

Family Leaders:

What They are Saying, and how UCEDDs and LENDs can help

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Sponsored by AUCD's Early Childhood Special Interest Group.



Chioma Oruh, Ph.D. is a mother of two brilliant young sons with Autism Spectrum Disorder that current attend nonpublic schools, and have attended DC public schools, both traditional public and public charter schools. In learning to navigate the systems of care for her family, she also learned to put her skills in service of other families and organizations serving families of children with special needs, including behavioral health. Dr. Oruh is an experienced education advocate, working over two years under the supervision of skilled attorneys to build cases that protect the educational rights of students with disabilities and is versed in federal guidelines articulated in the Individuals with Disabilities Education Act (IDEA) of 2004, Section 504 of the Rehabilitation Act of 1973 and the American with Disabilities Act.



Karen Young Lewis, currently serves as the chair of the Georgia State Interagency Coordinating Council (SICC) as well as secretary of the Cobb Douglas Local Interagency Coordinating Council (LICC). Karen is also a Parent Resource Coordinator for Babies Can't Wait in Cobb/Douglas as well as serves as a member of the NICU Advisory Board at Children's Healthcare of Atlanta/Scottish Rite. She has served on the Cobb County Stakeholders for Children with Disabilities Committee and was previously a member of the Quality Care for Children Regional Team as a parent advisor. She previously held in a similar position as Parent Educator for BCW working with SCEIs (Skilled Credentialed Early Interventionists) in Georgia. As a parent of a non-verbal child with neurodevelopmental disabilities and Parent Resource Coordinator for BCW in Cobb/Douglas Counties, Karen is uniquely suited to share her knowledge and experience as a mom of a child that has special needs and is medically fragile.



Doris Tellado, the parent of two children. Her youngest son has Larsen syndrome, a rare genetic disorder that affects the development of bones throughout the body. He also has Autism and hearing loss. Since birth, her son has needed multiple surgeries and acute medical care. Along with her husband Jose Luis, Doris has always been a partner in his care and education, collaborating closely with medical professionals and educators. Since 2007, she has been sharing her experiences with other families by working as a Family Resource Specialist for the University of Florida North Central Early Steps, a part of the early intervention program for the state of Florida. In her role, she helps other families to navigate early intervention and other systems of care providing information, supports, and resources to enhance their children's learning and development.



Rud and Ann Turnbull, are Co-founders and former Co-directors of the Beach Center on Disability and Distinguished Professors Emeriti of Special Education at the University of Kansas. Between them, they have authored over 40 books (including two leading textbooks now in their 7th and 8th editions) and over 500 articles and chapters. In 1999, they were selected by the National Preservation Trust in Developmental Disabilities as two of 36 individuals who have "changed the course of history for individuals with intellectual and developmental disabilities in the 20th century." Their greatest learning has come from their son, Jay Turnbull (1967-2009), who experienced multiple disabilities and whom they have always called their "best professor."

FAMILY- CENTEREDNESS: THE BUILDING BLOCKS FOR EQUITY IN THE SYSTEMS OF CARE

BY

CHIOMA M. ORUH, PH.D.

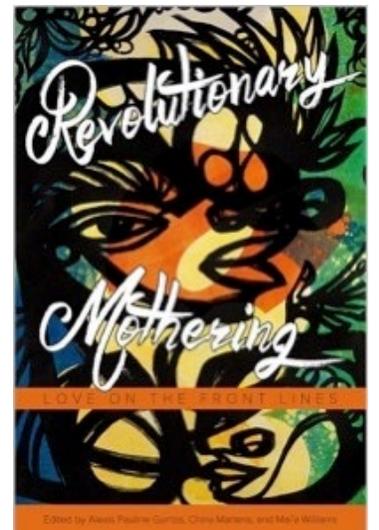
CONSULTANT AND PARENT COACH





MOTHERING JOURNEY: IT STARTS AT THEORY

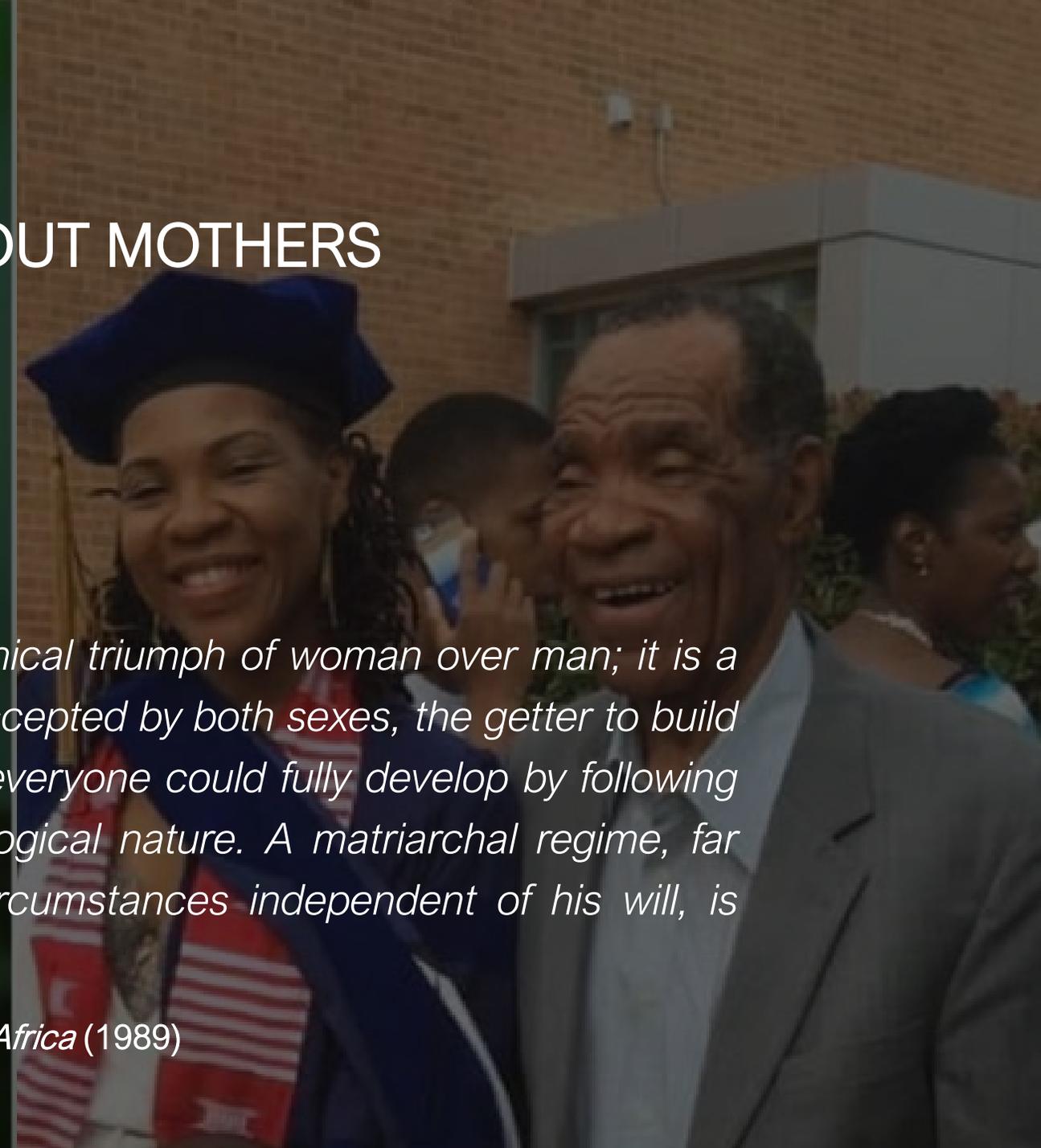
“What if mothering is about the ‘how’ of it? In 1987, Hortense Spillers wrote ‘Mama’s Baby, Papa’s Maybe: A New American Grammar Book,’ reminding her peers that motherHOOD is a status granted by patriarchy to white middle-class women, those women whose legal rights to their children are never questioned, regardless of who does the labor (the how) of keeping them alive. MotherING is another matter, a possible action, the name for that nurturing work, that survival dance...”



MOTHERING IS NOT JUST ABOUT MOTHERS

“Matriarchy is not an absolute and cynical triumph of woman over man; it is a harmonious dualism, an association accepted by both sexes, the getter to build a sedentary society where each and everyone could fully develop by following the activity best suited to his physiological nature. A matriarchal regime, far from being imposed on a man by circumstances independent of his will, is accepted and defended by him.”

- Cheikh Anta Diop, *The Cultural Unity of Black Africa* (1989)





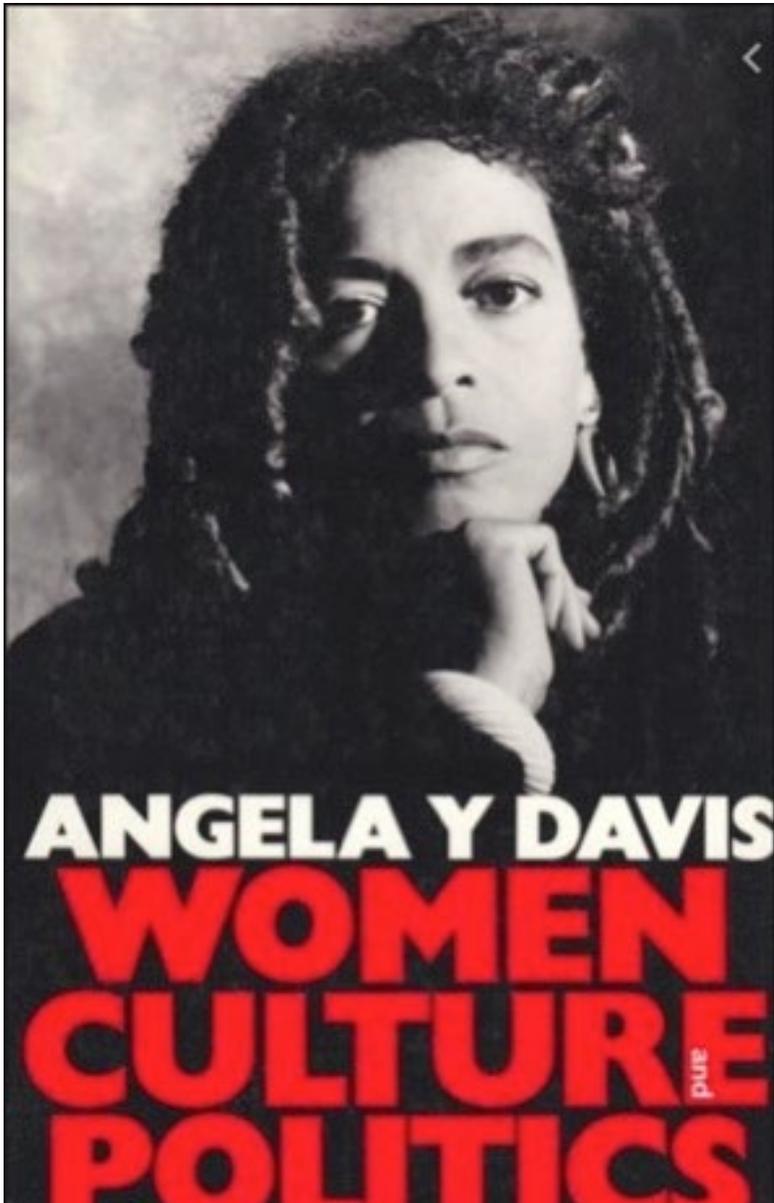
DISSERTATION LESSONS:
THE FAMILY IS A POLITICAL INSTITUTION

"...Neither Black men nor Black women [currently] rule family networks...rather, African-American men's nor women's positions within slave political economies made it unlikely that either patriarchal or matriarchal domination would take place." – Patricia Hills Collins, Black Feminist Thought (1990)



THE POLITICS OF DISEMPOWERED FAMILIES

- Colonialism was a multi-national project whose impact is both systemic and historic;
- African Matriarchy is the system violently uprooted by European Patriarchy;
- 1965 Moynihan Report (“The Negro Family: A Case for National Action”) argues that the problem of the Black family structure is due to mother-led households;
- President Ronald Reagan’s administration blamed the welfare system on black mothers (i.e. Welfare Queens); and
- In *Women, Culture and Politics* (1990), Angela Davis argues that the African concept of family has always clashed with European concept of family and that “the traditional male-supremacist hierarchy in the family, based on male ‘providers’ and their economically dependent wives and children” is constantly challenged particularly by ultra-conservative interpretations of European family structure – particularly when it comes to issues the welfare system and socialized childcare.



NAVIGATING THE SYSTEMS OF CARE

*“It is not enough to
prepare our children for
the world, we must
prepare the world for our
children.” – Luiz J. Rodriguez*



TRYING TIMES...

- People with an autism spectrum disorder are seven times more likely to encounter police than "neurotypical" individuals, or those without developmental disabilities, according to autism experts;
- The Centers for Disease Control and Prevention estimate that 1.2 million children under the age of 21 have been diagnosed with autism;
- White children are 30 percent more likely to receive an autism diagnosis than black children—experts say the discrepancy may lie in health-care access and parental education;
- Of those black children who do get diagnosed, roughly 48 percent also have some sort of intellectual disability;
- In a Washington Post analysis of nearly 400 police-involved deaths, a quarter of which involved someone with a mental illness, black people were killed three times more often than whites or other minorities;
- Taken together, these statistics suggest that black people with developmental disabilities and mental illnesses are less likely to get diagnosed or get medical treatment than their white peers. And if they do encounter polices...they are more apt to do, they are more likely to be shot and killed.

From, Adreinne Hurst, "Black, Autistic and Killed by the Police," *Chicago Reader* (Dec. 17, 2015)



Reading and Mathematics Proficiency

Disparities separating children whose

(1) parents had not graduated from high school, compared to those whose

(2) parents had a bachelor degree were, respectively:

- 16 vs. 49 percent for reading proficiently (at grade level) in Eighth Grade
- 16 vs. 52 percent for proficiency in mathematics (at grade level) in Eighth Grade

School Enrollment and Completion

Disparities separating children whose

(1) mothers had not graduated from high school, compared to those whose

(2) mothers had a bachelor degree were, respectively:

- 63 vs. 36 percent for not being enrolled in PreKindergarten at ages 3-4
 - 40 vs. 2 percent for not graduating from high school on time (by age 19)
-

Health

Disparities separating children whose

(1) mothers had not graduated from high school, compared to those whose

(2) mothers had a bachelor degree were, respectively:

- 9.0 vs. 6.8 percent for low birthweight
- 8.2 vs. 3.9 deaths to children under age 1 per 1,000 live births
- 27 vs. 13 percent for obesity
- 29 vs. 8 percent for not in excellent or very good health
- 16 vs. 4 percent for not covered by health insurance

Following the presentation of detailed statistics for the nation and for individual states, the report identifies opportunities for federal, state, and local governments to take the lead or to collaborate with others to develop and implement dual-generation strategies for low-education, low-income families that could lead to improved academic and life outcomes for children, greater employment opportunities for mothers, and higher incomes for families who currently have the fewest resources and greatest needs.

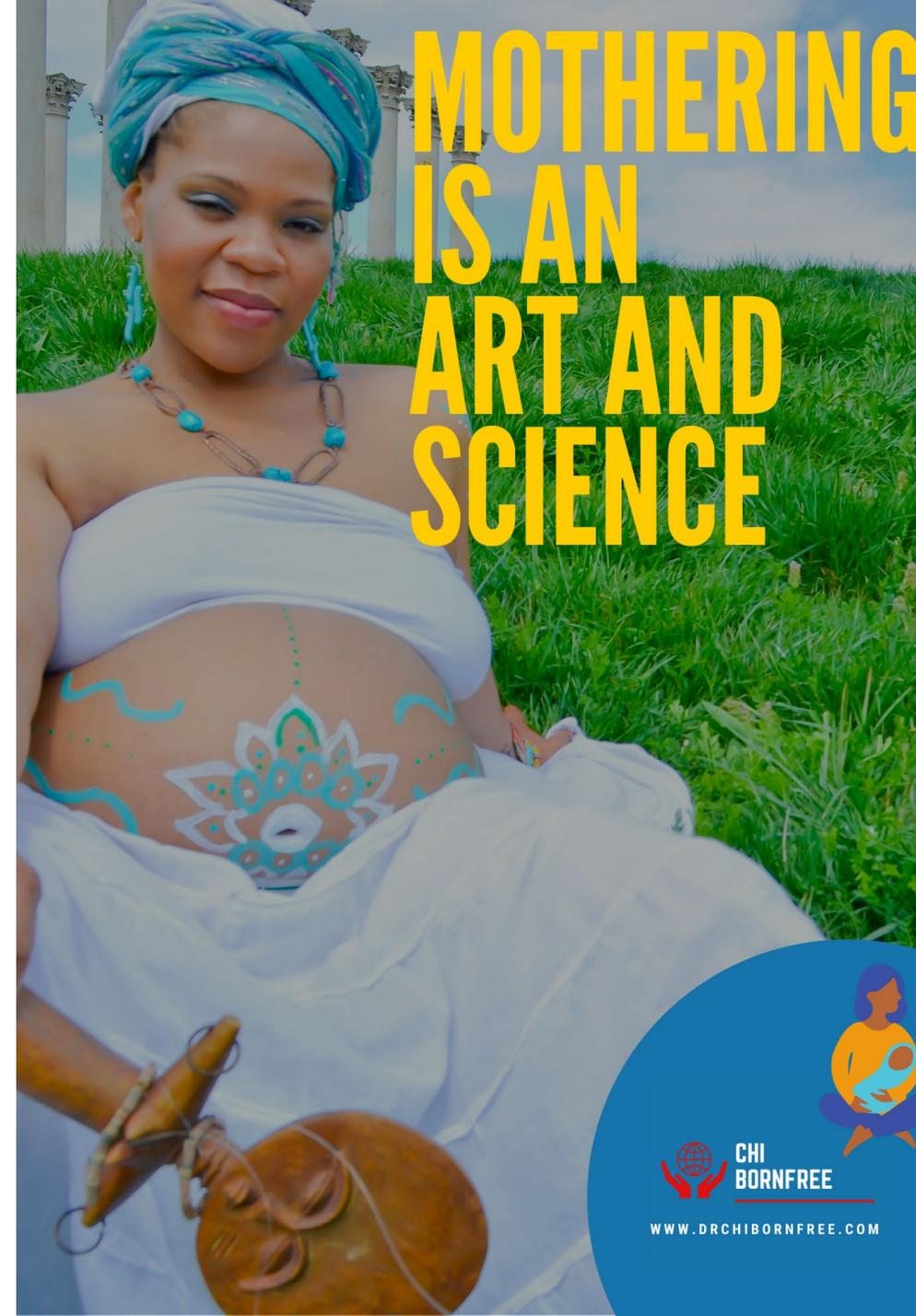
RESILIENCE IS NOT THE ONLY TOOL FOR POOR MOTHERS

“Policies and programs aimed at increasing educational and economic opportunities typically targeting either low-income children or their mothers, but not both, which limits their impact in fostering intergenerational mobility. This insight undergirds the development and implementation of dual-generation strategies, which focus simultaneously on both children and mothers to foster long-term learning and economic success for low income families.”

– Donald J. Hernandez and Jeffrey Napierala, “Mother’s Education and Children’s Outcomes: How Dual-Generation Programs Offer Increased Opportunities for America’s Families” *Disparities Among America’s Children* (Foundation for Child Development, 2014)

THE MENTAL HEALTH OF THE PARENT IMPACTS THE MENTAL HEALTH OF THE CHILD

- Ex. EEGs (electrical readouts of brain) of children's whose mothers are depressed and those whose mothers aren't; and researchers found a difference in brain activity
- Infants pick up stress from caregivers, leading to generational traumas
- In a baby's life a million neuro connections are being made
- Humans are the only species whose brain develops at an equally fast rate inside the womb as a in outside of womb during the first 2 years of life
- After the 3 years of life, the human brain is adult-size
- Absence of a non-stressed, emotionally present, constantly available caregiver, the brain circuits won't develop properly



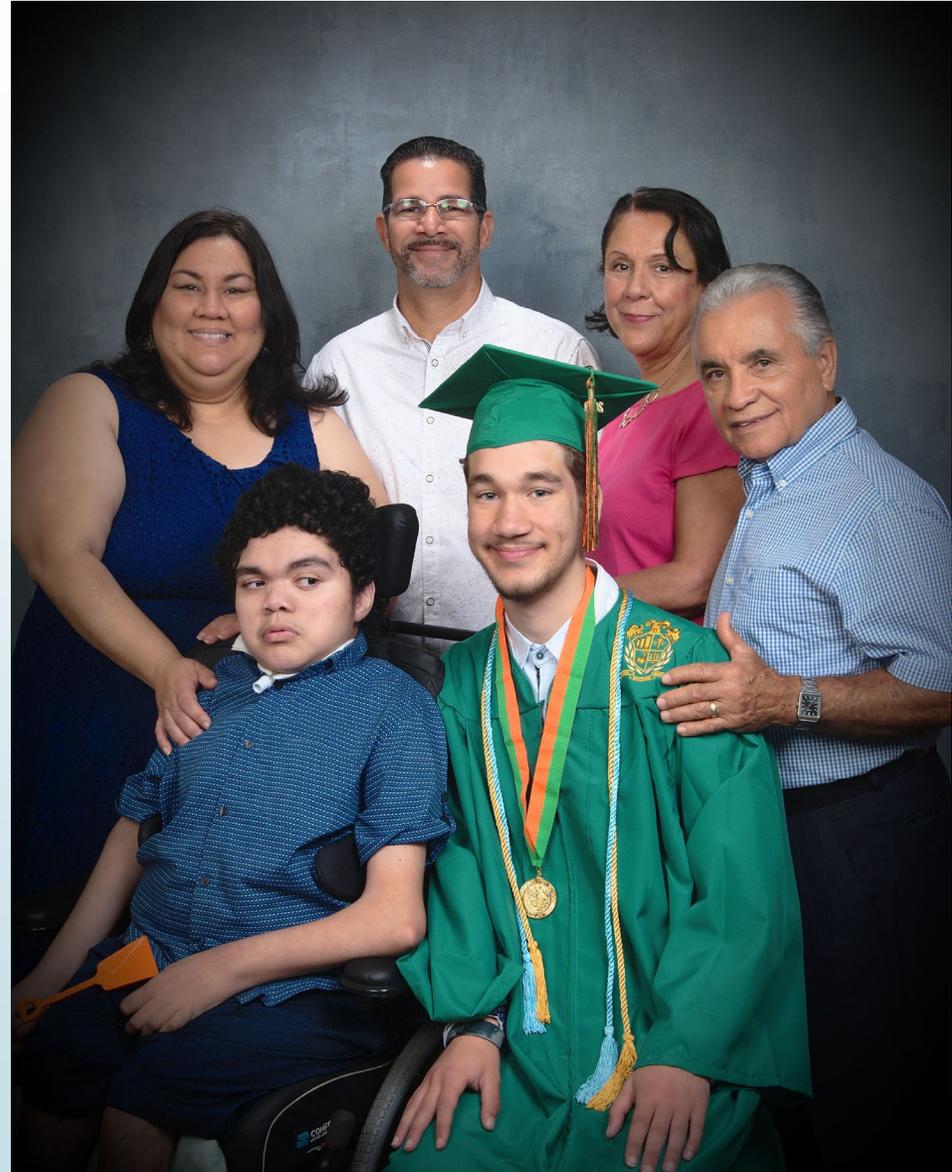
THE JOURNEY
CONTINUES...

OUR DEEPEST FEAR
IS NOT THAT WE ARE INADEQUATE.
OUR DEEPEST FEAR IS THAT WE ARE
POWERFUL
BEYOND MEASURE.
IT IS OUR LIGHT
NOT OUR DARKNESS, THAT MOST
FRIGHTENS US. WE ASK OURSELVES,
"WHO AM I TO BE BRILLIANT,
GORGEOUS, TALENTED AND FABULOUS?"
ACTUALLY, WHO ARE YOU NOT TO BE? YOU ARE A CHILD OF GOD.
YOUR PLAYING SMALL
DOESN'T SERVE THE WORLD.

SELF CARE



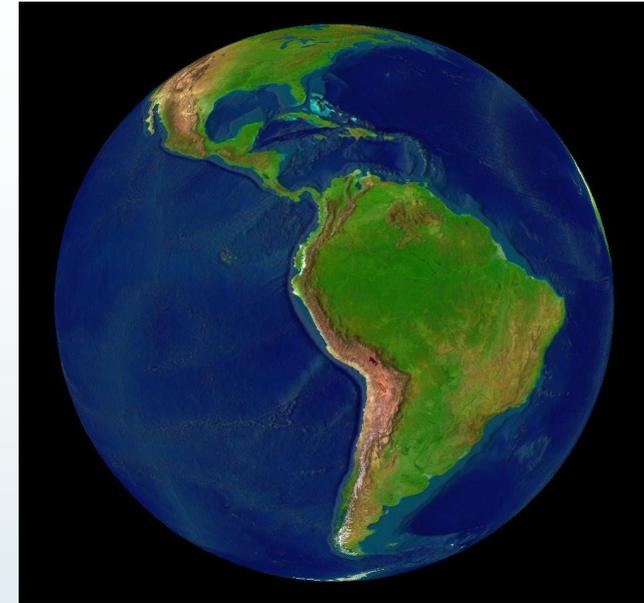
Mi Familia!



Our Latinx Community

Diverse

- Multiethnic
- Multiracial
- Multilingual
- Multigenerational



Approximately **60 million**
living in the USA

About **7.6** million are undocumented or unauthorized immigrants

Challenges

Limited Financial Resources
Low income jobs without benefits

Limited Access to:

Healthcare

Safety Net

Transportation

Information

Technology

FEAR



Strengths

Family

Community

Responsibility

Hope

Resilience

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Promote Family Leadership

Meet the Locals

Dignity

Support their Efforts

Build on Strengths

Treat them as equals