things such as substance use, sexually transmitted infections (STI), etc. and are at high risk for depression, anxiety
 - Quality First Urgent Care is offering STI testing
 - Need to provide guidance, counseling and other services
 - People with substance dependencies
 - Definitely substance abuse in the community
 - Often starts with alcohol and progresses
 - Various programs, such as Project Safe, Amudum, and other NA groups are available
 - Lots of stigma and there isn't a coordinated effort to reach out and provide services
 - Naloxone isn't widely available within the community, only by secular EMT services
 - Becoming more visible, but lots of denial within the community
 - HPV Vaccination
 - Not widely offered by pediatricians
 - Avoidance is due to marketing as something associated with STI
 - It's a hard sell within the community – many think that they or their children do not need this
 - Community does not want to have public conversations about this
 - Requires health care providers to take the time to convince and provide all information about the vaccine and explain that the risk of contracting the virus does exist
 - Women
 - Young mothers
 - Postpartum
 - This has started to get more attention and is less stigmatized than before
 - Has it become too normalized? Can prevent getting proper help when needed
 - Lactation program screens for signs of postpartum with each visit

- Many organizations within the community but all are a bit disjointed
 - Need to develop a comprehensive research guide and emphasize care follow-up
 - Many organizations offering specific services, but are not centralized
 - This group could be used to disseminate information about these services
 - Where do we put this information and who should it be for (providers, patients, etc.)?
 - Important to consider what kind of outreach has there been for prior outbreaks and after the outbreaks have ended?
 - Varicella
 - Declared community wide outbreak
 - Excluded all kids from school without documented immunity
 - Engaged with UJO in Williamsburg, but this didn't really go anywhere
 - It's important to look back
 - Current measles outbreak is raising issues and increased outreach
 - Distributed booklet to practices
 - Trying to counter propaganda being distributed by PEACH (anti vaccinating group)
 - Want to work with the community to develop a plan that will work
 - Had a meeting ~ one month ago with school administrators and elected officials
 - Frank discussion about religious exemption
 - Identified misunderstandings about vaccination about school admin staff
 - Should use measles outbreak as momentum for the Haredi Health Coalition
 - Also interested in seeing how the flu vaccine requirement works in this community
 - Have noticed that families are requesting religious exemption for some vaccinations but not for others
 - Primary care/preventative
 - Screening
 - Smoking cessation
 - Alcohol cessation
 - Build on existing organizations
 - Some refuse to branch out
 - Important to engage
 - Note that community hospitals do not provide many community services
- Open discussion (10min)
 - Common denominator is the lack of education and having fear in its place, as well distrust
 - Important to understand the Haredi community
 - Do not idolize secular education
 - To be influential, the information needs to come from the religious community and the community itself in general
 - Important to note that DOH cannot influence all levels of the community
 - Ex. can exclude kids from school and say that they should be quarantined, but parents still take children to other public events

- Who can fill this role?
- Three levels important
 - Involvement of healthcare professions, physicians, providers
 - Rabbidic support
 - Needs neighbors, community influencers
- Next steps (10min)
 - Continue to be in contact
 - Conference calls
 - Email
 - Develop comprehensive resource guide
 - Share information across organizations
 - Gain rabbi support
 - Engagement from the grassroots level