



Raising Special Kids

2018 Annual Report to the Community



Raising Special Kids

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.

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Letter from the Board President



We are proud to present the 2018 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 2018 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 Delgado family. Jennifer Delgado tells the real story of 2018.

For 40 years Raising Special Kids has been there: for the Delgado 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

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Delgado Family Story

Jennifer Delgado is a full-time certified pharmacy technician and a single mom of three beautiful kids. She loves to read and work out. Although 5-10K obstacle courses are her favorite activities, she completed two half-marathons. Within the last year she began bodybuilding/personal training and participated in her first bodybuilding competition. Jennifer's youngest child, Gabriel, is a happy, smiling 10-year-old boy who loves to give hugs. When he was 5 years old, he was diagnosed with autism. Jennifer recalled, "Even before his diagnosis, I knew something was going on with him. Little did I know, our lives were going to change forever."

Once Gabe had a diagnosis, Jennifer began identifying what next steps she needed to take. She worked to separate areas that were simply part of his unique personality from areas where Gabe really needed help to develop his skills. She remembered, "If it hadn't been for tenacity, a deep fighting strength that came from the support and love of friends and family, I don't know where I'd be today." At one point, someone in her circle of support recommended she call Raising Special Kids. Jennifer shared, "When I called, they listened, guided me through the IEP process, helped me understand how to deal with challenging situations at school, gave me resources to seek help for my son, and encouraged me; they taught me to advocate for my son." Having a student with autism has been a learning experience for Gabe's school as well.

Cooperating with his IEP team has become easier for Jennifer. She is happy the school's increased awareness will help them more easily accept future students with autism, effectively address their behaviors, and provide them with appropriate academic challenges. Increased school support and private tutoring have helped Gabe's academics soar to new heights, giving Jennifer a sense that the future will be OK for him. Jennifer is now a volunteer parent leader with Raising Special Kids. Sharing her thoughts on why she wanted to become a parent leader, she said, "You can't put a price tag on kindness, compassion and peace of mind. Every parent struggles with making the right decision for his or her child and they all need encouragement, hope and acknowledgment for doing the best he or she can with the



"You can't put a price tag on kindness, compassion and peace of mind. Every parent struggles with making the right decision for his or her child and they all need encouragement, hope and acknowledgment for doing the best he or she can with the resources they have"

-Jennifer Delgado

resources they have." She added, "If I can help just one person and make a difference in their life, it's all worth it. When I hear back from a parent with good news, I am so thankful this process has come full circle. What was once a difficult time in my life helped me grow into a better mother and person. I'm grateful for this special life.

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.

Who We Serve

- 84%** families with disabilities and special health care needs
- 16%** professionals (health, education, social services)
- 10,674** families received information, training, and individual assistance
- 100%** of parents said they received information to address a critical need related to their child's education
- 387** Parent to Parent Matches
- 92%** 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

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.

- 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

- 3,201 Training/Conference Attendees (Parents 1,306; Professionals 1,895)
- 98% of educational professionals reported being better prepared to work with families
- 45 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

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

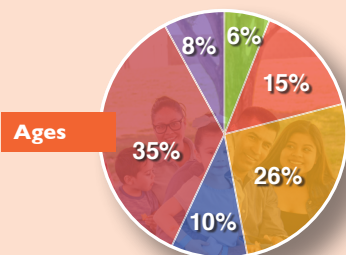


Trudy John, Tribal Program Manager for Raising Special Kids Project CARES

Project CARES (Cultivating American Indian Resource Expansion in the Southwest) in Partnership with New Mexico

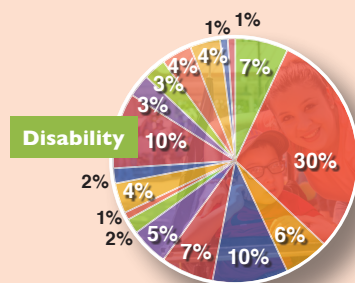
Project CARES (Cultivating American Indian Resource Expansion in the Southwest) in Partnership with New Mexico is our new collaborative project to expand our services to Native American Families in collaboration with Parents Reaching Out in New Mexico.

Children Demographics



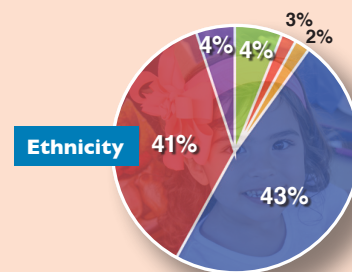
Age

- 0-2 years – 6%
- 3-5 years – 15%
- 6-11 years – 26%
- 12-14 years – 10%
- 15-18 years – 35%
- 19+ years – 8%



Disability

- ADD – 7%
- Autism – 30%
- Cerebral Palsy – 6%
- Deaf/Blind – 0%
- Developmental – 10%
- Down Syndrome – 7%
- Emotional/Mental – 5%
- Epilepsy – 2%
- Gifted – 0%
- Hearing Impairment/Deaf – 1%
- Intellectual & Cognitive – 4%
- Multiple Disabilities – 2%
- Other Health Impairment – 10%
- Orthopedic Impairment – 3%
- Specific Learning Disability – 3%
- Speech/Language – 4%
- Suspected/Undiagnosed – 4%
- Traumatic Brain Injury – 1%
- Visual/Blindness – 1%



Ethnicity

- African American – 4%
- Asian/Pacific Islander – 2%
- Bi-Racial – 3%
- Caucasian – 43%
- Hispanic/Latino – 41%
- Native American – 4%

Fiscal Year 2018 Financials

Where Does Revenue Come From?

	2018
Grants and contracts	\$1,813,775
Donations	\$252,743

\$1,813,775
Grants and Contracts

\$252,743
Donations

PROGRAM EXPENDITURES

	2018
Family Support Services	\$702,225
Training and Education for Families and the Professionals who serve them	\$778,164
Fundraising	\$104,871
Management and General	\$282,675



Parent Testimonials

"I cannot thank you enough for taking as much time as you did this morning talking with me! Your sincere kindness and understanding was comforting beyond words! Wow, looking over the information you sent me, this will help my boys get additional assistance to help them grow as individuals, in their education and transition to work. Again, thank you from the bottom of my heart!"

"Your Family Support Specialist provided me support for my five year old son with Down syndrome, I am so happy with the support provided by Raising Special Kids. My five-year-old son had been denied four times by ALTCS. I used the information that she provided and it helped me obtain approval of services for my son!"

"I wanted to thank you for all your support thru this process of understanding and answering my many questions in regards to my son's IEP. I also want to let you know that I am very grateful that you have also been a cheerleader on my side reminding me I can do this & I got this in the difficult moments I have encountered, again thank you! I never knew how much support Raising Special kids could offer!"

"Great program! Great resource for parents with a child with a new diagnosis – sometimes we as parents are uniformed. It is great to talk with parents who have already walked that path and have gone through it"

"I've just been so impressed by how much Raising Special Kids knows about guardianship and other options, this Parent to Parent Connection along with help from Raising Special Kids training helped our family make an invaluable decision about our child's future." - Parent

"I've just been so impressed by how much Raising Special Kids knows about guardianship and other options, this Parent to Parent Connection along with help from Raising Special Kids training helped our family make an invaluable decision about our child's future."

"Hearing your story and hearing that there is a support structure for families like us, it was good to know it's ok to be emotional and stressed and that there is help moving forward."

Thank you Parent Leaders for all you do for families!

1,929
Hours
Donated

Total 1,929 hours would equal over \$45,000



Raising Special Kids' Partners in Care 2018 Arizona Symposium on Children with Special Health Care Needs

216 Attendance Total

136 Professional Attendees

65 Parent Attendees

15 Youth/Young Adult Attendees

100% of the attendees who responded found the content was useful

99% of attendees who responded said they were satisfied with the Symposium

99% of attendees who responded said they would encourage others to attend the Symposium in the future

216
Attendance Total

28
CME Credits



Sue Swenson, MBA, recently served as Acting Assistant Secretary in the U.S. Department of Education for special education and rehabilitative services (OSERS). As parent of an adult son with profound disabilities, Swenson spoke about how Health intersects with everything else in the life of a person with a disability, the accommodations they need, the rights they hold, and the communities where they will live and work as adults.



Christopher Tiffany, Executive Director, Raising Special Kids with Kathy Levandowsky, Office Chief of the Arizona Department of Health Services, Office of Children with Special Health Care Needs (OCSHCN) who provided significant parent scholarships for the 2018 Symposium.



Thomas J. Betlach, MPA, Director of Care Cost Containment System, State Medicaid Agency, since 2017 Medicaid Update.

Professionals:

"I wish I had brought more educators. This is one of the most valuable and well run events I have been to – choice of speakers was excellent, nicely balanced."
– Professional

Symposium Sponsors

Title Sponsor

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Breakfast Sponsor

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Director of the Arizona Health Care Community Plan (AHCCCS), Arizona's largest health plan. In 2009 provided an Arizona



Dr. Jan Cawthorn, Executive Director of Special Education, Mesa Public Schools in recognition of her exceptional leadership in directing special education programs in Arizona's largest school district, her true commitment to the spirit of the Individuals with Disabilities Education Act (IDEA) and ensuring equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities presented with the Families First Award by Christopher Tiffany, Raising Special Kids, Executive Director.



Julianne Beckett, Keynote Speaker, "Parent Leadership – The Time is Now" Julianne is the parent of Katie Beckett, a young girl from Iowa who was the very first Medicaid Home and Community Based Services waiver, granted by the Secretary of Health and Human Services in 1981.

Parents:

"One of the best symposiums I have attended relative to children with special needs and their parents. Thank you for keeping the cost of the symposium attendance affordable for parents. It is truly appreciated by this mother of a beloved son with multiple Disabilities." – Parent



Christopher Tiffany, accepts check for \$56,000 from Mitch, CareScape, Inc.

Thank You CareScape for 11 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.

2018 marked the 11th 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 \$56,000.

Thank You 2018 Dandelion Golf Classic Sponsors



Gold Sponsors - \$2500

Heinfeld Meech
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Silver Sponsors - \$1,500

I GPA
Truly Nolen
American Fire Sales & Equipment Sales and Service Corp.
Hedges Family Charitable Fund
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Helen and Jerry Holden
Brent/Lensink Family
The Rainmaker Institute

Lunch Sponsor - \$500

Sechler Morgan CPAs PLLC

Foursome - \$600

American Fire Sales & Equipment Sales and Service Corp.

Beverage Sponsor - \$500

Hedges Family Charitable Fund

Raising Special Kids Executive Transition

On March 23, 2018, Raising Special Kids celebrated the exceptional service of Joyce Millard Hoie and welcomed Christopher Tiffany as our new Executive Director.

Since 1985 when Raising Special Kids first began, our organization has had just three Executive Directors. Each has guided the organization using their unique strengths and talents but the one thing they share is the ability to inspire us daily to keep families at the heart of everything we do.



Christopher Tiffany 2018-present, Joyce Millard Hoie 2000-2018, and Mary Slaughter 1985-2000



Paulina, Jeremy, and Christopher Tiffany

Christopher Tiffany and Family

Our son Jeremy was 3 ½ years old when I came to Raising Special Kids and first met Joyce Millard Hoie, then Executive Director for the organization. We talked about our children, both boys and diagnosed with autism at a young age, and Joyce shared a story with me about her son at age 11, Jeremy's age now. My world was small then, and had room only for thoughts of therapy, school, and all the things I should and should not be doing as a parent of a child who has a disability. From that conversation I learned that there were parents outside of my small world that felt as I did, who struggled as I had, and who would gladly share information, strength and their experience. My whole perspective changed and my world expanded, as I began my journey with Raising Special Kids in 2010.

I was honored and humbled to accept the baton from Joyce as she stepped down after 18 years of service to Arizona parents

and families. As a Greek philosopher points out, the only constant is change. However, I choose to hear Joyce's words, "things change, people change and systems change, but the mission of family support remains the same."

As 2018 drew to a close, I found myself in reflection of all that Raising Special Kids accomplished as a staff, and as an organization. This Annual Report is a small reminder of the great work Raising Special Kids does from the voices of the parents, family members and professionals we serve.

When people ask me how I like this new position, how it is going, am I enjoying the new role, or any variation of those questions, my response is never exactly the same, however, there are always a few common threads to the answer that I would like to share as we reflect back on 2018:

- I am continually amazed at the depth of knowledge and skills of our staff
- Our board of directors are a dedicated and passionate team of folks that believe in our mission
- Raising Special Kids is a special place with the job, itself, being much bigger than I had anticipated

I feel honored to be able to do something that I love every day, and every day I am humbled by the Arizona families and professionals that we serve

The theme we adopted in 2018, 'the only thing that is constant is change,' has proven its truth and will continue to do so in 2019 and beyond, however, it was once suggested by my friend, mentor, and former Executive Director - Joyce Millard Hoie, "Chris, I always felt it was my duty and responsibility to celebrate the good works of the organization with the staff, the board and the public."



Thank You to Our 2018 Donors



LEADERSHIP CIRCLE



Renaissance Charitable Foundation, Inc./Mary Ressler Family \$75,000

CareScape, Inc. \$56,024

\$2,500 - \$9,999

Phoenix Children's Hospital
The CHA-07C Foundation Trust/
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The Hannah B Foundation –
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\$1,000 - \$2,499

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Jennifer and Steve Kupiszewski
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Helen Holden
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\$500 - \$999

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Paul Tiffany
Edith Barrera
Joseph Errante
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Phil Pangrazio
Theresa Rowland
Troy & Lisa Stockstad
Victor & Elsie Badger

Medical Resident quotes after a home visit with a family:

"I'm glad a program like this exists. I could never empathize with families and know they would greatly benefit having support from people who have been there and are in their shoes. The families are incredibly strong, resilient, and brave." - Dr. Tiffany Hoang, Phoenix Children's Hospital

Your generosity helps us serve thousands of families each year.



\$100 - \$249

Patricia Winner & Tom Snidecor
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to \$99

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Freda Mills
Laurie Shook
Rachel Hanzuk
Angelica Lara



"I will refer families, I feel like they will benefit greatly with these services and I feel comfortable doing it. Great insight into what families have to do."

- Miguel Gonzales, Abrazo Central Campus Hospital

Raising Special Kids

- 14 Board Members
- 26 Staff Members
- 27 Advisory Council Members
- 366 Parent Leaders



Boards and Councils Served by Raising Special Kids Staff

Raising Special Kids
5025 E. Washington St., Ste. 204
Phoenix, AZ 85034

Phoenix: 602-242-4366
Northern Arizona: 928-444-8834
Tucson: 520-441-4416
Yuma: 928-444-8803
Toll Free: 800-237-3007
info@raisingspecialkids.org

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Raising Special Kids

ABLE Act Oversight Committee
Arizona Autism Coalition
Arizona Community of Practice on Transition
Arizona Department of Education

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

Arizona Disability Advocacy Coalition
Arizona Division of Developmental Disabilities (DDD)

- Advisory Council
- Arizona Developmental Disabilities Planning 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 Committee

Autism Spectrum Disorder Crisis Workgroup Meeting

- State Medicaid Advisory Council (SMAC)

Arizona State University, Presidents Community Council
ASPIRE Advisory Council (Achieving Success by Promoting Readiness for Education and Employment)
Cochise County Networking Coalition

Comprehensive Systems Task Force
Community of Practice on Cultural and Linguistic Competence on Developmental Disabilities
Early Childhood Personnel Center (ECPC)
First Things First, Early Childhood Comprehensive System Task Force
Flagstaff Unified School District Special Education Advisory Committee
Interagency Coordinating Council (ICC)
Maricopa County Family Support Alliance
Mohave County Special Needs Advisory Coalition (SNAC)
Native American Parent Technical Assistance Center (NAPTAC) Governing Board
Parent 2 Parent USA, Board of Directors
Phoenix Children's Hospital

- Family Advisory Council

Pima County Community of Practice on Transition
Pima County Family Support Alliance
Positive Behavior Interventions and Supports of Arizona, State Advisory Council
Shift Project Governing Board
Southern Arizona Special Education Directors' Group
Southern Arizona Transition Consortium
Pinal County Special Education Director's Consortium