

## Reforming Health Care

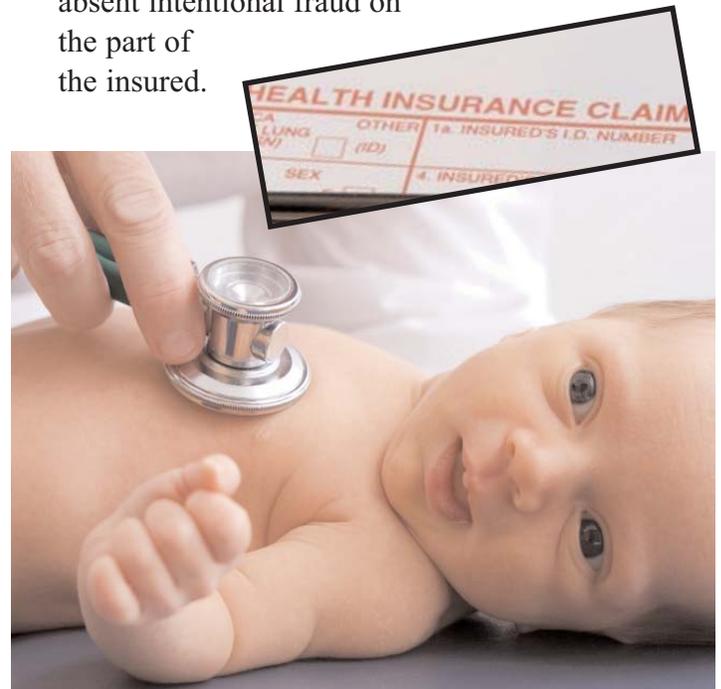
The new health care reform law went into effect on September 23, 2010 and makes changes in our nation's health care system for children and youth with special health care needs and disabilities. How and when some of the changes affect consumers varies greatly depending on whether their plan is new or "grandfathered" (*see box on page 4*) and when the re-enrollment period for their plan occurs.

Benefits of note to families of children and youth with special health care needs and disabilities include:

### **Elimination of lifetime benefit caps and a prohibition against rescinding coverage when someone gets sick.**

*Example 1:* A premature baby is in the hospital for many months and has been diagnosed with multiple health issues. Due to the length of stay in the hospital, the family is near reaching its lifetime maximum for the child. With the elimination of

lifetime caps, the family will not have to worry whether their child will be able to continue to receive medical treatment. *Example 2:* A family has had coverage for several years. Their teenage child is injured and needs expensive rehabilitation. The insurance company suddenly rescinds the policy, claiming that the family had failed to disclose that the child had the pre-existing condition of acne, and therefore, the policy is invalid. The new law prohibits such cancellation of policies, absent intentional fraud on the part of the insured.



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lifetime caps, the family will not have to worry whether their child will be able to continue to receive medical treatment.

*Example 2:* A family has had coverage for several years. Their teenage

### **A prohibition against denying children coverage for treatment of pre-existing conditions.**

(As of September 23, 2010, children have access to insurance regardless of pre-existing conditions. By 2014, no one can be denied access to insurance or coverage for treatment related to a pre-existing condition.)

— continued on page 3

# From the Director...

It was 1979 when Betsy Trombino started doing “pilot parents” at her kitchen table. Convinced that parents of children with disabilities needed the support and encouragement of experienced families, Betsy and others founded an organization to provide it. Information about Parent to Parent mentors was kept on note cards and filed in a recipe box. Parent training lasted for weeks, and one of those parent volunteers was Peggy Storrs.

If you remember what you were doing 25 years ago (I have to admit to that and more), you might recall things were a bit different. In 1985, Pilot Parent Partnerships became a nonprofit organization, and Peggy was employed as a receptionist. Sometimes when the call volume was heavy, Peggy would shake a box of paper clips to attract attention and some back-up support. Peggy handled so many calls from parents and others over the years that people she had never met would often tell me how wonderful it was to hear the warmth, caring, and personality she expressed over the telephone. I heard this comment so many times in my first few years at Raising Special Kids that I started calling Peggy, The Voice of Pilot Parents — and she is.

Nearly an entire generation of children were born and raised during the time Peggy has been at Raising Special Kids. Parents at all stages of their journeys have been helped by a good listener- with kindness and compassion — someone who knew how important the lifeline of parent support can be to a family who just received life-changing news.

Thank you, Peggy, on behalf of all those families for your twenty-five years of exemplary service. Maybe it is a long time, and we’re grateful for all those years, but it’s not long enough.



**Raising  
Special Kids**®  
*families helping families*

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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 both Spanish and English. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)3 non-profit organization.

continued from page 1 —

*Example 1:* Sally, age 7, has cerebral palsy and is in need of a baclofen pump to assist with spasticity. Prior to the law’s passage, the insurance company could have denied this due to her pre-existing condition of cerebral palsy. With passage of the law, this should no longer happen.

*Example 2:* A 6-month old is discovered to have a congenital heart defect. The insurance company refuses to cover necessary surgery because the defect is considered a pre-existing condition. This is prohibited under the new law.

*Example 3:* Laurie has Down Syndrome. Since children can no longer be denied insurance policies due to pre-existing conditions, Laurie’s family will be able to add her to their plan.

**DID YOU KNOW?**

“Over 60% of all bankruptcies in America are the result of medical debt or lost employment due to illness, even though three quarters of these individuals have health insurance and most own their own homes.”

*2010 Health & Disability Working Group*

**The establishment of a national high-risk pool for those who have been uninsured due to pre-existing conditions** (until 2014, when insurance can be purchased on “Exchanges”).

*Example:* Christina, a self-employed young adult, age 28, has been unable to get insurance due to her Type 1 diabetes. If she has been uninsured for at least six months, she can get coverage through a high-risk pool that will be established within the 90 days from the signing of the bill.

continued on page 4 —

“One in five households with children in the United States have at least one child with special health care needs.”

*Data Resource Center for Child & Adolescent Health*

**91% of children with special health care needs (CSHCN) have 1 or more conditions on the list of sixteen shown below.**

COMMON CONDITIONS	% OF CSHCN
Allergies	53%
Asthma	38%
ADD/ADHD	30%
Depression, anxiety, or emotional problems	21%
Migraine/frequent headaches	15%
Mental Retardation	11%
Autism or autism spectrum disorder	5%
Joint problems	4%
Seizure disorder	4%
Heart Problems	4%
Blood problems	2%
Diabetes	2%
Cerebral Palsy	2%
Down Syndrome	1%
Muscular dystrophy	0.3%
Cystic fibrosis	0.3%

**85% of CSHCN experience 1 or more of the following functional difficulties and 28% of CSHCN have 4 or more of the difficulties listed.**

FUNCTIONAL DIFFICULTIES	% OF CSHCN
Respiratory problems	43%
Learning, understanding, or paying attention (ages 2–17 yrs old)	41%
Feeling anxious or depressed	29%
Behavior problems	28%
Speaking, communicating or being understood	23%
Making & keeping friends (ages 3–17 yrs old)	20%
Chronic pain	18%
Gross motor	14%
Self care (ages 3-17 yrs old)	12%
Fine motor	11%
Swallowing, digesting food, or metabolism	10%
Difficulty seeing even with glasses	4%
Blood circulation	2%
Uses a hearing aid	1%

Source, both tables: 2005-2006 National Survey of Children with Special Health Care Needs, [www.cshcndata.org](http://www.cshcndata.org)

**A requirement that young adults be permitted to stay on their parents' insurance policies until age 26, unless they have an offer of employer coverage.**

*Example:* Sam is a 23-year old with spina bifida, unable to find a job since he graduated from college, and unable to get insurance on his own because of his pre-existing condition. Under the new law, Sam can stay on his parents' insurance until he is 26 years old.

**No-cost preventive care for children in new insurance plans (excluding ERISA plans), based on the "Bright Futures" recommendations of the Maternal and Child Health Bureau and the American Academy of Pediatrics.**

*Example:* Children will be able to receive comprehensive preventive care, including developmental screenings, at no cost.

**Extension of funding for Family-to-Family Health Information Centers.**

Other important provisions, to take effect in 2014, include:

- Expansion of the Medicaid program to all individuals with incomes up to 133% of the federal poverty level. (Currently, states cannot receive federal Medicaid funds for covering childless adults.)

## High Risk Pool

Families with special health care needs may be eligible for the new **pre-existing condition insurance plan (PCIP)**. The federal PCIP is available to Arizona residents. Currently, there is only one option, but there will be more enrollment options beginning in 2011: the Standard Plan, the Extended Plan and the Health Savings Account eligible plan. In addition, The Department of Health and Human Services will be offering a child-only rate for PCIP enrollees between 0-18 years of age.

Information is available at: [www.pcip.gov](http://www.pcip.gov)

## Grandfathered plans

*New reform provisions do not affect all health insurance plans the same way. Some provisions apply to all group plans or individual plans, others may not affect "grandfathered" plans. Consumers may experience changes immediately, when they re-enroll in their current plan, or when they enroll in a new plan. Call your benefits department to determine what the status of your plan is.*

**Questions to ask about your health coverage:**

- Is it self-funded? (A 2010 Kaiser Family Foundation survey reported 59% of covered workers are in a self-funded plan.)
- Was it in effect on or before March 23, 2010?
- Have there been no significant changes made to benefits, cost sharing, or employer contribution?

**'Yes' answers may indicate a grandfathered plan.**

For further explanation of grandfathered plans and a chart of how recent reforms apply, see Georgetown University's "*September 23 Health Care Reforms: Making Insurance Work for children and Families*" at <http://ccf.georgetown.edu/index/september-23-reforms>

- Elimination of all pre-existing condition exclusions (i.e., guaranteed issue of insurance), and a prohibition on charging higher premiums for people with pre-existing conditions.
- Elimination of annual benefit caps.  
*Example:* Jack has required extensive hospitalization for multiple heart surgeries in his first year of life, exceeding the annual limit his insurance company will pay on his behalf. Under the new law, Jack's family will not have to pay out-of-pocket for the balance of his expenses that year.
- A loan repayment program aimed at reducing shortages of pediatric subspecialists, including non-physician providers of mental and behavioral health care and substance abuse prevention and treatment services.
- Incentives for more community-based, long-term care in Medicaid and establishment of a voluntary, public long-term care insurance program (the CLASS Act).

- Support for establishment of medical home models.
- Significant increases in funding for prevention and wellness efforts and the development of the public health infrastructure.
- Authorization of a new program to support school-based health centers and provision of \$200 million for immediate construction of such centers.
- Provisions to improve the oral health of children. (Inclusion of oral health care among the benefits required of insurance plans offered through state “Exchanges” with no charge for preventive pediatric oral health services.)

### Family-to-Family Health Information Centers.

*Raising Special Kids is a Family-to-Family Health Information Center (F2F HIC) and Arizona’s chapter of Family Voices.*

These statewide, family-run centers were slated to lose all funding in May. With enactment of this law, F2F HICs will be able to continue their invaluable help to families whose children have special health care needs and disabilities. The 51 centers throughout the country provide information and assistance in securing health care and health care financing for the complex health needs of families of children and youth with special health care needs and disabilities.

### *Adapted from Family Voices’ Statement On The Patient Protection And Affordable Care Act*

*Family Voices is an organization of families whose children have special health care needs. Its mission is to achieve family-centered care for all children and youth with special health care needs and disabilities. [www.familyvoices.org](http://www.familyvoices.org)*



### Resources:

- Bright Futures recommendations <http://brightfutures.aap.org/>
- Georgetown University’s Center for Children and Families: <http://ccf.georgetown.edu/index>
- Federal website for information on health care reform [www.healthcare.gov](http://www.healthcare.gov)
- Office for Children with Special Health Care Needs: [www.azdhs.gov/phs/ocshcn](http://www.azdhs.gov/phs/ocshcn)
- Health Reform Hits Main Street (Kaiser Family Foundation) <http://healthreform.kff.org/the-animation.aspx>

## Spanish Practical Parenting Forum

Saturday, January 8, 2011

8:00 am – 2:00 pm

Registration Begins at 8:00 am

**Banner Estrella Medical Center**

9201 W. Thomas Road, Phoenix, AZ 85037

Topics include:

- Children’s Health and Wellness
- Special Education
- Behavior, Mental and Emotional Health Needs

**FREE**

## Practical Parenting for Foster Parents & Kinship Caregivers

Saturday, January 29, 2011

7:30 am – 2:00 pm

Registration Begins at 7:30 am

**Disability Empowerment Center**

5025 E. Washington Street, Phoenix, AZ 85034

Topics include:

- Psychology/Therapy
- Meeting Educational Needs
- Transition to Adulthood
- Resources For Families

Registration: Raising Special Kids 602-242-4366 or register online at [www.raisingpecialkids.org](http://www.raisingpecialkids.org)

# Raising Special Kids Calendar

Register through our online calendar or call 602-242-4366 or 800-237-3007.

*Our office location is a fragrance-free environment, please avoid wearing fragrances.*  
Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034

## Positive Behavior Support

Training on effective techniques for behavior management.

Mon. 12/06/10, 6:00 – 7:30 p.m.

Wed. 1/12/11, 10:00 – 11:30 a.m.  
(Family Partners)

Thu. 1/27/11, 1:30 – 3:00 p.m.

Wed. 2/23/11, 10:00 – 11:30 a.m.

Thu. 3/10/11, 10:00 – 11:30 a.m.

Tue. 4/12/11, 3:00 – 4:30 p.m.

## Resilient Relationships

Create and maintain a healthy couples relationship through the journey of raising a child with special needs.

Mon. 1/10/11, 6:00 – 8:00 p.m.

Mon. 3/7/11, 10:00 – 12:00 p.m.  
(Family Partners)

Mon. 3/21/11, 6:00 – 8:00 p.m.

## Can You Hear Me Now?

Techniques for effective advocacy. What to ask, how to ask it.

Mon. 1/24/11, 10:00 – 11:30 a.m.

Fri. 2/25/11, 10:00 – 11:30 a.m.

Fri. 3/25/11, 10:00 – 11:30 a.m.

Thu. 4/14/11, 6:00 – 7:30 p.m.

## Getting and Keeping the First Job

Assist families with identifying the importance of employment for youth with disabilities and special needs.

Thu. 1/20/11, 6:00 – 8:00 p.m.

Thu. 2/17/11, 10:00 – 12:00 p.m.

Tue. 3/22/11, 6:00 – 8:00 p.m.

## The Journey to Adulthood

Provide parents with information about physical, emotional and social changes that adolescence and puberty bring to every child.

Wed. 1/12/11, 6:00 – 8:00 p.m.

Tue. 2/08/11, 6:00 – 8:00 p.m.

Wed. 3/09/11, 10:00 – 12:00 p.m.

Thu. 4/21/11, 6:00 – 8:00 p.m.  
(Touchstone Behavioral)

## Turning 18, What's Next?

Guardianship: Making the decision; understanding the process. Learn what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

Tue. 1/25/11, 6:00 – 8:00 p.m.

Mon. 2/7/11, 10:00 – 12:00 p.m.  
(Family Partners)

Thu. 2/17/11, 6:00 – 8:00 p.m.

(Touchstone Behavioral)

Mon. 3/28/11, 10:00 – 12:00 p.m.

Thu. 4/28/11, 10:00 – 12:00 p.m.

## Special Education Overview

Learn the structure and process of the special education system and primary intent of the IDEA federally mandated program.

Sat. 1/15/11, 10:30 – 12:00 p.m.  
(Family Partners)

Tue. 1/18/11, 1:00 – 3:00 p.m.

Thu. 4/14/11, 10:00 – 12:00 p.m.

## IEP Basics

Learn about the purpose of IEP's, parents' role in the process, and how to prepare for meetings.

Mon. 12/13/10, 6 - 8 p.m.

Thu. 1/13/11, 10:00 - 12:00 p.m.

Sat. 1/15/11, 9:00 – 10:30 a.m.  
(Family Partners)

Thu. 2/10/11, 1:00 – 3:00 p.m.

Mon. 3/07/11, 1:00 – 3:00 p.m.

Wed. 4/06/11, 10:00 – 12:00 p.m.

Wed. 5/04/11, 4:00 – 6:00 p.m.

## Advanced IEP Training

Receive an in-depth view of the IEP and strategies to help maximize the potential of each student. (Recommended: First attend IEP Basics.)

Thu. 2/24/11, 10:00 – 12:00 p.m.

Thu. 4/21/11, 1:00 – 3:00 p.m.

## Understanding 504

Learn about the rules and regulations of a 504 Plan and how it differs from the IEP (IDEA).

Wed. 1/26/11, 10:00 – 12:00 p.m.

Thu. 3/24/11, 1:00 – 3:00 p.m.

Tue. 5/10/11, 1:00 – 3:00 p.m.

## Turning 3, What's Next?

AzEIP to Preschool Transition. Learn how to transition your child from AzEIP services to preschool services provided by the school district.

Thu. 1/20/11, 9:30 – 11:30 a.m.

Thu. 3/03/11, 9:30 – 11:30 a.m.

Wed. 4/20/11, 9:00 – 11:00 a.m.

Thu. 5/12/11, 9:00 – 11:00 a.m.

## Preschool to Kindergarten Transition

Learn eligibility differences and strategies for an effective transition into school age services.

Wed. 3/02/11, 9:30 – 11:30 a.m.

Wed. 4/27/11, 9:00 – 11:00 a.m.

Wed. 5/11/11, 9:30 – 11:30 a.m.

## High School Transition

Learn how the transition plan in a student's IEP in high school can prepare for higher education, employment, and life in the community. Resources discussed.

Wed. 1/26/11, 4:00 – 6:00 p.m.

Wed. 3/23/11, 4:00 – 6:00 p.m.

Thu. 5/5/11, 1:00 – 3:00 p.m.

## Bully-Free Environments

Learn how to recognize bullying, effectively respond, and build positive solutions.

Thu. 12/09/10, 10:00 – 12:00 p.m.

Tue. 2/15/11, 4:00 – 6:00 p.m.

Thu. 3/17/11, 6:00 – 8:00 p.m.

(Touchstone Behavioral)

Thu. 3/31/11, 10:00 – 12:00 p.m.

Mon. 4/04/11, 10:00 – 12:00 p.m.  
(Family Partners)

Attendance at all workshops is at NO COST.  
For Southern Arizona workshops please call 520-324-3150 or visit [www.pilotparents.org](http://www.pilotparents.org)

**Notice our  
ALTERNATE LOCATIONS**  
(workshop times listed in red )

**Family Partners**  
9051 W. Kelton Lane, Ste. #7  
Peoria, AZ 85382

**Touchstone Behavioral Health**  
15648 N. 35th Avenue  
Phoenix, Arizona 85053



**Self-Advocacy for Youth**

Learn how students can independently advocate for themselves.

**Wed. 2/02/11, 4:00 – 6:00 p.m.**  
**Thu. 4/28/11, 6:00 – 8:00 p.m.**

**Parent/Professional  
Collaboration**

Develop an effective partnership between parents and professionals in Special Education.

**Wed. 01/12/11, 12:30 – 2:00 p.m.**  
(Family Partners)

**Wed. 2/16/11, 9:30 – 11:30 a.m.**  
**Thu. 4/07/11, 4:00 – 6:00 p.m.**  
**Tue. 5/03/11, 1:00 – 3:00 p.m.**

**Organizing Your Child's  
Records**

Bring your child's special education records to this "make and take" session to create your own filing system.

**Fri. 1/21/11, 1:30 – 3:30 p.m.**  
**Fri. 4/15/11, 10:00 – 12:00 p.m.**

**IEP 1-to-1 Consultation**

Bring your child's current IEP for review, as well as your questions and concerns.

**Call for an appointment:  
602-242-4366 or 800-237-3007.**

**NORTHERN ARIZONA  
WORKSHOPS**

Register via website calendar or call 928-523-4870

**Flagstaff**

Institute for Human Development (IHD)  
Northern Arizona University  
Parking lot 13  
Riordan Ranch Rd.

**Turning 18 what's next?**

Guardianship: Making the decision; understanding the process. Learn what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

**Wed. 1/19/11, 5:30 – 7:30pm**

**Positive Behavior Support**

Training on effective techniques for behavior management.

**Sat. 2/26/11, 9:00 – 11:00 a.m.**

**Lake Havasu City**

Arizona Children's Assoc. Office  
228 London Bridge Road

**Lake Havasu City Double  
Workshop**

**Sat. 3/26/11 8:00 – 12:00 p.m.**

**High School Transition**

Learn how to recognize bullying, effectively respond, and build positive solutions.

**Self-Advocacy for Youth**

Learn how students can independently advocate for themselves.

**Kykotsmovi**

Hopi Tribal Complex  
Risk Management Conference Room

**IEP/504**

An overview of the IEP process and 504 plans.

(For parents and professionals)

**Wed. 1/05/11, 10:00 – 12:00 p.m.**

**Bully-Free Environments**

Learn how to recognize bullying, effectively respond, and build positive solutions.

**Wed. 1/05/11, 2:00 – 4:00 p.m.**

**High School Transition**

Learn how to prepare youth for transition from high school to higher education, employment, and life in the community.

**Wed. 2/09/11, 10:00 – 12:00 p.m.**

**Getting and Keeping the  
First Job**

The importance of disability self-awareness, how families can help youth with career planning and strategies to navigate resumes, job interviews and job accommodations.

**Wed. 2/09/11, 2:00 – 4:00 p.m.**

**Reviewing Your Child's IEP**

**Wednesday, Feb. 23, 2011, 6 pm - 8 pm**

An interactive class on how to look at your child's IEP document, write and add relevant SMART goals and how to prepare for the meeting. **Please bring your child's IEP.** We will break into work groups.

Raising Special Kids, 5025 E Washington St. #204, Phoenix 85034

Register at 602-242-4366 or online at [www.raisingpecialkids.org](http://www.raisingpecialkids.org)

**NEW  
WORKSHOP**

# New changes to laws

## Rosa's Law

Signed into public law by President Obama on October 5, 2010, Rosa's Law will replace the term "mental retardation" with "intellectual disabilities" in the following federal laws: the Individuals with Disabilities Education Act (IDEA), the Elementary and Secondary Education Act (ESEA), and the Higher Education Act and the Rehabilitation Act.

The bill does not affect services, responsibilities, rights, or educational opportunities for over 6 million people with intellectual disabilities. Changes to state laws and regulations are not affected.

## Technology Access Bill

Also signed into law was The Twenty-First Century Communications and Video Accessibility Act of 2010. Provisions of the bill include giving individuals with hearing or vision impairments greater access to communications devices by requiring that

- Internet-enabled mobile phones are hearing aid compatible
- Ensuring people with vision loss have access to emergency broadcast information.
- \$10 million per year will be allocated from the Interstate Relay Service Fund for equipment used by individuals who are deaf-blind.

# CRS Transferring to AHCCCS

Starting on January 1, the Arizona Health Care Cost Containment System (AHCCCS) will take over the administrative oversight of the Children's Rehabilitative Services program (CRS). CRS provides medical care and support services to children and youth who have certain chronic or disabling conditions. Children and families should not see a change, since the same services will continue to be provided by the same physicians at the same CRS clinics.

Arizona Department of Health Services and AHCCCS agreed to simplify the administrative structure of CRS by moving all of its oversight to AHCCCS. ADHS and AHCCCS are working closely together to ensure a smooth transition to members and providers.

Although the Office for Children with Special Health Care Needs (OCSHCN) will no longer oversee the CRS contract, OCSHCN will continue to be available to support families with information and resources. OCSHCN promotes access to integrated healthcare and the development of medical homes and offers resources and training for families and providers on care coordination, transition to adulthood, family-centered care, cultural competence, and families as partners at all levels of decision-making.

OCSHCN can be reached at 602-542-1860, 800-232-1676 or by email at [OCSHCN@azdhs.gov](mailto:OCSHCN@azdhs.gov).  
Website: <http://www.azdhs.gov/phs/ocshcn>

*Excerpt from letter from Arizona Department of Health Services to stakeholders*

# Third Party Billing:

## *Billing for health services included in your child's IEP or IFSP*

What is Third Party Billing for IEP health-related services? And how does it affect my child?

Schools are required to try to obtain reimbursement from private and public health insurance for health-related services included in your child's IEP. The school can bill your insurance only if you give your written consent. This means that they have to ask you for information about your insurance and obtain your permission to bill your insurance.

Whether you permit the school to bill your insurance or not, your child must still receive all of the services in the IEP at no cost to you. Under the Individuals with Disabilities Education Act (IDEA), your child is entitled to a free and appropriate public education. If your child needs health-related services at school to obtain a free

and appropriate public education, you cannot be required to pay for it. The amount and type of IEP services your child receives cannot be tied to whether the school can bill your insurance. Your child's IEP team—which always includes you, the parent—should develop the IEP before billing is even considered.

**For more information, visit:**

**<http://www.pacer.org/health/billingForIEP.asp>**

# 25 Years with “phenomenal parents”

*Then and now, recollections of Peggy Storrs*

After 25 years with Raising Special Kids, Peggy Storrs has not lost her spectacular smile or the warm, assuring tone that earned her the nickname “the Voice of Pilot Parents.”

“Don and I were part of the Community Advisory Council set up to study the concept of parent to parent support,” she recalled while describing how she and her husband became involved with the grassroots efforts that generated Arizona’s premier parent support center originally known as Pilot Parents.

Peggy helped navigate the rapidly growing organization through many changes including the name change in 1998. “In one of our early office spaces, our phone ‘system’ consisted of me loudly shaking my paper clip holder whenever I needed help answering the phones,” laughed Peggy. “We’ve moved locations five times over the years. In the first move we were assisted by some volunteer firemen—we paid them with pizza.”

Peggy relishes the opportunities she has had to meet and work with other families. “I’ve been connected to other phenomenal parents and many resources we may otherwise not have found that helped us advocate for our son, Sean. Plus I’ve had the benefit of a career that I’ve loved.”

Sean commented “My parents’ involvement with Raising Special Kids has kept me grounded in a way because I’ve gotten

insight into the kinds of challenges other people are up against. When I was born, my parents had to navigate the healthcare and social service systems on their own without any kind of support system. It’s great that they helped put that support system in place for other parents and that Mom and the staff at Raising Special Kids continue to ensure that parents have someone to turn to when they need help.”

Peggy noted, “Don and I were part of the second class of volunteer Parent Leaders. We had 80 parent referrals during our first year. Last year Raising Special Kids helped 9,000 parents and professionals. That’s a lot of growth!”



*Peggy with son, Sean at age 7 and husband, Don.*



*Peggy cuddling a special guest at Raising Special Kids’ 25th Birthday Party.*



*An avid Barbershop quartet singer, Peggy (front) and her group members have performed for Raising Special Kids at a number of special events.*



*Peggy recently visited her son, Sean, who works in the President’s Office at Arizona State University.*

*Happy 25<sup>th</sup>  
Anniversary  
Peggy*

*Raising Special Kids  
looks forward to many  
more years with you!*

## Reformando el acceso al cuidado de la salud

Declaración de la organización Family Voices sobre el Decreto de Protección al Paciente y Cuidado Asequible

Family Voices es una organización de familias cuyos hijos tienen necesidades especiales del cuidado de la salud. Su misión es lograr la atención centrada en la familia para todos los niños y jóvenes con discapacidades o necesidades especiales de la salud.

La nueva ley realiza una serie de mejoras al sistema del cuidado de la salud de nuestro país para niños y jóvenes con necesidades especiales del cuidado de la salud (CYSHCN por sus siglas en inglés) y discapacidades. Éstas incluyen varios beneficios que entraron en vigor el 23 de septiembre de 2010, como:

### Eliminación de los toques de por vida en beneficios y una prohibición contra la anulación de la cobertura cuando una persona se enferma.

Ejemplo 1: Un bebé prematuro está en el hospital durante varios meses y ha sido diagnosticado con varios problemas de salud. Debido a la duración de la estancia en el hospital, la familia está cerca de llegar a su máximo de por vida para el niño. Con la eliminación de los toques de por vida, la familia no tendrá que preocuparse con respecto a que el niño podrá continuar recibiendo tratamiento médico.

Ejemplo 2: Una familia ha tenido cobertura durante varios años. Su hijo adolescente se lesiona y necesita rehabilitación muy cara. La compañía de seguros de repente anula la póliza, alegando que la familia no había revelado que el niño tenía la condición preexistente del acné, y por lo tanto, la póliza no es válida. La nueva ley prohíbe dicho tipo de cancelación de pólizas, cuando está ausente el fraude intencional por parte de los asegurados.

### Una prohibición contra la denegación de cobertura para el tratamiento de condiciones preexistentes de los niños.

(Para el año 2014, a nadie se le podrá denegar el acceso a seguro o cobertura para el tratamiento relacionado con una condición preexistente; HHS tiene la intención de aclarar mediante reglamentación, que seis meses después de la aprobación del proyecto de ley, los niños tendrán acceso a seguro independientemente de las condiciones preexistentes.)

Ejemplo 1: Sally, de siete años de edad, tiene parálisis cerebral y necesita una bomba de baclofeno para

ayudar con la espasticidad. Antes de la aprobación de la ley, la compañía de seguros podría haber negado esto debido a su condición preexistente de parálisis cerebral. Con la aprobación de la ley, esto ya no deberá de ocurrir.

Ejemplo 2: Se descubre que un niño de seis meses de edad tiene un defecto cardíaco congénito. La compañía de seguros se niega a cubrir la cirugía necesaria debido a que el defecto se considera una afección preexistente. Esto estaría prohibido bajo la nueva ley.

Ejemplo 3: Laurie tiene Síndrome de Down. Una vez que se emitan los reglamentos para aclarar que no se puede negar a los niños pólizas de seguro debido a condiciones preexistentes, la familia de Laurie podrá añadirla a su plan.



### El establecimiento de un grupo nacional de alto riesgo para quienes han estado sin seguro debido a condiciones preexistentes (hasta el año 2014, cuando se podrá comprar seguro en "Intercambios").

Ejemplo: Christina, una mujer adulta de 28 años de edad que trabaja por cuenta propia, no ha podido obtener seguro debido a que tiene diabetes tipo 1. Si ella ha estado sin seguro durante por lo menos seis meses, podrá obtener cobertura a través de un grupo de alto riesgo que se establecerá dentro de 90 días de la fecha en que se firme el proyecto de ley.

## Reformando el acceso al cuidado de la salud

### **Un requisito que establece que adultos jóvenes podrán permanecer en las pólizas de seguros de sus padres hasta los 26 años de edad, a menos que cuenten con una oferta de cobertura del empleador.**

Ejemplo: Sam es un joven de 23 años de edad con espina bífida, quien no ha podido encontrar empleo desde que se graduó de la universidad, y no ha podido obtener seguro propio debido a su condición preexistente. Bajo la nueva ley, Sam puede permanecer en el seguro de sus padres hasta que cumpla 26 años de edad.

### **Cuidado preventivo sin costo para niños en planes nuevos de seguros (a excepción de los planes ERISA), basándose en las recomendaciones de "Bright Futures" (futuros brillantes) de la Oficina de Salud Infantil y Materna y de la Academia Americana de Pediatría.**

Ejemplo: Los niños podrán recibir atención preventiva integral, incluyendo pruebas del desarrollo, sin costo alguno.

### **Extensión de la financiación de los Centros de Información de Salud de Familia a Familia (vea abajo).**

Otras disposiciones importantes que entrarán en vigor en 2014, incluyen:

- Ampliación del programa Medicaid a todas las personas con ingresos de hasta 133% del nivel federal de pobreza. (En la actualidad, los estados no pueden recibir fondos federales de Medicaid para cubrir a los adultos sin hijos.)
- Eliminación de toda exclusión de condiciones preexistentes (ejemplo: emisión garantizada de seguro), y la prohibición al cargar primas más altas para personas con condiciones preexistentes.
- Eliminación de los topes a los beneficios anuales.

Ejemplo: Jack ha requerido extensa hospitalización por múltiples cirugías cardíacas durante su primer año de vida, sobrepasando el límite anual que su compañía de seguros pagará en su nombre. Bajo la nueva ley, no habrá límites anuales arbitrarios, por lo que la familia de Jack no tendrá que pagar de su propio bolsillo el saldo de sus gastos ese año.

- Un programa de reembolso de préstamos destina-

dos a reducir la escasez de sub-especialistas pediátricos, incluyendo a los proveedores que no son médicos de cuidado mental y de la salud del comportamiento, así como para los servicios de prevención y tratamiento del abuso de sustancias.

- Incentivos para más cuidado a largo plazo basado en la comunidad en Medicaid, y el establecimiento de un programa de seguros público voluntario a largo plazo (el Decreto CLASS).
- Apoyo para el establecimiento de modelos de hogares médicos.
- Aumentos significativos en la financiación de actividades de prevención y bienestar, y el desarrollo de la infraestructura para la salud pública.
- Autorización de un programa nuevo para apoyar los centros de salud basados en la escuela, y el suministro de \$200 millones de dólares para la construcción inmediata de dichos centros.
- Disposiciones para mejorar la salud oral de los niños. (Inclusión del cuidado de la salud oral entre los beneficios requeridos de los planes de seguro ofrecidos a través de "Intercambios" del estado, sin cargo para los servicios preventivos de la salud oral pediátrica).

### **Centros de Información de Salud de Familia a Familia.**

*Raising Special Kids es un Centro de Información de Salud de Familia a Familia (F2F HIC por sus siglas en inglés) y el grupo en Arizona de la organización Family Voices.*

Estos centros administrados por familias a través de todo el estado, estaban programados para perder todo su financiamiento en mayo. Con la promulgación de esta ley, los centros F2F HICs podrán continuar su invaluable ayuda a las familias cuyos hijos tienen necesidades especiales del cuidado de la salud y discapacidades. Los 51 centros a través de todo el país, brindan información y asistencia en la obtención de cuidado de la salud y financiación para el cuidado de la salud para las complejas necesidades de los niños y jóvenes con necesidades especiales del cuidado de la salud.

## CALENDARIO EN ESPAÑOL

Por favor llamar al 602-242-4366 o 800-237-3007 para confirmar su asistencia a los talleres  
Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034  
*Somos una oficina libre de fragancias.*

### El Comportamiento Positivo

El vínculo entre las familias las intervenciones y el apoyo conductual positivo es muy importante.

Lunes, 2/14/11, 10:00 – 11:30 a.m.  
Lunes, 3/14/11, 1:30 – 3:00 p.m.  
Lunes, 4/25/11, 10:00 – 11:30 a.m.

### Organizando los archivos de sus niños/a

Aprenda modos efectivos para organizar sus archivos

Viernes, 1/21/11, 1:30 – 3:30 p.m.  
Viernes, 4/15/11, 10:00 – 12:00 p.m.

### Entrenamiento Para Padres Líderes

Acompañenos a un entrenamiento para voluntarios y así desarrollar su liderazgo ayudando a otras familias a aceptar y sobrellevar el diagnóstico de un hijo (a) con necesidades especiales de salud.

Viernes, 1/21/11, 10:00 – 11:30 a.m.  
Lunes, 2/28/11, 10:00 – 11:30 a.m.  
Viernes, 3/18/11, 1:30 – 3:00 p.m.  
Lunes, 4/11/11, 10:00 – 11:30 a.m.

### Al cumplir los 3 años, que sigue?

Intervención Temprana

Aprenda sobre los requerimientos para la transición e ideas para lograr un proceso más fácil.

Martes, 1/11/11, 1:00 – 3:00 p.m.  
Miércoles, 3/16/11, 9:00 – 11:00 a.m.

### Es su Hijo Blanco de Burlas?

Estrategias de Intervención para Padres de Niños con Discapacidades.

\*Una forma de abuso en la escuela a través de la intimidación, tiranía y aislamiento.

Viernes, 1/14/11, 10:00 – 11:30 a.m.  
Viernes, 2/4/11, 1:30 – 3:00 p.m.  
Viernes, 4/1/11 10:00 – 11:30 a.m.

### Familias Resistentes

La Estructura más Básica para una Relación de Familia Saludable la habilidad de volver de un trauma o una situación difícil.

Jueves, 1/6/11, 10:00 – 11:30 a.m.  
Viernes, 3/4/11, 10:00 – 11:30 a.m.  
Viernes, 4/8/11, 1:30 – 3:00 p.m.

### Al cumplir los 18 años, que sigue?

Tutela: Tomando la Decisión y Entendiendo el Proceso Aprenda lo que la Tutela implica y sus alternativas antes de que su adolescente cumpla los 18 años de edad.

Viernes, 1/28/11, 10:00 – 11:30 a.m.  
Viernes, 2/25/11, 1:30 – 3:00 p.m.  
Lunes, 3/28/11, 1:30 – 3:00 p.m.

### Conceptos Básicos del IEP

Aprender acerca del propósito del IEP a través de una visión general del documento y reunión.

Viernes, 2/18/11, 10:00 – 11:30 a.m.  
Viernes, 4/22/11, 10:00 – 11:30 a.m.

### Transición de Escuela Secundaria (High School)

Aprenda como el plan de transición en el IEP de su estudiante de Escuela Secundaria (High School) puede prepararlo para una educación superior, empleo, vida en la comunidad y recursos disponibles.

Miércoles, 4/20/11, 6:00 – 8:00 p.m.

Para descripciones de talleres y más información, llame a nuestra oficina al 602-242-4366 o al 800-237-3007 o vea el Calendario en español en nuestra página web:  
[www.raisingsspecialkids.org/](http://www.raisingsspecialkids.org/)  
Por favor llámenos para confirmar su asistencia a los talleres.



## Foro Práctico para Padres en Español

Sábado 8 de Enero del 2011

8:00 am – 2:00 pm

Registraciones comienzan a las 8:00 am

**Centro Medico Banner Estrella**

9201 W. Thomas Road, Phoenix, AZ 85037

Tópicos que se incluirán:

- Salud y Bienestar de los niños
- Comportamiento, Necesidades de Salud Mental y Emocional
- Educación Especial

## Parent Leadership

*Migdalia Morales, Parent Leader within the Spanish-speaking community*

A proud mother of two, Migdalia Morales first connected with Raising Special Kids after learning through a parent support group about the workshops offered in Spanish on various topics. She quickly became involved as a volunteer, and after two years as a Parent Leader helping other parents of children with disabilities, Migdalia truly appreciates the rewards of parent-to-parent support.

“There have been many benefits of being a volunteer at Raising Special Kids. I am especially grateful when the parents I contact express how relieved they are to share their concerns with another mother. They realize they are not the only ones who are going through the difficulties of raising a child with special needs.”

Migdalia has the same dreams for her son with disabilities as all parents do for their children—a good quality of life, to be a productive member of his community and “to never lose his smile.”

“Raising Special Kids has been very helpful for my family,” she added “because, thanks to their workshops and advice, I learned how to cope and defend



*Migdalia Morales with her son, 9-year-old Alfonso, her daughter, Kathia, and husband, Joaquin.*

the rights of my son in a more effective way. Each of my calls has been answered in a very short time, and they have given me valuable information.”

“As a Parent Leader, I feel useful and I know that in order for what I have learned to have the most value, I must share it.”

## Liderazgo de Padres

*Migdalia Morales, una Mamá Líder dentro de la Comunidad de habla Hispana*

Una orgullosa madre de un hijo y una hija, Migdalia Morales primero fué conectada a Criando Niños Especiales y después de asistir a un grupo de apoyo de padres tuvo conocimiento acerca de los talleres que se ofrecen en español sobre varios temas. Rápidamente se involucró como voluntaria, y después de dos años como padre líder ayudando a otros padres de niños con discapacidades, Migdalia realmente aprecia las recompensas que ha obtenido.

“Han sido muchos los beneficios de ser voluntario en Criando Niños Especiales. Agradezco especialmente cuando contacto a los padres y me dan las gracias, y expresan cómo les ha ayudado el compartir sus preocupaciones con otra madre. Y se dan cuenta de que no son los únicos que están pasando por las dificultades de criar a un niño con necesidades especiales.”

Migdalia tiene los mismos sueños para su hijo con discapacidad, como todos los padres para sus hijos: una buena calidad de vida, ser un miembro productivo dentro de su comunidad y que “nunca pierda su sonrisa”.

“Criando Niños Especiales ha sido muy útil para mi familia”, agregó “porque, gracias a sus talleres y



*Migdalia Morales con su hijo Alfonso de años de edad su hija Kathia y su esposo Joaquin.*

consejos, aprendí a hacer frente y defender los derechos de mi hijo en una forma más efectiva. Cada una de mis llamadas ha sido respondida en un plazo muy breve, y me han brindado información valiosa.”

“Como voluntaria, me siento útil y he aprendido que compartiendo mi experiencia es de máximo valor.”

# Raising Special Kids News

## Dandelion Classic

Carescape, Inc. raised \$35,000 for Raising Special Kids and family support programs.

“The volunteers and staff from Carescape Landscape Management Services have consistently supported the programs at Raising Special Kids for three years through the Dandelion Golf Classic. We are so grateful for their generosity and concern for families of children with disabilities,” said Joyce Millard Hoie, Executive Director.



Mitchell Owens, President of CareScape, Inc., presents a check from the 2010 Dandelion Golf Classic to Joyce Millard Hoie.

## Thank you to our sponsors

Carescape, Inc.

Arizona Business Bank

Salt River Solar & Wind, LLC

Silverhawk Financial  
Planning, LLC

Fennemore Craig

City Property Management

Star Roofing Company

Wooldridge Engineering

Raising Special Kids

Perkins Coie Brown & Bain,  
LLP

Metal Money

Liberty Buick

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Services

Malarkey Roofing Company

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Cannon & Associates

S & S Tire Company

Simplot Partners

Sechler CPA. PC

Maxim Healthcare Services

Advanced Business  
Learning, Inc.

Carescape Arbor Care

Clubhouse Sports Grill

Multi Systems Inc.

People's Mortgage Company

### Save the date!

## Special Day for Special Kids

A fun family day hosted by  
Scottsdale Sunrise Rotary Club

### Saturday, March 26, 2011

McCormick-Stillman Railroad Park  
NW Indian Bend & Scottsdale Rd.

## Newsletter survey results

Raising Special Kids asked the Research and Evaluation Staff of Virginia G. Piper Charitable Trust to conduct an evaluation of the newsletter, *Connecting*. This is an on-going effort to assess the standard of providing authoritative, useful, relevant, family-friendly, and high-quality information.

The research staff at the Piper Trust, Dr. Wayne Parker and Catherine Jahnes, developed the

newsletter survey which was distributed electronically to more than 2,000 readers.

Highlights of the survey include the following:

- “Reader satisfaction with the newsletter is extremely high. Readers almost universally found that information is presented in a manner that is family friendly and easy to understand. The reputation for being trustworthy and reliable is excellent.”
- 96% Provides information that is family-friendly and easy to understand
- 81% Provides information on important topics
- 94% Provides useful information that parents want to read
- 95% Is a trustworthy and reliable source of information
- 77% Links me to other helpful sources of information
- 72% Helps me in advocating for my child's services and care

# In The Spotlight

## Making a Difference in the Lives of Children Thank You for referring families to Raising Special Kids

August 2010 - October 2010

**A Place To Call Home**  
**ABIL**  
**Advisory Council**  
Brad Harper  
**Agape Adoption Agency**  
**Aid to Adoption of Special Kids**  
**Arizona Autism United**  
**Arizona Child Study Center**  
Dr. Dan Kessler  
**Arizona Children's Association**  
Davida Simmons  
**Arizona Christian Family Care**  
**Arizona Dept Of Education-PINS**  
Allison Meritt  
Maureen Mills  
**Arizona Dept Of Health Services-OCSHCN**  
Marta Urbina  
**Arizona Early Intervention Program**  
Flor Berber  
**Arizona Kinship Coalition**  
Oralia Gracia-Alinea  
**Arizona State University**  
Jessica Debaise  
**Aspire Therapy**  
Meagan Aldrich  
**Association for Supportive Child Care**  
Angela Navarette  
**AZ-ASSIST**  
**Banner Copper Basin Medical Center**  
Dr. Jacqueline May  
**Banner Desert Medical Center**  
Sandy Beck  
**Capstone**  
**Cardon Children's Medical Center**  
Arin Close  
Amira El-Ahmadiyyah  
Jennifer Hamblin  
Jennifer Leimbach  
**Carl T. Smith Elementary**  
Kathy Dancil  
**Catholic Charities**  
Soledad De La Rosa  
**Centpatco**  
**Child Protective Services**  
Mindy Backus  
**City of Phoenix Early Childhood**  
Sylvia De Leon Marquez  
**City of Phoenix Headstart**  
Jessica Flores  
**Coconino County Juvenile Court**  
Cydney Boyer  
**Crisis Nursery**  
**Department of Children & Family Services**  
Florence Escalante  
**Desert Star Elementary**  
Selena Nakano  
**Devereux**  
Heather Cano  
Lea Gage  
**Division Of Developmental Disabilities**  
Carmen Aguilera  
Melissa Alanza  
Kimberly Becker  
Flor Berber  
Ruthann Bilkey  
Sarah Bravo  
Kathleen Calder  
Paul Candelaria  
Robin Chanto  
Tina Chapman  
Annie Converse  
Jenine Cook  
Wanda Copeland  
Teresa Cromer  
Mabel Cruz  
Meredith Dohanyos  
Alexandra Dominguez  
Alma Espinoza

Rose Fabris  
Maria Fernandez  
Barbara Greenshield  
Jade Guerrero  
Kathi Guildig  
Christina Hari  
Billy Henderson  
Debbie Hooper  
Tani Hough  
Latasha Janowitz  
Monica Joe  
Jill Keyes-McClements  
Jeannie Kildoo  
William Kilgore  
Carly Konieczny  
Vanessa Kruse  
Nadine Laman  
Marie Elena Mangiameli  
Lucia Marquez  
Martha Mills  
Tammy Molash  
Marta Monyer  
Laura Moore  
Courtney Parker  
Karen Patten  
Lisa Rennells  
Alma Reyes  
Lynn Rhodes  
Jordan Robinson  
Renee Rodriguez  
Ramona Sands  
Kizzy Sepulveda  
Christina Singh  
Dana Southworth  
Susan Stewart  
Lola Summers  
Ernestine Thompson  
Jo Ann Valdez  
Marietta Valdez  
Patty H Walters  
Megan Wiley  
Elizabeth Williams  
Meagan Woelfel  
Lucinda Yazzie  
**Impact**  
**Excell**  
**First Southern Baptist Church @**  
**Sahuaro Ranch**  
Steve French  
**First Things First - Coconino County**  
Cristi Mallery  
**Friendly House**  
Jessica Leon  
**Good Samaritan Hospital NICU**  
**Highland High School**  
**Jewish Family Services**  
Debbie Cross  
**Kid's Care Clinic**  
**KKONA**  
**Mesa Public Schools**  
Stacey L. Fears  
**Milemarkers Therapy, Inc.**  
Becky Stark  
**Mountain Park Health Center**  
Bridgette Terrazas  
**MPS**  
Joan Kern  
**Murphy School District**  
Jenna DelCostello  
**Northern Arizona University**  
Dana Davidson  
**Northern AZ Autism Society of America**  
**Pascua Yaqui Tribe Education**  
Valencia Blackhorse Gonzalez  
**PEDI Center**  
Margaret Bunting  
**Phoenix Baptist Hospital**  
Lucille Lane  
**Phoenix Children's Hospital**

Kiran Aurora  
Amy Edmonds  
Tiffany Glick  
Cynthia Nakamura  
Cheryl Searles  
Jennifer Stallteri  
Cheryl Wingate  
**RISE, Inc.**  
Ashley Blunt  
Rachel Cervantes  
Malea Grace  
Amy-Lee Verfaillie  
**SAARC**  
Janet Kerwin  
**Scottsdale Healthcare**  
Erin Miller  
**SHARING Down Syndrome**  
Gina Johnson  
**Southwest Behavioral Health Services**  
Therese Hensler  
Martha Sainz  
**Southwest Human Development**  
Julie Gonzalez  
**St. Joseph's Hospital**  
Kristen Bayne  
Lindsey Kern  
**Step By Step Pediatrics**  
Dr. Tanya Horner  
**The Family Learning Center**  
Maritsa Beltran  
**Touchstone Behavioral Health**  
Shemeka Gooden  
**Tourette Syndrome Support Group**  
**UMOM**  
**United Cerebral Palsy of Central Arizona**  
**Valle del Sol Sabrina Nelsen**  
**Washington High School**  
**Wilson Elementary School**  
Luz Rios  
**Individuals**  
Dr. Robin Blitz-Wetterland  
Jessica Burnside  
Bonita Carter  
Sarah Hales  
Lindsay Hall  
Jessica James  
Becky Lent  
Chris Mercado  
Gabriela Orozco  
Jill Pears  
Theresa Rimer  
Dr. Karlsson Roth

## Parent Leaders are the heart of Raising Special Kids Thank You!

August 2010 - October 2010

**Avondale**  
Gabriela Sanchez Orozco

**Buckeye**  
Lydia Martinez

**Cave Creek**  
Mark Trombino

**Chandler**  
Patty Chan  
Brenda Crockett  
Beth Maloney  
Marsha Rosser  
Noelle White

**Flagstaff**  
Cindy May

**Fountain Hills**  
Susan Morris

**Gilbert**  
Peter Graf  
Terri & Dave Hesson

**Glendale**  
Pam Baldwin  
Dawn Kurbat  
Danielle Martinez  
Annette Navarro

**Laveen**  
Beatriz Acosta  
Linda Cannon

**Mesa**  
Kim Cohill  
Julie Folmer

**New River**  
Glen Dinsmore  
Sydney Dinsmore

**Peoria**  
Sharon Blanton  
Mark & Tricia Mucklow

**Phoenix**  
Paula Banahan  
Hermelinda Barrios  
Jeannie Bremercamp  
Patty Coe  
Lisa Case  
Jim Cole  
Debbie Demland  
Sharon Hayes  
Luke Hinds  
Marty Krecko  
Maureen Mills  
Jesse Pap  
Damita Radke  
Ched Salasek  
Carolyn Sechler  
Hannah Swearengin  
Marc Voirol  
Leslie Williams

**Scottsdale**  
Jill Castle  
Jodi Feuerhelm  
Chris Linn  
Shauna Mattson  
Katie Petersen  
Mary Quinsler

**Sun Lakes**  
Philip Sanabria

**Tempe**  
Kelli Cunningham  
Janet Romo

**Tolleson**  
Kristie Amator

**Waddell**  
Sharon Atwood

We post about  
news, events, and  
more that are of interest  
to families living with  
disability. Want to  
know what's up?

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## Letter from a parent

November 2010

I just want to let you and everyone at Raising Special Kids know that I had been stuck in a place of sad hopelessness not understanding how to navigate very political and confusing systems. They gave me packets of how-to and go-to information, but even as a business person who writes and reads contracts for a living, I found the paperwork very perplexing because the lines are blurred from grief and love.

Oddly, I'm very glad I got to a place of emotional turmoil and frustration that I couldn't pull myself through. I'm glad because I finally called on you for assistance, never imagining how helpful you would be. Honestly, I anticipated I would receive a word or two of advice, but what you offered was so much more. Knowing in my heart that you really care and are dedicated to help lightens my load and eases my fear and frustrations.

As a parent caring for a terminally ill child, I find it a challenge every day to discern my feelings. I doubt myself and wonder if I'm standing for what he needs, or if I am out in left field drowning in sorrow, taking anger out on innocent people. You have been helping me sort these things out.

So for now, I thank you for the hours and hours and hours of consultation. I thank you for calling to touch base and ask me how things are going. I thank you for the comfort of knowing you are still there at the other end of the phone for us.

*We are still here for your family, too!  
Best wishes for the holiday season.*

Raising Special Kids accepts donations online at [www.raisingpecialkids.org](http://www.raisingpecialkids.org)

