

A Film by Jason DaSilva



Release Date: April 26, 2019 at Hot Docs in Toronto, Canada

Run Time: 78 minutes

Rating: Not Rated

Language: English

Official Web Site and Photos: www.whenwewalk.com

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LOGLINE

Long description:

Filmmaker Jason DaSilva has been living with a severe form of multiple sclerosis for over 10 years. In his wheelchair, Jason begins to realize just how many places he is unable to experience with his son. To solve that, he continued working on the website AXS Map to help him determine the places he could go. When his son moves 1700 miles away to Austin Texas he is unable to cope with this loss. He attempts to relocate to Austin which reveals to him the extent of the broken medicaid system. He discovers that state-run Medicaid would require him to live in a nursing home.

When We Walk documents a devoted father and filmmaker with an indestructible drive to keep the cameras rolling no matter what and to show his son what it means to never give up.

Short logline:

Filmmaker Jason DaSilva explains the disparity between the different states and the national healthcare crisis as he tries to be closer to his son who lives 2,000 miles away.

SYNOPSIS

In February 2013, I received the greatest gift of my life, the birth of my son. Over the next three years, I watched him grow into a clever, energetic and humorous little boy. He embodies the best qualities of his mother and his father, in all the ways a parent dreams. And even though I have [primary progressive multiple sclerosis](#), the condition didn't hinder my ability to be a father to him. His mother and I provided a loving and supportive environment.

Then his mother and I separated. She and my son moved to Austin, Tex., while I remained in New York City. I was determined to move there too, to co-parent our son. So I went to Texas to investigate what life for a Medicaid-dependent person with disabilities would be like there. I quickly found the quality of health care in Texas did not come close to what I receive in New York.

I next looked at surrounding states to see if they had adequate Medicaid coverage. I discovered that funding for Medicaid varies widely by state, creating huge hurdles for sick and disabled people like myself who need to move to another state, especially those of us who need in-home round-the-clock care.

The disparity amounts to institutionalized discrimination against aging and disabled people, and it prevents me from truly having a choice about where I can live.

If I were to move to a nursing home, where the best level of 24-hour care in Texas is available, I would have to give up my personal aide; aides in nursing homes are expected to help multiple people simultaneously. The most basic tasks of life — showering, shaving, food preparation, eating, going to the bathroom, checking emails, answering phone calls — would be significantly more difficult, diminishing my independence as a father, personal well-being, health and even my life expectancy. In New York, because of the one-on-one care I receive, I am able to keep up with my career as a filmmaker and activist.

Life has presented me with these challenges because I'm strong enough to endure them, grow from them, and help others dealing with them, too. Regardless of my disability, each day I strive to spread awareness of the damaging discrimination against the disabled population of the United States. Despite these challenges, I remember what's most important: my son. If having a physical disability has infringed on my right and ability to be a parent to him, I fear that other disabled people may lose their right to be a parent too, to get the care they need while being with the families they love.

DIRECTOR'S STATEMENT

I have been in a state of crisis for the past three years. My health is declining, you moved away from me. Had I been able to see into the future, I would have done everything to keep you with me. When you left, I had the ability to use my hands. I am now quadriplegic; I cannot use my arms or legs. These days, I drive using a head mount on my special wheelchair. I turn left or right and go forward or back, just by moving my neck. I know the time we have together is limited.

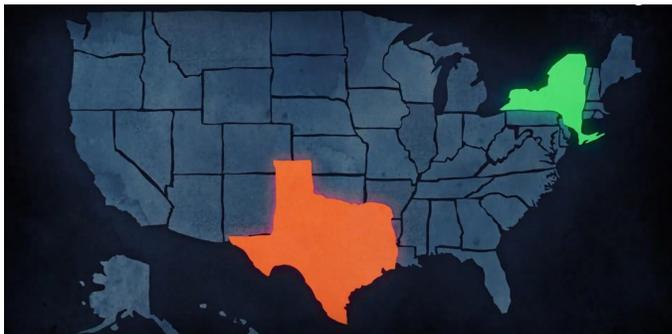
My son, I think about you all the time.
I want you to grow up with me.
I want you to know me.
I want to be an active part of your life.
I want to be there whenever you need me.
I want to be able to watch you at your soccer games, school plays, and musicals.
I believe that a father and his son should be around each other.
I want you to know that there is no one I love more than you.



Take a step back with me, you may not understand all of this yet, but you will as you grow up. I know that you are going to grow up to be a smart and inquisitive individual. So I have no doubt that you'll be able to comprehend what I'm about to break down below:

Currently, New York Medicaid provides me with 24/7 in-home care. Recipients like me would lose their benefits if they move to a new state. After they move, they must reapply, a process that may take 6 months to 3 years. Additionally, there is no guarantee that they will be accepted.

Even if they are accepted, they may suffer a decline in services.



If I move to Texas to be close to you, once I received my Medicare benefits, they would only cover a maximum of 48hr/week. With such limited coverage, I would have to be placed in a nursing home. If that happened, my life as an independent filmmaker, activist, and a contributing member of society would

end. The drastically reduced level of care available in nursing homes would mean the loss of my mental and physical well-being.

I know firsthand as I actually checked into a Texas nursing home. No one was available to help me do basic things when I needed them like using the restroom, eating, or making phone calls.

Tasks relating to my filmmaking and advocacy work like writing, responding to emails, and editing, were impossible. It was difficult to make arrangements to see you. I was not free to be the father I want to be for you.

As a filmmaker, I created AXS Lab which gives a voice for people with disabilities through its storytelling and its transmedia projects. Through filmmaking, I try and do what is right.

Primary Progressive Multiple Sclerosis has been a consistent challenge to say the least. When I first started, I was diagnosed in 2005, I documented my challenges on film with *When I Walk*. Now I continue telling our story through *When We Walk*. In the past year of post-production, my vision has deteriorated. It's been difficult because I've had to watch the film on a magnified screen and give my director's commentary to the editor, all while having a heartbreak of you not being around me and restarting a new life on my own. For me everyday is precious, being around you, my son, is precious. Somethings I do know are that I cannot come to you because I live in New York and people help me 24/7, I would like to spend as much time as possible together, and *When We Walk* will be my legacy to you.



-Jason DaSilva, Director

CREDITS

Directed by
Jason DaSilva

Produced by
Jason DaSilva
Leigh DaSilva
Richard O'Connell

Executive Producers
Simeon Hutner
Chase Muratore
Alice Elliot
Remy (Smartie Papa) DaSilva

Written by
Jason DaSilva

Edited by
Simeon Hutner

Additional Editors
Charnelle Quallis
Albert Puoh Share See
Christina Stiles
Nathan Paul
Ivan Antipov
Leigh DaSilva

Director of Photography
Jason DaSilva

Production Designer
Mihai Wilson

Color Grading/Online Facility
Hell's Color Kitchen

Colorist/Online Editor
Jon Fordham

Color Grading Prep & Media Wrangling
Ian Heifetz
Bahron Thomas

Post Production Supervisors
Keith Shapiro
Sheila Lynch

Camera
Dan Gold
Ivan Antipov
Karin Hayes
George Leedy
Albert Puoh Share See
Nathan Paul
Erica Robert Pallo

Simeon Hutner

Story Consultants

Julie Talen

Assistant Story Consultant

Mark Dhaniram

Composer

Todd Griffin

Ryan Rumery

Jeff Beal

Sound Design/Re-Recording Mixer

Bob Barzyk

Animation

Mihai Wilson

Konstantin Steshenko

Wyatt Banks

David Disaro

Derrick Ramirez

Additional Music

Frank Henville

Music Score

“Strange”

Built to Spill

Warner Bros. Records

2001

“Drunk at the Carnival”

The Malchiks

Spawner Records

1996

Web Design

Leo Lemos

Legal

Holland and Knight

Lin Weeks

Publicity

Adam J. Segal

Production Assistants

Yining Pan

Nyaisha Pete

Daniel Cho

Mayta Lor

Thanks to:

Edward DaSilva

Marianne D’Souza

Daniel DaSilva

Leigh DaSilva

Lucy Hutner

Jane Brill

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Jamal Hodge
John Alpert
Raj Soni
Rakesh Nair
Sharon Hughes
Robert Salisbury
Chris Bravo
George Gallego
Alex Elegudin
Alberto del Moral
Margaret Mize
Suri Nisker
Susan Olivo
Mimoza Thana
Nate Fairchild
Alice Elliott
Shilpi Gupta
Nancy Yap
Jase DaSilva
Alice Cook
Cheryl Einhorn

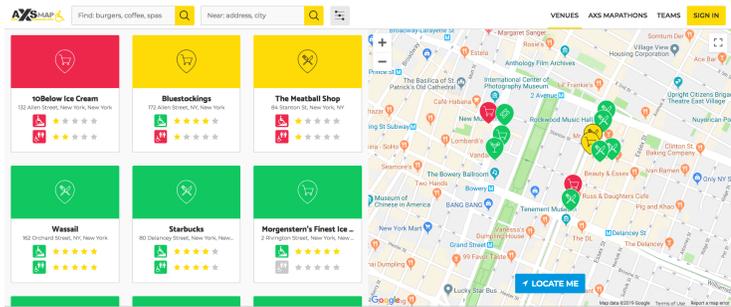
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New York Community Trust
Reader's Digest Partners for Sight
Ruderman Family Foundation

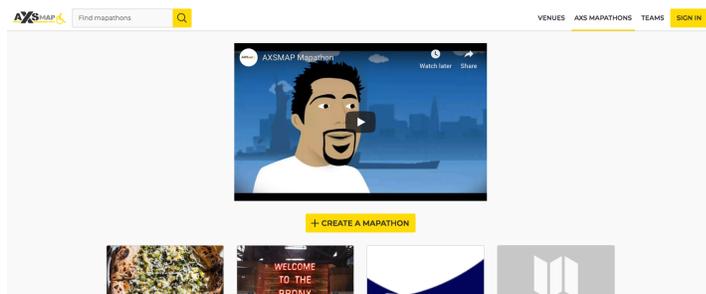
ABOUT AXS MAP

AXS Map ('access map') is a crowd-sourced tool for sharing reviews on the wheelchair accessibility of businesses, restaurants, entertainment centers, and other day-to-day destinations available online or via mobile web, as well as Android and iPhone applications. To learn more and start mapping, visit www.axsmap.com.

For some it may be surprising to learn that as many as nine out of ten businesses on a city block may be inaccessible to people using wheelchairs and scooters. For many, inaccessibility is an endless source of frustration; lack of awareness, social attitudes, and exclusionary design situate people with disabilities on the periphery of their communities and society at large. This a result in a “civil death,” often a greater torture than living with the disability itself. This marginalization is reflected in numerous studies showing disproportionately high instances of unemployment and low income among people with disabilities.



For the 13.2 million people in North America who have mobility impairments, AXS Map aims to ease the burden of social exclusion by providing people with disabilities the freedom to be spontaneous about where they eat, shop, work, and play. Want to go to dinner and a movie, but unsure if there's an accessible restaurant near an accessible theater? Search AXS Map to



get a literal lay of the land, complete with reviews and details about the particular levels of access; is the business technically accessible (e.g. no steps to enter the establishment, but the ramp is too steep), or truly accessible (e.g. the entrance ramp has an easily navigable incline).

ABOUT THE FILMMAKERS

Jason DaSilva - Producer - Director - Writer

Jason DaSilva has been a prolific filmmaker for the past 15 years. He has directed four short films (*Olivia's Puzzle*, *A Song For Daniel*, *Twins of Mankala*, *First Steps*) and two feature length-documentary films (*Lest We Forget* and *When I Walk*). *Olivia's Puzzle* premiered at the 2003 Sundance Festival. Three of his films have had national broadcasts on PBS, HBO, and CBC. DaSilva's latest film, *When I Walk*, won a 2015 Emmy Award for Outstanding Informational Programming, was an Official Selection of the 2013 Sundance Film Festival and won Best Canadian Feature at Hot Docs 2013. In 2014, Jason also won three awards: AAPD Mobility Magazine's Person of the Year, the Paul E. Hearn Leadership Award, and the Christopher Award for Excellence in Film. Currently he is working on a new feature film *When They Walk* and on AXS Map, a website and accessibility database to find disability friendly places around the world.

Richard O'Connell - Producer

Richard O'Connell is an Emmy Award winning filmmaker, producer and educator living in San Francisco. Richard worked for 15 years at the Independent Television Service serving as Head of Production and later a Senior Producer of National Productions. During his time at ITVS, Richard oversaw the production, delivery and broadcast of over 500 films to PBS and all the national series including *Frontline*, *American Masters*, *POV* and *Independent Lens*. Richard is also a filmmaker working in both documentary and narrative. His current film, *The Corridor* looks at the first high school to be built inside an adult jail. Richard's work has appeared on national television in the U.S, been released theatrically and exhibited at major film festivals. Additionally Richard has worked as a journalist, freelance editor, cinematographer, and lectures at Berkeley City College. He has participated in selection committees for the San Francisco Film Festival, Mill Valley, INPUT and is a Director of Programming at the San Francisco Irish Film Festival, and won a National Emmy Award as a Producer of the film *The Homestretch*.

Leigh DaSilva - Producer

Leigh Dasilva began his independent filmmaking career producing alongside award-winning filmmaker Jason DaSilva on *First Steps*, which premiered at the Tribeca Film Festival (2009), and also screened at the Vancouver Film Festival (2009). He then went on to produce the feature length documentary *When I Walk*, which premiered at the Sundance Film Festival (2013), broadcast on PBS/POV (2014), won Best Canadian Feature Documentary award at Hot Docs (2013), Grand Jury Award for Best Film at the Los Angeles Asian Pacific Film Festival (2013), and Most Popular Canadian Documentary at the Vancouver International Film Festival (2013). It won a News & Documentary Emmy in 2015. Leigh also produced the mobile application AXS Map, which is a crowd-sourced platform for mapping wheelchair accessible locations. It has received funding from numerous donors, including Google through the Tides Foundation, The Nathan Cummings Foundation, and the Canada Media Fund. He is the President of the award-winning production company In Face Films. As a PMP certified producer/project manager that also specializes in transmedia storytelling and digital media, he currently sits on the Moving Images Distribution Board of Directors as Vice-Chair. He is pursuing a Master's Degree in Business Administration from the University of South Dakota.

Simeon Hutner - Producer/Editor

Simeon Hutner has over twenty-five years of film and television credits, including award-winning works shown at Sundance and many other film festivals, as well as on HBO, BBC, Bravo, A&E and PBS. He is currently editing the documentary feature *My Ascension*, directed by Greg Dicharry, about teen suicide. He just finished editing *When We Walk*, directed by Jason DaSilva, and also recently edited *Cooked*, directed by Judith Helfand, about the 1995 heat wave disaster in Chicago. He edited *Vessel*, directed by Diana Whitten, about the Dutch abortion activist Rebecca Gomperts and her organization Women on Waves. Simeon also edited and co-directed *Harlem Street Singer*, about the influential blues and gospel musician the Reverend Gary Davis. Additional selected editing credits include: *When I Walk*, *Everything's Cool* and *Blue Vinyl*, which premiered at Sundance in 2013, 2007 and 2002, respectively. He was editor on *Chicks in White Satin*, which premiered at Sundance and was nominated for an Academy Award in 1994. He has an MFA in Film Production from USC, an MBA in Finance from New York University and a BA in English Literature from Middlebury College.

Chase Muratore - Executive Producer

Chase Muratore is a Writer-Producer from New York, NY. Chase has partnered with Director Jamal Hodge to produce multiple award-winning short films including the Kind Ones and A Happy Divorce (winner, LAFA best inspirational picture). Chase is currently producing Pierre the Pigeon Hawk, a children's animation feature, starring Nick Cannon, Whoopi Goldberg, Keenan Thompson, with animation veterans Exodus Film Group. He has recently partnered with Emmy-award winning Director Jason DaSilva to help produce When We Walk. Chase also serves as a board member for AXS LAB (founded by DaSilva) to help empower the disabled through media and technology, by developing business partnerships that are mission-oriented toward the promotion of an accessible world. Starting as an entrepreneur in the Executive Recruiting business, Chase helps broker strategic partnerships for non-profits, films and businesses that are mission driven to be of genuine service to others.