

## Visionaries, Trail Blazers & Advocates

### *Parents as change agents*

Where can parents put to use many of the skills they developed while “learning the ropes” of navigating systems of care or special education?

When does improving conditions for all children enhance personal growth and development?

The answer to both questions can be found in Parent Leadership. Parents report a tremendous return on investment of their time and effort by helping other families or by educating students and professionals in fields that serve children with disabilities. Through varied opportunities such as mentoring parents, presenting to professional audiences, serving on community councils, committees, or focus groups, or reviewing state agency policy materials, parents have found they often receive as much or more than they have contributed.

The sense of self-fulfillment or the good feeling experienced from having helped someone else may be hard to measure. Other benefits from service as a

Parent Leader may bolster a job seeker’s resume, improve communication and collaboration skills, or provide public speaking experience.

Kathy McDonald, a Parent Leader who participates in presentations



*The Mucklow family hosts physicians in their home to provide a deeper understanding of their challenges in raising a child with special needs.*

for professionals, noted “One of the great things Raising Special Kids does is provide us with feedback and evaluations from the audience. You really know you’re making a difference when you get that feedback. It’s very rewarding to have been able to actually influence and help change how professionals view children with disabilities or what a family is going through.”

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“I will be more concerned about the needs of each child and be sure to ask parents for advice and tips to make dental visits more comfortable... very beneficial, I enjoyed hearing about each of your family experiences.”

—Dental Student’s comment on Parent Panel

# From the Director...

Parent leaders are a special breed. It's remarkable to hear how their lives can be transformed in positive ways by the experience of having a child with a disability or special health need. There are countless examples of parent leaders who inspire and lead efforts to change laws, guide public policy, remove barriers to participation, and generate interest in funding new research and treatments. In the process these exceptional leaders fundamentally change established systems and structures.

In many situations, and from parents of diverse backgrounds, the collective response is often the same — we can't change our children, so we'll change the world. Recently, a Parent Leader related how proud he was to hear his daughter introduce her sister with the following: "All kids are special, my sister's needs are just different."

It's a form of creativity to be able to imagine the world as a place where understanding and respect for human differences is the foundation on which we build our communities, policies, and new opportunities. At all levels, we're experiencing a severe financial crisis in our public systems and programs which calls for a form of intense creativity in how we achieve cost savings and improve quality at the same time. It always starts with advocacy for your child, and being able to understand the systems of supports and services to meet their needs.

Parent leadership is vital in meeting the current challenges, and it can lead us forward on an extraordinary path with the promise of a better future for generations of children.



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

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**Raising Special Kids**  
5025 E. Washington St., #204  
Phoenix, AZ 85034  
602-242-4366 • 800-237-3007  
Fax: 602-242-4306  
www.raisingpecialkids.org

## STAFF

Joyce Millard Hoie  
*Executive Director*

Marissa Huth  
*Editor*

Anna Burgmann, Kathleen Collins,  
Vickie French, Dolores Herrera,  
Steve Lee, Janna Murrell,  
Kat Rivera, Vicky Rozich,  
Nannette Salasek, Heather Snider,  
Peggy Storrs, Carrie Swearengin,  
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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 —

Some of the benefits from the Parent Leader experience that Kathy appreciates most:

- friendships and connections with other parents
- understanding that we're not alone—others are going through this
- gaining acceptance of my own situation
- becoming a better public speaker
- effecting change and improving systems for all children and families

“As a leader, you have a responsibility to take your leadership experience and skills, your dedication to children and families, the tools and information you have gained, and make a difference . . . We can improve things where we live, in our own homes, neighborhoods, communities, towns, counties.”

— Polly Arango, Co-founder of Family Voices

The experience of being a Parent to Parent mentor is something that Dawn Kurbat values. “There is no text book that tells you how to deal with your situation. I had to work through that and learn to explore options. I want to share information, and ease the process for other parents. That’s why I keep doing it—that’s the best!”

Dawn appreciates the flexibility of scheduling Parent to Parent connections, “I’ve been able to do so much from my own home,” she noted. Many tasks may be accomplished by phone or email and at varied times.

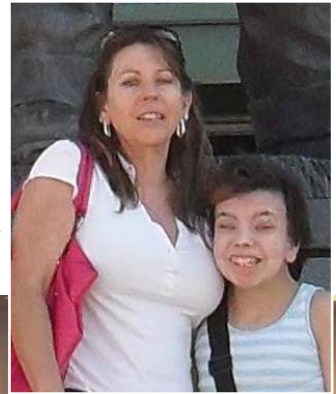
“... the presenters made me think more about inclusion—how that looks at home, in school, and in the community, and how forging good communication bonds with parents can produce the best outcomes for students with special needs.”

— College Student majoring in Special Education

The opportunity to model an example of self-advocacy for her children is another bonus for Dawn. “All my kids are watching and learning from this. I am setting an example for them.” Additional benefits Dawn pointed to are: improving communication and listening skills, practicing creative problem solving skills, and expanding awareness of issues in the state for families of children with special needs.

Some parents have seen their experience as a parent leader become the foundation for a career. Vickie French began volunteering in the Parent to Parent program when her youngest children (twins) were three

Right: Parent Leader, Kathy McDonald, with daughter Allie



Below: Kathy presents to dental students at A.T. Stills University.



years old. As her children grew, she progressed to additional activities in supporting parents of babies in NICU, Train the Trainer for Student-led IEP, and served on the Board of Directors for almost six years.

When Vickie was ready for full time employment, joining the staff at Raising Special Kids was a natural step. Vickie explained, “Most of our staff have followed a track from volunteering to employment. As Parent Leaders, they have already demonstrated their passion for helping families, and they’ve had opportunities to gain experience and acquire many of the skills we look for.”

Opportunities are available in working with families of diverse cultural backgrounds and those who speak a variety of languages. Presenters at a forum in Tuba City provided an opportunity for families in Northern Arizona and rural areas to ask questions and learn information in person-to-person activities.

### Ready for Parent Leadership?

- Have you reached acceptance of your family’s situation?
- Are you ready to share your experience with others?
- Are you comfortable reaching out to others and listening with an open mind and compassion?
- Can you maintain confidentiality at all times?
- How much time can you offer?

“We are especially eager to find more volunteers that can help us in the Northern Arizona area,” said Vickie. “We have some wonderful opportunities available there.”

Raising Special Kids provides the support parent leaders need to be successful. All volunteers are trained and given detailed assistance as needed for each activity. Research-based best practices are in place for the Parent-to-Parent program and Parent Leaders meet high standards of accountability and maintaining confidentiality. Parents keep records and do evaluations of their activities to ensure families’ needs are being met. Parent Leaders sometimes receive a stipend or compensation for their involvement.

Maintaining a positive working relationship with Parent Leaders is a top priority. Flexibility is crucial for parents, and they can decline activities that are not a good match. Many parents have realized that being able to help other parents brings greater purpose and meaning to their own lives.



(Above) Elidio Reyes and his son, David. Elidio has been a parent leader for nine years



(left) Elidio recently presented at a forum for Spanish speaking families.



Dawn Kurbat is able to connect with families from her home as a Parent-to-Parent volunteer.

“My kids are watching and learning from this. I am setting an example for them.”  
— Dawn Kurbat, Parent Leader

## What is a Parent Leader?

Parent Leaders want to improve systems of care for all families by sharing their story and perspective on raising a child with a disability or special health needs. Parent Leaders have reached a place of acceptance and are ready to participate with support from Raising Special Kids to share their wisdom and knowledge. Here are some ways Parent Leaders contribute their unique talents:

- **Parent Mentor** - Provide one-to-one mentoring and support to another parent of a child with the same diagnosis over a period of 8 weeks.
- **Family Faculty** - Participate in the training of physicians in pediatrics or family practice residency, includes hosting a home visit.
- **Community Outreach** - Assist in planning and staffing community events to reach other parents and the larger community. Host a Raising Special Kids information table, provide information about family support services, parent leadership, and other programs.
- **Advisory Groups, Councils, Committees** - Share the parent perspective by serving on a board, council, or committee to affect change at a systems level.
- **Legislative Advocacy** - Represent the parent perspective on key issues affecting children and families with local, state, and other government officials.
- **Panelist, Training Presenter, Media Interview** - Participate in training professionals in health, education, and social services. Speak at public events, or be interviewed by media to raise awareness about children with special health care needs.
- **Program and Policy Development** - Assist in reviewing state agency information, policy revisions, manuals, web sites and other resources.
- **Project Planning and Coordination** - Help plan and coordinate activities for events or special projects.

For more information or to volunteer, please call (602) 242-4366, or (800) 237-3007 or email [info@raisingspecialkids.org](mailto:info@raisingspecialkids.org)

[www.raisingspecialkids.org](http://www.raisingspecialkids.org)

## Free Conference

# Collaborative Therapies Forum



## For Parents of Children Birth to Five

Phoenix Children's Hospital  
Mel Cohen Conference Center  
Saturday, May 7, 2011

8:30 a.m. - 2 p.m.



PHOENIX CHILDREN'S  
Hospital

Presented by professionals in the areas of developmental pediatrics, speech language pathology, occupational and physical therapies and developmental special instruction.

### Developmental Pediatrician

- How to work with your doctor
- Child development (cognitive, language, fine/gross motor, self-help, social/emotional)

### Speech & Language Pathologist

- How to recognize & encourage communication, including baby sign language

### Physical Therapist

- Interactive and hands on therapy techniques

### Occupational Therapist

- Defining Sensory Integration, playful activities

### Developmental Special Instructor

- Developing activities and environments that help child development from birth to three

**A panel of experienced parents who have “been there” will share experiences.**

Breakfast and lunch included. Spanish translation will be available. Due to space limitations and no child care; adults only should attend. Please register by contacting Raising Special Kids at 602-242-4366 or online at [www.raisingpecialkids.org](http://www.raisingpecialkids.org)

## Resource for nutrition information

Parents and professionals may find helpful information in a report about nutrition for children with special health care needs. An excerpt from the report, published by the Washington State Department of Health, is below followed by instructions for accessing the full text.

### **Nutrition Interventions for Children with Special Health Care Needs** Third Edition, 2010

#### **Nutrition Screening and assessment**

Nutrition disorders and compromised nutritional status are common among children with special health care needs. As many as 40% of infants and children with special health care needs are at nutritional risk. A survey of children from birth to age three years with developmental delays in early intervention programs found 70-90% had one or more nutrition risk indicators. Indicators of nutritional risk include altered growth, increased or decreased energy needs, medication-nutrient interactions, metabolic disorders, impaired ability to utilize nutrients, poor feeding skills, and partial or total dependence on enteral or

parenteral (*Nasal Gastric Tube, G Tube, J Tube or IV*) nutrition. A well nourished child has increased alertness and stamina to participate in therapies, educational activities, and social interactions and benefits from fewer illnesses and improved coping skills. Improved nutritional status and feeding skills may increase the level of independence the child is able to achieve. It can improve the child's perception of self and the caregivers' perceptions of their abilities to meet the child's needs.

To download a free pdf file or order a CD with the full report visit:  
<http://here.doh.wa.gov/materials/nutrition-interventions>

# 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.

Thu. 3/10/11, 10:00 – 11:30 a.m.

Tue. 4/12/11, 3:00 – 4:30 p.m.

Thu. 5/19/11, 6:00 – 8:00 p.m.

Thu. 6/23/11, 3:00 – 4:30 p.m.

Mon. 7/11/11, 10:00 – 12 noon  
(Family Partners)

## Resilient Relationships

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

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

## Getting and Keeping the First Job

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

Tue. 3/22/11, 6:00 – 8:00 p.m.

Mon. 5/02/11, 10:00 – 12 noon  
(Family Partners)

## The Journey to Adulthood

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

Wed. 3/09/11, 10:00 – 12:00 noon

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

Mon. 6/06/11, 10:00 - 12 noon  
(Family Partners)

## Special Education Overview

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

Thu. 4/14/11, 10:00 – 12:00 noon

## Guardianship

### Turning 18, What's Next?

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

Mon. 3/28/11, 10:00 – 12 noon

Thu. 4/28/11, 10:00 – 12 noon

Thu. 5/26/11, 3:00 – 4:30 p.m.

## IEP Basics

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

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. 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).

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. 3/03/11, 9:30 – 11:30 a.m.

Thu. 5/12/11, 9:00 – 11:00 a.m.

## Preschool to Kindergarten

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

Wed. 3/02/11, 9:30 – 11:30 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. 3/23/11, 4:00 – 6:00 p.m.

## Bully-Free Environments

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

Thu. 3/17/11, 6:00 – 8:00 p.m.

(Touchstone Behavioral)

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

## Parent/Professional Collaboration

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

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. 4/15/11, 10:00 – 12 noon

## 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.

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



**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.

**Advanced IEP**

An in-depth view of the IEP and strategies to help maximize the potential of each student.

**Wed. 3/23/2011, 5:30 – 7:30 pm**

**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

**Wed. 4/20/11, 5:30 – 7:30 p.m.**

**Journey to Adulthood**

Information about physical, emotional, and social changes that adolescence, and puberty bring to every child.

**Wed. 5/18/11, 5:30 – 7:30pm**

**Yavapi Apache Nation**

Administration Bldg  
2400 W. Datsi Rd., Camp Verde

**Journey to Adulthood**

Information about physical, emotional, and social changes that adolescence, and puberty bring to every child.

**Tue. 3/22/11, 5:30 – 7:30pm**

**Kykotsmovi**

Hopi Tribal Complex

**Organizing Your Child's Records**

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

**Wed. 5/04/11, 10:00 – 12 noon**

**Special Education Overview**

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

**Wed. 5/04/11, 2:00 – 4:00 p.m.**



**Summer School for Parents**

Join us for a day of learning!

**Saturday, June 25, 2011**

**8 a.m. to 4 p.m.**

**Disability Empowerment Center**

The Nina Mason Pulliam Conference Center, 5025 E. Washington St., Phoenix, AZ 85034

**Workshops will be presented in English and Spanish**

8:00 a.m. -10:00 a.m.

Pre School to Kindergarten Transition

10:15 a.m. - 12 noon

Bully Free Environment

12:15 p.m. - 1:45 p.m.

High School Transition

2:00 p.m. - 4:00 p.m.

Guardianship

Lunch provided. No child care.

Space is limited, please register by contacting Raising Special Kids at 602-242-4366 or online at [www.raisingpecialkids.org](http://www.raisingpecialkids.org).

# Changes to Arizona graduation requirements?

“They have been telling me all along that Johnny can stay in school until he is 22. At the last IEP everyone was talking about graduation, but Johnny is only 17!

What is going on?”

Questions like this have been the subject of a growing number of calls to Arizona disability organizations including Raising Special Kids. Some parents have reported their school is using new procedures concerning graduation for students in special education.

While Federal law has not changed regarding services schools are required to provide, the state’s interpretation of graduation requirements is affecting the way transition services are delivered. The result is that some students in special education are becoming eligible for graduation sooner than their families expected.

Until recently in many high schools, students in special education worked primarily toward fulfilling academic requirements during the first four years. Then the focus turned to job skills and other transition services until the student was prepared to graduate, or turned 22.

Due to the state’s stricter interpretation regarding which students schools can claim in their Average Daily Membership count (on which funding is based), schools are finding it difficult to claim compensation for students who are receiving only transition services after their academic requirements have been completed.

“The expectation of every student is to graduate from high school in four years with their class,” explained Christopher Tiffany, a Family Support Specialist. “A decision for a student to continue receiving services beyond four years should be an IEP team decision.” He added that a plan for transition services should be based on assessment data and focused on measurable postsec-

ondary goals. Transition services should be addressed in the IEP before the students turns 16.

Thoughtful planning by the IEP Team is needed to ensure transition services are embedded into each student’s education plan so that functional skills are scheduled along with academics. Students who complete their academic requirements for graduation before reaching vocational or life skills goals may no longer qualify for Free Appropriate Public Education (FAPE) paid for by the state.

For questions about transition, please call Raising Special Kids for assistance.

## Terms to know

**Graduation Requirements** - Specific number and type of credits a student needs to earn a High School Diploma.

**FAPE** - Free Appropriate Public Education is the right of every child with a disability, aged 3 – 21, residing in the United States, and is guaranteed by IDEA (Individuals with Disabilities Education Act).

**ADM** - Average Daily Membership is a calculation based on attendance and enrollment used by school districts to claim local, state and federal funds.

“The funding and the services available through IDEA are not available once the student has received a high school diploma, or aged out of the school system.”

— from *Autism Speaks’ Transition Tool Kit* available free at [http://www.autismspeaks.org/community/family\\_services/transition.php](http://www.autismspeaks.org/community/family_services/transition.php)

## What you can do

*from Arizona Center for Disability Law’s information sheet on high school graduation and transition services*

If you do not agree with the school’s decision to graduate your child because he still needs transition services or other IEP services, you can:

1. Ask the school in writing for an IEP meeting. Be sure to ask the IEP team to decide that your child needs more than four years of high school in order to receive all of the services in his IEP. Make sure that any IEP team members who have the power to make this happen come to the meeting.
2. If you are not happy with the result of the IEP meeting:
  - a. Ask the school for written notice of its decision to graduate your child even though she has not received all of the services in her IEP.
  - b. Contact the Arizona Center Disability Law at (602) 274-6287 or (800) 927-2260 between 9 a.m. and 1 p.m. on Mondays, Tuesdays, Thursdays or Fridays.
  - c. You can file a complaint with the Arizona Department of Education. You can also ask for mediation. Go to <http://www.ade.state.az.us/ess/dispute/> or call (602) 542-3084 for more information. Remember, under the IDEA you have the right to due process to challenge decisions made by the school about your child’s educational services.



# Health Survey Results

To date, more than 150 parents have participated in an online survey conducted by Raising Special Kids regarding the health care experiences of families in Arizona.

## What issues are most important to you about Arizona's services for children with a disability and/or special health care need?

<u>Answer</u>	<u>Percent</u>
<b>Finding Services and Providers in my Area</b>	<b>61.7%</b>
<b>Amount of Time Spent on Coordinating Care (appointments, specialists, therapies)</b>	<b>43.6%</b>
<b>Lack of Public Programs</b>	<b>40.9%</b>
Cost of Insurance	33.6%
Not Eligible for Public Programs	32.2%
Difficulty Understanding Benefits and Insurance Coverage	31.5%
Lack of Insurance Coverage for Special Health Conditions	28.9%
Under-insured (insurance doesn't cover costs)	28.2%
Screening for Health and Developmental Conditions	27.5%
Youth Transition to Adult Health Care	26.8%
Services should be More Family-friendly	24.8%
Problems Understanding or Working with Professionals	13.4%
Other	13.4%
Providers Don't Understand Family's Culture	4.7%

### HOW TO TAKE THE SURVEY

Tell us how health care issues affect families of children with special needs. If you haven't yet taken the survey, log on to

[www.surveymonkey.com/s/HealthSurveyforAZFamilies](http://www.surveymonkey.com/s/HealthSurveyforAZFamilies)

Thank you for helping increase awareness and understanding of the challenges families face.

### Comments:

"The older our son gets, the more support that is fading away. Our therapists for OT, PT worked with pediatric-aged clients, so both have stopped support."

"I have had adequate services through the years, but in the last couple of years I have seen more and more cuts, and more and more children going without the services they need."

"I would really like to find other families interested in doing interventions so that we can support each other, share resources, swap stories and tips, find out who the best people are for various services. If you can help me do this in the Northern AZ area, please let me know."

## Two new health reform resources

The Catalyst Center and the National Academy for State Health Policy have released a new report to help state policymakers understand how the Affordable Care Act (ACA) impacts children with special health care needs. A companion piece to the report is a new paper from the Catalyst Center that offers a concise description of select provisions in the Patient Protection and Affordable Care Act (ACA) with a side-by-side analysis of their implications for children and youth with special health care needs (CYSHCN). Download the reports: <http://www.hdwg.org/sites/default/files/ACAandCSHCNpaper.pdf>  
<http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf>

## Visionarios, Pioneros y Defensores

*Padres y Madres Son Valorados Como Líderes*

Cómo puede un padre o una madre ocupados criando a un/a niño/a con discapacidades encontrar tiempo para aumentar sus habilidades y experiencia de trabajo, socializar con otros adultos, modelar buen carácter a través de la responsabilidad cívica para sus hijos, y añadir un sentimiento de realización personal?

¿Dónde más pueden los padres de familia utilizar muchas de las habilidades que han desarrollado mientras que “aprenden el camino” navegando a través de los sistemas de atención o educación especial?

¿Cuándo es que el servir a otros apoya el desarrollo de las cualidades de liderazgo en uno mismo?

La respuesta a todas estas preguntas puede encontrarse sirviendo como voluntario en el programa de Liderazgo de Padres de Familia de Raising Special Kids.

Muchos padres reportan un gran retorno de su inversión de tiempo y esfuerzo ayudando a otras familias o educando a estudiantes y profesionales en los campos que proveen servicios a los niños con discapacidades. A través de las variadas oportunidades, como mentores de padres y madres, haciendo presentaciones a audiencias de estudiantes y profesionales, sirviendo en concilios comunitarios, comités o grupos de enfoque, o revisando materiales informativos, los padres han encontrado que a menudo reciben mucho más de lo que han contribuido. A pesar de que el sentido de cumplimiento o la buena sensación experimentada por haber ayudado a alguien más puede ser difícil de medir, otros beneficios de servir que los Padres o las Madres Líderes ven, puede ser reforzar el currículum de alguien buscando empleo, mejorar las habilidades de comunicación, o proveer la experiencia de hablar en público en un ambiente amistoso con el apoyo de personal muy comprensivo.

Kathy McDonald, una Madre Líder que participa en presentaciones a estudiantes y profesionales, señaló que “Una de las mejores cosas que hace Raising Special Kids, es obtener la opinión de nuestra audiencia y pasárnosla. Usted sabe realmente que está haciendo la diferencia cuando recibe esas opiniones. Es muy gratificante haber podido tocar a alguien y ayudarlos a cambiar cómo ven ya sea a un niño con discapacidades o por lo que está pasando una familia”.

Algunos de los beneficios de su experiencia como

Madre Líder que Kathy aprecia más son:

- amistades y conexiones con otros padres de familia
- mejor entendimiento con respecto a que no estamos solos—que otros también están pasando por esto
- ganar aceptación sobre mi propia situación
- convertirme en mejor oradora pública

Su experiencia como voluntaria de padres a padres “Parent-to-Parent” es algo que también valora personalmente Dawn Kurbat. “No hay libro alguno de texto que le explique cómo enfrentarse a su situación. Tuve que trabajar a través de ello y aprender a explorar opciones. Yo quiero compartir información y facilitar el proceso para otros padres de familia. Por eso lo sigo haciendo — ¡Eso es lo mejor!”

Dawn aprecia la flexibilidad de la programación de conexiones de padre a padre, “He podido hacer mucho desde mi propio hogar”, ella señaló. Muchas de las tareas de los voluntarios pueden realizarse por teléfono o correo electrónico, y a distintas horas.

La oportunidad de modelar los valores para sus hijos es otro bono para Dawn. “Todos mis hijos están viendo y aprendiendo de ello. Estoy poniéndoles el ejemplo”.

Algunos beneficios adicionales que Dawn mencionó incluyen:

- mejoramiento de las habilidades comunicándose y escuchando
- practicar la resolución creativa de problemas
- ampliar la concienciación comunitaria

Algunos padres han visto su experiencia como voluntario convertirse en la base de una carrera. Vickie French comenzó como voluntaria del programa “Parent-to-Parent” cuando sus hijos más jóvenes (gemelos) tenían tres años de edad. Mientras sus hijos fueron creciendo, ella avanzó a actividades adicionales apoyando a los padres de bebés en la Unidad de Cuidado Intensivo Neonatal, en Capacitación del Entrenador para el Plan Individualizado de Educación Dirigido por Estudiantes, y sirvió en la Mesa Directiva durante casi seis años.

Cuando ella estaba lista para trabajar de tiempo completo, unirse al personal de Raising Special Kids fue una elección natural para Vickie. Ahora, como

## Visionarios, Pioneros y Defensores

Subdirectora Ejecutiva, Vickie explicó, “Mucho de nuestro personal ha seguido el camino de voluntarios al empleo. Como voluntarios, ya han demostrado su pasión por ayudar a las familias, y han tenido la oportunidad de adquirir experiencia en muchas de las habilidades que buscamos”.

Hay oportunidades disponibles trabajando con familias de diversos antecedentes culturales y que hablan una variedad de idiomas. Los ponentes en un foro en Tuba City proporcionaron una oportunidad para que las familias en el norte de Arizona— muchos de los cuales viven en áreas extremadamente rurales— hicieran preguntas y obtuvieran información a través de actividades de persona a persona.

Las oportunidades para voluntarios de la Oficina de Jóvenes y Niños con Necesidades Especiales del Cuidado de la Salud del Departamento de Servicios para la Salud de Arizona, ofrecen un estipendio para miembros de la familia que trabajan como voluntarios, en reconocimiento del valor de la sabiduría de los padres. “Estamos especialmente deseosos de encontrar más voluntarios que nos puedan ayudar en el área del norte de Arizona”, dijo Vickie. “Tenemos algunas maravillosas oportunidades disponibles por allá”.

Raising Special Kids proporciona a los Padres y Madres Líderes el apoyo que necesitan para tener éxito. Todos los voluntarios son capacitados y se les da asistencia detallada, como vaya siendo necesaria, para cada actividad. Se han establecido las mejores prácticas, basadas en la investigación, para el programa “Parent-to-Parent”, y los Padres de Familia Líderes satisfacen altos estándares de responsabilidad y manteniendo la confidencialidad. Ellos mantienen registros y realizan las evaluaciones de sus actividades para asegurar que se satisfagan las necesidades de las familias.

El mantener un entorno y una relación de trabajo positivos con los voluntarios son de alta prioridad. La flexibilidad es crucial para los padres, y ellos pueden negarse a realizar cualquier actividad que no se les acomode. Como resultado, muchos padres se han dado cuenta de que poder ayudar a otros les brinda propósito y significado a lo que ellos han pasado con su propia familia.

### ¿Está Listo/a para Ser Padre o Madre Líder?

- ¿Ha usted llegado a aceptar la situación de su familia?
- ¿Está usted listo/a para compartir su experiencia con otros?
- ¿Se siente usted a gusto extendiéndose hacia otros y escuchando con la mente abierta y con compasión?
- ¿Puede usted mantener la confidencialidad en todo momento?
- ¿Cuánto tiempo puede usted ofrecer?

### ¿Qué es Un/a Padre/Madre Líder?

Los Padres de Familia Líderes desean mejorar los sistemas de cuidado para todas las familias, al compartir eficazmente su historia y perspectiva sobre la crianza de un/a niño/a con una discapacidad o necesidades especiales de la salud. Los Padres de Familia Líderes son hombres o mujeres que han alcanzado un lugar de aceptación, y están dispuestos a participar en la capacitación y el desarrollo de habilidades, con el apoyo de Raising Special Kids, compartiendo su sabiduría y conocimientos con otros padres de familia. Aquí hay algunas formas en las cuales los Padres de Familia Líderes contribuyen sus talentos especiales para ayudar a las familias:

- Padre de Familia Mentor – Provee asesoría y apoyo personal al/la padre o madre de un/a niño/a con el mismo diagnóstico durante un período de ocho semanas.
- Familia Facultativa – Participa en la capacitación de médicos pediatras o de medicina familiar en residencia, incluyendo el invitar a un médico a una visita al hogar para que experimente de primera mano los desafíos únicos a los que se enfrentan las familias de niños con discapacidades y necesidades especiales del cuidado de la salud.
- Alcance Comunitario – Ayuda en la planeación y dotación de personal de eventos comunitarios para llegar a otros padres de familia y a la comunidad en general. Son anfitriones de una mesa con información de Raising Special Kids, proveen información sobre los importantes servicios de apoyo familiar, oportunidades de liderazgo para los padres, y conexiones con otros programas.

*continúa en la página 12*

## 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, 3/14/11, 1:30-3:00 p.m.  
Lunes, 4/25/11, 10:00-11:30 a.m.  
Lunes, 5/16/11, 1:30-3:00 p.m.  
Lunes, 6/13/11, 1:30-3:00 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, 3/18/11, 1:30-3:00 p.m.  
Lunes, 4/11/11, 10:00-11:30 a.m.  
Viernes, 5/20/11, 10:00-11:30 a.m.  
Viernes, 6/17/11, 10:00-11:30 a.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.

Lunes, 3/28/11, 1:30-3:00 p.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, 4/1/11 10:00-11:30 a.m.  
Jueves, 5/26/11 10:00-11:30 a.m.  
Jueves, 6/9/11, 6:00-7:30 p.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.  
Miércoles, 3/16/11, 9:00-11:00 a.m.

### Organizando los archivos de sus niños/a

Aprenda modos efectivos para organizar sus archivos  
Viernes, 4/15/11, 10:00-12:00 p.m.

### Familias Resistentes

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

Viernes, 4/8/11, 1:30-3:00 p.m.  
Lunes, 5/23/11, 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, 4/22/11, 10:00-11:30 a.m.  
Viernes, 5/13/11, 10:00-11:30 a.m.  
Jueves, 6/16/11, 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.raisingpecialkids.org/](http://www.raisingpecialkids.org/)  
Por favor llámenos para confirmar su asistencia a los talleres.

Viene de la página 11

- Grupos de Asesoría, Concilios, Comités – Comparten la perspectiva de los padres de familia, sirviendo en un concilio, comité o junta para afectar el cambio a nivel del sistema.
  - Abogacía Legislativa – Representan la perspectiva de los padres de familia con respecto a cuestiones clave afectando a niños y familias ante funcionarios del gobierno local, estatal, y otros oficiales gubernamentales, o ante comisiones legislativas.
  - Panelista, Presentador de Capacitación, Entrevistas con los Medios – Participan en la capacitación de profesionales en las áreas de salud, educación y servicios sociales al “Contar Su Historia” en un salón de capacitación, sala de conferencias, o aula universitaria. Hablan en eventos públicos, o son entrevistados por los medios de comunicación para sensibilizar al público con respecto a los niños con necesidades especiales del cuidado de la salud.
  - Programa y Desarrollo de Normas – Ayuda a revisar la información de la agencia estatal, modificaciones a las normas, manuales, sitios en la red y otros recursos para las agencias y los programas estatales.
  - Planeación y coordinación del Proyecto – Ayuda a planear y coordinar actividades de Raising Special Kids en eventos o proyectos especiales.
- Para más información ó para ofrecer sus servicios como voluntario/a, por favor llame al 602-242-4366 ó al 1-800-237-3007, ó envíe una nota electrónica a [info@raisingpecialkids.org](mailto:info@raisingpecialkids.org)

# Community Notes

## Request to speak

*Participate in legislative process from anywhere*

The Arizona Legislature's Request To Speak (In Committee) System offers an electronic way to make your voice heard regarding bills being considered in committee. After registering for an account at the kiosks available at the capitol complex, those wishing to testify in Senate or House committees can log on to their account to record their comments for consideration during a hearing. Go to [www.azleg.gov](http://www.azleg.gov) to register. A brief how-to manual is available at <http://alistrack.azleg.gov/RTS/RTS%20Manual.pdf>.



**2011 AMCHP and Family Voices National Conferences** (from left): Jeanette Shea, M.S.W., A.C.S.W., Assistant Director, Public Health Prevention Services; Vickie French, Raising Special Kids; Sheila Sjolander, Chief, Bureau of Women's and Children's Health Arizona Department of Health Services

## Health & Wellness Fair

**FREE**

**Saturday, April 9, 2011  
9 a.m. to 4 p.m.**

at the

### Disability Empowerment Center

5025 E. Washington Street, Phoenix, AZ 85034

- Health Screenings
- Demonstrations
- Workshops
- Door Prizes
- Food
- Free Shuttle

Get details and updates at [www.abil.org/wellness](http://www.abil.org/wellness)

### DID YOU KNOW?

Last year Raising Special Kids:

- supported 10,098 families of children and professionals who serve them—and average of 841 per month.
- matched 265 families with parent to parent mentors to provide emotional support and resources

## Free Safety ID Tag

*Extra help in an emergency*

*I've worried about what to do. My child does not talk, and he has gotten out of our house. He also has special health care needs that medical personnel would need to be aware of in an emergency situation.*

*It was a relief when I found out about a free Identification Tag program offered by the Division of Developmental Disabilities. My child was provided with an ID tag that contains his DDD case number and a 24-hour phone number for first response emergency personnel to contact.*

*I chose the "shoe string slide" model of tag for my son. It attaches directly to his shoe strings which*



*works perfectly for him since he would not tolerate a bracelet or necklace because of his sensory issues.*

Is your child at risk of not being understood in an emergency situation? If your child receives services through the Division of Developmental Disabilities, and could benefit from having an ID tag, please contact your DDD Support Coordinator or call Raising Special Kids at 602-242-4366 or 800-237-3007 for an order form.

# Raising Special Kids News

## Forums for family needs

Presenter  
Steve Lee

Two recent forums by Raising Special Kids introduced professionals to audiences of parents for an exchange of insights and valuable information. Approximately 200 people attended the January 8th Spanish Forum and the January 26th Foster Care Forum sponsored by the Virginia G. Piper Charitable Trust which featured information for foster families and Spanish speaking families of children with disabilities and special needs. Topics included:

- Resources for Families
- Children's Health and Wellness
- Special Education
- Behavior, Mental and Emotional Health
- Transition to Adulthood



Presenter H.E. "Bud" Eckholm



Presenter Dr. Andrew Erlich, Ph.D.



*In Washington D.C. Vickie French met Chance Hammock, Legislative Assistant for Health Affairs at Congressman Jeff Flake's office.*

"We were so happily surprised at how much valuable information we were given! It was such a fantastic day of learning new information and sharing with other parents that are in similar situations. The speakers were excellent! We are so grateful to Raising Special Kids for this awesome opportunity!"

— Family at Foster Care Conference

## We gratefully acknowledge our Community Partners in bringing forums to families

Dr. Andrew Erlich, Ph.D.

Elidio Reyes, MAC

H.E. "Bud" Eckholm, Licensed Family Therapist.

Beverlee Kroll, DCYF Young Adult Program

Denise Beagley, Magellan Of Arizona Coordinator

Joanne Chiariello, Aid To Adoption Of Special Kids

Terry Tyner, Court Appointed Special Advocate

Sharing Down Syndrome, Raising Arizona Kids Magazine

Dunkin Donuts, Southwest Human Development

Wist Office Supplies, Banner Estrella Medical Center

### Exhibitors:

Aid To Adoption Of Special Kids, Catholic Charities Community Services, Down Syndrome Network, Arizona Magellan of Arizona Brain Injury Association of Arizona, Arizona Autism United Arizona Technology Access Program

Special thanks to  
**Pastry Chef  
Lance Whipple  
and  
The Four Seasons  
Resort**

for selling gingerbread cookies to benefit Raising Special Kids!



# In The Spotlight

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

November, 2010 - December 2010

### **A Place to Call Home**

**AASK**  
**Arizona Center for Disability Law**  
**Arizona Child Study Center**  
Theresa Rimer  
**Arizona Children's Association**  
Tina Adams  
**Arizona Dept of Education-PINs**  
**Arizona State University**  
Jessica DeBiase  
**Association for Supportive Child Care**  
Rene Hobbs  
**AzEIP/ NRTA**  
Stephanie Camisa  
**AZPAC**  
**Banner Desert Medical Center**  
Heidi Solak  
**Cardon Children's Medical Center**  
Josie Jones  
Jennifer Lembach  
**Care Partnership**  
Bev Baker  
**Cartwright School District**  
Rhonda Hancock  
**Child & Family Resources/AzEIP**  
Nubia Garcia Shinagaw  
**Child Protective Services**  
Crystal Thomson  
**Childrens Rehabilitative Services**  
Ramona Cano  
**City of Phoenix Headstart**  
Mercy Madrid  
**Devereux**  
**Division Of Developmental Disabilities**  
Brittany Adkins  
Carmen Aguilera  
Fran Altmaier  
Kimberly Becker  
Ruthann Bilkey  
Sarah Bravo  
Lois Brooks  
Kathleen Calder  
Robin Chanto  
Lovelda Chase  
Chelle Colton-Rutledge  
Wanda Copeland  
Donna Cruse  
Maria Fernandez  
Tanya Goitia  
Jade Guerrero  
Kathi Guildig  
Ty Hample  
Claudia Hart  
Katherine Hartnett  
Billy Henderson  
Debbie Hooper  
Latasha Janowitz  
Monica Joe  
Cynthia Keller  
Jill Keyes-McClements  
William Kilgore  
Carly Koniecoczny  
Vanessa Kruse  
Nadine Laman  
Maria Elena Mangiameli  
Lucia Marquez  
Martha Mills  
Tammy Molash  
Marta Monyer  
Laura Moore  
Sonia Navarro  
Karen Nugent

Courtney Parker  
Karen Patten  
Lisa Rennells  
Richard Schloe  
Kizzy Sepulveda  
Alberto Serpas  
Julie Sigmund  
Madelyn Slowtalker  
Michael Smith  
Dana Southworth  
Lola Summers  
Patty H Walters  
Megan Wiley  
Elizabeth Williams  
Meagan Woelfel  
**Early Head Start**  
**East Scottsdale Medical Care**  
Tracey Drummond  
**FACE Program**  
Amy Mestaz  
**Family Involvement Center**  
Blanca Zazueta  
**Family Partners**  
**Fiesta Speech Therapy Link**  
**GANE**  
**Getz School**  
Gail Hales  
**Gilbert School District**  
Emily Haskell  
**Gilbert Parent Council**  
**Head Start**  
Judy Bell  
**Horizon Elementary School**  
**Hurley Ranch Elem/Union Elem District**  
Shari Gray  
Josiah Vasquez  
**Isaac School District**  
Ibhar Enriquez  
**Jewish Family & Community Services**  
**Joni & Friends**  
Pam Baldwin  
**KKONA**  
**La Casa Lutheran Church**  
Jennie Ullibarri  
**La Frontera Impact**  
**Maricopa Medical Center**  
Dr. Anderson  
**Melvin E Sine Elementary**  
**Mensendick Elementary School**  
Nancy Forster  
**Mesa Public Schools**  
Jan Umhay  
**Mountain Park Health Center**  
Bridgette Terrazas  
**Mountain Pointe High School**  
Darla Foster  
**NICU Neonatal Follow Up**  
Jackie Stout  
**Office for Children with Special Health Care Needs**  
Rita Aitken  
Marta Urbina  
**One Life Unlimited**  
**Paradise Valley Parent Council**  
**PEDI Center**  
Margaret Bunting  
**Phoenix Interfaith Council**  
**Phoenix Children's Hospital**  
Maria Flores  
Tiffany Glick  
Cynthia Nakamura

Maritsa Saucedo-Graham  
Cheryl Searles  
Jennifer Stalteri  
**Phoenix Interfaith Council**  
**Quality Care Network**  
Hugo Gonzalez  
**Quest Alliance**  
Annette Reyes  
**Rhodes Jr High School**  
Maria Hunington  
**RISE, Inc.**  
Flor Berber  
Amy-Lee Verfaillie  
**Scottsdale Behavioral Health**  
**Sharing Down Syndrome**  
Rachel Haznuk  
Gina Johnson  
**Southwest Network**  
**Tempe Union High School District**  
**Texas PTI**  
**Touchstone Behavioral**  
**UMOM**  
Stacy Campbell  
Rachel Day  
Karly Savoy  
**United Cerebral Palsy of Central Arizona**  
**Williams School District**  
**Yavapai Apache Nation**  
**Yavapai School**  
Mary Simpson  
  
**INDIVIDUALS:**  
Kristina Blackledge  
Nannette Bowles  
Jodi Hanover  
Lisa Norman  
Don Storrs  
Lola Summers  
Cathy Uno  
Elizabeth Williams


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

November, 2010 - January, 2011

**Avondale**  
Claudia Lizarraga  
Gabriela Sanchez Orozco  
**Chandler**  
Beth Maloney  
Noelle White  
**Gilbert**  
Katie Wride  
**Glendale**  
Dawn Kurbat  
Annette Navarro  
**Mesa**  
Julie Follmer  
Kristi Kleban  
Susan Melton  
**Phoenix**  
Rebecca Bailey  
Paula Banahan  
Jeannie Bremerkamp  
Veronica Castillo  
Inilda Christensen  
Patty Coe  
Daphne Cunningham Thompson  
Sara Eaton  
Jim Gootee  
Nancy Gunderson  
Sharon Hayes  
Nancy Licht  
Maureen Mills  
Migdalia & Joaquin Morales  
Elizabeth Naughton-Ketzler  
Ched Salasek  
Lori Stuart  
Hannah Swearengin  
Paulina Tiffany  
Dana Wayne  
**Queen Creek**  
Elizabeth Bird  
**Scottsdale**  
Jill Castle  
Shauna Mattson  
Lynn Michels  
Katie Petersen  
**Sun Lakes**  
Iris Sanabria  
**Tolleson**  
Kristie Amator  
**Waddell**  
Sharon Atwood  
  
**Office Volunteer**  
Philip Sanabria

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

**Find us on  
Facebook.**



Designate  
**Raising Special Kids**  
to be your charity of choice  
when you use  
**Goodsearch.com**  
— a Yahoo-powered Internet  
search engine that donates  
50% of its revenue,  
approximately a penny per  
search, to the charities  
designated by its users.

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

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**March 26**

Mark your calendar for the 25th Annual  
**A Special Day**  
for  
**Special Kids!**

**Sponsored by Scottsdale Sunrise Rotary Club,  
Phoenix El Puente Rotary, Raising Special Kids &  
Scottsdale Unified School District Service Learning Classes**

**Saturday, March 26, 2011**  
**10 am - 2 pm**

**McCormick-Stillman Railroad Park, Scottsdale**  
(located on the southwest corner of Indian Bend and Scottsdale roads)

**Please join us for FREE train rides, carnival activities, carousel rides, games,  
activity booths, clowns, face painting, petting zoo, plus lots of food and  
ice cream...all for FREE! Register on the day of the event.**

**Questions? Contact Dan McAuliffe 480-624-2338 or Raising Special Kids (En Espanol) 480-242-4366**

[www.raisingpecialkids.org](http://www.raisingpecialkids.org)