One Family’s Medicaid Story

Just How Important is Medicaid for Children & Youth with Disabilities?
It is with great pleasure that I share with everyone that Joyce Millard Hoie was awarded the Leader of Distinction from the Organization of Nonprofit Executives (ONE).

Joyce was recognized before a room full of nonprofit executives from across the valley. As we stated on the nomination:

Joyce is an innovative leader, a trusted and collaborative communicator, and an effective organizer who consistently anticipates needs and meets them in a prompt and thoughtful manner. She instills, models, and develops the principles of respect, hard work, integrity, self-esteem, encouragement and human dignity.

Please join me in congratulating Joyce on this wonderful and well-deserved recognition!

Karin Smith
President, Board of Directors

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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in English, Spanish and other languages. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)(3) non-profit organization.
Five years ago, Nicole Guysi and her husband, Brett, felt that their young family was drowning financially. All of their money was going toward Brett’s treatment for melanoma and to pay for doctor visits as they tried to find a diagnosis for their young daughter, Brooke.

“We hardly had any money in our savings,” Guysi said. “We were really struggling.”

Then came some good news. Her husband was declared cancer free and doctors finally agreed on a diagnosis for their daughter, which allowed them to know what specific course of treatment she needed.

Brooke was diagnosed with Cohen syndrome, a rare genetic disorder that affects her physical development. It also causes her to have progressive vision loss and weak muscle tone. In addition, Brooke struggles to eat on her own, so she needs a feeding tube.

When they found out Brooke’s diagnosis, Nicole and her husband wasted no time and began taking their daughter to see a number of specialists. Today, Brooke is 6 years old and sees six different doctors: a geneticist, hematologist, dermatologist, ophthalmologist, gastroenterologist and an orthopedic specialist. In addition, she needs several treatment visits from therapists every week.

“Her condition has stabilized since we learned more about it and learned how to be more proactive,” Nicole said.

At first, the private health insurance through Brett’s employer covered most of Brooke’s doctor visits. But they had to pay significant costs in out of pocket expenses for co-pays and deductibles not covered by the insurance. That all changed three years ago when Brooke was approved for the Arizona Long Term Care System, or ALTCS, a Medicaid health insurance program offered through AHCCCS.

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ALTCS covers much of what the family’s private insurance doesn’t, which is a big relief for Nicole and her husband. “We’re finally in a better place financially,” she said.

The couple no longer worries about paying for Brooke’s medical bills or for the various therapies – including speech, occupational, and physical – she receives. As a result, Nicole and her husband were able to buy a house, pay off debt, and build up an emergency fund.

Nicole added that she and her husband no longer have the constant worry about finding money to pay for unexpected doctor visits or trips to the emergency room whenever Brooke gets sick. “Those were drastic circumstances from five years ago which really hurt us financially,” she said.

Now that Congress is considering cuts to Medicaid programs, such as ALTCS, Nicole said she is worried about how that would impact Brooke’s medical care. She fears they’d have to go back to paying out of pocket costs for care their private insurance doesn’t cover. Plus, she knows they’d have to

Nicole said she’d tell [lawmakers] that protecting her daughter’s health means continued coverage from ALTCS. “Keeping Brooke healthy increases the chances that she’ll need less government assistance as she gets older.”

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FACT:
Many children receive **MEDICAID SERVICES** through their schools.

The Medicaid program provides support for children eligible for special education services who have specific healthcare needs that affect their educational performance as identified in their Individualized Education Program (IEP).

There are four conditions that must be met for Medicaid to reimburse schools for IDEA-related services. They are:

- The child receiving the service must be enrolled in Medicaid.
- The service must be covered in the state Medicaid plan or authorized by the federal Medicaid statute.
- The service must be listed in the child’s IEP.
- The school must be authorized by the state as a qualified Medicaid provider.

Where Worlds Collide
Many Children Receive Medicaid Services Through Their Schools
Arizona Symposium on Children with Special Health Care Needs

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raisingspecialkids.org
Our daughter, Brooke, was diagnosed with a rare genetic disorder called Cohen Syndrome in May of 2013. I can’t remember exactly when we were told about Raising Special Kids, but I do know it was very early-- about the time we received our daughter’s diagnosis.

I remember talking with RSK and speaking with a very helpful person who gave me a lot of information. We were at the very beginning of our journey. After “the dust settled” I actually starting taking more time to read all of the material and resource information that was being provided by RSK. It has been so beneficial to our family and a huge blessing. Not only has RSK guided us and given us information to help with our daughter’s care, like IEPs for school, understanding health insurance, changes in policies in AZ, programs that are available, etc.

RSK has been such a great support in helping us find answers. We know who to call if we are feeling overwhelmed, and know that RSK not only understands logically how to help us (which is obviously important), but also understands compassionately how to help us (which is also a necessity as the challenges we face almost daily can really add up and take a toll on you if you don’t have that compassionate support).

RSK has also given me an opportunity to give back. One challenge for families like mine who are sometimes overwhelmed with caring for their child needs is self-absorption. It is very easy to get so focused on your daily struggles that you lose sight of what others are going through. At RSK I’ve been given an opportunity to receive training to become a Parent Leader which has prepared me to help other families and be there for them as a coach and mentor, or for whatever they need. I’ve also been given opportunities to attend conferences and give presentations in meetings for families with children of special healthcare needs. It gives me an opportunity to not only share our story, but to make an impact for ALL families in the special needs community, not just us. It has also given me insight into the programs or resources that families need and how to meet and overcome the challenges we face. Often, it seems like families have to fight for services for their child, and they don’t always have support to learn how to advocate for them (the difference being when advocating you are working with, not against, the program or professional to come to a solution that benefits everyone).

I feel very fortunate to have the chance to collaborate and to work alongside people to accomplish their goals and objectives. Being a Parent Leader means I get to learn about self-advocacy and how working TOGETHER we can find solutions that benefit everyone. All of this has been made possible by Raising Special Kids. They are an amazing resource that truly understands the journey of a family who is raising a child with special healthcare needs.

One of the things I really appreciate about RSK is how they are always there. At the beginning of our journey they were there in the background as we were overwhelmed by all we were learning and doing for our newly diagnosed daughter. As time went on and I wanted to learn more, receive more and do more, RSK was there and is still there, helping me be a better advocate for our daughter and for other families as well. It’s an invaluable gift and one that I will be forever grateful for.
2,800 parents and children had fun at Special Day for Special Kids!
March 18, 2017
Parent Leaders

Thank You! Parent Leaders Are the Heart of Our Mission.

The following Parent Leaders participated in leadership activities from December 2016 through February 2017. We appreciate our 300 Parent Leaders who have been trained to volunteer, but we do not have room to list their names.

Avondale
Jennifer Priddy

Buckeye
Jill Nico

Chandler
Gilbert Alonzo
Dawn Bailey
Marti Baio
Samantha Flores
Aimee Johnson
Beth Kaib
Cathy Turner
Noelle White

Chino Valley
Jody Brigham

Flagstaff
May Sheppard-Ketchner

Gilbert
Randa Canter
Holland Hines
Sonya Kanidis
Karen
McLoughlin
Louise Murphy
Heather Prouty
Kim Updegraff

Glendale
Bethany Alcorn

Becky Getz
Nicole Guysi
Meriah Houser
Cathy Humphrey
Rachael Pirie
Tina Wildoner
Lorie Williams
Michelle Wolfson

Goodyear
Krista Hill

Kingman
Art Gode

Lake Havasu City
Christy Rail
Vijette Saari

Laveen
Bonnie Carroll

Mesa
Carrie Aranda
Cynthia Elliott
Brittany Miller

Peoria
Sharon Blanton
Brittany Johnson
Nicole Swim
Lisa Thomas

Heather Joy
Magdelano
Stephanie
Mickelsen
Maria Del
Carmen Nuñez
Kris
Ohanessian-Dean
Margarita
Ramirez
Jessica
Robertson
Ched Salasek
Sherri Scruggs
Chuck Smith
Gissela Welle
San Tan Valley
Courtney
Burnett
Shauna
Marconato
Jacqueline Tate-Tafoya
LaTasha
Whitaker
Scottsdale
Amber Bailey
Maura Knoell

Steve Lee
Carol
Levenseller
Gina Merola
Laura Michael
Katie Petersen
Carolyn Sostrom
Amy Stroth
Heidi
VanderMolen

Sedona
Julie Perreault

Sun City
Melissa
McQueen

Tempe
Syed
Aitkuzzaman
Crystal Leon
Janet Romo

Tolleson
Sasha Diaz

Tucson
Mindy Kellogg
Melissa Ward

Yuma
Brenda Higuera
Whitney Kala

El Comportamiento Positivo

Aprenda cómo reducir el comportamiento no deseado y aumentar el buen comportamiento mediante apoyos de comportamiento positivo en casa y en la comunidad. Comprenda el papel que juega usted en la conducta de su hijo y cómo trabajar con la escuela cuando el comportamiento interfiera con el aprendizaje.

Criando niños especiales talleres y entrenamientos
www.raisingspecialkids.org o llame al 800-237-3007

Entrenamiento del IEP

Aprenda sobre la educación especial y el propósito del Programa Educativo Individualizado (IEP). Se hablara sobre los siguientes temas: el documento IEP, el papel de los padres dentro la educación especial, cómo prepararse y ser un participante eficaz en las reuniones, quienes son los miembros del equipo del IEP, cómo realizar el seguimiento de progreso de su hijo, y qué hacer si el equipo no está de acuerdo.

Cumpliendo los 18 años - Opciones Legales

Aprenda sobre las diferentes opciones legales que las familias deben considerar cuando sus hijos se convierten en adultos a la edad de 18 años. Familiarícese con los pasos del proceso de la Tutela. Los participantes aprenderán cómo pueden permanecer involucrados en la toma de decisiones con las escuelas, médicos y otros profesionales.
Muchos niños reciben servicios de Medicaid a través de sus escuelas.

El programa Medicaid provee apoyo para niños elegibles para servicios de educación especial que tienen necesidades específicas de atención médica que afectan su desempeño educativo según lo identificado en su Programa de Educación Individualizado (IEP).

Hay cuatro condiciones que deben cumplirse para que Medicaid reembolse a las escuelas los servicios relacionados con IDEA. Son:

- El niño que recibe el servicio debe estar inscrito en Medicaid.
- El servicio debe estar cubierto en el plan estatal de Medicaid o autorizado por la ley federal de Medicaid.
- El servicio debe estar listado en el IEP del niño.
- La escuela debe ser autorizada por el estado como un proveedor calificado de Medicaid.
Thank You for Referring Families

To refer a family, download our referral form from [http://bit.ly/2nQszAI](http://bit.ly/2nQszAI)

Space no longer permits printing individual names. You can find individual names on our website.

AASK
Ability360
Abrazo Central Family Medicine
Achieve Human Services
ACTS
Thank you to the 11 employees who made referrals
Acts of Kindness Pediatrics
Adelante Healthcare
Agua Fria Union High SD
Alhambra Elementary SD
Amphitheater Unified SD
A New Leaf
A Place to Call Home
Applied Behavioral Intervention
ARC
Arizona Autism United
Arizona Care Providers
Arizona Dept of Education
Thank you to the 10 employees who made referrals
Arizona Dept of Health Services
Arizona Developmental Disabilities Planning Council
Arizona Early Intervention Program
Arizona Learning and Literacy Center
Arizona Long Term Care System
Arizona Partnership for Children
Arizona School for the Deaf and the Blind
Arizona State University
Arizona’s Children’s Association
Thank you to the 8 employees who made referrals
ASPIRE
Thank you to the 10 employees who made referrals
A to Z Therapies
Aurora Behavioral Health Autism Speaks
Awakening Seed Private School
AzASSIST
Banner Health
Thank you to the 7 physicians, therapists and social workers who made referrals
Birth to Five
Brain Injury Alliance
Building Resilient Families
Cardon Children’s Medical Center
Thank you to the 10 Cardon’s physicians, therapists and social workers who made referrals
Care First
CASA
Casa de los Niños
Catholic Charities
Catholic Diocese of Phoenix
Centro de Amistad
Chandler Regional Hospital
Chandler USD
CHC Pediatric
Chicanos Por La Causa
Child & Family Resources
Thank you to the 7 employees who made referrals
Childhelp
Child Parent Centers
Chinle Unified SD
Christian Family Foster Care
City of Phoenix Birth-S Program
Clubhouse Therapy
Cochise College Adult Education
Colorado Children’s Hospital Community Legal Services
Corazon Integrated Health Services
CPLC Parenting Arizona
Children’s Rehabilitative Services
Thank you to the 9 physicians, therapists and social workers who made referrals
Davis Montannah AFB
Dept of Child Safety
Thank you to the 8 employees who made referrals
Desert Heights Academy
Desert Shores Pediatrics
Desert Valley Pediatrics
Devereaux Advanced Behavioral Health
Dignity Health
Division of Developmental Disabilities
Thank you to the 81 Support Coordinators who referred families
Desert Heights Academy
Desert Shores Pediatrics
Desert Valley Pediatrics
Devereaux Arizona
Dignity Health
Dr. B’s Children’s Office
Dynamite Therapy
Dysart Unified SD
Early Head Start- PGCCS
Easter Seals Blake Foundation
El Mirage Family Health Center
El Rio Health Center
The Emily Center
EMPACT
EPICS/NAPTAC
Estrella Pediatrics
Exceptional Family Member Program- Ft. Huachuca
Family Partners
Family Service Agency
Family to Family NAMI
Family Voices
Flagstaff Medical Center Foundation for the Blind
GALA
Gateway Pediatrics
Gilbert Unified District
Glendale Union High School District
The Griffins Workshop
Happy Kids Pediatrics
HeadStart
Healing Hearts Pediatrics
Thank you to the 6 employees who made referrals
Housing Hub
Hu Hu Kam Memorial Hospital
Isaac Elementary SD
Urban Family & Children’s Services
Thank you to the 11 employees who made referrals
Jordan Developmental Pediatrics
Juvenile Courts
Keogh Health
La Frontera Behavioral Health
Littleton Elementary District
Longview Community Church
Make Way for Books
Maricopa Home School
Maricopa Integrated Health System
Thank you to the 13 employees who made referrals
Mariana Medical Center
Mariposa Community Health Center
Maximus
Mercy Care Plan
Mesa Pediatrics
Mesa Unified SD
Mikid
Mohave County SNAC
Mountain View Pediatrics
Mountain Park Health Center
Northern Arizona Healthcare
Northwest Pediatric Clinic
PACER Center
Palominas Elementary SD
Paradise Valley Unified SD
Parenting Arizona
Peoria Unified SD
Pediatras Arizona
Pediatrich
Pendleton Pediatrics
Peoria Community Center
Peoria Unified SD
Phoenix Children’s Hospital
Thank you to the 12 physicians, therapists and social workers who made referrals
Phoenix Rescue Mission
Phoenix Union High School District
Pilot Parents of Southern AZ
Pinal Gila Community Child Services
Primavera Online High School
ResCare Workforce Services
Saddle Mountain Unified SD
Salvation Army
SARRC
Save the Family Foundation
Sonoran Sky Pediatrics
Southwest Human Development
Thank you to the 15 employees who made referrals
Southwest Network
St. Johns Unified SD
St. Joseph’s Hospital
St. Nicholas Adoptions
Stern’s Pediatric Clinic
Stride Psychological Services
Sunnyside Unified SD
Sunrise Therapy Services
Sunshine Pediatrics
Teleos Preparatory Academy
Tempe Elementary SD
Terrence Matteo PhD LLC
Terros
TOPS
Touchstone Behavioral health
Thank you to the 6 employees who made referrals
Trumpet Behavioral Health
Tuba City Regional Healthcare
Tucson Medical Center
UMOM
Un Desafio Inc.
UnitedHealthcare
Union Elementary SD
University of Arizona
Vail Unified SD
Valle del Sol
Vermont Family Network
Vista del Camino
Vocational Rehabilitation
The Voice Program
WACOG Head Start
Washington Elementary SD
Whiteriver Unified SD
Wilson Community Center
Wilson Elementary SD
Yuma Union High SD

July - December 2016

raisingspecialkids.org
Early Childhood Education
(Birth - Kindergarten)
Learn the basics of the Individualized Family Service Plan (IFSP) and how to make a smooth transition from early intervention services to preschool at age 3. Participants will learn about the process of evaluation, eligibility and of services provided through an Individualized Education Program (IEP) by your local public school district. The discussion will include the transition process from preschool to Kindergarten and skills parents can help with at home.

IEP Training
Have a better understanding of Special Education and the Individualized Education Program (IEP). The following topics will be discussed: the IEP document, the parent’s role in the special education process, and how to prepare for, and be an effective participant at the meeting. You will learn who is a member of your child’s IEP team, how to track your child’s progress, and what to do if the team does not agree.

Positive Behavior Support
Learn how to reduce unwanted behavior and increase good behavior by using Positive Behavior Supports in your home and in the community. Understand the role you play in your child’s behavior, and how to work with the school when behaviors get in the way of learning.

High School Transition
This workshop explains the IEP transition planning process which should begin for students no later than 16 years of age. Discover how to identify classes, activities and services that help prepare students with disabilities for higher education, vocational training, employment, and additional resources that help with planning for adult life.

Turning 18 - Legal Options
Learn about the different legal options families should consider when their child becomes an adult at the age of 18. Become familiar with the steps of the guardianship process. Participants will learn how they can stay involved in decision-making with schools, doctors and other professionals.

These trainings and more are available statewide and at no cost for families. Please visit our website at www.raisingspecialkids.org for the most current schedule and locations or call 602-242-4366 or 800-237-3007.

To request a Raising Special Kids presentation for your school or organization, see http://raisingspecialkids.org/trainingworkshop-request/ or call our office at 602-242-4366 or 800-237-3007 for more information.
Raising Special Kids Recognized with Outstanding Leadership Award from Council for Exceptional Children

Raising Special Kids is honored and delighted to be recognized with the Linda M. Levine Outstanding Leadership Award. We are so pleased to join with our terrific partners and colleagues, like the Council for Exceptional Children and First Things First, to support and advocate for families of young children with disabilities. The recognition of our work with families of young children inspires us all to even better efforts.