>> Hello, we'll be getting started.

My name is Myra Nova and my presentation is special needs mom twice. And I want to thank you for coming to hear a parent perspective on having two children with special needs and as well to my cultural lens of having two children with special needs and as welcoming from a Hispanic community.

I will be going over my daughter's journey, Emma, my son's journey, Enrique, talk about mental health and Dad's and I's journey, self-care and support. I am a parent guide with Illinois Hands & Voices Guide By Your Side. I am a first generation Mexico American, mother of two special needs children. I also have experience working as a paraprofessional in the d/Deaf/Hard-of-Hearing program, and special needs program at my local school district. I'm currently learning American Sign Language. And I actually just started to learn cued speech as well, like two to three weeks ago. But I am just a very passionate, dedicated person. I love spreading awareness and I guess even more so when it comes to my children, because it's near and dear to my heart.

Being a parent of a special needs child is most of the time unexpected, but two is even rare. There are about 11.2 million children with special healthcare 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 or 1.3% reported raising two or more children with a disability.

How many of you all have one child with a special need?

Or has worked with a family that had one child with a special need?

And how about two children or more?

Okay.

My first born, her name is Emma, she's nine years old. When we had Emma, her diagnosis was that she has 22Q11.2 deletion syndrome. And this is a genetic disorder missing a piece of the 22nd chromosome on the Q arm. A lot of providers know 22Q deletion syndrome as vel oh craniofacial syndrome and deGeorge syndrome. Have anyone heard of these before?

There's an estimate one in 2148 live births are born with 22Q.

These are all of my daughter's diagnoses. Since birth til now. And we don't know what the future might hold, so there might be more diagnoses in the future. But these are the ones she has had so far.

There are a lot so I didn't want to just say all the names of them. But I do want to tell you which ones have been her biggest challenge. She does have congenital heart disease. She has a pulmonary valve stenosis and she follows up with a cardiologist once a year. So far there's no intervention needed. Her other biggest challenge was feeding and swallowing issues. That was right in the beginning of like NICU days that they felt she was aspirating so they did a swallow study and at that moment they had I had no idea what they were talking about. All I knew was she couldn't drink a bottle and needed an NG tube. This was all new to me, since she was my first. Her other biggest challenge is thrombocytopenia, which is a blood disorder where it causes low blood platelets in her system.

So to this day this still is her biggest challenge. She has to take medication on the daily in order to have safe counts. Otherwise, if they're too low, she's at risk for internal bleeding in the abdominal or the brain.

And she has a lower immune system and not too severe but definitely coming colds, it takes her longer to overcome them than a typical kid. She does have speech delay. Her speech has gotten better over time. Simple words, simple phrases, sentences, but the intelligibility drops when she's trying to string more sentences together so she still struggles with that. We recently got the diagnosis of ADHD this January. So we're looking into options for that to kind of help her with school because school has been very challenging for her.

And this is Emma since she was very little up to now. She's gone through a lot in her 9 years of life, but a lot of you could see like her G-tube, NG tube. When she graduated from having a G-tube. She did graduate when she was three years old so now she can drink and eat everything but she doesn't want to drink and eat everything. She just wants protein and carbs, no fruits, no veggies, it's a constant battle, but I'm grateful that she's at least able to eat safely. The other biggest one was lab draw. That's been very challenging. She got diagnosed at 11 months old with low platelet counts and she started off getting blood draws once a week to be checking her platelet levels and then slowly went to every two weeks and then once a month and then every two months. And that's how far we've gotten. It's every two months. Not six months or once a year; it's been like seven, 8 years, and we haven't gotten to that point. They want to closely monitor those blood counts. As she's gotten older she has learned how to advocate. The top, middle picture, she's asking the phlebotomist that she wants to check her name on the test tubes to make sure that her name is correct. She will tell the phlebotomist which arm she prefers and that she does not like the cold freezey spray and what type of BAND-AID, she usually does not like the BAND-AIDs, she just likes the wraps. We've come across challenges where phlebotomists will undermine her opinion. And I then, being Mom, have to advocate and say: She just told you what she prefers. You need to listen to her. It's her body and she's gone through this a lot so she knows what she's doing. And sometimes, you know, they give me an apology and sometimes they roll their eyes. But they're kids, they've gone through a lot and they kind of get to the point where I see she's starting to advocate and I'm proud of her, too, for doing that.

My second born is Enrique. Enrique's main diagnosis is he's d/Deaf/Hard-of-Hearing. But his biggest challenge was he was born -- he had meconium, he swallowed meconium and he was in the NICU to just observe. And seven days into it, he became sepsis and he also stopped breathing and they had to resuscitate him.

And that sepsis caused a whole bunch of issues. His heart function decreased. He had an enlarged liver. He had a brain clot in the vein of his brain. And newborn hearing tests was not an option because they were more concerned of his other medical needs until we got closer to going home. At five weeks they did the newborn hearing screening and he failed twice and they referred me to follow up with the hearing test.

And we did. At four months old we did a sedated ABR, confirmed mild to moderately severe hearing loss. He got aided at five months old and has been wearing his hearing aids up until about a year ago, he lost more hearing. He went from mild to profound and then we decided to go for a cochlear implant on the left ear and he just recently got his right cochlear implant last month.

But other than that, he's been pretty healthy other than the beginning stages of his life where he needed some medications and things like that. He's been pretty healthy. He does have food allergies. He's allergic to dairy and egg. And his speech was -- is coming in a little later, but it's normal. He also ended up getting low platelets.

And it was strange because I was like I know this, I know this petechiae on the skin, the bruising, I said this looks like what my daughter has but that I know of, he doesn't have this condition and I thought that was strange. I called my daughter's doctor, who was also his doctor when he had the clot in the brain, so he's a hematologist. He said go to the hospital and just do a blood count and see what happens. And sure enough, his blood platelets were at like 11,000. He got admitted the next day his platelet count went down to 2,000. He was bruising like crazy in the little like crib that the hospitals have. He would bump his head and a big ol' bruise. So the doctors were confused. They said thrombocytopenia usually isn't hereditary so they were requesting tests and labs. But what we ended up finding out was that he had a treks reaction to his MMR vaccine. He had gotten the MMR vaccine about 10 days before I started noticing symptoms. Luckily he bounced back after two months. He got treated at the hospital with steroids to bring those platelet counts up. We followed up a month and then two months and then three months later and everything was stable. But we are not giving him his second MMR vaccine just due to the risk of him getting that again and we don't know if he does end up getting it, if it will be acute, because sometimes it can become chronic and we don't want that. This is Enrique. This is my little guy. We see when he got his implants, he had some feeding challenges. He had a little helmet when he was a baby.

We involved him in the whole cochlear implant process. We explained everything to him. We interpreted everything for him. He was part of the whole thing. Sometimes some providers were like I don't know if you really want to tell him like everything. He's kind of young.

But it worked for my family and it worked for him and I want him to have a good experience. I did not want him to get rolled away and him not knowing what's going on. I mean, that's what worked for my family.

And then making it fun, so the little ear piece that the doctors look through your ear, just popped it on his nose. He was getting a little frustrated. And while we're there, just trying to make it fun also.

And sibling bond. They are so close to each other and they fully understand each other's needs. And I feel that they're very compassionate. They have empathy with one another. They advocate. They support. They're very loyal to each other. Obviously, under empathy, little brother always goes and holds Emma's hand whenever she needs blood tests. Advocacy, my daughter is signing with Enrique at Disney and they're having their own little conversation. Support, my daughter does have low muscle tone and midline issues, so it's harder for her to put her socks on. And brother was like, oh, I'll help you put your socks on. And I was like -- I'm trying to collect pictures and I'm like oh, that's great!

And I was in the moment, I took the picture for the presentation.

Rock your Q is a nonprofit organization that helps with the 22Q deletion syndrome. They support each other. They also have like Deaf awareness T-shirts that they both wear and things like that. But I'm very grateful that even though they have their own medical journeys, that that also brings them together and gives them that understanding for one another.

So I want to talk about mental health because it is a big -- it's not really talked in my culture. We really don't believe that we need help when it comes to mental health. So there is a perception that Latinx and Hispanic communities, especially among older people, that discussing your problems is isn't appropriate and it can create impairment, weakness, shame for the family resulting in zero people seeking treatment and growing up I definitely saw that. I saw my mom and dad have issues. They didn't ever seek help.

And it kind of rolled over to me as well, just growing up in that environment, but in 2018, 56.8% of Latinx, Hispanic young adults between 18 and 25 and 39.6% of adults between the ages of 26 and 49 with serious mental illness did not receive treatment. They just would rather not follow through. Maybe they will get to that initial stage where they kind of want to ask for that help and they do, but then they kind of get scared and like back off and then they don't follow through with treatment.

And based because of that and how we grew up and how my culture, you know, I could only speak for myself, but how that impacted myself was that things were tough. Having my first child with 22Q, I did not expect having her with special needs and it was hard to kind of like wrap my head around with what everything was going on. All I knew was I needed to be strong because I'm her mother and my mom said God does everything for a reason. Have faith. Pray.

It's in hisHis hands. And yes, I understand that part, but I think I just needed more support and it would have been helpful if they would have said you know what, this is a lot. You know there are helps out there and therapy or counseling. Maybe you should try that. But because in our community we really don't talk much about that and like older generations, they really don't know either like what resources there are or things like that, and the belief as well. Like don't drink. Depression medication, you become addicted to it or it's not good for you, things like that. So I didn't really have an escape or who to go to. I just soaked it in and just kept it in.

It was hard to accept the fact that I have a special needs Highland. -- it took me a process to get there. When I was pregnant they said something was wrong with her and I was hopeful wishing. Like there's a lot of cases where ultrasounds say the baby has something and they're born and they're fine, so I never really processed it and I was just hoping for the best. When she was born, they're like she has issues, she has problems.

So that picture of having like the perfect child was kind of torn from my idea, even though I didn't have her yet. It was just an idea of mine of what I thought my child was going to be like. I think it was just I had to grieve the whole process of not having that child. And it's the whole process, you know?

The denial and the acceptance of the whole journey. For Dad it's a little different because Dad is -- he is primarily Spanish speaking, so he's a little different. He was born in the U.S., but parents decided to move back to Mexico, so he moved back at age two, spent his whole childhood there, came back to the U.S. at 18, not knowing the language, but being a U.S. citizen and kind of feeling that he didn't belong here. The language barrier, the rules of everything of what is expected from this country, he really didn't know. And even though he was born here, they would say how do you have this license, aren't you undocumented?

And like, no, well, I actually do. I was raised in Mexico and we came through all those barriers as well. But his experience, he felt guilty. He felt really guilty that our daughter was born this way, that what was it that he did wrong, that we had a daughter with special needs. That was his biggest challenge.

And bringing her into this world unhealthy was his biggest also that he would tell me like I just feel that why, like why did I bring her into this world?

It's so unfair for her. But we got through it. He felt very isolated as well. Most of his family's in Mexico, back at home, so he didn't have anyone either. And being male, he definitely did not want to talk to nobody regarding his problems. So that's kind of like what our experience was. Barriers to -- oops -- barriers to these mental health is, one, is language barriers within our community then as well as poverty or not having health insurance as well is a big one. Legal status, the fear of going into ask for help because you might not be documented. And the lack of not having a perfect culture of physicians you can relate to or the physicians can relate to our culture and kind of help us through the process of going through therapy or counseling, just having that understanding is really hard.

Self-care was another big one for me that was really hard but Latinas are taught take up less space. The role in the family is that of a caregiver and a mother. So I was raised this way, we're household wives, you clean, you do everything. The male goes off to work and provides for the family. And I didn't want to ask anything for myself.

It took me a while, like after having my son, I just felt Burton Blatt -- burn The Out. I didn't know that it could be the little things that could make a big change in taking care of yourself. But self-care can look like physical, emotional, social or spiritual care. It doesn't have to be super expensive. Obviously, it can be if you want to. You have the means for it, go for it. But it doesn't have to look that way.

But definitely a sense of belonging and feeling grounded, I feel, is what I needed to have self-care. But some of the things or strategies that I enjoy was podcasts, talking to friends, exercising, dancing, singing, music, drawing, painting, taking a walk, long sho long. What I tend to do a lot is taking the long way home to have the extra minutes before getting home. Or when I'm at the grocery store, I'll take another 30 minutes, I don't have to do anything, I already got all my groceries. It's just nice, peace and quiet, it's my time, and it just kind of recharges me.

The growth in myself and advice I would give others is allow yourself to make mistakes. It's okay and we don't have to be perfect all the time. Give yourself some grace. I think it's very important. But another big thing was also processing your fear. It was hard for me to say things out loud.

My daughter has deGeorge syndrome. My daughter has a feeding tube. Like when I said it out loud, it felt real. When I wouldn't say it out loud, it was just kind of like my safety net, but saying it out loud was so hard for me.

But I learned that after I had my son, Enrique, that a social worker came over to our room and kind of explained that to me. That really helped kind of helped in the process to process my own fears and it was okay. Trust yourself in decisionmaking. I know it's hard. You're the only person that's going to make the right decision for yourself, your family, for your children. You could ask other's opinions, but at the end of the day it's your choice. And I feel it just makes it harder to make your own decision because you're thinking about what everybody else is thinking. But I would say as well stop comparing, because I would do that a lot when my children were young. I would always feel like embarrassed or jealous that I would see other babies that could drink bottles and my daughter had a feeding tube. And I didn't want to go out. I didn't want them to see her. I didn't want to be asked questions. I wasn't ready for that. And that's okay. If you're not ready, that's okay. Then maybe you'll eventually get there.

But don't worry what other peoples' opinions, kind of what I said before, it's your journey. And you're going to embrace it in your own time and that journey, you'll lead but your children will help you lead it as well, because they will definitely show you what works and what doesn't work for them. And listen for like those cuse cues from them. Validate each other's strengths and weaknesses. So I always try to do little things with my daughter loves to bake. I don't know where she got that from because I'm not a baker. My sister is but I am not a baker. I try to follow the instructions and then my cookies get burned on the bottom. My daughter's like why are they a little black?

I'm like well, I think I went over the time a little bit.

But we try to do things like that. She loves music and art and I think that's one of the things I've learned is to embrace that. She has a hard time in academics, really hard time. She's a third grader and with a kindergarten level reading. And that sometimes gets to me a lot. But sometimes I have to remind myself like it's not always about academia. I need to embrace what she loves and what she enjoys and expose her to that. She's taking violin lessons now. And my son loves to swim and will take everything off, his cochlears and we have a sign language interpreter in the pool with him for access of language and he loves books!

He just loves books!

Even if he can't read, he pretends he's reading and I really love that and I want to encourage that as well. And give each other their own time, too. That's important too.

Biggest supports for myself was nonprofit organizations. The one with the red T-shirts is the 22Q Family Foundation. They had a lot of events, things like that, so connecting with other families I felt was my number one, relating to others. We went to Disney World, we had sign language interpreters interpreting the shows for my son to make sure that he had access to language. So I want to raise them with supports and for them to have a sense of identity of who they are and be proud of who they are regardless of -- they have all these challenges. At the end of the day, they're still human beings and they need to appreciate every little thing, good or bad, you know?

And I think those supports are so helpful. Obviously, if you're working with providers, language, materials, in their native language.

Overall, a diagnosis or condition marks the start of a process, not an end point in the game of life. And we are capable of generational change with the right tools and support.

Thank you.

>> Thank you all so much for coming. If you wouldn't mind filling out your surveys, we would appreciate it. Thank you.