

Raising Special Kids

2017 Annual Report to the Community



Statewide with offices in Northern, Southern and Central Arizona

Raising Special Kids Mission

*Strengthening families and systems of care to
improve the lives of children with disabilities.*

Letter from the Board President

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We are proud to present the 2017 Annual Report. This report celebrates our achievements and highlights the incredible work of our exceptional team. On behalf of Raising Special Kids Board of Directors, Staff and Families, we express our gratitude to all of you for supporting our mission of strengthening families to become effective advocates for children with disabilities.

As you read through the report, you'll see how hard we've been working to support parents of children with the full range of disabilities. We served more families in 2017 than we have in previous years, forged more community partnerships, and trained more professionals than ever before. We are particularly proud of the fact that so many professionals in health, education, and social services attended training last year to improve their skills in providing a better quality of care for families and for children with special health care needs. 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.

From its beginning in 1979 until today, Raising Special Kids has been about the kids, each and every single one of them. I hope you will take the time to read the story from the LeBlanc family. Erika LeBlanc tells the real story of 2017.

For 39 years Raising Special Kids has been there: for the LeBlanc family, for your family, and mine. For all our children, here's to a bright future full of promise and potential. The annual report gives us a chance to thank all of our partners, including our individual donors, our many community collaborators we work with in Arizona. The list of RSK supports gets longer and longer each year, and for that, we say thank you!

Karin Smith, President
Board of Directors



"Raising Special Kids gave me guidance...increasing my understanding of special education. I had the tools for advocating effectively for Becca"

-Erika LeBlanc

LeBlanc Family Story

My family story starts with Becca. Becca is 8 years old but she was 6 when I called Raising Special Kids. She was diagnosed with Specific Learning Disorder at 4 years old but I didn't know what it meant. I didn't know that it was Dyslexia until she was 6 years old. My husband and I were paying for reading tutoring privately and the developmental pediatrician asked why the school wasn't.

I called Raising Special Kids and they were amazing! I didn't understand Becca's IEP or the process. Raising Special Kids explained that Becca had qualified for special education under the Speech category the year prior. The school had not qualified her under Specific Learning Disorder even though she had a diagnosis. Raising Special Kids gave me guidance by having me watch videos, clarifying what I saw and then suggesting attending their workshops. After increasing my understanding of special

education at school, I had the tools for advocating effectively for Becca.

A few months later I called Raising Special Kids about my son Andrew, who has Autism, ADHD and was in 2nd grade. Andrew did not have an IEP but only a 504. He was starting to have meltdowns due to kids teasing him. Raising Special Kids walked me through the process of getting Andrew tested for special education and getting through his IEP.

When we were talking about moving they also helped me understand the difference between public schools and charter schools as far as their resources available for special education. Giving me this knowledge helped our family choose where to live in our upcoming move and which school to choose. That information was invaluable because the public school our kids currently go to has been amazing with both of our special needs kids!

Programs and Services



Connections with a trained Parent Mentor skilled at providing information and support.



Accurate, authoritative information related to your child's disability or special health condition.



Special education consultations, training, and problem-resolution services.



Education and coaching for parents to learn the most effective methods in managing challenging behavior.

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Who We Serve

87% families with disabilities and special health care needs
13% professionals (health, education, social services)

10,589 families received information, training, and individual assistance
92% of parents said they received information to address a critical need related to their child's education

366 Parent to Parent Matches

99% of parents said that Parent to Parent support improved their ability to advocate for their child's needs, services, and care

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 continued

- 4,295 Training/Conference Attendees (Parents 1,983; Professionals 2,292)
- 97% of educational professionals reported being better prepared to work with families
- 57 pediatric and family practice physicians from five hospitals and medical centers completed training and home visits
- 98% of physicians reported training improved ability to communicate with families

- Community outreach exceeds other community support services
- Response time is respectful
- Have a vast pool of resources related to multiple diagnoses
- Are ALWAYS friendly, reliable, and offer valuable resources
- Offers superb free blanket of programs to our families!
- Feedback from families is consistently positive
- Parent Leaders, including parents who are bi-lingual serve on our Councils and Committees

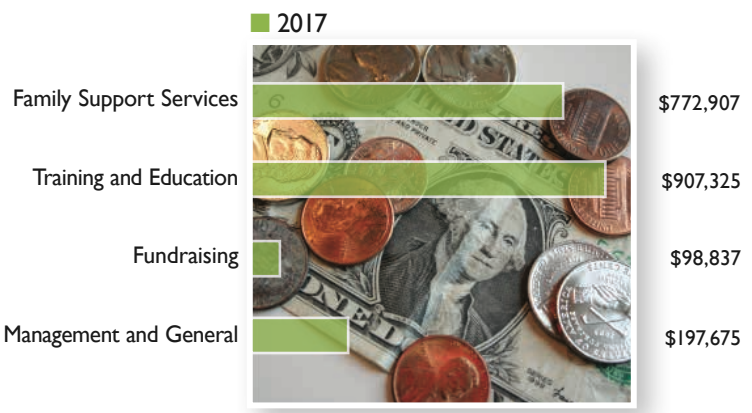
Teresa Boeger, MS, CCLS, CTRS
Director, Division of Family Centered Care
Phoenix Children's Hospital

Financials

Where Does Revenue Come From?
2017
Grants and contracts\$1,760,151
Donations.....\$216,593



PROGRAM EXPENDITURES
(in thousands)



Karin Smith, Joyce Millard Hoie, Paula Banahan

ONE Leader of Distinction

It is with great pleasure that I share with everyone that Joyce Millard Hoie was awarded the Leader of Distinction from the Organization of Nonprofit Executives (ONE).

Joyce was recognized before a room full of non- profit executives from across the valley. As we stated on the nomination: Joyce is an innovative leader, a trusted and collaborative communicator, and an effective organizer who consistently anticipates needs and meets them in a prompt and thoughtful manner. She instills, models, and develops the principles of respect, hard work, integrity, self-esteem, encouragement and human dignity.

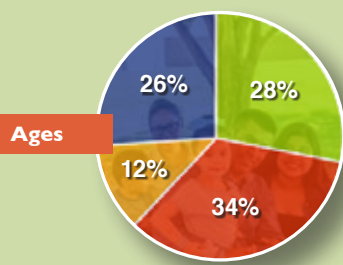
-Karin Smith, President, Board of Directors



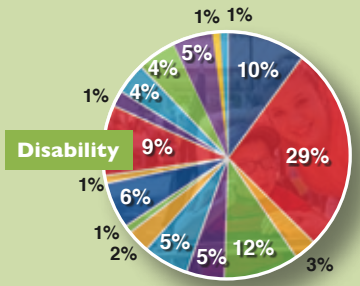
Raising Special Kids Recognized with Outstanding Leadership Award from Council for Exceptional Children

Raising Special Kids is honored and delighted to be recognized with the Linda M. Levine Outstanding Leadership Award. We are so pleased to join with our terrific partners and colleagues, like the Council for Exceptional Children and First Things First, to support and advocate for families of young children with disabilities. The recognition of our work with families of young children inspires us all to even better efforts.

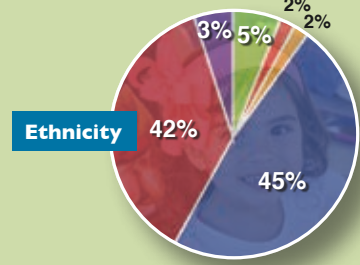
Children Demographics



- Age
- 0-5 years – 28%
 - 6-11 years – 34%
 - 12-14 years – 12%
 - 15 years & above – 26%



- Disability
- ADD – 10%
 - Autism – 29%
 - Cerebral Palsy – 3%
 - Deaf/Blind – <1%
 - Developmental – 12%
 - Down Syndrome – 5%
 - Emotional/Mental – 5%
 - Epilepsy – 2%
 - Hearing Impairment/Deaf – 1%
 - Intellectual & Cognitive – 6%
 - Multiple Disabilities – 1%
 - Other Health Impairment – 9%
 - Orthopedic – 1%
 - Specific Learning Disability – 4%
 - Speech/Language – 4%
 - Suspected/Undiagnosed – 5%
 - Traumatic Brain Injury – 1%
 - Visual/Blindness – 1%



- Ethnicity
- African American – 5%
 - Asian/Pacific Islander – 2%
 - Bi-Racial – 2%
 - Caucasian – 45%
 - Hispanic/Latino – 42%
 - Native American – 3%

Thank you Parent Leaders for all you do for families!



Janna Murrell, Director of Family Support and Education presented DDD Support coordinator, Lucia Marquez, with The Most DDD Referrals Award for referring more than 200 families to Raising Special Kids since her employment began at the division in 2010. Also pictured, DDD Supervisor Sylvia Acosta.

Raising Special Kids’ Partners in Care 2017 Arizona Symposium on Children with Special Health Care Needs

Total Attendance 164: 102 professionals and 62 parents, including from 17 cities and 11 (Apache, Cochise, Graham, Maricopa, Mohave, Navajo, Pima, Pinal, Yavapai, and Yuma) of Arizona’s 15 counties.

28 physicians and healthcare professionals received CME Credits.

96% of attendees who responded found the content was useful.

98% who responded found the presenters to be of high quality.

164
Attendance Total

28
CME Credits

Medicaid Awareness, Education and Advocacy

Medicaid is the largest insurer of children with disabilities and special health care needs in the state of Arizona. Raising Special Kids’ Medicaid awareness and advocacy took place not only at the Symposium but in many other ways throughout 2017 including articles in the quarterly print newsletter and weekly Monday Memo e-news. Parent Leaders were interviewed by Cronkite News, and one Parent Leader shared her Medicaid story at Phoenix Mayor, Greg Stanton’s press conference.



Joyce Millard Hoie, Executive Director, Raising Special Kids:
“There are 250,000 children in Arizona with special health care needs. Medicaid is the largest insurer of children with disabilities and special health care needs.”



Karen Remley, MD, FAAP, MBA, MPH CEO/Executive Vice President American Academy of Pediatrics



Thomas Betlach, MPA, Director of the Arizona Healthcare Cost Containment System. Speaking about the importance of Medicaid in Health Care.



Transition to Adult Care Panel.
Moderator: Sara Salek, MD
Panelists: W. Carl Cooley MD; Gary A. Strobbe, MD; Sydney Rice MD; Janna Murrell



Kathy Levandowsky, Office Chief Arizona Department of Health Services, Office of Children with Special Health Care Needs (OCSHCN) accepts the Families First award. OCSHCN provided significant parent scholarships for the 2017 Symposium. Presented by Karin Smith and Paula Banahan of the Board of Directors.

Professionals:

“I knew this would be really good, but it exceeded my expectations! I had the honor of attending the Partners in Care symposium and wanted to thank you for the opportunity to broaden my thinking towards how to improve our system in serving youth with special and complex needs. I had many take-aways from the symposium both philosophically and in tangible ways.”
—Karrie Steving, Children’s System of Care Administrator, Mercy Maricopa Integrated Care

“This is very impressive for your first symposium. My thanks and appreciation for the opportunity to participate in your wonderful conference. I thought the conference was amazing especially for a first time event. I am sure this bodes well for an annual event that will continue to draw a large and diverse audience.” —W. Carl Cooley, MD

Parents:

“It was beyond amazing and beautiful! I loved the program and everyone I met. It’s amazing to witness so many people from different backgrounds coming together for a similar cause. Thank you so much for having me there!” —Rachael Pirie, Parent Leader
“It was Amazing! So much gratitude...I enjoyed myself. Our table was very positive and upbeat!” —LaTasha Whitaker, Parent Leader
“I very much enjoyed it and appreciate the opportunity so much! I was at a table with mostly DDD support coordinators and heard some of their challenges and talked about some successes we’ve had with previous coordinators and how/why they were successful.” —Nicole Guysi, Parent Leader

Thank You CareScape for 10 Years of Support for Raising Special Kids



The continued generosity of CareScape and Arizona Business Bank allows Raising Special Kids to reach thousands of Arizona families of children with disabilities, regardless of their diagnosis, through programs focusing on parent-to-parent support; special education information and training; health care information; and assistance with challenging behavior.

2017 marked the 10th visit that Mitchell Owens, CEO of Arizona-based landscape company, CareScape, Inc., has made to Raising Special Kids to present the organization with the funds raised at their annual Dandelion Golf Classic. Arizona Business Bank has been the event’s title sponsor each year. This year’s donation to Raising Special Kids topped \$51,000.

Joyce Millard Hoie, Executive Director (left), accepts check for \$51,000 from Mitch Owens, CareScape President, and Marcy DeChandt, Accounting Manager.

Thank You 2017 Dandelion Golf Classic Sponsors



Gold Sponsors - \$2500

Kile & Kupiszewski, LLC
Heinfeld Meech

Silver Sponsors - \$1000

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Peoples Mortgage Co.
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Batson Financial Group of Wells Fargo Advisors
Arizona Heart Foundation
Truly Nolen
Douglass Communications
Shields Magnetics

Hole Sponsors - \$500

IGPA
Legg Mason
ASU Alumni Association
Sechler CPA

Beverage Sponsor - \$500

Helen and Jerry Holden



Thank You Peggy for 32 Years of Service

Peggy noted, “Don and I were part of the second class of volunteer Parent Leaders. We had 80 parent referrals during our first year. In 2017 Raising Special Kids helped over 10,000 parents and professionals. That’s a lot of growth!”

An entire generation of children were born and raised during the time Peggy had been at Raising Special Kids. Parents at all stages of their journeys have been helped by a good listener—with kindness and compassion—someone who knew how important the lifeline of parent support can be to a family who just received life-changing news. Thank you, Peggy, on behalf of all those families, we are grateful for your service.



Peggy Storrs accepts her 32 year recognition certificate from Joyce Millard Hoie, Executive Director



Thank You to Our 2017 Donors

Your generosity helps us serve thousands of families each year.



CareScape, Inc. \$51,000

\$2,500 - \$9,999

Alegeus Technologies
Karen Barr
Phoenix Children's Hospital
The Hannah B Foundation
Virginia Piper Charitable Trust

\$1,000 - \$2,499

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Rosa Fernandez
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Tom Batson



The Julia Leadership Circle is named in honor of Julia Banahan.

Julia demonstrates leadership to others through the personal example she lives every day. Julia was born with something she views as one of her greatest gifts: Down syndrome. She'd be the first to tell you she's had challenges, but she would also tell you about what her determination looks like. Julia is a high school and college graduate, who is now a Certified Nursing Assistant. She loves children, volunteers at Phoenix Children's Hospital, is a public speaker, and inspires people everywhere she goes.

Thank you, Julia, for your leadership by proving time and time again that you can do things the rest of the world thought to be impossible.

\$500 - \$999

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Terra Garcia
Timothy & Donna Driscoll
William Vann

St. Joseph Hospital and Medical Center Partners with Raising Special Kids to Provide Support to Parents with Babies in the NICU

St. Joseph Hospital and Medical Center and Raising Special Kids has a MOU (Memorandum of Understanding) to provide a Family Support Specialist to facilitate support and education in Spanish and English to parents and caregivers in the Neonatal-Intensive Care Unit (NICU), and postpartum departments within St. Joseph's Hospital and Medical Center. 92 families were provided family support and NICU Parent Resource Manuals in 2017.



Paulina Serna, Family Support Specialist who had twins and NICU experience, holding NICU Parent Resource Manuals in Spanish and English which she provided to parents who have babies in the NICU at St. Joseph's Hospital and Medical Center.

Raising Special Kids

12	Board Members
30	Staff Members
35	Advisory Council Members
364	Parent Leaders



Boards and Councils Served by Raising Special Kids Staff

Raising Special Kids
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Phoenix, AZ 85034

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Flagstaff: 928-444-8834

Tucson: 520-441-4416

Yuma: 928-444-8803

Toll Free: 800-237-3007

info@raisingspecialkids.org

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ABLE Act Oversight Committee

Arizona Autism Coalition

Arizona Community of Practice on Transition

Arizona Department of Education

- National Technical Assistance Center on Transition Intensive Technical Assistance
- Special Education Advisory Panel (SEAP)
- State Inclusion Coalition

Arizona Developmental Disabilities Planning Council

Arizona Disability Advocacy Coalition

Arizona Division of Developmental Disabilities (DDD)

- Advisory Council
- Employment First
- National Core Indicators Steering Committee

Arizona Health Care Cost Containment System (AHCCCS)

- Arizona Long Term Care Services (ALTCS) Advisory Council
- Autism Spectrum Disorders Advisory Council
- State Medicaid Advisory Council

Arizona State University, Presidents Community Council

ASPIRE Advisory Council (Achieving Success by Promoting Readiness for Education and Employment)

Dignity Health Communities of Care

First Things First, Early Childhood Comprehensive Systems Task Force

Flagstaff Unified School District Special Education Advisory Committee

Maricopa County Family Support Alliance

Native American Parent Technical Assistance Center (NAPTAC) Governing Board

Parent 2 Parent USA, Board of Directors

Phoenix Children's Hospital
• Family Advisory Council

Positive Behavior Interventions and Supports of Arizona, State Advisory Council

Southern Arizona Special Education Directors' Group

Pinal County Special Education Director's Consortium