

# POV

Community  
Engagement & Education

DISCUSSION GUIDE

## When I Walk

A Film by Jason DaSilva



I love New York. When I was younger, the city was my playground. You could find me on any given weekend catching brunch with a friend at a café, going to an East Village restaurant for dinner, and then hopping the subway, headed to a nightclub in Chelsea. But at age 25, nine years ago, I was told I had multiple sclerosis (MS), and I saw my freedoms slowly vanish. All of a sudden, I found myself using a walker—now, a motorized chair—and planning daily activities with precise schedules and strategies for getting from one place to another, trying to maintain some semblance of the spontaneous city life I loved to live.

I wanted to capture this transformative experience—becoming disabled—in **When I Walk**, because I hadn't seen it done before, and people need to see how a degenerative disease impacts the lives of those living with it. The first scene in the film is of me on the beach with my family. I brought my camera along to film the get-together, but the footage we captured meant more than I could have imagined: I fell down and couldn't get back up. It was the very first time my MS made something in my life go completely awry and made itself visible and impossible to ignore. What was supposed to be a nice family vacation turned into an inciting incident. Soon after, encouraged by my family, I chose to not ignore my MS, but to turn my camera on it instead. I had made films all my life, so making a film about the progression of the disease seemed a natural way for me to process the journey.

Documentarians often want to build trust and acceptance with their subjects. Being that I was the subject of my own film, and that I didn't yet have that acceptance of myself, the filmmaking was arduous at first. There was always the internal struggle of putting myself on camera and deciding how much of myself I wanted to reveal. As I got worse and worse, reviewing the footage became emotionally difficult and physically draining. Living my life in the present while also reflecting upon it creatively, actively editing it and putting the pieces together in real time put me in a psychological feedback loop that was tricky to negotiate. Every night after filming and editing, I would have dreams of being able to walk; then I'd wake up unable move and start the process of filmmaking all over again.

Also difficult was being forced to hand the camera over to my brother, my mother, my filmmaker friends and my non-filmmaker friends. This was necessary partly because of my MS (my vision was getting worse), but also because being in the shot meant that I couldn't capture it myself. This was perhaps the most frustrating part of making this film. I used to have total control over the camera and I was a meticulous shooter, so you can imagine the torture that was trying to give on-the-fly lessons in visual composition and camera exposure to my mother! The beautiful cinematography of my past was sacrificed, and my priority became capturing emotion. I found a new love for the expression of emotion, the subtlety of story and capturing quietly compelling moments of human experience.

I've discovered that and other new loves since we began filming **When I Walk**. And while I miss the incredible spontaneity and unlimited access to the city I had—and am developing ways to make that more of a possibility for those with mobility challenges through AXS Map—my diagnosis was not the end of the world. Instead, and with a bit of determination, it has provided a new way for me to see and be in the world. This was the voice and heart that emerged in the film, almost as though the film itself willed it. As director, my role was to foster that spirit, to learn to adapt and to enjoy the ride.

### Jason DaSilva

Director/Producer, **When I Walk**

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Jason DaSilva was 25 years old and a rising independent filmmaker when he was diagnosed with multiple sclerosis.

**When I Walk** (90 minutes) is Jason's candid chronicle of his struggle to adapt to the harsh realities of MS while holding on to his personal and creative life.

We see Jason in both triumphant and vulnerable moments as he gamely tries various healing strategies, copes with the loss of independence and battles depression. We also meet Jason's extraordinary support system. With help and encouragement from his family, Jason picks up the camera, turns it on his declining body and sets out on a worldwide journey in search of healing and self-discovery. A cure remains elusive, but he does find a treasure: love. Alice Cook becomes his wife and filmmaking partner. Together the newlyweds work through the unusual twists that Jason's disability creates for them.

By revealing the daily frustrations of living with body parts that no longer function as they once did, Jason challenges viewers to join in his struggle. When he can't hail a wheelchair accessible cab, we wonder why there isn't a better system in place. When he can't get his chair into a favorite restaurant or when the battery powering his scooter fails, we find ourselves asking what responsibility we all have to create a world that is accessible to more people. How can we support Jason—and those like him—in their determination to survive and thrive? Can we help create the space that families need to make sense of a devastating disease and still remain connected to community? And if we do that, what will we all learn?

**When I Walk** is well suited for use in a variety of settings and is especially recommended for use with:

- **Local PBS stations**
- **Groups that have discussed previous PBS and POV films relating to disability inclusion, accessibility and family illness, including *Freedom Machines*, *Life. Support. Music.*, *If I Can't Do It*, *Big Enough*, *No Bigger Than a Minute*, *In the Family* and *Sun Kissed***
- **Groups focused on any of the issues listed in the Key Issues section**
- **High school students, youth groups and clubs**
- **Faith-based organizations and institutions**
- **Cultural, art and historical organizations, institutions and museums**
- **Civic, fraternal and community groups**
- **Academic departments and student groups at colleges, universities and high schools**
- **Community organizations with a mission to promote education and learning, such as local libraries**
- **Groups interested in supporting and/or fundraising for a cause**

**When I Walk** is an excellent tool for outreach and will be of special interest to people looking to explore the following topics:

- Accessibility**
- Alternative medicine**
- Art**
- Autobiography**
- Autoimmune disorders/diseases**
- Caregiving**
- Disability rights**
- Family**
- Filmmaking**
- Healing**
- Inclusion**
- Medicine**
- Multiple Sclerosis**
- Neurological diseases**
- Universal design**

## USING THIS GUIDE

This guide is an invitation to dialogue. It is based on a belief in the power of human connection, designed for people who want to use **When I Walk** to engage family, friends, classmates, colleagues and communities. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people try to understand one another and expand their thinking by sharing viewpoints and listening actively.

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the issues in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. And be sure to leave time to consider taking action. Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult.

For more detailed event planning and facilitation tips, visit [www.pov.org/engage](http://www.pov.org/engage).

## Jason DaSilva

At just 25, filmmaker Jason DaSilva had seen his documentaries *Lest We Forget* and *Olivia's Puzzle* screened at dozens of film festivals around the world, from Sundance and Tribeca to the International Documentary Film Festival Amsterdam, and his short film *Twins of Mankala* had aired on POV. Young, handsome and adventurous, he had the kind of life that is a dream for many documentary filmmakers.

Then, in 2006, Jason was diagnosed with multiple sclerosis, or MS. In just five years, he went from being a strong, healthy young man, to walking on wobbly legs, to using a cane, a walker, a wheelchair and eventually a motorized scooter. He fought tirelessly to keep his body going, spending hours at the gym and undergoing experimental procedures with underwhelming results. He even traveled to his ancestral homeland of India to try traditional medicine, as well as spirituality. He visited an uncle to find out more about his family history and got no answers, and he followed the advice of an aunt on the Catholic side of his family to go to Lourdes, France, but still he found no miracle cure. In spite of it all, Jason held tight to the one thing he's always been and will always be—a filmmaker.

When Jason met Alice Cook, his resolve to fight continued to grow. Jason documented their relationship, from their first meeting, to falling in love, getting married and deciding whether to start a family. Alice helped Jason complete his film, with both emotional and production help. Together, Jason and Alice worked to create AXS Map (access map), a crowd-sourced online tool for sharing reviews on the accessibility of places across the country. For Jason, the dream behind AXS Map is to catalogue and share accessible places throughout the country, in order to regain the spontaneity and adventure he enjoyed when he was able-bodied.

Additionally, Jason's project *We Keep Moving* gathered unique stories of ten individuals living with multiple sclerosis across the United States, and his short film *First Steps*, about the beginnings of his health crisis and identity as a filmmaker, screened at the Tribeca Film Festival and the Vancouver International Film Festival. He also kept a video diary while working to finish **When I Walk**, sharing his progress and day-to-day life during filming. In 2006, Jason took a short break from filmmaking to earn a master's degree in applied media arts from Emily Carr University of Art and Design. He produced and directed an op-doc (opinion documentary) for *The New York Times* entitled "The Long Wait," published in January 2013.

Jason's work captures his own bravery, and the journey of a man coping with difficult changes in his body and his life, while finding a way to persevere through creativity, love and an unshakeable appreciation of what he still has. He currently lives in New York City with his wife, Alice, and their son.

### Sources:

National Multiple Sclerosis Society.  
<http://www.nationalmssociety.org/online-community/personal-stories/jason-dasilva/index.aspx>

*Olivia's Puzzle*. "Jason DaSilva."  
<http://www.oliviaspuzzle.com/personal.html>

POV Press Room. "When I Walk."  
<http://www.pbs.org/pov/pressroom/2014/when-i-walk-premieres-on-pov-pbs.php>

YouTube. "When I Walk." <http://www.youtube.com/user/wheniwalkinc>

## Multiple Sclerosis and Autoimmune Diseases

Multiple sclerosis (MS) is an autoimmune disease that affects the central nervous system—the brain, spinal cord and optic nerves. When a body's immune system is healthy, it attacks harmful viruses and bacteria to fight illnesses and diseases, but a body with an autoimmune disease mistakenly attacks its own cells. In cases of MS, myelin, which insulates nerve fibers in the body, is eroded, causing damage to nerve fibers and interrupting brain signals. Symptoms and effects of the disease can be mild or severe and range from numbness in limbs to paralysis and loss of vision.

The American Autoimmune Related Diseases Association estimates that 50 million Americans suffer from autoimmune diseases, and the numbers are on the rise. At least 80 diseases are currently identified as autoimmune diseases, including MS, Graves' disease, celiac disease, rheumatoid arthritis, lupus and type 1 diabetes. Women are more likely to develop autoimmune diseases, as are people with a genetic predisposition, though both environmental and genetic factors are believed to be contributors.

MS is not contagious or fatal, but the disease is largely unpredictable, as is its progress. MS can develop at any age, but most commonly occurs in people between 20 and 50 years of age. The cause of MS is still largely unknown and, while there are various treatments for different types of MS, as of yet no definitive treatment or cure for MS has been found.

**Sources:**

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National Multiple Sclerosis Society. "CCSVI."  
<http://www.nationalmssociety.org/Research/Research-News-Progress/CCSVI#section-3>

National Multiple Sclerosis Society. "Definition of MS."  
<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-is-ms/index.aspx>

**Different Courses of MS**

There are four different courses of MS, each of which can be mild, moderate or severe.

**Relapsing-Remitting MS (RRMS)** is the most common form of the disease—approximately 85 percent of people with MS begin with RRMS. This course is characterized by acute attacks followed by full or almost full recovery, and a lack of disease progression.

**Secondary Progressive MS (SPMS)** begins with a relapsing-remitting course, followed by an aggressive progression of disability. People with SPMS experience less recovery following attacks but suffer from fewer attacks overall. Studies show that 50 percent of people who have RRMS will develop SPMS within 10 years.

**Primary Progressive MS (PPMS)** is the diagnosis of Jason's type of MS. It is characterized by an aggressive progression of disability from the onset, with few plateaus or remissions. However, a person with PPMS does not experience acute attacks as with RRMS. Only 10 percent of those diagnosed with MS have PPMS, and diagnostic criteria are less secure. Many with PPMS are not diagnosed until they are already living with significant disability.

**Progressive-Relapsing MS (PRMS)** is the least common disease course, with only five percent of those diagnosed with MS falling into the category.

PRMS is characterized by aggressive progression of disability alongside acute attacks.

**Source:**

National Multiple Sclerosis Society. "Types of MS."  
<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/what-is-ms/four-disease-courses-of-ms/index.aspx>

**Accessibility and the AXS Map**

The issue of accessibility quickly became important to Jason as his MS progressed. In **When I Walk**, Jason navigates New York City first with a walker and then with a motorized scooter, experiencing daily the frustration of not being able to get around due to lack of accessibility. Just getting to a destination is a frequent obstacle, as accessible cabs are few and far between (currently, only two percent of all taxis in New York City are wheelchair accessible) and a number of New York City subway stations are either inaccessible or have only partial access. The busy 14th Street-Union Square station, for instance, has wheelchair access to some subway lines, but not others. Buses and Access-a-Ride provide the most accessible options (all of the city's buses are equipped with lifts for wheelchairs), though wait times and traffic make them less time-efficient.

Jason's experience is not unique. Throughout the United States, one third of those who use wheelchairs and motorized scooters report issues with accessibility outside their homes, even before taking into consideration the use of public transportation. Four fifths of wheelchair users say that their local public transportation systems are either difficult to use or difficult to access, and nearly half of those who use any kind of mobility device, such as a wheelchair, scooter or walker, say that public transportation is very difficult to access. These obstacles lead to what Jason defines as exclusion from public space due to physical barriers.

The Americans with Disabilities Act (ADA), enacted by the U.S. Congress in 1990, worked to address these issues by mandating that buildings and other facilities become more accessible to those with disabilities. While the ADA has made significant headway, Jason found that the law is enforced and executed with very little consistency, and many buildings constructed before 1990 are exempt from ADA regulations. This inspired the creation of AXS Map, a crowd-sourced online tool for sharing reviews of the accessibility of places around the country. Apps like Jason's allow users to rate the accessibility of a business based on their personal experiences, creating a more informative review for other

users. The point of the AXS Map isn't to rate how compliant a structure is with the ADA, but to give people with mobility issues a resource for determining whether they'll be able to access a destination before making the trip to it.

Just as Yelp and other platforms rely on participation from the community, AXS Map relies on user contributions. Anyone can contribute simply by adding ratings and reviews of the accessibility of his or her local neighborhood restaurants, businesses and other locations. The more ratings and reviews the app collects, the more reliable the information will become.

To contribute to AXS Map, visit <http://www.axsmap.com/> and register with your email address.

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## Did You Know?

**Did You Know?** 6.8 million people in the United States use mobility assistance devices, ranging from motorized scooters and wheelchairs to walkers and canes.

([http://dsc.ucsf.edu/publication.php?pub\\_id=2&section\\_id=4](http://dsc.ucsf.edu/publication.php?pub_id=2&section_id=4))

**Did You Know?** Accessibility varies widely city by city. The Christopher and Dana Reeve Foundation created a list of the top 10 wheelchair accessible cities in the United States, based on factors ranging from climate and air quality to medical services and accessible transit systems. Seattle ranked number one, in part because its public transit system was built after 1990 and is therefore more accessible than the systems in older cities that have been retrofitted.

([http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.6150343/k.F282/Top\\_20\\_Most\\_Livable\\_US\\_Cities\\_for\\_Wheelchair\\_Users.htm](http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.6150343/k.F282/Top_20_Most_Livable_US_Cities_for_Wheelchair_Users.htm))

**Did You Know?** Only 97 out of the 490 stations in the New York City Transit and Staten Island Railway systems are wheelchair accessible.

(<http://web.mta.info/accessibility/transit.htm> and <http://web.mta.info/mta/network.htm>)

**Did You Know?** Only 233 of the 13,437 taxis in New York City are wheelchair accessible, though Mayor Bill de Blasio has committed to making 50 percent of the city's taxis accessible by 2020.

([http://www.nyc.gov/html/tlc/downloads/pdf/2014\\_taxicab\\_fact\\_book.pdf](http://www.nyc.gov/html/tlc/downloads/pdf/2014_taxicab_fact_book.pdf) and [http://www.nytimes.com/2014/02/28/nyregion/timetable-set-for-rules-on-wheelchair-accessible-taxicabs.html?\\_r=0](http://www.nytimes.com/2014/02/28/nyregion/timetable-set-for-rules-on-wheelchair-accessible-taxicabs.html?_r=0))

**Did You Know?** Kenguru, a Budapest-based company, designed a small electric car that wheelchair users can roll onto and drive without ever leaving their wheelchairs.

(<http://cars.chicagotribune.com/fuel-efficient/news/ch-wheelchair-electric-car-20130531>)

Selected People Featured in **When I Walk**



Jason DaSilva



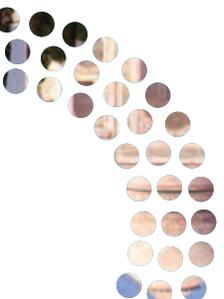
Alice Cook



Jason DaSilva's mother, Marianne D'Souza



Jason DaSilva's brother, Leigh DaSilva



**Immediately after the film, you may want to give people a few quiet moments to reflect on what they have seen or pose a general question (examples below) and give people some time to themselves to jot down or think about their answers before opening the discussion:**

- If a friend asked you what this film was about, what would you say?
- What did you learn from this film? What insights did it provide?

- If you could ask anyone in the film a single question, whom would you ask and what would you ask him or her? Why does that question interest you?
- Describe a moment or scene in the film that you found particularly disturbing or moving. What was it about that scene that was especially compelling for you?

## DISCUSSION PROMPTS

### Changing Perceptions of Self

How do the changes in Jason's body affect the way he sees himself as a person?

How do Jason's symptoms change the way he sees and experiences life in New York City? In terms of perspective, what does he lose and what does he gain?

Jason frequently comments on how quickly his disease progresses: "Getting worse so fast, I feel like my time is running out. I may be walking slower, but inside I'm racing." How does the speed at which Jason's symptoms progress influence his thinking about his own mortality?

In the early stages, Jason's symptoms were unpredictable. How do you think you would react if suddenly you couldn't rely on your body (or if you have experienced this, how did you react)?

Trying to stay positive on another Friday night home alone, Jason says, "The truth is, I can't complain. I've gone out with my fair share of beautiful women. But as my MS gets worse, I'm finding that the girls disappear." In your experience, what is the effect of physical ability and appearance on relationships?

Jason says that on prior trips to India he felt like he fit in, but now he doesn't. What changed? How do our outward appearances influence how people react to us (or not) and how we experience our own identities or sense of belonging? What is it like for Jason to be conspicuous and invisible at the same time?

Jason questions how much longer he can live by himself. What was your reaction to his mother's response: "Wherever you live in this world, really Jason, you are alone. We are really all alone in this world. We are. Even though we have support systems, we're really alone." How is Jason's identity intertwined with his sense of independence, and how does the meaning of "independence" morph as his MS gets worse?

Jason finds himself unable to rush to his wife's side during a medical emergency. What emotions do you think he experiences and how might those emotions complicate his vision of himself as a husband, a prospective father and a man?

While filming in India, Jason says, "Not being able to see properly, I can't get the shots I want." Upon realizing that, he decides to end the project. How is he able to abandon the project without abandoning his identity as an artist or a filmmaker?

### How Others React

How does Jason's illness affect his relationships with his family?

How does the speed of onset affect the ability of his family, friends and colleagues, to adjust?

Jason says, "For the past year, my MS was almost invisible. I'd walk around like a normal person, but on the inside my body is at war with itself." How does the absence of easily visible symptoms complicate the lives of people with dis-

abilities? What's the difference between the disease being invisible and the person with the disease being invisible?

Of all the advice that Jason receives from his mother, what did you find most and least helpful? Explain your reasoning. You might consider one or more of the following quotes in your discussion:

"When you feel down, think of other countries, other people...When you think your life is bad, think of situations like this [in the slums of Jakarta] where people are stuck."

"We're just here for a short while and we don't know when we will die, so we just have to enjoy every day."

"Things are tough in life. Get real!"

[on staying in New York City] "It has to do with attitude, too. If you're happy here, you'll feel better. If you're in a place you don't want to be, you'll feel worse. And you will spiral downhill because it's mind over matter, too."

If you have experienced major illness or injury, what advice did you hear in relation to it? What helped?

Jason says, "I think it's really hard to be involved with somebody with such a hard disability." Alice says, "There's a possibility that I'm more attracted to you [now] that you have a disability, because to me it shows this, like, soft side." What messages do we typically see or hear about people with disabilities and romance? How did Jason and Alice's experiences compare with mainstream media depictions you have seen?

Alice acknowledges that she had to think about committing to someone who, in a few years, "could be in a state where they don't walk, they don't talk, they don't see." If you were Alice's friend or parent, what would you have said to her about the prospect of marrying someone with MS?

As Jason and Alice consider their pending marriage, what kinds of things do they have to think about that fully able-bodied couples do not? Do you think it would be useful if every engaged couple asked questions such as, "What happens when I can't use my hands anymore or if I can't have sex?" Why or why not?

## Healing

Consider the various healing strategies that Jason pursues:

physical therapy

yoga

pilgrimage to Lourdes

prayer

vein stretching procedure

What are the strengths and limitations of each approach? What do you think Jason took away from each of the experiences?

Jason asks himself, "What could I have done to not have gotten this?" Why do you suppose this type of self-blaming question is common? What assumptions about individualism, independence and society underlie the question?

Jason's yoga teacher (in India) advises him, "Be patient. When you wake up in the morning, start your day on a positive and spiritual note and never have any sort of inferiority complex. For you are normal just like anybody else." In what ways can the belief in mind over matter give people strength? How might it make someone feel worse?

When Jason is asked how it feels to watch himself on film, he initially responds, "Well it sucks, because mentally inside I think that I can walk." However, he goes on to say, "This is actually really good for me because... allowing myself to see myself is actually some kind of healing process in itself." In what ways is filmmaking therapeutic for Jason? What does he learn about himself because he is making a film that he wouldn't have learned otherwise? How might people who aren't professional filmmakers benefit from making videos about their experiences with disease or disability?

## Coping

It's easy to chronicle Jason's frustrations and difficulties stemming from MS. What are his triumphs and what sorts of things set the stage for those triumphs?

Jason's mother says, "If I start thinking of you, your health, what you were, what you are now and what is going to be, it's all just really depressing. And I try to be positive, but there is nothing positive about this MS. What is positive is the way you cope with it... and what you are doing about it and the film. That is very positive and that's what I brag about to everybody." What's the difference between what she says and those who romanticize Jason's courage and resilience?

After two years of continuous caregiving, Alice plans a hiking trip. She says, "I feel really guilty. I don't like leaving. I don't like leaving you here, but I am on the verge of insanity." Much attention is focused on what Jason needs, but what do caregivers like Alice need and how could families and communities help meet those needs?

At the end of the film, Alice announces her second pregnancy. Why do you think that was chosen as the end of the film?

### The Meaning of Accessibility

What do you learn from the film and Jason's experiences about the meaning of "access"? Do you think lack of access always indicates the existence of discrimination? Why or why not?

What types of assistive technologies do you see in the film? Which of these are available and affordable to the people in your community? What could be done to make them available to everyone?

When Jason and Alice are creating the initial AXS Map app, what do you notice about the details that the app contributors are seeking? What did the criteria tell you about things that inhibit mobility?

How do slush and snow impact Jason's mobility? How about sand on the beach, stairs, garbage cans on sidewalks or lack of wheelchair accessible cabs? Have you ever experienced limits on your mobility? What was it like? How does your ability to move around influence the types of activities you do and the places you go? What types of changes could communities make that would expand Jason's options?

In addition to mobility issues, Jason experiences problems with his hearing and his vision. What does access mean to someone who is blind? How about someone who is deaf?

As Jason tries to move around his community, he encounters obstacles that seem easy to change, like sidewalks that haven't been shoveled and protruding garbage cans. Why do you think so many people overlook or ignore access?

What situations do you see in the film that cause problems for Jason, but could be altered to provide accessibility? If you lived in his neighborhood, what kinds of recommendations would you make to city officials, landlords, business owners or neighbors? How could cities be made more accessible?

After struggling to navigate a shoot on the beach, Jason's brother asks him, "When was the last time you felt the perils of not being able to get somewhere?" Jason responds with an incredulous look. How would you answer that question? Have you ever experienced limits on your mobility?

What was it like? How does your ability to move around influence the types of activities you do and the

places you go? What daily routines do you take for granted that require careful planning (or are impossible) for people with disabilities like Jason's? Consider how you make connections with people, attend school or a job, shop or enjoy events such as movies or concerts or meals with friends.

In addition to people with obvious issues with mobility, such as Jason, who benefits from living in accessible communities? Consider challenges faced by the elderly, people pushing strollers, people with injuries and so on. Who does not benefit? If many people stand to benefit, why do you think so many places are still not accessible?

**Additional media literacy questions are available at:**  
[www.pbs.org/pov/educators/media-literacy.php](http://www.pbs.org/pov/educators/media-literacy.php)

- Create or contribute to the AXS Map app for your community. Organize a mapping meet-up or an AXS Map Mapathon (#mapathon) with your friends and family, students, staff or community members to rate the accessibility of areas in your local neighborhood and add them to AXS Map, just as Jason and Alice do in the film.
- Create a special event at a maker space where attendees focus on developing adaptive technologies. Screen *When I Walk* so people can look at the tasks that are challenging for DaSilva and devise solutions. Use the event to facilitate ongoing dialogue between prospective inventors and people with disabilities (and their families) in your community. When possible, create partnerships between inventors and people who are willing to “field test” inventions.
- Host a screening of *When I Walk* in conjunction with a local Walk MS event.
- Convene an annual community “check-up” for compliance with the ADA. In addition to advocates, people with disabilities and their families, involve people responsible for transportation systems, construction and zoning, availability of medical care, public policy and other related issues. Also look for instances where the ADA falls short and recommend changes.
- Increase the visibility of people with ambulatory disabilities in your community by distributing small cameras such as GoPro cameras and inviting them to record their typical days. Collect and display what they shoot in an online gallery, at a live venue or both. With permission, distribute the footage to local news outlets and encourage them to do stories about accessibility issues.

**FILMMAKER WEBSITE**<http://wheniwalk.com>

The film's website offers additional information about the film and filmmakers, as well as ways to get involved.

**Original Online Content on POV**

To enhance the broadcast, POV has produced an interactive website that viewers can use to explore the film in greater depth. POV's website for **When I Walk** website—[www.pbs.org/pov/wheniwalk](http://www.pbs.org/pov/wheniwalk)—offers a broad range of exclusive online content to enhance the PBS broadcast. Watch the full film online for free for a limited time following the broadcast, watch an extended interview with filmmaker-subject Jason DaSilva and see what's happened since the cameras stopped rolling, download a discussion guide and other viewing resources, and find out how you can "make the world a more accessible place" with AXS Map.

**What's Your POV?**

Share your thoughts about **When I Walk** by posting a comment at <http://www.pbs.org/pov/wheniwalk>

**Multiple Sclerosis****THE AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES (AAPD)**[www.aapd.com/](http://www.aapd.com/)

The AAPD is the largest disability rights organization in the United States. The website offers resources and support for a range of issues, including education, employment, health and benefits and transportation.

**AXS LAB**<http://axslab.org/>

The site that Jason and Alice created has a blog, ways to get involved and instructions for accessing and contributing to the AXS Map.

**NATIONAL MULTIPLE SCLEROSIS SOCIETY**<http://www.nationalmssociety.org/>

The National Multiple Sclerosis Society site includes general information about MS and related resources.

**PUBMED HEALTH**[www.ncbi.nlm.nih.gov/pmc/?term=Multiple%20Sclerosis](http://www.ncbi.nlm.nih.gov/pmc/?term=Multiple%20Sclerosis)

This National Institutes of Health site aggregates research studies on treatments for MS.

**UNITED SPINAL ASSOCIATION**<https://www.unitedspinal.org/>

The United Spinal Association site provides programs, services and resources for those with spinal cord injuries and disorders.

**Accessibility and Living with Disabilities****AXS MAP**<http://www.axsmap.com/>

Users can search the AXS Map, created by Jason and Alice, for accessible businesses throughout the United States and also have the opportunity to add to the database.

**CENTERS FOR DISEASE CONTROL AND PREVENTION: ACCESSIBILITY & THE ENVIRONMENT**<http://www.cdc.gov/healthyplaces/healthtopics/accessibility.htm>

The Centers for Disease Control website provides information about accessibility and universal design, as well as links to further resources.

**DISABILITY.GOV****<https://www.disability.gov/>**

This site is the federal government's one-stop shop for information on disability programs and services nationwide, including resources on topics such as housing, transportation, employment and civil rights.

**MATCH.COM: DATING AND DISABILITIES****[www.match.com/magazine/article/5823/Dating-And-Disabilities/](http://www.match.com/magazine/article/5823/Dating-And-Disabilities/)**

This online dating site offers tips on dating a person who uses a wheelchair. See also [www.wheelchairdating.net](http://www.wheelchairdating.net).

**Family and Caregivers****CAREGIVER ACTION NETWORK (CAN)****<http://caregiveraction.org/>**

The Caregiver Action Network provides peer support, education and resources for family caregivers. The Caregiver Community Action Network is a group of caregiver mentors active in more than 40 states, accessible through the CAN website.

**FAMILY CAREGIVER ALLIANCE (FCA)****<http://caregiver.org/>**

The Family Caregiver Alliance offers classes and webinars, in addition to advocacy work and resources. The FCA is also the home of the National Center on Caregiving and the Family Care Navigator, which locates support services by state.

**MULTIPLE SCLEROSIS FOUNDATION:  
SUPPORT GROUPS****<http://www.msfocus.org/support-groups.aspx>**

The Multiple Sclerosis Foundation has a searchable network of more than 100 MS support groups nationwide. The site also has information on starting a support group and training opportunities.

**NATIONAL MULTIPLE SCLEROSIS SOCIETY:  
FAMILY MATTERS****<http://www.nationalmssociety.org/Resources-Support/Family-Matters>**

The National Multiple Sclerosis Society has resources for individuals with MS, their family members, their friends and their care partners. The organization's Family Matters section also has downloadable guides on children of parents with MS, hiring help at home and other topics for families.

**Public Policy and Disability Rights****AMERICANS WITH DISABILITIES ACT****[www.ada.gov](http://www.ada.gov)**

This is the official government site for information and technical assistance on the Americans with Disabilities Act.

**CENTER FOR DISABILITY RIGHTS****[www.cdrnys.org/](http://www.cdrnys.org/)**

Focused on peer-to-peer support and independent living, this upstate New York based organization is typical of such groups across the United States. On a search engine, search for "disability rights center," "council for disability rights" or "independence center" followed by the name of your state or city to find an advocacy group where you live.

**CENTERS FOR DISEASE CONTROL AND PREVENTION****[www.cdc.gov/nchs/nhis/nhis\\_disability.htm#data\\_highlights](http://www.cdc.gov/nchs/nhis/nhis_disability.htm#data_highlights)**

The website of this government organization provides statistics on people living with disabilities.

**CORNELL UNIVERSITY: DISABILITY STATISTICS****[www.disabilitystatistics.org](http://www.disabilitystatistics.org)**

Cornell University provides a searchable compendium of statistics related to disability with easy to understand explanations of sources and calculations.

**SOCIETY FOR DISABILITY STUDIES****[www.disstudies.org](http://www.disstudies.org)**

This organization is devoted to research on the social and cultural, as well as political and medical, aspects of disability. Resources include an open-source academic journal.

## HOW TO BUY THE FILM

To order **When I Walk** for home viewing, visit [amazon.com](http://amazon.com).



Produced by American Documentary, Inc. and beginning its 27th season on PBS in 2014, the award-winning POV series is the longest-running showcase on American television to feature the work of today's best independent documentary filmmakers. Airing June through September with primetime specials during the year, POV has brought more than 365 acclaimed documentaries to millions nationwide. POV films have won every major film and broadcasting award, including 32 Emmys, 15 George Foster Peabody Awards, 10 Alfred I. DuPont-Columbia University Awards, three Academy Awards and the Prix Italia. Since 1988, POV has pioneered the art of presentation and outreach using independent nonfiction media to build new communities in conversation about today's most pressing social issues. Visit [www.pbs.org/pov](http://www.pbs.org/pov).

### POV Digital [www.pbs.org/pov](http://www.pbs.org/pov)

POV's award-winning website extends the life of our films online with interactive features, interviews, updates, video and educational content, as well as listings for television broadcasts, community screenings and films available online. The POV Blog is a gathering place for documentary fans and filmmakers to discuss their favorite films and get the latest news.

### POV Community Engagement and Education

POV's Community Engagement and Education team works with educators, community organizations and Public Media stations to present more than 650 free screenings every year. In addition, we produce and distribute free discussion guides and curriculum-based lesson plans for each of our films. With our community partners, we inspire dialogue around the most important social issues of our time.

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### American Documentary, Inc. [www.amdoc.org](http://www.amdoc.org)

American Documentary, Inc. (AmDoc) is a multimedia company dedicated to creating, identifying, and presenting contemporary stories that express opinions and perspectives rarely featured in mainstream-media outlets. AmDoc is a catalyst for public culture, developing collaborative strategic-engagement activities around socially relevant content on television, online, and in community settings. These activities are designed to trigger action, from dialogue and feedback to educational opportunities and community participation.

You can follow us on Twitter @POVengage for the latest news from POV Community Engagement & Education.



Front cover: Jason DaSilva at the Taj Mahal.  
Photo courtesy of Long Shot Factory

