

Storytelling and Community Empowerment to End TB

We Are TB & Wisconsin Tibetan Association

November 8, 2023

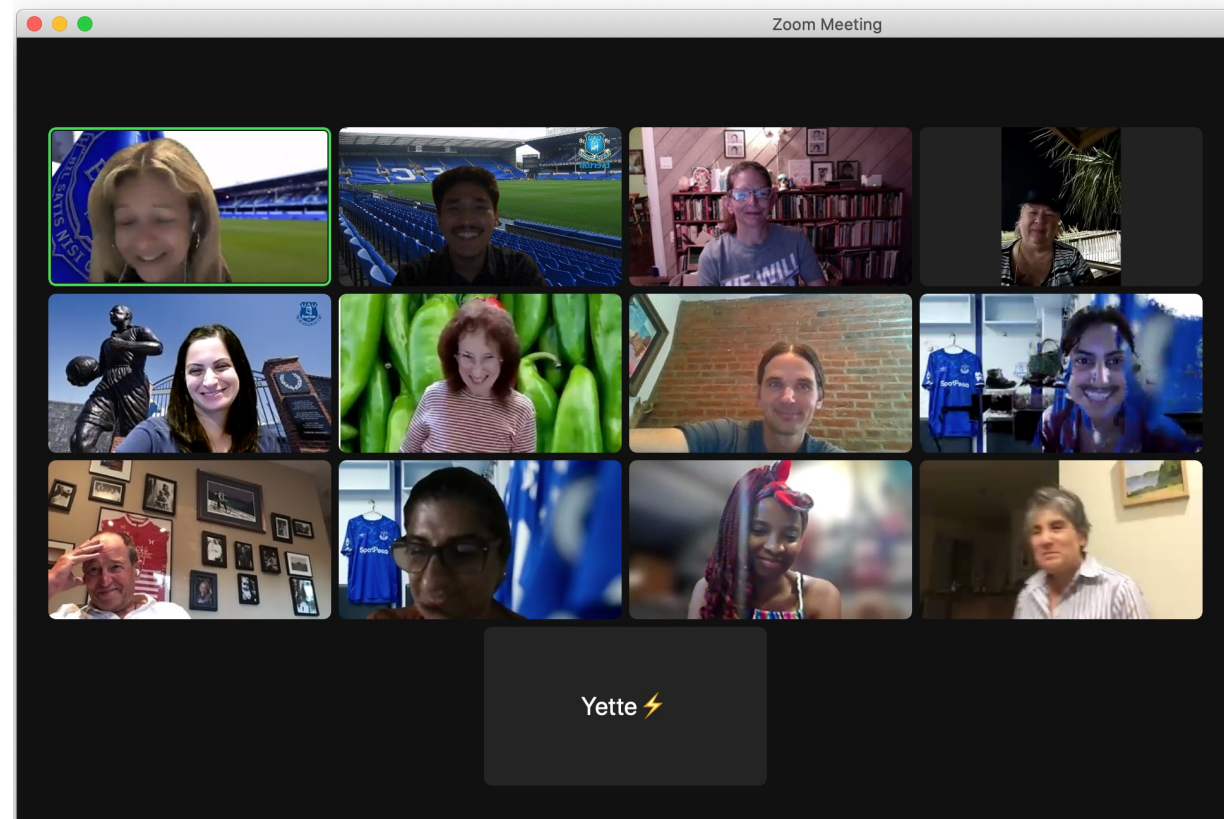
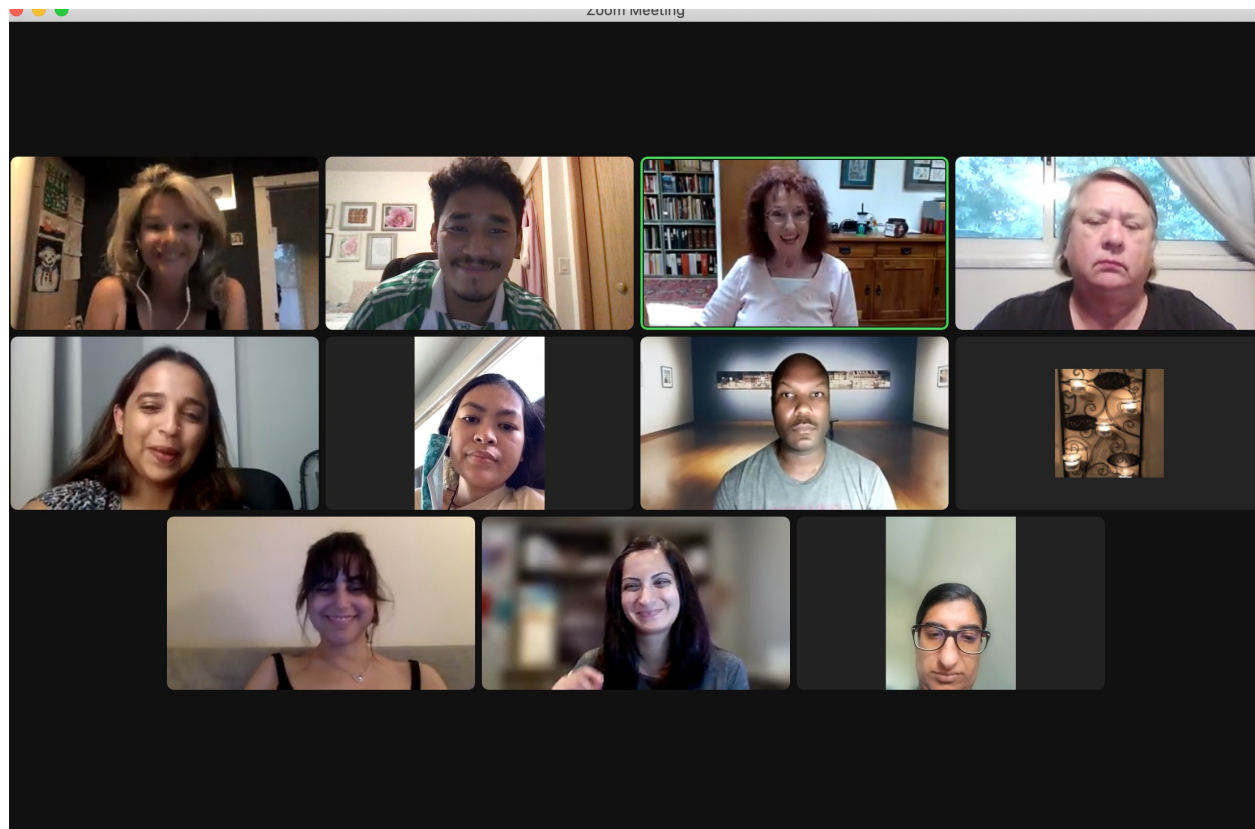
Our project

Objectives

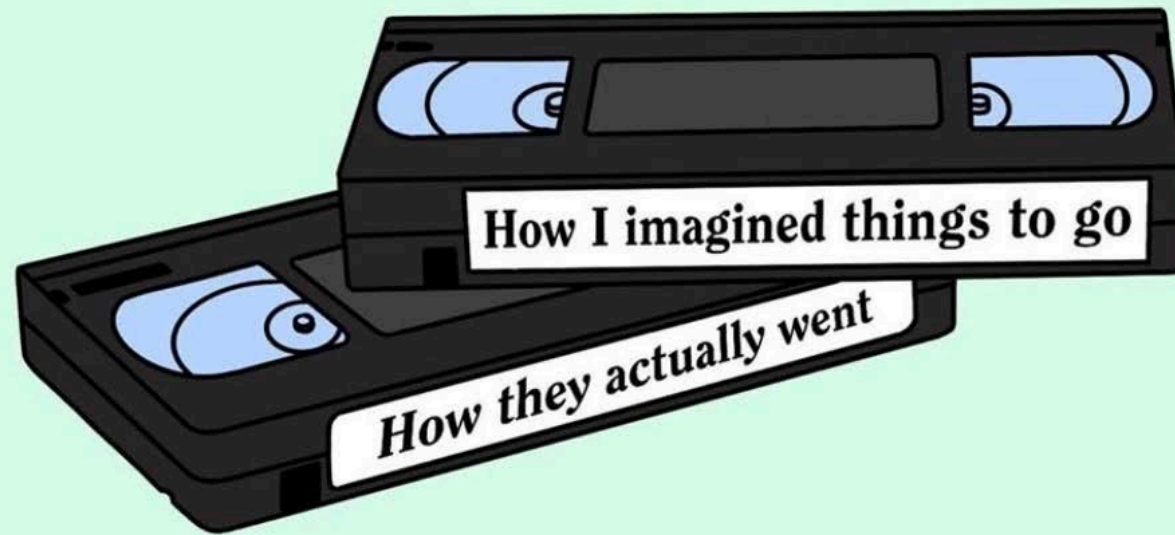
- To raise awareness about the link between LTBI and TB disease among Tibetan Americans in Madison, Wisconsin.
- To create culturally and linguistically appropriate LTBI and TB education training and community engagement resources for Tibetans in Madison, Wisconsin.

This includes building awareness through translated informational materials on TB and LTBI, reducing stigma through programming on TB engaging TB survivors, and facilitating a support space

With hopes of cultivating a sense of agency and empowering people to make informed decisions regarding the options for treating latent TB







Conversations with 11 TB survivors in the community

- Open-ended exploratory work in the form of unstructured interviews
- More of a learning role about their thoughts, perspectives, and social worlds
- Framing questions with more curiosity, less assumptions. More seeking to learn from, less trying to explain/educate
- Topic is a complex social question → attempting to identify and unpack puzzles
- Implicating ourselves in this process... The data and findings were co-constructed

Four key findings:

1. Stigma is nuanced and complex, primarily due to the unfortunate familiarity of TB
2. The role and impact of socioeconomic, political, and historical contexts on people's health
3. The change in TB education and awareness over the past few decades
4. Community-centered ways of being as an asset and a facilitator for building resilience

Stigma is nuanced and complex

- What does stigma look like within the community?
- Cultural norms are challenges (e.g. mask wearing in home with active TB)
- TB and other illnesses (as well as health in general) stigmatized
- The different types of stigma - apathy as stigma from the community and then it is internalized
- Unfortunate familiarity of TB leading to perceived sense of apathy and lack of problematizing the situation... “It’s just the way it is”
- Accounts detailing multiple exposures was not unusual (e.g. in next slides)



“So I was born in Tibet, so I think in Tibet TB was unknown. I think I haven't heard anybody talking having TB in Tibet, but then after coming to India when I was in school, that was in 1960s, **one of my roommates, he was suffering from tuberculosis, but there was no treatment at that time. And then finally he died. And I think that was the first exposure I had.** We were in the same room. We were about six boys together. Then later on, our headmaster, he got sick. He got really sick. Then he also got TB. So he was hospitalized. So as students were required to go taking turns looking after him. **So I also went to the hospital taking care of him.** So in the hospital, it's not isolation. You know what, I think there used to be about six or seven patients. I ask, “All TB patients?” He replies, **“All TB patients, all TB patients and then no mask nothing we just go and you know so that was my second exposure.** Then later on in Mundgod when I was working in Mundgod my brother, he got sick. He was exposed to TB with one of his co-workers. **I think he had the multi-drug resistant TB and most probably my brother must have got from him. So that was my third exposure.** Then other one is that in Mundgod we have a TB ward, hospital like, where we put all the TB patients. Since I was working as in charge of the whole settlement, **I had to go and see them occasionally so I used to go to their rooms no mask nothing and talking with all the patients so I got a lot of exposure then.”**

The role and impact of socioeconomic, political, and historical contexts on people's health

- You can't understand a generation without understanding the one before
- Illness is a manifestation of one's life experiences and history
- Trauma from economic, social, political factors/consequences such as genocide, oppression, loss of land, loss of agency
- Social and economic disruptions – a need for social protections e.g. money for food, transportation, living expenses



“At that time in 1959, 60s, there were a lot of Tibetans suffering, they had tuberculosis. **First of all, they just came from Tibet and some of them lost their children on the way, some lost their parents and some of them left their relatives in Tibet and some you know had one of their family members been killed by Chinese in Tibet** so there were a lot of mental problems for the Tibetan people. Then coming to India the food habit, the climate, Tibet is cold and India, the places where they landed in was really hot. **Then the food habit was different. Then as refugees, they put a lot of people in one room together. Then children were put in boarding schools. Monks were put in the monasteries.** So they all put in groups in one room like that. So that way tuberculosis has become kind of rampant for the Tibetan community and it went on for so many years until more recently, the TB was the most dominant kind of disease for the Tibetan people in India and still now, now it's getting better.”

TB education and awareness over the past few decades

- Impact of covid: masks more socially acceptable + more knowledge about infectious diseases
- LTBI drugs not readily available and many not aware of shorter treatments for TPT
- Misunderstanding, lack of education/awareness
- Zero TB Kids Project in India



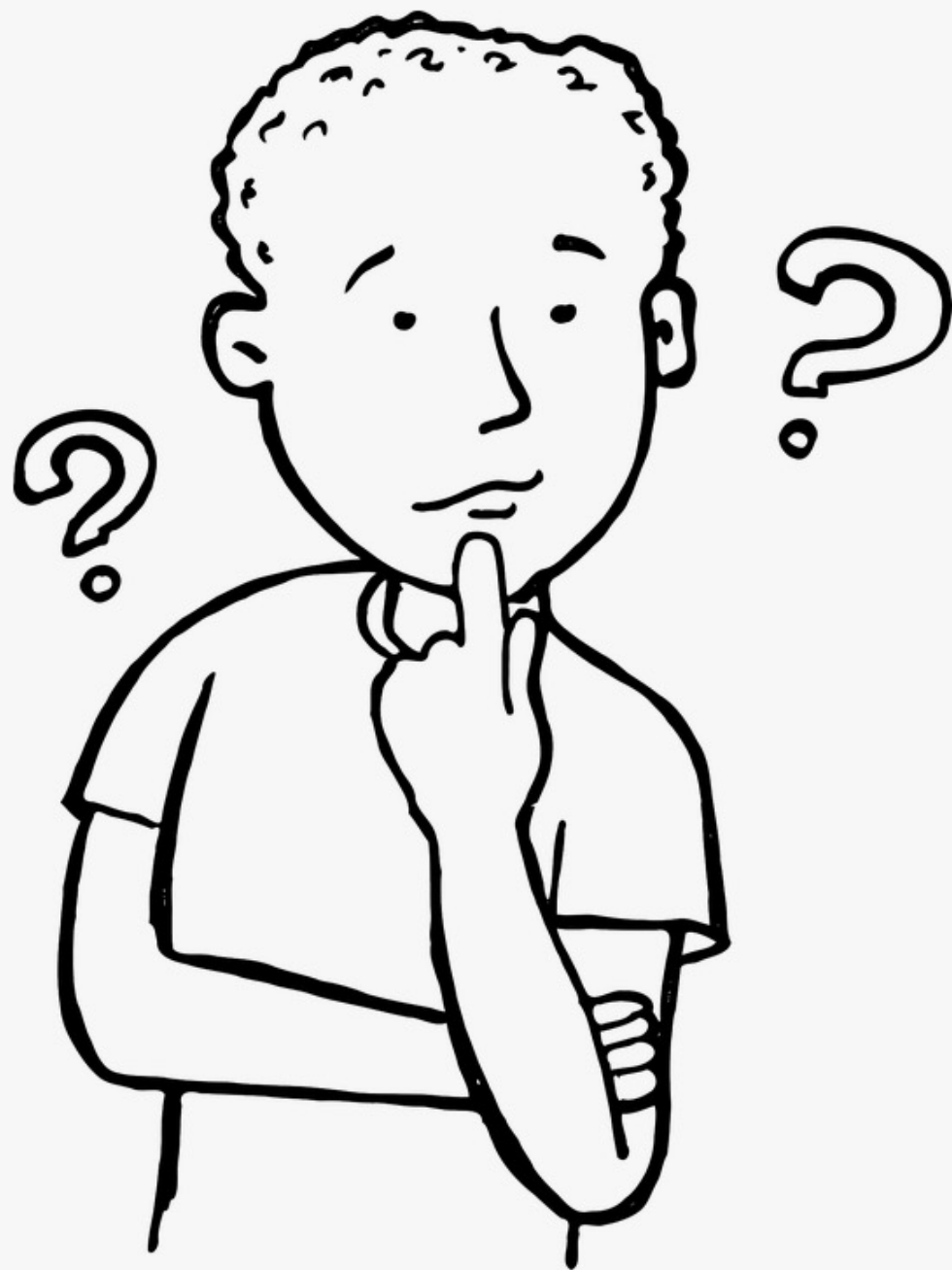
NIH Grant for "Zero TB Kids"
Researcher Kunchok Dorjee

Community-centered ways of being as an asset and a facilitator for building resilience

- Being highly concentrated and connected as a strength
- Individual mental fortitude and inner strength cultivated also at community level
- Social and economic mobility
- TB as a social disease: how families are affected by TB and how compassion and care can be understood

“There is trauma, but then not to the extent where it could be. I think globally if you look at it like I think as a refugee like our community you know our Tibetan people came to exile after the invasion probably doing the best out of all the refugees around the world you know, whether in terms of mental health or whether financially or health-wise or all that stuff I think we did amazing. **You know we came to exile with nothing.** You know we were able to establish a system where we had education system, health care system – one of the biggest education systems in exile. People come from Tibet, escape, they come to exile so they can learn their own culture. It's crazy. So, you know, your parents, even you, before you came, went to Tibetan school in exile. **I mean it's not perfect, but I mean you look at anywhere in the world in places of crisis, right? What we have achieved in the last 50, 60 years. is extraordinary so I think we're not perfect, but every year we are progressing”**



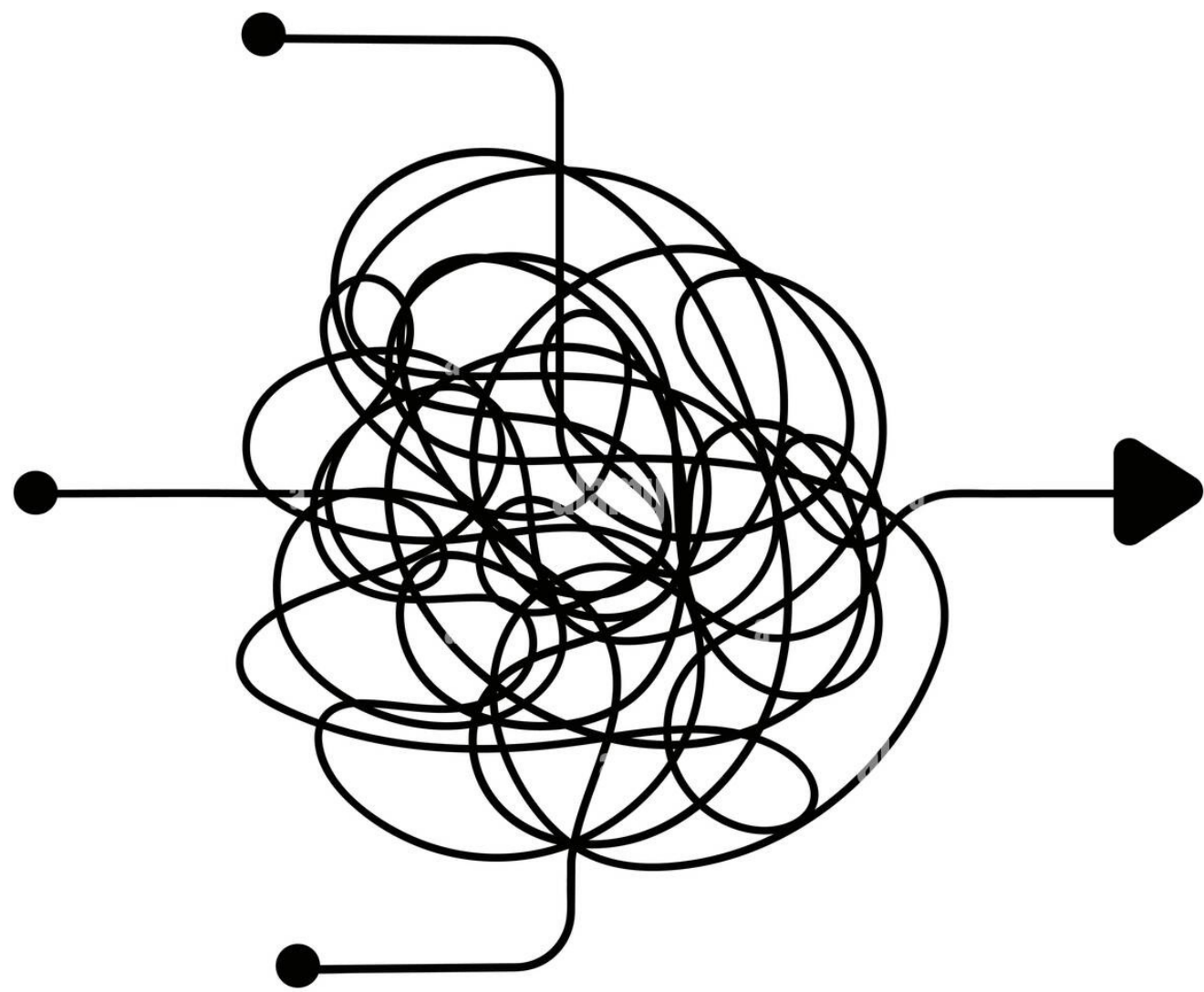


“And with mine, I had no symptoms. And with you, obviously, you looked like, almost like, you’re bedridden. Like when you got out of the car, you could barely walk, when you, when you came from La Crosse. That’s the only memory I have of you. And I was thinking to myself, mine was the total opposite of you and I wish I was that sick and you were how I was. I wish I could’ve switched places with you at that moment.”



The challenges

- So much of this work can begin with or quickly become deficit oriented
- Community engagement and health promotion work is difficult
- Initially ambitious and perhaps premature – but later turned into a needs assessment/exploratory exercise to better understand the community and experiences of TB survivors



What's next (and lessons to apply)

- Build upon the relationships and the rapport
- Develop and sustain a reputation of service, integrity, humility
- Backtrack and start with some different questions:
 - How do affected community members want to share their story?
 - Do affected community members want to share their story?
 - What would be supportive and empowering?
 - What would be most important to the community?
- A need for asset framing and a need for creativity

Thank you for you time and attention

Happy to connect after Q&A as well (tenzinkunor@gmail.com)