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 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.”

— continued on page 3

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

“...very beneficial, I enjoyed hearing about each of your family experiences.”

—Dental Student’s comment on Parent Panel
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.
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

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 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.

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

www.raisingspecialkids.org
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

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

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.

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.raisingspecialkids.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.
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)

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.

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.

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)

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.

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)

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)

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)

Parent/Professional Collaboration
Develop an effective partnership between parents and professionals in Special Education.
Tue. 5/03/11, 1:00 – 3:00 p.m.

Special Education Overview
Learn the structure and process of the special education system and primary intent of the IDEA federally mandated program.
Thu. 4/14/11, 10:00 – 12:00 noon

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

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.

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.

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.

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.

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 – 7:30 pm

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 – 7:30 pm

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.

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

Attendance at all workshops is at NO COST.
For Southern Arizona workshops please call 520-324-3150 or visit www.pilotparents.org

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.raisingspecialkids.org.

www.raisingspecialkids.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 postsecondary goals. Transition services should be addressed in the IEP before the student 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

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?

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

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.hd wg.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 pasarnosla. 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
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—hiciesen 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/l a padre o madre de un/a niño/a con el mismo diagnóstico durante un periodo 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.
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
Acompáñenos 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 3 años, qué sigue?
Intervención Temprana
Aprenda sobre los requerimientos para la transición e ideas para lograr un proceso más fácil.
Miercoles, 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.

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.

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.
Miercoles, 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 pagina web: www.raisingspecialkids.org/
Por favor llámennos 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 o 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@raisingspecialkids.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 to register. A brief how-to manual is available at http://alistrack.azleg.gov/RTS/RTS%20Manual.pdf.

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

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.

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

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

www.raising.specialkids.org
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

“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

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

Special thanks to
Pastry Chef
Lance Whipple
and
The Four Seasons Resort
for selling gingerbread cookies to benefit Raising Special Kids!

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

Dr. Andrew Erlich, Ph.D.
Eldio 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

www.raisingspecialkids.org
In The Spotlight

Making a Difference in the Lives of Children
Thank You for referring families to Raising Special Kids
November, 2010 - December 2010

Parent Leaders are the heart of
Raising Special Kids
Thank You!
November, 2010 - January, 2011

A Place to Call Home
AAAS
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 DeBlase
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
Children's Rehabilitative Services
Ramona Cano
City of Phoenix Headstart
Mercy Madrid
Devereux
Division Of Developmental Disabilities
Brittany Adkins
Carmen Aguilara
Fran Althiser
Kimberly Becker
Ruthann Bilkey
Sarah Bravo
Lois Brooks
Kathleen Calder
Robin Chanto
Loveda Chase
Chelle Colton-Rutledge
Wanda Copeland
Donna Cruse
Maria Fernandez
Tanya Gotia
Jade Guerrero
Kathi Guild
Ty Hample
Claudia Hart
Katherine Hartnett
Billy Henderson
Debbie Hooper
Latasja Janowitz
Monica Joe
Cynthia Keller
Jill Keyses-McClements
William Kilgore
Carly Konieczny
Vanessa Kruse
Nadine Laman
Maria Elena Mangiameli
Lucia Marquez
Martha Mills
Tammy Molash
Marta Monier
Laura Moore
Sonia Navarro
Karen Nugent
Courtney Parker
Karen Patten
Lisa Rennels
Richard Schloe
Kizzy Sepulveda
Alberto Serpas
Julie Sigmund
Madelyn Slowtagler
Michael Smith
Dana Southworth
Lola Summers
Patty H Walters
Meghan 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
GAN
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
Ishar Enriquez
Jewish Family & Community Services
Joni & Friends
Pam Baldwin
KRONA
La Casa Lutheran Church
Jennie Ulibarri
La Frontera Impact
Maricopa Medical Center
Dr. Anderson
Melvin E Sine Elementary
Mensendick Elementary School
Nancy Forster
Mesa Public Schools
Jan Umhau
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 Aiken
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
Marlta Saucedo-Graham
Cheryl Searles
Jennifer Stalteri
Phoenix Interfaith Council
Quality Care Network
Hugo Gonzalez
Quest Alliance
Annette Reyes
Rhodes Jr High School
Maria Hunnington
RISE, Inc.
Flor Berber
Amy-Lee Verfaille
Scottsdale Behavioral Health
Sharing Down Syndrome
Rachel Haznuk
Scoa Johnson
Southwest Network
Tempe Union High School District
Texas PTI
Touchstone Behavioral
UMOM
Stacy Campbell
Rachel Day
Karl 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

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.

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

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