

The Voices Project: Disability Script

written by Intro to Psychology students

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Roles

Narrator	Alicia Nordstrom
College student with cerebral palsy	Melanie Shepherd
Man who is blind	Rory Giovannucci
Daughter of parents who are blind	Peggy Rapp
Woman with spinal cord injury	Kit Foley
College student with femoral hypoplasia	Kayla Mellish
Little Person, Voice #1	Molly Vitale
Little Person, Voice #2	Roya Fahmy Swartz
Man with spina bifida	Eric Lutz
College student with AS	Kimmie Wrazien
Man who is deaf	Rob Williams
Teenager who is deaf (Hailey)	Tiffany Coveney
Teenager who is deaf (Hannah)	Aimee Dilucido
Son of father who is deaf	Keith Williams
College student with stroke	Brian Quinlan
Man with stroke	Todd Hastings
Daughter of father with stroke	Grace Riker
Man with arthrogryposis	Chas Beleski
Mother of teenager with arthrogryposis	Vicki Austin
Teenager with arthrogryposis	Hope Austin
College student with stuttering	Melvin Jay Busi
Man with heart/motor problems	Tom O'Neill
Man with spinal cord injury	Scott Woolnough
Mother of teenagers who are deaf	Amy Lahart

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Misericordia University, Dallas PA.**

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Daughter of Blind Parents
Woman with Spinal Cord Injury
College Student with Femoral Hypoplasia
Female Dwarf
Man with Spina Bifida
College Student with AS
Man who is Deaf
Teenager who is Deaf (Hailey)
Teenager who is Deaf (Hannah)
Son of Father who is Deaf
College Student with Stroke
Man with Stroke
Grace
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Mother of Teenager with Arthrogyriposis
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Son of Father who is Deaf

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Man with Stroke
Man with Spina Bifida
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Man who is Blind
Mother of Teenagers who are Deaf

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Alicia

Introduction

Alicia

My name is Alicia Nordstrom and I am a psychology instructor here at Misericordia University. The Voices Project first started in 2009 with a psychology assignment examining “difference” in society. I asked my students to interview people from diverse groups that crossed different races, religions, ethnicities, social classes, and more. I selected groups considered outside the “social norm” in mainstream American society that typically experience stereotypes, prejudice, and discrimination. The purpose of the assignment was for my students to learn about how being part of these groups affected their lives. My students wrote stories of their interviewee’s lives and a team of faculty members and I integrated the stories into a staged reading program.

I found that the project had a profound impact on my students, so I decided to do it again this semester, with a focus on physical disability. I chose disability as a theme because it is rarely talked about. Talking about “disability” in conversation is seen as taboo and inappropriate, which sends the message that disability is bad and should be avoided. I felt that the college environment was the ideal place for students to begin exploring their thoughts about disability before they go out into their careers and start to work with “real” people with health conditions. I worked closely with the staff at the Center for Independent Living in Scranton who helped identify volunteers to be interviewed. Students in my Intro to Psychology class conducted their interviews and wrote their stories, which we will be sharing with you today.

Many individuals with disabilities have to work harder than the average person to accomplish the same tasks. They might undergo countless hours of rehabilitation or surgeries to help their bodies return to “normal functioning”. Some have to endure endless stares in public or be asked to explain themselves to complete strangers. For the next hour, we will be the voices of individuals with disabilities, so you don’t have to. This is The Voices Project.

Labels

Voices

College Student with Cerebral Palsy

Woman with Spinal Cord Injury

Man who is Blind

Daughter of Parents who are Blind

College Student with Femoral Hypoplasia

Female Dwarf: Voice #2

Man with Spina Bifida

College Student with AS

Man who is Deaf

Teenager who is Deaf (Hailey)

Teenager who is Deaf (Hannah)

Son of Father who is Deaf

College Student with Stroke

Man with Stroke

Grace

Man with Arthrogyrosis

Mother of Teenager with Arthrogyrosis

College Student with Stuttering

College Student with Cerebral Palsy

I have cerebral palsy.

Woman with Spinal Cord Injury

I am quadriplegic.

Man who is Blind

I am blind.

Daughter of Parents who are Blind

So are my parents.

College Student with Femoral Hypoplasia

I have femoral hypoplasia with scoliosis.

[Close captioned: Femoral hypoplasia: also known as “unusual faces syndrome,” this rare condition is characterized by underdeveloped thigh bones and specific facial features (Source: National Institutes of Health)]

Female Dwarf: Voice #2

I am a dwarf.

College Student with AS

I don't usually tell people what I have.

Man who is Deaf

Signs: “I am Deaf”

[Closed-captioned: I am Deaf.]

Teenagers who are Deaf (Hailey & Hannah)

So are we.

Son of Father who is Deaf

So is my father.

College Student with Stroke

I had a stroke.

Man with Stroke

So did I.

Grace

So did my father.

Man with Arthrogyrosis

I have arthrogyrosis.

[Close captioned: Arthrogyrosis: a congenital condition in which joints are fixed in a contracted position (Source: National Institutes of Health)]

Mother of Teenager with Arthrogyrosis

So does my daughter

[Points to daughter who stands up]

Teenager with Arthrogyrosis

So do I.

College Student with Stuttering

You can't tell by looking at me what I have.

Man with Spina Bifida

I have spina bifida.

[Close captioned: Spina bifida: the most common birth defect in the US; a problem with the closure of the spinal cord or its coverings which causes nerve damage and some paralysis in the legs (Source: National Institutes of Health)]

College Student with AS

These are the names of the health conditions that our doctors told us that we have.

Man with Spina Bifida

They aren't who we are.

Man with Stroke

But they have affected our lives in different ways.

College Student with Stroke

When you see us, you don't see normal, regular, everyday people. Instead, you see...

College Student with Cerebral Palsy

A young girl in a wheelchair.

Woman with Spinal Cord Injury

An older woman in a wheelchair.

Man with Arthrogyrosis

A man in a wheelchair.

Man who is Blind

A man who can't see.

Man who is Deaf

Signs: "A man who can't hear"

[Closed-captioned: A man who can't hear]

Teenager who is Deaf (Hailey)

Girls that are dumb...

Teenager who is Deaf (Hannah)

...because they can't hear.

College Student with Femoral Hypoplasia

A short person who limps.

Female Dwarf: Voice #2

A short person who can't reach things.

College Student with AS

A college athlete.

Teenager with Arthrogyrosis

A high school athlete.

College Student with Stroke

A college student who lost her friends.

Man with Spina Bifida

A man who didn't have friends until he met other people with disabilities.

Man with Stroke

A father who was given a second chance to do something meaningful with his life.

Grace

A daughter who is helping her father learn to talk and write again.

Mother of Teenager with Arthrogyrosis

The mother of an honors student who fought to keep her daughter out of special education classes.

College Student with Stuttering

A shy college student who tries not to speak in class.

Daughter of Parents who are Blind

We are here tonight to tell you our stories.

Woman with Spinal Cord Injury

To tell you the things that you can't tell by looking at us.

College Student with Femoral Hypoplasia

To tell you the things that you won't know by staring at us.

Man with Arthrogyrosis

To tell you the things that you don't know by ignoring us.

Mother of Teenager with Arthrogyrosis

We want you to get to know us.

College Student with Stuttering

The real us.

College Student with AS

The people we are both inside and out.

Defining Disability

Voices

College Student with Cerebral Palsy

Man who is Blind

Woman with Parents who are Blind

College Student with Femoral Hypoplasia

College Student with AS

Teenager with Arthrogyposis

Man with Heart/Motor Problems

Son of Father who is Deaf

College Student with Cerebral Palsy

I define disability as anything that puts you outside the norm, and changes the way you function within the wider world. It does not change who you are but changes how you interact in social situations. I tend to view it as a negative yet it has affected me positively.

Man who is Blind

If you are not what society believes to be “normal”, then you may feel like you do not fit in, but I have come to terms with society. My belief is that everyone has some type of disability or just a different way of doing things. Everyone has their strengths and weaknesses.

Daughter of Parents who are Blind

I do not look at the word disability as negative. To me, disability is ability; it is different abilities and characteristics that someone has to offer. Everyone has a way of living, even if it is different from what society believes is “normal”.

College Student with Femoral Hypoplasia

My name is Brittney and my disability is called femoral hypoplasia/unusual faces syndrome with scoliosis, which has resulted in being only four foot one inch and walking with a severe limp. My disease is very rare and at one point, while searching for a diagnosis, the doctors told my parents that I would be nothing but a vegetable. My life had no worth.

College Student with AS

I'm Emily and I have Ankylosing Spondylitis also known as AS. AS is a lifelong form of arthritis as well as an autoimmune disease that effects my entire body. It starts in the lower back and can climb up to the neck. It causes pain and stiffness in the spinal joints and the peripheral nerves that come out from the spinal cord. I don't like it when people worry about me constantly or try and make things better for me because they feel that I'm "different." I feel that I'm just like anyone else and that I have a disease not a disability.

Teenager with Arthrogyrosis

To me a person with a disability is someone who has things they can't do and is different from most people causing them to have more challenges. Mine just happens to be physical but it doesn't affect much of my life because I just don't allow it to. I only have a few challenges in my life and they revolve around my house, some school stuff, and my way of getting around.

Man with Heart/Motor Problems

This disability that was bestowed upon me was not supposed to happen. I wanted to overcome this, continue on with my life and do the activities or events I wanted to do, so I did just that.

Son of Father who is Deaf

Something I envy about my father is that he has never expressed that he wants to be anything other than deaf. This makes me think that he does not see it as a disability, but as "I am what I am"; he would not wish it away.

College Student with Cerebral Palsy

Being disabled has made me learn a lot about myself. I am not afraid of pain because I know it will go away. I am no longer afraid of being sick. I must learn to be open to questions from different people even if they are invading my privacy. This disability has also taught me some big lessons. For example, it is okay to advocate for yourself. It is also okay to ask for help from others and have them accommodate. Also, just because I cannot control something does not mean that I have to be passive. I have become a stronger person and better at being disabled.

Normal

Voices

Teenager with Arthrogyrosis
College Student with Femoral Hypoplasia
College Student with AS
Man with Spina Bifida
Man with Arthrogyrosis
Teenager who is Deaf (Hailey)
Teenager who is Deaf (Hannah)
College Student with Stuttering
Daughter of Parents who are Blind
Man with Stroke
Man who is Blind
Grace

Teenager with Arthrogyrosis

I am a “normal” 18 year old girl. I attend a “normal” high school with “normal” people and I go to “normal” places. I do typical teenage things like go to the movies, go to the mall, and just go and hang out with my friends. I have been in a wheelchair my whole life, but nothing else is wrong with me. We got an elevator in my house, a lift for the stairs, and then changed the bathroom in my room so my wheelchair can fit. So now I can live in a “normal” house and still do things on my own.

College Student with Femoral Hypoplasia

I started dance around the age of two. When I dance I feel like I am like everyone else. I participated in ballet, tap, jazz, hip-hop, and Pointe in classes where my instructor did not treat me differently than my other friends. Dance was a place where I could hang out with my friends and escape the difficulties that I struggled with. When I went to college, I felt like an outcast in the one area of my life where I truly felt I always belonged. I was not good enough.

College Student with AS

I do not face too much discrimination in my life because, unless I tell you that I have this disease, you would not be able to tell by looking at me.

Man with Spina Bifida

School was tough for me, not going to lie. I was bullied, I was used, and it was just plain difficult. When the kids I went to school with found out I couldn't feel my legs, they would kick me. One kid kicked me so hard, he broke my ankle and I didn't find out until I got home and there was a stain of blood on my sock. The bone was sticking through and everything.

College Student with AS

The only form of discrimination I receive is from other students who see me go into our academic support center to take a test. It isn't because I am "slow" or need help. It is simply because I need extra time to take a test because I can't hold a pen or pencil for too long without it starting to bother me enough that I can't write.

Man with Arthrogyrosis

When I am in public, I receive different reactions from people. Some give me weird looks or stare. It is not in a mean way; it is just a sense of curiosity and a lack of knowledge and awareness about my disability. Some parents will tell their kids to stay away from me and say, "Don't go near him, you might catch his disease."

Teenager who is Deaf: Hailey

There is one place that I genuinely feel accepted and that is the motocross track. At the track, I am just chasing my dream like everyone else. I'm not the first girl to be deaf in motocross. It doesn't matter that, to society, I'm not "normal"; at the track I'm just like everyone else. I can race and do something that I am passionate about. There is nothing better than beating up on the boys on the track.

Teenager who is Deaf: Hannah

I am extremely involved with animals and enjoy volunteering for the SPCA. I have my own horses and am part of the Pony Club. My sister has motocross and I have this, my passion for animals. We both have our passions. They are outlets for us and give us a place to find acceptance.

College Student with Stuttering

It is astounding how oblivious I was to the fact I had a stutter. I must have first realized my uniqueness during either third or fourth grade, when a group of students interrupted my speaking by yelling “Spit it out, C-C-C-Clyde” while teasing me to no avail. After expressing my embarrassment to my mother, she intervened by letting the principal know. There wasn’t much that could be done to “fix” my pain and my stutter. I remember being the happiest child in my own world one moment, then rudely shaken by reality in the next. Although very self-conscious, I eventually became numb to the words of my peers, even though their insults stung like bees.

Daughter of Parents who are Blind

My parents gave us such a great home life that I had no idea others did not grow up the same as me. I realized that my family was different because we did not have a car. We walked everywhere or used public transportation. As a teen I was resentful because everyone around me was driving and I was still walking. One time, I was sick and my mother was going to send a cab to pick me up. I was so embarrassed and wished that we just had a car like “normal” families.

Man with Stroke

I do all the things you are not supposed to do as a stroke survivor. In order to help me walk I hike my hip, meaning I lift it up to bring it with me. I also think about walking, rather than just doing it. I sometimes tend to let my right foot drag behind me. I can do all the things everyone else does in life; it just takes me longer.

Man who is Blind

I have faced discrimination in both the community and my line of work. I have had people take advantage of me and make me feel that I cannot do something as well as them because I can’t see. It is a relief to be able to joke with my coworkers about my visual impairment or silly things that may happen.

Teenager with Arthrogyrosis

Differences don't define me. Being in a wheelchair doesn't hold me back. I still do "normal" things, like joining groups in my community. I go to a nearby college for classes even though I am only a senior in high school, I drive, I swim, I lift weights at the gym, and I go places with my friends, like the movies, the mall, and other "normal" teenage stuff. My car has a ramp for my chair to help me get into the driver's seat.

Man with Stroke

When it comes down to it, I live a normal life just as everyone else does; I just have a mishap with my one side. I do not mind if people talk with me about my disability, but it bothers me when they say, "God love you! What happened?" I also do not like Jerry Lewis shows or the MDA telethon because it is a "pity party." The children are wheeled out on stage to make others cry and give money. I want to see more of the positive aspects of people with disabilities with the focus on how the people live independently or how they contribute to society!

Grace

My mom sat in that hospital room for 37 days, only leaving for quiet hour and night to come home and attempt to sleep. She really lived her vows, for better or worse, and my parents just recently celebrated their 26th wedding anniversary. My dad didn't forget what the day was. We try to live as normal as possible. My brother and I split responsibilities; buying cards for holidays and having my dad sign them since he can't get out on his own anymore, or we'll take him out and have him pick out things to give my mom. We also find the humor in things. We have to laugh. We could be sorry for ourselves every day of our life, but that would get us nowhere.

Teenager with Arthrogyrosis

I will always get those stares and the questions, but I have to remember that there is nothing else wrong with me. I am normal, I have pride, and I am successful.

Skydiving

Voices

Man with Spinal Cord Injury

Man with Spinal Cord Injury

Twenty years ago when I was twenty one, on a cool morning when the sky was clear and the sun was shining, I was excited to go skydiving for the first time. I had taken some lessons and today was the day. I was excited but also nervous; I boarded the plane and took a seat, filled with anticipation. On my instructor's cue, I rose from where I was sitting, walked towards the open door and prepared for my jump. As I jumped from the plane a rush of excitement and adrenaline went through my body. It felt like I was flying, even though I was technically falling. I just enjoyed the view for a moment and was overcome with joy.

Seconds later, another rush of adrenaline went through my body, but for a completely different reason. As I went to pull the tab of my parachute, it wouldn't open. Frantically, I tried to open my backup chute, but that had also malfunctioned, leaving me defenseless. I surveyed my surroundings looking for the best and safest option to save myself; my choices were a group of trees or a plot of pavement. I chose the lesser of two evils, the trees. I angled myself, trying to land as best as possible with the little experience I had and braced myself for the impact. It hit the trees and that's how I broke my back, pinched my spinal cord and acquired a spinal cord injury.

[Pause]

At least, that's what I like to tell people.

[Pause]

The truth is, after a night of hanging out with my friends and drinking, I got into my car to drive home. I wasn't driving particularly fast, but I did flip my car and was thrown from it because I wasn't wearing a seatbelt. I am now paralyzed from the chest down and my mode of transportation is a wheelchair.

[Pause]

I like to tell people the skydiving story to relax them around me. I feel it's a little more interesting and a good conversation starter, and it's good for a laugh at least.

Children of Disability

Voices

Alicia

Daughter of Parents who are Blind

Son of Father who is Deaf

Grace

[Note: the lighting for this scene should be lights on the Son and Grace, but no light on the Woman with Parents who are Blind; she can read from behind the curtain or with a book light on her music stand so that she is in partial darkness]

Alicia

This year, we added in a new set of voices that were interviewed by an upper-level Psychology major in addition to the work of my Intro to Psychology class. We wanted to expand our perspectives of disability by talking with children who had a parent with a disability.

Daughter of Parents who are Blind

My father was born prematurely which resulted in him having no eyes. My mother had a degenerative visual condition with some sight throughout her childhood, but she fully lost it after giving birth to me. Both of my parents went to a school for the blind and became college graduates.

Son of Father who is Deaf

My father lost his hearing as an infant, so he could not speak many words, except for his name which was mine as well. Growing up in my family was like any other, except that if we heard my father make a noise we knew to stop in our tracks because we were probably in danger or doing something we should not have been. The rules were different when my father was watching us; we had to be more attentive. Having a deaf father made us more attentive and disciplined as children and adolescents.

Daughter of Parents who are Blind

I was the youngest child of four. My mother was innovative and put bells on our shoes when we started walking and used play pens to keep us safe. The journey of my childhood was amazing because of the love, trust, and respect each member of my family had for one another. Every day, my parents had to trust that we would go to school, that if we needed money we would take just a \$5 bill from our father's wallet rather than a \$20, and that we would put our belongings away so that our parents would not trip over them. If I wanted to, I could have gotten away with things others couldn't have.

Son of Father who is Deaf

I thought my father was Superman. He is a well-accomplished basketball player with trophies everywhere. He is in the Deaf Basketball Hall of Fame for his achievements. This may be why I never felt like my father was different. His deafness never held him back from what he wanted to do. He knew and played with the big names. Meeting Julius Erving (Dr. J) made me realize that my dad was the real deal.

Daughter of Parents who are Blind

I had to be responsible for myself and sometimes for my parents. I helped them do the grocery shopping and knew how to write out checks and balance a checkbook at a young age. My mother did the household chores and cleaning, but my siblings and I did the outside work like mowing the grass, weeding the garden, and shoveling snow.

Son of Father who is Deaf

My father worked at night and slept during the day, and most people did not really see him. He was very close with the deaf community and felt more comfortable communicating with others who were also deaf or hearing impaired. Outside of your immediate family, the deaf community is your family.

Something I envy about my father is that he has never expressed that he wants to be anything other than deaf. My father's wish would be that I am deaf too, so that we could share a special

kindred. As an adolescent, I thought he was crazy for that, but being a part of their community is such a special bond. If I were deaf, I would be closer to him. My personality mirrors my father's; we could sit for hours in close proximity and not speak. That is the nature of being with a deaf person, you have to get used to isolation. We can just exist together.

Grace

After my second year in college, my dad suffered a massive brain aneurysm. The severity of it didn't hit me until I finally got to see my dad again after the surgery that saved his life. Ventilator helping him breathe, shunt coming out of his head to release the pressure in his brain, IV's everywhere, his hands restrained to the sides of the bed and the big cotton bandage that went down the side of his head, starting at his forehead, crossing his temple and ending just above his ear. I was supposed to believe that was my dad lying in that bed. My dad, the farmer, his hands still calloused from the days work he had already put in. My dad, the coach, the one who taught me how to hit a baseball and how to fish. My dad, who would burn popcorn at 2am so he and I could have a snack while playing pool in the basement and talk about life. Looking at him laying there was just like looking at a badly battered shell of my dad.

Three days after the aneurysm, Dad awoke suddenly and was himself. Our whole family was in the hospital room and he wrote to us.

[Note: project image of Grace's father's notebook page on screen]

Unable to speak, he would give a nod of his head when we were right with our guesses, or wrong. After a line of writing he was getting frustrated because my mom couldn't guess right. Then she had him slow down and she said the single letters out loud: B-R-A-I-N, D-A-M-A-G-E. My mom then burst into tears. "No, you are not brain damaged," she said. A nurse in the room even reassured her saying to my dad, "If you can spell brain damaged, you can't be that brain damaged." Afterwards, he was holding my hand and playing with my rings on my right hand. Almost ripping them off, I kept asking him if he wanted me to take them off and he shook his head no. I think now he thought he was going to die, so he was trying to memorize what they felt like when I was the one trying to memorize every line of his hand and the color of his eyes.

He went downhill after that day. He never really opened his eyes again for a couple weeks, and three weeks later he suffered a stroke. It was 37 days in the Intensive Care Unit and 30 days at a rehab facility before we got him home for more therapy that continues today.

As a child with a parent with a disability, it still hasn't hit me yet. I know the reality, but I have my days where I think of him the way he was before the aneurysm. I think I need those days, though. And there are moments when he talks to me, that I hear his voice, instead of the usual mumbles that I have to decode. His short term memory is what has really been affected. He doesn't always remember where I am and he's still learning the date and the year. I've come to the realization, as hard as it is, good and bad things happen to everyone. You just have to keep living. I'm just lucky that he's still here and I have a dad to give me a hug and a kiss.

Daughter of Parents who are Blind

As my brother was holding me in his arms, consoling me through what seemed to be the hardest moment of my life at the time, I realized that my mother could finally see me for the first time. She could really see me and my siblings. Not only was she seeing me, but she was now my angel. She was a woman who shaped the person I had become, someone who advocates for people like her and my father. After my father passed away, I knew he was also watching down, seeing everything he always wanted to see. My parents' blindness was something that defined our family because it entered a deep love into our hearts. They were wonderful parents, hard workers, survivors, and ultimately my guiding light.

"Special" Education

Voices

College Student with Cerebral Palsy

Man with Arthrogyriposis

Mom of Teenager with Arthogryposis

Teenager who is Deaf (Hannah)

Teenager who is Deaf (Hailey)

Mother of Teenagers who are Deaf

College Student with Cerebral Palsy

On my first day of kindergarten I was placed into a Special Education class, but I was confused as to why I was putting pegs in boards all day. My mom called the school and I was moved into a regular homeroom until sixth grade. Then I was pulled out for months at a time, so it became easier to do Cyber School for high school. In college, I am able to conduct my own research, but I never get to experience things like other students. At first, I thought about living on campus, but then I got a tour of the "handicap accessible" dorms. I could not even roll into the shower because there was a step. In college, I used to have an aide that followed me around to all my classes. I hated this, and I got a lot of strange looks from students which made it hard to make friends. I told my mom I didn't want to depend on anyone, so now I do it alone.

Man with Arthrogyriposis

I went to school at the Intermediate Unit for kids with disabilities--in totally segregated classes. One time, I was talking to a friend who didn't have a disability; we were comparing math books, and they were different. The math he was doing was a lot harder than the math I was doing. For example, we were just starting to do multiplication in 7th and 8th grade, and the other kids had started doing that when they were in 3rd or 4th grade.

When I was 15, my mother fought against the Intermediate Unit to get me into a school without disabilities. The Intermediate Unit did not want us to go and told us that we wouldn't survive without their help. When I finally switched schools, I did not really need much help even though I was behind everyone else.

Mom of Teenager with Arthogryposis

The hardest part of the public school system was the administration. They thought that, because my daughter was in a wheelchair, she would need to be placed in a special education room. There was no way I would let that happen. The only thing that makes her different is her mode of transportation and her hands get tired when she writes for a long period of time. I went to the administration and demanded that my daughter get a fair education. She is now in all honors classes.

Teenager Who is Deaf (Hannah)

My mom has had to work so hard to advocate for my sister and me to get the accommodations we deserve. We have had so many problems getting the school to give us good interpreters and getting our teachers to see that we are smart. We deserve to have what we need and it seems to be a constant struggle for us.

Teenager who is Deaf (Hailey)

I hate going to school. I wish we were home schooled.

Mother of Teenagers who are Deaf

My daughters have hearing devices so they can hear others speak, but they can also read lips and are fluent in sign-language. The school system has done so many things to push my girls away, but they keep fighting and I will continue to push them. I want the school to help them to succeed in life, not to make them feel like they do not matter or are less important than other students.

Support

Voices

Man who is Deaf

College Student with Stuttering

Teenager who is Deaf (Hailey)

Teenager who is Deaf (Hannah)

Man with Spinal Cord Injury

College Student with AS

College Student with Stroke

College Student with Femoral Hypoplasia

Man with Spina Bifida

Man who is Deaf

[signed & close captioned]

From what I heard from other peers who are deaf and attended public schools, there were major differences. Could you imagine going to school and having no peers? Going through school alone, having other people ignore you, and feeling like you are an outcast is terrible. Back then people who were deaf were looked down upon.

Teenager who is Deaf: Hailey

At school, a kid walked up to me and punched me in the face—because I am deaf.

Teenager who is Deaf: Hannah

At school, people pick on me and bully me. If it was not for me sticking up for myself and my sister, we would be beaten down (emotionally and maybe even physically).

College Student with Stuttering

My peers would mock my name or the way my words came out. At times I felt so alone. I had so many things I wanted to say but I did not have the ability to do so without my stutter.

Man with Spinal Cord Injury

I lost friends after my accident, but who's to say if it was due to the accident or just the natural separation of friends moving forward in life. You definitely realize who your true friends are when you have this type of experience.

College Student with AS

My closest friends that I actually told about my disease don't know how bad it really is for me sometimes. It even can become annoying. I get frustrated sometimes when my friends complain and want sympathy for back pain. They don't come close to understand what I live with every day. Occasionally, they even try to use it to their advantage. They know that because of the auto-immune aspect of my disease I am not supposed to drink alcohol. So, they usually insist that I am the "designated driver."

College Student with Stroke

By the two year anniversary of my stroke, many of my 'so called' friends had pushed me out of their lives. My former roommate was one of the people who hurt me the most. She was getting married and asked me to be in the wedding party. But, after my stroke, she told me that I couldn't be in the wedding party because I wasn't involved in the planning. As it turned out, I never even received an invitation. I was devastated and furious. We were friends for four years and I don't even get an invite to the wedding? You have got to be kidding me.

College Student with Femoral Hypoplasia

I have been socially outcasted when I have gone out with friends to a bar. I notice that they get a lot of attention because they are pretty, and I am often not even noticed. If I am noticed, people believe I am the child of my friend or their little sister. I see people laughing at me. I've spent time talking with guys on the phone and then when I go to meet them, they want nothing to do with me because I am different. These reactions break my heart.

Man with Spina Bifida

I always got nervous around people without a disability. My hands would shake and I would get tongue-tied. In school I only hung out with people like me. I usually just kept to myself. I just didn't think people would understand what I go through with living with a disability. I still get nervous around "normal" people but it's not as bad as it used to be. I had to get used to the fact that I would be surrounded by them for the rest of my life.

College Student with Stuttering

If the people I encounter in my life are not comfortable with my stutter, than we should not be friends.

College Student with AS

My disease has affected the relationship I have with my father. My mom and dad divorced when I was young. Ever since, I lived with my mom and always spent time with my dad playing softball. Softball was our time to be close. Since my diagnoses, I haven't been able to play softball, which led to us growing apart. Softball was the only time we had together.

Man with Spina Bifida

I grew up in Texas with my mom, dad, and sister. My dad, well, he's a lawyer, and he's a "rough guy." He always thinks I'm just looking for attention because I have a disability. He also thinks that the job I have now was just handed to me. I mean, maybe it was, but I like to think that I've earned it.

College Student with Femoral Hypoplasia

My family has always been there for me. When I was unable to reach door handles and light switches, my dad moved them within my reach. Because I was too short to use the sink, my dad lowered it. My family made sure to keep the food that I liked on the lower shelves.

College Student with Stroke

My Dad is the person who really stepped up. He was there for me, whether it was helping me through rehab with doctors or on my own. Sometimes he would bring my cat Kippar to cheer me up. Kippar was my first cat and seeing him helped me recover a little bit. It was one of the many things that Dad did to make me more comfortable, and I was happy that he was willing to do those things for me.

No Limits

Voices

Man who is Deaf

Man who is Deaf

[Note: this story is to be signed in ASL and close captioned on a screen; it should not be read aloud, as the audience should “hear” it like the narrator would]

I have severe to profound deafness. I was born hearing and lost it around the age of one. My parents didn't realize until I was about two years old when I didn't react to noisy situations. My parents sent me to the Pennsylvania State School for the Deaf and I did not face any alienation going to school with people who were the same as me. The students, staff, and teachers were all deaf. For college, I attended Gallaudet University, an all-deaf liberal arts school in Washington, DC.

Once out of school, I was hired in a big company where I faced isolation. People sometimes didn't want to be bothered trying to communicate. I could read their expressions and actions and see they were alienating me. For example, if we had meetings, and there was no interpreter I would sit there lost and everyone else knew what was going on except me.

Some believe in Cochlear implants or hearing aids instead of just accepting their deafness. A Cochlear implant is a surgically implanted device that provides a sense of hearing sounds. I had only one hearing aid when I was about three or four years old. I was confused by the sounds and felt dizzy. I ended up not wearing it. My parents did not want the Cochlear implant surgery for me, because they go in very close to the brain and is very risky. I do not believe in implants. If people are deaf they should embrace who they are and learn about the Deaf culture and language.

My family is also a huge part of my life. My beautiful two daughters and my loving wife are always with me. I am the only person who is deaf in my family. My wife is deaf, and my two daughters are hearing. Their first language was sign language.

We are normal people who live normal lives without any limitations. I adapt to things and adjust like other non-disabled people do. I say I can do it, and I try not to look at the barriers. There was only one time I almost resented being deaf. When I was around hearing people I would wonder, "Why am I not like them?", but then I would say to myself "Stop, why are you being so negative, beating yourself up?" I have to stay positive and remember this is who I am and I should embrace that.

I am not the type of person who looks for pity; I am an independent person. But deaf children need to see role models that are older, and that's who I want to be. I want them to know other people with the same disability are out there, we are successful, and that they can accomplish anything that they set their minds to. I'm living proof that the Deaf can do anything.

Fighting Back/Giving Back

Voices

College Student with AS
College Student with Femoral Hypoplasia
Man with Arthrogyrosis
Daughter of Parents who are Blind
Mother of Teenagers who are Deaf
College Student with Stuttering
Man who is Deaf
Mother of Teenager with Arthrogyrosis
College Student with Stroke
Teenager with Arthrogyrosis
Man with Heart/Motor Problems
Man with Spinal Cord Injury
Man with Stroke
Female Dwarf: Voice #2

College Student with AS

I originally wanted to pursue a Medical Imaging degree. This is no longer an option for me because I got terminated from the program due to low grades. I had a flare up in my freshman year and I missed about a month of the fall semester. I received a 1.0 grade point average. When I was younger and my doctors thought my hips weren't connected, I had to go to therapy that was unbearably painful. I want to be a "Play Therapist" and help kids who were just like me.

College Student with Femoral Hypoplasia

Last year, I applied for a nursing internship at a prestigious research-medical hospital. I was questioned whether I would be able to perform the tasks of the position I was applying for. I was rejected and told I was not what the medical center was looking for. I had a feeling that they would not give me the position at the start of the interview because after hearing the person call 'Brittney', I stood to meet her and she did not even see that I was there.

Man with Arthrogryposis

At work I think outside the box. I get sticks of wood from Lowes that I call a mouth stick. I put them into my mouth, and I use the other end of the stick to type into the computer or to dial on the telephone. I can do just as much—if not more—with the mouth stick than any voice recognition program.

Daughter of Parents who are Blind

The biggest challenge my father ever faced dealt with employment. He was never able to reach his full potential because he was not always given the opportunities he deserved. My father ended up leaving a few positions because of discrimination, which is so admirable. He provided for my family and did so with his pride intact.

Mother of Teenagers who are Deaf

I have been through so much to get my children what they deserve and I will never stop fighting for them.

College Student with Stuttering

After receiving the letter about being named a high school Valedictorian, I prepared a speech that summarized my experience with stuttering. With the help of my speech therapist, I delivered my speech to an auditorium filled with people to the maximum capacity. While speaking, I felt the butterflies of adrenaline rush right through me. I stuttered on a few words, but the crowd in front of me supported the whole speech. I had difficulty looking at my parents because my mother's tears caused tears to well-up in my own eyes. Despite this, I remained focused and finished my speech and received not one, but two standing ovations.

Man who is Deaf

[Signed and close captioned]

Can deaf people drive? And have normal licenses and cars? Of course. Do you think that there are deaf pilots? Yes, there are over 200 pilots in the United States today.

Mother of Teenager with Arthrogyrosis

My anxiety was definitely magnified around the time of my daughter's birth. Why was *my* daughter born with this disability? I was told, by one of the nurses, "God doesn't give these children to just anybody." That was when I knew what my purpose in life would be. I would be my daughter's voice and advocate for everybody with a disability. I am with the parents' consortium with the department of health and on the board of directors of an agency that supports individuals with disabilities.

College Student with Stroke

When I was first recovering from my stroke, many stroke survivor groups consisted of people who were old enough to be my grandparents. So I decided that it was time for somebody to start a young stroke patient group, which is what I did. I feel like age matters when it comes to connecting with each other. We all understand what the other is going through and has been through which is why I feel that we connect so well. Meeting new friends through this group has made me feel a little bit more comfortable with dealing with my stroke.

College Student with Femoral Hypoplasia

The manager at Old Navy, where I once worked, told me that he thought he was not going to give me the job, but then he was glad that he chose *me*.

Teenager with Arthrogyrosis

I am part of a political leadership group and gave a speech at City Hall. I was in the newspaper, got to meet a judge, and want to go into the Criminal Justice field and study law. I have also done a lot of work in the Proud group speaking out for people with disabilities. I'm also part of the Youth Forum in the Department of Health. I try to get programs together for people with disabilities, such as a basketball team or swimming team for people in wheelchairs, because there just isn't anything like that in my area.

Man with Heart/Motor Problems

I drive and I even race. I had hoped to be able to take part in a NASCAR race, but they do not allow modified cars.

Man with Spinal Cord Injury

My disability provided me the opportunity to reach out to school kids about the dangers of drinking and driving. I gave hundreds of speeches at different schools. The elementary students were my favorite. They ask the best and most interesting questions. Their curiosity is great and I believe the best time to educate children on the dangers of drinking and driving or maybe even disability, is when they are younger. If I can save one person's life with my experience, my disability, or my speech, it's all worth it to me, and I'll be happy.

Man with Arthrogryposis

The title of my job at my agency is Community Organizer. I do American with Disabilities Act related advocacy for issues for people with disabilities. I was at the signing of the American with Disabilities Act at the White House when the first George Bush signed it into law.

Teenager with Arthrogryposis

I am the one who drives the car because I can do it. I go to college, even though I am only a senior in high school.

Man with Stroke

After my stroke, I majored in counseling psychology, so I could help others. Today, I am a peer counselor at an agency that helps people with disabilities live independent lives. I do things such as skills training, advocacy housing, and information referrals. I enjoy doing this because I do not want to see people suffer. Some people need to hit rock bottom so that they can understand their purpose in life. I did just that and I am here today to help others who struggle.

College Student with Stuttering

I have begun to let others see my true or “smooth” stutter without changing the words I intended to say. I am proud that I can present my stutter to strangers and acquaintances without feeling as much shame as I did in previous years. I am no longer afraid of speaking in class or giving a presentation. I have come to see that my stutter is a fact of life and it is what sets me apart from others. I have made the decision to use my disability as the gateway to my future. My speech disorder has led me to pursue a career as a speech therapist. I no longer see myself as an outsider, but a capable human being who has the will-power to always keep pushing forward.

Female Dwarf: Voice #2

A gentleman once told me I should get a bicycle flag on the back of my wheelchair because people could hold me responsible if they run into me. I said, “I beg your pardon. If you can’t see me in a wheelchair, that’s not my problem. It’s *yours*.”

My New Life

Voices

Woman with Spinal Cord Injury

Woman with Spinal Cord Injury

Tonight my husband and I are going on a date to dinner and the movies. We hold hands and we walk to the door as that sweet middle-aged couple picture. We walk to the car and it starts snowing. We stop at a stop sign just a few blocks from our home. As he starts pushing down on the gas, I turn my head and see is a car driving full speed at me.

I wake up, I can't feel anything, my sight is a little blurry. The doctor looks at his charts and says "You injured your spinal cord, some of your "c" segments are damaged. This will cause you to be quadriplegic, I'm sorry to tell you that you will never walk again."

I feel like I should be dead.

I am coming home from the hospital today. My home assistant unstraps me, wheels me to the lift and lowers it to the sidewalk. We are approaching the porch so she calls for my husband. She wheels me backwards up the steps and my husband supports the front. I can't even get into my own house without help. I am like a baby. The life I knew was over.

I have been home from the hospital for a month now. It is getting harder for me. The house is not adapted to me at all. I can't get to most household items that are too high or out of reach like the phone, the cups, the back of the fridge, and my kitchen table. My family has their own system now and I'm not in it. They refused to adapt for me because they want me to get better. I know I'm not going to get better again; why is it so hard for them to accept it?

It seems like I'm getting in the way. My son pushes my chair under the table and goes to do his homework upstairs. I pushed my plate off the table and started to cry. Soon, crying turned into

bawling. My son ran down the stairs and asked me, “What’s wrong?” I told him that I couldn’t do this anymore, that I feel useless and I’m just being a hassle. He responded in a disappointed, mad voice, “If you say that again I’m going to put you on the porch and I won’t bring you in until you think differently. We are here for you. We love you.”

I feel like a prisoner in my own home.

It’s Christmas, but it doesn’t feel like Christmas because my house isn’t decorated and I’m not cooking. We all sit around the Christmas tree and exchange presents. My daughter gives my father his present. He says, “A tie. I really needed another one of those. But what I really want is for you to walk again, soon.” I looked down at the floor as if I was ashamed, but then I looked up at him and stood up for myself. I told him that this is who I am now; what’s done is done. He apologized, telling me how he never realized what a toll it has taken on me and how he was trying to pressure me. This Christmas was the best I have ever had; I received the best present of all: support.

A few years have gone by and all my children have moved out. I am homebound to the first floor of my house. My house feels emptier than ever. My attendants come around more often now but I still feel distant in all my relationships. I call John into the room. “John, I have been telling you for a while now that it is okay to leave me. You didn’t sign up for this.” He hesitated and then said “but, honey, I did this to you, I drove the car.” I looked back at him and told him I wanted to leave. He didn’t ask why because he already knew.

My son helped me move in to an apartment and I love it here. The people understand me. I decided to go to college. I wake up every morning at five am for my nine o’clock class. It takes me about four hours to get to school, which is only a few minutes away. I graduated with my psychology degree and volunteer to help other disabled people.

In the end I am normal, I am happy, my disability is what it is. I am like you, a person, a life.

Internal Struggles

Voices

Alicia

Female Dwarf: Voice #1

Female Dwarf: Voice #2

Alicia

All of the stories read tonight are based upon interviews that my students conducted with a community member who was willing to share their life experience. I asked the students to capture the thoughts, emotions, and beliefs of interviewees as best they could. One interviewee, in particular, described her social and emotional experiences in great detail. This story had deep layers that, at times, reflected very different themes and messages about disability and its outcomes. We asked two different readers to read this story so that we can illustrate the contradictions that we all struggle with, within ourselves.

Female Dwarf 1 and 2 (in unison)

My name is Charlotte. I am 64 years old, and I am a dwarf.

Female Dwarf: Voice #1

Growing up as a dwarf was just the same as a normal person. I was born into a dwarf family and raised with kids who were normal sized, so for the longest time I felt no different from the other kids. I never let my disability hold me back.

Female Dwarf 2

Growing up in a big world has been a life long struggle for me. Not only was it a struggle for me to do things for myself, but also it was a struggle to watch and see people do things for me.

Female Dwarf 1

I attended girl scouts and did normal activities. In school, I had people who accepted me and people that didn't, but I made the best of it. . . . I faced a lot of discrimination in my years but I usually never let it get the best of me.

Female Dwarf 2

I had grown up with a lot of teasing, people always saying “ooh look at the midget”. Little kids came up to me and asked why I was small and I used to joke about it saying “god made me little ... because there has to be some little people in this big world”.

Female Dwarf 1

When people judge me or call me names, I never let it bother me directly . . .

Female Dwarf 2

. . . but I always felt bad for the people I was with. I was embarrassed for my friends, but they told me they were never embarrassed. They said they saw me as one of them. Even when my friends said I wasn't different, I still felt different.

Female Dwarf 1

Just like my mother I was able to raise a family on my own. I got married to my husband who is a normal sized man. We had two kids. My son is a dwarf and my daughter is 5'6. I raised my kids just how any other parent would raise their children.

Female Dwarf 2

Having a son who is a dwarf was difficult. It was hard putting him in and taking him out of the crib, or the carriage. And my daughter got to the size when I couldn't hold her, and when her legs were longer than mine and I couldn't chase her anymore.

Female Dwarf 1

I don't like having people do things for me, so my friends and family always wait to give me help until I ask for it. They are never condescending when I ask for help.

Female Dwarf 2

I was always the one who took care of other people, and now my husband has to do everything for me and I can't stand it. They want to do it for me, but I know they will eventually get tired and not want to help me anymore.

Female Dwarf 1

When I did have a job, I gave it my all so I could prove that just because I am small doesn't mean I can't do what normal people could do. I never missed a deadline. I like working because it makes me feel like I am accomplishing something for other people.

Female Dwarf 2

Having a job was never easy. Looking for work was hard, having people look at you and know they are thinking, "what can you do?" Most of the time I would fill out an application and the people would say, "Oh we will get back to you." But I knew, when I turned, exactly where that application was going.

Female Dwarf 1

Being constantly judged and having people make comments was always difficult, but I never let it get the best of me. I never let it bother me.

Female Dwarf 2

When my sister was getting married, we were in the store looking at stuff for the wedding. There was a group of women standing in a circle talking, staring at my mother and sister, and saying "look, look at the midgets!" I walked up behind them, tugged on one of the gentlemen's coats and said "You wanna look at a midget, take a good look! Want me to turn around so you can see every part of me? Go ahead, take a good look!" They turned around and walked away, and there I was standing, shaking in my boots, still in disbelief that I had stood up for being small. When you are small, you are used to hearing things from little kids. But having grown adults making comments because someone is different than they are, I couldn't stand it.

Conclusions

Voices

Man with Spinal Cord Injury

Teenager with Arthrogryposis

College Student with Stroke

Man with Stroke

Man with Spina Bifida

Man with Heart/Motor Problems

Man who is Blind

Mother of Teenagers who are Deaf

Man with Spinal Cord Injury

My disability taught me about life and about myself. I got used to my new life. In high school I wasn't able to play basketball because I wasn't good enough, but now I play in a wheelchair league and I love it. It's really nice to be able to do something that I wasn't able to do before.

Teenager with Arthrogryposis

One thing that is different about me is my mode of transportation. You might walk between here and there but I just roll. There just isn't that big of a difference. It affects me when I have to go places that aren't wheelchair accessible because I can't go into that store, or I can't go with my family. That is really the biggest struggle and I wish more places thought about people in wheelchairs.

College Student with Stroke

I was just weeks away from finishing my psychology degree when my stroke happened. I realized that I was going to have to start my life again, basically from scratch. Walking, talking, eating, driving, swallowing, balancing, bladder control, writing, and so many other things were all foreign concepts to me. I had no recollection of how to do any of these things. I had no idea if I ever would be able to do these things again. The longer I rehabbed and the more coherent I became, the more I realized that I did not know what to make of the stroke. But at the same time, I was fortunate to recover as much as I did. The feeling is hard to describe. I wasn't happy, I wasn't sad, but I was not content either.

Man with Stroke

The stroke I had was the worst possible, so I am lucky to be where I am today. I never said, “why me” or “I wish this never happened.” I just accepted it and moved on with my life.

Man with Spina Bifida

This is my life and everything I’ve been through. This is who I am and I wouldn’t change anything about it.

Man with Heart/Motor Problems

My disability was not a disability to me, but an inconvenience more than anything. I can do most of what others can. I refuse to let my inconveniences get in my way. I am now 69 years old, living on my own, and living such a life that I could not ask for more. I will not let the little things bother me. You can do whatever you set your mind to.

Man who is Blind

If I had the opportunity to wish away my blindness, I would, but who wouldn’t? I would because I had the opportunity to see for many years and I know what I am missing.

Mother of Teenagers who are Deaf

If I had one wish, it would not be to change my girls. Being deaf is who they are. My wish would be to change the people around them. People can be so awful, and I would wish that they could just be accepted by others.

College Student with Stroke

I think to myself, that this was not the plan; this is not where I am supposed to be. Right now I should be married, living with children in my own house. Not here, in an apartment. I think how so many of my friends or former friends are happily married and I just get frustrated knowing that should be me. I should already have the psychology degree that I want. I should have a steady job by now. But no, I don’t. I had a plan.

Teenager with Arthrogryposis

My disability has affected me in a positive way, and has only made me a stronger person. I am a more mature person because of my wheelchair. I am proud and love what I have made of myself. I would never change anything about my disability.

College Student with Stroke

To this day, almost ten years after it occurred, I still do not know if I consider my stroke a blessing or a burden. Sometimes I am content with where I am, but other times I just want to go back. I want to know what my life would be like if I never had my stroke. I will never know, but maybe it is for the better. But then again, maybe not.

Resolution

Alicia

Society has a fear of “difference”. We like things and people who are familiar, and the more we have in common with others, the more we feel connected to them. The problem is that the people who have the most characteristics in common set the “social norm,” which becomes the rule and standard of how things should be, including how people should look, act, talk, and think.

For individuals with disability, some may be able to remain in the social norm, by hiding their disability or through rehabilitation. Others simply can't—their body will not allow it. The question is, what does it matter? Why do we—in society--make judgments about a person based on what your body looks like or does? The social norm is that we are expected to have “ability”—the ability to walk in an upright posture with even distribution of weight across our legs. We are expected to have perfect senses of vision, hearing, smell, touch, and taste. We are expected to speak in a rate and pace that is very specific, not too fast or slow and with no bumps or stops. We are expected to be within a specific height and weight range to be considered “attractive”. And we cannot have any health conditions that may slow down or inhibit movement, or else we will begin to seem lazy or weak and unproductive.

Who can possibly fit these criteria? What person can do all of these things? How many of us have poor vision and need “corrective” eyewear? How many of us have broken bones or lost our ability to speak, move, or get out of bed? How many of us have a health diagnosis that we don't advertise to others, but affects our

energy levels, mobility, and may cause pain or discomfort? At some point in our lives, we will all have a disability. So, for those of us who are “able-bodied” at the moment, we should realize that we are already members of the disabled group, or will be joining this group in the future.

If so many of us have, or will have, a disability, then why isn't having a disability the norm? Why isn't it just expected that people have different bodies that function in different ways? Why are we trying to live up to a standard of physical perfection, when that is just impossible, and none of us can do it.

When people hear ‘disability’, they usually think limitation and impairment. So, who decides what it is that people with disabilities can't do? For most people, the greatest limitations experienced by people with disabilities are not due to the disability itself. They are from the social and emotional barriers placed on them by people in society and the constraints of the physical environment. These limitations are created by the “able-bodied” and make people with disabilities feel inferior, as if they lack “ability”. People in wheelchairs can get anywhere they need to go, except when their chair can't fit into doorways, or under tables, or up onto a curb. The concept of “accommodation” means to adjust the environment to match the person's needs. A person who is deaf needs an interpreter for communication. A person who is blind uses a cane or guide dog to move around their environment. What does it matter if a person needs these things or not? It reflects difference, that's all. But we are so used to thinking like the social norm—that we all have to act in one particular way, the “best” way. There is no “best” way that is best for everyone.

Perhaps, starting now, we can begin to think about what is the “best” way for each person, and stop assuming that everyone has to be the same. People with disabilities are confined by society, not their disability. The world privileges the “able-bodied;” those who can walk up stairs, talk perfectly, see and hear, and move all appendages without assistance. For those that can’t do these things, you need to figure it out on your own; it is not our problem.

As future brothers and sisters of disability, it is our problem. Everyone’s problem.

Some people say, “that’s just the way society is, get used to it.”

We are society.

We are the ones who set the social norms, and we can change them.

We can remove the judgment from disability.

We can start seeing people as different, and realize that difference adds quality to our lives.

We can make sure that the physical environment, and our behavior, allows everyone to be included.

My guess is that you would do these things for someone in your family.

Well...welcome to the family of disability.