

An Allen C. Crocker Fellowship Project

**Same-Same But Different:  
Reflections from Adult  
Siblings on Caregiving  
and Securing Resources**

By Jess Mendes



Dedicated to my brothers, Jessie James and Jason

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## PREFACE

This body of work is curated by Jess Mendes. Jess grew up in Boston, Massachusetts. She completed her undergrad at Fairfield University, in Connecticut, earning her Bachelor of Arts in Communication and Black Studies.

In 2014, she moved to New York City to pursue a career in content development and marketing. She worked at BuzzFeed in the creative department, executing social and editorial branded campaigns. In 2016, she moved on to accept a position at Complex where she elevated brand partnerships and pioneered experiential activations, including ComplexCon. In 2018, she embarked on her own journey as an independent strategist and producer for a variety of agencies, artists and brands.

Like many, Jess moved back home during the 2020 pandemic to be closer to and to support her loved ones. As a first-generation Cape-Verdean American and the oldest of three, she honorably became the advocate for her family. At the time, her youngest brother, a young man with high-support needs relating to numerous disabilities, had just turned 22-years old. This milestone birthday meant he “aged out” of all educational programs supported by the school system. A seemingly routine challenge for young adults like him was inflamed in COVID-19 turmoil. In search of resources, Jess joined Mass Families, a grassroots coalition educating families about advocacy, services and resources. Her time at Mass Families introduced her to the Allen C. Crocker Family Fellowship, created in honor of a pediatrician who was a leader in supporting people with developmental disabilities.

As a recipient of the Crocker Fellowship, Jess gathered first-person narratives of adult siblings living at the intersection of multiple marginalized identities, including disability. Her project titled, “Same-Same But Different” is a collection of essays created in response to a world turned upside down and inside out. This isn’t intended to be traditional journalism. It is a rare privilege for individuals to unpack how disabling attitudes, environments and systems play a role in their sibling relationship. In doing so, “Same-Same But Different” serves as a platform for families to articulate their needs within social and political systems that weren’t built for their loved ones.

## PREFACE

Sibling relationships are the longest standing ties of our lives. Typically, this unique connection becomes our most enduring source of support as we age. The value of each sibling relationship is based on the bond formed during shared circumstances. Many siblings have comparable family stories and memories. However, when a disability exists within the sibling dynamic there are distinct and complex variations. This is an exploration of those seldom shared stories.

The easiest part of this project's development was securing the participants. The experience of being a sibling to an individual with a physical, intellectual, behavioral and/or developmental disability is common, yet rarely considered. The participants for this project were only two degrees of separation from Jess:

- **Trina Martinez** is the mother of Daniel, a visual artist turned friend Jess met during her frequent visits to the Pacific-Northwest. From Trina's delicious recipes and her joy for running marathons to her selfless devotion to her family, there are numerous reasons Jess' admiration for Trina continues to grow.
- **Saam Niami** and Jess met at a Fashion Week event in New York City. The serendipitous friendship began as small talk over film cameras and eased into an open dialogue about cultural attitudes towards disability and their experiences as siblings.
- **Edward Haynes** is the father of Jess' dearest friend, Nicole. Nicole and Jess' bond formed fifteen years ago in high school. The Haynes family exudes a love for music that is truly endearing, and their taste in music is impeccable.
- **Isaiah Mulligan** and Jess met when she would visit Nicole during her undergrad at Emmanuel College. His sense of humor was the gravitational pull to start their friendship. Born and raised in the Bronx, Isaiah is now a school teacher in Washington, DC. kissed by the wanderlust bug.
- **Cristina Cortez** and Jess were introduced to each other via a local advocate and mentor. Cristina is the only contributor to this project that lives with a disability. It was important for Jess to include perspective from both sides of the sibling relationship, emphasizing the invaluable communal caregiving.

## PREFACE

The research for this project happened simultaneously in four parts: academic, arts and culture, lived experience and grassroots organizing.

The inspiration behind the name of this project came from an article included in *Impact* magazine. *Impact* is published by the Institute on Community Integration (UCEDD) and the Research and Training Center on Community Living and Employment (RTC) within the College of Education and Human Development at the University of Minnesota. Three times a year, it provides information useful to educators, policymakers, community service providers, advocates, individuals with disabilities and their families. In Spring 2020, the 32nd issue focused exclusively on sibling dynamics across all age groups, accessibility needs, and life milestones. The article titled “Same-Same But Different” by Alison Whyte, the Executive Director of Disabilities Council in Washington, D.C., acknowledges 90% of research on siblings affected by disabilities is white, relatively middle class, and female. The article goes on to list a few reasons for this discrepancy in research, ending with a strong call to action that reads:

*Ultimately, we are left with more questions than answers and my hope is that this sparks curiosity and action to learn more about this beautifully diverse community of siblings.*

In January 2021, the White House released an Executive Order broadcasting: *People with disabilities confront multiple barriers to inclusion and participation in the community, and to positive health and employment outcomes. These barriers can be societal, attitudinal, physical, or systemic. These barriers are compounded for people with disabilities who are from one or more underserved communities, such as Black, Latino, and Indigenous and Native American persons; Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; LGBTQ+ persons; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.* (Executive Order 13985)

As we now find ourselves in 2023, locally, nationally, and globally, humanity is confronting issues of accountability, equity and universal access. This radical and polarizing shift is an opportunity to cultivate revolutionary thinking and practices for those with various intellectual and physical abilities.

## PREFACE

Alison Whyte's article, "Same-Same But Different," reiterated a reality we are all too familiar with: mainstream narratives are typically white and single-issue. Research that focuses on equity must account for and critically assess systemic inequities, including the roles of ableism and racism. This body of work also serves as a response to Whyte's call-to-action. It is open-source information intended to encourage more questions, conversations and research.

Lastly, this is a love letter to kinship. May siblings, both giving and receiving care, find power in knowledge and community. As you spend time with each story, ask yourself, how do we truly restitch the social fabric of our communities?

but  
different



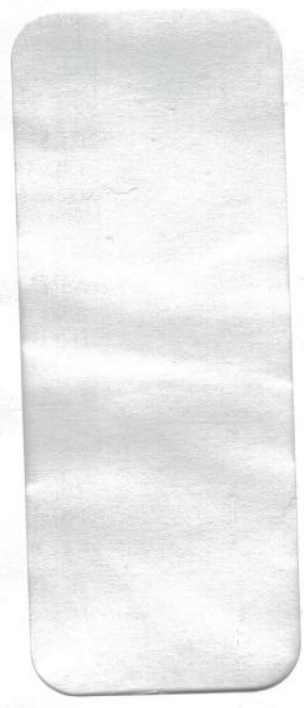
Same-Same But Different

Concept by Jess Mendes  
Illustration by JP Abascal

FIRST CLASS MAIL  
PRESORTED  
US POSTAGE  
PAID  
GGA

JESS MENDES  
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**IMPORTANT INFORMATION**  
**IMMEDIATE RESPONSE REQUIRED**



SERVE NOTE

10

06

THE UNITED STATES  
OF AMERICA



*We the People*

THE AMERICAN DREAM  
AND DISABILITY

DOLLARS

## THE AMERICAN DREAM & DISABILITY

For generations, people have journeyed across oceans and continents to sow their hopes in fertile American soil. The glittering promise of a land paved with gold has beckoned countless seekers in search of a better life, including my family, who came here from Cape Verde— a beautiful archipelago nestled off the West African coast. As a first-generation American, I was raised in Roxbury, a vibrant district of Boston. I am a daughter, sister, cousin, auntie, lover, and friend.

Like many children of immigrants, my mother had specific expectations of success for my younger brother, Jessie James, and me. But everything changed when our youngest brother, Jason, was born. He was diagnosed with cerebral palsy, epilepsy, global developmental delay and low vision impairment at 18-months. This diagnosis upended experiences we never could have imagined.

In April of 2020, Jason turned 22, a significant milestone for people with intellectual and developmental disabilities and their families. It's known as "jumping off the 22-year-old cliff." For many families, this can be a daunting and overwhelming time filled with social, emotional, and economic challenges. For us, the stark reality of Jason's situation was painfully apparent. How could we hope to achieve a better life when 25% of the population is underserved? How could we reconcile American values of independence while facing the reality that one in four adults are living with a disability? How could we define "better" when there is such a lack of knowledge, resources, and representation in culture, media, and the workforce?<sup>1</sup> Despite being a common experience statistically, Jason's story often feels isolating and singular.

For over 860 days, Jason went without services, which meant no day habilitation or in-home therapies and occasional Zoom calls with healthcare providers. These responsibilities became ours to bear. This was especially challenging during the COVID-19 pandemic. Individuals with complex needs, like my brother, and the network that surrounds them, have been underserved for far too long. They have been denied access to community and independence, and this lack of personal and social skill-building can put them on a regressive path towards crisis.

Sadly, the promise of progress has stalled, as our national leaders continue to waver on their commitments. The cost of living continues to rise and resources remain scarce. As a result, I'm left feeling both pained and curious. I wonder how other siblings are affected by ableism and racism while juggling this complicated, bureaucratic web. This experience has inspired me to create a project that explores these issues and aims to bring greater awareness to the struggles of our most vulnerable community.

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<sup>1</sup> Centers for Disease Control and Prevention. (2021, March 3). Disability Impacts All of Us. National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>2</sup> di Prima, D. (1990). *Pieces of a Song: Selected Poems*. City Lights Books.

Embroidery thread, 35mm Print and Canvas. Design by Bobbie Lebron.



THE ONLY WAR THAT MATTERS IS THE WAR AGAINST <sup>2</sup>  
THE IMAGINATION



31. Do you need an interpreter? / Necesita Traductor? (Y/N)

Yes MY SISTER CAN ASSIST

32. What is your reason for visiting our office today? / Cual es la razon de su visita a nuestro oficina hoy?

The attorney that helped with my mom's case explained that the embassy is taking longer to process a permanent residence status.

My brother FRANCISCO has Global Synchromi and I need what my mom also needed a green card in April 2017

33. Address (Street, City and State) Dirección:  
105 Ocean Blvd St. Corpus Christi, TX 78411

34. Home Phone / Telefono de la casa: 361.442-7196  
35. Email / Correo electrónico: Trippa.cervantes@gmail.com

Please note that all recommendations given during this consultation are only based on the information discussed with the attorney during the consultation and may not be applicable if new facts or circumstances arise. More documentation or facts may be necessary to reassess the case. Legal fees are only valid for 30 days and may be adjusted if the facts or circumstances surrounding the case change. Filing fees are set by USCIS/EOIR/DOL and are separate from the legal fees.

This consultation does not create an attorney-client relationship. Unless you hire Haupt Immigration Law PLLC to handle your case, we will not file any applications on your behalf, attend any hearings or interviews, or monitor your case.

Tenga en cuenta que todas las recomendaciones del abogado solo se basan en la información presentada durante la consulta y puede que no sean aplicables si de repente nuevas hechos o circunstancias surgen. Para evaluar el caso adecuadamente, los abogados podrían pedir más información. Las cuotas legales son válidas solo por 30 días y pueden cambiar si los hechos del caso o las circunstancias cambian. El costo de entregar las solicitudes está dividido por el USCIS / EOIR / DOL, y es un gasto separado de la cuota legal de este bufete.

Esta consulta no forma una relación entre el cliente y el abogado. No vamos a presentar aplicaciones por usted a la corte, ir a una entrevista, ni monitorear su caso hasta que contrate Haupt

Immigration Services

What kind of visa?  
What kind of work?  
What kind of job?  
What kind of salary?  
What kind of employer?  
What kind of country?  
What kind of method of entry?  
What kind of passport?  
What kind of visa?  
What kind of work?  
What kind of job?  
What kind of salary?  
What kind of employer?  
What kind of country?  
What kind of method of entry?  
What kind of passport?

B2  
B2  
B2

## ACCESS TO RESOURCES & IMMIGRATION LAWS

My name is Trina Martinez, I am originally from Venezuela, and I came to the United States in 1999 for a job opportunity. During this time, I was offered a permanent employment status that led me to decide to stay and become a USA citizen in 2012.

I come from a big family of six siblings, with my brother Francisco Martinez, who we call Pancho, as the youngest. Francisco has Down syndrome, and he is 49 years old. We are now five siblings, as my sister passed away when she was 35 years old.

During the time I lived in Venezuela, life was very nice. The economy was not great, but it was not too bad. As we know, every country has its own internal problems, and Venezuela is not the exception. The country had a lot of issues related to corruption in politics, and was not very economically diverse, among other issues. This situation unfortunately led to a change in direction and the government became authoritarian.

Due to this political change, Venezuelans started migrating to different places around the world. The oil industry, which was the main economic resource in the country, was dismantled and many people lost their jobs. Some of these people migrated to other countries in South America, Canada, USA, and Europe.

Because of these geopolitical, economic, and safety issues in Venezuela, my siblings also started migrating. After my father died, my husband and I decided on the best arrangement for my mother and Pancho.

Our decision back in 2012–2013 was that we would help my mom and Pancho migrate and have a base in the USA with us, with the expectation that we could get additional support from everyone in the family.

The plan was for my mom and Pancho to spend some time with us, and share the time and other responsibilities with my other siblings to eventually help them have a more independent life.



## ACCESS TO RESOURCES & IMMIGRATION LAWS

In Venezuela, we lived in a small city, and resources for Francisco's disability were not in abundance. In countries like Venezuela, the better resources are always located in the big cities.

In our city, Punto Fijo, there are two non-profit institutions named AFALPANE and Luz y Hogar that were founded by a Jesuit priest, who, after his research in the city, found that a great number of children and young adults who lived with mental and physical disabilities. AFALPANE was founded in 1971 and Luz y Hogar was founded in 1977.

**The mission was to provide education, speech therapy, and other basic services to help these kids with communication and to learn skills that will help eventually create some kind of independence.**

He dedicated his life to improving the quality of life for these individuals. The mission was to provide education, speech therapy, and other basic services to help these kids with communication and to learn skills that will help eventually create some kind of independence. The schools have a team of professionals, like special aid teachers, medical/dental clinics for basic care, and psychologists. These institutions help provide guidance and education for small kids up to when they reach 18 years old.

One final goal for these institutions was to have a program for the students to go back to after they were no longer eligible to attend due to their age. They could serve as volunteers in other activities in the schools and even have some housing for when parents and/or relatives could no longer take care of them. This was never accomplished. While attending these institutions, Francisco received speech therapy services. Unfortunately, he was not able to learn how to properly speak the language, much less read or write. Although you can

# WHAT WILL HAPPEN WHEN I AM NOT ABLE?

Almost **87%** of siblings plan to **engage in caregiving** for their brothers/sisters with a disability.<sup>3</sup>

Only **25%** of siblings **receive supports** regarding the adult service disability system, despite **80%** of adult siblings reporting needing this support.<sup>4</sup>

<sup>3</sup> Lee, C., Burke, M. M., Arnold, C. K., & Owen, A. (in press). Compound sibling caregivers of individuals with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*.

## SOURCES

<sup>4</sup> Lee, C., Burke, M. M., & Arnold, C. K. (under review). Sibling participation in service planning meetings for their brothers and sisters with intellectual and developmental disabilities.

## ACCESS TO RESOURCES & IMMIGRATION LAWS

intuitively know what he needs, as he tries to make himself understandable, he cannot hold a continuous conversation and instead uses small phrases and questions to communicate. Sometimes these become very repetitive.

Francisco is able to take care of himself; for instance, he is able to take a bath, dress, walk, and even prepare small things to eat, such as sandwiches. He is capable of performing and learning small chores and organizing things. He used to work in a retail store organizing shelves with merchandise. This happened after he was too old to attend school.

Francisco's main support system has been our family. He has been living with my parents all his life and has not lived independently apart from the family circle. It has been fortunate that I can continue to provide the care he needs and cover his needs. The problem becomes what will happen when I am not able to fulfill all these tasks.

There are several government programs that could help individuals with Down Syndrome live independent lives. One of them is the Supplemental Security Income, which requires the individual to meet several qualifications, such as US citizen or permanent residency status.

There are also other non-profit institutions that provide daily programs to advance the achievement and knowledge of adults with disabilities in the areas of vocational, social, and life skills. These programs may require some payment to register the individuals but do not provide off-hours care.

I am the primary caregiver for my mom and Francisco. When they came to the USA in 2015, I filed a petition for permanent residency for both of them. I was under the assumption that Francisco could obtain the residency while living with me in the USA due to his disability and the fact that he is not able to live an independent life here (much less in Venezuela), but that has not been the case. The immigration hurdle has limited my ability to obtain additional benefits that could economically better help me to care for Francisco. Currently, I cover all of Francisco's needs and expenses. These include, but are not limited to, health plans, day-to-day care, participation in daycare programs, and more.

## ACCESS TO RESOURCES & IMMIGRATION LAWS

My main goal is to pass the immigration status hurdle. This is the biggest problem so far. I am navigating the system to see what other alternatives I have, which are very challenging according to my immigration lawyer.

I think there are more programs the government could offer, but they have strict rules for eligibility and maximum economic targets. If, for instance, the individual makes additional money on a yearly basis that surpasses this target, the individual could lose the benefit that they are receiving.

Another limiter is his immigration status, as the immigration laws are very restrictive. I do not know how many people have a similar case to mine, being a USA citizen who provides care for a sibling with a mental disability who cannot obtain permanent residence for the sibling while living in the USA.

For health care options, it is my understanding that once Francisco's immigration status is settled, he will be able to obtain a Social Security number that could allow him to find a job that he can perform based on his disability and may make him eligible for Medicare/Medicaid.

This still comes at a cost, but it is an improvement from not having affordable health coverage. The state of Texas only offers two personal/private health plans, Christus Health Plan (only in Texas) and Blue Cross Blue Shield of Texas. These plans are very expensive. Ideally, it would be great to have places where he could spend time by himself with the confidence that he is well taken care of. This will allow for some flexibility in the event that I have to travel for work or go on vacation with my family.

Image to the right: Multimedia collage on cardboard puzzle. Art by Daniel Godoy, Trina's son.

10/30/09  
12/10/09

HAUPT  
MUNICH  
GERMANY

HOYA  
ENTWENDE

BOON



USCIS  
Form I-171 Notice of Entry of Appearance in  
Court or Acceptance of Representative  
DHS Form G-25 05/31/02

Application for Temporary  
Protective Status

USCIS  
Form I-171  
07/12/2012

I-170 PETITION  
FOR ASYLUM SEEKING  
PROTECTION

FRANCISCO  
MIRET INEZ  
MY ASYLUM  
WILL REPRESENT  
ME

APRIL  
10, 1973

VISA BE  
OBTAINED

10/30/09 - 10/16/10  
12/10/12 - 12/10/13  
10/18/13 - 1/1/14  
11/1/14

Venezuela

B2 B2 B2

THE PROCESS THAT HELPED  
ME TO GET HERE HAS EXPLODED  
SIBLINGS, IT TAKES MONTHS TO  
PROCESS A PERMANENT RESIDENT  
STATUS. MY OTHER (FAMILY)  
SIBLINGS IN PROGRESS AND I AM WITH MY  
MOM WHO ALREADY OBTAINED A PERM  
CARD TO ENTER THE US.

MADRID, TN, 17017  
BY SIS BY COUNTRY CO. 17017

DIJON SYNDROME  
SYNDROME DUND

Portaria  
de regulacao  
de imigracao  
para o Brasil



## **ACCESS TO RESOURCES AND ISLAMOPHOBIA**

Any content marked as redacted is  
to protect the privacy of the family.

**OK**

I acknowledge this story is only one experience

## ACCESS TO RESOURCES & ISLAMOPHOBIA

[REDACTED] My name is Agha Mirza Saam Nicholas Khan Miami Jalinous. [REDACTED] I'm 24 years old. I have two brothers, one older and one younger. My older brother Cyrus and I have not spoken in four years.

We are Iranian Americans, and we were all born in Washington, DC to a well-off family. [REDACTED]

My parents both endured great perils in their immigration process, but in spite of this, they were both educated in America and came from well-respected and powerful Iranian families. [REDACTED]

My early memories of childhood were filled with joy and closeness between my brothers and me.

[REDACTED]  
We lived in a beautiful, large house in Northwest Washington, DC and we attended prestigious schools. My father [REDACTED] was a businessman, and when we were born, he was on his way to developing [REDACTED] a company that was partnered with the United States Department of Commerce and a number of media giants to become an early internet platform that would have both been a revolutionary early moment for the internet, and would have provided my family with enough wealth to last us generations. [REDACTED]

[REDACTED]  
[REDACTED]  
9/11 changed everything.

[REDACTED] Fearing sanctions against the Gulf states following the attacks on the World Trade Center, [REDACTED] investors from various Gulf Emirates backed out of my father's company. The media giants suspected that the Gulf backers knew something nefarious or untrustworthy about my father that they didn't, so they quickly backed out as well. [REDACTED]

The company was basically sold for parts. [REDACTED]  
For the next 10 years, my parents struggled to keep our lavish lifestyle afloat, and eventually my family broke apart completely and we started from zero.

## ACCESS TO RESOURCES & ISLAMOPHOBIA

[REDACTED]

No one left this experience in a stable mental state. [REDACTED]

[REDACTED]

And, over the course of this time, my brothers and I started to experience what most Americans still fail to understand: [REDACTED] although [REDACTED] the direct responsibility over the events of 9/11 remain confused and vague, the people who have suffered in its aftermath have been brown people [REDACTED] internationally. [REDACTED]

[REDACTED] For us, it meant that we went from being normal children of immigrants to subjects of suspicion. Other kids. Parents. Teachers. [REDACTED]

[REDACTED]

The anger and responsibility over the tragedy of 9/11 befell us. [REDACTED] Rocks were thrown. [REDACTED] Names called. Osama. [REDACTED] Al Qaeda. Terrorist. Terrorist. Terrorist. All. The. Time.

[REDACTED] And you began to believe it. How could you not? On the news, every day, they're showing the photos of men that look like your uncles on TV in military wear, in caves, in the streets screaming "Death to America." [REDACTED]

[REDACTED]

[REDACTED]

The next 10 years was an experiment in how quickly a race of people could go from some vaguely dark people from a land the United States had little relationship with (outside of oil or the Iranian Hostage Crisis) into a land filled with people who hate you, your family, your race, your country, and your way of life.

[REDACTED]

What else can you say except, "I'm not one of them"? And would you ever not be "one of them" anyway?

And what about when they call you monkey? S---t face? [REDACTED] Eventually it becomes just "ugly." And it's all you start to hear from your lighter peers. [REDACTED] Ugly. Ugly. Ugly.



## ACCESS TO RESOURCES & ISLAMOPHOBIA

“Mental illness,” is the best term to describe what, in my opinion, is a vastly over-diagnosed, insufficiently empathetic field of “science” that pervaded our home. [REDACTED] None of us were well, not my brothers, my parents, nor me. [REDACTED] Yet, when they started calling us “special,” “different,” or “disruptive,” none of us could yet process that they were watching the same things on TV that we were.

[REDACTED] The countless trips to doctors, our parents begging them, “Please, what can you give my child to make them feel more normal?” [REDACTED]

[REDACTED] Because isn’t that all they came here to do? To be normal? To have a normal life in America? To chase the American dream?

[REDACTED] How is it going so far? [REDACTED]

And what if one brother is doing “better” than another?

[REDACTED] Better according to whom?

What happens to them? When once they were three, it becomes two and one? When trust and relation becomes comparison and resentment. When two, constantly, are told, in so many ways, how different they are from each other. One becomes resentful, the other becomes vile in his elitism.

[REDACTED] And they’re told, constantly, to love. To trust. To hold. [REDACTED]

How? It’s us against the world, and it’s every man for himself.

They scream. They fight. They take sides. [REDACTED] They make grand, disgusting statements about who loves which parent more. [REDACTED] They move away. They develop lives that are just better without the other because they both have to survive in this horrible world.

[REDACTED] So, finally, one brother decides it’s over. No more visits. No more family vacations, even if it means he doesn’t come. There’s no use left in trying.

## ACCESS TO RESOURCES & ISLAMOPHOBIA

Brotherhood is over. [REDACTED] The other brother is angry, sad, pained, and spiteful. Except, deep down, he knows the truth: he always wanted this but he could never be the one to say it.

[REDACTED] One brother saved both. [REDACTED]  
[REDACTED]  
[REDACTED]

Our world does not yet understand what it did to itself, trusted the words of evil men to make money off wars whose victims are all innocent. [REDACTED]

[REDACTED] Many of us whose identities and relationship with the State were forever changed by 9/11 still do not understand these inconsistencies.

[REDACTED] It certainly took me many years to get there, and I came to this greater sense of understanding with myself and peace with the artificial, learned ignorance of the world since my brother and I last spoke. [REDACTED]

[REDACTED] It's now become one of my missions in life to help the world heal from this great distraction like I have found healing.

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

In lieu of speaking on my brother Cyrus in this reflection on our relationship, I'd rather let the photos and the words I've written on them speak for themselves. They tell of a time when life was beautiful and filled with love. They tell of two brothers, not one and another, but one unit of love. It's a time that I hope to see again soon.

I haven't spoken to him in a long time, and it doesn't feel right for me to tell you about what happened between us and to speak on his history before we've had a chance to speak about it. Last we spoke, we were angry, hurt, and broken young men. In our own ways over the last couple of years, we have both tried to grow. I wasn't yet talking about the past in the way I have described it to you, and I certainly wasn't talking about it with him.

## ACCESS TO RESOURCES & ISLAMOPHOBIA

[REDACTED]  
[REDACTED]  
[REDACTED]  
For as long as I can remember, I saw my brother as a burden, someone who could not be more different from myself. Someone whom I was expected by my family to love unconditionally because family is everything, a task I took on in spite of my anger and my ignorance of his pain. [REDACTED]  
And he viewed me as a symbol of something both wicked, false, and improperly praised. [REDACTED]  
[REDACTED]

Thanks to him, we have both had time to become people whose identities do not rely on each other. And in that time, through this project, I have come to understand that our problems were not our differences from each other, from the world. Our problems was our refusal to see that together. We are stronger because we understand each other in ways the ways the world is not yet ready for.

I love you, Cyrus. [REDACTED] I hope to see you soon.

Ink on 35mm Photo Reprints.  
Poems by Saam Niemi.



I think about the love you want, and the love  
you think I've come to find. Let me tell you,  
before you get defensive, that I've rarely known the love  
I've known for you.

In many ways,  
I've made your life mine.

I've attempted, with the mental free time given me to reach  
the root of our mutual suffering, not only in history, but in  
current, incomparable, finally, struggle

In all your rage,  
in all your unforgiving,  
in all your brilliance,  
in your resentment,  
your ignorance,  
and your absence,  
I've hardly known a love  
no matter how I've tried  
that has shown me  
the meaning  
of existing apart  
together

My savior.  
My messiah.

And you were also  
my reminder of hope  
hope, hope, hope,  
the weird kids, the other  
you did it first,  
the desire to make life  
a movie, something  
so much bigger  
than what they thought  
you were capable of  
the Muhammad  
they called you  
you were him  
to me.

I must rest  
now and find  
my own future.  
I hope you  
find mine  
in yours.

You've always been extra—extra-ordinary, it's all you want to be now. They killed your specialness.

They fucking killed it. And I only now understand what it did to me too. I was proud of being "normal," sane, cool, and forgiving. And lighter, of course.

And you were critical for being experimental, eccentric, and radical. Darker, of course.

Now we have switched.

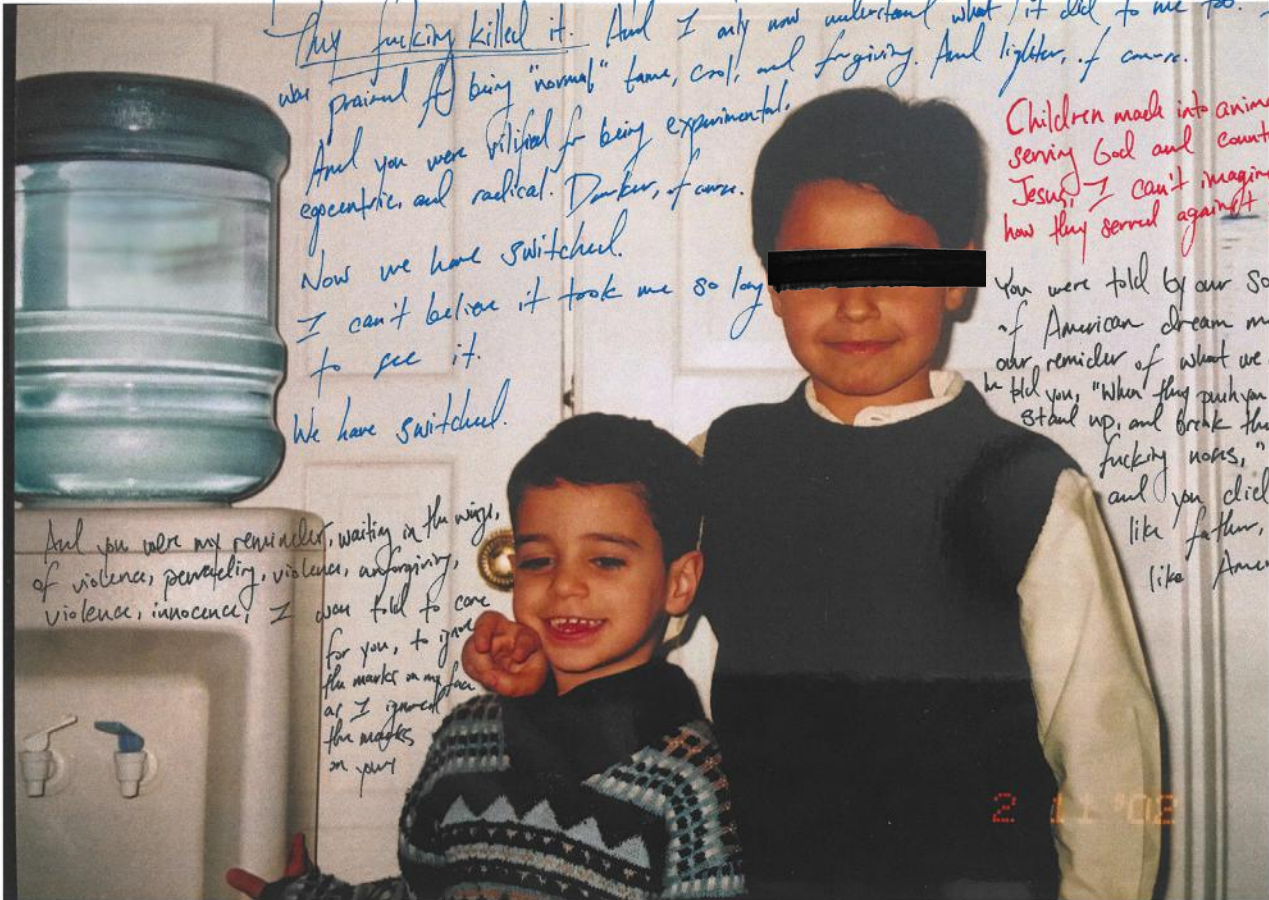
I can't believe it took me so long to see it.

We have switched.

Children made into animals serving God and country Jesus, I can't imagine how they served against you

You were told by our source of American dream making our reminder of what we owe to America to stand up, and break their fucking noses, and you died like father, like son, like America

And you were my reminder, waiting in the night, of violence, penetrating, violence, and forgiving, violence, innocence, I was told to care for you, to give the marks on my face as I ignored the marks on yours



Oh. hap-py day!

Choir: Oh. hap-py day!

Oh. hap-py day!

When Je - sus washed.

When Je - sus washed.

When Je - sus washed.

# FAITH AND FAMILY SUPPORT

A TRIBUTE TO THE LIFE OF  
LLOYD ALEXANDER "BUCK" HAYNES  
SEPTEMBER 19, 1955-SEPTEMBER 25, 2019

## FAITH & FAMILY SUPPORT

Hello,

My name is Edward Haynes. I am the brother and former caregiver for Lloyd Haynes who suffered with mental illness and substance abuse issues as an African American man. My hope with participating in this project is to help someone open themselves to others and seek out the care, resources, and support that are so needed in our communities.

Lloyd Haynes was born the eldest of four children to my parents Lloyd and Jean Haynes of Cambridge, Massachusetts. My two sisters, Cindy and Lori, were born 18 months later. Then, six years later, I came along. We were all raised in a modest single-family home in what would be considered a diverse neighborhood and city, West Somerville, Massachusetts.

Lloyd was the first in our family to go to college at the University of Massachusetts Amherst. Lloyd was eight years older than I was, so growing up, I idolized my brother. I wanted to be and do everything he did, from basketball, to music, to chess, and science. For my sisters, because they were all much closer in age, they were especially close with Lloyd. There are some who only know the three of them (Amigos) as Brother and Sisters, before I came along later.

I can recall the conversations and aspirations my parents had for us all to attend college. Being a 2-parent working household raising four children, saving for college was not realistic for my parents. So, our plan was to help each other, one by one. Everything changed when, in his senior year of college, Lloyd began showing acute symptoms of what would later be diagnosed with paranoid schizophrenia.

Google's definition of schizophrenia is a long-term mental disorder involving a breakdown of the relationship between thought, emotion, and behavior, leading to faulty perception, inappropriate actions and feelings, withdrawal from reality and personal relationships, and a sense of mental fragmentation.

In 1977, having never heard of this condition before my brother Lloyd would be diagnosed with it, we were at a loss and unsure what exactly we should do to help Lloyd regain himself. However, I remember the first thing I was told to do was pray.

## FAITH & FAMILY SUPPORT

Over the years following, I'm sure at different times, we would all learn that we would never be the family we thought we would be and that Lloyd would not be who we all prayed he would be. He would become something much more than we could imagine.

### **What role did the church play in supporting my family and my brother's disability?**

I don't remember anyone from our church ministry specifically talking with me or anyone in my family regarding my brother at that time. My parents may have had talks that did not include us children at the time. Within the Black community, family issues, regardless of the nature, are mostly kept private. As a result, I learned to not talk about my brother, his illness, or my feelings about God, church, and prayer.

As an adolescent, I built walls around my feelings. I had questions and I was told to go to one place for answers. When I did not feel that answers were coming, it led to more questions. Why? Why Lloyd? Why not me? Why is he not getting better? Why don't you hear me?

There is an old saying that goes "The Lord moves in mysterious ways." I remember taking that as the adult way of explaining something that they don't have an answer for. From those years and into my adulthood, I have struggled with my faith in church.

A generation later, I cannot speak to how much things have changed within the church. My hope is that the church recognizes the mental health challenges within the family and the community, especially now during the COVID-19 pandemic. For people and communities of color, the church is usually the first stop when searching for help. Faith-based organizations can and should be a starting point for resources and information that encompass all necessary avenues for treatment, care, and support.

Today, I have the benefit of over 50 years of lived experience to help reflect upon how far I've traveled, where I am, and where I hope to go. My greatest blessing has been my wife of 32 years. She came along when my walls were the highest, and brick by brick, helped me to take them down so they would not block the blessings meant for my life. As each year passed, as the first of my three



## FAITH & FAMILY SUPPORT

children would arrive, and I continue to live the life that my parents wanted for all their children, I am still left with the same unanswered questions that start with “Why?”

### **My last Why is “Why did he leave so soon?”**

In 2019, six months before the start of the pandemic, my wife and I would relocate to begin the final chapter of our lives in a new city. Having done this before with many years of planning, we could not have been more excited about the future for ourselves and our family as a whole.

Two weeks after leaving, we would get a call that my brother had passed away.

Death can be many things. Sometimes we receive time to prepare, sometimes it is even welcomed. Often, we are unprepared, and it is usually not welcomed. I was certainly not prepared to say goodbye to someone I have loved and cared for my entire life. Now, instead of building walls, I have learned to lean on the Word and my ever-growing faith in the Lord. My favorite passage comes from Proverbs chapter 3, verse 5–6:

*Trust in the Lord with all thine heart;  
and lean not on thy own understanding.  
In all thy ways acknowledge him,  
and he will direct thy path.*

This passage has helped to answer the questions I have asked my entire life.

- 1.** Trust God! Don't rely on your own very limited understanding, rely on His.
- 2.** Acknowledge Him! Acknowledge the good, the bad, and the in-between, and He will direct your path.

My God has a plan for my life that is still revealing itself, and I have been taught patience in waiting for the story to unfold. I may not understand everything that has happened or is yet to happen, but I have the faith now to know that, in the end, it is only good that He has planned for me.

A.

Music tribute by Edward Haynes.  
Curated in memory of his brother, Lloyd.

B.

Photo of Edward (left) and Lloyd (right). This is the last photo taken of the two in 2019.








### Buck Knucks (A Musical Tribute)

"Growing up, Lloyd had crates of albums. These songs bring me back to those days 😊" - Edward Haynes

▶ Play

↻ Shuffle

-  One Nation Under a Groove  
Funkadelic
-  Bustin' Out (On Funk)  
Rick James
-  That's the Way of the World  
Earth, Wind & Fire
-  Funkin' for Jamaica  
Tom Browne
-  Superstition  
Stevie Wonder

5 songs, 28 minutes

C.

These song remind me that I come from a family that prioritizes joy when things are hard. Especially when things are hard.

C.

Notes from Edward's daughter, Nicole Shanelle Haynes

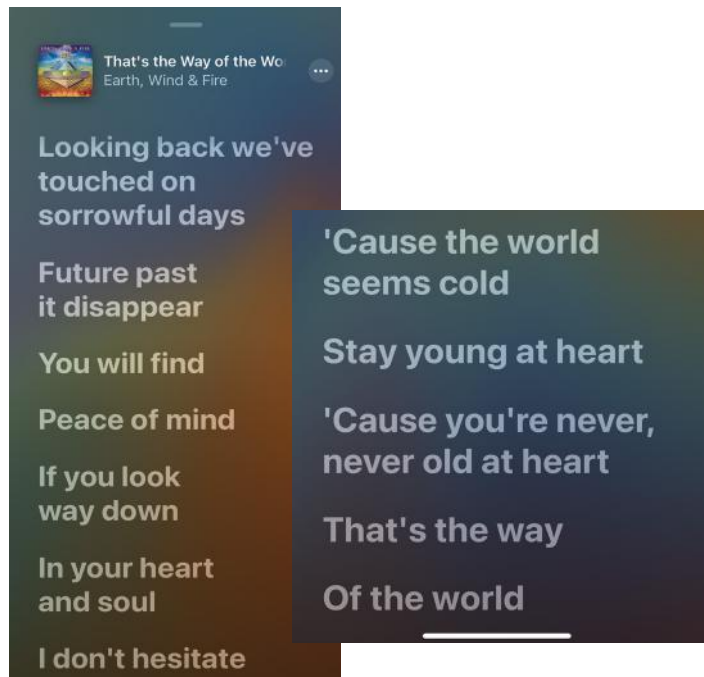
These songs bring back such good memories. Car rides anywhere, or even just hanging out around the house.

Just like your brother you instilled a deep love of music in Jennette, Angela and I. Cassettes, those little small records, posters of artists like Janet Jackson.

It was pretty much inevitable that we'd create our own love stories with music too.

D.

Lyrics from "That's the Way of the World." The Earth, Wind & Fire studio album was released on March 15, 1975 by Columbia Records.



That's the Way of the World  
Earth, Wind & Fire

Looking back we've touched on sorrowful days

Future past it disappear

You will find Peace of mind

If you look way down In your heart and soul

I don't hesitate

'Cause the world seems cold

Stay young at heart

'Cause you're never, never old at heart

That's the way Of the world





**Legal & Financial  
Planning**

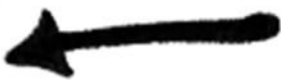


**Housing**



**Future Planning  
for  
First Generation  
Americans**

**Recreational**



**Transportation**



## FUTURE PLANNING FOR FIRST GENERATION AMERICANS

My name is Isaiah Mulligan, and I am a 32-year-old, Antiguan American educator in the D.C., Maryland, Virginia (DMV) area. My sister is Nakela Mulligan, a 30-year-old, Antiguan American woman. Both born in the South Bronx, only two years apart, we share a bond that is special. Nakela was diagnosed with autism at a really young age. My family does not consist of many people with disabilities, so my sister's diagnosis was new territory for my family. Not with a clear understanding of all services and support that could benefit my sister, my parents provided the maximum opportunities told to them by hospital providers. My family also having an immigrant background did not make this transition any easier. When people come to the United States, they come with the mindset that this is a country with all possibilities, but no one tells you how to access them and the struggle you go through to find resources to support you.

Lately my mind circles back to the idea of the future and how my sister and mine are intertwined. I know that if anything ever happens to my parents, I will have to become her primary caregiver. I love my sister with all my heart, but even thinking about this huge responsibility is life changing. Activities I enjoy like traveling will be put on pause. Every decision I would make would have to be one that is selfless. I also will need to educate myself more about what she needs and how to best support her. Usually, I would do this as a brotherly figure, but a primary caregiver shifts that relationship and responsibilities.

Many families, especially immigrant families, do not know how to access important information to support people with disabilities. Doctors usually provide the foundation of support when there are so many more resources available that have not been utilized. There need to be more offices, websites, and support hotlines to support hot-lines our people with disabilities, especially since the number of people is so high. I do believe if we had access this, many people, including my sister, Nakela would have been able to take advantage of so much more. People need to have access to finding jobs, parenting/family classes on how to support our loved ones, therapy, classes, and much more.

Life does not stop because you have a disability. It has not stopped for my sister. I do believe we have a responsibility to serve all people and meet their needs, which starts with providing people with all the resources available. As a product of an immigrant household we especially lack the understanding of how to access the support we need on a regular basis.



Digital collage inspired by  
Isaiah and Nakela's bond.

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# DESIGNING AN ACCESSIBLE LIFE





## DESIGNING AN ACCESSIBLE LIFE

# SISTER AND AUNT

My name is Cristina Cortez. I am 28 years old and I have quadriplegic cerebral palsy. Being part of this sibling study about the relationship between siblings with and without disabilities offers up an opportunity to show how people with disabilities are essential part of their families and are valued family members to all around them.

I am Latina, born to immigrant parents from El Salvador, Central America. I am the younger sister of my brother who is 15 years older than me. My brother Carlos Mario Cortez, age 44, is married and father to two sons, my nephews, Alejandro, age 7, and Leonardo, age 3.

My relationship with my brother has always been a strong one. Even though we did not grow up together, we are strongly involved in each others' lives. We often keep tabs on each other through texts and voice messages. Our conversations through these mediums are mostly about checking in with each other and plans for the day ahead, which often include time with the boys.

Three years ago I moved with my parents to Massachusetts from Washington state after completing my Master's in Fine Arts in Creative Writing from the University of Washington Bothell. Since my arrival in Washington, in fall of 2017, my power wheelchair had been two years overdue for a replacement.

## DESIGNING AN ACCESSIBLE LIFE

It's often recommended/required that a wheelchair user get a power wheelchair every five years to adjust and accommodate his or her needs. In the event of the move, the process of replacing my wheelchair was overlooked so I used my previous wheelchair for seven years instead of the usual five. During these two extra years of use, my chair held up pretty well.

**BY 2017. . .**

My brother had already made me an aunt for the first time. During my last days of usage of my previous wheelchair, I consciously took into consideration the playful activities I'd take part in with my nephew Alejandro as he grew older, and became more aware of me as someone who he could have fun with.

Following this train of thought, when I moved to Massachusetts, one of the first things on my to-do list was to replace my wheelchair.

Going through the selection process I knew I wanted to upgrade the secondary function of my chair to make me more capable of performing functions such as elevation and repositioning. As a way of improving my access to my environment, particularly my home. My previous wheelchair was a front-wheel-drive with the big wheels in the front. Having just learned about the mid-wheel-drive chair, where the big wheels are in the middle of the chair, I told Alejandro about the wheelchair, the one I am using now. The mid-wheel-drive build of the chair allows for greater stability when driving indoors and outdoors.

Having chosen this drive configuration for my chair I told him about the functions I wanted to have on it, such as recline, tilt, elevation, etc. This array of options would allow me to have extensive functionality for me to engage in activities around the house. With these functions on the chair, it became eligible for a lighting package. And this was one feature that my nephew would remind me to include in my wheelchair so that I could find him in the dark during hide-and-seek if we turned off the lights and this has often come in handy. One of the last elements to be added to the chair was the choice of color for the back

## DESIGNING AN ACCESSIBLE LIFE

shell that houses the wiring of the chair. To address this, I decided that to get my nephew further involved in the process he would be the one to choose the color. I never chose colors for my previous chairs, but since this was a new chair and a new configuration of chair, I wanted to set it apart from the others, and the way I thought to do that was to change the color to mark the change and difference. From the array of color choices for the chair, my nephew chose what is called “sunset orange.”



**MY DISABILITY  
IS JUST A  
FACTOR OF HOW  
I PLAY OR  
PARTICIPATE IN  
THE ENJOYMENT  
OF BEING WITH MY  
FAMILY**

I should mention that in the midst of this process of getting a new chair the Covid pandemic hit and I got the first of a few customary home visits and deliveries from my assistive technology provider who set up the chair. One of the upgrades that I made it to my chair was a better adjustable seat system that elevates the seat up to 12 inches so that I'd be shoulder height when I'm elevated next to my brother who is 6 feet tall; it was a thrill to notice that since I've never gotten that high before. One of the immediate benefits of having the elevator with that capability was that my breathing improved and it's easier to talk to people in the crowd inside or outside the house. Also when it comes to my nephews it's a fun way to compare ourselves to see how much they're growing. I use myself in these cases as a ruler to measure them against.

## DESIGNING AN ACCESSIBLE LIFE

An added benefit of having my wheelchair is having my nephews be involved in the constant discovery of their uses. We've found that my youngest nephew Leonardo likes to sit on my footrests right in between my feet while watching TV together, or sit on my lap, while the chair is in the elevated position, just to have a new perspective of the environment around him.

It has become second nature for my nephews to see me as a fully engaged member of the family that is involved in the activities we participate in together. My relationship with my nephews is an extension of my relationship with my brother as he often celebrates these little glimpses of moments between the three of us. One such moment is when my eldest nephew got his new Nintendo Switch, and taught me how to play video games which I haven't played in a long time. The joystick controller came in two different colors, black and white. The difference between these controllers is that the black one requires very precise hand control, often involving two hands. Suffice it to say that the usage of two hands for precise control handling and fine motor skills is mostly outside my hand function range. As my right hand is the more capable. Noticing this, I and my nephew realized that I needed to use the white controller as it is more accepting of irregular or imprecise hand movement since the controller is mostly joystick-based.

Participating in the game is like driving a wheelchair. But during the game, I found that in the normal position with the side buttons facing my palm I found that these buttons were hard for me to operate. So during one Mario Kart race, I chose to flip the joystick upside down so that the side buttons were facing my thumb and my index finger. This would flip the joystick directions upside down so instead of forward meaning forward in the game, it became backward and vice-versa.

I've found that one of the easiest ways for me to engage with my nephew is to compete with them in races when they are using their scooters, since my wheelchair is typically faster than any human-powered vehicle. My nephews often get a head start and we are mostly evenly matched. Win or lose, I'm happy to just simply be part of the active activities we share in. During these activities, my disability is just a factor of how I play or participate in the enjoyment of being with my family.

## DESIGNING AN ACCESSIBLE LIFE

My disability is not a hindrance to these activities. Rather, it is an enabler of activities and it is a part of how I participate and engage with my family members. It is part of how we operate as a family.

The family dynamics that I hope are explored here are examples of how I am not someone who has to be included in family games and activities. Life is just life. My disability is part of the life I lead.



## DESIGNING AN ACCESSIBLE LIFE

I'm the privileged brother to Cristina Cortez. I'm 45 years old, married and a proud father of 2 beautiful boys, Alex & Leo. My sister has special needs but has always fought for everything she has wanted. Cristina and I are fortunate to have two parents who have dedicated their lives to the prosperity and advancement of their children. Growing up, I remember my mother, in her broken English, always questioning everything and everyone that came around my sister. It didn't matter if you were a teacher, doctor, principal, counselor, therapist, or family member. My parents always helped charter Cristina's journey through the lens of Cristina's own dreams and desires. This is where I believe my sister gets her grit to go after what she wants for her life.

Having her in my life has been extraordinary. She is always a beacon of hope and inspiration. When I became a father, I worried how my boys would relate to her and be able to see her in the same way I do. As time progresses, I am able to see the special place she has claimed in the minds and hearts of my boys. Nothing could have been more natural. An unbiased mind and pure heart that can just recognize the love given to them by another.

Living with a sister with special needs requires some extra planning and sensitivity to some social situations. But we are better humans for being considerate to those needs!



There is nothing that we feel is prohibited to us, and when the obstacles present themselves, we figure it out. Participation is an expectation, not the exception. I am proud of her and feel fortunate to have her be a part of my boys' lives.

**PARTICIPATION**  
**IS AN EXPECTATION**  
**NOT THE EXCEPTION**

# Rufinamide

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# Rufinamide



## CLOSING STATEMENT

Dear Reader,

First, I would like to express my deepest gratitude to you for taking the time to read this zine. Your willingness to dedicate your attention and energy to this conversation means a lot to us. In a world where our attention is pulled in a million different directions, it is an act of respect and compassion to give someone your full attention.

The topic explored here emphasizes the importance of having knowledge and resources to create a care giving planning. The reality is that many of us will have to step up as caregivers for our loved ones as we age. It is a daunting task, one that can feel overwhelming and anxiety-inducing at times.

However, the key to success lies in confronting our fears and anxieties head-on and intentionally strategizing for the future. We cannot afford to be short-sighted; our families' well-being depends on our ability to create a long-term plan. This is especially true when it comes to the 61 million disabled Americans and their caregivers. It is not an easy task, but it is one that we must undertake if we hope to achieve harmony.

But this issue goes beyond just our families. It speaks to a larger problem: we need societal, attitudinal, physical, or systemic equities that preserve the Earth and humanity. We all have a role to play in creating policies and environments that are more empathetic and mindful towards the needs of all individuals, including those with disabilities. "Same-Same But Different" is art-based research that advocates for better health and human rights, offering a new perspective for policymakers, researchers, advocates, and family members. It intentionally leaves space for the reader to input something into this conversation.

How can society benefit from everyone's participation, and what is the adverse effect of not including everyone? As we navigate the democratic age of technology, design, art, and culture, this is an opportunity for us all to collectively think about how we can reconceptualize what it means to be responsible for humanity.

The end game is ours.

Unconditionally yours, Jess



Resin and Mica Pigment on Cardstock Medical Packaging. These are close up images of a canvas painting by Jess Mendes.

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## RESOURCES

It's important to note this list is not exhaustive and that it may vary depending on the location and the specific needs. There may be other organizations locally. It will be helpful to consult with local disability organizations, universities or healthcare providers to learn more about what is available in your area.

### [Family Support Centers]

- » **The Arc** is a national organization that advocates for people with intellectual and developmental disabilities and their families. The Arc offers a range of services and resources, including health insurance and workshops.
  
- » **The Department of Developmental Services (DDS)** is a government agency that works to ensure that individuals with developmental disabilities have access to the resources they need to live fulfilling and independent lives, such as residential services, day programs, employment support, respite care and other community-based services.
  
- » **National Sibling Leadership Network, Sibling Support Project** and **SibShops** have a directory of local sibling support groups and organize national conferences for siblings.

### [Financial and Legal Assistance]

- » **Affinia Financial Group's Special Needs Planning Team** is a group of financial professionals who specialize in developing strategies with families for the long-term care and financial security of the individual with special needs, as well as coordinating with other professionals, such as attorneys and accountants, to create a comprehensive plan.
  
- » **Disability Law Center** and **Disability Rights Legal Center** helps eliminate discrimination and other legal barriers.
  
- » **Easterseals** is a national service for financial resources, including loan programs and respite care services.
  
- » **The National Council on Independent Living** supports and advocates for individuals with disabilities who want to live independently, including resources on financial planning and government benefits.

## RESOURCES

### [Small Business and Organizational Resources]

- » **ADA National Network** is a federally-funded network of ten regional centers that provide information, guidance, and training on the Americans with Disabilities Act (ADA) and other disability-related laws. The network has free tools, including webinars and online courses, to help businesses understand their obligations under the ADA.
  
- » **Disability Employment Resource Centers (DERCs)** are funded by the U.S. Department of Labor and provide services to individuals with disabilities who are seeking employment. They also offer resources and training to businesses to help them become more inclusive and accessible.
  
- » **The Institute for Human-Centered Design (IHCD)** is a non-profit organization that provides consulting, training, and design services to businesses, governments, and organizations to ensure that their products, services, and environments are accessible and usable by everyone. IHCD's goal is to create a more inclusive and equitable society through design.
  
- » **Small Business Administration (SBA)** gives resources and training to small businesses, including those related to disability compliance. They offer online courses, workshops, and one-on-one counseling to help businesses understand the ADA and other disability-related laws.

## RESOURCES

### [Books]

- » **Being Heumann: An Unrepentant Memoir of a Disability Rights Activist** by Judith Heumann recounts the story of Heumann's life as a disability rights activist, from her childhood struggles with polio to her fight for disability rights legislation in the US and around the world.
  
- » **Black Disabled Art History 101** by Leroy F. Moore Jr. celebrates the art and activism of Black disabled artists throughout history, challenging the erasure of their contributions from mainstream narratives.
  
- » **Care Work: Dreaming Disability Justice** by Leah Lakshmi Piepzna Samarasinha dissects the intersections of disability justice and social justice movements, and how care work can be used as a tool for activism.
  
- » **Crip Theory: Cultural Signs of Queerness and Disability** by Robert McRuer examines the ways in which disability is often overlooked or ignored within discussions of identity and power
  
- » **Disability Visibility** edited by Alice Wong is an anthology of essays and stories by disabled writers of color, highlighting the experiences and perspectives of disabled people in America.
  
- » **The Sibling Survival Guide** by Don Meyer provides practical advice and covers a range of topics, including dealing with grief and loss, handling family dynamics, advocating for your sibling's needs, and building a fulfilling life for yourself.
  
- » **Untitled** is a photobook by Diane Arbus featuring previously unpublished photographs taken at residential homes between 1969 and 1971. The images are emotionally powerful and mythic, showcasing Arbus's unflinching regard for reality and celebrating the uniqueness of each individual.
  
- » **We're Not Broken** by Eric Garcia pulls apart the stereotypes and misconceptions about autism and neurodiversity, offering a candid perspective on the author's personal journey as an autistic person navigating a world that often fails to understand and accommodate neurodivergent individuals.

## RESOURCES

### [Films]

- » **Crip Camp** retells a group of disabled teenagers who attended a summer camp in the 1970s and later became activists for disability rights. The film explores their journey of self-discovery, political awakening, and their fight for accessibility and inclusion in society.
  
- » **Healing Voices** by PJ Moynihan is an award-winning documentary which explores the experiences commonly labeled as ‘psychosis’ in western culture, and offers a critical look at America’s mental health care system.
  
- » **The Changing Reality of Disability in America** is a documentary film produced by the Institute for Human Centered Design (IHCD) that highlights the experiences of individuals with disabilities and the progress made in creating a more accessible and inclusive society. Through personal stories and expert commentary, the film highlights the ongoing challenges faced by people with disabilities while also showcasing the importance of design and technology in creating a more equitable future.
  
- » **Tuesco** a documentary directed by Daniel Poler follows the life of a childhood friend, who was left wheelchair user after a nurse’s medical malpractice, and explores his family’s experience caring for him in Panama. The film offers a candid and humorous perspective on disability, challenging misconceptions and highlighting the importance of distinguishing between special care and unnecessary special treatment.

## ACKNOWLEDGEMENTS

I would like to express my heartfelt gratitude to everyone who has helped make this zine possible. First, I would like to thank my family for their unwavering love. I am also immensely grateful to Jessie James, Nikki Jackson, and Alain Cortez for writing my referral to the Crocker Fellowship grant, and to Nicole Haynes, Adavia Thornton, Sapphire Stubbs, Abdul Ali, and Marcus Taylor for their encouragement and advice throughout the two-year journey of creating this zine.

I would like to extend my heartfelt thanks to the invaluable support of countless grassroots organizers, including Andrew Census of Food with Fam (FWF), Craig Shepard of Defying Legal Gravity (DLG), and Britt Tabor of Girls Only NY, who have championed me on this journey. Rania Kelley, Keila Torres, and Sophia Johansson at Mass Families were instrumental in supporting me at the beginning of the pandemic; Sophia empowered me to submit my idea for the grant opportunity.

My gratitude also goes to Cindy Thomas, David T. Helm, and Maria Paiewon-sky at UMass Boston's Institute for Community Inclusion (ICI), whose expertise provided invaluable insight in refining my vision for this research project. I would also like to thank Jason Folger, Amy Szarkowski, Gyasi Burks-Abbott, Beverly Gilligan, Angela Lombardo, and the LEND Fellows of 2021-2022 for enriching my understanding of disability. Additionally, I want to recognize Liz Fancher and Anna Krieger at Massachusetts Developmental Disabilities Council (MDDC) and Maura Sullivan at The Arc of Mass for their counsel and encouragement throughout this time.

I am deeply beholden to all the artists and families who have contributed to the development of this project. Your thoughtfulness, time, and enthusiastic commitment have expanded the meaning of this work in ways I could never have imagined.

Lastly, I would like to express my appreciation to Valerie Fletcher at the Institute for Human Centered Design (IHCD) for her unending support. The art showcased in this zine will be on display at IHCD's headquarters in SoWa Art + Design District from April 25th for Boston Design Week.

Thank you all once again for making this project possible.

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To order prints, or inquire about gift or group orders  
contact Jess Mendes via [jessmendes.com](http://jessmendes.com).

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support and funding from Massachusetts Developmental Disabilities Network.

## MASSACHUSETTS DEVELOPMENTAL DISABILITIES NETWORK



The Massachusetts (MA) Developmental Disabilities (DD) Network is a collaborative of four organizations that promote self-determination, independence, productivity, integration and inclusion in all facets of community life for people with developmental disabilities and their families. The network partners accomplish this mission through advocacy, education, research and dissemination of information.



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