



Statewide Parent Advocacy Network (SPAN)

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Empowered Parents: Educated, Engaged, Effective!

Family Healthcare Story Book:

**Why children with special healthcare
needs and their families need
healthcare reform now!**

**Family Voices-New Jersey
Family to Family Health Information Center of New Jersey
Federation of Families for Children's Mental Health Chapter**

Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.

**The Statewide Parent Advocacy Network's
Family to Family Health Information Center @ Family Voices-New Jersey**

FAMILY HEALTHCARE STORY BOOK

The Statewide Parent Advocacy Network (SPAN) is New Jersey's Parent Training and Information Center and Family to Family Health Information Center, and houses New Jersey's Family Voices and Federation of Families for Children's Mental Health chapters and New Jersey Statewide Parent to Parent. SPAN provides information, training, technical assistance, support, and advocacy for families of children birth to age 26 on health, mental health, education, child welfare and child protection, family support, juvenile justice, and other systems that serve children and families. Last year, SPAN provided information and assistance to over 100,000 families and professionals.

In December, SPAN held a statewide Health Care Community Discussion with 50 parents as part of the Obama-Biden Transition Project. Many of the parents had children with special health care needs.¹ 40% indicated that the cost of health insurance was the biggest problem in the health care system, while 36% said that the cost of health care services was the biggest problem (10% noted that health care quality was the biggest problem, with 8% noting that difficulty finding health insurance due to a pre-existing condition was the biggest problem). 32% of participants felt that community meetings like the Health Care Community Discussion was the best way for policy makers to develop a plan to address the health system problems, while an additional 32% felt that the surveys soliciting ideas on reform would be best (18% called for a White House Health Care Summit, and 14% wanted traditional town hall meetings).

There were many questions and concerns that were raised at the Community Discussion. One of the most important was, "How can we help healthcare professionals understand and implement the concept of a 'medical home' for children with special healthcare needs, so that their healthcare services are coordinated and so that we do not have to spend so much of our time coordinating their healthcare?" The impetus behind this question becomes clear upon a review of the National Survey of Children with Special Health Care Needs. Almost 37% of New Jersey parents of children with special healthcare needs report that their child's insurance is inadequate, with over 25% paying more than \$1000/year in out-of-pocket medical expenses for that child. 17.5% reported that their child's special needs caused financial problems for the family, and over 25% reported that their child's special needs caused family members to cut back or stop working. 22% had difficulty getting a referral for their child's health care; over 16% have unmet needs for specific healthcare services; and almost 40% report that they do not have access to family-centered care.

The family stories in this Family Healthcare Story Book reflect examples of the realities faced by so many New Jersey families who have children with special healthcare needs. Each of these parents has agreed to share their story so that policymakers in New Jersey and in Washington, D.C. understand the challenges that they and so many other families face trying to access comprehensive, culturally competent, family-centered healthcare for their children with special needs. As New Jersey's Family to Family Health Information Center, a project of Family Voices-New Jersey at SPAN, we share these stories with you so that together we can make a difference.

¹ There are an estimated 2286,826 children and youth with special healthcare needs in New Jersey, representing over 13% of all children in the state.

The Agoratus Family

“My daughter Stephanie spent her first two weeks of life hooked up to a respirator, heart monitor, feeding tube, and IV in the neonatal intensive care unit at Children’s Hospital of Philadelphia. In addition to being ‘in survival mode,’ we also had to worry about health costs even though we had double coverage. The first bill for Stephanie’s NICU stay was \$28,000 and I figured we were already up to \$60,000 by the time we brought her home. I was on a 10-month leave of absence and another 4 month leave 6 months later. We didn’t qualify for DDD respite, SSI, children’s catastrophic illness program, or any other programs because we both worked and made too much money. We went into debt and almost lost the house. I knew I needed help on information regarding children’s health issues from the beginning. It became more apparent as time went on. Stephanie was developmentally delayed and it took me 1 ½ years to resolve her first claim for physical therapy even though it was listed as a covered expense in both employee handbooks, and I was assured over the phone that it was covered. (Lesson learned: Always get a written, predetermination of benefits.) That’s when I started getting information from Family Voices. *Now I am New Jersey Coordinator for Family Voices and help other families like mine get the services their children need.*”

Lauren Agoratus, familyvoicesnj@aol.com

Anonymous Family

“I am working with a family who have an almost two year old with quadriplegic cerebral palsy. Before the dad lost his job in February, they made too much money to qualify for most Medicaid programs. We applied for the DDD Medicaid waiver program, for which they would have qualified, last June. We were told that the program had been terminated by the state. This was confirmed in a face to face meeting last October and in a subsequent letter in November. The family has outstanding medical bills of around \$4,000.00. The NJ Department of Human Services told us to contact Medicaid. So far, they have been unable to help. The crux of the issue is that the state chose to shut down a program for providing health insurance (and case management) within DDD without first ensuring that a comparable program was created within Medicaid. This has left many families in a dire situation. Meanwhile, I have reapplied for Family Care for the family in order to get current health insurance coverage.”

Stan Jones, Social Worker, Virtual Early Intervention Program, sjones1@virtua.org

The Belko Family

“We are a family of six, 2 parents, a 9 year old boy, three 6 year old girls, one of those with mild cerebral palsy, and all the issues that go along with that. We visit her pediatrician, eye doctor, orthopedist, enterologist, orthotist for brace construction, and the dentist. We have private insurance that we pay for through my husband's employer with large deductibles. We should be getting other therapies for her that we must forego, because we have other children with general health needs as well that need the check ups, the dentist visits etc. As parents we too are a bit older and our healthcare needs are growing as well.”

Katie Belko, Katieb199@verizon.net

The Druskin Family

“My name is Irene Druskin and I have a 19-year old with Asperger Syndrome. I don't have health insurance. My son has Medicaid and I cannot seem to find a doctor that accepts his insurance. He has some health issues as well and we often go without treatment. Unfortunately, I work and cannot afford to take time off to come to the meeting. We basically live paycheck to paycheck. If there is ever a time offered in the evening or on the weekend I feel our situation is worth listening about.”

Irene Druskin, druskinfam@att.net

The Egan Family

“My oldest daughter Bridget became ill at seven months of age. As a result, she is a quadriplegic. For the first few years after getting ill she spent time in and out of hospitals. Over the last six years, Bridget has participated in Early Intervention, Preschool Disabled, and currently her local public school. She continues to have significant health needs and requires ongoing skilled care...She has participated in every available therapeutic intervention, including some clinical trials on major rehabilitation facilities...Canine Companions have provided Bridget with a service dog.

Bridget is the second of four children, and until Bridget became ill both of us (her parents) were working full time. Bridget's significant health needs have necessitated that one of us remain home and available to her. We have had to make significant adjustments based on her level of need.”

Mary Ann Egan, maegan@thestettlergroup.com

Grejda Family

Maria and Dave Grejda live in Riverdale in Morris County. They have four children, the oldest of whom are twin boys, Kyle and Justin, born 1/1/99, who were born with extreme prematurity and many severe health problems. After discharge from a NICU at Children's Specialized Hospital, Kyle was on a state waiver program for private duty nursing care because he had a tracheotomy and ventilator. They each required early intervention and extensive rehabilitation and saw numerous medical specialists. They required pre- school disabled education in an out of district placement and have returned to their school district for elementary special education services. Their father was recently laid off from his job and the family pays over \$1,100.00 per month for COBRA. They don't dare give it up due to health care needs. Kyle had extensive orthopedic surgery in Minnesota last year and is returning for additional surgery this year. Justin also had surgery. The family has two applications pending with the NJ Catastrophic Illness Relief Fund in Children but expended many funds out of their own pocket and borrowed from family members.

Maria & Dave Grejda, kjjmg@aol.com

The Hopkins Family

“When you plan a family, nobody ever expects to have a baby that would end up with 15 specialists at Children’s Hospital of Philadelphia (CHOP) or any hospital - but that is my reality. My nine-year-old boy has been through more than most of us goes through in a lifetime. He is a fighter & I thank God for him, but my experience with the healthcare system has been torturous at times.

I purposely tried to have most of his specialists at CHOP (rated #1 for several years) so that there would be a constant communication between all of his doctors. That is not what I have experienced at all. I have to convince the doctors that they need to talk to each other. The doctors will say to me, ‘Well, I sent the report to them, they haven’t gotten back to me.’ I then will ask them, ‘Could you follow up with them?’ and the general response is ‘Well, I already sent it.’ So I am the one to speak with the other specialists to try to get them to track down the report and deal with the situation. In the midst of them not communicating, my son at times was getting worse. The situation that frustrated me the most was when medical tests would be scheduled and we would get them done and then one of the specialists would say, ‘I wish I knew because he needs more blood drawn.’ So instead of being pricked once, it could be 2 or 3 times because they didn’t communicate. Or when one doctor disagrees with another – instead of them talking – I have to decide which one is right. I have become my son’s doctor and I am the one to say yes or no to procedures. I didn’t get a degree in this field but I have no choice but to make the decisions.

Another issue is insurance. Most of the time, it takes 6 to 12 months to get into a specialist for the first time. You would think after all the time parents have waited for appointments in the hopes to help their child the hospital would make sure all the information about insurance, referrals, prescriptions are in order. That isn’t the case. My friend waited 12 months for a Neurology visit. She ended up getting stuck in the Horizon saga with CHOP (Children’s Hospital of Philadelphia). She thought it was resolved and when she went to the appointment she was told that they would have to cancel because it wasn’t the commercial Horizon but the Medicaid one. When in desperation, she asked for help they said there was nothing they could do and that she would have to reschedule. She said to me – I can’t believe I am going to have to wait again.

Hospitals forget that parents are dealing with their child and all of the medical aspects that go with that – they need help - not more frustration.

Through all of trials and appointments I have learned to become my son’s doctor, nurse, psychologist, insurance expert, time manager, protector, school advocator, and administrator for all the appointments, insurance questions, referrals and most importantly I am his Mom. My son had 65 doctor’s appointments this year and that was less than the following years.

This past year was the first year that CHOP offered me help in the sense of a child specialist, in case, my son needed someone to talk with and help him through all his procedures. I was amazed that now – now I am told about this service. I also have never received help organizing his appointments through the years or making sure doctors communicate. There is a lack of organization and consideration for the families. Medical community should be considering these problems and going out of their way to help families so the families can concentrate on the real problem their child.”

Nicole Hopkins, ndhopkins1@hotmail.com,

The Krill Family

Jessica Krill is the mother of two little girls with special needs. She met with Senator Menendez in Washington two years ago advocating on behalf of Children's Specialized Hospital, where she is also a Family Faculty employee. Jessica says:

"I speak with families on a daily basis on many different issues. Many of the issues involve our healthcare system. Just last week I was in our lobby and a mother was sitting there crying. I approached her and asked her if she was okay. She broke down sobbing horribly to me and said that her second child who was diagnosed with Autism has been denied for speech therapy by there insurance companies. WHY???? Why are these children being denied??? Don't insurance companies realize the earlier the intervention the better chances so many children have to become taxpayers in the future? Why do kids with developmental disabilities get punished because they were born with a disability??? My children were born with a piece of their chromosome missing and were unable to get therapy because it was considered 'developmental.' It is not bad enough that our children will never be able to live a 'normal' life. My passion for this issue is great and I would love to sit down with anyone and discuss healthcare issues."

Jessica Krill

The Krupp Family

"My sister is a young widow with two young children. She lost her husband at the age of 39 to cancer. They were not eligible for insurance through Kenny's company once the COBRA had expired. She is currently working as a consultant and is not eligible for health benefits through her employment. I have tried to get her benefits through but have been faced with many legal issues. The cost for private insurance for herself and her 2 kids is more than \$800 a month and it is becoming more and more challenging for her to find a way to make the payment. She had not been eligible for NJ Child Health insurance in the past and began paying for private insurance. She would be eligible for health insurance under the new pay scale guidelines, however, she was told that she would need to drop her insurance and be without health insurance for six months in order to qualify. This is not a realistic expectation for a single woman with two small children. The thought of being uninsured is scary to someone who already knows the hardship of tragedy. The fact that I have not been able to help my sister who is living on a very modest income saddens me. I know her story personally and am sure that there are many other families in the same position that she is in."

Mary Krupp, mary@progressivestepsnj.com

The Malley Family

"My Carissa has very complex health care needs that we have had to work and advocate for to continually make sure they are met. Currently she has specialists in three states. I have my third Medicaid fair hearing scheduled this month to keep her skilled night nursing services, and I am struggling to find somewhere that will take Medicaid to get her new hearing aids. No traditional health insurance has ever come close to meeting her complex needs."

Dianne Malley, dmalley@spannj.org

The Micheletti Family

The Micheletti family lives in Milford, NJ in Hunterdon County. They had to fight all the way to the appellate court to get medically necessary treatment for their son Jake.

On January 17, 2007, two separate decisions by the Appellate Division of the Superior Court of New Jersey reversed decisions by the State Health Benefits Commission (SHBC). In those earlier decisions, the SHBC had declined coverage for Occupational Therapy, Speech Therapy, and Physical Therapy for their two children with autism.

The SHBC denied requests for services based on its interpretation of non-restorative exclusions contained in the Members Handbook: The plan does not cover services “that are rendered with the primary purpose being to provide the person with...a service or supply that is being provided to promote development beyond any level of function previously demonstrated.” SHBC argued that because the child did not have certain speech or functional skills that were fully developed, they were not obligated to provide service to restore those skills

In the case of *Walter Mankiewicz v. SHBC*, the Appeals Court noted that the SHBC recognized autism as a biologically-based mental illness (BBMI), and that the child suffers from it, and that the therapeutic services were medically necessary. Nevertheless, it denied coverage for these services.

In reversing the SHBC, the Appeals Court decisions held that the denial of occupational, physical, and speech therapy for children with autism went contrary to the NJ Mental Health Parity Act, which specifically names autism and Pervasive Developmental Disorder as covered conditions. The Appeals Court in *Jacob Micheletti v. SHBC* said that the motivation and spirit of the parity statutes is to afford greater coverage to those afflicted with BBMI.

In the Micheletti decision, the Appeals Court made note of a 2005 NJ Department of Banking and Insurance position stated in discussing the Mental Health Parity Act and whether insurance carriers could exclude therapy services for children who are not developing typically: “To allow carriers to exclude the primary mode of treatment for autism and PDD (speech, occupational and physical therapy) would render the statutory directive meaningless and therefore, it cannot be permitted.”

In the Micheletti decision, the Appeals Court held that the prescribed treatment of occupational and speech therapy were traditional, not exotic or wasteful of resources. It also took issue with the SHBC decision to exclude “non-restorative” services, saying, “The words ‘restorative’ or ‘non-restorative’ when used in this context are also ambiguous and largely inapplicable to infants and young children. Every child is born with the potential to develop those skills necessary to life in society. Autistic children and other children afflicted with BBMIs are hindered from achieving that potential.” To read the entire decisions, go to <http://www.judiciary.state.nj.us/opinions/index.htm> and find them under Appellate Court, Published decisions for January 17, 2007.

Joseph and Elizabeth Micheletti, njcm@ptd.net

The Moore Family



Kia Moore is the single parent of Xavier Hylton, age 20 months old, who was born with double kidney failure. At 8 days old he was admitted into the hospital where he stayed for 69 days. Currently Xavaier is on dialysis seven days a week, 16 hours a day. Practically since his birth, Kia has had major problems with insurance coverage and benefit coordination.

Kia's son has double private insurance from her job at American Express and from his father's job. Because he was born with full renal failure, he is automatically qualified for Medicare. However, when she tried to get Medicare benefits for her son in Camden County, no one seemed to have heard of a child being in full renal failure at the time of birth and kept asking her questions about whether or not he could work – and he was only 7 days old! He also should have been automatically qualified for SSI and SSDI as he is totally disabled, yet when she went down to apply for SSI benefits for him, they would not qualify him for disability benefits based on her income.

Kia expressed her frustration with trying to get health care for her son. She has Blue Cross Blue Shield (BC BS) while Xavier's father has Aetna. Initially Aetna was the primary coverage, but she switched so that BC BS is the primary. She had to go all the way to the NJ Department of Banking and Insurance to make it happen. It took over a year to get coordination among the insurers. She needed to go through this process because Aetna refused to cover Xavier's kidney transplant. They wouldn't allow him even to be tested as long as it was coming through St. Christopher's Hospital for Children. Aetna said that Xavier had to go to another hospital and select a whole new medical team of doctors and work with them for a minimum of six months before they could certify him for a transplant. "Here I had a child in critical need for a transplant who was finally big enough to get an adult kidney and they wanted me to go to another place where they could get the best deal! He can not have any transplant that requires steroids; only three hospitals in the country, including St. Christopher's, do steroid-free transplants and Aetna doesn't have a contract with any of those. All Aetna kept addressing in the 3 appeals is denying it is based on continuity of care and offering to let us go somewhere else. They never said anything about his care being managed by the same team since he was a newborn and they never addressed the need for a steroid proof transplant."

Xavier had the surgery, and nursing care was coordinated prior to discharge. Aetna was paying for the nursing care. Then Aetna sent a letter to the hospital saying that they were going to drop the nursing care because he didn't need it. "Your health carrier says you have an unlimited benefit for private duty nursing but we choose to limit it even though your doctor says you need it so, now I have to go and tap a benefit from the state to cover those missing hours; if my policy says I'm entitled to it, I should have it and have it without hassle." After much advocacy, Aetna agreed to cover private duty nursing, but only for 12 hours/day, even though the doctors all agree that he needs a minimum of 16 hours/day.

With the help of her county Special Child Health Services Case Management Unit, she was able to get a nursing care waiver to pay for additional nursing hours. Thankfully, Kia's job is allowing her to work at home to take care of her child; otherwise, she would have to quit her job.

Kia Moore, kilolo@hotmail.com

The Nemeth Family

Barbara Nemeth is a registered nurse at Robert Wood Johnson University Hospital. She has a son, born in March 2007, who has multiple medical problems. Barbara writes:

“I received information that you are looking for families that can tell their thoughts and concerns about healthcare. In March, 2007, my son was born with multiple medical problems. Zachary has a tracheostomy, a feeding tube, and is on a ventilator at night. He receives 16 hours of nursing per day. Zachary actually has 2 private insurance companies. My most recent experience was 2 days ago when I was called at work and told that his nursing benefits would be decreasing to 12 hours and I had less than 24 hours to make other arrangements. I was also told by this insurance company that I should not be working and that I needed to apply for Medicaid for my son. I also have a 9 year old daughter who is hearing impaired and has an auto immune disease (vitaligo) and I can't get equipment to treat the skin condition because they consider the treatment cosmetic. I have so many other experiences also especially since I am dealing with two different insurance companies and trying to coordinate benefits.”

Barbara Nemeth, rnbarbie@aol.com

The Prior Family

My wife, Amy, and I realized our son Benjamin was autistic last summer, and he was officially diagnosed shortly thereafter...Over the next nine months, we confronted the usual emotional hurdles of fear, anguish, sadness, and then total resolution to help our son. We worked tirelessly to research, make doctors' appointments, arrange therapies, and act quickly as though Ben had a traditional “life threatening” illness...We wanted to objectively try methods with little downside that may help Ben, and if they did, then we'd continue them. So far, many of the traditional OT and speech therapies that are recommended for autistic children have indeed helped. I see it everyday. He's improved dramatically. Like so many, we have found that financing an autistic child is a challenging and emotionally draining process. Most of the therapies that help our son are not covered by insurance, and in our case the cost has been over \$13,000, and will certainly increase annually. We've had to make a few sacrifices, but are able to get by. Yet, I'm sure there are many in this economy that cannot.

My hope over the coming years is twofold. First, that there will be greater research, awareness and understanding. With this understanding will then come the realization that many families with Autistic children won't be able to provide what these kids need due to this financial hardship. My hope is that government officials such as Senator Menendez, advocacy groups, and most importantly, parents, can all work together to help.

Adam & Amy Prior, priorae@yahoo.com

The Torres Family

The Torres family includes the mother, whose family is from Columbia; father, whose family is from Puerto Rico; and three children. All of the Torres family was born in the U.S. Alison Torres notes:

“We are a family of five struggling on one income to survive. We have three children diagnosed on the autism spectrum. All three of our children have private insurance through my husband's job and the three children receive Medicaid through social security insurance. We continue to have many trials and tribulations with getting appropriate coverage for the services my children need. I would like to share our stories with Senator Menendez so that he can know the importance of public health insurance and the loop holes that Medicaid currently has in provided needed coverage.

The worse part of our private health insurance is that we have a \$1500 deductible that we need to meet before the insurance will pay 80% of what therapy costs, and they only cover 26 visits per year. With three kids receiving therapy, Gabriel five times a week, Nathan five times a week, and Benjamin three times a week a 20%, our co-pay is really expensive. We cannot afford to take our children to get the therapies they really need.

Our children get Medicaid through SSI. At this time Medicaid picks up our co-pay but two-three months every year Medicaid is suspended. Those months we have to cancel all therapies and our children go without. Also, our private insurance does not cover things like orthotics or diapers through their durable medical department. Through Medicaid, diapers and orthotics are covered but again we lose these benefits for two-three months per year. I am still trying to get our private health insurance to cover ABA therapy but every time I send them documentation they ask for, they then ask for something else, thus dragging it out until I give up (which will be never). With insurance paying for the much needed therapy my children are progressing. When it comes to the two-three months they go without we can see the regression.”

Alison Torres, alnraf226@yahoo.com



What's the next chapter in these stories?

As a Family to Family Health Information Center, Family Voices-New Jersey at SPAN is in a unique position to help families of children with special healthcare needs. Our F2F Center is led and staffed by parents of children with special needs who have directly experienced the challenges of navigating the maze of health care and health coverage. SPAN's F2F staff understand the issues that families face and help them make their own informed decisions through providing information and options, offering a multitude of resources, and connecting families to a network of other families and concerned professionals for support and information.

As a member of the New Jersey Health Care for America Now Coalition (HCAN-NJ), Family Voices-New Jersey at SPAN is actively working to expand access to and enhance the quality of health insurance and health care for all New Jersey children and families, including children and youth with special healthcare needs. As noted by SPAN's Public Policy Director, Peg Kinsell, at an October, 2008 HCAN-NJ press conference, "Access to quality health care is one of the most pressing needs for New Jersey's children and families. In particular, immigrant children and families suffer from a lack of such quality care. Health care is at the core of life, liberty, and the pursuit of happiness, and thus must be seen as a right, not a privilege for a select few." Family Voices-NJ at SPAN reiterates our support for the principles of the HCAN-NJ campaign, including:

- Guaranteed coverage and care for everyone in America;
- Affordable coverage and care, with premiums and out-of-pocket costs based on a family's ability to pay;
- Everyone gets a choice of health insurance plans;
- Standard, comprehensive benefits, with a choice of providers that meet our families' health care needs – from preventive care to care for serious illness;
- Equity in health care access, treatment, research and resources to people and communities of color and strengthening health services in low-income communities;
- Coverage that is predictable and affordable for working families and others;
- Government sets and enforces rules on insurance company practices and charges, requiring them to put our health care before their profits; and
- Controls costs while improving quality, with measures such as lowering administrative expenses, investing in preventive care, actively managing disease, setting standards for performance, reducing medical errors, and using the public's purchasing power to lower drug and other prices.

Family Voices-New Jersey at SPAN also endorses the recommendations of the Governor's Blue Ribbon Advisory Panel on Immigrant Affairs, including but not limited to:

- Improve immigrant access to health insurance and culturally and linguistically competent health services, including through the use of "community navigators/cultural brokers;"
- Enhance targeted outreach to immigrant communities and families with limited English proficiency to increase enrollment in New Jersey Family Care; and
- Enhance treatment capacity for uninsured persons.

Together families, professionals, and policymakers can change health policies and practices so that every child and family has access to quality health care in New Jersey and in our nation. For more information or to join us, contact us at (800) 654-SPAN or familyvoices@spannj.org.