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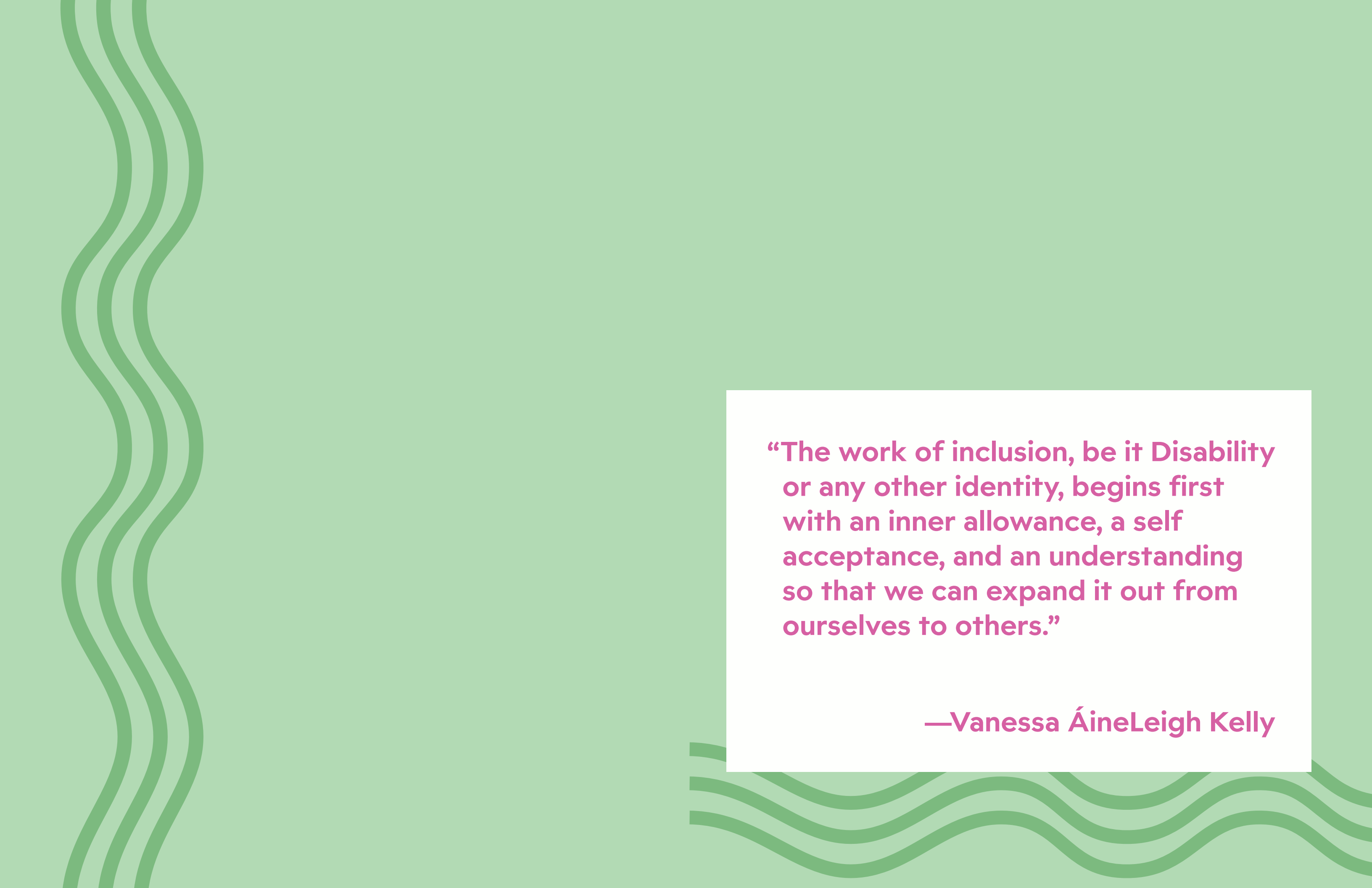
FIND YOUR FREQUENCY

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for Mom



“The work of inclusion, be it Disability or any other identity, begins first with an inner allowance, a self acceptance, and an understanding so that we can expand it out from ourselves to others.”

—Vanessa ÁineLeigh Kelly



PREFACE

THIS IS MY STORY.

I grew up in Jacksonville, Florida with my Mom, my Dad, and my little brother. Growing up, I knew my mom had hearing aids, but we didn't really talk about it much. I never took care to change my behavior or gave extra attention to how my mother accessed sound. The only time her hearing loss affected me was when I might hug her a little too tightly and hear the sharp squeal of her hearing aids.

As I grew older, I began to notice more. My mother began sharing her listening needs with me, and I realized that my behaviors had an impact on how my mother was able to listen and participate in conversations with me. It was important for me to be in the same room when speaking to her. It was important to speak up and speak clearly. Eye contact was a must.

“I realized that my behaviors had an impact on how my mother was able to listen and participate in conversations with me.”

Eventually, the time came when my own hearing loss became identified. It was so slight at first that I wouldn't have noticed it, but I'd had my hearing assessed nearly every year since high school. I realize now that I am so incredibly lucky to have a mother so in-tune to the experience of hearing loss.

My mom started losing her hearing in high school, which made communicating with peers difficult at times, especially in the hallways. I recall her sharing with me memories such as when classmates would greet her in the hall, then become offended when she didn't react.

“Their perception was that she was stuck-up, but in reality, she just couldn't hear them saying “hi.”

There were times when her hearing loss led her into uncomfortable social situations. There is a memory she shared of when she was speaking with a friend and having trouble hearing what she was saying. As those early on in their hearing journeys often do, my mother was attempting to mask her hearing loss by smiling and nodding along, but in reality, she could hardly hear a word. It wasn't until her friend shared some unfortunate news and my mom responded with a lighthearted laugh that the friend became upset. Her friend couldn't understand why my mom was laughing at the news of someone close to her passing away.

Scenarios like this are not uncommon amongst people experiencing hearing loss, so it makes sense why social situations tend to be a source of stress and anxiety for us.

Early in life, hearing loss affected my mother's relationships, how she communicated with others, and her overall experience as a young person. She received little outside support aside from being gifted a pair of refurbished hearing aids.

Navigating a new way of experiencing the world is challenging. Because of my mother's lived experiences, she wanted to make sure that we could identify my hearing loss early and connect me with the support I needed as soon as possible. After years of testing, my hearing loss was identified, and I was fitted with hearing aids. End of story.

While this seemed like a solid plan to set me up for success, when the time came for me to embark on my hearing journey, I was reluctant to set out. I knew little about what it might be like to try wearing my hearing aids in public for the first time. I didn't know how to notice or talk about my listening needs. Most of all, I didn't feel comfortable identifying with or even accepting my new understanding of my hearing abilities. In beginning my thesis work, I began to wonder where these internal barriers came from, and how I might learn to dissect and challenge them.

Perhaps they stemmed from internalized ableism taught to me by society. This is something that I'm working every day towards unlearning. Perhaps the high value I had placed on my independence and productivity, coupled with my fear of asking for help, kept me from even considering the option of seeking out or accepting support or assistance. I was operating under the mindset of:

if I couldn't do everything myself, I probably just wasn't trying hard enough ...right?

I've noticed that the early part of the journey is the most difficult, not just because acquiring the proper tools might be difficult, but because it all starts with accepting yourself for all that you are. Acceptance is the most important step to living a full life with hearing loss, yet so many resources people are exposed to early on in their journey feel very technical and clinical.

Quite often, people are given tools such as hearing aids or other assistive listening technology with little to no support for grieving one's previous way of experiencing the world and embracing a new one. I've yet to encounter a resource that focuses on the emotional processing around hearing loss in the beginning of a hearing journey, aside from traditional talk therapy.

These beginning phases of my hearing journey have certainly been interesting. Although I've known of my hearing loss for nearly 5 years, I'm just now stepping into my identity as a Hard of Hearing person, and although I feel I definitely have made some progress in learning how to navigate my hearing health, the journey is far from linear. I often circle back because I'll forget to charge or pack my hearing aids, or I'll find myself self-isolating so I don't have to deal with the challenges presented by my hearing loss at all.

I've only just begun to seriously wear my hearing aids in certain settings and speak about my sound access needs with confidence during the past year or so of my life. This thesis work has been a huge contributor to that progress, but I still have a long way to go.

I continue to question whether or not I fit in with the d/Deaf community or if I belong in the hearing world, and I find that I am learning to navigate the in-betweens.

After learning to navigate the world a bit differently, I have finally begun to understand some of what my mother has been experiencing my entire life. After I chose to focus on hearing health for my thesis, my mother and I began having more in-depth conversations about the challenges we experienced. We noticed that we both had grown to prefer self-imposed social isolation to putting ourselves in a position to be uncomfortable, overwhelmed, or exhausted due to our hearing loss.

I found it so refreshing to be having more open conversations with my mother about our lived experiences. I felt that it brought us closer, and we were able to find a deeper level of understanding one another. It made me wonder what it might be like to have conversations with others that have had similar experiences.

My hope with this work is to continue holding space for open conversations about hearing health and encourage more openness and mindfulness around connecting and communicating with people of all hearing abilities.

THIS IS MY STORY.
I'M A STAKEHOLDER.

“I am learning to navigate the in-betweens.”

TABLE OF CONTENTS

Preface	6
Table of Contents	11
Glossary	13
Tuning Into the Issue	14
Discovering the Secret Garden	19
My Research Journey	21
How Might We and Visioning	28
Theaory of Change	30
Planting Seeds Along the Path	32
Growing Beyond the Garden	41
Gratitude	43
Credits, Citationsm and Resources	45



GLOSSARY

(Paraphrased from the National Association of the Deaf)¹

Hard of Hearing may describe an individual who has a mild-to-moderate hearing loss. HOH may also describe a deaf person who doesn't have or want a cultural affiliation with the Deaf community. HOH may even describe someone that identifies anywhere in between. A Hard of Hearing person can be described as "in some ways hearing, in some ways deaf, in others, neither."

D/deaf According to Carol Padden and Tom Humphries, in *Deaf in America: Voices from a Culture (1988)*: "We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people."

Assistive Hearing Technologies Technologies or devices such as hearing aids and Cochlear Implants(CI) that people experiencing hearing loss may utilize to support their hearing, listening, or access to sound.

TUNING IN TO THE ISSUE



48 million Americans experience some degree of hearing loss.

Source: Hearing Loss Association of America

IMAGINE NAVIGATING YOUR DAILY LIFE WITHOUT ACCESS TO SOUND.

So many interactions and situations would be much more challenging. Placing a coffee order, listening to announcements on public transportation, calling a friend, engaging in conversation with coworkers; all of these situations might become points of unwanted stress, anxiety, or discomfort.

Without sound, you might have to find other ways to communicate and connect with those around you. Undoubtedly, this would require intense focus and practice. Special skills like lip-reading and interpreting body language would become tools in constant use. Listening fatigue would likely leave you ending each day feeling beyond exhausted.

The fact is, our world has been designed for hearing people, and few environments have been designed with d/Deaf and Hard of Hearing folks in mind. Most of the Earth's population rely on spoken language to navigate their daily lives. For the estimated 48 million Americans experiencing some degree of hearing loss, navigating day-to-day is challenging.²

"...our world has been designed for hearing people..."

Hearing loss affects everyone differently. Some people may be challenged by hearing and differentiating certain vowels or consonants. Others may hear different tones of voice at different levels. Regardless of how individuals experience the nuances of hearing loss, participating in conversations with others, especially in crowded spaces tends to emerge as a pain point.

For those that utilize assistive listening technologies, such as hearing aids and cochlear implants, crowded environments can prove to be incredibly overwhelming and difficult to navigate. Hearing aids and CIs amplify all sound, so it can be challenging and often exhausting to process all of the sounds in a given space and focus in on a conversation. Think of what it might be like to listen to several songs at the same time and isolate a single melody. Even if you've heard the songs before, the conflicting melodies would sound utterly chaotic, and undoubtedly feel overwhelming and difficult to follow.

For many people experiencing hearing loss, common public locations such as restaurants, bars, and coffee shops can be difficult to navigate and the cacophony of different sounds contribute greatly to listening fatigue. Listening fatigue is a form of exhaustion that may emerge after a stretch of time when someone has had to focus intensely to be able to follow conversations or distinguish between and identify different sounds. It may show up as exhaustion, trouble focusing, or even headaches. Because of this, d/Deaf and Hard of Hearing folks may grow to prefer the comfort of their own home to large social gatherings.

D/deaf and Hard of Hearing people are often more isolated, and tend to be more at risk for anxiety and depression. According to Johns Hopkins Medicine, untreated hearing loss can result in loss of sound discrimination skills, or the ability to distinguish between and identify different sounds. It can also contribute to a greater chance of brain degeneration as people age.³





Hearing loss affects how we connect to one another. Without the proper support, folks with hearing loss can become socially isolated, and consequently at greater risk for anxiety and depression.³

Effective support and resources for folks with hearing loss do exist, and they often seek to provide education and support around accommodations, self-advocacy, assistive hearing technology, and even seek to provide opportunities for community and emotional support. For example, some organizations provide information and connect people with services and resources for self-advocacy and accommodations, such as **the Hearing Loss Association of America**. HLAA is community-led, which is exciting and encouraging to see.

Some organizations, such as the **New York University Cochlear Implant Center** and **the Center for Hearing and Communication** work directly with folks with hearing loss and their families to understand their needs and help connect them with hearing assistive technology, educational resources, and emotional support services.

Some resources operate mostly online to provide skill-building software that aims to help folks with hearing loss better identify sounds. An example of this type of resource is Hearoes. Skill-building software and courses have the potential to be useful, but they unfortunately place the burden on d/Deaf and Hard of Hearing folks to adapt and conform to a hearing society built without them in mind.

There are also a number of blogs related to hearing loss, but they are mostly targeted towards, or primarily connecting with, older audiences.

When it comes to the social and public health issue of hearing loss, there's an evident gap in support for populations younger than 45. According to the Hearing Loss Association of America, **1 in 5 Teens experience some degree of hearing loss.**² If that's the case, I wonder why so few young people talk about hearing health.

Organizations aiming to provide support and assistance for folks with hearing loss are struggling to identify and connect with younger individuals, but are interested in doing so. In my early research, I found that, although there have been instances of subchapters or independent groups for young people experiencing hearing loss by young people with hearing loss, they tend to fade away in time.

Past solutions aiming to engage with young d/Deaf and Hard of Hearing folks, specifically community-led young adult groups, appear to have a limited life span. For example, the Facebook page for "Hear YA Now" was started in 2009, remained active through 2016, and has since laid dormant. My community partner, the NYC Chapter of the Hearing Loss Association of America, even had a subchapter for young people at one time, which eventually faded away. As part of my thesis work, I set out to learn more about why this is.

I ASKED MYSELF...

Are people aging out of the groups?

Are people finding support elsewhere?

Or is there not enough focus on finding and connecting with new younger members of the community?



DISCOVERING THE SECRET GARDEN

One thing I've discovered while on my hearing journey is that there are an abundance of resources available, but at the same time, **they're difficult to find**. Organizations like the Hearing Loss Association of America and the Center for Hearing Loss and Communication are well connected to one another and others within their network, but as a new potential member of the community, it was difficult to tap into that network at first.

This challenge of discovering and engaging with resources, I realized, wasn't because the resources or organizations were inaccessible. The issue was that I, like many others at the beginning of their hearing journeys, lacked the confidence in myself and my identity to reach out and connect with them. After conversations with other d/Deaf and Hard of Hearing folks, I realized that this was a common challenge for people soon after learning of their hearing loss.

Coming to terms with hearing loss and finding the courage to ask for help are some of the greatest internal obstacles that people may face at the start of their hearing journeys.

When you're trying to find yourself and unsure of your identity, what hearing loss means for you, and how you experience the world differently, it can be difficult to put yourself out there. Finding the capacity to ask for help first requires you to accept that you may benefit from help.

Because hearing loss is an **invisible disability**, or not identifiable by simply looking at someone, it's difficult for the existing communities to reach out to new folks. Organizations and existing communities don't know who is in need of their support. Existing resources appear to effectively support D/deaf and Hard of Hearing folks once they've connected with them, but there's an evident challenge in connecting with people outside of the existing community.

I've come to think of this network of hearing health support like a secret garden.

Once you find your way there, it's beautiful, warm, and nurturing. People are blooming and blossoming in their wholeness because they've found an environment that wholeheartedly accepts and nurtures them. There are resources for education, emotional wellness, advocacy, and more. People are able to explore the wholeness of their own potential with the support of their community.

All of this is wonderful, but why did it take me nearly five years to discover?

I WONDER...

How might I share this beauty, this supportive environment with others?

How can I throw seeds over the wall? What path can I lay to help guide others along their journey to this sanctuary?

My chosen approach is openness.
More Connections. More conversations.

MY RESEARCH JOURNEY

THE APPROACH

I approached this project from a very personal place of lived experience. Because I am in the unique situation where I am my intended end user, I had to be careful of not relying on assumptions. Although I honored my own story and gut feelings throughout the process, I had a plan to supplement my personal experiences with secondary desk research and primary research such as surveys and interviews.

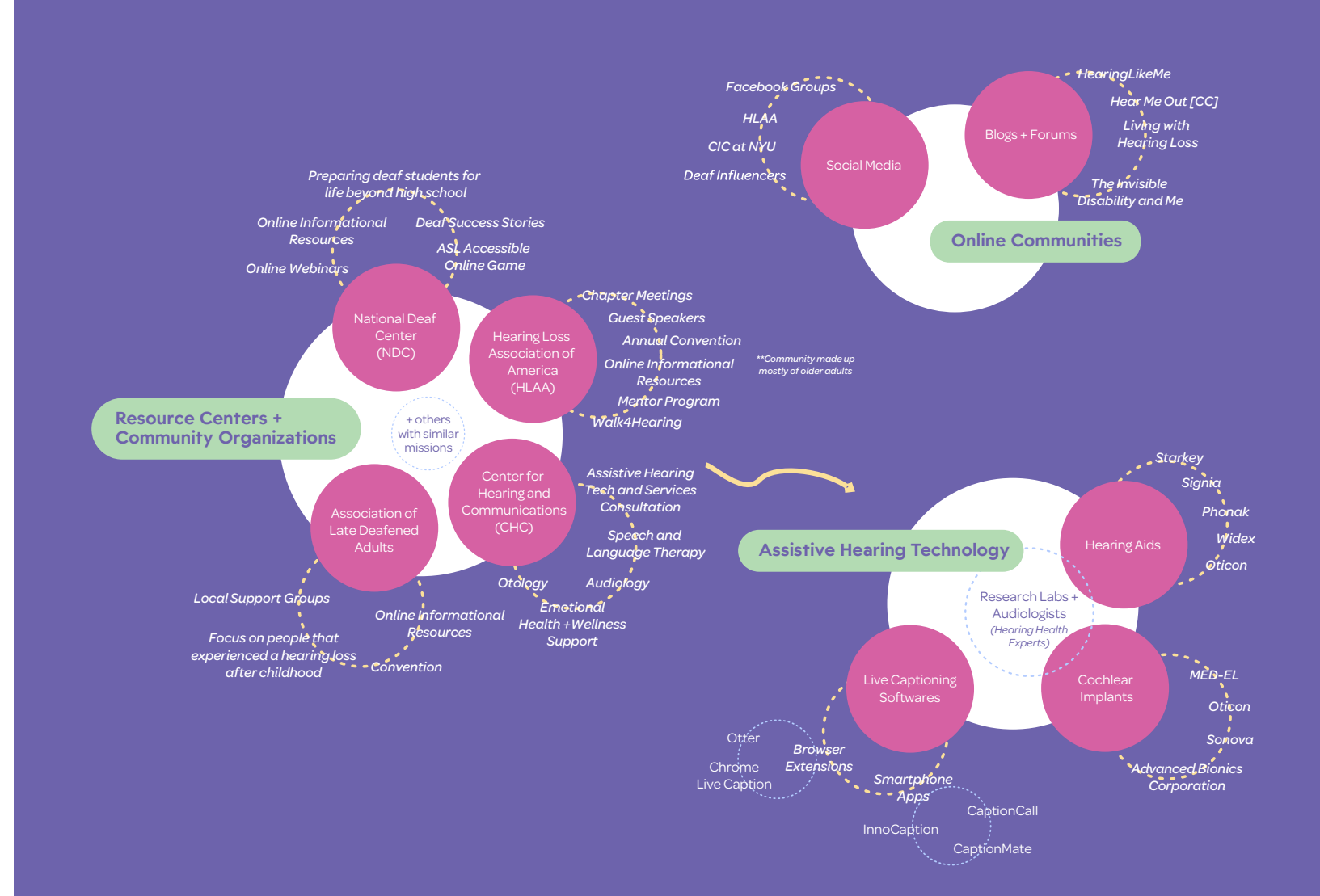
I've been on my individual hearing journey for the last five years. Unfortunately, I very much ignored my hearing loss for the first three years or so of that journey. I had hearing aids, but I wasn't comfortable using them. I wasn't comfortable asking for accommodations, much less talking to others about my hearing loss. This is because I hadn't felt supported in coming to terms with what hearing loss meant for me. I hadn't accepted myself or the idea of benefitting from help around my hearing health, and so I felt uncomfortable asking for or accepting any.

After collecting stories from other d/Deaf and Hard of Hearing folks, I found that my experience was not uncommon.

I was tested, a hearing loss was detected, and I was given hearing aids. Period. End of story.

I felt like there was no discussion around how to reflect on how my hearing loss might affect the way I experience the world. There was no holistic reflection that I was exposed to. The support I experienced at first was almost exclusively related to medical diagnosis and assistive hearing technology.

I felt different from other people my age, strange even. I had learned about something that altered the way I view myself in the world, and I felt like I had no one to discuss the emotional side of it with. As I would soon find out, others felt similarly.



ASSESSING THE CURRENT SOUNDSCAPE AND CONNECTING WITH KEY PLAYERS

To begin understanding the issue at a more systemic level, I began to examine the key players already in the space. Above, you'll see an early exploration of the current landscape that I created in early 2022. The purpose of creating this map was to support my processing of my early secondary research and understanding of the current state of the hearing health ecosystem.

Looking at the organizations currently operating in the space, I identified two key players that I might be interested in pursuing a partnership with for this work, the Center for Hearing and Communication (CHC) and the Hearing Loss Association of America (HLAA). Both of these stakeholders are well-connected within the D/deaf and Hard of Hearing community, which makes them key gatekeepers and my first choices as potential community partners.

I reached out to the Hearing Loss Association of America first because their community-led model intrigued me. I connected with leaders of the New York City chapter, current and former HLAA-NYC Presidents Katherine Bouton and Jon Taylor, respectively, in early 2022. Katherine is a writer with two published books about her experiences with hearing loss and an active "Smart Hearing" blog.

I began volunteering with HLAA in the Spring of 2022, using my digital marketing experience to reestablish HLAA-NYC's social media community on Facebook. They had previously been operating a page on Facebook, but their community engagement was limited by the fact that only page admins could make posts on their timeline. To encourage

increased engagement, I created a Facebook group, which would allow community members to have discussions independent of the page admin. I also volunteered my time to help edit their website as needed.

To further immerse myself in NYC's hearing health community and connect with others doing work in the space, I volunteered to assist with the livestream of the annual Walk4Hearing Event in the Fall of 2022. It was here that I met Katherine Bouton and a number of other HLAA members in person for the first time. While at the walk, I was responsible for assisting David Landsberger with the organization's livestream of the Walk.

As we set up the livestream, I learned that he was a lead researcher at NYU's EAR Lab, where he and his team were working with d/Deaf and Hard of Hearing people to develop an algorithm that would help cochlear implants filter sound. This technology could greatly improve the listening experience for those that use CI technology to access sound. I admired how David talked about involving Cochlear Implant users in his research, and I was impressed by how he was centering those with lived experience in the development of his work, a key principle of social design we practice at DSI.

I feel so lucky to have had the great opportunity to listen in as David interviewed walk attendees. Some of the first interviewees were from New York City's Center for Hearing and Communication, which provides hearing health services and emotional support for people of all ages experiencing hearing loss. CHC representatives detailed the services they offer at the Center and encouraged listeners to pay them a visit. Carolyn Ginsberg-Stern, CHC's Head of Outreach, spoke about how difficult outreach can be, especially when seeking to engage with younger populations. "We don't know who we don't know," she said. This is true; it's hard to reach folks in need of hearing health services if we don't know who they are. So, how do we find folks in need of support?

I decided to research how folks typically become aware of their hearing loss. This led me to an interesting finding: very few people actively assess their hearing or reflect on the role of sound in their lives. Less than 16 percent of general practitioners regularly assess their patients' hearing.³

How can we expect people to find or seek out support if they are unaware of their hearing health and that they may benefit from support?

This helped me identify the following facets to amplify when connecting with people around their hearing health:

- Awareness of the importance of hearing health.
- Interest in exploring how we access sound and assessing our hearing ability.
- Openness and acceptance around one's hearing abilities.
- Empowerment to communicate one's hearing abilities and needs.

With this new clarity in the different areas I sought to influence with my intervention, I became interested in exploring how to encourage people to approach hearing health with more openness.

PRIMARY RESEARCH

A key part of social design is honoring the lived experience of the community you are designing with. Although I myself am a stakeholder, I am susceptible to bias just like anyone else. I needed to confirm that my experience was not unique to my mother and I, so I set out to connect with other folks that may have experienced similar challenges at the beginnings of their hearing journeys.

In performing my primary research, I crafted two different online surveys in Google Forms. One survey was designed for folks of all ages with an interest in reflecting on the role of sound in their lives. The goal of this survey was to gain a deeper understanding of how folks think about sound access and hearing health. I wanted to know how people felt about hearing loss and why they might feel that way. This was also a great opportunity to connect with potential collaborators.

The second survey invited people with hearing loss to share their stories and experiences related to sound access and hearing health. The goal here was to understand how folks navigated the early stages of their hearing journeys. I learned about how folks overcame internal and external barriers to sound access and where they needed additional support.

These surveys, along with an informed consent form, were posted to the following pages and online communities:

- Hearing Loss Live - 264
- Healthy Hearing - 11k
- Living with Hearing Loss - 5.5k
- SVANYC - 47k
- Hearing Loss- the Emotional Side - 1.9k
- My Hearing Loss Story - 1.6k
- SVA Parent Class of 2025 - 570
- SVA Disability Resources - over 300

Posting where people with hearing loss have already connected with community was a way of meeting people where they are and inviting those with lived experience to collaborate on this project. Even with pushing the surveys out to a massive total audience, I only managed to get a total of 44 responses across both surveys. As a student-led project, I'm pretty happy with that number. It was clear that the folks who participated in the surveys were dedicated to sharing meaningful responses.

As I perused the survey results, I found the following responses particularly compelling:

I had no idea I had lost hearing/sound. I needed education and assistance.

I was extremely anxious and depressed. I thought there would be a dramatic improvement in my emotional state once I received my cochlear implant and it was activated, but I actually felt worse because learning to hear again has been so much harder than I hoped for or anticipated.

I avoid many social experiences due to the fear and the actual of not being able to hear sounds

Early on I was frustrated no one believed me that I was struggling to hear. Everyone thought I was lazy and failing school for attention not because I actually couldn't hear the teacher

Some common themes from both surveys were:

- A lack of support for folks at the beginning of their hearing journeys
- Feelings of isolation or disconnection due to hearing loss
- Initial hesitancy to have conversations around hearing health, followed by confidence once acceptance has settled in.

This confirmed insights from my desk research and lived experience supporting the need for a more proactive approach

to hearing health and fostering openness around the topic amongst young people.

Of the 48 million Americans with a recorded hearing loss, there are approximately 15 million that do not seek any sort of assistance, and those that do so typically wait an average of 7 years.⁴ By the numbers, over 30 percent of those with a recorded hearing loss don't seek assistance, and more than half of that same group choose to wait several years before seeking help.⁴

You may be wondering: Why is this time gap important? According to Johns Hopkins Medicine, the longer a person with hearing loss delays seeking assistance around a recorded hearing loss, the more likely they are to be at an increased risk of health



15 million do not seek any form of assistance.
That's just over 30 percent.

Source: The Center for Hearing and Communication

complications later on, specifically brain atrophy or cognitive decline.³

Now you may be wondering why I'm using the term "recorded hearing loss." Well, a Reuters Health study found that, while roughly 17 percent of adults identified their hearing as "less than excellent," only 28 percent of that same group has had their hearing tested.⁵ This is due to as little as 16% of general care physicians regularly assessing their patients' hearing.⁴

One of the greatest challenges that hearing loss organizations face is that existing organizations "don't know who we don't know," as shared by Carolyn Ginsburg-Stern with the Center for Hearing and Communication. I hypothesized that this might be due to the fact that few people get tested for hearing loss, and even fewer people do the work to move towards acceptance of their hearing ability or seek out assistance once it is discovered. What gets counted counts, and it's impossible to know if someone has hearing loss if they have not been tested for it or recorded as having a hearing loss. Perhaps there are even more d/Deaf or Hard of Hearing folks

out there that have absolutely no idea!

So how do we go about increasing the number of people getting their hearing assessed regularly? First, folks need to know that their hearing health is something they should be monitoring. We can begin to work towards this by holding space for more conversations around hearing loss and the role of sound in our lives.

It starts with awareness and education. These are the seeds we must plant and nurture to cultivate growth beyond the secret garden.

INSIGHTS AND OPPORTUNITIES

In my research so far, I've identified the following Insights and opportunities:

Teens and young adults in particular are an underserved group by existing organizations and resources. One in five teens have some degree of hearing loss, but existing organizations cater to children and older adults. Because of this, there is an opportunity to reach out to this community of people in need, especially as they begin to learn about taking control of their own health.

How might we better connect with young people around hearing health?

People are rarely aware of emergent changes in their access to sound due to lack of testing and lack of reflection. Unless their physician is actively testing for hearing loss (which less than 16% do),⁴ it's difficult to pick up on a gradual change in hearing. **How can we expect people to seek support if they don't even know they might benefit from it?**

When I learned of my own hearing loss, it was only because my mother, who had her hearing loss identified in high school, was proactive in getting my hearing tested every year. Had I been raised by someone less in-tune to the importance of hearing assessments, I might not have even identified my hearing loss for another few years, much less been fitted with hearing aids.

And yet, I still don't feel comfortable using them all the time; I still avoid assistance. I've never once gone to disability services or checked a box identifying myself as Hard of Hearing, and I still struggle to embrace all of my identity as a young Hard of Hearing person. I wonder where this internal barrier is coming from, and how I might design an intervention that helps people approach conversations around how they access sound with more openness.

How might we design tools that enable reflection around the role of sound in our lives and relationships, as well as the internal and external barriers to accessing sound?

Current hearing assessment tools and language often subscribe to a harmful medical model of disability. For so long, deafness was communicated and thought of as a strict, clinical, quite polarized classification. In reality, it's more of a spectrum. Hearing loss affects everyone differently, so our definition and philosophy of deafness should reflect that.

How might we design with care to center deafness as a spectrum, existing beyond a clinical diagnosis?

And my final insight: **Most Americans do not approach the topics of sound access or hearing health with openness, if at all.** There's a clear opportunity to hold space for and encourage open discussion around access to sound and deafness as a spectrum. The goal of these discussions would be to foster more openness and reduce the stigma that currently surrounds the topic.

How might we encourage and hold space for discussion that fosters more openness around the topic of hearing health among young people?



THE VISION

HOW MIGHT WE empower young people in the United States to challenge internal and external barriers to sound access at early stages of their hearing journeys and beyond by cultivating openness around hearing health?

DESIRED FUTURES

Nurture Openness by Cultivating the Conditions for Connection, Conversation, and Community

Create and hold space for openness, curiosity, and conversation with community members.

Jump-Start Sound Journeys

Reducing the gap between identifying a hearing loss and seeking assistance is crucial to preventing greater health issues such as mental decline later in life. This work seeks to accelerate the early stages of young people's hearing journeys through community support, open conversation, and increased access to resources.

Plant Seeds for the Development of More Holistic Hearing Health Practices

Existing treatment often focuses on providing assistive listening devices, which is helpful, but only when paired with additional resources. In addition to assistive technologies, people about to embark on their hearing journeys should be connected to resources that support emotional and mental health.

THEORY OF CHANGE

FIND YOUR FREQUENCY is a series of gatherings supplemented by an online community that aims to hold space for conversation and reflection around hearing health and sound access with young people.

Components of Find Your Frequency include:

- A safe, nurturing environment and interactive experience that holds space for open dialogue around sound access and hearing health.
- Reflection tools, resources, and activities. (ie: guiding questions, free hearing assessments, experimenting with assistive hearing technology)
- An online space for people to connect with one another, share experiences and resources, and amplify voices related to sound access and hearing health. (ResoNation online community)

SO THAT...

we increase awareness of the importance of sound access and hearing health among young people; increase openness around hearing health and sound access among young people; increase the number of online hearing assessments completed by young people; increase access to knowledge and resources that support young people on their hearing journeys.

SO THAT...

we increase confidence and capacity among young people to start conversations around hearing health and sound access; increase interest and motivation among young people to learn more about sound access and hearing health; increase interest and motivation among young people to begin their hearing journey by practicing reflection around how they access sound; increase understanding among young people of hearing loss and d/Deafness as a spectrum.

SO THAT...

we increase confidence and capacity among young people to notice and more clearly communicate their listening and sound access needs (ie: asking people to slow down/repeat themselves/etc, requesting accommodations such as captions, etc.); increase confidence and capacity among young people to practice self-advocacy around sound access in educational, professional, and social settings; increase confidence and capacity among young people to seek support and assistance around hearing health and sound access.

SO THAT...

we empower young people in the United States to challenge internal and external barriers to sound access at early stages of their hearing journeys and beyond.

AND EVENTUALLY...

we reduce the time interval between awareness of hearing loss and seeking assistance and reduce internal and external barriers to sound access.

SUCCESS LOOKS LIKE...

- More Conversations
- More inclusive language
- More welcoming environments
- Journey Jump-starts (a reduced time interval between detection and assistance)

DREAM GOALS:

Reduce barriers to sound access

Reduce the time interval between awareness of hearing loss and seeking assistance.

Empower young people in the United States to challenge internal and external barriers to sound access at early stages of their hearing journeys and beyond.

THEESIS GOAL



THE INTERVENTION:

Find Your Frequency is a series of gatherings supplemented by an online community designed to hold space for conversation and reflection with young people around sound access and hearing health.

PLANTING SEEDS ALONG THE PATH

Earlier, I referred to existing resources and communities around hearing health as a secret garden. It was there long before my time, but I wasn't capable of discovering it until I really set out on my own hearing journey. I found that the path was difficult to follow. I found myself getting turned around a few times, mostly because I was uncertain of my own wayfinding.

When I finally discovered the secret garden of resources and community, I was in awe of how much work has gone into cultivating conditions for everyone to bloom. I began wondering why it had taken so long to make the journey there, and I wondered if there might be an opportunity to encourage folks to look for it sooner. Maybe I could start planting seeds beyond the garden that help travelers find their way to the garden.

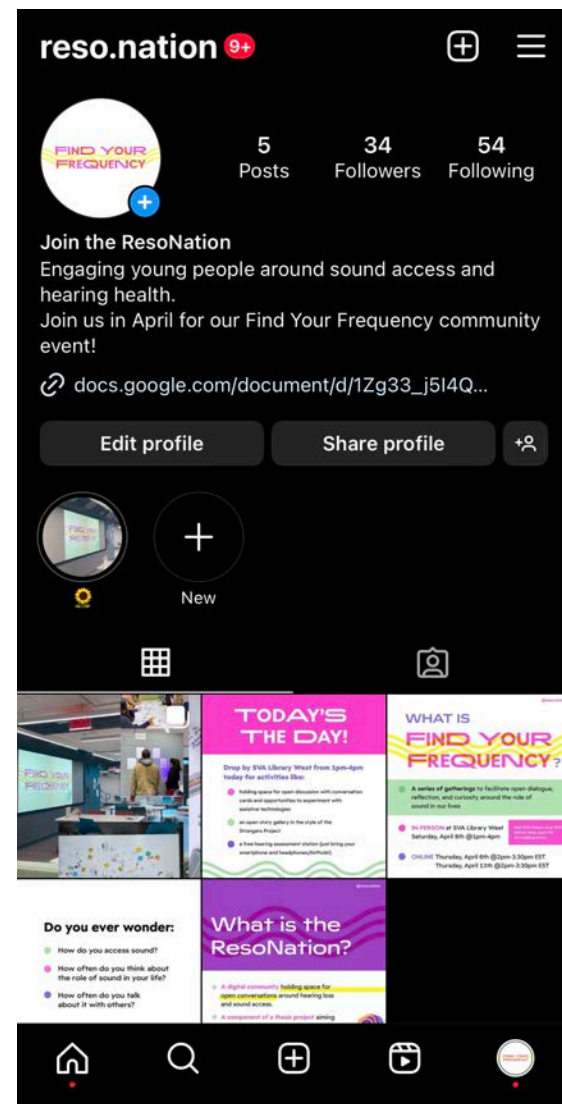
COMPONENTS

ONLINE COMMUNITY

The ResoNation is an online community that aims to provide a safe space for folks to engage in open dialogue around sound access and hearing health. Right now, the community exists only as an Instagram page, with just over 30 followers. Once the community begins to engage and grow, the next step would be to ask members if they'd like more opportunities to connect with one another on platforms like Discord or Reddit that might be more conducive to conversation.

GATHERINGS

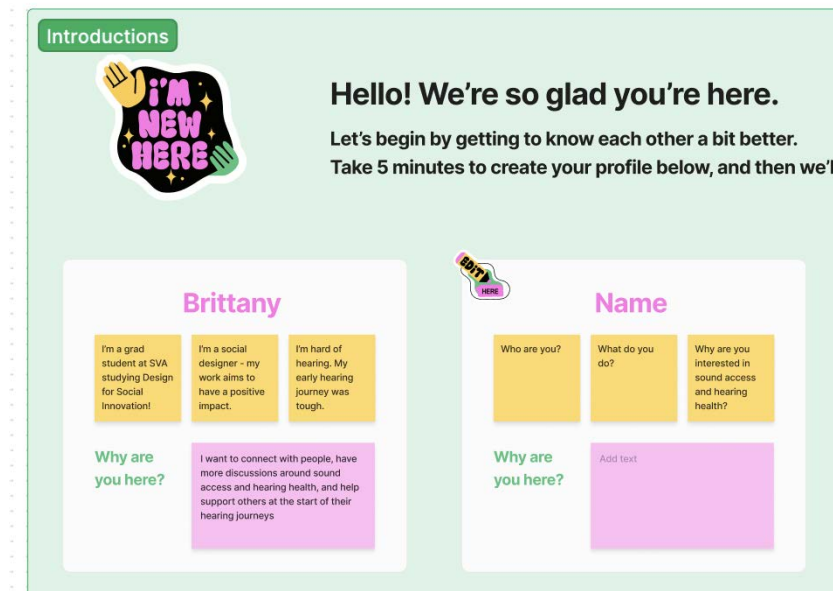
The components of my intervention pulling the most weight are the digital and in-person Find Your Frequency gatherings that took place in May 2023. These gatherings aimed to bring people together to hold space for open conversation and reflection around hearing health and the role of sound in our lives.



ONLINE GATHERINGS

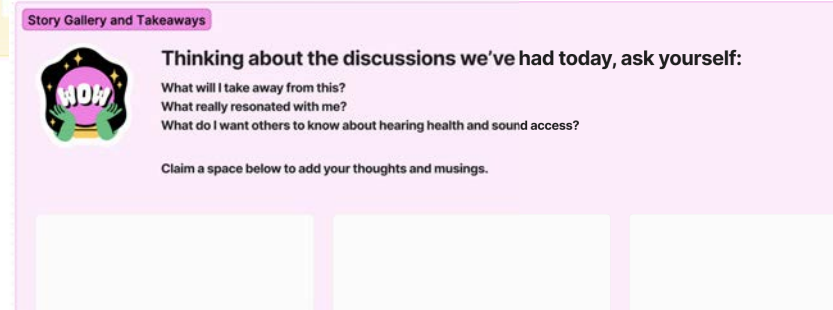
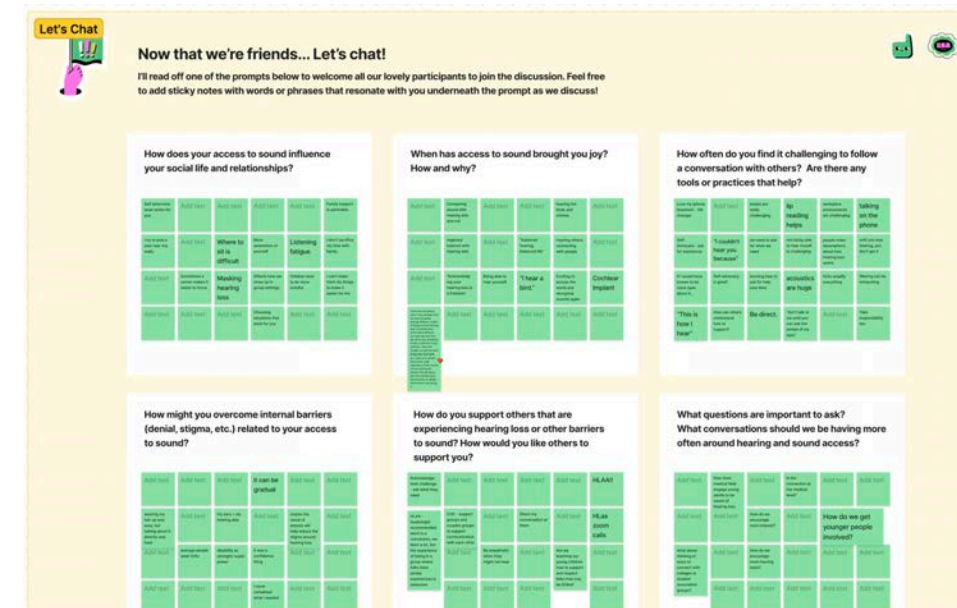
The two Find Your Frequency online gatherings hosted in April 2023 succeeded in holding digital space for conversations around hearing health. Leveraging free tools like Google Meet and FigJam, the prototype consisted of two separate 90-minute sessions where participants held space for open dialogue around hearing health and sound access experiences. We began with introductions to build trust, then moved into a group discussion guided by thoughtfully-selected questions:

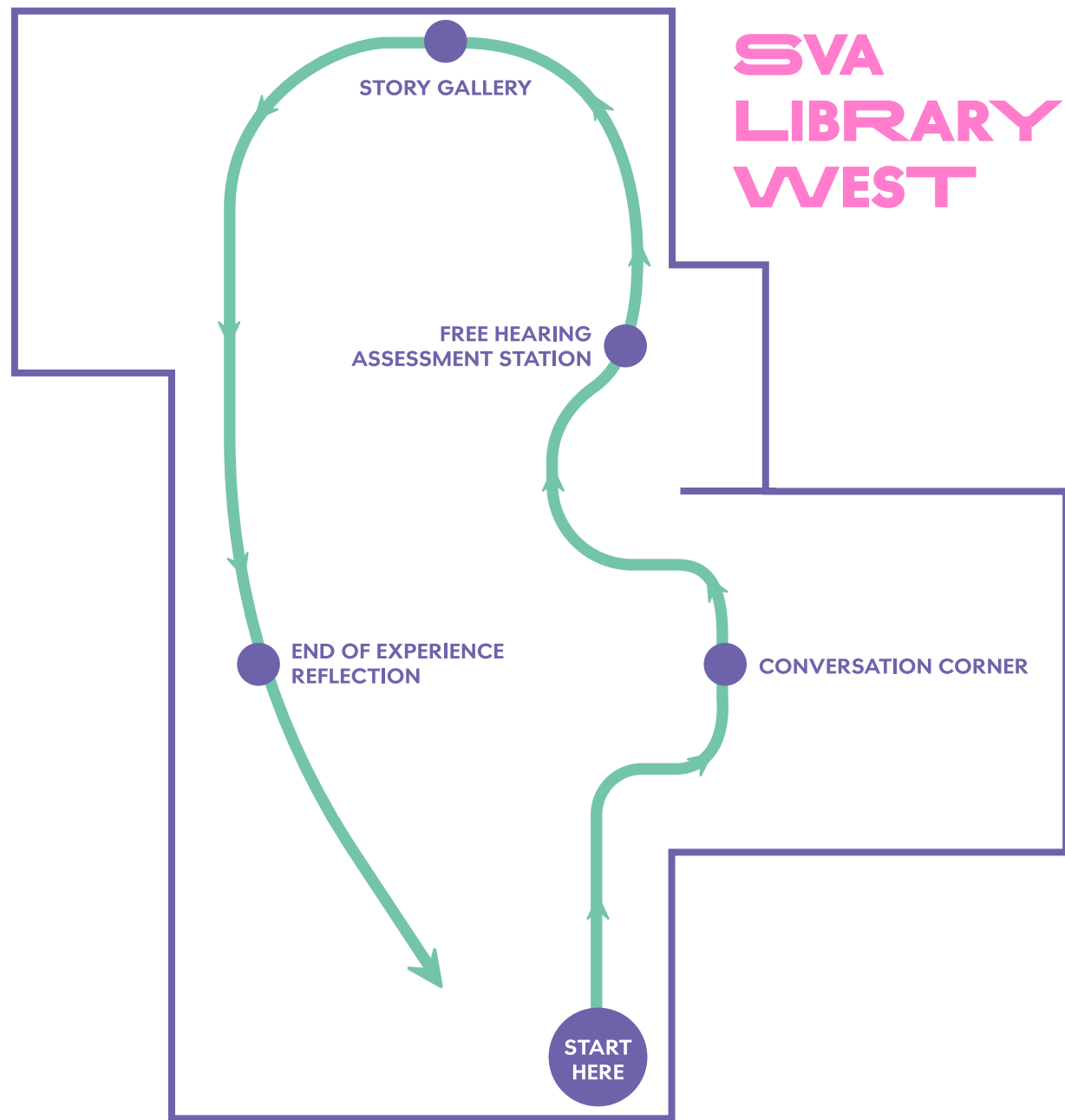
- How does your access to sound influence your social life and relationships?
- When has access to sound brought you joy? How and why?
- How often do you find it challenging to follow a conversation with others? Are there any tools or practices that help?
- How might you overcome internal barriers (denial, stigma, etc.) related to your access to sound?
- How do you support others that are experiencing hearing loss or other barriers to sound? How would you like others to support you?
- What questions are important to ask? What conversations should we be having more often around hearing and sound access?



After the group had a chance to move through the different discussion questions, they were invited to reflect on what they might take away from the experience.

Both sessions' groups consisted of 5-6 participants, myself included. Although I was discouraged by this small turnout at first, it ended up being the perfect size group for everyone to have a chance to share their perspective in our facilitated conversations. Because the group was small, it felt more intimate, and I feel that we were able to get more vulnerable than we might have with a larger group. Time certainly would have been much more difficult to manage, especially with 6 key questions to soar through in an hour and a half.





SVA LIBRARY WEST

IN-PERSON GATHERING

The in-person Find Your Frequency gathering was hosted Saturday, April 8th, 2023 in SVA Library West. The concept was to create a space of curiosity and openness in a location where young people already gather. Meeting the target audience where they are was the key to this prototype.

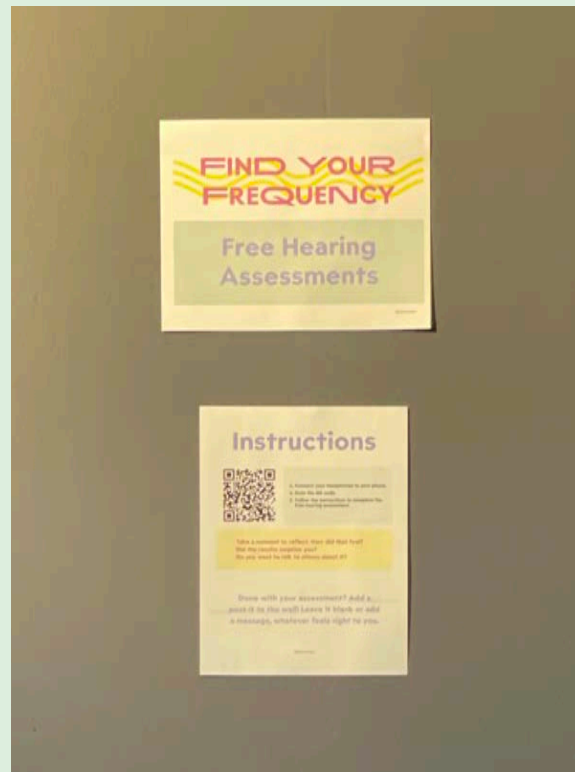
COMPONENTS INCLUDED:

- Conversation Corner + Experimenting with Assistive Listening Technologies
- Free Hearing Assessments
- A Story Gallery
- End-of-Experience Reflection and Feedback

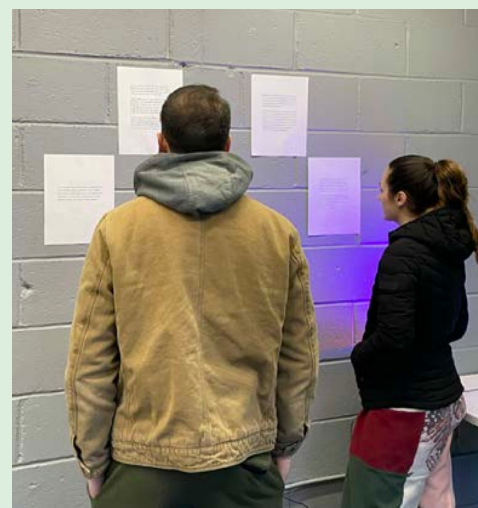
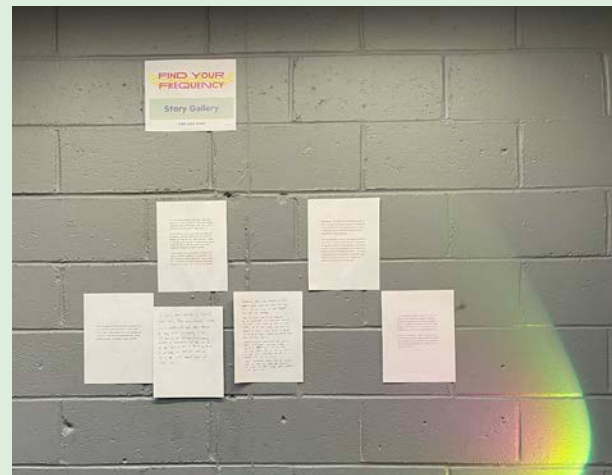
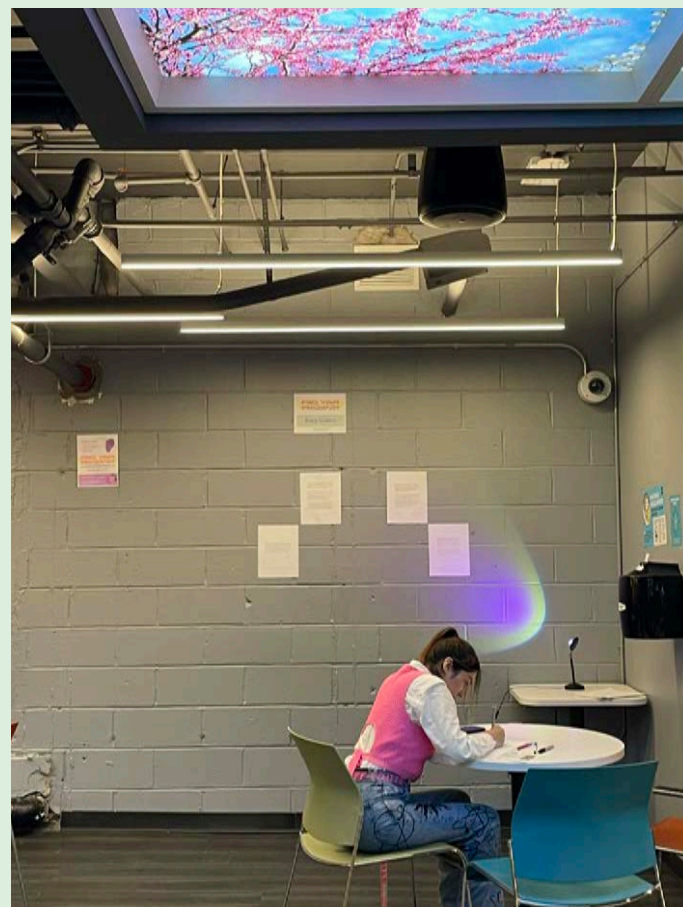


CONVERSATION CORNER

FREE HEARING ASSESSMENT STATION



STORY GALLERY



REFLECTING ON THE IN-PERSON GATHERING:

I'm still reeling from the events of April 8th. I had the incredible opportunity to connect with eight young people and hold space for a conversation around sound access and hearing health.

The first group I spoke with was made up of people within my sphere of influence. I already had a baseline level of trust with these people, which allowed conversation to flow freely. I learned more about the people in my life than ever before. I felt cared for when I shared my experiences with hearing loss, and **I was able to learn more about how others view D/deafness and hearing loss.**

It was clear that folks saw sound as a channel for connection with others, whether that was through language and discussion or music. One friend shared the joy that came from being able to hear laughter. It became clear that sound is something that connects people, and being socially

isolated due to a hearing loss made more sense from the outside looking in.

I left the day feeling so full of joy and hope.

All of my gut instincts and hypotheses were affirmed by the 8 meaningful conversations I held space for that day. I had succeeded in creating a space where young people can gather safely. **A space that was utilized by students daily for studying and gathering was transformed into a space of openness and care.** One participant described the experience as "nurturing." It was not a word I would have identified myself, but hearing it come from someone else made it feel like a perfect fit for what I had intended to create.

I aimed to create an environment where I might cultivate seeds of curiosity and care, nurture new perspectives and encourage the growth of new connections. I was a gardener tending to my flowers, a writer captivating new audiences.

END-OF-EXPERIENCE REFLECTION



IMPACTS

I learned that the connections fell into one of two buckets: folks within my sphere of influence, and people that happened to stumble upon my secret garden. Both were magical in their own way. The connections that already existed were deepened by the exploration of new ideas and perspectives. I learned more about the people closest to me, and they learned more about my experiences as a Hard of Hearing person.

We left the table with a shared understanding of how important it is to ask questions and communicate our needs.

When it came to the newer, spontaneous connections, I felt a sense of joy when people walked into the space and immediately displayed a sense of curiosity. These spontaneous connections almost felt that much more magical because they were unexpected—serendipitous, even.

The first unexpected connection was with an artist. Already interested in contemplating his senses of sight and hearing, walking into the library and stumbling upon my project was “a pleasant surprise.”

We had a short conversation around hearing health before breaking and allowing him to explore the other activities in the space. **I felt excited that someone passing by was able to discover such an interest in and commitment to the project in a matter of seconds.** I felt validated and encouraged to continue on, even though I had already stayed an hour past my scheduled event time. This gave me hope that this sort of gathering had the potential to reach more people. The key to the success of the prototype was creating an open, nurturing space where young people are known to gather.

The discussions I had with participants that day encouraged me to think even more deeply about how to involve people of all hearing levels to engage in this work. The people that attended, while they may not experience hearing loss themselves, gained perspective on how they might be able to act as allies to friends, family, and peers experiencing hearing loss.

Awareness is important, but in order to support D/deaf and Hard of Hearing folks, **it will take effort from people of all hearing abilities to advocate for open, accessible spaces.** We make spaces more accessible by recognizing, communicating, and honoring the needs of all who enter.

Feedback was collected in the form of end-of-experience reflections. Some of the common themes across these writings included:

- **Increased awareness of the importance of hearing loss (“opened my eyes...”)**
- **Increased openness and mindfulness of others’ needs related to listening and sound access.**
- **Increased reflection around one’s own hearing needs and abilities.**
- **A new sense of collective responsibility around hearing health.**

This was really exciting to see in the end-of-experience reflections. My goals had been met, and this first prototype passed with flying colors. I definitely have a few points to iterate upon, but I’m wrapping this first test with feelings of joy and fulfillment.

In the next iteration, I’d like to make the following changes:

- **Provide headphones and a quiet space dedicated to hearing assessments.**
- **Increase attendance from 8 participants over 4.5 hours to at least 15 participants. To achieve this number, I’d need to collaborate with a partner that has a connection with young people and would be willing to serve as a second facilitator, preferably a college program or resource office and another young person with lived experience or an interest in hearing health.**

GROWING BEYOND THE GARDEN

REFLECTING

If you would have asked me about hearing loss last year, I would have been reluctant to share my personal experiences. Over the past several months, this work has transformed the way I think about my own access to sound and the way I communicate with others. I've gained enough confidence in my own identity and abilities to speak openly about hearing health and my needs in nearly any given environment. I hope to continue practicing reflection around my abilities and how I communicate with others. I will continue to hold space for open dialogue, and I hope to participate in more conversations around hearing health in the near future.

This work must continue. I'm making sure that it does.

The first step is **meeting people where they are**. Much of the success from the in-person gathering came from creating an interesting, nurturing space where young people were known to pass through. Some of the most interesting interactions I had that day were with the folks that stopped by the library for other reasons and became captivated by the space I had created. At first they seemed puzzled. The space looked slightly different, and they were curious as to why. Almost immediately after explaining the premise of my project, they were happy to sit down for a chat. It's a magical feeling, meeting someone new and diving into a conversation about something you care deeply about.

Moving forward, I'd like to continue hosting gatherings and having conversations with young people. This will help me achieve my goal of having more conversations around sound access and hearing health, and in turn, foster a greater attitude of openness around hearing health.

One of the main successes of the in-person gathering was that I was able to meet students where they are. I created an open, nurturing environment in a space that young people already frequent, and passersby stopped and engaged. I hope to create more opportunities for spontaneous connections with young people around sound access and hearing health.

I'm currently pursuing conversations with SVA's Disability Resources Office to discuss the potential of coming back to host gatherings or help develop programming as an alumni. I am hopeful that more in-person gatherings can create an opportunity at SVA to spark new curiosity among young people around hearing health and the role of sound in our lives. If I were to have the opportunity to host another gathering, I would hope for more participants, so that I might expand my reach, and I'd love to invite other D/deaf advocates to the event to help facilitate conversations with participants.

If gatherings at SVA perform well, I'd like to aspire to scale up and host gatherings at multiple schools and universities in the New York City area. Perhaps I could reach out to NYU, CUNY, Columbia, and other educational institutions in the city.

Beyond educational establishments, Find Your Frequency may also have potential to create positive impact in professional settings. The conversation cards and frameworks for sharing stories and invoking self-reflection might prove useful in organizations looking to add additional training to their onboarding and professional development programs.

GRATITUDE

Thank you to my family and friends for your endless love and support, and for accepting and loving me.

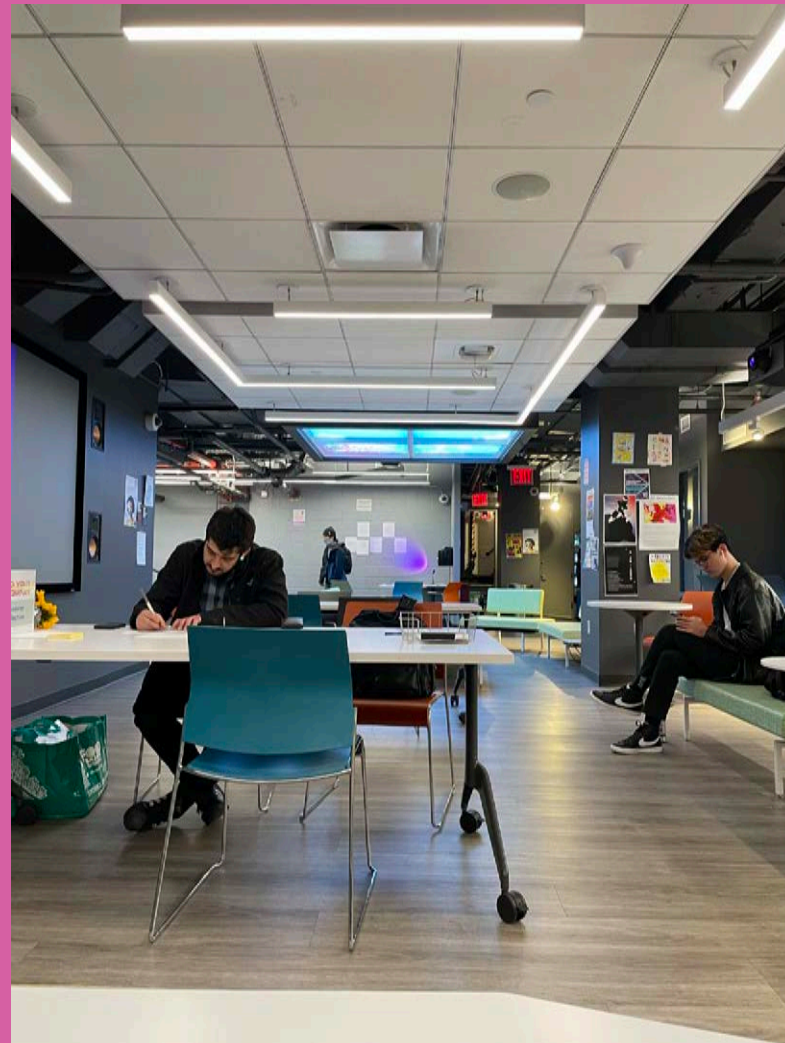
Thank you to Krutika, Pallavi, Sophia, and Riddhi for being my safe space, my most trusted confidants, my greatest cheerleaders, and my dearest friends. We've made it through the forest. The sun has set, and the stars are smiling down on us.

Thank you to Kara for listening to me ramble through all the ideas jumbled up in my head and helping me make sense of them. Thank you for pushing me to be the greatest version of myself and to keep thinking "and then, and then, and then." Your guidance has led me through this journey, and I am beyond grateful.

Thank you to Liz Jackson for your perspective and words of wisdom. I appreciate your supportive energy more than you know.

Thank you to Vanessa ÁineLeigh Kelly, for affirming that this is valuable, necessary work. I appreciate you taking the time to speak with me. Your work is so inspiring, and I hope to continue learning from you.

Thank you to Katherine Bouton, Jon Taylor, and HLAA-NYC for being a fabulous community partner. Thank you for providing endless encouragement throughout this entire process. I've enjoyed every moment of our time together, and I'm excited to continue this important work.



CREDITS, CITATIONS AND RESOURCES

ENDNOTES

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ORGANIZATIONS MENTIONED IN THIS PAPER:

Hearing Loss Association of America, New York City Chapter (HLAA):
<https://hlaanyc.squarespace.com/>

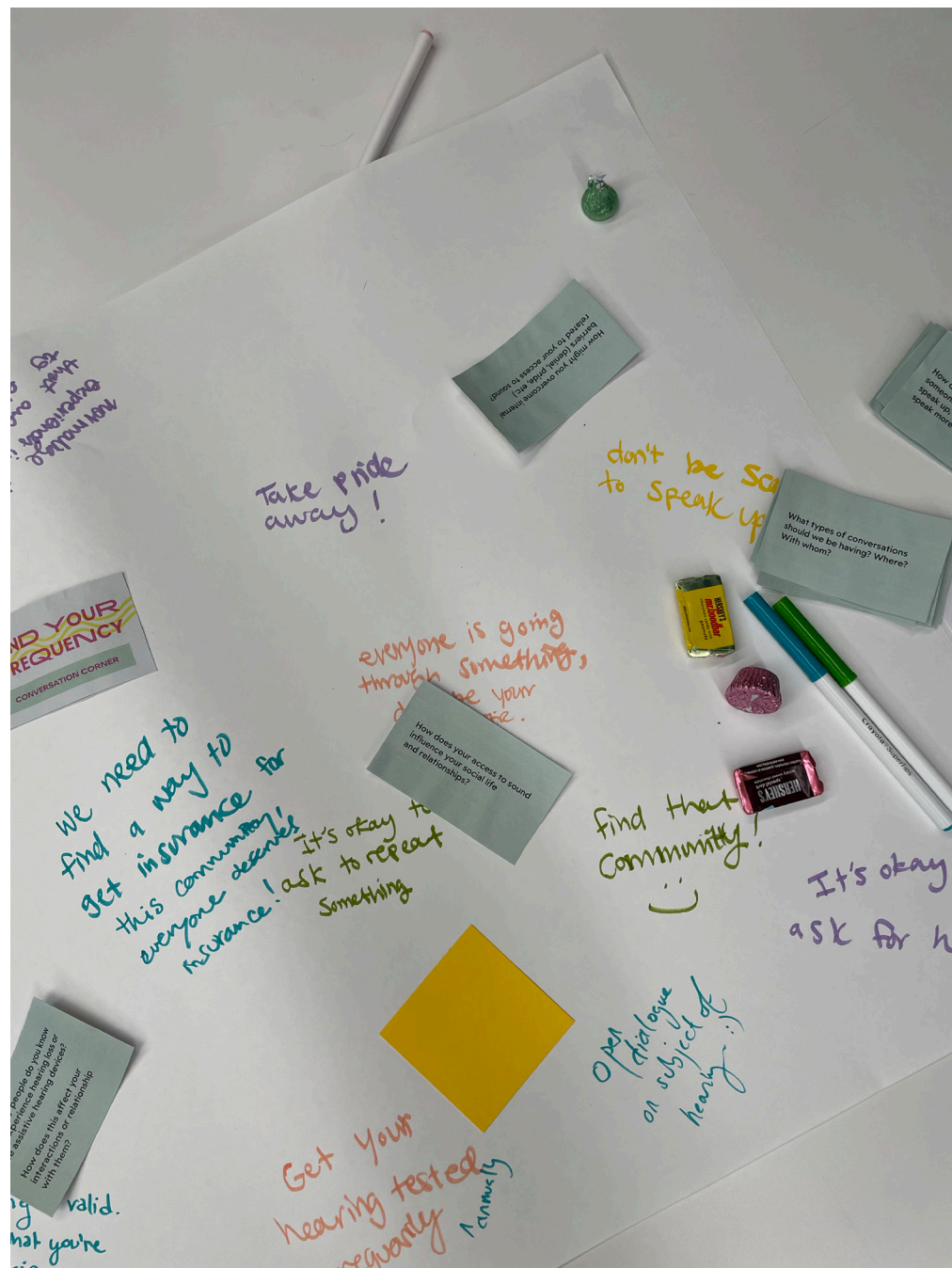
NYU EAR Lab: <https://www.ear-lab.org/>

NYU Cochlear Implant Center:
<https://nyulangone.org/locations/cochlear-implant-center>

Center for Hearing and Communication (CHC): <https://www.chcheating.org/>

Hearoes: <https://www.games4hearoes.com/>

Hear YA Now: <https://hearyanow.wordpress.com/about/yan/>



Thank You.