

# **Raising Special Kids**

2013 Annual Report to the Community



**Raising Special Kids Mission:** Raising Special Kids exists to improve the lives of children with the full range of disabilities, from birth to age 26, by providing support, training, information and individual assistance so families can become effective advocates for their children.

**Credo:** Each parent of a child with a disability or special health need will have access to reliable sources of information, training, and assistance to help them advocate effectively for their child.

#### **Letter from the Board President**

Joyce Millard Hoie, Executive Director

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2013 flew by! Each year seems to bring new changes and growth and we are pleased to present this Annual Report to feature the latest news about our mission and accomplishments from the past year:

A Yuma office opened in April, with a bi-lingual staff member. The partnership with the Arizona Department of Education to expand parent training and

information in special education. Three achievement awards recognized the organization's efforts to excel in family support and community service

As a medical professional, and a parent of a beautiful, accomplished daughter with Down syndrome, I am particularly proud that over 2,000 professionals in health, education, and social services participated in our training for physicians, nurses, teachers, and case managers. The response from the professionals has been overwhelmingly positive and life-changing. You can read more about this on page four.

As you read through the pages, you'll see how hard we've been working to achieve our mission of family support for parents of children with the full range of disabilities. We served more families in 2013 than we have in previous year, forged more community partnerships, and trained more professionals than ever before. The numbers are all described and presented, and you can see the impact we've had on the community, but Raising Special Kids has never been about the numbers. Raising Special Kids is about the kids, each and every single one of them. I hope you will take the time to read the story from the Shook family. These parents tell the real story of 2013. For 34 years Raising Special Kids has been here: for the Shook family, for your family, and mine.

For all our children, here's to a bright future full of promise and potential.

Paula Banahan, President Board of Directors



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Celebrate with Raising Special Kids for the awards and recognitions received



"I could talk to someone who understands and someone who is a few steps ahead of where we were at the time. I now know just how important Raising Special Kids is to those who have kids with special needs."

- Laurie Shook

#### **Programs for Parents and Families**

Parent-to-Parent support has always been the heart of Raising Special Kids. Each year, more than 300 families in Arizona are connected with veteran "mentor" parents who have walked a similar path, and who understand the challenges of raising a child with a disability or special health care need. Raising Special Kids provides training and consultation in special education to families, schools, teachers, and other professionals.

# **Programs and Services**

Raising Special Kids provides information, training, resources, and support to families of children with disabilities and special health care needs in Arizona. Experienced staff lend an understanding ear and assist families in identifying and locating appropriate resources.

Workshops offer training in a variety of skills including advocacy, effective communication and collaboration techniques. Our newsletter,
Connecting, reaches more than 10,000 parents and professionals and e-news alerts are shared by request with a growing list of interested individuals.

Over 8,000 parents and professionals were reached through e-news alerts by request.

#### Who we Serve

68% Families with disabilities and special health care needs

32% Professionals (health, education, social services)

#### Programs and services for parents and families

7701 families received information, training, and individual assistance

93% of parents said I gained useful knowledge about my child's needs and services

70% of parents said I received information to help me address a critical need related to my child's education

94% of parents said training materials were of high quality

381 Parent to Parent Matches

90% of Parents said that Parent to Parent support improved my ability to advocate for my child's needs, services, and care

98% of parents would recommend P2P for another parent

96% of parents said that P2P is a reliable source of information for the future

#### I felt overwhelmed, stressed, sad.

When Laurie and her husband adopted Adilynn, they anticipated a few minor medical issues. What they couldn't have anticipated was the hospitalizations, medical procedures and over a dozen specialists necessary to meet Adilynn's medical needs. We have been hospitalized a total of four times and with every stay we would leave with more doctors, tests, and stress to come," Laurie said.

"We were bombarded with paperwork, insurance issues, and the feeling that we were drowning and couldn't catch up." In addition to Adilynn, the Shook's have a two year old

foster son who also has special needs. "I felt overwhelmed, stressed, sad, and even hopeless at times. I would sit at the hospital and cry some days because I wasn't sure how to move forward or where to begin."

"They helped me cope...I finally felt like I could breathe again."

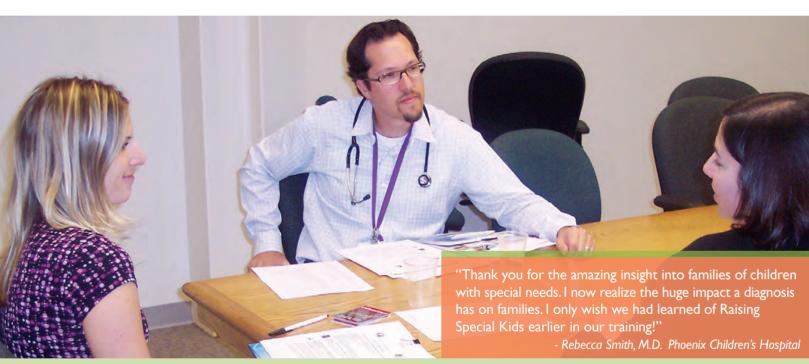
Following Adilynn's surgery, Laurie received a call from Raising Special Kids. "They helped me cope with her new feeding tube and the best help of all was that I got pointed in the right direction on how to get Long Term Care set up! I finally felt like I could breathe again!"
Through Raising Special Kids' Parent-to-Parent Connection program, Laurie was connected with another mom who also has a child with complex medical needs. "I could talk to someone who understands and someone who is a few steps ahead of where we were at the time. I now know just how important Raising Special Kids is to those who have kids with special needs."

# **Programs and Services continued**

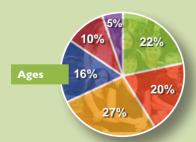
## **Programs and Services for Professionals**

Programs for resident physicians in pediatrics and family practice relay information about parents' perspective on issues relating to medical services. Parent Panels and staff-led workshops are available to students in education, medical, oral health and social service fields.

- **4,931** Training/Conference Attendees (Parents 2,578; Professionals 2,335)
- 91% of Educational professionals reported being better prepared to work with families
- 59 pediatric and family practice physicians from five hospitals and medical centers completed training and home visits
- 96% of physicians reported training improved ability to communicate with families



## **Children Demographics**



## Age

0-2 year - 21%

3-5 years - 19%

6-11 years – 26%

12-15 years - 16%

16-18 years - 10%

19+ years - 5%



#### Disability

ADHD - 12%

Autism - 20%

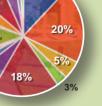
Intellectual – 5%

Deaf/Blind – 3%

Developmental – 18%

Emotional/Mental - 6%

Epilepsy – 2%



## Hearing Impairment/Deaf – 1%

Multiple Disabilities – 1%

Other Health Impairment – 11%

Orthopedic – 1%

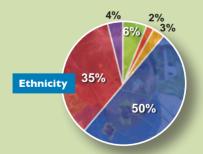
Specific Learning Disability – 5%

Speech/Language – 7%

Suspected/Undiagnosed – 4%

Traumatic Brain Injury – 1%

Visual/Blindness - 1%



#### Ethnicity

African American – 6%

Asian/Pacific Islander – 2%

Bi-Racial – 3%

Caucasian – 50%

Hispanic/Latino – 35%

Native American – 4%

## **Financials**

## Where does our money come from?

	2013
Federal and State Grants	\$921,525
Other grants and contracts	\$0
Donations	\$141,963

### What makes up our program expenditures?

	2013
Parent Support Services	\$738,608
Training Support Services	\$146,912
Donations	\$141,963
Fundraising	\$3,866
Management and General	\$133,321

2012



"Raising Special Kids was extremely helpful and a great starting point. When we received the diagnosis I did not know anything about how to help my child. Raising Special Kids support and materials taught me a lot!"

### **Community Outreach**

- DES Conference for Foster Parents Flagstaff
- *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
- Maricopa Family Support Alliance Engaging Fathers
   Seminar Tempe
- African American Conference on Disabilities Phoenix
- Arizona School Social Workers Conference Tucson
- Davis Monthan Air Force Base Outreach Tucson

- Hopi Disability Conference Kykotsmovi
- *Back to School Blitz* Rio Rico
- *Back to School BBQ* Rimrock
- WACOG Western Head Start Yuma
- Yuma County Health Department Yuma
- Window Rock Transition Conference Fort Defiance
- *Partners for Transition* Lake Havasu City
- ADE Transition Conference
- Special Education Director's Institute

At Raising Special Kids we are committed to using funds responsibly to ensure we help families today and in future generations.

\$135
Revenue
Per Family

Each workshop only required \$135 of revenue

2870
Donated
Hours

Donated goods and services - Total 2,870 hours would equal over \$60,000

# PROGRAM EXPENDITURES

(in thousands)



## **Our Supporters**

#### 2013 Donors

#### Friends \$1 to \$249

Karen Ross Diane Dimmock Diedra Freedman Margo Himes Kelli LeVasseur Veronique Vaillancourt

Jeffrey Turner
Jennifer Hood
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Robert Rouhani
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Sharon Shelley Robin Smith

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Steven & Jane Carter Enterprise Bank & Trust Jason and Laura Lewis Michaelene Barlow James & Christina Speros

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Christopher Goeman Georgeanne Hanna Daniel & Gladys Haren

Vickie Herd
Ingrid Huang
Patty Iwaoka
Angela Jennings
Beth Kozik
Joyce Lefco
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Ramona Napier

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Mary Slaughter Richard Thompson, Jr Thomas Timmer Betsy Trombino Lori Walk Heidi Wesolowski Eric & Caryle Zaharia

Kristin Eng Janelle Tassart Paula Friedlund John Carroll

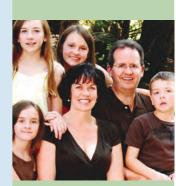
Christopher & Paulina Tiffany

Shari Capra
Diane Bradley
Barbara Buchanan
Lynn Fox
Lin Stoudt

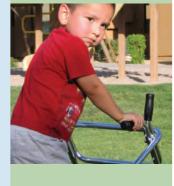
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Leah Alger
Dr. Mary Allare
Susan Cannata
Anne Chase
Marilyn Coffman
Karim Diab
Alex Eckert
Michele Ferber
Hugh Foy
Michelle Gardner
Art Gode
Nancy Gretzinger

386 Community Partners



7701
Families
Assisted



2870 Donated Hours



"We really enjoyed the whole workshop – presenters and vendors. The information will help us go forward with planning for my son's special needs with better understanding and resources."

Thomas Halpern Brad Harper Trigon Ms Madelyn Harper Karen Hayenga Karen Hinds Ellen & William Leibow lill Linden Richard & Joanne Masica Kathy McDonald Sharon Melton Zell Millard Heather Nassar Mary Neil Tonya Price Kelly Randall Sechler, CPA PC Carolyn Sechler Binumon Sivaraman Michael Stanley Jo Ann & Gordon Watkins Claudia Weiss Leslie Williams Cherie Wright Cynthia Malbrough Lisa Baird Sheri Lehmann Wells Fargo - The Private Bank

#### Mentors \$250 to \$499

**Emily Kile** Jody Kris Gregory Lechowski Stan Morris Peoples Mortgage Company Jill Nico Scott Anderson Dixon Golf, Inc. Jill Hernandez Geraldine Kasten Joseph Errante Barbara Brent Great American Title Agency Laura Alger Sandy Bawden Walter Brown



Evangeline & Patrick Buckley leni Calkins Kathy & Yves Dumaplin Steve & Vickie French Steve & Diana Gruber Randy and Frymet Hare Nathaniel Hastings Gary Heinfeld Samantha Heinrich David Hesser Barry & Becca Hornstein Valerie Iwinski Potana Kumar Gupta Jamili Elizabeth Kearns Jennifer Kupiszewski Michelle Langan Mr Jack Larsen Andrew Martin Nancy Maser Nancy Meech Dr. Shawn Meyer lanet Moeur Janna & Mark Murrell James O'Connor Ndidiamaka Obiesie Ioni & Tom Owen Kenneth and Bern Peterson Amy & Shaun Pressley Pam & Mark Remsey Chuck & Donna Riser Ross Robb Maulik Shah Stephanie Smith Jon & Lisa Soeby Troy Stockstad Srikanth Surukuntu Gayle Taylor Tigran Unciano Marc Voirol Debbie Voll lill & Michael Walker Patricia Winner **Neil Wintle** Rich Zawtocki Maureen Mills State Employees Charitable Camp Tim & Sally Watters Shelly Shaffer

#### **Guardians \$500 to \$999**

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#### Champions for the Cause \$1,000 to \$19,999

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Debbie Voll

Tim Watters





Aaron Shane Vernon

Rob & Kelly Watson

The "Parent Center of Excellence Award" is the highest award given to Parent Centers which achieve 100% of the "Required" indicators, at least 75% of the "Effective" indicators, and at least 75% of the "Best Practice" indicators.



# Raising Special Kids Receives Award for Excellence

The Parent Center Standards for Excellence, developed by the National and Regional Parent Technical Assistance Centers funded by the U.S. Department of Education, Office of Special Education Programs (OSEP), consist of indicators that measure quality in nonprofit management and family-centered services. The standards reflect current best practices and federal requirements for OSEP-funded Parent Centers.

\*Exemplary practices noted: office location and accessibility; the strategic use of an Advisory Council; fund diversification efforts; parent leadership practices, outreach to diverse populations and communities; and professional development opportunities.



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Phoenix: 602-242-4366 Flagstaff: 928-444-8834 Tucson: 520-441-4007 Yuma: 928-444-8803 Toll Free: 800-237-3007 info@raisingspecialkids.org

DONATE TODAY!

## Boards and Councils Served by Raising Special Kids Staff

Alliance of Arizona Nonprofits,

- Public Policy Council

Arizona Autism Coalition

Arizona Department of Education

- Community of Practice on Transition
- Special Education Advisory Panel
- Rules Committee

Arizona Developmental Disabilities Planning Council

Arizona Disability Advocacy Coalition

Center for Parent Information and Resources

Dignity Health

- Smooth Way Home

Division of Developmental Disabilities Advisory Council

**Employment First** 

First Things First

Flagstaff Medical Center

Patient and Family Advisory Council

Institute for Patient-Centered Design

Inter-Agency Coordinating Council

Magellan Autism Spectrum Disorder Workgroup

Maricopa Family Support Alliance

Parent 2 Parent USA

Phoenix Children's Hospital

- Family Advisory Council
- Genetic Services Advisory Committee

Positive Behavior Intervention Advisory Committee

Promise/ASPIRE Initiative Rehabilitation Services Administration