



Agenda

Introduction

Emma's Journey

Enrique Journey

Mental Health

Mom and Dads Journey

Self-Care

Support



Introduction

Maira Nava is a parent guide through IL Hands & Voices Guide By Your Side. She is a first generation Mexican American. Mother of two special needs children. She has experience as a Paraprofessional in a DHH program and a special needs program. Currently learning American Sign Language. She is a passionate, dedicated, and devoted person who enjoys educating and spreading awareness to others!.



- Being a parent of a special needs child is most of the time unexpected but of two is even more rare. There are about 11.2 million children with special health care needs in the United States or one in five households caring for a special needs child. However, there are an estimated 2.8 million families, 1.3 percent, reported raising two or more children with a disability.



Emma

First Born Child



22q11.2 Deletion Syndrome

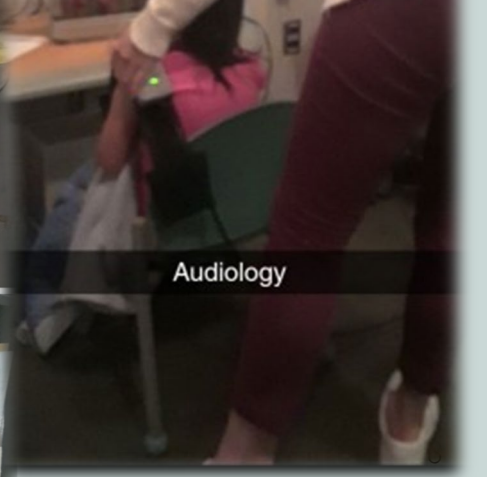
- Genetic Disorder missing a small piece of the 22nd chromosome on the Q arm.
- Also known as Velocranialfacial Syndrome and DiGeorge Syndrome
- A Multisystem disorder
- Can present with up to 180+ symptoms.
- Estimate prevalence of 1 in 2148 live births

Emma's Multiple Diagnosis's

Acid Reflux Inability To Sleep Congenital
Constipation Evans Syndrome Heart Disease
UTIs Narrowing of the Larynx Allergies
Excess Ear Wax Thrombocytopenia
ADHD Immune Deficiency Eczema
Astigmatism Asthma Decrease muscle tone
Congenital Web of Larynx Hearing loss
Speech Delay Feeding/Difficulty Swallowing



Feeding therapist 🍌💕🍌🍌



Audiology

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Enrique

Second Born Child



Deaf/ Hard of Hearing



Decreased Cardiac Function Enlarged Liver
Deaf Meconium Aspiration Eczema Helmet
Food Allergies Constipation Bilateral Loss
Sepsis Thrombocytopenia Speech Delay
Amblyopia Suspect Hearing Aids Mild to
High Blood Pressure Brain Scaring Profound
Cochlear Implants Venous Thrombosis loss





Sibling Bond



Compassion

Empathy

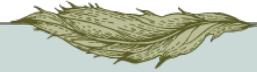
Advocacy

Support

Loyalty

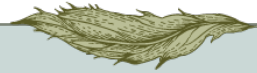


Mental Health



- There is a perception in Latinx/Hispanic communities, especially among older people, that discussing your problems is inappropriate and can create embarrassment, weakness, and shame for the family, resulting in fewer people seeking treatment.

Our Experience



Mom's Dad's
Journey Journey



Barriers





Self-Care

Latinas are taught self-sacrifice over self-care and to take up little space. Traditionally, the primary role of a Latina within the family is that of a caregiver and mother.



Stratagies

- Sense of Belonging
- Feel Grounded
- Podcasts
- Talking to Friends
- Exercise
- Dancing/Singing/music
- Drawing/painting
- Talking a Walk
- Long Showers

Saying NO
Forgiving yourself
Spending time alone
Putting yourself first





Growth

Advice to other

- Allow yourself to make mistakes
- Process your fears
- Trust in yourself and decisions
- Stop comparing
- Don't worry about other's opinion
- Validate each child's strengths and weakness
- Spend one on one time with each child.





Support



- Connections between families who have gone through similar experiences.
- Materials in home language.
- Look out for silence can be an indicator of various underlying cause. (not getting the audiogram)
- Social Events.

- Training and workshops with outside agencies.
- Non-profit Organizations
- [The Focus On You](#)
- [Latinx Therapy](#)
- Book Recommendations
- Ask Questions

- Use appropriate reading levels
- Recognize parents needs by validating their feelings,
- Help them see the positive aspects
- Recognize all their hard work and help them find programs , services, and financial resources.



Summary

A Diagnosis or Condition Marks The Start of A
Process, Not an End Point in the Game of Life

We are capable of generational change. With
the right tools and supports!





Thank you



Maira Nava

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Guide by Your Side

Parent Guide

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Questions?



Resources



- imenez, D. E., Bartels, S. J., Cardenas, V., & Alegría, M. (2013). Stigmatizing attitudes toward mental illness among racial/ethnic older adults in primary care. *International journal of geriatric psychiatry*, 28(10), 1061–1068. <https://doi.org/10.1002/gps.3928>. Accessed from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3672370/>.
- [The Focus On You](#)
- **What role does Hispanic culture play in depression**
- Medically reviewed by [N. Simay Gökbayrak, PhD](#) — By [Louise Morales-Brown](#) on August 30, 2021
- Pew Research Center tabulations of the 2017 American Community Survey (1% IPUMS). <https://www.pewresearch.org/fact-tank/2019/09/16/key-facts-about-u-s-hispanics/>
- [3] US Census Bureau. (2019). Hispanic Heritage Month 2019. <https://www.census.gov/newsroom/facts-for-features/2019/hispanic-heritage-month.html>
- SAMHSA. 2018 National Survey on Drug Use and Health (NSDUH): Hispanics, Latino, or Spanish Origin or Descent. https://www.samhsa.gov/data/sites/default/files/reports/rpt23249/4_Hispanic_2020_01_14_508.pdf
- **A Latina’s Journey to Self-Care** By: [Priscilla María](#), NOV 21, 2018
- **Machismo and Mental Health in Latinx Families, Mary Llanes, April 12, 2021**
- Help and Hope for Parents of Atypical Children Not What I Expected by Rita Eichenstein, PhD