What Do You See? Perceptions of Disability

iris.peabody.vanderbilt.edu/module/da/challenge

Challenge

View the movie below and then proceed to the Initial Thoughts section (time: 1:29).

Video Player

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01:28
Use Up/Down Arrow keys to increase or decrease volume.
Credits

Music

Shutterstock

Photography

- Benjamin (little boy with red cups) is courtesy of the IRIS Center.
- John Cronin is courtesy of John's Crazy Socks.
- Michael Hingson is courtesy of Michael Hingson.
- Dylan, Mia, and family is courtesy of the IRIS Center.
- Tony Melendez is courtesy of Tony Melendez.
- Russ and Melody Stein is courtesy of Russ and Melody Stine, photograph by Clare Cassidy Photography.
- Kathy D. Woods is courtesy Kathy D. Woods.
- The Smith family is courtesy of the IRIS Center.

- Jay and the Music City Thunder is courtesy of the IRIS Center.

Description

The Challenge movie displays eight photographs that then combine to form a collage. A description of each image follows.

- Picture One: A young boy smiles while holding two red plastic cups over a tub filled with dried beans.
- Picture two: A young man with Down syndrome poses in front of a banner advertising a business.
- Picture three: A middle-aged man pets his service dog.
- Picture four: A family of four—a woman, a man, and a young boy and girl—smile for a photograph in their home.
- Picture five: A man without arms plays a guitar on stage using his bare feet and toes.
- Picture six: A man and a woman in chef's coats pose outside a restaurant on a city street.
- Picture seven: A woman of short stature poses in front of a rack of clothing on a floormat emblazoned with a business logo and the name "Kathy Woods."
- Picture eight: A family of four—a woman, a man, an adult son, and a teenage son—pose together for a photograph in their home.
- Picture nine: A young boy in a wheelchair plays basketball.

The movie ends.

Here is your Challenge:

- What feelings did you have about the photos?
- What thoughts did you have about the individuals in this challenge?
- Do perceptions matter?

What Do You See? Perceptions of Disability

iris.peabody.vanderbilt.edu/module/da/cinit

Initial Thoughts

Write down your initial reactions to the pictures you have just seen by answering these questions:

What did you see?

What feelings did you have about the photos?

What thoughts did you have about the individuals in this challenge?

Do perceptions matter?

When you are ready, proceed to the Perspectives & Resources section.

What Do You See? Perceptions of Disability

iris.peabody.vanderbilt.edu/module/da/cwrap

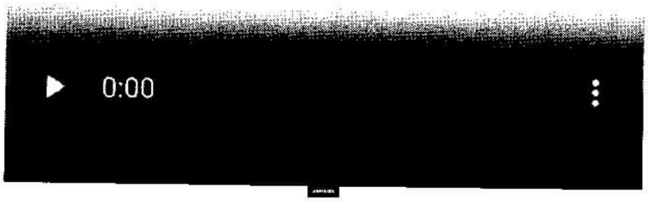
Wrap Up

Throughout this module, you were introduced to a number of people with disabilities and learned a little about their abilities, interests, and challenges. Like people without disabilities, they may attain higher education, be successfully employed, and take part in social and community activities. You also learned that our perceptions about people with disabilities can be shaped by cultural backgrounds and experiences, media portrayals, and common misperceptions. These perceptions, in turn, influence our treatment and expectations of people with disabilities.

Our perceptions can also influence the language we use when interacting with or referring to people with disabilities. Moreover, language shifts and changes over time so that words that were once considered inoffensive or neutral may later take on meanings or connotations that are no longer considered acceptable or are even regarded as offensive. To address this issue, most disability communities encourage the use of *people-first language*, a positive, respectful way to refer to individuals with disabilities.

Listen to sculptor Michael Naranjo share his experiences (time: 5:11).

Video Player



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05:10

- ● None
- ○ English

Use Up/Down Arrow keys to increase or decrease volume.

Credit: KNME TV

View Transcript

Transcript: Wrap Up

After I looked at the Moses, two years later I got to look at Michaelangelo's David. As I was on top of the scaffolding and started to feel the David, I started to cry. My dream again had come true.

And so as I looked at him… I looked at his eyes and the beauty of the eyes. His eyelids were just incredible—the tear ducts in the eyes, in the corner of the eyes, that no one was going to see from down on the ground from the floor looking up. They're there hiding in the corners of the eyes, the pupils of the eyes that look like hearts.

His lips, his lips are soft, they're so soft that you can feel the heart beating, pumping, pushing this blood through his lips. And his lips look like they're going to open any second and he's going to start talking. The veins in his neck are bulging from the adrenaline that he's feeling of looking at Goliath standing in the distance. And his hands, the tension in the hands on holding the rock.

This hard cold stone was so soft, so warm that you could just feel the bones, you could feel his heart in there maybe pumping and beating. And it was just amazing to feel this flesh of a man 18 feet tall.

The last thing that I remember seeing was a Vietcong through the end of the sights on my rifle. And he was looking for some more of my friends, my fellow soldiers to shoot at, and he suddenly turned his head towards me, and we were 20 yards apart. He looked at me, and I could see his eyes. I just remember seeing his eyes. Our eyes met; our eyes locked. And in two seconds, we knew what was going to happen. I put the sights of my rifle right at him and I shot. And at that moment after shooting, my friend who was right behind me said something. And so I ducked, and a grenade rolled into my hand. I let go of my rifle and I pulled my hand back away from this grenade, and it exploded and I was suspended. And I was blind.

The name of this piece is the "Taos Deer Hunter," and the man on the bottom is the clown and he plays the part of the hunter. And the man thrown over his shoulders is the deer hunter and he's a dancer that the clown shoots with his willow bow and straw arrows. And once he shoots him, he puts him over on his shoulders. And the hard part about this piece was getting the balance. And the way I got the balance for that "Taos Dear Hunter" was I had to put something up on my shoulder. And the only way I could get it done was by putting Lori up there. ([To wife] Come here honey. Let me show them how. Lean over.) It gave me an idea that I really didn't lean forward but I had to arch my back backwards to get that balance just right.

I don't think that I am disabled. I don't have a disability. I don't have time to have a disability because I'm working too much, too hard, and I'm having too much fun doing what I'm doing. And I haven't got time in my life to think/ feel disability; to think blind.

Revisiting Initial Thoughts

Think back to your initial responses to the following questions. After working through the resources in this module, do you still agree with your Initial Thoughts? If not, what aspects of your answers would you change?

What did you see?

What feelings did you have about the photos?

What thoughts did you have about the individuals in this challenge?

Do perceptions matter?

When you are ready, proceed to the Assessment section.

What Do You See? Perceptions of Disability

iris.peabody.vanderbilt.edu/module/da/cr_assess

Assessment

Take some time now to answer the following questions. Please note that the IRIS Center does not collect your Assessment responses. If this is a course assignment, you should turn them in to your professor using whatever method he or she requires. If you have trouble answering any of the questions, go back and review the Perspectives & Resources pages in this module.

In this module, you have had the opportunity to examine your attitudes and perceptions about people with disabilities. As you watch the movie below, take note of how you react to the images as they appear on your screen. When you are finished, complete the related questions (time: 1:37).

Video Player

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01:37
01:37
Use Up/Down Arrow keys to increase or decrease volume.

Description

The assessment movie displays nine photos of students, both with and without disabilities. Each photo is displayed individually at first but then recedes into a collage as the movie progresses. A description of the photos follows.

- Picture one: A male student smiles as he sits in his wheelchair in the library.
- Picture two: A female student smiles while holding a coloring pencil.
- Picture three: A male student with Down syndrome smiles holding up a tablet.
- Picture four: A young female student sits on the floor reading a book in braille.
- Picture five: A male student looks intently at the tablet in his hands.
- Picture six: A young girl with a backpack on her back smiles holding a book.
- Picture seven: A young male student with a hearing aid reads a book.
- Picture eight: A female student smiles as her arms are folded across a stack of books.
- Picture nine: A male student sits outside in his wheelchair holding folders in his right hand and a pencil in his left hand.

The movie ends.

1. Some of these children have disabilities. Do you think people's perceptions of children with disabilities play a role in their success? Why or why not?
2. Based on your own perceptions, how would you feel about having these children in your classroom?
3. If you were put in charge of a movie production about a person who is blind, what type of perceptions would you want to make sure your film portrayed?

Page 1: Learn More About the People in the Challenge

iris.peabody.vanderbilt.edu/module/da/cresource/q1/p01

Now, what do you see?

On this page, you'll find the people you met in the Challenge movie. Take a moment to learn a bit more about them and reflect on this new information. Did learning more change your initial perceptions about them? If so, how? If not, why not?

- **Benjamin** is a happy, loving three-year-old who happens to have autism spectrum disorder (ASD). Here Benjamin takes part in one of his favorite activities, repetitively scooping dried beans from a tub and dumping them back in again.

- **John Cronin**, a young man with Down syndrome, began contemplating what to do with his life during his last year of high school. Inspired by World Down Syndrome Day, a celebration that encourages participants to wear "crazy" socks with bright colors and loud patterns—one of John's passions—John and his dad founded John's *Crazy Socks* in 2016. Not only has the business exploded, it has offered job opportunities to people with different abilities. *Photo is courtesy of John's Crazy Socks,* https://johnscrazysocks.com/

- **Michael Hingson** was working as a regional sales manager on the 78th floor of the World Trade Center on September 11, 2001. He and many of his co-workers were able to evacuate the building safely because of Michael's guide dog Roselle. Michael wrote a best-selling book about his partnership with Roselle—*Thunder Dog, the Story of a Blind Man, a Guide Dog, and the Triumph of Trust at Ground Zero*—and served as the National Public Affairs Director for Guide Dogs for the Blind. He now tours the United States as a motivational speaker. *Photo is courtesy of Michael Hingson*, https://michaelhingson.com/

In the video below, Michael explains how Roselle helped so many people on 9/11 and also discusses the importance of positive attitudes and perceptions toward people who are blind (time: 3:22).

Watch Video At: https://youtu.be/Rzf39fRYxM8

View Transcript

Reporter: Michael Hingson and his guide dog have no problem with escalators. Michael has been blind since birth but he can get along just fine pretty much anywhere. On this day he's speaking to the California State Association of Counties. He's telling these government leaders how he finally convinced a computer company to hire him as a salesman.

Michael: Because as a blind person I have had to sell all my life just to be able to function. I've had to sell to be able to ride a school bus. I've had to sell to sell to be allowed to go on an airplane with my guide dog.

Reporter: Michael eventually became regional sales manager for that company.

Michael: I ran the office. I had staff. I had their people call my people and we did lunch every so often.

Reporter: Ten years ago he was working on the 78th floor of the World Trade Center when terrorists flew one of those planes into the building. Michael's co-worker could see fire out of the window.

Michael: We said good-bye to each other because we thought we were going to take a 78th floor plunge to the street.

Reporter: Michael's guide dog Roselle was there too. Around the office people began to panic.

Michael: But I knew something that nobody else was observing which is that my dog wasn't acting afraid or indicating that she was nervous in any way.

Reporter: That was enough to help Michael calm other workers. In the last ten years he's told the story of the harrowing trip down the stairs hundreds of times. One of the worst moments was when they finally got outside.

Michael: We heard this rumble that quickly became this deafening roar.

Reporter: Tower two collapsed. The dust cloud engulfed them. Now no one could see, and they could hardly breathe. They moved forward trying to find a way into a building that was just to their right.

Michael: So I kept telling Roselle right right and give her a hand signal and kept saying right right. And I was listening for the opening if there was an opening to go into. Suddenly I heard it obviously Roselle saw it she turned took one step to the right and stopped.

Reporter: It turned out they were at the top of the stairway into a subway station. Roselle's abrupt stop saved them from falling. Then she helped guide them down to safety.

Michael: You know it's teamwork um in every sense of the word.

Reporter: Michael lives in Novato (CA) now but (Michael: Thank you.) travels the world (Michael: I've got to go catch an airplane.) giving talks about the importance of teamwork. Sadly Roselle died earlier this year at the age of 13. Now a new dog is helping Michael advocate for the blind.

Michael: We live in a country where the unemployment rate among employable blind people is 70 percent.

Reporter: Michael has a master's in physics. He's written a best selling book. He and Roselle were celebrated as heroes. Still he says he's not that unusual. With a little help from a good dog and good technology

Michael: This device I have here is called a Note Taker.

Reporter: Most blind people can accomplish a lot if you just give them a chance.

Michael: Blindness isn't the handicap. A handicap consists of the poor attitudes and misconceptions that people have about blindness.

- **Dylan** is an extremely bright 13-year-old boy who enjoys playing games on his computer. **Mia**, his 11-year-old sister, enjoys spending time creating detailed artwork and playing with her pets. Both siblings have autism. At age 10, Dylan—who has an exceptional ability to recall past conversations, things he has seen, and things he has read—was diagnosed with ASD. Mia was diagnosed at the early age of two because she was not meeting developmental milestones. Although Mia recognizes facial expressions, she still has difficulty understanding the intent of others in social situations.

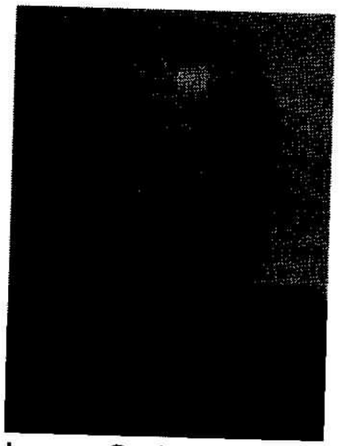
- As a result of his mother taking thalidomide, a drug prescribed to reduce the symptoms of morning sickness during pregnancy, **Tony Melendez** was born without arms. A multi-talented songwriter and entertainer, Tony plays the guitar using his feet. Mr. Melendez has entertained audiences around the world, including several performances for Pope John Paul II, and he has been the recipient of dozens of awards, commendations, and honors, including from former President Ronald Reagan. Tony continues to release music through his company, Toe Jam Music. *Photo is courtesy of Tony Melendez*, https://www.tonymelendez.com/

- **Russ and Melody Stein**, a deaf couple, own a four-star restaurant and pizza truck in San Francisco. In 2020, they will open a new pizzeria in Washington, DC. *Mozzeria* will be staffed by deaf employees. The location is special to the couple, who met there while attending the world-renowned school for the deaf and hard of hearing Gallaudet University. Their goal is to reduce unemployment and underemployment in the deaf community by offering employment as well as franchising opportunities. *Photo is courtesy Russ and Melody Stein. Photograph by Clare Cassidy Photography.* https://www.mozzeria.com/#welcome

- **Kathy D. Woods** is a former pre-school teacher who now owns and operates a women's clothing line for adults of small stature. Kathy embraced her entrepreneurial spirit and began the KDW Collection, the first ever ready-to-wear clothing line for little people. A disability awareness activist and advocate, Ms. Woods is also a promoter for Step 'n Wash, a system designed to help little people to more safely reach sinks and faucets in public accommodations. In 2015, she was a guest of President Barack Obama and First Lady Michelle Obama at the White House's 25th Anniversary celebration of the Americans with Disabilities Act. *Photo is courtesy Kathy D. Woods*, https://www.kathydwoodsstore.com/Default.asp

- Meet the **Smith family**. Jim and Leona have two sons, Lance and Taylor. **Taylor** (front middle) has Angelman Syndrome, a genetic disorder that causes developmental disabilities, can affect a person's ability to speak, and often causes other neurological issues like seizures. Individuals with this disorder are generally happy and frequently burst into smiles and laughter, although not always at socially appropriate times.

  In the interviews below, Lance gives his perspective on having a sibling with a disability. Next, Leona discusses family dynamics and considerations for parents.



Lance Smith
(time: 1:14)

Audio Player

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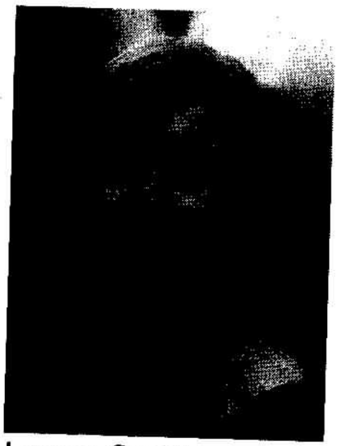
Use Up/Down Arrow keys to increase or decrease volume.

View Transcript

For any sibling that has a brother or sister with special needs, look at it as an opportunity to grow, learn, gain, get an advantage on the world, honestly. Because everyone else that has no experience with anyone with special needs sees the world in a certain way. I mean we're conditioned by society, by pop culture, by entertainment that our world is built XYZ, built a certain way. And when you have someone with special needs, someone with a disability in your family, your perspective changes immensely. And my advice is to accept that and take that as a badge of honor. Learn from it, grow from it, and allow your experience with that person in your family to help you grow, make you see the world differently from a higher perspective. And then really there's a lot to be gained from it. I think people think, "Oh, woe is you that has to deal with this burden." But, while the needs themselves can be burdensome, the person can teach you more than you ever would have thought. So you just have to look at it and take it from sort of a great learning experience. I wouldn't change it for the world. I love my brother.



Leona Smith
(time: 1:38)

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Use Up/Down Arrow keys to increase or decrease volume.

View Transcript

Lance is such a good hearted young man that he did honestly help us raise Taylor because it was his desire for his little brother. He loved him so much and he never once thought, “Oh, look what I’ve got to do” or go gripe to his friends. Never ever ever. He was always so sweet and loving. There were struggles but it made it easy to have all hands on deck so to speak. And so the family dynamic was, I would say, of good posture. That’s a good way to say it because of Lance honestly.

Taylor is the love of our life. We’ve always said that if there’s somewhere that Taylor can’t go, perhaps we shouldn’t go. He goes to the Titans ball games. He goes to concerts. Lance went on tour with the Dixie Chicks in his earlier career. And we took Taylor to the Dixie Chicks concert. He’s been to symphonies; he’s been to plays. He loves to watch opera on TV. We’ve taken him on a submarine tour.

Embrace the child. And the disability is something that goes along with the child because that is part of the child. Lance excels in his career. And we embrace that and we love him. And we love Taylor even though they’re so different. But they’re still both our children and we love them equally. We have to pay a little bit more attention to Taylor sometimes, but just embrace the child.

- **Jay** is a member of **Music City Thunder**, a competitive, organized wheelchair basketball team. Music City Thunder is part of ABLE Youth, a program designed to create opportunities for young people who use wheelchairs to learn independence, skills, and sports, as well as to build self-confidence. In practice and in tournaments, players like Jay discover what they are able to do on the court, both individually and as a team.

Page 2: Common Perceptions

iris.peabody.vanderbilt.edu/module/da/cresource/q2/p02

Do perceptions matter?

Just as our perceptions influence how we respond to the world around us and interact with others, so too can our beliefs and attitudes affect how we perceive disabilities and those who have them. Though our perceptions are frequently accurate, at other times these inwardly held beliefs are based on misinformation or misunderstanding. Sometimes, our beliefs are so deeply ingrained within us that we are unaware of them altogether and come to regard them as self-evident truths. Take a moment to consider the table below and the common misperceptions it describes.

Common Misperception	Fact
It takes a special, rare kind of courage to navigate the world if you have a disability.	People with disabilities adapt to their environment and preferred lifestyle just like anyone else, their peers without disabilities included.
It is the special responsibility of people without disabilities to look out for and take care of those with dis-	Most people with disabilities are more than capable of taking care of themselves. If a person without disabilities sees a situation in which assistance might be required, it is okay to po-

abilities, because people with disabilities are almost always in need of some kind of assistance.	litely offer help, but the wishes of the person with the disability should always be honored.
People without disabilities and those with disabilities lead completely different lives.	In the case of most people with disabilities, there are far, far more similarities in lifestyle, behavior, professional and personal ambitions, and day-to-day routines than there are differences. As captured in the photo at the top of this page, a child with a disability is enjoying a day at the beach with his father, just like any other child.
Let's face it, there are always going to be at least some barriers for people with disabilities somewhere, and there's very little individuals can do to change that.	By working together, there is so much we can do to lessen or eliminate many of the barriers faced by people with disabilities, but to do so we have to listen to their needs, involve people with disabilities in community discussions, and focus on a goal of creating shared spaces where everyone is valued and welcome.

Source: Adapted from https://www.easterseals.com/explore-resources/facts-about-disability/myths-facts.html

Activity

Erik has *retinoschisis*, a congenital condition that caused the gradual deterioration of his retinas. Before losing his sight entirely around the time of his 14th birthday, Erik participated in the general education classroom at school, rode his bike, and played basketball.

Based on what you have read above, describe what you think Erik's life will be like after losing his vision. Take a moment to write down a few of the barriers you believe he might face.

Once you are finished, let's check in on Erik as an adult.
When you described Erik's life, did you consider education, employment, recreational and sports activities, community engagement relationships, and honors? The table below showcases some of the highlights of Erik's life.

Education	• Graduated from Boston College with a double major • Earned a master's degree from Lesley College
Employment	• Middle school English and math instructor, wrestling coach • Author of *Touch the Top of the World* (a memoir), *No Barriers: A Blind Man's Journey To Kayak the Grand Canyon*, and The *Adversity Advantage: Turning Everyday Struggles into Everyday Greatness*, among others • Motivational speaker whose appearances include the Asia-Pacific Economic Cooperation (APEC) Summit in Chile • Film producer of Touch the *Top of the World*, *Blindsight*, and *Blind Skiers Edge*, among others

Recreational and Sports Activities	• Wrestler: In high school, represented Connecticut in the National Freestyle Wrestling Championships
	• Mountain climber:
	  ○ While in high school, became the first blind person to trek the 50-mile Inca Trail to Machu Picchu
	  ○ Completed the Seven Summits, the highest point on every continent (only 150 individuals have achieved this accomplishment)
	• Skydiver: Became one of only two blind solo skydivers
	• Bicyclist:
	  ○ Biked tandem with his father from Hanoi to Ho Chi Moinh City (1,200 miles)
	  ○ Completed a six-day bike pack of the White Rim Trail
	• Runner: Competed in the New York Marathon
	• Kayaker: Kayaked the entire 277 miles of the Colorado River through the Grand Canyon

Community Engagement	Co-founded an organization, No Barriers, to help individuals with disabilities to face and overcome their challenges
Rela-	• Married his girlfriend, Ellen, at the summit of Kilimanjaro

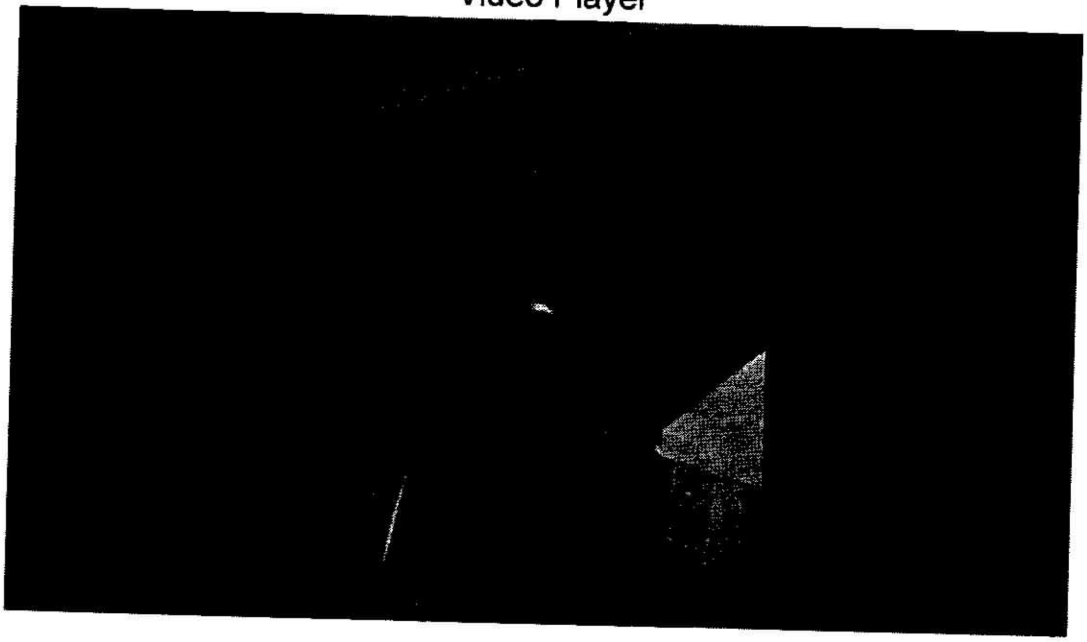
tionships	- Has two children
Honors	- Carried the Olympic Torch through Phoenix - Honored with a *Time* cover story about his conquest of the world's highest peak - Received multiple honorary doctorate degrees - Received the National Courage Award - Received the ESPN Excellence in Sports Performance Yearly Award

1. Now, think back to the list of barriers you predicted for Erik.
   1. Is it possible any of those barriers reflect society's biases?
   2. Would you eliminate some of the barriers now that you know the whole story? If so, which ones?
2. Consider the following quotations and answer the related questions.
   1. "Society makes the handicaps, not the disability." Paul Longmore
      Consider the sponsorship for Erik's climb. His major sponsor was American Federation for the Blind. Do you think a "non-disabled" organization would have agreed to be a major sponsor? Why or Why not?
   2. "We all experience barriers and have challenges." Deb Smith
      Imagine that you are climbing a mountain for the first time. Who would you rather have on your team: Someone who has summited all seven of the world's highest mountain peaks but has a visual impairment or someone who has never climbed before but has no visual impairment? Explain your response.
   3. "Society imposes low expectations of those who have disabilities." Erik Weihenmayer
      Let's assume that at least some people would opt to climb alongside the inexperienced climber with "normal" vision. Why do you think they might do so? What attitudes or beliefs might sway their decision making?

Perhaps the most important thing to remember when interacting with people with disabilities is simply that they are people first. And just like all people, they are unique. They have preferred activities, social circles, ambitions, hopes, fears, and challenges, visible or otherwise.

They are also unique in how they view their disability. Consider the case of Jay, who uses a wheelchair. A common misperception is that people who use wheelchairs are chronically ill or feeble. Some might believe that wheelchair use prevents participation in certain activities enjoyed by people without disabilities. In the video below, Jay dispels this mistaken belief (time: 1:55).

Video Player



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01:54

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- ● None
- ○ English

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View Transcript

Narrator: What kinds of things do you like to do?

J-Rod: Alone, I like to draw. Drawing is, like, a stress-reliever. I'm into making my own anime because I love watching anime. Like *Fairy Tail*, all of that. Like *Dragon Ball Z*. But with friends, sleepovers just like normal kids do. Like, one of my brother, cousins here, we try do something at least for every weekend, try to get together, since we know that school is kind of, like, since we're in 8th-grade, going onto high school next year, we might not be able to chill with each other that much because of all that work. Yeah, that's mainly what I do with all of my friends.

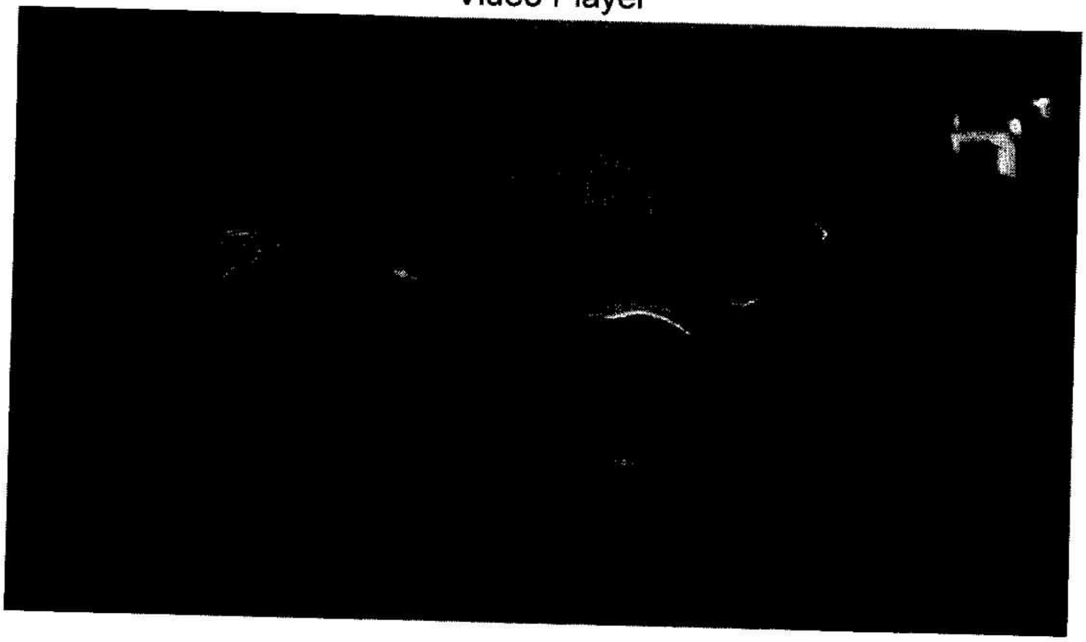
J-Rod: I'm doing track, shooting, and archery. Oh yeah, and they just put me in weight lifting recently. So I think I'm going to be, like, bench pressing for that. Working out again. I'm practicing shooting, which will also help me in archery because both of those take time and patience, aiming, setting up the thing to shoot.

Narrator: What are your strengths?

J-Rod: I'm optimistic, which really brings my spirits up even though it might be, like, a grim situation or a gloomy situation. I try to think on the bright side of mostly everything, which is another thing that helps me not, like, succumb to obstacles that try to stop me.

Now watch Jay's parents talk about his greatest strengths and needs and describe what they would like people to know about their son (time: 2:46).

Video Player



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02:46

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- ● None
- ○ English

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View Transcript

Narrator: What do you see as J-Rod's greatest strengths?

Mother: He has a conquering spirit. Every time we even want to feel disheartened about a situation or we think that there's something that someone is saying it can't happen, it's almost as if he has the decision in his mind, like, "You're going to tell me what it is I can't do, but I'm going to show you what I can do." And he does it with a humble spirit. He doesn't try to talk trash. He's out to prove to himself.

Father: In many ways, he's an overachiever. So I'm not mad about that at all. Go ahead and overachieve. So, you know, do what you need to do to be successful. One thing that I am happy about as far as his overall mentality is we've taught him to make the best out of his situation and not allow his situation to make him.

Narrator: What would you like people to know about J-Rod?

Father: We want people to know that J-Rod is…he's a kid. He's a regular ol'boy. He's silly. First and foremost, he's a boy. I mean, regardless of whatever, regardless of him being in a wheelchair, he's a boy. He'll be on the couch, jump down on the couch, and wrestle you. Like right then…*grrrrrrrr…* and really be playing for real, so he's a boy. He's a regular ol'boy. He's a regular ol'boy.

Mother: If there was something I wanted to say, that I wanted people to know about Jay is his heart's bigger than his body. I believe that there's nothing he can't accomplish. I believe that there are a lot of kids out there that have the same hunger that he has, or it could be opened and or enhanced if just given an opportunity. If somebody just cared. If somebody just actually showed interest in what that child did instead of talking about everything they think they can't do. Find out what it is that they can and have a genuine interest in it. I believe that J-Rod blooms and shines because of his smile and his demeanor, his character. He's very contagious. And there's probably some other kids out there just like him if you just give them a chance to let them bloom.

Page 3: Cultural-Based Perceptions

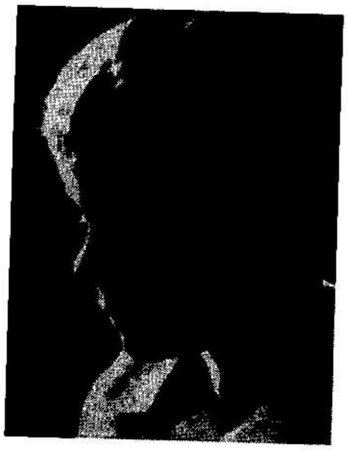
iris.peabody.vanderbilt.edu/module/da/cresource/q2/p03

Do perceptions matter?

Among the major factors shaping our beliefs and attitudes about disabilities are our own cultural backgrounds and experiences. And just as our culture influences the way we think about technology, food, religion, and family, so also can it inform how we regard disabilities. For example, depending on your cultural background, you might perceive a disability to be:

- A blessing. The person with the disability possesses unique gifts that contribute to the family or community.
- Something to be addressed through medical or educational interventions. A disability is a potential barrier than can be mitigated or overcome through various means.
- A curse. The disability is a punishment on the family for any number of violations or transgressions.

The strength of a family's cultural beliefs affect how they treat a family member with a disability. Some people with disabilities face little bias or discrimination, while others may be shunned or excluded.



In her poem "Ursa Minor," Jody Barnes writes about her perceptions of her son Alex. As you read it, consider whether Jody, who is Native American, has a similar or different perception of disability than the teachers and doctors who work with her son. When you are ready, complete the activity below (time: 2:32).

Audio Player

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Ursa Minor

They want to trap you in the flatness of their paper charts
They lay snares of straight lines and sharp corners
Because you are different
they name you with short, sharp words
autistic, A.D.D., hyper

They say something's wrong
He won't speak when spoken to,
He won't count to five or say his ABCs
or play with other kids his age

With pens poised above graphs they wait
'What color is the umbrella, Alex?'
You look through them
past the picture of the yellow umbrella
past the calm beige walls
through time and space

Tattooed behind your cautious eyes is the path
through the Milky Way
In the dark of your room when I lean down to kiss you
I can still see how the stars laid themselves out
and guided you down to nestle under my ribs

When you were born I didn't count fingers and toes
Instead, like momma bear, I nuzzled you
and breathed in your familiar scent
You smelled like new clothes and cedar
and the water from the river behind my grandfather's house

I touched the oblong scar on your belly
knowing then you were a gift from the spirits
What had made that mark?
Musket ball?
Arrowhead?
Spear?

The woman with the clip board calls you 'cute' and 'precious'
She can sense the agenda stamped on your soul
But she doesn't have the words to articulate
so she speaks in baby talk, thinking it's you
who doesn't understand

The nurse bends down to peer into your eyes
I want to ask her if she can see it too
But she turns away without comment
maybe the bright reason in the room has nullified the answers
that I find there
the same way the blinding lights of the city
wash away the path through the stars at night

Activity

As you reflect on the poem you just read, take a moment to independently answer the questions below.

- What do you think is Jody Barnes's perception of disability? What do you think the teachers' and doctors' perceptions are? Explain your answers.
- How would you feel if you had a child born with a disability? Do you think your cultural background influences your views of disability? Explain your answers.
- What is Jody Barnes's message?

Meet with a small group of classmates or colleagues. Take turns sharing your responses to the questions above, including the impact of cultural beliefs.

- Are your cultural beliefs and experiences similar to or different from the others in your group? In what ways?
- What else did you learn from your classmates or colleagues that could be beneficial to you as a teacher working with students with disabilities? When working with parents?

Page 6: People-First Language

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Do perceptions matter?

The language we choose to express ourselves conveys meaning, but it also communicates attitudes, perceptions, and emotions. For example, there are a number of words to describe someone who is quiet or reserved in social situations: introverted, shy, aloof, bashful, timid, diffident. If you were such a person, which of those terms would you prefer others use when referring to you? Do any of these words carry a more positive or negative connotation than the others?

Among people with disabilities and their families, language is an especially important issue, particularly as pertains to the use of positive terminology. Over time, language shifts and changes. Words that were once considered inoffensive or neutral may later take on meanings or connotations that are no longer considered acceptable or are even regarded as offensive. For example, we no longer refer to people with mobility issues or who use a cane as "crippled." In other cases, the order in which words are placed or spoken is problematic. Disability advocates prefer the use of "a person with a disability" because the once-common "disabled person" places greater emphasis on the disability than on the individual.

As a remedy, most disability communities advocate for the use of *people-first language*, a positive, respectful way to refer to individuals with disabilities. When we use people-first language, we must take into account:

Word order
Place the individual before the disability.

Preferred word order	Non-preferred word order
a person with a disability	a disabled person the disabled
a student with ADHD	an ADHD student
students who receive special education services	special ed kids IEP kids sped kids

Current terminology
Use current terms rather than those that are outdated, negative, or derogatory.

Current terms	Outdated terms
intellectual disability cognitive disability intellectual and developmental disabilities	mental retardation
a person with a disability	handicapped
a person with a physical disability	crippled

Use of positive or neutral descriptions

Use terms that reflect positively on the person, rather than those that convey negative assumptions or judgments. For instance, a person who uses a wheelchair considers it a tool that provides him with greater mobility, and not as something to which he is confined. Ironically, he would be more confined without the wheelchair to get him from place to place.

Appropriate terms	Non-preferred terms
a person who uses a wheelchair	• a person who is confined to a wheelchair • a person who is wheelchair-bound
a person who has microcephaly	a person who suffers from microcephaly

As with any rules or guidelines, there are exceptions to the use of people-first language. Individuals who are blind or Deaf are often referred to as *blind individuals* or *Deaf individuals*, particularly for those in the Deaf community, which has its own language (American Sign Language) and culture. Similarly, many individuals with autism refer to themselves as *autistic* or as *autistic individuals*.

Lance Smith, who you met on Page 1, addresses the issue of language and terminology in his poem, *Special Needs World*, which he performs in the video below (time: 2:12).

Video Player

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- ● None
- ○ English

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Description

Special Needs World

My brother Taylor has Angelman Syndrome,
a depletion of the fifteenth chromosome,
which is all scientific mumbo-jumbo to say
that he is not the same

He can't talk and, yes, he rides
the short bus,
you know, the one the rest of us make fun of
And he gets off that bus to go to that
special class
Yes, the one you would pass
and look inside, seeing a kid

go for a ride in a wheelchair
while you stare at his hair
because it looks like he cut it himself

And he probably did, because raising
a handicapped kid is hard
Sometimes it's like having a toddler in the body
of a twelve-year-old
He's big and bold
and can't be told
to get down off the TV

My brother Taylor was always into something,
if not that then one thing
like a bull in a china shop
He can't stop
because he is who he is
My brother has deficiencies
It's not a disease,
so please
don't give him your sympathies
If anything, he'll give you his
You're the one who's having trouble
understanding his situation
All the while he sits
and smiles,
thinking of his evaluation of you

My brother knows nothing
of the problems of this world
like war, poverty, famine,
religious contention,
or social ascension
He can't comprehend that we can't
mend something like racism
It's not of his world,
and the only problem that faces him
is when he gets to open his
Christmas presents

My brother Taylor has a simple loving mind
in a world that can be unkind
and where it's hard to find peace and equality
and that's a fault of me
and you
and anyone who has ever refused
to help someone in need
because of their own greed
or maybe just because of their busy schedule

So the next time you think
of the problems
and difficulties
that everyone on Mother Earth must tend to,
remember who thinks you are only here
to make him smile,
my brother Taylor and his
simple life style

Activity

Take some time to think about the following scenarios:

- Someone you know casually uses the word *retarded* to refer to a friend who does not have a disability.
- Someone you know uses the word *retarded* in a derogatory fashion to refer to someone who has a disability.

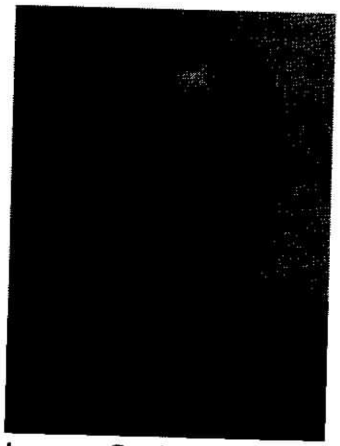
How would you approach these situations? Would you handle them differently? Why or why not? Discuss this situation with others in your class. Can you think of several different ways to respond?

SPREAD THE WORD
TO END THE WORD

At one point in history, *mental retardation* was a clinical term used to refer to people with a specific set of characteristics. Over the years, variations on this term (e.g., *retard* or *retarded*) were used in a derogatory way to insult or to demean others. Used this way, these thoughtless and hurtful terms reflect negative stereotypes about people with intellectual disabilities.

Now, over 200 organizations like Special Olympics and Best Buddies have joined forces to end the use of the "R-word." You can learn about their campaign, pledge to eliminate the use of these terms, and find more ways to be involved in this movement at r-word.org.

You might have noticed that Lance uses some terms in his poem that do not reflect people-first language. He did so purposely to draw attention to the issues of language and labels. In the audio interviews below, Lance and his mother Leona offer their insights about the use of disability related terms and labels.



Lance Smith
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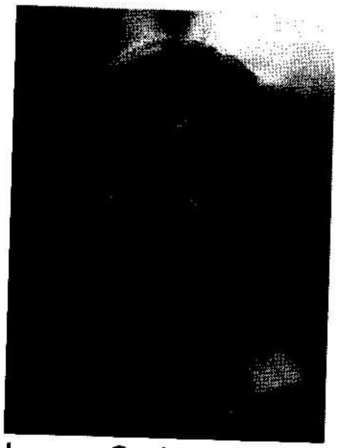
View Transcript

Well labels matter. They matter because we make the labels matter as a society. And there's a lot of controversy about what you call someone with special needs, and you know there's the R-word now and before it was just a fact. I specifically put the word 'retarded' in the piece because I don't want us to run away from it. And I don't think it's fair that someone who uses it in a derogatory term should sort of make it demeaning or take power away from someone.

The people born with special needs are born into their own universe. But parents have to adjust and that's the first thing they have to do is learn their child has a label. I believe that the labels we use matter, but it's also where it's coming from, how we're using it. And then at the end of the day how you're using it and then it doesn't matter what you're saying. I say my brother has special needs. He is mentally handicapped. I don't necessarily say "retarded," not that I'm ashamed of that but other people don't understand the connotation or they hear it in a negative tone now. Society has taken that word and it's something else. That's just a factual word the way I see it, but you know labels are for other people.



Leona Smith
(time: 1:27)

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View Transcript

Before we had Taylor I never gave thought to when somebody would just loosely say, “Oh, you act so retarded.” It’s loosely saying it because I don’t think that they’re really in their mind comparing you, if you do something silly or goofy, that you’re acting like someone with Angelman Syndrome. So, those terms are very loose. But then after we had Taylor we would hear that and I think his dad, Jim, I saw him first take the offense. He said, “I really wish that you wouldn’t do that. There are children with special needs who know that they have special needs.” And so I think that if we watch what we say then we won’t offend any of these children.

At one time I said to someone, “This is Taylor. Taylor has Angelman Syndrome.” And I gave them the characterizations: the non-speech and giggling, inappropriate laughter. I did say, “Well, he’s mentally retarded.” But my sister noticed. She said, “When you said that, he looked down and his eyes kind of drooped.” And I thought, “Well how much does he understand what I’m saying since he can’t communicate verbally?” So we try to be careful with that, not just because of Taylor and because of the way that we would perhaps be perceived, but we have to be cognizant for other children as well.