

# Raising Special Kids



#### From the Director

#### Reflections on the Walk Out

Recently, children across the State of Arizona experienced an unplanned pause in their education as Teachers walked out of classrooms for higher wages and secure, sustainable, education funding.

As Arizona's Parent Training and Information Center, Raising Special Kids is often asked to comment publicly on events that may impact students with disabilities and special health care needs and their families. In response to this we landed on a few key points:

- Our experience is that parents and families raising a child or children with disabilities are resilient in the face of challenges, whatever form those challenges take.
- Parents of children with disabilities often struggle with appropriate child care under normal circumstances.
- A walkout is a change in the educational routine for students that may have the similar result we would see over a holiday break. Skills that students are developing in school may be lost, or may take time to relearn, after coming back from a planned, or unplanned, break from school.
- Special Education services not delivered to a child, through no fault of their own, need to be made up, and public schools will need to work with parents and IEP Teams to ensure the child receives the services and supports entitled to them under the IDEA.

All of that being said, and whichever side of the debate we find ourselves, I would like to thank the broader Arizona community for their service during this time. A mentor of mine once said, "I'm less concerned with assigning fault as I am finding a solution." Churches, City Parks and Recreation Departments, Boys and Girls Clubs, YMCAs, Community Centers, Day Care facilities, Friends, Neighbors, and all that opened their doors and rallied volunteers for the hundreds of thousands of Arizona families whose children were out of school, we say, "Thank You for helping families find a solution."

Christopher Tiffany, MEd

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This publication is partially supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the Family to Family Health Information Centers, CFDA No. 93.504. The information, content, and conclusions should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.



Connecting is published by

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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.

#### In Their Role as Their Child's First Teacher

Being the parent of an infant or young child is an important job, but it isn't an easy one.

First Things First knows that today's parents are looking for easily accessible, high-quality parenting information. That's why FTF partners with families to provide resources and tools to help them support the growth and development of infants, toddlers and preschoolers in Arizona.

#### **DIGITAL PARENT KIT**

For example, the FTF digital Parent Kit is designed to support parents from the day they bring baby home, to the ages and stages of a young child to caring for your family's physical and emotional well-being.

The kit covers a wide-range of topics from pregnancy, child development, safety, physical and emotional health, to finding quality child care. The information is presented through useful tips and dependable online information and resources to help parents do their best in supporting the healthy development of their baby, toddler or preschooler.

## QUICK ANSWERS: BIRTH TO 5 HELPLINE

Another resource is the FTF-funded Birth to 5 Helpline, (1-877-705-KIDS). This program is free and open to all Arizona families with young children birth to age 5, who want the latest child development information from experts in the field. Have a question about your baby's sleep schedule? Give them a call. The experts field questions on everything from health and

nutrition, safety to potty training and more.

#### PARENTING CLASSES

FTF funds family resources throughout Maricopa centers County. At these comprehensive centers for families of kids birth to age 5, the focus is on strengthening families, providing positive parenting tools and nurturing childhood development. early Families and caregivers can attend parenting classes on topics such as early literacy, the importance of play to children's learning and how to deal with challenging behaviors. To find one near you, visit: http:// www.familyresourceaz.org/.

## IDENTIFYING QUALITY CHILD CARE

FTF is also there to help families identify what quality looks like in child care and preschool settings. Knowing that a child's early childhood experiences are achieved through a variety of methods, FTF helps parents understand what a quality early learning environment looks like. Whether it is through at-home care by a trusted adult or in a child center, check out FTF's signature program, Quality First. The website, qualityfirstaz.com gives tips on what quality looks like and types of questions to ask when choosing a caregiver.

#### THE GIFT OF YOU

Remember, one of the best ways to be a child's first and best teacher is to give your son or daughter your time. Everything they see and experience, especially positive interactions with the adults in their lives, shapes them.

continued on page 2

#### We Hear It All the Time!

Almost every day at Raising Special Kids, parents share with us that they have received this advice from other parents or professionals:

"More than anything, your child is a child first. As much as possible, treat them as you would any other child in your family. Their diagnosis or disability should not define them."

Our friends at First Things First know a thing or two about parenting and have shared with us some great advice and information. Whether or not a child has a diagnosis or a disability, the resources in the adjacent article will be useful for new parents.

If you are ever concerned about how your child is developing, it is always best to ask your pediatrician. They can provide you with additional resources or, if necessary, refer you to specialists for further evaluation.

looking you are information specific to children with disabilities, reach out to us at Raising Special Kids and one of our family support specialists will provide you with resources and support specific to your needs. Call 602-242-4366 or 800-237-3007 or email info@ raisingspecialkids.org.

Look for opportunities every day to read, talk, sing and play together. These experiences will mean the most to a young child's learning and build memories that last a lifetime. And best of all, time doesn't cost a dime. These types of quality interactions between adults and a young child are what will help them make sense of the world. You can get other parenting tips by signing up for the FTF First Things newsletter at FirstThingsFirst.org.

First Things First (FTF) is a votercreated, statewide organization that funds early education and health programs to help kids be ready to succeed when they enter kindergarten. Decisions about



how those funds are spent are made by local councils staffed by community volunteers. To learn

more, visit FirstThingsFirst.org.



### **Raising Special Kids Symposium**

Bringing together professionals and parents who have children with special health care needs

Parents and professionals alike raved about the sold-out Raising Special Kids Symposium on Children With Special Health Care Needs which was made possible by our generous sponsors including United HealthCare, Blue Cross Blue Shield of Arizona, First Things First, Mercy Care Plan and Mercy Maricopa Integrated Care.



Joe Gaudio accepting Title Sponsor Award for UHC from Chris Tiffany.

Presenters and sponsors gathered the evening prior to the



Platinum Sponsor Award for Blue Cross Blue Sheild of Arizona.

event at Seasons 52 in Phoenix to meet and discuss their mutual interests and diverse methods of supporting families of children with disabilities.

LEADERSHIP CIRCLE

Members of the Julia Leadership Circle including the group's namesake,



Julie Beckett sharing the inspiring story of her daughter Katie, the first recipient of the Medicaid Waiver which allowed her to receive services in her home rather than in an institutional setting.

Julia Banahan and her parents Jim and Paula, were also in attendance. Organizations and individuals become members of the JLC once their annual donations to Raising Special Kids reach \$1,000.



Chris Tiffany presenting Platinum Sponsor Award for First Things First.

The Symposium began with an inspirational keynote by Julianne Beckett who shared the story of how she and her daughter Katie paved the way for millions of children with disabilities to receive home- and community-based services. At the conclusion of her presentation, Ms. Beckett challenged the crowd to

"Get out there and lead!" Adding, "Your kids can be powerful!"

One parent shared, "When we left we sat in the car and just cried! The knowledge we gained, and the feeling we are not alone, was overwhelming!"

While one professional shared, "This is one of the most valuable and well-run events I have been to. The speakers were excellent."

Learn more about the speakers and topics at <u>rsksymposium.org</u>.

Follow us on Facebook to keep up to date with information on the next Symposium scheduled for October 2019. The focus for 2019? Behavior and behavioral health.



Recognizing Platinum Sponsors Mercy Care Plan and Mercy Maricopa Integrated Care.

### "They Taught Me to Advocate for My Son"

One parent's full-circle journey with Raising Special Kids

Jennifer Delgado is a full-time certified pharmacy technician and a single mom of three beautiful kids. She loves to read and work out. Although 5-10K obstacle courses are her favorite activities, she recently completed her second half-marathon.

Jennifer's youngest child, Gabriel, is a happy, smiling 10-year-old boy who loves to give hugs. When he was 5 years old, he was diagnosed with autism. Jennifer recalled, "Even before his diagnosis, I knew something was going on with him. Little did I know, our lives were going to change forever."

Once Gabe had a diagnosis, Jennifer began identifying what next steps she needed to take. She worked to separate areas that were simply part of his unique personality from areas where Gabe really needed help to develop his skills. She remembered, "If it hadn't been for tenacity, a deep fighting strength that came from the support and love of friends and



Gabe, Isabel and Isaiah



Jennifer Delgado family

family, I don't know where I'd be today."

At one point, someone in her circle of support recommended she call Raising Special Kids. Jennifer shared, "When I called, they listened, guided me through the IEP process, helped me understand how to deal with challenging situations at school, gave me resources to seek help for my son, and encouraged me; they taught me to advocate for my son."

Having a student with autism has been a learning experience for Gabe's school as well. Cooperating with his IEP team has become easier for Jennifer. She is happy the school's increased awareness will help them more easily accept future students with autism, effectively address their behaviors, and provide them with appropriate academic challenges. Increased school support and private tutoring have helped Gabe's academics soar

to new heights, giving Jennifer a sense that the future will be OK for him.

Jennifer is now a volunteer parent leader with Raising Special Kids. Sharing her thoughts on why she wanted to become a parent leader, she said, "You can't put a price tag on kindness, compassion and peace of mind. Every parent struggles with making the right decision for his or her child and they all need encouragement, hope and acknowledgment for doing the best he or she can with the resources they have." She added, "If I can help just one person and make a difference in their life, it's all worth it. When I hear back from a parent with good news, I am so thankful this process has come full circle. What was once a difficult time in my life helped me grow into a better mother and person. I'm grateful for this special life."

## Raising Special Kids Workshops & Training

Register online at www.raisingspecialkids.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 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.



**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 <u>www.</u>
<u>raisingspecialkids.org</u> 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.



**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.





Ser padre de un lactante o niño pequeño es un trabajo importante, pero no es fácil.

First Things First sabe que los padres de hoy buscan información sobre la crianza que facilite el acceso fácil y de alta calidad, por lo que FTF se alía con las familias para proporcionar recursos y herramientas para ayudarles a apoyar el crecimiento y desarrollo de lactantes, niños pequeños y niños en edad preescolar en Arizona.

#### KIT DIGITAL PARA PADRES

Por ejemplo, el Kit digital para padres de FTF está diseñado para apoyar a los padres desde el día en que lleven al bebé a casa hasta las edades y etapas de un niño pequeño y hasta cuidar el bienestar físico y emocional de su familia.

El kit cubre una amplia gama de temas, desde embarazo, desarrollo infantil, seguridad, salud física y emocional hasta que pueda encontrar cuidado infantil de calidad. La información se presenta mediante tips útiles e información y recursos confiables en línea para ayudar a los padres a hacer su mejor esfuerzo por apoyar el desarrollo saludable de su bebé, niño pequeño o en edad preescolar.

### RESPUESTAS RÁPIDAS: LÍNEA DE AYUDA DEL NACIMIENTO HASTA LOS 5

Otro recurso es la línea de ayuda del nacimiento hasta los 5 financiada por FTF (1-877-705-KIDS). Este programa es gratis y está abierto a todas las familias de Arizona con niños pequeños, desde el nacimiento hasta la edad de 5 años, que quieran la información más reciente sobre desarrollo infantil de parte de expertos en esta área. ¿Tiene preguntas sobre el horario de sueño de su bebé? Llámelos. Los expertos responden

#### ¡Lo escuchamos todo el tiempo!

Casi a diario, en Raising Special Kids, los padres nos comparten que otros padres o profesionales les han dado el siguiente consejo:

"En Primer lugar su hijo es un niño. En la medida que sea posible, trátelo como trataría a cualquier otro niño de su familia. Su diagnóstico de discapacidad no debe definirlo".

Nuestros amigos de First Things First saben algo sobre lo que significa ser padres, y han compartido con nosotros ciertos consejos e información muy buenos. Los recursos del artículo adyacente serán útiles para los padres de niños pequeños, con o sin discapacidad diagnosticada.

Si en algún momento Ud. tiene algunas inquietudes sobre el desarrollo de su hijo, siempre es mejor hacérselo saber a su pediatra, quien le podrá brindar recursos adicionales o, de ser necesario, canalizarlo con especialistas para una valoración más profunda.

Si está buscando información específica para niños con discapacidades, contacte a Raising Special Kids, y uno de nuestros especialistas de apoyo familiar le proporcionara los recursos y el apoyo específico a sus necesidades. Llame al 602-242-4366/800-237-3007 o envíe un correo electrónico a info@aisingspecialkids.org.

preguntas sobre cualquier tema, desde salud y nutrición hasta seguridad y entrenamiento para ir al baño y más.

#### **CLASES DE CRIANZA**

FTF financia cuenta con centros de recursos familiares por todo el condado de Maricopa. En Estos centros integrales son para familias que tengan niños de recién nacidos hasta la los 5 años de edad, el enfoque es para fortalecer a las familias, brindándoles herramientas de crianza positivas y fomentando el desarrollo de la infancia. Las familias y los cuidadores pueden asistir a clases de crianza sobre temas como la alfabetización temprana, la importancia de los juegos para el aprendizaje infantil y cómo lidiar con comportamientos desafiantes. Para localizar uno un centro cerca de usted, visite http://

www.familyresourceaz.org/.

## IDENTIFICAR CUIDADO INFANTIL DE CALIDAD

FTF también está ahí para ayudar a las familias a identificar si hay

calidad en el cuidado infantil y los entornos preescolares. Sabiendo que las experiencias de la infancia temprana se alcanzan por medio de varios métodos, FTF ayuda a los padres a entender cómo se ve un entorno de aprendizaje temprano de calidad. Ya sea mediante cuidado en casa por parte de un adulto de confianza o en un centro infantil, eche un vistazo al famoso programa de FTF, Quality First (la calidad es primero). El sitio web, qualityfirstaz.com da sugerencias sobre cómo debe ser la calidad y sobre los tipos de preguntas que hay que hacer al escoger a un cuidador.

#### **EL REGALO PARA USTED**

Recuerde, una de las mejores maneras de ser el primero y mejor maestro de un niño es darle a su hijo o hija su tiempo. Todo lo que ven y experimentan, en especial las interacciones positivas con los adultos en sus vidas. los forma.

Todos los días busque oportunidades de leer, hablar,

cantar y jugar juntos. Estas experiencias significarán mucho para el aprendizaje de un niño pequeño y crearán recuerdos que durarán toda la vida. Además, lo mejor de todo es que el tiempo no cuesta un centavo. Este tipo de interacciones de calidad entre adultos y un niño pequeño es lo que le ayudará a entender el mundo. Puede obtener otros tips de crianza si se inscribe al boletín de FTF *First Things* en <u>FirstThingsFirst.org</u>.

First Things First (FTF) es una organización creada por electores a nivel estatal que dan la financiación para programas de educación de la temprana edad y salud para ayudar a los niños a estar listos para tener éxito cuando entren al jardín de niños. La toma de decisiones sobre cómo se deben gastar estos fondos las hacen los consejos locales dotados con el personal voluntario y comunitario. Para más información, visite <u>FirstThingsFirst.</u> org.

### Talleres y entrenamientos

www.raisingspecialkids.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.



**Entrenamiento del IEP** 

Aprenda sobre la educación especial y el propósito del Programa Educacional Individualizado (IEP).



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.

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, <u>www.raisingspecialkids.org</u>, o llame al 800-237-3007.

#### To refer a family, download our referral form from <a href="http://bit.ly/2nQszAl">http://bit.ly/2nQszAl</a>

A New Leaf A to Z Therapies Ability360 Abrazo Community Health Network American Leadership Academy Charter School **Applied Behavioral Interventions** Arizona Autism Coalition Arizona Charter Academy Arizona Cooperative Therapies Arizona Department of Child Safety Arizona Department of Education Arizona Department of Education/ Arizona Developmental Disabilities Planning Council Arizona Pediatric Neurology & Neurogenetics Associates Arizona Pediatric Pulmonary Arizona State Schools for the Deaf and the Blind Arizona Youth & Family Services Arizona's Children Association Assurance Health & Wellness Center **AZ Care Providers** AZA United Banner Health Benevilla Booker T. Washington Child Development Center Canyon Vista Medical Center Cardon Children's Medical Center Care1st Avondale Resource and **Housing Center** Care1st Health Plan Arizona

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Children's Clinics-Tucson CRS Christian Family Care Community Health Center of

Yavapai

Court Appointed Special Advocates

Davis-Monthan EFMP

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Arizona Early Intervention Program Division of Aging and Adult Services Division of Developmental
Disabilities
Division of Employment and

Rehabilitation Services/ Rehabilitation Services Administration

Desert Senita Community Health Center

Desert Valley Pediatrics Dignity Health Center for Transitional Care

DMG Children's Rehabilitation Services

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Gila River Health Care
Happy Kids Pediatrics
Healing Hearts Pediatrics
Heritage Health Care Center
HRT

Institute for Human Development Isaac Elementary School District Jewish Family & Children's Service Joubert Syndrome & Related

Disorders Foundation
Kidabilities Occupational Therapy
Laveen Elementary School District
Liberty Elementary School District
Litchfield Elementary School
District

Maricopa Integrated Health System

Mariposa Community Health Center

Maya Charter High School Mesa Public Schools Mountain Park Health Center Mountain View Pediatrics New Life Center

NOAH — Neighborhood Outreach Access to Health

North Country HealthCare Northern Arizona Healthcare Northwest Clinic for Children Open Hearts Family Wellness Page Unified School District
Paradise Valley Unified School
District

Parent Aid Pendleton Pediatrics

Peoria Unified School District Phoenix Children's Hospital Phoenix Head Start Program

Phoenix Indian Medical Center Phoenix Union High School District

Pilot Parents of Southern Arizona Pinal Gila Community Child

Services RAK Magazine RISE Services

Roosevelt Elementary School District

SAGE Counseling Save the Family

Sharing Down Syndrome Arizona Sierra Vista Unified School District

Southwest Autism Research & Resource Center (SARRC)

Southwest Behavioral & Health Services

Southwest Human Development Southwest Key Programs St. Joseph's Hospital

Stride Psychological Services Summit Regional Healthcare

Medical Center Sunshine Pediatrics SySTEM Phoenix Cha

SySTEM Phoenix Charter School

Terros Health The Clubhouse TOPS

Touchstone Health Services
Tucson Unified School District
UMOM New Day Center

University Family Care

Valle Del Sol

WACOG Head Start

Yavapai County Community Health Services

Yavapai Pediatrics

Yuma High School District

#### A Guide for Getting & Using Your Health Records

The steps, tips, and tools you'll need to get, check, and use your health records

#### LEARN HOW TO GET YOUR HEALTH RECORD

The Guide to Getting & Using Your Health Records is for patients, parents, and caregivers who want to get their health records. A health record (also known as a medical record) is a written account of a person's health history, including appointment notes, prescriptions, treatments, tests, and vaccines. It's also for people who need the record of someone they represent or care for, like a child, elderly parent, or an adult with a disability.

#### YOU HAVE A RIGHT TO YOUR HEALTH RECORD

According to federal law, you have a right to see and get a copy of your health record from most health insurance plans and health care providers, including clinics, hospitals, pharmacies, labs, and nursing homes. Yet it can be a real challenge to get your health record if you've been cared for by multiple doctors in multiple places. Each one may have a different process for asking for and getting your record

#### HOW TO GET YOUR HEALTH RECORD — **AND USE IT**

The guide is to help you through the process of getting your health record. It will show you how to make sure your records are accurate and complete — and how to use them to get the most out of your health care.

You can access the guide at:

https://www.healthit.gov/how-to-get-your-healthrecord/

#### Parent Leaders

Thank you! Parent Leaders are the heart of our mission.

**Avondale** 

Belinda Johnson

Buckeye

Angie Jeffreys

Jill Nico

Cave Creek

Sarina Siebenaler

Chandler

Susan Alonzo

**Christy Holstad** 

Aimee Johnson

Lisa Myers

Kara Swierz Chino Valley

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Kris Ohannessian-Dean

Niccole Swim

Phoenix

Karla Bautista

Rosa Chacon

**Susan Coates** 

Lucia Cota Aimee Craumer

Cecilia Hartke

Marissa Huth

Adriana Jimenez

Gabriel Maytorena

Anna Olea

Stephanie Mickelsen Kimberly Poeling

Sherri Scruggs

**Eadie Smith Carol Stanton** 

Susie Turrey

Queen Creek

Kin Counts

San Luis

Melissa Velez

Scottsdale

Jill Castle

Nicole Kauffman

Maura Knoell

Steve Lee

Laura Michael

Katie Petersen

Heidi VanderMolen

Sedona

Julie Perreault

Sun City

Melissa McQueen

Surprise

Jessika Moreno

Tempe

Stephanie Bayliss Janet Romo

Tolleson

February - April 2018



Thank you to Parent Leader Ellen Wilson for representing Raising Special Kids as an ADHS OCSHCN Advisor serving on the Arizona Safe Sleep COIIN project and presenting on a COIIN Safe Sleep National webinar.

Brisneida Ceron

Tucson

Courtney Deeran Jaclyn Larson Kimberly Williams

Yuma

Jennifer Delgado

The Parent Leaders listed above participated in leadership activities from February through April 2018. We appreciate each of our 300 Parent Leaders, but we do not have room to list all of their names.

Raising Special Kids 5025 E Washington, Ste #204 Phoenix, AZ 85034

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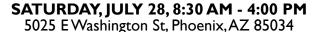
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#### FOR PARENTS, YOUTH & YOUNG ADULTS

(Youth & young adults aged 14-26 invited. If under 18, must be accompanied by a parent or guardian)

Whether you're a parent, a teen, or a young adult, participating in this day-long interactive event will help you learn about yourself and develop ideas of what you can do NOW that will contribute to a successful transition.



(fragrance-free building)

please register at <a href="https://bit.ly/2rHQFRg">https://bit.ly/2rHQFRg</a>





