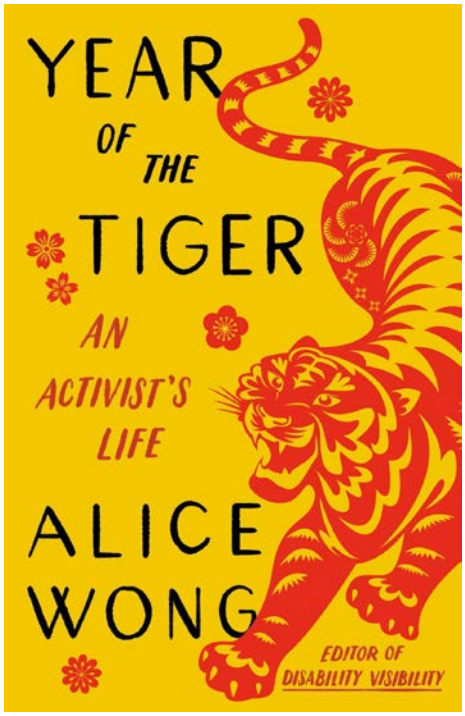
Plain Language Summary

Year of the Tiger: An Activist's Life
By Alice Wong

By Kelsie Acton



Plain Language Testing by Dominic Bradley
Plain Language Consultation by Riki Entz

Image Description: The book cover for Year of the Tiger: An Activist's Life has a yellow background. On the right side is a drawing of a crouching tiger. The tiger is red. It is drawn in the style of Chinese paper cutting. Chinese paper cutting is an art form where paper is cut into delicate shapes. The tiger has a strong look. It's eyes and jaws are wide open. It's teeth are big. The tiger has large paws with four claws extended. On the left in black large text reads YEAR OF THE TIGER at the top. The words ALICE WONG are below. In the center smaller red text reads AN ACTIVIST'S LIFE and in the lower right corner EDITOR OF DISABILITY VISIBILITY. An activist is someone who works with other people to change the world. Disability Visibility is the book Alice made before this one. Small, delicate red flowers are sprinkled throughout. Book cover by Madeline Partner.

Suggested reference: Acton, Kelsie. (2022). Plain Language Summary for Year of the Tiger: An Activist's Life by Alice Wong. https://disabilityvisibilityproject.com/book/tiger/

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Introduction to the Plain Language Translation

This is a plain language translation of **Year of the Tiger**. **Year of the Tiger** is a book about Alice's Wong's life so far. It has a lot of different pieces of writing about different parts of Alice's life. Some of these pieces of writing Alice shared in other places. Some of these pieces of writing are new for this book.

What does plain language translation mean?

Plain language translation can mean a lot of different things in different places. I like the way the US government talks about plain language. They say that plain language is writing you can understand the first time you read it. Plain language translation means I took Alice's ideas and how she sounds when she writes. Then I tried to write this in a way that keeps Alice's ideas and voice but is clear and easy to read.

To make writing that is clear and easy to read I:

- Use the 3000 most common words in English. If I can't use a word that is one of the 3000 most common words I will tell you what the word means. There are a couple of pieces where I don't do this.

Those pieces are about food. I've left the names of food and the words for how you make that food in those pieces. I've done this because Alice loves food. Sometimes it really matters that you know the specific types of food she's talking about. There's a note at the start of any of those pieces of writing about food letting you know this.

- Use short sentences.
- Make it clear who is doing what.
- Don't assume you'll read this book from start to finish. I also don't assume that you'll remember what happened in the book before. So if I need to tell you what a word means in one piece, I'll let you know in another piece.
- Made a timeline. I find time super confusing. So I took all the events in Alice's life that she talks about and wrote them out in order. You can find it right before Alice's introduction.
- Added context. I've tried to let you know a little bit about some of the people Alice quotes. Sometimes I've added a little bit about some of the ideas and history Alice talks about.
- Used bullet points and lists when it made sense.
- Used 14 point font and double spacing.

I hope you find this plain language translation clear and easy to read. If it's not, please let me know! You can email me at plainlanguageyearofthetiger@gmail.com to let me know what's difficult. I'll change and correct the google document of the plain language translation.

Why do a plain language translation?

Sara Luterman said all this way better than I can in the introduction to Alice's other book, **Disability Visibility**. (You should go read it here.) But here it is in my words:

I love disability culture. Sometimes disability culture writing uses long sentences and big words. I don't think anyone should feel disability culture isn't for them because they find long sentences and big words hard to understand or tiring. I believe everyone deserves to be able to read and understand Alice's ideas.

I also do plain language translation for two selfish reasons. First, as I get older, sometimes my brain isn't that great at making or understanding words. Some days I need plain language. I do plain language translation because I want more plain language out there for me. Second, plain language helps me understand the world. In "Activist Wisdom" Alice says, "Don't use words or ideas you don't totally understand yet." Plain language helps me understand what I'm saying. It helps me wrap my brain around the way the world works. I keep hoping that the better I understand the world, the more I can change it.

Who helped you?

I didn't do this alone. I had disability community helping me. Here are some people I'm grateful for:

- Jess Thom: Three years ago Jess told me I should pay more attention to plain language. That small suggestion turned into me working a lot of work on plain language. That work has given me a lot of joy.

- Aimi Hamraie: Aimi let me practice plain language a lot through the Critical Design Lab. This is just one of the many ways they've helped me grow over the past few years.
- Dominic Bradley and Riki Entz: Dominic and Riki gave me feedback on this plain language translation. They made sure that the writing was clear and complete. I'm deeply grateful to both of them. They are responsible for the good parts of this work. Any mistakes are mine.
- Adrienne Acton: Adrienne went through and fixed all the weird things my brain does when I'm writing. Sometimes she asked me really hard questions. I couldn't ask for a better sister.
- Alice Wong: Alice wrote a really great book. Plain language translation means I spend a lot of time thinking about the writing I'm working on. It's always a joy to think about Alice's writing.

Timeline

This is a timeline of Alice's life. It starts in 1973 when Alice's parents move to Indianapolis and ends in 2022. It has important events in Alice's life.

Year	What happened?
1973	Alice's parents move from Hong Kong to Indianapolis.
1974	Alice is born.
1976	Alice goes from sitting to walking. Doctors tell her parents she has muscular dystrophy.
1980	Mrs. Schrock is Alice's first grade teacher. Alice spends a lot of time reading books and watching TV. Alice goes to Hong Kong with her family for Lunar New Year.
1982	Alice gets her first wheelchair. Meowmee, Alice's cat, joins her family.
1987	Alice has surgery on her spine. She spends the summer in hospital.
1990	The Americans with Disabilities Act is passed. Alice sends a letter to Time Magazine about how important accessible buses are. Alice's drama teacher, Ms. Tudor, decides Alice can't take drama because she uses a wheelchair.
1992	Alice moves out and goes to Earlham College. She gets sick and has to drop out. She starts using a ventilator.
1993	Alice is feeling better. But while she's sick Medicaid has changed the number of hours of help she gets each day. She decides to stay at home. She goes to Indiana University.

Year	What happened?
1997	Alice goes to the University of California San Francisco. She spends a lot of time talking to the University about the kind of access she needs.
1999	The Supreme Court of the United States makes the Olmstead Decision.
2001	Alice is tired. She stops being a student at University of California San Francisco. She finishes with a masters degree. She becomes a researcher at University of California San Francisco.
2012	Alice meets Sandy Ho and becomes friends with her.
2014	Alice starts the **Disability Visibility Project**. Alice works with StoryCorps to record the stories of disabled people in the Bay Area.
2015	Alice goes to the White House and meets President Obama through a robot.
2016	Alice starts #CripTheVote with Andrew Pulrang and Gregg Bertran.
2017	The Disability Visibility Podcast starts.
2018	Alice publishes **Resistance and Hope, Essays by Disabled People**.
2020	**Disability Visibility, First Person Stories from the Twenty-First Century** is published. The COVID pandemic begins. Alice starts sheltering in place in San Francisco with her parents. Stacey Park Milbern dies.
2021	People start to be vaccinated against COVID. Phillips Respironics tells people using some of their ventilators to stop using them because they are dangerous. Alice's ventilator is one of the ventilators that could be dangerous.
2022	Alice publishes **Year of the Tiger, an Activist Life**.

Image Description for the Timeline: The timeline has two columns. On the left is Year, on the right is What happened? The two columns are divided by a black line running from the top of the page to the bottom. These are the dates on the timeline.

1973, Alice's parents move from Hong Kong to Indianapolis. 1974, Alice is born.

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Introduction

When I was younger, the year we're living in was "the future." This book is from the future. I've traveled a very long time to talk to you. I have a lot to share with you.

I've lived for many years. I'm a disabled Asian American woman. The world is not kind to me. Disabled means that doctors and a lot of people think my body isn't "normal." I've had to fight through the pandemic. I've had to fight to get access to vaccination. I've had to fight against people who make the rules about pandemics and vaccines, and think that people like me shouldn't exist. I've had to fight against all these things just to be alive and be part of society. After all that fighting I needed to stop and think about everything I've been through.

I realized in 2020 that I needed to tell my story right away. I was in danger. I use a ventilator to breathe. A ventilator is a machine that pushes air in and out of your lungs. COVID could kill me because COVID hurts people's lungs. COVID is more likely to kill me than other people. Still, the State of California decided that I shouldn't get the COVID vaccine before

other people. I was an Asian American disabled person living with my parents in the pandemic. Many white people were violent towards Asian American people. My parents are older than seventy-years old and COVID could also kill them. I was told when I was younger that I wouldn't live to be this old. So I decided to tell my story now. I decided to write this book now.

I don't have children. My work, stories, and the people in my life are the most important things to me. They are what will keep going if I die. So, this book is very important to me.

When I was young I didn't dream about being an activist. An activist is someone who tries to change how the world works. I had to become an activist because of ableism and racism. Ableism is the way the world is set up to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[1].

[1] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

Racism is the violence that people who are Black, Indigenous, Asian and other people of color experience. It is also when the world is set up to give more chances and money to white people than Black, Indigenous, Asian and other people of color. Ableism and racism work together. People think that white, non-disabled people are the people that matter most, and non-white, disabled people matter least. We can see this in how laws, governments, organizations and companies work. For me activism is getting what you need, working with other people, making trouble, and sharing information. There are a lot of ways to be an activist.

Feeling angry is part of being an activist. When you do activism you never stop working. No one will thank you for all your hard work. Hypercapitalism, white supremacy and ableism all work to make the world we live in the way it is. They stop us from changing the world for the better. Capitalism is the system we live in where we work to get money in order to buy the things we need to live. Hypercapitalism is very fast capitalism. Everyone everywhere is connected and involved in making more money. White supremacy is when people think that white people's needs and wants are more important than non-white people's lives. In capitalism, white supremacy means that Black, Indigenous, Asian, and

other people of color don’t get paid or don’t get paid as much as white people for their work. It also means that white people steal Black, Indigenous, Asian, and other people of color’s ideas, things and land to make money.

I’ve had to learn to find joy in my activism. I’ve had to learn that activism doesn’t just make you tired and angry. Learning to think about things differently is also a type of activism. I learned to think about activism differently.

A lot happens in the world that puts me in danger of dying. For example, I live in San Francisco where sometimes the power stops because of the heat. Smoke from fires in the trees fills the air for many days each year. When things get difficult people work together to change things. For example, a group called Mask Oakland gave out free N95 masks to help people with the smoke and to help stop COVID from spreading. I’ve seen how other people whose lives are threatened take care of each other. They know that no one else will take care of them.

We should all follow the principles of disability justice which were created by Patty Berne. Patty Berne is one of the people who started and leads a group called Sins Invalid. Patty Berne believes that:

- Counting on each other is a strength.
- All bodies are whole and perfect and do not need to change.
- We don't become free on our own, we need other people to be free too.
- We should listen to the people who are hurt most by a problem because they know the most about that issue.

I wrote this book, **Year of the Tiger**, because now was the time to tell my story.

Year of the Tiger has seven sections:

- Origins.
- Activism.
- Access.
- Culture.
- Storytelling.
- Pandemic.

- Future.

There are new essays in **Year of the Tiger**. An essay is a short piece of writing on a particular subject. There's also essays I've written before, talks I've had with other people, pictures and art. I hope you will find this book fun. Please color in it, write on it, make notes, and give it to other people. It's a lot of different things because I am a lot of different things. This book is a lot of little pieces of who I am.

I really love writing essays. Essays are my jam. When I write my thoughts for Teen Vogue, or for a blog post on my website, I am taking time to say something I really care about. The way an essay is written means I need to be short and clear with my ideas. Essays can do many things. They can:

- Show you new things.
- Make you think about something you thought you knew again.
- Make you wonder.
- Make you think.
- Celebrate people or ideas.
- Make fun of people or ideas.

A good essay, or a good story will be read by a lot of people. A story that people haven't heard before can reach many people and change many minds.

Essay writing is the way I do my activism. I also use social media. Sometimes I have to squeeze my thoughts, and all the pieces of me that go into writing, into 800 words. That is hard, but it is also magic. Dr. Tressie McMillan Cottom said:

> Beneath all the prose and the argument, an essay is public. The best essays build a public through process and form, driven from creative impulse to address a social problem.

Dr. McMillan Cottom means:

> Essays talk about public problems. They bring people together to think about those problems and address them. Essays bring people together through the way they are written. Essays and people coming together are creative and can solve problems.

When I wrote the proposal for this book I looked at my past writing. I was surprised. I've written a lot, and about a lot of different things. Now, when I read the pieces I wrote in high school and college I hate them. I cringed hard. But I can see that they were all part of the journey that brought me here. I want to look at how those ideas grew and who helped me to think those ideas. I planned to have so much fun writing and putting together this book. I was worried about writing about my life, but I tried not to think about this. I didn't read any other books about people's lives because I knew they would make me more anxious. Maybe I shouldn't have told you that, but I want you to know about how I wrote this book.

As I was putting together this book I knew that I had new things I wanted to write. I also wanted to show you some of the anger of activist life. So this book has some angry texts and callouts. Callouts are when you tell people what they're doing wrong in front of other people. This anger is part of me just the same way my activism and me telling stories is important to me.

I will swear, I promise.

People think stories about people's lives should be a certain way. I think they're wrong. People think stories about people's lives should have a lesson or make you feel good. I don't think that stories about people's lives should teach people anything. Since this is my first time writing a whole book about myself, you should know these things about how I wrote it:

- I did not want to make white people or non-disabled people feel safe or comfortable.
- I did not write about winning against hard things.
- I did not write about going through hard times without complaining.
- I didn't write a book filled with all the pain and shame I've gone through because of ableism. I have a lot of those stories. But I'm only going to share a few. A life story can only give you a little bit of a person. I have reasons for sharing what I'm going to share.
- I did not write about identity and pride. Some people might expect me to write about:
    - If I am too Chinese
    - If I am disabled enough

    - Being caught between being disabled and Chinese
    - How my parents didn’t understand me.

  I am not Chinese enough and I am very disabled. I am very okay with that. There are other books out there that tell those stories. Aren’t they enough?

When I wrote this book I was worried about how publishers love stories about disabled people’s lives. Publishers make and share books. But the people who make books don’t want disabled people to write anything except about their lives. There are more books about disabled people's life stories than there are any other kinds of books by disabled people. Maybe this is because:

- Publishers expect disabled people to explain disability and not to explain any of the other things they are interested in?
- The world doesn’t like to think of disability as something that everyone should be thinking about?
- It’s easier to learn about one person rather than all the things that are wrong with the world?
- People expect that they will feel good about themselves when they finish reading the book?

- Life stories sell lots of books?

Publishers decide what stories to tell because they want to sell more books. So many disabled people don't get to say the things they want to say in books.

Most of the disability life stories I've read make me roll my eyes. Most of them are about people heroically winning against hard things. Instead I wanted to write you a book that doesn't tell one story. I wanted to give you a sense of my life. But I'm still worried about how my book will be understood and sold.

Are you reading this book because you want to understand a life that you find fascinating but can't imagine? Do you want to feel proud for reading an experience so far from your own?

Whatever your reason, when you're finished reading **Year of the Tiger**, please question everything.

Life stories are important because remembering lets us imagine and gives us power. I have created myself again and again. The power to remember is connected to the power to create the future. I use a lot of energy to travel through time. Living and fighting as long as I have takes a lot of energy. Right now, I'm here. I'm alive. I'm going to stay alive as long as I can.

I want a lot of things for me. I want a lot of things for all of us. I like to think about writing and stories by disabled people as parts of spells. Eventually there will be enough parts of spells in the world that the parts of the spells will join together and magic will happen. The world will not be able to stop our truth and our messages will spread far and wide. We write and tell stories and dream together so the world can finally see us as we are.

Origins

Cats rule the world. —JIM DAVIS, Creator of Garfield

Tell me, everybody's pickin' up on that feline beat, 'Cause everything else is obsolete. —AL RINKER and FLOYD HUDDLESTON, "Ev'rybody Wants to be a Cat".

Al Rinker and Floyd Huddleston are people who wrote a lot of songs together.

Which means:

Everyone is dancing to cat music. All other music is old news that no one wants to hear.

A Mutant from Planet Cripton: An Origin

Shared on **The Nerds of Color** blog on April 3, 2014.

I'm going to tell you a story about growing up. I'll tell you the story as if I was a mutant from Planet Cripton. A mutant is someone whose genes are different from everyone else' genes. Genes are the parts of a cell that tell a body how to work.

In 1974, a baby arrived in Indianapolis, Indiana. She was from the planet Cripton. She looked like Ma and Pa Wong. Ma and Pa Wong had come to the US from China. Ma and Pa Wong named her Alice. But something was different.

This baby couldn't lift her head. She couldn't get on her hands and knees. She sat and then she walked. Ma and Pa Wong were confused. They took the baby to a doctor and found out she is a mutant from Cripton, a Crip!

The baby learned how to fit in quickly. She watched Sesame Street and read books, and learned from everything around her. She talked and moved in ways she knew wouldn't scare the other kids. She talked to adults when they looked at her and tested her to understand how she was a mutant. Eventually, she grew up and realized there were other mutant Crips on earth.

As she grew up Alice was proud of being a Crip and found other Crips. Together they would fight for the world to treat mutants and non-mutants the same. Many people did not like this and called Alice and the other Crips bad and wrong.

This story is kind of true. I was born in 1974 to two people who moved from Hong Kong to Indianapolis. I love science fiction and cartoons. Science fiction is stories about the future. Science fiction and cartoons helped me understand who I was as a disabled Asian American woman. Disabled means that doctors and a lot of people think my body isn't "normal."

My genes are different from a lot of other people. This difference means I have muscular dystrophy. When I was growing up I heard people use these words to talk about me:

- Weakness
- Born-with
- Something wrong
- Different
- Not normal

I didn’t realize then how those words hurt me. But through reading, writing and watching lots of tv, I started to think about those words as a kind of power.

I stopped walking at seven or eight. This meant I couldn’t do some of the things other kids were doing. I spent a lot of time watching TV and in the library. I remember getting up early every Saturday to watch **Super Friends**, which was on at 7:00am. I think it was my first time seeing an Asian Character, Samurai, in a cartoon. He flew around by moving wind really fast around his legs.

In elementary school I read Madeleine L'Engle's **A Wrinkle in Time**. I loved it. Then I discovered Octavia E. Butler, who changed how I thought about the world. Butler has three books that together are called **Lilith's Brood**. In them, the Onakali are aliens who do not fear difference. The Onakali think difference in genes is a good thing. I was a nerd, someone who really loves a subject and knows a lot about it. Nerds often love science fiction and cartoons.

I liked stories about groups of friends. I enjoyed **Super Friends** and I also enjoyed **Star Trek: The Next Generation**, **Star Trek: Deep Space Nine** and **X-Men: The Animated Series**. I was so happy that Charles Francis Xavier, one of the most powerful mutants, used a wheelchair. It made me feel like I could say, "Fuck, yeah! If you talk down to me I'll blow up your heart!" Although really that's more like Magneto. Professor X is calm and cool. Everyone has respect for Professor X and never questions him.

Many kinds of people felt like the X-Men showed them their lives. People who love or have sex with people who aren't the opposite gender, people who are not the gender people thought they were at birth, people who moved to different countries than the ones they grew up in, disabled

people, all saw that the X-Men were a little like them. The stories in X-Men ask complicated questions about making yourself the same as other people, who you are, if countries should have a big army, and what is right and wrong.

Seeing stories that are like your life in popular culture feels really good. Sometimes when we read, watch or listen to science fiction, fantasy and comic books we feel connected to the people like us in the stories. Sometimes we feel connected to the people who aren't like us or the people we want to be like in stories. I want to be like Professor X. But I'm really a bit more like Magneto.

Books, movies and tv gave me strength and changed the way I thought about my disability. Nerds are left out. Most people don't think nerds are important. But nerds know they should welcome differences, make friends with others who are left out and support the people that the world isn't kind to.

Lessons from a Chinese School Dropout

When I was growing up in Indianapolis, I hated Sunday nights. Sunday nights were for trying to finish homework and worrying about school the next day. I also had to go to Sunday school, lunch and then Chinese school. The church was my Chinese American world. At church I learned about community, who I was and Chinese food, art and ways of understanding the world. But I was not good at Chinese school.

I have two sisters, Emily and Grace. All three of us grew up with a small group of Chinese American kids. Their names were:

- Amy
- Wayne
- Ellen
- Simon
- Sang
- Ming
- Mark
- Jeff

- Jemie
- Iris

All of us were born in the States but our parents lived in China before coming to America. In the summer the moms would meet for 婦女会 fù nǚ huì. Fù nǚ huì is a women's group. Our moms would study the Bible, chat to each other and learn to make things like Auntie Anita's 花卷 huā juǎn. Huā juǎn is bread with green onion, cooked in hot, wet air. All the kids except me ran around. Auntie Jean would give us ice pops, which were sweet water in bright colors. She would cut the top off the long plastic tubes and give them to us. Mmmmm, so good. There were garage sales, parties where we all brought food to eat. We also had birthday parties, and we cut and curled each other's hair. A lot of the hair cuts and curls were not good for thick Asian hair but we tried. At weekly Friday-night Bible study we hung out in Amy's basement. I really remember these pieces of growing up.

The church had started with people who had come from China to the United States and Chinese students who were studying in the area. They went to each others' houses for Bible study in the 1960s and 1970s. The

group grew, so they started meeting at Northminster Presbyterian Church. It was a large brick building. It was in the north part of Indianapolis. I thought it looked like a church for rich white people.

After the service people would talk to each other and eat lunch. People paid whatever they could for lunch. The lunch was simple. For example, it might be rice with beef cooked with carrots and potatoes. Or maybe lunch would be ground beef mixed with vegetables. It could feed a lot of people. The women volunteered to cook it and they also cleaned up afterwards. Auntie Rosario would make angel food cake with whipped cream and crushed pineapple. She would cut it into small squares. There was always half a maraschino cherry on top. I thought it was such a grand treat.

Then, the older people in our church bought a church of our own. It was an old building. There were scary stairs going down to the basement. The basement had a kitchen, stage, rooms for teaching, and a large meeting space where almost everything happened. The aunties would make everything happen in that basement. Chinese school, summer vacation Bible school and Sunday school were all in the basement. Mom or Dad

would carry me down the scary stairs. There were bugs. I was frightened of bugs. I still am.

It started to get really hard for me to walk around in the basement. I would hold on to the tables and chairs for dear life and it made me tired. I don't know if that was why I quit Chinese and Sunday school. Or maybe I just wanted to stay home and watch TV. I felt safe watching TV. My family made sure that I could do anything they did together that I wanted to do. But they also let me decide when something was not worth the effort. They were never upset. They never told me I was a failure because I didn't want to do something. Now that I look back on this, this was them letting me make choices for myself.

I chose when I didn't want to work. Lots of white people say that Asian people are a "model minority." This means that they're hard working, achieve a lot and fit in. It's dangerous to say that all Asian people work hard, achieve a lot, and fit into the culture of the United States. Saying that gives white people an excuse to ignore the racism that Asian people experience. Racism is the violence that people who are Black, Indigenous, Asian and other people of color experience and when people

are kinder to white people than Black, Indigenous, Asian and other people of color. It is also when the world is set up to give more chances and money to white people than Black, Indigenous, Asian and other people of color.

Asian people who believe that they are a model minority are less likely to support Black or Indigenous people or other people when they experience racism. I don't believe that Asian people are a model minority. Even at a young age I decided I didn't want to work hard so people could say that I was a model minority.

Auntie Ling-Ann was in charge of our Chinese school for many years. One year Uncle Paul was my teacher. Uncle Paul taught us from a book with lessons about a person called 王大中 Wáng Dà Zhōng. Wáng Dà Zhōng is a silly sounding name. The books were in order - 1, 2, 3, 4, 5. The books got harder the bigger the number. I never made it past book four. I learned some characters in 注音 zhù yīn and how to write my name. Zhù yīn is a system of writing out the way Mandarin Chinese sounds in the English alphabet that is most commonly used for Taiwanese Mandarin.

Here are a few of the other things I remember:

Lesson One: You have to write characters in a certain order.

王 Wong is my last name. It is a hella common name. It means “king.” I am very happy it is simple to write. It has four lines. There are three lines, drawn left to right, from top to bottom. You draw the line that goes down the center of the other lines last.

Lesson Two: Some characters are very complicated.

The second character in my name, 美 měi, has lines that must be the right size compared to one another. Characters can have lots of lines, dots, boxes and swoops. I describe the characters to myself using lines, dots, boxes and swoops. Other people don't use those words. All of these parts of the character help make the meaning, but only when they’re in the right place with other parts of the character. So you have to be very careful when writing to make sure that all the parts of the character are correct. It takes a lot of practice. When I went to Chinese school I had to write the characters over and over again, say things with the words I’d just learned or copy out lots of characters in order. We had special paper for the

homework. It had a space for writing the characters and a space on the right for the zhù yīn. You could look at the zhù yīn and see how to say the word. This was important because you needed to say the words with the right sounds and right pitches. (I could say a lot more, but this isn't a school book.)

Lesson Three: There can be many words in a word.

A single character can mean one thing. But then you put it with other characters and then it is a different word. 美 měi means "beautiful." You can put 美 měi with 國 guó, which means "country." Together they are 美國 měiguó, which means the United States. The third character of my name 華 huá means China. When you put it with 僑 qiáo, the word for someone who has left their country it is 華僑 huá qiáo. 華僑 huá qiáo is the word for all the Chinese people who live in places that are not China.

Writing characters is really hard. Calligraphy is a type of art where people mix colors with water on a stone, then use a brush to write characters on paper with the coloured water. One year Uncle Paul showed us calligraphy. I watched Uncle Paul carefully. Uncle Paul made the coloured

water. I also watched how he held his hand and wrist. He moved very carefully. I learned that words are more than what they mean. Words are art.

My dad and his father, my grandfather, also did calligraphy. My grandfather made us a large piece of calligraphy of 福 fú, which means luck. He made it with thick black lines that curved. It was on red paper with little bits of gold. It hung in our home in Indianapolis. My grandfather made a bigger piece of calligraphy that hangs in our home in San Francisco. It shows all the different ways people have written 福 fú over the years. All the 福 are different, but they all mean the same thing. When I look at it I think, luck is different for everyone. That's an important thought - some deep shit.

My grandfather named me. He got to do this because of tradition and patriarchy. Patriarchy is where men have the power to decide things and women and other people who aren't men don't. I am the first person in my family born in the United States. So my name is 王美華, which I think means "a Chinese Wong in America." But I could be wrong. Is my name boring and common? Sometimes I wish I had a cooler name like "Brilliant

Spring” or Ferocious Tiger.” But maybe my grandfather named me this to remind me of China and my past. Even if I can’t ever totally know or understand my past. Today, I like my name, but I have decided it means: “King of the Chinese Americans.”

Troublemakers

This is an interview with Ellen Wu. The interview happened on June 4, 2015.

Alice Wong: My name is Alice Wong. I'm forty-one years old. Today is June 4, 2015. I'm at the San Francisco Public Library. The San Francisco Public Library has a special room to record sound in. The room is here because of StoryCorps, which is a group that helps people tell stories about their lives and talk to other people to find out their stories. Ellen Wu has been my friend for a long time. She's going to ask me some questions.

Ellen Wu: I'm Ellen Wu. I am also forty-one years old, oh my god. Today is June 4, 2015. I am here at the San Francisco Public Library. I am going to ask Alice Wong some questions. Alice is one of my greatest friends. And we used to make trouble together.

Alice: Yes, we are trouble-makers in the best sense of the word.

Ellen: Okay, Alice, first things first. How do you make or take your coffee? This is an important question for someone who lives in San Francisco.

Alice: It's an important question for people who love coffee everywhere. Everyone has their own perfect way to make coffee. I like to use a single cone drip. I crush the fresh beans first. I put the beans in a filter, a special piece of paper that lets water through. There's a thing that holds the filter above a cup. Then I pour hot water on the beans. The water sits on the beans and then it slowly drops down into the cup below. And then I used to add two and a half spoons of sugar.

Ellen: You don't put sugar in your coffee anymore?

Alice: I know you're surprised by me not putting sugar in my coffee. A while ago I started using less and less. I use less than a spoon of sugar now. I'm very proud of myself. I can taste the coffee more. I don't miss the sugar. Now I add a lot of half and half. I love full fat milk.

Ellen: Milky and sweet.

Alice: No soy milk in the coffee! Not that there's anything wrong if you use soy or almond milk.

Ellen: I agree with you.

Alice: Give me real milk.

Ellen: People ask me how you and I know each other. I always say that we've been friends a long time. We were born three weeks apart. You were born three weeks after me. We've known each other since the day you were born.

Alice: That's right.

Ellen: One of the big things we have in common is that we both grew up in Indiana. We were both daughters of Chinese people who left China. We both grew up in the 1970s and 1980s. What are some of your memories from growing up? What were some of the best parts of growing up? What were some of the worst parts of growing up? Maybe what were some of the okay parts of growing up?

Alice: We grew up in a way most people don’t. We were Asian Americans living in the Midwest. People always assume that Asian Americans live on the east or west coast. When I moved here to San Francisco no one guessed that I was a Midwesterner, which is someone from one of these states:

- Illinois
- Indiana
- Iowa
- Kansas
- Michigan
- Minnesota
- Missouri
- Nebraska
- North Dakota
- Ohio
- South Dakota
- Wisconsin

I'm proud of being a Midwesterner too. That's something that not a lot of people in the Bay Area are. Midwesterners are outnumbered by people from other places. I'm a Midwesterner, I'm from Indiana, I was born and raised there.

Ellen: Don't ignore me because I'm from the Midwest!

Alice: Yes, exactly. You made up the name Hoosier Chino, which I love. Hoosier is a name for people from Indiana. Chino is a name for Chinese people. So, Hoosier Chino is a word for Chinese people from Indiana. Most of my memories are about our very small Chinese community. We were so lucky. There were a lot of kids the same age as us. We had a Chinese community church. We lived close to each other. We went to different schools but so much of our life was about this church community. We went to Chinese school. I was the worst student. I didn't try at all. You, and Simone, your brother and my sisters Emily and Grace all got better. I don't know what happened. I sort of….

Ellen: Stopped being interested?

Alice: Yeah, I wasn't interested. I was so not interested that around 12 or 13 I just stopped going. It's funny. And our moms were all in this ladies' group. They would get together and make things. All of us would be in one house, having fun. We'd go to play games at each other's house, to Friday-night Bible study, Saturday hang outs and Chinese school after church. I love those memories. I had a sense of community. The group of kids was really small. There were maybe 10 of us who were about the same age. From Monday to Friday we went to our schools. In our schools there weren't any other Asian kids. It was so special to have that group of Asian kids. I'm really glad we had it because it helped me feel like I had support.

Ellen: That's right. I remember you got mad at me once. I'd told you, "I'm really glad we don't go to the same school." I didn't mean, "I don't want people to know I hang out with you." But we had our…

Alice: Separate lives.

Ellen: Yes, we had lives at school. Then on the weekend we were together in a totally different world. In that world we knew each other and it wasn't weird if your parents yelled at you in Chinese.

Alice: And in our weekend world it was okay to not be the usual school kid who needs some things. I remember that in junior high and high school you and our friends started driving. It was great being in different schools because we would go to each other's events.

I remember you were really into theater. In high school we would go see you do theater and you'd sing. I remember you being in Fiddler on the Roof.

Ellen: Right.

Alice: It was really cool to support each other. It was nice. But I feel bad I got mad at you for saying you were glad we didn't go to the same schools.

Ellen: It does sound rude.

Alice: But you remember it and that’s what makes me feel bad.

Ellen: I've done much worse to you. No worries.

Alice: When you were a kid you could always make something up. You always knew what you were doing and you did everything well. I was always very impressed with you. I remember you had your own library at home. You had library cards so when I came over you let me check out a book.

Ellen: I feel weird about that. Like I was telling you what to do.

Alice: No, it was really cool. You wanted people to fill out actual library cards to take books. You also wrote your own newspaper called the Jelly Donut Press. You made a comic book character called Super Pickle. I was very impressed.

Ellen: Making the newspaper is probably what led me to making zines. Zines are magazines that you make yourself or with friends.

Alice: Yes.

Ellen: I think when you were a kid you were cool in ways that would become cool. People talk about foodies, which are people who really love food. But you were really into food since we were little. I have lots of great memories of food and drink. We were eight or nine when your aunt and uncle came from Hong Kong. They fixed us hot Coca-Cola with ginger or lemon which is a treat in Hong Kong. Most Americans would think that's gross. I always try to get my husband to try it.

Alice: Coca-Cola with ginger or lemon is good!

Ellen: It is! One of the best things was in grade 12 or 11 when you had us go on a field trip to Chicago.

Alice: Yes! So fun!

Ellen: You tell the story.

Alice: I really loved the arts. Not making art, but I liked looking at it. The Arts Institute in Chicago had some Claude Monet paintings that were only going to show for a little while. You could buy tickets and I thought: road trip! Lots of Chinese families, including ours, would sometimes go to Chicago for the day for dim sum and to buy food. Dim sum is lots of different foods, mostly from the South of China. Dim sum is cooked in hot oil or with hot, wet air. Everyone shares the food along with tea.

Ellen: It was a three hour drive to have lunch and buy food.

Alice: That's what you do when you're Chinese Americans who can't get good food or dim sum in Indiana in the 1990s.

Ellen: People really needed dim sum and good food.

Alice: I think it's better now. You had to go so far and work so hard to get that food. So you really enjoyed it. I thought since we were going to buy food we could go to the museum? And you and Simon could come with us? We went in a van with my parents, me, Emily, Grace and you and Simon. We definitely ate something before or after.

Ellen: I think we went for pizza with cheese in the crust.

Alice: Mmmmm.

Ellen: I was in awe. It was the first time I'd been in an art museum. There were so many Monet paintings.

Alice: They were awesome. I remember a huge painting of peaches.

Ellen: You always knew about the cool things. For my birthday you would give me fancy books. One year it was **Angels in America**. For another birthday you gave me a book about coffee. I started to be picky about coffee because of that. Once you made us watch a David Lynch movie. I don't know how you knew about all these things.

Alice: I knew because I was a nerdy weirdo, who got excited to learn about things other people didn't know about.

Ellen: There was a lot of being a nerdy weirdo. I remember going to Olive Garden with you and asking for iced coffee. They thought we were strange. It was 1989, so no one was drinking iced coffee then.

Alice: That was before Starbucks existed.

Ellen: I'm very proud of us asking for iced coffee in 1989.

Alice: I think we learned a lot from each other. I remember going to your house for my birthday. You threw me a fancy pizza making party. You gave everyone the base and we chose what to put on top. You even had asparagus to put on the pizza. We were really ahead of our time I think.

Ellen: I think I got the idea from a story about Wolfgang Puck. Wolfgang Puck was a famous cook. There was an article about him in Seventeen magazine.

Alice: One time you took me to a neighborhood in Indianapolis called Broad Ripple. We went to Bazbeaux Pizza and they had all these cool new pizza toppings.

Ellen: You were shocked.

Alice: Yes. I had quattro formaggio pizza, which is pizza with four different types of cheese. I had never had four cheese pizza before. It was fun. We helped each other be creative.

Ellen: We both wanted to find out about the world. I think we both felt like we were in boxes.

Alice: We were interested and curious. Even if we'd stayed in Indiana we would have wanted to try new things and bring new things to Indiana.

Ellen: You can try new things wherever you are. I think this takes me to my next question. You've spent most of your adult life in San Francisco. Why did you move to San Francisco? Did the move do what you wanted it to do?

Alice: I think most people think San Francisco is something that it's not. I used to watch **The Real World: San Francisco** and would think: is that

what San Francisco is like? Does everyone have those cool places to live and furniture from Ikea? This is so fancy.

I moved to San Francisco for lots of different reasons. Some of it was about disability. Because of my disability I need help to do things like get dressed and go to the bathroom. In Indiana I did not have the help I needed. My dream college was Earlham College in Richmond, Indiana. When I went there I moved out for the first time. When I lived at home my parents and my sisters helped me a lot. I had to work with a company to pay people to show up and help me. But I couldn't pay for enough hours of help to let me live away from home.

The big problem was Medicaid. Medicaid makes sure that people who don't have a lot of money have medical care and help with things they need to do each day. But Medicaid doesn't work as well as it should. Medicaid would only pay for someone to help me for a few hours each day. I had to be very careful because it was not enough time.

Ellen: What did you do if you needed something but you didn't have someone to help you who was paid by Medicaid?

Alice: I had to ask the people I lived with or other people in my dorm for help. It was not easy. I was learning how to trust other people to do the things I needed. It felt bad. Also, I really wanted to fit in. I was Earlham College's only student who used a wheelchair.

Ellen: Ever?

Alice: I think so? A year before I graduated from high school I talked to the people at Earlham College. I told them that I was very interested in going there. I told them the things I would need to come to Earlham College if they wanted me to go to school there. They made an accessible bathroom in the one dorm that didn't have steps. Accessible means that disabled people can get into a place, use a thing or enjoy an event. Only one dorm was accessible so I couldn't visit -

Ellen: Other friends.

Alice: Yes. Most of the bathrooms were not accessible. There was only one bathroom in the entire college that I could use. Can you believe that?

A lot of the buildings weren't accessible so they put my classes in the buildings that were accessible. The people at Earlham College used me to experiment with accessibility. This was in 1992. That's two years after the Americans with Disabilities Act passed. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with disabilities. This meant that most universities that get money from the government had to make their campuses accessible. But I think because Earlham doesn't get money from the government they didn't have to work as hard to make things accessible as colleges that got money from the government. Over my life lots of people have tried out access for the first time with me.

I got sick in my first term of school. I had respiratory failure, which means it's really hard to breathe on your own. Respiratory failure is really dangerous. I had to stop school for a year and live at home. When I was ready to go back there was less money for Medicaid. With fewer hours of help I couldn't live on campus. My parents were paying for me to go to school. I didn't want them to have to pay for people to help me as well.

That felt unfair to me. I didn't want to do this, but I decided to stay at home and go to Indiana University at Indianapolis.

I felt really down for about a year. I was still pretty sick. I took classes where the university would send the work to my home. Then I would send it back. I was jealous of all my friends who were going to university buildings, meeting new people and having fun. I hated it and it also gave me time to get stronger and think. I learned a lot about policies for disabled people, which are rules that governments and groups make about how they do things. I learned about programs. Programs are things governments and groups do for a reason, to make something happen. I read about California and how California had more support for disabled people. In California there were more chances for disabled people to live their lives how they want to.

I needed to figure out how to get to San Francisco or the Bay area. So I applied to graduate school. I got into University of California San Francisco. Again I had to work hard to make sure I could go. I had to talk to people at University of California San Francisco a year before I wanted to go there about accessibility.

They were really honest with me. They didn't have any accessible places for me to live. So they built me a little room in a garage. They built a one room unit in the garage of some professor's house so I could move in for fall term.

Ellen: Did it have windows?

Alice: I don't think so.

Ellen: Running water?

Alice: Yes. The most important things were a bathroom I could use and no steps. Often when you talk to people about accessibility you're asking for what you need. But you're also asking for what other disabled people will need in future. So that other disabled people will not have to struggle the way you did.

I know that the University of California San Francisco built wheelchair-accessible places to live after I went there, but they didn't have anything when I went there.

Ellen: I like that. I read a piece you had written recently. It was in **Amerasia Journal**. You were talking about growing up Asian American with a disability. I was surprised because we've known each other a long time and I didn't realize -

Alice: How angry I was?

Ellen: Yes, how angry you are. I thought a lot about the ordinary things non-disabled people don't have to think about. You have to plan so far ahead. Things didn't always work out. And then you had spent so much time thinking about your plans. I thought about how hard that must be for you. I thought about how much planning and then not having your plans work must hurt you.

That makes me think of another question. You have muscular dystrophy. That means your muscles get weaker over time. So your body changes

as you get older. You have to find new ways to do things. I know it's a big part of your life. I wanted to ask you how having muscular dystrophy has made you think about living, dying and about the fact that you're going to die someday?

Alice: I'm glad you asked this question. Thank you. You shared with me when **Amerasia** asked for people to write about being sick and disability. I was so excited to see a magazine about Asian American experiences talk about being sick and disability.

I said to you, "What should I do? I haven't found out about other people's experiences and stories. But maybe they'll share some writing about my experience?"

It was wonderful to tell my story. It was one of the first times I told my story. I want to thank you for telling me to do that.

I know my body really well. I know how my body changes really well. I think people with disabilities who are like me, we know what are normal changes. And how my body works and how much I can do without help

changes a lot. People think independence is doing everything by yourself. But I think it's about being able to tell people how they need to help you and make decisions for yourself.

Ellen: So being able to make your decisions on your own.

Alice: Independent means someone is able to make their own decisions. People should get to make choices. People should get to do things that might not work out for them. People with disabilities live in a world that hates disability. We have to protect our power to make decisions. We have to protect ourselves against people who think we can't make decisions and people who hate us. It's not just about being able to get around. It's about all the places where people can make fun of you.

I remember people just not being nice. In second grade a kid pushed me down because I couldn't balance. She pushed me. I hit my head and had to go home. When things like that happen, you grow up fast. It helped me learn to watch people and think about people. I learned about power, about how people were different, about how people understand each other. Later I learned about sociology, which is the study of how people

live together in big groups. Sociology helped me think about disability as something that was bigger than just a person's body. Disability is also the ways the world isn't fair to disabled people. Learning about sociology helped me use my anger. I started to use that anger to help myself and other people.

I joke about being an angry disabled Asian girl. But I'm proud of being an angry disabled Asian girl. That anger made me who I am.

Ellen: Your anger makes change happen.

Alice: It does. I like my anger. I am really thankful for my anger. It makes me think, it makes me take action. So I try to use my anger to make other people think and take action. Some people I have to be clearer with than others. I remember a few times when I had to tell people what they were doing was wrong. I made people cry. I remember making one of the people I was living with in college cry after she did something really shitty. She started crying. I remember thinking, "Oh god, now I have to say I'm sorry."

Ellen: You are just very good at making people see your point of view.

Alice: Now I say: I'm sorry I made you cry, but I don't regret anything I said.

Ellen: Sorry, not sorry.

First-Person Political: Thoughts from an Angry Asian American Disabled Girl

Shared in **Amerasia Journal** in 2013.

A little while ago, a friend sent me a photo of my sisters and me at a birthday party in 1983. I knew who I was in the photo. I was the chubby girl in overalls. My mom made me those overalls so I would have clothes that fit. I look at that photo and I see a girl who enjoys a good bowl of noodles. I looked at that photo and I also see the look on my face. I looked sad, like I'm going along with something I don't like.

I was happy growing up. I had lots of friends and family to support me. But when I look at old photos or talk with my sisters about my childhood I also remember being angry and tired. I have a disability that changes my body and what I can do as I get older. That disability changed my childhood.

How I move changed while I was a kid. I stopped walking when I was 8. Stopping walking changed my relationship with people and with the world around me. Sometimes the changes to my body hurt my relationship with

other people. I'm sharing some of my memories in this essay. This is a way for me to think about how I was a very angry girl. I'm also thinking about how I became a very angry disabled woman.

My parents moved from Hong Kong to Indianapolis, Indiana in 1973. I was born in 1974. I am the oldest of three daughters. My mom's friend noticed that I didn't lift my head up when I was one and a half. That was the first sign I was different. My neck was too weak to support my head when I was on my hands and knees. So I just went from sitting to walking. A doctor told my parents I had muscular dystrophy when I was 2.

At that time doctors didn't really understand what muscular dystrophy meant. The doctor told my parents I would die before I turned 18. My parents would cry a lot. My Mom would cry at home washing dishes, my Dad would cry at his job. They were in a new country, speaking a new language. They were trying to start a family. My parents didn't know people with disabilities so they didn't know what to expect. This was good because they just raised me as best they knew how to. They used their common sense. My parents practiced parenting on me because I was born first. My parents also expected me to be an example of good

behavior for my sisters. My disability didn't matter. It's a big job being 老大 lǎodà, the bossy older sister.

The way I moved changed over time. I walked when I was young. Then I used a walker. A walker is a frame on wheels that you can stand inside and hold onto while you walk. I used a manual wheelchair, a wheelchair where I pushed the wheels to move. When I was eight I started to use an electric wheelchair, a wheelchair that moves using power. When I was very young I needed to have surgery.

I had to have the surgery because my leg bones didn't join into my hip bones right. Afterwards I needed to wear a brace at night to keep my legs apart. A brace is something hard you put around a body part to keep it in position. The brace made it hard to fall asleep. I'd ask my parents to leave their bedroom light on. I could see the light from their lamp come under my door. The lamp made me feel better. I was trying to forget about the stretch in my hip muscles. I would try to think about anything except my hips. I learned to slide down and undo the brace around my legs to make my hips feel better.

Even after the surgery one of my legs was longer than the other. I always felt off balance. I fell a lot. I got hurt a lot falling. When I was seven I started to get tired when I walked. I felt out of breath and couldn't keep up with other kids my age. I was afraid of falling so I would hang onto chairs for support. I felt like I was in danger at the playground. I was scared of other kids. At my school there were places with lots of rocks where the cool kids hung out. I didn't go out there. I stayed near the school. I escaped into books like **The Incredible Journey** by Sheila Burnford and **The Mouse and the Motorcycle** by Beverly Clearly. Each break I couldn't wait to go back into the school and the safety of my desk.

One day I went out to join the other kids at break. Three big girls came up to me. I'll call the three girls Piper, Phoebe and Paige. Piper was in charge of Phoebe and Paige. She was tall and had curly hair. Piper, Phoebe and Paige wanted to know why I had come out. Then bam! Piper pushed me down. I hurt my ankle when I fell. That evening my teacher called me at home. My teacher asked who had pushed me. I said Piper had pushed me. Piper got in trouble and went to the principal's office. I thought I was in danger. The next year all the kids were talking about how Piper wanted to hurt me. Piper didn't hurt me, but I can't forget how she

pushed me down. It is one of the times people have hurt me because of my disability.

All my teachers knew about my disability. But they didn't know about accommodations. Accommodation is changing things so someone with a disability can do the same things as everyone else. My parents and I also didn't know about accommodations. So I didn't know how to ask for help or say no. For example, one day in second grade my class walked to the library. I wasn't as fast as my class. Also, I had a hard time carrying my heavy books. Then, my arms stopped holding the books. The books fell to the floor. My class was gone, there was no one to help me. I went to the library without my books. This was normal for me. I didn't think about telling my parents how hard things were. I didn't ask for help or say no until I was older. No one thought that maybe someone could help me to go from room to room at school.

When I was young, sometimes my friends would tell me to walk more. They would cheer me on to walk more around the room. My friends thought walking more would make me stronger. My physical therapists also thought I should walk for as long as I could. Physical therapists are

people who treat you by having you move special ways when you're hurt or ill. I walked because if I didn't, people would think I was giving up. I walked because if I didn't, people would think I was a whiner and a bad patient. When I walked I was tired, in pain and angry. No one asked me if walking was worth being tired, in pain and angry.

Later I became weak. I needed something to hold onto to stand or walk. The physical therapist gave me a walker. I was supposed to use the walker to get around school. My legs were so tired when I pushed the walker. One step then another. I felt like a monster with the walker. It made squeaking noises that told everyone I was coming. I wish grown-up me could go back in time. If I could go back in time, I would tell my parents and my doctors, "I am so fucking tired, guys. I have tried my best to walk for you. But it just isn't worth it." No wonder I look so angry, sad and in pain in photos from my childhood.

When I was seven my body decided it was done walking. It said, "Okay, I'm done. I need a break. Walking is so 1981."

I started using a manual wheelchair. The wheelchair was easy to get in and out of our home. But then it became clear that I wasn't strong enough to push myself. I started using an electric wheelchair.

Using an electric wheelchair was pure happiness. I was a queen and the wheelchair was my throne that got me around. I was comfortable. Most importantly, I didn't need my parents or other people to move me around. I pushed the joystick, the little stick that moves the wheelchair, and I zoomed off, fast. I could move the way I wanted to for the first time. Non-disabled people might think it's terrible to use a wheelchair. For me, using a wheelchair was the next thing I needed to do to become a person who made decisions for myself.

My body changed. That meant I needed to change how I dealt with the places and people around me. But the places and people around me also had to change to deal with me. My parents built wooden ramps so I could get in and out of my home. Later my parents bought a van with a lift that would let me travel in my electric wheelchair with my family. Years later, my parents could pay to have a home built with ramps and bigger doors.

My family having money to spend on access meant I was part of my family and my community, and I had freedom.

There were lots of reasons to use an electric wheelchair. I could move fast around the house and the streets of my neighborhood. I never used the sidewalk. (Sidewalks are for suckers.) But there were lots of downsides. I couldn't pretend not to be disabled by sitting on a couch or leaning against a wall. People paid a lot of attention to me because I used a wheelchair. I learned that lots of people thought that walking is normal and that not walking is different and terrible. I felt like I wasn't as important as the other people around me when I couldn't get into a building because of steps or when I had to go around the back to the ramp. All these hard moments are common for anyone who is different.

People always paid attention to me as a kid. Sometimes that didn't make me feel good. I also learned I needed to be careful about how I talked to other people and treated them. There were very few Asian American kids at my school. I was the only student with a physical disability. I was always the only person like me or one of only a few like me.

In elementary I was the only kid who used a wheelchair. I didn't take the school bus. I took the "short bus," which was for students with disabilities. I got to school forty-five minutes early because my bus then had to go to the school for students with disabilities. I would get off the bus in the dark. Most of the teachers hadn't come to work yet. Sometimes I would sit in the room where we ate lunch, watching the sun come up and my classmates coming to school on "normal" yellow buses. Some days I would sneak into the classrooms. Sometimes I would look inside the desks. Looking in the desks wasn't a great thing to do, but I was bored as hell.

I think lots of people with disabilities feel like they can deal with the differences in their bodies and minds. I think lots of people with disabilities feel like they can deal with the ways the world around them isn't built for them. But what makes people with disabilities angry and tired is the way other people treat people with disabilities. People often say things that hurt you. People look at you or talk about you when you're out. Or sometimes people ignore me and talk to the person I'm with or ask if I'm with someone. That question means they think I can't be out alone.

Here are some of the comments I remember:

- How did you get like this?
- Were you in a car accident?
- Do you wish you could play sports?
- I'm praying for you. Jesus loves you!
- Do you know if you can be healed if you accept Jesus Christ as your personal savior?

The way I talked to these people changed because of how I felt each day. Sometimes I would be polite and not tell them they were wrong. Sometimes I would tell them how they were wrong and rude. Sometimes people were surprised when I told them they were wrong and rude. Those people thought that their way of thinking about disability was the only way of thinking.

Once I went to an Evangelical revival with Mom and her friend. Evangelicals are Christians who believe that they need to live their lives according to the rules in the Bible. They need to convince other people to be Evangelical Christians. A revival is a kind of church meeting where lots

of people come together to celebrate. My mom got a sense of community and energy from the church.

My Mom and her friend gave me a pack of gum to come with them to the revival. I was eight or nine. I was convinced by the pack of cherry gum. I got the entire pack of gum. I didn't have to share any of it with my sisters. Score!

At the revival there were a lot of people singing and dancing. The preacher talked about God. People prayed a lot. People even spoke in tongues, which means they felt God was around them so much that they made sounds that aren't a language. The end of the revival was a big deal. The preacher asked everyone if they wanted a blessing and chance to be made better by God. Mom took me to the stage. The preacher put his hand on my head and prayed. Someone moved the footrests on my wheelchair out of the way. The preacher held my hand and I stood up. I took a few steps. The crowd went wild. They yelled, "She has risen!"

I was everything they had ever believed in. They were so happy for me.

If I had gotten a chance to talk to the crowd I would have said this, “Hey! I use a wheelchair but I can take a step if someone helps me. Even though I use a wheelchair I can move my legs. Me standing isn’t a miracle!”

A miracle is when God makes something impossible happen. I don’t believe in miracles. I especially don’t believe in miracles that are about getting rid of my disability or making me walk. I tried really hard. Sometimes I hoped to get better. But it never worked. I could have been angry about what this preacher did. But mostly I was just confused.

Some Asian American people don’t let people with disabilities be part of our community. Some Asian Americans feel ashamed of people with disabilities. Sometimes people in my family’s Chinese American church in Indianapolis would ask my parents why they took me out. After church services on Sunday an auntie from China said to me, “Do you know how lucky you are to live in America, to have a wheelchair and a family who loves you?”

I was upset. That auntie thinks I should be thankful just for being alive. That auntie thinks that my Mom and Dad should have gotten rid of me

before I was born because I would make their lives hard. But I've also seen lots of Asian American families who love and support their family members with disabilities. My parents and sisters were never ashamed of me. I was part of all my family's important activities.

I became aware of the way the world is unfair to people with disabilities in my second year of high school. I took Drama I. To take Drama II next year, you need to pass Drama I. I got a B and I signed up for Drama II. When I met with the guidance counselor, the person who helps students plan their classes and what they'll do after they finish school, she was uncomfortable. She asked me to speak to the Drama II teacher. Ms. Tudor taught Drama II. Ms. Tudor explained to me that I couldn't take Drama II because you had to do pantomime. Pantomime is when you act out a story using your body and movement. I asked if I could do a pantomime of someone doing something I could do, like sitting down eating. She said I couldn't. She said I wouldn't move enough. She never thought that she could change the activity so I could do it. The guidance counselor agreed. I tried to argue with them and I failed.

It was discrimination. Discrimination is when people and the world is unfair to other people based on things they can't control, like their disability or their race or where they were born. I saw myself as someone who could do many things. Ms. Tudor looked at me and just saw how my body couldn't do all the things her other students could. This meant that I couldn't take drama with my friends. I still joined the drama club but it wasn't the same. I felt so unhappy. I thought teachers and people who work with young people would encourage young people. This was not the only time I experienced discrimination in high school. I regret not fighting back more. After Ms. Tudor told me I couldn't take Drama II, I decided I would never let anyone do that to me again.

I was angry and sad. So I went to the places where I felt good about myself. I went to the library during lunch. At the library I learned about all the people making disability culture in Berkley, California. I learned about the independent living movement. In the independent living movement people with disabilities told schools and governments that:

- They should have the same rights as everyone else.
- They should get to live where everyone else lives.
- They should do the things everyone else does.

I learned that disability was an important part of who I was. Disability was just as important to who I am as being Chinese American and female. I was part of a group of people who had similar experiences. Understanding that other disabled people had similar experiences to me helped me understand my experiences and how they made me feel.

I went to college in 1992. I learned about disability and how people think about disability and culture. I felt like other people thinking about disability were family. Paul Longmore, Irving K. Zola, Jenny Morris, Michael Oliver, Susan Wendell and other people all wrote things that completely changed how I thought about disability. They gave me new ways to think about my life. I felt hope because some of those writers were disabled like me and they did things I wanted to do. I was angry and tired when I was younger. I took that anger and turned it into writing and research about disability. It was the start of my journey in disability research and trying to make the world better for disabled people.

I’m going to stop remembering my life now. I want to say something to nine-year old me first:

Dear nine-year old me in the photo, I know you're tired. I know that life sucks a lot. I promise you, when you grow up you're going to have fun and do many exciting things. The world will change for you. Laws like the Americans with Disabilities Act and programs like Medicaid personal care services are going to let you live the way you want to live. You'll get to be in control. You'll have lots of choices. You are going to live in the best city in the world, San Francisco. You will drink so much good coffee. You will stay up all night, every night. You just need to keep going, keep reading. You need to stay angry.

Rest in Peace Meowmee

Plain Language Translation Note: This piece has a great photo of Meowmee. You might want to go look at it after you read this.

This is my cat Meowmee. In grade 7 a friend gave me Meowmee. Meowmee was a weirdo. He didn’t like people touching him. He never wanted to sit on my lap. Meowmee was also scared of the vacuum. For a special treat we would give him canned tuna, with the tuna water. On Thanksgiving Mom would give him liver from the roast duck or turkey. I never got another cat after Meowmee died because my entire family sneezes when they’re near cats. I still love cats, but I love them from a distance.

The Americans with Disabilities Act

An interview with Rochelle Kwan. The interview happened July 26, 2020.

Rochelle Kwan: I'm excited to talk with you because the Americans with Disabilities Act (ADA), is 30 years old today. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with disabilities. Accessible means that disabled people can get into a place, use a thing or enjoy an event.

Alice Wong: Yeah. I love that you're younger than the Americans with Disabilities Act.

Rochelle: I know!

Alice: I love that you're younger because it's funny. Should we call this a conversation between an older person and a younger person? I guess so.

So I'm really happy to talk to you about this. I was 16, in my second year of high school, when the Americans with Disabilities Act became law. I

don’t remember much about it. At that point in my life I didn’t think of my disability being something that I had in common with other people. I didn’t think that it was important to who I was. I knew I was disabled, but I never said the word disabled, you know. I had a really hard time. Being between 13 and 20 years old, no matter when you grow up, is hard. I didn’t like my body. I felt ashamed of myself. I would wish that I could be invisible. But when you use a wheelchair, everyone always looks at you.

I didn’t have anyone to model my life on. I didn’t know any adults in my life who had disabilities. No adult with disabilities ever said to me, “Hey, I know what you’re going through. It’s going to get better.” I also wonder if an adult with disabilities had said that to me, would I have been okay with that? Maybe I would have felt even more uncomfortable because I was so uncomfortable and so ashamed. I didn’t want to be around other disabled kids. Sometimes I didn’t hang out with other disabled kids because I wanted to be like everyone else.

Rochelle: Yeah, it sounds like you didn’t have disability community. When I say disability community I mean other disabled people around you to support you, teach you about being disabled and help you be proud of

yourself. Not only did you not have disability community but you didn't think that there were parts of your life that were shared by other disabled people. Before you realized you were a disabled person and there were other disabled people out there, did you think, I have to deal with this on my own?

Alice: Yeah. After the Americans with Disabilities Act was passed and I was a bit older I started reading and hearing more about disability. I realized there were people with disabilities doing things that were bigger than what was going on in my world. One of the first things I read was in **Time** magazine around the time the Americans with Disabilities Act was passed. The article was about accessible ways to get around. I was so wowed by the idea of an accessible bus. Back then, accessible buses were really rare. I thought, what would it be like to live somewhere where I could leave my house and take a bus or a train all by myself?

Back then, I lived on the edge of the city where there were a lot of houses. My parents drove me everywhere. I didn't know how to drive. To change a van so I could drive it would cost a lot of money. Lots of kids start to be adults when they start to drive. But I didn't get to start to be an

adult that way. I felt stuck. I was reading about places like Berkley, California, which was where a lot of disabled people who fought for their rights were. I was reading about how California was more accessible. I started thinking, wow, there's disabled people living in a place that's better and more accessible. Maybe one day I can live there too. I dreamed about living somewhere better and more accessible.

I wrote a letter to the person in charge of **Time** magazine. I was still in high school. Maybe that was the first time I thought of myself as disabled and as someone who wanted to change the world. I learned more and more as I went to college. I learned that there were people studying how people think about disability. I realized that all the work I was doing so I could have some of the things I wanted wasn't going to help other people. I wanted things to change for everyone, not just me. I realized I could get accessible housing for myself as a student. But until the university's rules changed another disabled student would have to do all that work too. I got angry. I started asking, "How can we do this? How can we make a difference? How can we work with other people?"

Because what I need is important but what other people need is also important.

Rochelle: When the Americans with Disabilities Act became law, did you imagine the Americans with Disabilities Act would change everything? Did you think the Americans with Disabilities Act would make things better for disabled people?

Alice: I think a lot of people don't really understand the Americans with Disabilities Act. I think people hoped it would change things for the better. But the Americans with Disabilities Act did not solve every problem. Especially in 1990 when it passed. It was a lot of years before we saw the changes it created. Things like dips in the sidewalk to make crossing the street easier. Not having just stairs to get in somewhere. These are all the things we should not have to worry about if they are there. But we still have to fight for them. The Americans with Disabilities Act is a law that is supposed to help the disability community. There were other laws before it, but the Americans with Disabilities Act was the first one people with disabilities could really use.

I think it’s a tool. It's a way to start change. But laws can only change so much. Sometimes more change happens because people believe in the purpose of the law. What does it mean for people with disabilities to belong in public like everyone else? How do we get everyone to believe that? I don’t think everyone believes that disabled people belong in public, even thirty years after the Americans with Disabilities Act became law. People don’t change their minds easily. There are a lot of people, especially people who have power, who are afraid of change. There’s also a lot of people who know how important it is for everyone to be part of the world. Disabled people know how important it is to be part of the world because in the past they’ve been hidden away and not been allowed to be part of society.

Rochelle: I’ve been thinking a lot about how we’re all at home because of COVID. Everyone is connecting and working from home the way that disabled people have been for a long time. Disabled people know a lot about making friends and finding support at a distance. Do people ever talk about how disabled people have been doing that for a long time?

Alice: Real talk. I find it funny, a little sad and a little happy that before COVID I couldn't go to conferences. Conferences are when people meet to talk about one subject. I would have needed to go to the conference on my computer. But now! People planning conferences are planning them so everyone goes to the conference through their computer.

Rochelle: Yeah.

Alice: So many disabled people have asked to work from home and were told no. Now so many people are working from home. I think that's really painful. There's still a lot of people with disabilities who would like to work but can't.

No law is perfect. There is no way to make people do what the Americans with Disabilities Act says they have to do. There's no one checking on companies. So disabled people have to ask the company or group for what they need. Maybe the company or group says yes, we need to do that for you. But the people at the company or group might still be angry with the disabled person who asked for what they need. So many disabled people are scared to ask for what they need because people

might get angry with them. I think that's why a lot of disabled people don't have jobs. And people who have a job and have a disability might not tell their company. Because they don't want to be different. I don't think anyone likes making a complaint or filing a lawsuit. Making a complaint or filing a lawsuit are both official ways of making sure that a company or a group have to deal with the problem. A complaint or a lawsuit is a way to change an unfair situation.

Rochelle: Mmm-hmmm.

Alice: If there's one thing I could say to people who are not disabled, it's that access is more than following the Americans with Disabilities Act. Access is something we can give, in one way or another, to one another. For example, if I say, "Hey Rochelle, can we talk later tonight instead of tomorrow morning? I've had a bad day. I'm tired."

Then you could say, "Hey, yeah. No problem." That's a form of access, right?

Rochelle: Do you have anything you want to say about the **Disability Visibility Project**? The **Disability Visibility Project** is the website you created and work you do to share disability culture? Do you want to say anything about how the **Disability Visibility Project** marks the Americans with Disabilities Act and how you want everyone to keep making things better for disabled people?

Alice: I'm really grateful for the last thirty years of the Americans with Disabilities Act being law. And I'm looking forward to the future. I want to dream about what might be possible. There's so much work to do. We're going to have to fight hard. There's so much that I want to change and so much I need to think about. But I also have so much hope.

It makes me so happy to see kids growing up knowing other disabled people. I get to welcome the next group of kids with disabilities into the world. That is magic. I know things are going to get better. Things are better now than they were thirty years ago. Everything is possible.

Letter to Time Magazine

Alice sent this letter to **Time Magazine** July 2, 1990.

I am 16 years old and I'm a disabled person. My friends can drive and I can't. I'm happy to know that disabled people will get to move around as they like. Maybe with this new law, people who control if other people get jobs will see that disabled people can do a lot of things. The people who think disabled people can only do a few things are the ones who really have limits on what they can do.

Alice Wong

Carmel, Indiana

Untitled High School Poem

Content Note: This piece talks about Alice's time in hospital, about having surgery (when doctors cut into you to try to help you get better), about the marks on her body from surgery and about how the hard things that happened in the hospital have stayed with her.

All responses to the world take place within our bodies. —GLORIA ANZALDÚA

Gloria Anzaldúa was someone who wrote poetry, thought deeply about the world and wrote her ideas down. This writing comes from a piece called **Speaking Across the Divide**. In it, she talks about how making new ideas and things starts in the body.

Which means:

Everything that happens to us happens to our body. So our body is how we understand the world.

When I was putting together this work I really wanted to share a poem from my school magazine. I wanted to show you the emo goth inside of me. Emo goth means a really emotional person who wears black clothes,

plays sad music and hangs out with other people who also wear black clothes and play sad music. I talked to the person who ran the library at my high school asking if they had the student magazine, **The Prerogative**, from 1991 or 1992. No luck. I also asked a teacher who taught at my high school in 1991 and 1992. No luck.

But, I remember three lines of a poem. Here they are:
I have a tube that feeds me
I have a tube that breathes me
Beeep!

You're supposed to understand that the beep is the sound of a heart monitor flatlining. Heart monitors show a flat line when people die. I ended the poem with death. Ugh. I was often really sad. I'm a bit ashamed of how I did my hair, how I dressed and what I wrote when I was a teenager. But I also think I understood a little bit about who I was going to be when I wrote that poem. Since I've grown up I've written and talked about disabled people as cyborgs, people who are part machine. I've also talked about disabled people as oracles, people who can see a little bit of the future.

The Prerogative shared two of my poems. But the poems almost didn't get into the magazine. I remember the second poem was about feeling angry for a long time and candy. I remember it had the word sucking. I don't remember anything else. Like I said, ugh. A student who worked on **The Prerogative** told me that the student in charge thought my poems were "too dark." The student in charge didn't want to share them. Some friends snuck my poems into the magazine. Thank you!

(I still write things that people think are 'too dark'.)

I think about the poem suggesting I'm a cyborg. I was already a cyborg in high school. I just didn't call myself a cyborg.

When I was fourteen I had severe scoliosis. Scoliosis is when your spine has big bends in it. My bends meant that my lungs didn't have a lot of room to move and breathe. I also tip to the right. When I was a kid and I walked it was wobbly and slow. When I started using a wheelchair I still tipped to the right. My spine bent because my back muscles couldn't hold

up my upper body. I tried a back brace. A brace is something hard you put around a body part to keep it in position. It was sweaty and miserable.

My bent back shows up in other ways. When I looked down at my legs they were not the same. Living and muscular dystrophy has shaped my body. I think of my body like an abstract sculpture. Abstract sculpture is art that doesn't look like something else. Abstract sculpture just makes you think and feel. I have lines that bend in on themselves, bumps and curves. I can move some of my body only a little bit. My muscles are weak. I feel a stretch in some parts of my body. I am great art. Great art comes at a great price.

My doctors wanted me to have surgery to make my spine straight when I was 12. The surgery would help me breathe and make me less tired. I was really scared of the surgery. My parents waited but when I was 13 they told me that if I waited any longer I couldn't have the surgery.

I went to Riley Hospital for Children in downtown Indianapolis. The hospital was beautiful. There were huge toy animals on every floor. It felt like a hotel, not a hospital. There were doors that opened without people

having to touch them and spaces my wheelchair could get into. Lots of colors on the walls. Ice-cream in the lunch room! Hospitals and doctors can make you upset. But I felt at home in hospitals. In hospitals no one was surprised by my wheelchair or how I looked, or that I needed help eating or using the bathroom.

I spent six weeks in the hospital after my surgery. I was mostly in the part of the hospital that looks after people who need a lot of medical support and are in a lot of danger of dying. The doctors probably had to work harder at my surgery because I had waited so long. My parents tell me that they can't remember but they think the surgery must have been complicated and dangerous. I was given gas to put me to sleep for the surgery. Because of my muscular dystrophy I needed a machine to breathe for me. When the doctors finished I couldn't breathe on my own. Doctors who know a lot about kids' breathing had to slowly help me breathe on my own again.

Thank you Dr. Kling, who did the surgery, Dr. Eigen, who had a plan for me to breathe on my own again and all the nurses who looked after me.

I was in a lot of pain. Stuff like water would start to fill up my lungs. I would hear crackles and gurgles and know that my lungs were getting full. I couldn't talk so I would buzz a nurse. The nurses would know what I needed. They put saline, water with salt, down my breathing tube. This loosened the stuff in my lungs. Then they would put a tube into my lungs and suck it all out. Sometimes the tube would poke me and I saw spots of blood in the stuff the nurses sucked up. But being able to breathe again was great.

I also had a tube that went through my nose to my stomach to feed me. I had to swallow the tube as a doctor stuck it in my nose. I had some bleeding inside of me and the doctor had to do surgery again. It was really hot in my room, which made me hate it. And I still got my period. I also got a yeast infection from all the pills I was taking. A yeast infection makes your genitals itch really badly. That was my summer vacation.

One of my parents was with me all the time. So my sisters Emily and Grace were mostly on their own. Families from our church brought Emily and Grace food. Emily and Grace spent most of the summer watching TV. They didn't have a good summer vacation either.

Mom and Dad also had a really hard summer. They were never upset around me or showed me that they were worried. They were always there for me. Mom sat with me. She helped the nurses. Mom was the first person who would notice when I was confused because I was breathing too much or too little oxygen. By being there all the time, my Mom and Dad were telling everyone who worked at the hospital that they were watching how the people who worked at the hospital treated me. Mom and Dad being there probably made the people who worked at the hospital treat me better.

Sometimes Mom would try to sleep in the parents' room. But one night her wallet was stolen. I hope the person who took it needed the money. Who would steal from tired parents of sick kids? I mean, really?

When I was ready to go home from the hospital, the doctors told me that my breathing had changed. The surgery had made the muscles that make my lungs move weak. I was going to need to do breathing work to help my lungs at home. I was also going to need intermittent positive pressure breathing, which means a machine pushes air into my lungs. It would

make my lungs get bigger and help me get medicine into my lungs. The doctors told me I would need to do this for the rest of my life. I cried. I cried because this was another big change in my life right after I stopped walking and started using a wheelchair. I also had to wear a thin tube under my nose at night. That thin tube gave me extra oxygen. Later, when I was eighteen I would start using a BiPap. A BiPap machine pushes air into my lungs and it also pulls the air out. I'm a cyborg because I use machines to breathe. When I started to use intermittent positive pressure breathing and then the BiPap machine both those moments were moments in my journey of becoming a cyborg.

I had to change or die. I was a cyborg. I had things inside my body the doctors put there. I had machines on my body all the time. I needed to figure shit out. There would be more shit to figure out in my twenties, thirties and forties as my body changed.

I don't regret waiting to have the surgery. I'm glad my parents let me be in control of that decision. But I didn't know that I wouldn't ever be the same as I was before the surgery. My body would just keep changing and I would need to change with it.

I have a lot of marks from that surgery and my time in the hospital. I don't forget they're there. There is a long mark down my back. The long mark down my back is spikey to touch. I can't feel the left part of my back and it's also itchy as hell. That's from where the tubes inside of me hurt my nerves. Nerves are the parts of your body that send your brain information about how your body feels. My right wrist has two dark marks. These are from the needle that was put in my wrist to take my blood during my time at the hospital. I was in the intensive care unit so long that the nurses needed to take out the first needle and put another needle in. Now, if I scratch or brush them it hurts. The marks have dry skin and I always want to pick it off. Everything I feel is information. Everything I feel tells me what I have survived. I may be old, but I have changed and made things work over the years.

The poems I wrote in high school were the first time I tried to understand what had happened to me during my surgery and time in the hospital. My mind was starting to understand what might be coming for me. Nora Shen, a family friend, recently found two copies of **The Fine Print**. **The Fine Print** was a college magazine at Indiana University while I was

there. Nora didn't know that I was writing about my life, or that I was writing this piece. The universe heard me and gave me some more of my angry sad poetry about becoming a cyborg. Even bad poetry can tell you about the future.

Plain Language Translation Note: Alice has two poems here. You can understand what a poem says, but poems are meant to be felt too. The poems are written out. First, I'll tell you a little bit about what each poem says. Then, you might want to try reading the poem to see how it makes you feel.

Hooked Up Online

(1995)

This poem is about being in the intensive care unit. Alice talks about all the tubes that take care of breathing, food and peeing for her. Alice thinks about all the stuff in her body moving around. She talks about the itching, the dirt, and sweat. All the tubes are working to take care of her body. At the same time the tubes hurt her body.

I have a tube that pees me

I have a tube that feeds me

I have a tube that breathes me

fluids dripping while others

swim in a raging torrent

urgently delivering goods

importing necessities

exporting wastes along these

worn down roads

no office left

unplugged

all functions hygienically

maintained

plastic wrapping

hermetically sealed

plastic straws

stick

rub

itch

the skin

sweat and dirt builds up around

the point of insertion

with a mound of ragged stained bandages

gauze and tape securing

the connections down

despite the incessant mosquito bite itch

tube upon tube,

intricate byways that laugh at nature

interconnecting, overlapping

the interstate of my body

Time Restrained

(1996)

In this poem Alice talks about the brace that was meant to stop her spine from bending more. She talks about herself as if she is the Statue of

Liberty. In the 1980s the Statue of Liberty was fixed. Workers had to put metal and wood around the Statue of Liberty to hold it up while it was fixed. Alice says her brace is like the wood and metal around the Statue of Liberty. Then Alice talks about how doctors used stuff that would dry hard to make a brace in the shape of her back. The doctors made the brace from the shape of her back and gave it to Alice. The poem ends with the image of Alice dead inside her brace as she sits in the sun during school.

a fiberglass corset
a hull with
foam padding
the brace was constructed to slow the curvature of the
        bones

pressure on the structure
weakens the stature
like the one for that lady in new york
hers was made of iron and steel
to hold up her bulk

even she had problems with posture

old men surrounding her in

her underwear

applying plaster and

creating a mold of a girl aged nine

now you won’t waddle like a duck

they said

when the orthotist presented her with this new appliance

now you’ll need to wear this every day

so it can hold you up

and give you balance

it’ll be part of your normal routine in no time

in no time

encased in this insulated shell is a soft mass of flesh

atrophied and decaying with

pockets of larvae wriggling for space

yearning to breathe

as the girl goes to school and sits

under the hot sun during recess

Did You Enjoy High School?

An interview with Anna Sale for the **Death, Sex & Money** podcast.

Shared on October 21, 2020.

Anna Sale: Did you enjoy high school?

Alice Wong: Oh gosh! Do you want the truth?

Anna: Yes!

[Anna and Alice laugh]

Alice: Do you want the truth? Okay. I am so glad you asked. I was so excited to leave Carmel High School. I was ready to leave as soon as I started high school.

[Anna laughs]

Alice: I knew life was going to be better when I went to college. Even when I was young I knew when I was angry. Knowing when I was angry was a helpful thing.

Anna: I love that. I love that. High school made you angry. You want to thank high school for helping you know when you were angry. Why were you angry? Did people push you around? Did you feel like no one could see you?

Alice: It's funny because no one could see me but also everyone looked at me at the same time. I was one of a few wheelchair users at my school. My locker was a desk in the office because I couldn't open any of the lockers. The people who worked at the school never thought about how that made me different from the other kids. And my bus dropped me off at my high school forty minutes before school started -

Anna: Oh!

Alice: Because that bus took disabled students to another school. The bus would drop me off. It was so early it would be dark. I would sit alone

and wait for everyone else to come to school. I'd go to the gym. They had a soda machine at the gym. I'd buy Mountain Dew and drink it. Mountain Dew was how I stayed awake. The person who taught drama decided I couldn't keep taking drama class. She made me so sad. I can tell you that story.

Anna: Yes, I want to hear about the person who taught drama. I love high school stories. [laughs]

Alice: I didn't know we were going to talk about high school. But I'm here for this.

[Anna laughs]

Alice: Talking about high school is a gift. It's a gift because I get to be salty. Salty means I get to share my anger with you and be a bit funny about it. Okay, so I love drama. I took Drama I which was taught by Ms. Tudor. I got a B. So I signed up for Drama II. Ms. Tudor called me after class. Ms. Tudor asked me to talk to the guidance counselor, who helped students plan which classes they took. This was because Ms. Tudor was

scared to be mean to me about my disability. She wanted the guidance counselor to be mean for her.

My guidance counselor told me that Ms. Tudor wasn't going to let me take Drama II. Ms. Tudor thought I couldn't do pantomime. Pantomime is when you act out a story using your body. Ms. Tudor assumed I couldn't do pantomime because I use a wheelchair! So I went to Ms. Tudor and I asked her to let me take Drama II. Ms. Tudor just shook her head and said, "I'm sorry, I don't think so."

Drama class was one of the things I liked. I passed the class before it. But Ms. Tudor thought I couldn't do it because of my disability. Ms. Tudor had no imagination. She was supposed to support young people. She was supposed to get the best out of young people. But Ms. Tudor just made me angry.

Anna: I'm curious. So you were angry. Did you tell people what had happened? That Ms. Tudor was unfair to you?

Alice: I told my friends and they all felt terrible. Now, 46 year-old me would take serious action. But when I was younger I felt so terrible about myself. Also, I didn't think any of the people who taught me would agree with me. I thought everyone would think Ms. Tudor was right to stop me from taking drama class. I didn't tell my parents. I wish I'd told my parents. But I didn't think my parents would think it was important when I had a lot of other things happening in my life. I understand that. I knew I was responsible for getting what I wanted. So I learned to -

Anna: Make a lot of trouble.

Alice: Later I learned to make a lot of trouble, yeah.

[Anna laughs]

Alice: Look at me now. Look at me now.

Activism

So much of the work of oppression is about policing the imagination. —SAIDIYA HARTMAN.

Saidiya Hartman is a Black writer and professor. She writes about how slavery shaped Black people's lives today.

Which means:

One of the ways people keep the world unfair and stop justice is by stopping people from thinking up new ways the world can work.

You have to act as if it were possible to radically transform the world. And you have to do it all the time. —ANGELA Y. DAVIS.

Angela Davis is a Black writer and professor. She writes a lot about how important it is to get rid of prisons.

Which means:

You have to act as if it’s possible to change the world in big ways. You have to act that way all the time.

My Medicaid, My Life

Shared in **The New York Times** on May 3, 2017.

I am a Medicaid moocher. Moocher is the word that Republicans use to talk about people who get money from programs like Medicaid, Social Security and food stamps. Programs are things governments and groups do for a reason, to make something happen. Republicans use moocher to suggest that people like me get a lot of money we shouldn't have. Republicans suggest that people like me take money away from people who work hard.

But being a disabled person who has Medicaid is really complicated. Most people don't even know there's a difference between Medicaid and Medicare. Lots of people don't think about all the money that the government gives to big companies and rich people through tax cuts and subsidies. A subsidy is money the government gives companies to keep the things the companies sell cheap. Lots of people don't know that Medicaid is more than a health care program. Medicaid is a life-giving program.

I'm an Asian-American woman with a disability. I'm the daughter of people who came to America from China. When I turned eighteen my dad told me I needed to apply for Medicaid. I lived in a part of Indianapolis where people had more money than most people. I was upset with my dad. I thought Medicaid wasn't for me because I wasn't poor. My dad told me that my parents paid a lot of money for my health care. Only one company in our state would give them health insurance. Health insurance is when you pay a company money every month so when you need medical care the company will pay for most of the medical care. My parents didn't have a choice of health insurance because I have a type of muscular dystrophy. Muscular dystrophy is a condition where your muscles get weak over time. I had no idea that my parents had been working so hard to get basic health insurance because of my disability.

I finished high school in 1992. The Americans with Disabilities Act became law in 1990. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with disabilities. Accessible means that disabled people can get into a place, use a thing or enjoy an event. I learned about disability history. I realized I was part of a group of people who the world

treated unfairly. I was also part of a group of people who fight to be treated fairly. I started to imagine and create the life I wanted. I realized I had a right to Medicaid and applied for it.

I began to receive help for several hours a week. People paid by Medicaid would help me with things I needed to do everyday like washing and getting dressed. I went away to college and could live on my own for the first time. It was freedom. That freedom let me imagine more freedom. Before Medicaid, my family, including my sisters, cared for me. My family helped me take a bath, dress and go to the bathroom. With Medicaid I had choices and could make my own decisions.

The year after I went to college, the government of Indiana gave less money to Medicaid. I got fewer hours of help. My family couldn’t pay for me to go to college and pay for people to help me live on my own. I had to leave college and move back home.

I went to a college near my house. I kept learning. I learned about how disabled people fought so governments would offer disabled people support. I learned about how disabled people fought for a more

accessible world. I moved to San Francisco for school in the late 1990s. California has support for disabled people that lets disabled people decide how they want to be helped. In California I could hire and train the people helping me. The program that let me do this is called In-Home Supportive Services (I.H.S.S.). Without this program I would not have been able to go to school, or work or have fun.

But it's not fun or easy to get Medicaid. I have to follow strict rules. I've been able to work because of a program called Medicaid Working Disabled Program. This program lets me still use Medicaid, but I have to pay a little bit for Medicaid. Over time, my disability made me weaker. I needed a lot more care. If I didn't have people helping me in my home I would have had to move into a hospital or nursing home. I got more hours of help through Medicaid so I could stay in my community. Staying in my home also means I save money for the California government.

When you are disabled and you need government help, you never feel safe. I feel danger in my bones. I feel danger every time I have to deal with the government. Changes in how much money the government has and who is in charge of the government decide important things for me.

Those important things are if the people helping me will be fairly paid and if I'll get enough hours of help. I can deal with my body. I'm not afraid of my body. I'm afraid of how the government will change the programs I need to live.

The Republicans didn't replace the Affordable Care Act. But the Republicans attack poor, disabled, sick and older people. The Centers for Medicaid and Medicare give lots of people in the United States health insurance through lots of different programs. The Centers for Medicaid and Medicare can also change the kinds of medical services and help people can get. State governments can ask for money from the national government saying it's for Medicaid and Medicare and then not spend that money on Medicaid or Medicare.

"Program flexibility" are words people use when they want to get rid of Medicaid. Getting rid of Medicaid will put me and people like me in danger. Some people with disabilities will have to go back to living in hospitals and nursing homes if this happens. People with disabilities do not want to go back to being trapped in hospitals. Republicans talk about

freedom and choice. Republicans don’t realize that Medicaid gives freedom and choice to people with disabilities.

Medicaid has been giving me support for 25 years. When I was younger I was ashamed and embarrassed to be “on benefits.” Being on benefits means I get money from the government because I am disabled. Today I am not ashamed to be disabled. I am part of the world and I do good work for the world. I could not do this without Medicaid.

Every day, people say that I’m a problem or that I’m responsible for problems in the world. With other people with disabilities I share my story and I talk back to people who want us not to have a future. I hope my story and my life will continue for a long time.

The Politics of Change by Lizartistry

This piece was shared at 2019 Autistic Self-Advocacy Network Annual Gala.

Plain Language Translation Note: This piece is a beautiful image by Lizartistry[2]. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

I find purpose for my life in change. I think of change as an art that I need to practice.

When I was a baby, I was not an activist. An activist is someone who works and fights with other people to change the world. We all have to start somewhere. We can all do things that can change the world for the better. There are a lot of different things that can change the world for the better. I was a disabled baby in a world made for non-disabled people. I had to ask and argue for the things I needed to survive. When I was a young person I realized I didn't just want things to change for me. I

[2] If you want to see more of Lizartistry's work you can visit this website here.

wanted things to change for everyone. I wanted the way the world works to change to get better for disabled people.

It took me a long time to think of myself as an activist. I didn't think of myself as an activist because a lot of people think activists have to do things that I couldn't do because of my disability. Thinking you can only change the world by standing outside important places and yelling really loud, is unfair to disabled people. It's unfair because disabled people work to change the world in a lot of other ways.

I want disabled people to change the world for us.

Here are some ways we can change the world:

- Civic Participation: Civic participation means when you work with your local, state or national government. This could mean:
    - Voting.
    - Helping someone you believe in run for office.
    - Writing letters to your politicians.
    - Working with other people to tell politicians what's important to you.

- Mentorship: Mentorship is when people share their skills, knowledge and resources with other people.
- Experimentation: Experimentation means that you try things and see if they work.
- Collaboration: Collaboration is when people work together to make change happen.
- Social Media: Social media is when people create and share on places like Twitter, Facebook and Tik Tok. People also use social media to make friends and form relationships.
- Boundaries: Boundaries are rules people have so that they can be well and happy.
- Practice: Practice is when we do something again and again so we get better at something we want to get better at doing.

People are different from each other. We should be happy that people are different. Difference creates good change. Difference creates beauty.

Here are some questions I have:

- How do we treat everyone with the importance they deserve?
- How do we stop asking people doing activism to do so much work?

- Activists know things that are hard to learn. How do we respect activists' knowledge and time?
- How do we welcome people who are disabled but don't think of themselves as part of disability community? By disability community I mean other disabled people around you to support you, teach you about being disabled and help you be proud of yourself.
- How do we help and learn from other people who are working to make a better world?
- How do we change people's ideas about who is an activist and what activists do?

Snack Manifesto

Plain Language Translation Note: This piece is a beautiful image. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

Snacks are little bits of food. Snacking is eating little bits of food.

Snacking is good.

Snacking often is better.

Sharing snacks is a way of showing love.

Snacks help me be an activist. An activist is someone who works and fights with other people to change the world.

Snacks aren’t bad for you. You should eat whatever makes you feel good!

You shouldn’t eat snacks you don’t like.

You need snacks to live. You also need rest to live.

Rest and snack when you can. There will be rough times when you can’t rest or snack.

The Olmstead Decision and Me

This piece was shared on the **Disability Visibility Project** blog on June 27, 2019.

I want to take a moment to think about all the people who lived and died trapped in hospitals. We will never know the names or the stories of everyone who lived and died trapped in hospitals.

I want to take a moment to think about all the people who are trapped in hospitals right now. The people trapped in hospitals right now are in danger of being hurt and forgotten.

I want to take a moment to think about the people who have to fight to live in their community, who wouldn't have to fight if they had more support. I want to think about the people who are waiting for help from other people, money and places to live.

I have never been trapped in a hospital. But I am at risk of being trapped in a hospital. I am someone who needs a lot of care, help from other people, to live my life. Everyday someone helps me get out of bed.

Someone helps me get dressed. Someone helps me with almost every part of my day.

The 1999 Olmstead decision was a decision made by the judges on the Supreme Court. The Supreme Court decides on laws for all of the United States. The judges said that governments couldn't make people with disabilities live in hospitals. Governments couldn't give people with disabilities the support they needed only in hospitals or nursing homes. People with disabilities had a right to live in their community with everyone else. The 1999 Olmstead decision was important to my life because I use two programs:

- Medicaid Home and Community-Based Services (H.C.B.S)
- In-Home Supportive Services (I.H.S.S)

These two programs give me the care and support I need to live in my community and not in a hospital.

I am so thankful for everyone with a disability who has worked for better lives for people with disabilities since the Americans with Disabilities Act and the Olmstead decisions. I am grateful to Lois Curtis and Elaine

Wilson. Lois Curtis and Elaine Wilson were the people who were hurt by being kept out of their community and took legal action to right that wrong. Their legal action is a case called Olmstead v. L.C. 527 U.S. 581. The decision the judge made in that case is called the Olmstead decision.

I am also very angry at politicians who try to take money away from the programs that help me and a lot of other people live. Programs are things governments do for a reason or to help change something.

So I'm going to be real with y'all.

I have the help that I need to live day to day. But every day is still a lot of work. I am scared because I know if one thing goes wrong in my life I'll have to live in a hospital or nursing home. If one thing in the government changes then I'll have to live in a hospital or nursing home.

A lot of disabled people are in the same position as I am. They're also scared.

I’m also scared because the programs are set up to make me scared. Here are some of the ways the programs I need to live scare me:

- I have to do a lot of work to keep getting the support I need.
- I have to talk to a social worker every six months and tell them how I’m dealing with my medical condition. I have to do this to stay on Medi-Cal, which is California’s Medicaid.
- I always have to show social workers that I need the help I get. There’s a lot of paper to fill out.
- The government wants me to be poor. I can only have $2000 dollars in savings. I live in my community but I’m not the same as the people around me.
- I can’t save for the future or plan my life like non-disabled people.

All of this makes me really scared. It’s even scarier when my papers get mixed up. Or the people who work for the government are slow to look at my papers. Some years, the people who work for the government want to see my medical history. I am so scared when I have to find this information, put it in the computer, and send it to the people who work for the government. I can never stop doing this. It never ends.

The judge who made the Olmstead decision thought that disabled people should live in their communities and have the same rights as non-disabled people. There's still a lot of things that need to change before that is true.

Here are some of the things that need to change:

- Disabled people can't move from state to state. This is because states give disabled people different kinds of help. Some states have less money to support disabled people than other states. So if you need one type of help to live you have to stay in a state that will give that to you.
- All states that get money from Medicaid from the federal government have to care for disabled people in a hospital or a nursing home. But states get to decide if they accept money to care for disabled people in the community through H.C.B.S.
- Some people hire disabled people and pay disabled people less than non-disabled people. It's legal to only pay disabled people $1 or $2 an hour.
- Politicians can change how much support people get. For example, Anna Landre is a student at Georgetown. She almost had to drop out because the State of New Jersey decided that she only got 10

hours of help a day and not 16 hours. She had to fight hard. She had to talk about her experiences on Twitter. She got to keep 16 hours of help a day but it took a lot of work. There are a lot of people like Anna who just want to live their lives and follow their dreams. They don't want to have to fight the government to just live their lives.

These are all barriers rooted in ableism. Ableism is the way the world is set up to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[3]. Part of ableism is when people think that disabled people:

- Can't make their own decisions.
- Can't decide how they need help.
- Don't deserve the same rights as other people. These rights can be the right to marry, get a job and go to school.

[3] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

Another part of living in the community is getting involved in government. We don't talk about how disabled people are stopped from getting involved in government. For example, not as many disabled people vote as non-disabled people. But it isn't just about voting. It's about disabled people feeling like they're an important part of their community. It's about disabled people being able to be involved in local government and community groups. It's about disabled people being able to ask their government to take action about things disabled people care about. But a report by the Miami Lighthouse for the Blind and Visually Impaired found that Blind people couldn't access any of the web pages for the people running for president in 2020. Yeah, that's right. How basic can you get?

People sometimes say to me, "Alice you're so amazing."

I say, "Yeah, yeah, yeah, whateves."

Then I roll my eyes. But you know what? I want people not to be surprised that I'm in the same space as them. But people are surprised because so many disabled people are kept out of their community and out of government and community groups. People are still surprised that

disabled people have children, or jobs, or are good at doing things or take risks. That's a problem. That's why making sure that everyone can see disabled people do great things and day to day things is so important to me.

What does living in my community look like to me? Well, I want to be able to eat ice cream for dinner if I want. I want to stay up to 4:00am and watch Netflix for hours and hours (I do this a lot). It's my life! That's community living. When disabled people can live the lives they truly want. And until every disabled person can live the life they truly want the fight is not over.

Hashtag Activism and #CripTheVote by Lizartistry

Plain Language Translation Note: This piece is a beautiful image by Lizartistry[4]. Here is the plain language translation of the words in the image. I've also put in a few words here and there to make some ideas clear if you aren't looking at the image. But you might want to look at the original picture too.

Alice says, "Social media saved my life." Social media is when people create and share on places like Twitter, Facebook and Tik Tok. People also use social media to make friends and form relationships.

Hashtag activism is when people work together to create change by sharing on social media. If a lot of people share on social media about one problem, lots of people learn about it. A hashtag is this: **#**, followed by some words. Using the same hashtag means that people who are on social media can see that a lot of people are talking about the same thing.

[4] If you want to see more of Lizartistry's work you can visit this website here.

Moya Bailey is an African American professor. She has studied how activism on social media works. She says that hashtag activism is, “a tool that helps organize what’s already happening on the ground.” This means that people talk to each other on the internet about changes they’re making off the internet.

Working with other people to change things online is just as real and important as activism that happens by lots of people showing up at one place. A lot of different people can be activists on social media, even if they can’t do the kind of activism where you show up with a lot of people at one place. Activism on social media brings people together. Activism on social media works well for a lot of people.

Activism belongs to everyone. Activism takes place everywhere.

Every issue is a disability issue.

Disabled people know a lot and know things that other people don’t.

Disabled people belong everywhere. Disabled people deserve to see themselves everywhere.

Andrew Pulrang, Gregg Beratan and Alice Wong made #CripTheVote.

#CripTheVote is a hashtag. It's also a lot of people coming together on the internet to get disabled people excited about being involved in politics. #CripTheVote also wants to get politicians excited to talk to disabled people. It is non-partisan which means that Andrew, Gregg and Alice don’t use #CripTheVote to ask people to vote for any politician or political party.

From 2016 - 2022 #CripTheVote had 64 live tweet events, Twitter chats and Twitter town halls with people running for political office.

An example of online activism:
In the image there’s a phone that says:

- Archived Chat.
- 302 Tweets.

- Sins Invalid (a disability justice and disability arts group in the Bay area).
- The pandemic is making things worse for people who were treated badly before the pandemic. Disabled people of color often don't get the care they need from doctors, nurses and other people in the medical system. The pandemic is making this worse. #CripTheVote

Tips For Making a HashTag

- You don't know what will happen with the hashtag
- Going viral, which means lots and lots of people use the hashtag, is not always as great as it sounds
- You can't control how other people use the hashtag you started
- Have fun! Make hashtags that mean something to you!

#CripTheVote Then and Now

This is a discussion with Andrew Pulrang and Gregg Beratan on the **Disability Visibility Podcast**. There were two discussions. One was on September 13, 2017 and one was on March 21, 2021. There's a line of periods between the two discussions. Like this: …….

Alice Wong: Hey there. Welcome to the very first episode of the Disability Visibility podcast. The podcast will have discussions about:

- How the world should be different to support disabled people
- Art that disabled people are making
- How disabled people think about the world
- How the world thinks about disabled people and how that should change

I'm Alice Wong. I'll be the podcast host, the person who is almost always on and who will talk to guests.

There's lots of podcasts out there. So why have another podcast? Why do it now? I'm doing this because I don't see shows about disability culture and politics. N.P.R. doesn't have them, other media groups don't have

them. So I'm going to do it. The new way of doing things is here. We're going to change things one podcast at a time. We'll change things one transcript, which is where you write out what people say on a podcast, at a time. And we'll change things one tweet at a time.

Today I'm talking to Andrew Pulrang and Gregg Beratan. The three of us work together on **#**CripTheVote. **#**CripTheVote brings people together on the internet. People come together to get disabled people excited about getting involved in politics. We also want to get politicians excited to talk to disabled people.

We made this episode in July 2017. We made it just days after the Senate voted that the Republican health care bill shouldn't become law. We're going to talk about:

- All the things people have tried to get rid of the Affordable Care Act.
- What Medicaid means to disabled people.
- All the work disabled people did to make sure the Republican health care bill didn't become law.

I'll explain those things in a moment.

So let's talk about disabled people trying to change things in 2017. Let's talk about the Republican health care bill. The Republican health care bill has been known by a lot of different names. First it was the American Health Care Act. Then people started calling it the Better Care Reconciliation Act. The Republican health care bill would have meant that poor and middle class people couldn't get health insurance. Health insurance is when you pay a company money every month so when you need medical care the company will pay for most of the medical care. It would have also meant that people with lots of money paid less in taxes. Two days ago the Senate decided this bill shouldn't be law.

Gregg, Andrew, how do you feel about the Republican health care bill?

Gregg: Can I start by saying that I hope the Republicans don't try to make it law again?

Alice: Yeah!

[Gregg laughs]

Andrew: I agree! I think the Republicans will try to make it law again though. I think we'll have to fight against it again in the future.

Alice: We also have to remember that laws aren't the only way that politicians try to get rid of Medicaid or other programs that support people. The Centers for Medicare and Medicaid Services are the people who manage and run things like Medicaid. Medicare gives health insurance to:

- People who are over 65.
- Younger people with disabilities.

Medicaid gives health insurance to:

- People with disabilities.
- People who don't make a lot of money.
- Pregnant people.
- Older people.

The people who work at the Centers for Medicare and Medicaid can make lots of changes that would be very bad for people who use Medicare and Medicaid. So we have to watch them. Right now lots of people are talking

about Medicaid and how they use Medicaid and how Medicaid lets them live their lives. I think people will still need to share stories about Medicaid for another four years. But hopefully they won't have to share those stories as much after four years. But I think all the people sharing their stories about what Medicaid does for them has given non-disabled people some understanding of what Medicaid is, what it does and how many people it helps.

Andrew: I agree. Six months ago I didn't think there could be as much support for Medicaid as there is right now. I didn't think as many disabled people would support Medicaid. I didn't think as many non-disabled people would support Medicaid. I think lots of people have realized that Medicaid is a thing people like. Medicaid isn't something that people pay a lot of money for and that no one likes. People really like it. People are grateful for it. Of course there are things people want to change about Medicaid. But most people who are on Medicaid are pretty happy with it.

And half the reason people don't like the Health Insurance Marketplace is because they would rather have Medicaid. The Health Insurance Marketplace is run by state governments. It helps people find health

insurance plans. People feel like they pay a lot more for insurance plans they found through the Health Insurance Marketplace and they don't get as much medical care as if they were on Medicaid.

Alice: Also, lots of people are happy to have Medicaid because they know people who can't get insurance because they're sick or disabled. We live in a country where some people can't get health care. So we're grateful for Medicaid because not everyone can get insurance. I'm really grateful for these stories about how Medicaid helped people in school. People didn't realize that people other than poor and disabled people used Medicaid.

Andrew: Right.

Alice: I think people realized that people use Medicaid when they get older. Or kids need access to the services Medicaid gives in school. Non-disabled people realized lots of people use Medicaid. Now more non-disabled people are involved in fighting for Medicaid.

Gregg: Yeah. Seeing people realize that Medicaid helps a lot of people has made me really happy. People are able to work, live, raise their families, go to school, and give birth because of Medicaid. I think this helped people understand how great Medicaid is. Disabled people don't like a lot of things about Medicaid. Disabled people have talked a lot about the problems with Medicaid. But no one disabled wanted to get rid of Medicaid.

Andrew: The Republicans made a mistake thinking that people saying what they don't like about Medicaid meant they could get rid of Medicaid. They can't - we won't let them. Hopefully.

Alice: Right, Republicans wanted to get rid of it and not give us another program that would do the same thing. People got worried when they understood that Republicans wanted to get rid of Medicaid.

Gregg: I think Republicans want to serve one set of people and not everyone they're supposed to serve. That's not a good plan.

Alice: Look at Senator Mitch McConnell. Senator Mitch McConnell is supposed to serve the people of Kentucky. So many people in Kentucky need Medicaid. But McConnell wasn't thinking about them when he wanted to get rid of Medicaid.

Gregg: Yes.

Andrew: It's really complicated. Some people really need Medicaid and other support systems. But other people really don't like people who need Medicaid and other support systems. So in Kentucky, people complain about their neighbors being on Medicaid. These people think people get support through Medicaid that they shouldn't. They talk about how they don't like that people are on Medicaid. So politicians hear this and they think, okay, the people I serve don't like Medicaid. But the politicians don't hear from people who need Medicaid. And really, if the people talking about how they don't like people being on Medicaid thought about it again they would probably support Medicaid.

Alice: Those people complaining aren't just in Kentucky. They're not just in the south. They're everywhere. And often they're on insurance that gets

money from the Affordable Care Act. The Affordable Care Act was brought in by President Obama. Its goal is to make sure that no one goes without health insurance because it costs too much.

Gregg: I think people are starting to realize they're on insurance that gets money from the Affordable Care Act though. People are starting to realize that people they know need Medicaid all across the country. That's why people showed up to protest, stand outside of government buildings to make their feelings clear, in thirty different cities.

Andrew: That's fantastic.

Gregg: Isn't it?

Alice: There's still work to be done. All three of us are on Twitter. We see people saying ableist things about Trump. Saying ableist things means saying that disabled people aren't important or good people. Sometimes people don't say this directly. So a lot of the ableist things that were said about Trump were people saying that maybe Trump has a disability and that's a bad thing. That's not okay and shows how far we need to go. And

a lot of disability activism isn’t about big issues that would change things for a lot of people. It’s about what one person needs, not changing things for everyone.

Gregg: We’ve gotten to see some change. **#**CripTheVote could have become people talking on Twitter about which politician they’ll vote for. But the disability community made sure it was about the issues. The talks we had on twitter were never about people or about parties. It was always about how the changes politicians wanted to make would change things for the disability community.

Alice: #CripTheVote has been around for a year and a half. We’ve been doing this since July 2017. We had planned to stop after Election Day in November. I’m so glad we didn’t. **#**CripTheVote isn't just about votes, it's about disabled people being involved in the political process. It’s also about having a space to discuss the issues that will change things for disabled people.

#CripTheVote mostly happens on Twitter. Once a month we talk on Twitter about a disability issue.

Andrew and Gregg, what are some things you remember from our last four **#**CripTheVote chats?

Andrew: I don't remember anything clearly. But I remember that we're talking about issues that other people aren't talking about anymore. We take a little bit of time each month to talk about things people would have forgotten about. I think that's really important. Lots of the issues that matter to disabled people aren't issues that lots of people are talking about right now. But they're still important.

Gregg: I remember the chat we did about how people who report on stories talk about disabled people and disabled people's issues. I was surprised when I saw how many people wanted to talk about that. People were really frustrated and they finally got to talk about that.

Alice: I felt that way when we talked about the death penalty. The death penalty is when the government kills someone because a jury, a group of people, decide they're guilty of doing something wrong. But sometimes juries are wrong. And a lot of the people who are killed by the government

are people with disabilities. I am really surprised that death penalty issues aren't really important to the disability community.

Andrew: A lot of people are changing their thinking about disability. People thought disability is a pretty simple issue and now people realize that disability is related to a lot of different issues.

Alice: There's so many things to think about around race, class and disability. I think this is another thing we could do with #CripTheVote. We could look at issues that don't seem like disability issues and say, yes those are our issues.

……

Alice: Welcome Andrew and Gregg. We're talking again in 2021 on one of my last podcast episodes. We started **#**CripTheVote in 2016. Have politicians changed how they talk about disability since then?

Gregg: I think when we started in 2016 disability was a tick box. A tick box means that politicians had to mention it, but they didn't really need to know anything about disability. Politicians didn't need to make promises

about disability issues. Politicians talked about disability to show people that they were good people.

Things started to change in the 2018 midterms. Midterms are elections that are held half way through a president's time in office. In midterm elections, people vote on who will hold all of the 435 seats in the House of Representatives. People also vote on who will hold 33 or 34 of the seats in the Senate.

But in 2020 some of the people running for president started to take the disability community very seriously. The politicians were making plans that really gave disabled people what they needed. They were well thought out. Like some politicians were talking about Language Equality and Acquisition for Deaf Kids. Language Equality and Acquisition for Deaf Kids is a plan to support parents of Deaf kids and Deaf kids learning American Sign Language as early as possible. Lots of Deaf and disabled people care about Language Equality and Acquisition for Deaf Kids, but it's not a plan that a lot of other people know about. So seeing politicians talk about that was amazing. I don't think that would have happened four years ago. I think there's a slow change we're seeing.

In the 2018 midterm elections we saw people asking politicians what the politicians thought about particular issues. I don't think politicians had been asked about disability issues by so many people before. Then in 2020 politicians came out with well thought out disability plans. Joe Biden came out with his plan later than everyone else. And lots of disabled people were disappointed in that. But in 2016, Biden's plan would have been the best plan. I like watching politicians and the public change their minds about what's important.

Alice: Yes, and I've really noticed that there's more disabled people working with politicians and helping politicians make these platforms and policies. Molly Doris-Pierce worked on Senator Warren's campaign. Now she works for Joe Biden. Emily Voorde worked on Pete Buttigieg's campaign to be president. Lots of disabled people have been talking to politicians and sharing what they know. Disabled people have been doing that for years. Andrew, what do you think?

Andrew: I think it's hard to know exactly what kind of change we made. Maybe Alice is right and we didn't make all of the changes. I think we

were a way to change the ways politicians think and talk about disability that no one planned for.

One thing I do want to say is that a lot of disabled people loved some of the things that politicians were saying and thinking about disability. But there were also a lot disabled people who thought politicians got things wrong and said so. You could tell that some politicians thought they were going to get told they were doing well and were surprised when people didn't think they did well. That's a really good thing. It's easy for people to agree over meaningless feelings. It's easy to agree with politicians saying, "I support the disabled."

It's not easy to agree about a clear and thought out plan.

Alice: What are some of the things you're interested in now that Biden is the president?

Andrew: I have four main things I'm interested in:

1. Who will Biden hire to address disability issues?

2. How will Biden address all the changes caused by COVID? Will he address those changes in ways that mean disabled people's lives aren't made harder?
3. President Trump changed a lot of things in ways that were really bad for the disability community. Will Biden change them back?
4. Will Biden address some of the big disability issues, where if new rules and ways of doing things were put in place, disabled people would have a much better time of it?

I think of specific things like Social Security and Supplemental Security Income and Social Security Disability Insurance. How those programs work with Medicare and Medicaid and working a paid job. What if more people with disabilities could work while getting support from Medicaid? People with disabilities have been asking for that to change for forever. Now, finally politicians are starting to listen and there's hope of changing that.

Changing that system may take a really long time. It's really hard to change the rules around Social Security. And then there are the ongoing

problems with people getting care in their homes so they don't have to move into nursing homes or long term care and out of their community.

Gregg: All of those things are on my list of things I hope President Biden deals with. Making sure people can get care in their community and keep living in their home is really important to me. The pandemic has made it really clear that there's lots of problems with nursing homes and long term care. We have to fight one at a time to get people into the community. People with disabilities who want to stay in their community have to go to court to do that. But what if staying in your community was what usually happens? We need a system that makes sure that anyone who wants community or home based care can get that. People live better lives in their community than in nursing homes. I'd love to see a politician recognize that.

I'd love to see things change around health care. I don't think President Biden will do that. But there's a bill in New York, the New York Heath, that is a great model. It's a Medicare for All bill that has rules about long-term care. It would give more people access to home and community based

support. It would assume that people want home and community support instead of moving to a nursing home. I want more of that from politicians.

I don't think that Biden will do a lot on disability issues. Biden didn't think disabled people were all that important when he was running for president. We had to ask him and his team for a disability plan again and again. The plan they put out was good. I don't want to say the plan isn't good. I just don't think Biden and his team care about us. There's only so many things a president can do the first four years. I don't think Biden is going to see disability issues as important enough. I hope I'm wrong. And I hope we'll keep pushing Biden and his team to talk to and make change for the disability community.

Alice: With that I want to say thank you. Greg and Andrew, you've been great to work with on this project for the last four years. And you're great friends. Thank you Gregg, thank you Andrew.

Gregg: Thank you Alice, it's been great.

Andrew: It’s been one of the best things in my life. Especially the last few years. And one day we’ll meet in person.

Alice: Yeah! If not 2021, then 2022.

Andrew: There you go.

Inclusive Politics and the Disability Community by Lizartistry

Plain Language Translation Note: This piece is a beautiful image by Lizartistry[5]. Here is the plain language translation of the words in the image. I've also put in a few words here and there to make some ideas clear if you can't look at the image. But you might want to look at the original picture too.

I gotta say, I am angry as fuck. People talk about inclusive politics, which means making sure everyone whose life is changed by an issue should have a say. Inclusive politics can also mean that people should think about how an issue changes things for a wide range of people. But in my opinion, when people talk about inclusive politics, often they don't mean it.

Here's a letter to progressives. Progressives are people who want the world to get better over time. Progressives especially want the world to get better for people the world is particularly unfair to, like Indigenous people, Black people, Asian people, people of colour, disabled people,

[5] If you want to see more of Lizartistry's work you can visit this website here.

trans and two spirited people, poor people and lesbian, gay, bisexual, queer, pan, asexual, aromantic and questioning people.

Dear Progressives,

Make your shit accessible.

Some ways to do that are plain language, image descriptions, transcripts and live captions. Plain language is when you write things in a way that people can understand the first time they read it. Image descriptions are when you write out what a picture looks like. Transcripts are when you write out what people say. Live captions are when someone writes what people say as they say it.

Disabled people are people you should be thinking about when you're working to bring a lot of people who have had very different lives together.

Disabled people want you to talk to us about what we need and pay attention to us.

You can build and change things with disabled people.

Every issue is a disability issue.

Don’t be angry because you did something wrong, learn and grow and heal the relationship.

If you don’t know how to make things accessible or you don’t know how issues affect disabled people, then hire disabled people to help you.

Learn new ways of thinking about disability. Most of you think disability is not normal and something you don’t need to care about. These ways of thinking are ableism.

And now for some hot disabled sparkles. Hot disabled sparkles are the ways the disabled people can make your life and everyone’s lives better:

- We know that inter-dependence is a strength. Inter-dependence is the way that we are all connected. We all need and help each other to survive and be happy.

- We know a lot about how government systems and organizations work because we have to deal with them all the time.
- We are creative as hell. We have to make new ways of doing things all the time because the world was not built for us.
- We know access is everyone’s responsibility.
- People are important even if they don’t work. Everyone is important.

Bay Area Day of Mourning

Content Note: This piece talks about the murder of disabled children.

I spoke at the Bay Area Day of Mourning on Sunday, March 1, 2015. People from the Bay Area disability community came to the Ed Roberts Campus. They were there to remember the disabled people who were murdered by their parents, caregivers, care providers, police or other authorities. The Day of Mourning takes place across the United States and around the world. Here's what I decided to say:

Hi, my name is Alice Wong and I started the **Disability Visibility Project**. One of the things I wanted to do with the **Disability Visibility Project** is record the stories of people with disabilities by people with disabilities. I wanted people with disabilities to talk about their lives in the way they want to, using their own words.

Why is this important? It's because our lives, disabled people's lives, are so easily forgotten. Or people decide not to pay attention to our lives. When we're alive, we have to fight for people to know we're here, and for

people to listen to us. When we die people tell stories about our lives that make us less than human.

I'd like to say a few words and remember the lives of Ben, Max, and Olivia Clarence. Ben, Max, and Olivia were three disabled childen murdered by their mother Tania Clarence, on April 22, 2014 in London.

Tania Clarence's husband and non-disabled daughter went out of town. Then Tania Clarence stopped her three children from breathing. Then she tried to kill herself. Tania Clarence said she could see no hope for the future of her children. She said that she thought that how healthy, comfortable and happy her children were was more important than how long their lives were.

The lawyer who was supposed to speak for Ben, Max, and Olivia said that it was clear that Tania Clarence killed her children because she thought they were in pain. She wanted to end their pain. The lawyer who was supposed to speak for Ben, Max, and Olivia also said Tania Clarence was in pain too. Killing her children was a way to end her pain.

When I learned about this case, I felt like I'd been hit in the gut. I have a disability like Ben, Max, and Olivia's disability. Ben, Max, and Olivia had spinal muscular atrophy. When reporters wrote news stories about Ben, Max, and Olivia they described spinal muscular atrophy as a "muscle-wasting" disease. The reporters used words like "suffering", "deformities", which means things that are made wrong. They used "life-limiting", which means having a short life. The reporters used all these words to talk about my life. The reporters never mentioned the kinds of support and care that people with this disability need. The reporters never mentioned disability pride.

In another world, with another set of parents, I could have died the same way as Ben, Max, and Olivia.

If I could speak to Ben, Max, and Olivia I would say:

Yes, you need help with things every day. Some of those things might be eating, going to the toilet, getting dressed and brushing your teeth.

Yes, your muscles will get weak over time.

Yes, lots of people will talk about you using words like, “vulnerable” and “wasting away.” This means they think you are more likely to be hurt and that your body is getting weak.

But, you know what? I bet you also knew how to have fun, enjoy life, and dream big.

I wish that people didn’t think you were trapped in your body. I wish people didn’t think you couldn’t do anything and that you were in a lot of pain.

I wish that the three of you lived until you were old enough to use a computer. You could have written me an email or found me on Twitter. I would have liked to talk to you.

I wish my disabled friends and I could have shown you our world. Our world is a cool universe filled with disabled people who are proud of being disabled. I wish my disabled friends and I could have taught you whatever you wanted to know about being disabled and being proud.

As another disabled person please know:

Even in death you are not alone.

You are important.

We remember you.

We love you.

Ben, Max, and Olivia will never get to decide what to do with their lives. They'll never get to make their own decisions. They'll never get to make what they wanted happen. They could have done that if they lived to 15, 45 or 80 years old. Their mother took that from them. Tania Clarence decided that her opinion about their happiness and comfort and the opinion of the world was more important than what Ben, Max, and Olivia wanted. Tania Clarence spent time in a hospital for what I think was a hate crime. I think Tania Clarence believes disabled people shouldn't live. Tania Clarence killing Ben, Max, and Olivia was a part of a bigger

problem. The bigger problem is that many people think disabled people are better off dead. The bigger problem is the many of the ways the world works to kill disabled people.

It's because of the murder of Ben, Max, and Olivia and countless other childen and adults with disabilities that I'm here. Ben, Max, and Olivia, and other children and adults with disabilities are murdered by their parents, guardians and care givers. So I'm here to remember them. And I'm here to fight like hell for the living.

I'd like to dream about a future when disabled people don't have to prove that they're people. I'd like to dream about a future when disabled people don't have to defend their right to live. There's a lot of work to do. It's up to us. We have to fight the people, the way the world works and the ways of thinking about disabled people that say our lives aren't worth living. We have to fight the people, the ways the world works and the ways of thinking that kill us. We are here. We will not forget.

Just Say Nope

Plain Language Translation Note: This piece is an image. Here is the plain language translation of the words in the image. I've put in a few words here and there to make some ideas clear if you can't look at the image. But you might want to look at the original picture too.

Alice: These are some of the things that people ask me to do. I wish I could show you all the weird things that people say when I say no. People feel like they get to have my time and my energy but I just say no.

Do you teach people about disability issues and how to act around disabled people?

Alice: Nope.

Can you teach me how to support disabled people?

Alice: Nope.

Would you like to talk to a large audience? Could you do this tomorrow?

Alice: Nope.

Activist Wisdom

Here’s some advice for people who want to work with other people to change the world.

Good shit takes time. Think about how long you give yourself to do things. Give yourself more time. Use crip time, which is the many complicated ways disabled people use time.

If you can, back up the shit on your computer. You can use a hard drive, you can back up your stuff onto the internet. Whatever works for you.

Make whatever you’re making, or any events you’re having accessible. Keep learning about accessibility. Accessible means that disabled people can get into a place, use a thing or enjoy an event.

When other people are happy, don’t make them feel bad. Don’t talk about why people shouldn’t be happy. Or at least don't talk about how they shouldn’t be happy where they can see or hear you. Talk to your friends quietly about why people shouldn’t be happy.

Don’t believe every good thing people say about you.

If you’re going to make fun of someone or point out all the things they’re doing wrong, make sure that they have power and money. Making fun of someone who doesn’t have power and money or pointing out all the things they’re doing wrong isn’t cool.

Keep cool new projects and ideas to yourself until they’re ready.

You will forget things. There will be things that you need to do that you forget to do. It happens. Don’t be too angry at yourself when you forget things or can’t do them.

Tell everyone about people who helped you and who are doing good work. Be loud and proud and support the people you love and who are doing great things.

Give the people you care about lots of your time and energy.

Don’t use words or ideas you don’t totally understand yet.

Sometimes, you don’t need to share your opinion or your thoughts on an issue. Always ask yourself if you are the right person to do a particular thing. If someone asks you to do a job and you’re not the right person to do a job but you know who is, tell the person asking you who that is. Don’t expect thanks or people to be happy with you for sharing the chance to do cool things.

If you can end something when everyone is really happy with it, do that. Don’t ever feel like you need to continue something unless you want to.

Work with people you trust. If working with those people doesn’t go well, then you know that for the future.

Fuck me over once, I will learn from it. Fuck me over twice, you are dead to me.

Find a way to remember all the people who hurt you. You can keep pictures or anything else you need to remind yourself of what they did.

Build relationships with people. Relationships are more important than getting more power.

Say no to the things you want to say no to. You can be picky.

Being “very busy” isn’t actually that cool. The way the world is set up, where we have to work to get money to live, makes us believe that we have to be working all the time. Working all the time isn’t actually that great.

One way you can tell people what you can and can’t do is put an auto-reply on your email. This is an email that gets sent to anyone who sends you an email.

Here’s mine from 2021:

> I can’t answer every email I get asking for advice. The Disability Visibility Project is NOT a disability rights group and I do not support other people to get what they need or tell people where to get what they need. The Disability Visibility Project is just me, Alice. I share

stories, I write things and I sometimes give information or advice.

Thanks for understanding.

Make sure joy, pleasure and care are part of every day.

Fuck You Pay Me

Plain Language Translation Note: This piece is an image. This piece doesn’t need a plain language translation. So I’ve just written out the words in the image.

Fuck You Pay Me

Access

Access for the sake of access or inclusion is not necessarily liberatory, but access done in the service of love, justice, connection, and community is liberatory and has the power to transform. —MIA MINGUS.

Mia Mingus is a queer disabled korean person who was adopted. She's a writer and teaches people about disability justice and transformative justice. Disability justice means that in our fight to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So we need to be lead by disabled people who are Black or Indigenous or people of colour, who are trans or non-binary, or who are treated badly because of who they love and who they have sex with[6]. Transformative justice is a way of dealing with violence that is about what people and communities need, not about what the justice system needs. Transformative justice also helps us think about why violence happens, so we can stop it before it happens.

[6] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

Which means:

Access for access won’t change the world for the better. Access to make disabled people less disabled won’t change the world for the better. Access for love, justice, being with people and community is freeing and can change the world for the better.

One of Those Aha Moments

This is an interview with Eric Koenig. Eric was in charge of the Office of Student Life at the University of California, San Francisco. The interview happened at StoryCorps San Francisco on October 25, 2014.

In 1987, there were two students with disabilities at University of California, San Francisco. In 2013, there were more than 150 students with disabilities. When I was a new student at University of California San Francisco, Eric was one of the first people I met.

Alice: I was thinking about going to the University of California, San Francisco. I was worried about moving from Indianapolis to San Francisco. I was worried about going to school and having a disability people could see. I was worried about where I would live and a lot of other really basic questions.

I called the school, found your name and you called me back. I remember it was evening in Indiana. When I talked to you, you were so open and willing to talk about what University of California San Francisco would offer me. But you also talked about what would be hard. To me, that

made me think about moving in new ways. I felt like you were so generous and wonderful to talk to me about those things. It felt like there was a possibility that I should go to school. So then I went on a trip to the University of California, San Francisco. On that trip I met you. We talked a lot about what would need to happen if I went to school at University of California, San Francisco. We didn't assume I would go, but we talked about what we would need to do if I did.

Eric: I remember we had a few talks. I had been expecting you, or someone like you, for a few years before you called. In some ways it was really good. There were accessibility issues at University of California, San Francisco. Accessibility means that disabled people can get into a place, use a thing or enjoy an event. You were asking about specific things that would need to be fixed, like housing. I think we really quickly understood each other. So we could work together on issues. When you talked about the things you were worried about, I could talk about how we could fix those things or at least say that the university was willing to work on it.

Alice: Mm-hmm.

Eric: I think our main issue was about accessible housing. There just wasn't anywhere where you could live.

Alice: I think that was when the Aldea San Miguel student homes were being built. They had accessible homes but it wasn't finished yet. So, you know, I think the main thing you told me was that the University of California, San Francisco is small. It's one of a kind and we could figure things out together.

Eric: Right.

Alice: When I went to the University of California San Francisco it was at a really interesting point. I was able to get support that was about what I needed and that's really rare. Once I was accepted to study there, things started to happen. Eric, we met the director of housing. The director of housing decided to make some changes to a home for professors on Fifth Avenue. Fifth Avenue is only a block away from the main campus. In only a few months, the director of housing hired people to change the bathroom. The apartment was already on the ground floor. But the

accessible bathroom was a big thing. It takes so long to get money and plan any changes to buildings. University of California, San Francisco made that happen before I arrived as a student. That meant a lot to me because I felt so much like the only disabled person in some ways.

I was not the first person with a physical disability at the University of California, San Francisco, but I felt like there were not a lot of people with physical disabilities. There have been others, right?

Eric: Yes. The university was interesting when you came to study. The university was not very accessible. At the same time we did a good job of getting students who came to study here what they needed. So, what I was trying to say to you was, if you're willing to be the first person on campus who needs things like an accessible bathroom, we will change things for you. And so, we weren't accessible, but you and your family were very kind about the fact we weren't accessible. And we were able to tell you that we would make changes to be accessible.

I want to say something about how you talk with people to teach them. And how you ask for change and figure out how much change they are

ready to make. You have a great sense about how to make change happen. You're also very good at figuring out who will support you. Which people will be important to talk to. It's not always easy for people with disabilities who are in places that aren't made for them. You were a really positive model of change because you could make a connection with people. You helped them understand what was in your way and then helped change things. And that change made the campus better for everyone, not just people with disabilities.

Alice: I do feel like we were equal in making those changes. I think that wasn't usual. You were in charge of an office at the university and I was a student. You had a lot more power than I did. But I feel like we worked so well together to change things on campus. And I think part of this was the culture of University of California San Francisco. When I became a student, it was 1997. You were really clear with me that there were issues and I knew what they were. I accepted that there were going to be issues. And I thought, I think I can work with the people who work for the university to make it a better place.

Eric: When I did my job of services for students with disabilities I tried to remember that the students know more than I do. I needed to know from each student what they needed. Especially if we hadn't had another student with the same disability or accomodation or who had the same barriers before. I was always really interested in knowing what had worked for students before. Students taught me a lot. You taught me a lot.

It was fun to see how the Americans with Disabilities Act started to change things. The Americans with Disabilities Act is a law that is supposed to make sure that big companies, groups, and some buildings are accessible to people with disabilities. At the university, there was a big group of all the people who needed to talk together about the changes to accessibility. So for example, people who needed changes to the accessibility of parking and buildings to use them. But also the people who designed and made the buildings on campus. So there was a big group of people working on changing the campus. But some changes were more important than other changes. So not everything was done. When you came you showed me that the elevator buttons went up in a straight line instead of side to side. This meant that some people who use

wheelchairs couldn't reach the higher buttons and couldn't get to the high floors.

Alice: Because there's like so many floors. There was no way to reach all of them from sitting. I remember we met with one of the people in charge of the building or who had planned the building. I wanted to add buttons that went side to side. He said, "oh, we can do that!" And now there are buttons that run side to side that are used by a lot of people and whenever I see them it makes me smile. That change started because I needed it. But it makes a difference in a lot of people's lives.

Eric: That's universal design. Universal design is a way of thinking about designing places and things so that the most people possible can use them.

Alice: And I notice in elevators that able-bodied people will use the side buttons if the elevator is full. So if they are standing on the side of the elevator they don't have to reach over people to push the button for the floor they want. That makes me so happy.

Eric: The elevator-button story is the one of the best changes we made. Whenever I walk into an elevator on campus I think of you. It's a beautiful story about how change happens. I think what happened was the bus stop at Arguello Boulevard and Irving Street was made accessible. That gave you better options for taking the bus. But the bus stop was near an elevator in a dark corner of the basement of a building. One evening at 10:30 pm or 11:00 pm you were waiting by yourself because you couldn't reach the buttons in the elevator. That's a safety issue. I thought, okay, this change should happen. You know, someone could be in danger because of how the elevator was planned. So we used that fact and got together with the people who made the decisions and went to an elevator…

Alice: I think I had to show people. I think having a real person who uses it made it make sense for the engineer. And they said, "Oh yeah, we can do that." They saw and they got it.

Eric: It was one of those aha moments. Sometimes people who plan buildings or keep them working never think how buildings can stop people from doing what they need to do.

I love this story. Because the campus has a lot of elevators and the people who decided about changes to the building saw the issue. The people who made decisions knew they had to do something but also there were a lot of elevators on campus and that would be a lot of money. So, we said, “Where do you go on campus?”

The people who make decisions need to not spend more money than they had. But they wanted you to be able to get around campus. So they decided that every time an elevator was fixed they would add side to side buttons. I thought it was a beautiful example of a big university changing. They saw that you were a member of the campus community and you couldn’t get around easily. So they let you give them a list of everywhere you went.

Alice: Yeah.

Eric: And they did it. In the end they didn’t even wait to fix the elevators. They just started putting side to side buttons everywhere. You told them

what you needed, you did it in a kind but firm way and you talked to the right people.

Alice: And this is where we worked well together. You made sure I talked to the right people. You were with me in those conversations and that meant a lot to the people I was talking to. It wasn't just a student coming to see someone who designed the building. It was a student and the person in charge of services for students with disabilities. That's what people that serve students with disabilities should be - people who push for change so students have what they need.

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Then there's a series of tweets from Alice that share the rest of her story at University of California, San Francisco.

Alice: I really appreciate everyone's powerful stories. These stories are tagged with **#**WhyDisabledPeopleDropout on Twitter.

Here's my not-so-short story.

I loved sociology ever since high school. Sociology is the study of how people live together in big groups. I knew that studying humans and their cultures was my jam.

Alice: I had a big health crisis my first year of college. I had to take time off. When I was ready to go back to college, the government decided to give less money to Medicaid. Medicaid is the program that pays for a lot of health care including helping people live in their home. Less money for Medicaid meant that I didn't have as many hours of home support as I needed.

Alice: My family couldn't pay for college and pay for more hours of home support. I decided to stay home and go to my local university. I decided that I would somehow find a way out of Indiana. College was rough but I found some great friends and teachers.

Alice: I wanted to be like my professors. I wanted to write, research and teach. I wanted to create new knowledge. I knew there were disabled scholars out there. People like Irving K Zola and Barbara Waxman Fiduccia and Paul Longmore gave me hope.

Alice: I decided to apply to do a PhD in California. I got into a medical sociology program. Medical sociology is the study of the social reasons for and results of health and being ill. I wanted to study disability and qualitative research. Qualitative research doesn't use numbers. Instead it uses pictures, writing, talking and doing to understand what people believe, what they think is important, how they feel and what their lives are like.

Alice: Hooo whee, I felt so awkward and like I knew nothing when I got there. There were seven people in the program with me and everyone was so smart and so worldly. Some of them already had big jobs and had other degrees.

Alice: I was one of the few physically disabled students at this health sciences campus. The people who worked for services for students with disabilities were trying new things with me.

Alice: I understood two things in my first few years of grad school. I was having a hard time with school work. I felt like I was trying to do too much.

I also needed to stop. I hadn’t realized how hard I had pushed myself since junior high. I was done and just couldn’t keep going.

Alice: I ended up taking incompletes. Taking an incomplete is where you don’t finish the class in the time given to you but you promise to do the work later. I kept going back and saying I needed to do the work later. I felt so guilty. The longer I did this the more stuck I felt. Finally, the professor who was working with me met with me and told me I had to finish my courses and qualifying exams. Qualifying exams are the big tests you do to prove that you’re ready to do research.

Alice: I stuck with it. I finished the work on time. The big question was if I should start doing research. It felt impossible for me to finish my studies after having such a hard time the first two years. I felt like I had failed.

Alice: Internalized ableism made me think that getting my degree would make people take me seriously. Internalized ableism is when we believe all the terrible things the world tells us about disabilities. It's when we believe we don’t deserve the respect and freedom that people without disabilities are given. I thought studying would get me chances I wouldn’t

have otherwise. I realized my health and happiness was more important. I also realized I could do research while being a staff member at a university, not a professor.

Alice: So I ended with what the school called a terminal Masters. I had finished just enough classes and exams that they could give me something. It still felt like there was a note on everything I'd done, saying that I hadn't done this one thing I was supposed to do. I felt like I had failed myself a little bit.

Alice: Years later, a professor from my program came up and said sorry. He said he was sorry the department hadn't done more to support me. The department wasn't ready to have a disabled student. I didn't listen to what my body and mind needed or care for them enough. The speed of the program was impossible for me.

Alice: I ended up working for ten years as research staff at that school. I had a really good time. I was able to work on projects and grow as a researcher. I also got more involved with activism, which means trying to

change things for the better, and the kind of research where a community works to understand themselves and what they want and need.

Alice: I don't feel bad about my decision to quit graduate school. That decision set me free. It made it possible for me to be here, which is where I should be.

But I still remember the pain, being lonely, thinking I wasn't good enough, worrying and not having support.

Alice: Sometimes I wonder what I could have done if I had finished my degree. I wonder what I would have researched and how I would have changed disability studies and medical sociology. It would have been huge. But that's the university's loss. We'll never know.

That's the end of my **#**WhyDisabledPeopleDropout story.

My Day as a Robot

Shared on the **Ability Tools Blog** on May 1, 2018.

Resistance to assistive technology is futile. This means that you can't stop the use of technology that helps disabled people do what they want to do. Technology is using science to make new things and new ways of doing things. It's also a Star Trek reference. In Star Trek the Borg are lots of different aliens who become one people through technology. The Borg say, "Resistance is futile." I have to make a reference to Star Trek when I talk about technology and disabled people.

The disability community is living in a very scary universe right now. Trump is president. And at the same time we have the internet, places like Twitter and Facebook, and technology which have changed the ways we talk to each other and are a part of our community. People with disabilities are fighting for their rights. Politicians want to take away the money and support that keeps us alive. But it's also important to take the time to think about all the fun, amazing things we do. This is one of my stories of something fun and amazing.

In 2015 I was invited to the White House for a party for the twenty-fifth year the Americans with Disabilities Act had been law. The Americans with Disabilities Act is a law that is supposed to make sure that big companies, groups and some buildings are accessible to people with disabilities. At that time I was a member of the National Council on Disability. The National Council on Disability is a group of people that gives advice to governments about disability policy. I had also started the **Disability Visibility Project** the year before.

I don't travel by plane anymore for a few reasons. So I wasn't planning on going to the party. Not taking planes is just a fact of life now. But it took me some time to feel okay about that. I felt sad to miss meetings and chances to talk with people because of my disability (and the way the world stops me from doing things I want to do). But I've learned to focus on the ways I can do things at a distance or behind the scenes. Fear of Missing Out is the feeling that you'll miss out if you don't go out and do something. Fear of Missing Out is ableist! Fear of Missing Out is unfair to all us disabled people who don't go out. I decided this after years and years of being sad that I couldn't go to events because they weren't accessible.

Maria Town was one of the people in charge of the White House's Office of Public Engagement. The Office of Public Engagement makes sure that lots of different people get to talk to the President and the people that work at the White House about the work the government is doing. Maria told me I could come to the celebration because she had arranged for me to use a Beam Pro telepresence robot. I had assumed that I couldn't go. I didn't realize that I could join from a distance. I was so moved and thankful to Maria and everyone involved who made this possible. I hope to see more robots at the White House.

A telepresence robot looks like a computer screen on wheels. I could see everything through its web camera on my laptop at home. And everyone could see and hear me. I could move around pressing the arrow keys on my laptop. It was very simple to use.

Of course, I started to tell people on Twitter about what I was doing. I took pictures of what I saw and shared them. This was a major adventure! I needed to make sure I could remember it. I got to walk the robot around the Blue Room and the Green Room while I waited to meet President

Obama. I didn’t expect to meet President Obama! I was already excited just to come to the party.

I don't remember what I said to President Obama. We met for about five minutes. President Obama was very interested in the fact I was there as a robot. I got to show President Obama how I could move around. At the end we took a photo. A copy of that photo is now in my living room. It’s an experience I’ll never forget.

Lots of disabled people use technology to let them be a part of the world. I think a lot about how lucky I am when it comes to technology. I can afford a smartphone, a laptop, and internet service. Nothing stops me from using Youtube, Twitter or Facebook. I can get online and I understand what’s going on online pretty easily.

I want all disabled people to have what they need in order to have the lives that they want. Ableism and not having enough money keep technology away from the people who need it most. People who don’t have access to technology have less money than people who do have access to technology. They can’t take part in their communities or work or

learn online. This difference between people who have technology and people who don’t is called the digital divide.

In a dream world I’d buy a Beam Pro, one of those robots I used. But they cost way too much for me to buy. Even if I had one, I’d have to mail it to the place and have someone set it up, charge it and mail it back. For people who would use it for work or school I hope this would be a reasonable accommodation. A reasonable accommodation are words that come from the Americans with Disabilities Act. Reasonable accommodation means a change so that a person with a disability can take part. There are also a lot of fun things you could do with a telepresence robot. You could meet with friends, or travel or enjoy nature.

All technology is assistive technology because it helps people do things. So many things exist now that weren’t made for disabled people but disabled people use them. I love this. There isn’t really a big difference between disabled and non-disabled people. Sometimes it's hard to tell what is and isn’t access. Access means that disabled people can get into a place, use a thing or enjoy an event. I look forward to a world with lots of robots.

Net Neutrality, Accessibility and the Disability Community

Let’s face it, social media can be a dumpster-fire. Social media is when people create and share on places online like Twitter, Facebook and Tik Tok. People also use social media to make friends and form relationships. There’s trolls on social media. Trolls are people who are really mean to other people on the internet. So comparing social media to garbage that has been set on fire isn’t a huge reach. Some days I don’t want to be on the internet. I try to stay off as a way of taking care of myself. But I always come back to social media and the internet because it is my second home, my playground and my workshop.

Net neutrality is the idea that your internet company should give you access to all sites at the same speed. Your internet company shouldn’t be making it easier or harder for you to go where you want to go on the internet. Net neutrality is important to me because the internet and social media are important when I’m trying to change the world and when I want to hang out with my friends.

I started the **Disability Visibility Project**. The **Disability Visibility Project** is an online community that creates, shares and draws attention to disabled people and disability culture. With the **Disability Visibility Project**, I have been able to build a community and draw attention to disabled people's thoughts, ideas and worries. I do that with Twitter chats, a podcast and blog posts. Without net neutrality I wouldn't be able to talk to as many people as I do. I'm one of the people who works on #CripTheVote. A hashtag, which is the # sign followed by words connects a post or a tweet to a bigger conversation. Hashtags are an important tool. Hashtags can create conversation and push people into action.

The internet is also where I go to find support, share my life and make friends. On the internet, I don't need to be in the same place at the same time to talk to people. Some disabled people like me have a hard time when we try to go out. Some disabled people are alone because of where they live or how they exist in the world. There are diabled people who cannot leave their beds and are badass activists on social media. The internet is a lifeline for me and many other people. For me, net neutrality is a civil right, one of the ways I'm promised an equal place in society.

Before the internet I felt very alone. I didn't see anyone like me in the news, in movies or on TV. I didn't know I was part of a powerful and complicated community. Then I found my people online, especially disabled people of color. It's really difficult for me to go to large events in person, including protests. Protests are when a lot of people go to one place to demand change. So social media is the way I work with other people to solve the problems I'm concerned about. I use the internet to create a community and to share disabled people's stories. I also fight the stories that non-disabled people like to tell about disabled people that aren't true. My blog posts and podcasts can't get to people unless there's net neutrality. Without net neutrality folks are going to miss out on all my glorious knowledge.

Even with net neutrality, there are lots of problems that stop disabled people from coming together to make change. In 2016, the people at the Pew Research Center found that people with disabilities usually use the internet less. People with disabilities own fewer smartphones, computers and tablets compared to people without disabilities. The digital divide is the difference between people who have access to technology and the internet, and people who don't have access to technology and the

internet. People who don’t have access to technology have less money than people who do have access to technology. They can’t connect and take part in their communities online or work or learn online. The digital divide is a big issue for people with disabilities.

Part of the reason lots of people with disabilities have less access to the internet and technology is because of poverty. People with disabilities often have less money than people without disabilities. Another big problem is that people, companies and other groups don’t want to follow web accessibility standards. Web accessibility standards are rules about how companies and groups are supposed to build their websites so disabled people can use them. For example, web accessibility standards say that people need to be able to get around a website by pressing the tab or arrow keys. The standards also say that a website needs to be able to be read by a screen reader. A screen reader reads words on a computer or the internet to Blind people and other people.

Imagine if you could only access a few Youtube videos or podcasts. That’s the reality for a lot of Deaf and disabled people. There’s videos and sound files without the sounds written out. There are images without

descriptions or apps that don't work with assistive technology. Imagine not being able to put in an application for a job or access services online. Imagine trying to take the same online course with your classmates at universities that refuse to follow the Americans with Disabilities Act. The Americans with Disabilities Act is a law that is supposed to make sure that big companies, groups and some buildings are accessible to people with disabilities.

Here's my message to everyone: Stop making media and technology that isn't accessible to disabled people. Make media and technology disabled people can use. Stop treating disabled people badly. Disabled people have the same right to information and the internet as everyone else.

There's a song in the musical Hamilton. The song goes, "I wanna be in the room where it happens."

The song is about wanting to be in the places where big decisions are made so that you can make change. Net neutrality lets me be in the rooms where things happen. Net neutrality lets me be in every room. Net neutrality lets me say what I need to say. It lets me support the voices of

people I want other people to hear. Net neutrality lets me do this without apology. Net neutrality allows me to be me. We all deserve to have our say, to be in the rooms where decisions are made.

Internet access is power. This power belongs to everyone, not just a few companies.

The Last Straw

Shared in **Eater** on July 19, 2018.

Plain Language Translation Note: Some of this piece talks about food. I've kept a lot of the food words that aren't common. I've kept them because I think they're an important part of Alice sharing the joy of going out and getting food. If those words are confusing it may help to look up a picture of that food.

I live in the Mission District of San Francisco. There are amazing places to eat everywhere. I'm a disabled person who uses a wheelchair to get around. I use a ventilator, a machine that pushes air into my lungs, to breathe. So having fun eating and drinking depends on a lot of things.

When I leave my home for a latte or burrito I think:

- Will the place I'm going have the door open so I can get in?
- If the door is closed, will someone open it for me?
- Is the counter low enough for the person working there to see me?
- Can the person working there hear and understand me with my mask over my nose if it's noisy inside?

- Will I be able to sign my name to pay if the counter is really high?

Sightglass Coffee is one of my favorite neighborhood coffee places. When I make my order, I'm comfortable enough to ask for help. I'm comfortable enough to accept help. I'll ask the person working there to take my drink to my table because I can't reach the high counter or carry a full cup of coffee. I'll even ask for help adding sugar when I feel like treating myself. The sugar is too heavy for me to lift. When I'm at a coffee place, two items I always ask for are drinks with a lid and a plastic straw. It needs to be a plastic straw. A lid stops the coffee from coming out of the cup when I'm dealing with bumpy sidewalks. Straws are important because I do not have the hand and arm strength to lift a drink and tip it into my mouth. Plastic straws are the best for hot drinks. Compostable straws just break apart when I drink hot drinks. Compostable straws are straws that fall apart in the trash.

It's not nice to ask for help from workers in public places like coffee shops or restaurants. It's not nice because you don't know how people will feel about you. Maybe they won't care. Or maybe they'll feel pity, and want to push you away. I don't think the kind of help I need is special or should

make people feel better about themselves or something that people should post on Twitter or Facebook. Helping me get my coffee or my burrito is just doing a good job.

A lot of people see plastic as cheap. A lot of people think plastic is kind of gross, a waste and bad for the environment. All true. Plastic is also something I need for my health and happiness. My disability makes my muscles weak so plastic straws are the way I drink and often the way I eat. Right now, environmentalists want us to get rid of plastic single-use straws so we make less waste. Environmentalists are people who really care about saving the planet. Big restaurant companies like the Union Square Hospitality Group and companies like Starbucks have said they'll get rid of single-use plastics.

I was upset with Starbucks saying they wouldn't have plastic straws. I was also really upset with the news that Vancouver and Seattle recently got rid of plastic straws. Other cities like New York and San Francisco are also thinking of telling people they can't have plastic straws. (I won't tell you about the problems with recycling plastic or greenwashing. Greenwashing

is where companies care more about looking like they care about the environment than actually caring about the environment.)

Here are some of the reasons I was upset:

1. Environmentalists think plastic straws aren't necessary. They talk about straws as "gateway plastic" which means straws are a way to have a bigger conversation about waste. For example, Dune Ives who runs the Lonely Whale Foundation said, "Plastic straws are social tools and props, the perfect conversation starter." Dune Ives means that plastic straws can draw attention to the bigger conversation about how everyone uses plastic. When Dune Ives says this he means that plastic straws aren't really that important. But for people who need plastic straws to eat, plastic straws are important. It's as if people who need straws - older people, children and disabled people - don't matter. It's as if the needs of people who need straws are less important than the environment. I feel like I don't exist when people talk about plastic straws this way.
2. Plastic straws are everywhere. When people have something that gives them access and then you take it away from them, it's difficult and hard. Most of the people who need plastic

> straws don’t have the money or resources to find something else that works (if anything works). So it's extra work for them. I live in a world that was never built for me and every bit of access I get I fought for. I value all the access I have because of this. Telling people they can’t have plastic straws is not the way to build a better world.

The way we deal with straws is the same as the way we deal with a lot of issues around disability rights and justice. The Americans with Disabilities Act turns 28 next week, on July 26. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with disabilities. The Americans with Disabilities Act has been around for 28 years. Restaurants still won’t let people with disabilities eat in them. Lots of small business owners and the National Restaurant Association think the Americans with Disabilities Act lets people take legal action just so they can get money. The National Restaurant Association is a group that supports and works for restaurants. People talk about disabled people being “fakers” or “complainers.” But it’s actually really painful for disabled people to not be able to eat and drink where everyone else can.

Lots of people are asking what we can use instead of plastic. At the same time, people with disabilities are talking about how they'll have to work harder if cities tell people they can't have plastic straws. People tell me to bring my own straws. Bringing my own straws is a lot of work! Why should disabled people have to bring something in order to drink when non-disabled people can just eat and drink with what the restaurant or shop gives them for free? That's not just, fair, or kind.

The world is not built for me or other disabled people. So we have to explain and defend ourselves. Non-disalbed people say we have to work harder even when we're already working harder than non-disabled people. There are days when I want to say over and over: Believe disabled people. Period.

I won't say sorry for the way my body works or what I need to live. Everyone uses things and makes waste. We all do what we can to reduce, reuse and recycle. We should understand that people need different things, so people will need to find different answers to the problem of lots of plastic waste being where it shouldn't be. I'm not a

monster for using plastic straws or other plastic things that let me live, like oxygen tubes.

Restaurants are places where it's easy to see the ways the world isn't fair. Sometimes when I go out, the person working at the restaurant will ask the person I'm with what I want to eat instead of me. I have to go through the side door because the main door is not accessible. Usually these side doors are creepy and dirty. Sometimes the people working at the restaurant call me "the wheelchair." Sometimes people working at the restaurant are upset because they think I take up too much space. I also love the places where I feel welcome. The places that welcome and respect me are truly friendly and generous. So I come back again and again to enjoy those places.

When the city of Seattle said people couldn't have plastic straws anymore, they said that people with disabilities could still have them. The City of Seattle said that people with disabilities had to ask restaurants for the plastic straws. People who run restaurants can decide if they want to have plastic straws. This is unfair. People with disabilities will have to ask the people who work at restaurants if they have plastic straws. Then

people with disabilities will have to ask for the plastic straws. This is a lot of extra work. They have to tell the people who work at restaurants that they have a disability. Maybe the people who work at the restaurant will ask for information about people's disabilities. No one should have to prove they need plastic straws or even have to say they have a disability when they're having a fun night out with their friends. This is not friendly or generous.

What do we do now? How do we make going out a friendly and generous experience and reduce plastic?

Until there is another straw that works the same as a plastic straw, I have some ideas:

- If you have straws at your counter, have both plastic and compostable straws. Put signs on each type of straw so people can choose which type of straw works best for them. If you want people to ask for straws, have waiters ask people if they want plastic straws or compostable straws. This is the same as asking people if they want still water or sparkling water. This way you won't make disabled people feel alone. People can decide what is best for them.

- Think about the kinds of plastic you use. Maybe you use plastic wrap or plastic containers? Maybe there are other ways to reduce the plastic you use?
- Providing a friendly, generous experience to customers is the same as accessibility. If you're not accessible you're not friendly and generous.
- Think about the barriers, the ways you keep people from coming to your restaurant or shop. Maybe you meant to put in some of those barriers, maybe you didn't. Listen and learn when people say they don't like something. The disabled people who want to come to your shop or restaurant have important things to teach you too. Don't wait for the disability community to say that what you're doing is wrong. Don't wait for the disability community to start telling people not to give you money. I see you, Starbucks!

If a coffee shop can offer 4 types of milk for coffee drinks, then they can offer 2 types of straws. If a restaurant can serve 50 types of wine and beer, then they can offer 2 types of straws. Companies can also make sure that everyone has the same access to straws instead of making

disabled people ask for them. You can meet everyone’s needs and lower the amount of plastic you use. People like having choices.

In the end, isn't it all about making sure everyone feels welcome by being friendly and generous?

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This letter was given to the clerk of the board of supervisors, the assistant clerk of the Land Use and Transportation Committee and the board of supervisors for the City and County of San Francisco. All of these people help make decisions about how the City of San Francisco works.

July 31, 2018

Hello President Cohen and Supervisors Brown, Fewer, Kim, Mandelman, Peskin, Ronen, Safai, Stefani, Tang and Yee,

My name is Alice Wong. I live in District 9. I’m a disabled person who uses plastic straws to drink outside of my home. I’d like to ask you to vote no to item 29 on today’s agenda, the Food Service Waste Reduction

Ordinance. The ordinance is the rules about if and how companies can give out plastic straws. I know a lot of people really like item 29, but I don't. I'd like to explain why.

Right now the ordinance says, "Strict compliance with this Chapter 16 is not required in instances where it would interfere with accommodating any person's medical needs." I think this means that restaurants and shops can have plastic straws for disabled people. But this is hard to understand and not good enough for disabled people.

What does "strict compliance" mean for companies? What is the difference between "strict compliance" and "compliance"? Compliance means following the rules. How do you follow these rules strictly? Won't most companies find this hard to understand?

This ordinance needs to say that companies need to keep plastic straws on hand. Companies need to give plastic straws to disabled people when disabled people ask for them. If you don't tell companies they need to have plastic straws, companies won't have to have them. You have to put this in the ordinance because the ordinance is what companies will follow.

Right now, this is in the implementation plan which companies can ignore. Implementation plans say how an ordinance or a rule will happen.

You also use the words, “medical need” in the ordinance. This means that people might have to tell the restaurant or explain to the restaurant what their medical diagnosis is. This will mean that companies will think that people like me who need straws must look a particular way. Or companies will expect people to tell them that they have a particular diagnosis. You can’t tell what a person needs by looking at them. Anyone should be able to get a plastic straw by asking without being questioned. People who have to explain or answer questions about their disability to get a straw have to do a lot of extra work that other people don’t.

I think Supervisor Tan and other people who use straws that can be used many times for their drinks are doing a good thing. But there are other people who can only use plastic straws because other straws could hurt them. Some people have more money and support than other people. Not everyone has a machine to wash dishes or someone to clean a straw. People with little money have a hard time buying food and paying rent. They don’t have money to buy something they used to be able to get for

free everywhere. And why should people with disabilities have to bring their own straws to eat and drink if non-disabled people don’t have to?

People hurting the earth less and producing no waste are good goals. We should work towards those goals in ways that don’t leave out or hurt people who already have less access and less support. This ordinance tells older people and people with disabilities that their ability to eat and drink doesn’t matter. The ordinance tells them that they are shit out of luck if their local shop doesn't have plastic straws anymore. My need is not medical. My need is because the world is not built for me. I ask you to stop and write the ordinance with the people who will be hurt if you pass it.

Sincerely,

Alice Wong

Founder and Director

Disability Visibility Project

August 27, 2018

To: Supervisor Katy Tang,

Ashley Summers, Legislative Aide to Supervisor Tang

Debie Raphael, Director, S.F. Environment

Nicole Bohn, Director, Mayor's Office on Disability

From: Alice Wong

Disabled resident, District 9

Re: Food Service Waste Reduction Ordinance Amendment

Hello! I was on the phone at the disability community stakeholder meeting on August 23. I hope you got a sense of disabled people's lives. I hope you understand why we need plastic straws to go out and be a part of the world. At the end of this letter I have added some more stories by people with disabilities. Please read them if you have time.

Here's a few things I'd like to see in the changes Supervisor Tang is making to the rules that let restaurants give disabled people plastic straws.

1. All restaurants and shops must have plastic straws to give disabled people when they ask for them. If restaurants and shops don't have to have plastic straws, they won't. This will mean that lots of disabled people won't be able to go to those restaurants and shops.
2. Replace the words 'medical needs' with 'access needs' in the paragraph and any signs that San Francisco Environment makes for restaurants and shops.
3. Disabled people need to have the same access to straws as non-disabled people. Disabled people shouldn't have to do extra work to get straws that non-disabled people don't have to do. For example, if a coffee shop has compostable straws that customers can ask for, then they should also have plastic straws that customers can ask for. If a coffee shop has a stack of straws that aren't plastic on their counter, they should also have a stack of plastic straws.
4. If people have to ask for plastic straws, restaurants and shops should have signs that clearly tell everyone that.
5. Write clearly in the rules that people who ask for plastic straws should not have to tell companies anything about their disability. People who ask for plastic straws should get one, no questions

asked. This also needs to be on any signs and anything official San Francisco Environment says.

Next, could you host another meeting with people who won't be able to go to restaurants and shops if you get rid of plastic straws? You need to talk to people about how you'll change the ordinance. It would be good to do this before the next Land Use Committee hearing on the issue. We need to have lots of time to think about what we want to say to everyone before the hearing. We deserve to see how everything we've told you changes the rules.

After all, what's the point of listening to us if we don't have a say on policy that will affect our lives?

Respectfully,

Alice Wong

Disabled activist, lover of coffee and Mission District resident

Ode to a Spit Cup

From **Body Talk: 37 Voices Explore our Radical Autonomy**, put together by Kelly Jensen.

Spit. Drool. Our bodies make a lot of spit every day. Your spit can be watery, sticky or bubbly. It can taste of what is in your mouth. It all depends on what you drink, eat, any pills you take and other things. I find the fluids that our body makes really cool. I have new respect for spit because I am finding it hard to swallow now.

I have a power chair. My power chair is part of my body. It is part of the space I take up and my sense of myself. Now, my spit cup is part of my body too.

What is a spit cup? It's a cup I keep by me so I can spit into it instead of swallowing my spit. I was born with a neuromuscular disability. This means that my muscles get weak over time. I don't know how fast my muscles will get weak, just that they will. I stopped walking when I was 7. When I was 7 my spine started to bend. I had to have surgery on my spine to help straighten it when I was 14. The surgery was complicated

and I had to deal with some changes to my body from it. My diaphram, the muscle that pushes and pulls air in and out of your lungs, got weak. It became hard to sleep and breathe. I used a nebulizer, which turned my medicine into tiny drops I could breathe in. I used a machine that pushed air into my lungs and I used oxygen at night. All of this worked okay until when I was 18 when I couldn't breathe well enough to get the oxygen I needed to live. I had sleep apnea, which means my breathing stopped and started when I slept. I needed a BiPap machine, a machine that pushes air into my lungs, otherwise I would die.

I can swallow. But swallowing again and again over the course of a day is really tiring. The spit cup makes things a little easier. It also means it's less likely that I'll breathe in my spit. My spit cup is my new friend, a brilliant adaptation and a source of wonder.

I think about breathing and swallowing and how they're related to each other a lot. Before I was always thinking about breathing. I'm still scared of how getting sick will hurt my body. In particular, trying to cough is really hard. I still worry about whether my battery on my Bipap machine will last when I'm out for a long time or when the power goes out. When I eat a full

meal, I can’t talk or breathe well. I’ve changed how I live as my body and breathing have changed. I make sure I'm not around a lot of people during flu season. When I started to need my Bipap machine all day I connected it to my wheelchair battery so it would last longer. I changed how I eat. Now I eat high fat and high protein food so I get the most out of every bite. I eat smaller meals and snacks so I’m comfy. Snacks are little bits of food.

When I wear my Bipap machine it breathes a set number of times per minute. I don’t control when I breathe. The machine controls when I breathe. When I talk, there’s stops that sound strange because I’m breathing. Swallowing is complicated because when I swallow depends on my Bipap machine. I can’t swallow my spit or anything else when I want to. I have to time it after a breath. Sometimes a breath comes mid-swallow which makes me choke and feel scared. The Bipap gives me a huge amount of breathing support. I know I have more energy for what I want to do because of the Bipap machine. I will live longer because of the Bipap machine. But I can’t separate it from my body. So I have to work with the Bipap machine when it wants me to breathe.

Maintaining my ability to breathe is in the back of my mind, everyday. In the last five years, I've started to think about swallowing just as much. Think about how many times a day you swallow food, drink or spit. Think of all the parts of your body that you use to chew, swallow and breathe. For most people, they can chew, swallow and breathe without thinking about it.

As I get weak I think about when I breathe, swallow, eat and talk. I love how each of these things works with the others. I even love how careful I have to be about breathing, swallowing, eating and talking now that I have to think about them. I used to choke on simple things - spit, a drink, laughing while eating. Breathing in water feels like I'm dying. I work to breathe but no air can come in. My eyes get bigger and I start to tear up. My face turns red. I try to cough. I feel like death is coming for me. Everything tenses. And then I relax as my throat opens up again. By then, my face is wet from tears. My breathing is fast and I gulp for air. And I'm so glad to be alive.

Is spit my enemy? I don't think so. It's always there and it's an important part of getting energy from food. Breathing in water is a shock. It reminds

me that life is always under threat. I could have fought when I started finding swallowing tiring. I could have taken pills to stop it or gotten sad that my body was once again changing. But instead I started using a spit cup. The spit cup is a solution I found for myself that makes choking less likely. It gives my stomach muscles a little break. The spit cup is a gift to myself. It's a life hack, a tool that makes my life longer.

I learned how to move with this new tool. I also learned how to be with other people with the spit cup. Most people think spit is gross and messy. Spitting and letting spit come out of your mouth isn't something people do. When people think of spitting and letting spit come out of your mouth, we think of babies. Doing something that makes people think of babies makes it easy for me to feel ashamed of my disability. At the start of using the spit cup I felt like everyone was looking at me. I would hold the cup to the side. Or I would try to hide that I was spitting into a paper cup when I went out with my friends. I worried about spilling the cup. (Yes, I've spilled my spit a few times.) I worried about people staring or looking at the cup of spit. But the hardest part was that I didn't like looking at a full cup of my spit.

Every day my spit looks different. Maybe it's icky but I also like to think of my spit as fancy, abstract art. Abstract art is art where you don't know what it is. My spit has food in it. My spit has rainbow colors from coffee and soup. After I talk with someone, my spit looks like cappuccino foam. Sometimes there are solid pieces from my nose that go into my mouth and I spit out. Or, there's strange shapes like sculpture as the spit soaks into the tissues I put inside the cup. My body makes spit every day. Spit outside my body makes me see it differently. I like Yayoi Kusama, a Japanese artist who creates beautiful, abstract work with patterns that repeat. Maybe I can become the Yayoi Kusama of spit art?

Seeing my spit everyday and touching it shows me the beauty in and how complicated the human body is. Spit helps me. And spit can be dangerous to me if I breathe it in. The spit cup is a sign that I am getting weak, that my disability is changing. My spit cup is also a sign that I am hella creative.

When we think of interdependence, we often think of the ways we need other people. As my body has changed, I need objects. I see objects are part of the big web of things and people that keep me alive. I'm a cyborg,

part machine and part person. My body is connected to numerous objects that travel with me. These objects, machines and tools don't live and breathe, but they're still part of me. They set me free. They keep me feeling stable and let me make the most of my life.

Like breathing, swallowing spit is something most people do all the time and don't think about. My disability forces me to pay attention to my body. My disability forces me to be creative and find new ways to keep living well. I am grateful to be a cyborg. I'm grateful for my ever-trusty spit cup.

Getting to the Marrow

Plain Language Translation Note: A lot of this piece talks about food. I've kept a lot of the food words that aren't common. It's important because Alice loves those specific foods. If those words are confusing it may help to look up a picture of that food.

In my family I am known for being 馋裴 chán pēi. My Shandongnese

Northern Chinese parents use 馋裴 chán pēi to describe someone who

loves food and is a little bit naughty. I think about it as someone who thinks about food a lot, who dreams up food, who loves eating, and knows what, where and when to eat. I like to think of myself as a cat because cats will not eat food they do not like. I can be a pain in the ass about food.

I like to have scones that have been cut in half, spread with butter and heated till they're golden brown. Then I like to put strawberry or peach jam on them. I like eating only the skin and fat of pork heated slowly with soy sauce, pig feet, or roast duck. I like the hard bits of a muffin or a cookie. I will slowly eat just those hard bits. I like to think of myself as a

snobby squirrel, only eating the best bits. I like fries fried twice in duck fat with garlic or ranch dressing. The ranch dressing better be made with real herbs and buttermilk. I like thin crust pizza where the bottom is hard and the toppings aren't wet. I think you can put old food in the microwave. But why would you put old food in the microwave when you can heat it in the oven or on a stove? Even if heating in the oven or the stove is more work. Did I mention I can be a pain in the ass?

In our family I help out by finding new ways to cook food, getting food on the internet and making lists of food to buy. I'm bossy like a cat. Being bossy makes sure we have food ready to cook. We never have to wonder what to make for dinner. My parents need healthy low carb meals with lots of vegetables and meat, and I need totally different food. When I get super excited about my next treat, my parents say that my eyes are too big for my stomach. This means I like the idea of eating a lot more than I will actually like eating a lot. That's the problem with liking food but not having a lot of space in my stomach. I think that is what it means to be 馋

裴 chán pēi.

I plan my day around eating. Being a 馋裴 chán pēi has kept me alive

sometimes. When I was younger I ate everything! Before I had surgery to make my spine less bent, I wore a body brace. A brace is something hard you put around a body part to keep it in position.The body brace kept me straight and was tight. After a big delicious meal, I would ask my parents to make the straps loose. When those straps were loose it was sweeeeet relief! That delicious meal might have been comfort food like barbecue ribs, mashed potatoes, gravy, corn and apple pie from Gray Bros. Cafeteria in Mooresville, Indiana. Maybe it was corned beef on rye with mustard or a potato latke (made of short pieces, not long pieces of potato) with applesauce. Or maybe the delicious meal was macaroni and cheese at Shapiro's Delicatessen in Indianapolis in the 1980s.

My parents would make my brace loose and then we would drive home. The loose brace let me breathe easier. It was the best feeling! I am so thankful that my parents never made me feel like I shouldn't eat or that I was a "bad" person for making my brace looser. Both my parents' families did not have a lot of money when they were children. They knew what it was like to be hungry. So my parents thought eating well was important.

In my late 30s and 40s, I started to find it hard to breathe during the day. I already used a Bipap machine, a machine that pushes air into your lungs, and oxygen at night. But I started to feel tired when I would talk, eat and swallow. I also started to feel pain in my lower back. Being in pain all the time was new to me. I didn't realize how pain would change my energy and how hungry I was. The pain would change how well I ate. I was also scared of choking on water and food. All this meant that I lost weight and didn't eat enough of some food. It was hard to know how much weight I'd lost. Weight scales that wheelchair users can use at home are super expensive. It also wasn't easy to find out my weight at my doctor's office even though it had an accessible scale. It makes me angry, but it's part of living in a world that isn't built for you.

I went to talk to a nutritionist. A nutritionist is someone who knows a lot about food and how food can help you be healthy. I wanted to try changes that wouldn't involve surgery. The nutritionist thought I should get a feeding tube. A feeding tube, or a G-tube, or a gastronomy tube, is a tube to your stomach. You can eat, take pills and drink water by putting it in the tube. I knew eating, drinking and taking pills would be a lot easier with a G-tube. I also talked to other disabled people who have G-tubes and still

eat and drink by mouth sometimes. Those disabled people loved having G-tubes. I'll definitely get a G-tube in the future, but I wanted a little more time before I have to change my day to day life again.

A G-tube would mean a big change to my day to day life. It's easy for a doctor or a nutritionist to tell you that you need a new tool or procedure. But doctors often don't think about all the extra work that comes after. I had to ask myself, do I have room in my closet for all the new G-tube supplies? Do I have the energy to train myself and the people who help me every day to use one and keep it working? Even if the G-tube worked well, do I want to deal with germs growing where the tube was put in, skin problems and my stomach fluids coming out? All of that happens with a G-tube. In the end I decided I didn't want a G-tube yet. I wanted to change what I ate in ways that make my life better at this moment.

Food access is about whether or not people can feed themselves well. People often talk about lack of money stopping people from eating well. People living too far away from places they can get good food is also an issue. For me, food access is about all of those things. Food access should also be about eating safe food, easy to make food and good

tasting food. Pleasure, taste and joy should be part of what we talk about when we talk about access. When I found myself having a hard time eating well, I tried to make eating food that I like an important part of the solution. I pay attention to how my body changes and I try out ways of working with those changes.

Here's a few things I figured out:

- I started using a BiPap machine during the day. Using the BiPap machine means I use less energy to breathe between eating. I don't have to worry about feeling short of breath after eating. Bonus: I drink more water too.
- I plan to eat small meals and snacks throughout the day. This means I'm not eating lots of food all at once.
- I try to avoid talking while I eat. I also pay a lot of attention to eating. People who think they're really cool would call this 'mindful eating.' I call it 'trying not to choke to death.'
- I also lean forward with my chin down while I swallow. This also stops choking.
- I have a spit cup just in case I'm eating and there's a chunk that's going to be hard to swallow. Sometimes I chew meat and then spit it

out just to enjoy the taste. Sometimes I tip the spit cup over but you just gotta suck it up (that’s a joke).

- Soft things with lots of fat are easiest for me to swallow. I try to make my favorite flavors into that kind of liquid. I can still have some crispy food that I don’t have to chew a lot (I can still have potato chips, fried chicken skin and tempura sweet potatoes!). Fat tastes good and means I'm less likely to choke!

I miss popcorn a lot. But aged white cheddar Pirate's Booty is close enough. Instead of a lobster roll I have lobster bisque. I can’t eat beef or lamb but I love some sexy, jiggly bone marrow on a Parker House roll with a glass of sparkling wine or a mug of hot bone broth. I can’t eat barbeque ribs anymore but I can eat gooey slow cooked baked beans with burnt ends so I can taste something smoky and meaty. And thank god for creamy peanut butter, yogurt, tofu, eggs, ice cream, cheese, jook, and pureed soups.

Lots of disabled and chronically ill people deal with loss. Loss makes us sad and angry. Loving a body that works in ways that you don’t expect isn’t easy. But it makes me really thankful for what I have now and what

I've gotten to experience in the past. I have warm memories of excellent meals. Right now, I can be hungry and eat well, and I can look forward to new food. I just have to find a way to taste what I really want to taste.

I’ve given myself permission to be a hard-core 馋裴 chán pēi. I can’t eat so many things, so I'm going to be picky about what I can eat. I’m going to hold onto my ability to feed myself good food and feel good about food as long as possible. I’m not going to fear the day I need a G-tube. And I’m not going to skip whipped cream or a second slice of pumpkin pie while I can have it! Adaptation is changing to work with your body and the world around you. Adaptation is care work. Adaptation is living on. Adaptation is learning to be okay that what you had in the past is different from what you’ll have in the future. Adaptation is like a science experiment. Adaptation is like art. Adaptation is finding new ways of living. And in finding new ways of living, I create new futures.

Food Heaven by Felicia Liang

Plain Language Translation Note: This piece is a beautiful image by Felicia Liang[7]. It has pictures and labels of some of Alice's favorite foods. I've listed the food but you might want to look at the original picture too. I've kept the food words that aren't common. It's important because Alice loves those foods. If those words are confusing it may help to look up a picture of that food.

Soondubu Jjigae with seafood

Potato chips and champagne

O-Toto Nigiri

生煎包 Pan-fried Buns

韭菜鱼水饺 Fish & Chive Dumplings

蛋撻 Egg Custard Tarts

Peaches and mangoes

Chawanmushi

[7] Felicia Liang is a Taiwanese American artist working in the Bay Area. If you want to see more of Felicia Liang's work you can go to her website here.

卤豬蹄 Braised Pig Trotters

French Fries with Aioli

Let's Recognize Why #AccessIsLove

Shared on the **Rooted in Rights** blog on February 14, 2019.

I spent a lot of time as a child and a young adult finding me and finding people who would support me. I didn't know words like ableism. Ableism is the way the world is set up to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[8]. I didn't know words like intersectionality.

Intersectionality is the way that all of these things connect:

- Disability.
- Race.
- Gender.

[8] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

- The kind of schooling you have.
- The amount of money you have.
- Who you love.
- Who you have sex with (or don't have sex with).

All these parts of you either make you more likely to experience good things or bad things in your life[9]. People have very different lives depending on their experiences of disability, race, gender, the kind of education and the amount of money they have, who they love and have sex with, or don't have sex with. Ableism and intersectionality helped make me who I am.

It took me a long time to think about myself as disabled. It took me a long time to be proud of being disabled. But that process really started when I started meeting other disabled people. I didn't need those other disabled people to look like me. I didn't need them to be my best friend. But I felt like I knew them and they knew me. We understood each other's lives a little and that kept me going.

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[9] This definition owes a lot to an interview with Kimberle Crenshaw. Kimberle Crenshaw thought up the word intersectionality. You can read more here: https://time.com/5786710/kimberle-crenshaw-intersectionality/

When I moved to the San Francisco Bay area 22 years ago, I felt really small and like I didn't know anything. I had arrived at the center of crip culture. Crip is a word that was used to insult disabled people that some disabled people have taken back and use for themselves with pride. In the Bay Area, disabled women and disabled people of color in particular made me feel at home. They shared their lives, time and culture with me. I learned from them about disability justice. Disability justice means that in our fight to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So we need to be led by disabled people who are Black or Indigenous or people of colour, who are trans or non-binary, or who are treated badly because of who they love and who they have sex with[10]. I started to connect with people outside the Bay Area through the internet.

[10] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work

I started to love and accept myself. I understood that feeling shame about being disabled will always be part of me. But thanks to the love and everything disabled people shared, I learned new ways of being, thinking and getting around. All the little bits of love and kindness became something bigger. That something bigger was interdependence, which connected everyone and supported everyone.

Every community big or small has fights, drama and a whole lot of people acting in ways you wish they wouldn't. Every community also has older people who have knowledge to share and energy and love that can create change. I belong to multiple communities. I love all of them. I get to belong in a lot of places and explore other places. I also get to bring people together and create new things with other people.

Last fall, after years of being friends, I got to spend time with Mia Mingus and Sandy Ho. Mia Mingus is a queer disabled korean person who was adopted. She's a writer. She teaches people about disability justice and transformative justice. Transformative justice is a way of dealing with violence that is about what people and communities need, not about what the justice system needs. Transformative justice also helps us think about

why violence happens, so we can stop it before it happens. We talked about what Mia had said at the 2018 Disability and Intersectionality Summit. Sandy started and helped put together the Disability and Intersectionality Summit. Mia gave the big speech at the 2018 summit. It was called “Disability Justice is Simply Another Term for Love.” This quote from it moved me deeply:

> I would argue that disability justice - disability justice the term - it’s simply another term for love. And so is solidarity, access, and access intimacy. Those are just other ways of saying “love.” I would argue that our work for liberation is in itself simply a practice of love and it’s one of the deepest and most profound practices of love there is…And the creation of this space is also an act of love.

What Mia means by this is:

> Disability justice means that in our fight to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. When we say disability justice we mean all that[11]. But we also mean that we love

[11] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in

the people who are most shut out and have the least. When we use other words like solidarity, which mean supporting and working with people against the ways the world isn't fair, we also mean we love the people we support and work with. When we use the word access, we're not just talking about getting rid of the things that stop disabled people from being in the world and doing what they want to do. We're not just talking about making sure disabled people can get into buildings, use tools or enjoy events. When we use the word access we're also talking about loving disabled people. And when we talk about access intimacy, which is that feeling when people understand each others' access needs, we're definitely talking about love. When we work together to correct the ways the world isn't fair, that's love. That's one of the most important ways we can love. And creating this space, the Disability and Intersectionality Summit, where we can talk about how we can correct the ways the world isn't fair together is an act of love.

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plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

Magic happens when brilliant disabled people are together. Mia, Sandy and I talked about how we could share the ideas above in a creative and fun way. We created a new project: #AccessIsLove.

We had these goals when we started the #AccessIsLove project:

- Make people understand that access is more than following the rules in the Americans with Disabilities Act. The Americans with Disabilities Act is a law that is supposed to make sure that big companies, groups and some buildings are accessible to people with disabilities. People also need to understand that access is about all the other parts of someone's life.
- Get people excited to make access something they do everyday.
- Get people excited to support a lot of different people working to make the world more fair. Disabled people and non-disabled people all have important things to give and to do to make the world a better place.

We made a list of writing and people that will help people understand access and disability justice. We also gave people ten steps that they can

take to start thinking and making decisions about access. We designed some tote bags, t-shirts and mugs to share these ideas with other people.

I'd like you to think about these questions:

- Who do you love? Who are your people?
- How do you show love for all the people in your life?
- What does it mean to support and help other people?
- What are the ways that access, solidarity and disability justice are love?

The big ideas and systems that shape our world help decide who we love. We show who we consider family through our actions and words. It's not easy or simple, but I hope everyone will find their people. I hope everyone finds ways to express love for everyone in their life each and every day.

Suck It Ableism

Plain Language Translation Note: This piece is an image. You might want to look at the original picture too.

Suck It Ableism! Ableism is the way the world favors people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[12]. Suck it means: Fuck off! Suck it means: We don't have to listen to you! Fuck off Ableism!

It's also a joke because Alice needs plastic straws to drink and eat. So the image is telling everyone who would take away plastic straws because of ableism to fuck off.

[12] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

Culture

I am a mutant. And I want people to know who and what I am. I tell people because, hey, if we're going to have a problem with it . . . I'd like to know.
—KITTY PRYDE, ALL-NEW X-MEN #13
Kitty Pryde is a mutant who can walk through walls. She's also great with technology, can dance really well and speaks a lot of different languages.

Which means:

I am a mutant. A mutant is someone whose genes are different from everyone else's genes. Genes are the parts of a cell that tell a body how to work. I want people to know who I am. I want people to know I'm a mutant. I tell people I'm a mutant because, hey, if they're going to have a problem with it, I want to know.

Without community there is no liberation. —AUDRE LORDE
Audre Lorde is a Black lesbian writer. She wrote about a lot of different subjects but she always wrote to make the world more just.

Which means:

Without our community we can’t be free.

The One Percent Disabled Club

A conversation with W. Kamau Bell on the **Denzel Washington is the Greatest Actor of All Time Period** podcast, Episode 63. Shared on January 21, 2016.

Kamau Bell: Welcome Alice Wong, to **Denzel Washington is the Greatest Actor of All Time Period**. Thank you for coming on.

Alice Wong: Thanks for having me. I'm thrilled!

Kamau: Thank you! We met at a show that I did in Berkley, **Home by 10**. You came to the show and afterwards we talked and took a picture. And then, Kevin and I talked about the movie **The Bone Collector**. It was just the two of us. And in the middle of the review I thought, "I really don't know enough about disabled people to really know that part of this movie". So we should talk about that part of **The Bone Collector**. Because it's important that the character, Lincoln Rhyme is disabled. So Adam Hartzel talked to me on Twitter and he said that I should talk to you. I saw your picture and was like, "Why does she look familiar?" And then you sent me the picture of us at **Home by 10**.

Alice: That picture was proof I had met you.

Kamau: Yeah, proof!

Alice: I need to thank Adam for suggesting I talk to you. And I'm happy to talk about how disabled people think about stuff like **The Bone Collector**.

Kamau: Yeah, I really appreciate you doing that. And to let people know, on Twitter, your @SFdirewolf.

Alice: Yep.

Kamau: That's a lotta Twitter name. Direwolf sounds like it's a superhero or something.

Alice: Direwolves are from **Game of Thrones**. I don't know if you watched it?

Kamau: Oh! No, sorry.

Alice: You got to get into **Game of Thrones**!

Kamau: I just don't like fantasy Alice! It's funny because my cousin loves N.K. Jemisin. N.K. Jemisin is a really good fantasy writer. One of her books was in the New York Times top 100 Notable books of 2015.

Alice: Wow.

Kamau: And I've never read any of them.

Alice: You are a bad cousin.

Kamau: She likes fantasy, I don't.

Alice: You're not a blerd, a Black nerd? A nerd is someone who really loves a subject and knows a lot about it. Nerds often love science fiction and cartoons.

Kamau: I'm a blerd, but I like superheros, not full on swords.

Alice: Have you ever heard of Cyborg?

Kamau: Yes! **Teen Titans**!

Alice: Yeah.

Kamau: See, I'm old-school Alice, I know **Teen Titans**.

Alice: Not only is Cyborg Black, he's disabled!

Kamau: Oh, that's so funny to think about because Cyborg, for people who don't know, he's a cyborg. Which is why his name is Cyborg. He's a Black guy who is part machine. Alice, this is why I'm glad I'm talking to you. Cause you kinda blew my mind. I never thought of him as being disabled.

Alice: Oh my god. Well, my friends and I, we use technology every day. Lots of us have technology that's on our bodies, attached to our bodies. I

joke to my friends all the time that we're already cyborgs. We are already living in science fiction. We're just already there.

Kamau: Yeah, it's coming. It's coming.

Alice: Yeah!

Kamau: So, we're here to talk about **The Bone Collector**. Alice, you made me watch **The Bone Collector** again!

Alice: I made you? You made me watch **The Bone Collector**.

Kamau: It's true. And it's a Denzel Washington movie that I didn't like. I looked at what I thought of it the first time. I gave it a "Led Astray", which means it wasn't good. We watched it early in the podcast and… I think I didn't want to watch it. I don't like police movies where they have to find the killer. I mean, I did watch **Law and Order**, we all did.

Alice: Yeah.

Kamau: So, Jeffrey Deaver wrote some crime novels. They're all about this character, Lincoln Rhyme. And the book was made into the movie **The Bone Collector**. The movie stars Denzel Washington and young Angelina Jolie, who plays a police officer. Lincoln Rhyme is a police officer whose spinal cord was hurt. The spinal cord is made of nerves that connect your body to your brain. So after Lincoln Rhyme's spinal cord is hurt he's quadriplegic. Quadriplegic can mean a lot of things. For Lincoln Rhyme it means he can't move his arms and legs. He had to stop being a police officer. He was a really good police officer. But then the police ask him to help solve these murders by a serial killer. A serial killer is someone who likes to kill a lot of people. Basically it's a movie about finding out who the killer is. It was made in the late 90s. The people who made it probably saw **Seven** and really like that movie.

Alice: Right.

Kamau: There's a lot of blood. There's this thing that happens where in every scene someone walks around a corner and gets scared. But they didn't need to be scared. So, that's the plot. Also I didn't like it.

Alice: Oh, go on.

Kamau: So, have you seen this movie before?

Alice: Yes I have.

Kamau: My mom says that at some point, she saw every movie that Black people were in. Just because there were so few movies with Black people. And she was so excited to see Black people on the screen. Even if she didn't like the movie, my mom was really excited. Is it the same for you to see disabled people on the screen? I know this is different because Denzel Washington isn't quadriplegic. But did you go see the movie because Denzel is playing a quadriplegic?

Alice: I don't remember if that was why I saw it. But I do remember that it does show life for disabled people. So some things did feel true to me. The equipment he uses felt true. The camera shots from his bed felt true. And the way people treat him felt true. And I thought that was unusual. You don't see many movies where the main character is a disabled person.

Kamau: For Denzel as an actor, it's a pretty difficult role. Denzel isn't an action movie hero, but people like how he moves. He's known for his walk. So, in this movie he's a character who stays in his bed for the whole time until the very end. I think that was probably one of the reasons Denzel wanted to do this movie.

Alice: Yeah, and I think this is where some of my friends in the disability community and I get mad. Non-disabled people playing disabled people is Oscar bait. Which means that non-disabled people just get given Oscars for playing disabled people.

Kamau: Oh, yes.

Alice: I mean, characters with disabilities are assumed to be a stretch. It's assumed that it's really hard for actors to pretend to be disabled. It's assumed that disabled people's lives are really different from other people's lives. Which is rude. And it's rude when people think non-disabled actors are so great for playing disabled people. Like **My Left**

Foot. And that movie about Stephen Hawking, **The Theory of Everything**.

Kamau: Yes.

Alice: Disabled people shouldn't just be for non-disabled actors to show off by playing them.

Kamau: I just want to make this clear. I just said it was hard for Denzel to play a disabled character and you called bullshit on that. Thank you, Alice.

Alice: Sure.

Kamau: I appreciate it.

Alice: I know actors want to be different. It's an interesting role for Denzel and really different from what he had done before. There's nothing wrong with that. But it's weird to think that it's brave for non-disabled actors to

play disabled people. It means disabled actors don't get to work. And it says that disabled people's lives are really horrible.

Kamau: Yeah, yeah it's interesting to think about how Lincoln, who Denzel Washington plays, is the only disabled character in the movie.

Alice: Yes. But then again, this movie is about Lincoln Rhyme and his Padawan. Padawan is a word from the Star Wars movies. It's the word for someone who learns from a Jedi Knight or Jedi Master.

Kamau: His young Padawan! But let's talk about if you think Denzel did a good job of playing a quadriplegic in the movie?

Alice: Well, I'm not quadriplegic myself.

Kamau: Okay.

Alice: But I do use ventilation to breathe. So he uses what I think is a sip and puff ventilator. You saw that little straw that's on his bed. So he sips on that and the ventilator pulls air out of his lungs and pushes it in. And

that was nice because you don't see that used in movies that often. I think you see his hospital bed, and then later on in the movie you see his wheelchair. And that wheelchair looks right. I have to give the people who made the movie that.

Kamau: They didn't give him a hoopty? A hoopty is an old car in bad condition. I'm using hoopty to talk about the wheelchair.

Alice: No, they did not.

Kamau: They got him a nice sedan.

Alice: Yeah. And I like how he talks to his computer - I think that was a bit ahead of its time in the 90s.

Kamau: Yeah, we talked about this when I talked about **The Bone Collector** before. **The Bone Collector** is showing technology that's really ahead of its time. Which leads to one of my favorite things on the show. I call him Al Bundy, but what's the name of the actor who plays Al Bundy?

Alice: Ed O'Neill.

Kamau: Ed O'Neill. So at one point everyone is talking about how they need to search everywhere for clues and he says, "Check the internet." As if that's a thing.

Alice: Yes, I remember that chess game Lincoln Rhymes plays on the internet.

Kamau: Yes.

Alice: It's so old-timey. And it makes you think, shouldn't Lincoln Rhyme have been watching porn on the internet?

Kamau: And the movie starts pretty dark. It starts with him talking about how he's trying to decide how to kill himself. Because he has nothing to live for.

Alice: Yeah. I have two sections in my notes, the nice parts of the movie and the problematic parts. Problematic is when someone or a story says

something negative about a group of people. Lincoln deciding how to kill himself is in the problematic part.

Kamau: That's two weeks in a row we've done Denzel Washington movies that are problematic.

Alice: I think you should use the word problematic a lot on this podcast.

Kamau: Yes. And what do you mean? What is problematic about Lincoln wanting to die?

Alice: Well, I guess this is similar to people who were injured recently or recently disabled. They can't imagine a future, they don't want to live their life, they feel trapped in their bodies. And they feel like they "want dignity." Dignity means feeling valued and respected. They feel like their life doesn't have dignity. They feel like they've lost control over their life.

Kamau: Yeah.

Alice: At the same time Lincoln Rhyme has a lot of money. He has a lot of skills. I think the Ed O'Neill character talked about Lincoln and said, "This guy is a genius. He's written books, he's given talks." Lincoln can still do those things.

Kamau: Oh yeah.

Alice: Right.

Kamau: Yeah.

Alice: No one says you need to have two working legs to write a book or to work with the police. So it's really sad that Lincoln Rhyme thought his life wasn't worth living. That shows how a lot of people think about disability.

Kamau: Oh!

Alice: If I can't breathe without help or if I can't move without help my life isn't worth living! And that's a really able-bodied point of view. And I'll tell

you, Kamau, people have told me, “Oh my god! I can’t imagine what it’s like to be in a wheelchair.” And I’m like, “Yeah.”

Kamau: Whoa! People have said that to you?

Alice: All the time! People don’t think. They just think that everyone wants to be non-disabled, right?

Kamau: Yeah.

Alice: And people truly believe that everyone who’s disabled should want to be non-disabled. And they never stop to think what’s wrong with that though.

Kamau: Yeah, and I hear what you’re saying. The movie doesn’t explain why he wants to die. It starts with him having a nightmare about how his accident happened.

Alice: Yeah, he’s been through some hard stuff for sure.

Kamau: The movie doesn't show how his life is so bad that he wants to die.

Alice: Right, I mean, did you see his apartment?

Kamau: Yeah, his apartment is nice! It's huge! I don't know how he got all that space in New York.

Alice: Oh my god. Also, he has all the equipment he needs. He has a loyal and amazing 24-hour nurse played by Queen Latifah. That was one of my problematic parts. I was like, he's got a job and he has great insurance to pay for lots of help.

Kamau: Cheer up!

Alice: He has this nurse who never takes a shift off.

Kamau: Yeah, she's just there all the time.

Alice: I mean, hello! That is, you know, the one-percenters of disabled people. One-percenter means extremely rare and with a lot of money.

Kamau: Yeah.

Alice: There are not a lot of one-percenters out there.

Kamau: Wow, I didn’t even think about that. Like, he’s living better as a disabled person than most able-bodied people are. And I couldn’t see that. I don’t think a lot of able-bodied people would.

Alice: Hell yeah. So he wants to kill himself because he’s rich, smart and has great support.

Kamau: Yeah. It’s not about a disabled person on Medicaid. Medicaid is the program that pays for a lot of health care including helping people live in their home. Medicaid doesn't pay for a lot of the support people need, only some. And if you have Medicaid you can’t have a lot of money.

Alice: For sure. And his apartment. For anyone to get a place that you can use a wheelchair in like that.

Kamau: Yes, I'm being sarcastic here, but his apartment doesn't have a water view. You didn't notice that, Alice. How can he be forced to live in his gorgeous apartment with no water view?

Alice: He does have a visiting falcon. Falcons are very fast birds that hunt for their food.

Kamau: That's right!

Alice: The people who made the movies are really obvious.

Kamau: A bird, who is free to go wherever it wants to, visits him to show how trapped he is.

Alice: And in the end he becomes the falcon. Not really but he has wings because he can work with Angeline Jolie's character.

Kamau: Oh, and he got a nicer wheelchair. And at the end, he and Angelina Jolie are flirting.

Alice: Oh, at the station? Yeah.

Kamau: Yeah, when she's trying to help him get something out of his lap. And he says, "take your time." Like he wants her hands in his lap.

Alice: Also, didn't he seem to change really suddenly at the start of the movie? He was making plans to die and suddenly he wants to solve the case?

Kamau: Yes.

Alice: That was before he even met the Angelina Jolie character. This movie isn't good at showing characters' reasons for doing the things they do.

Kamau: Yeah.

Alice: It’s actually the photos of the crime scene that get him interested in living again. So a serial killer saves Lincoln Rhyme.

Kamau: You’re funny. The people who made the movie should have hired you to write the words on the poster. But it is funny. If I were single and sad and Angelina Jolie started coming to my house, I would be far less sad.

Alice: And I think it is nice. She doesn't give a shit about his attitude you know. She doesn’t feel sorry for him. She calls him out on his bullshit and that's nice. Sometimes people get really thrown when they meet disabled people. And they try to be super nice. Or treat disabled people like children. Angelina Jolie doesn’t do any of that.

Kamau: No.

Alice: I thought that was nice. And it’s pretty clear that Lincoln Rhyme and Angelina Jolie’s characters like each other a lot.

Kamau: Yeah.

Alice: And it's super close and a little sexy, him talking to her through her ear piece.

Kamau: Yeah, it is. I don't know if I buy that by the end, they're a couple. Like the end of the movie says that they're now dating.

Alice: Yeah. It does.

Kamau: Well, the end of the movie happens a while after the first parts of the movie, so maybe they get together. At the end, she's at his house for Christmas. She calls his sister to come over and she puts her hands over his hand. Touching hands says that they've been having sex. I want to see a movie about that relationship. That would have been interesting. They could have made more movies but they did not.

Alice: I would prefer a follow-up to **Devil in a Blue Dress** over **The Bone Collector**.

Kamau: I think you're right. So anything else in your problematic list?

Alice: That he has lots of money and great nursing care all the time.

Kamau: Yes.

Alice: To me, that is not true.

Kamau: So basically you need a scene where he calls the nurse, Thelma. First, let's talk about how Thelma is one of the most classic Black names ever. So he calls for Thelma. And then the other nurse comes in, who is not Thelma, who is mean, doesn't care, doesn't pay attention and doesn't like his falcon.

Alice: Yeah. Thelma is not just a nurse, she's a lot of other things. Did you notice how many things she did that a nurse wouldn't do?

Kamau: Yeah. That a nurse would also pick up dry cleaning seems weird.

Alice: She was teaching Anglina Jolie how to access online files too.

Kamau: Yes. [Being Lincoln] “Get her up to speed on the computer.”

Alice: I’m being sarcastic, but, “You think I went to nursing school for this?”

Kamau: Yeah.

Alice: Not to pick on the small things too much.

Kamau: No, that’s why I wanted to talk to you. I missed all those things. Like, I was just thinking that Denzel Washington was acting well.

Alice: Yeah.

Kamau: I just thought it would be hard for Denzel to play a disabled person. And then I thought about what happens. Which is -

Alice: What happens is really the least interesting thing about the movie.

Kamau: Yeah.

Alice: I think they did try. They made the movie really gross. But the killer wasn't that interesting.

Kamau: Yeah, it's the thing where you think the killer will be one guy. But you know it's not going to be that guy because the people who made the movie want you to think the killer is that guy. In **The Bone Collector** they want you to think it's the angry police detective. But it ends up being some guy you never knew.

Alice: Yeah, and I was really sad that the killer ended up being his respiratory therapist or someone who works on Lincoln's ventilator. And he killed Thelma! No!

Kamau: That was the saddest part of the movie, when Thelma died.

Alice: Totally sad.

Kamau: No one wants to see Queen Latifah die in a movie.

Alice: I know!

Kamau: And then the other thing is that Lincoln fights the killer. Lincoln falls out of bed. Lincoln bites the guy in the neck.

Alice: Yeah!

Kamau: I don't know that I could ever bite some guy in the neck. I wouldn't be able to do it. I would have to say to him, "I think you need to beat me up sir." In the book he bites the killer in the neck and the killer dies. But in the movie Angelina comes in to help him.

Alice: I didn't like that. It's a scary scene. I use a hospital bed, I'm attached to a lot of devices. If the power goes out, or someone pulled me down…to me the fear was real.

Kamau: Oh wow.

Alice: And I just loved that scene. As a physically disabled person you're vulnerable, but if you also need power to breathe you're even more

vulnerable. I thought he was just going to play dead. But Lincoln talks really quiet and gets the guy close to him. And then he uses the physical ability he has, his voice, his mouth. And then he bit the killer! I really wanted to see more blood fly, okay?

Kamau: [Laughs]

Alice: Lincoln bit the killer's neck! There should have been more blood.

Kamau: You just said the movie was gross earlier. Now you want more blood.

Alice: Just to add to Lincoln beating the killer. Because there's an idea that disabled people can't defend themselves. They need help, they're weak. And it was nice to see Lincoln biting the killer and not needing help.

Kamau: And Lincoln uses the killer thinking that Lincoln needs help to get him close enough to bite him.

Alice: I just didn't think there was enough blood. And I was sad that Angelina got to shoot the killer.

Kamau: When they go back and make this movie again, you can add more blood and get rid of Angelina shooting the killer. Lincoln can kill the killer by biting through his neck.

Alice: And then he finds he has a taste for blood.

Kamau: The next movie is **Bone Collector II: Taste for Blood**.

Alice: And then Lincoln starts eating the marrow. The marrow is the center of the bone. Get it?

[They laugh]

Kamau: Bone marrow! Because it's **The Bone Collector**! Well done. This whole conversation has been a set-up for that bone marrow joke.

Alice: I've done my job.

Kamau: You've done your job. And I'm glad I got to talk to you about this movie. I learned a lot about it and see it in a different way. And now maybe I'll start watching **Game of Thrones**.

Disability Fight Club

Plain Language Translation Note: This piece is an image. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

The time is meow. This is a play on words for, the time is now.

Ableism won't stand a chance. Ableism is the way the world favors people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[13]. We're going to fight ableism and get rid of it.

[13] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

Cat Life (artwork and captions by Sam Schäfer)

Plain Language Translation Note: This piece is a cartoon by Sam Schäfer[14]. Here is the plain language translation of the words in the image. But you might want to look at the original pictures too. They're pretty great.

I love cats. They delight and amaze me.

Everyone knows that cats know how to live.

Humans have a lot to learn from cats.

Cats are very clear about what they like and don't like.

Cats spend most of the day sleeping, playing and doing what makes them happy. We could learn from cats how to love ourselves better.

[14] Sam Schäfer is a queer and blind artist and writer. If you want to see more of his work you can go to his website here.

Cats sit and sleep wherever they choose. They don’t question if they belong somewhere. They belong everywhere.

Cats work together to get what they want. They fight for what they want. Enemies of cats should be worried about what cats might do.

When people think they’re in charge, cats say no. Cats are in charge! Cats judge anyone that is wrong. Cats especially judge anyone pretending to be right and good.

Cats are assholes when they want to be.

Cats have boundaries. This means they let you know how you can act with them. If you touch a cat and the cat doesn’t want you to touch them, the cat will let you know it’s not okay.

Cats give love and get loved. But they decide when and how they give and get love.

Cats know what's going on around them. They notice small things that mean something isn't right.

Body positivity is the idea that everyone deserves to feel good about their body. Self-care is the idea that people should protect their happiness and health. Both of these ideas have ended up doing harm instead of doing good. Instead of setting people free, the ideas of body positivity and self-care are used to sell people things. I have thought a lot about what body positivity and self care should do. I think cats are the best model of what body positivity and self care should be. Cats let themselves enjoy their lives and have good things. Cats lie in the sun, eat as much as they want and hiss at people they don't like. I'm trying to do these things too. It takes practice to live the Cat Life, but eventually I'll do it.

So even if you're not a cat person, you can find the cat inside of you. Let the cat inside of you out! That means act like a cat by enjoying your life and your body.

How I spend my Caturdays (and Nights) at Home

Get Out of Bed and Sit On the Toilet For a Good 20 to 30 Minutes

Plain Language Translation Note: In this piece I've kept the food words that aren't common. It's important because Alice loves those foods. If those words are confusing it may help to look up a picture of that food.

I sleep with a Bipap machine, a machine that pushes air into my lungs. When I use the BiPap machine and sleep with my mouth open, my stomach gets full of air. I feel full of air and gross after I get up. Babies have lots of gas. I understand why they're so cranky! So I start what I call the "degassing process."

Gas and not being able to poop… Human bodies are really picky. It's easy to make humans feel bad. Sitting on the toilet, taking my time, is the closest I get to meditation. Meditation is when you train your brain to think a particular way. Often people do meditation to feel calm. I feel calm on the toilet. When I sit on the toilet my mind goes to all kinds of places. Sometimes I think up a sentence or a title for some new writing or a new project. I sit and think. Eventually my neck hurts from holding my head up

and my legs fall asleep. Then I know I need to get back into my wheelchair.

Wakey Wakey

After getting dressed, I have my first meal. There are three parts to my meal (plus pain pills):

- One big-ass mug of coffee (dark or medium roast).
- One huge spoon of creamy peanut butter.
- One sweet treat: a cookie, doughnut, slice of cake, a pastry.

When I drink coffee, I try to be present in that moment. The first taste at a perfect temperature feels like I'm stopping time. When I drink coffee, I feel like I am one with the universe. Then I'm ready for the rest of the day. The hot coffee runs down my throat to my stomach. It feels like a hug with energy. I think, "You've got this, Alice. Let's fucking do it."

The coffee isn't as good twenty minutes later. But I'll still drink it. I want quality, but I'm not ridiculous. At the same time, I hold the spoon with the peanut butter and lick it. My tongue is hot from the coffee, so the peanut

butter gets soft. (If you want to think sexy things here, go for it.) This means it's easier for me to eat the peanut butter, which is a really important source of protein. The sweet treat goes perfect with the taste of my coffee. I don't put sugar in my coffee, just milk or whipped cream. I eat my breakfast in front of the T.V. I watch the news. I catch up on what's happening in the world. Then I start my day.

Tweets, Zooms, Texts and More

I usually get up in the afternoon. Often I meet people on the Internet then. Or I'll meet people in the afternoon and then again after dinner. While I'm waiting for someone, I check my Twitter, texts and WhatsApp chats. Sometimes I'll look at Facebook Messenger and Instagram. Every day there are usually a couple of people asking me to share something on social media. If people want me to write back they usually need to wait. If someone on Twitter just wants me to share something I can usually retweet it easily.

Post Meeting Administration

After I have a meeting, there's usually a shit load of things I need to do. I try to do these things right away. If I don't, I'll forget. I use the stickies and notes on my MacBook Pro and Iphone to remind myself of what I need to do. I am always looking at my to-do list. I ask myself, what is the most important thing to do? I also put reminders in both my Calendar app and my Google Calendar. Reminders tell me to do something. So if the reminder isn't in one, hopefully it's in the other calendar and I'll still remember. And still, I'll mix things up or forget something. C'est la frickin' vie. Which is sort-of French for, "That's life, get used to it."

It's a Chinese Thing

A few hours after breakfast I drink at least one hot mug of water. I love hot water and don't understand why more people don't love it too. As I'm writing this, white people haven't figured out how great hot water is and I hope it stays that way. But sometimes the water is too hot and I burn my tongue or throat. Once I had a very hot coffee with chocolate and burned my upper lip. I only noticed I'd burned my upper lip later. I knew because my lip got big. But making my body warm with hot drinks is worth the risk.

I’m really careful now. I start with dainty little sips, the size a kitten could drink.

Relaxation and Doing Nothing

I will watch TV for several hours. I switch between shows and I fast forward through others. I like to relax after eating. I hate going right back to work. I am that bitch who has a lot of TV options. I have cable, premium cable channels, a D.V.R., and subscriptions to a couple of streaming services. I can watch TV on my computer, phone, wherever. But I can’t give up the TV even though I know that makes me old like the dinosaurs. Food delivery and a whole lot of TV shows and films add a lot of joy to my day to day life.

Inbox Hell

There are days when I’ll check my inbox early in the day. Usually if I check my inbox early it's because I know there’s an important email coming. But usually I don’t look at my email until after most other people stop working. I used to not check my email every day. But there were so

many emails when I didn't check it. I'd feel the same way about looking at my emails as I did about looking at a dead body full of gas. So now I check it every day. I also spend a lot of time getting rid of email and moving emails around. This helps me deal with my email. But I feel really weird that I spend 2 to 3 hours on emails every day.

Here are some of the emails I get:

- Would you like to present at a conference, submit an essay for publication, or give advice?

There's a number of different replies. Sometimes I say no, thank you, and suggest other people who would be better. Sometimes I ask the person lots of questions about money, access, time and why they want to work with me. Sometimes I say yes right away if I feel like I can add something.

I have a speaking agent: Emily Hartman of Steven Barclay Agency. She figures out if, when and how I give talks. Paying Emily to sort out my talks was one of the best things I did. It was too much work to fill out all the paper to get paid by a university, group or a company. I could write a book called The Unpaid Work of Getting Paid, because it took so much time. It might sound fancy to have a speaking agent, but it's an important

type of support. Having a speaking agent means I can spend more time on my work and less on filling out paper. I hope everyone gets the help they need to make their work a little easier.

- Random question or request for information or advice

Sometimes if I've got energy I do a quick search and offer some ideas. Sometimes I let people know that I don't know the answer to what they're asking. Sometimes I give the information they need from me like when I'm free. Sometimes I tell people my opinion is not actually important or that I can't give advice on a subject. Sometimes I let my auto reply, the email that gets sent to everyone who emails me, let people know what I can and can't do. But sometimes people don't read my auto reply!

- Personal messages I actually like reading

Sometimes I set a date to catch up with someone. Sometimes I ask people how they are. I am so happy to talk with someone about something that's not about work.

Meal

For this, I try to eat something that is soft, easy to swallow and high in calories. Calories are the energy in food. If I talk for too long then my throat is tired. When my throat is tired, it's more likely I will get something stuck in my throat. On the days I'm worried about getting something stuck in my throat I usually eat something like soup. Sometimes I eat a bottle of Boost, which is a drink that is supposed to be a meal. It doesn't taste good. But it has a lot of protein and vitamins and minerals - all things my body needs. I can't eat vegetables or fruit or thick and chewy meats. So Boost gives me what I'm missing and helps me stay the weight that I am. Staying the same weight is really hard with my type of disability. And no, I don't want any advice on what to eat.

More Doing Nothing and Administration

During the day I often look at Twitter. Twitter sends me to a lot of different places on the internet. Maybe I end up watching a Youtube video, shopping or looking at books and writing I'll never read. I also spend a lot of time talking about other people in group chats with my sisters or

friends. Twitter and group chats are the main ways I connect with other people other than Zoom.

No More Messing Around

Later is when I get down to business. I write emails.

Here are some things I might do:

- Answer interview questions or decide what I'm going to say for a talk.
- Send interview questions for the **Disability Visibility Project**. When people ask me to talk to them on my website or podcast, they think it's easy to ask good questions. It's not! I spend a lot of time thinking about what to ask people. Sometimes people never answer, even after a reminder.
- Put up new writing on the website and schedule tweets about the new writing.
- Write and schedule a new newsletter. In my newsletter I give away books by disabled people.
- Look at other people's work and give advice.

- Give advice to businesses and non-profit groups whose board I’m on. Boards are groups that help run businesses and non-profit groups.
- Make images and write out what is in those images for social media and my website.
- Make sure my website runs properly. Often I need to clear the cache, which means the place where your internet saves information so it doesn't need to download that information again and again. Clearing the cache usually makes websites work better.
- Schedule meetings and send email reminders.
- Share people’s work and talk about how great other people’s work is.
- Write down my ideas for books like this one.
- Financial stuff like paying bills and keeping track of money.

I do all this. And I also do all the work of being disabled. The work of being disabled is:

- Giving people information.
- Planning meals.
- Getting medical supplies.

- Finding information.
- Scheduling help.
- Talking to doctors.

And don’t forget the work it takes to keep track of all of that. And the work it takes to keep your feelings in check and be nice to people while doing all of that.

Snack and Relaxation

More hot water and a smaller snack. Snacks are little bits of food. Maybe a spoon of peanut butter, a bowl of yogurt with peach jam, a sliced banana, some applesauce or a bowl of ice cream.

Sleepy Time

Time to sleep. I brush my teeth, spend some quality time on the toilet thinking. I take more pain pills. I’m ready to sleep. I need my sleep to be a scary badass and hopefully appear in someone’s nightmare.

Disabled Faces

This is a discussion with artist and author Riva Lehrer for the **Disability Visibility Project** blog. It was shared on December 9, 2020.

Alice: Hi Riva, please tell us who you are. Share a little bit about yourself.

Riva: Okay, So, I'm sixty-two. I'm white, I'm Jewish. I'm short, I'm under five feet tall. I have spina bifida so I have a curved spine and large shoes. Those large shoes are a big theme in my life. I have white hair that I streak red. That's what I look like. I'm telling you what I look like for Blind people's access. I'm also telling you what I look like because in my book, **Golem Girl: A Memoir**, I talk about what I look like and how people treat me because of it.

I'm from Cincinnati, but I've lived in Chicago for over forty years. I'm a portraitist. That means I paint portraits, pictures of people. And I mostly paint people who deal with stigma. Stigma means that many people don't like a particular group of people. That could be because the person is disabled, or the person loves or has sex with people who aren't the opposite gender, or because their gender isn't the same as the gender

the world decided they were at birth. Anyone who has gotten the message that their body or the way they are is not okay. People who deal with all that are beautiful to me.

So for 25 years I've been doing portraits of disabled people. At the beginning, I was one of the only people doing it and there are still not that many people doing it. My pictures are a way to talk about disability that isn't about what doctors think about the person. My portraits are a part of disability culture, which is a way to share part of our lives.

Alice: On October 6, 2020, your first book came out. It's called **Golem Girl: A Memoir**. First, congratulations! What has it been like since your book came into the world?

Riva: Strange. The people who make books thought a lot of people were going to buy the book. They made a lot of copies. But there's been a lot of things happening in the world. When the book came out there was Trump, and COVID. Ruth Bader Ginsberg, who was a judge on the Supreme Court, just died. Amy Coney Barett became a judge on the Supreme Court. So it's been really hard to get journalists to write about my book.

Journalists are people who write or talk about the news. The most attention I've gotten has been from Jewish journalists. So I'm disappointed but I also hope that this book sticks around for a long time. And hopefully I get to see more and more people read it.

But I'm also really angry that we're dealing with COVID and no one is talking about disability. You know? My editor, the person who makes sure the book is good, said, "Your book is going to be important. There's COVID. Everyone is dealing with illness and the right to health care and all of this. Your book will help people talk about those issues." Instead, no one is talking about my book. And no one is talking about disability issues. I'm shocked.

Alice: What do disabled people say about this book? It's clearly something written by one of us for us.

Riva: Yes.

Alice: So what do disabled people who have read it say?

Riva: So far, I haven't heard from a lot of people. But the people who I have heard from liked it. I'm sure some people won't like parts of it. And there are certain things that I've said that people can argue with. But the support from disabled people has been great. I hope that when it starts to be read in schools, that's when I'll be able to have interesting talks. I am getting nice phone calls and emails. And nice notes from people who read it. I couldn't be happier about that. That's kept me going. It was really hard to write. If I had written a book just for disabled people, it would have been a different book. I wouldn't have had to start at the beginning with disability. Because I knew if I didn't explain disability from the beginning, non-disabled people wouldn't know what I'm talking about. So I was trying to balance talking to us, disabled people, and talking to them, non-disabled people. I guess time will tell how well I did.

But I was happy that the book is about how great disabled people are. I want to keep talking about disabled people as a culture, as a community. When I was writing, there were people who wanted me to just focus on my life. And I said, "The point is that you need to understand disability culture because disability culture is part of my life." I ended up doing what I do because of my personal experience. But it was the fact that I'm part

of disability culture that was important to me. I wanted to bring people's attention to disability culture. I wanted to talk about the beauty, how there's nothing else like it, the way we can keep changing that I see in disability culture.

Alice: What do you love about painting other people, especially disabled people?

Riva: Oh god, everything! People's faces and bodies say so much. Especially as we get older, we start to really know our bodies. And the person you are on the inside shows more and more on the outside. I like looking at pictures of people when they were younger. I like thinking about that earlier version of the person and the person I know now. But the thing about disabled bodies, the thing I find beautiful is that there's a kind of presence. I think it's because we are so often looked at. I think it's like so-called 'normal' people are driving in the dark. They don't know where they are, they don't know where they're going. They feel empty to me.

With disabled people, their lives are hard-won. You can see that. I think of it like something that is on their skin. I don't really have words for it. But I see this kind of light and presence in disabled people. That's what I love.

Alice: Thank you. Could you describe this portrait you did of me, what the piece is made of and what it looks like?

Riva: It's on something called mylar vellum. Mylar vellum is plastic you can draw on. It's about 17 by 22 inches. I drew it while we met on Google Meet. So we were talking. I was drawing while we were talking. So you're looking straight at me like you have something important to say. People say a lot how fierce your eyes are in the picture. People feel like they have to stop when they see the picture. That makes me happy because I feel like that's how you are in real life.

So, in the picture you're wearing your BiPap ventilator, which is milky white and blue. A BiPap pushes air in and out of your lungs so you can breathe. And there's a purple ring around one of the hoses. So it has beautiful colors like the sky. And that's against the gold and pink of your skin color and your reddish-brown eyes. Behind you, there's a little bit of

your wheelchair. Then a door to the rest of your apartment and some art on the wall. Then I drew a frame around the photo. The same way there would be a frame around you in Google meet. So I tried to show what we were doing. So that people knew that the point was we were talking over the internet.

Alice: It was really interesting when you posted a photo of that picture on Facebook a few months ago. And I remember one of your Facebook friends said, “She looks tired!” And that was the first thing she thought when she saw me. And I thought, “That’s all she saw?” And I learned from that. I learned everyone will have different feelings about bodies and age. But I thought it was really interesting. I think she mentioned the dark circles under my eyes. I really wanted to say, “You know lady, if only you knew half the story!” But I didn’t say anything. Life is too damn short. I can’t waste my time on Facebook.

Riva: That’s part of what I call “pain reading.” It happens with my pictures over and over again. As soon as someone sees a wheelchair, or crutch or an adaptive tool, I think they see suffering and misery. Because that person’s brain has been shaped by ableism to assume that disabled

people are miserable. And if you show a disabled person being happy or sexy or just complicated, people assume they're covering up how bad it is. Those people can't actually see you in the picture. I think the picture shows you being strong and at peace. But my friend saw your BiPap machine and was upset. I'm working on getting people to see anything else.

Alice: I think it's so important to have different kinds of pictures of people. You don't need to explain the pictures. Sometimes people will see what you want them to see. And sometimes other people just see the circles under my eyes. That's fine. To each their own! Could you talk a bit about how the way you make pictures has changed over time? I think the portrait you did of me was the first time you did a picture over the internet?

Riva: Right.

Alice: How did that change how you think about painting people? How did it change the relationship with the person you're painting?

Riva: So, from the beginning of painting disabled people, I wanted to make sure the people I was painting were in charge. I knew that being looked at, for disabled people, is complicated. Sometimes being looked at is really painful. People feel ashamed. It was important to me not to do that. It was important to me that people not remember feeling ashamed. But I didn't know how to do it at first. It took a really long time learning to listen to the people I was painting. You can always be a better listener. There are times when I mess up, but I really try. And I want to give people a choice. I am never going to force people to be painted a particular way. It has to feel okay with them. I've tried so many ways to give people as much power as possible.

But working with you over Google Meets made me think about some things. It made me think about access. I've been only painting people who could be in the same room as me. Which means coming to my home, which is not accessible enough for a lot of people. My bathroom isn't accessible. My elevator is tiny. A power chair won't fit in my elevator. So there were a lot of people I couldn't paint. But I wasn't thinking of ways around this. I realized this was one way to paint people who could be in

my house. You can change. Even when the pandemic is over, I want to keep painting people over the internet.

But it's also about wanting and being apart and missing people. Everyone hates Zoom and Google Meets and video calls. And yeah, if I'm on video calls all day, I'm pretty tired. But I am sitting here looking at you. I'm really happy to see you. I'm really happy to see you and to have you see me. And I just feel like, "God those whiny people!" I live alone and video calls are the only times I get to look at someone. And they look at me. I'm grateful for that.

Westward Ho

This is a 2020 interview by Grace Bonney with me and Sandy Ho. Sandy is the founder and co-organizer of the Disability and Intersectionality Summit. Intersectionality is the way that all of these things connect:

- Disability.
- Race.
- Gender.
- The kind of schooling you have.
- The amount of money you have.
- Who you love.
- Who you have sex with (or don't have sex with).

All these parts of you either make you more likely to experience good things or bad things in your life[15]. The interview is about Sandy's and my friendship. It's for the book **Collective Wisdom**. **Collective Wisdom** is a series of conversations between younger and older people, where the younger and older people share their knowledge.

[15] This definition owes a lot to an interview with Kimberle Crenshaw. Kimberle Crenshaw thought up the word intersectionality. You can read more here: https://time.com/5786710/kimberle-crenshaw-intersectionality/

Grace: Alice and Sandy, how did you meet and become friends?

Sandy: I think it was around 2011 or 2012. I don't really remember. But I was running the Thrive mentoring program. The Thrive program was in Massachusetts. It worked with young women with disabilities who were between the ages of 14 and 26. The program put those young women with older women with disabilities. The older women with disabilities would share what they knew with the younger women. So it was different. Usually mentoring programs for youth with disabilities pair them with non-disabled adults. One of the activities I had the women do is write a letter to themselves when they were young. I wanted to get the younger and older women talking about issues that would have been harder to just talk about. And because of that I was looking for other women with disabilities on the internet.

I was just starting to think of myself as disabled. I was starting to think of myself as a disabled young woman who is a part of a big community. And I was looking online and I found Alice Wong's work. I don't know why I sent a cold email. Because I was just this person just starting to get into

disability community. So I sent Alice an email saying, “Hey, we’re doing this Letters to Thrive project on Tumblr. I would love to meet you.” And then, Alice answered!

Alice: And the rest is history! I think now I don’t answer cold emails as much. I think Sandy emailed me at a good time when I wanted to answer.

I remember getting the email from Sandy. I thought the project, Letters to Thrive, was lovely. Letters to Thrive was all about helping young people, but also about hopes, and dreams and thinking about your past. I thought, oh my goodness. What a gift to have this project on Tumblr. Tumblr is a social media website. I know we’re dating ourselves because it’s Tumblr and Tumblr is old. But I thought, what a gift to give people a chance to share their stories.

I think Sandy asked if I’d be interested in writing a letter to my younger self. And I told her, “I have a piece that just came out in an Asian American studies journal called **Amerasia**.” I think that was one of the first times I wrote a piece about who I am as a disabled Asian American.

And this was a special issue on disability and elders. Elders are older people who know a lot.

I think that's when our friendship started. We started sharing information. I started learning about Sandy's work. I was so impressed by the way she cares about disabled young people. She works with a lot of young disabled women and young girls. She's so cool. I knew she was someone I was going to be friends with. I think we became friends right away.

Sandy: Yeah, so many people on Tumblr were so excited by the Letters to Thrive project. The young women and the mentors really just expected to read each other's letters. But they let me post their letters on Tumblr. And then disabled women from across the country and the world found the posts. And disabled women from across the country and the world sent me letters. I didn't expect that! The letters made me and the people in the Letters to Thrive program realize that we have people who support us. That we can feel proud of ourselves and each other.

I think Alice was one of the first disabled Asian American folks I became friendly with in a real way. A lot of my friendships were set up by people

trying to help me or teachers or parents. So my friendships felt forced. But being friends with Alice was natural. I was ready to be friends with Alice. Alice helped me a lot. I tell young people, your community will be there for you when you're ready. Older people are responsible for supporting young people.

Grace: Can you remember a moment when you knew your friendship was something special?

Alice: Well, we've been friends for a few years. But I think this year for me, we've really been there for each other. COVID and all the things we've been involved in are hard. We text each other, check on each other. We give each other space to relax and talk. We don't have to talk about changing the world. We don't have to talk about disability. We can talk about other people. I know I need that. COVID has made my relationships with my friends stronger. Now I know who I can call on. And I'm grateful for that.

Sandy: For me, the moment where I realized Alice was my friend was that she made it clear that she's there to answer the questions no one

else is talking about. So for example, I've spent most of my career not making a lot. Being an activist, someone who is trying to change the world, means you don't have a usual job. So when people ask me to train them, Alice reminds me that I'm more than teaching about disability. I'm more than just being there so people can say that there was a disabled Asian American woman in the room. Alice reminds me that my work is important. Alice reminds me that I'm part of what disabled people are trying to build.

Alice also answers the hard questions, like, how much money do you ask for? How do you tell your parents you don't want to go to school and you want to be an activist for a bit? Those are really difficult questions that can change someone's early disability community activism career. And I think there's lots of people in our community right now who don't have someone to answer those questions. I hope the people who don't have Alice to answer questions have someone like her. Having someone to answer the hard questions and cheer you on is important.

Alice: I think a lot of Sandy's questions are about knowing the world you're working in and how to make it work for you. I am a bit older than

Sandy. I have made some mistakes, right? I value sharing and a relationship with someone a bit younger than me who I trust. I don't want to do this for everyone, right? I don’t see our relationship as me teaching Sandy because it's really about two equals. Although sometimes Sandy calls me an older sister. And I guess I can be like an older sister. I can be as bossy as an older sister! I am the older sister in my family. So I can be a sister.

But Sandy knows just as much as me. I see Sandy as the future. It’s really important to me that the next generation of disabled activists can challenge the way the world works. I think this has to do with me knowing that I’m going to die one day. I ask myself, what can I share that’s going to be helpful? What can I share that’s helpful that I can’t say to everyone, but would really help Sandy and the people that I care about? I feel like it’s a way I want to help people. But I don't feel like I have to do it. It’s about love. I love disabled people and I want to make sure that young disabled people get seen, heard and supported.

I think young disabled people are still really alone. They’re not aware that they have rights. They don’t feel like they are a part of a group of people.

And that's okay too, right? Like, no one should ever feel like they have to belong to the bigger community of disabled people. But I think for those people who do want to be part of a bigger disability community, they want to know other disabled people. And Sandy and I, we have a lot in common because we're Asian American. But not just because we share culture. We get along because we just click and we love food and all kinds of things. So we're not friends just because we're both disabled Asian American women. Sometimes people think that all disabled Asian Americans know each other. And no. But Sandy and I know each other.

One of the things I'm most proud of Sandy for is the Disability and Intersectionality Summit. Sandy created it and makes it happen. It started in 2016 and it happens every two years. There was one in 2016 and another in 2018. Then the one in 2020 didn't happen because of COVID. And in 2021, the Summit was on the internet. The Disability and Intersectionality Summit is such an important example of bringing people together to learn together and take action on their shared issues. I respect Sandy so much for her work and leadership. She asked me to be in the group of people who decide what's most important for the Summit to work on. I got to see the way she helped get people to agree, worked with all

kinds of people, managed people who don't get along and solved problems. She is dedicated to disability justice and making sure that disabled people who are treated badly or don't get chances because of other parts of their identities get heard. It makes me feel good to be around that.

Sandy: Thanks Alice! One of the most powerful moments for me was in 2018. The Disability and Intersectionality Summit has always been in Massachusetts. But in 2018, we also had part of the conference in San Francisco. In 2018, one of the things we did was celebrate the first collection of writing that Alice self-published. That collection is called the **Resistance and Hope** anthology. I feel really lucky to be able to make events like that happen but also to be able to celebrate my friend was wonderful. I felt like, okay this is why we are friends. This is why we work together and we make plans together.

I wish I could have been in San Francisco for that. I was in Boston. But then after the conference I went to Chicago and then I went to San Francisco. I wanted to visit the disability community in Chicago. They've got great people at Access Living. But I always wanted to visit San

Francisco. San Francisco is the place where the independent living movement started, where disability rights started. The independent living movement was people with disabilities fighting to live in their communities and to make decisions about their own lives. I so wanted to visit San Francisco. And of course, my work around the Intersectionality Summit and disability community meant I wanted to visit my friends who I'd never met in person til that moment.

Getting to meet Alice in person was amazing. She was so warm. This is just what Alice does. You think she'll do one thing and then she just does it times a hundred. She brought her friends and community to meet me. To say to me, "Hey, this is who we are. This is what we're doing.This is what we're about." It was great to not talk about activist work but still be together.

Alice: Yeah, I love to host people. I think about how I haven't left my home since March. I think about how lucky I was to have parties or to have friends over. Wow. At least Sandy and I got together once when she was here. And we got to meet a few times. At least we had that. Meeting up with Sandy is very special to me.

Sandy, do you want to talk about the question and answer in 2016 with you? The question and answer was an event to tell people about the summit and get them excited. And I think that maybe, it was the first time you called yourself a queer disabled woman. You're queer because you love or have sex with people the world doesn't think you should. So I think that might have been important for you? Do you want to talk about what that meant to you? If it meant something to you?

Sandy: Yeah. You want my work to succeed. But you also want me to learn about myself. That's been so important to our friendship as well. It's because of Alice that I was able to call myself queer in a disability space and feel comfortable doing that. I knew her, what she stands for and I trust her. Trust is really important in friendships and bringing people together to make change. Because you need to trust the people you're working with if you're going to take risks. That's what helps us keep pushing and growing. That moment where I called myself queer was a long time coming. I needed the space and the person and to find the right way. I didn't want to say it on Facebook or on Twitter. But it was important to me to be able to call myself queer in a way that I knew would be

respected, because it’s Alice. And I knew that it would be important to other queer disabled people of colour who are looking for other people like themselves.

Alice: I think that moment showed me that our friendship had changed. You felt safe to call yourself queer with me. It wasn't something I asked because I didn’t know. I just wanted to ask you questions. But the fact that you felt safe and comfortable enough to call yourself queer meant a lot to me. That’s the world we want to create, where everyone can be themselves and not have to explain anything or worry about anything. That’s the future. That’s what we're working towards. We’re not there yet. I think of us as always building towards justice. And I think that’s just one example of the ways we can support each other to build towards justice. We should be there to support each other in the big ways. But also in the smaller ways that are harder to see. I think that’s what happens in friendship too.

Grace: That’s so lovely. I’m curious. I think this might be a hard question to answer. What do you hope your friendship brings to each other?

Alice: I'm older than Sandy. So I hope to help Sandy make her dreams real. I want to see her do whatever she wants to do. I want to make sure that Sandy knows she has choices and she has a lot to offer. One of the things I hope is part of our friendship is me gently saying, "Apply for this," "Try that," "Do this." It's bossy of me, but I think we all need someone who sees that in us. Sometimes we talk ourselves out of doing things. We think, "I'm not the right fit." Or, "it's not something I know anything about." But I'm going to be the person who says in Sandy's ear, "Do it, do it!"

Oh, that sounded weird. But I'll be weird if that's what helps Sandy do the things she wants to do. I'm ready for Sandy to take over the world and I want to get the world ready for that.

Sandy: Yeah. Part of getting the world ready for me is Alice using a hashtag that is #WestwardHo because she wants me to move to California.

Alice: Someday Sandy is going to move to the West Coast. So I'll just say: #WestwardHo. I'll put it in a text: #WestwardHo. Don't forget,

#WestwardHo. It’s not happening yet but it will. I think the universe will make Sandy move west. It’s #WestwardHo 2024 or bust!

Year of the Tiger Crossword

This is a crossword puzzle. A crossword puzzle has boxes in lines that go up and down. The lines cross each other so there are boxes that are part of two lines. There are clues to help you guess words. You figure out the clues to fill the boxes with letters that make up the words. I haven't given a plain language translation because crosswords are supposed to make you think hard. The answers are on the page after the clues.

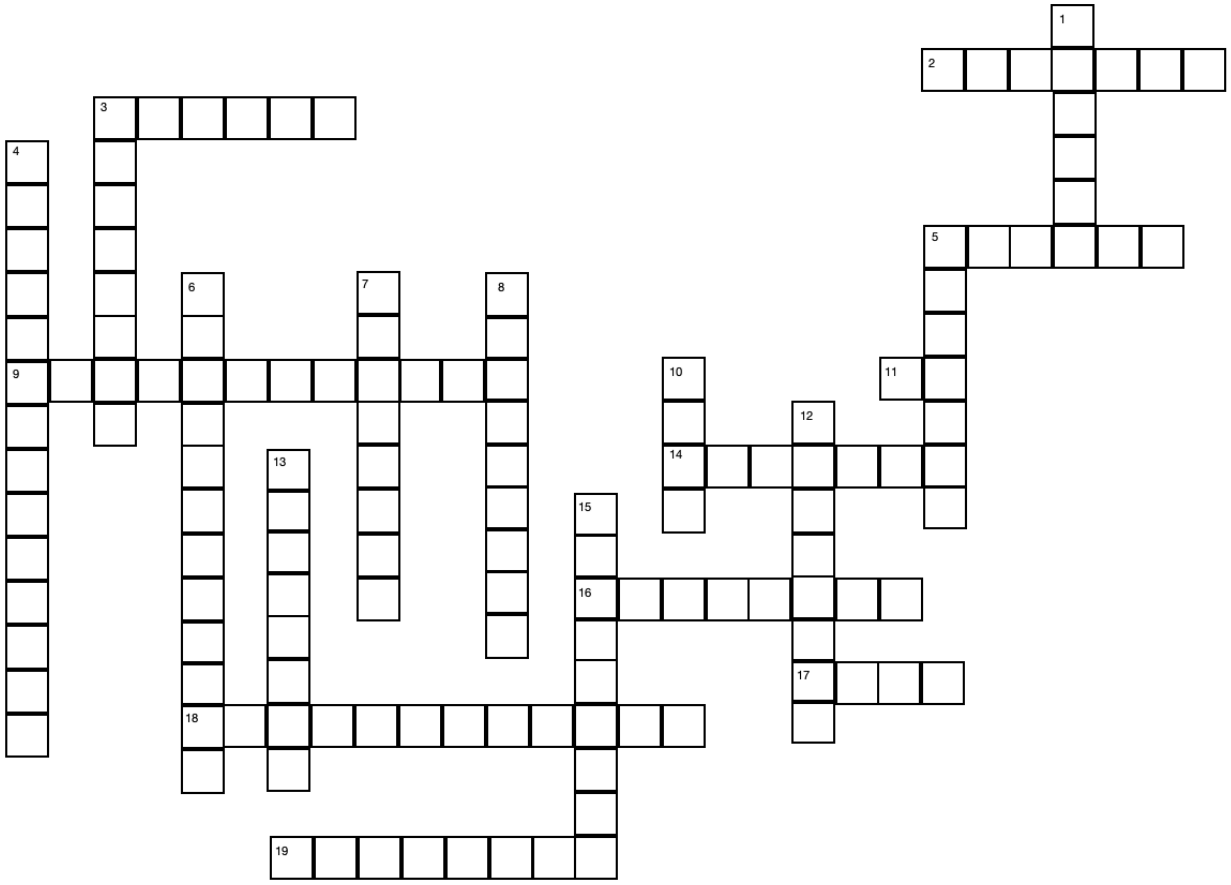

Image Description: A crossword puzzle has boxes in lines that go up and down. The lines cross each other so there are boxes that are part of two lines. The boxes are empty. This crossword puzzle has eleven words that go up and down. It has ten words that go side to side.

Clues for the Boxes Across

2) Watch it jiggle (6)

3) Hot yoga (6)

5) A form of love (6)

9) Northerners (12)

11) I *heart* _____ (2)

14) Resistance is futile (7)

16) A lifeline (8)

17) #____The Vote (4)

18) Cross-training routine (12)

19) It’s alive! (8)

Clues for the Boxes Down

1) Cassandra-esque (6

3) Every day (8)

4) Care is _____ (14)

5) Suck on it (7)

6) Hoosier city (12)

7) “Greetings, Mork!” (8)

8) Not so easy (9)

10) A fave word (4)

12) Shady scam (8)

13) Peachy keen (8)

15) Show me the money (9)

Answers for Boxes Across

2) Watch it jiggle: MARROW

3) Hot yoga: COFFEE

5) A form of love: ACCESS

9) Northerners: SHANDONGNESE

11) I *heart* __: ME

14) Resistance is futile: CYBORGS

16) A lifeline: MEDICAID

17) #____TheVote: CRIP

18) Cross-training routine: INTERVIEWING

19) It's alive!: EUGENICS

Answers for Boxes Down

1) Cassandra-esque: ORACLE

3) Every day: CATURDAY

4) Care is _____: INFRASTRUCTURE

5) Suck on it: ABLEISM

6) Hoosier city: INDIANAPOLIS

7) "Greetings, Mork!": NANU NANU

8) Not so easy: BREATHING

10) A fave word: FUCK

12) Shady scam: NORMALCY

13) Peachy keen: MASUMOTO

15) Show me the money: DUMPLINGS

Lunar New Year Memories

Plain Language Translation Note: A lot of this piece talks about food. I've decided to keep a lot of the food words that aren't common. It's important because Alice's family eats those specific foods. If those words are confusing it may help to look up a picture of that food.

I wonder what it was like for my parents to move to Indianapolis from Hong Kong in the 1970s. They had no friends, family. They didn't know anything about American culture. Two years after they got to Indianapolis they had me. Then they had my sisters Emily and Grace. One big part of missing home is missing Chinese food. When I was in grade school our family took weeks off. We would go back to Hong Kong for Lunar New Year. We would listen to our family speak Shangdonese loudly. We would smell incense in the streets. Incense is something that is burned because it smells good. And I remember eating all the best food.

Lunar New Year is a week. During that week guests would visit my grandparents' two bedroom apartment in North Point. The guests would bring fruit, or alcohol or 紅包 hóngbāo, the lucky red paper with gold,

folded into envelopes. The 紅包 hóngbāo were for the kids and had money inside. How much each kid got was decided based on who the person giving was and what their relationship was to our family. My sisters and I had never had 紅包 hóngbāo before. We carefully saved all our envelopes. We were planning to go shopping. I never got to go shopping. Mom took all our red envelopes and bought us a Texas Instruments Speak and Spell toy. The toy was meant to help us learn to spell! I am still mad at my Mom. Buying us a toy to teach us to spell was so mean.

My 婆婆 pópo grandmother made fish and chive dumplings for the guests who came to the apartment. Chinese food has to be hot and fresh. So my grandmother had to keep cooking all day. I remember seeing pópo cooking in the small, tight kitchen. She was so tired after she didn't even want to eat. Because of the patriarchy, the idea that men are more important than women, she ate dinner last. She was cooking while everyone else ate. I think about my pópo and wonder if she got to eat dumplings only as a child? Did she ever eat dumplings when she was a wife or mother? Did she get to dip dumplings in soy sauce and vinegar?

Did she eat raw garlic to go with the dumplings? Who gave her food or helped her eat more when she was older?

Sometimes I see how tired my Mom is after she makes dumplings. In my family everyone helps with making dumplings. I used to peel shrimp, but now I don't. Mom makes the dough and filling, which are the important parts. Dad rolls the dough out long and cuts it. Then, he rolls out the dough into a wrapper for the filling. Each wrapper gets dusted with flour. Then Mom and my sister take the wrappers, add the filling and fold the edges into a pattern. I take photos and videos so my sisters and I can save these memories.

When the Center for Asian American Media decided to save people talking about Lunar New Year in 2015, I talked to my mom. I talked to her so that our Chinese American story could be saved for the future. My mom is very outgoing.

Some families ski or camp together. My family, the Wongs, make food and eat together. We talk about, plan and dream about the next meal. Sometimes we talk about great meals we had together. This is the way

our family shows love. This is how we remember our culture and our history.

Alice Wong: My name is Alice Wong. I am 40 years old. Today is February 12, 2015. I'm with my mom, Bobby Wong. We're at the San Francisco Public Library. I'm going to talk to my mom today.

Bobby Wong: My name is Bobby Wong. I'm 65 years old.

Alice: And you're here to talk to me!

Bobby: Yes, you're my daughter, Alice Wong.

Alice: Yay. So today we're going to talk about our memories and about Lunar New Year. We'll talk about the different things we've done for Lunar New Year in the past and now.

Bobby: Okay.

Alice: So tell me a little bit about where you were born. And when you grew up, what was 新年 xīnnián, Lunar New Year, what was that like?

Bobby: I was born in Hong Kong a long time ago. In 1949. We have the Lunar New Year in Hong Kong. It's a major holiday for Chinese people.

Alice: It's like the biggest.

Bobby: The biggest.

Alice: Bigger than 中秋節, zhōngqiūjié, the mid-Autumn Festival.

Bobby: Yes, yes. Because Lunar New Year is a day for the family to come together. It's bigger than Christmas. It has a similar meaning to Christmas. But Lunar New Year is for everyone, the whole village. Everyone has Lunar New Year on the same day.

Alice: So it's really the biggest important day of the year for Chinese People.

Bobby: Yes.

Alice: So tell me how did you celebrate it as a kid? What are some of your best memories of 新年 xīnnián?

Bobby: So, when I was a kid I didn't have to cook anything for New Years. My mom made all the food. All I did was have fun. One of the things I liked the most is eating the money dumpling. You only have money dumplings once a year on Lunar New Year.

Alice: How would you say money dumpling in Mandarin?

Bobby: 錢水餃 qián shuǐjiǎo. Yeah.

Alice: And do many people make money dumplings? Or was that something just your family did?

Bobby: People from the north part of China make money dumplings.

Alice: Oh!

Bobby: I didn’t know if you knew other people from the north part of China who make money dumplings.

Alice: Uh-huh.

Bobby: But I know the Shandongnese do that.

Alice: Both you and Dad are 山東人 Shāndōng rén, Shangdongnese people. So it's funny that you met Dad in Hong Kong. There are so few north Chinese people in Hong Kong. So it’s pretty unusual to have traditions from north China in Hong Kong right?

Bobby: Yes.

Alice: So what is a money dumpling? How does a money dumpling work?

Bobby: So, for Lunar New Year, the tradition is to always make ten things. Ten is perfect. Like you have ten pieces of candy. But money is important. So you put ten 10 cents in the dumplings. Then you make lots

of dumplings for the whole family. You'd cook dumplings for five to ten people. And you only have ten dumplings with money in it. So you'd push the dumplings with your chopsticks to see if there was anything hard in them. And if you thought there was money in it you'd eat it right away.

Alice: So it's like an eating treasure hunt.

Bobby: Yes! An eating treasure hunt.

Alice: How many dumplings would you make for your family? How many dumplings for one meal?

Bobby: There are six people in my family. My mom would make 150 - 200 dumplings.

Alice: Oh my gosh!

Bobby: You make that many dumplings because you need leftovers for a few days. You don't want to run out. So you make lots of dumplings.

Alice: It feels like Lunar New Year is a time you share how well you're doing. Even if you're poor. So you buy new clothes, have a lot of food, and have guests over to party, right?

Bobby: Yeah.

Alice: So even people who don't have a lot of money, they usually buy new clothes at Lunar New Years?

Bobby: Yeah.

Alice: What else did you do during Lunar New Years? Would everyone in your family buy new clothes?

Bobby: Yeah. I grew up in a poor family, but all the kids got new clothes for New Years. I remember once my parents borrowed money to have lots of food and new clothes for us. Borrow means they promised to pay the money back.

Alice: Wow. Did a lot of poor people borrow money for Lunar New Years?

Bobby: Yeah.

Alice: People had to borrow money to keep up with what people have always done.

Bobby: yeah. You try to pay back the money you borrow before the New Year. Then, once you've paid it off, you borrow more for the New Year.

Alice: So pay off the money for last year's New Year to go borrow more money for this New Year.

Bobby: Yeah. But when we had more money we would always have something with red. We would have a red flower on clothes or something like that.

Alice: What does the color red mean in Chinese culture?

Bobby: I think red means happiness. Yeah, like in a wedding everything is red. And the writing paper for New Years is all red. And we wear red

clothes for Lunar New Year. Not totally red, but one or two pieces of clothing. We would wear a red hat or a red blouse or something like that.

Alice: Yeah, the color red means a lot in Chinese culture. There's also signs that you put up on New Year's Day. What are some of the characters on the signs?

Bobby: We put up signs with double happiness. So 囍, which is 喜 xǐ, happiness twice. And then 恭喜发财 gōng xǐ fā cái, wishing someone lots of money and luck.

Alice: Mmm-hmm.

Bobby: And we wrote poems and posted them on both sides of the door. Poems are a type of writing you feel as much as you understand.

Alice: In Chinese calligraphy, right? Calligraphy is a type of art where people mix colors with water on a stone, then use a brush to write characters on paper with the coloured water.

Bobby: Yes.

Alice: People have always put up poems right? You make calligraphy art and then post it. Anyone can do that because all you need is ink and paper right?

Bobby: No, no. Calligraphy shows how much school your family went to. So if you didn't do a lot of school you don't write it yourself. You buy the calligraphy.

Alice: Ah.

Bobby: Or you ask people who are known to do good calligraphy to write the poem for you.

Alice: Wow. So it really shows people who your family is. No?

Bobby: Not really, because everyone does the same thing.

Alice: But you can tell that some people know how to do calligraphy.

Bobby: Yes.

Alice: And other people buy the calligraphy.

Bobby: Yeah.

Alice: So there is a bit of a difference right?

Bobby: Yeah, you can see how much school the family did.

Alice: And I remember the paper is so pretty. The paper is red with little bits of gold.

Bobby: Always.

Alice: It's such pretty paper. And the paper doesn't cost a lot of money and is everywhere, right?

Bobby: No. The red paper with gold is a lot of money. Lots of people don't use that.

Alice: Really?

Bobby: Yeah.

Alice: I remember 爺爺 yéyé, Grandfather used to do calligraphy. I remember seeing that beautiful red paper that the black calligraphy was on. It's so elegant.

Bobby: He always used his best paper to show off his calligraphy.

Alice: Yeah. I remember he used the table we ate at on holidays. You could smell the ink. The ink smells like ink. It doesn't smell like anything else. And he didn't like to be stopped. I remember one time I stopped him and he was mad.

Bobby: Mmm-hmm.

Alice: Writing calligraphy is smooth. Grandfather never stopped moving when he was writing calligraphy. It’s very difficult, right?

Bobby: Yeah, yeah.

Alice: I think I remember you and dad saying that you could see the energy of the person in the calligraphy. I thought that was really cool.

Bobby: Yes. Because when you’re writing calligraphy you have to use 氣功 qìgōng, life energy. You hold your breath, then you pick up the brush. So you have to prepare your mind. You have to know where to put the words and where your hand has to go. Even the space you are working in has to be right. Otherwise it doesn't look right. You have to have 100% focus. So Grandfather didn’t like people stopping him when he was writing calligraphy.

Alice: Especially a little kid who makes trouble.

Bobby: Yeah.

Alice: It sounds like calligraphy is something you do to bring yourself closer to God or the universe. You have to be in the right state of mind to do it. That's not something many people can do.

Bobby: Yeah, yeah.

Alice: People through history taught their children calligraphy and now most people don't know how to do it.

Bobby: Most people use simplified Chinese now. The Chinese government changed the way you write some characters. The changes make them easier to read and write.

Alice: Calligraphy is definitely not simple. There's a lot of symbolism, where one thing stands for another thing. And a lot of art and history that's in calligraphy.

Bobby: Yes. Especially now when everyone uses computers. We use computers to write now. We don't write Chinese characters by hand anymore. Because it takes too long.

Alice: Too many moves.

Bobby: Yeah.

Alice: But we kept the money dumplings. That's one of my favorite things that Dad and you brought from Hong Kong, or from Shandong. When we were young in Indiana, you would make money dumplings with dimes.

Bobby: Yeah.

Alice: I remember we would look for the dumplings with the dimes. But if we pushed the dumplings looking for dimes we had to eat the dumplings we pushed.

Bobby: Yeah.

Alice: So you can't just go pushing dumplings!

Bobby: Yeah.

Alice: Sometimes we would stare at the dumplings looking for the shape of a dime. Sometimes we would look for the bigger dumplings. But it was still hard to find the dumplings with dimes.

Bobby: Yeah.

Alice: It seems like looking for the dumplings with dimes was about getting us to eat more.

Bobby: Yeah.

Alice: Helping people eat is a big part of Chinese culture, yeah?

Bobby: Yes, I agree. When we came to the US, we were just a small family. So I made less dumplings. So it was easier for you or your sisters to find the dumplings with the dimes. And when you found a dumpling with a dime, you would get a prize. Usually the prize is a red envelope with money inside. So yes, just get you to eat more. The more you eat the better.

Alice: Our family has a really great way of sharing the work of making dumplings. Mom, you always make the filling, which is made with 韭菜 jiǔ cài, Chinese chives. Chinese chives look like long grass. One year you grew Chinese chives in our backyard, but the person who cut our lawn thought it was grass and cut it down! Chinese chives smell strong and taste strong. Lots of north Chinese people eat Chinese chives.

Bobby: Yeah.

Alice: And you and Dad would make the dough. You'd cut the dough in two, roll it out long, and then cut it very small into -

Bobby: Round pieces.

Alice: Round pieces. And then you'd roll each round piece flat. As my sisters and I got older we helped. Now Emily and Grace are learning. They don't know how to make the filling but they know how to wrap the dough around the filling.

Bobby: Yeah.

Alice: Which is a big deal. It's really hard to put the right amount of filling on the dough and then pinch the dough into a beautiful looking dumpling.

Bobby: The dumpling has to be fat enough to -

Alice: Sit up. It has to be round.

Bobby: If you don't do it right your dumpling will be flat.

Alice: That's how you know if it's a good dumpling, if it's round. Because if it's round there's lots of dumpling filling. You want a lot of dumpling filling. Sometimes when we were little we would have Chinese friends come over. They would help make dumplings. Everyone has their own way of pinching the dumplings. Sometimes we would have a contest to see whose dumplings were fattest.

Bobby: And who could wrap dumplings the fastest.

Alice: But your dumplings were always the fattest. They were always very good and the wrapper wouldn't let water into the filling when you put them in hot water.

Bobby: Yeah.

Alice: The worst part of dumplings is when they break in the water. That's always sad.

Bobby: Yeah.

Alice: But usually you -

Bobby: But not me! My dumplings don't break!

Alice: No, not you! And you're teaching Emily and Grace really well, too.

Bobby: Yeah. They get better each time.

Alice: Yeah, and now they're getting really good at rolling the dough and pinching and stuffing dumplings. One day they'll need to learn how to make the filling.

Bobby: Yeah, one day.

Alice: Do you think making the filling is the hard part of making dumplings? Is the filling hard because you need to get the taste just right?

Bobby: Yes, I think getting the taste right in the filling is the toughest part of dumpling making.

Alice: You've got to get the spice right.

Bobby: Yes, the spices are important. And the dough has to feel right. Not too soft, not too hard. So that too.

Alice: Emily and Grace are just beginning to learn. I hope they will get to make dumplings a lot.

Bobby: Yeah.

Alice: I think Emily and Grace and I are so lucky to have parents who came to America and who know the old ways from China.

Bobby: Mmm-hmm

Alice: Knowing how to make dumplings, knowing what our people have always done, is something that we can share with younger people in our family, right?

Bobby: Yeah.

Alice: And our culture is really passed through food right?

Bobby: Yes. I have been making dumplings for over forty years. Your sisters are interested in carrying this on. They'll get better at making dumplings and hopefully teach their children how to make dumplings.

Alice: For us, dumplings are about family. We do eat dumplings other times of the year. But it’s always a treat.

Bobby: Mmm-hmm.

Alice: Because it's so much work.

Bobby: And the whole family works together.

Alice: Yeah, there’s always someone who boils the water. And someone who makes the dough. There’s always something for everyone to do.

Bobby: Yeah, yeah.

Alice: And there’s also the sauces, the things you dip the dumplings in and-

Bobby: Vinegar.

Alice: So, also we eat ground garlic. This is another Northern Chinese thing. Dad would crush raw garlic and make a paste with salt, which is super salty, super strong. Dad would eat whole raw garlic cloves with dumplings. And we would also eat crushed cucumber that has been in vinegar and raw garlic. So North Chinese people, we really love our garlic.

Bobby: Yeah.

Alice: But you would eat just a little bit of garlic with your dumplings. And we also used to use half soy sauce, half vinegar. That tastes good with dumplings because dumplings are meaty and it's nice to have a bit of zing with the vinegar.

Bobby: Yeah.

Alice: So who taught you to make dumplings?

Bobby: Obviously, my mother. She needed lots of help, to help her do the dumplings.

Alice: What was your job when you were younger?

Bobby: I started with rolling the dough. That's the first thing you learn. Then you learn to wrap the dumplings. Then you learn to knead the dough. The last big thing is to mix everything together and put in the spices.

Alice: Yeah.

Bobby: That's the very last test.

Alice: That's the hard part, right?

Bobby: Yes, yes, yes.

Alice: So what did you learn from your mom about making the dumpling filling? Did you learn by watching?

Bobby: Yes, mostly by watching. Once you watch enough you know what to put in and how much. Then, when it's time for you to do it, you just copy those steps. And you can taste the filling before you wrap it.

Alice: So, when you were young and your mom made dumplings, did you ever make the filling? Or did your mom always make the filling? Did you ever get to make filling for your family?

Bobby: No, no. My mom did that. Because if I made the filling myself I could ruin it.

Alice: So she wouldn't risk you making the filling.

Bobby: Yeah.

Alice: She was always making the filling.

Bobby: And she always made the dough. Only when I moved to America, I did it myself. So I tried to make it and I learned. For example, once it was too salty so the next time I put less salt in.

Alice: You know, when you and Dad moved to Indianapolis there was a small Chinese community and Bible study group you were part of. The Bible is the holy book for Christians. Bible study groups read the Bible and think and talk about it. Most of the people in the small Chinese community were students at college.

Bobby: Yeah.

Alice: For Lunar New Year you would usually have people over right?

Bobby: Yeah, yeah.

Alice: What did it mean to have a little bit of home for those Chinese students studying in Indianapolis?

Bobby: I was part of the church group that helped overseas students. They didn't have family during the holidays, especially during Chinese New Year, so I would invite them to our house. And I made the dumplings

and other food so that they could have a fun time and wouldn't miss home too much.

Alice: And they would miss home a lot because New Year is such a big deal, right?

Bobby: Yeah, yeah.

Alice: Do you think they liked the dumplings? They probably lived at the college and didn't have any real Chinese food.

Bobby: Yeah.

Alice: So for those students to taste dumplings would have been quite the treat.

Bobby: Yeah. Back in the 1970s, Indiana didn't have a lot of Chinese people. You couldn't get good Chinese food, especially North Chinese food. So the South Chinese students would go to another family's home for Chinese New Year. And all the North Chinese students would come to

our home. So the students could have the same food and do the same things they would have had at home.

Alice: Yeah.

Bobby: So they really enjoyed that and treasured that.

Alice: Yeah, it must have been really sad for you and Dad to be so far from family. When you first moved to the States most of your family lived in China. But then later, lots of our family moved to the States.

Bobby: Yeah.

Alice: Now we've got more family around. But in the beginning it was just you, Dad, me, Emily and Grace. Everyone else was in Hong Kong.

Bobby: Yeah.

Alice: So did it feel weird to celebrate Lunar New Year with just a small group? Or did you feel like it was just something you needed to do?

Bobby: Of course you need to change when you move to a new place. I think we changed pretty quick and made the best of it. And we had the people from the church. We'd see Chinese people there. So it made the change easier and I didn't miss home quite as much.

Alice: Yeah, in a way, the Chinese church was our family.

Bobby: Yeah.

Alice: I thought it was really great when I was young, first or second grade, you and Dad would take us out of school for a month.

Bobby: You remember that?

Alice: You can't do that now!

Bobby: No.

Alice: But when I was 6 or 7 you took us out of school for all of February. We would go back to Hong Kong and celebrate New Year.

Bobby: Yeah.

Alice: It was great. You and Dad got to see your families during an important holiday. And us kids got to learn about what our families do to celebrate.

Bobby: Yes, that was the point. We did that because when you were in kindergarten, first grade and second grade it was not a big deal for you to do your homework in Hong Kong.

Alice: Ugh, homework.

Bobby: But later on you needed to stay in school.

Alice: On the day of New Years so many visitors, family and friends, come to our house. And you'd say hello and invite them in. I don't know how pópo did it but she made so many dumplings.

Bobby: Yeah, yeah.

Alice: It was just a two-bedroom apartment. I don't know where she kept all the dumplings! Every time a guest came you gave them freshly made dumplings.

Bobby: Yeah.

Alice: And she did this for the whole day.

Bobby: Yeah. And people would come by for the whole week too.

Alice: I just remember the day. But it was a whole week!

Bobby: Yeah.

Alice: So you had a whole week of parties. And you and Dad would go out at night and have big, fun dinner parties. Afterwards you would play

mah-jongg. Mah-jongg is a game that uses flat, rectangle pieces and is played with four players.

Bobby: Mmm-hmm.

Alice: But the fun thing about being a kid is that every visitor would give the kids a hóngbāo, a red envelope with some money. And as a kid who grew up in the U.S. I was like “What? You get money on this holiday?” All you had to do was be a kid. And you had to say 恭喜恭喜發財 gōng xǐ, gōng xǐ fā cái!” “Happiness and money!” Then the guest would give you a red envelope. Some of the visitors would give you a $10 Hong Kong dollar bill. That was $15.00 in American dollars. And some people would just give you a dollar. I’d be like, “Aww! This dollar!” and then some people would give a $50 Hong Kong dollar bill. And I would be like, “Whoa!”

Bobby: Yes. How much you give is about your relationship to the family.

Alice: Yeah! And to me it was weird because these visitors didn’t know us. But pópo and yéyé were our grandmother and grandfather so they just

gave it. And they gave out a lot of envelopes because they were going to visit other people too.

Bobby: They would give different money to different children. You want to give the right value of money for your relationship with the family.

Alice: You don’t want to mix up the envelopes and give the wrong money. So tell me why it’s important that the money be brand new. Even in Indiana, you made a point to go to the bank and get brand-new money for the hóngbāo.

Bobby: So everything is new: New clothing, new beginning of the year. So you get new money. Especially for the money dumpling, you want to use new coins.I also put the coins in water with alcohol to get rid of viruses or bugs even if they were new.

Alice: Don’t worry people, it’s not dirty money.

Bobby: [Laughs] Yeah.

Alice: I think when I was a kid I would eat 10 to 15 dumplings to find the coin.

Bobby: Yeah.

Alice: That's a lot. But I remember Dad and one of our uncles, Simon, they could eat thirty, forty dumplings in one sitting.

Bobby: Yeah.

Alice: But Dad can't do that anymore!

Bobby: So let me tell you a secret. When I cooked the dumplings, I knew which ones I put the money in. So I would save some of the money dumplings for the kids plates so it was easier for you to get the money dumplings.

Alice: Ahhh!

Bobby: Otherwise there is no way that you would get the money dumplings. Your dad and uncle Simon would eat so many dumplings.

Alice: So the plate you gave us.

Bobby: Had more chances for you to get the money.

Alice: Awww, you're too nice Mom.

Bobby: That's what moms are for.

Alice: But when I think of being Chinese American, I think about food and dumplings. Because making dumplings is something uniquely Shandongese that we do. And making dumplings is something that we do a lot. We don't stick too close to Shandongnese ways but we do make dumplings a lot. That's something we've been keeping alive.

Bobby: Mmm-hmmm.

Alice: So, you know, what do you want for the future? What do you hope about our family making food that the people who came before us made?

Bobby: For us older Chinese people, especially northern people, we don't say "I love you."

Alice: Right.

Bobby: We can't say that word. But we show it through making you food. We give you good food that makes you healthy. So my job is to keep feeding you. Hopefully you and your sisters learn how to make the food I make so you can continue to do this with your own families.

Alice: Yeah, I really hope so. I think about the future. I think about how you and Dad will eventually die. Everything I've learned about Chinese culture and Shangdongese culture really comes from you two. That's a very special version of our culture you've shared. And we will lose that 30 or 40 years from now. Then it will be our job to pass on that culture.

Bobby: You can make it easier on yourself. You don't need to do everything my mother did. I don't do everything my mother did. Life is really busy for young people. Maybe you can keep a little bit. Maybe you don't need to make the dough by hand. You can buy ready-made dough.

Alice: Nah, not as good!

Bobby: Oh, you have to add to the ready-made dough!

Alice: The memories of it are really special.

Bobby: Just to eat together. The main thing is to be together.

Alice: You share food together. You eat the love. You don't say the love.

Bobby: Yes, yes, you are right!

Alice: That's the Chinese way!

Bobby: Okay!

Alice: Thanks for talking with me Mom!

Bobby: You're welcome. Happy Lunar New Year.

Alice: Yes, 新年快乐 xīnnián kuàilè!

Bobby: Xīnnián kuàilè!

Proust-ish Questionnaire

Plain Language Translation Note: In this piece I've kept the food words that aren't common. It's important because Alice loves those foods. If those words are confusing it may help to look up a picture of that food.

What is your idea of perfect happiness?

- Eating little bits of food and laughing with my sisters, Emily and Grace and our friend, Rani.
- Having afternoon tea with small sandwiches, warm scones, clotted cream and jam.
- Meeting friends for coffee.
- Eating lots of food with my family.

What are your greatest fears?

- Spiders.
- Breathing in water.
- Not having enough help to do the things I need to do every day.
- The power cutting off.
- Having to leave because there's an emergency.

- Not being able to tell people what I want and need during an accident or a medical emergency.

What are your favorite lipstick colors?

- Chanel's Le Rouge Duo Ultra Tenue in "Daring Red."
- The Lip Bar's lipstick in "Merlot."
- Yves Saint Laurent's Rouge Pur Couture lipstick in "Rouge Unapologetic."
- NARS Powermatte Lip Pigment in "Don't Stop."

What cat is most like you?

- The Pallas's cat, a small wild cat. The latin name for the Pallas's cat is Otocolobus manul. The Pallas's cat has light gray fur, small ears and a thick body. Pallas's cats look angry and like they might hit you with their claws.

Which quote from a TV character do you love?

- "This is my design." - Will Graham in the TV series Hannibal (2013).

What is your love language? Love languages are the ways people like to show and get love.

- Closing and then opening your eyes slowly (the same way a cat shows love).
- Writing pretty letters and cards.
- Sending gifts to friends for no particular reason.
- Making people laugh.
- Feeding people.

What sounds do you love?

- Thunder, the loud crash that follows lightning.
- Loud wind.
- Rain hitting the window hard.

What are your strengths?

- Wanting to find out about things.
- Snarkiness, or the ability to say things that are funny and mean at the same time.
- Knowing what I like and don’t like.

Who do you not like the most?

- There’s too many people to list all the people I don’t like.

What do you think people like too much in other people?

- Being on time.
- Being neat.
- Exercising.
- Doing the same thing each day.

When do you lie?

- Often.

What do you dislike about the way you look?

- The way my skin falls off in little bits.
- My bony bits.

What do you like about the way you look?

- My lips. Definitely the best looking part of me.

What words do you over use?

- Abundance, meaning having lots of things.
- Joy.
- Capacity, or being able to do something.
- Resonate, which means to feel the same way.
- Problematic, which means there's something wrong.

What or who is the greatest love of your life?

- Me!!!

What musician do you listen to over and over right now?

- Bruno Mars. I don't know why it took me so long to realize how great Bruno Mars is. That man has talent.

If you could change one thing about yourself, what would you change?

- I'd like to learn another language like Spanish or Mandarin.

What do you think is the best thing you've done?

- Stay alive. Seriously.

If you died and could come back as a person or a thing what would that be?

- I would come back as a ghost to scare all the people I don't like.

Where would you like to live?

- Tokyo. Or New York City if New York City wasn't so cold in winter.

What is your favorite thing?

- My memories. I like to call them my murrmories.

What is the worst thing ever?

- Having to ask the government to help you. I have to ask for Medicaid and it makes me feel like I have no power. I'm trying to live in my community and make decisions about my own life. I want to meet my needs and get my pills. I have to get the help I need from other people and get the medical equipment I need. I have to ask the people who run Medicaid for all of that. Medicaid helps me a lot, but I have to fill out a lot of paper. I also have to deal with people who think my life is terrible. All of which makes me feel terrible.

What's your motto?

- Fuck the fuckers.

What are you grateful for?

- I'm grateful to live now.
- I'm grateful for my friends and family.
- The freedom to make art and writing that make me happy.
- That I get to decide how I spend my time.

How would you like to die?

- I would like to die with friends and family all around me. I'd like to have a big fire in the room I die in. I'd like to have an electric blanket, with cats all around me. I want to finish a spoon of coffee ice cream and smell lemons. I'd like to have a death without pain.

Storytelling

You got to make your own worlds; you got to write yourself in. —OCTAVIA E. BUTLER

Octavia Butler is a Black science fiction writer. She wrote stories about people who work together to find new ways to live.

Which means:

Writing is important because you get to imagine a new world. If you're not important to the world you can write a new world where you are important.

We never know how our small activities will affect others through the invisible fabric of our connectedness . . . In this exquisitely connected world, it's never a question of "critical mass." It's always about critical connections. —GRACE LEE BOGGS

Grace Lee Boggs was an Asian American activist in Detroit. An activist is someone who works with other people to change the world. She worked on a lot of different issues over her life, but often she supported African American activism.

Which means:

We don’t know what our actions will do. We don’t know how we’re connected. Our actions might be very important to other people. Our world is full of connection. We don’t need a lot of people to make change. We need the right connection to the right people in the right way to make change.

Remembering is one way to resist erasure. —MIHEE KIM-KORT
Mihee Kim-Kort is a Korean American minister and writer.

Which means:

When we remember people we lost to racism we are fighting racism. Racism is the violence that people who are Black, Indigenous, Asian and other people of color experience. It is also when the world is set up to give more chances and money to white people than Black, Indigenous, Asian and other people of color.

Storytelling as Activism

A talk with Longmore Institute Director Catherine Kudlick for the fifth annual Longmore Lecture in Disability Studies. This talk happened on April 3, 2018.

The Paul K. Longmore Institute on Disability at San Francisco State University is named after the late Dr. Paul Longmore, a disabled historian and activist. A historian studies history. An activist works with other people to try to change the world. Dr. Longmore is famous for burning his book, **The Invention of George Washington**. He burned it because the money he made from the books meant he might lose his Social Security money. Eventually the Social Security Administration made it so disabled people could make money. The rule that let disabled people make money is called the Longmore Amendment. Today the Longmore Institute shares disabled people's life stories, disability history and disability culture through teaching, research and events. One of the events is Superfest, an international disability film festival.

Catherine Kudlick: It's so great that you're here. I'm really honored to be talking to you because you are known for talking to people. I'm a little scared and excited.

Alice Wong: I'm not ready!

Catherine: So, we'll talk for about forty-five minutes. I have some questions. Can you tell me more about how you met Paul Longmore and how he got you here?

Alice: Yes. I want to start by thanking everyone here listening, and everyone listening on the internet. And thank you to everyone who works at the Longmore Institute.

I am so lucky I knew Paul Longmore. A long time ago in the 1990s, I was a student at Indiana University-Indianapolis. I was living in the Midwest. I felt very alone. Then, I read about disability studies and learned about the independent living movement. The independent living movement was the fight to let disabled people live in their communities. I knew I wanted to go west. I knew the Bay Area would be the place I would feel at home. I was

thinking about going to school in the Bay Area. One of my teachers, Dr. Carol B. Gardner, knew Paul. She just gave me Paul's telephone number. His home phone number! [laughs]

I felt so small, small as a mouse, calling up this guy Paul Longmore. And we talked. I just asked him, "I'm a disabled student who's thinking of going to University of California San Francisco. What do you think? Can I do it?" And he said, "You can do it. Just come to San Francisco. You're going to love it here."

At the time I felt a bit scared. Moving to San Francisco felt like such a risk. I didn't know if I could do it or not. And Paul was just so sure that I could do it. He was excited for me to move without even knowing me. When he did that I started to understand the power of the disability community. I didn't have disability community when I was growing up in Indiana. And I knew I wanted to find disability community. So I'm so thankful because he was the first person I met in the Bay Area disability community.

Catherine: That's great. So, Alice, everyone has the first time they become an activist. Do you remember when you became an activist?

Alice: I think as someone who was born with a disability, I always had to be an activist. I first got into activism when I studied at University of California San Francisco. I got involved with a group started by three disabled and Deaf students, Michele Gomez, Maria Lopez and Dana Odom. It was called the Disability Interests Group. It brought together teachers, staff and students at University of California San Francisco. We realized there were a lot of issues no one was working on. People made solutions for themselves, but this didn't solve the problems for everyone. So, after a few years, we got the university to start a group that would give the university advice on disability issues. That shows me the power of working together and also the need to think carefully about how you push for the change you want. And also that you need to be patient - changing things takes a lot of time.

Catherine: So what about the activism of the **Disability Visibility Project**? That's another kind of activism. It's not protesting, going out on the streets with a lot of people to ask the people in charge for change. But talk about why you decided to start the **Disability Visibility Project**?

Alice: Yeah, I started the **Disability Visibility Project** because I was really angry that disabled people couldn't see themselves in history, in the news or in pop culture. Where are our stories? Why aren't our stories being told to lots of people?

I have always been a fan of StoryCorps. StoryCorps works across the United States to help people tell their stories and the stories of people in their community. When I started the **Disability Visibility Project** they had a location in San Francisco. I went to an event where they were talking and they talked about all these ways they were working with Bay Area groups. So I asked them if they worked with the Bay Area disability community.

They were like, "No, we don't."

I'm like, "Do you know how rich and cool and powerful our community is?"

I thought, "This could be my thing."

I could use StoryCorps because they had a lot of what I needed set up. Anyone can go to them and tell their story. It's free and you can have your story in the Library of Congress. To me that was the hook. It was giving all of us a way to tell our own stories, in our own words. We weren't waiting for someone who studies history to think we're important. The idea of making a record of what my community felt like now and sharing it with future people was really exciting to me.

I thought I would spend one year doing this. I would just meet my friends. I would talk to people I thought were wonderful even if not everyone knows about them. I really wanted to tell the stories of the people not everyone knows about. Because it's really about them. To me, sharing our stories is activism.

This bit of sound is from a **Disability Visibility Project**. It was made with help from Allison Lee from our local radio station K.A.L.W. and it was shared on the show **Crosscurrents**. You'll hear Hana Baba, the host of the show, introduce a story about the 504 sit-in. Then Jessie Lorenz and Herb Levine will talk about the sit-in.

Hana Baba: This is **Crosscurrents**. I'm Hana Baba. Protesting, going to a public place with a lot of people to demand change, is part of Bay Area culture. Recently there's been the Black Lives Matter marches, before there were the AIDS activists of the 90s and before that the anti-war demonstrations of the 60s and 70s.

There's also the fight for disability rights. The 1973 Rehabilitation Act gave disabled people across the United States the same rights and protection as other people. But even though this was law, disabled people weren't treated like they were the same. So in 1977, activists across the country went to federal government buildings, sat down and wouldn't leave. This is called a sit-in. In San Francisco, the sit-in went on for 25 days. At the end of the sit-in, the government brought in a law that said it was illegal for any program getting money from the federal government to treat people with disabilities differently from other people. This was the law that would lead to the Americans with Disabilities Act of 1990. Herb Levine joined the protest in 1977 when he and a friend came across the sit-in and decided to stay. Levine and 2 other people would sneak in and out of the building. They had to make sure the guards didn't spot them.

Herb shared his story with friend and former coworker Jessie Lorenz. They talked in the StoryCorps space at the San Francisco Public Library.

Jessie Lorenz: Tell me about the clergy. Clergy are people who can do religious work.

Herb Levine: [laughs] The guards kept stopping people from coming back to the sit-in. People would want to leave, take a trip, walk around the block, go home or something. And when they'd come back the guards would say, "No one gets back in except support workers and clergy."

We actually had clergy there. There was this guy Norm, who was a minister. Eventually the guards said that only people who were clergy could come and go. So I went out to get some stuff for people. I slept in my own bed that night. And the next morning I came back. The guards came and they said, "You can't come in here."

I said, "Oh, you know, I'm not really going to come in. I'm Reverend Levine and I'm here to ask if my singing group has come? We're here for Easter services."

The guard went over to the desk. I heard him say, “I don’t know, some Reverend.”

The guards called upstairs and then he told me, “No, they’re not here, would you like to come in and wait?”

I said, “No, that’s okay. I’ll wait outside for a bit.”

I’m waiting outside and who the hell do I see but Jim and Gina Ann coming down the block in their wheelchairs. I just thought, “How the hell do they think they’re getting back in?”

I think I said something to them like, “Don’t say anything, just follow me.”

I knocked on the door and I said, “Two people from my singing group are here. I think we should go in and get ready.”

And they let us in.

Jessie: Oh my god. That's awesome. That's such a great story.

[music]

Catherine: So okay.

Alice: I love that story.

Catherine: It's such a great story. What is the same in your activism and the activism that Herb is talking about? Because I can tell you feel something when you hear that story.

Alice: Well, I do think this story is an example of the people who history doesn't remember. Every group has so many people that history just doesn't know about. I think stories like this show all the humor, joy,work and the new things that happen when people come together and decide to do something. That's a really beautiful thing. That's what I love about being part of the disability community. People don't realize how smart we are. People don't know how much we can do with very little. We are the real trouble-makers, right? Disabled people are the people who figure out

how to use everything, to make it into something that works for them. To me, that’s activism too. It's a way of being, figuring out your way through the world.

Catherine: And to figure things out with what is thrown at you. So suddenly you have something new.

So you can tell from all these things that Alice has been doing that Alice is at the center, but she’s not. She makes things happen in a way that lets people be their very best. She lets people share their activism and their stories and their experiences. That’s a powerful thing. It’s not, Alice Wong wants you to think this. It’s that the world needs to know this. And that’s a very wonderful thing.

I want to end by asking you to ask the audience something. Ask them something you want them to think about.

Alice: I’m actually really enjoying talking to you Cathy. You’ve been very kind.

So the late Harriet McBryde Johnson once called storytelling a way to survive. She writes in her book **Too Late to Die Young**, “Stories are the closest we can come to shared experience.”

I think of storytelling as a chance to know ourselves better. We get to question who we are, where we’ve been and who we want to be. Each person has an entire universe inside of us. So my question for you all is: What is your story? How do you want to share it with the world?

If you aren’t ready to share, then tell your stories to yourself. Let your stories feed you and guide you. Your stories should make you happy. They don’t have to make anyone else happy. When you’re ready to share, it’ll be there with other disabled stories, pushing against the stories the world likes to tell about disabled people.

Big Pussy Power

Plain Language Translation: This piece is an image. You might want to look at the original picture.

Big Pussy Power. Pussy is a word for a type of genitals. Sometimes people talk about big dick energy. Dick is another type of genitals. Big dick energy means you know you’re good. But you don’t have to talk about how good you are. You know you can handle most things but you don’t need to say that. Maybe big pussy power means the same thing?

Diversifying Radio with Disabled Voices

Shared on the **Transom Blog** on May 10, 2016

Radio was something I always liked. I never thought it was something I could tell stories with. I did a Community Storytelling Fellowship at Making Contact. A fellowship is when someone has a short time with a group to learn or do something. Making Contact is a group that makes media that thinks carefully about social and environmental issues. Social issues are things that are issues for groups of people. Environmental issues are issues with the planet like climate change. I prepared by reading writing from Transom and the Association of Independents in Radio about talking to people, telling stories, and production. Production is how you make a radio show.

I felt nervous as I read about “how to do radio.” There were some parts that were very physical like holding a microphone close to a person for a long time. I asked, “Where do disabled people like me fit in the radio community? Why doesn’t writing about diversity in radio ever talk about people with disabilities?” Having a lot of different people doing a job or an art form is a type of diversity. Al Letson’s 2015 **Transom** call for change

talks about the straight white male voice being the only voice that's heard on radio. Al Letson is a Black writer who also works on radio and podcasts. It rang true to me right away. I'd add that most of the voices on the radio are able-bodied too.

Good Voices/Bad Voices

Radio can be a familiar friend, a way to learn. It can let you know where you are and what's happening. But radio shows only part of the world. Radio shares the world's understanding of disability. One of the ways radio does this is through what people understand as a good voice for radio. A good voice for radio:

- Is nice to listen to.
- Is clear.
- Can share ideas easily.
- Doesn't make you think of disability when you hear it.

When we think that only good radio voices belong on the radio we forget that disabled people exist. Dr. Bill Kirkpatrick studies disability media. He wrote about how disabled voices and bodies are shut out of radio in a

2013 book chapter, “Voices Made for Print: Crip Voices on the Radio.” He says:

> There is no shortage of self-evident reasons why non-disabled voices thoroughly dominate radio, not least of which is the commercial imperative: broadcasters want listeners to stay tuned, therefore they find speakers and speaking styles that audiences are willing to listen to, with voices that listeners can easily understand and find pleasing to the ear. While undoubtedly sensible as a matter of capitalist logic, however, we need to question the aesthetic reasoning at the root of this supposedly listener-centered approach to speaker selection as well as the idea that “pleasing to the ear” is somehow a sufficient explanation for the absence of disabled voices on the radio . . . We cannot begin to expand the range of permitted voices on radio without simultaneously undermining the ideologies of ability and disability that disqualify those voices in the first place.

Dr. Kirkpatrick means by this:

> There’s lots of reasons why there’s only non-disabled people speaking on the radio. The big reason is that the people who make radio want people to keep listening. So the people who make radio

> find voices that people will listen to. These voices are easy to understand and people like listening to them. But, we need to think hard about this. Maybe the idea that people on the radio need to be easy to listen to does not totally explain why there are no disabled people on the radio. We can't start to listen to other voices on the radio without asking what we think about ability and disability. Those ideas of ability and disability are what kept disabled people off the radio in the first place.

When people talk about making sure there are lots of different people on tv, in films, on radio and writing, I can see myself as a disabled woman of color. But often, people don't talk about disability because people don't see disability as culture. For radio, this is total bullshit. Disabled voices would make public media better.

Letson says in his **Transom** manifesto:

> Stories are told that are incomplete, cultures are discredited because they don't conform. We are a symphony with one instrument playing all the parts. To make the symphony as dynamic as can be instruments must be given to other players.

Letson means by this:

> We don't tell the full story when we leave certain people out of storytelling. We ignore cultures when they don't fit with what we think they should be. A symphony is a lot of people playing different instruments together. Radio with only white straight men is like trying to have a symphony with just one instrument playing. The music would be better with a lot more instruments. Radio would be better with many different instruments (people). We need all kinds of people to make radio something that includes everyone.

We need to talk about disability when we talk about diversity. Diversity is including a lot of people with different life experiences in something. We need to talk about all the people who have been shut out of radio when we talk about diversity. We also need to start thinking of diversity as something that changes groups, systems and structures. Diversity can't just be hiring people who don't usually get the job.

Diversity is a word everyone uses. But diversity needs to mean something. To mean something, it needs to serve the people who have

been shut out and ignored. I really like what Chanelle Adams wrote about diversity in college campuses for the **Black Girl Dangerous** blog. Chanelle Adams is a writer and researcher. She often writes about music, healing and people who live far from their homeland.

She wrote about college campuses:

> This ‘just add and stir’ model for instant-diversity is flawed. . . . I want a diversity that does more than change the faces that surround us from white to Brown and Black, but also demands issues that affect our communities are brought to the forefront.

Chanelle Adams means this:

> We can’t just bring in more Black and Brown people but not change anything else about colleges. I want diversity that changes the faces around us from white to Brown and Black. But I also want diversity that makes our issues, Black and Brown people’s issues, important to everyone.

This idea of diversity can be used everywhere, not just at colleges. This is the really hard part of diversity. I don't have the answers, but I can share my story as a disabled person and someone new to radio.

Story of My Voice

In 2015, I got interested in radio because of a project I worked on with StoryCorps where I would record the stories of people with disabilities. I was worried because telling your story with sound is inaccessible to people who don't use sound to talk. I figured out ways to give access to people who talk with sign language or without speaking. I thought more and more about radio. I started to ask if disabled lives, voices, and bodies are part of public media.

Even with a healthy set of lungs, I have a weak diaphragm. Your diaphragm moves your lungs to make you breathe in and out. I had a medical crisis where it became very hard to breathe because of sleep apnea. Sleep apnea is when your breathing starts and stops as you sleep. My diaphragm needed help. I started using a ventilator called a BiPap machine. A BiPap pushes air into a person's lungs. I wear a tube

and mask that the BiPap pushes the air through. I became Darth Vader. Darth Vader is the villain in Star Wars. His breath whooshes when he breathes because he breathes with a machine.

A big part of how I think about myself is through my voice and writing. When I started using a BiPap I had to learn to be okay with my new sound and body. My sound and body has become more and more like a cyborg over the years. A cyborg is someone who is part machine and part body. I love the poem “You Get Proud by Practicing,” by the writer and activist Laura Hershey. An activist is someone who tries to change the world for the better. Laura Hershey was also a woman who used a BiPap. In it, Laura Hershey talks about how the world always teaches you to be ashamed. So you have to keep working to be proud of yourself. I have to keep working to be proud of my sound and body.

I know disability isn’t a problem or something to be ashamed of. But I have to remind myself that the problem is really how the world thinks about my sound and body. I also have to remember I am not alone. I am part of a large community of disabled people whose voices sound

different. One community is **Did I Stutter?**, a project on the Internet that questions how people think about stuttering. Its website says:

> We understand disability and stuttering not as an individual defect, but first and foremost as a social discrimination against certain forms of human speaking . . . Stuttering is only a problem—in fact is only abnormal— because our culture places so much value on efficiency and self-mastery. Stuttering breaks communication only because ableist notions have already decided how fast and smooth a person must speak to be heard and taken seriously. An arbitrary line has been drawn around “normal” speech, and that line is forcefully defended.

This means:

> A person who stutters is not a problem. The problem is the way the world treats people because of how they speak. Stuttering is only a problem because our culture likes to move fast and thinks people should be in control of the way they speak. Stuttering is only wrong because the world has decided how fast and slow someone should speak. There’s no reason why people have to speak at a certain

speed to be taken seriously or treated well. But the world makes it clear to anyone who stutters that they are a problem.

Radio makes sure we only ever hear from people who sound ‘normal.’ Radio usually only shares ideas that are considered ‘normal’ by a lot of people. Radio’s idea of normal is all about hearing and speaking with a voice that is good for radio. There are a few radio shows made by disabled people. Disabled people are making more and more podcasts. But generally, you don’t hear a lot of people who sound different because of disability on public radio. It’s time for people in radio to think about what they’re saying by excluding certain voices and lived experiences.

Symphonic Disabled Voices

On radio, I want to hear people who:

- Lisp, which is a sound with a lot of ssss.
- Gurgle, which is a wet sound.
- Stammer or stutter.
- Wheeze, which is a sound with a lot of air.
- Repeat themselves.

- Pause when they need to breathe.
- Make noises when they talk.
- Drool, which is when spit comes out of your mouth.
- Say things differently.
- Use different speech patterns.
- Use ventilators or other technology.
- Use sign language interpreters or other people who support them to talk.
- Have voices made by computers.

I want to change what's thought of as a public radio voice. I want people to question who should be on the radio as they ride the subway, jog on their treadmills, and drive to work. Maybe people will need to concentrate more to listen to us. I believe our stories are worth the effort.

Cripping the Instruments of Radio

How do we make radio a place people want to work? How do we get disabled people talking on radio, making radio shows or in charge of what goes on the radio? First, you need to start with groups doing things right.

Making Contact is a group that wants social justice and wants to share the voices of people who aren't usually heard from. So they support people who are new to making radio. Lateef McLeod, Making Contact's first Community Storytelling Fellow, is a disabled person who uses augmentative and alternative communication (A.A.C.). Augmentative and alternative communication is when someone communicates without using their voice. For example, some people might use pictures, some people type on a computer. I was so excited when I listened to his story and knew that was his voice. These are the kinds of stories I want to hear. When I heard Lateff McLeod's story I decided to apply for Making Contact's 2015–2016 fellowship. I started ten weeks with Making Contact in October 2015.

How do disabled people take radio and make it ours by "cripping" it with our culture? When disabled people "crip" a space, they change it with their culture, bodies, and thoughts. I wasn't sure how I would actually "do" radio. I wanted to do something new. I wanted to feel uncomfortable. I decided to create a story about disabled people from the San Francisco Bay Area. This let me tell a story in a new way and learn new skills while

telling stories that are important to me. During my time with Making Contact, I learned some ways to crip radio. They are:

- Use what's already there. I was worried about how I would record people talking and sound. There are some things I'd need help with, like taking equipment on and off my head. I thought ahead and asked some people to do interviews before I started at Making Contact. I used the StoryCorps to record them. StoryCorps works across the United States to help people tell their stories and the stories of people in their community. I used its free recording room, which has a person who worked the equipment. Plus, I left with a high-quality sound file that I could use for my radio project.
- Accessible and free tools. Before working with Making Contact, I used Audacity to edit oral histories. Oral histories are where people talk about their lives and their past. Audio editing programs that are open source, free, and easy to use let all kinds of people learn to produce radio.
- Flexible problem solving. The person helping and teaching me while I was with Making Contact, Laura Flynn, was willing to come to my home. This meant I did not need to go to Oakland for our meetings.

This saved me time and energy. This helped me so much and let me work with Making Contact.

- Asking for help. Getting sound from someone is physically hard. Holding a microphone close to a sound or person was inaccessible to me. I use a wheelchair and my arms aren't that long. I asked Laura to come with me to two interviews. Laura held the microphone so that I could get good sound.

As I started recording interviews, I also had family help me. They turned sounds on and off as I recorded them. They put in earbuds so I could check the sound levels. They took me to talk to people. I found it hard to upload sound files to my laptop by myself. I'm used to asking for help with a lot of things. I just have to be careful because there's a few things I need support with.

What Can Radio Stations, Media Organizations, and Newsrooms Do?

Radio stations and groups need to be the people to change and be creative. People with disabilities working in radio will bring important knowledge and views. Al Letson's call for change talked about the ways

groups can make sure they're working with lots of different people. He said:

> Letting them know they are valued, letting them hear themselves in your local programming. It's going into these communities physically—being a presence. . . . What makes a station diverse is the work it puts into the community.

Al Letson means that:

> People should be able to hear people who sound like them on the radio. When people hear themselves on the radio they know they're important. Radios also need to go out to their community. They need to build relationships with the community.

Radio can include more disabled people. Including more disabled people will make radio better. Here's some examples of how radio can become more accessible and work with different people:

- When you look for people to train in radio make sure you look hard for people from groups that radio has shut out in the past. One of those groups that you should be looking for is people with disabilities.

- Have money for accessibility. You need to make transcripts of your work. Without text transcripts, radio is inaccessible to people who do not hear and people who understand information better by looking at it. A great model is the Broadcasting Accessibility Fund, a group that gives money for accessibility in radio or television in Canada.
- When you post a job, make sure you say that you're committed to accessibility. Do this as well as saying that you're interested in talking to people who come from groups who have been shut out of radio.
- Make stories about people with disabilities. Make at least one story a month or a week
- Work with disability groups in your area as part of the work you do to make sure that a lot of different people can work in radio
- Work with people with disabilities who already host shows on local community radio or podcasts

Saying you want lots of people with different lives working in radio is one thing. Making it happen is another. Giving just one person with a disability a job won't do it. Even giving a few people with disabilities jobs won't do it.

In a piece of writing in the **Seattle Journal for Social Science**, Dr. Jennifer Lisa Vest talks about diversity in universities. Dr. Vest is a teacher and performer of Black and Native American heritage. She says:

> Diversity is a word that does not offend, does not highlight inequality, does not refer to historical injustices, or point the finger or lay blame. Diversity has a certain neutrality about it that makes it palatable. . . . Without explicit dialogue and action on ending oppression and privilege, diversity programs cannot change racist, sexist, homophobic, and ableist beliefs and practices.

Dr. Vest means:

> Diversity is a really easy word for people to use. Diversity doesn't say someone did something wrong. People need to talk to each other and take action to make their workplaces fair to everyone. If people don't talk and don't take action, diversity will not change people's minds or actions. People will still act in racist, sexist, homophobic and ableist ways. Racist means that people are violent towards people who are Black, Indigenous, Asian and other people of color, or they treat white people better than Black, Indigenous, Asian and other people of color. It also means that the world is set

> up to make things easier for white people. People who are sexist are violent to people who are not cis men and are kinder to cis men. Cis men means men whose parents and doctors thought they were men when they were born. Sexist can also mean that the world is set up to make things easier for cis men. Homophobic means being violent or unfair towards people who don't love and have sex with people of a different gender. It can also mean the ways the world is set up to make things easier for straight people.

Talking to each other, taking action and working with the community make change more likely. My work at Making Contact involved talking, taking action, and working with my community. During my time at Making Contact I made my first story ever, "Choreography of Care." Public radio is letting more people in. The voices of disabled people and their stories are an important part of that.

Choreography of Care

A piece of the podcast episode Caring Relationship: Negotiating Meaning and Maintaining Dignity, an episode of the **Making Contact** podcast. This episode was shared on April 13, 2016.

Alice Wong: [Yawn, sounds of an oxygen machine. An oxygen machine lets you breathe in more oxygen than usual.] Hey Mom, I'm ready to get up.

Bobby Wong: [Alice's mom, speaking in Chinese] Did you sleep well?

Alice: Not too bad.

Bobby: Okay

Alice: Can you turn off the oxygen and the hospital bed?

[Beeping of machines]

Alice: I don't want to get up. But here I am in bed. I need to get up and get into my wheelchair. From the minute I wake up, there are people. Can't get away from them, even if I wanted to. Kenzi Robi is an artist in San Francisco. He has lots of people who work for him. Like me, he's in bed when his attendant, the person who helps him with the things he does every day, comes to work.

Kenzi Robi: I have no use of my legs. So I really need my attendant. When someone comes in the morning, the first thing they need to do is wash their hands. Then they get gloves, then check that I'm clean. I can't pee unless someone puts a little tube in my bladder. Your bladder is the part of your body that collects pee from your kidneys. So I need to do that a few times a day.

Alice: When you need help with almost every part of your life, it changes your relationships with other people. I talked to some of my friends in the Bay Area about their relationships with the people who help them every day. Kenzi says it's different every time he gets a new attendant.

Kenzi: I've had people that are able to take directions and can be taught in 30 minutes or 2 hours. And other people say: Why are you picking on me? Why do I need to change my gloves? You're making waste. I have to tell them that you can throw away gloves, but you can't throw away me.

Alice: Some people have the person they're married to or family as attendants. Sometimes they're paid, sometimes they're not paid. Ingrid Tischer lives in Berkeley with her husband. Here's their usual morning.

Ingrid Tischer: When we get up, he starts the day by making coffee and starting breakfast. I sleep with a Bipap machine at night.

Alice: A Bipap machine helps a person breath by pushing air in and pulling air out of their lungs.

Ingrid: So I take care of the machine. It's funny, being married has been the first time in my life that I could wear what I want to or do my hair how I want to. He helps me with buttons, pulling things on, zippers, pulling back my hair. He's really kind about it. He makes it nice.

[Sound of Alice meeting with Alana]

Alice: Alana Theriault also lives in Berkley. She's been living independently, not in a nursing home or hospital, for 34 years. She has six attendants to work through the week and back-up attendants to help out. Her attendants go where she goes, including in her home and out.

Alana Theriault: I hate driving on the big roads. But they're all very good sports and drive me where I need to go. They bring me home, get me a snack, help me with everything I need to do to keep the house running, make dinner. Then they leave at 6pm. I have a break then which is nice.

Alice: It's hard to have things that are just for yourself when you need a lot of help.

Alana: I don't have enough alone time. I have the hours of help I need, and that's amazing, but I also miss alone time.

Alice: Anyone who uses attendants has to be able to tell people what to do and where to go. Patty Berne is in charge of Sins Invalid, a performing

arts group in Berkley. She thinks her work is a lot like the way she gets her care needs met.

Patty Berne: People are like, “How did you get so good at running a performing arts group?”

And I’m like, “Do you know what I have to do to get dressed every day?”

That’s kind of a show. I make an event happen every day when I’m dressed and fed and comfortable.

Alice: It’s a well planned dance, right?

Patty: Yes, oh my god, yes.

Alice: Being disabled and having help is a big show where relationships are the key to making it good.

[Sounds of Alice talking to her Mom]

Alice: One important part of my day is how I need to have my coffee every afternoon when I'm working from home. I can't make it myself and I have strong opinions about how my coffee should be made. So I need to make sure my mom, who is one of my attendants, does it right. My coffee is important! For Alana, it's all about teamwork.

Alana: I try to get my attendants to have relationships. I train them for two to three days and then maybe one or two other attendants are involved in that training. So they know each other. That means they can say, "I don't know, maybe I should call this other attendant to know what to do." Or I try to get them to call each other when they need someone to take their shift, so it's not just on email.

Alice: There are a lot of ways disabled people say thanks to their attendants. Thank you can go a long way.

Alana: Once a year I have an attendant thank you dinner. We all go out. I build relationships with them. I care about them, then they start to care about me.

Alice: Care is part of the work of being an attendant. But you can't ignore who has the power in the relationship. Rachel Steward, who lives and works in Alameda, describes how she's careful with the relationship.

Rachel Stewart: I'm still learning and I think it's a very fine line. You also need to let people know when that line is crossed. I'll say, "Okay, I need you to be on time because I'm going to pee my pants unless you're here." Just being really honest with people is important. Being honest and showing that you're thankful. It's a hard one to figure out.

Alice: Power can be hard, especially if your attendant is family. Ingrid describes how she and Ken, her husband, understand the relationship.

Ingrid: I don't ever have to be worried that one of us will get back at the other while helping. I think it's really important. At some point Ken will need help from me more than he does now. I think we know what each other's lines are and where we don't go. That's what makes a healthy relationship.

Alice: Being grateful, trust, talking to each other and a shared sense of responsibility keep relationships strong between attendants and disabled people. Making sure you do what you think is right is also important. Patty talks about a time she supported her attendant.

Patty: One of my attendants, she broke her wrist. Rather than just getting someone else to take her place, I hired an assistant for her. The assistant helped with the bits of her job that she couldn't do. So that's just how we get our needs met together? It's really cool because she didn't understand my work in disability justice, and now she's seeing that.

Alice: For Patty, this is disability justice in action. Disability justice is a movement to make the world more fair and better for disabled people, that is about what the disabled people who are most shut out and have the least need. So disability justice is lead by disabled people who are Black or Indigenous or people of colour, who are trans or non-binary, or who are treated badly because of who they love and who they have sex

with. In disability justice, we also leave no one behind[16]. When Patty didn't just hire another attendant, this was disability justice in action.

Jessica Lehman is in charge of Senior and Disability Action in San Francisco. She tells me when she first understood that disability justice and the rights of people who work in homes are connected.

Jessica Lehman: What happens in my home is just a little piece of the work I've dedicated my life to. Treating the people who work in my home well felt like a chance to live what I believe is right. I get to feel what I think is important in my body and my home and work on making the world I want real with other people.

Alice: Hey Mom? I'm ready to go to bed now.

Bobby: [speaking Mandarin.] Okay, you should sleep. It's so late.

[16] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

Alice: Can you turn on the hospital bed?

Bobby: The bed, okay.

[Sound of the mattress turning on]

Alice: Can you turn on the oxygen please?

It's time for me to go to bed. My mom has turned on my oxygen machine and my air bed. I'm going to leave you with these thoughts:

- Disabled people and attendants are more likely to be hurt than some other people. And they're both more likely to be very good at staying alive.
- The health and happiness of disabled people and their attendants is connected.
- How we treat each other shows us the kind of world we want to live in.
- The work we do has value.
- We are stronger together.

Tiger Tips on Interviewing

This piece is about how to interview people. Interviewing people is talking to them, usually to get information.

Before

Take your time to decide who you want to talk to. Find out what they do. Read, watch or listen to pieces about them. Find out how to get in touch with them and find their pronouns and their biography. Pronouns are words that you use for a person when you don't use their name. A biography is a short piece of writing about a person and what they do. When you ask the person if you can interview them, give some details. Let them know:

- Why you want to talk to them.
- What you want to talk about.
- How long you think the interview will be.
- Give them a date that's good for you or ask them when you can talk to them.
- If they can talk to you by email, video or phone.

Ask if they have any access needs or anything they need for the interview. If this is for research or an event, let them know how much you can pay. End the message by thanking them. Let them know you can answer any questions they have. Give links to your website or past work so they can decide if they want to talk to you.

If the person says no, thank them for replying.

If they don’t reply, leave them the fuck alone! I might ask again after a couple of weeks, but I try not to push people to talk to me. You shouldn’t ask them why they didn’t say yes. You don’t try to make them feel guilty for saying no. Move on and don’t be an asshole about it.

If the person says yes, then huzzah! Now the work starts. Make sure both of you know:

- The date and time you're talking.
- How you’re talking.
- What access they need.

Some people like to know the questions you're going to talk about ahead of time. I think of this as a form of access. People can feel nervous about interviews and they may want to write notes to prepare themselves. Not everyone knows how to talk about themselves. It's important for you to make them feel as comfortable as possible. If you are someone who writes news and you won't send questions ahead of time, you should tell the person.

Also, let the person know if you plan to record the conversation. Let them know if you plan to make what they say shorter when you write your piece. Send the person a calendar invite with any links or information on how to join. Remind them a day or two before the interview. Before the interview, prepare in a way that works for you. You probably need to think of a few questions you want to ask. Ask yourself:

- What is the most interesting thing about this person?
- If this person has been interviewed before, are you asking questions they've been asked before? Will your questions be about something they're tired of talking about?
- Are your questions open enough to let the person share what they care about?

- If you want to talk about something specific, what do you need to know?
- Do you need to have notes to help you remember the details in the interview?

During the Interview

At the beginning of the interview, thank them for their time and work. Ask if they have any worries. Ask them if it's okay that you record the interview.

Make them feel good! Let them know they can take a break or change how they want to answer. Let them know that you can leave anything they want out of the piece you write. Let them know that they can stop at any point.

Now get interested! I like to start with asking the person to tell me about themselves. How they think about who they are can help you talk about them in your piece. It’s also a great way to start talking. You did the homework. Now it’s time to listen and go with the person. It’s not time for

you to share what you think or talk a lot. This is their time. You're in charge of making them feel safe to share.

Keep in mind:

- Follow your interests. Don't stick to the questions you decided on before if it seems like the person is not interested. They can feel it if you're interested in what they have to say.
- Listen carefully. Ask the person for more details or about an issue that's tied to what they're talking about. There are no perfect answers. If you want to learn more about something, ask! If you don't know something, ask! Don't act like you know what they're talking about if you don't.
- If the person is going on a bit too long, find the right time to say, "Thank you for sharing. . . I'd like to switch gears and ask you about. . ." or "I want to be mindful of the time, and I'd like to talk with you about a few more things. . ."
- If the person doesn't like a question or is angry, this is a good time to pause. Ask how you can change or correct any mistakes. Say sorry and offer to stop if the person doesn't want to keep going.

- Listening is at the heart of being a good interviewer. Talking about something you didn't plan to talk about is part of a good interview. Learning something new can make talking to someone exciting.

Near the end of the interview, check in with them. Here are a few things you can say:

- We are almost at the end of our time, how are you doing?
- Would you like to continue a bit longer?
- I'd like to ask one last question
- Before we end, is there anything else you'd like to talk about?

After

Thank the person, and let them know that you will be in touch once the interview is ready. Ask them to let you know if they think of anything they want to add, change, or leave out. Give the person a date when it will be ready.

Before sharing the interview, check with the person if there are any details that you need to know, like:

- How they spell and say their names.
- How to spell and say any words that are new to you.
- A biography.
- Any Internet links they'd like to share.
- If they are okay with being tagged on social media.
- If they'd like to review the interview ahead of time.

Send the person a link to the interview once it is on the Internet. Ask if you need to make any changes. Thank them again!

Interviewing makes me a better writer. Interviews are one of the ways I've chosen to tell stories. With interviews, I learn how to create a specific type of space. That space gives both the person I'm talking to and me the chance to listen and learn from talking to each other. I really like other people. I'm really interested in what other people have to say. Other people can tell that I'm interested and excited.

Interviewing also helps me as I talk to myself. I'm trying to figure out who the fuck I am and what the fuck do I really want to say. I wish I felt as good about my writing as I do about my interviews. Most of my writing is

about asking myself good questions. Asking good questions is something anyone can learn to do.

Podcasting as Story-Telling

A talk with guests Geraldine Ah-Sue, Cheryl Green, and Sarika Mehta on the **Disability Visibility Podcast**, Episode 100. Shared on April 3, 2021.

Sarika Mehta: You know, Alice, I think we've said this a few times and with all of your guests. Putting disabled voices on air is not something that people do a lot. You have to have a radio voice to work in radio and podcasts. A radio voice means someone's voice is:

- Warm.
- Deep.
- Clear.
- Changes in a way that helps people understand what they're saying.
- Easy to listen to.

People train their voices so they don't sound like themselves anymore. And what does that mean when the whole point is storytelling? Why do we have to sound a certain way to tell our stories? What does that mean?

It means we're not true to ourselves. So I love the idea of people just being themselves and telling their stories. The stories could be really sad, or share history. The stories could help us understand family or why we are the way we are. And, obviously, we should have transcripts. Transcripts are what people say written out. We should have transcripts because some people won't be able to access sound. Or maybe English is not easy for you or maybe your kid is very loud in the background. You know!

We have to make radio and podcasting - sound - accessible to everyone. And that's really one of my passion projects.

Alice Wong: Yes, thank you for that. When I started this podcast I wanted to start with transcripts. You know, I know that there's a lotta different issues for people making podcasts. They say, "I don't have the money. I don't have the time. How do I make a transcript?"

But I did a lot of planning and looked at the money. I just made a promise to have transcripts. Because it would be just silly and hurtful if I did a podcast about the disability community without transcripts. And Cheryl,

your podcast, you were one of the people I looked up to. You were somebody that I reached out to early on. You were just so helpful for me just starting. You helped me understand how you make a podcast. So I just wanna give you a shout-out. There have been disabled podcasters way before this podcast. I'm always trying to learn and get better. But also, you were so kind with sharing your knowledge. So thank you for that.

Cheryl Green: Oh my gosh. Well, since it's sound only, you can't see my cheeks going red. Thank you, Alice. When you were planning this podcast, I actually had you on my show. I did an episode on my show about disabled voices.

So, when I'm on my show, I feel like there's a disabled person on the show 'cause I'm there. But I don't have a disabled voice. You don't hear that I'm disabled in my voice most days. Some days you do, but I usually don't record on those days. And you were the person in my episode about the power and beauty of having disabled voices on the air. And this whole time when I was interviewing you, you were planning your podcast, and I had no idea. And then the episode came out and then your podcast came

out. And I was just blown away. I'm so happy to do anything for you any time, Alice.

Geraldine Ah-Sue: I am thinking about what Sarika and Cheryl shared. And I'm just thinking about the stories and the issue of disability. I'm thinking about how we listen to those stories and who we think is listening. And I'm thinking how hard it is to really get a voice that sounds disabled on the radio or on podcasts. Especially on radio or podcasts that are listened to by a lot of people. And I was really excited to be learning with you and within myself.

I think hearing from you about your feelings about starting out, it really brings it back to me. I am still so scared. I'm a producer working on a podcast that is about disability stories and disability culture. But I'm not a disabled person. I often stop and think and change things over and over again. Working with you, and learning with you in a lot of ways has just really changed my life. I'm so lucky.

I'm also thinking how chill you are as a boss! [laughs] I respect that about you. And also, there's something I'm learning from how chill you are,

about disability community and disability culture. I can't say it really. But I'm sort of go, go, go and I want to do lots of things fast, you know? I have just learned so much. I can't even begin to say how much I've learned.

Alice: Thank you for that. You know, I was also kinda nervous, too. I was nervous about being a boss. I knew what I wanted out of each episode. I would give you notes and a sense of what I would like when you were cutting the episode up and putting it together. But really, I wanted to give you, all of you, that freedom to play as well. I wanted to give you just enough direction but not too much.

And I think another thing I tried to do was build in as much time as possible. And this is why, for people who were former guests probably, they wonder, "Why did it take four months for my episode to come out?!"

That's because I work very far ahead, and I take my time. Because I'm working with audio producers. I'm making sure that I have my text transcript. I have all these little things that I wanna put together, and I'm not a fancy-shmancy kind of podcast on a network. Podcast networks are groups of podcasts with people in charge. I have control over my

schedule and how I work. And I think that's just something that I learned from my own lived experience. How about you, Cheryl?

Cheryl: Whew, hallelujah. I remember feeling like, fresh air, when I found out that you were doing a podcast. I love the way you do what is right. I love the way you live disability culture. But I just had a sense of what you were going to bring to podcasting from the **Disability Visibility Project**. I was just so excited that you were going to do podcasting. And then to be part of it, I mean, yeah, there aren't actually words to say what it feels like to be part of it.

Alice: Oh, Cheryl! How about you, Sarika?

Sarika: How am I supposed to follow the both of you? My goodness. I mean, like Geraldine, I'm not a disabled person so to be asked to be a part of this is a huge honor. And you saying you felt scared to try something new! I mean, I was so scared - I don't wanna screw up. Because I just wanna do my best work for you, you know? And for this vision that you had.

So I think I started out nervous just because I wanted to do this job really well. I mean, to be honest, working for your podcast is the first paid work in sound news that I've ever had. I've been doing that work for ten years. But this was the first paid job I ever had. When you work in community radio, you do whatever you want. Community radio is great, you know. It's a work of love.

I'm a sign language interpreter so I've worked in disability community for almost ten years. I learned so much! And I felt ashamed that I didn't know things already. I was learning and also like, well, why didn't I know this? Because none of us know these things until you listen to the podcast! I remember other episodes where you and your guests were talking about being tired from a disability or being tired of having to explain yourselves. There's tired and there's, I need an extension on a deadline because I am so tired.

It was something I might kind of understand. Having my first child was so hard. I think I never got back to the way I was before. Then I lost my next baby. Then my next pregnancy was so terrible. All of that happened while I was working for you! And you were so kind and understanding.

So, Geraldine and Cheryl are talking about you as a boss and how you're laid-back and wonderful. I listen to that and I realized that you're a leader in this community who is saying we are human bodies. We are not machines. And when things are not going well, we have to listen to our bodies. I remember feeling really bad that I couldn't give you work on time. But all three of you, you had my back.

Alice: What questions do you have for me, and is there anything you want to share about me? Go for it, this is your time.

Geraldine: [laughs] I love this part. I don't know if I have any questions, but I do want to say that Alice is one of the best bosses that I've ever worked with. If you are looking for somebody to feel really human with, Alice is your person.

Sarika: Yes to that. [laughs]

Cheryl: I have nothing to share. I mean, the thing that I remember is I get very, very scared when I meet people for the first time. But Alice is so down-to-earth. I quickly got over being scared.

I don't know how long we'd been working together when you started ending your emails to me with meows and other cat sounds. Or maybe I started. I don't know who started it, but it's been going on for several years, and I just love it. I love having this work relationship that's very healthy, but then ending the emails with "meow for now". It's just—it's the best.

Sarika: This is not about the podcast, but Alice was a guest on **United Shades of America** with W. Kamau Bell. **United Shades of America** is a TV show. They did an episode on disability history. And Alice was talking about able-bodied actors playing disabled characters, all the time. And then they win Oscars for playing disabled people! It's how you win an Oscar. And so Alice said something like, "Suck it, Hollywood!" If you ever wanna know Alice in one sentence, that's it.

And I think at another talk, somebody asked you . . . maybe it was about picking battles or something. But you were like, “I have no fucks to give!”

Cheryl: “Eat more pie! Eat more cookies!”

Sarika: [laughs] I do not have fucks, either!

Alice: I think everything that’s worth doing, should be done with humor and joy, you know. This podcast would not exist and would not be what it is without the three of you. So, I just want to make this very clear: we have done this together. I think it’s where the best things come out, right? Just this magic of working together. Thank you all for being with me in this.

Cheryl: Thank you, Alice.

Sarika: Thank you, Alice.

Geraldine: Thank you, Alice.

Alice: Mew, Cheryl!

Cheryl: Meow, meow, meow! Meow meow, meow meow!

You’re a Snack!

Plain Language Translation: This piece is an image. You might want to look at the original picture.

You’re a Snack!

This means you’re something small and good to eat. People say it when they think you look really good and sexy.

Letter to Asian American Disabled Women and Girls

Hello!

I got your letter, email, tweet or direct message. Or maybe I met you on the internet or at a party pre-pandemic. Or maybe your mom stopped me while I was shopping. She cried and told me how amazing it was to see someone like you, but older. Or maybe it was a friend of a friend who said we should meet because we are both Asian American and disabled. We're not all the same. But people keep thinking we'll have a lot in common. No matter how we met, here I am, writing to you.

Thanks for sharing your story with me. Thank you for asking questions. Thanks for asking for help. I see and hear you. I hoped things would be better in the 21st century, but disabled people of color still feel alone. Asian American disabled women and girls still feel alone. I didn't decide to tell stories or be an activist. That just happened as I tried to find myself and my people. I hope my story and my work helped you. But please

know that I am just one person. There's a lot of work to do and we can all be successful in our own ways.

Shit is hard right? Growing up and learning to like ourselves is a tough job. I am still working on myself. You're probably working on yourself too. I hope as you work hard you're taking time to find joy. Building and growing relationships gives me joy. It might take some time, but eventually you'll find people who have your back. They might have your disability or come from the same culture. They might not. Maybe there aren't answers to the questions you're asking right now. All we can do is figure out what or who makes us happy now.

We don't need a group to make community for us. We don't need to talk about who we are, use the "right" words, or have a club card to be together. We exist and that is everything! It's easy to say and hard to accept, but you are enough. If you're too much, be happy that you're all that and more. It may seem like everyone says this, but you do you.

Don't feel like you need to talk about how important it is that everyone is different. Don't feel like you need to talk about who you are. Don't feel like

you need to talk about being disabled and Asian American and a woman. There will be people who only want you to do that. Those are not your people, no matter how nice and helpful they seem. You can talk about disability any way you want. Talk about the uncomfortable, difficult, messy stuff about disability. Fuck the rules. Fuck the model minority myth and being “good”. Lots of white people say that Asian people are a “model minority.” This means that they’re hard working, do a lot and fit in. It’s dangerous to say that all Asian people work hard, do a lot and fit into the culture of the United States. Saying that gives white people an excuse to ignore the racism that Asian people experience. Racism is the violence that people who are Black, Indigenous, Asian and other people of color experience and when people treat white people better than Black, Indigenous, Asian and other people of color. It is also when the world is set up to give more chances and money to white people than Black, Indigenous, Asian and other people of color.

There will be times when you feel like you can’t be yourself. You’ll feel like you have to choose between parts of yourself. Or that you need to be thankful to be in America because things are “better” here. All of America is land stolen from Indigenous people. That’s nothing to be thankful for.

Don’t think that disability rights and disability justice in the United States is the solution to disabled people’s problems around the world. Both disability rights and disability justice want to make things better for disabled people. Disability justice says that to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So disability justice is led by disabled people who are Black or Indigenous or people of colour, whose gender is different than the gender that doctors thought they were at birth, or who are treated badly because of who they love and who they have sex with[17]. Thinking that disability rights or disability justice is better than what people are thinking about disability in other places is some capitalist colonizer bullshit. Capitalism, which is the system we live in where we have to work to make money to buy the things we need to live, tells us we have to be the best. Colonialism is when one group of people go somewhere they aren’t from, control that place, and use it to make money. Let’s not do that shit. We can learn what it is to be human

[17] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

by taking the best parts of all the cultures we are part of. There's knowledge and beauty from disabled people everywhere. We just have to look and learn.

I know it must have been hard for you to reach out to me. To be 100 percent honest, I'm not your role model, someone to learn from, or friend. I want to be your equal, and maybe make good trouble with you in the future. Being a role model means people expect a lot from me. And that I end up with a lot of power I don't want. Role models can do more bad than good because they aren't honest about the things they need to work on. Over the years I've become really uncomfortable with the way people see me. It's just a lot. I want to be the person who makes sure I act in a way I think is right. I don't want the way other people see me to decide how I'll act. Being clear about what I can and can't do is a way to protect myself. I want you to be excited to do the same when you are ready.

Not being treated fairly because of your disability and because you're Asian American is very hard. Being disabled and being Asian American doesn't cancel each other out. Being disabled and being Asian American together makes you whole and wonderful. Maybe you don't see yourself

that way yet. But I do. I believe in you and who you will become. No matter what, even if we never meet or speak again, I’m so glad we’re in the universe together.

Your comrade,

Alice

Respect My Time

Plain Language Translation: This piece is an image. You might want to look at the original picture. No plain language translation is needed, so I've just written out the words here.

Respect My Time

About Time

It takes me a while to wake up. I'm also slow to start writing. I don't like to have to start anything quickly. I love doing anything but writing. I try to build in as much time as possible, so I can change when I need to finish. This is the best set up. Although sometimes I do need to respond to something quickly. Before I start writing, I go through my thoughts, feelings, and ideas in my head. I take a lot of time doing things that aren't writing:

- Cleaning my desk? Yes.
- Look at Twitter? Yes.
- Getting rid of emails? Yes.
- Say I'll help other people with their projects? Yes.
- Cleaning my laptop and phone? Yes.
- Cleaning my hands? Yes.
- Watching Korean cooking videos, finding tips for taking care of pet snails on YouTube, and looking at Instagram accounts of cats? Yes. Yes. Yes.

While I’m doing these things, something will come to me. When I do nothing I’m writing, even if the words don’t come to me right away. The best bits come to me when I try to fall asleep at night. My hips and elbows have contractures, which means they stay bent. I use a lot of pillows to help me get comfortable to sleep. I find it difficult to relax and fall asleep, so my mind runs wild. If the thought is a good one, I’ll remember it and write it down. If I forget, that’s okay too. I trust my mind to bring me back to the good idea.

Doing something that isn’t writing is a creative practice. It’s also how I get my excitement. When I need to get something done then I feel alive. When I was in school, I was never good at homework. I spent a lot of nights staying up late to finish something. No matter what I’m writing I ask myself questions. There are some of the questions I ask:

- What am I saying that’s new?
- Is writing this what I want to do right now?
- What could I lose by sharing more of myself with the world?
- What do I want to share with the reader?
- What do I want to learn from writing this piece?
- When’s my next snack?

I think about these questions again and again. I thought about these questions when I was writing this book. What I want to do with a piece of writing is important. When I share a piece of writing it is important. Some of my stories I'll never tell. Some stories I need to take some time to think about before I share them. There are also stories that should be told by other people.

After a lot of doing nothing I start to write. It feels great when the words come easily. I write and write. Then I get rid of some words and move some of the words around. When I get rid of, add and move words around to make the writing make sense and give the writing power, that's editing. When I was working on this book I realized editing never ends. I like to think about editing as time travel. In this book I'm jumping around in time. I'm finding ideas that I've thought about again and again over the years and putting the pieces that talk about those ideas together. I delete words and stories until only the most important ones are left. I tell stories and then tell them again. When I'm editing I talk with my demons, the people who came before me and the future. Editing is witch magic.

I’ve written a lot about imposter syndrome and internalized ableism. Imposter syndrome is when you feel like you’re pretending. When you feel like you don’t deserve your success. Internalized ableism is when you believe all the bad things the world believes about disabled people about yourself.

I worry that no one wants to read this piece. It's another piece of writing about writing. Thousands of people have written about writing.

I don’t have a lot to suggest. I like doing nothing, thinking and then writing a lot all at once. I don’t think you need to write in a particular way. If you think you need to write in a particular way, you’ve probably assumed that all people’s bodies and brains work in one way. If you need to write a certain number of words a day, great! If a writing tool helps you, great! If you need to write at a certain time, great! If not, find another way to write. No one should feel they don’t want to work or like they’re not like a real writer for writing one way. However you write, it’s still work. You will need to work at writing but you can work however you need to.

Disabled and chronically ill people know about death. Disabled and chronically ill people often don’t know what is going to happen in the future. Sometimes, I feel like getting through the day and taking a shower deserves a gold medal. Disabled life doesn't happen the way you plan. Sometimes I have to throw out all my plans for writing. If you can tell yourself that you should write one way, then you’re probably lucky. You probably don’t worry about paying rent, being in pain, getting sick or taking care of yourself and your family.

The world thinks being fast is the best thing. I live in a body that doesn’t let me be fast. My body tells me how, when and why I write. I don’t write so that people who put together books and blogs can say they had writing from a disabled person. I don’t write so that people can read a real story from someone who is a disabled Asian American. I write because I want to. I write because it’s fun. I write so I can fight the way the world is. I write to remind myself who I am. I write clearly and from my heart.

Everything dies eventually. I’m 48 years old. That’s four times through the Chinese zodiac. The zodiac is a way of counting years. The Chinese zodiac matches animals to years and repeats them every twelve years. I

wonder if I’m thinking about time wrong? Maybe I shouldn’t treat time like it’s something I need to catch and hold? Making it to 48 is an act of great strength. I should tell my story to feel free. I should tell my story because eventually I’ll die. But when I die people will be able to find me in these words long after I’m gone.

Pandemic

This shit is bananas B-A-N-A-N-A-S —GWEN STEFANI, “HOLLABACK GIRL”

Gwen Stefani is a singer and songwriter. She sings with the band No Doubt and as a solo singer.

Which means:

What’s going on right now is wild.

You better check yo self before you wreck yo self. —ICE CUBE, “CHECK YO SELF”

Ice Cube is a rapper and an actor.

Which means:

You should think hard about what you’re doing or saying. What you do or say will have results you might not like.

I’m Disabled and I Need a Ventilator to Live. Am I Expendable During This Pandemic?

Shared in **Vox** on April 4, 2022

Times are strange. It’s strange to be an Asian American disabled person who uses a ventilator right now. A ventilator is a machine that helps you breathe. COVID has changed people’s lives and a lot about living in the United States. Lots of sick and disabled people like me are used to never knowing what will happen. We’re good at changing our lives to work with a world that was never made for us. Are you hitting the door opener with your elbow so you don’t touch the door? You should thank the Americans with Disabilities Act and the disabled people who made that happen. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with disabilities. Accessible means that disabled people can get into a place, use a thing or enjoy an event.

Technology, accessibility and hard-core will to live has made me a cyborg oracle. A cyborg is someone who is part machine, part human. An oracle

is someone who can see a little of the future. I am ready to tell the truth. I have a lot of things that keep me alive:

- A power wheelchair.
- A ventilator that goes over my nose. The ventilator runs off my wheelchair's battery.
- Metal rods in my spine.

Lots of people are uncomfortable with how I move, sound and look. Maybe they pity me. That's normal.

My family and I have been sheltering in place, staying in our house in San Francisco, for over three weeks. The news is full of stories about too many people in hospitals. People who run hospitals are thinking about giving more care to some people and less care to other people. I'm worried. Disability rights groups have started legal action against some states like Alabama and Washington. These states told doctors that if they can't help everyone, they shouldn't help people with disabilities. The health department for the national government said that doctors should treat people with disabilities the same as everyone else. But I'm still

worried. The way people think about what is right to do when there is not enough care to go around means that people don't value my life.

Bioethicists are people who think about what is right and wrong in medicine and studying medicine. Peter Singer is a bioethicist who thinks disabled people shouldn't exist. He's said a lot about who should live and die when the world is the way it is right now. He thinks disabled people should die. But where are the disabled bioethicists and doctors? Those are the people we need to hear from right now. Dr. Joseph A. Stramondo from San Diego State University is a disabled bioethicist. He wrote this for the **American Journal of Bioethics**:

> There's a significant body of empirical evidence showing that there is a substantial gap between a disabled person's self-assessment and how their quality of life is judged by folks that have never experienced their disability. Some prominent bioethicists even refer to this as the "disability paradox." To me there is very little paradoxical about disabled people valuing their own life more than it is valued by non-disabled people making judgements based on stereotype and stigma. To conceptualize it as paradoxical is to wrongly assume that disability inevitably diminishes well-being.

What Dr. Stamondo is saying is:

> Non-disabled people think disabled people's lives are way worse than disabled people think their lives are. Sometimes bioethicists call this the disability paradox. This means that bioethicists think it's weird that disabled people and non-disabled people's ideas about their lives are so different. But I don't think there's anything weird. Disabled people actually know what their lives are like. Non-disabled people think disabled people's lives are terrible like the awful stories they've been told. You can't assume that being disabled means that your life isn't that great.

Eugenics isn't gone. It's alive today, in our culture, in the way the world works. Eugenics is the study of how to make the human race better by only letting certain people have babies. The people that made up eugenics thought that only white people from a few parts of the world, who had money, and who were non-disabled should have babies. Eugenics was very popular and led to white non-disabled people hurting disabled people, poor people, Indigenous, Black, Asian and other people of color in a lot of different ways.

We need the people in charge of how the world deals with COVID to work with people from communities who experience medical racism, ageism and ableism. Medical racism is when people who work in medicine and health treat Black, Indigenous and other people of color worse than white people. It is also the way medical systems are set up to treat white people better. This means that Black, Indigenous and other people of color can't get the care they need. Ageism is when the world assumes that older people are less important than younger people. Ableism is the way the world is organized to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[18].

Deciding who gets medical care shows how little our world values people who are the most vulnerable to COVID. States and other governments

[18] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

made lists of people they thought would not get better. These people were:

- People with dementia, which is when your brain, especially how your memory works, changes with age.
- People with cancer.
- People with intellectual disabilities.
- People who have other types of disabilities and illnesses.

Dr. James Keany, a doctor at Providence Mission Hospital said in the **Los Angeles Times**:

> As it stands in the US, if your family member is adamant that you would want everything done and you're ninety years old, wearing a diaper, severely demented, you would get put on a ventilator…Most countires consider that malpractice because what are you saving that person for?

What Dr. Keany means is:

> You are 90 years old and use diapers. The way your brain works has changed in ways that mean you find it hard to remember some things and make decisions like you used to. You get COVID. You

> are really sick and need a machine to breathe for you. Your family member wanted the doctors to do everything they could to save your life, so you would have a machine to help you breathe. But most countries would think that was a bad decision by your doctor. Because your life is not worth saving.

Everything is personal for me. I know people with brains that work in ways that are different from the way the world thinks their brains should work. I know people who have had a disability since the day they were born. I sometimes use underwear I can go to the bathroom in and throw away. I need help eating, dressing and washing. If I got COVID, I think a doctor would look at me and think I was a waste of their time and equipment. They might take my ventilator for other people who are more likely to survive COVID than I am. When doctors decide who is worth their time and equipment, they do not choose people like me. Doctors will choose to treat the people that the world is made for - white, non-disabled people with money.

People talk about the idea of “quality of life.” But they assume that a good, healthy life is one without disability or pain. I live with both disability and

pain and I feel so alive right now. I feel alive because of everything I've lived through and all the people in my life. People who are more likely to die from COVID are strong. They know how to live interdependently. Interdependently means they know how to count on other people and how to support other people. People who are more likely to die from COVID might not have a lot of political power. But we know how to support and protect each other. Disabled people, queer communities and communities of color have been working and helping each other since before COVID. Most of us know that the systems the government has to support us won't help us. We're going to have to save ourselves by sharing what we have and using our knowledge. We're going to have to save ourselves with joy and love.

It's not okay for disabled people to die from COVD. I want to believe that there's a future for me and for everyone. When one of us dies, we are all in pain and we all lose something. There's not a lot of time or ventilators. But we are creative. We can take action even when we have worry and fear. Together we can make a world for all of us.

Freedom For Some is Not Freedom For All

Shared on the **Disability Visibility Project** blog on June 7, 2020

Freedom for some is not freedom for all. I'm more likely to die from COVID than a lot of other people. I'm staying at home in San Francisco. I am not jealous that people are enjoying bars, beaches, and parks. I am angry seeing so many people not wearing masks or social distancing. Cities and states are starting to take away the ways they kept people from getting COVID. I'm worried for the millions of people the cities and states aren't thinking of. Lots of people want to get back to "normal." But lots of people are still dying in places like nursing homes and prisons. People are dying in shelters for people without homes, detention centers where our government holds people who tried to come to the US without permission, and hospitals. These places are sometimes called congregate care settings because a lot of people live together in them. No one is thinking of these people. I don't know why no one cares. Many of the people who are trapped and dying in these places are disabled people. They're part of my disability community. When people talk about why those people are trapped, usually they say it's for a good reason. They use words like "safety" and "care."

One of the first places there were a lot of COVID cases was at a nursing home in Kirkland, Washington. In two months 142 people caught COVID and 35 people died. As of June 4, 2020 more than 43,725 people in long-term care have died from COVID. New York has the most deaths. 6,237 people have died in New York. All these people who died had names, faces, and families. How many people have to die for people to care? Our politicians have completely failed.

Right now nursing homes all have rules for cleaning and using equipment to stop the spread of COVID. The government is thinking about no longer making nursing homes follow these rules. In 2017, a study of nursing homes showed that least 40 percent of the nursing homes didn't follow the rules at least once. Lots of states have laws that stop people from taking legal action against nursing homes for how the nursing homes have handled COVID. New York and New Jersey have decided that no one can take legal action against the people who run nursing homes. In California a group of hospitals and assisted living companies asked Governor Gavin Newsom to stop people from taking legal action against them. The disability community fought this.

Governors of states need to:

- Look into congregate care settings that have lots of COVID cases.
- Test all workers and people in congregate care settings.
- Give workers and disabled people personal protective equipment, like masks.
- Give workers more money and rights.
- Let people take legal action against nursing home companies.

In a video from May 6, 2020, Stacey Park Milbern, a disabled activist and a founder of the Disability Justice Culture Club, warned:

> There has to be checks and balances on hospitals and nursing homes. Otherwise, disabled people, especially people of color, are left alone in a system that already doesn't care about us.

Stacey meant:

> The government should make sure that nursing home companies and hospitals don't have too much power. Otherwise disabled people, especially people of color, will be alone in places that don't care about them.

Congregate care settings do not give people safety or care. Often, we don't know what life is like for people trapped in these places. The people who run congregate care settings don't answer to anyone. The people who are trapped in these places are used, hurt and forgotten. Congregate care treats people as less than human.

We don't have to have congregate care. We should get rid of the nursing homes. Nursing homes value money over lives. They put workers in danger. They do not answer to anyone. We also need to get rid of prisons and hospitals for people who doctors say have a mental illness. Both those places are also dangerous, unjust and treat people like they are not human.

People who feel safe with COVID around are probably really lucky to have good lives and lots of money. People shouldn't feel safe with COVID. There are people who can spread COVID without having signs of COVID. It will probably take a long time to make a vaccine. I will stay at home long after the government stops making me stay there. I don't feel safe. I worry that people are starting to talk about congregate care as the

best place for people who need support. The number of people who need support will grow as more and more people become disabled after having COVID.

I’m a disabled woman of color. My whole life is risky. I’m always one sickness, one medical crisis, one government policy change away from being trapped in congregate care or dying. COVID showed us that our government thinks it’s okay to let Black, Brown, Indigenous, poor, disabled, older, fat, and chronically ill people die. Our government also thinks it's okay that people who don’t have homes and who live in prisons die as well.

Right now, Black people are putting their lives in danger to demand that police and our governments stop killing Black people. Fighting for justice and freedom means that we need to end all the ways people are hurt just for living. No one can be thrown away. No one can be forgotten.

We can’t ignore the people dying in congregate care while we enjoy the sun and sand. By the time the Americans with Disabilities Act turns 60, I want older and disabled people living in the community. This is my

American dream. My dream will need creativity for politicians to support it. We'll need to talk to the people who are treated badly by our world to plan a new world. Freedom to live in the community is a human right. One day, everyone will truly belong.

Cooking in Quarantine

Shelter-in-Place JOOK, shared in **Al-Jazeera** on March 26, 2020

Plain Language Translation Note: A lot of this piece talks about food. I've kept a lot of the food words that aren't common. It's important because Alice's family eats those specific foods. Also you might want to eat those specific foods with your jook. If those words are confusing it may help to look up a picture of that food.

I love jook, also known as congee. It was the best comfort food when I was growing up in Indiana. My Chinese American family would eat it for breakfast. We'd have lots of other food to go with it. We'd have ground fried fish or pork floss, thousand-year preserved duck eggs, pickles, shaobing (sesame-covered Hot Pocket–like bread), or youtiao (fried sticks of dough). Another popular way to make jook is with a whole chicken. You cook the chicken until the meat falls off the bone. Then you add a bunch of green onions and ginger. I ate jook without anything else when I was sick. I filled my belly with it when I couldn't handle anything seasoned or oily. It could be thick like oatmeal or soupy. I always enjoyed it thick and would eat large bites with a traditional blue-and-white ceramic Chinese spoon.

My parents and I started sheltering in place in March 2020. We used our rice cooker a lot during those rough times. It's our trusted friend who never lets us down. With our rice cooker we can cook a meal in one pot. There's lots of things you can do with jook: savory, sweet, vegan, gluten-free, vegetarian. Using stock instead of water will give more taste and you won't need to add salt. It's food for times when you need to be cheap and you can add fried dumplings, boiled eggs, peanuts, kimchi, or anything crunchy on the side.

In my childhood memories, bowls of jook mean comfort, healing, and feeding ourselves. Those are all the things we need right now when we don't know if COVID will end. Jook is a simple meal that can use a lot of food you already have in your house. Jook can get you through another day. You can make jook on the stove, in a slow cooker, in a rice cooker or in an instant Pot.

Shelter-in-Place Jook

Ingredients

1 cup short-grain white rice (you can use short-grain brown rice if you put it in water for two hours before cooking)

6 cups chicken or vegetable stock, or water

1–2 cups greens:

- Fresh or frozen spinach.
- Or sautéed kale.
- Or bok choy.
- Or chard.
- Or any other green you have handy.

1 cup chopped protein:

- Cooked tofu.
- Or beef.
- Or ham.
- Or chicken.
- Or duck.
- Or sausage.
- Or ground beef.
- Or bacon.
- Or canned fish.
- Or rehydrated dried scallops.

- Or pork.

Garnishes (extra little bits of food you add to a plate):

- Chopped green onions.
- Or thinly sliced ginger.
- Or sesame seeds.
- Or kimchi.
- Or peanuts.
- Or boiled eggs.

You can add if you want:

- Sautéed peppers.
- Or onions.
- Or mushrooms.
- Or edamame.
- Or diced butternut squash or sweet potatoes.
- Or shiitake mushrooms.

Directions

Rice cooker instructions

1. Run the rice under water in the rice cooker bowl. Drain and run under water again. Do this 3 or 4 times, or until the water runs clear.

2. Add the cooking liquid and let the rice sit in the liquid for an hour before turning on the rice cooker.

3. Select the congee or porridge setting on your rice cooker. Press start. If you do not have a congee setting, just hit the cook or start button. Then come back and check on the rice in 45 minutes. Once the timer beeps, add the greens, protein, and anything else you want.

5. Close the lid and leave it on “stay warm" mode for another 30–45 minutes.

6. Serve with garnish. Put the garnish on the jook or put the garnish on another plate.

Stovetop instructions:

1. Run the rice under water in the rice cooker bowl. Drain and run under water again. Do this 3 or 4 times, or until the water runs clear.

2. Put the rice in a saucepan with a lid. Add the cooking liquid and bring to a boil.

3. Lower the heat, cover, and allow to simmer gently for at least 45 minutes and up to 2 hours. Simmer means boiling with little bubbles. Check on it every half hour or so.

4. Once the jook has reached the thickness you want, add the greens, protein, and anything else you want.

5. Serve with garnish. Put the garnish on the jook or put the garnish on another plate.

Slow the Fuck Down

Plain Language Translation Note: This piece is an image. No plain language translation is needed, so I've just written out the words in the image.

Slow the Fuck Down

It’s My Body and I’ll Live if I Want To

A talk with Ana Marie Cox on the **With Friends Like These Podcast**.

Shared on March 27, 2020.

Ana Marie Cox: Alice, welcome back to the show.

Alice Wong: Thank you for having me back on!

Ana Marie: And in case people are wondering why I am talking to someone who sounds like Darth Vader, I guess people should know you are a full-time ventilator user, correct? Darth Vader is the bad guy from Star Wars whose breath sounds loud and like a machine makes it. A ventilator is a machine that helps you breathe.

Alice: That’s right!

Ana Marie: We’re all dealing with COVID right now. But I want to talk about something that’s really personal to you. There’s this idea that we don’t have enough medical equipment to go around. We’ve heard doctors in Italy talking about how they’ve had to make choices about who lives

and who dies. You use a ventilator. When people talk about how there aren't enough ventilators, how do you feel?

Alice: Yeah. I mean, I've never heard ventilators, like that word, said so many times—

[Ana Marie laughs.]

Alice: —on the national news. I'm like, "Seriously? Now we're talking about this? Okay."

I think, first of all, people don't know what ventilators are. They don't know that there are different types. I'm using one that's called a BiPap. It's a "noninvasive ventilator." That means I wear a mask over my nose, and it helps me breathe. It's part of my body. I can't breathe or do much of anything without it. Even a regular cold is really hard for me.

And hearing these stories all over, it just hurts. It reminds me that I'm going to die. It makes me feel like people want me to die. And, you know, I've always felt threatened, but when people, so casually, are so ageist

and ableist it's hard. Ageist is is when people assume that older people are less important than younger people. Ableist is when people think that non-disabled people's lives are more important than disabled people's lives. This is because the world is organized to favor people who have particular kinds of bodies, minds and who can work in a particular way[19].

People laugh about COVID. They say, "You know, don't worry. Most of us will recover."

Yeah. When they say "most of us," they're talking about, like, a non-disabled person. They're not talking about the people who are really going to be hurt. They forget that there are lots of people who are more likely to die of COVID of all different ages. When we have these major problems, it shows who our society really values.

Ana Marie: I mean . . . it just must be something else. I can imagine how hurtful it is just to see people not worry about COVID. But the other thing

[19] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

that I imagine is hard is that people are talking about who lives and who dies. They're talking about having to decide who lives and dies. People just kind of bring it up. And sadly, doctors probably make that decision a lot. Doctors will probably decide that disabled people's lives are the worst so it's okay if they die. I mean, I would be very . . . scared. I don't want to say what you feel, but…

Alice: No, I think it's just this is something that I've lived with since birth. I think this is something that a lot of people know. People with disabilities, but also, people of color, women have not been treated well by the health care system. Doctors have a history of not listening to some people. Sometimes doctors have killed some groups of people.

COVID has just made doctors choosing who lives and who dies more common. I want to bring up this paper written by Samuel Bagenstos, at the University of Michigan Law School. Samuel Bagenstos is a lawyer who has worked a lot on disability rights, voting rights and worker rights. He wrote about doctors choosing not to treat people because of their disabilities. He says that not having enough medical equipment is a result of decisions people made.

Ana Marie: Mmm-hmmm

Alice: Someone decided not to store ventilators for an emergency. Politicians made these decisions. There are people who decided that if you're disabled or sick you shouldn't get a ventilator if you get COVID. All of this is done by people. People decide who lives and who dies in ways that match what they want. Those people have power. The people who have a hard time voting or being part of the political process don't get that power.

Ana Marie: How do you want people to be thinking about how few ventilators there are? It's too late for a lot of things. It's too late for us to stock up on ventilators. I hope it's not too late to make more ventilators, but we seem to be having problems with that. So it looks like we will be facing— Actually, let me say that again. We have so few ventilators that it's a problem for able-bodied white people. [laughs]

Alice: I'm being sarcastic, but I'm so worried about the able-bodied white people out there.

Ana Marie: Yeah.

Alice: I'm being very sarcastic, but I'm really scared for you all. I'm just, you know, hopes and prayers. Politicians often say, "thoughts and prayers" after something really bad happens. It usually means the politicians won't do anything to stop the bad thing from happening again. So, hopes and prayers! For all you white non-disabled people out there, all you cisgender white middle-class folks, I'm pulling for you! Cisgender means that you feel like the gender that doctors thought you were when you were born. I am pulling for you!

Ana Marie: [laughs] You have to deal with not having what you need all the time. People with disabilities, Black, Indigenous, Asian, Brown, and other people of color, have to deal with not having what they need. So what happens when people who have always had enough have to think about not having enough? What should we have been thinking about earlier?

Alice: Okay. I don't really have any answers. I do want the people who make decisions and who write the steps people use to make decisions to be thoughtful. I want the people who make decisions to ask what does this say about people? I do believe that there's a way to act the way that we say we want to act. And I know that's going to be hard. I know people will not get the care they need. There will be people who will be treated well. But I think this is a chance for us to say that there's another way. We have to use our imagination, be creative and make things happen. We've got to use everything we have to make this happen.

I feel like we haven't seen politicians use everything they have. They haven't used the Defense Production Act. The Defense Production Act lets the government tell companies what they have to make.

Ana Marie: Yes.

Alice: I mean, let's use that. I don't understand why we care about the economy and not people. The economy is how things are made, and how things are sold and used in a country, and what people do. The economy

is all about making money. Money's not really going to be much use if people are dead.

Ana Marie: Also, I think companies aren't going to give people what they need. The politicians are saying that people will give and do hard things for each other. I know people do give and do hard things for others all the time. But I think politicians are not taking responsibility.

Alice: Absolutely. And also, people can't keep giving and doing hard things forever. We can't count on individual people. But the government does have certain powers. I see what states or local towns and cities are doing. They're just getting shit done. And I see a lot of people within the disability community helping each other. There's so much care that's happening right now. It's beautiful. It's also really sad that we can't count on our government.

Ana Marie: Alice, this is already personal for you, I know. But I want to talk a little more. It's funny. I've seen astronauts talk about dealing with being all alone. Astronauts are people who live in space. I've seen people who live in submarines, which are boats that go underwater, about how to

live in a small space. It's weird to me, Alice, how come no one's thought, let's talk to disabled people.

Alice: Yeah! I mean why aren't we giving our opinions on this? It's amazing to see so many people finally learn to make a video call. Video calls are something disabled people have known about for a long time.

[Ana Marie laughs]

Alice: Or "I didn't know I could have online classes?" You see all these amazing people performing on the internet. Disabled people have been fighting for decades, begging, to have these kinds of things. It's just really weird. I think this shows the ableism in our society where we don't really want to see what disabled and chronically ill people are doing. We don't want to think about the fact that people have different ways of doing things. Accessibility is not a bad thing. Accessibility means that disabled people can get into a place, use a thing or enjoy an event. It makes things better for everyone. And hopefully people learn that there's different ways to spend time with each other, there's different ways for people to ask for change, people are doing amazing things from their home or their

couches, on their beds. I hope that people learn there are people out there who know so much.

Ana Marie: Alice, it is always so nice to talk to you. I always learn things and you make me laugh. And I hope the same things that you hope. I hope that this gives people a chance to think about the ways that other people relate to the world. And I hope you take care of yourself, Alice.

Alice: Thank you, Ana Marie! And may the Force be with all of us. In Star Wars the Force is the power inside every living thing. May the Force be with us means, I hope we're lucky.

Ana Marie: [laughs] Thank you.

A High Risk Timeline of Alice Wong

Plain Language Translation Note: In this piece Alice talks to us like we are in the future. Alice talks to us like we are at the Oracle Archive where people learn about the 21st century.

Location: Earth, North America, California
Time: Pre-Outage.

(We never find out what the outage was. It's one of the things we never learn about the future.)

Master Meow: Welcome to the Oracle Archive young people! This is the place where we store our history. My name is Master Meow. I have been in charge of the Oracle Archive for 2 millenia, a very long time. For everyone here from out-of-galaxy, that's 5.6 boops. You are grown-up enough to learn about a sad part of Earth history. This is history from before the Outage. The Outage led to everyone becoming free.

History from long ago can teach us about the terrible things that we do as well as the good. There was a time when viruses would spread very

quickly through humans and make a lot of people sick. Do you remember learning about the Scarcity Games and how bad they were? This is a time a lot like the Scarcity Games.

(We never find out about the Scarcity Games either. But scarcity means not having enough of something. So it sounds bad).

Master Meow: We were able to find a record from an early Oracle, Alice Wong. It was made when she was 47 years old, in the Earth year 2021. We found bits and pieces of her story in tweets, articles, emails, texts, images and sound. If any of those words don't make sense, please look at this book about how 21st century people talked to each other. All these parts of Alice's story show what it was like to live in that time. Together all these parts make up what we call a timeline. Please take a look at the timeline. We'll meet after to talk about how the people who lived before us lived.

And don't forget to take a look in the gift shop!

Timeline

January 20, 2021: The **Los Angeles Times** says, “Vaccinating Californians 65 and Older May Last Till June. Other People Won’t Get Vaccinated When They Thought They Would”

January 23, 2021: A text from the people who figure out how to get COVID vaccinations to people in San Francisco.

Alice Wong, we will let you know when you can get the COVID vaccination. We don’t have a lot of vaccines. It may take a few months before you can get the COVID vaccine.

If you don’t want to get these text messages anymore, reply with STOP.

January 25, 2021: The **Los Angeles Times** says, “California will Decide Who Gets the COVID Vaccine First by Age, Not by People’s Work”

January 29, 2021: Alice’s notes for an online event organized by Disability Rights California and other disability rights groups. At this event these groups talk to people who write the news.

Hi, my name is Alice Wong. I'm a disabled activist and I live in San Francisco, District 9. I have not left my home since March of last year. I left once for a flu shot. If I get COVID I will die. I am not alone. I and a lot of people were in phase 1C for the COVID vaccine. That meant we were going to get the next vaccines. But this week, the government said they wouldn't do this. Instead, the government is going to give people the COVID vaccine based on age.

But age is not the only thing that makes people more likely to die from COVID. The government is leaving out all the people whose lives have been most changed by the pandemic. This decision is racist, since Indigenous, Black and other people of color are more likely to get COVID. This decision is classist because poor people are more likely to do jobs that put them at risk of getting COVID. This decision is ableist because disabled people are more likely to die from COVID. There are also disabled people who are more likely to die of COVID whose jobs can't stop being done or be done at home. There are also disabled people who are more at risk from COVID because they don't have somewhere to live or can't go to doctors because they don't have the official piece of paper

to prove who they are. There are disabled people who are people of color. I am so scared for myself and others.

I refuse to argue about who deserves the vaccine more. We are all at risk from COVID. If you want to read more stories from people in phase 1C, look at the hashtag #HighRiskCA on Twitter. I'm also on Twitter at @SFdirewolf. Thanks.

February 4, 2021: A text from the people who figure out how to get COVID vaccinations to people in San Francisco.

Thank you for asking for more information about extra vaccines near [the place is blacked out]. We will let you know by texting you here.

If you don't want to get these text messages anymore, reply with STOP.

February 7, 2021: A text from the people who figure out how to get COVID vaccinations to people in San Francisco.

Hi, this is Dr. B! You are the 8, 285th person to sign up. We decide who gets the COVID vaccine first based on who the government wants to be first. Then we look at who is next in line. We will text you if we get a vaccine for you. If you have more questions, go to: hidrb.com/faq

February 11, 2021: Alice's writing from the **Disability Visibility Project**

On January 25, 2021 Governor Newsom of California told everyone that the government would decide who got vaccines first based on age. This meant that disabled people, who thought they would be next to be vaccinated, were not important. I made the hashtag #HighRiskCA to share about this. The hashtag was also a place for people under 65 who were at risk from COVID to share how this change hurt them. California was not alone. Different states had different plans about who to give vaccines to first.

Here's some ways you can celebrate Valentine's Day. Please ask people to take action. Ask people to demand that all people who are at higher risk of dying or becoming very ill from COVID get vaccines. These are:

- Disabled people.
- Chronically ill people.
- People who are heavier than doctors think they should be.
- People working jobs that make them more likely to get COVID.
- People who don’t have papers to prove who they are.
- People without somewhere to live.
- People who live in prisons.

High risk is high risk. No one’s life can be thrown away.

Plain Language Translation Note: There are a few Valentine’s Cards. I’ve written out the words here. But you might want to look at the pictures too if you can.

Vaccines for everyone, given in a fair way.
Will you be my Valentine?
#HighRiskCA #HighRiskCOVID19 #NoBodyIsDisposable

Be Mine COVID Vaccine
You give me life

#HighRiskCA #HighRiskCOVID19 #NoBodyIsDisposable

I Love You, Vaccine Equity. Vaccine Equity means that vaccines are given out fairly.
No Governor will keep us apart
#HighRiskCA #HighRiskCOVID19 #NoBodyIsDisposable

February 12, 2021: The **Los Angeles Times** says, "California to Give COVID Vaccine to People with Cancer, People who Weight More, People with Other Conditions"

February 15, 2021: Message to Alice's Doctor

Hi [name taken out],

The Department of Public Health said on February 12 that disabled people who are at risk of dying from COVID can get the COVID vaccine sooner. This is a change from their earlier decision to make us wait. Can you ask the vaccine clinic what I need to do to make an appointment after March 15th? March 15th was the date given in the Department of Public

Health's statement. I know it'll take time for you to get an answer. Maybe we can start asking now?

Thanks!

Alice

February 16, 2021: Reply from Alice's doctor

Hi Alice,

I'm talking a lot to the people in charge of vaccinations. I think about you all the time, especially as we get closer to giving the vaccine to people like you. It's been really hard to watch everyone making decisions decide that age is the best way to decide the order in which people get vaccines. I, and other doctors and patients are really happy that things are changing.

When they start taking appointments you can log onto a website or call them. They're not making appointments yet. I'll try to watch for when they

start taking appointments. I'll send you a message. Us doctors need to find a way to invite people to make appointments as soon as they can. Thanks Alice. Hope you're well,

Dr. [Name taken out]

February 22, 2021: Email forwarded to Alice by lots of people

Hello East Bay community group,

Here's some information about the place that will give the vaccine to lots of people. The site is at Oakland Coliseum, 7000 Coliseum Way, Oakland, C.A. 94621.

The place will have enough vaccines for 6000 people each day. It will be open from 9:00am to 7:00pm. People will be there to show people where to go, answer questions and help with translation. The purpose of this place is to give out vaccines to people whose lives have been changed a lot by COVID. It's also to give vaccines to people who are more likely to die from COVID.

We've set aside appointments every day for Black, Indigenous, people of color and disabled people who live close by. The appointment can be made with an access code. The code will be shared with disability leaders and other people pushing for vaccine equity, who will know a lot of people who need the vaccine.

To make sure the people in the community who need the vaccine get it, the State of California is working with [name of group taken out]. They are talking to community groups to help tell people about vaccines being available and to help people sign up for appointments.

People can get vaccination appointments at the Oakland Coliseum by going to the state's website or calling the toll-free number. When the system asks for the "Accessibility Code, optional", that is when you put in the code.

People who can sign up for vaccine appointments are:

- Health care workers.
- Paid caregivers.

- Family caregivers.
- People who live in long term care or nursing homes.
- Teachers.
- People who work with children.
- Firefighters and paramedics.
- Food workers.
- Farm workers.

Disabled people who are at risk from COVID can sign up for appointments from March 15.

Thanks for helping the people in our community get vaccines. Thank you for telling the government they should be doing better.

February 23, 2021: Texts between Alice and a friend

Friend: Did you use the code to make a vaccination appointment?

Alice: I did, but the day they gave me is when my parents get their vaccination. I will try again next week with a new code. If you find out the

new code, do you mind telling me? I know four disabled friends who got their appointments with the code.

Friend: Yes! A lot of getting a vaccine appointment is luck.

February 24, 2021: Text messages between Alice and a friend

Friend: Are you up? There are appointments for this weekend with a code.

[The friend tries to call Alice]

Alice: Just saw your message. I am going to try to get an appointment!

February 24, 2021: Text messages between Alice and another friend

Friend: Did you get a vaccine appointment? The codes work!

Alice: Can’t believe it.

February 24, 2021: An email about Alice's vaccine appointment

You have an appointment!

Hello Alice, your COVID vaccination appointment is made.

Appointment number: 3qsgbaw1x

Patient: Alice Wong

Vaccination Location: Alameda County - CalOES (Drive through C) 7000 Coliseum Way, Oakland, California, 94621

Your appointment date and time: Sunday, February 28, 20221, 5:00pm

Your appointment date and time: Sunday, March 21, 2021 at 5:00pm

February 26, 2021: A text from the people who figure out how to get COVID vaccinations to people in San Francisco.

Your vaccination appointment will NOT happen. You are younger than 65. You are not a health care worker, firefighter, paramedic, teacher, or food or farm worker. Vaccines are only available for these people.

February 27, 2021: Texts between Alice and a friend

Friend: The code was for disabled people and Black, Indigenous, and people of color. But people need to be older than 65 or doing the jobs that let you get a vaccine. I'm worried about how many vaccines there will be on March 15th. I think I'll hear more next week.

Alice: People told me to use it. So I'm confused.

Friend: We want booking appointments to be easier and less confusing in future. Sorry to hear about your appointment. I'm hearing lots of people were told their appointments won't happen.

Alice: I know other disabled people who got vaccinated last week.

Friend: So they've changed how they make sure - [text message is cut off]

February 27, 2021: Texts with a friend

Friend: Hey are you okay to lie and say you're 65? There's a new code and appointments today and no one is checking when you show up.

Alice: I guess? Will they cancel more appointments?

It doesn't feel right but I really need that vaccine.

Send me the latest code and I'll think about it. Another friend said I should say I'm a teacher but that feels wrong.

This is wrong. I put my age into the website before. They'll figure it out.

Friend: It could work? It's all wrong. What the government is doing is wrong too. What is right is that you get a vaccine.

Alice: No, I already put my age in the website

Friend: Oh fuck.

Alice: People are telling me to do things they would never do. They feel so guilty. Just stop.

Friend: Yes, I hear you.

Alice: This is not disability justice.

Friend: No, no it's not.

Alice: It's not the help or support I need.

Oracle Archive's Note: Disability justice was an important movement in the 21st century. Disability justice says that to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So disability justice is led by disabled people who are Black or Indigenous or people of

colour, whose gender is different than the gender that doctors thought they were at birth, or who are treated badly because of who they love and who they have sex with[20]. Eventually disability justice would be an important part of rebuilding a just and free world after the Outage.

February 28, 2021: Vaccine Equity Memes, shared on the Disability Visibility Project blog

Oracle Archive's Note: Alice uses the meme known as "woman yells at cat" here. Memes were an important way of sharing your feelings in the 21st century. They often used cats to comment on the world.

On the left is a scene from the Bravo T.V. show **Real Housewives of New York**. A blond woman has her mouth wide open. She is pointing in rage. It looks like she is pointing at the picture to the right. Her friend, a woman with long dark hair, is by her side. White text under the picture

[20] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

says: “VACCINE PRIORITIZATION BY STATE.” To the right a white cat sits at a table. It looks confused and unhappy. A plate of cooked vegetables is in front of the cat. White text under the picture says: “HIGH-RISK PEOPLE TRYING TO GET APPOINTMENTS.” Usually when people used the “woman yells at cat” meme they were saying that the people on the right are confused, like the cat. They are confused by what the people on the left, represented by the blond woman, are doing.

Alice: I’ve had a hard time trying to get a vaccine appointment. I’m a disabled person who is likely to die from COVID. I’m younger than 65 years. There’s lots of people in my situation. Time is not on our side. When I feel angry and tired, it helps to make myself laugh. Please share these memes as well as things that might help.

March 5, 2021: Texts between Alice and a friend

Friend: Good morning! This is your code for a vaccine appointment. There is now one code per person. Once you use it, it won’t work again. Use it starting tomorrow. Just keep trying until you get an appointment.

Alice: I still can't get an appointment. They still want people who work jobs that put them at risk and people over 65.

Friend: This is for people with disabilities.

Alice: I think it's for people with disabilities who's jobs put them at risk and people with disabilities over 65.

Friend: When you use it, you'll be given an appointment after March 15. I'm sorry, I know it's really fucked up. I'm trying to make it better.

Alice: Okay, I'll give it a try. I just hope it actually happens.

Friend: None of these appointments have been stopped. I'm working with [name taken out]. I just got these codes five minutes ago.

March 13, 2021: Two photos from Moscone Center, San Francisco, 4:45pm

Plain Language Translation Note: There's two pictures. I've written out the text in plain language but you might want to look at the original pictures too if you can.

Alice: This is a black and white picture of a nurse. She's a white woman with long brown hair, wearing a face mask. She's on the left, giving me a COVID vaccine. The vaccine goes in the muscle near the top of my left shoulder. I am sitting looking away from the camera. I have a clear plastic sheet over my BiPap mask. The Bipap mask goes over my nose. It has a long gray tube that leads to a machine at the back of my power wheelchair.

What a great day. What a fucking journey. I am so grateful to all the disabled people who tried to make vaccinating people in California fair and accessible. Afterwards, my parents and I ate sushi because we were so happy.

Alice: A black and white picture of me waiting after I got my first COVID vaccine dose. I am wearing a plastic sheet over my face and my Bipap mask. The BiPap mask has a long gray tube. I wear a long sleeved black

shirt that reads, ‘Access is Love.’ The o in love is a heart. In my hands I have a white vaccination card and a spit cup. I am smiling with relief.

Alice: A black and white picture. As I was leaving the vaccination place, I needed to get a photo with the life-sized picture of Dr. Anthony Fauci. Dr. Fauci was in charge of how the United States dealt with COVID. I’m wearing a jacket and clear plastic that covers my face and BiPap mask. To my right is the picture. Dr. Fauci is an older white man with short gray hair. He’s wearing a long white doctor's coat. His arms are crossed in front of his chest.

Thanks for visiting the timeline of Alice Wong, early Oracle. You can also look at these timelines to learn about the 21st century:

- The Trouble With Asking Your Friends and People You Don’t Know for Money for Health Care
- Who Gets to Breathe?
- People Being Forced to Move Around the World: The Problems with Countries that Really Like Capitalism

In Praise of Peaches

Plain Language Translation Note: There's a couple of times in this piece where I've kept in a food word that isn't common. It's important because this piece is about peaches. And sometimes what you make with peaches.

San Francisco's shelter-in-place order started on March 17, 2020. A lot of people felt cut off from the world. I didn't, mostly because I already worked from home. Most of my social life is on the Internet. I did miss going to Sightglass Coffee, the coffee shop down the block. I missed going to Safeway and the bank, both close to my home in the Mission District. It wasn't safe for me to be outside. So the only time I went out after lockdown was in October for a flu vaccine. I needed joy and pleasure. I was feeling so much fear. So I tried to find all the pleasure I could in the things I could have. I'd also dream about what I was missing.

I don't eat a lot of plants. I like to focus on the four main food groups: fat, sugar, coffee and bread. But sometimes I do eat fruit. Fruit is one of the gifts of living in California. In spring 2021, my friend Emily Nusbaum checked in with me after the death of my friend Stacey Park Milbern.

Stacey was my friend and someone who worked very hard to make the world better for disabled people. Emily asked if I would like a homemade peach pie. A week later, Emily dropped off a gold-brown pie made with peaches. I stayed inside while Mom met Emily by our door.

The peach filling was like jam: gooey, warm, smelling of cinnamon. It was such a sweet way for Emily to show me she cares about me. The pie was made with love when I was sad. I loved this act of kindness. Emily's pie made me feel a little better. I was really sad about Stacey's death.

Emily is a member of Peachful Easy Feeling, a group of people who look after a tree at Masumoto Family Farm. Masumoto Family Farm is in Del Rey, three hours from San Francisco. It is on land that the Yokut people used to live on. Emily and everyone from Peachful Easy Feeling go out every summer and pull the peaches off their tree. The tree can make up to 400 pounds of Elberta peaches. Elberta is a smooth peach. It's bright yellow on the inside and gold on the outside when it's ready to eat.

Emily invited me to Peachful Easy Feeling. She offered to pick and bring me some of the peaches to my home in August. Eating a fresh Elberta

peach is magic. It's firm and full of juice. It's not too sweet and not too sharp. Its skin isn't too tough so I can eat it easily. When I bite into a peach, I feel the circle of life and death that created that peach. I feel the hands that picked and packed it. I feel the family and farmworkers who helped it grow. The pandemic made my world much smaller and much harder to know what was going to happen. But eating that peach brought me joy. It made my heart hurt a little less and gave me peace.

Emily gave me the best part of summer. She brought summer into my inside world where I stay far away from other people. Our friendship is an example of how life is better when we need each other and we help each other. Even before COVID, I wouldn't have the energy to go all the way to the farm and pick peaches. The months of staying inside were heavy on me as I ate the peaches with my parents. Ever since then, we talk about the peaches as if they're friends we can't wait to see again. Am I talking up these peaches too much? Do I remember the peaches as better than they were because I ate them when I was alone? Does it matter because I was happy and full?

Team Peachful Easy Feeling started with Emily, her friend Kathy Wage, and the Takeuchi family. The Takeuchis know the Masumotos from the Japanese American community in the Central Valley.

Emily knows Kathy Wage, who is a speech-language pathologist. Speech-language pathologists help people talk in a lot of different ways. Kathy introduced Emily to Kayla Takeuchi. Kayla is a young autistic non speaking person. Kayla didn't have the things she needed to say what she wanted to until she was fifteen. When she was 15, someone called Janna Woods worked with Kayla. Janna Woods tried supported typing with Kayla. Supported typing is when someone holds another person's hands to help them type. Supported typing is a type of alternative and augmentative communication. Alternative and augmentative communication is when someone talks without using speech. Janna helped Kayla find how to say what Kayla wants to say.

Sadly, Janna died of cancer. Emily's brother Jonathan also died of cancer. The group was made to remember Janna and Jonathan. The group was a way to come together and do something beautiful each year.

Emily described eating a peach as “tasting the sun, the flower that it started from, the bees, the air, sky, and water.” Emily can taste all the parts of nature that made the peach. Humans and nature need each other. We are tied together.

The ways we are tied together kept growing. David “Mas” Masumoto emailed me in January 2021 without knowing how much I love peaches. He wrote:

> Thanks for all the work you do and your spirit. I’m an organic peach and nectarine farmer (and a writer) and the stories you capture reflect the true “natural world” we live in (and eat in an organic peach!).

He meant:

> Thank you for everything you do. Thank you for being you. I’m an organic peach and nectarine farmer. I’m also a writer. The things you write share the natural world we live in (and eat in peaches).

We wrote to each other. I learned that David was working on a book, **Secret Harvests**. **Secret Harvests** is about the life of his aunt, Shizuko Wong Sugimoto. Shizuko was taken from her family because of her

disability when Japanese Americans were forced to leave their homes and live in camps in World War II. In 2012, David found out about her. Shizuko being taken away was a family secret that was still hurting his family. I got to read an early version of his book. I gave him some notes on disability history, language, and culture. There is so much warm feeling between Emily, David and me. Our communities and histories and nature are all tied together. Making life needs care and connection. Like fruit trees with flowers, making stories needs care and connection, too. The people we love who are no longer alive are still with us. Our stories about them are seeds planted gently. We plant their stories with hope for the future. Sometimes a peach is just a peach. Sometimes a peach is the universe opening to other people who will support and love us.

No to Normal

I was one of several people who spoke at a 2021 online event, Night of Ideas. Night of Ideas is about culture, connection, and community in the San Francisco Bay Area. Night of Ideas was about “Closing the Distance.” This is what I said:

How do we close the distance? Access. Access means that disabled people can get into a place, use a thing or enjoy an event.

Working together to make access will bring us together as people, communities, and countries. I am a disabled person living in the Mission District of San Francisco. I use a wheelchair and ventilator all the time. A ventilator is a machine that pushes and pulls air in and out of my lungs so I can breathe. Every day I feel how different my world is from the non-disabled world. But we all have to exist in the non-disabled world. I’m talking about the ableism in our political systems, the space around us and how we connect with each other. Ableism is the way the world favors people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people’s lives

are more important than disabled people's lives[21]. Disabled people have to live in the non-disabled world. So disabled people have to ask for access. They always have to prove that they need access and they always have to make non-disabled people feel like they deserve access. When the world isn't built for you, people doubt you. People think you're getting special treatment. But disabled people have a right to access because they are human.

And then in March 2020, San Francisco asked everyone to stay at home. Almost everyone had to find new ways of working and connecting. For years, disabled people who had been asking to learn and work on the internet. Disabled people had asked for people to meet, hold events on the internet. Disabled people were told "it's too difficult" or "It takes away from the face-to-face experience."

But in March 2020 it was dangerous to be close to other people. So non-disabled people needed access. Which meant that everyone had access.

[21] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

I'm more at risk of dying from COVID than other people. So I have been outside for the last 11 months. I left my home for a flu shot. Even though we now have vaccines, I'm still scared. The vaccines will not get rid of COVID. Like a lot of other people who are more at risk of dying from COVID, I worry people will stop trying not to get COVID. I worry people will stop washing their hands, staying far away from other people and wearing masks.

I feel far away from people who don't have to worry about dying from COVID. That is the distance I feel. Access and working to make the world more fair is a way to make that distance smaller. You will need to believe that everyone needs each other. You will need to believe that everyone has value to create access and justice. The pandemic showed how bad things are. Hypercapitalism and white supremacy mean that the people who have the least are hurt the most. Hypercapitalism is very fast capitalism, where everyone everywhere is connected and involved in making more money. White supremacy is when people believe that white people's needs and wants are more important than the lives of people who aren't white. Hypercapitalism and white supremacy mean that

governments believe that the lives of people who have the least aren't worth saving. Hypercapitalism and white supremacy mean that the people who have the least find it hard to get good health care, good work, somewhere to live and to go to school.

But what if we decide to not go back to normal? What if we learn from these difficult times and make a better world centered on access, care, and justice? San Francisco would need to stop making it easy for people with lots of money to move here and change the city. San Francisco would need to stop making not having a home, being older, disabled, without paper showing who you are, being poor and being a person of color a crime. We can all make access for each other. Things are still very dark but I do have hope. I have hope because we can all learn and grow. We can close the distance I feel together. I'll give you two questions to think about:

- Who is missing from all the spaces you are in?
- What can you do to demand access and to make access?

Thank you for listening.

Normalcy is a Scam

Plain Language Translation Note: This piece is a beautiful image. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

The idea that things should be normal is a lie. It’s worse than a lie. The idea that things should be normal will take your money, time and happiness.

Future

When something can’t be fixed then the question is what can we build instead? —MARIAME KABA

Mariame Kaba is an activist and teacher. An activist is someone who works with other people to change the world. She works to get rid of prisons and the police. This is because prisons and the police hurt and kill Black people just because they are Black.

Let’s fly. —CAPTAIN MICHAEL BURNHAM, USS DISCOVERY

Captain Michael Burnham is a character on **Star Trek: Discovery**. She always tries to save everyone, even if it costs her everything.

We are each other’s harvest: we are each other’s business: we are each other’s magnitude and bond. —GWENDOLYN BROOKS, “PAUL ROBESON”

Gwendolyn Brooks was a writer. She was the first Black person to win a Pulitzer Prize. She often wrote about Black people’s struggle for justice. In this poem she writes about Paul Robeson. Paul Robeson was a performer. He lost a lot of work because he refused to tell the United States government that equal rights for Black people was wrong.

Which means:

We help each other grow. We should look after each other. The possibilities of our lives are each other's responsibility. We belong to each other.

My Disabled Ancestors

Plain Language Translation Note: This piece is a beautiful image. I've written out some information about the image and the names in the image. But you might want to look at the original picture too.

These are the names of the people who I think of as my disabled ancestors. Ancestors are the people in your family who lived before you.

Stacey Park Milburn

Ing Wong-Ward

Erin Gilmer

Ki'tay Davidson

Stella Young

Greg Smith

Laura Hershey

Barbara Waxman Fiduccia

Carrie Ann Lucas

Harriet McBryde Johnson

Paul Longmore

Ancestors and Legacies

What do we leave behind when we die? I'm not dead yet, so I don't know. Disabled people and other people the world does not treat well know what it is to lose people. We miss people who died earlier than they should. This was true before the pandemic. It will always be true.

My dear friend Stacey Park Milbern died on May 19, 2020. I found out from our friend Leah Lakshmi Piepzna-Samarasinha. Leah texted me and messaged me on Facebook. I get up late so I missed a lot of messages. I found out later than a lot of people in the disability community.

I looked through Facebook, where Stacey and I were linked to a lot of other Bay Area disabled people. I felt like some people were saying things they didn't mean. They didn't know Stacey and they were saying they were so sad. Some people wanted to organize events to mark her life. Some people wanted groups to recognize her during the year that the Americans with Disabilities Act turned 30 years old. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies and groups are accessible to people with

disabilities. Few people were taking time to think of the people who knew Stacey best. People put Stacey's friends, who were sad and in shock, in the position of having to talk to people and do things.

I don't have a lot of respect for white disabled people who want to help disabled people of color. Those white disabled people didn't understand Stacey's sense of what was right, or disability justice. Disability justice says that to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So disability justice is led by disabled people who are Black or Indigenous or people of colour, whose gender is different than the gender that doctors thought they were at birth, or who are treated badly because of who they love and who they have sex with[22]. Those white disabled people never supported Stacey's work when she was alive. I was angry.

[22] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

I was close to Stacey, so I wrote a piece titled “Loving Stacey Park Milbern." I wanted people to remember Stacey’s actual words and work. I wanted to honor her and tell the “good white people” to back the fuck off.

Stacey and I knew of each other from the Internet. We met for the first time in 2015 at the Ed Roberts Campus in Berkeley. I thought we had the same disability. But Stacey looked at me and said, “I think you have a different type of muscular dystrophy because of your hands.” Muscular dystrophy is a condition where your muscles get weak over time.

I thought she was a bit rude. But it turns out she was right. I got my genes tested recently. Genes are the parts of a cell that tell a body how to work. Some of the ways my body works are the same as Stacey’s. But my type of muscular dystrophy is very rare. Thank you Stacey, for seeing what I couldn’t and just saying it.

This was classic Stacey. She was funny and without fear. She dreamed big. She said exactly what was on her mind. She loved ice cream, boba tea and Mariah Carey as much as helping people out and talking people into working together to make the world better. Stacey lived disability

justice. She believed that everyone was important. No one should be left behind. She believed that counting on each other is the way forward. She believed that there were answers right in front of us.

Stacey is best known for being an activist, someone who wants to change the world. But she was also a beautiful writer. She would post things she'd thought a lot about on Facebook. One post she wrote about ancestors, the people who came before us, moved me. I asked if she would make it into a guest essay for my website. I shared **On the Ancestral Plan: Crip Hand Me Downs and the Legacy of Our Movements** on March 10, 2019. The piece talked about the people who came before Stacey and changed how she thought and worked. In it, Stacey talked about a pair of socks Harriet McBryde Johnson gave to Laura Hershey. Laura Hershey then gave the socks to Stacey. Harriet McBryde Johnson was a disabled writer, lawyer and activist. Laura Hershey was a disabled writer and activist.

Stacey wrote:

> I do not know a lot about spirituality or what happens when we die, but my crip queer Korean life makes me believe that our earthly

bodyminds is but a fraction, and not considering our ancestors is electing only to see a glimpse of who we are. People sometimes assume ancestorship is reserved for those of biological relation, but a queered or cripped understanding of ancestorship holds that, such as in flesh, our deepest relationships are with people we choose to be connected to and honor day after day.

Stacey meant:

I don’t know what happens to us when we die. But living a crip queer Korean life makes me think there’s a lot more that just what we live here. Crip is a word that used to be used against disabled people. Disabled people have taken it back. It means disabled and proud. Queer can mean someone who loves and has sex in ways that a lot of the world doesn’t like. We need to think about the people who came before us. They are part of who we are. Sometimes when we talk about the people who came before us we only think of family. But queer people and crip people teach us that the people we choose are our families. The people we choose are our ancestors.

I put Stacey's piece in my book **Disability Visibility: First-Person Stories from the Twenty-First Century**. A few weeks after the book came into the world, Stacey died. It feels a bit sad and happy all at the same time. It made me happy to think that people might learn who Stacey is from that book. When I was talking about **Disability Visibility** I could hear Stacey's laugh. I wish she got to celebrate with me and the other writers. But she was there on the page and in spirit.

In 2021, Dr. Jess Whatcott from San Diego State University organized a talk on disability justice. Dr Whatcott asked me and Leah to talk about Stacey and disability justice. I was so excited to do this with Leah, who knew Stacey much longer than I had. We talked a lot to make sure we were ready. I woke up that day excited and ready. But there was a text from Leah saying, "Hey, are you there?"

I'd slept in and missed the talk. It was one of my biggest fears.

It was the first time I'd done that. It was horrible. I looked at my planner the night before. I figured out when I needed to get up and eat. But my body had other plans. My body said, "Bitch, I am the captain now. Your

nerve pain has been really bad lately. You haven't been sleeping and it's hard to focus. You're doing too much. I know you want to be there. But I'm going to keep you sleeping. You'll thank me later. Byeeee!"

Leah and everyone understood in a way that only other disabled people do. I was so ashamed that I messed up. While sleeping through an event is not really access, what everyone showed me is access intimacy.

Mia Mingus says this about access intimacy:

> Access intimacy is also the intimacy I feel with many other disabled and sick people who have an automatic understanding of access needs out of our shared similar lived experience of the many different ways ableism manifests in our lives. Together, we share a kind of access intimacy that is ground-level, with no need for explanations. Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability.

By this Mia means:

> Access intimacy is the feeling I get with other disabled and sick people who know what it's like. They also know what it's like to have the world treat you badly because you are disabled and sick. We don't need to explain ourselves to each other. We can listen and know what bad access feels like. We know how much work went into access. We don't have to tell each other why we need what we need. We are able to be open with each other and this is strength.

I am still sad and guilty that I missed that event. I didn't want to let anyone down. But I did. And I know that's okay. Stacey would have wanted me to take care of myself. She would have wanted me to listen to my body. Missing that event made me think of what I learned from her. Thank you, Stacey.

Being open and honest is key to making the world better. This is one of the things I understand from disability justice. It's not something that happens right away. You can't buy a candle, listen to a podcast or read a book and then be able to be open and honest. You have to try every day. And you need support from people who care about you. Being open

means you might be open to pain. That means you have to experience the pain, take the time to sit with it and respond to the pain.

I was really upset to see people get details about Stacey's life wrong in 2020. Then they got them wrong again in 2021 on the anniversary of her death. Stacey died on her birthday. Friends and family of Stacey had to ask people to make details right. They had to talk to people and spend a lot of time teaching them. They should have been able to remember Stacey with love.

Then a white person sent me a message on Twitter. They asked, "Possibly weird question - do you know who got Harriet McBryde Johnson's socks after Stacey Milbern?"

This person, a disabled writer, wanted to do a radio story. The story would be about a piece of Harriet's writing, "Unspeakable Conversations." "Unspeakable Conversations" was shared in the **New York Times** on February 16, 2003. I love this piece of writing. It's also in **Disability Visibility**. I like to imagine Stacey and Harriet talking to each other, ancestor to ancestor, in **Disability Visibility**.

I wrote back to say that this was not an okay thing to ask. I was sad, like a lot of Stacey's friends. I should have been able to remember Stacey and her life, not answer questions like this. I want to treat people with kindness. But at this moment I needed to make it clear that some people needed to back the fuck off.

I wrote a reply. I never sent it because that person doesn't deserve my time.

This is it:

> You ask me where my friend's socks are? Because it is an interesting way to tell a story? That's not okay. There's no way in hell I'll share how to get in touch with anyone who is dealing with Stacey's things right now. And I'm not going to ask anyone close to her. How you do something is just as important as what you do. I've seen the way you treat people in the disability community. I fucking see you.

What do we leave behind when we are gone? Maybe part of what I'll leave behind is how much I care about what the people I love left behind. Stacey left so much writing. She left a Bay Area disability justice collective. She built relationships that last as long as any story or book. The real gift anyone can give is how we connect with each other. If we love each other, then our ancestors speak to us through our memories. Loving deeply is building what we'll leave behind. Maybe that's the best way to honor people. One day, I'll die. After I die, I'll have ice cream with Stacey and talk shit about people again. I can't wait.

S. T. F. U. White People

Plain Language Translation Note: Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

S.T.F.U. White People. S.T.F.U means Shut the Fuck Up. Shut the Fuck Up White People.

Tiger Tarot - The Parasite by Hatiye Garip

Plain Language Translation Note: This piece is a beautiful image by Hatiye Garip[23]. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

This image is a tarot card. Tarot card reading is when people look at tarot cards to learn about the past, now and the future. In tarot decks, each card has a meaning. This is Tiger Tarot, a new tarot deck.

The new moon is coming. People who will suck your energy are coming. They will try to take your power. Do magic around yourself. Protect your time and energy so you can keep doing things you want to do.

[23] If you want to see more pictures by Hatiye Garip you can go to her website here.

As I Lay Breathing

June 3, 2021:

Dear Diary,

I'm very proud of myself. I made a sound piece on breathing for Radiolab today! I did it on the internet first. But there was an issue and the producer, the person who organizes making the sound pieces, called me. They asked if they could send someone to my home. My chest got tight… No one has been in my bedroom, where I also work, except my family since March 2022.

Getting someone's sounds means you have to be close. But the person who came wore a mask and was really nice. Could this be the start of me slowly trying out seeing people? The start of my Hot High-Risk Girl Summer? Hot Girl Summer means a summer where you party and have fun. We'll see.

I can't wait for this piece to come out. Who gets to breathe? I really want people to think about that after they listen.

June 11, 2021:

This is my sound piece “Breath”, made by Radiolab, WNYC Studios, written out.

I can feel something in the air. Something is wrong. My chest feels tight. Then I see it. The trees are on fire. The trees are on fire hundreds of miles away. I live in San Francisco. I know when a fire starts because of how I breathe. My diaphragm, the muscle that moves your lungs and lets you breathe, lets me know the secrets in the air.

My diaphragm is weak. So I use a ventilator, a machine that pulls the air out of your lungs. Without the ventilator, the CO2, the air that’s left when you breathe, stays in my body. If it stays in my body too long, my blood changes. I die slowly. This almost happened when I was 18 years old and I had respiratory failure. Respiratory failure means it’s really hard to breathe on your own. Respiratory failure is really dangerous. It was hard to think clearly. I went to the hospital. I remember seeing my blood being drawn. It was thick and black because it had no oxygen. But I lived to tell the tale. And I hope you’re willing to listen.

When COVID came, many states decided that people like me, who need a machine to breathe, didn't deserve medical treatment. New York went further. New York said that doctors could take ventilators from people and give them to other people. They could steal breath from someone like me and give it to other people.

New York State calls my body broken. New York State says they can do math that shows my life is not worth saving. But I call my body an oracle. An oracle is someone who can see a bit of the future. I know fire is coming before you. And the math that says who deserves to breathe, the math that says my life isn't worth saving? I can see that math is coming for you.

June 14, 2021:

Medical Device Recall Notification (U.S. Only)/Field Safety Notice (International Markets)

Philips Respironics

This is writing from Philips Respironics. Philips Respironics makes a lot of medical equipment that helps people breathe. This writing is telling people who use one type of ventilator that they make that there is a big problem with it.

What is the danger?

The ventilator has foam, which is small plastic bubbles, that make it quieter. You could breathe in the foam. The foam may come loose through cleaning it with ozone. Ozone is a type of gas. High heat and living somewhere wet could make the foam break loose. You could also breathe in chemicals from the foam.

If you breathe in the foam, your skin, eyes, and throat could get red and hurt. Parts of you could get bigger. You could get a headache. You could find it hard to breathe. Your kidneys, liver or other parts of your body might be hurt. You might be more likely to get cancer.

Several people have told Philips Respironics that they see little black bits in the ventilator tubes. People have also said they have headaches, red

throat and nose, a feeling like something is pushing on their chest, a runny nose, cough and feeling like something is pushing on their cheeks and eye.

For people who need their ventilator to live:

Do not stop using your ventilator until you've talked to your doctor. Philips knows that getting another ventilator might not be something you can do. You may have to keep using our ventilator because the danger of not using a ventilator is greater than the danger of using it.

If your doctor decides you need to keep using the ventilator, use an inline bacterial filter. An inline bacterial filter is a flat thing you put between your machine and your tube. It stops germs, dust or dirt from getting into your air. Please look at your **Instructions for Use** book for how to put the filter in your machine.

June 15, 2021:

Dear Diary,

Fucking hell. Like, fuck a duck. I can't believe that I found out about my ventilator on Facebook yesterday. My ventilator comes from Philips Respironics. Yesterday they told everyone who uses one of their ventilators that we might be breathing in little pieces of foam. They said everyone needs to stop using their ventilator. Unless they're like me and you need the ventilator to live. I'm just supposed to suck it up (that's a joke). I'm supposed to keep on using my ventilator because I don't have a better option. So my best option is breathing in foam that might give me cancer. Philips Repironics figures that my body and life is fucked up anyways, so oh well.

I'm dreaming of revenge right now. I wrote about this on Twitter with the hashtag #SuckYouPhilips. A hashtag lets people talk about one thing on Twitter by letting you keep track of everything anyone has said about a subject. People wrote me back and said Philips didn't tell them. They found out from me on Twitter. I guess Twitter isn't all bad.

I've always known no one will save us but us. The government and the medical system aren't meant for us. How many times do things need to go wrong before non-disabled people give a fuck? How many people need to

die? When COVID happened, suddenly things were more accessible. Accessible means that disabled people can get into a place, use a thing or enjoy an event. But only because non-disabled people needed more access. Now states are going back to how things were before COVID. States are getting rid of the rules that say people need to wear masks. And the little bit of access we got from learning and working and playing on the internet and pickup and delivery is starting to go away.

I motherfucking survived 2020. I fought hard for people like me who are more at risk of dying from COVID. I fought for us to get vaccines after California decided it wasn't important to vaccinate us last February. The things I talked about in the Radiolab sound piece and all my writing about disabled oracles are real. But oracles need to breathe. You need breath to speak the truth. Maybe that's the point. They don't want us to be able to speak the truth in the middle of COVID. COVID is making more and more people disabled. People don't want to hear from disabled people. I guess oracles are people who just refuse to die despite everything.

I know I should be grateful. I am. My parents are good. My sisters are good. I'm still alive. But that's not really enough, is it? That's low-bar shit.

Living is more than surviving. You shouldn’t have to be grateful that your heart is beating. This is the end of the world for people who do not get to breathe in the same space as other people. Maybe those people don’t get to exist in the same space because of white supremacy, climate crisis, medical racism, settler colonialism or systemic ableism. White supremacy is when people think that white people’s lives and wants are more important than non-white people’s lives. Climate crisis is when natural disasters happen because humans have warmed the earth. Medical racism is when people who work in medicine and health treat Black, Indigenous and other people of color worse than white people. It is also the way medical systems treat white people better. This means that Black, Indigenous and other people of color can’t get the care they need. Settler colonialism is when a government tries to get rid of the original people and bring in new people to live on the land. This can be by killing the original people of the land or by destroying the culture of the original people. Systemic ableism is the way the world favors people who have particular kinds of bodies, minds and who can work in a particular way.

This leads people to think that non-disabled people's lives are more important than disabled people's lives[24].

Water, air, breath - everyone needs them. But only a few people get to have them. I want to burn it all down. But oops, fire will make more smoke. And I can't breathe in that smoke.

Maybe I'll start some fire with my words.

Ta-ta for now, bitch.

June 15, 2021:

An email Alice sent at 5:34am.

Hello people who work at my respiratory care agency.

[24] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

You helped me get my ventilator and other equipment. I hope you're well and you don't mind me writing to you. Did you see that Respironics is recalling lots of machines? They're recalling the Trilogy100 that I use.

I'm pretty freaked out. I'm worried that I'm inhaling those little pieces of foam. I do use a filter. So maybe that will help?

I'm looking forward to hearing from you. Let me know what you think I should do.

Thank you!

Alice

June 15, 2021:

Email sent by people who work at the respiratory care agency at 3:16pm

Hi Alice,

We’re letting everyone know. But yes, the recall is about the Trilogy ventilators. It’s the foam that is used to make them quiet.

Philips says that the foam may be breaking into little pieces because of ozone cleaners. We don’t tell our patients to use ozone cleaners. We don’t know of any of our patients who use ozone cleaner. If you’re using an ozone cleaner, please stop and let us know.

We can send you an extra filter as this gets worked out!

If you notice any changes with your filter please let us know.

We don't know a lot. The only thing we know is that Philips doesn’t have ventilators or PAP devices to give you a new one right now.

We’re trying to work with Philips. We hope they’ll sort this out.

Thanks,

[name]

June 17, 2021:

Email sent at 6:02am

Hi [Name],

Thanks for letting me know. I'd love more filters. I have a DreamStation, a type of ventilator, I use at night. I didn't get the DreamStation from you. Is it safe to use a filter if the air in the DreamStation is warm and wet? Or will the filter get mold?

I'm glad that you don't use or tell your patients to use ozone cleaners. The foam can still break down. I'm a bit worried. I've had watery eyes for years. I assumed that it was from the ventilator pushing air into my nose.

Thanks. I hope to hear more from you soon.

Alice

June 17, 2021:

Email sent 12:08 p.m.

Hi Alice,

Yes, don’t use the filter with air that’s warm and wet. The filter will stop the air if it’s wet. I know it’s not great, but you could take the heater off. Then you could use the filter.

Lots of people who use ventilators get watery eyes. The air from the ventilator is pushed into your nose. The eyes and nose are connected. I had one patient whose eye would get a bit bigger each time she breathed in. I know it doesn't make you less worried, especially with the recall. [Name] can help you with your filter.

I’ll let you know as soon as I know more!

[Name]

June 30, 2021:

Certain Philips Respironics Ventilators Machines Recalled Due to Potential Health Risks: Food and Drug Administration Safety Communication.

The Food and Drug Administration are the people in the US government who try to keep everyone healthy. They do this by making rules for companies that make:

- Food.
- Drugs.
- Medical equipment.
- Vaccines.
- Medical tests.

Philips Respironics has asked people to stop using some of the ventilators they make. This is because the foam in the ventilator is breaking down into little pieces. If you can’t stop using one of their ventilators, talk to your doctor about using a filter. Right now the Food and Drug Administration doesn’t know if using a filter works to stop you from breathing in the pieces of foam. We’re trying to figure this out.

You may want to think about these facts:

Filters will not stop you from breathing in the chemicals that might be coming from the foam.

Filters might make it harder to breathe.

You should look at your filter after you've put one in to see if there are little pieces of black foam on it.

July 1, 2021:

Dear Diary,

I'm thinking after talking to the people at my respiratory care agency. The filter in my ventilator turns gray after using it for a couple of weeks. During the times of year when there are a lot of fires, the filter turns gray faster. How many little pieces of black foam are in there with all the dust and smoke? I'll never know.

At night my throat is dry and hurts. I cough, tear up, then wake up. Did I cough because I slept with my mouth open? Or did I cough because I'm breathing in bits of foam? My nose is all fucked up. I've spent years wearing a mask over my nose. The mask pushes cold, dry air into my lungs during the day. Only when I sleep is my air warm and wet. Does my nose hurt because of my mask? Or does my nose hurt because of the pieces of foam?

Is my throat and mouth supposed to hurt? I can't stop using this machine. It's part of me being a cyborg. My ventilator is part of me. I guess the only thing I can do is change the filter more often. Which means I'll have to order more filters. I'll have to pay for them myself because there's so few of them.

I felt even worse after I saw the safety communication from the Food and Drug Administration. I was hoping the filters were doing something. But it makes sense that the chemicals from the foam wouldn't be stopped by a filter. Should I still order more filters? Is it better than nothing? Or am I just getting more filters so I can feel like I'm doing something?

Shit. Shit. Shit. Fuck. Fuck. Fuck.

When I turned forty, I started using my BiPap more often during the day. I used to use the BiPap machine only at night. Now I use it about 22 hour each day. I've done the math. I've spent 7 years using the BiPap machine 21 hours each day. That's 53,655 hours. I've spent 53,655 hours maybe breathing chemicals that might make me sick. Maybe I've spent even more hours breathing chemicals that might make me sick. I've used a lot of different brands of BiPap machines, including some from Philips Respironics, since I was 18. Shiiiiiiiiit. What does the future hold? Who knows. But this machine has made my life longer. I'm hurt that Philips Respironics has maybe hurt me and shortened my life. I love every breath. I know the fight when I breathe in water or am sick. I have to fight to breathe. But when I breathe, I may be breathing in chemicals and pieces of foam that could hurt me.

I'm so angry. I have to be careful because I can get too angry. But I am so angry. And so far, my anger has made things happen. Especially when I balance the anger with rest and joy. But I'm also tired. So tired. One day I'll be stopped by how tired I am. But not today.

Maybe I could be an octopus in my next life. Octopuses live in the sea and have eight legs. I’d like to be able to change my colors. Octopuses are very soft. I’d like to swim away from danger and never break.

Kisses!

Alice, your friendly neighborhood disabed octopus cyborg.

Recharge and Revolt

Plain Language Translation Note: Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

Recharge and Revolt. Recharge means to build up energy. Revolt means to fight against the people who have power.

The Future of Care?

This piece is made of titles of pieces of news. All the news is about caring for people. Some of the news is about the Infrastructure Bill in the US. President Biden wanted to give more money to caregiving in the Infrastructure Bill.

June 3, 2021: “More People are Using Care Machines. Care Machines are Replacing Human Caregivers”, written by Alexandra Mateescu and Virgina Eubanks for **The Guardian**.

June 9, 2021: “President Biden Wanted Money for Care to Be Part of the Infrastructure Bill. The Infrastructure Bill is a Suggestion About How to Spend Government Money. Republicans Won’t Support the Bill Unless Biden Took Out the Money for Care” written by Joey Garrison and Ledyard King for **USA Today.**

June 10, 2021: “A Group of Republican and Democratic Senators Say They Can Agree on the Infrastructure Bill”**,** written by Emily Cochrane, for **The New York Times.**

June 26, 2021: “President Biden Promised More Money for Caregiving in Homes. The Infrastructure Bill WIll Not Have More Money For Care” written Suzy Khimm for **NBC News**.

July 2, 2021: “When a Computer Makes Healthcare Decisions the Results Can Be Cruel” written by Erin McCormick for **The Guardian (London).**

December 28, 2021: “New Technology Promises to Tell You How Long You’ll Live. But Telling Disabled People How Long They’ll Live Can Kill Them” written by Brandy Schillace for **Wired.**

Dream Dispatch

Society of Disabled Oracles

Year: 2021

Location: Turtle Island, the returned land of the Ramaytush Ohlone people (formerly known as San Francisco, California)

Notes written to get ready for a talk with Ai-jen Poo and Alicia Garza on the **Sunstorm** podcast. The podcast was shared on June 9, 2021.

These notes were recently discovered on Mars. We've figured out what they say, so we can learn about the 21st century. These notes are a little unclear. There are questions and answers, but they don't always match up.

Questions:

- Why do hospitals, nursing homes and extended care exist? All these places are places where disabled people have to live together, away from their community.

- Why don’t people see these places for what they are? These places trap disabled people. The people who work there control every part of the disabled people’s lives who live there.
- Why do people think that old people and disabled people shouldn’t be out in the world? Why do people think that old people and disabled people can be forgotten?
- Capitalism is the system we live in where we have to work to make money so we can live. Why does capitalism make people who give care the enemies of people who get care? People who give care and people who get care should be working together.
- Why do old people not support disabled people? Why do disabled people not support old people? Why do disabled people who have money not support poor workers?

Answers:

- Care is a shape, a way of putting things in place. Having a place is care. In the future, the way we plan care will be led and planned by disabled people and others who need care. Disabled people and others who need care will work with the people who give care to lead and plan how care works.

- Care will be free. Care will be paid for by everyone through taxes. People will not need to be poor to get care. People will not need to work or have worked in the past to get care.
- Care will not add to the ways our planet is being destroyed. Care will happen in homes that people can afford. Care will happen in accessible homes. Care will happen in homes that can be reached on the bus.
- You won't need to keep living in one place to keep getting care. You won't need to prove again and again that you're disabled.
- Care will include changing where you live. Care will include getting technology to help you live your life. Care will help you go to school, to work and live your life in the world.
- In the future there will be lots of people who do care work in your neighborhood. They will help if an emergency happens. You will not need to plan for months for an emergency you didn't know was coming.
- In the future care will be planned so that everyone, no matter who they are, can get care.

- In the future, people will see getting care as a normal part of life. People won't think care means that you've failed or that you're weak.
- In the future, we'll understand that care workers have knowledge and skills. We'll give care workers the pay and support they deserve.
- In the future, care will support people who need care to make decisions about their own lives. Care will let people make decisions about the kinds of risks they want to take.
- In the future, care will not be decided by doctors. People who give care will not treat disabled, older and chronically ill people as if there is something wrong with them.
- In the future, we'll understand that care is about freedom, justice, and love. We'll understand that care is about supporting everyone to live the life they want. Everyone deserves to live the life they want no matter what they look like, how they move and how they think.

Tiger Tarot - The Rainbow by Hatiye Garip

Plain Language Translation Note: This piece is a beautiful image by Hatiye Garip[25]. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

This image is a tarot card. Tarot card reading is when people look at tarot cards to learn about the past, now and the future. In tarot decks, each card has a meaning. This is Tiger Tarot, a new tarot deck.

You will have so much joy and so many chances to make your life good. You will have double the joy and chances. Stay open to the joy and chances. Enjoy them the same way you'd enjoy the warm sun and a rainbow. Feel lucky.

[25] If you want to see more pictures by Hatiye Garip you can go to her website here.

How to Create a More Inclusive Future Post-COVID

A talk with Nikolay Nikolov for **Mashable**. Shared on March 3, 2021.

In our society, some people matter more than others. A lot of people think that some people deserve to have more and some people deserve to have less. Bioethicists are people who think about what is right and wrong in medicine and studying medicine. Bioethicists often think that some people deserve more than other people. But there are a lot of reasons people might think that some people deserve more than others. These reasons could be:

White supremacy: White supremacy is when people think that white people's lives and wants are more important than non-white people's lives.

Sexism: Sexism is when people think that cis men's lives are more important than anyone who isn't a cis man. Cis means that someone feels like they are the gender they were given when they were born.

Ableism: Ableism is the way the world is set up to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[26].

Ageism: Ageism is when we assume young adults are more important than people who are older or who are children.

The idea that some people matter more than others is really personal for me. I wrote a lot in 2020. I wrote a lot to argue against the stories that would hurt disabled, chronically ill, fat, older, and immunocompromised people. I'm high risk, but I want to live, too. But I think a lot of people who are not disabled just think, "Oh my god. I cannot imagine living in your body, you must just have it so hard." It is difficult, but what's really difficult is the way the world is not built for me. What is difficult is the way society hurts some people just for living.

[26] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

Disabled and sick people know so much about how to slow down. Disabled and sick people know so much about how to live with a lot of change. I wish people paid attention to what disabled and sick people know. I hope that people learn from COVID that disabled and sick people have always been there. Disabled and sick people have always found ways to live. And often we have the answers everyone needs.

I think a lot about the people who are calling themselves “long-haulers.” They’re calling themselves “long-haulers” because they are still sick from COVID. They might never get better from COVID.

One of the worst things ableism teaches us is that we’re only important if we can do things. And doing more things means we’re more important. We all count on each other and we all help each other. We know that we’re worth more than the taxes we pay. We’re worth more than working 40 hours a week. There’s so much we need to learn. We need to think about taking more risks. We need to change how we live our lives. We need to make things more accessible. We need to listen to the people who are hurt the most by the way our world works right now. We need to let them make the decisions and find the answers.

When you've been hurt by the way the world works for your entire life, you know how to figure things out. People who have never had to deal with the world working against them are often the people who decide how the world works. That's a huge problem. We all lose when people who have never had the world working against them make the decisions. People didn't listen when people with disabilities asked again and again for things like working or learning from home. Now we've learned we can actually make access happen very quickly. Things might not be perfect, but when they need to they can happen very fast.

We need to think about power in the future. We need to ask how power will be shared? How will we get power? How will we make power? I think about Star Trek. In Star Trek, the Vulcans, who are wise aliens, have a saying. The saying is "infinite diversity in infinite combinations." The Vulcans use this to mean that the universe is better when there are many different people in it. Being different makes us better.

We need to stop thinking that "normal" is something we need to go back to. I want everyone to think of this moment as a chance to think hard

about the world. We can make the world again. We can make a world that is about justice, freedom, counting on and helping each other. We can make a world where we respect each other. I don't think we'll have a world that's "post pandemic." Post pandemic means after COVID has gone away. I don't think COVID will go away.

Maybe people should learn from our mistakes. We were slow to act. We were slow to believe people. We lied about what freedom is. Freedom from wearing masks doesn't mean shit if you're dead. In the future, we'll need to have each others' backs. We need to understand that asking for help is not being weak. I think the only way we can survive is if we're in this together.

A lot of disabled people have to fight for their future today. There are a lot of people that want to get rid of us. One of the ways people can get rid of disabled people is with genetic editing. Genetic editing is when a scientist changes human genes. Genes are the parts of a cell that tell a body how to work. Scientists might take some of the molecules in the genes out or put different molecules in. Molecules are tiny. Everything in the world is made up of molecules. In one kind of gene editing when people have

babies, those changes in their genes are passed on to their children. This makes me scared. It’s about getting rid of disabled people, especially people like me who have what people think of as “bad genes.” Technologies like gene editing say that disabled people don’t belong in the future. I don't believe that. Disabled people belong in the future. We’re going to fight as hard as we can for the future.

The Last Disabled Oracle

On August 6, 2020, I gave a talk called **The Last Disabled Oracle** as part of Assembly for the Future. The Assembly for the Future is a project of The Things We Did Next, based in Melbourne, Australia. The Things We Did Next was created by Alex Kelly and David Pledger and Not Yet It's Difficult and Something Somewhere Inc made it happen. One purpose of the event was to imagine lots of different futures together.
People met in small groups and created messages from 2029 to respond to my talk. In my talk I imagine that it's 2029. Here's my talk.

Alice Wong: Welcome, everyone! It's 4:15 p.m. Pacific time in California. I'd like to start the December meeting of the Disabled Oracle Society, for people in North America. I am an Asian American woman wearing a black jacket. I have a mask over my nose with a tube to my ventilator. While people are coming in on the Internet and in person, please help yourselves to some drinks and food.

Louise brought some Tim Tams back from her visit to Melbourne to meet the Disabled Oracles Society in Australia last month. Please remember

we have people coming online, on the phone, and through an all-new Internet platform.

It's December and we're about to start another year. Let's take some time to think about the past. We'll talk about the major issues we've dealt with as disabled oracles. Oracles are people who can see a bit of the future. We started the Society of Disabled Oracles in December 2020. The last nine years have been very hard. We had COVID, then another virus in 2024. The weather has changed a lot. A lot of people have had to leave where they live and move to other places. All of these things have made life harder for people. In particular, people of color and Indigenous, poor, older, and disabled people have had to deal with a lot of very difficult years.

The biggest danger we face is other people who believe that disabilities created by people's genes are something to be fixed. Genes are the parts of a cell that tell a body how to work. Human gene editing has always been around. But in the next 10-15 years human gene editing will become very common. This August, McEdit, a big company, said they were going to do gene editing for anyone who wants it. McEdit says that this is so

people's children can have the best chance at life. I think they will start doing this in 2030 or 2031 at the very latest.

No one except disabled people are upset with McEdit saying this. This means we have a lot of work as disabled oracles. What will this mean for us? How do we argue against the stories McEdit tells about being strong, healthy, just better? How do we figure out what is really wrong and right when it comes to gene editing?

Before we talk about what to do next, let's talk about what some of these words mean. This might help our new members.

Genetic editing is when a scientist changes human genes. Genes are the parts of a cell that tell a body how to work. Scientists might take some of the molecules in the genes out or put different molecules in. Molecules are tiny. Everything in the world is made up of molecules. There are two types of genetic editing: somatic and germline. We'll talk about germline genetic editing today. Germline genetic editing is when scientists change the genes in eggs, sperm or early embryos. So scientists change the genes in things that could become human babies. This means that any

baby that came from eggs, sperm or embryos with genetic editing would have those changes to their genes. And when that baby grew up, any children it had would also have those changes.

CRISPR-Cas9 is one gene editing tool that became popular because it's fast and cheap. CRISPR was used in 2018 by He Jiankui. He Jiankui made two babies. He tried to change the babies' genes so that they would be less likely to get HIV. HIV is a virus that causes AIDs. AIDs makes it hard for people's bodies to protect themselves from other germs and viruses. He went to prison for three years for doing this.

Back in 2018, people were talking about if germline genetic editing was right or wrong. But lots of countries didn't have rules against doing germline editing. Over the years scientists made CRISPR work better. More and more people stopped worrying if genetic editing was wrong. People were excited that they might be able to get rid of some kinds of disease. They didn't stop to ask if what they thought was healthy really was. They didn't stop to ask why they thought disability and difference were bad things.

Parents love the idea of giving babies something people wished they had. Sometimes they wanted to make sure their baby would be less likely to get a disease. Sometimes they wanted their kids to have other things they thought were good. They wanted to give their kids “the best.” The best means a life without disability. That’s why McEdit and all the other companies studying gene editing want to offer this to anyone who can pay for it.

The Disabled Oracle Society started in 2020. We started during COVID when sick and disabled people were trying to tell the world about how important it was to wear masks. Disabled people tried to show the world that access is important and that everyone depends on each other. During the COVID pandemic, it became very clear that lots of people didn’t think disabled people’s lives were important enough to save. People cared more about making money than about saving people’s lives. People and governments used words like “acceptable losses” and “high risk.” This meant that they didn’t think the lives of the people most likely to die from COVID were worth saving.

The Disabled Oracle Society was started because of a piece of writing in the **New York Times**. The **New York Times** shared pieces of writing for the 30th year the Americans with Disabilities Act had been law. The Americans with Disabilities Act is a law that is supposed to make sure that some buildings, big companies, and groups are accessible to people with disabilities. A writer named Katie Hafner wrote a piece called, “Once Science Fiction, Gene Editing Is Now a Looming Reality.” The piece shared the thoughts of parents of disabled children, scientists and bioethicists. Bioethicists are people who think about what is right and wrong in medicine and studying medicine. Katie Hafner only talked to one disabled person for her piece.

My friend and disabled oracle Rebecca Cokley said on Twitter:

> Hey @nytimes how DARE you have a non-disabled writer write about what CRISPR means for disabled people in your #ADA30 spread?!?! You don’t respect disabled people. You don’t think disabled people are important. And it shows!

When I saw that, I was so angry. Us disabled oracles have been telling the truth and warning everyone for a long time. This is nothing new.

Throughout history, people don't want to believe the people they treat badly. It makes people uncomfortable to listen to disabled people because we don't fit their idea of normal. Even when what we say is clearly true and right, we're not listened to. For example, I talked to Dr. Jaipreet Virdi in August 2020 about her book, **Hearing Happiness: Deafness Cures in History**. Dr. Virdi is deaf. She studies history, especially the history of medicine, technology and disabled people. She said this about human gene editing:

> There is no guarantee that genetic engineering will eradicate hereditary deafness nor any certainty that it will not cause any further complications. Moreover, this is essentially, at the core, a form of cultural genocide. To argue that this needs to be "avoided" at the level of genetics is an affront to generations of Deaf people who do not perceive themselves to be genetic defects.

By this Dr. Virdi means:

> We don't know for sure that genetic editing will mean deaf people won't be born. We also don't know that trying to use genetic editing to get rid of deaf people won't hurt future people in ways we don't know about. Trying to stop Deaf people from being born is cultural

genocide. Cultural genocide is when one group of people try to destroy another group of people's language, traditions, values and art. It's wrong to say that we need to avoid having more deaf people in the world. Lots of Deaf people don't think there's anything wrong with their genes.

This was a little bit of our history. I share it because our purpose has not changed. Our purpose is:

- To tell our stories and truths in our own words.
- To decide who we are.
- To take our place in the world.
- To fight to be seen and heard.
- To live with joy and love ourselves no matter what the world says about us.

I'm the President of the Disabled Oracle Society. I take the responsibility of being President seriously. Friends, I am so tired of defending my value every day. I am so tired of saying my life is important to people who want everything fast, shiny, and new. We try to talk to people in a way they can understand. We talk about the possible danger to future humans from

changed genes. We talk about how gene editing will change the entire human race. We say these things all the time:

- All people are important.
- We can't forget anyone.
- Technology always makes life harder for the people who the world already treats badly.
- The idea that technology makes the world harder is not new.

What else can we do except say these things again and again? How do we love each other? How do we keep each other going? How can we imagine a world we want to live in right now and in the future?

Now, I'd like to talk to all of you. Here's a question from someone listening:

Emily: Hi, I'm Emily from New York City. What is the role of a disabled oracle?

Alice: Thank Emily. You get to decide what a disabled oracle is. What are you comfortable talking about? Just living your best life is a way of fighting

back against a world that thinks disabled people's lives are terrible. I don't know how to talk with McEdit and all the millions of people who will buy their gene editing. But I'm good at asking questions. I'm good at telling my story and talking about how my story is tied to the way the world works. When I'm asking questions, I want people to think about how other people feel about germline editing. I want people to think about why germline human gene editing is incredibly worrying for so many people, not just disabled people.

We're almost out of time, here's one last question:

Grace: Hi, I'm Grace from Tempe, Arizona, disabled oracle. I'm scared. What is the point of doing all this if disabled people won't be born anymore?

Alice: Thanks, Grace. I'm really scared, too. Things feel like they're too much and impossible every day. Just know that you can choose how much you want to do. I believe everyone can change the world while we are still alive in big and small ways. I remember this tweet from 2017 by Dr. Ruha Benjamin, who studies race, medicine, data and technology:

> Remember to imagine and craft the worlds you cannot live without, just as you dismantle the ones you cannot live within.

When Dr. Benjamin says this she means:

> You need to imagine and make worlds you will love. You need to make worlds you love so much you will fight for them. You need to make these worlds as much as you are trying to take apart the world you can’t live in.

We’re disabled oracles, so we use the dreams and knowledge of the people that came before us to build new worlds. The people who came before us left their mark on the planet, as will we. After we’re long gone, we will show up in other ways. Someone will find us, and we’ll talk with them from the past.

Tiger Tarot - The Seedling by Hatiye Garip

Plain Language Translation Note: This piece is a beautiful image by Hatiye Garip[27]. Here is the plain language translation of the words in the image. But you might want to look at the original picture too.

This image is a tarot card. Tarot card reading is when people look at tarot cards to learn about the past, now and the future. In tarot decks, each card has a meaning. This is Tiger Tarot, a new tarot deck.

You should hold the things you want close to your heart. Share what you know with everyone.

You can’t see the future. But when you plant seeds you want them to grow. That’s growing a future you want. Make sure you grow the future you want with everything you do.

[27] If you want to see more pictures by Hatiye Garip you can go to her website here.

My Grown-Ass Disabled Person Make-A-Wish List

The Make-A-Wish Foundation tries to make wishes happen for children between 2 and 18 who are ill. Usually the Make-A-Wish Foundation needs the children to be ill in a way that means they will die young to grant their wish. The Make-A-Wish Foundation asks people for a lot of money. To get people's money, they share a lot of sad stories and cute pictures of disabled children. Lots of disabled activists don't like groups that ask for money using sad stories and cute pictures of disabled children. When the only stories about disabled people are about disabled children, people start to think that disabled adults are children. Or they think disabled adults don't exist. This is my wish list, the wish list of a disabled adult.

I hope I:

- Run part of a company that makes books. I would run the part of the company that shares the writing of disabled people. I'd hire lots of disabled people to work there.
- Star in, direct, write, and make a weird, funny show about disability culture. It would be a bit like **Reading Rainbow**, **Masterpiece Theatre**, and **The Muppet Show**.

- Start a company with other people to give money to disabled people to start their own business.
- Am in charge of making T.V. shows, movies and documentaries, which are movies about true events.
- Am in charge of a show on disability activist culture at the Smithsonian. The Smithsonian is the biggest museum in the world.
- Work with a major brand to develop a new lip color, “Tiger Power.” Be in all the pictures to sell that lip color.
- Make a Netflix series with Samin Nosrat about making and eating snacks. Snacks are small pieces of food that are fun to eat.
- Work with a company that makes ice cream to make a new ice-cream flavor.
- Take a private jet that will store my power chair safely to Tokyo with friends and family. Stay in a fancy hotel. Visit my friends Adam, Seiko, and Mizuki. Eat all the food. Take a train to Nagoya to visit the Studio Ghibli theme park. Studio Ghibli makes cartoons. They make amazing cartoons like **Howl’s Moving Castle** and **Spirited Away**. The theme park lets you be in a place that looks a lot like their cartoons. And eat bento on the train.

- Am a voice actor in cartoons like **Tuca & Bertie** or **Bob's Burgers** and in video games.
- Throw the biggest fiftieth birthday party in 2024.
- Feed a koala eucalyptus leaves. Take a photo with a koala at the San Francisco Zoo.
- Fall madly in love. Watch T.V., cook, eat snacks, go to the grocery store, and write hot sexy letters with my love.
- Have sex with a ghost.

Make It Weird

Plain Language Translation Note: Here is the plain language translation of the words in the image. But you might want to look at the original picture too. No plain language translation is needed so I've just put the words here.

Make It Weird

Thank you Mrs. Schrock

You can think about death. But you can also think about death too much. I was supposed to die before I was 48 years old. Now I am 48. I am in my fourth year of the Tiger, according to the Chinese zodiac. The zodiac is a way of counting years. The Chinese zodiac matches animals with years and repeats them every 12 years.

I knew that I would likely die young. That changed how I lived my life. When I was a baby, I sat and then I walked. I never crawled on all fours. My neck was too weak to hold my head up while on all fours. Doctors told my parents I had muscular dystrophy. Muscular dystrophy is a disease that makes your muscles weak. My parents cried. It’s a big deal to me to think about my parents crying. My parents must have been so scared. My parents were new to the United States. What did they understand about muscular dystrophy? How did they figure out how to work with doctors and the services I would need for the rest of my life?

My parents’ story isn’t mine to tell. I also shouldn’t try to guess how they felt about not knowing how long I would live.

I watched lots of TV to teach children. I didn't go to school until I was 5. From TV, I learned that aqua means "water" and when you count from 1-12 you need to sing.

When I was little I lived at 1022 West 78th Street in the north part of Indianapolis. I went to Delaware Trails Elementary which was close by. I had three great teachers in a row:

- Mrs. Fisher in kindergarten,
- Mrs. Dixie Shrock in first grade, and
- Mrs. Sorrell in second grade.

When I started going to school, I learned I was different from other kids. The Individuals with Disabilities Education Act had passed only a few years before I went to school. The Individuals with Disabilities Education Act is a law that says that schools in the US have to teach students who have disabilities just as well as non-disabled children. I went to a school for all children, not just children with disabilities. My teachers were happy to have me there. Mrs. Shrock was one of my favorite teachers. She was kind and had a sense of humor. She cared a lot for her students. During story time, she would take down her long brown hair. I thought she looked

like Rapunzel. When my class walked to the gym or art class we would line up in two lines. Mrs. Shrock would show everyone where to go. I was slow, so sometimes it was just me walking in the hallway.

I have a lot of memories from school that make me angry. I wasn't treated fairly by adults. Other students would bully and embarrass me. One good memory is that one day Mrs. Shrock asked me to be at the front of one of the lines. She showed us where to go and she let me decide how fast we went. I have not felt that seen, safe, or cared for by a teacher since.

I met Mrs. Shrock again when I was in my 20s. She found out I was a student at Earlham College. I was a student at Earlham for a few months before I had to stop. I think she had family who had gone to Earlham and had seen some writing about me. We started sending each other holiday cards. Mrs. Shrock kept teaching first grade at Greenbriar Elementary School. She taught for over 30 years.

Here is some of a letter I sent Jamie Alexander, who was in charge of Greenbriar Elementary School and Dr. Nikki Woodson, who was in charge of the school district:

Dear Mrs. Alexander,

I am writing to tell you how excellent Mrs. Dixie Shrock is. I don't know if you have a prize for great teachers. But if you do, I would like to suggest that Mrs. Schrock gets it. I listened to a story on the radio a little while ago. The story was about a student who found his teacher after years to say thank you to her.

I want to share what I think of Mrs. Shrock and say thank you to her. Mrs. Shrock taught me first grade in 1980 at Delaware Elementary. One day, when I was in second grade I couldn't walk as fast as the other students. I ended up alone in the hallway. I tried to walk back to my classroom. I fell down because I was so tired. I started crying. Mrs. Schrock came out of her classroom to comfort me. Mrs. Shrock cared about every student. She made lots of students feel like they could do anything.

She made me feel like I could do anything. This was really important. I was a student with a disability. Lots of teachers and grown-ups would decide that I couldn't do what I wanted to. But before I met those teachers

and grown-ups, I met Mrs. Shrock who made me feel like anything was possible. Mrs. Shrock never made me feel different. In her class I was just another kid who was excited to learn.

Over the years I've let Mrs. Shrock know what's happening in my life. Sometimes I wonder if I'm bragging. But the reason I send her news about me is so she knows that she helped me become who I am. What I wanted to say with that news and the cards I sent her was, "Thank you Mrs. Shrock. Part of who I am today is because of you. Some of my best childhood memories were in your classroom."

With Mrs. Shrock as a teacher I felt safe. I felt loved. I felt part of the class. Those feelings helped make me someone who is still excited about learning. Those feelings gave me confidence in myself that I still have today. Dixie Shrock is a very good teacher. The School District should know this and tell her that she's very good. People who are in charge of schools should reward teachers who care about their work and give students a sense of wonder and hope.

I’m writing to say thank you to Mrs. Shrock. And to say congratulations to her for a lifetime of being a great teacher.

When COVID started, I wanted to know how Mrs. Shrock was doing. I sent her a copy of my book **Disability Visibility** with a thank you note. (I love sending and getting cards. I keep a lot of the cards I get.) Mrs. Shrock wrote me a note with an amazing story.

Dear Alice,

What joy, pure joy, when I got **Disability Visibility**. At the start of the book you said what you want to do with the book. You put so much thought into what you want to do and that is powerful. You’ve used your life to help other people. You always kept going. I always felt that as we walked hand in hand.

One day, when we went to the lunch room, you said, “Mrs. Shrock, am I going to die?”

We kept walking for a few seconds. I said, “No, you aren’t going to die.” I knew right then that you were thinking on a much deeper level than the people around you. I am so proud of all the things you have done for others.

I have just stopped teaching because of COVID. I am going to read a lot now. So your book is first on my list!

Thank you! You are always in my heart,

Dixie Shrock

I remember watching the Muscular Dystrophy Association telethons. Telethons are events to raise money. People put on a show on TV. The people watching call a number and give money. They used to raise a lot of money for disability charities. When I saw the Muscular Dystrophy Association telethons, I couldn’t imagine being 30, or 40, or 50. How do I know what I want to be when I grow up if no one thinks I’ll grow up? Doctors and science said I had no future. Mrs. Shrock said I did. Mrs.

Shrock saved my life. Along with my family and friends, technology, the internet, Medicaid, and many other things, Mrs. Shrock saved my life.

I am my greatest dream. I didn't dream about "overcoming" my disability. My dream is looking at the dark and then making something from nothing. Dreaming is universe building. Thank you for everything, Mrs. Shrock. Thank you, 6-year-old me, who was working out life and death.

Sometimes I talk to 6-year-old me.

Alice at 6: Who are you?

Alice at 48: I am you.

Alice at 6: Um, you're old. So old.

Alice at 48: I know. Weird, right?

Alice at 6: When am I going to die?

Alice at 48: I have no idea. I'm still alive. I'm surprised I'm alive.

Alice at 6: Can you eat anything you want and stay up all night?

Alice at 48: Pretty much. That's one of the good things about being a grown-up. I still feel like I'm your age though. What else do you want to know?

Alice at 6: Is it scary being alive at your age?

Alice at 48: I'm not going to lie to you. We never had it easy. I have a lot of friends now. I am doing all kinds of cool things. This makes life fun. But there will always be risk and danger. And, girl, the planet is in danger!

Alice at 6: What's so great about the future? Can you go to space and say "Nanu nanu" to Mork? Mork is from **Mork & Mindy**, a tv show about an alien who comes to earth.

Alice at 48: Not yet, but it would be nice to float around and find out about the planets. Maybe we could become friends with an alien.

Alice at 6: I knew it. Aliens are real. Mork is real. **Mork & Mindy** the T.V. show was just to get us ready for them. Do you get tired? I'm tired.

Alice at 48: I am still tired, probably more than you. I wish I wasn't, but things are worse with our body. But that comes from age and our disability.

Alice at 6: That's not fun.

Alice at 48: Nope, it's not. Hey, remember Mrs. Shrock? I'm still in touch with her!

Alice at 6: Nice! What about my best friend from kindergarten, Heather Lynch?

Alice at 48: We're still in touch on Facebook.

Alice at 6: What's a Facebook?

Alice at 48: Nothing good. Never mind! What else do you want to know?

Alice at 6: When am I going to die?

Alice at 48: Oh brother. I don't know, but the not knowing part isn't all bad. We can't know or control everything no matter how hard we try.

Alice at 6: Can we still get an Orange Julius and a hot dog? Mom and Dad get them for me whenever we go to Lafayette Square Mall. I like the salt and sweet.

Alice at 48: I wish we could, kid.

Alice at 96: Um, hello? Is anyone there?

Alice at 48: Whaaaa? Is that us? We look great!

Alice at 6: Are you a witch?

To be continued in **Year of the Tiger: The Fur Will Fly,** coming from Vintage Books in 2070

Future Notice

Alice Wong died in 2070. She was 96 years old. It was the Year of the Tiger in the Chinese zodiac. The zodiac is a way of counting years. The Chinese zodiac matches animals with years and repeats them every 12 years. She was an oracle, someone who can see a bit of the future. She told stories. She was part machine, part human. She made good trouble. She tried to change the world. She stayed up late.

Alice's parents were Henry and Bobby Wong. Henry and Bobby came from Hong Kong to Indiana in the 1970s. Alice moved to San Francisco in 1997. She moved to go to school there and for the Bay Area disability community. San Francisco was her home for many years. In 2014, Alice started the **Disability Visibility Project**. The **Disability Visibility Project** led to writing on the internet, podcasts, books, television shows, movies and documentaries, which are movies about true events.

In 2026, Alice was put in charge of a major publishing house. A publishing house is a company that makes books. Working with many other disabled people, Alice made sure that disabled writers' work was shared.

Alice lived through the 1999 Olmstead Decision of the Supreme Court of the United States of America. The Supreme Court decides on laws for all of the United States. Alice lived to see the places that kept disabled people trapped disappear. Places like psychiatric hospitals, nursing homes and prisons went away. Conservatorships, where someone is given control over a disabled person's life, disappeared too. Instead of conservatorships, people used supported decision-making. Supported decision making is when disabled people get help to make decisions about their life.

Disabled people and the people who believe in disability justice fought for everyone to live in their community. Disability justice means that in our fight to make the world more fair and better for disabled people, we need to focus on what the disabled people who are most shut out and have the least need. So we need to be lead by disabled people who are Black or Indigenous or people of colour, who are trans or non-binary, or who are treated badly because of who they love and who they have sex with[28].

[28] This definition is based on the 10 Principles of Disability Justice by Sins Invalid. You can read more here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. Or if you want to read the 10 Principles in

Changes in the weather, war, disease and people leaving their homes meant that there were a lot more disabled people. Everyone realized that work isn't what makes people good and important. Everyone realized that no one can do everything alone and supporting each other is far better. These changes meant that Alice could do everything she wanted to in the last half of her life.

In 2032, Alice became a rock star. (She wanted to be like the Linda Lindas, a punk rock band from Los Angeles.) Alice's band was called Rage Against the Ableism. Ableism is the way the world is organized to favor people who have particular kinds of bodies, minds and who can work in a particular way. This leads people to think that non-disabled people's lives are more important than disabled people's lives[29]. The band was famous for wearing Aggretsuko masks. Aggretsuko is a Japanese cartoon, where the characters are all animals. Alice and her band mates

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plain language Jenny Mae Viets translated them: DJ Resource Modified from Sins Invalid's Work.

[29] This definition owes a lot to Talia A. Lewis' working definition of ableism. If you want to read more you can here: https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update?utm_source=substack&utm_medium=email

would dance fiercely to help their fans feel like fighting for justice. They made five records in twelve years. They made hits like:

- **Ableism is Trash.**
- **Fuck You Pay Me.**
- **STFU White People.**

These songs are still sung everywhere from Memphis to Mars.

In 2045, Alice moved to a zero gravity house on the moon. Zero gravity means nothing has weight. She found zero gravity much easier on her body. She was part of the second group of Crips in Space. Crips in Space was where the government sent disabled people to space to do science, make art and explore.

Between 2050 and 2070, Alice supported and shared the work of the next generation of disabled cyborgs. Alice wrote in her book, **Year of the Tiger**, “Good shit takes time.” She took her time with both her work and the good things in life. She didn’t find success until her late 40s, but she made the most of her life. She was known for:

- Throwing great parties.

- Sharing disability culture.
- Loving a good latte and pastry.
- Being a bossy, loving sister to close friends and people she made good trouble with.
- Messing around at all hours of the night.

Alice is deeply missed by her sisters, Emily and Grace; family friend Rani Singh; and a few others. Her sisters will continue her legacy by giving her writing and some of her other things to the Society of Disabled Oracles. The Society of Disabled Oracles will keep Alice's things so future people can learn about Alice and the 21st century. Her sisters will also make sure to share her money and things with her community. She is missed by her cats Blueberry, Claude, Cinnamon, Meowmee Jr., Mittens, and Phil. Her cats are holocats, which are cats made of light.

Instead of sending flowers, give money to your local:

- Animal shelter.
- Food bank.
- Library.

- Group that makes sure people have what they need to live and be happy.

If you want to know about the memorial, go to the **Disability Visibility Project**. Memorials are to remember people and have fun in their honor. The memorial is put together by the Cabal. The Cabal is a group of Alice's friends and family who will make sure Alice's life is remembered the way she would want it to be. The memorial will be a week-long dance party with movies and food both in person and on the internet. Please talk to the Cabal if you want anything or have questions. The Cabal knows what Alice wanted. They want to make sure that anything anyone says about Alice's life is true.

Enjoy all of Alice's good shit. Make some good shit of your own.

About Kelsie Acton

Image Description: Kelsie, a white woman with long curly dark hair and blue eyes, leans against a wood wardrobe. She has gold rimmed glasses and a shiny gray-pink button up shirt. Her head gently leans on her right hand and she has a small smile.

Kelsie is neurodivergent. She's also really interested in access. She's a member of The Critical Design Lab, a group of artists, designers, and researchers who think about critical access together. She wrote the plain language summaries for MsSweeney's **The Audio Issue** and San Allard's **Writing from the Groin**. She's also the Inclusive Practice Manager at Battersea Arts Centre, the world's first Relaxed Venue. She hopes someone invents holo-cats soon. She really wants a cat in her tiny flat.

You can find her on Twitter @KelsieActon.