

Family Voices En Español Magazine Team



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The first edition of Family Voices en Español magazine marked the beginning of a new collective project, where Family Voices launched a virtual magazine written in both English and Spanish.

The first edition was distributed to over 17,000 readers, including families and professionals across the country, including Puerto Rico and the US territories.

Read past issues of Family Voices en Español Magazine at <u>familyvoices.org/enespanolmag</u>.

If you would like to collaborate on the summer 2024 issue, contact us at enespanolmag@familyvoices.org.

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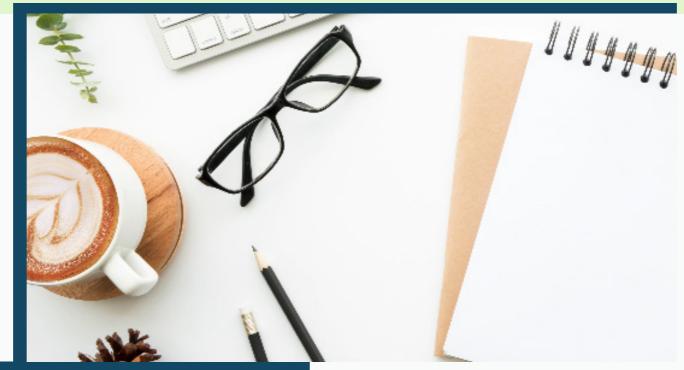
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What's new at Family Voices?

Family Voices received funding from Lucile Packard Foundation and MCHB to help families understand and address issues related to the unwinding of the public health emergency and Medicaid. Family Voices is providing mini-grants to amily to Family Health Information Centers (F2Fs) and Family Voices Affiliate Organizations (FVAOs) to assist families navigating through the redetermination process. Learn more at familyvoices.org/unwinding.

Our staff is growing!

Visit <u>familyvoices.org/team</u> to learn more about our staff and the tremendous experience they bring to our work.

As 2023 comes to a close, I am reflecting on my first seven months as the Executive Director of Family Voices. I entered this position on the shoulders of the amazing women that have come before me, which are big shoes to fill. Many programs and structures have been put in place over the 30 years that have made enormous strides in serving families of children and youth with special health care needs (CYSHCN). Because of our rich history, I wanted to listen and understand the successes and challenges from the past and the hopes and needs for the future. A critical part of this process was for me to approach these conversations as a learner.

My conversations with staff, network members, and Board members demonstrated the tremendous hope that people have for the future of Family Voices. The input gathered was used to help develop Family Voices' strategic plan for the next 5 years. As our team developed the strategic plan, we heard strong calls for equity, expanded partnerships, and realigned infrastructure for Affiliate Organizations. Another idea that came out of my "listening tour" was the desire for everyone to feel included and valued in the family leadership space.

From Allysa's Desk



Allysa Ware Executive Director Family Voices

Because of all I heard, it is critical that I work hard to ensure that we honor, preserve, and respect the voices of those who have paved the way for this important work, while also introducing, including, and elevating the voices of family leaders whose voices have not always been a part of the conversation. Doing this takes a lot of time and sensitivity, which has required me to slow down in my role as Executive Director.

As I look forward to 2024, I am excited to unveil our strategic plan, and begin to implement it with our staff, Board, and network. I look forward to leading family-driven transformation in systems that serve CYSHCN, widening our circle of influence through expanded partnerships, and building the capacity of our staff, network, and Board to effectively advocate and transform the systems that serve CYSHCN. Additionally, our program work at Family Voices will focus on integrating systems through the life course, family-driven research, training and technical assistance, and language access.

The future of Family Voices is bright, and I am honored to have the opportunity to lead this amazing organization. We are so proud to elevate the importance of families and those with lived expertise at the forefront of systems change.



Managing Mental Health During the Holidays

Steph Lomangino
Project Director at Family Voices

In 2021, a national survey reported that three in five Americans feel their mental health is negatively impacted by the holidays. This time of year may create triggers that might require additional help. For disabled youth and their families, holiday-related stress may be compounded by existing needs or challenges, such as managing medical complexity during this time of year. Hispanic and Latino families may face additional stress if they are away from family in different countries during this special time of year.

Although mental health challenges might be heightened during the holidays and new year, existing services for children's mental and behavioral health remain limited or difficult to access.

THE MENTAL HEALTH EMERGENCY

Families often turn to the Emergency Room (ER) as the only option to address mental health-related issues in a time of need. Recent data show that between 2011 and 2020, the annual number of mental-health related visits for people ages 6 to 24 rose from 4.8 million to 7.5 million. At the same time during this period, the total number of youth visiting the ER decreased.

This growing need added to an ongoing problem: overflowing Emergency Rooms combined with a lack of other services. This problem puts children, families, and providers in a situation with nowhere to turn.

In 2022, Family Voices signed on to a letter to President Biden from the American College of Emergency Physicians calling for the urgent need of more mental health services so that children don't get "stuck" in the ER.

INVESTMENTS IN MENTAL HEALTH

The federal government and many states have begun to address the problem of unmet mental health needs that both children and adults are facing. This includes large investments in mental health services and expanding crisis services such as the 9-8-8 hotline and behavioral health urgent care centers.

Despite these positive changes, there continue to be enormous challenges in accessing mental health services, and these challenges vary greatly from state to state. These problems include:

- Little or no funding for 9-8-8 or urgent care;
- A fragmented offering of accessible services beyond crisis care;
- Unaffordable coverage due to inadequate or no health insurance;
- A shortage of diverse and culturally competent mental health providers; and
- Outdated provider contact information.

For professionals, working toward improving these problems should be a top priority, guided by the voice of families and youth.

COMMUNITY MENTAL HEALTH SUPPORTS

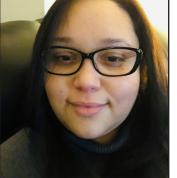
Beyond professional services, natural community supports are an important part of supporting one's mental health. As we continue through the holiday season and into 2024, there are many other ways to offer support and destignatize mental health challenges. This might look like:

- making a mental health plan for yourself or helping someone make a plan for themselves;
- being open to talking about mental health with people in your communities;
- inviting someone to celebrate with you if they are alone during the holidays;
- or joining an online support group to connect with others who might be experiencing a similar challenge.

Professionally and personally, we can support the children and families in our lives to make strides through difficult situations, during the holidays and beyond.



Accommodations and gifts to celebrate special occasions with children with special health care needs



Vanessa Rodríguez Project Director at Family Voices

For many families, the winter holidays are a representation of the happiest season of the year. These festivities tradition bring a special and happy reason to celebrate with loved ones, but they can be chaotic for parents of children with special health care needs. The reality for many of us is that we are often absent or missing family gatherings for numerous reasons, some of them out of our control.

Being the parent or the sibling of a child with special health care needs and disabilities should not be a reason to avoid going to a family reunion or not getting an invitation. Our children should be included in every happy celebration, birthday, party, or event. They enjoy being part of these long-lasting wonderful memories. If there is gifting involved, every child deserves a gift, including those who might play in a different way.

COMMUNICATION IS KEY

We should always communicate to other family members the limitations, specifications, accommodations, or any other specific need that the care of the child includes. Help the host understand your family's needs and plan ahead with them to make a great experience for everyone. As soon as you receive the invite, start planning. Identify a support team among your family, relatives, and friends attending the event that could help with your child when you need a break.

BE PREPARED

You will need to communicate with the host prior to the event to explain your child's diagnosis and behaviors, and plan to bring any medications and supplies your child needs. Bring extra clothes, enough diapers, wipes and pads, a large blanket, or a throw. Be sure you don't forget medications and medical equipment and supplies. Bring snacks and food that you know your child will enjoy and prefer.

Prepare a plan that includes what could go well and what could go wrong and stick to it, do not improvise. Let the host know in advance that there will be a possibility of you leaving early, and don't feel worried if you must. If they have a gift distribution, communicate with the host what type of toys your child likes. Be honest if you prefer a specific item rather than cash or a gift card.

ONCE YOU ARRIVE

Be attentive to lights, noises, and sounds that might trigger behaviors, and have a plan to calm down your child. Identify an area in the house that could serve as a safe space during the visit. You may want to bring some headsets with sound reduction. Bring toys and entertainment that will keep your child calm. If he has more than one toy, don't give them all at the same time.

MONETARY GIFTS

Some children receiving benefits like SSI could experience a problem if they receive substantial monetary gifts from generous family members. If your child receives benefits that could be taken or lowered based on their income, it's important to share this with generous family members. Explain the income limitations to your relatives, and let them know if you have an able account, trust fund, or any other account set up for your child. You can also create and share a gift registry of items that your child likes instead of accepting cash gifts. If you prefer not to accept traditional gifts, you can create a holiday campaign to support a non-profit that helps your family, and share the link among your relatives and networks.



What does a gender of "Other" mean?

Clarissa Hoover
Data Lead at Family Voices

When I was five years old, my family moved a short distance to a new city and a new house. My mom told me, "Your old room was yellow because we didn't know whether you would be a boy or a girl, but you can have a pink room now if you want one." BLECH, no! "I want my new room to be yellow, too." And it was, and for the next 10 years (until we moved again), I was perfectly happy with my yellow room.

THE COLOR OF GENDER

Green and yellow have always had a gender to me. Green is male, but not as male as blue – it's somewhere between blue and pink. And yellow is female, but not as female as pink. That is what I am, what I have always been – yellow, not pink. About two years ago, I was reading an article about a non-binary woman trying to get a wedding dress that she liked. I started to realize that she was talking about feelings that I had always felt, but never expected anyone else to share. For the first time, I started to think carefully about what my gender was, and to realize that there were a lot of women like me.

Because of where and how I grew up, I never felt horribly out of place as a yellow woman. However, realizing that I was non-binary still changed my life. I am a lot more confident about myself, my gender, and my sexuality now. Last summer, I went to a family wedding with a dress recommendation of garden formal. I googled

"non-binary garden formal" before deciding what to wear. I wore a little black dress to the cocktail party, a navy-blue pants suit to the wedding, and nice pants and blouse to the farewell brunch. I didn't fit in all that well with what the other women were wearing, but suddenly that felt okay, and I was gloriously happy with all of those choices!

WHAT IT MEANS TO BE NONBINARY

Of course, being non-binary isn't just about clothing. It spreads through every part of life, because gender spreads through every part of life. My appearance, my interests, even my values, have a masculine quality. That's not a problem for a man, but it's always been a problem for me because I don't match peoples' expectations of a woman. People assume I'm a lesbian. They think I'm too careless about house-cleaning and child-rearing. They don't understand why I like power tools and DIY.

As for how I would like to be treated, there is one overarching rule that a lot of non-binary and trans people recommend – don't make a big deal about it. If you use the wrong name or pronoun for someone, apologize, self-correct, and move on.

"For parents: Look for online resources that focus on helping you understand your options rather than on telling you what to do. While no one says it is easy to be trans, nonbinary, or intersex, the best resources will help you feel confident that you can guide your child through these challenges to the best of your ability. " - Clarissa Don't pressure people to self-identify or label themselves, and of course, don't pressure people to conform to gender-based expectations.

However, it's also important to make traumainformed decisions when working with trans and non-binary people. A lot of people in this category have experienced severe trauma, up to and including violence and estrangement from their families. Creating a sense of safety is critical! It may sound like there's a huge divide between these two pieces of advice, but they're truly very closely related. In both cases, the shared theme is acceptance.

UNDERSTANDING GENDER TERMS

Queer: A broad term that covers the entire LGBTQ+ community.

Gender: The part of social identity that is based on cultural interpretations of biological sex. Note: In English, "gender" is often used as a synonym or euphemism for "sex", but its true meaning is closely related to how it is used in the study of languages.

Intersex: A person whose sex was difficult to determine at birth. They vary a lot, but may have been born with no physical sexual traits, or may have been born with both male and female traits. Roughly 1-2% of infants are born intersex.

Assigned male at birth (AMAB): "Male" on birth certificate, dressed in boy's clothes, and so on.
Usually AMAB is based on male appearance;
however, intersex infants may be AMAB based on their parents' or physician's preference.

Assigned female at birth (AFAB): "Female" on birth certificate, dressed in girl's clothes, and so on.
Usually AFAB is based on female appearance;
however, intersex infants may be AFAB based on their parents' or physician's preference.

Cis gender, usually shortened to "cis": A person whose gender matches what they were assigned at birth.

Transgender, usually shortened to "trans": A person whose gender is different than what they were assigned at birth.

Non-binary: A person whose gender does not fall clearly under the labels of either male or female.

Gender queer: Depending on context, "gender queer" may refer to non-binary people, trans people, or both. I have seen sources that insist either that non-binary is a subcategory of trans, or that trans is a subcategory of non-binary. Not true! People can be both, or one or the other. As the definitions above suggest, they are closely related, but they are not the same thing.

Trans man: a man who was AFAB.

Trans woman: a woman who was AMAB.

Gender dysphoria: Poor mental health that
can result from assigned gender or physical
characteristics that don't match gender identity.

Gender-affirming care: Treatments that help gender dysphoria by changing sexual characteristics. The decisions that trans and intersex people make about gender-affirming care are highly personal and vary widely based on personal needs. It is not appropriate to ask a trans or intersex person questions that go beyond what you would ask anyone else. I mention this because of the distressing frequency with which trans people report getting asked questions such as, "What have you got down there?"

Hormone therapy: As part of gender-affirming care, use of male or female hormones to change sexual characteristics.

SHARED STORIES

Managing Complex Care over the Holidays

As the mom of a 12-year-old with complex health care needs, the holidays can be complicated to enjoy. There's the usual joy of the holiday season, and my son's excitement about gifts and family gatherings. But also, there's my nervousness about cold, flu and COVID, medical emergencies, and less in-home care. Balancing it all is hard, but it's possible to have a great holiday season with the support of friends and family members.

The holidays can be tough for those of us whose children have different types of in-home care.

Nurses and aides often take time off, leaving families like mine to manage care with less help. As much as I can, I plan rest for myself, and I do less – fewer errands, fewer appointments, and fewer demands can make the season easier for everyone. That allows me to be less stressed and more open to having fun with my family. Maybe a family member or friend is willing to help with feeding your child, helping them take breaks, or even staying up for a few hours at night so you can sleep. Share your child's schedule in advance and ask for help where you need it.





Nikki Montgomery Director of Communications at Family Voices

I try to remind family members about my son's medical complexity when we gather for the holidays. For example, my son does not eat orally – he uses a feeding tube – so it's important that family members don't try to pressure him into eating and don't make him feel bad about not eating orally. My son also has very specific interests, so I make sure my family understands the types of gifts he's interested in receiving and will appreciate. I also think family members need to understand that my son's social interactions might look different than they expect, so they can be considerate of different ways to interacting. My child may not want to hug, or may not give eye contact, and neither I nor my child should be shamed or scolded for those different ways of engaging.

The holidays are exciting, but they can also be very overstimulating. I make sure to plan ways to escape the noise and activity, for myself and for my son. Planning quiet space can help with sensory meltdowns and feeling overwhelmed.

As a caregiver, you need and deserve rest and breaks just as much as anyone else – actually more.



Felix is infinitely loving and caring, is always smiling, and is pure innocence.

Felix is an 18-year-

old, immensely loved

child. He has various

conditions, including

intellectual disability.

and deafness.

The winter holidays can be especially difficult and sad because oftentimes they are a reminder of what Felix cannot do, doesn't understand, and will never know. He doesn't ask or dream of presents, toys, or eating birthday cake surrounded by friends. We almost always celebrate every special moment with just the two of us, and the only places where we can celebrate with others and where Felix is included in group celebrations are at his school and his care center.

FAMILY INCLUSION DURING THE HOLIDAYS

To be completely honest, it's a complex situation. Thinking about how my family treats him, in their own way and with the best intentions, but they don't really know how to act or get involved, what to do, or when to be present in his life. As a mother, I often feel that Felix is a bit of a stranger to my family and isn't part of the "tribe." Over the years, Felix has not always been included in family affairs; I'm not sure my family thinks of him much. As a mother of a child with special health care needs, the festive season is bittersweet and involves lots of mixed feelings. I experience anguish, fear, and self-blame, and I begin to wonder "Why didn't/don't I speak up?," "Why don't I just get up and leave?," "Why do I continue to attend these holiday gatherings?"

Once, in a moment of bravery, I spoke up and was told "He [Felix] doesn't know any better. If you want him to receive gifts, ask others for gifts and just

Advocating for Inclusive Family Celebrations

Coralaidee Jimenez Burgos works for the Puerto Rico Department of Health as a family representative for Children and Youth with Special Health Care Needs.

it's for you." That person has yet to gift him any presents. It's not a matter of gifts though. I wish others would treat Felix like anyone else and include him. It is a battle that makes me want to shout at the top of my lungs like they do in the movies, until others can understand that Felix is a child like any other child, who deserves the joy of presents, who enjoys playing, and who enjoys the season of Christmas and all the other holidays. My job as a mother is to protect Felix, be his voice, and educate my family so that they can include my son in every holiday.

HOW TO MAKE THE HOLIDAYS INCLUSIVE

To family members and friends of children like Felix, it is very important that you ask questions. "What types of gifts would the child like?," "Is there anything they need?," "In what ways can I include them in each holiday or special occasion?" Often times, people are asking themselves these same questions but don't feel comfortable or know how to bring them up.

To other parents of children like mine, I'd encourage you to be honest with yourself and with others and to try to find the most comfortable form of communicating what you are feeling. This could take the form of a text in the family group chat with details about what your child likes, their clothing sizes, favorite treats, or their favorite toys. I'd encourage you to be open with everyone, always be respectful with your words, and don't say or do anything you may regret later. If you decide to shout out your feelings in the middle of a gathering and leave with your child and never come back, that's also your right.

In the end, the most important thing is that our children are happy and that we try to guarantee them that happiness. 13

Partner Highlights: Academy Health

Partner Highlights showcase Family Voices' project partners and collaborators' initiatives to improve the health and life of children with special health care needs and their families.

In this issue, we highlight our partnership with Academy Health. We sat down with Steph, the project director. Steph shares their excitement to be part of this initiative and introduces Dr. Elizabeth Cope, Vice President of Academy Health. Dr. Cope gives an overview of the project and how this collaboration will impact children with medical complexity and their families.

IMPROVING LIFE FOR MEDICALLY COMPLEX CHILDREN

"As a project director at Family Voices and a member of the Enhancing Systems of Care Coordinating Center leadership team, I'm enthusiastic about family engagement being an important pillar of this project. While my own lived experience doesn't classify as having medical complexity, I have experienced some of the barriers to care that so many families often face: lack of access to easy-to-understand health information, missed opportunities for early screening, gathering family history, and identifying social needs, as well as a fear of retaliation when asking for help. Families, especially those with children who have some of the most complex health needs, deserve to have high-quality care that is affordable, coordinated, and compassionate. The partnerships within this initiative can help us get there." - Steph

Elizabeth Cope, PhD, MPH Vice President AcademyHealth



ENHANCING SYSTEMS OF CARE COORDINATING CENTER (ESC CC)

The Enhancing Systems of Care Coordinating Center is working to support five HRSA-funded Demonstration Sites across four states as they implement evidence-informed care models designed to optimize the care experience and outcomes for children with medical complexity (CMC) and their families. There are approximately three million CMC nationwide, representing 1-4 percent of all children and 5-6 percent of children covered by Medicaid--and many face a range of social determinants of health challenges, including poverty, housing instability, language barriers, or foster system involvement. Effective models of care should be designed in partnership with families to help them establish a medical home, have better access to services and innovative technologies, and experience equityinformed ways to receive the resources they need.

To establish the Coordinating Center, AcademyHealth brought together a group of partners, including Boston Children's Hospital, Family Voices, University of California San Francisco, American Academy of

"According to the World Health Organization, the social determinants of health (SDH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life."



Pediatrics, and Patient Advocate Foundation.

Together, this partnership provides technical support to the Demonstration Sites, evaluates their success, and creates and shares tools to spread the work. Through a series of activities, the ESC CC will help local systems to implement, evaluate, and scale-up practices and models that improve equity, health, and well-being for CMC and their families.

THE IMPORTANCE OF LIVED EXPERIENCE

As is by no means unique, I bring my own lived experience to this work, with first-hand knowledge of the limitations of our health and social services systems. This work is not about my story. But my story has given me a deep, personal understanding that the system needs to be rebuilt, and that any changes will not be for the better unless those with lived experience are empowered and working in direct partnership with everyone else. This project, with its close partnership with Family Voices along with a Coordinating Center and five Demonstration Sites that are all-in on their commitment to equity and family engagement, lifts my spirit and brings newfound hope that we are on track for a better system of care for children with medical complexity and their families.

COORDINATING CENTER LEADERSHIP TEAM

- Elizabeth Cope, PhD, MPH, AcademyHealth (Principal Investigator)
- Richard Antonelli, MD, MS, Boston Children's Hospital (Co-principal Investigator)
- Amanda Brodt, MPP, AcademyHealth
- Jeff Schiff, MD, MBA, AcademyHealth
- Steph Lomangino, LMSW, Family Voices
- Wayne Steward, PhD, MPH, University of California San Francisco
- Christina Boothby, MPA, American Academy of Pediatrics
- Rebekah Angove, PhD, Patient Advocate Foundation

Demonstration Sites

Childkind, Inc. · University of Florida · University of Montana · University of Texas at Austin · University of Texas Health Science Center of San Antonio

To learn more about AcademyHealth:

<u>Enhancing Systems of Care for Children with</u>

<u>Medical Complexity (CMC) Coordinating Center |</u>

<u>AcademyHealth</u>



academically.

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Featured Family Leader

Roseani Sánchez Director of Programs at Family Voices

A LITTLE ABOUT ME

My name is Roseani Sánchez. I am the mother of 8-year-old twins, two very active and awesome boys. I love being a mom. I am an extremely organized person and I enjoy cleaning. I live in Puerto Rico, I am very proud of where I come from and my roots. As you may guess, my favorite food is the authentic Puerto Rican food. The thing I really enjoy when I am with others or when I'm alone is a good cup of coffee.

MY STORY

Since I finished high school, I knew that I had a calling for special education and psychology. This is the reason I decided to academically prepare myself in both specialties. While getting my degree in psychology I had the opportunity to work with children diagnosed with autism. Since that moment it has been the focus of my career. I moved to Spain to pursue a specialization in autism and behavioral management.

Services in Puerto Rico for children diagnosed with autism were not covered by medical insurance, and finding a job in that area was very difficult, even when the need and demand were very high. In 2006, I relocated to the US, searching for better opportunities as an educator, as well as for professional and personal growth.

FACING LANGUAGE BARRIERS

With high expectations, I prepared for this new journey, leaving family, friends, and some dreams behind, eager for what the future had for me. I knew that some sacrifices needed to be made as I started this new adventure. Without hesitation, I jumped onto a plane to conquer this new chapter in my life.

However, the reality was completely different from my expectations. Once I got to the US, everything started to shift in a different direction. I was barred by many challenges and a different language; at that time, I was not fluent and did not have an extensive vocabulary to communicate in English.

Months went by and I was not able to find a job and start working on what I was passionate about and had the preparation for, just because I was not able to speak English. I remember one time after a very long day of job hunting, I went to a fast food to get something to eat and I was not able to order food because nobody spoke Spanish and it was hard for me to explain what I wanted from the menu. I don't even remember how many English courses took, how many job applications and interviews I went to, the little English I knew was not sufficient to get a job in my area of expertise. I got a job working at a department store to earn some money, but I never forgot what I wanted to do; it was my passion and goal to work with children diagnosed with autism.

A BEAUTIFUL COINCIDENCE

After four years working at the department store, one day a mom came into the store with her with her child. It was clear that her child showed severe behavioral difficulties, and I offered to help her. After a couple of minutes, I was able to calm the child, redirecting his behavior to one that was appropriate. The mom was amazed and very grateful, she asked me what I was doing working there with all this knowledge. My answer to her was that was not able to find a job due to my language barrier. I will never forget this family. One week after the event, that same mom came back to the store and offered me a full-time job working with her child. They did not care about my accent, poor English, or any other limitations of the English language; they trusted my skills and expertise helping their child move from challenged behaviors to responsive and structured ones. That was a

new beginning for me, and since that day I have been working non-stop with families of children with autism, helping them achieve better health outcomes, and supporting them in both English and Spanish.

THE POWER OF PERSEVERANCE

Just because people don't speak the English language, they confront many challenges and difficult situations. Not knowing English closed many doors and opportunities. However, the challenges helped me develop a positive attitude, perseverance, and hard work, which led me to overcome my fears and insecurities. Joining support groups and promising myself to learn, practice, and keep trying every day were the first step in conquering that giant barrier that we call "English". 18 years have passed, and I haven't mastered the English language completely, but I know enough to communicate effectively, be understand, and do my job of helping others do the same. Don't give up!

RAISING BILINGUAL CHILDREN

My children were born in Virginia. Since they were born, they have been exposed to both languages. I wanted to prevent them facing all the barriers and challenges I went through. When I moved back to Puerto Rico, where the primary language spoken is Spanish, my sons lost some of their English vocabulary and currently, they speak more Spanish than English. This has impacted their communication with their father, who doesn't speak Spanish. It's my goal to guarantee that my children are fully bilingual, which is why they attend a bilingual school here in PR. Being proficient in both languages will strengthen their relationship with their father and it will open doors for them in the future. As a parent and a professional, I spend my days being a voice for all these families who face language barriers every day.

My story and my children's story are the mirror of many families who immigrated to the US in search of a better life and better opportunities. Language barriers affect how we receive basic services like medical, educational, entertainment, and work opportunities, even when you are highly prepared

THE RIGHT TO LANGUAGE ACCESS

It's very challenging to leave aside the prejudices we constantly face due to an accent that represents our culture and where we come from. Today I consider myself an advocate for language access; I want to acknowledge how important is that immigrant families, not only Hispanic/Latino but also those who speak any language other than English, know that they have the right to receive interpretation, translation services in their own language.

My greatest achievement is my two boys who I love, and they are my inspiration and motivation to become a better version of myself every day. I have two bachelor's degrees, one in psychology and the other in mental health, a master's degree in Curriculum and Instruction with a specialty in ABA and a specialization in autism.

Three years ago, an incredible door opened, and I started working at Family Voices National as a project coordinator. Today I am the Director of Programs, and every day at work I can promote language access from a national level and continue my work with family leaders who have children with special healthcare needs. If you ask me how I did it, I will tell you with hard work, perseverance, consistency, positivity, and commitment to myself.





A Taste of Home

Maribelis Arroyo Family Leader

COQUITO

Coconut beverage

Ingredients

2 cinnamon sticks (for inside the bottle)

1 can sweetened condensed milk

1 can cream of coconut

1 can coconut milk

4 cans of evaporated milk

½ teaspoon ground cinnamon

½ teaspoon of chopped ginger

½ teaspoon ground allspice

½ teaspoon vanilla extract

4 tablespoons shredded coconut (optional)

1½ cups of Bacardi or Don Q Cristal rum (optional)

Instructions

In a blender, puree all the ingredients.

- Pour into a bottle and add 2 cinnamon sticks.
- Chill for at least 4 hours before serving.
- Store in an airtight container in the refrigerator for up 6 weeks. Shake vigorously each time before serving.



Coquito is a traditional Christmas drink that originated in Puerto Rico. The coconut-based beverage us similar to eggnog and is sometimes referred to (incorrectly) as Puerto Rican eggnog, but coquito does not have eggs.

PUERTO RICAN HOLIDAY MENU

The classic holiday menu consists of rice with pigeon peas, roasted pork, and pasteles (tamale-like green plantain and meat empanadas). Sides may include potato salad or elbow salad.

Arroz con gandules, or rice with pigeon peas, is the traditional main dish served in all family celebrations including the holidays.



ARROZ CON GANDULES Ingredients

3 cups of medium grain rice (or preference)

3 cups of water

1 can of gandules (pigeon peas) drained

1/2 cup cured salted pork chopped

1/3 cup of vegetable oil

1/2 cup of sofrito (blended onions, peppers,

cilantro, garlic)

6 oz tomato sauce

1 packet sazon

1/4 cup spanish olives

Instructions

 Add the vegetable oil to the caldero (pot) and set the stove heat to medium. Toss your chopped cured salted pork into the pot and cook until fried.

2. Add the sofrito, tomato sauce, Sazon, and Spanish olives.

3. Cook and stir the mixture for 3 to 4 minutes.

4. Add the water and salt.

5. Rinse the rice and add it to the caldero; stir everything gently.

6. Cook for 30 minutes over medium heat without opening the lid at all.

7. Salt to taste.



Traveling Tips for Families of CYSHCN

Planning for a Winter Vacation

The winter season is a fantastic time for families to plan a vacation. People who live in cold states plan vacations to visit warmer states, and those living in all-year warm states travel to experience the snow and the beauty of the cold frozen rides and white mountains. Whether you pack skis or a surfboard, consider experiencing winter as a season to enjoy with the family.

Families of medically complex children can have a great vacation experience if they plan with enough time to prepare children and the whole family. Planning a vacation should not be stressful, if planned with enough time. There are many priorities on your list, and it is very important to balance the needs of your child and your family. Begin with the basics; ask your family about what kind of activities they would enjoy, include them in sorting a list of destinations, and start planning.

STEPS FOR PLANNING AN UNFORGETTABLE VACATION WITH THE ENTIRE FAMILY

- 1. Make a budget. A budget will help you know how much you can afford, and this will determine if this will be a road trip to the next town or plane travel to a faraway place.
- 2. Use the budget to estimate how far you can travel, destination, tickets to attractions, transportation, length of vacation, hotel, and food costs.
- 3. Make a list of places based on the activities preferred by your family. Ask friends and relatives for suggestions and feedback from places they have already gone.
 - Online reviews use apps like Yelp, Google Maps, booking.com, and others to learn from others' experiences. Feel free to post questions that will help you decide.
 - Location and area search for safety,



distance from hospitals, pharmacies, malls, airports, and attractions. Ask your phone/ internet provider about the coverage in the area.

 Hotel – Find out what kind of accommodations are available for your child and family. Confirm the type of room, accessibility, closeness to the elevator, wheelchair accessibility, and whether you prefer a lower or higher floor. Check parking and costs per night. Communicate your preferences and needs to the staff when booking your hotel.

4. Organize the list from most to least preferred. Narrow the list down to your top three, based on the budget and your research.

By Air or on the Road

If you are traveling by plane, call the airline to find information around accommodation, carrying supplies and devices, wheelchair access, equipment or any other concern. Notify the airline about your child's needs. If you are renting a car, be sure that the car you reserve has space for your child's equipment and supplies and your family's luggage. Decide if you will need a shuttle.

PLANNING ACCOMMODATIONS

If your family is going to any attraction, contact them in advance to ask what kind of accommodation is available for your child's needs. Many parks and children and adults who are medically complex. Connect with the staff to get more information about the services provided.

If you need to bring specialty food or formula, please let the staff know because there are many places where outside food is not allowed. They can help you coordinate to bring your child's preferred food.

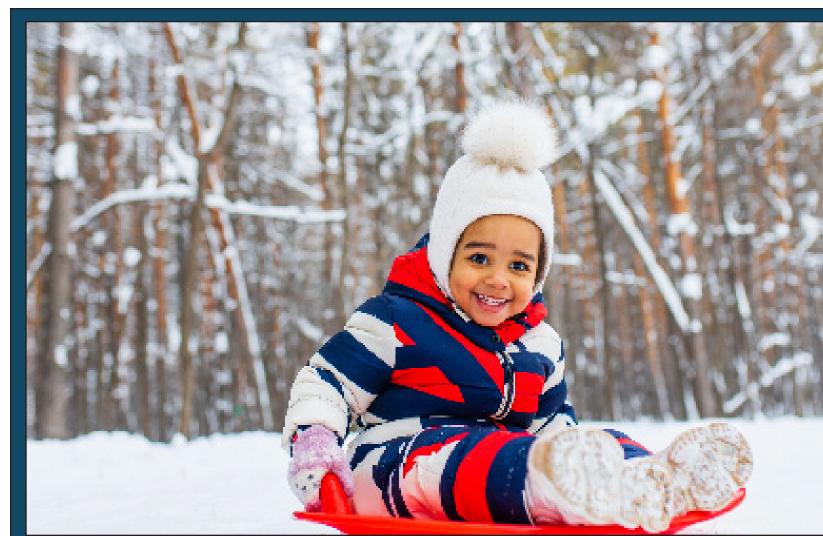
HANDLING UNEXPECTED DELAYS

Traveling during high season can include some unexpected experiences like losing your bags and/ or changes in the travel plans. Prepare for delays and organize a carry-on bag that includes the most important items for your child.

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Include your child's favorite toy, iPad, phone, or any video game device. Consider bringing toys that will keep your child calm without the need for internet. Bring extra clothes, diapers, a blanket, socks and comfort shoes, along with snacks, drinks, formula, and water. Don't forget medicine, supplies, and bandages, as well as your child's medical card, doctor's contact information, and emergency contact information.

Vacations can take months of preparation, and traveling with medically complex children can feel like a lot of pressure. Even if there are many things to prepare in advance, the outcome will be worth it.





The Harms of Fatphobia during the Holidays and Its Impact on Mental Health

mav Vega Grants and Contracts Manager at Family Voices

My favorite thing about being Puerto Rican is the way we love through food. There is nothing more comforting than preparing holiday specials for your loved ones like lechon, alcapurrias, pasteles, and in our home, mac and cheese and yams. However, the joy of feeding our families often comes with the pressure of having the perfect body. Our mamas, tías, and cousins exposed to harmful beauty standards and expectations want thinness for all of us, regardless of the cost.

The holiday season is a time for joy, celebration, and togetherness. However, for many individuals, the holidays can also bring an undercurrent of stress and anxiety, multiplied by societal pressure to conform to unrealistic beauty standards and ideals. This pressure, often referred to as fatphobia, can have a profound impact on mental health. The harms of fatphobia during the holidays can affect mental well-being.

UNDERSTANDING FATPHOBIA

Fatphobia is the irrational fear or hatred of fatness and those who are perceived as overweight or obese. It manifests in various ways, from teasing and bullying to discrimination in various aspects of life, including employment and healthcare. During the holiday season, this toxic mindset can be particularly pronounced. The pervasive images of thin, attractive models in holiday advertisements and media coverage can reinforce the idea that being thin is a prerequisite for happiness and acceptance.

THE HOLIDAY SEASON AND BODY IMAGE

The holiday season, with its emphasis on food and gatherings, can trigger complex emotions in

individuals who experience fatphobia. For those already struggling with body image issues, the holidays can be a time of heightened anxiety. The holidays often revolve around abundant meals and special treats. While indulgence is a natural part of the holiday spirit, fatphobia can push individuals into the toxic grip of diet culture. They might feel the need to restrict themselves, leading to feelings of deprivation and guilt. These moments of "Should I grab some mac and cheese, or should I get an extra plate?" get intensified by the side eyes and small comments of "Mami, you look like you put on some weight; aren't you watching what you're eating?"

The constant pressure to conform to idealized body standards can lead to negative self-perception. Individuals may feel ashamed of their bodies and unworthy of enjoying the festivities. For individuals with eating disorders, the holiday season can be particularly challenging. The focus on food and family gatherings can make disordered eating behaviors worse, leading to both physical and psychological harm. Fear of commentary on their bodies, the way they eat, or how healthy other family members look in comparison, may cause some family members to opt out of attending family celebrations, intensifying the feelings of loneliness that can come with the holiday blues. The anticipation of holiday gatherings or the fear of judgment can result in higher stress and anxiety levels. The constant worry about how one looks or what they eat can overshadow the season's joy. However, the holidays don't have to be this way, and you can make sure your friends and family members of all sizes can feel safe and welcome in your homes this season.

BREAKING THE CYCLE OF FATPHOBIA DURING THE HOLIDAYS

To combat the harmful effects of fatphobia during the holiday season, it's essential to raise awareness and promote acceptance and inclusivity. Here are some steps we can take to make the holidays more enjoyable for everyone:

We don't have to talk about our bodies. It is a norm and usually accepted that we have conversations about everyone, we get nosy and indulge in chisme. This year keep the conversations about what people are achieving, succeeding in, and if they're happy, and if someone mentions body size, keep the conversation moving in another direction.

Rather than promoting fad diets or excessive exercise, focus on well-being and self-care during the holidays. Promote balanced and healthy relationships with food and exercise. If you care about your family's physical well-being, instead of targeting family members and providing commentary (they didn't ask for) offer a predinner walk, play Nintendo sports on Switch, or break out the Wii sports for nostalgia's sake.

If you are concerned about health, be concerned for everyone's health. If we discuss health during the holidays, make sure all your family members feel like they are a part of the community, they make meaningful contributions to the family, and that everyone has what they need to feel physically and mentally their best.

Fatphobia during the holidays is a pervasive issue that can have a significant impact on mental health. The pressure to conform to unrealistic body standards, along with the focus on food and gatherings, can trigger anxiety, depression, and social isolation. Remember, the size of one's body does not indicate their health - your fat cousin may be perfectly healthy while skinnier family members struggle with sickness.

To break the cycle of fatphobia, it is crucial to promote conversations that do not center on body size, reject diet culture, foster inclusivity, and support all your loved ones' mental and physical health. By taking these steps, we can create a holiday season that brings joy, celebration, and togetherness for everyone, regardless of their body size.



Closing Gaps and Building Bridges in Autism Services

I began working with the Hispanic community in 2017, when I dedicated myself to advocating for their needs and providing essential Spanish interpretation and translation services. I have actively engaged with families in the school environment, serving as an interpreter during Individualized Education Program (IEP) meetings. This valuable experience has given me firsthand insight into the specific needs of families navigating the educational and health care systems and seeking support for their children. It also allowed me to develop a deeper understanding of the unique challenges faced by Spanish-speaking individuals and families.

It is my genuine passion to empower the autistic community. My experience of working extensively within under-served and minoritized communities has allowed me to witness firsthand the challenges that parents encounter while navigating the complex issues that come with raising a child with autism. These hurdles come from cultural factors, language barriers, limited access to information and resources, and the way society and family members view autism.



COMMON BARRIERS FOR UNDER-SERVED AND MINORITIZED COMMUNITIES

Lack of Awareness and Understanding

When there is more awareness or understanding of autism within a community, children may be identified earlier, and the signs of autism may be noticed early. Parents who are familiar with the developmental milestones can better understand behaviors associated with autism.

Stigma and Cultural Beliefs

Cultural stigmas and beliefs about disabilities, including autism, can create barriers for parents. Parents might look for help or talk about the diagnosis more when they don't fear judgment or stigma from having a child with a disability.

Language Barriers

Language access services can make it easier for parents to get information, communicate with health care professionals, and participate in their child's education. This can help parents feel empowered to advocate for their child's needs.

Limited Access to Culturally Relevant Resources

Information about autism, interventions, and available services should be available in people's preferred language. Autism resources and support services should also show an understanding or connection with their culture.

Navigating the Healthcare System

The healthcare system can be complicated, and families can have an easier time understanding the diagnosis process, treatment options, and available services when information is provided in their preferred language.



Michelle Mejia is the Spanish Helpdesk Coordinator and Outreach Support at Milestones Autism Resources in the vibrant city of Warrensville Heights, Ohio, a suburb of Cleveland. Her role involves connecting families navigating autism to vital resources, including doctors, therapists, and educational supports. She is also the only Spanish-speaking individual who serves as a Charting the LifeCourse Ambassador in Northeast Ohio.

Educational Disparities

Parents may experience disparities in the educational system, such as a lack of culturally competent educators or support staff.
Understanding the special education process and advocating for appropriate services can be less challenging in a system that addresses cultural differences.

Financial Limitations

The cost of therapies, interventions, and specialized education may affect whether families can access support services.

Social Isolation

Parents of children with autism from minoritized communities may experience social isolation. Understanding and support from friends, family, or community members can reduce feelings of isolation.

Cultural Mismatch in Service Providers

The cultural mismatch between service providers and families can create challenges in effective communication and collaboration. Better cultural competence among professionals may lead to better understanding and family engagement.

Multiple Cultural Identities

Parents may find themselves navigating more than one cultural identity and balancing the expectations and norms of their cultural background with those of the mainstream culture. This balancing act can be emotionally and psychologically demanding.

Limited Representation in Advocacy and Support Groups

The participation of minoritized families in autism advocacy and support groups can help contribute to more culturally relevant information, opportunities for mentorship, and a sense of community for parents.

PROMOTING CULTURAL COMPETENCE

To address these barriers, it is crucial to promote cultural competence among healthcare professionals, educators, and service providers. Families can request information in their preferred language. They can also encourage providers to offer culturally sensitive support services and actively involve diverse families in decision-making processes to help break down these barriers and improve the overall well-being of families raising children with autism.

Every family deserves equal access to support and resources necessary for their journey. Through ongoing collaboration with community organizations, I aim to break down these barriers and foster an environment where every individual, regardless of their background, can thrive within the autism community.

As I continue this meaningful work, I am driven by the vision of a more inclusive and supportive future for all. Each connection made, each resource shared, is a step towards creating a stronger community that celebrates diversity and embraces the unique strengths of every individual touched by autism.

Together, we can close gaps and build bridges toward a more understanding and compassionate world.



Network Spotlight: Serving Families at Raising Special Kids

Paulina Serna Certified Family Support Specialist, BHT, Development Associate Raising Special Kids

I am the parent of three kids - two girls, and one boy. My son was born with Spina bifida and Cerebral Palsy. He is now 15 years old and in high school. We have overcome many challenges, and I am happy to say he is doing great and enjoys traveling.

ABOUT RAISING SPECIAL KIDS

I have worked at Raising Special Kids for ten years, contributing to the development of procedures for families of infants and toddlers. She is actively involved in various organizations, including the Alliance for Children and Youth with Unique Challenges. Proficient in English and Spanish, Paulina serves as a Parent Advisor for the Arizona Department of Health Services. Recently, she joined Raising Special Kids' Positive Family Coaching team, helping families with children receiving behavioral health services. Paulina finds fulfillment in bringing happiness and hope to families, drawing from her own experiences and genuine passion for work.

Raising Special Kids is a parent-led organization that provides support and information for parents of children with disabilities and Special Health care needs. We teach parents how to effectively advocate for their children, provide parent-to-parent support, and facilitate trainings on different topics like Understanding IEP, Turning 18 Legal Options, Triple P and recently we added our positive family coaching program in which we provide a higher level of support to families navigating the Behavioral Health system.

All trainings are available in Spanish, we have bilingual staff, social media in Spanish, our website has resources in Spanish, and we also partner with other organizations to expand our reach to the Latino community.

It's hard for me to identify one typical issue presented when working with families because we serve families of children from newborn to adults and our services range from parent-to-parent connections, Special education training, finding a provider to connecting with community resources.

SUCCESS STORY

I'm delighted to share that our work with families has resulted in numerous successes. A recent example involves a Spanish-speaking parent who sought our assistance during a period when they felt unheard, lacked respect, and believed their child's medical needs were not being addressed by the physician. Additionally, they faced challenges in communicating with the school and navigating the complexities of the special education process.

During our collaborative efforts over the course of a year, this family not only found their voice and inner strength but also acquired the skills necessary to navigate and comprehend the special education process. They successfully mastered the ability to advocate for both their child's medical and educational needs. The outcome of our year-long collaboration was truly heartening – a significant improvement in the child's life.

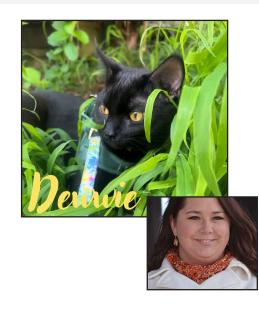
Connection to Lived Experience

I've dedicated 10 years to the organization, forging connections with families through shared lived experiences. My passion for this work runs deep because it holds personal significance for me. Providing support to families, whether through peer-to-peer assistance, conducting training sessions to guide them through complex systems of care, or simply being a comforting presence when they grapple with fear, uncertainty, or daily challenges, is immensely meaningful. This role is not just a job; it's a heartfelt commitment.















Learn more about Raising Special Kids at raisingspecialkids.org



An Unstoppable Gift Called Mya

By Angela LaManna - Mya Grace's Mom

Eight years ago, the universe gifted me the unstoppable force that is Mya Grace, born in November and ready to take on the world. As an attorney and a single Mom facing a prenatal diagnosis of Down Syndrome, I dived into a sea of research and preparation. Little did I know, the concept of early labor was lurking in the shadows, and before I could say "Thanksgiving turkey," we found ourselves celebrating her first holidays (yes with an "s" Thanksgiving, Christmas and the New Year) in the NICU, with Mya weighing in at a whopping 1lb 11oz after deciding to make her grand entrance three months early.

Fast forward through a whirlwind of 20 medical diagnoses, 10 surgeries, and countless specialist visits—Mya Grace is a living testament to the power of perseverance, with a dash of "Grace." Google the meaning of Mya, and you'll find a list longer than her favorite Disney movies. From *fighter* to *beloved*, she embodies them all, turning every day into a celebration.

DAILY CELEBRATIONS

Living with Mya is like a non-stop celebration, we sing, we dance, and we hug daily, transforming our home into a lively party reminiscent of Poppy Troll's world. Birthdays, whether hers or yours, are extravagant affairs, complete with music, decorations, and, of course, presents galore.

Naturally, her second favorite holiday after her own birthday is Christmas, the ultimate feast of gifts, decorations, and, you guessed it, more presents. Our annual traditions, some courtesy of the Down Syndrome Association of Delaware, from Breakfast with Santa to Christmas Train rides and our special one Disney on Ice, are etched in the holiday magic that defines the season.

FAMILY CONNECTIONS

Beyond the festivities, Mya's heart beats for family, especially her Mom-Mom and her partner in crime—Pop-Pop. Their bond is so unbreakable that sometimes I wonder who's the boss and who's the child when they're together.

Living life at Mya's pace demands patience and strength, but the joy and happiness she brings are immeasurable. I may have given her life, but in return, she's given my life profound meaning.



PEALS LANGUAGE ACCESS

If your preferred language is not English, you have a right to translation of medical documents and interpretation when you visit health care providers.

Learn more about language access services and download free resources to help you access these services at **familyvoices.org/languageaccess**.

