



Raising Special Kids

Families Helping Families

One Family's Medicaid Story

Just How Important is
Medicaid for Children &
Youth with Disabilities?



Connecting

Spring 2017

Spotlight

Joyce Millard Hoie ONE Amazing Executive Director

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 non-profit 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



Karin Smith, Joyce Millard Hoie, Paula Banahan



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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.

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One Family's Medicaid Story

Just How Important is Medicaid For Children & Youth with Disabilities?

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

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.



Guysi Family

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

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."

years old and sees six different doctors: a geneticist, hematologist, dermatologist, ophthalmologist, gastroenterologist and an orthopedic specialist. In addition,

Medicaid health insurance program offered through AHCCCS.

ALTCS covers much of what the family's private insurance doesn't, which is a big relief for Nicole and

figure out which of Brooke's therapies they could afford.

"She absolutely needs every single one of those therapies," Nicole said. "It is devastating emotionally for parents to make those hard decisions."

If she were given a chance to

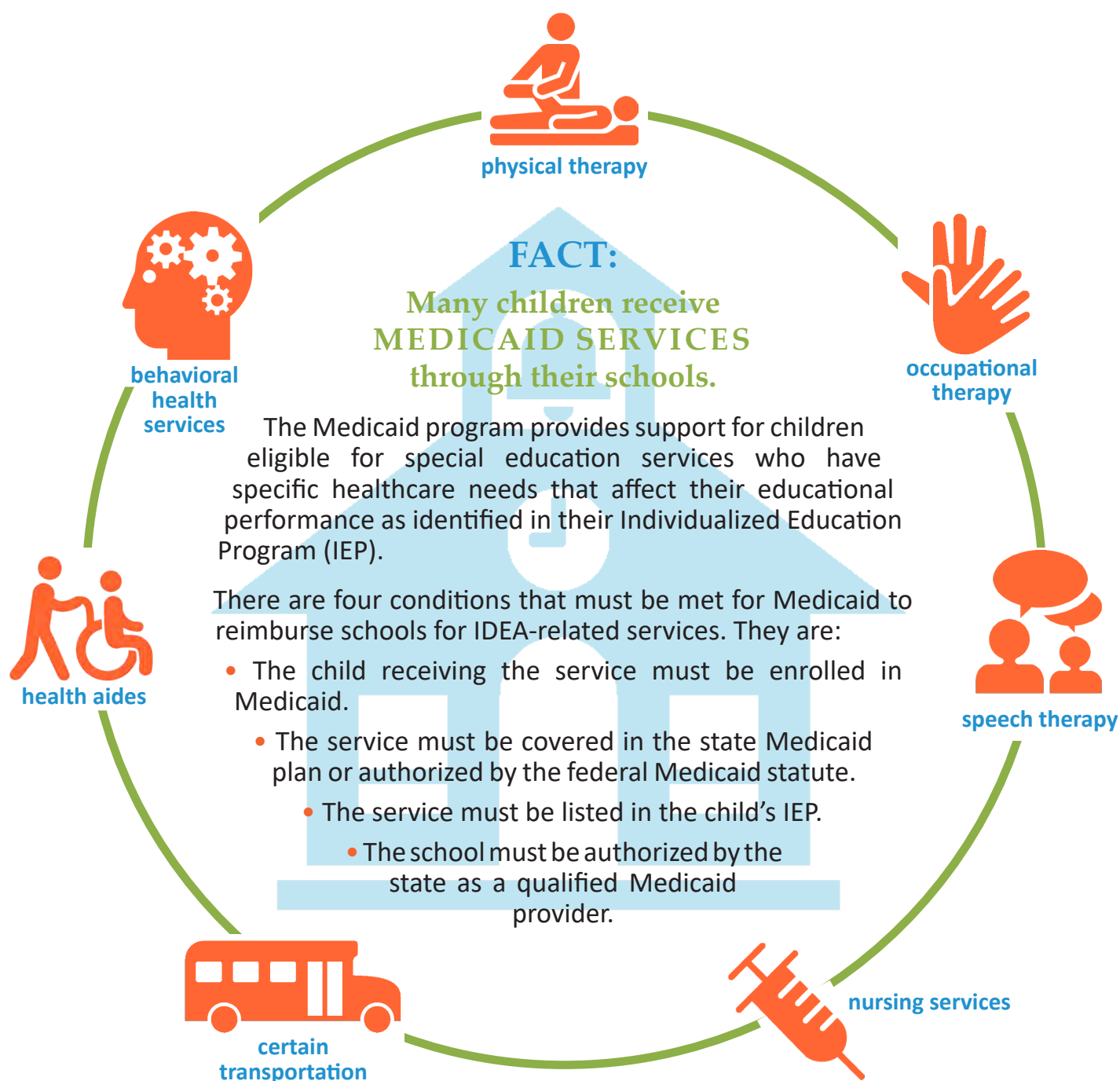
speak with lawmakers who are considering cuts to Medicaid programs, Nicole said she'd tell them that protecting her daughter's health means continued coverage from ALTCS. "Keeping Brooke healthy increases the chances that she'll need less government assistance as she gets

older."

"What I hope lawmakers would do is look at it from both a financial and logical perspective," she said. "If you were to make cuts to Medicaid, what will that do to children like Brooke? Yes, you'd save money, but how does that really save money in the long run?"

Where Worlds Collide

Many Children Receive Medicaid Services Through Their Schools





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Raising Special Kids is Always There

An Invaluable Gift That I Will Be Forever Grateful For



Nicole and Brooke Guysi

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 started 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.

December 2016 - February 2017

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
Niccole Swim
Lisa Thomas



Parent Leader Rachael Pirie and Governor Doug Ducey

Phoenix
Brittany Buchanan
Denise Chrisco
Angela Christensen

Patricia Dean
Isabel Dorame
Claudia Gamez
Marissa Huth
Nicole Kauffman

Heather Joy Magdelano
Stephanie Mickelsen
Maria Del Carmen Nuñez
Kris Ohannessian-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 Atikuzzaman

Crystal Leon
Janet Romo

Tolleson
Sasha Diaz

Tucson
Mindy Kellogg
Melissa Ward

Yuma
Brenda Higuera
Whitney Kala

Criando niños especiales talleres y entrenamientos

www.raisingsspecialkids.org o llame al 800-237-3007



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 interfiere con el aprendizaje.



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.

Éstos, y otros entrenamientos, están disponibles en todo el estado y sin costo para las familias. Por favor vea nuestra página de web para el horario y los lugares más actuales, www.raisingsspecialkids.org, o llame al 800-237-3007.

Donde los mundos chocan

Muchos niños reciben servicios de Medicaid a través de sus escuelas



Thank You for Referring Families

To refer a family, download our referral form from <http://bit.ly/2nQszAI>

July - December 2016

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

AASK	<i>social workers who made referrals</i>	Estrella Pediatrics	Phoenix Children's Hospital
Ability360	Care First	Exceptional Family Member Program- Ft. Huachuca	<i>Thank you to the 12 physicians, therapists and social workers who made referrals</i>
Abrazo Central Family Medicine	CASA	Family Partners	Phoenix Rescue Mission
Achieve Human Services	Casa de los Niños	Family Service Agency	Phoenix Union High School District
ACTS	Catholic Charities	Family to Family NAMI	Pilot Parents of Southern AZ
<i>Thank you to the 11 employees who made referrals</i>	Catholic Diocese of Phoenix	Family Voices	Pinal Gila Community Child Services
Acts of Kindness Pediatrics	Centro de Amistad	Flagstaff Medical Center	Primavera Online High School
Adelante Healthcare	Chandler Regional Hospital	Foundation for the Blind	ResCare Workforce Services
Agua Fria Union High SD	Chandler USD	GALA	Saddle Mountain Unified SD
Alhambra Elementary SD	CHC Pediatric	Gateway Pediatrics	Salvation Army
Amphitheater Unified SD	Chicanos Por La Causa	Gilbert Unified District	SARRC
A New Leaf	Child & Family Resources	Glendale Union High School District	Save the Family Foundation
A Place to Call Home	<i>Thank you to the 7 employees who made referrals</i>	The Griffins Workshop	Sonoran Sky Pediatrics
Applied Behavioral Intervention	Childhelp	Happy Kids Pediatrics	Southwest Human Development
ARC	Child Parent Centers	HeadStart	<i>Thank you to the 15 employees who made referrals</i>
Arizona Autism United	Chinle Unified SD	Healing Hearts Pediatrics	Southwest Network
Arizona Care Providers	Christian Family Foster Care	<i>Thank you to the 6 employees who made referrals</i>	St. Johns Unified SD
Arizona Dept of Education	City of Phoenix Birth-5 Program	Housing Hub	St. Joseph's Hospital
<i>Thank you to the 6 employees who made referrals</i>	Clubhouse Therapy	Hu Hu Kam Memorial Hospital	St. Nicholas Adoptions
Arizona Dept of Health Services	Cochise College Adult Education	Isaac Elementary SD	Stern's Pediatric Clinic
Arizona Developmental Disabilities Planning Council	Colorado Children's Hospital	Jewish Family & Children's Services	Stride Psychological Services
Arizona Early Intervention Program	Community Legal Services	<i>Thank you to the 11 employees who made referrals</i>	Sunnyside Unified SD
Arizona Learning and Literacy Center	Corazon Integrated Health Services	Jordan Developmental Pediatrics	Sunrise Therapy Services
Arizona Long Term Care System	CPLC Parenting Arizona	Juvenile Courts	Sunshine Pediatrics
Arizona Partnership for Children	Children's Rehabilitative Services	Keogh Health	Teleos Preparatory Academy
Arizona School for the Deaf and the Blind	<i>Thank you to the 9 physicians, therapists and social workers who made referrals</i>	La Frontera Behavioral Health	Tempe Elementary SD
Arizona State University	Davis Monthan AFB	Littleton Elementary District	Terrence Matteo PhD LLC
Arizona's Children Association	Dept of Child Safety	Longview Community Church	Terros
<i>Thank you to the 8 employees who made referrals</i>	<i>Thank you to the 8 employees who made referrals</i>	Make Way for Books	TOPS
ASPIRE	Desert Heights Academy	Maricopa Home School	Touchstone Behavioral health
<i>Thank you to the 10 employees who made referrals</i>	Desert Shores Pediatrics	Maricopa Integrated Health System	<i>Thank you to the 6 employees who made referrals</i>
A to Z Therapies	Desert Valley Pediatrics	<i>Thank you to the 13 employees who made referrals</i>	Trumpet Behavioral Health
Aurora Behavioral Health	Devereaux Advanced Behavioral Health	Maricopa Medical Center	Tuba City Regional Healthcare
Autism Speaks	Dignity Health	Mariposa Community Health Center	Tucson Medical Center
Awakening Seed Private School	Division of Developmental Disabilities	Maximus	UMOM
AzASSIST	<i>Thank you to the 81 Support Coordinators who referred families</i>	Mercy Care Plan	Un Desafio Inc.
Banner Health	Desert Heights Academy	Mesa Pediatrics	UnitedHealthcare
<i>Thank you to the 7 physicians, therapists and social workers who made referrals</i>	Desert Shores Pediatrics	Mesa Unified SD	Union Elementary SD
Birth to Five	Desert Valley Pediatrics	MiKid	University of Arizona
Brain Injury Alliance	Devereaux Arizona	Mohave County SNAC	Vail Unified SD
Building Resilient Families	Dignity Health	Mountain View Pediatrics	Valle del Sol
Cardon Children's Medical Center	Dr. B's Children's Office	Mountain Park Health Center	Vermont Family Network
<i>Thank you to the 10 Cardon's physicians, therapists and</i>	Dynamite Therapy	Northern Arizona Healthcare	Vista del Camino
	Dysart Unified SD	Northwest Pediatric Clinic	Vocational Rehabilitation
	Early Head Start- PGCCS	PACER Center	The Voice Program
	Easter Seals Blake Foundation	Palominas Elementary SD	WACOG Head Start
	El Mirage Family Health Center	Paradise Valley Unified SD	Washington Elementary SD
	El Rio Health Center	Parenting Arizona	Whiteriver Unified SD
	The Emily Center	Peoria Unified SD	Wilson Community Center
	EMPACT	Pediatrics Arizona	Wilson Elementary SD
	EPICS/NAPTAC	Pendleton Pediatrics	Yuma Union High SD
		Peoria Community Center	
		Peoria Unified SD	

Raising Special Kids Workshops & Training

Register online at www.raisingpecialkids.org or call 602-242-4366 | 800-237-3006



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.



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.



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.



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.

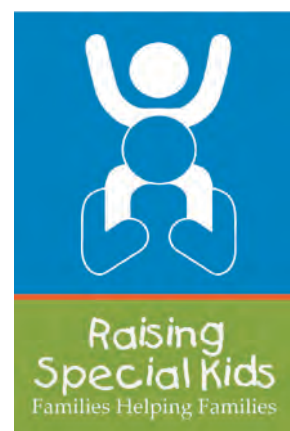


Turning 18 - Legal Options

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.raisingpecialkids.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://raisingpecialkids.org/trainingworkshop-request/> or call our office at 602-242-4366 or 800-237-3007 for more information.



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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.

