

Family Voices

EN ESPAÑOL

Magazine



FAMILY VOICES®

Family Voices En Español Magazine Team



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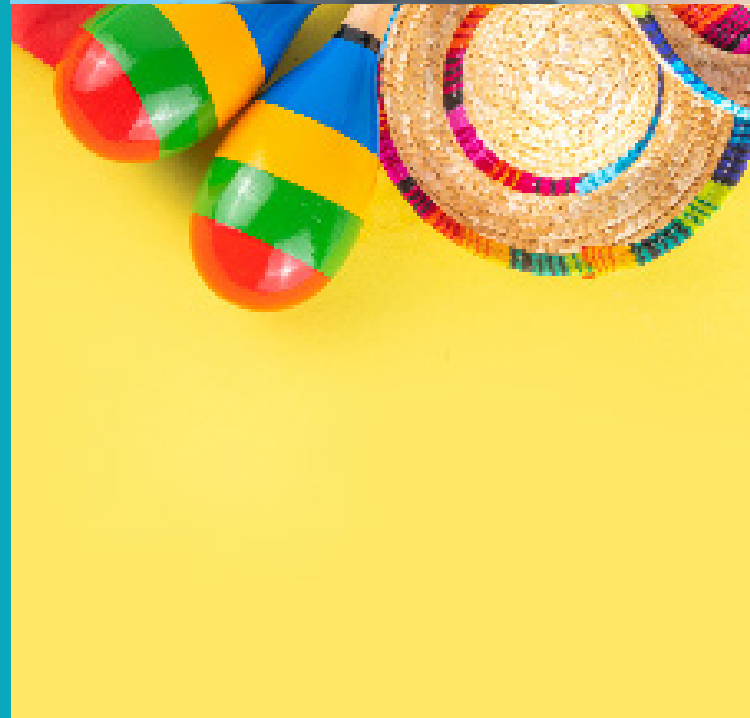


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"Health equity has become a broad, widely used concept that focuses on making sure we make changes for marginalized populations and undo decades of ongoing oppression. We have to make sure that fighting oppression is always a priority because we don't have decades to make sure that families see real change within their lifetimes."

- Steph Lomangino, Family Voices Program Strategy Manager

A Dad's Perspective on Engaging Fathers



Edgar Gamba

Cultural Broker
Latino/a/X Communities
Center for Family Involvement
Virginia Commonwealth University VCU

I come from a beautiful tropical country in South America, which has coasts on the Atlantic and Pacific Oceans, surrounded by the incredible mountains of the Andes and the beautiful Amazon River, a country with the world's softest coffee and the most precious and valuable emeralds in the world, the land of Gabriel Garcia Marquez, and birthplace of Shakira. I am proudly Colombian.

In my role as a cultural broker serving the Latino community of people with disabilities, both in Virginia and nationwide through other non-profit organizations, I have seen a common issue in our culture - the low participation, involvement, and support of Latino fathers in families with kids with special health needs. It is often the mother who is in charge of almost all activities and tasks when it comes to children with physical or developmental disabilities.

The beauty of family

One of the priceless rewards in my career of supporting people with disabilities is seeing how families find their ways to advocate for the well-being of their loved ones with special health care needs. I am a witness to how families rebuild their lives and dreams after having received discouraging diagnoses that affect the future of the children.

It is very rewarding to see how Latino families commit to working together (parents, children, siblings, grandparents and other family members) around a person with special health care needs, and step by step see those families rise from the ashes. I enjoy seeing them develop the goals they have proposed for their beloved children. It is priceless to see the smiles of these children and young people reaching their goals, as well as the families who find the light on the other side of the tunnel.

Barriers to Engaging Fathers

Growing up in a Latino family is a symbol of strong, lasting roots and social pride.

Latino fathers have a lot of traditional values about family. Latino fathers are the family leaders who provide financial support as providers of well-being and have great love for their wives and children. Engaging fathers with organizations that serve children with special health care needs is a not always a simple task. They are often absent for many complex reasons, including cultural, socioeconomic, family and legal nuances.

Gender roles are established by society and culture within Latino family tradition. The role of each gender still has a lot of influence, with

the man being the one who provides financial well-being and the woman who provides social and family well-being.

Latino Fathers participating in the lives of children with special health needs may feel socially isolated, feel embarrassed by their children's behavior in public, or feel guilt over the false feeling that they may be responsible for their children's challenges.

Economic challenges are one of the most common reasons that fathers are less involved with the family and children with special health needs. The stereotypical Latino father is the leader and main provider of the family, so work does not leave time for him to engage in the care and attention of their children with special health care needs.

Physical and mental exhaustion, and the stress in families with children with special needs, are significant, largely affecting mothers closest to caring for children with disabilities. This phenomenon can create family tensions between couples and among other family members.

Beyond gender roles, there are very common traumatic events in the lives of families, such as divorce, separation, the absence of the father due to work location (temporary moves), debts and financial problems, all of which can harm family functioning.

The lack of engagement of divorced or absent fathers with their disabled children is another factor. Legal separation can prevent fathers from sharing quality time with their children and participating in their health, well-being activities, and care tasks.

Latino fathers participating in the lives of children with special health needs may feel socially isolated, feel embarrassed by their children's behavior in public, or feel guilt over the false feeling that they may be responsible for their children's challenges. Fathers may also experience frustration over the difference between the parenting experience they are having and the one they had imagined, despair due to the irreversible nature of a health condition, or even resentment of their child and anger towards themselves, doctors and spouse.

Among the other situations that may highly affect fathers' engagement is immigration status. Migrants are a highly vulnerable group, due to legal situations that represent structural inequalities. This leads to differences in access to state resources and services. There are also cultural stigmas about migrants, such as prejudice, xenophobia and racism, which make it difficult for migrants to integrate into society. Many Latino immigrant fathers do not request services for their kids because of their fears surrounding their legal status. Those who are permanent residents of the US and have green cards are often afraid that using services for their children will jeopardize their opportunity for citizenship.

Continued on the next page

A Dad's Perspective on Engaging Fathers (continued)

Lastly, the lack of information and education for fathers about the special health needs of their children limits fathers' engagement. This widely impacts the low awareness and engagement of the father figure in the family structure.

Finding solutions for engaging fathers

As an advocate, I want to be able to help to close the gap of these disparities, creating a positive environment for access to services, information, support and intervention to empower parents and families. As a Latino father with a child who has special health care needs, I got involved in advocacy many years ago, and I convinced myself that working hard works.

Unity and unconditional love within the family are essential factors to successfully navigating the hardships of raising a child with any disability. Positive family relationships have a positive effect on the behavior and well-being of a child. Overcoming health and behavior challenges requires a consistent approach from both parents, who must support and care for each other. It's plain to see that some parents who have a child with a disability grow strong as a family, while others grow apart over tensions.

Raising awareness and educating fathers about participation in the health and development of their children with special health care needs is a good first step. It's important for fathers to be informed about

laws and regulations that legally protect kids with disabilities and to advocate for their rights. Knowledge about disability and everything related to their child's care can help fathers to identify the potential, abilities, and capacities of their children. Fathers can also be encouraged to connect with the community to take advantage of the resources, services and support to face both positive and negative situations.



Keeping Covered!



Diana Autin

Senior Director for Organizational Capacity-Building for the SPAN Parent Advocacy Network (SPAN)

Keeping Covered!

Medicaid is the single most important health insurer for our nation's children with special healthcare needs (CSHCN), especially those with complex medical conditions. Over 35% of children, and over 50% of CSHCN, are covered at least in part by Medicaid or the State Children's Health Insurance Program (SCHIP). Having health coverage means that children can access the primary care, immunizations, prescriptions, screenings, therapies, and specialty care that they need. Without that health coverage, access to health care is limited and children's physical and mental health suffers.

What is Medicaid unwinding?

During the COVID pandemic, states were provided with additional resources from the federal government to maintain all current Medicaid recipients without going through redeterminations of eligibility. Now that the public health emergency has ended, states must determine continued eligibility for everyone covered by Medicaid. This is called "Medicaid unwinding."

The Centers for Medicare and Medicaid Services (CMS) requires states to make

all reasonable efforts to locate, notify, and determine eligibility for all potentially eligible children and families. They must provide reasonable accommodations for people with disabilities and provide language access for individuals whose preferred language is not English proficiency.

How is the unwinding going?

States had a lot of flexibility in how to deal with the redetermination process. Some sent letters to mailing lists that often were not updated during the pandemic, leading to the removal of some families from the program because they had moved. Few states took the recommended approach of using existing income tax data or other data sources such as eligibility for WIC (Women, Infants and Children program) to determine continued eligibility.

Unfortunately, in too many states, efforts to locate, notify, and determine eligibility for all potentially eligible children and families have not been sufficient. Across the US, as of March 26, 2024, 32% of Medicaid enrollees have been disenrolled (19,156,000 individuals). Nearly 70% of these individuals,

Continued on the next page

or more than 13.4 million people, were disenrolled for procedural reasons. That means that they were disenrolled not because they were no longer eligible, but because they either never received the re-enrollment information, they didn't understand the information (because it was too complicated or wasn't in their language), or they did not submit the necessary documents in time. There is significant racial inequity in disenrollment. You can find out what is happening in your state or territory by going to <https://www.kff.org/report-section/medicaid-enrollment-and-unwinding-tracker-overview>.

Inequities in the unwinding

A study published in the Journal of the American Medical Association Health Journal found that African Americans were over 10% more likely than Whites to be disenrolled, and Hispanics were nearly 20% more likely to be disenrolled, while Native American and Alaska Natives were more than twice as likely to lose coverage. Unfortunately, most states do not report disenrollment data by race, ethnicity, or language.

Several national advocacy organizations have filed complaints about the lack of disability and/or language access in Medicaid unwinding, such as the National Health Law Project and Unidos US. Many families who speak languages other than English report that the Medicaid hotline in their state is not available in their language, there are few if any individuals

at the Medicaid office who speak their language, and the information that was sent out to them was only in English. One study of Medicaid enrollees with limited English proficiency (LEP) in Illinois found that respondents were over five times as likely to lose their Medicaid benefits as English-speaking respondents. The majority of respondents reporting difficulty understanding the Medicaid renewal documentation and felt that completing the renewal form was difficult or very difficult. Nearly half reported limited awareness of the redetermination process.

Efforts to improve on unwinding issues

In response to the large numbers of individuals who have been dropped from Medicaid due to procedural reasons and not ineligibility, CMS issued a new regulation aimed at making the Medicaid, Children's Health Insurance Program (CHIP), and Basic Health Program application and renewal processes simpler. The regulation requires states to take proactive measures to contact applicants and enrollees, resolve information discrepancies, and minimize automatic terminations, so that eligible people continue to be enrolled. It establishes clear processing timelines for changes in circumstances, transfers between insurance affordability programs, redeterminations of eligibility, and new applications. It also extends consumer protections from the Affordable Care Act to Medicaid and CHIP enrollees, like banning lifetime limits and waiting periods. This new

rule takes effect at the beginning of June, 2024.

Children are also protected from losing coverage once they are re-enrolled thanks to a new law that keeps eligible children on Medicaid covered for at least a full year before needing to renew their coverage. (See <https://aspe.hhs.gov/reports/increased-childrens-coverage-continuous-eligibility-expansion>).

CMS issued a new regulation aimed at making the Medicaid, Children's Health Insurance Program (CHIP), and Basic Health Program application and renewal processes simpler

Getting help in your community

If you or your family members, friends, or other community members, need help with maintaining your Medicaid coverage, contact your state Medicaid agency, which should have individuals that can provide the help you need. If you have a child with special health care needs, contact your Family to Family Health Information Center! You can find your F2F at familyvoices.org/FELSC. You can find lots of resources at familyvoices.org/unwinding. Get covered and stay covered!



Don't Lose Your
Medicaid Coverage

Medicaid Unwinding: Supporting State Efforts

The needs of families have increased due to the ending of the COVID-19 public health emergency. Family to Family Health Information Centers (F2Fs) and Family Voices Affiliate Organizations (FVAOs) benefit from their staffs' increased understanding of the public health unwinding needs of CYSHCN in their respective states. Family Voices developed targeted technical assistance on the public health unwinding for these organizations to meet the needs of children with special health care needs (CYSHCN) and their families in each state.

Find resources from our Stay Covered! Academy at:

familyvoices.org/unwinding

Partner Profile: The Arc's National Center on Criminal Justice and Disability



Family Voices and our core partners at the Center for Transition to Adult Health Care for Youth with Disabilities worked with The Arc's National Center on Criminal Justice and Disability to learn more about the needs of youth with intellectual and developmental disabilities who have been in detention facilities.

What we know about youth with IDD in the juvenile justice system

- An estimated 33% of youth and young adults who are in detention have an intellectual or developmental disability (ID/DD) (Quinn et al., 2005).
- While in detention, they face barriers to adequate care, including inadequate health histories, lack of subspecialty care, and an insufficient number of providers (Perry & Morris, 2014).
- Upon release, follow-up of medical and psychological care is often neglected (Society for Adolescent Medicine, 2000) due to lack of access to health insurance (Golzari

& Kuo, 2013) and primary care in their community (Feinstein et al., 1998).

- Youth and young adults who have been in detention are at increased risk of poor health outcomes, including shorter life expectancy and worse social functioning (Massoglia, 2008).
- 85% of youth and young adults who were previously in detention report not seeing a health care provider after release (Golzari & Kuo, 2013).

We conducted key informant interviews and surveys to learn about the health care transition needs of youth with ID/DD in detention. We used the information from the interviews and surveys to develop an info brief for juvenile justice facilities, health care providers and youth with IDD to learn about the health care transition process. We also held

Continued on the next page

Partner Profile: The Arc's National Center on Criminal Justice and Disability (continued)

a webinar called "Pathways and Pitfalls: Helping Youth with IDD in the Juvenile Justice System Move to Adult Health Care" in English and with Spanish interpretation. We also developed recommendations for youth and families, juvenile detention center staff, and health care providers, which are available at familyvoices.org/healthcaretransition/resources/.

Josh Branch, Attorney and Program Manager at The Arc's National Center on Criminal Justice and Disability, was a key leader in this work. Here's what Josh shared about his personal connection to the work.

I first became interested in juvenile justice work as a special education teacher. As a teacher I saw my students regularly have School Resource Officers called on them. They would be arrested and that would start their juvenile justice system contact. I think of my students when I think of the population I serve. I also think of my family members, as I am half Black and half Puerto Rican. We are overrepresented in the juvenile and criminal justice system, and



Josh Branch
Attorney and Program Manager at The Arc's National Center on Criminal Justice and Disability

therefore, this work is personal to me and my family.

There is little to no research on youth with intellectual and developmental disabilities in the juvenile justice system and how their health care transition needs are handled. However, we know that youth with cognitive disabilities or those enrolled in special education courses make up a big proportion of children in it. By shining a light, we can hopefully call to detention staff to better account for their health care needs.

In conversations with juvenile justice staff, one thing I heard with regularity was that Hispanic/Latino staff are hesitant to have contact with U.S. governmental systems, especially if they are undocumented. There is also regular confusion due to language barriers or information is not provided by an interpreter. Our report shows that juvenile detention staff need to make better inroads and build trust with the Latino community so that they can be seen as a bridge to assistance. Of course, that is

There is little to no research on youth with intellectual and developmental disabilities in the juvenile justice system and how their health care transition needs are handled.

hard to do when juvenile detention staff are perceived/coming from a place of law enforcement authority.

I want to continue researching how the juvenile justice system communicates with other governmental systems (health care, education, social benefits). In our report we found, unsurprisingly, that a lot of the times these government agencies do not communicate well with one another. The

result is that children's treatment services get disrupted. If we can find a better way to have these systems communicate with one another automatically or seamlessly then we can work against having breakdowns in treatment plans and work against recidivism.



catch the replay

Pathways and Pitfalls

Helping Youth with IDD in the Juvenile Justice System Move to Adult Health Care

Funded by the WITH Foundation

Speakers



Josh Branch
The Arc's National Center on Criminal Justice and Disability

Panelists



Peggy McManus
The National Alliance to Advance Adolescent Health



Caleb Alford
The Arc of the Capital Area



Johnitha McNair
Exec. Director, Northern VA Juvenile Detention Center



Jeremias Silva
Valencia County Grants Director

Moderator



Nikki Montgomery
Family Voices National





Moving Towards Disability Justice



Steph Lomangino
Program Strategy
Manager at
Family Voices

July is Disability Pride Month. This month and every month, it is important we promote the visibility of disabled people in the United States and make sure that disabled people are included in ways that are meaningful for them. Despite progress, ableism still shows up in our everyday lives and decenters the needs and experiences of those with disabilities.

Talia A. Lewis, a community lawyer and disability justice advocate, defines ableism as a “system of assigning value to people’s bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness.” Our 9 to 5 work schedules and strict rules about how to dress, behave, and work are examples of this. Ableism goes beyond our interactions with individuals; it is built into our schools, hospitals, public spaces, and other institutions. Because of this, disabled people are often treated poorly by non-disabled people as well as the systems that claim to serve them. Like racism, sexism, or other forms of discrimination in the United States, ableism is everywhere. Our society



mav
Grants and Contracts
Manager at Family
Voices

normalizes ableism so that disabled people are seen as “less than.”

Ableism shows up in many ways that we might not even recognize. For example, we may misuse disability terms in our everyday language in ways that mock or minimize a disability. Many people expect children with disabilities to learn in separate school environments from their peers. We hold events in places that are not accessible for people who use wheelchairs and other movement aids. We promote panels and speaking engagements without captions so those who are deaf, disabled, or hard of hearing cannot access them.

Beyond the ways people think about disability, our systems deny disabled people opportunities to live whole, healthy lives. This includes the healthcare system, the education system, the housing system, the legal and prison systems, and more. Race, gender, income level, and geographic location all affect how someone with a disability is treated. For example, Black disabled people face a higher risk of experiencing police violence; one-third to one-half of police use-

of-force incidents involve a person with a disability. In prisons over 40% of people who are incarcerated are disabled, even though the population of people with disabilities in the US is 27%. Disabled women and trans people also have difficulty accessing reproductive care, including preventative screenings and maternal health services.

For disabled people to live full lives that are free from ableism, discrimination, and

Beyond the ways people think about disability, our systems deny disabled people opportunities to live whole, healthy lives.

harm, we must focus on centering disability justice. Sins Invalid, a disability justice-based performance project, defines a disability justice framework by the following principles:

- All bodies are unique and essential.
- All bodies have strengths and needs that must be met.
- We are powerful, not despite the complexities of our bodies, but because of them.
- All bodies are confined by ability, race, gender, sexuality, class, nation-state, religion, and more, and we cannot separate them.



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Moving Towards Disability Justice (continued)

A disability justice framework leads with an understanding that all oppressed people should fight together toward liberation and embrace the concept of interdependence. Mia Mingus, one of the founders of the Disability Justice movement, writes: “Interdependence moves us away from the myth of independence and towards relationships where we are all valued and have things to offer.” Interdependence rejects

the idea that disabled people are “dependent” on others or are a burden. We can begin this work by shifting our own thoughts and beliefs to value the knowledge, contributions, and imaginings of disabled people. As Leah Lakshmi Piepzna-Samarasinha tells us, we can imagine, and create, a disabled future together. We must protect and care for one another, especially when our systems fall short.

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From Allysa's Desk



Dr. Allysa Ware
Executive Director
Family Voices

Family Voices mission is to transform systems of care to work better for all children and youth, especially those with special health care needs or disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes. Language access is critical to centering the voices and experiences of families across the country.

We are excited about the release of the environmental scan report from the language access project funded by the Office of Minority Health. We heard from families, community health workers, medical interpreters, and providers about the strategies and challenges of getting quality language access services across the country. What we learned overall is that both health care providers and families need more information and education on how to use language access services in the health care setting. You can find the report and the executive summary at www.familyvoices.org/languageaccess.

We are developing a training series for families and community health workers about language access services in health care. The series will launch in fall 2024, and it is free. You can [sign up to receive information](#) about how to register for the training. We are also working with our partners at the American Academy of Pediatrics to train health care providers on using language access services.

In addition to our language access initiative, we are also in a partnership with New York University to understand and build a toolkit to help providers engage with families whose preferred language is not English. This work is being guided by a diverse community advisory board.

Ensuring that information and materials are clear, transparent, and accessible to any family is critical to building systems of care that work for everyone. Family Voices is committed to building the capacity of providers and the health care field to better serve all families with children with special health care needs effectively. These two initiatives are two ways that we are working to achieve our mission.


 The logo for Family Engagement and Leadership in Systems of Care (FELSC) features the letters 'FELSC' in a bold, sans-serif font. The 'F', 'E', and 'L' are light blue, the 'S' is orange, and the 'C' is red.


 The logo for Family Voices features the words 'FAMILY VOICES' in a serif font. A white heart is positioned above the letter 'V' in 'VOICES'. A registered trademark symbol (®) is located to the upper right of the word 'VOICES'.

familyvoices.org/felsc

Family Engagement and Leadership in Systems of Care (FELSC)

Family Engagement and Leadership in Systems of Care (FELSC) is a five-year grant funded by the Health Resources and Services Administration (HRSA). FELSC provides national leadership on family engagement to support youth and family leaders, Maternal and Child Health (MCH) programs, and other stakeholders that serve children and youth with special health care needs (CYSHCN). Year one activities included:

- A Learning Collaborative of families and organizational partners who explored topics about family engagement
- Family and Youth Engagement Workgroups that helped to develop a plan to learn about family engagement and how it works, and doesn't work
- An Environmental Scan that included finding resources and learning from others about defining family engagement

FELSC works with families, youth, and partner organizations to increase the impact of family and youth engagement and to support and develop the network of Family-to-Family Health Information Centers (F2Fs). F2Fs are family-led organizations that support families of CYSHCN. Family Voices' role as the technical assistance (TA) provider for the F2Fs includes goals for increasing their capability to engage diverse, underserved CYSHCN and their families in direct patient care, organizational design, and governance, along with increasing F2Fs' capability to collect, monitor, and report on family engagement data.

FELSC provides technical assistance and support to MCH entities and state Title V agencies as well as connecting F2Fs with state Title V agencies. FELSC provides TA and support to a network of 59 Family-to-Family Health Information Centers (F2Fs) that are in 50 states, 6 territories, and 3 tribal nations.

Creating the PATH to Leadership



Nanfi N. Lubogo
Co-Executive Director
of PATH CT

My name is Nanfi Lubogo. I am a mother of three beautiful young adults: Aaron, Stephanie, and Emily. I am a parent leader with 24 years of lived experience that has become expertise over the years and has informed my advocacy and work.

My personal connection to the work

Twenty-four years ago, my daughter Stephanie was born with medical complications that led to a diagnosis of Prader-Willi Syndrome, juvenile scoliosis, sleep apnea, and, in her teenage years, mental health concerns. Our lives were forever changed on that day in June. We had a beautiful baby girl, who we loved dearly, even as we learned that her diagnosis and disability would impact her life and ours forever.

My husband and I quickly learned all we could to support our daughter, and thus began my journey into advocacy in the disability world. We knew that for Stephanie to thrive, we needed to get involved and learn all we could to access supports and services.

We were incredibly lucky to have a wonderful social worker at the hospital who gave us

information about CT's Birth to Three Early Intervention program and about getting connected with a family organization named Parents Available to Help (PATH). Through our Birth to Three team, I attended trainings, met with other families, and began to educate myself about becoming a parent leader. I was a sponge, taking in every training opportunity and slowly finding my voice as an advocate. I was extremely fortunate to meet and be mentored by women who were leaders in the disability field.

My professional growth as an advocate

When my daughter was born, I was in college pursuing a degree in graphic design, but once I started volunteering, I knew I'd truly found my calling. I'd complete my associates later, but I knew I would spend many years giving back and supporting other families as I was once supported. That became my passion and my life's work, starting as a volunteer and leading up to a leadership role with PATH CT, the organization that was a lifeline for my family.

I serve as Co-Executive Director for PATH CT, a statewide grassroots family organization in Connecticut that is dedicated to connecting and empowering families, children, and youth living with disabilities or special healthcare needs through support, education, and advocacy. PATH CT has the support of the nation's four largest networks for families of children with disabilities and special healthcare needs. We are CT's Family Voices

Affiliate Organization, the Alliance Member of Parent to Parent (P2P) USA, and state chapters for Sibling Leadership Network and National YASA (Youth as Self Advocates).

Our staff and initiatives at PATH CT

We have a diverse staff, each with individual strengths in parent support, in healthcare as health information specialists, and as special education advocates. Together, we support over 1,000 families per year through our programs.

At the core of PATH CT's mission lies our Parent to Parent Support Program, a one-to-one matching service through which we connect parents with trained veteran parents who have "been there" and understand the challenges a newly diagnosed family faces. This training also includes an introduction to Charting the LifeCourse, an approach designed to help individuals with various abilities improve their lives by enhancing personal self-determination and independence throughout their lifespan. This forms the foundation of the support we offer to families through all our programs.

One of the initiatives we are deeply involved in and extremely proud of is the amplification of the work and advancement of Community Health Worker (CHW) certification and payment reimbursement within our state's legislation. Most of our staff are Certified Community Health Workers (CCHWs) licensed by Connecticut's Department of Health, with a few actively working toward certification.

Another significant initiative focuses on mental health, considering its impact on

many of our families, including my own and our team's. Connecticut has made substantial strides in expanding mental health services and improving access to care. The expansion of Medicaid services through the Affordable Care Act has facilitated the establishment of federally qualified health centers, which provide comprehensive mental health services accessible to individuals in their communities. This expansion not only granted access to many families who were previously unable to afford services but also broadened the pool of providers, ensuring that providers working in these centers are representative of the communities they serve.

At the core of PATH CT's mission lies our Parent to Parent Support Program, a one-to-one matching service through which we connect parents with trained veteran parents who have "been there" and understand the challenges a newly diagnosed family faces.

Additional improvements include the implementation of mobile crisis intervention units and the expansion of beds for inpatient pediatric patients, including a 12-bed psychiatric unit at Connecticut Children's Medical Center and at Yale New Haven Children's Hospital. Both centers collaborate with Connecticut's Emergency Medical Services for Children (CT EMSC) and local Pediatric Emergency Care Coordinators

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(PECCs). A PECC plays a pivotal role in coordinating pediatric care delivery, ensuring high-quality emergency care for children, and advocating for pediatric needs across all aspects of care (1). Through our partnership with CT EMSC, we are currently advocating for PECCs to collaborate with us and provide information to families with children in crisis seeking support from other families impacted by mental health issues.

Supporting the next generation of leaders

One of my greatest passions is nurturing the leadership skills of youth with disabilities. Our fundamental belief is that every individual is capable and should be provided with opportunities to contribute to the best of their ability. We facilitate this through our youth leadership program, CT KASA, tailored for youth and young adults aged 13-26. It is

incredibly fulfilling to witness each member finding their advocacy voice and using it to improve services for other young people.

As a leader and a Black woman, I am always mindful of my role and impact within the FV network. It has always been important for me to ensure that other parent leaders of color have access to the same opportunities I have had, both for their children and for themselves. I have had the privilege of serving on the Family Voices Board of Directors for several years, the last two as President, and now as Past President. Throughout my tenure, I have advocated for and created spaces for parent leaders of color. As a network, we still have much work ahead, and I am committed to continuing to push for and create opportunities for parents of color to assume leadership roles.

Buliding a Career of Service



Giannina López Pérez, Psy.D.
Coordinator PR-F2FC

I studied for a doctorate in Clinical Psychology at the Carlos Albizu University in Old San Juan, PR. During my fourth year, they offered for the first time an elective class about autism. I took it out of curiosity, and I loved it. When it was time for me to select an internship program, I was interested in the Autism Center of the Institute for Developmental Deficiencies (PR-UCEDD). I did my internship for one year and I confirmed my love for the population of people with special health care needs and disabilities. Once I finished the internship, they offered me a job at the PR-UCEDD, and I have been growing professionally and personally in this beautiful space for 11 years. This job has given me many opportunities to work with individuals with disabilities and has allowed me to train and lead in different areas.

My work and why I love it

I live in San Juan, Puerto Rico, and I say it with a lot of love. I am very proud of my homeland. I am the coordinator of the Puerto Rico Family to Family Center and the associate director of the PR-UCEDD, in charge of family engagement, interdisciplinary and clinical services.

What excites me most about my work? To be able to provide hope to families. In a place “country” where the systems are very deteriorated, I feel that we can provide families hope and help them reach outstanding achievements and, above all, have a better life. I love the feeling of helping and changing lives. Sometimes, we don’t stop to think how much of an impact our role or work has on other people’s lives. Being able to explain to my 7-year-old child everything we do, and seeing his admiration, has helped me see and understand what a fantastic and great job we do at each F2F.

My life outside of work

Free time? What free time? Haha! I have a 7-year-old boy and an almost 4-year-old girl. We love spending time together as a family. During my free time, I love to rest, take time away from the hustle and bustle of the week, and enjoy my children. We love to go to the pool, share time with friends who are like sisters, and, of course, go to the beach, which is one of our favorite activities.

Continued on the next page

My children are my inspiration for everything I do; watching them grow in a healthy way makes me a very grateful mother. I admire peer-to-peer support too much, and I have always said that my commitment to the special health care needs population is enormous. Still, I will never be able to compare my level of empathy with the matched parents and mothers. In August 2022, my son was diagnosed with Henoch Schlein Purple. Even though it is a condition that has a cure, we have been struggling for over a year to get to the cure. We experienced firsthand the Puerto Rico health system and the challenges our families face daily and sometimes throughout their lifespan. My admiration for all those families and caregivers has grown in a way I could never have imagined possible. I am grateful to God for the health of my children and to be able to hear them say “I love you mom!”

Finding meaning in my work

Working with families is my daily engine. I understand the impact of having a member of the family with a special health care need. For me, receiving each family at our center and being able to support them is a privilege because we know and understand their needs and how we can support and help them, and this is reflected in the lives of individuals with special health care needs. An empowered family, a stronger and united family, will result in better development and quality of life for the individual and the family.

I love the feeling of helping and changing lives. Sometimes, we don't stop to think how much of an impact our role or work has on other people's lives.

We are constantly advocating for Early childhood intervention. We work very hard providing workshops to professionals who work in early childhood to increase awareness and learning opportunities for families, to provide families with the knowledge of recognizing and identifying when a child is not achieving milestones, and to help seek for professional help. The evidence has shown the importance of early childhood intervention and how it can change the life of the child and their family.

As a US Territory, Puerto Rico has a lot of disparity. Individuals with special health care needs have fewer benefits, affecting their quality of life and their families'. This results in caregivers having to stop working to take care of their children with special health care needs, higher poverty levels, less access to services, and fewer opportunities for work and independent living, among other things. I would like the special health care needs population in Puerto Rico, as American citizens, to have access to the same opportunities as if they were living in the United States, so they would not have to leave the island and their families to look for better opportunities and services.

Community Collaboration

Working with other leaders is important, as we cannot do this work alone. By forming alliances and collaborations, wonderful things come together, and the impact is bigger. I love to work with other organizations and agencies that share the same priorities and goals.



Family Voices has offered great support to the PR-F2FC as a new program in Puerto Rico and continuously during all five years we have been operating. This support helps the F2F stay united as a team and provides orientation, support, and learning opportunities. In addition, Family Voices has provided me the opportunity to participate in many different projects working with different topics on the transition to pediatric to adult health care. I participated as a member of the LFPP Project Advisory Committee and currently as a member of the PAC for the project Promoting Equitable Access to Language Services for Families of CYSHCN (PEALS), which allows me to continue to grow, personally and professionally. I am grateful to Family Voices and their wonderful staff for the opportunities for myself and the PR-F2FC.

This year PR-F2FC celebrates 5 years. It is not a personal success, but the work of a dream team. We need to recognize the achievements and celebrate them. To see the PR-F2FC grow from a program that started at zero and see where we are now fills me with satisfaction and pride. The team that we have is amazing and very committed. A year ago, we started a support group for families of children and youth with autism, where we meet monthly, and it has been a personal growing experience for everyone involved. I get very excited that we will be opening an evaluation clinic with an amazing interdisciplinary team for children of ages 0 to 5, and we have found two mother participants on this support group who will offer peer support to other families in the clinic.



We want to hear from you!

Are you:



a parent or caregiver of a child/children with special health care needs (CYSHCN)?

OR



a health care professional?

OR



someone whose preferred language is not English?



Your responses will help us learn more about language access services in the health care setting. This project is led by Family Voices Inc., with funding from the Office of Minority Health.

Learn more at www.familyvoices.org/LanguageAccess

We want to hear from you!

Family Voices Inc. invites parents or caregivers of children with special health care needs, health care professionals, and individuals whose preferred language is not English to complete a brief 4-minute survey on your experiences as part of a project titled **Promoting Equitable Access to Language Services (PEALS) for Families of Children and Youth with Special Health Care Needs.**

PEALS survey link:

www.surveymonkey.com/r/PEALS_Supplemental_Survey

Please share the survey with others. Responses will help us learn more about language access services in the health care setting and the development of free, educational resources for families, providers, and medical interpreters. Family Voices Inc. is a national family engagement organization leading this project with funding from the US Office of Minority Health.

Learn more about this project at:

www.familyvoices.org/LanguageAccess

Thank you for supporting this project!



Help for Hispanic/Latino Families for Children's Mental Health



Lauren Agoratus, M.A.

Parent and State Coordinator for Family Voices NJ at SPAN Parent Advocacy Network

The issue

Post pandemic, families are dealing with mental health issues in children. Some children who didn't have mental illness do now, and some of those who already had mental illness worsened due to isolation and loss. The American Academy of Pediatrics declared a mental health emergency (see [AAP-AACAP-CHA Declaration of a National Emergency in Child and Adolescent Mental Health](#)) and surgeon general issued advisory on the same, [Protecting Youth Mental Health](#).

My Journey

My daughter Stephanie is on the autism spectrum so I took every training I could find. She used to hit, pinch herself, and pull her own hair, as well as hitting and kicking us. Stephanie's acting out was due to frustration not being able to communicate. Early intervention evaluations when she was exiting at age 3 showed she had comprehensive language at a 7-year-old level, but expression language of an 18 month old. There are many resources for families, and most importantly families don't feel so alone.

Impact of Mental Illness

Mental health impacts all areas of a child's life as well as their family. Challenging behaviors affect home, school, and socialization of children. According to the National Institutes of Health, it is important to note that there are comorbidities with mental illness and intellectual disability so some students may need special education services. Children with challenging behaviors are often isolated at school and in their communities. Even a Photo NPR trip to the store can be challenging for the child and family. Some children may develop school avoidance. As a bilingual individual, I found that there was also some shame/blame regarding mental illness in some Spanish speaking cultures, although this is improving. This is also true in some other cultures, which shows the need for culturally responsive resources.



Systems Issues

Systemically, Hispanic/Latino families are traditionally underserved. This means that screening is done later, diagnosis is later, and early intervention is delayed. Unfortunately, this continues through school with some children getting less intervention for less time under Intervention and Referral Services and referred to special education. There are disparities in school discipline as well, such as suspensions/expulsions and even the inappropriate use of restraints and seclusion. There are also inequities in school placement into more segregated settings. Finally, health disparities exist in the medical system as well, even starting with lack of health coverage. Families need to know how to advocate for their child to get the best educational and health outcomes.

For school issues, families can get help from their Parent Training and Information Center found at <https://www.parentcenterhub.org/find-your-center/>. There are also resources in Spanish at <https://www.parentcenterhub.org/lista-espanol/>.

By learning about their child's condition, families won't feel so helpless or hopeless. There is help for all families, including working with the school district, and family support.

Even a trip to the store can be challenging for the child and family



Resources

Find Your Parent Center

parentcenterhub.org/find-your-center

National Alliance on Mental Illness

[Mental Health in the Latino Community](#)

[Your Journey](#)



Family Voices Staff Hidden Talent



Ian Whitney
Digital Operations
Manager at Family Voices

I've been playing music since the early years of my life, and the highlight of that has been playing drums. Primarily, that has been the drum set, and more recently, congas and other percussion. About 15 years ago I began playing the drum set and fell in love with it. The day I brought my first drum set home, I invited a close friend named Giovanni to come over and jam. Today, Giovanni, myself, and our other close friend Ben make up the band Populace, performing in clubs, bars and every stage that we can. The three of us make up the core of the group with the drums, guitar, bass, and vocals, but we often bring with us a horn section, vocalists, and others to our live shows. We are very passionate about the band and the music we create together.

Populace is a dynamic trio, known for our electrifying fusion of funk, rock, and rhythm.

Click here to see a video of Populace



Staff Hidden Talent



Every performance is an unforgettable experience. Our ability to adapt from soulful acoustic sets to a 7-piece, horn-driven spectacle energizes the audience and fills the dance floor.

With some of our recorded music already released, we are excited to be back in the studio this spring and summer and releasing more music very soon (you can find us on Spotify, YouTube, Apple, or wherever you listen to music!). We hope to be at a music festival near you soon and are planning some east coast tours and other tours in the near future. To find our music and learn more about the band, please feel free to check out our website wethepopulace.com.

A Taste of Home

Flan

Ingredients

- 4 eggs
- 1 can of evaporated milk
- 1 can of sweetened condensed milk
- 1 tablespoon of vanilla
- 1 tablespoon of cornstarch
- 1 ½ cup of sugar

Instructions

Preheat the oven to 350 degrees.

Caramel:

Melt the sugar in a 9-inch round pan and cook it on medium-low heat until it melts and turns golden. Move the caramel around the pan to cover the bottom evenly. Let it rest.

Put the rest of the ingredients in a blender and mix for approximately 1 minute until all ingredients are mixed.

Pour the mixture on top of the caramel in the baking pan. Let it rest.

Place the pan into a bigger roasting pan and carefully add water to cover half of the baking pan (Bath of Mary).

Bake in the preheated oven for about 1 hour.

If a toothpick or a knife comes clean when inserted into the middle of the flan, then it is done.

Let it rest for about 10 minutes, then refrigerate for 3 to 4 hours.

Before serving, use a knife to trim the edges of the dish, carefully invert it onto a plate, and let the caramel cover the flan.



A TASTE OF home

Family Voices Staff Hidden Talent



Nikki Montgomery
Director of Strategy and
Communications at Family Voices

I've always been a writer. I started writing as a child and published my first poems while I was in elementary school. I majored in literature and writing in college.

My first children's book was inspired by my son, who uses a power wheelchair. He was two years old when he got his first chair, and it took some time and creativity to figure out how to teach him to drive safely. Because he loved to read at an early age, I wrote Power Wheelchair Safety for Kids so he could learn wheelchair safety in a kid-friendly way. My illustrator even made the main character look like him. The book and toolkits gave us a fun way to rehearse safety rules and build skills.

My work on hospital safety committees led me to write the other books in the Super Safe Kids book series, as a way to involve children in being safe in the hospital and at home. In my work on these committees, I noticed that all of the communications about patient safety were directed at parents, and not at the children. Key safety issues like infection control, falls, and managing complex medical care and

Staff Hidden Talent

devices are important for children and families, and children can play a role in staying safe and healthy. The books are written to help children advocate for their care and safety, with the support of their families.

There are six books: Power Wheelchair Safety for Kids, Hospital Safety for Kids, Central Line Safety for Kids, Tracheostomy Safety for Kids, Feeding Tube Safety for Kids, and The Spine Surgery Book for Kids. I love that the characters are diverse and that the books are written from the perspective of the child. Kids and families can read the books together. I also wrote or cowrote two books for caregivers: Home Care CEO: A Parent's Guide to Managing In-Home Pediatric Nursing, and We Dare Be Brave: African American Moms and the Emotional Journey of Raising Children with Disabilities. The entire collection is intended to inform and empower families of children with special health care needs to take a leading role in their care and in their lives.

[Click here to see a video about Super Safe Kids books and toolkits](#)



Nikki Montgomery is the parent of a child with autism, complex health care needs, and a rare and disabling genetic condition. Nikki has master's degrees in English and in Educational Psychology, with research on critical thinking and health literacy for parents of children with complex needs.

Partners on the Journey: Families and Youth are Essential If We Are to Design and Deliver Equitable Care



Richard Antonelli

General, Primary Care Pediatrician.
Medical Director of Integrated Care, Dept. of Accountable Care and Clinical Integration
Co-PI, HRSA/ MCHB Enhancing Systems of Care for Children with Medical Complexity (CMC) Coordinating Center

They say that “information is power.” As a pediatrician over the last 40 years, I have observed that families seek information to help them gain access to services that they know their children and youth need. But they often report that they don’t routinely have access to information when they need it and in a format that is helpful for them to use. That is not to imply that information is ever withheld intentionally, but families report that they often “don’t know what they don’t know.” I have spent my career listening to children, youth, families, caregivers, and family leaders. Without doubt, these people have been—and continue to be—some of the most influential teachers I have ever had! I am honored to be invited to contribute to this issue of Family Voices En Español Magazine.

When I was in my medical and pediatric training in the 1980s, I was inspired by the courage, wisdom, strength, compassion, and resilience of the families whose children and youth had special health care needs (CYSHCN). CYSHCN are defined as children and youth who have medical needs beyond what is typical. I decided to dedicate my career to improving care for these children,

youth, and families. In my first few years, I was privileged to meet and learn from some of the most remarkable teachers. Polly Arango, the founder of Family Voices, Trish Thomas, Leolinda Parlin, Nora Wells, Barbara Popper, Betsy Anderson, Julie Beckett, Carolyn Allshouse, Richard Robison, Mallory Cyr, Molly Cole, Patti Hackett-Hunter and her son, Glen, Dawn Bailey, Brad Thompson, and Meg Comeau—to name just a few. These pioneering thought leaders with decades of lived experience and wisdom about how care should be designed to meet the needs of children, youth, and families brought a depth of knowledge and experience to me that profoundly shaped my approach to being a pediatrician.

“Nothing about us without us”

“Nothing about us without us” is the core message from these influential teachers. While it may sound obvious, putting this into practice takes dedication, commitment, respect, mentorship, and partnership. As a result, in the subsequent decades of my career, each project, each course, each initiative has included youth and families

as key thought leaders and collaborators—from the very beginning. So, what does this look like? Well, it means that each new activity begins with ensuring that we have appropriately engaged the voices and experiences of the diverse group of people we aim to serve. This includes offering financial support as well. For me, partnering with my colleagues at Family Voices has been a consistent and reliable resource in all of my work.

While I appreciate the invaluable wisdom of these family leaders, I have learned that not all families desire to serve in the capacity of “system change agents.” However, it is critically important to understand that in any given single encounter—whether in my clinic, a hospital, a community center, church, synagogue, or mosque, or in a school, there is wisdom to be gained. In these situations, I recognize the importance of offering space and time in order to ensure that the child, youth, family member, foster parent, guardian, caregiver feels valued as being at the center of the care team. In these circumstances, we must take into account cultural expectations, as well as issues related to literacy.

Health equity and justice

As my work increasingly focuses on health equity and justice, I am mindful of the need to acknowledge that many in our communities have suffered through oppression, trauma, stigma, and loss. Working with our Family Voices colleagues across the country enables us to acquire the necessary skills to respectfully engage with these families. We must listen more than we speak. This

is often challenging, however, since there is pressure on health care providers to see more and more patients. I find that in spite of this pressure to “work faster,” my family partners offer so much to influence how we can build capacity to make a difference in the lives of families. As a result, as a member of a multidisciplinary care team centered around the strengths and needs of the patient and family, I find much joy and hope. It is deeply rewarding to partner with families who seek information which enables them to lead loving, productive, dignified lives.

How can I, a pediatrician, impact a community by myself? It is difficult, but I’ve chosen to bring my skills to each interaction, whether in a large group or individual meeting. As a member of a care team, with the patient and family at the center, I work to establish linkages with colleagues in schools, daycare settings, Early Intervention agencies, Title V programs, and community organizations (such as food and housing resource agencies).

Example: Miguel is a 4-year-old child born in the Boston area. His family immigrated from Guatemala. He is followed by a dedicated primary care pediatrician. He was diagnosed with asthma when he was one year old, and often came to the Emergency Room when he had trouble breathing. At his 18-month-old visit, he was noted to have some behavioral and developmental concerns. His speech was not progressing in terms of the number of his words, and he had trouble following directions. He was referred to Early Intervention. At his 3-year-old visit, he was

Continued on the next page

Partners on the Journey: Families and Youth are Essential If We Are to Design and Deliver Equitable Care (continued)

again noted to have issues with his speech and behavior. The child's pediatrician referred him to his local school for an assessment of his learning needs. Mother was given the name and phone number to call. However, the team did not ask the mother why he was never seen by Early Intervention. If they had asked her, she would have told them that she was not sure how to get access to the service. At age 4, he was seen for the first time in my own clinic following a visit to the emergency room for asthma. By this time, it was clear that he had significant social and behavioral issues. He was subsequently referred for developmental assessment. Importantly, we assured mother that we would work with her to gain access to the developmental clinic, and that we would support her to ensure that he was able to receive the necessary services.

The important lesson here is that the child received all of the right services whenever he was in the primary care clinic or the emergency room. However, the linkages from one setting to another—initially to Early Intervention, then to the school district—did not happen since there was an assumption that care coordination would happen.

Care Mapping

In 2012, I was working with a parent partner, Cristin Lind, on a care coordination research project. I had a general idea about how many different services her son, Gabe, received but I was curious to see how many and how they fit together, if at all. That evening, Cristin created the Care Map. It's a depiction of all

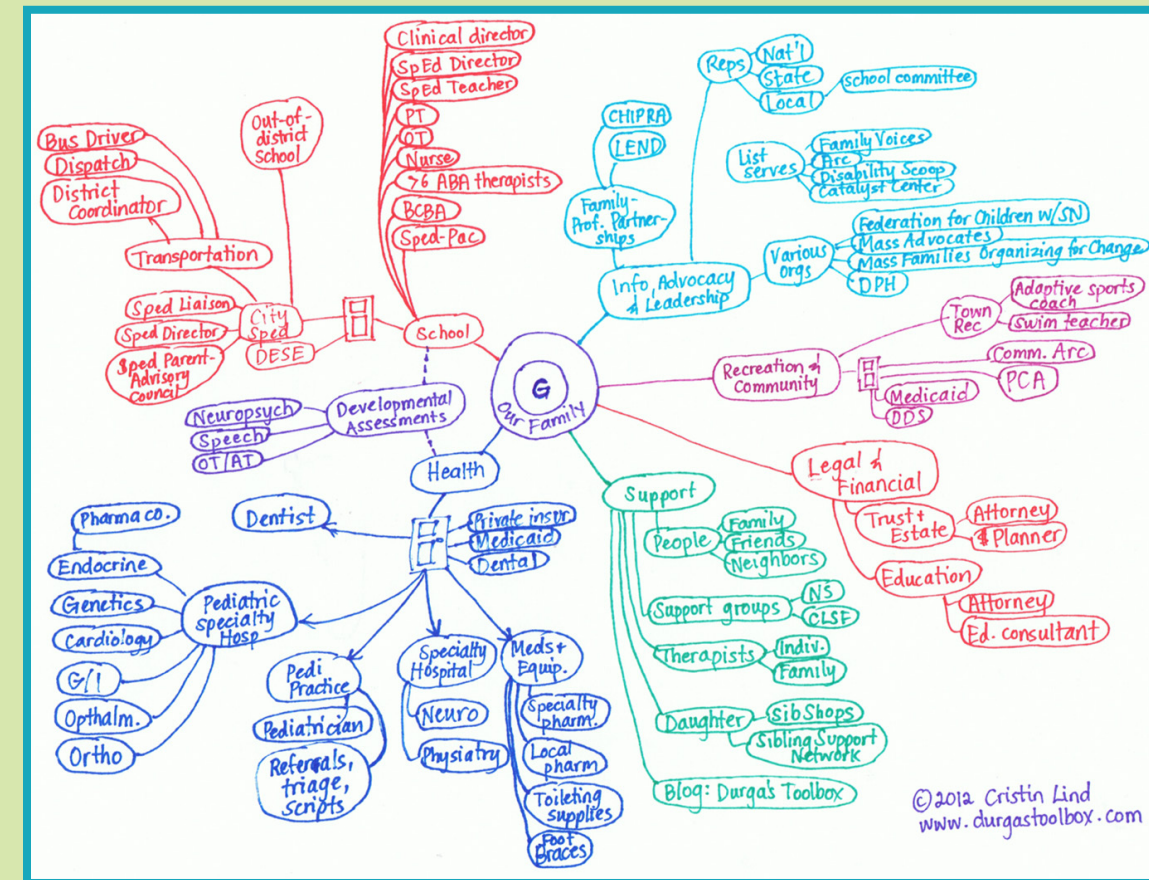
the necessary resources that a child might need in order to grow and thrive: education, medical, dental, developmental, and family to family peer support, among others. You can appreciate how much effort a family puts into linking with each of these settings, assuming, of course, that that the family has a way of learning what all the necessary services might be in their community. Editor Note: we can put image and link here if desired.

Example of a Hand-Drawn Care Map

Example of a hand-drawn care map showing a network of support that contains various participants in health care, legal, financial, education, community, and other resources centered around the patient's family (Courtesy of Cristin Lind and the Boston Children's Hospital)

Care Coordination

Making connections across disciplines and settings is the work of care integration. But it does not happen on its own. In fact, families with children and youth with special health care needs often find that there are challenges to coordinating services across the different providers. To address these barriers, I had the privilege of partnering with my Family Voices colleagues to create, test, and validate the very first survey of the family experience of care integration—the Pediatric Integrated Care Survey (PICS). Funded by the Lucile Packard Foundation for Children's Health, this survey is used across



Example of a hand-drawn care map showing a network of support that contains various participants in health care, legal, financial, education, community, and other resources centered around the patient's family (Courtesy of Cristin Lind and the Boston Children's Hospital)

the United States and around the world as a way of measuring families' experience of how care team members are working together to achieve the outcomes most important to them. The data from the PICS has been used to create quality improvement projects for diverse populations around the US and the world. We learned that family-centered is not the same as families feeling "satisfied." To be satisfied means that a person must have well-informed expectations about a service, a relationship, or an activity. Current work with improving equity of care means that we must consistently ensure that families are aware of their rights to access and receive services.

So, in support of fulfilling our commitment to sharing information so that they have "power", we must work together to learn what the most important information is that families are seeking. We must commit to sharing that information in a way that families can access it when they need it. And we must find ways to ensure that we are evaluating the impact of putting "power" in the hands of youth, families, and caregivers.

Building a Structure to Serve Families



Debbie Doherty
Tender Hearts, Inc.

The American Academy of Pediatrics defines a medically complex child as someone with chronic, multisystem health conditions, significant healthcare needs, major functional limitations, and high use of resources. In the United States, there are about 3 million such children each year, with over 4,000 residing in Delaware alone. In 2014 I established Tender Hearts, Inc. with the support of my loving family. This organization has emerged as a vital support system for families in Delaware with medically complex children, earning recognition for its comprehensive services tailored to meet their needs.

My personal connection to the work

I, myself, was a medically complex child, grappling with hip displacement during an era marked by limited understanding and treatment options for such conditions. Tragically, two of my siblings were born with spina bifida and passed away prematurely. Transitioning from navigating my own medical complexities to becoming the grandmother of medically fragile twins, my firsthand experiences helped me understand

the challenges faced by families of medically complex children.

Frequent visits to Nemours Children's Hospital made me familiar with the struggles these families endured. My individual journey through medical complexities has equipped me with invaluable first-hand knowledge of what's available for families of medically complex children, or to put it more bluntly, what's not. To raise awareness and enhance the quality of life for medically complex children, Tender Hearts introduced a range of programs including Adopt-a-Family, Beads of Courage, Early Learning Success in Academics for Preschoolers, Milestones Program, and the Mobility Program.

Building a strong Board of Directors

With the mission of enhancing the quality of life for Delaware residents through support for medically fragile children, Tender Hearts has tirelessly worked to establish itself as a reliable resource for families with children requiring complex, ongoing medical care. This reputation has been solidified under the guidance of our robust Board of Directors.



Tender Hearts boasts seven active board members, including a medical advisor from Delaware's own Nemours Children's Hospital, recognized as one of the top 50 nationally ranked children's hospitals. Recognizing that nonprofit boards thrive with a diverse array of skills and assets, in addition to time and resources, I emphasize to our board members the importance of assembling a board comprising individuals with varied backgrounds. Typically, board members are individuals who have engaged with the organization in some capacity—whether through attending events, supporting programs, receiving assistance from Tender Hearts, or expressing a desire to advance the agency's mission.

Once a potential candidate has been identified, an interview is conducted. If the majority of the board votes to accept the application, we initiate a background check. Upon successful clearance, another vote is held to formally accept the candidate as a

board member. Then, the individual takes an oath and signs paperwork outlining their duties as a board member.

When recruiting board members, it's crucial to establish clear expectations that are both understood and agreed upon. Board members should be prepared to participate actively in various ways. Within Tender Hearts, board members play a pivotal role in decision-making, including allocating funds for disadvantaged children, providing recommendations, representing the organization at events, and acting as advocates. Additionally, as part of their commitment, board members adhere to a give/get policy, pledging to contribute \$500 annually and attend at least seven out of ten regular board meetings.

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Recognizing the voluntary nature of board service and the dedication of its members, I foster regular communication among the board. Meetings are flexible, allowing attendance in person, virtually, or via phone, with communication channels such as email and texts. Board members are also encouraged to participate in events and join committees, ensuring ample opportunities for involvement and staying informed about our activities.

Running a nonprofit is a formidable task, demanding resilience, and a keen eye for identifying and addressing pressing needs. It hinges on gaining support, securing funding, and receiving guidance from a collective of like-minded individuals who are deeply committed to the organization's mission and values. As I reflect on my experiences with Tender Hearts, I'll share one of the profound lessons I have learned: the uncertainty of tomorrow underscores the significance of making each day count. Particularly when working with children and families, where every moment holds weight, striving to enhance their quality of life becomes paramount. There is something

so transformative about bringing joy and smiles to these children, knowing that these moments can shape a brighter tomorrow.

Recommendations on Board Involvement

- Recruit members who have an interest in your organization, a passion for your mission, and the ability to support the programs and services offered – financially or otherwise.
- Make sure board members have a clear understanding of the expectations – meeting attendance, give/get policy, event and program support, terms of service, and available committees.
- Maintain frequent communication with board members so they know where they are needed and any action items to be aware of.

FAMILY VOICES[®]

Our Vision

All children, youth, and families, especially those with special health care needs and disabilities, experience their best health and quality of life.





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familyvoices.org/enespanolmag