



Raising Special Kids
Families Helping Families



Annual Report
to the Community

2012

Raising Special Kids

Mission

To improve the lives of children with disabilities and special health care needs by providing parents with information, training and support.

Programs and services are offered free of charge, in English and Spanish, without regard to the child's disability, age, family income, qualifying conditions or other eligibility factors.

Credo of Family Support

We believe that experienced families are a key source of knowledge & support to help parents in becoming effective advocates for their children.

We believe that professionals are important allies for families. The shared wisdom, counsel, respect and support creates enhanced positive outcomes for children.

We value diversity and celebrate our commitment to serving families in many forms.

We believe in supporting the role of the family in establishing public policy, and promoting public awareness related to families and disabilities.

We believe that parents who model effective self-advocacy encourage a child's pursuit of his or her own dreams.

“The parent support is amazing — you understand exactly what I am going through.”



Letter from the President of the Board

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This report is full of data showing the impact Raising Special Kids has had on Arizona families raising children with special needs. But the real effect of the critical services offered by our organization are reflected in the faces of parents and families who have found comfort and assistance at the hands of our experienced, capable team of dedicated parent staff and community leaders.



Kevin Bonner

This year brought exciting changes. We began a collaborative effort with the Parent Information Network Specialists of the Arizona Department of Education to bring much-needed educational workshops and information to under-served areas of the state. The groundwork was laid for a new relationship with the Arizona Early Intervention Program to expand our services to parents of children birth to three.

As we move forward with these projects and further efforts to maximize services to families, I know our 34th year will continue to help parents improve hopes for the future for their children.

A handwritten signature in black ink that reads "Kevin Bonner". The signature is written in a cursive, flowing style.

"I had to tell you that we think Raising Special Kids is the best organization ever! I don't know what I would have done without you."



Improving life for children with disabilities and special health care needs

Helping families

Raising Special Kids strives to improve the lives of children with disabilities and special health care needs by supporting people who care for them—families and professionals.

7,656 families received
information, training, and
individual assistance



Parents at Collaborative Therapies Conference

“My daughter's world has changed dramatically due to Raising Special Kids. She now has real friends and a social life at school and in our neighborhood for the first time in her life.”



Developing Parent Leaders



Parent Leaders

333 Parent to Parent Matches

All participants in our parent mentoring program receive follow-up contact from staff

Most families are not prepared with the skills and knowledge to address the unique challenges of raising a child with a disability. Each step of a child's development reveals the need for new creative solutions which are made more complex by the presence of extraordinary health or ability issues unfamiliar to the family or their support network. Bringing families new to these challenges together with experienced parents who can share their knowledge has proven to help provide children with the environment and support they need to fully develop their potential. The staff and trained volunteers of Raising Special Kids are family members with experience raising a child with a disability.

90% of parents reported parent to parent support helped them become more effective in advocating for their child

91% of parents reported being better prepared to make decisions regarding their child's needs and services

“I was amazed at the prompt response and the quality of information I received. Raising Special Kids is like an awesome highway of information which has been instrumental in getting my son the help he needs.”



Supporting Professionals

Understanding the challenges families face each day helps professionals in health, education, child care and social services provide more effective services to children and their parents. The insight professionals gain from informed parent leaders results in improved care, and better outcomes for children with disabilities and the communities in which they live.

60 pediatric and family practice physicians from five hospitals and medical centers completed training and home visits



Parent Panel for education students at Arizona State University.

96% of education professionals reported being better prepared to work with families

Parent Panels

Trained Parent Leaders present to students in education, health and social services. Their perspective on the challenges of raising a child with special needs adds fresh insight to training programs and helps prepare future professionals to provide family friendly services.

Family and Community Medicine

Through the Family and Community Medicine Program, pediatric physicians in residency complete training with Raising Special Kids followed by a home visit with Family Faculty for a first-hand look at the challenging role of raising a child with special needs.

“Thank you once again for the insightful parent panel you provided for my students. These students are preparing for their first year of teaching in the fall and really benefit from opportunities to put their in-class theoretical knowledge into actual practice. Today’s panel was a wonderful chance for them to explore what it is like to walk in the shoes of parents and families impacted by disability.”



Serving Arizona and Diverse Communities

Raising Special Kids provides support through information, training, and assistance to thousands of Arizona families each year. Services are offered at no charge to families in English and Spanish throughout the state. Assistance is designed to meet the unique needs of each family and is available through varied methods including individual consultation, workshops and conferences, and parent leadership development opportunities.

Community Outreach Activities

- Collaborative Therapies Conference - Show Low
- Special Day for Special Kids - Scottsdale
- Workshops, training, and family support services were provided to meet the unique needs of vulnerable families in transitional housing with UMOM.
- Navajo Nation Disability Conference - Tuba City
- Parent Conference - Yuma
- Healthy Families Spanish Conference

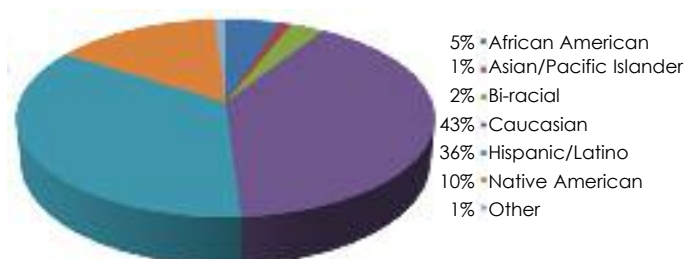
Staff and Parent Leaders represented the family voice on systems-level boards, committees, and activities:

- *Special Education Advisory Panel*
- *First Things First*
- *Developmental Disabilities Planning Council*
- *State Rehabilitation Council*
- *Interagency Coordinating Council for Infants and Toddlers*
- *Cultural Competence Committee - Arizona Department of Health Services*
- *Foster Care Review Board*
- *Division of Developmental Disabilities Sustainability and Innovation Task Force*
- *Arizona Autism Coalition*
- *Arizona American Academy of Pediatrics Visioning Summit Planning Committee*
- *Arizona Disability Advocacy Coalition*
- *Build Arizona Healthy Children and Families Workgroup*
- *Maricopa Family Support Alliance*
- *Partners in Preparedness State Emergency Planning*
- *Arizona Health Care Cost Containment System (AHCCCS - Medicaid) integration with Children's Rehabilitative Services (CRS)*



Parents confer with volunteers.

Families of Diverse Language and Culture Served



“I just wanted to say thank you for all of the support your staff has provided over the last year. It is so comforting to know that anytime I have a question there is always someone there to answer it for me.”



Education

Many parents find special education to be overwhelming. Some families have seen their child exiting high school before they fully understood the complexities of qualifying for special education services, developing Individual Education Programs (IEPs), and the availability of assistive technology.

Raising Special Kids has helped thousands of parents understand their rights and how they can advocate effectively for what their child needs to receive a “Free and Appropriate Public Education” (FAPE) as guaranteed by law.

The U.S. Dept. of Education awarded Raising Special Kids a 5-year federal grant to serve as Arizona’s Parent Training and Information

Center. Parent centers in each state provide training and information to families of infants, toddlers, school-aged children, and young adults with disabilities and the professionals who work with them. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities.

98% of parents surveyed reported receiving information that will help them make better decisions about their child’s education

Health

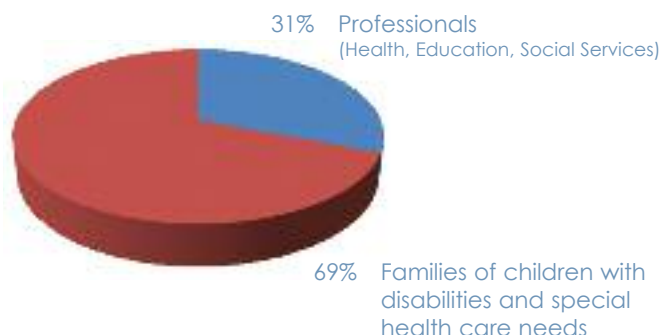
Raising Special Kids serves as Arizona’s Family to Family Health Information Center under grant award from the U.S. Department of Health and Human Services.

Our services encourage principles of family-centered care, and educate about policy and regulatory developments that may impact children and youth with special health care needs and their families.

Principles of Family Centered Care

- Acknowledges the family as the constant in a child’s life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.

Who We Serve



98% of physicians trained reported improvement in their ability to communicate with families

"Without Raising Special Kids' help and information our daughter would not be receiving the services that she needs."



Riley's Family

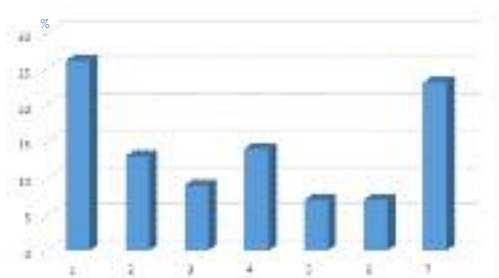


Riley on his dad's lap next to his sisters with Kristie.

Riley was seven years old and his mom, Kristie, didn't remember a time in his life when they did not rely on Raising Special Kids to help. Kristie learned about Raising Special Kids while Riley was still in NICU. She has benefitted from Parent to Parent connections; help with Riley's IEP, and arranging appropriate services for him at school.

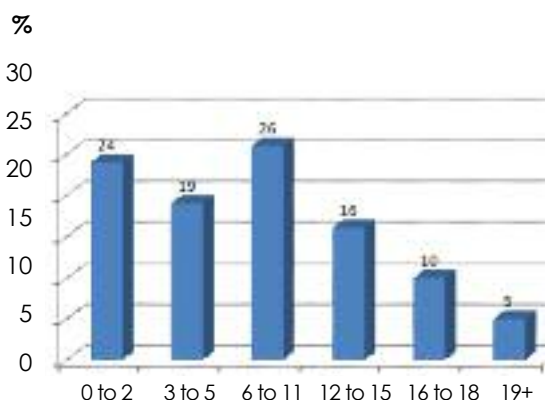
"Any time I have a concern or I feel lost, I call you guys! It's wonderful to have someone on the other end of the phone who understands. It makes the road less bumpy. I'm always glad when I hear from you because even when I don't realize I need you—I need you!"

Disabilities of Children of Families Served 2012



- 1 ADD/ADHD
- 2 Autism
- 3 At Risk (0-3) for Developmental Disabilities
- 4 Down Syndrome
- 5 Intellectual & Developmental Disability
- 6 Other
- 7 Speech/Language Disorder

Age of Children of Families Served 2012



“There were times when I just didn’t think I could fill out one more piece of paper or make one more phone call. When I reached that point, you made the call for me. To me, this is an act of kindness that will always be treasured. You have been my strength when I had none. Your organization is more than amazing!”



Milestones

- Collaboration with Arizona Department of Education Parent Information Network to expand services throughout the state with new workshops and conferences in Southern Arizona
- Parent education project for families who are homeless with children birth to five. A project with Raising Special Kids, UMOM, and First Things First.
- Completed NICU Parent Support Manual and began distribution to families of children in Neonatal Intensive Care Units
- Two new Collaborative Therapies Conferences: one in Spanish and one in Southern Arizona



(From left) Stacey Campbell and Kim Williams of UMOM with Janna Murrell

Financial Statement

Reporting year revenue and expenditures

\$ 1,033,527	Total Revenue
\$ 673,203	Parent Information, Support & Training
\$ 172,641	Training for Professionals
\$ 187,683	Community Support
<hr/>	
\$ 889,386	Program Expenditures
\$ 133,321	Administrative Functions
\$ 1,022,707	Total Expenditures

2012

“Thank you for all that you have done to improve the lives of families of children with disabilities. Many thanks for what you do as an individual each time you answer the phone and spend an hour compassionately listening to a parent tell their story.”

— Physician



Thank You to Our Donors

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Raising Special Kids has been instrumental in informing and supporting families throughout the past 34 years, and it has produced many leaders who continue to make a difference in the lives of Arizona's children with special health care needs and their families.

—Judie Walker, Ombudsman/Member Advocate, UnitedHealthcare



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“I am a teacher and a parent of a child with special needs, and as a teacher I didn’t know a lot of the great info that I learned at this workshop! We went from having NO accommodations to eighteen accommodations because of the workshop and the help from Raising Special Kids.”



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