

UNM Pediatric Department Grand Rounds 2022

Good morning. Thanks for inviting me to speak to you today.

I'm going to focus on changes in health care for children with special healthcare needs, but to start off, here are a couple of examples of the magnitude of the changes in children's healthcare during my lifetime:

- When I was a child, if friend had measles, mumps or chicken pox, my mother arranged a playdate in hopes that I would get infected, to, as they said, "get it over with"
- Our pandemic was polio, then called "infantile paralysis". One of my best friends lost use of his left leg. An acquaintance died. No one worried about our mental health. In fact, the popular term "children's mental health" didn't exist.
- We lived in a three-block complex of two-story apartments. A family with a child with Down Syndrome moved into the complex. The neighborhood was outraged. "That child belongs in an institution."

Jumping ahead ten years:

In 1967, Polly Egan and I were married. She grew up in Green Bay along with Vince Lombardi's kids, went to Northwestern for two years, and then transferred to UNM because, she said, "I could play golf and ski the same day". And she did: she was a member of both teams at UNM.

Starting in late 1968, we lived in San Francisco, where my son Carlos was born. Then Panama, where I was Peace Corps County Director and where my daughter Francesca was born. And finally, to Ecuador where I continued with the Peace Corps and we adopted my daughter Maria. While there, Polly helped set up Ecuador's first adoption agency.

In late 1973 we returned to New Mexico. Polly continued working on adoptions and linked up with several national adoptive parent organizations. In 1976, we decided to adopt another child. Just after Christmas, we drove to Santa Fe to pick up our new son, Nicolas Quinia. Nick was an active, happy baby.

About a year later, it was clear that Nick was not developing as our other children had. Dr. Lance Chilton, a pediatrician at UNM, who we knew

because his and our kids were at the Albuquerque Pro-School Coop, arranged for Nick to be evaluated at UNM. The diagnosis was mild physical and intellectual impairments.

About a year later, he heard about UNM's "Programs for Children" led by Dr. Stan Handmaker. Stan did a more thorough evaluation, told us that Nick had Cerebral Palsy, and recommended that he be enrolled in the pre-school program at the Rehabilitation Center.

The Rehab Center did not allow parents to be in the room when their child received physical and occupational therapies. Parents waited outside until the treatments were finished. This gave Polly and me the opportunity to meet other parents and to share stories and experiences.

Gradually, we realized that every family faced the same four problems:

- First, limited access to information, support and services
- Second, inability to buy health insurance
- Third, Medicaid's "institutional bias"
- And fourth, no role for parents in health care systems

In more detail:

First, limited access to information, support and services

- Every family was on its own. There was no easily accessible information about how to care for our children, and no agencies to provide in home support.
- Once families suspected that a child was not developing as expected, it was almost impossible to get a professional evaluation. Families waited months—sometimes years—for an evaluation. In our case, we got one because we knew a pediatrician at UNM.
- Once a child was determined to have a disability, services were limited, or —unavailable—if you lived outside Albuquerque. And, if your child did not have one of the "big three"—cerebral palsy, epilepsy and what was then called "mental retardation"—evaluations and services simply didn't exist.

- School aged children faced even more significant barriers. Before 1975, schools were allowed to deny an education to children with “emotional disturbances” or “mental retardation” and very few schools were accessible. More than a million children with disabilities were not in school, and 3.5 million children were kept in segregated facilities where they received little or no education.

Second, inability to buy health insurance

- Families with kids with disabilities seeking to buy health insurance on the private market were routinely denied coverage.
- Those that had health insurance from an employer were often stuck in their job because they feared that if they left, they would not be hired once an employer learned that they had a child that would drive up the employer’s health insurance premiums.

Third, Medicaid’s institutional bias

With one exception, only people in institutions were eligible for Medicaid health insurance. The exception was, if a child had been hospitalized for 30 days and needed continuing in-home treatment, the child would be eligible for Medicaid. But it took months to qualify. In the meantime, the child stayed in the hospital.

And fourth, no role for parents in health care systems

Hospitals had “visiting hours” when parents could be with their children. Otherwise, they were not allowed in the hospital. If your child needed treatment at a Children’s Hospital, you dropped off your child at the door, went home, and waited days or sometimes weeks to be called to pick him or her up. The widespread belief was that parents were “too emotional” and, if present in the hospital, would interfere with their child’s treatment.

Further, parents were not allowed to see their child’s medical records. Although I did hear about one parent who learned to read her daughter’s medical chart upside down.

Faced with these problems, in 1980, the Rehab Center parents agreed to form an organization. They called it “Parents Reaching Out” or “PRO”.

Backing up for a minute to look at what was happening in the east and in Congress:

- In the early 1970’s, a group of parents in Pennsylvania, working with United Cerebral Palsy and the Association for Retarded Citizens, pressured their legislature to set standards for special education. The legislation that passed included funds for a family-staffed organization to provide information about the standards and support to families throughout the state.
- A year or so later the same thing happened in Massachusetts. The families called their organization the “Federation for Children with Special Needs”
- In 1975, Congress passed the “Education for All Handicapped Children Act” which provided funds to states that agreed to accept federal standards for special education. The Act also included funds for family organizations to provide information and support.
- In the meantime, staff in a Bureau in the federal Department of Health and Human Services then called “Crippled Children’s Services” (and later called the Maternal Child Health Bureau) began to think about its continuing role, and, in particular, about the role of families in the health care system.

One of the Bureau’s functions was to make grants for improvements in child health care. Most of those grants went to individual pediatricians and to academics. The Massachusetts Federation decided to apply for a grant to bring leaders of parent organizations from across the country together to share experiences and expertise. To their surprise, they were awarded a grant.

- In the meantime, the Federation parents learned that there was an obscure provision in a federal law providing funds for hospital rehabilitation that allowed 12 people to petition for a hearing when a hospital was planning a rehabilitation.

The parents submitted such a petition to one of the four children's hospitals in Boston, were granted the hearing, and laid out their requirements for patient rooms: enough space for a bed and showers for parents spending the night; meeting space for a parent-professional advisory board; and, by the way, access to their children's health records. The hospital accepted their recommendations.

- The Boston parents also formed another organization called SKIP: "Sick Children Need Involved People". It capitalized on the four children's hospital's competition for patients to persuade those hospitals to allow parents to stay with their children, to establish parent-professional advisory groups, and to allow access to records. Once this practice became established in Boston, it gradually spread to hospitals around the country.

Back to New Mexico

Stan Handmaker was also chair of a state agency called the Developmental Disabilities Planning Council. The Council's purpose was to make plans for delivery of state services to people with developmental disabilities. He arranged for me to join the Council.

The Council decided to issue a contract for a plan for services for young children. I resigned from the Council, competed for the contract, and won.

The plan called for "early intervention"—specifically:

- Every child should be screened for disabilities at birth.
- Every child with a suspected disability should have immediate access to a professional evaluation.
- Every child found to have a disability should immediately receive appropriate services while living at home.

A meeting was called to review my final draft. Stan was there, along with the state Director of Special Education, and Ginny Gilmer, from the Developmental Disabilities Division at the Department of Health. Stan and Ginny fully supported the plan's recommendations. The Special

Education Director said: “I know all about early intervention. We don’t need it in New Mexico.”

That was all we needed to mobilize families across NM.

Jump to Cedar Rapids, Iowa.

Julie and Mark Beckett’s daughter, Katie, had been in the hospital since shortly after birth when she contracted viral encephalitis and required a ventilator. About 4 months later, Katie was cleared to go home with her ventilator. Her family had health insurance from the school where Julie taught but had maxed out their benefits. Katie was then covered by Medicaid, but only while she was in the hospital.

The myth is that Julie wrote a letter to President Reagan, who removed the institution requirement and Katie moved home. Actually, it was more complicated.

Julie had taught her students that, when faced with a difficult situation, they should call their Congressperson. So, she called her Congressperson.

It was the Congressperson, Thomas J. Tarke, who wrote the letter. Julie’s understanding is that it reached the President’s desk with help from the Vice-President, Herbert Walker Bush, who, you may recall, lost his 4-year-old daughter to leukemia.

Two days later, the President, in a news conference, described the plight of an unidentified family that could not bring their child home because of the Medicaid institutional requirement. The next day, the Beckett family was identified by the hospital where Katie was living. A day after that, the New York Times and other national newspapers were interviewing Julie. A day later Julie was flown in a private plane to Chicago for an appearance on Good Morning America. The public response was overwhelming. Still, Katie spent 30 months in the hospital while changes were made in Medicaid regulations.

State Medicaid agencies then paid for Julie to come to their state to explain how they could apply for what was then known as the “Katie Beckett Waiver”.

Back to New Mexico

PRO began to publish a monthly newsletter. The mailing list grew quickly as word circulated that a source of information was finally available. Parents then began to support each other and finally to meet, first in local groups, and then in statewide meetings.

The most important of those meeting was held in Angel Fire. Julie Beckett came to describe how New Mexico could obtain a Katie Beckett waiver. Equally important, Patty Ikard, from Roswell, came to the meeting.

Patty was a tall, elegant woman, with a great sense of humor and a will of iron. She was particularly interested in health insurance. Her husband worked in the oil and gas industry. No health insurance company would sell insurance to an oil patch worker, much less one with a daughter with Down Syndrome.

During that meeting Polly and Patty agreed to work together to improve health care. As leaders of literally hundreds of families and their pediatrician allies, they transformed health services for New Mexico children with disabilities.

Patty was the public face of the effort. Polly was with her at every meeting and public appearance but focused more on strategy and on mobilizing family and public support. Together they:

- Created the Medically Fragile Program.
- Then, they secured stable funding for “Programs for Children”-now known as the “UNM Center for Development and Disability”.
- They persuaded the New Mexico legislature to pass a bill instructing the Human Services Department to apply for a Katie Beckett waiver.
- Working with a much larger group of parents and educators, they persuaded the legislature to instruct the State Superintendent of Education to apply for funds available from the federal All Children’s Education Act. This very substantially increased funds for special education.

It also required the state to accept federal standards for special education, the first definition of what constitutes an “appropriate” education for children in special education in NM.

- After recognizing that creating a truly statewide network of services for children with special needs and their families would be prohibitively expensive, they persuaded the legislature to lower the school age for children with disabilities to 3, thereby making every school in NM a source of services.
- Along with some, but definitely not all, New Mexico pediatricians and orthopedists, Polly led the campaign to first, move Carrie Tingley Hospital from Truth of Consequences to Albuquerque and then to merge it into the UNM Medical Center.

One day, Patty showed up at our house with an armful of documents. When asked what she was up to, she said she was going to create a health insurance pool that would sell insurance to people that could not buy it on the private market. What she was holding were copies of the laws that created these kinds of pools in other states. She proposed to craft legislation for New Mexico by borrowing the best features each of those bills. We thought she was out of her mind. But, with the support of the insurance industry, she was able to create the New Mexico Medical Insurance Pool.

It was the first (and until the Affordable Care Act), the only organization offering “guaranteed issue” health insurance to anyone with a disability or chronic health condition in NM. At its height in 2012 it had nearly 10,000 policy holders, with losses, covered by the insurance companies, of more than \$125 million a year.

Patty became the Pool’s board chair and volunteer executive director. One of her best ideas was to recognize that Medicaid was a health insurance company and therefore required to help cover the Pool’s losses. That meant that a substantial part of the Pool’s continuing losses to this day are covered by federal funds.

Another of Patty’s brilliant ideas was to allow state agencies that received federal funds for medical treatments for specific groups, such as children and adults with HIV, to use those funds not for treatment but to buy insurance from the Pool. This allowed Children’s’ Medical Services and the Ryan White HIV program to multiply the impact of their limited funds many times over.

Initially, policy holders paid high premiums, but Patty introduced a Low-Income Premium Plan that substantially reduced premiums for policy holders earning less than 400% of the federal poverty level. The Pool immediately grew to the point that it could no longer be managed by a volunteer. Patty incorporated herself, hired staff, and contracted to manage the Pool.

In 2008 when Patty was dying of breast cancer, she gave her corporation to Deborah Armstrong, a former Secretary of the Aging and Long-Term Care Department with the understanding that Debbie would continue to manage the Pool. Debbie partnered with another former Aging Department Secretary, Michelle Lujan Grisham, whose sister had a disabling chronic medical condition.

All of these efforts have their own, often complex, sometimes very funny stories. A couple:

- When Polly and Patty moved to lower the school age, they scheduled an appearance before what was then called the Legislative Education Study Committee. Standing the hall outside the hearing room after their testimony, they were joined by one of the Committee members. He said “You don’t know what you’re doing. I’ll help you.” This was Tim Jennings, then a member of the House from Roswell. He ultimately rose to be President Pro Temp of the Senate.

Very little of the transformation described earlier could have been accomplished without his help. Later, Tim and Patty were married. Tim was elected mayor of Roswell a couple of weeks ago.

- For the Medically Fragile campaign, Polly and Patty commissioned a video that was then widely shown. One scene was particularly persuasive: a mother, pulled over on the side of I-40, with giant trucks rushing by, so she could suction her baby.
- Much of the transformation happened between 1984 and 1987, when Toney Anaya was Governor. Two members of his staff: Toni Martorelli and Marg Elliston, were key members of the team in Santa Fe. To give you some idea of the Governor’s commitment to

the effort, when the Medically Fragile bill was being debated, he agreed to hold a joint press conference in support of the bill with Congressman Manuel Lujan. That was as unlikely then as a joint conference with Governor Lujan Grisham and Congressperson Lynn Herrel would be today.

- Loretta Armenta was another key figure. She had a son with very significant disabilities. She also sold insurance all over Northern New Mexico. Everybody knew Loretta. She was able to reach legislators that no one else could. She went on to be President of the Hispano Chamber of Commerce and a key figure in the creation of the National Hispanic Cultural Center.

Other key figures were:

- John Foley, the director of the ARC New Mexico, who spent years working to reduce the waiting list for Medicaid Waiver Services. (As an aside, I should note that John's (and Tim Jennings') goal was finally achieved this January, when the legislature approved the funds needed to eliminate the wait list over the next two years).
- Another was Lou Landry, who directed the Developmental Disabilities Division of DOH. And Gail Beam, then director of the Albuquerque Special Preschool and now a state legislator, who secured support from the organizations that served children with disabilities.
- And Alice King, the Governor's wife, who, as a member of the Carrie Tingley board, led the effort to recapture the Hospital's operating reserve that had been swept up by the legislature. Gary King, her son, was then chair of a key committee in the legislature. He secured instant passage of the recapturing legislation by muttering the immortal words, "If we don't pass this bill, my mother will kill me."
- And last, but certainly not least, Bob Greenberg. It's one thing to jawbone about social determinants of health and another entirely different to create an organization that tackles those determinants head on.

Bob and two other pediatricians founded the Coalition for Children in 1987. It is now known as New Mexico Voices for Children. It is universally recognized as the premier source of research and

information about NM's children as well as a powerful advocate for every child in New Mexico.

The National Family Movement Begins

Polly became the chair of PRO's board of directors. Some funds were secured and Sallie Van Curren, another of the Rehab Center's waiting room parents, became its PRO's Executive Director. PRO still exists as a source of information and support for families with kids with disabilities and as one of two organizations that assists students and families with special education issues.

Recall that the Massachusetts Federation received funds from the Maternal Child Health Bureau to identify and convene leaders of parent groups in other states. These meetings connected leaders from across the country—too many to name here. Three of them were Polly from New Mexico, Julie Beckett from Iowa, and Josie Woll from Hawaii. They developed close ties with the staff at the federal Maternal Child Health Bureau. Key Bureau officials included Dr. Vince Hutchins, the director of the Bureau, Dr. Meryl McPherson, senior physician, and Diana Denboba, who administered the programs for families.

Another key federal figure was Surgeon General C. Everett Koop, a pediatric surgeon. With the help of Maternal Child Health staff he convened a series of "Surgeon General's Conferences" for family leaders. Surgeon General Koop was a commanding figure, especially when wearing his white uniform with plenty of gold braid.

The conference for the southwest was held in Houston. One night, Vince Hutchins awoke with a pain in his right side which he suspected was appendicitis. He called his friend the Surgeon General for help in getting to a hospital. Imagine the scene in the hospital emergency room when the Surgeon General of the United States, in full uniform, burst thru the door and in his booming voice, commanded the staff to attend to his friend.

The leaders at the Surgeon General's Conferences typically represent one segment of the disabled children's community: Cerebral Palsy via United Cerebral Palsy. Or intellectual disabilities via state "Associations of

Retarded Citizens”. Or polio survivors in “The March of Dimes”. The Maternal Child Health staff began urging the leaders to form a national organization that would advocate for all children with disabilities.

At a conference in Washington in December, 1992, attended by most of the key leaders, a side meeting was held in which the leaders agreed to form a national organization. Towards the end of the meeting, one leader suggested that they name it “Voices for Families”. Polly suggested they shorten it to “Family Voices.”

Julie Beckett was rooming with a leader from Arkansas. Bill Clinton initially staffed the White House with people who worked for him as Governor of Arkansas. He made one of them, Carol Rasko, his first Domestic Policy Advisor.

Julie’s roommate was a good friend of Carol Rasko. She gave Julie a handwritten note urging Carol to meet with Julie and Polly. So, the next day they went to the in-coming administration’s Washington office, gave the note to one of the receptionists, and soon found themselves in the office of the future Domestic Policy Advisor. Turns out that Carol had a daughter with Down Syndrome. The bond was immediate. The just formed Family Voices found itself with access to the White House.

A couple of weeks later President Clinton announced that his wife, Hillary, would chair the President’s National Task Force on Health Care Reform, and that the director of the Task Force would be one of his campaign’s aides, Ira Magaziner.

Hillary and Magaziner then convened meetings of key groups to explain their approach to reform and to seek their support for needed legislation. Carol Rasko arranged for Polly, Julie and other leaders to attend most of those meetings.

A few months later, Iowa Senator Tom Harken’s staff called Julie and told her to get to Washington immediately. By then Polly and Julie had enough frequent flyer miles to circle the globe, so they were able to get to Washington in time for a meeting convened by Magaziner to announce the outlines of the proposed legislation and, in particular, to describe the groups that were to receive special attention.

After he finished, Julie stood up and said: “My daughter will not receive what she needs from your plan”. Then another person said “My baby won’t be covered”. Ira Magaziner’s response was “Actuarially, children with disabilities don’t exist”.

Again, a simple phrase was all it took to energize families around the country.

Ruby Hearn from the Robert Wood Johnson Foundation found \$75,000 to create an office for Family Voices. MCHB matched the grant. Polly became the first executive director. Family Voices national headquarters was located in a former bar in Algodones, NM.

Thus began a long-term national effort to transform health care for children with disabilities. Again, lots of stories and too little time, so just a few highlights.

Months were spent in meetings convened by Maternal Child Health staff aimed at defining exactly who the children of interest were. It was clear that it was more than kids with the “big three”—cerebral palsy, epilepsy and mental retardation—and larger even than children with disabilities. Kids with chronic health conditions also needed to be included. All of this was important not only for explaining what the effort was all about, but also for persuading the Census Bureau to determine the number of kids in the group.

Ultimately, the term chosen was “Children with Special Health Care Needs”. The Census Bureau first surveyed using an earlier definition—children with a condition that limited at least three “activities of daily living”. That survey showed roughly 12% of all children had such conditions.

The current definition (on the Bureau’s website), is slightly different because youth has been added:

Children and Youth with Special Health Care Needs are children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally.

Note also the addition of “behavioral or emotional” conditions. Children’s mental health was not included in the original discussions nor in the earliest definitions.

Partly for that reason, the percentage of children now considered to have special health care need as grown. Again, from the Bureau’s website

According to our [National Survey of Children’s Health \(NSCH\)](#), in our country:

- About 13.6 million children under 18 years old (that is, about 18.5%) have a special health care need
- 25% of homes had one or more children with a special health care need
- Children and Youth with Special Health Care Needs are more likely to live in poverty, be non-Hispanic Black, and have public insurance than non-CYSHCN.

The second major task was to define the role of families in health care. The outcome of this discussion was the statement: “families are their child’s chief caregiver”. Seems obvious now, but recall that 20 years earlier, family members weren’t allowed to stay with their hospitalized children nor to see their health records.

The next step was to agree that pediatricians, therapists and other health care providers were families’ essential partners, as were educators and volunteers needed to raise a child with special health care needs. This came to be called a “parent-professional partnership” and remains fundamental in any discussion of services for children with special health care needs. While the family is literally the chief caregiver, it is the other partners that ensure that each child’s impairments are reduced or removed, and every talent fully developed as a prelude to a productive, self-directed adulthood.

Attention then turned to where services should be delivered. Although New Mexico closed its two “schools” for people with developmental disabilities in the 1980’s, many states still maintained such institutions. Since partnership was now a key part of the desired future, “in-home” services seemed too narrow. So, the phrase “community-based care” came to be used to describe the village surrounding each child.

The fact that special health care needs arose in every racial and ethnic group was next considered. Work on defining exactly how this issue

should be addressed continues to this day. The early discussions at the Bureau recognized that this was a complex topic that, while it could not be fully developed at the time, had to be incorporated into any plan for improving the life of Children with Special Health Care Needs and their families.

Finally, the discussions turned to crafting a phrase that captured the kind of care that was needed. That phrase was:

“Comprehensive, family-centered, community-based, culturally-responsive care”

Today’s Bureau website uses a slightly longer phrase that emphasizes the role of professionals:

- an interprofessional, family-centered, community-based, and culturally-responsive systems of services

I might note here that at the heart of all these definitions is the idea that people with disabilities and chronic health conditions are different than the rest of us. Note, for example, the end of the Bureau’s current definition:

“require health and related services beyond that required by children **generally**.”

Special educators are now attacking the idea that children with special needs are different. They propose that “special needs” are simply another kind of diversity. That makes children with special needs “us” rather than “them” and adds special needs to the on-going discussion of “equity”.

Institutionalizing the family movement

Once established, family Voices grew like a weed. We stopped entering member names in its database when it passed 50,000. Instead, the Family Voices central office provided materials to groups in each state that reproduced those materials for families in their states. Ultimately Family Voices became 50+ state organizations each with its own information, support and advocacy program, with the central office serving as the national coordinating and advocacy group.

A multi-year campaign ultimately produced federal legislation that provided operating funds for the state Family Voices affiliates. They are now “Family to Family Information Centers”.

Family Voices and families all over the US fully supported Hillary’s unsuccessful effort to reform health care, although relations with Ira Magaziner remained frosty. This effort to gain Congressional support paid full dividends in 1997 when Senators Ted Kennedy and Orin Hatch introduced, and Congress passed, the State Children’s Health Improvement Program that expanded state health insurance coverage to millions of children.

Polly became a public spokesperson for families and the MCHB. She appeared at many state and national conferences. She also represented the US at international conferences in Chile and Norway, where she made contacts that enable her to work with families and agencies in Slovakia, China and Russia.

She was invited to speak at a conference sponsored by Vice-President Gore in Tennessee. That led to her speaking at a dinner at the Vice-President’s mansion to a group of national leaders, including the President of the AFL-CIO and the Secretary of Health and Human Services.

A few weeks later, the Vice-President came to New Mexico to determine if he had the support he needed to run for President. At a meeting with Democratic party faithful, he mentioned that he had recently had dinner with Polly and wondered if she was in the audience. She stood up and said, “Looking forward to dining with you again at the White House”. To say that the audience was dumbfounded by this exchange is an understatement.

When the National Institute for Children’s Health Quality (NICHQ) split off from the Institute for Healthcare Improvement (commonly known as IHI), Polly became a member of its first board. That led to her becoming involved with the IHI itself. She was a keynote speaker at one its international conferences and participated in many meetings where her role was to remind the physicians in the room that every health service involved a patient who should be seen as more than the embodiment of a disease or a chronic condition.

Family Voices and families across the US very strongly supported the Affordable Care Act—to the point that Senator Bingaman, whose role in passing the Act has never received its due credit, kept a room in his suite of offices for Polly. She lived to see the Act passed before dying in a one car accident in 2010.

Where are they now?

Katie Beckett died in 2012. Julie Beckett died in May, 2022.

It turned out that our son, Nick, had a genetic disorder rather than cerebral palsy. No one had ever seen anything like it. In early adolescence he developed a seizure disorder and began a decline that I described as very slow muscular dystrophy. He died at the UNM Rio Rancho hospital in 2014. The doctors at Carrie Tingley and UNM hospitals, and especially, Drs. Lance Chilton, Javier Aceves, Leslie Morrison and Alan Firestone provided him with excellent care from birth to death.

Nora Wells, one of the original Massachusetts Federation mothers, is now the Director of the Family Voices national office in Boston.

Family Voices always paid attention to equity issues. Polly was the first Family Voices employee. Trish Thomas from Laguna Pueblo was the second, and Veronica Rosales, a high school student from Algodones, was the first office volunteer. Of the original 10 board members, two were African Americans from southern states.

Family Voices now has several major grants to help achieve equity in health care settings. Another of its projects focuses on helping young families see pediatricians as long-term partners rather than the person they see when their child needs a shot. It has a staff of 20 experts, mostly parents of kids with special health care needs, and a budget of several million dollars.

Why were these efforts successful?

First, they were truly grassroots efforts. That was rare in Washington where most so called “grass roots organization” were paid fronts for lobbyists.

Second, its leaders capitalized on every opportunity, no matter how unlikely they first appeared.

And, most importantly, they were led by women—mothers—with outstanding leadership skills, no egos, and a willingness to work with anyone who could help them transform healthcare for kids with special healthcare needs.

John Arango
March, 2022