

Plain language translation of

Disability Visibility

First-Person Stories from the Twenty-First Century

By Sara Luterman

To order *Disability Visibility*:

<https://www.penguinrandomhouse.com/books/617802/disability-visibility-by-alice-wong/>

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Forward

“Social justice is not a magic spell. Saying the right words does not make equality or respect happen.” - Julia Bascom

Disability advocacy spaces can be unfriendly to people who don't know all the right words. Jargon, academic language, and policy speak are access barriers too many disability advocates forget.

We build palaces out of words, then fill the moats with crocodiles and poisonous snakes.

There are many reasons someone might not know the right words. Sometimes it's because of a disability. Sometimes English is the person's second language, and second languages are just harder. Sometimes, people don't have equal access to education. Sometimes, it's all three.

Plain language is an attempt to help more people understand ideas that matter.

This book is a plain language translation of Alice Wong's *Disability Visibility* anthology. It might be the first of its kind -- A radical new kind of accessibility. There are popular books meant for adults that get adapted for younger readers. More nonprofits have been putting out plain language explainers in the past few years. But this is the first adult work of nonfiction in plain language.

I'm grateful Alice asked me to do it. It's an absolutely brilliant idea. And I'm excited about the results.

The essays in this book are deeply personal to their writers. People share their triumphs and struggles, and they do it in the words that best convey meaning. Sometimes, simplifying language can seem like an impossible problem. I tried my best to be true to the author's meaning. It is far from perfect. But I'm proud of the effort.

My work on this book was a translation process, like translating English to Cantonese or Hebrew to Romanian. There isn't always a word that means exactly the same thing

as the word the writer used. Words have shades of meaning and emotional truths. Sometimes a concept just doesn't exist in plain language.

Some of the essays are almost identical to the originals with small changes. Others have been changed substantially -- Not in meaning, but in form. In a few cases, I ended up having to make major structural changes to preserve meaning.

There is a short biography blurb at the beginning of each essay. Most of the essays are from a first-person perspective, so the bio helps establish that each story is by and about a different person.

To make the plain language translation, I started by assessing the reading level. There are a few [free tools](#) available online. The reading level is not a perfect way to know if something is easy to understand, but it is a good start. All of the essays are at a 5th grade reading level, at most.

It's important to note that a 5th grade reading level is not the same thing as appropriate for a 5th grader. "Grade level" is just the language used by most readability scales.

These essays are for adult readers. Many of these essays deal with hard topics, like eugenics or rape. Some of the essays talk about sexuality in a frank, explicit way. I kept most of the swear words. I firmly believe that "plain language" and "for children" are not the same thing.

For most essays, the grade level needed to be lowered considerably. To do that, I simplified sentence structure. Sometimes that meant taking out a few words. Sometimes it meant omitting an entire clause. Sometimes, it meant splitting a sentence into multiple separate sentences.

Next, I stripped down the number of hard words. Readability scores tend to define hard words as having multiple syllables. Rather than relying on syllable count, I prefer to use a tool called Upgoer Six.

[Upgoer Six](#) was not designed as an accessibility tool. It was designed as a bit of a joke. In the webcomic [XKCD](#), Randall Munroe challenged readers to explain complex science concepts using only the most common thousand words in the English language. Munroe wanted to encourage clearer science communication.

Munroe himself produced [“Upgoer Five: The only flying space car that’s taken anyone to another world.”](#) It explains the different mechanical parts of the Saturn V rocket.

A geneticist and XKCD fan named Theo Sanderson made an Upgoer Five text editor. It only lets you use the most common thousand words in the English language. It will list any words you use that are too uncommon at the bottom.

The Upgoer Six text editor soon followed. It color codes different words based on how commonly they are used. The dataset is over 29 million words from various TV and movie scripts. The less common a word is, the redder it is.

I try to only use the three thousand most common words in the English language. Upgoer Six helps me figure out which words are common enough. The idea is that the more common a word is, the more likely people are to understand what it means. For comparison, the average adult has a vocabulary of 20,000-35,000 words.

Some words are uncommon and there is absolutely no way to substitute them with another word. The work would end up meaning something else entirely. In those cases, I try to integrate short definitions into the work itself.

A major principle of plain language is chronological writing -- Things should be written in the order in which they happen. This rarely works for creative writing. In a few of the essays, I tried grouping different threads together. In others, it just wasn’t possible. I look forward to exploring the problem further in future projects.

Finally, I read everything out loud. If anything sounds unclear or a little off, I correct it. I have some issues with auditory processing and memory that actually help here. If I can’t remember the beginning of a sentence by the time I get to the end, it is too long and needs to be shorter.

Some of the pieces may still be confusing for people who struggle to read. Some of the pieces were highly conceptual to begin with. There is poetry, which I mostly left untouched. It’s impossible to translate poetry into plain language. Or at least, it’s way beyond my pay grade. So instead, I left an explanatory note reassuring readers that it’s OK not to get all of it. No one gets all of it. I don’t even get all of it, and I have an MFA in poetry.

I did not assume the reader is white. Plain language does not mean white. An important aspect of Alice’s book is the multitude of viewpoints that make up the disability

community. Alice's book does not explain words like "Ramadan" or "Tsalagi," so I didn't either. Different essays in the book are meant for different audiences, and will speak to different people. I tried to preserve that in the translation. A Muslim person with an intellectual disability probably knows what Ramadan is.

Social justice is not a magic spell. Saying the right words does not make equality or respect happen. But I hope the words I use have helped, at least, to advance understanding. I hope more people get to experience the work of luminaries like Harriet McBryde Johnson and crip theorists like Ellen Samuels. I hope that this book opens new doors for people who struggle to read. You belong in my community. You belong in our community. You absolutely belong.

Introduction

Alice Wong

Alice Wong is a disabled activist and writer. She lives in San Francisco, California. Alice is started and is in charge of the Disability Visibility Project. President Obama chose Alice to be part of the National Council on Disability.

My name is Alice. I am 46 years old. I am disabled. Staying alive is hard, because the world does not like disabled people.

When I was a child, there were few disabled people in books, film, and television. Last year, a picture of a girl in a wheelchair went viral on social media. In the picture, the girl looks at an ad. The ad is of a woman in a wheelchair. The girl and the woman have similar wheelchairs. Later, the girl and the woman met each other in real life.

Their story made me wonder about my childhood. How would I be different, if I had seen people like me? Finding and joining the disability community showed me many possibilities for disabled people.

I began to notice and save important stories about disability. In high school, I read an article in Time Magazine about accessible buses and trains. I was excited about buses and trains I could ride on with my wheelchair. I wrote a letter to the editor of Time Magazine saying that I want more accessible buses and trains. Back then, I lived far away from buses and trains. Time Magazine published my letter. It was the first time I'd advocated for something I wanted in a magazine. I was very happy.

I wanted more stories about disability. I had folders full of cut up newspapers and magazines. Now, I have hundreds of articles about disability on my computer. Finding these stories helped me tell my own story.

Stories about disability lead me to the disability community. When I was a child, there was no ADA, or Americans with Disabilities Act. The ADA gave disabled people equal rights to non-disabled people in the United States. The 25th birthday of the ADA was in 2014.

I wanted to celebrate the ADA's birthday by doing something for the disability community. I was not a part of any big groups. I did not know how I could do something for the disability community by myself.

I knew three things:

1. I wanted to see more stories about disabled people now.
2. I wanted to see more stories about common disabled people. Many stories are about very important, famous disabled people.
3. I wanted to see stories about different kinds of disabled people.

I created the Disability Visibility Project with StoryCorps. StoryCorps is a group that records many different people's stories. Together, we recorded people telling their own stories.

The Disability Visibility Project stories are kept in the Library of Congress. The Library of Congress is the most important library in America.

One of my favorite stories is about the 504 sit-ins.

A sit-in is a kind of protest. People sit in a place they are not allowed to sit. They refuse to leave until a problem is fixed. The 504 sit-in protesters protested longer than anyone else ever has. They were disabled people, like you and me.

A long time ago, there were no ramps. There were no bus lifts. There were no laws or rules that said disabled people need to be included anywhere. People in wheelchairs could not even cross the street!

Section 504 was a part of a bigger law called the Rehabilitation Act of 1973. Section 504 said that disabled people need to be included. Anything the government paid money for had to include disabled people. But the government was not including disabled people. The government was not doing what it was supposed to. That is why disabled people protested at the 504 sit-ins.

Herb Levine was a disability rights activist. He protested at the 504 sit-ins. Jessie Lorenz is also a disability rights activist. She did not protest at the 504 sit-ins. She is too young.

The police did not want people going in or out of the building where the sit-ins were happening. One time, Herb pretended to be a minister so he could sneak in and keep reporting. He also helped disabled people sneak in and out by pretending they were his choir.

I love this story. It is a funny moment in disability history. It is also an important story. Stories don't have to be about famous people to matter. Herb's story is now in the Library of Congress. We need to tell more stories like Herb's story.

The Disability Visibility Project grew a lot. We have recorded more than 140 stories like Herb's story. We also share stories on the Internet and social media.

I love working on the Disability Visibility Project. I also love working with other disabled people. It is important for disabled people to work together.

Disabled people working together is political. "Political" means how leaders make decisions that affect everybody.

These are some projects I have worked on with other disabled people:

I made #CripTheVote with Gregg Beratan and Andrew Pulrang in 2015. Gregg Beratan and Andrew Pulrang are disability rights activists. #CripTheVote is a place for disabled people to talk about politics on social media. #CripTheVote has also grown a lot. In 2020, we hosted a conversation with presidential candidates Elizabeth Warren and Pete Buttigieg. Reporters and politicians are paying more attention to disability rights.

Nicola Griffith made #CripLit in 2016. Nicola Griffith is a disabled writer. Nicola wanted to meet other disabled writers. I helped Nicola share #CripLit with more people. #CripLit is a place on social media where disabled writers can talk to each other. A lot of different readers and writers use #CripLit to talk to each other.

It is very hard to be a disabled writer. People do not want to listen to disabled people about what matters to us. In 2017, I talked to Vilissa K. Thompson and s.e. smith about being disabled writers. A lot of people in charge of the news say it is too hard to find disabled writers to hire. Bullshit! There are a lot of disabled writers. s.e. smith made a

website called Disabled Writers. It is a place where the people in charge of news can find and hire disabled writers. Vilissa K. Thompson and I helped. Working with other disabled people makes me happy.

I felt scared when Donald Trump became President in 2016. A lot of other disabled people were too. I still felt OK because disabled people always advocate for what we need. We are good at feeling calm when the world is scary. I decided to put together my first book in 2018. The book is called *Resistance and Hope*. It did not cost money. Anybody could get a book for free. A lot of different disabled people wrote stories for the book, including activists, artists, and dreamers. It felt good to help tell the stories of a lot of different kinds of disabled people.

The book you are reading right now has a lot of different disabled people's stories in it. It makes me very happy. My book is not a lesson about disability. It is also not a list of the best writing about disability. Some ideas in this book might not make sense to you. Some ideas in this book may make you uncomfortable. That's a good thing!

The stories in my book are not supposed to explain what disability is. The stories are also not supposed to tell you how to feel. The stories in my book are supposed to be stories about disabled people, by disabled people. Everyone is different! I am different from you. You are different from me. That is a part of my story.

My book is made of four parts. These are the names of the parts:

1. Being
2. Belonging
3. Doing
4. Connecting

Some stories might be sad or scary. There are notes at the beginning of those stories, so you can decide if you want to read them or not.

The first story in my book is by Harriet McBryde Johnson. Harriet McBryde Johnson was a lawyer and disability rights activist. The story, called "Unspeakable Conversations," was first published in the New York Times in 2003. "Unspeakable Conversations" is about a debate Harriet had with a professor at Princeton University. The professor believes that disabled people should not exist. He believes that killing disabled babies is good.

When I first read “Unspeakable Conversations,” it made me feel very upset. Harriet did a good job explaining the experience of ableism. “Ableism” is unfairness and hatred towards disabled people. Before I read “Unspeakable Conversations,” I thought I was alone. I did not know other people thought disabled people like Harriet and I could live good lives.

The last story in my book is by s.e. smith. The story is called “The Beauty of Spaces Created for and by Disabled People.” s.e.’s story was first published in 2008, on a website called Catapult. In s.e.’s story, s.e. writes about watching a show called, “Descent by Kinetic Light.” “Descent” is a word that means “going downwards.” “Kinetic” is a word that means “movement.”

The dancers in the show were disabled. The people who invented the dances in the show were disabled. Alice Sheppard, who helped make “Descent by Kinetic Light,” both have stories in my book.

In s.e.’s story, s.e. talks about the beauty of disabled people working together. We are creative and good at solving problems! Disability Visibility Project is also about the beauty of disabled people working together.

There are more disabled people in media now, compared to when I was a child. But it is still not enough. I want and expect more. We should all expect more. We deserve more. There are not enough disabled people working to make books, TV, magazines, and movies.

In the Lee & Low Books Diversity Baseline Survey, only 11% of people working to make books and magazines say they are disabled. This is a very small number.

A survey shows what a large group of chosen people think or do. A survey usually has choices on it. The people choose the choice they agree with. The number of people who pick each choice are written down. Using math, a survey can show how many people in a certain group agree or disagree.

There are only a few disabled people making books, TV, magazines, and movies. There need to be more. If everyone telling stories is the same, then they will only tell one kind of story. People who are different will feel left out. It is not fair for only some people to share their stories. Everyone should feel included.

Disability is complicated. I am proud of being disabled, even though it can be dangerous. There are a lot of different kinds of disabilities. A lot of different kinds of people can be disabled.

I don't want to ask anybody if it is OK to tell my story. I want to make the decision myself. I want all disabled people to tell our own stories without permission. Harriet McBryde Johnson wrote that storytelling is something people do together. Together, we can change the world so more and different kinds of stories get told.

Unspeakable Conversations

Harriet McBryde Johnson

Harriet McBryde Johnson was a disability activist, lawyer, and writer. She lived in Charleston, South Carolina.

Note: This story talks about killing babies, old people, and people with intellectual disabilities.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

Professor Peter Singer says he doesn't want to kill me. He just thinks it would have been better if my parents could have killed me when I was a baby. He wants to let other parents kill their disabled babies, if they want to. He thinks that having a disability is always worse than not having a disability. Peter Singer thinks that parents like babies that are not disabled more.

It has nothing to do with me. I should not feel scared.

Whenever I try to think about Peter Singer's tricky argument, I get dizzy. It's . . . almost fun. Mercy! It's like "Alice in Wonderland."

It is a cold day. I am at Princeton University. I am visiting Peter Singer. Some people call Peter Singer the most important philosopher in the world.

Philosophy is a way to study people and the world, by thinking about and asking questions. Philosophers help people figure out hard problems in their lives. Philosophers like Peter Singer think about what is right and what is wrong.

Peter Singer is the man who wants me dead. No, that's not fair. He wants to let parents kill disabled babies. I am disabled. Those babies could be like me when they grow up.

Peter Singer also says it should always be OK to kill disabled people with serious intellectual disabilities. Peter Singer thinks that people with severe intellectual disabilities. Peter does not think that people with severe intellectual disabilities are people.

What does Peter Singer say a person is? If you are a person, you know you exist. If you are a person, you can like some choices more than other choices. If you are a person, you can want one choice about the future more than another. If you are a person, you can want to be alive.

Peter Singer says I am a person. He says when I was a baby, I was not a person. Peter Singer does not think any babies are people. Babies do not know they exist.

When some people get old, they get dementia. Dementia is a kind of disability some people get when they are old. When people have dementia, they lose skills they had before. People with dementia forget how to do many things. Some people with dementia forget how to eat. Some people with dementia forget how to walk.

Peter Singer thinks people with dementia are not people. Peter Singer thinks if I get dementia, I will stop being a person. Then, my family or doctors could kill me, if they want to.

I agreed to debate Peter Singer twice.

A debate is an argument in front of other people. In a debate, people explain why they think they are right or wrong. Sometimes, the point of a debate is to get people to agree with you. Sometimes, the point of a debate is to help other people understand what you think.

The first time I debated Peter Singer, I explained, to 150 university students, why it is wrong to kill disabled babies.

Later that day, I had dinner with Peter Singer and some of his friends. We debated assisted suicide.

Assisted suicide is when someone wants to die, and a doctor helps that person die.

I am the only person with a disability in the room. I am the only person who thinks killing people with disabilities is wrong.

I agreed to debate Peter Singer for many reasons. Here are some of those reasons:

- I am a disability rights activist. I want people to know about disability rights.
- I want other people to understand what I think.
- I want to learn how to debate people who do not agree with me at all.
- A debate with Peter Singer is an interesting story. It is the story I am telling you right now.

I did not think I could change Peter Singer's mind about people with disabilities. But maybe I could change some students' minds about people with disabilities.

I have told this story to my family and friends. I have told this story to people I work with.

I have told this story at lunch and at dinner. I have told this story on long car trips. I have written many emails about this story.

I have given many speeches about this story.

The story still doesn't make sense. People ask me a lot of questions about the story. Here are some of the questions and answers:

Question 1: Was Peter Singer totally grossed out by how you look?

Answer: Peter Singer did not seem grossed out by how I look.

Question 2: How did Peter Singer treat you?

Answer: Peter Singer treated me with respect. He treated me like he would treat anyone else.

Question 3: Was it hard to debate about whether you should be alive?

Answer: It was very hard. It was also too easy.

Question 4: Did Peter Singer become a famous philosopher because people like his ideas about killing disabled babies?

Answer: Peter Singer's ideas about killing disabled babies did not hurt him. But Peter Singer is most famous for animal rights. He wrote a book called "Animal Liberation." Liberation is a word that means "to set free." Peter Singer wants animals to live and be free.

Question 5: How can Peter Singer care more about animals than disabled people?

Answer: I do not like this question. I used to say, "I don't know. It doesn't make sense to me." After reading Peter Singer's writing, it does make sense. It makes sense if you think about the world like Peter Singer does. But I don't want to think about the world like Peter Singer does.

I need to tell you more about question 1.

I am not ugly. But most people do not know how to look at me. I confuse people. People stare at my power wheelchair. I have a disability that has made me very thin. People stare at my body.

When I was a child, my muscles got too weak to hold up my spine. I tried wearing a back brace. I was lucky that a doctor said I should not have surgery. I did not like the back brace. When I was 15, I got rid of the back brace. My spine is shaped like the letter "S." I like that my spine is shaped differently. It feels natural. I like how I look.

I am 44 years old. People with disabilities did not used to live as long as I have. There are better medicines and doctors now.

Sometimes, people think I am beautiful. At a lesbian barbecue I went to, some of the women thought I was beautiful.

I live in Charleston, South Carolina. Some people in Charleston call me Good Luck Lady. They think it is good luck to see me when there is going to be a big storm. They kiss my head before it is time to vote.

Most people are not nice to me, even though they think they are being nice. They do not think my life can be a good life, because I am disabled.

People say to me:

It is good you are outside. Most people would give up.

God bless you! I'll pray for you.

If I had to live like you, I'd kill myself.

I used to tell people that I love being alive. It feels good to go fast in my power wheelchair. I do not want to die. But it is annoying to explain over and over again. God didn't make me so I could teach people about disability.

I do not believe God is real. I do not believe God made anyone to teach anybody about anything.

People think they know everything about me, because of my disability. It is not true. They don't know about me. They are confused.

When I first met Peter Singer, he did not look confused. He treated me like a person right away. I did not expect that.

In 2001, Peter Singer was invited to speak at the College of Charleston. The College of Charleston is a university two blocks from my house. His lecture is called, "Rethinking Life and Death."

Not Dead Yet sent me to Peter Singer's speech. Not Dead Yet is a group that is against killing people with disabilities. Not Dead Yet told me to give out a leaflet and to talk about disability rights.

I went to the College of Charleston an hour early. It was very peaceful.

I roll around the corner of the building. Two people I know are sitting on a bench with Peter Singer. Their names are Sharon and Herb. They are eating veggie pitas together. Sharon is a human rights activist. Herb is the most famous atheist in South Carolina. An atheist is someone who does not believe God exists.

I thought Sharon and Herb were nice people. But they were sitting and eating with a man who thinks it is good to kill people with disabilities. I did not want to talk to them. I try to leave before they see me. They see me. Sharon throws out her trash and comes over. After we say hello, she asks, "Would you like to meet Professor Singer?"

Sharon doesn't know Peter Singer wants to kill people with disabilities. She must like his book about animal rights.

I tell Sharon, "I'll just talk to him in the Q and A."

But Herb and Peter Singer are walking towards me. They are looking at me.

Herb is talking. Herb is probably saying nice things about me. Herb is probably telling Peter Singer that I'm a disability rights lawyer. Herb is probably saying I gave a talk against assisted suicide. Herb is probably saying that he didn't agree with everything I said, but that I am very smart.

Peter Singer looks interested in what Herb is saying. I sit where I'm parked.

I hang back. I shouldn't shake hands with the Evil One. But Peter Singer is Herb's guest, and I simply can't snub Herb's guest at the college where Herb teaches. Where I live, there is a rule: If you're not prepared to shoot someone with a gun, you have to shake hands.

I give Singer the three fingers on my right hand that still work. "Good afternoon, Mr. Singer. I'm here for Not Dead Yet." I want to think he is a little scared. Not Dead Yet protested at Princeton University, because Princeton University gave Peter Singer a job. I gave money to help my friends who were arrested at the protest. Some of them use power wheelchairs.

But if Peter Singer is scared, he does not show it. He answers my questions about his speech. Peter Singer says he wants to talk to me later. He looks like he means it.

During his speech, Peter Singer talks about why people should be allowed to kill disabled babies. He thinks non-disabled babies are happier. He thinks if people were allowed to kill disabled babies, everyone would be happier.

I get the microphone and ask to speak. I want to talk about killing disabled babies. I am a lawyer. I understand the law. I think that Peter Singer's argument is not enough to change the law. I am not religious. I think Peter Singer is wrong to say people who disagree with him are religious.

Peter Singer writes down notes while I talk. He wants to debate with me.

I get to the most important part: Disability does not mean someone is going to have a bad life.

Babies are not all the same. People are not all the same. My brother does not have a disability. We are both good at some things and bad at others. It does not make sense to say my brother is better or worse than I am.

Peter Singer talks to me in a polite voice. We debate for 10 minutes. He sounds very respectful and focused. When he is done, I'm not exactly angry with him. I am still very

angry. But I am angry at the 200 other people in the room. They sat and listened. They should have kicked Peter Singer out of town.

In December, I decided to send Peter Singer a Christmas card. He sent me back a very nice email. Dear Harriet (if he may)... He is just back from Australia. Peter Singer is from Australia. He agrees with me about the world. He supports my work. He says people with disabilities should live in the community. Then, Peter Singer asks some questions about killing disabled babies.

I reply. Fine, call me Harriet. I answer his questions about killing disabled babies. I ask some questions back. We send emails back and forth for weeks about baby killing. Dear Harriet. Dear Peter.

Peter Singer does not believe in God. I do not believe in God. Peter Singer wants to know why I think killing disabled babies is wrong. I want to know why he thinks it is OK to kill disabled babies, but not OK to kill all babies. Peter Singer says that parents like babies without disabilities more.

I ask Peter Singer about a different kind of baby. I ask about mixed-race babies. Does he think it should be legal to kill mixed-race babies? Singer agrees there is a problem. "It would be horrible to kill mixed-race babies," he says.

What's the difference? He says it does not make sense to like one skin color more than another. He says it does make sense to like non-disabled babies more than disabled babies. Why? To Singer, it's pretty simple: disability makes a person "worse off."

Are we "worse off"? I don't think so. Some people are born with disabilities. Some people become disabled later. Disability shapes who we are. We make our lives good. We love the same things other people love. We love secret things that are only for people with disabilities. We have something the world needs.

Peter Singer wants me to say disabled lives are less happy.

Peter Singer gives an example: Think of a disabled child on the beach. The child is watching the other children play.

I say, "As a little girl playing on the beach, I knew some people felt sorry for me. It annoys me. It still does."

I had fun playing on the beach. I did not need to stand, walk, or run. I've had enough. I tell Peter Singer that the conversation is over.

Peter Singer invites me to come to Princeton. Peter Singer teaches at Princeton I tell him maybe.

Of course I'm flattered. Mama will be impressed.

I have to think. Not Dead Yet says we should not treat Peter Singer like his opinions matter. Disabled lives should not be argued about. I think Not Dead Yet is right.

But I'm stuck. If I say no, Singer can say disabled people don't want to be taken seriously. It's an old trick. I fell for it.

Peter Singer invites me to debate him. He wants me to debate me in front of his students. He also wants to debate me in front of everyone at Princeton University. That is a lot of people.

It sounds like Peter Singer wants to debate whether I should be alive.

I tell Peter Singer what I want: I will talk to his class about baby killing. Then I will let him ask me as many questions as he wants.

Later, I will debate a different disability idea. It will be in front of people who are not all on Peter Singer's side. Peter Singer says a group of students and teachers might be good.

We agree on how to debate.

I tell some of my friends in the disability community that I am going to debate Peter Singer. I agree with my friends who say to debate Peter Singer, then leave right after the debate is over.

Peter Singer's assistant helps me make plans to go to Princeton. But Peter Singer still asks me a lot of questions. The questions are about my life.

There is only one wheelchair-accessible hotel room near Princeton. It is very expensive.

I say I can stay in a room that is not accessible, if it has some things I need.

Peter Singer asks me more questions: Do I need a van with a wheelchair lift? Can my assistant put me in a regular car? How wide is my wheelchair?

After we are done, Peter Singer knows a lot of personal things about me. Here are some of those things:

- He knows how wide my wheelchair is.

- He knows I can't steer my wheelchair if my hands get cold.
- He knows I am scared of big hills.
- He knows I cannot use stairs at all. I can't even go up one step.
- He knows I can only eat soft foods.
- He knows I use a bedpan. I do not use a toilet.

None of these things are secret. I am not embarrassed about my life. I am not embarrassed about anything I do. But I am worried Peter Singer is taking notes. I am worried Peter Singer will use personal things to show how "bad off" people with disabilities are.

Other people with disabilities got mad at me when I said I shook Peter Singer's hand. Some people are angry that I am debating Peter Singer at all.

We need to agree on one more thing before the debate: How to act. Will we be polite? Will we be rude? What are the rules?

I have to be polite to Peter Singer. It will not help me or other people with disabilities if I am rude. But I do not want to be nice to Peter Singer. I tell Peter Singer that he must call me "Ms. Johnson." I tell Peter Singer I will call him "Mr. Singer."

Peter Singer does not like my idea, but he agrees.

I tell another lawyer in my office about the debate. He shakes his head.

"That poor, sorry son of a bitch! He has no idea what he's in for."

When I go to Princeton, I take an airplane. A lot of things go wrong. The people who work on the airplane broke my wheelchair. They break a lot of people's wheelchairs.

I get very angry. I tell them they have to fix my wheelchair right away.

I can't find a safe place to use my bedpan. It is OK. I didn't drink water today. I will not need to use my bedpan.

My assistant is named Carmen. Carmen travels with me. She is a little scared. This is the first time Carmen has gone on an airplane with someone in a power wheelchair. I did not warn her enough. I did not tell her all of the things that could go wrong.

We get to the hotel. We are four hours late. I go to sleep. In the morning, I feel tired. I am happy my broken wheelchair is fixed. I still feel cranky. I do not like sleeping in hotels.

I stretch. Carmen helps me do my stretches. I tell her how. Then, I eat breakfast. I have tea and oatmeal. I use the bedpan. Carmen helps me shower. She helps me get dressed. She puts me in my power wheelchair. I feel good in my power wheelchair. I like that I can move in my power wheelchair without Carmen's help.

I drive to the mirror. I braid my hair. Carmen helps a little. I put on a scarf. Carmen keeps moving the scarf. I tell her that it's fine, and she stops.

I tell Carmen what she needs to do today. Here are some of the things Carmen needs to do:

- Carmen must be able to see and hear me all the time.
- Carmen must help me when I want.
- Carmen must leave me alone if I want.
- Carmen must be polite to me.
- Carmen must not answer questions people ask her about me.

I am happy Carmen is with me. She's good at her job.

We walk from the hotel to Princeton University. The hotel is very close. Our walk is short. It is cold outside. I do not like being cold.

To get to Peter Singer's classroom, we need to take an elevator. The elevator is also used as the janitor's closet. There is a cart with a big trash can, mops, and brooms in the elevator. It does not look like there are a lot of other people who use wheelchairs at Princeton.

I get to Peter Singer's classroom. Students begin to come in. They sit above me in a circle. I feel like an animal at the zoo.

I think about leaving. But Peter Singer pays me for debating him. I have to do my job.

I talk to the students about what is right and what is wrong. I talk to the students about beauty and love. I do not think Peter Singer talks about beauty and love. I talk to the students that people with disabilities lead good lives. I talk to the students about the bad ways people with disabilities get treated.

I talk for a little longer than I should. Then, I let Peter Singer ask me questions.

Peter Singer is very polite. He uses a lot of big words.

The students are also very polite. They use a lot of big words. I answer their questions.

A student asks me if I eat meat.

“Yes, I do,” I answer.

“Then how are you OK with--”

I interrupt the student. “I don’t know about animal rights.”

The next student talks about comparing disability and race. Peter Singer joins in and calls me a little bit racist. I do not disagree. I am not perfect. I am a little bit racist, but I work hard on doing better.

A student asks, “what if someone is unconscious forever? Keeping them alive is weird.” “Unconscious” means that the person does not talk to other people or things ever. It is like the person is asleep all the time.

I do not think keeping someone alive is weird. I think keeping someone alive is beautiful.

The student continues talking. “What about the caregiver? Caregivers are often women. Women have to do a lot of extra work. It’s not fair to women.”

I agree that it is not fair. I think we should pay workers to support people with disabilities. No one should be forced to do anything.

The students finish asking me questions. Peter Singer asks, “do you want to go for a walk?” I say yes. I will go for a walk with Peter Singer.

Peter Singer does not know where the elevator is. He is used to taking the stairs. Carmen shows Peter Singer where the elevator is. Carmen is my assistant.

Peter Singer asks what I thought about the students’ questions.

“They were fine. The question about meat surprised me,” I say.

Peter Singer apologizes. He explains what he thinks the student meant: “Why do you care about people but not animals?”

I say, “why do you care about animals but not people?”

I do not want to debate about the lives of people with disabilities anymore. I tell Peter Singer that.

Peter Singer changes what we are talking about. He tells me about the buildings at Princeton University. We stop walking.

Peter Singer points to a place near us. "That is where your friends in Not Dead Yet protested and yelled at me," he says. I think my friends were right to yell at Peter Singer.

We finish walking. A van picks me up and takes me to my hotel. I eat lunch and take a nap.

Later, a van takes me and Carmen to dinner. The van drops us off. Peter Singer is there.

"I hope you had a good afternoon," Peter Singer says.

I did have a good afternoon. We talk about disability rights and other things. It is easy to talk to Peter Singer. He is nice to spend time with. Too bad he sees disabled lives as mistakes.

I am looking forward to dinner. I'm hungry. We are going to talk about assisted suicide. Assisted suicide is when a doctor helps a person with a disability die. The disabled person wants to die.

It is easier to talk about assisted suicide than about killing disabled babies. I understand why people disagree about it. I understand why some people want assisted suicide. I think those people are wrong, but I understand them.

We sit down at dinner. There are other people sitting at the table. I talk for five minutes about why I think assisted suicide is wrong.

David Batavia is sitting at the dinner table. He talks about choices. He says disabled people should be able to make any choice they want. That means disabled should be able to choose death.

Carol Gill is sitting at the dinner table. She talks about how most people think disabled lives are bad. She thinks most people are wrong. Carol thinks people with disabilities should be treated the same as everyone else.

I agree with Carol Gill. I think choosing to die is not a real choice. People with disabilities will feel pushed to die, because other people have wrong ideas about disability.

People with disabilities get treated badly a lot. It is hard to need help doing things. But it does not have to be that way. People with disabilities could be treated better. Dying does not fix the real problem.

Other people at the table use a lot of big words. What they say does not make sense.

A man asks, “what if we pretend everyone is nice to people with disabilities? Would you still be against assisted suicide?”

“Why would we do that?” I reply. It does not make sense to pretend real life does not exist.

Dinner is over. I only ate a little bit. I ask Carmen to put my food in a box for later. Peter Singer comes back with a box and puts food in it for me.

I go home. I go back to South Carolina, where I live. Everyone wants to hear the story about my debate with Peter Singer.

Some of my friends with disabilities think I should not have been polite to Peter Singer during the debate.

My friend Laura has a disability. She does not like that I debated Peter Singer. She does not like that Peter Singer helped me eat dinner. She does not like that I treated him like a person.

It is hard to explain. Peter Singer is a person.

Laura and I talk about good and evil. We talk about the best way to advocate for disability rights. We talk about the best way to make disabled life better.

I keep working. I try to make disabled lives better. I help make a law that will keep disabled people safe. It is good to do this kind of work. But Peter Singer keeps talking to me. I ask myself a hard question: Why don't I yell at Peter Singer?

Here is the answer: I feel bad for Peter Singer. I think he is very smart. He is very good at writing. He is very good at debating.

But Peter Singer misses something important. He thinks disabled lives are bad. Peter Singer is wrong about people with disabilities. A lot of people are wrong about people with disabilities. I feel bad for Peter Singer because he is wrong.

Peter Singer does not understand that killing disabled is killing disabled people. He thinks it is just parents choosing what they want. He does not think we are people.

A lot of people with disabilities think I should yell at Peter Singer. I am not sure that is a good idea.

I go talk to my sister. Her name is Beth. She gives good advice.

Beth calls Peter Singer a monster.

“You kind of like the monster, don’t you?” she says to me.

I am uncomfortable.

“I do like Peter Singer a little bit. He’s not exactly a monster,” I say to Beth.

“Some Nazis were very nice to talk to. After killing people all day, they went home. They played with their children every night.”

I realize I am wrong.

Peter Singer does not know he is a monster. He does not think killing people is killing people. He thinks people with disabilities are not people, so killing us is OK. He thinks he is doing the right thing.

Right now, it is not OK to kill people with disabilities. If someone tries to kill a person with a disability, they will go to jail. But what if Peter Singer’s ideas change the rules? Peter Singer is very important. A lot of people listen to his ideas.

I hope that his ideas will not matter. I hope his ideas will not change the rules. But is that enough? I don’t know.

I need to believe most people are good. I need to talk about how people with disabilities have good lives. It’s the best I can do.

For Ki'tay Davidson, who loves us

Talila A. Lewis

Talila A. Lewis is a lawyer and teacher. Lewis made a list of deaf/blind prisoners in the United States. Lewis is the volunteer director of HEARD. At HEARD, Lewis advocates for deaf and disabled people who were wrongfully convicted. That means they were sent to prison, even though they didn't do anything wrong. Lewis co-created the Harriet Tubman Collective. Lewis has taught at Rochester Institute of Technology and Northeastern University School of Law. Lewis has won a lot of awards, including the 2015 White House Champion of Change Award.

Ki'tay Davidson was a proud Black Disabled transman. He died on December 2, 2014. This story is about Ki'tay Davidson. It is a eulogy.

A eulogy is a speech saying good things about a person who has died. Friends and family usually give eulogies.

This eulogy is by Talila Lewis. Sometimes, Talila Lewis wants to be called TL. TL is Talila Lewis's name in sign language.

These are the things you should know about Ki'tay Davidson:

TL loved Ki'tay Davidson very much.

Ki'tay was a social justice advocate. A social justice advocate is someone who wants everyone to feel included. Social justice advocates work to make the world better for people who are left out or treated badly.

Ki'tay won an award from the President of the United States for his work. The award is called "Champions of Change."

Ki'tay was good at explaining ways that the world is unfair to some people. There are groups of people that get treated worse than other groups. Black people get badly because they are black. Transgender people get treated badly because they are

transgender. People who do not have a place to live get treated badly because they do not have a place to live. People who go to jail get treated badly because they went to jail. People with disabilities get treated badly because they have disabilities. It is not fair. No one should be treated badly.

Sometimes, it is hard to know that someone else is being treated badly. It can be hard if you did not see the unfairness happen yourself. Ki'tay helped tell everyone what is fair and what is not. Ki'tay wanted everyone to be treated fairly.

Ki'tay loved everyone. Even people who hurt him. Even people who treat other people badly.

Ki'tay loved learning new things. He looked for new things to learn every day.

Ki'tay was a good teacher. He never made people feel bad for making mistakes. He never made people feel bad if they did not know something.

Assata Shakur said, "it is our duty to fight. It is our duty to win. We must love each other and protect each other. We have nothing to lose but our chains." Ki'tay told people this a lot.

TL said, "Ki'tay believed that the time is now to seek what is just."

What are some things you can to make the world fairer for everyone?

If You Can't Fast Give

Maysoon Zayid

Maysoon Zaid is an actress, comedian, writer, and disability advocate. She is the cofounder of the New York Arab-American Comedy Festival. She wrote a book called "Find Another Dream" for Audible. She acts in General Hospital on TV.

I was born and raised in the United States. I spent my school days in New Jersey and my summers in the West Bank. The first Ramadan I ever fasted was no joke. I was eight years old and on summer vacation in my parents' village. It was late June. The Middle East is very hot in June.

During Ramadan, people fast. Fasting is when someone does not eat or drink for a long time, on purpose.

A lot of people do not like fasting. I don't mind fasting. I'm one of those crazy Muslims who loves Ramadan.

I have cerebral palsy. That means I do not have to fast. Fasting is one of the five pillars of Islam. It is very important. Most Muslims have to fast. The Qur'an says in Surah 2, Ayat 185 that people who are sick or disabled do not have to fast.

I was treated like a champ for fasting. My family was excited. I refused to show any weakness. I knew that by fasting against the odds I had been born with, I'd totally get into heaven. More importantly, I would get amazing gifts for Eid. Eid is the celebration at the end of fasting. Muslims celebrate Eid for three days. After thirty days of fasting, one day of celebrating isn't enough!

It's fun to fast for Ramadan when you are in a country where everyone is fasting. Ramadan is not as much fun in America. In America, I am sometimes the only one fasting.

When I was a child, my teachers didn't know about Ramadan. Some teachers were scared I would die from fasting! They thought my parents were forcing me to fast. They

would try to give me candy. I would shove their candy away. I would tell them not to push their beliefs on me. I could eat whatever I wanted at sunset, thank you very much.

Every Ramadan, my mother says I do not have to fast. Those who cannot fast during Ramadan donate money to feed a hungry person for the whole month. If you do not have enough money, you should do anything good you can do for others.

My mom has donated money for me every single year I have fasted. This was just in case I got sick and had to stop fasting. How is that for faith?

My hardest Ramadan was during a ten-day road trip in 2011. I was in America's Deep South for a comedy tour. The comedy tour was called, "The Muslims are Coming." I was telling jokes on stage every night. We were also making a movie. We would spend all day interviewing people who did not like Muslims.

For the first time in my history of Ramadans, I complained. I was hot, thirsty, and tired of being treated badly. Some nights I didn't stop fasting until 10:30 at night. But I survived.

I broke down and broke my fast only once. We were at Elvis's house in Tupelo, Mississippi. The statue of Elvis spoke to me. Statues do not usually say anything. I realized if I didn't drink water I would drop down dead just like he did. I did not want to die where Elvis was born. It's okay to miss a day or five. It is OK to miss some time if you are sick, traveling, or if you have your period. You can make it up later in the year.

Some Muslims are slick and do their makeup days in December when the days are shorter. That way, they have a shorter fast.

On July 10, 2013, I had to stop fasting forever. I have cerebral palsy. I shake all the time, just like Shakira's hips. On the first day of Ramadan 2013, I shook a lot. By noon, I was not able to use my phone. By the time I broke my fast at 8:30 at night, I could not breathe. I knew that I had fasted for the last time.

The next morning, the water I drank tasted like poison. It felt so wrong to drink water during the day. Ramadan is something I think of when I think of the best times in my life. I felt like a tradition was lost.

I am not ashamed that I cannot fast. I know many who are, even though they do not have to for God's sake. I miss fasting. But I'm happy to tell people who can't fast that it's OK. Muslims fast to feel a little hungry. It is important not to die while fasting.

Instead, those who can't should give money and do good things for other people. It will help people who are starving.

If you can fast, don't bother other Muslims about their fasting. It is impolite to ask other people if they are fasting for Ramadan. Sometimes, you don't really want to know the answer.

There's a Mathematical Equation That Proves I'm Ugly Or So I Learned in My Seventh-Grade Art Class

Ariel Henley

Ariel Henley is a writer. She lives in Northern California. Her writing is in *The New York Times*, *The Washington Post*, and *The Atlantic*. She teaches people about disfigurement. She wants mainstream inclusion for people who look different. Her book is called *A Face for Picasso*. It will be out soon.

Note: This story talks about bullying and suicide. Suicide is when a person kills themselves.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

I am ugly. There's a math problem to prove it. The boy that sat behind me in my seventh-grade art class said so.

"I'm going to stick my pencil through the back of your eye," he told me, laughing. "It's not like you could get much uglier. Even the teacher thinks so."

Two years earlier, a different boy asked me what was wrong with my face. I do not remember his name. He was angry because I beat him at handball.

"You have the weirdest set of eyes I've ever seen," he told me.

My teacher heard the boy. My teacher sent the boy to the principal's office. Later, I would later go and give my side of the story. The principal told me I needed to not be so sensitive.

The boy in my art class kept poking my shoulder with his pencil. I said nothing.

My art teacher was a heavyset black woman/ Her name was Ms. J. She had a loud laugh. Ms. J wore beautiful bright colors. She taught us about artists and kinds of art that I had never heard of. Ms J wanted us to think about what art meant to us.

My school was filled with children who came more from rich families. Their parents were doctors and business executives and athletes. My family was well off, but I felt out of place. Other children were taken care of by nannies. Their fathers went to fancy universities.

My father made cabinets and owned a construction company. My mother worked in the next town over. They did not go to university.

My town was mostly white people. Having a black woman as a teacher felt special, in a way that only sheltered white children would understand. We did not know any better.

Every week, Ms. J told students to research an artist or a piece of art we liked.

Art isn't about what you see, Ms. J would tell the class. It's about what you feel. Show me what you feel.

We had to read books. Then we had to write one page about the art or piece of art. We had to write about what it meant to us.

After school on Wednesdays Ms. J would hold studio time. During studio time, students could come in to work on new things. We could also talk about what we learned in class. Usually, only my friends and I went to studio time.

One week, Ms. J spent the first half of class talking about beauty in art. She said that beauty means different things to different people. Two people can look at the same painting and see different things. She taught us about the golden ratio. The golden ratio is a math problem that explains beauty.

Euclid of Alexandria discovered the golden ratio more than two thousand years ago. Euclid noticed a pattern in nature. For example, the petals of a flower and a snail's shell are the same pattern. Flower petals and snail shells follow the golden ratio. People use the golden ratio when they make buildings or new inventions. The closer something follows the golden ratio, the more beautiful it is.

One week, we were talking about drawing faces in art class. Ms. J talked about the golden ratio again. She told us scientists have studied the golden ratio. They use the golden ratio to measure beauty.

“They measure from your hair to your nose. They measure between your eyelids. They measure from your eyelids to your nose. And they measure from your nose to the bottom of your chin. If these numbers are the same, then a person is more beautiful,” Ms. J said.

She told us that the ear should be the same length as the nose. The width of an eye should be the same as the space between the eyes. For a woman to be beautiful, the length of her face divided by the width should have a ratio of 1:1.618. This number is the golden ratio.

Ms. J showed us work by Renaissance artists like Raphael and Botticelli. The Renaissance was a part of the Middle Ages. A lot of beautiful art was made during the Renaissance.

I had never understood math problems or ratios. What I learned is that women need to look a certain way for other people to like them.

Ms. J told us about more research about the golden ratio and women’s beauty. Women’s beauty could be rated on a scale from 1-10. The scale is based on the golden ratio and the shape of a person’s face. Most women are between a four and a six. No one is a perfect ten.

If my face was measured using the golden ratio, I thought I would be less than a two.

I grew up having every problem pointed out to me. I grew up believing I was wrong. I was born with a facial disfigurement from Crouzon syndrome. A facial disfigurement means that my face looks different from most people’s faces.

The bones in my head do not grow normally. My eyes were too far apart. My eyes were too crooked. My nose was too big. My jaw was too far back. My ears were too low. My twin sister was also born with Crouzon syndrome. We went to see doctors who tried to fix us. Sometimes, it was because of our health. But sometimes it was just to look a little more like everyone else.

I would sit in a room while doctors took pictures of my face from every angle. They would pinch and poke. They would point out the problems with my face. I would sit and let them tell me everything that was wrong with my face. And I wanted it.

“Fix me,” I would beg.

They would do their best.

I'd have surgery, get better, and come back for more pictures. The doctors would point out more things that are wrong with my face. I felt like every part of my face needed to be in the right place. I wanted to look different.

When the boy in my art class told me I was ugly, I told my mother that I wanted to die. She took me to a therapist the next day. A therapist is a kind of doctor. A regular doctor takes care of your body. Therapists take care of your feelings.

My therapist was named Beth. Beth had curly red hair. Beth's body was round. Her glasses were round. Beth almost always wore green. I would sit in Beth's office and play a game. I would tell her about my dreams to travel and write. We almost never talked about how I look.

When I entered Beth's office that day, we did not play a game. Instead, Beth looked right at me. Beth asked me if I was happy.

I did not know how to answer, so I cried. She gave me a tissue and listened to me cry. When I stopped crying, we sat quietly for a long time.

"It's like when you reread the same words over and over again without understanding what they mean," I said. "That's how I feel about my life. That's how I feel about what I look like."

Beth nodded as I talked. She reached for a pen, but stopped. Instead she put her hands in her lap.

"I don't get it," I continued. "These things, they just keep happening, and I know it has to mean something. It has to. I want my pain to mean something. I want my pain to matter."

Beth responded by giving me homework. I needed to take a picture of my face every day for a few weeks. Beth told me I did not feel like my body was my body, because it had changed so many times. This made sense to me. I was surprised I had never thought about that.

"You don't have to show the pictures to anyone," Beth told me. "Just take them for you."

I was not sure pictures would help, but I agreed.

I used to cry when I saw pictures of myself. I would cry all day and not leave the house. Seeing pictures made me angry.

I was ugly.

When I was nine years old, magazine reporters came to my house. They took pictures of me and my twin sister. My mother put us in dresses and curled our hair.

We sat at the dining room table. We were allowed to sit at the dining room table on special events. The reporters took pictures of me and my sister. They asked us questions about our lives. I remember they sounded French. They kept saying that I was different.

There was a picture of my sister and me in the middle of the table. We wore matching blue-and-white sweaters and held pearl necklaces. It was one of those forced mall photos. Families like to hang them in their homes, so everyone else thinks they are happy. I hated the picture. My eyes were red and I looked weak. It was taken after I had surgery to make my skull bigger. The doctors broke my bones and shifted everything forward. They took bone from my hips and put it in my face. I had to learn how to walk again.

A few weeks after Beth gave me homework, I found the magazine article in the attic. It was covered in dust. The article was in French. I knew some French from school. The article talked about the bones in my head and things doctors invented in their garages to help me. I cried when I read it. The magazine made it sound so easy. They didn't talk about the weeks spent in the hospital. They didn't talk about my mother staying next to my hospital bed. She was too scared to leave. The magazine didn't say that I was a person and not a disease. And on the page, in big letters, the magazine said:

Their faces look like Picasso.

The words were printed under a picture of my sister and me. In the picture, we were sitting at our kitchen table and laughing like normal children. But we weren't normal children. Normal children don't get written about in French magazines. Normal children don't get called ugly in French magazines.

I was embarrassed or ashamed. I found myself wondering how I ever could have thought someone would think I was special. It felt as though the whole world was

laughing at a joke no one told me about. I threw the magazine on the floor. I spent the rest of the night in my room.

“Picasso was an artist. You are God’s art,” my mother told me.

“God should get a new job,” I would say back.

I tore up the magazine that night.

I told Ms. J about the article. About how my face was compared to a Picasso painting. I told her about the homework Beth had given me. I asked if I could make it part of my work from art class.

Ms. J liked my idea. She told me that beauty is different for everyone. There is no real reason to say one thing is beautiful and another thing is ugly. Beauty doesn’t only mean one thing. What we do is more important than how we look. What we do sets us apart. What we do makes us beautiful.

Ms. J walked over to her desk. She began typing on her computer. I stood still. I did not know if I should follow or not.

“Leonardo da Vinci looked at beauty with what he called the ‘divine proportion.’ He was a math guy so he made math part of his art, to make sure it looked good,” Ms J. told me.

Ms. J turned her computer screen toward me. She showed me pictures of Leonardo Da Vinci’s art. She showed me Profile of an Old Man, Vitruvian Man, and the Mona Lisa. They are famous and beautiful art. Ms J. looked up at me.

“Do you know what Da Vinci looked like?” Ms. J asked. She showed me a picture of an old man with long, white hair.

“I don’t know about you,” she joked, “but he doesn’t look too pretty to me.”

I laughed.

“Being told you look like a Picasso painting may seem mean, but it’s actually a good thing,” she told me. “You are a masterpiece.”

When I think about Da Vinci, I do not think about his body. I think about his talent and the amazing art he made. His work reminds me that we are all more than our bodies. We are more than how our faces are shaped.

Math that explained beauty used to make me feel better. It meant there was a perfect beauty to work towards. But art isn't always about beauty. Art is supposed to make you feel something. I began to realize how I looked was my art. My body, my face, my scars told a story—my story.

Sometimes I look at myself in the mirror. When I do, I remember what Ms. J said. Beauty is different for everyone. The person I see in the mirror doesn't look like a stranger.

The Erasure of Indigenous People in Chronic Illness

Jen Deerinwater

Jen Deerinwater is a citizen of the Cherokee Nation of Oklahoma. She is a bisexual, Two-Spirit, disabled journalist and advocate. She writes about issues in her communities. Jen is a contributor at *Truthout*. She started *Crushing Colonialism*. She is a Freedomways Reporting Project fellow.

Jen's writing can be found in *Bitch*, *Rewire.News*, and *In These Times*. Her writing is also in *Two-Spirits Belong Here* and *Sacred and Subversive*. Jen has been interviewed a lot about her writing. *The Advocate* named her a 2019 Champion of Pride.

Note: This story talks about settler colonialism. A long time ago, white people from Europe moved to the best parts of America. The white people forced the Native people who were already living there to leave, or they killed them. The land white people live on today is the same land they stole from Native people.

This story talks about genocide. Genocide is the crime of killing a lot of people because they are a different religion, race, or culture.

This story talks about racism. Racism is the wrong belief that white people are better than Black and brown people.

This story talks about sexism. Sexism is the wrong belief that men are better than women.

This story talks about ableism. Ableism is the wrong belief that non-disabled people are better than disabled people.

This story talks about rape and unwanted sexual touching.

This story talks about people hurting other people very badly.

This story talks about suicide. Suicide is when a person kills themselves.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

"Are you an Indian?"

I've answered this question a lot of different ways, in a lot of different doctor's offices. I wish I could shoot arrows at the question with my eyes. I'd like to bring together the anger of my ancestors to burn the question to the ground. Our crops and villages were burned to the ground by settlers.

Ancestors are parents, grandparents, great-great grandparents, and everyone who came before us.

Settlers are white people who came to America and stole from the Native people who were already living here. Their children are also white settlers.

Native people are often asked to name ourselves with names white settlers invented, like "American Indian." I am not an "American Indian." I am a citizen of the Cherokee Nation of Oklahoma. I am Tsalagi.

When filling out paperwork, I have to take a deep breath and pick "American Indian" or write in "Native American" in the space for "other." I also hate the name "Native American." We've been turned into "Americans" to make it seem more OK that our land was stolen.

Calling us "Indian" makes the idea that we are savages Columbus "discovered" stronger. There is also the "Other" box. Native people are not "other." We are hundreds of different nations in charge of ourselves.

Even when I pick a name I hate, I am still listed as "white" in my medical records.

Erasing who I am makes sure that I never get good medical care. I deserve good medical care. Doctors and nurses have said a lot of mean and horrible things to me.

"Are you Indian? Tell me about your people."

"I've been so excited to meet you! You're Native American, right?"

"Deerinwater? What an odd name. What does it mean? Does it mean something bad?"

"You haven't experienced racism in medical care. Some doctors may not give you your medications, but that's not racism."

I've had to answer these questions with my legs in the air and no pants on. I've had to answer these questions after surgery. I was in so much pain I couldn't move. I have even had to answer in the emergency room, after an abusive partner almost killed me.

The questions make me feel like I am something white people look at in a museum. It got when I moved to Washington, D.C., three years ago. I have experienced very bad anti-Native racism in D.C. After I had back surgery at the George Washington University Hospital, workers there bullied me for being Native. They used the slur “redsk*n” right in front of me. A white nurse even broke the doctor’s orders. She would not give me pain medication. I was in a lot of pain.

The white nurse said, “That’s ridiculous. You don’t need pain medication. I’m not giving it to you.”

I take anxiety medication before most doctor’s appointments. It is supposed to help me feel less worried. I’ve canceled appointments when I can’t handle thinking about if the doctor will be horrible to me.

While this might seem small, it is part of a bigger problem. Native people die a lot younger than other groups of people. Natives in Oglala County, South Dakota, where the Pine Ridge Reservation is, live to be 66.8 years old. That is the lowest in the United States. This is lower than how long people live in a lot of other countries.

- Most people in Sudan only live to be 67.2 years old.
- Most people in India only live to be 66.9 years old.
- Most people in Iraq only live to be 67.7 years old.

There have been big wars in Sudan and Iraq in the last 20 years. A lot of people in Sudan and Iraq die young because of guns or bombs.

There have not been big wars in the Pine Ridge Reservation in the last 20 years. But people there die young anyway. Why?

Here are some of the reasons Native people die young:

Native people get bad medical care.

The part of the American government that gives Native people healthcare is called the Indian Health Service (IHS). It is the only healthcare Native people living on the reservation are allowed to have. Most people think IHS is the worst healthcare in America. The government does not give IHS enough money to work the way healthcare should work.

There are not enough doctor’s offices and hospitals near reservations and tribal villages.

People have to travel hundreds of miles if they need to see a special doctor, or they just don't see the doctor at all.

Native people can't get abortions.

An abortion is a surgery to stop someone from being pregnant. In America, most people can choose to have an abortion. There are a lot of reasons someone might not want to be pregnant anymore.

There is a law called the Hyde Amendment. The Hyde Amendment says the government won't pay for most abortions. A lot of the time, even when the law says it should, the government still won't pay for an abortion.

The government pays for IHS. IHS can't pay for most abortions. So Natives living on reservations do not have the same choice everyone else gets to have.

About 84 percent of Native women are abused in our lifetimes. 84 percent is most Native women.

More than half of Native women have been raped at least once.

On some reservations, Native women are murdered ten times more often than anywhere else in America.

The Hyde Amendment says that if a woman is raped, the government will pay for her abortion. But it is almost impossible to get an abortion on a reservation if you are raped. The government does not care about the rules they made.

The government often does not collect rape kits at IHS hospitals. A rape kit is used to help find rapists and send them to jail. There are almost no nurses on staff who can do the kits right. Rapists get away with hurting a lot of people.

IHS doesn't have PrEP for people who need it.

PrEP is a medicine that helps people from getting HIV/AIDS. HIV/AIDS can make people very sick.

IHS has hurt a lot of Native people. Now they are afraid of IHS.

Native people are afraid for good reason. In the 1970s, between a quarter and a half of women were sterilized in IHS hospitals. They did not want to be sterilized.

“Sterilized” means that the women could never have babies again, if they wanted to have babies.

I went to the Claremore Indian Hospital as a child, when I was sick. The Claremont Indian Hospital sterilized so many people that did not want it.

Healthcare is terrible for Native people in cities too. During the 1950s, the U.S. government passed laws to move Native people to cities. This was called the “Termination Era.” Seven out of ten Natives live in or near cities. Most Natives live in cities. But only 1 percent of the IHS budget is for healthcare in cities. The IHS budget is already too small. So that is a small amount of a small amount.

Native people were moved to areas of “America” where the government does not recognize our tribal nations on purpose.

There is healthcare for non-Native people. For example, Medicaid and Medicare. Sometimes, Native people in cities can get that healthcare. But most doctors and nurses pretend Native people do not exist. They do not know how to treat us.

Native people have the highest numbers of a lot of diseases and disabilities. Here are some:

- Suicide
- Diabetes
- Autoimmune diseases
- Heart disease
- Murder
- Alcohol abuse
- Drug abuse

My grandpa Deerinwater died from a heart attack in his fifties. That was before I was born. My father used to drink too much. He stopped drinking, but was still horrible to me.

This is because of historical and intergenerational trauma. It wasn’t just that my father hurt. It’s that his father hurt, and his father’s father hurt. The world hurt them too. All of that hurt rolls up into one big hurt. That’s what historical and intergenerational trauma is.

I have diabetes. I've tried to kill myself several times. I've been raped so many times that I can't count them anymore. I also have health problems no one knows the answer to. I'm now being tested for autoimmune diseases.

Colonialism caused many of these health problems. Colonialism is when a more powerful, richer country takes over a less powerful country. People from the powerful country move to the less powerful country. They steal from the people who live in the less powerful country. America was built with colonialism.

Our land and water has been polluted. There has been mining, oil drilling, logging, toxic dumping, and nuclear testing.

Dr. Sophia Marjanovic is part of the Fort Peck Oglala Lakota and Santa Ysabel Ipai. She told me that her tribe had an oil boom in the 1980's. Where she lives, water comes out of the faucet red, yellow and orange. The water smells like gas. There are oil drops floating in the water. Most women die from cancer. More people are getting autoimmune diseases faster than anywhere else. No one takes responsibility.

The government has destroyed food we have always relied on. It has also destroyed the food traditions our ancestors had. Many of us can no longer grow, hunt, or fish the foods like they did.

The government gives out unhealthy food. On our tribal lands there are no jobs or vegetables for anyone. A gallon of milk can cost more than \$10. A lot of native people are starving. From 2000 to 2010, a quarter of Native people living in the countryside did not have enough food. The government gives out food, but the food is unhealthy. A lot of the time, the food has gone bad. These "handouts" have hurt food traditions Native people have had. They are also killing us. So many of our elders die young. We cannot learn and pass down our traditions.

I feel sick every time I have to teach others. I feel sick every time I have to stand up and fight for myself and my communities. I feel sick when I have to make official complaints to the medical system. These are fights I shouldn't have to fight. But the U.S. government was designed to kill us. Doctors are still killing us. I am choosing to fight.

I tell the doctors and the hospitals that they must have "Native" on their paperwork. I should be able to call myself "Native." Not a different word or name I hate. Leaving "Native" off paperwork sends a clear message: Native people are not welcome here.

I've had a meeting with people in charge of the George Washington University Hospital about their anti-Native racism.

Most hospital workers seem confused about why I am angry and sad. I am often the first Native person they have ever met. But I'm trying to get medical care. I want to keep living. I want to live well. My ancestors wanted to live well. They want me to live well.

When You Are Waiting to Be Healed

June Eric-Udorie

June Eric-Udorie is a twenty-year-old British writer and feminist activist. She is a cofounder of Youth for Change. Youth for Change works to combat female genital mutilation and forced marriage around the world. Her advocacy has taken her to classrooms, the Southbank Centre's Women of the World Festival, and the United Nations.

The church building was very hot. I was sweating. There were black folk around me. They were in every part of the church building. Everyone was very close together. It was hard to count exactly how many people were there.

Before Christmas, a lot of new people come to church. On Thanksgiving, we wore matching ankara and lace. Children danced in front of the entire church. The children's bodies were sweaty. They danced to very loud drums.

My grandmother was standing next to me. She was dancing. Her hips were swaying back and forth. She was swaying with the sound of the talking drum. She had a big smile and white teeth.

I wanted to dance too. I wanted to move my arms and legs. I wanted to take off my shoes. Everyone else at church was dancing. Everyone else at church was singing. They sang, "Come and join me. Sing hallelujah." But I was 15 years old. I was a teenage girl. I felt awkward. I felt like my body was not my body.

I wanted to go to the bathroom and hide. It was quiet there. But the pastor told the band to stop playing music. He told the church it was time for communion. My grandmother grabbed my arm. I could not leave.

A deacon gave me a little cup of wine. On top was a thin piece of bread. A cross was stamped in the middle of the bread.

"Dip the bread in the wine and place the communion on your eyes," my grandmother said. "If you really believe, if you really pray and cry out, then God will heal you."

I sighed. I took a deep breath. I felt shame. I did as I was told.

I whispered, "Pretty women wonder where my secret lies." It is part of a poem by Maya Angelou. It made me feel a little better.

I prayed to not have a disability anymore. I had prayed for it many times before. Nothing ever happens.

The piece of bread was soaked in wine. Then, the piece of bread was put over my eyelids.

I had stopped believing that God could even work miracles.

But that Sunday, I asked God for a miracle again.

For a huge part of my childhood, I felt like I was broken.

The feelings started early. I saw a lot of eye doctors with my mother. She wanted to know if my eyes could be cured.

"Her eyes can't be cured," the doctors said.

My mother would cry when we got home. The doctors told her the same thing when I was born. But she kept asking anyway.

I was born with nystagmus. Nystagmus means my eyes move back and forth very fast. Nystagmus makes it hard to see things.

Doctors think between 1 in 1000 or 1 in 2000 people have nystagmus. That means only a few people have nystagmus.

A lot of different things can cause nystagmus. Down syndrome can cause nystagmus. Albinism can cause nystagmus. Sometimes, it is random. My nystagmus is random. No one knows what caused my nystagmus.

When I was in first grade, a boy at school called me a witch. I could not move my eyes when he asked me to. I went to the bathroom and cried. That was when I learned there was something wrong with me forever. I could never be fixed.

We did not usually talk about nystagmus at home. If we did talk about nystagmus, it was something God would "deliver me" from. I got messages that didn't make sense. God does not make mistakes. Everything God creates is perfect. God fixes things that are not perfect. Why wouldn't God fix me?

I felt shame because of my nystagmus. I prayed a lot. I asked God to heal me so I could be normal. God did not answer my prayer. I tried asking for less. I asked God to let me see clearly for one day. I asked for less time. I asked for twelve hours. I asked for thirty minutes. I asked for ten seconds. None of my prayers were answered.

In 2012, an eye doctor at a hospital in Oxford, England, asked if I'd thought about registering as "partially sighted" with the government. "Partially sighted" is a kind of disability. If I registered, I could get more support for my disability.

I was very surprised. I did not think I was disabled. I hoped my nystagmus was something God would heal. I knew my nystagmus would not be healed. But I hoped anyway.

When you are waiting to be healed, you don't admit your disability is going to last your entire life. I did not want to admit my eyes would always be the same. It felt like I was ignoring the fact that God can do anything.

When I was growing up, my family told me I was not really disabled. Saying I was disabled felt like a lie. It felt like I was saying my life was harder than it is.

After a few minutes, I told the eye doctor that I would talk to my mom.

I walked back to school. On my walk, I called my ma. I told her what the doctor had said.

"He wants me to register as partially sighted."

My mother didn't say anything. She hung up the phone. We never talked about it again.

I stepped onto the train platform in Bath, England. I only felt fear. I felt so much fear.

The train platform was very quiet. It was early in the morning. Not a lot of people were awake. The sky was blue. The clouds looked like they went on forever. I was 17-years-old. It was the first time I had gone anywhere on my own. I was almost an adult. I needed to try and do things without help.

But I knew the truth. I was a disabled black girl. The truth made me feel afraid. I did not want to think about it.

Later, I sat in a café in Bath by myself. I had gone there by myself.

I did get lost on my way. I asked someone for help. The person pointed at things I could not see. I did not nod and pretend I could see.

“I have a visual disability,” I said. I said the truth. It has been the truth since I was born. I learned something very important: I should not be ashamed of who I am. I should not be ashamed of my disability. It is OK to miss a step sometimes. I had to let it go. I had to practice forgiving myself.

I took a deep breath. I let the breath out. I imagined that I was breathing out little bits of shame and fear.

Going places by myself was not a big deal. But it was still important. When I was a teenager, no one let me try to go places by myself. Everyone else was scared I would get hurt, because of my disability. They were worried something bad would happen to me. But nothing bad had happened to me. I felt like a winner. I sat in the cafe and looked at a green park.

I’ve been living in London for over two weeks. London is very big. People in London walk too fast. London is very loud. You can only hear birds if you wake up very early in the morning.

It is very early in the morning when I walk to church on Sundays. It is quiet. I can hear the birds.

When I walk into that church service, I do not believe the way I used to. I sing louder than the drums. I smile when I see children dancing. I come to church happy in my body. I come to church knowing that I am not a mistake. I am not waiting to be fixed.

I do not come to church begging God to change my disability. My disability is the most special part of me. I come to church happy and whole. I come to church free.

The Isolation of Being Deaf in Prison

Jeremy Woody, as told to Christie Thompson

Jeremy Woody was born in Omaha, Nebraska. He found out that he was Deaf when he was two years old. He attended the Iowa School for the Deaf until eighth grade, then moved to Georgia. In Georgia, he was mainstreamed. He raced in National BMX races for more than seventeen years. He was the only deaf BMX racer in the United States.

Note: This story talks about rape and unwanted sexual touching.

This story talks about being alone for a very long time.

This story talks about being with no one who speaks your language for a very long time.

This story talks about being in prison.

This story talks about audism. Audism is the wrong belief that hearing people are better than deaf people.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

When I was in state prison in Georgia in 2013, I heard about a class called Motivation for Change. I think it had to do with changing your mindset. I'm not actually sure, because I was never able to take it.

On the first day of class, the classroom was full. The teacher asked everybody's name. When my turn came, I had to write my name on a piece of paper and give it to a guy to speak it for me.

The teacher wrote me a message on a piece of paper: "Are you deaf?"

"Yes, I'm deaf," I said.

Then she told me to leave the room. I waited outside for a few minutes. The teacher came out and said, "Sorry, the class is not open to deaf individuals. Go back to the dorm."

I was very angry. I asked several other deaf guys in the prison about it. They said the same thing happened to them. From that point forward, I started filing grievances. Grievances are an official kind of complaint to the prison.

The prison kept denying the grievances, of course. I could not take any of the classes. I could not take the basic computer class. I could not take the vocational training class. I would get there, they would realize I was deaf, and they would kick me out.

It felt like every time I asked for a service, they were like, "Fuck you, no, you can't have that." I was just asking for basic needs. I didn't have a way to communicate. And they basically just flipped me the bird.

While I was in prison they had no American Sign Language (ASL) interpreters. None of the staff knew sign language. The doctors did not know sign language. The nurses did not know sign language. The mental health office did not know sign language. The people in charge did not know sign language. Nobody knew sign language.

In the barbershop and in the chow hall, I couldn't communicate with the other inmates. When I was raped, I couldn't use the phone to call the Prison Rape Elimination Act hotline. The Prison Rape Elimination Act is a law that is supposed to keep rape in prison from happening. I did not have a way to tell anyone what happened to me.

Everywhere I went, there was no access to sign language.

I met some other deaf people while I was in prison. But we were all in separate dorms. I would have liked to meet with them and sign and catch up. But I was alone.

The people in charge of the prison put us in the same rooms as blind folks. It was impossible for me to talk to blind folks. They couldn't see my sign or how I moved my hands. I couldn't hear them.

After a year, the people in charge of the prison put me in a room with another deaf person. It was pretty great to be able to communicate with someone. But then he got let out of prison. The people in charge put me with another blind person.

I met with the prison doctor. I explained that I needed a sign language interpreter to talk to him. They told me no. They told me we'd have to write notes back and forth.

The doctor asked me to read his lips. But when I encounter a new person, I can't read their lips. I don't read or write well, so it's hard for me to write in English. My language is sign language. That's how I communicate every day.

I stopped going to the doctor. I had no way to explain that I felt sick.

My health got worse. I found out later that I had cancer. When I went to the hospital to have the cancer taken out, the doctor did bring an interpreter. They explained everything in sign language.

I didn't understand. Why couldn't the prison do that in the first place? When I got back to prison, I had a lot of questions about the medicines I was supposed to take. But I couldn't ask anyone.

I did ask for mental health services. A counselor named Julie was very nice. She tried her best to tell the warden I needed a sign language interpreter. The warden said no. They wanted to use one of the hearing inmates in the facility who used to be an interpreter because he grew up in a home with deaf parents. But Julie felt that was not OK, because of privacy.

Sometimes we would try to use Video Remote Interpreting, but the screen often froze.

So I was usually stuck having to write my feelings down on paper. I didn't have time to process my emotions. I just couldn't get it across. Writing all that down takes a very long time. My appointment was only 30 minutes long. I didn't have the time to write everything I wanted to. Julie learned some sign language. But it just wasn't enough.

My communication problems in prison caused a lot of issues with guards, too.

One time, I was sleeping and I didn't see it was time to go to chow. I went to the guard and said, "Hey, man, you never told me it was chow time." I was writing back and forth to the guard. The guard said he can't write to me because it's considered "personal communication" It was against prison policy for guards to have "personal communication" with inmates. That happened several times.

I would have to be careful writing notes to officers, too, because it looked to the hearing inmates like I was snitching.

Once they brought me to court. My hands were shackled behind my back. I had no way to communicate. I couldn't sign. I couldn't write. Two of the guards in the room were speaking to me. All I saw were lips moving. I saw laughter.

One of the guards was actually a pretty nice guy, one of the ones who were willing to write things down for us deaf folks. He tried to get them to take the cuffs off me. He wrote, Guilty or not guilty? But the other guards would not uncuff me. I wanted to write not guilty. I wanted to ask for an interpreter. But I couldn't.

They said, "Okay, you have nothing to say? Guilty." I was so angry. I started to scream. That was really all that I could do. They sent me to the hole, and I cried endlessly. It's hard to explain how angry I was.

Prison is a dangerous place for everyone. That's especially true for deaf folks.

Jeremy Woody was released from Central State Prison in August 2017. He was there for four years. He was in prison because of a probation violation.

A probation violation is when you break a rule a judge says you must follow, or else you will go to prison. Sometimes a judge will say you must meet with a social worker at a certain time. Sometimes a judge will say you cannot be outside after a certain time.

It doesn't matter if you make a mistake. You can still be sent to prison for a probation violation.

Jeremy now lives near Atlanta. He is currently suing people in charge of Georgia Prisons, because of how he was treated. The American Civil Liberties Union's Disability Rights Program and the ACLU of Georgia are helping Jeremy.

Jeremy told this story to the Marshall Project through an American Sign Language interpreter.

We asked the people in charge of Georgia prison's about Jeremy's story. They did not say anything back.

Common Cyborg

Jillian Weise

Jillian Weise is a poet, performance artist, and disability rights activist. She wrote three poetry collections—*The Amputee's Guide to Sex*, *The Book of Goodbyes*, *Cyborg Detective*. She also wrote a book called *The Colony*. Peter Singer and Charles Darwin are in her book.

Note: This story talks about hate.

This story talks about people who hate women because they are women.

This story talks about bullying.

This story talks about rape threats.

This story talks about death threats.

This story talks about racism. Racism is the wrong belief that white people are better than Black and brown people.

This story talks about ableism. Ableism is the wrong belief that nondisabled people are better than disabled people.

This story talks about suicide. Suicide is when a person kills themselves.

This story talks about sterilization. Sterilization is a kind of surgery. Sterilization takes away a person's ability to have babies.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

Jillian Weise is a cyborg. That means some parts of her body are made from metal and plastic. Jillian's leg is made of metal and plastic. Some people call Jillian disabled. Jillian calls herself disabled, but she likes being called a cyborg too.

Jillian likes to read a magazine called *The Economist*. *The Economist* talks about news. She learns new words from *The Economist*. But *The Economist* talks about the world in

a strange way. The Economist acts like everything is pretend. Like bad things that happen do not actually happen, or that they happen somewhere else and far away.

Jillian is a little worried about saying she is a cyborg. She is worried it just sounds like a sexy way to say, “please care about the disabled.” Jillian does not think she should have to ask people to care about disabled people. People should just care about other people because they are people.

There are movies and TV shows about cyborgs. In those movies and TV shows, cyborgs have super powers. Jillian does not have super powers.

Jillian does not want people to think cyborgs have super powers. But she also does not want people to pity her. She does not want people to pity people like her. She does not want people to pity cyborgs.

Non-disabled people think that some kinds of cyborg are better than others. For example, they want deaf people to wear hearing aids. They want deaf people to have surgery so deaf people can hear. Non-disabled people do not want to learn sign language.

Non-disabled people think that pacemakers or going to dialysis are not things cyborgs do. They think cyborgs can shoot lasers out of their fingers or fly.

Jillian thinks real cyborgs have pacemakers and go to dialysis. Jillian thinks real cyborgs use wheelchairs. Jillian thinks real cyborgs take medicine to be healthy. Real cyborgs are disabled people who use machines and computers to stay alive.

Jillian had an amputation. That means her regular leg was cut off. Her new cyborg leg is made out of plastic and metal. Her new leg is not fancy. She does not want a fancy leg. The one she has is fine. Jillian does not want a leg with a lot of machines and computers in it. She is a common cyborg, not a fancy cyborg.

Jillian has a hard time finding other cyborgs to talk to sometimes. There are some creepy men who think that it is sexy that Jillian had her regular leg cut off. These men are called “devotees.” She does not want to meet devotees.

Humans have always thought about what the future could be like. People who dream about what the future could be like are called futurists. Today, there are futurists living in Silicon Valley. Silicon Valley is in California. It is where computers come from.

More than a hundred years ago, futurists lived in Paris, France instead. The new futurists in Silicon Valley are a lot like the futurists that were in Paris.

Jillian does not like Tryborgs. Tryborgs are people who think they are cyborgs. They try to be cyborgs. But they are not cyborgs. They do not have bodies made out of metal and plastic. Machines do not help them breathe. They do not use wheelchairs to move around.

Things tryborgs care about:

- Big words
- Texting

Things a cyborg care about:

- Can I afford my leg?
- Will a stalker kill me?
- Will a doctor kill me?
- Will the government kill me?
- My leg isn't working. I need to get it fixed.

Tryborgs are silly. They want to feel good. They want to live forever.

People ask Jillian if she still feels like a cyborg when she takes her cyborg leg off. The answer is yes. She doesn't have reasons for it. She is proud of being a cyborg.

Donna Haraway is a writer. Donna Haraway thinks cyborgs are a metaphor. That means she thinks cyborgs do not really exist. Donna Haraway thinks cyborgs are just an idea.

Jillian does not agree. Cyborgs are disabled people who use machines and computers to stay alive.

Jillian tells a story about Gamergate:

In 2014, Gamergate happened. A man was dumped. He wrote ten thousand words about being dumped. His friends threatened his ex-girlfriend. Her name is Zoe Quinn.

Zoe Quinn makes video games. One game she made is called Depression Quest.

The man's friends talked to other men. They all decided to be horrible to Zoe Quinn. They decided to call it Gamergate.

The men sent Zoe Quinn naked pictures of herself. They put their sperm on the pictures. The men called Zoe Quinn on the phone. They said they would rape her. They said they would kill her. She was afraid to go home, because the men knew where she lived.

The men decided to be horrible to more women. They decided to be horrible to Anita Sarkeesian. Anita Sarkeesian makes YouTube videos.

The men decided to be horrible to Brianna Wu. Brianna Wu works on computers.

The men liked being horrible to women. But why were the men angry? Was it really about Zoe Quinn breaking up with her ex-boyfriend? Or were they angry because a woman made a video game? Depression is a disability. Were the men angry because Zoe Quinn's video game was about a disability?

Jillian tells another story:

In 2015, a black woman protested with Black Lives Matter. She started writing and making YouTube videos about black people being hurt and killed by police. Her name was Sandra Bland.

Sandra Bland was driving. She got pulled over by the police. One of the lights on her car wasn't working right. But the police arrested Sandra Bland and said she tried to fight with them. The police lied.

Sandra Bland was found dead in jail. The police say Sandra Bland killed herself. Some people think the police killed Sandra Bland and are lying about it.

Jillian tells stories about black and brown women because Donna Haraway wrote about how being a cyborg makes a person more powerful. Jillian thinks these stories show that Donna Haraway is wrong about what a cyborg is. The women in these stories were not powerful. But they were still cyborgs.

Jillian tells another story. It is about a book called *The Ship Who Sang*. The book is by Anne McCaffrey. It is about parents of disabled children. In the book, the parents make it so their children can't grow and get bigger or taller like other children. The parents put their children in metal boxes, and put their brain into a computer. Donna Haraway talks about *The Ship Who Sang*.

The Ship Who Sang is not a true story. But there are true stories that are like *The Ship Who Sang*. Jillian tells two of those stories:

A white disabled girl named “Ashley X” was sterilized. That means her parents made it so she couldn’t ever have a baby. They made it so she would not get bigger or taller like other children. They cut off Ashley X’s breasts. They thought it would make it easier to take care of Ashley X. They thought if she did not have breasts, caregivers would not want to rape her. Ashley X’s parents were horribly wrong. But her parents and doctors thought they did a good thing.

In 2013, a black girl named Jahi McMath went to the hospital. Jahi needed to have her tonsils taken out. Tonsils are a part of your throat. A lot of people have tonsils. Usually, getting tonsils taken out is no big deal.

But something went horribly wrong at the hospital. Two days later, Jahi was declared “brain dead.” That means Jahi was breathing and her heart was beating because of machines, but doctors said her brain was not working anymore. The doctors agreed Jahi was dead.

But her parents did not agree Jahi was dead. She was still breathing. Her heart was still beating with machines. Jahi’s parents moved her to New Jersey. In New Jersey, there is a rule that says religious people do not have to believe that brain death is a real kind of death.

The government in New Jersey was going to try to decide if Jahi was dead or alive. She died before that happened.

Ashley X and Jahi McMath were cyborgs too. They were not powerful. Jillian thinks Donna Haraway does not understand what a real cyborg is.

Jillian talks about selling cyborg parts on eBay. People with arms and legs made out of plastic and metal sell them on eBay sometimes. Sometimes, it is because the person has grown, and the arm or leg doesn’t fit right anymore. But there are a lot of other reasons. Sometimes people get new, better legs or arms than their old ones.

Cyborg arms and legs are very, very expensive. They can cost thousands of dollars.

Jillian talks about spending time with her daughter. She loves spending time with her daughter. They went swimming in the ocean. Jillian got a special leg for going in the water. She stayed in the water for three hours. It was very cold. But nothing could have made her get out. Not even a shark.

I'm Tired of Chasing a Cure

Liz Moore

Liz Moore is a disability rights activist and writer. Liz also writes romance stories about people with disabilities. She uses the pen name Ada Lowell. A pen name is a fake name a person uses instead of their real name.

Are you better yet? Get well soon. Race for a cure. Pray for a cure.

Able people believe disabled people should want a cure. They think we should get rid of our disabled bodies. They think we should become impossibly like them.

The social model of disability pushes back against that idea.

The social model of disability is a way of thinking about disability. It says that disability is not caused by our bodies or minds. Instead, the problem is that the world is not accessible to us.

Here is an example of the social model of disability:

Ricardo uses a wheelchair. There are steps in front of a store he wants to go to. He cannot go into the store.

In the social model of disability, the problem is not that Ricardo is in a wheelchair. The problem is that the store does not have a ramp.

A lot of people love the social model of disability. It makes them feel free. It helps them learn to love themselves and not blame themselves for being disabled.

Some people do not like the social model of disability. Some disabled people want a cure. A lot of people with chronic pain and chronic illness want a cure. "Chronic" means they are in pain or ill all the time. A cure feels freeing to them. A cure would mean that they are not in pain or ill anymore.

But thinking about cures can be dangerous. Thinking too much about cures can lead to Eugenics.

Eugenics says that white and non-disabled people are the best kind of people. Eugenics says everyone else is bad and should not exist. Eugenics says disabled people should not exist. Eugenics is bad and wrong.

A lot of Deaf and Autistic people do not want a cure. They think advocating for a cure means advocating for them to not exist.

Sometimes it comes down to how we see our individual disabilities. Are they a part of who we are? Or do they come with pain we want to get rid of? How do we feel when abled people advocate for cures? Cures could mean getting rid of disabled people. Is it different when disabled advocates want a cure?

In this story, I want to talk about how some disabled people want cures and some disabled people do not want cures. I want to talk about how hard it is to try to get cured. I have chronic pain. That means I am in pain most or all of the time. I would love to be cured. I do not want to be in pain at all. But I can't spend all my time trying to get cured. I would never have a life.

In this part of the story, I have been diagnosed with fibromyalgia for five years. I am very religious. I am neopagan and think crystal cures and Reiki might work. I am tired of doctors who do not listen and blame my fatness for my disability. I want to feel a control over my life again.

This is what neopaganism offers: the belief that I can control my own pain. If I try hard enough. If I have "good energy." If I use the right combination of crystals. If I don't eat bread or pasta.

I want a cure so much. I want my life to be like it was before I was disabled. I want to hike and camp. I want to take classes. I want reading to be easy again. I do not want to take my medications anymore.

My friends in this part of the story are very ableist. That means they hate disabled people. One of my friends saw my shower chair. She laughed at me. She called me an old lady. The leader of our group is a chiropractor. A chiropractor is someone who thinks you can cure disease and disability by moving someone's back and neck in certain ways.

The chiropractor told me that his patients do better when they don't think of themselves as having fibromyalgia. They should think that they have pain to beat, instead. At first, I think what he said is disgusting. But then, I think maybe I should not say I have fibromyalgia. If I say "fibromyalgia," maybe that will make my fibromyalgia worse?

If I don't say "fibromyalgia" maybe I will not have fibromyalgia.

My therapist doesn't help. He is supposed to know how to work with people with fibromyalgia and other kinds of chronic illness. But he doesn't seem to understand some important things. He did not understand that I do not have the same amount of energy every day. I can't always do everything I want to do. I get tired.

I tell my therapist that I want to volunteer, but I am too tired. People expect me to show up at the same time every week. I can't always do that. I can't do a lot of volunteering from home. I feel very bad for not volunteering. Helping other people has always been an important part of who I am.

My therapist does not care about my feelings. He does not give me advice on what to do. He is not helpful.

My therapist says, "Well, when was the last time you helped someone else?" He sounds mean.

I feel shame. There are so many things that keep me from volunteering. Why can't I beat those things? Am I not trying hard enough? Maybe if I try harder, disability will not be a problem.

Back to the pagans. I am at a healing drum circle. We take turns lying in the middle of the circle. People drum around us. We are white and off the beat. But we try our hardest. The sound from the drumming is supposed to give us healing energy. We are told to say what we want when we go into the circle.

I think I need to be OK with my disability. I need to stop fighting myself. I want people to be OK with who I am.

I am drumming next to the chiropractor. He turns to me. "Are you going to wish for a cure?"

Maybe I should wish for a cure? If I wish for a cure, maybe I will have one? I won't have one without wishing. What is the harm?

I spend many more years hating myself because I can't beat my disability. I think I did the wrong thing, but I don't know how to love myself.

In this part of the story, I am in remission. That means I am not sick or in pain. It is not something that happens. I am taking antibiotics for Lyme disease. I don't feel sick. I don't feel pain. I go to my doctor. She pushes on the parts of my body that are supposed to hurt the most. None of them hurt. We are both amazed. Am I cured? Did I have Lyme disease and not fibromyalgia this whole time?

I go hiking. I take a video of the hike so I can remember what it feels like to be out here, walking, without pain. It is some kind of miracle, I think. I am afraid to hope. The antibiotics run out. I feel sick again. I feel pain again. If it was Lyme, wouldn't it be cured?

There is a big argument about Lyme disease. Some people believe that you can have chronic Lyme disease. People with chronic Lyme disease need antibiotics for longer; other people think chronic Lyme disease is made up.

I am not here to argue about if chronic Lyme disease exists. I believe that it does for some people. I support them. They are just trying to feel less sick.

I think I have chronic Lyme disease. I feel sick again. The pain is back. It is worse than it was before, because I know what remission feels like. I had started to forget what pain felt like.

I take more antibiotics. My doctor says I should not take more antibiotics. I found a different doctor. That doctor is an expert in Lyme disease. He gives me the antibiotics. He also tells me to take some expensive vitamins. I need to eat a special diet. I feel sicker. I feel more pain. Shouldn't I be getting better?

In this part of the story, I am in the hospital for bipolar depression. Bipolar depression is another chronic illness I have. I am off the chronic Lyme treatment. I get an infection of C. difficile. C. difficile is a kind of germ. It lives in everyone's bodies. When people take antibiotics for a long time, they can get too much C. difficile. That can make them very sick. It can even make people die.

I got very sick. I take medication for C. difficile. The medication makes my mouth taste like iron. I feel like I want to throw up. I get better. But then that winter I got C. difficile again. None of the medications worked. I could have died. I got something called a fecal transplant. It has only been tried a few times. It worked. I did not die.

I stopped trying to cure my chronic Lyme disease. I stopped taking antibiotics. I'm worried that if I keep trying, it will kill me.

I still want to feel like I did on that hike in the woods. But maybe that is impossible? I am afraid to hope. I am very sad.

I have come a long way since I chased every cure. I am a part of the disability community. I know things about disability. But on my birthday, I wake up and my head hurts so much. It does not go away. I had a headache for months.

I ask a lot of doctors why my head hurts. First I go to the emergency room. Then I go to my normal doctor. Then I go see special doctors that live near me. Eventually, I go to see special doctors in other states. No one knows what is causing my headache.

I am afraid that my head will hurt forever. My friend has had a headache since she was thirteen years old. Maybe this is my normal now. I remember when I knew the pain had become chronic. That I couldn't think normally because I had to think about ignoring pain. I couldn't read. I couldn't cook. I could barely dress myself. Everything hurt so much. Was this how my life was going to be? I cried. It hurt. I couldn't stop crying.

I have so many tests. Doctors scan me. They stick needles in my arms and legs. I will do anything to find out what is making my head hurt.

I now know I have a connective tissue disorder. A connective tissue disorder is a kind of disease that affects how muscles and bones fit together.

I read about mystery headaches and connective tissue disorders. There are only a few doctors who treat this near where I live. Some of them do not take any insurance. That means they will cost a lot of money.

Before I can see the most expensive doctors, my headache stops. I went to see a physical therapist. The therapist moves my neck and head so that the headache stops.

I cry. There is something I can do, if my head hurts again. My head does not need to hurt all the time. It is sort of like a cure.

But at what cost? I mean, don't get me wrong: I would have given almost anything to get rid of that pain. But I have spent my year using a heating pad and getting tests. I have lived. Living is a big deal.

I still have so many things "wrong" with my body. I am tired of doctors. I am tired of tests.

Maybe none of this makes sense. Or maybe it only makes sense if you live through it. If you live through the hope. If you live through all of the tests. If you live through hating yourself because your body won't do what you want. That your body won't get better

There is a cost to going after miracle cures. It is a high cost.

People ask me, "Have you tried yoga? Kombucha? This special water?" I don't have the energy to say yes. I've tried them. I've tried crystals. I've tried healing drum circles. I've tried prayer. I've tried everything.

I want to try being OK with myself. I want to see what happens if I can just be OK with who I am now. Even if who I am now hurts. I will still take a cure if someone gives it to me. but I am so tired of trying to get a cure. It costs too much to keep going after cures. I am missing living my life. If I spend all of my time trying to be the person I used to be, I will miss the person I have become.

We Can't Go Back

Ricardo T. Thornton Sr.

Ricardo T. Thornton Sr. is a strong self-advocate. He lives in Washington DC. He used to live in Forest Haven. Forest Haven was an institution.

Ricardo is co-president of Project ACTION!. Project ACTION! is an advocacy group of adults with disabilities. He is an ambassador with the Special Olympics. Ricardo served on the President's Committee for People with Intellectual Disabilities.

He has worked for more than forty years at the Martin Luther King Jr. Memorial Library. He is married to Donna. Donna was also in Forest Haven. They have one son and three grandchildren.

This story is from a speech Ricardo gave to the US Senate on June 21, 2012.

Note: This story talks about institutions and harm that happens in institutions.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

My name is Ricardo Thornton. I am here representing the ninety-two thousand people who are still living in institutions and large public and private facilities for people with intellectual disabilities—and for all of the people, like me, who used to live in an institution. With me today is my wife, Donna, and my son, Ricky.

I lived in institutions all of my childhood. I was first a resident of D.C. Village and then in 1966 I went to Forest Haven, D.C.'s institution for people with intellectual disabilities. My wife, brother, and sister also lived at Forest Haven.

For many years, no one told me that I had a brother and sister. We weren't told that we were related. In the institution, I didn't get to think for myself. The staff thought for me and made all of my decisions. For a long time, no one expected anything of me. I got to know some good staff and some really bad staff.

I witnessed abuse, especially of people with severe disabilities. My sister died in Forest Haven. She is buried at Forest Haven, and I still go back to visit her grave. I promised to advocate on her behalf and on behalf of others who cannot speak for themselves.

I left Forest Haven in 1980 when I was in my early twenties. That was a great day! I was in the first group to go out.

I lived in a few different group homes. Living in the community was a big adjustment.

Some people looked at us differently. The community didn't want us there. There was trash in the alley. The neighbors thought we put it there until they saw that we were cleaning it up.

At first, in the group homes, people treated us in some of the same ways as when we were in the institution. I wanted my own bank account. But the staff didn't want me to manage my own money, so I got in trouble.

While I was living in a group home I started to date Donna—and then she proposed to me. People didn't think we should get married. But a few people encouraged and believed in us. So we got married and invited everyone we knew to the wedding.

Later, we had a beautiful baby boy, our son, Ricky, two pounds eleven ounces. We are very proud of Ricky. Ricky has graduated from high school. He took a few college classes. He is now working part-time. He is married and the father of three children. We were written up in The Washington Post and got to be on 60 Minutes.

When I lived in the institution, no one would have believed that I could have the life I have today:

- Married with a son and grandchildren
- A good job for thirty-five years
- A driver's license and car
- Opportunities to speak on behalf of Special Olympics International, Project ACTION!, and other advocacy organizations.
- I have gone to places like Johannesburg and Alaska and across the country.

It's important to have people believe in you and to expect that you're going to succeed. People need to have high expectations for people with disabilities because then they'll give them opportunities to learn and grow. People don't grow in places like Forest Haven and in other institutions.

I have been working at the Martin Luther King Jr. Memorial Library for thirty-five years. I am an employee of the D.C. government. I started as a volunteer, then as a part-time worker, and then full-time.

My wife, Donna, worked for more than twenty-one years at Walter Reed Medical Center. She is now at the Army Medical Center in Bethesda.

My brother William works at Catholic University.

All of us pay taxes. All of us make a difference in our jobs and in our communities. Donna and I serve on many boards and committees to make things better for people with disabilities, and we are very active in our church.

I couldn't always advocate and do what I can do now. I had people who believed in me and who supported me—friends and providers.

I've seen people with severe disabilities who have grown and done great things given the right support. For many people, support comes through Medicaid, which helps people live in the community and get services such as personal care, transportation, and help learning to do things like plan and manage their household.

I hear people say that some people are too disabled to live in the community, but I've seen people just like the people still in institutions who do so much better in the community—because no one expects you to do anything in the institution but survive.

I love Special Olympics because they encourage us to focus on our abilities and to show off our abilities, not our disabilities.

Some of the best support Donna and I have received has been from friends. When you live in the community, you make friends and they support you in your advocacy and in raising your son when you have questions and when you have to make major decisions in your life.

When you live in the community, you don't have to depend on staff for all of your support, and you get to support others as well. You develop networks that you could never have in the institution. I've seen this happen for so many people, including people with severe disabilities.

When I was in Forest Haven, I had a chance to go to the cottage that had the people with the most severe disabilities, who mostly stayed in bed all day. Someone at Forest Haven got a grant so that we went in, gave people musical instruments, and played music while they played along.

The people with severe disabilities loved it and never wanted to go back to their beds. When the grant ended, that program ended. If they had lived in the community, their music would not have stopped and wouldn't have depended on a grant.

When I left Forest Haven, I was asked to be on the mayor's committee on people with disabilities that was set up to close it. It was a great day when the last person left Forest Haven in 1991. What I've seen is that when people are given a chance to grow and contribute, they grow and contribute.

We ask that you ensure that people continue to be given chances to have good lives and to grow in their communities with support. I believe that people can do anything if they're given the opportunity and support. We can't go back. We can't go back to a time when people are moved against their will to places where they have no opportunities to learn, grow, and contribute.

We need to keep moving forward. People invested in me and my wife and brother. When we were in the institution, we didn't have a voice. We were thought to be incompetent, so no one took the time to teach us things.

But people can accomplish great things with support. Having an intellectual disability doesn't limit what you can contribute. Being put in institutions limits what people can do and guarantees that people will be dependent for the rest of their lives.

Anyone can become disabled at any time. We are people just like everyone else.

The time needs to be over for people to be sent to institutions because there aren't options in the community or because people think it's cheaper or more protected. It wastes people's lives and, in the long run, keeps them from contributing.

There's no such thing as a good institution. Segregating people is always bad. People never grow in those places and are safer and happier in the community.

I'm one of many people who could be here today. People sometimes say that I'm not like some of the other people with intellectual disabilities. The only thing that's special about me is that people believed in me and in my potential to learn in spite of my disability, and they took the time to help me learn.

Please protect people from places where no one expects anything from them and where they're just kept alive. We can't go back. It's time to move forward.

Thank you for the opportunity to testify today and for your continued support of people with disabilities.

Radical Visibility: A Disabled Queer Clothing Reform Movement Manifesto

Sky Cubacub

Sky Cubacub is a nonbinary queer and disabled Filipinx artist from Chicago, Illinois. Sky created Rebirth Garments. You will learn more about Rebirth Garments in Sky's story. Sky is an artist and was named 2018 Chicagoan of the Year by the Chicago Tribune.

"The visibility which makes us most vulnerable is that which also is the source of our greatest strength."

—Audre Lorde

The world doesn't encourage trans and disabled people to dress stylishly or loudly. Society wants us to "blend in" and not draw attention to ourselves. But what if we pushed back against a world that is trying to make us invisible? What if, through changing clothes, we could say "no" to blending in?

Disabled and trans people need specific clothing. Mainstream clothing designers do not pay attention to those needs.

A few designers make clothing for disabled people. Other designers make clothing for trans and queer people. But designers only seem to care about how the clothes work. They do not seem to care about how clothes look.

A lot of clothes are for disabled people and queer people at the same time. Binders are a good example. Binders are used to make people's chests flatter. A lot of trans men and non-binary people wear binders.

Binders used to only come in three colors:

- White
- Black
- Nude "Nude" is really pinkish. Regular Band-Aids are "nude." It is silly to call the color "nude" because not everyone has pinkish skin.

These binders looked medical. For a long time, doctors thought that trans people were sick. The doctors were wrong. Trans people are not sick. They are just trans.

In 2013, the American Psychiatric Association took “gender identity disorder” out of the book it uses to diagnose mental health problems. That book is called the DSM. Feeling like your gender is different doesn't mean you are sick.

It is good that the American Psychiatric Association changed the DSM, but the new DSM still has problems. The new DSM uses “gender dysphoria” instead of “gender identity disorder.”

“Gender dysphoria” is when people feel very upset, because their bodies don’t match the gender they feel inside. Not all trans people feel gender dysphoria. So the American Psychiatric Association still needs to make their book better. They are still acting like some trans people are sick. That is not OK.

The world is getting better for trans people, but binders still look medical. Designers think people only wear binders under a lot of clothes, so nobody sees the binder. Binders don’t usually look pretty or fun.

Most clothing made for disabled people is for older people. An example is Buck & Buck. Buck & Buck clothes are not good for people who move around independently. Buck & Buck clothes look like hospital clothes.

Disabled people need clothes we can move in. We play sports. We go swimming. We dance. Older disabled people also need clothes they can move in. The world thinks that older people and disabled people can’t do anything. They are wrong.

Some designers make clothes for disabled children and teenagers. But those clothes are just smaller versions of senior clothing. They also look like hospital clothes.

No one likes wearing hospital clothes. Even if you are sick, wearing clothes that make you look sicker feels bad. It makes you feel like you are not a person.

I like IZ Adaptive clothes. Their clothes do not look like hospital clothes. IZ Adaptive makes business clothing for wheelchair users. But business clothes are for being in an office. We need clothes that are for everywhere else. Disabled people need clothes that celebrate us, and show how much the world should love us.

When I was twenty-one years old, my stomach stopped working the way it is supposed to. I couldn’t wear some pants, like jeans. It hurt too much. I could not eat. My anxiety

got very bad. I took time off from the School of the Art Institute of Chicago. I decided to become a different person.

On May 21, 2013, I held a performance art ceremony. I called it a Rebirthing Ceremony.

When I went back to school, I kept thinking about what clothing I could wear. I wanted to wear clothes that made my body feel good. In the past, I had made a scarf for my cousin Sophie. The scarf was made out of the same material towels are made of. Sophie had a disability that made wearing some clothing hard. But she could wear the scarf I made for her.

My aunt Jody is Sophie's mom. Aunt Jody suggested I make a clothing line for disabled kids. But I didn't want to only make clothes for kids. I wanted to make clothing for everyone.

I also wanted to make underwear to help trans and queer people feel good about our bodies. I have wanted to do it since high school. In high school, I started thinking about what I wanted my gender to be. I wanted a binder. I wanted packing underwear. But I was a teenager and did not have my own money. I could not buy a binder or packing underwear.

In 2014, I took a class at the School of the Art Institute of Chicago about how to make underwear. I started making underwear for my friends and me. I decided that instead of making clothes for disabled people or clothes for trans and queer people, I would make clothes for people who are disabled, queer, and trans at the same time. I wanted the clothes to fit everyone -- People with big bodies. People with small bodies. All kinds of different bodies.

I started my own clothing company. It was called Rebirth Garments. The clothes were made for each person as an individual. So everyone had special clothes made just for them. The clothes celebrate every part of the people who wear them.

Feeling good about how you look can make you feel happier. It can also help you feel good about advocating for what you need.

The clothes I make are about accessibility. It is important for me to let people who have less money pay less for my clothes. Many people can't afford to have clothes made just for them.

I don't have any sizes on my website. My customers send me measurements of how big or small different parts of their bodies are. That way, all of the clothes fit perfectly.

Most of my customers are disabled people, trans people, and fat people. Many of my customers need a binder but can't wear most other binders because of their disabilities.

For example, some of my customers have Ehlers-Danlos syndrome. Ehler-Danlos syndrome is a disability that can make people's ribs move in ways that hurt. So they need binders that are looser than normal.

For people with sensory sensitivities, I make clothes with the seams on the outside. Seams are the part of clothes where different pieces of cloth are sewn together. A lot of people find inner seams itchy because they stick out into their skin. I find inner seams itchy. If the seam is on the outside, it won't stick out into anybody's skin.

Pockets to hold pacers or insulin pumps can be added as needed. Everything is made from stretch fabrics. That means clothes can slip on easily. If someone gains or loses weight, the clothes will still fit. And people can move around a lot in my clothes.

I also make Rebirth Garments look different and special for every customer to meet the custom aesthetic needs of my clients. Rebirth underwear can be worn on the outside of your clothes, if you want. The patterns are colorful and fun. They can make people feel sexy and cute.

Society tells trans people and people with disabilities that it is better if no one sees us. But we are not sorry that we are different. We want to celebrate our bodies and who we are.

People can use clothes to say things about the world and about themselves.

My clothes say that everyone is beautiful. My clothes say that fat people and disabled people are beautiful. My clothes say that people with different genders are beautiful. My clothes say that trans people are beautiful.

Clothing is a way to tell people about yourself. it changes the way you feel. I think clothes are like armor, because they make me feel strong and good about myself.

Of course, my clothes can't make the world better for everyone. We need a whole style of clothes to make the world better. I want to call this style "Radical Visibility." "Radical" means advocating to change the world. "Visibility" means being seen by other people. It is important to be seen by other people. It helps people become more free and equal to each other.

Here is an example of how changing clothes can change the world:

In the 19th century, women were not allowed to vote. The 19th century was a long time ago. Some women wanted to change the rules so they could vote. Those women were called “suffragettes.”

Suffragettes helped change the world by changing how they dress. They called it the Women’s Dress Reform Movement, or rational dress for short.

Rational dress got rid of corsets. A lot of women used to wear corsets. Corsets are a kind of tight vest. Corsets squeeze your waist so it is smaller looking. This is a body shape men used to like. But corsets hurt the women who wore them. Clothing should not hurt. Women should not hurt themselves to look good for men. So the suffragettes stopped wearing corsets.

Rational dress clothes let women move around more. This told the world that women could run and jump just as well as men.

Rational dress clothes were easier to clean. Women should not have to spend all of their time cleaning. They had more important things to do, like thinking and voting.

Women could take rational clothes on and off without help. Before, they used to need help getting dressed from servants. Only rich women even had servants.

I want Radical Visibility to be like the rational dress Suffragettes wore. I want my clothes to change what people feel like they can do.

People should not be ignored. We should not have to look like everyone else. There isn’t a right way for all men to look or a right way for all women to look. There isn’t a right way for all non-binary people to look. With Radical Visibility, it is OK to be fat.

Sometimes queer communities are not as inclusive as they should be. In the summer of 2014, Gus Allis gave a talk at the Fed Up Fest. Fed Up Fest is a punk festival in Chicago. Gus Allis talked about how queer communities can be horrible to fat people. In the stories some queer communities tell, all of the bad people are fat! The bankers are fat. The landlords are fat. The rich people are fat. That is wrong. There is nothing bad about being fat.

Gus Allis is fat. She also has an eating disorder. That means it is hard for her to eat enough food. Sometimes, she makes herself throw up on purpose. Being told that fat is bad and ugly hurt her.

Gus Allis wrote a short book called “The Barf Zine.” In The Barf Zine, she talks about when her eating disorder started. She was 21 and at a punk protest at DePaul University. The next week, she made herself throw up on purpose for the first time. People at the protest made her feel bad about being fat.

People don’t think fat women with eating disorders exist. But that is not true. The world says fat women are not beautiful and not sexy. But everyone can be sexy. We have to make our own sexiness. We have to make up what beauty means for ourselves. We have to make our own rules about what is sexy.

Chrysalis is a company that makes underwear for trans women. They make two kinds of clothes:

- A bra to make breasts look bigger.
- Underwear to make tucking easier.

Chrysalis was the first underwear company for trans women, by a trans woman. But they did not make a lot of sizes. A lot of women wanted to wear Chrysalis underwear, but the underwear was too small. It was not fair.

When I first started Rebirth Garments, none of the people at my school thought that disabled people could be sexual, let alone queer. There were not a lot of people who looked disabled at my school. The school was very expensive. People at my school were taught to ignore their own needs.

At the time, all the big trans underwear companies made clothes that assumed trans people would want to have surgeries. They pretended there were only two ways for people to be transgender. That is not how gender works. Not everyone can get surgery. Not everyone wants surgery. Not everyone looks exactly the same.

Rebirth Garments celebrates all kinds of genders. Rebirth makes a community where people can be whatever gender they want to be. People can express themselves however they want.

Radically Visible Fashion

Here are some things I think about when I design clothes for Rebirth Garments and Radical Visibility. Feel free to add your own!

1. Using fantastically bright colors!
2. Use big and exciting shapes. I especially like triangles!

3. Clothing that shows our bodies instead of hiding them.
4. If you do wear or want to wear a prosthetic arm or leg, wear one that is not realistic looking. Pop star Victoria Modesta has a peg leg that looks like a spike, instead of a regular leg.

Radically Visible Sound

I host fashion shows with local models. The models have all different kinds of bodies. Some use wheelchairs. Some walk. Some are black. Some are white. Some are fat. Some are thin. Everyone dances in special clothes made just for them. Dancing shows how the clothes help them move and show off their true selves.

At the end of the show, we invite the audience to come dance with us. This does not usually happen at fashion shows. It makes the show into a party. It makes the show inclusive.

In November 2017, I gave a performance, speech, and class at the Whitney Museum of American Art. I usually give audio descriptions of the clothes after the show. Audio descriptions are a way to explain to blind people what art looks like, so they can enjoy it too. But this time, I did not have a lot of time. So I could only describe some of the clothes.

Afterward, a member of the audience came up to me. They said I should give the descriptions during the show instead of after. I hadn't figured out a solution that would be confusing and hard to listen to with music. Often in audio-described shows, an offstage speaker says what is happening and what people are doing. It is separate from the show.

I began to think about other possibilities.

Queer pop star Jake Vogds asked me earlier that year if they could write some music about my Radical Visibility manifesto. My radical Visibility manifesto is a bigger version of this story. I wrote it in April 2015.

After the show at the Whitney museum, I suggested that we write songs with audio-descriptive lyrics. I always interview my models in order to create their dream accessible clothes. But this time I also asked them to tell us about their dance moves and how they wanted to be talked about. It was important to me that the models get to choose how they are described. Audio describers tend to guess what gender people without asking. They also do not say if someone is black or brown.

Vogds worked with local Chicago queer song makers. He wrote five songs. The songs took quotes and inspiration from my manifesto and from the interviews I'd done with models. Vogds sang on four of the songs. The album's lyrics described clothes that me, Vogds, and our friend Compton Q made together.

We debuted the fashion show with music at the Chicago History Museum and the Evanston Art Center. We played the songs during our fashion show. In these shows, the audio descriptions were part of the music, instead of being separate. This is an example of what accessible art and design should be. It is more than a checklist of ADA rules. It truly celebrates access.

Guide Dogs Don't Lead Blind People. We Wander as One.

Haben Girma

Haben Girma is the first Deafblind person to graduate from Harvard Law School. President Obama named her a White House Champion of Change. She received the Helen Keller Achievement Award and a spot on the Forbes “30 Under 30” list. President Bill Clinton, Prime Minister Justin Trudeau, and Chancellor Angela Merkel have all honored Haben.

My guide dog crossed the street, then stopped. “Mylo, forward.” My left hand held the leather harness that wrapped around his shoulders. “Forward,” I said again. The harness moved, and I knew Mylo was looking back at me. There was something in our way that I did not see or hear.

Cars shook the street on our left. The road we’d just crossed was behind us. I made the decision: “Mylo, right.” He turned and headed down the sidewalk. I told him to move around whatever was in our way.

My dog never knows where I’m going. He thinks about it, of course. *You went to this café yesterday, so clearly you’re going there again, right?* Or he’ll go to an open door. *Seriously, Haben, we need to step in here for a sniff.*

People assume guide dogs lead blind people, and once upon a time, I thought so, too. My senior year of high school, I was worried about going to college as a Deafblind student. Perhaps I would get a guide dog to help me go places. A dog would make me feel brave. I needed to feel brave?

“You want a dog to feel brave?” a blind friend texted me.

“It sounds funny when you put it that way,” I typed.

“If a blind person doesn’t feel brave, then the dog and person both end up lost. Don’t depend on a dog to feel brave. Make yourself feel brave.”

So instead of training with a service animal at guide dog school, I spent my summer before college working on my blindness skills at the Louisiana Center for the Blind. I learned how to cross streets with a white cane. I learned how to bake a banana cream pie. I learned how to use electric saws.

I tapped my way through college with confidence. My bravery didn't come from the cane but from my hard work. How could I have thought that would be different with a dog? Still, brave as I was, something felt missing from my life. I wanted a travel partner whose eyes and ears would share more of my world.

Maxine the Seeing Eye dog joined me for my last year at Lewis & Clark College and for all three at Harvard Law. We moved around so much more easily than when I traveled with a cane—imagine switching from a bicycle to a fancy car. I learned to read her body language. Her big brown eyes and pointy ears opened new experiences for me. Having a big scary-looking dog even kept me safer from sexual harassment.

Me and Maxine were together for nine years. In 2018, Maxine died of cancer. I missed her so much. Her death still makes me feel sad. I also knew I could not, would not, go back to life with only a cane. I was without my guide dog of nearly ten years, but I was not lost.

The school that trained Maxine matched me with another dog. That summer, I joined Mylo for three weeks at the school's campus in New Jersey. We tripped over curbs and crashed into chairs, but with a lot of work, our teamwork got better.

Now we move together perfectly. In the year we've spent together, we've traveled to twelve states and four countries. One morning during a trip to Park City, Utah, for a friend's wedding, I woke to Mylo jumping onto my hotel bed. He was ready to start the day. After a few strokes of his puppy-soft ears and some tugging of his toy whale, we left our room.

Mylo went right to the elevator. I read the braille labels and pressed the button for the main level. The doors opened. I told Mylo to go across the lobby and toward the front doors. "Right." He turned down a hallway. "Right." He turned into a room that felt empty. "Sorry, not this one. Mylo, left." I gestured for him to go back to the hall. "Right." He turned into the next room.

I could smell good food and coffee from the far wall. "Here it is! Forward." After I ordered my hard-earned breakfast, another wedding guest approached us.

“Haben, hi! It’s Michael. Who brought you here?” I told him Mylo did. But really, I did. It makes me tired that people think I don’t go where I want to go. For now I know it—and so does Mylo. He goes where I want to go.

Taking Charge of My Story as a Cancer Patient at the Hospital Where I Work

Diana Cejas

Diana Cejas is a pediatric neurologist in Durham, North Carolina. She is working on a collection of essays that describe her life as both physician and patient.

She was in a car accident when she was nineteen. It changed her whole life. That's the beginning of the bedtime story that my nurse told me three nights after the stroke. I'm a hard stick, so she had plenty of time to tell the tale.

As my nurse searched my arms for veins that would take the needle, she told me her story. She was young and wild and carefree, right up until she got hit by a car.

I imagined that my nurse must have looked like me in my own hospital bed afterward: covered in wires and full of fear and feeling very small.

"I was a mess," she said. "Before. That accident was a blessing."

She pressed on my arm and counted to ten. "Maybe this is, too." She looked at me like she could see into my future. I looked at her and I drooled. I coughed. I tried to call her a liar. My tongue didn't work right and my brain didn't work right, so I couldn't say the words. She mixed my medications in applesauce. I imagined what I must look like: lifeless arm and hurt throat and destroyed mouth.

I was released from the hospital eight days after my second surgery, six days after my stroke, and started trying to get better.

I was tired all the time and watched daytime television. I played with putty and ate mushed up fruit. Every other day, I went to a different kind of therapy, or a different kind of follow-up appointment to see a different kind of doctor.

I spent so much time in waiting rooms. I lost track of time. All of the waiting rooms looked the same. They all had old magazines, a broken clock, and a TV playing hospital ads over and over again. It was confusing.

The people in the waiting rooms were all the same, too. We were quiet. We looked at our phones. Most of us did not want to talk to other people. But there was always, always one person talking loudly. Sometimes, that person was a woman complaining

loudly about her husband or children on the phone. Sometimes, that person was a man who would loudly talk about the news to other people in the room who were not interested.

Sometimes, people talked about trying to live during cancer treatment. People wore bandages. They talked about vitamins and support groups. They talked about getting sick and getting better. I listened and learned a lot from those people.

Working in a hospital is not like it is on TV. In real life, working in a hospital is boring. When patients do not need anything and nothing is happening, the hospital gets boring fast. To make the hospital less boring, doctors and nurses talk. They talk about patients, their jobs, and each other. Stories spread fast.

When I got back to work, I realized everyone at work knew I had cancer. I was a resident. A resident is a doctor in training. My program was small. It was the same hospital where I had been a patient.

Before I had cancer, I was working sixty to ninety hours every week. I spent all day working in the hospital and all day reading books about how to be a doctor. Then I got sick and things changed all of a sudden.

I had a stroke. I also had an unusual cancer. You are more likely to win the lottery than to get the kind of cancer I had. I was very unlucky.

Other doctors thought I was an interesting patient, because I had an unusual cancer, and because I was a doctor myself. It made me feel like I was famous, but not in a good way.

All of the nurses were always talking about me. Doctors wrote about my cancer in books, and talked about my cancer at conferences. I would try to say hello to them, but they already knew who I was. Or worse, I had said hello before, but forgot.

There are a lot of things I will never remember because I had a stroke. One doctor told me, "I'd be surprised if you remembered me." We were in the cafeteria. I was trying to decide between mashed potatoes and pudding for lunch. Mashed potatoes and pudding are safe to swallow, but joyless.

"You were kind of a mess," the doctor said. He decided to have chicken for lunch. I got jealous.

"You were so out of it. You tried to kick me out of the room. Do you remember? That's when we called the code." I shook my head. A code is what doctors call an emergency

patients could die from. I forced a smile. I wiped spit from the corner of my mouth. He kept talking about me. I didn't say anything.

The people I work with were not good at comforting me. They always seemed to say the worst thing they could say, at the worst time they could say it. You would think doctors and nurses might be different. Doctors and nurses should know better. But doctors and nurses are still people.

I had to tell the other doctors and nurses that I was sick. The hours I work were planned up to a year in advance. There are patients to see. Not being at work can mess up the other doctors' plans. I emailed the doctors and nurses. I told them I have cancer. I told them I needed to have surgery. I said "sorry" for messing up the other doctors' plans.

I went back to work weeks after the cancer was over. The other doctors hugged me. They asked me about my cancer. At first that was OK. They are doctors. Doctors want to know about bodies. But I did not want to talk about it. Hugs wouldn't fix the hole in my brain from surgery.

Some people told me, "everything happens for a reason." But there isn't a good reason for cancer.

One of the other doctors got me a cake. He wanted to celebrate that I was back at work. I didn't feel like celebrating. I didn't have cancer anymore, but I still felt sick. It was a nice thing for him to do. But it made me a little angry. I felt broken. Why would I celebrate feeling sick and broken?

I mashed up some cake and ate it. I wanted to hide, but I couldn't. My bosses said I looked good. They said I was taking everything very well. They asked me how I felt. I lied and said that I was fine.

Another doctor was standing near me. After everyone else left, she whispered to me. "It's awful right? I know they're trying to help, but sometimes you just want to be left alone. When I..."

She paused. She had been sick a few months before. Everyone was talking about her too. "I just wish everyone had let me talk about things when I felt like it."

It takes years to become a doctor. Some people feel like God calls them to be doctors. It is still very hard for everyone. We have to study sickness all the time. We learn how

bodies work. We spend the rest of our lives learning. But none of that mattered when I found out I had cancer. Medical schools teach doctors how to be doctors. They do not teach us how to be patients.

At first, I was not good at being a patient.

I only learned one thing as a doctor that I used as a patient. I knew how to work, when I was tired all the time.

Being a new doctor is hard. You can't sit, eat, or pee for hours. You go days without sleeping. You get used to it. When I was a new doctor, I took naps. I drank a lot of coffee. I called my sister and told her about the night and the nurses. I told her about the good things and the bad things at work. Telling stories made me feel better. It also helped me stay awake enough to drive my car home. I used the same skills as a patient.

You can get used to anything if it happens for long enough. I got used to my sick body. My cancer did not get worse. I got better.

I started working again. I did one of the hardest jobs at the hospital -- taking care of sick babies. It was hard, but I knew what I was supposed to do. I knew who I was at work.

But sometimes, my body would remind me I was still getting better. I was slower than all of the other doctors. I limped. I tried to hide it, but I couldn't. I drooled when I talked about a patient to the other doctors. I drank a lot of energy drinks and tea.

I gave speeches and lessons to students and newer doctors. In the afternoon, I would sit and talk with them. They would notice that my smile droops on one side. Or they would remember the rumor they heard about my cancer. They wanted to know. So I told them. I became OK with my body. I stopped hiding my scar. I stopped saying bad things about myself.

But I was still worried about how other people saw me. They had seen me when I was sickest. They had seen me when I had tubes in my throat. They had seen me when I was tied down, so that I would not pull the tubes out by mistake. I tried not to think about that.

I told stories about how well I was doing. I did not tell the other doctors about the parts when I felt angry, sad, and alone. But I wanted to tell the whole story, even the worst part. I wanted someone to really know how I felt. I wanted someone to comfort me.

One afternoon I was talking about therapy and didn't notice my boss had come into the room. I was still going to be at work for a long time. I hoped that telling stories would make the time pass faster.

"How are you with movies?" My boss said. I stopped talking and looked at him. I was confused.

"I had a hard time watching movies," my boss said. "After my stroke. They never made me cry before."

My boss told a story about when he was a young man. He told me when he had a stroke, like I did. He told me about how he had to stop and start again. He was a doctor, then he was a patient, then he was a doctor again. It was his story, but it was the same as my story.

I did not know there were any doctors like me. But then my boss told his story. I knew I wasn't alone.

"It's not movies," I said. "It's commercials."

My boss smiled at me.

People tell me their stories. It's always been that way. Another doctor noticed once. "It must be your face," she said. "You look like you listen to me." I learned how to listen in medical school. When you talk to a patient, all you're doing is asking the patient to tell you a story. The patients just want you to listen to them. Isn't that what everyone wants? We want to be seen. We want to be heard. We want to be understood.

I moved on to a new job at a new hospital. I thought I could leave bad memories behind. But I couldn't. I worried other people would see me and think of when I was sick. So I told them. I told doctors at my new job that I had been sick. I told my story how I wanted to tell it.

"I had a stroke," I said. "I had cancer," I said.

The responses were usually the same: Awkward and quiet. Sometimes people said "sorry" to me.

If I told more of my story, something else would happen.

"I get so tired now," I said.

“My mother was so tired when she had cancer,” another doctor told me.

“I used to be ashamed of my scar,” I said.

“So did I,” a nurse told me. The nurse showed me her scar. I showed the nurse my scar.

We all told each other stories. Some stories were about getting sick. Some stories were about getting hurt. Some stories were about people dying. Some stories were about love. After, we’d sit quietly. We didn’t have to explain how we felt.

A woman in a doctor’s coat said hello to me. She told me she might faint. I was confused. I am always confused. I was sitting on the floor, waiting for a workshop to start. She was a new doctor. Her coat was brand new. She was also sweating. It was very hot. The air conditioning was always broken.

“Hot in here,” I said.

“I had a condition,” she said.

“Oh yeah? Me too.” I gave her my best crooked smile.

“A brain tumor,” she said, and she frowned. She looked young, scared, and small.

“I had a stroke,” I said, “but cancer came first.”

I turned my head to show off my scar.

She brightened and showed me her own scar.

I told her my story. She told me hers. I sat back. I listened. I understood.

Canfei to Canji The Freedom of Being Loud

Sandy Ho

Sandy Ho is an activist, and disability policy researcher. She is the founder of the Disability & Intersectionality Summit. She is also part of Access Is Love, a campaign with Alice Wong and Mia Mingus.

When my nephew was born, my family crowded around. We took turns holding him. He was born a little early, but once he was well enough, we couldn't wait to hold him. But my mother did not reach out. She looked at me instead of him, and said, "I'm scared to hold him because of you."

The rest of my family did not notice. They were all looking at the new baby. He had his first birthday recently. It never seemed like there was a good time to talk about what my mother said. I was born disabled. People say bad things about disability to me a lot. When people say bad things about disability, they expect me to be quiet.

But I can't be quiet anymore. I am a disabled Asian American woman. My life is not quiet.

When I was a kid, my mother often told a story about a disabled man in her neighborhood. She was born in Hanoi, Vietnam in 1960.

"He couldn't walk and would drag himself from door to door, begging. I was so afraid [that] I'd cross to the other side of the street to avoid him," my mother would say.

But her childhood memory became a warning.

"When you were born, at first I was afraid of you. But then with the support services available here, I learned to take care of you. You should be grateful you were born in the United States."

But what if I hadn't been born in the U.S.? What if I'd been born in any East Asian country? I wondered as a child. I never asked. Maybe I wanted to protect myself—or my parents—from knowing the answer.

Now I know that I shouldn't have to be quiet when people say bad things about disability. But I am still quiet. I don't want to know how little value my life might hold for others.

In China, a man named Deng Pufang pushed for the equality of disabled people. It was 1968. 1968 was the peak of the Cultural Revolution. The Cultural Revolution was a time of big changes in China. Mao Zedong and Deng Xioping both wanted to be in charge of China's Communist Party. They were powerful leaders.

Deng Pufang was Deng Xioping's son.

No one knows if Deng Pufang jumped out of a high window at Beijing University, or if he was pushed by Mao Zedong's followers. But the result was the same. Pufang was paralyzed from the waist down. He could not move his legs at all.

Pufang taught everyone in China about the bad ways disabled people were being treated. Pufang created the China Welfare Fund for the Handicapped and was in charge of the China Disabled Persons' Federation. These groups helped some disabled people in China go to school and get jobs.

But most people in China still thought disability was a bad thing. That started changing in the 1980's. Life began to get better for disabled people in China. But my parents did not live in China anymore. They lived in the United States.

Chinese words shape how people think about people with disabilities. The Chinese word for people with disabilities used to be *canfei*. *Canfei* means useless.

In the 1990's, the Chinese word for people with disabilities changed to *canji*. *Canji* means sickness.

In China right now, disability advocates want people to use the word *can zhang*. *Can zhang* means blocked. People with disabilities are not the problem. It is that the world is not accessible to us. But most people do not use the word *can zhang* to talk about disability in China yet.

When I was born, my family split into two sides. Some parts of my family told my mother she should leave me at the hospital forever. They thought my disability made me useless.

The other parts of my family told my mother to be careful: "The heavens wouldn't give you anything more than you could handle. She is a blessing."

My parents named me after my great-aunt Sandra. She was a good woman. She housed and took care of family while they worked to become Americans. My Chinese name is Hoa Tien Yun. Hoa Tien Yun means “gift from the heavens.”

I am old Chinese ideas about disability and new immigrant choices about disability put together. In America, we are told that people with disabilities belong. But my parents are not from America. They are from China. And in China, they were told I am some kind of test from God. Both of these things are true. I can’t separate one from the other. They are both a part of me.

Erasing disabled people is one of the most common crimes around the world. “Erasing” means getting rid of and hiding. It can mean killing, but it can also mean other things.

In 2016, a man in Sagamihara, Japan believed that all people with disabilities should be killed. He went into an institution and killed nineteen disabled people. He hurt twenty-six other disabled people. He tried to kill them, but they did not die.

Four years later, the victims still haven’t been publicly named. This is supposedly because families are embarrassed that they had a disabled family member.

We don’t know if the victims were named on their own terms while they were alive. Did people talk about them the way they wanted? After the killings, disabled people all over the world felt a loss. When I was a child, I wondered if I would have a worse life if I had been born in China or another Asian country, instead of America. It seems like the answer is “yes.” I would have had a worse life.

In Asia and America, people think disabled bodies are bad. But that’s not true. There are no bad bodies. All bodies are good bodies. That means disabled bodies are good too.

I talk to my family about people like the man in Sagamihara. He hurt and killed disabled people. The man is like us. We are both East Asian. I am disabled like the people he killed. My family does not want to talk about it. But I don’t want to be quiet. I want to say what I think to my family and to people outside my family. What I think matters.

Taking up space when you are disabled is a big deal. Having a name is a way to take up space. It is a way to show you matter. It is hard for disabled people to take up space. It is hard to show that we matter. My parents gave me two names. Both names are important. My names tell the world who I am. They knew I was going to make my

own choices, as a disabled Asian American. I can make those choices as Sandy Ho, or Hoa Tien Yun, or both at the same time. I am whole.

I am a disabled Asian American woman. This is true everywhere I go. I am learning how to love myself more. Asking my family to listen to me would only help a little. It would not be enough. I want it all. I want everyone to share their experiences. I want to do more than survive. I want us all to feel the freedom that comes with being louder.

Nurturing Black Disabled

Keah Brown

Keah Brown is a journalist and writer. Her writing is in *Glamour*, *Marie Claire UK*, *Harper's Bazaar*, and *Teen Vogue*, and other places. Her book, *The Pretty One*, talks about being a young African American woman with cerebral palsy.

I love my own joy now. I didn't always. Hope is my favorite word, but I didn't always have it. We live in a world that thinks joy is impossible for disabled people. The world thinks disability is only about sadness and shame. So my joy—the joy of wins at work and in relationships, of pop culture and books, of expressing love out loud—is a big deal in a body like mine. The fact that I feel joy may confuse, frighten, or anger people. As a black woman with cerebral palsy, I know what it is like to get all three.

In 2019, I wrote my first book. It is called *The Pretty One: On Life, Pop Culture, Disability, and Other Reasons to Fall in Love with Me*. Most people loved my book. But some people sent me emails or wrote reviews where they were confused, scared, or angry -- and sometimes all three.

But my book is about a journey to joy. I want readers to feel hopeful for a future of inclusion, representation, equal rights, and joy.

I wondered why any of that made people angry. I could only think of one reason: These readers do not like that my story is not about them. Figuring this out has only made me work harder and smarter. I want to tell more of my own stories and to raise up the stories of people of color.

I especially want to raise up Black women's stories. Black women aren't truly and properly seen or respected in or outside of our communities.

The disability community can look very white. People don't think of people of color or of LGBTQ+ people when they think of the disability community. Instead, they think of cis white men who use wheelchairs and hate themselves. That's the way TV and movies show us. I'm not a cis straight white man who uses a wheelchair. So on TV and in movies, I don't exist. That's not OK, because it's not reality.

I exist. I am a real person and I deserve to be seen.

I made #DisabledAndCute in 2017. #DisabledAndCute is a hashtag on social media. Hashtags are used to share ideas and start conversations. I wanted to remember how I felt when I made it. I wanted to trust myself to keep choosing joy every single day.

At first, the hashtag was for me and for my black disabled joy. I wanted to celebrate how I finally felt that, in this Black and disabled body, I, too deserved joy.

The hashtag went viral and then global by the end of week two. That means people all over the world saw it and were talking about it.

When disabled people started using #DisabledAndCute to share their stories, I was shocked and honored. Some people hated that I used the word “cute.” They said I was making inspiration porn. But I got a lot more good responses than bad responses.

I live proudly every day. I am proud for myself, of course. But I am also proud for future disabled black women.

Living proudly looks like sharing nice things people say about my writing on social media. Living proudly means calling out unfairness towards disabled people, people of color, and LGBTQ people in my writing.

It means that I’ve literally stopped apologizing for the space I take up on stages or in airports— especially in airports. I use their wheelchairs to get from gate to gate to avoid body pain. I do not say sorry for the space I take up anywhere I exist. I’ve stopped saying sorry to the people around me as the airport attendant pushes me to my gate. I feel free.

I may not find joy every day. Some days will just be hard, and I will simply exist. That’s okay, too. No one should have to be happy all the time. No one can be happy all the time. On those days, it’s important not to think about the joy you don’t have. But it is important to remember what joy feels like. It is important to remember that joy is one of the greatest gifts we have in life. When that doesn’t work, we can remind ourselves that joy isn’t gone forever. It will come back. That’s just the way life works sometimes. Not every day is good but every day has openings for small bits of joy.

Some days I can’t get out of bed because my body pain is too much (from my cerebral palsy). I write in the notes app on my phone or spend the day reading books or watching romantic comedies on the Hallmark Channel. The days I use to take care of myself are important for my well-being.

For most of my life, hope was hard to find. It felt impossible in a body like mine. I used to be a very angry person. I made fun of myself. I didn't think happiness was real. I thought I would die before I ever saw a day where I felt happy to be alive.

In 2016, just after Christmas, I realized I was wrong. I promised to hold on to and take care of my joy, even if I wasn't sure it would work. I made myself think good thoughts instead of bad ones. Instead of saying what I hated about myself, I said what I liked about myself.

Because I changed how I thought, hope and joy became special and holy. I shared my story with the people who loved me before I ever thought I could. I shared my story with the world. The person I will be can only happen because of the person I was. I want the world to know that is what makes it so beautiful. My joy is my freedom. My joy lets me live my life how I want. I won't die without the world knowing that I chose to live a life that made me happy. I chose to live a life that made me think. I chose to live a life that made me whole. I won't die without the world knowing that I chose to live.

Last but Not Least—Embracing Asexuality

Keshia Scott

Keshia Scott is pursuing an MS degree in cultural foundations of education with a CAS in Disability Studies from Syracuse University. She is an intersectional feminist, an eater of all pastas and breads, and a great lover of spoken word.

Note: This story talks about unwanted sexual touching. This story talks about unwanted sexual words.

These can be hard and scary things to read about. If you are worried you will be too sad or scared, it's OK to not read this story. You should take care of yourself and your feelings.

Growing up, I was always the last girl in my group of friends to reach a milestone. I got my period last. I started shaving last. I felt sexual last. I started touching myself.

I am blind and multiracial. My dad is black. My mom is mixed. Some of my friends are disabled. Some of my friends are not.

I didn't realize how different I was from my friends until I was sixteen.

When I was fifteen, I wanted to get my period. But I was also afraid of getting my period. All the girls around me had theirs.

I couldn't talk to people about periods, because I didn't have one yet. My friends would talk a lot about pads and tampons. They would talk about shots, pills, and teas that were supposed to make periods hurt less.

None of it sounded great, but at the time I foolishly thought that being a woman meant having your period. I wanted to be a woman so much. I did not want to be a little girl anymore. I wanted to grow up.

My friends were allowed to sit at the adult table. They talked about boys, children, and sex. I wasn't interested in any of those things.

Boys weren't annoying, but they did scare me sometimes. Their hands always seemed to be grabby and wet. They always sounded like they wanted something.

I tutored blind elementary students a few times a week. They were sweet. I liked coming up with games to teach them braille. But I was just as happy to see them go somewhere else.

Sex didn't make me scared. It did not interest me at all. I did not think good or bad things about sex. Sex was sex and that was that.

I was jealous of my friends' curves and height. I was jealous of their smooth skin. They didn't have moles and pimples. But I wasn't jealous of the way boys and men looked at them. They made me nervous. I didn't like being whistled at. I didn't like the slimy invitations to have a "good time." I didn't like that boys paid attention to my friends clothes and bodies. The boys did not pay attention to their own schoolwork or their plans for the future.

I wanted my period because to me, that was the first step to become a woman. I know it sounded silly. But I wanted that respect. I wanted my family and friends to stop treating me like a little kid. I wanted to have a voice. I wanted to be heard and listened to. And to have those things, I had to grow up.

I was sixteen when I got my period for the first time. It hurt. It felt like someone had their hands inside me and pinched everything they could reach. I don't have a regular period. It doesn't happen once a month like it does for most people. I don't know if that's good or bad. I don't know when I will have my period, so I don't know when the pain will start. It makes me nervous. But not having my period at all for a few months is good.

After I got my period, I learned that being a woman isn't about getting a period. Being a woman isn't about your body pushing blood out of your vagina. Being a woman is hard work.

I was seventeen when I started shaving hair off my armpits and legs. I did it for the worst reason: Because my friends were doing it. My legs have not felt as soft and smooth since then.

I was nineteen when I started shaving my vagina. My brother's friend asked me why I didn't shave my vagina. Then he told me I really, really should. I felt shame because I was not "the right kind of beautiful." I stayed on the beach towel for the rest of the time we were at Daytona Beach.

Thinking about that day still makes me feel shame. My brother's friend sounded grossed out. It makes me want to get a razor and shave all the hair off my vagina as fast as I can. It took me two years to stop shaving all of the hair off.

I became friends with a Poet when I was twenty-one. That's Poet with a capital P. He was tall and dark. He sounded beautiful when he sang. His poetry was beautiful too. He saw writing as a way to pray to God.

It was fall. For the first time, I wondered about what it felt like to be touched by someone else. By spring, I needed more. I couldn't just listen to his songs and poems. I wanted to feel his hands, hips, tongue, and neck.

I was eight when I first saw porn. My cousins and I stared at it for ten minutes. We were confused and scared, but we couldn't look away. We only wanted to watch it because our parents told us not to. We got bored fast. Playing outside was more interesting.

I was sixteen when I first saw a dildo. I knew my dad's girlfriend had one. I looked through her drawer one night, while they were out. The dildo was wrapped in a smooth cloth. It was at the back of the drawer. The dildo was bendy and seemed like it was made of jelly. It was ten inches long and bumpy.

I remember rubbing the dildo against myself. I tried to copy the way my friends talked about their partners' tongues and hands. I blushed and laughed to myself. I wondered why anyone thought this felt good. I didn't understand why anyone would like it.

I was twenty-two when I first touched my vagina with my hands. It was almost ten years after my friends did. I read books about how to touch my vagina. The books said to "romance yourself." But I wasn't interested in flowers, candles, or hot baths. I couldn't do it. I felt like I was trying to be someone else. My clothes, words, and the way I moved weren't right.

My friends told me, "get to know yourself. Find out what you like and don't like. Think of things that excite you." Whatever the hell that meant. I'd never had sex with someone before. I'd never kissed someone at the lockers. I'd never made out with someone during lunch behind the stairs. I didn't know what I liked. But I did know what I didn't like. I didn't like the way it felt when boys touched my breasts without asking.

"I'm blind. How was I supposed to know your boobs were there?" " the boys in my class would say. They'd laugh. I slapped their hands away. I was angry. They were blind, but they knew exactly what they were doing.

I didn't like the way strangers would grope me while "helping" a blind girl. They'd put an arm around my waist. Or curl their hands around my neck. Or pat my ass. Or trail their fingers at the skin under my shirt.

I couldn't romance myself. It felt too much like people were looking at me, even though I was alone in my room. The door was locked. The lights were off. I remember getting under the covers. My underwear and shorts were still on.

The first time, I didn't touch my vagina at all. I only touched my clit. I moved it up and down with the tip of my finger. I tried quick, light touches. Then I tried slow, hard touches. I moved my finger around it in a circle. I only thought about how it felt. I did not think about another person. It was just me.

I had my first orgasm. My tongue was between my teeth. My legs didn't stop shaking for a minute or two. I couldn't stop smiling for the rest of that day.

Seven years later, I still touch myself. I am still under the covers. The door is still locked. The lights are still off. But I am braver. My fingers move in ways I would have never imagined before.

I was twenty-four when I bought my first vibrator. It was called The Military Rocket. It was shaped like a green rocket. I bought it at a sex shop. My dad's ex-girlfriend took me there. We were at the sex shop for an hour. A worker helped us. The worker had a bag full of batteries around her waist. She took dozens of toys out of boxes for me to touch. Since then, I've tried out four different vibrators. They've all made my legs tremble after a big orgasm. They still leave me smiling for the rest of the day.

I was twenty-three when my friends started asking me about men, sex, and whether I wanted to have kids. Some of my friends were parents already. Some were pregnant. I did not have a man in my life. Thinking about sex still made me feel awkward. Thinking about having children gave me nightmares.

But my friends and family kept asking me about men. At dinner. In the middle of the movie theater. On the city bus. In Publix. I was already worried. It was not about being in a relationship or having kids. Some women don't want relationships. Some women don't have kids. But I didn't seem to want to have sex. That made me worried.

What was wrong with me? I liked men. I touched myself (a lot). But why was the thought of having sex such a turnoff? So I started to watch porn and read sexy books.

Porn did nothing for me. The sounds the men and women made didn't turn me on. Men's sounds made me laugh. Women's sounds made me roll my eyes.

The sexy books didn't work either. The only time I got turned on was when people in the books touched each other a little bit. The people in the book acted before they had sex. But when the people in the book had sex, I got bored.

I didn't find out why I didn't want sex until after I bought my first vibrator. I found out nothing was wrong with me. I found out that I was completely OK. There was nothing to worry about.

I took a class about sex and sexuality at university. After class, I complained to another student. It seemed like no one was thinking about how sex and disability affect each other.

The other student said that disabled people were either asexual or hypersexual.

Asexual means not wanting to have sex at all.

Hypersexual means wanting to have sex all the time.

The other student said, "you are just blind, so you aren't considered hypersexual. Only the extremely mentally challenged are hypersexual."

It was a very silly and wrong thing for her to say. I didn't know if I should be angry or if I should laugh. Your disability does not make you sexual.

I felt angry that she called me asexual. I thought asexual people were cold and mean. I thought asexual people didn't feel good when they touched themselves. How could I be asexual? I got horny. I touched myself. I just didn't have sex. That didn't mean I was asexual.

I could not get the idea that I might be asexual out of my mind. Normally I am shy. But suddenly I wanted to talk to everyone. I spoke to men with motorbikes, bicycles, and skateboards. I spoke with Asian guys, black guys, and Mexican guys. I spoke with tall and short guys. I spoke with stocky guys and thin guys. I felt nothing. Thinking about most of them turned me on. But thinking about having sex with them turned me off.

I was worried about asking my mom and friends about asexuality. I did not want to ask them if I was asexual. I was scared they might say I am. Did being disabled mean I had to be asexual or hypersexual?

Then, I found a website about asexuality. I started to read more about asexuality. I read stories from asexual people. Some of those people were disabled. Some were not. They were all fine. Some were married. Some had kids. Some had sex every once in a while. Some never had sex. Some were single. They all had normal lives. They all had friends. I began to relax.

One day, my mom told me how worried she was. She didn't want me to be alone. Didn't I want to be with someone? If I told my dad I didn't want to be married, my dad would be worried, but he probably wouldn't care. In the United States, some women don't get married.

But my mom was from a small town in Switzerland. She thought women needed to have a family. She thought a woman should care the most about her husband and children.

I told my mom no. I didn't want to get married. I took a deep breath and said, "I am asexual."

My friends and I are in our late twenties now. Some of my friends are married. Some of my friends have kids. Their lives are filled with diapers, mother-in-laws, and engagement rings. I am in grad school. The idea of sex still turns me off. I still don't want to have kids. I am still learning what being a woman means. I look forward to what happens next. I'm still smiling.

Imposter Syndrome and Parenting with a Disability

Jessica Slice

Jessica Slice is a writer. She lives in Durham, North Carolina, with her husband, David, her son, Khalil, and their sleepy dog, Batman. She is at work on a memoir about acquired disability, pain, transracial adoption, and motherhood.

I didn't know that I was going to be a mother. We found out our son existed twelve hours before I brought him home from the hospital. His name is Khalil.

Sometimes I still don't feel like a mother. When people talk about parenting, they talk about long nights with a crying baby. They talk about carpooling. They talk about potty training. I can join in, but a part of me feels like a fake. That's because I have a disability.

I have Ehlers-Danlos syndrome. Ehlers-Danlos syndrome affects skin, joints, and other parts of your body. It can cause a brain problem called dysautonomia. I can walk a little bit, but I have a hard time standing up. My joints dislocate easily. Staying in the right temperature is hard. Being in weather hotter than 75 degrees is dangerous for me. I can't do a lot of the things most parents do.

This morning, for example, Khalil climbed into bed with me. We played with plastic animals. I held the small rhino and he had the tiger. We pretended they went shopping for pineapples, ate mac and cheese, and sang "B-I-N-G-O."

After, Khalil wanted to cuddle. He asked me to sing "hush baby." That is his favorite lullaby. He put his head on my belly while I lightly stroked his nose and forehead. He pretended to sleep.

After fifteen minutes, Khalil started to have what we call "big feelings." He kicks his legs and flops around on the bed. My husband, David, has to stop Khalil. He could hurt me by mistake.

I wasn't there for Khalil's breakfast. I was so dizzy and fatigued. I didn't help with lotion or pick out his little clothes. I won't drop him off or pick him up at preschool today. I can't drive. Sometimes I am so sick in the morning that I cannot leave the apartment.

I miss little moments. Sometimes, I feel like I'm only pretending to be a mom. I can't do a lot of the things most other moms do.

Many of my friends with disabilities worry that they should not be parents. My friends who are already parents are afraid that their disabilities are hurting their children.

It's a lot easier to ignore my worries at work—to fake it until I make it. But how can I fake my way through parenting? Talking myself out of my deepest fears is harder when I want to be able to lift my son.

During the first few blissful months after Khalil became our foster son, I never worried if I was a real parent. We didn't have child care. David worked full-time. Khalil and I were often alone together. Many new moms hate being stuck inside, but I loved it. I spend most of my time at home or in bed. Khalil made me so happy.

Khalil was a happy baby, as long as we were touching, and cuddling him for most of every day was an easy need to meet. To this day, whenever he's away from me, I feel like I want to hold him. It aches a little and feels too light.

When he was six months old, Khalil needed less cuddling and more exploring. David took three months off work. We went on family adventures, all three of us, because Khalil started to need to do things I couldn't help him do by myself. As a family, we drove up and down the California coast. We camped in Marin and spent two weeks south of Mendocino. We had playdates. We put Khalil in a music class.

Khalil started daycare at nine months, when David returned to work. I still helped him get ready for his day. But when he reached fourteen months, I couldn't keep up with him for more than a couple hours. He is strong and fast. I am not powerful enough to protect him from running into harm's way. When we adopted him, at eighteen months, I could only spend an hour alone with him.

I switched from a manual wheelchair, which I needed help pushing, to a power chair. The chair that I now use tilts back, and I can move around in it on my own. The power chair and wheelchair-accessible van were very expensive. We spent nearly \$100,000, even with Medicare's help.

I had thought about getting a power chair in the past, but Khalil made me want to get one. Even if I can't be alone with him, I still want to be with him. He rides on my lap around town, around the children's museum, around the nearby hotel with pink penguin statues. The movement of the chair soothes him, and the weight of his body comforts

me. We whisper to each other and he pats my arm. He leans his head back, resting right on my chest.

One Mother's Day, a friend posted a photo on Instagram of herself at the beach with her kids. Her caption was about how beautiful a "mombod" is: how she needs her muscular body so she can lift her kids, run to their rescue, give birth to them. She talked about being a mother as a list of skills that I don't have.

Another friend, Sarah, understood how hard it is to be a mom with a disability. She was a very close friend. She died of ALS just after turning forty, in November 2018. ALS is a disease that affects the whole body. ALS gets worse over time.

The May before she died, we cried together about Mother's Day. Mother's Day seems to hurt everyone. We weren't the kind of mothers we saw in books we love. We were not strong. But love isn't a list of things a person does. I love my son, even though I can't carry him up the stairs.

At some point, Khalil will probably become easier to talk to. He'll need to move less and want to talk more. I like to imagine that soon he will love that I'm so often around, steady and patient, ready to listen.

Years of having trouble moving has helped me learn how to slow down and enjoy life. Parents and children both grow and change together.

Not long ago, David took Khalil to see a heart doctor. It was a warm day. I couldn't go outside, because of my disability. David called from the heart doctor's office. That way, I could listen in from home.

But Khalil only wanted me to hear about what he saw on the mural on the wall. A big shark! Another crocodile! A tiger!

The doctor started explaining Khalil's heart problem, but it was hard to hear over Khalil saying "Mama! Mama! Mama!" He heard my voice over the phone. Instead of being scared of the new doctor, he felt loved. He knew that I was there for him, even if my body wasn't. He has no doubt that I am his mom.

How to Make a Paper Crane from Rage

Elsa Sjunneson

Elsa Sjunneson is a Hugo and Aurora award-winning editor. She is deafblind. Her writing is in *Uncanny Magazine* and *Fireside Magazine*. Sjunneson helps teach other writers to write disability respectfully.

In this story, it looks like Elsa is telling two stories at the same time. In one story, she talks about making a paper crane. In the other story, she talks about being angry. She talks about the ways the world has hurt her.

But really, Elsa is only telling one story. She is telling the story of how she learned how to turn her anger into art.

The art she makes is not like a paper crane. It is not small or pretty. The art she makes with her anger is angry. She tells people exactly how and why she is angry.

Here are some things you should know about Elsa's anger:

The first time Elsa felt angry, she was seven years old. Her father was dying from AIDS. Before doctors knew what AIDS was, people used to be very afraid. A lot of gay men got AIDS. People were afraid of gay men. They hated gay men. There was nothing for them to be afraid of. You can't get AIDS from a sneeze or a toilet seat. But they were afraid and hated anyway.

Elsa is queer. Her father was gay. People hate her because she is queer. They also hated her father because he was gay. She has been hurt by both. This is called "generational trauma." She feels her own pain and her father's pain from being hated.

Once, a man had sex with Elsa in a way she did not want or like. She thought, "why is he doing this to me?" for the first time.

Elsa is deafblind. People think she can't do anything by herself, because she is disabled. That makes her very angry. It is not true.

People think Elsa can only be an adult if someone helps her. People assume that because she is disabled, she's not a real adult. It is not true.

Elsa does not like that she is not supposed to be angry. She should be allowed to feel angry.

Elsa's eyes look different from most people's, because she is blind. People tell her to hide it, because it makes people uncomfortable. Elsa thinks her eye looks fine. She does not want to hide any part of herself.

Elsa is very smart. People have bullied her because she is smart. Some people hate smart women. Those people are wrong.

Some people think that women's anger can't be useful. Elsa thinks her anger is useful. To Elsa, her anger feels like a weapon.

Elsa has been telling more people about herself. She wants people to see her as a person. She wants other people to see she is just like them.

Elsa has had to go into a fancy restaurant using the garbage elevator, because the normal door wasn't accessible.

A woman once told Elsa she was AMAZING and BRAVE because she ordered coffee by herself.

Elsa isn't angry because people hate her. She is angry because the world makes hating some people easy.

Elsa tries to use her anger to teach people how to be better.

Elsa tells people about all of her feelings. She tells people about her whole life. She wants them to understand what being disabled is like.

Are you angry? What are some ways you can turn your anger into art? How can you make your anger useful? Do you want to make your anger useful? It's OK if you don't. It's OK to just feel angry.

Selma Blair Became a Disabled Icon Overnight. Here's Why We Need More Stories Like Hers

Zipporah Arielle

Zipporah Arielle is a writer from a small town in Maine. She currently resides in Nashville, Tennessee, with her service dog in training.

In 2019, Selma Blair stepped out onto the red carpet at an Oscars party. Selma Blair is an actor. She wore a colorful dress and cape. The dress and cape were designed by Ralph & Russo.

The dress and cape were black, blue, green, and pink. She had a black cane. The cane was a special cane. Selma Blair had the cane made just for her. The cane had a real pink diamond on it.

This was the first time Selma Blair had gone out since she told everyone she has multiple sclerosis. Multiple sclerosis is sometimes called MS.

Selma Blair looked beautiful. I watched her on TV. She looked proud. She looked perfect. But then, she started to cry a little bit.

Selma Blair's manager helped wipe her tears.

Selma Blair said, "it just took so much to get out."

I am a disabled woman. I am in my mid-twenties. I live with my parents in Maine. I was wearing pajamas and slippers. I was not wearing any makeup. I was wearing a scarf on my head. My hair is getting thinner. I have a cane too. But my cane does not have a pink diamond on it. I got my cane for \$12 on Amazon.

But I understood what Selma Blair was feeling. I felt it too. When you are disabled, it is very hard to go out sometimes. I feel tired all the time. Selma Blair also feels tired all the time.

Even though Selma Blair feels tired all the time, she put on a fancy dress. She put on beautiful makeup. She put a pink diamond on her cane. And she went out on the red carpet. It must have been very hard. I was happy she was there.

I know who Selma Blair is. I saw her in movies and magazines when I was growing up. I saw *Legally Blonde* and *Cruel Intentions* when I was a teenager. Those are movies she was in. But I did not know she was disabled like I am.

It felt good to see Selma Blair talk about her disability on TV. Not enough people talk about having a disability. I feel like I never see people like me on TV. But I saw Selma Blair.

On TV, Selma Blair told her story. She talked about what being disabled is like. She talked about feeling very tired all the time. She talked about how sometimes, it is hard for her to talk. She talked about her balance. Sometimes, she is worried she will fall down. A lot of disabled people have these problems.

Selma Blair talked about how doctors often don't believe women who say they feel sick. Sometimes, women can feel sick for years before a doctor will tell them why. Doctors didn't believe Selma Blair for five years. That is a long time! Because doctors did not believe Selma Blair, she did not get medicine or support she needed.

Selma Blair talked about how hard it is to find nice clothes and canes for disabled people. "Dressing is a shitshow," Selma Blair said. She said she would make her own nice clothes for disabled people. "Let's get stretchy pants to look a little bit better."

After I had surgery, I had to wear stretchy pants. Regular pants, like jeans, hurt to wear. I did not like how my stretchy pants looked either.

A lot of disabled people feel embarrassed because canes, wheelchairs, and walkers are unfashionable.

My first wheelchair was clunky. It came from a hospital. It was hard to move around in.

My first cane was also clunky. It looked like it came from a hospital.

When I go out, I used to try to hide my cane. If someone was taking pictures, I'd lean against a wall or the person next to me. I did not want my cane to be in the pictures. This was not a safe thing for me to do. I could have fallen and hurt myself.

The world tells us that having a cane is embarrassing. It is not. Selma Blair says the world is wrong. She is proud of her cane. She made her cane beautiful.

The world also tells sick and disabled people we can't work or have jobs. That is also not true. Selma Blair is still making movies. She was in *Lost in Space* and *Another Life* on Netflix recently. She says "no" to pity. She does not want people to feel bad for her.

Sometimes Selma Blair still falls and drops things because of her disability. It does not mean she cannot work. I hope more people see Selma Blair and learn about disability from her.

I want to see more disabled people on TV and in movies. I want to see more disabled actors and singers. Everyone should get to see people that look like them on TV and in movies.

A lot of the time, when people on TV talk about disability, they used the word “inspired.” They think that disabled people exist to make non-disabled people feel good about themselves. That is not true! I usually do not like the word “inspired.”

Selma Blair inspires me, but in a different way. She makes me feel good about my disabled body. She makes me feel good about my cane. A lot of other disabled and sick people feel the same way I do. That is a good kind of inspiration.

I am still trying to be OK with my disability. But seeing someone like Selma Blair talk about disability on TV helped a lot. Seeing Selma Blair’s cane helped a lot. I am not going to hide my cane in pictures anymore.

Why My Novel Is Dedicated to My Disabled Friend Maddy

A. H. Reaume

A. H. Reaume is a feminist activist and writer. Her life was changed by a head injury in 2017. Since then, writing can be painful for her. She continues to write in order to ensure her voice and other disabled voices are heard. Reaume writes for *Open Book* and finished writing her first book *Unfinished: A Novel* in 2019.

People often say that they couldn't have written their books without the help and support of friends and family. This is especially true for disabled writers. I needed a lot of help from my friend Maddy to finish my book.

Maddy and I met about a year ago. We met at a work event. I was trying to recommend a book to her. But I couldn't remember the name of the book.

"I'm so sorry—I'm bad at names," I said. "I had a brain injury."

Maddy's eyes lit up with recognition. "What kind of injury?" she asked. "I did, too."

Maddy and I have very different injuries. She had a brain hemorrhage six years ago. A brain hemorrhage is when someone bleeds inside their brain.

I had a bad concussion two years ago. A concussion is when someone gets hit on the head very hard. People with concussions feel dizzy, tired, and confused. They often have a hard time remembering words.

My brain injury and Maddy's brain injury are different. Her left side is weaker than her right side. I have a hard time using computers and watching TV.

But our brains also have some of the same problems. When we talk, we close our eyes. It helps us find words for what we want to say. We both also know what it is like to feel sick in a way no one sees or knows about. People assume we're OK, when we're really feeling bad.

"Let's meet up," I said.

And so we met up.

Sometimes, when I meet a person, I know we will be close friends. I knew Maddy would be my close friend right away.

The first time we hung out, we went strawberry picking. We talked about what learning to walk again is like. We talked about what learning to drive again is like.

There are a lot of things most people never think about. They are used to being able to do anything. But people with brain injuries know not to take anything for granted. We know what it is like to lose skills, just for a little bit, or even forever.

We talked about how much it hurts to suddenly lose a skill. We talked about bosses, friends, and family saying bad things to us because of our disabilities. We talked about how lonely we are. Most people do not understand what it is like to have a brain injury.

We laughed and we cried. We ate a lot of strawberries. It was a beautiful day.

I told Maddy I felt upset because I could not finish my book. The book was written, but it still needed to be fixed in a lot of places. This is called “editing.” I could not edit my book.

“I can’t work on my computer because it makes my head hurt. I can’t think. I need to think so I can edit. But if I print my book and write the edits on paper, I can’t put the edits onto the computer. Looking at the computer still hurts. I feel so stuck. I worry I will never finish my book,” I said.

Maddy listened and nodded. “I’m so sorry,” she said. “Our injuries have taken so much from us. I wish it wasn’t taking this from you, too.”

I thought about what Maddy said for several weeks. I thought about how much we had both lost. I thought about how hard we were working to learn things we used to know, and to do things we used to do.

At my job, I had an assistant who helped me do computer work. Maybe I could get an assistant to help me finish my book?

I started doing extra work. That way, I could pay an assistant to help finish my book.

After my brain injury, I stopped working on my book for a year. I was excited there was a way to work on it again.

I looked for an assistant.

“I can do it,” Maddy said.

“Are you sure?” I asked. I didn’t want her to feel like she had to help.

“Absolutely,” she said. “You would be helping me too. I’m looking for more work.”

Working with Maddy was the best. Maddy would come over on a weekend. I’d make food. Before we started working on my book, we’d eat and talk about our day. We would talk about how we were feeling. We would talk about our families. Our families did not always know how we felt. They did not know what being disabled is like. But Maddy knew.

Sometimes, we would cry together. We loved each other. We cared about each other. She knew what having a brain injury was like. She knew what it was like to lose skills and have to learn them all over again.

Brain injuries change who you are. They change how you think. They change how you act. Maddy knew that too.

Maddy made me want to work harder on my book. She is one of the smartest and most careful people I know. She made my book so much better. She pointed out when I said something more than once. She helped me think about what the book should look like.

The work was good for Maddy, too. She needed a job that could work with her disability. Being my assistant did that. It also helped her get out of the house more. She loved working with me.

“I feel so happy we met,” she told me recently. “I haven’t known you for very long, but you’re like family to me.”

I feel the same way about Maddy, but I never told her all of it. Before I met Maddy, I thought I would never finish my book. But with Maddy’s help, I finished my book.

Maddy helped shape my book. I couldn’t do it alone, but I did it with her help. We need each other. We help each other. It’s a kind of love I did not know about before my disability.

“Disabled people caring for each other can be a place of great healing,” Leah Lakshmi Piepzna-Samarasinha wrote in her book, *Care Work: Dreaming Disability Justice*.

Meeting Maddy healed me. It’s given parts of me back to myself. Maddy gave me my dreams and my voice. She made me see how I could still be a writer. She made me see

how I could still finish my book. She made me see how I could write other things, too. But she also did more than that.

We both have “broken” brains, but our brains work in different ways. We can help each other do everything we need to do. We have helped each other get better. We are helping each other imagine a different world, where people love and care for us. Not just for our abilities, but for our disabilities too. We have taught each other so much.

“I want to dedicate my book to Maddy,” I told a friend recently. That means I wanted to thank her in the beginning of my book, for everything she did for me. “To Maddy and all the disabled writers who think they can’t finish their books themselves, and who can’t pay for an assistant to help.”

I am very lucky. I can pay for an assistant to help me finish my book. I can work in ways other people can’t. My body makes writing hard and painful, but I can still write.

Not all disabled people are as lucky as I am. Many can’t pay bills. Many get yelled at and hurt, just for being disabled. Many disabled people get ignored.

Some disabled people get hurt and ignored for more than one reason at the same time. Sometimes it is because a disabled person is also gay. Sometimes it is because a disabled person is also black. Sometimes it is because a disabled person is also poor. Sometimes it is because a disabled person is also transgender. We miss out on how wonderful and smart those disabled people are.

Every disabled person has a story. I don’t want to just celebrate my new book. I want to talk about how many disabled people get ignored. No one should be ignored. The world should be different. Everyone should get to tell their story, like I get to tell my story.

Independence is fake. No one can do anything all alone. Everyone needs help sometimes. The community and government should support disabled people more. Families help some people, but not everyone has family support.

We tell stories about disabled people doing everything by themselves. Those stories say that if a person has a hard time, it is that person’s fault and no one else’s. Maybe they are just not trying hard enough?

But that is not true! The community should help that person more. The community is responsible, too.

There are not a lot of books written by disabled people. A lot of disabled people cannot write a book without help. Some disabled can finish books, but their books might have more problems than a non-disabled person's book. This is not because we are worse. It is because we don't get enough support.

The world says disabled people aren't really people. That is not true. When we tell our stories, we show everyone that we are people.

Maddy and other disabled people like me are trying to change the world. The world could learn a lot from disabled people. To learn from us, the world has to listen to us.

I am not going to tell a story about how I bravely overcame my disability all by myself. That is not a real story. I wrote this book with support. Another disabled person supported me.

Not everyone gets enough support. It's not fair.

Maddy helped the most. Lots of other disabled writers and advocates also helped me finish my book. Here are some of them:

- Amanda Leduc
- Andrew Wilmot
- Adam Pottle
- Erin Soros
- Arley Cruthers
- Elee Kraljii Gardiner
- Esme Wang
- Leah Lakshmi Pipzina-Samarasinha
- Imani Barbarin
- Rahim Ladha
- Alice Wong

Disabled people need support to live our best lives. But the world tells us we need to do everything by ourselves, or we're horrible. That is not fair. And it is not true.

How can you help change the world to be more fair? How can you be someone's Maddy?

The Antiabortion Bill You Aren't Hearing About

Rebecca Cokley

Rebecca Cokley is the director of the Disability Justice Initiative at the Center for American Progress (CAP). She joined CAP after leading the National Council on Disability for four years. From 2009 to 2013 she worked for President Obama.

Notes: This story talks about people hating disabled people because we are disabled.

This story talks about eugenics. Eugenics is a set of beliefs and rules that most doctors used to agree with. A few doctors still agree with Eugenics.

Eugenics says that white people and people who do not have disabilities are the best kind of people. Eugenics says everyone else is bad and should not exist. Eugenics says people with disabilities should not exist.

This story talks about people being hurt very badly.

This story talks about rape.

This story talks about doctors hurting patients very badly.

This story talks about being in prison.

This story talks about sterilization. Sterilization is when doctors take away your ability to have babies. It should be your choice.

These are hard topics to read about. If these are things that have happened to you or your family, they may be extra hard to read about. They may make you feel sad, scared, and angry. You can choose not to read this story if it would make you feel too sad, scared, and angry. Please take good care of yourself and your feelings.

This story was first published on May 20, 2019. It was a response to Texas Senate Bill 1033.

People in the government of Texas wanted to make a law about disability and abortion. So they made a bill. A bill is an idea that might become a law. Laws are rules everyone has to follow.

Rebecca Cokley thinks there should be fewer laws about abortion. She thinks everyone should get to choose for themselves. She did not like Texas Senate Bill 1033.

There have been big anti-abortion bills in Alabama, Georgia, and Ohio. Those bills could hurt a lot of people. But there is another bill we should think about. Not a lot of people are talking about it: Texas Senate Bill 1033.

Texas Senate Bill 1033 would make it illegal for a woman to choose abortion, if she finds out the baby is disabled. Before a baby is born, doctors do a bunch of tests. These tests are called “prenatal screening.”

There are a lot of disabilities we can find out about from prenatal screening. Here are some examples:

- Down syndrome
- Cystic fibrosis
- Dwarfism

Doctors who give abortions, if they knew about the disability, would be breaking the law. They would lose their jobs. They would not be allowed to be doctors anymore.

Anti-abortion advocates say that Texas Senate Bill 1033 would “save poor defenseless disabled babies.” But the truth is, Texas Senate Bill 1033 just takes away women’s choices. It takes away control over our own bodies.

If the bill gets enough votes, it will go to the governor. The governor is Greg Abbott. He uses a wheelchair. Anti-abortion people say this bill is “saving our community.” But that is not true. The truth is, this bill takes away the right to make choices about our bodies. This bill takes choices away from disabled people.

Republicans and Democrats both say they know what is best for disabled people. They both say they care about the disability community. They don’t know what is best for disabled people. They don’t really care about the disability community.

It is hard to talk about prenatal testing in the disability community. Some disabled people do not want to be disabled. They do not want their children to be disabled.

But some disabled people like being disabled. They like themselves how they are. They want their children to be disabled, like them. People in the deaf and dwarfism communities feel like their disabilities are a good thing.

After Iceland started doing prenatal screening, almost no babies with Down syndrome were born there. Imagine knowing your community was small, but then all of a sudden it was just gone. It was not coming back. Some people think that's a good thing. Some people don't think people with Down syndrome should exist at all. This is why the Down syndrome community is mostly anti-abortion. Pro-choice advocates need to respect how people with Down syndrome feel about abortion.

It is hard to be a pro-choice disabled person sometimes.

I believe that everyone should be able to choose what happens to their bodies. This idea is called "bodily autonomy."

I believe everyone should be able to choose to have an abortion, or to not have an abortion.

But sometimes, people choose to get an abortion because they think disabled babies should not exist. They think people like you and me should not exist.

It is hard for me to support that choice. We need to talk about it.

Both my parents had dwarfism. They decided they wanted to have a baby. They tried three times, but the babies died.

My parents tried again. I was born. I did not die.

The deaths hurt my parents a lot. This is why my mom always supported abortion if wanted. A person should have the right to choose.

I do not like how people talk about disability and abortion.

Laura Dorwart is a writer. She has a PhD. She went to University of California, San Diego. In 2018, Laura wrote about her opinion about disability and abortion in the New York Times.

Laura said that people who are anti-abortion talk about people with intellectual disabilities like they are angels, not people. They treat adults with intellectual disabilities like babies. They say people with intellectual disabilities need them. They say people with intellectual disabilities will die without them.

People who are pro-choice also talk about people with intellectual disabilities the same way sometimes. They also talk about disability as something bad and scary. They say our lives do not have dignity, independence, or worth.

Our lives have worth because they are our lives. Why is that not enough?

Sometimes, disabled people need abortions too. Disabled people can get pregnant. Disabled people can have children. Disabled people should get to choose for ourselves.

The Supreme Court is the most important court in America. They decide what laws mean.

Justice Brett Kavanaugh was picked to be on the Supreme Court. But when he was a judge, he did some things that hurt people with intellectual disabilities.

Justice Kavanaugh said that women with intellectual disabilities do not have the right to say “yes” or “no” to doctors. He said they do not have the right to make choices about surgery, tests, or medication.

90% of people with developmental and intellectual disabilities are raped. They were treated like they could not say “no” to sex. They had their choice taken away.

It is very, very important for people with developmental and intellectual disabilities to make their own choices about their bodies. That includes choice about getting or not getting an abortion.

Disabled people are taught that we do not own our own bodies. Let the doctor look at you. Let the personal care attendant wipe your bottom. Show your friend’s mom your latest pressure sore.

Sometimes it may feel like your body belongs to everyone except you.

Many disabled people talk about learning to pretend they are somewhere else, when they go to see the doctor. Doctors hurt and scare them.

Sometimes, when you make choices caregivers don’t like, you get called “difficult” or “noncompliant.” That is not fair.

In America, disabled people get sterilized without a choice all the time.

“Sterilized” means that they can never have babies, if they want to have babies.

People in institutions were sterilized. A lot of people in prisons are disabled. Some people in prisons get sterilized too.

The government thinks disabled people should not exist. They want to make sure we don't get to make choices about our own bodies.

Rich people will always be able to make choices about abortion. If abortion becomes illegal, they can go to another country to get an abortion. But most people with disabilities are poor. They do not have as many choices. Bills that make rules about abortion only take away more choices.

So. Not. Broken.

Alice Sheppard

Alice is the founder and artistic lead for Kinetic Light, an ensemble working at the intersections of disability, dance, design, identity, and technology. Her writing has appeared in academic journals and *The New York Times*.

“I’m broken,” I say as I bounce onto the physical therapy table.

My physical therapist takes some notes. She doesn’t laugh.

It’s been years since this joke was funny.

Being broken is a way of life for me. It has nothing to do with my disability. I keep making the same joke because I think “brokenness” is interesting. “Brokenness” is important to how I dance and the dances I make for other people.

A lot of nondisabled people think disability is the same thing as brokenness. They only think about what we can’t do. They think disability is a problem that makes us different from them.

I learned about disability from disability studies books. I also learned from people like Corbett O’Toole and Simi Linton. I learned disability was more than what I can and can’t do. I don’t think about ability much anymore.

I was a history professor. Now I am a dancer and choreographer. A choreographer is someone who makes up dances for other people to do.

Dance has taught me to think about my body differently. My first problem when I started dancing was what to do with my wheelchair. I had to learn how to move in it.

But I also had to understand what it meant to be a black woman in a wheelchair. What do people see when they look at me? What do I want them to see?

It was easier to learn how a wheelchair moves.

I think about my wheelchair as part of my body, instead of something separate from me.

When I used to explain my wheelchair to other people, I said, “my chair is my legs.” It helps the airline understand why breaking my wheelchair when I travel is bad.

But “my chair is my legs” does not make sense when dancing or making dances. Wheels are not legs. They move differently. But my wheelchair is still a part of my body. Learning that was important for my art.

I think using a wheelchair can be beautiful. Using crutches can be beautiful. The way disabled people move is beautiful.

When I make up dances, I don’t just think about disability. I try to think about all kinds of different bodies. I try to think about all different kinds of people.

When I make up dances, I want other people to see how beautiful disability can be.

I do not think disabled people are broken. I do not think disabled people are “whole.” Disabled people are more than just two things.

How a Blind Astronomer Found a Way to Hear the Stars

Wanda Díaz-Merced

Wanda Díaz-Merced is an astronomer. She is currently based at the University of Colorado Boulder.

This story first appeared as a TED Talk in February 2016. To watch the full talk, visit bit.ly/38Lg7Jw. It is easier for some people to watch or listen than to read. That's OK! Everyone is different.

Once, there was a star. Like everything else, she was born. She grew to be around thirty times bigger than the sun. She lived for a very long time. No one knows exactly how long the star lived. Just like everything in life, she reached the end of her regular star days when her heart ran out of fuel. But that was not the end of her story.

The star turned into a supernova. She made so much light and heat. She was brighter than everything else there is. In one second, she made as much light and heat as the sun makes in ten days. And she turned into something else. Supernova explosions are very bright and hot.

To turn into a supernova, the inside of the star crunches in on itself. It starts spinning faster and faster. Stuff floating around the star is dragged around. That makes even more light and heat. That is how our star was brighter than anything else in the universe.

My star, the one in the story, is called a magnetar. Magnetars are powerful. They look like explosions. But we can't see the explosions with our eyes. They are a color our eyes can't see.

Astronomers are people who study stars and planets. I am an astronomer. I am also blind. I was not blind when I started being an astronomer. I got very sick and could not see anymore.

After I went blind, I thought I could not be an astronomer anymore. I can't see the charts and pictures most astronomers use to look at the universe. It was very hard. I wanted to still be an astronomer. I needed to figure out a different kind of chart.

Astronomers look at the stars, but they also measure them. They use numbers. Usually, those numbers get turned into a normal chart or a picture. But worked with a team to make numbers into sounds instead.

Using sound, I noticed things other astronomers missed. I found out that the way stars are born might be an important part of the way they explode and turn into supernovas.

Now, other astronomers use sound too. They can find out more information that way.

When I lost my sight, I noticed that I didn't have access to as much information as sighted astronomers. The information I did have wasn't as good. Using sound made me able to discover great things in astronomy. But it also made astronomy better for everyone. Everyone learned more than before.

What happens if a scientist becomes disabled? Do they need to quit their job? Making science accessible gives disabled scientists a chance to make the world better. Disabled people who want to be scientists can be scientists.

I am working on more ways to make science inclusive. I am working with students at the Athlone School for the Blind. They are learning radio astronomy. The students have a lot of different disabilities. We are learning how to make science more accessible for everyone. I call this "development." And it is happening right now.

I think science is for everyone. If we don't let disabled people be scientists, the world is worse. I want science to be fair. I want everyone to respect each other. I want people to share ideas and explore together. If people with disabilities are allowed to do science, we will all learn so much more. I am sure.

Incontinence Is a Public Health Issue—And We Need to Talk About It

Mari Ramsawakh

Mari Ramsawakh is a disabled and nonbinary writer, teacher, and podcaster. Mari has written for *Xtra*, *Leafly*, *Nuance*, and other news websites. Mari's fiction has been published in the *Hart House Review* and *Toronto 2033*. Mari is also co-host of the podcast *Sick Sad World*.

Note: This story talks about suicide and thinking about suicide. Suicide is when people kill themselves.

This story talks about bullying.

This story talks about adults being treated like babies instead of adults.

These are hard topics to read about. If these are things that have happened to you or your family, they may be extra hard to read about. They may make you feel sad, scared, and angry. You can choose not to read this story if it would make you feel too sad, scared, and angry. Please take good care of yourself and your feelings.

We need to talk about incontinence.

Incontinence is when you pee or poop when you don't mean to.

TV commercials say only babies, toddlers, and elderly people have incontinence. Movies and TV say sad and scared children have incontinence. I have incontinence. I've never seen anyone like me on TV or in movies.

I have spina bifida. I had surgery for it when I was ten years old. I have trouble moving my legs because of the surgery. I can walk, stand, and bend. But I also have incontinence. I don't know if the surgery made my life better or not.

I didn't understand that my body was different until first grade. I didn't know it was weird for a nurse to take me to the bathroom at the same time every day. I didn't know other kids weren't still wearing diapers. I didn't know that other kids didn't have to miss an entire day of school to see the doctor.

I wore clothes that hid my surgery scar and my diapers. I could pretend that I was normal.

I didn't feel disabled until I was in third grade. In third grade, an older boy saw my diaper. He followed me around at recess and called me "diaper girl." He told me only babies wore diapers. For the first time, I felt like there was something wrong with my body.

In fourth grade, I wanted to kill myself. I wanted to be normal more than anything else. But I didn't seem to fit in with the other students.

I didn't have words to talk about how I felt. I don't use a wheelchair. I'm supposed to be grateful for that. I didn't think I was "disabled enough" to let my disability stop me from doing anything. So I tried to overcome it.

I fought with my parents a lot. I told them I didn't want to wear diapers to school anymore. I said I didn't want a nurse to go with me to the bathroom. I thought that if I tried hard enough, I could just be a normal kid. But things only got harder.

It took me longer to use the bathroom. I spent all of recess trying to put in my own catheter. A catheter is a tube that helps me pee. The other kids got to play outside.

If I skipped going to the bathroom, I would have an "accident" in class. Then I'd have to walk home, change clothes, and walk back.

I felt like a weirdo. I went from "Diaper Girl" to "Pee Girl." And I just didn't understand why I couldn't get it under control. I stopped drinking water at school, but I still had "accidents." There were even times when I had finished my entire bathroom process, but if I ran or jumped—even thirty minutes later—I was embarrassed once again. Before I turned ten, I started to question whether or not I should be alive.

Doctors still had no support for me. They could not fix my incontinence.

In high school, I told a nurse I wanted to have sex. But incontinence was getting in the way. I would pee or poop when I tried to have sex with my partner. I wanted advice.

The nurse said that there would be people who would be "into that." So I could only date people who liked pee and poop?

A later boyfriend threw up after I pooped when we were having sex. He stopped answering his phone. I felt too gross for anyone to love me.

We should treat incontinence as a human rights issue. A lot of people have incontinence. If I'd had better support, I could have had a better childhood. I still feel bad about myself because of my incontinence. I've avoided sex and dating out of fear that I'll be left embarrassed and alone again. I am in a long-term relationship right now. I still wonder if and when my incontinence will be too much for my partner to look past.

I know I'm not the only person who must feel this way. Twenty-five percent of young women and 44 to 57 percent of middle-aged women also have incontinence, according to Practice Bulletins of the American College of Obstetricians and Gynecologists. That is not most women, but it is a lot of women.

Doctors can't give long-term solutions to incontinence if they're not prepared to even talk to their patients about it. 50 to 70 percent of people with incontinence don't ask for help. They are probably afraid, like I was.

I've done everything I can to use the bathroom faster. But the ways I do it are actually dangerous. I could get a bad infection.

I need at least \$50 a month to get safer supplies. I can't afford that. My health insurance won't pay for it.

If I don't self-catheterize every day, I could get a kidney infection. I could even get kidney failure later. So I pay for some supplies, even if it is not all of the supplies I really need.

These are important issues we need to talk about. I want talking about the danger disabled and incontinent people put ourselves in to be seen as normal. I want to be able to talk about my experiences without shame. I want to be able to know how people with different races, people with different amounts of money, and people with different genders are affected by incontinence. But I can't do this until it's normalized to even talk about incontinence in general.

Incontinence is not just embarrassing. It's a public health issue. And until we're able to talk about it, people who experience incontinence will always be alone and putting our health at risk.

Falling/Burning: Hannah Gadsby, Nanette, and Being a Bipolar Creator

Shoshana Kessock

Shoshana Kessock is CEO of Phoenix Outlaw Productions and a part of the immersive art installation Meow Wolf. She is a producer of live-action role-playing games, a contributor to dozens of tabletop role-playing games, the author of games like Dangers Untold and SERVICE, and a creator of multiple immersive events enjoyed worldwide.

When she isn't producing live-action games, she writes fiction, comics, and screenplays. She hails from Brooklyn, New York, and is now living in Santa Fe, New Mexico, with her nineteen-year-old cat, Lilo.

Note: This story talks about medicine and choices about medicine.

These days, I call it burning, but for most of my life, I called it flying.

It's that feeling when you're wrapped up in a writing project so hard you look up, and half a day is gone. You haven't moved. You haven't drunk or eaten or talked to anyone. You work and work until your knuckles hurt. There are words flowing out of you. You can't stop until it's all done. Then you look up, realize what time it is, and fall over because the words are done for the day and you've been doing it. You've been flying.

That's what writing when you're me feels like.

Well, a lot of the time. Some days it's just normal. I get up. I do my morning routine. This is what my morning routine looks like:

- Take my meds
- Eat
- Boop the cat
- Check my email
- Go on Facebook

And then I go to work. I check an outline, I write notes, I putter around, I get the words going however I can.

Those are the hard days at the job because that's what it is – writing, like making any art, is a job. It's craft and talent and passion rolled up into one ball. It's doing a thing you worked hard to learn to do the best you can. You're catching those weird little ideas rolling around in your head and making them into words, then lines, then paragraphs.

Somehow they're all supposed to reach out to someone who reads them. They're supposed to make someone's brain go POOF, I LIKE THIS.

No pressure or anything, writer. You do the best you can.

Then, there are the other days. The days when BLEH becomes BANG. The days when writing is easy. I call it burning these days because that's what it feels like. It feels like there's an idea inside me burning its way out.

But when I was younger, I called it flying. What I really meant was careful falling. Like there was a tornado going on and I would leap off something and ride right through the middle of it, all the way up, chasing words. I am bi-polar, and that's what it felt like.

There's a lot of folks who think bi-polar manic energy is the same thing as creativity. They point to great artists in history who lived with mental illness and say, "there it is, that energy! That's what made them great!"

Except for so many artists, mental illness didn't make them great. It made them ill. And if they weren't careful, it made them die.

Hannah Gadsby is a comedian. She has a comedy special called "Nanette" on Netflix.

In Nanette, Hannah Gadsby was supposed to get up on stage, make some jokes, and entertain us all. Instead, Gadsby took the audience from laughter to silence and ultimately to the entire audience standing and clapping for her.

Gadsby has been a queer comedian for ten years.

She started her Nanette with some regular jokes, drawing in the laughs. Then she started explaining how jokes worked. Jokes increase tension. That means they make people feel uncomfortable. Then, she gets rid of the tension with laughter.

Then, she stopped breaking the tension. And just rose it higher and higher by telling the truth.

She told the audience about a lot of things. Her family, and what it was like coming out to them. She talked about the hard and scary parts of life. She stopped trying to be funny halfway through. She talked about quitting comedy. She is a lesbian, and has trouble loving herself sometimes. She was tired of making fun of herself. She was tired of being what people laughed at.

I watched in silence as Hannah Gadsby took comedy apart, then put it back together again. She told the audience about her pain and what scared her. She was out to speak her truth. I was amazed.

In the middle of Nanette, Hannah Gadsby told people to fuck off when telling artists to “feel” for their art. It made me cry.

She talked about Vincent Van Gogh. Vincent Van Gogh had mental illness. He drank. Doctors tried to help him, but it was a long time ago. Doctors didn’t know anything about mental illness. Vincent Van Gogh wanted to succeed. He was an amazing painter, but his sickness made painting harder.

Gadsby talked about what she knows about Vincent Van Gogh. She studied art history in university, so she knows a lot about Vincent Van Gogh. He only sold one painting his entire life. It wasn’t because people thought his paintings were bad. It was because he struggled to be with other people.

I thought about when I feel manic. I thought about when I was up, but I still couldn’t write. I thought about the anger and sadness. I thought about how hard it is to talk to people sometimes, because I am thinking so many things at once.

Hannah Gadsby said artists don’t have to suffer for their art. I am thankful she had the guts to stand up and say that to the world. Because I used to believe it was true.

When I was sixteen, I was diagnosed with bipolar disorder type 2.

My family didn't really get what being bipolar meant. My parents tried to get it, but when I'd do something dangerous, it was always because I was 'bad.'

I tried to explain how it was impossible to keep my mind straight sometimes. It was hard to get up in the morning. It was hard to go to class.

When I failed in school, I tried to explain why. When I spent too much money, I tried to explain why. When I cried for days and couldn't stop, I tried to explain why. But those were the bad days. And the good days – those were the days I could take on the world. No one could stop me. I was manic. I was out of control.

I went to a therapist. My school told my parents it was a good idea. A therapist is supposed to be a doctor for your feelings. But the therapist took one look at my behavior and sent me to a psychiatrist. A psychiatrist is a doctor for your brain.

The psychiatrist was a loud and pushy man. He listened to me talk fast for fifteen minutes. Then he gave me pills.

The psychiatrist didn't tell me what being bipolar really meant. He never explained which behaviors were weird. He never explained which behaviors were because of the bipolar. He never taught me any coping skills. He gave me pills. He saw me every two weeks. I didn't know why I felt the way I did. I realized I needed to learn more.

I went online.

My family didn't know about bipolar disorder. My psychiatrist wasn't telling me anything about bipolar disorder. So I learned a lot from the internet. It was the 1990's. Everyone was in AOL chat rooms. I found a community of roleplayers. They taught me how to write. But I also got a lot of bad advice about mental illness.

I read a lot of stories about people being on too much medication or the wrong medication. I heard stories about people being locked up by their families if they didn't hide what was wrong with them. I saw the same story over and over again from people who were on medication. "If you take medication," they said, "you stop being creative. If you want to be an artist, stay away from medication. It'll kill your art."

I didn't believe it. I was taught that I should trust doctors. And besides, I knew I needed help. So I took the medication the doctor gave me.

The medication killed my creativity. It also made me sleep too much. I felt nothing. I couldn't remember anything. I gained tons of weight. Every time I told my doctor, he'd add another pill.

I had a bad doctor. I'd spend my days sleeping or staring at a television. I felt nothing. I couldn't even cry. But maybe worst of all, I struggled to write. I didn't feel creative anymore.

I was so messed up that I dropped out of high school. I got my GED. I went to college, but I failed there too. The medication made me feel slow and blank.

I could barely function. I didn't know I was badly medicated. All I knew was everything was falling apart all the time. I couldn't feel a real feeling long enough to care.

In 2002, I decided to stop taking my medication. I thought: The internet is right. Taking medication is a bad idea.

Everything got worse. For ten years, I was manic and confused. I'd go back on medication sometimes, but I'd always stop for some reason. I'd make excuses. I convinced myself I didn't feel right on the medication. I was afraid that I couldn't feel creative.

I can't say I feel bad about those ten years. I learned a lot. I feel bad about a lot of the horrible decisions I made. I feel bad about the people I hurt. I feel bad about when I got hurt.

But I remember the creative highs. I could write 12,000 words in a night. How I could map out entire books. I wrote papers. I read whole book series. I stayed up for days on end. I played games from morning until night. I never, ever saw anything wrong with my life. I thought I was being an artist. This is me. This is who I am.

I know now the truth. That was my mental illness. If I don't have medication and coping mechanisms, my life got scary fast.

From 2002 until 2012 I didn't take much medication. I didn't realize how messed up my life was.

I went back to university in 2012. My life changed. In November 2012, I had a meltdown. I had only been in school for two months. I was crying. I felt like I couldn't breathe. I went to the health clinic and asked to see a therapist.

My therapist's name was Bob. He was a very nice man. He talked to me about bipolar disorder.

Bob told me some truth about what I needed. He was surprised I'd gotten as far as I did. He listened to my fears about taking medication. I was scared of feeling nothing again.

Bob calmly explained how he was going to give me medication. We'd work together to find what worked for me.

The first day I took medication, I felt a little more calm. I called a friend. My friend was taking the same medication. I started crying on the phone. I asked him: is this what normal felt like? I had no idea it would get even better.

I have taken my medication every day for six years. I've graduated from university. I lived through brain surgery. I ended up using a wheelchair. I started my own business. I became a writer. Good things and bad things happened. I felt sure of myself.

When I write, it is not wild and uncontrolled anymore. Well, most of the time.

Not everything became perfect when I started taking medication. That would be a lie. Being bipolar is still hard. I still end up manic sometimes. My body and brain change, so the medication I need changes too.

I learned new ways to cope. life never goes the way you expect. I still have a hard time. But the day I went on medication was one of the greatest days of my life. It was the day I stopped letting my illness kill me. I stopped using my creativity as an excuse.

I did some research about artists with mental illness. Here are some artists who had mental illness:

- Vincent Van Gogh
- Ludwig Van Beethoven
- David Foster Wallace
- Georgia O'Keefe
- Sylvia Plath
- Kurt Cobain
- Francisco Goya
- Robin Williams
- Amy Winehouse

I found out a lot of artists I love are bipolar. Here are some of them:

- Maria Carrey
- Demi Lovato
- Catherine Zeta Jones
- Vivien Leigh
- Russell Brand
- Linda Hamilton
- Carrie Fisher

I love Carrie Fisher the most.

I take my medicine and I write at the same time. Artists don't have to feel hurt all the time. I don't need mania to make art. I can do that on my own.

I am going to fight mental illness for the rest of my life. But to quote Hannah Gadsby: "There is nothing stronger than a broken woman who has rebuilt herself."

The day I started taking medication was important. I am allowed to be healthy and make art. I get a little better and a little healthier every day.

Hannah Gadsby reminded me that I made the right choices. I don't need pain to make art.

Thank you for your strength, Hannah.

Six Ways of Looking at Crip Time

Ellen Samuels

Ellen Samuels is an associate professor at the University of Wisconsin– Madison. She is author of *Fantasies of Identification: Disability, Gender, Race* (NYU Press, 2014). She is working on a new book called *Sick Time: Disability, Chronicity, Futurity*.

In this story, Ellen Samuels talks about crip time.

Some people with disabilities call themselves “crips.” “Crip” used to be a mean word for disabled. It is short for “cripple.”

But some disabled people call themselves “crips” on purpose. The word “crip” belongs to disabled people now.

In universities, people learn about disability studies. Another name for disability studies is “crip theory.”

Crip theory is a way to think about disability. Where do disabled people belong in society? What do people think about us? What is our history? How do words affect how people think? Crip theory involves a lot of big questions. It can also be very confusing. People spend years studying it.

“Crip time” is an idea from crip theory. Ellen Samuels thought of it. But it is also something you already know about, a little bit.

It often takes disabled people longer to do certain things. We might need more time to get on the train. We might need more sleep. We might need more time to get work done. That is crip time.

Some disabled people are treated like children no matter how old we get. Other disabled people need canes or walkers. We need things old people need.

The way we grow up is different. We have different milestones. We do everything at our own pace.

Ellen Samuels says it is like time travel. Our lives are not straightforward. That is also crip time.

Some people become disabled later in life. Or they might have a disability that gets worse over time. It is normal to feel sad that you can't do what you used to do. It is also normal to like who you are now. Feeling both of these things at the same time can feel strange. That is also crip time.

Sometimes, disabled people need to take breaks, even if we don't want to. Our bodies are too tired and need rest.

The world tells people that we should ignore how our bodies feel. We should work hard no matter what. That is not healthy for anyone.

You might feel bad because you can't ignore how your body feels. You might feel broken. It's OK. It is better to listen to your body. Taking breaks when you need them is crip time.

How can crip time be so many things at the same time? It is a complicated idea. It's OK if it doesn't make sense to you right away. It's OK if it never makes sense. Learning at your own pace is also crip time.

Can you think of some examples of crip time from your life?

What does crip time mean to you?

Lost Cause

Reyma McCoy McDeid

Reyma McCoy McDeid is the executive director of Central Iowa Center for Independent Living and serves as treasurer for both the National Council on Independent Living and the Autistic Self Advocacy Network. She is also a single mom.

Note:

This story talks about people hurting other people very badly.

This story talks about parents hurting their children very badly.

This story talks about parents not taking care of their children.

A person in this story uses the R word.

This story talks about a woman hurting herself.

This story talks about poisoning.

These are hard topics to read about. If these are things that have happened to you or your family, they may be extra hard to read about. They may make you feel sad, scared, and angry. You can choose not to read this story if it would make you feel too sad, scared, and angry. Please take good care of yourself and your feelings.

When we are young, a lot of disabled people get told we are a “lost cause.” A “lost cause” is hopeless. Nothing anyone does will fix the problem.

My grandfather called me a “lost cause.”

He didn’t say it to me. He said it to my aunt.

My mom left me alone for five days. I was too young to take care of myself. She was at a fancy weight loss class in Los Angeles. Child Protective Services found me.

My grandfather didn’t want to take care of me. My grandmother didn’t want to take care of me.

My grandparents had adopted children in the 1970's. But those children were white. My grandparents were white.

I was their white daughter's little Black mistake.

I was also autistic.

I went to go live in foster homes.

I didn't find out that my grandfather had called me a "lost cause" until after I finished high school.

My aunt told me while we were driving on a highway. I had only known her for four years.

"I was going to take care of you, but your grandfather said not to. He said you were a 'lost cause,'" she said.

"Lost cause?" I asked.

She cleared her throat. "Well, you rocked back and forth a lot. You repeated what everyone around you said all the time. Your hair was a mess. You wouldn't stop picking at it. He and your grandma... I guess they were worried you were retarded or something."

My aunt sat up straighter. She patted my knee. "All those awards you won really show how wrong he was. Not everyone gets offered university for free. Especially if their moms die during freshman year like yours did! Good for you. I know he's proud."

"Yeah," I said.

I didn't mention autism again for nearly fifteen years.

When I was thirty-one, I went back to California from the Midwest.

I was fed up with work. I felt sick.

I'd had nearly a hundred jobs since finishing high school. I was a telemarketer for an hour and eleven minutes. I was a flight attendant for one weekend. I was in charge of a nonprofit for three months. I didn't last long at any job. I'd try to ignore that I wasn't good at talking to people. I tried to ignore all the bright lights and loud sounds around

me. I was stressed out all the time, from pretending to be neurotypical all the time. I failed.

I felt like a lost cause. So I'd given away everything I owned and gone out to Mount Shasta. I wanted to become a Zen Buddhist monk. Why not? Zen Buddhist monks just sit around all day, quietly thinking. Or so I thought. I was young and didn't know any better.

I worked at a small farm run by two rich hippies.

The commune was up the road from Shasta Abbey. An abbey is a place where monks or nuns live.

Sharon was Jewish and from Newark. But she called herself a "sturdy old Vermont Unitarian."

Kelly was the boomer son of a Belgian countess. He looked down when Sharon spoke for him. Sharon spoke often.

Sharon wrote a book and published it herself. She had a PhD from a fake university. She was working on another book about the difference between bipolar disorder and autism.

In the kitchen, she told me all about it. "You can't be autistic and bipolar at the same time! Autism is a left-brain phenomenon and bipolar centers in the right brain."

"How do you know that's true?" I asked. I stacked plates in the cupboard. Kelly sat at the kitchen table and stared into space.

"I live with Kelly and he's autistic," Sharon said. Kelly looked down.

Sharon kept talking. "Plus my mother was autistic. My daughter is autistic. I diagnosed them all. I know more about this subject than anyone else!"

I put a plate down on the counter. I looked at Sharon and said, "I'm autistic."

She looked at me like I'd thrown her plate at the wall. Then she smiled and said, "I know that. I diagnosed you, too."

I replied, "No, you did not. I was diagnosed when I was six years old. You had nothing to do with it."

Kelly looked up at me.

“It’s fine to self-diagnose as autistic. Especially women, who get missed by doctors all the time. But I’m worried. You have no training in developmental disabilities. You don’t know how to diagnose autism. You don’t know how to write a book about autism.”

Sharon walked out of the kitchen. I returned to stacking dishes.

The next morning, Sharon and I were back in the kitchen.

“The abbey will get all of my land and money when I die,” Sharon said.

Sharon opened a cupboard and took out a small bottle. She put a few tablespoons of stuff from the bottle into a glass.

Kelly walked in. Sharon handed him the glass. He drank it.

“Do you want to try some, Reyma? It helps chelate heavy metals out of your brain. The heavy metals cause autism.”

I felt like I wanted to run out of the room.

“No. I’m good.”

Later, I went back to the kitchen to look at the bottle. The label said “MSM” in big letters.

MSM is bleach. “Chelation therapy” meant giving Kelly bleach to drink.

I started being more careful. I wasn’t living somewhere safe.

I spent all of my free time in the abbey. I learned. I meditated. I gardened.

I started feeling less sick.

Then Kelly got sick. He lost weight. He felt like throwing up. He felt tired all the time. Kelly had been drinking bleach for years. It had probably made him sick.

Sharon, Kelly, and I were the only people living at the farm. We were far away from most other people. Sharon and Kelly started drinking more bleach.

I talked to a monk at the abbey. “I know Sharon gives a lot of money to the abbey, but I’m worried about—”

“Reyma, this abbey does not talk to people who are trying to cause problems,” the monk told me.

“Oh, OK.”

I left everything one week later. I went back to the Midwest. I got a job as a manager for a supported employment program. I got married.

I got pregnant.

It is harder for me to deal with bright lights, loud sounds, and strong smells when I feel sick. I have a harder time spending time with other people. I felt sick during my pregnancy.

My husband told me he didn’t want to be a parent. I moved out.

I told my boss about my autism. I didn’t have a choice. I couldn’t hide it anymore.

Everyone at my job cared about serving people with disabilities. But they didn’t want a disabled coworker. They didn’t want a disabled boss.

I was eight months pregnant. My boss told me I needed to act happier at work.

I went home and had a meltdown.

I punched my stomach once. I had forgotten I was pregnant for a second. Then I switched to hitting my head on the bathroom door over and over again.

“She’s a lost cause.”

I heard my grandfather say that every time my head hit the door.

I took a day off.

I went back to work.

Eventually, I drove myself to the hospital and had my baby.

Four days later, I drove us home.

I became the executive director of Central Iowa Center for Independent Living in Des Moines. Some people call it CICIL, because that’s shorter. My daughter was still a baby.

A week before I started, someone at my old job told me, “Good luck with that! That place is a lost cause!”

I didn’t know anything. I’d never heard of the independent living movement. I didn’t know CICIL existed before I applied for the job. I didn’t know anything about disability rights. I learned.

I went to a monthly board meeting the Saturday before my start date. It lasted six hours. Board members slept at the table. People came in and out of the boardroom to eat our donuts, or to use one of the computers in the room.

All the men quit. They didn’t want to have a woman for a boss. They definitely didn’t want to have a black woman for a boss.

A man who used to work at CICIL sued for discrimination. He felt CICIL was unfair to him.

I shut CICIL down for two weeks. We trained staff. We did a lot of paperwork. We tried to figure out if the man could sue us.

“You should start looking for a new job. This is a lost cause,” CICIL’s lawyer told me.

“I’d really love it if people would stop telling me that,” I said.

I meant it.

Since then, CICIL has won awards. It is the best supported employment provider in Iowa.

My autism helped me make CICIL great. I was willing to talk about hard problems. Racism is a problem in the independent living movement. Racism is when people are treated unfairly because of their race.

I worked to make independent living and CICIL better.

Recently, I was elected treasurer on the National Council on Independent Living’s board of directors. The National Council On Independent Living is a leading, national disability rights group. I am the first developmentally disabled person to hold such an important office.

Lost cause, indeed.

On NYC's Paratransit, Fighting for Safety, Respect, and Human Dignity

Britney Wilson

Britney Wilson is a civil rights attorney and writer from Brooklyn, New York. Her work has been featured in *Longreads* and *The Nation*, on HBO's *Brave New Voices*, and the radio show and podcast *This American Life*.

The Access-A-Ride driver pulled up on the wrong side of the street. He was fifteen minutes late for my pickup time. I was sitting outside. I was in front of the New York City office building where I work.

I stood when I saw him. I tried to get him to see me. I waved my crutches in the air.

He looked up and down the street. I wasn't sure if he'd seen me.

"Excuse me," I said to a man on the sidewalk. "do you see that Access-ARide across the street?"

"The what?" the man asked.

"The Access-A-Ride," I repeated. "That little blue-and-white bus across the street." I pointed my crutch at it.

"Oh," the man said.

I was about to ask for help, but the driver saw me. The driver put his hand up. I knew I should stay put.

"Never mind. I think he sees me," I said. "Thanks anyway."

My bus driver was a skinny older Black man. He had glasses and a graying beard. He got off the bus and crossed the street toward me. I went to meet him at the curb.

"Come on," the driver said when he reached me. He wanted me to step out into the street. There were cars coming.

“I’d rather wait for the light to change,” I said.

“Don’t worry, I’ll stop traffic for you,” the driver said. He walked into the street. He held his hand up, telling the cars to stop. I tried to cross the street fast. I was worried about tripping on something. I was worried about getting knocked over by other people.

“Take your time. I’ll make them wait,” The driver said. Said. He was trying to make me feel better. I did not feel better.

Access-A-Ride is New York City’s paratransit. Paratransit helps disabled people go places in New York.

Most people in New York use the subway. But only 20 percent of subway stations are accessible to disabled people. That is a very small amount.

Access-A-Ride is supposed to pick disabled people up and take us anywhere we want to go. Access-A-Ride is only in New York.

Access-A-Ride is not like a taxi or Uber. It is shared. That means it will pick up and drop off more than one disabled person at the same time.

Sometimes Access-A-Ride is a car. Sometimes it is a van. Usually it is a bus. All of them say “Access-A-Ride” on the side in big letters.

There are a lot of different Access-A-Ride drivers. You never know who you will get.

I had never seen this driver before.

I was born in New York. I have cerebral palsy. I have used Access-A-Ride for sixteen years.

Access-A-Ride was often late. Sometimes it did not show up at all.

I complained to family and friends a lot.

I complained on social media a lot.

I wrote a lot of blog posts.

But I did not write official complaints to Access-A-Ride.

I decided to become a lawyer. I wanted to advocate for myself and other disabled people. I am a disabled Black girl. I wanted to fight all kinds of unfairness.

I went to University of Pennsylvania Law School. Then I came back to New York. I advocated to make Access-A-Ride better. I advocated for myself and for other disabled people.

I have written a lot of official complaints since then. Official complaints work better than complaining on the internet.

I went on the local news. I wanted to tell more people about problems with Access-A-Ride. I didn't get to watch it. I was stuck on an Access-A-Ride bus instead.

I live close to where I work. It's not close enough to walk. But it is close enough to be a short drive. It should not take a long time.

The ride took two hours. I was picked up fifteen minutes late. So I missed the news.

Access-A-Ride trips usually took hours longer than they needed to. The routes didn't make sense and changed all the time.

My uncle texted me about the news.

"I'm missing it," I texted back. "I'm on Access-A-Ride, of course. Did they talk about the changes I want?"

I had recently talked at a Metropolitan Transportation Authority meeting. The MTA is in charge of all busses and subways in New York. The MTA is also in charge of Access-A-Ride.

These are the the changes I wanted:

- The routes should make sense. It should not take hours to go a short distance.
- Riders should not have to wait outside for a long time.
- Riders and drivers should talk to each other about rides. The driver should be able to call and say if he is close or far.

This is how Access-A-Ride works. Access-A-Ride riders must make their plans by 5 PM on the day before travel.

Next, the rider gets sent a pickup time. Sometimes the Access-A-Ride comes hours before the pickup time. Sometimes they come hours after. That is not fair.

Riders are supposed to wait outside for Access-A-Ride. An Access-A-Ride can be 30 minutes late and still say it is “on time.” 30 minutes late is not on time.

Riders can’t be late at all. If we are not on the Access-A-Ride in five minutes, the driver can leave without us.

One time, I was on an Access-A-Ride bus. It was cold and dark outside.

The driver stopped to pick up a rider. But the rider wasn’t outside.

After a few minutes, an old Black woman came out of a McDonalds. She used a walker.

“You’re lucky I didn’t leave you. It’s been more than five minutes,” the driver said.

“Five minutes?” the woman asked. “I’ve been waiting for three hours.”

The woman explained, “the people in McDonald’s let me sit and wait inside. I didn’t see you right away.”

The woman had three black garbage bags on her walker.

“You’re over the bag limit,” the driver added. “You are only allowed to have two bags. You have three bags. That’s what’s wrong with Access-A-Ride people. You take advantage. You’re spoiled and entitled.”

“Entitled” means to expect special treatment.

When people get called “entitled” they are just asking to be treated fairly. Some people think we have no right to ask to be treated fairly. We should be happy with whatever we get. We should be happy we have anything at all.

I was angry at the driver. He was not treating this woman fairly.

The woman told the driver about her garbage bags. The garbage bags were full of food. The food was from the store. Garbage bags are bigger than the bags from the store. You are only allowed to have two bags on Access-A-Ride. The size does not matter. The woman used big bags, so she could carry more food home.

“Do you have a mother?” the woman asked the driver. “Would you want someone treating her this way when she gets old?”

New York is one of the biggest cities in the world. Traffic is always jammed. It makes sense that Access-A-Ride takes a long time to go places.

But it is very hard for a rider to tell the driver important information. That information could make the trip shorter.

Here is an example:

A rider is waiting for an Access-A-Ride. He wants to know how far away it is. He can't call the driver. He has to call a person in an office.

The person in the office looks at a computer. The person in the office tells the rider where the Access-A-Ride is.

But sometimes the computer does not know where the Access-A-Ride is. Sometimes the computer is broken.

If the computer is broken, the office calls another office. Then that office calls another office. Then that office calls the driver.

A simple question becomes complicated.

Access-A-Ride rules for riders are very strict. If a rider cancels a trip, the rider gets in trouble.

Access-A-Ride cancels all the time. In 2015, they did not pick up 31,000 people they were supposed to pick up. That is a lot of people!

If an Access-A-Ride is more than 30 minutes late, riders are supposed to take a taxi. Access-A-Ride say they will pay for a taxi later. But they do not pay riders back for two or three months. That is not fair.

I try not to complain about bad things Access-A-Ride drivers have done. Instead, I complain about the Access-A-Ride rules. One bad driver can hurt a few people. But a

bad rule can hurt a lot of people. I am a civil rights lawyer. Fighting bad rules is part of my job.

One time, I was on an Access-A-Ride. We were driving through the Financial District in Manhattan.

“I hate driving in Manhattan,” the driver said. “Look at all the suits crossing in the middle of the street. They’re probably lawyers—crooks not looking where they’re going. Don’t you hate lawyers?” she asked.

“Yeah, sometimes,” I said. I am a lawyer. I do not tell her.

I am a short Black woman. I use crutches. Some drivers do not want to listen to me. They think my opinion doesn’t count.

Sometimes, drivers talk on their cell phones. They put it on speaker, so everyone in the Access-A-Ride has to listen to them talk. Some of what they say is personal and embarrassing. They act like no one is on the Access-A-Ride.

Sometimes drivers turn on radio stations that play rap and hip hop. If a white rider gets on the Access-A-Ride, they turn the radio off.

One time, a driver took the whole Access-A-Ride through a McDonald’s drive through. She ordered breakfast for herself. She did not offer anyone else food from McDonald’s.

These are small problems. But they show a bigger problem with the rules.

I do not make official complaints about small problems.

One time, I was riding home from work. There were only two riders on the Access-A-Ride bus. We were driving to the other rider’s house.

Suddenly, the driver started shouting swear words. He swore at the road. He swore at other drivers. He swore at anyone who was listening.

The driver turned. He faced me and the other rider. “I apologize for all the swearing,” he said.

He dropped the other rider off. We got to my house. There was no one else outside.

“I’ve got to pee,” the driver said. “I’ve had to go since I picked you up.”

Why would he tell me that?

The driver grabbed an empty cup. He walked towards me. I thought he was going to help me get off the bus.

“I’m just going to pee in this cup,” the driver said. He sat down close to me.

I was confused. Was he going to get off the bus to pee? Why wasn’t he helping me get off the bus?

The driver unzipped his pants. He took out his penis. He started peeing right in front of me.

I didn’t know what to do. Should I scream? A lot of disabled people are raped. What if he hurt me?

I needed to get off that bus.

I thought about running away. But I needed help to leave the Access-A-Ride. I could get hurt if I tried leaving without help.

The bus was right in front of my house. I was so close to home.

I was scared of the driver. What if he hurt me? So I didn’t say anything. I looked away.

The driver finished peeing.

Then he pretended like nothing weird had happened. He asked if I wanted help carrying my purse or my lunchbox.

“No, it’s OK,” I said. “I’ve got it.”

Why was he so calm? I still had questions. Why did he pee in front of me? Why didn’t he stop and use a bathroom? Why did he wait until we were alone? If I was white, would he have peed in front of me? Why did he sit close to me?

He helped me off the bus. Then, he held the front gate open for me.

“No thank you,” I said. “I’ve got it.”

I went inside as fast as I could.. I washed my hands. I wiped down my crutches. I called to make an official complaint.

After, I told my grandmother and uncle what happened.

“Man, that’s crazy,” my uncle said.

“You were alone with him. You didn’t take a video?” my grandmother asked.

“No, Grandma.” I wasn’t expecting the man to pee in my face. “I was trying not to see it.”

“Well then, there’s nothing you can do,” my grandma said. “It would be your story against his story. Who will believe you?”

I don’t know, I thought. I can barely believe it happened myself.

Gaining Power through Communication Access

Lateef McLeod

Lateef McLeod is a writer and a scholar. He published his first book of poetry, *A Declaration of a Body of Love*, in 2010, chronicling his life as a black man with a disability. You can also hear his perspective as a co-host of the podcast *Black Disabled Men Talk*, which can be heard on a variety of podcast platforms.

Adapted from “Assisted Technology,” episode three of the podcast Disability Visibility, first aired in October 2017

Lateef McLeod talked to Alice Wong on her podcast. A podcast is a kind of radio. Alice asked questions. Lateef answered them.

This story explains what Lateef and Alice talked about.

Alice and Lateef talked about using AAC. AAC is alternative and augmentative communication.

Lateef types to talk. Maybe you have a friend who types to talk. Typing to talk is a kind of AAC. Pointing to pictures or letters is also a kind of AAC.

Lateef is getting his PhD at the California Institute of Integral Studies. He wants people with serious disabilities to have more power in the world.

Lateef is writing a poetry book and a novel about disability.

Lateef does advocacy with his church. His church is the Allen Temple Baptist Church.

Lateef helps lead the International Society for Augmentative and Alternative Communication. They want to improve access to AAC.

Lateef uses a power chair.

Alice also uses a power wheelchair.

Lateef uses an app called Proloquo2Go on his iPad to talk. He types words, and then the iPad says the words for him.

AAC is a way for people with speech disabilities to talk.

Lateef started using AAC when he was six-years-old. He got a Touch Talker. A Touch Talker is a machine used only for AAC. It is big and has pictures on it.

Lateef likes using his iPad better. Machines that are only for AAC are expensive. A lot of people use iPads. iPads can do a lot of different things. iPads are less expensive.

Lateef would like AAC devices to be less expensive. He wants everyone who needs an AAC device to get an AAC device.

This is a poem Lateef wrote. Alice really loves this poem. It's OK if some of it doesn't make sense. Poetry doesn't have to all make sense. Poetry is about feelings. Try reading this poem out loud. What does this poem make you feel?

“I Am Too Pretty for Some ‘Ugly Laws’?”

By Lateef McLeod

I am not suppose to be here
 In this body,
 here
 speaking to you.
 My mere presence
 of erratic moving limbs
 and drooling smile
 used to be scrubbed
 off the public pavement.
 Ugly laws used to be
 on many U.S. cities law books
 beginning in San Francisco in 1867
 stating that “any person who is
 diseased, maimed, mutilated,
 or in any way deformed
 so as to be an unsightly or disgusting object,
 or an improper person to be allowed
 in or on the streets, highways, thoroughfares, or public places.”
 Any person who looked like me
 was deemed disgusting
 and was locked away
 from the eyes of the upstanding citizens.

I am too pretty for some Ugly Laws,
Too smooth to be shut in.
Too smart and eclectic
For any box you put me in.
My swagger is too bold
To be swept up in these public streets.
You can stare at me all you want.
No cop will buss in my head
and carry me away to an institution.
No doctor will diagnose me
a helpless invalid with an incurable disease.
No angry mob with clubs and torches
trying to run me out of town.
Whatever you do,
my roots are rigid
like a hundred year old tree.
I will stay right here
to glare at your ugly face too.

The Fearless Benjamin Lay

Activist, Abolitionist, Dwarf Person

Eugene Grant

Eugene Grant is a writer and activist in the dwarfism and disability communities.

I didn't know who Benjamin Lay was until I was thirty-one years old. This matters, because I have dwarfism. There are few books about people with dwarfism. There need to be more stories about people like me.

There are people with dwarfism in movies like Austin Powers and Wolf of Wall Street. But I do not think they are good stories. The people with dwarfism are treated like jokes. Hurting people with dwarfism is treated like a joke.

Marcus Redliker wrote a good story about dwarfism called The Fearless Benjamin Lay. It is a true story.

Benjamin Lay was born in England. He was born in 1682. That is a long time ago.

Many black people in 1682 were enslaved by white people. They were taken far away from their homes. They were forced to work on farms. White people were allowed to hurt black people as much as they wanted. A lot of black people died.

Benjamin Lay was one of the first white abolitionists.

An abolitionist was a person who wanted to get rid of slavery.

Benjamin Lay wanted to get rid of slavery. He saw it was wrong.

Benjamin Lay had a lot of different jobs. He was a sailor, a glove maker, a book seller, and a writer.

He wrote one of the first books about ending slavery. It is called All Slave Keepers That Keep the Innocent in Bondage, Apostates.

Benjamin Lay was a Quaker. He was very religious. He wanted his church to kick out people who owned slaves.

Benjamin Lay protested slavery at Quaker meetings.

Once, he hid a balloon full of red juice in a book. He stabbed the book with a sword. The juice got all over the white slave owners who were watching. They were very surprised! He told them it was blood.

Back then, a lot of white people liked slavery. They liked getting work for free. They did not care that they were hurting and killing black people.

The Quakers did not kick out people who owned slaves. They kicked out Benjamin Lay instead.

When people talk about Benjamin Lay, they do not always say he had dwarfism. Some people said Benjamin Lay didn't matter, because he had dwarfism. They called him a "little hunchback."

Benjamin Lay has dwarfism. His wife, Sarah, also had dwarfism. Dwarfism was an important part of who he was.

I like how Marcus Redliker talks about Benjamin Lay's dwarfism. He asked Little People of America for advice on how to write a good book about someone with dwarfism. People with dwarfism are treated unfairly. Marcus Redliker notices. And he talks about it in his book.

Benjamin Lay is a hero. He is a dwarf hero.

I want to have children. My children will have dwarfism too. I want to tell them bedtime stories about Benjamin Lay's life. I want to tell them about the brave things Benjamin Lay did. And when they are older, they will read Marcus Redliker's book.

To Survive Climate Catastrophe, Look to Queer and Disabled Folks

Patty Berne as told to and edited by Vanessa Raditz

Patty Berne is the cofounder and the executive and artistic director of Sins Invalid, a disability justice performance project. Sins Invalid focuses on disabled artists of color and queer and gender nonconforming artists with disabilities.

Every year, there are more disasters because of climate change. The United States government spends a lot of money trying to fight the latest fire, flood, or earthquake. But these are emergencies. The United States government is ignoring long-term needs.

The United States government is ignoring people who are treated unfairly. People with disabilities are treated unfairly. Poor people are treated unfairly. Black and brown people are treated unfairly. Women are treated unfairly. Gay people are treated unfairly. Transgender people are treated unfairly. People can be black and gay, or poor and transgender. Those people are treated even more unfairly.

There are too many stories. These are just a few:

There was a hurricane in Puerto Rico. Transgender people in Puerto Rico could not get medication they needed anymore.

There were fires in Northern California. A climate change activist lives there. She is black and queer. She has asthma. The fires made her very sick. She got a brain injury from the fires.

The world is very unfair.

Some people can buy ten houses. Other people can't even buy food.

Black and brown people are treated badly for being black and brown.

Disabled people are treated badly for being disabled.

Transgender people are treated for being transgender.

Gay people are treated badly for being gay.

Climate change is killing the world.

But we know how to keep living when things are hard or bad. We are poor. We are black and brown. We are disabled. We are transgender. We are gay.

We are good at solving problems. We've had a lot of practice. But people don't listen to us. They ignore us. They ignore what we need.

Activists fighting climate change should listen to us. We can help them survive.

Disability Solidarity: Completing the “Vision for Black Lives”

Harriet Tubman Collective

It is important to know some things about this story.

The Harriet Tubman Collective is a group of Black Disabled and Deaf leaders.

Harriet Tubman was a Black anti-slavery advocate. She was also a nurse, a spy, and a leader. She lived a long time ago. You might have heard about Harriet Tubman in school.

When Harriet Tubman was alive, many Black people were enslaved by white people. They were taken far away from their homes. They were forced to work on farms. White people were allowed to hurt black people as much as they wanted. A lot of black people died.

Harriet Tubman was born into slavery. She later escaped. She helped 300 other Black people escape slavery too.

Harriet Tubman had a disability. A white man threw a rock at her head. The rock made Harriet Tubman bleed. It knocked her out. She had seizures for the rest of her life.

Harriet Tubman was a Black disabled hero.

These are the leaders in the Harriet Tubman Collective:

- Patricia Berne
- Kylie Brooks
- Neal Carter
- Patrick Cokley
- Candace Coleman
- Dustin Gibson
- Timotheus Gordon, Jr.
- Keri Gray
- Christopher DeAngelo Huff
- Cyree Jarelle Johnson
- Lorrell D. Kilpatrick
- Carolyn Lazard
- Talila A. Lewis
- Leroy F. Moore, Jr.

- Vilissa Thompson
- Alexis Toliver
- Heather Watkins

Some of the leaders in the Harriet Tubman Collective wrote stories that are in this book.

Note: This story talks about anti-Blackness. Anti-Blackness is the wrong belief that Black people are worse than other people.

This story talks about racism. Racism is the wrong belief that white people are better than Black and brown people.

This story talks about audism. Audism is the wrong belief that hearing people are better than deaf people.

This story talks about ableism. Ableism is the wrong belief that non-disabled people are better than disabled people.

This story talks about police hurting people very badly.

This story talks about being in prison.

This story talks about murder.

These are hard topics to read about. If these are things that have happened to you or your family, they may be extra hard to read about. They may make you feel sad, scared, and angry. You can choose not to read this story if it would make you feel too sad, scared, and angry. Please take good care of yourself and your feelings.

People with disabilities are at least 20% of all Americans. That is a lot. In fact, people with disabilities are the biggest “minority” group in America.

More people in the Black community are disabled. A quarter of Black Americans have a disability.

The Movement for Black Lives is a group that advocates for Black communities. On August 1, 2016, they put out a plan. The plan talked about what is needed to build a fairer world for “all Black people.” But their plan did not talk about all Black people. Deaf Black people and Black people with disabilities were left out.

The plan is mostly good. But why was disability left out?

Police are not supposed to hurt or kill people for no reason. But they do. It happens all the time. The law makes it easier for police to get away with hurting people. A lot of the people police hurt and kill are Black.

The Movement for Black Lives wants to change the law. They want police who hurt and kill people for no reason to be fired. They also want communities to make the rules for police. They want to make the law more fair. These are good ideas.

But most people the police kill are deaf or disabled. It matters.

Children with disabilities go to jail more often than children who do not have disabilities. It matters.

Most people in prisons have mental health conditions. Most do not get any help or support for their mental health conditions. Mental health conditions are disabilities too.

Sometimes, just being Black and disabled is treated like a crime.

Here is an example:

Darnell T. Wicker was Black and deaf. He was also a veteran. Police in Louisville, Kentucky killed Darnell T. Wicker. Darnell did do what the police told him to do right away. Darnell could not hear what the police said, because he is deaf. It was not possible for him to do what the police said right away. The police shot him several times.

It mattered that Darnell was deaf and Black. The police treated him differently than they might have treated someone white.

The Movement for Black Lives did not include Black Deaf and Disabled leaders in plan writing. So the plan is missing important parts. The Movement for Black Lives needs our leadership.

We are not an afterthought.

We are here.

We are fighting for all of our lives.

We are Black.

We are Disabled.

We are Deaf.

We are Black.

Our Black Disabled Lives Matter.

Our Black Deaf Lives Matter.

We are the Harriet Tubman Collective. We are Deaf and Disabled Black leaders. The Movement for Black Lives needs to include Deaf and Disabled people.

Time's Up for Me, Too

Karolyn Gehrig

Karolyn Gehrig is a queer disabled artist, writer, and performer. She lives in Los Angeles.

Note: This story talks about unwanted sexual touching.

This story talks about a husband hurting his wife very badly.

This story talks about rape.

These are hard topics to read about. If these are things that have happened to you or your family, they may be extra hard to read about. They may make you feel sad, scared, and angry. You can choose not to read this story if it would make you feel too sad, scared, and angry. Please take good care of yourself and your feelings.

Karolyn Gehrig has a physical disability. That means her body is disabled.

Sometimes, Karolyn goes on dates with non-disabled people. "You're sexy," they tell Karolyn. But they sound confused. They think it is not possible to be sexy and use a wheelchair. Sometimes they ask Karolyn how people with disabilities have sex. Karolyn does not like that question.

Karolyn married a man who made TV shows. He would talk about how pictures shape stories. He raped and hurt Karolyn. Usually, he raped and hurt Karolyn when she was sleeping.

Karolyn told the police that her ex-husband raped and hurt her. But they did not think Karolyn would win in court.

Karolyn had proof. Her ex-husband hurt Karolyn badly enough that she needed to go to the hospital. But the police and lawyers still did not think Karolyn would win in court.

The lawyer said, "we do not think anyone will believe your husband raped you, because you are disabled."

When Karolyn was a child, she lived with her Aunt Virginia. Virginia had an intellectual disability. People used to call Virginia and other people with intellectual disabilities the R word.

Karolyn's mom took care of Virginia. She helped Virginia get dressed and eat breakfast. Then, she would help Virginia get on the bus to work.

Virginia worked in a sheltered workshop. Sheltered workshops are places that give disabled people jobs. But, these jobs do not help workers gain skills. Workers have to do the same task over and over.

Virginia was paid less than minimum wage for her work at the sheltered workshop. Virginia was usually paid \$6 a week. Virginia worked 40 hours every week. That is a full-time job.

At the sheltered workshop, a man named Freddie touched Virginia in a sexual way. Freddie also had a disability. Freddie was thirty years older than Virginia. He did not wash or brush his hair.

Karolyn does not know if Virginia wanted to do anything sexual with Freddie. Virginia could not tell the story in a way that made sense to other people. Karolyn thinks that Virginia did not like Freddie.

Karolyn's mom talked to the staff at the sheltered workshop. She wanted the staff to protect Virginia. She wanted the staff to keep Virginia safe. But instead, Virginia got fired. Even though Virginia was paid badly, she liked her job. She was upset that the sheltered workshop fired her.

Karolyn used to argue with her mom about Virginia. Karolyn thought it was wrong that Virginia was paid less than minimum wage. Karolyn tried to explain that disabled people deserve equal rights.

Karolyn's mom thought it was OK that Virginia was paid less than minimum wage. Virginia had an intellectual disability. Karolyn's mom thought intellectual disability was worse than other kinds of disability. She thought people with intellectual disabilities don't have the same rights as people with physical disabilities. She thought Virginia did not have the same rights as Karolyn.

Karolyn feels strongly that she and Virginia deserve the same rights. They both deserve to be safe. They should not be raped or hurt by other people. They both deserve to be treated fairly. Karolyn feels close to Virginia because they are both disabled.

Still Dreaming Wild Disability Justice Dreams at the End of the World

Leah Lakshmi Piepzna-Samarasinha

Leah Lakshmi Piepzna-Samarasinha is a queer disabled nonbinary femme writer and disability justice worker. She is Burgher/Tamil Sri Lankan and Irish/Roma. Leah is a Lambda-award winning author.

This is a poem Leah Lakshmi Piepzna-Samarasinha wrote. The poem comes before her story in this book.

It's OK if the poem doesn't make sense to you. Poetry doesn't have to all make sense. Poetry is about feelings. What does this poem make you feel?

Psych Survivors Know

for the people in the ICE concentration camps

Whisper to each other in the corners
 Evade capture
 Run
 Find a corner
 There is always one
 Even if it's only in your brain

You are still human no matter how much they treat you
 otherwise
 Maybe you become partially other than human
 because of what you endure
 This does not make you less
 There is also dignity in feral
 We have been here before
 We inhabit these lands
 We are with you

Bathrooms are your friends
Even if it's just five minutes
Even if it's no door

I wish we didn't have to keep
whispering
enduring
Play dead
be invisible
Disassociate
Suck cock for a phone
Organize in ways they never know how to see
bank on their incompetence
their petty squabbles over jurisdiction
them distracted by porn on a screen

Find each other again
Disappear into the sky
Memory
Dream as long
as you need to
We have the tech for it
There will be an after.
Survive for it.

Alice Wong asked me to write a followup to "Crippling the Apocalypse; Some of My Wild Disability Justice Dreams." I had a hard time writing it. It's hard to dream when you're scared, and these are scary times.

A lot of bad things have happened in the last three years. Refugees are being put in prison. The President keeps trying to ban Muslims from America. The Polar ice caps are melting. There are fires all the time.

Is the world ending?

I've been on tour with my book. My book is called *Care Work: Dreaming Disability Justice*. I often wear a t-shirt that says "The Future is Accessible" on it. The t-shirt was made by Annie Elaine Segarra. Annie Elaine Segarra is queer, Latinx, and disabled.

I want you to think about the future. We are disabled. We know accessibility is important. But we should want more than that. A lot of people have a hard time imagining a good future for disabled people.

We are disabled. One of our biggest gifts is our dreams. We are always dreaming. We have always been dreaming. We dream more than we are allowed to dream.

We don't dream about being nondisabled. We don't dream about walking. We don't dream about being just like everyone else. We don't dream about being inspiring.

We have small dreams and big dreams. I look in the mirror. My body hurts. I say, "You know what, I'm not going to hate myself today."

We dream about disabled homes. We dream about disabled communities. We dream about disabled ways of loving. We dream about disabled ways of fighting unfairness in the world. Nondisabled people can't dream what we dream.

Sometimes it feels like we are in Hell. But we are still dreaming right now. We are building disabled homes, care teams, conferences, and art projects.

I go to three care network meetings a week. The care network meetings are to support disabled friends. One friend has cancer. One friend is getting kidney surgery. Another friend has mental health support needs.

I ask for care from my friends. I accept care from friends. It is hard to do. But my friends make me feel safe.

I become a disabled middle-aged artist. I stop flying in planes as much. I learn to write and speak. I learn to share my work without having to go to Nebraska or Maine. I learn from other disabled writers and artists. They are crippling the ways we make, show, and live excellent disabled artist lives.

We're dreaming about how disabled people can deal with climate change. Climate change will hurt and kill a lot of disabled people.

Mask Oakland is a disabled and trans activist group. After the Paradise Fire and Camp Fire in California, they gave more than eighty-thousand people free masks. They made sure homeless people got masks first.

Twelve disability groups made #PowerToBreathe. #PowerToBreathe helps get generators and air purifiers to disabled people who need them. #PowerToBreathe is by disabled people, for disabled people.

We are creating Black and brown disability groups. These are groups anyone can go to and learn from.

Dustin Gibson lives in Pittsburg. Dustin put together a part of his local library. The part is focused on Black and brown disabled people. There are books by Audre Lorde and Leroy Moore in Dustin's library.

Black disabled artists are making new kinds of dances for disabled people. Alice Sheppard, NEVE, and Jerron Herman make new kinds of dances. They also dance.

Disabled-run groups are saving our asses from Donald Trump.

Too many disabled people die because of doctors and insurance.

Carrie Ann Lucas was a disability rights activist. She started the first Medical Abuse Hotline. Disabled people could call and get help if doctors or nurses were hurting them.

UnitedHealthcare was Carrie Ann's insurance company. Carrie Anne got sick. She needed a \$2000 antibiotic to live. The insurance company did not want to pay that much money. Carrie Ann died.

Talila "TL" Lewis advocates for Black Deaf and Disabled people in prison. Many of them didn't do anything wrong. They do not have access to ASL interpreters, so they can't ask for what they need. They can't tell their side of the story.

We are helping each other live. We saved Medicaid. We saved the Affordable Care Act. People still have healthcare because of us.

We stopped Donald Trump's public charge rule. The public charge rule said that disabled immigrants could not come to the United States anymore. Disabled people beat it.

Stacey Milbern is so close, she is like family to me. Stacey is queer, Korean, and disabled. She lives in Oakland. She let the Disability Justice Culture Club use her home to fight unfairness against disabled people.

Two hundred disabled people held signs that said #Irreplaceable and #NoOnesDisposable. Their protest was called "Crips and Fatties Close the Camps."

They were protesting ICE camps. ICE camps lock up immigrants. ICE locks up entire families.

Disabled people know what being locked up is like. We get locked up in institutions, nursing homes, and psych wards. No one should be locked up.

We use the internet to find each other. We plan events where we can meet, like Sins Invalid and the Disability & Intersectionality Summit.

I want to remember and remind us. All of these are huge wins. Even when we are scared, we are still dreaming about the future. And we are still making a better future happen.

Remembering the Past to Dream the Future: We Have Always Found Each Other.

“You know the kind of disabled person who just wants to help other disabled people, doesn’t ask for credit, and just wants to do the right thing?” my friend M. says to me. Of course I do. I think he is that kind of person.

M. and I used to live in Toronto. Our houses were the only houses with ramps on our block. Our neighborhood was full of poor people. People liked to hang out at his house. He made his house safe and open to people who are treated unfairly, like disabled people. He would invite everyone to come over for dinner.

M. worked extra hard for unpopular people. He cared about disabled people who are cranky, angry, or “difficult.” He wanted people who were the most alone to have a community. He wanted them to feel home.

I was giving a workshop at a community center. I was teaching people how to make care webs. A care web is when disabled people help take care of each other. I talked about how some people are expected to do a lot of work for free. I talked about trouble asking for help.

“Think of a need you have. Take a minute to think about how to get it well met,” I said.

People in the room were suddenly sad and angry.

“I noticed everyone is sad and angry. Do people want to talk about why?” I asked. And they did.

Some people did not know how to give or get care that did not hurt. Some people did not think anyone ever had. They did not believe disabled people ever cared for each other. Some people thought I had told a fairy tale.

I had a lot of different feelings at the same time. I felt sad. I forgot some disabled people did not know what good care felt like. But I also wasn't sure.

"No one has ever given you a cigarette while you were waiting for food stamps? No one has ever brought you food when you're sick?" I thought. That didn't sound true to me.

But I also understood. No one sees us unless they know where to look for us.

I thought about times other disabled people had cared about me. I thought about raising money to buy an accessible van for a friend. I thought about how we hung out without trying to "fix" each other. I thought about visiting friends in nursing homes.

Making disabled friends and community hangouts for disabled people is lifesaving.

The world pays attention to disabled people and ignores us at the same time. I thought about the special, secret ways disabled people build communities.

We don't need anyone else's money or understanding. We have each other.

Sometimes I worry about losing everything. But I remember that we have always found each other. I know that no matter how bad things get, we will always keep finding each other.

Wilder, Like Wildfires

I keep talking about wild, disabled dreaming. Here are some wild-ass disabled dreams about the future:

How will we communicate with each other? Should we make rules about the best ways to help each other?

Disabled people are going to keep making art. Black and brown disabled people are going to keep making art. Transgender disabled people are going to keep making art. Queer disabled people are going to keep making art. How can we reach out to each other?

Social media helps disabled people who are far away talk to each other. But social media like Facebook punishes us for saying things other people don't like. What if we made our own social media?

I do not want anyone to die. Death does not make me happy. But some of the white disability community is old and racist. When they die, we'll get to lead instead of them. The disability community will be better when that happens.

In twenty-five years, most Americans will be Black and brown people. Right now, most Americans are white. More young, Black and brown disabled people are becoming more comfortable with themselves. How will the disability community change and grow?

The water level is rising from climate change. Big cities cost more and more money to live in. Where will we live in the future? What will that look like?

We advocate to save Medicaid. But support workers are underpaid and hard to get. Friends can take care of each other, but not everyone has friends. What if there was a way for everyone to get the support they need from each other?

Maybe we will all be dead in five years. Maybe we will be killed by wildfire smoke. But I know we have lived through danger before. And I know this:

We have what we always have had, and more.

We know how to mourn

to pray

to persist

to find resistance in the smallest of spaces

to find each other and make homes, alone and together

to lay down in the middle of the road and keen with grief and rage and block traffic

to crip innovate to do some shit that no one says is possible

to do something wild and unexpected under the radar

to keep going.

Love Means Never Having to Say . . . Anything

Jamison Hill

Jamison Hill has written essays for *The New York Times*, *The Washington Post*, *Men's Journal*, the *Los Angeles Times*, *Writer's Digest*, *Vox*, and *Vice*. Hill was part of *Forgotten Plague*. *Forgotten Plague* is a documentary about myalgic encephalomyelitis. Hill was also part of a Netflix original series about mysterious diseases.

I dated Shannon for several months. I needed to tell her something, but I couldn't. I wasn't nervous or unsure. I couldn't speak at all. I couldn't make the right sounds.

This is our lives. I can't talk to Shannon about anything. I can't talk to Shannon about the weather. I can't talk to Shannon about her day. I can't talk to Shannon about how beautiful she is. Worst of all, I can't tell her I love her.

This was never a problem with women I dated before. They knew my voice. They heard it every day. But they never knew what I was actually thinking.

They never knew how sick my body felt. I was able to hide my illness well enough to seem healthy. I could go on dates, talk on the phone, and even drive to my girlfriend's house to spend the night.

But over time my condition worsened. Lyme disease made myalgic encephalomyelitis worse. Myalgic encephalomyelitis is a disease that can leave patients unable to speak or eat.

I'm now twenty-nine. I have been sick for eight years. In the last three years, I have been unable to get out of bed. I have been unable to speak. I have been unable to eat solid food. I used to be a body builder. I used to work out for hours every day. I got sicker fast. I couldn't care for myself. I had to put off relationships while I waited to feel less sick.

That's when Shannon came into my life.

Shannon lives in Ottawa. Ottawa is two thousand miles from my house in California. We met online. We are two people very much in love but also very sick.

Shannon has the same condition I do. She has been sick longer, but never lost her ability to speak. Instead, she feels like throwing up all the time. She has trouble eating food. She is often too thin.

She can't walk without fainting. I can't sit up in bed without a lot of pain.

I can't get out of bed, so Shannon has to come see me. But traveling can make her sicker too. Sometimes we don't see each other for months.

When we are together, we spend weeks in bed. We hold each other. Because I can't speak, we text each other.

Being sick is awful. I feel a little better because we're going through similar things.

Our lives are a little different. Shannon can get up to use the toilet and bathe. On a good day, she can make food.

But I have to do everything in bed. I brush my teeth in bed. I bathe in bed. I use the "bathroom" in bed. I use a plastic bag for poop and a bucket for pee. These are not sexy things but are part of life—my life and ours together.

I was embarrassed at first. I asked Shannon to look away while I peed. I didn't want her to think about peeing in the same place we kiss. But I know better now. It's all part of sharing our lives. Nothing about my life makes Shannon uncomfortable. I love her for that.

I have had relationships with women who became upset at anything even a little annoying. One ex-girlfriend threatened to break up with me because she thought my beard trimmings were clogging the bathroom sink. Another ex-girlfriend blamed our problems on trouble sleeping.

These failed relationships remind me that people can be very different. But also love can overcome anything, if you find the right person.

Before we started our relationship, I asked Shannon, "Do you think two sick people can be together?"

"Yes," she said. "I think when you're both sick it makes it easier and harder at the same time."

"I guess the downside," I said, "is there's no healthy person to take care of you."

"But when you're alone, there's no healthy person to take care of you, either," she said.

I had never thought about it like that. I didn't know two sick people could be in a relationship together. Two sick people can't take care of each other.

But Shannon and I take care of each other in ways. They are ways I never thought possible. I may not be able to cook for her, but I can have takeout delivered. And she may not be able to be my caregiver, but she can post an ad looking for one.

We share an understanding that only two people with the same condition can feel. We know what the other person is going through on bad days. We know how hard it is to explain feeling sick to doctors. The doctors do not believe us because they can't see what's wrong. And we know what it's like to be stuck in one place, while everyone else is moving.

Even so, we don't know everything about each other. We don't know what we were like as healthy people. We don't know the differences between who we are now and the people we were before getting sick. How have we grown up since then? How have we changed? Most importantly, we don't know what it's like to speak to each other.

Shannon has never heard my voice. She has never heard me yell at a telemarketer. She has never heard me mumble to myself after making a typo. She has never heard me mess up a dinner toast or tell a corny joke. She has never heard me whisper into her ear or come up with a funny reply. She has never heard me ask a question or speak my mind, to anyone.

And she may never get to hear me do any of these things, but that's okay. She loves me for the words I type to her on my phone. She doesn't judge me.

I never loved any of my ex-girlfriends the way I love Shannon. I wanted to tell her how much spending time together means to me. I had tried before, many times, without success.

Still, I felt I had to try again. Somehow I had to say what I was feeling without typing it. My text messages were not enough. I thought about using hand signals. I could make a heart shape with my hands? But it seemed too cliché.

So I tried to use my voice. To my surprise, I heard sounds coming from my mouth.

"I . . . love . . . you." I whispered.

"What?" she said. She looked surprised.

I took a deep breath. I tried to ignore how much my throat and jaw hurt. I started crying a little bit. I whispered again. I used all of the strength I had: "I . . . love . . . you."

“Oh, sweetheart,” she said. “I’m so sorry. I don’t know what you’re saying.”

I wasn’t sure what was worse: not being able to speak or how much it hurt to try. After everything I had been through, I couldn’t tell Shannon that I loved her.

Lucky for me, I didn’t have to. Shannon took my hand, gave me a soft kiss, and said, “You don’t have to say anything. I love you!”

Months later, it is still true: For us, love means never having to say anything.

On the Ancestral Plane: Crip Hand-Me-Downs and the Legacy of Our Movements

Stacey Milbern

Stacey Milbern is an Oakland, California/Chochenyo Ohlone-based Disability Justice community organizer and writer.

My favorite boots are socks. They are made out of brown leather to look like shoes. I call them “crip socks.” Wearing them in public as a wheelchair user is still socially acceptable. I loved these boot socks so much. I wore them every day, until two years. Two years ago, I slipped in the bathroom at work. I fell because socks do not have soles like shoes do. A nondisabled coworker had to check on me on the bathroom floor. It was embarrassing. I put the boots away. I was angry for letting myself love shoes that could hurt me.

I don’t have strong feelings about all clothes. These boot socks are special. These boots were worn by two of my personal heroes: Harriet McBryde Johnson and Laura Hershey. They were crip elders. They became crip ancestors when they died.

Some disabled people call ourselves “crips.” “Crip” used to be a mean word for disabled. It is short for “cripple.” I call myself a crip.

Ancestors are the people who came before us. Usually that means parents, great grandparents, and great-great grandparents. But sometimes it means important teachers. Our deepest relationships are with people we choose to be connected to and honor day after day.

Harriet McBryde Johnson and Laura Hershey were important teachers to me.

Harriet McBryde Johnson was an American writer and a disability rights lawyer. She went up against assholes like Peter Singer and Jerry Lewis. Her sister sewed these boots for her. Harriet’s writing meant so much to me. If I ever name a baby, I will call the baby “Harriet.” When Harriet died, her friend Laura Hershey sent the boots to me.

Laura Hershey was a queer. She was a disabled poet. She was a feminist thinker. Her poetry talks about disabled experiences most people can’t imagine. But a lot of different people still read and love her work. She is one of my favorite poets. When

Laura died, her partner asked for my address. The boot socks arrived in the mail two weeks later.

I don't know why I was sent the boot socks, but I am honored to follow Harriet McBryde Johnson and Laura Hershey. Wearing the boot socks made me feel powerful and good in my body. That's why I was so disappointed when I fell. I felt like my ancestors had let me down. Like my ancestors didn't know better, and it had hurt me. It's not fair to them, but it's how I felt.

I think about what crip ancestors are. So many disabled people live short lives. We die because of lack of healthcare or unmet basic needs. Other times the short lives are just how our bodies are.

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 bodies are only a small part of us. We need to think about our ancestors. They are a big part of who we are.

Ancestorship, like love, is big. It breaks boundaries. My ancestors are disabled people who lived looking out of institution windows. They wanted so much more for themselves. They taught me what a "good life" is. Helping other people is just as important as getting needed support. My ancestors are torn from loves by war and violence. I know the power of building home with whatever you have, wherever you are, whomever you are with. I know this because of my ancestors. My ancestors are queers who lived in the American South. It's because of them I understand the importance of relationships and place. I understand why I need to live life big, even if it is dangerous. All of my ancestors know longing. Longing is often where we connect.

I believe that our ancestors laugh, cry, hurt, rage, and celebrate with us. Most importantly, I believe they learn as we are learning, just as we learn from them. We grow ideas with them. We think about the future with them. We want the world to change the way things have always been done. We do it with our ancestors. We change ourselves with them. They learn through us. When we become ancestors, we will also continue to learn.

I think that Grace Lee Boggs loves the conversations right now about disability and what it means to be human. We need to add disability justice to social justice. Not just because it's another kind of diversity or representation, because disability justice can change everything we think about quality of life, purpose, work, relationships, and belonging. Ria DasGupta told me last week, "We can no longer afford add-and-stir politics."

I think that a lot of the women behind third-wave feminism are watching us. They are watching us learn to be who we are. Trans liberation is changing the way some of them talk about their genders. They like questions about the “ethics of pace.” “Ethics of pace” is an idea Moya Bailey created. The ancestors say that our politics are based in real life. We want loved ones to live life well. We want to have needs met. We want to experience joy. We want to love. We want to do what needs to be done. We want to feel freedom. We all want things to be better for people in the future and for ourselves. We want things to be better for our ancestors too.

Soon Carrie Ann Lucas will settle into her ancestorship. She will remind people to be brave and proud. She’ll lead wherever she is. She was a leader here. She will keep changing how we think about the world. She will keep changing how to live in the world. I wonder what she might learn from us, too.

I wear my boots. Not on days where I need to transfer standing on tile, but often. My ancestors and I are learning and loving. Together.

The Beauty of Spaces Created for and by Disabled People

s.e. smith

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The theater is dim and warm. I don't need my sweater. I hang it on the back of my creaky wooden seat. We are quiet. We wait for the lights to come up. The stage is a swooping ramp. *Descent* will be performed. *Descent* is a dance show that Alice Sheppard and Laurel Lawson created together.

I love the part of a stage show that's right before it starts. Anything might happen. All the barriers between us are gone.

Sheppard and then Lawson roll out. They begin dancing with their bodies and wheelchairs. The music rises. Michael Maag's light and pictures flow around them. The audio describer speaks in a low, steady voice. His voice mixes together with the dance and the music.

There is something sacred here.

I am a disabled person. I rarely feel belonging. Sometimes I feel put up with or included. But I do not feel like the space is mine. "This space," I whisper to myself, "is for me." Next to me, my friend has the same electrified feeling. This space is for us.

I am spellbound. I am overwhelmed. I feel something swell in my throat as I look out across the crowd.

I look at the wheelchair and scooter users at the front of the seating. I look at the ASL interpreter next to the stage. Canes hang from seat backs. A golden prosthetic leg glitters under the lights. A blind woman in the row below me turns a tiny model of the stage over in her hands. She traces her fingers along with it in time to the audio description.

"I really wish I could have crammed all my disabled peeps in there," I say later

Members of many minority groups feel this way. They feel a surprising and powerful belonging. They want to pass the feeling to other people. Some can remember their first time in a place full of people like them.

For disabled people, those places are often hospitals, group therapy sessions, and other clinical settings. That is often on purpose. We are kept apart from each other, as if more than two disabled people in the same room will start a riot or make everyone feel awkward.

It is a big deal to suddenly understand that a place is for disabled people. I cannot remember the first time it happened to me. Maybe a house party in San Francisco or an art show or a meeting of friends at a café. The experiences blend together. They create a sense of communal belonging. There is a deep rightness in not having to explain or justify your existence. I call this “crip space.”

Crip space is special. It is a place where disability is celebrated. Many parts of the world think it is inappropriate to be proud of disability. Many people think being disabled is bad. Why do we need disabled spaces? Isn't that segregation?

For newly disabled people, crip space can seem scary. Newly disabled people have just experienced a huge life change. They are not always ready for disability pride. They need a kinder, gentler introduction.

People argue about if it is good to make a space just for a minority community. Supporters say such spaces are needed. The spaces allow community members to talk to each other in a safe place. They also may say that it is empowering. This is especially true for people cut off from community

It isn't that nondisabled people are unwelcome at this dance performance. But the space has not been tailored to their needs. It is not made to accommodate them. They stand out. The experience pushes the borders of their understanding and expectations.

During the questions and answer part, the dancers roll forward. The ASL interpreter comes up behind them.

“Any questions or comments?” a dancer asks. The interpreter's hands move quickly. The audience is frozen for a moment. The disabled people are still processing. We feel a little giddy. This is a piece that speaks our common language, silently and beautifully. It reaches the deep parts of us we normally keep buttoned up and hidden away. The nondisabled people are nervous, unsure about what to say.

“I liked . . . the ramp,” one of the nondisabled people says.

Being in our space must have been an uncomfortable experience. To be on the other side of the access divide. To see disabled people dancing. To see wheelchairs do things that are impossible for people who walk on two legs.

People in power barge into minority spaces all the time. They worry that people are talking about them behind closed doors. They say these spaces divide us. They say we aren't treating allies right. These bursts of petty anger are because there is a place in the world not open to them. It shows why we need these spaces.

Claiming our own space is treated like we're picking a fight. That's why we need our own space. We need the sense of community created in crip space. But it's not perfect. There are still problems.

Some of us feel welcome in crip space. But some of us do not. There are many different kinds of disabilities. There are many different kinds of disabled people. Not everyone thinks about disability the same way.

This is the tricky thing about crip space: When we are proud, whose experience are we refusing to see? Who are we leaving out? How can we make spaces where everyone feels included? How can we make space to have hard conversations?

Crip space is fragile. It must be protected. Sometimes, that protection means giving up certain things. Sometimes it means awkward questions. But it is still very important. Everyone deserves the safety of crip space. Everyone deserves to find their people. Everyone deserves a place to call home.

After the show, we have to go back outside. It is a cold night in December. The theater is in the Tenderloin. The Tenderloin is a community that is changing. Nudie cuties are right next to hipster bars.

We cross the street. We have to go back to the world outside crip space. The barriers reappear.

A child across the street points at the group of wheelchair users. She says, "Look, Mommy!" Two adults stare. They are surprised to see an adult wheelchair user with no attendant, braving the world alone. The wheelchair user transfers into his car. He puts his wheelchair into the backseat. Then he drives away. At the BART station around the corner, the elevators are out-of-order, as usual.

About Sara Luterman



[Image description: A white, butch person with brown hair and glasses smiles for the camera. There are trees and parked cars behind her.]

Sara Luterman is a freelance writer and editor, with a focus on disability politics, policy, and culture. She writes plain language guides on complex topics, to help make those topics more accessible to people with developmental and intellectual disabilities. Topics have ranged from voting to the US federal budget process and more. This is her first attempt at translating creative nonfiction. You can find Sara's journalism in *The Nation*, *Vox*, and *Washington Post*, among other outlets.

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