



Raising Special Kids

Connecting

Winter 2018

*Visionaries,
Trail Blazers &
ADVOCATES*

PARENTS *as* CHANGE AGENTS

From the Director

Thoughts on the beliefs that drive our mission



In this edition of Connecting I hope you will enjoy our lead article about Parent Leadership and the family voice in systems change, originally published in 2011. The message is just as relevant today, as it was seven years ago, and as it was 40 years ago. Over the past four decades our work with individual families and our beliefs are unchanged. The beliefs that drive the mission of Raising Special Kids, the foundation of our work, are articulated here in our Credo of Family Support:

- We believe that experienced families are a key source of knowledge and support to help new parents become 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.

We caught up with Dawn Kurbat and Kathy McDonald, the featured agents of change and true advocates for their daughters, and I am happy to pass along these family updates as we head into the holidays. Kathy is proud to report that Ally is finishing her associate degree in Administration and is working part time with support from Vocational Rehabilitation. Dawn says that Matti is a recent graduate of Project Search (a transition to employment program run out of the University of Arizona), is currently working and has a boyfriend. What wonderful examples of effective parent self-advocates encouraging their children's pursuit of their own dreams.

Happy holidays from all of us at Raising Special Kids.

Christopher Tiffany, MEd

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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in English, Spanish and other languages. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)(3) non-profit organization.

Visionaries, Trail Blazers & Advocates

Parents as change agents

Where can parents put to use many of the skills they develop 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



Kathy McDonald Family



Dawn Kurbat

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.”

Some of the benefits from the Parent Leader experience that Kathy appreciates most:

- gaining acceptance of my own situation
- becoming a better public speaker
- effecting change and improving systems for all children and families
- friendships and connections with other parents understanding that we’re not alone—others are going through this

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 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 to work with families of diverse cultural backgrounds and those who speak a variety of languages. Presenters at a forum in Tuba



Vickie, Jeremy & Steve French

City provided an opportunity for families in Northern Arizona and rural areas to ask questions and learn information in person-to-person activities.

“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

continued on page 4

"Raising Special Kids Helped Me Find My Voice"

From advice-seeker to advocate

Kara and Jim Swierz's daughter Zoey was an easy baby to adore with her big blue eyes, her cherubic facial features, and blond hair that shone like the sun. It didn't take long for Kara and Jim to recognize that her muscle tone was low and that she had limited head control and gross motor delays. By the age of 10 months, Zoey had been to several specialists. With every new test came additional clues into the root cause of Zoey's symptoms. Some information was insignificant and some was devastating and difficult to hear. Kara shared, "We are on a long curvy path to determine the cause of her global delays, short stature and hypotonia. We have a lot of support in the medical world but our adventure continues as we keep searching for a true diagnosis for Zoey."

While preparing to move back to Arizona from New Hampshire where the family had moved shortly after Zoey's birth, Kara came across the Raising Special



Jim, Zoey, Kara Swierz with Daisy

Kids website. She recalled her first conversation with Raising Special Kids, "I immediately connected with a very beloved gal who was my first introduction to Raising Special Kids. She provided me with recommendations and resources to prepare for the impact that moving from out of state would have on my

daughter. She has made a lasting impact on our family. I still call on her for guidance, to shed some tears, and above all, have a good laugh."

Once they arrived in Arizona, Kara quickly faced challenges with Zoey's out of state IEP and getting her approved for the Arizona Long Term Care System. She shared, "I was uneducated and quite overwhelmed." Throughout the entire process, Raising Special Kids was there for her. "I was given websites and books to research, seminars and webinars to attend, advice on how to organize documentation, and the tools I needed to effectively advocate for my daughter. Raising Special Kids helped me find my voice."

Kara also talked about the positive support she received from Raising Special Kids when she has felt frustrated, desperate or isolated,

continued on page 4



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, websites and other resources.

Project Planning and Coordination - Help plan and coordinate activities for events or special projects.

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 compassion and an open mind?
- Can you maintain confidentiality at all times?
- How much time can you offer?

For more information or to volunteer, contact us at:
602-242-4366 or 1-800-237-3007 or info@raisingspecialkids.org.

"Raising Special Kids support comes without judgement or criticism but instead, with a soft voice of encouragement and inspiration. Even when I have made mistakes, I am welcomed with grace and guidance." She appreciates that the people who work at Raising Special Kids also have family members with disabilities, "They have their own unique perspective on challenging situations. Raising Special Kids

can empathize and get it. Raising Special Kids has helped Kara find humor at times of great sadness or frustration. "I think Laughter is the greatest medicine and goes a long way to help me persevere."

Persevere she has. Kara is now a Raising Special Kids Parent Leader mentoring other parents and participating on parent panels. "As a mom, I feel my voice is the greatest when I am advocating for Zoey. It is

an honor I will never outgrow."

Though she says it has been a tough year, Kara has found that moving to Arizona has been a blessing for the entire family. "We have come a long way and though the road has been long and not every day has it been paved with roses, I now know I have the strength, connections and resources to endure."

Raising Special Kids Workshops & Training

Register online at www.raisingpecialkids.org or call 602-242-4366 | 800-237-3006



Early Childhood Education (Birth - Kindergarten)

Learn the basics of the Individualized Family Service Plan (IFSP) and how to make a smooth transition from early intervention services to preschool at age 3. Participants will learn about the process of evaluation, eligibility and of services provided through an Individualized Education Program (IEP) by your local public school district. The discussion will include the transition process from preschool to Kindergarten and skills parents can help with at home.



Positive Behavior Support

Learn how to reduce unwanted behavior and increase good behavior by using Positive Behavior Supports in your home and in the community. Understand the role you play in your child's behavior, and how to work with the school when behaviors get in the way of learning.



IEP Training

Have a better understanding of Special Education and the Individualized Education Program (IEP). The following topics will be discussed: the IEP document, the parent's role in the special education process, and how to prepare for, and be an effective participant at the meeting. You will learn who is a member of your child's IEP team, how to track your child's progress, and what to do if the team does not agree.



High School Transition

This workshop explains the IEP transition planning process which should begin for students no later than 16 years of age. Discover how to identify classes, activities and services that help prepare students with disabilities for higher education, vocational training, employment, and additional resources that help with planning for adult life.



Turning 18 - Legal Options

Learn about the different legal options families should consider when their child becomes an adult at the age of 18. Become familiar with the steps of the guardianship process. Participants will learn how they can stay involved in decision-making with schools, doctors and other professionals.

These trainings and more are available statewide and at no cost for families.

Please visit our website at www.raisingpecialkids.org for the most current schedule and locations or call 602-242-4366 or 800-237-3007.

To request a Raising Special Kids presentation for your school or organization, see <http://raisingpecialkids.org/trainingworkshop-request/> or call our office at 602-242-4366 or 800-237-3007 for more information.



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



Kathy McDonald Family



Dawn Kurbat

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

comprendido.

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 pasárnosla. 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



Vickie, Jeremy & Steve French

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 voluntaries 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— hicieran 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?

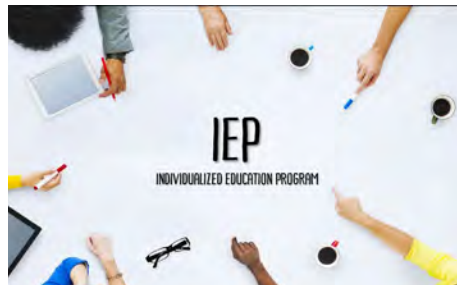
Para más información ó para ofrecer sus servicios como voluntario/a, por favor llame al 602-242-4366 ó al 1-800-237-3007, ó envíe una nota electronica a info@raisingspecialkids.org.

Talleres y entrenamientos

Por favor vea nuestra página de web para el horario y los lugares más actuales, www.raisingspecialkids.org, o llame al 800-237-3007



El Comportamiento Positivo



Entrenamiento del IEP



Cumpliendo los 18 años -
Opciones Legales

Thank You for Referring Families

To refer a family, download our referral form from <http://bit.ly/2nQszAI>

January - June 2018

A New Leaf
Ability360
Adelante Healthcare
Applied Behavioral Interventions
Arizona Autism Charter School
Arizona Charter Academy
Arizona Children's Academy
Arizona Cooperative Therapies
Arizona Department of Child Safety

Arizona Department of Economic Security

Arizona Early Intervention Program
Division of Aging and Adult Services
Division of Developmental Disabilities
Division of Employment and Rehabilitation Services/
Rehabilitation Services Administration

Arizona Department of Education
Arizona Department of Education/
ASPIRE
Arizona Developmental Disabilities Planning Council
Arizona Healthcare Cost Containment System
Arizona Early Head Start
Arizona Hands & Voices
Arizona State Schools for the Deaf and the Blind
Arizona Youth & Family Services
Arizona's Children Association
Arrowhead Montessori
AZA United
AZ Care Providers
Banner Health
Barrow Neurological Institute
Bethesda Pediatrics
Camelback Education

Canyon Vista Medical Center
Cardon Children's Medical Center
Care1st Avondale Resource and Housing Center
CareScape Landscaping
Cartwright School District
Chicanos Por La Causa
Child & Family Resources
Child & Family Support Services
Children's Rehabilitative Services
Children's Clinics-Tucson CRS
Cigna
Clinica Hispana of West Valley
Community Legal Services
Desert Choice Schools
Desert Heights Academy
Desert Shores Pediatrics
Dignity Health-St. Joseph's Pediatrics
DMG Children's Rehabilitation Services
Dr. Stone's Children's Way Tutoring
Dynamite Therapy
Easterseals Blake Foundation
El Rio Community Health Center
EMPACT
Family Involvement Center
Family Partners
Family Voices Tennessee
First Things First
Flagstaff Unified School District
Florence Unified School District
Fort Huachuca EFMP
Foundation For Blind Children
Fun Van by First Things First
Gilbert Public Schools
Head Start
Healing Hearts Pediatrics
Healthy Choice of Arizona
Hidden Treasures
Hip Kids Pediatrics
Homeward Bound

Human Resource Training Inc.
Isaac Elementary School District
Jewish Family & Children's Service
Joni and Friends International Disability Center
Kingman School District
Kyrene School District
La Frontera
Lincoln Learning Center
Liberty Elementary School District
Maricopa Integrated Health System
Maricopa Medical Center
Maryvale Pediatrics
Maximillian Melquiades
Mesa Public Schools
Metropolitan Neuro Behavioral Institute
Mountain Park Health Center
Mountain View Pediatrics
Muscular Dystrophy Association
NAMI
National Autism Society
New Hope of Arizona
New School for the Arts
Nilam Khurana
NOAH — Neighborhood Outreach Access to Health
Northern Arizona Healthcare
Open Hearts Family Wellness
Paradise Valley Unified School District
Parent Aid
Pendleton Pediatrics
Peoria Unified School District
Phoenix Children's Hospital
Phoenix Christian Preparatory Academy
Phoenix Indian Medical Center
Phoenix Union High School District
Pilot Parents of Southern Arizona
Pinal Gila Community Child

Services
Premier Children's Center
Rio Salado Behavioral Health
Roosevelt Elementary School District
SAGE Counseling
Salt River Pima-Maricopa Indian Community
Save the Family
Sierra Vista Unified School District
Southwest Autism Research & Resource Center (SARRC)
Sojourner Center
Southwest Behavioral & Health Services
Southwest Human Development
Southwest Network
Southwestern Pediatrics
St. Joseph's Hospital
St. Thomas the Apostle School
Step Up Arizona
Stride Psychological Services
Summit Regional Healthcare Medical Center
Sunrise Therapy
Teen Outreach Pregnancy Services
Terros Health
The Sandbox
Touchstone Health Services
Tourette Association Arizona
Tucson Unified School District
UMOM New Day Center
Un Desafio Inc.
understood.org
University of Houston, Parent Education Project
Valle Del Sol
Yuma Elementary School District
Yuma Regional Medical Center
Yuma High School District
YWCA Southern Arizona

Parent Leaders

Thank you! Parent Leaders are the heart of our mission.

August - October 2018

Buckeye
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Jill Nico
Brittany Retsinas
Cave Creek
Sarina Siebenaler
Chandler
Regan Iker-Lopez
Aimee Johnson
Lisa Myers
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Jacqueline Tate-Tafoya
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Nicole Kauffman

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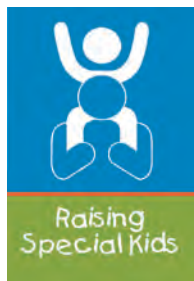
Amanda Steele, Lisa Myers and Christy Holstad joined Raising Special Kdis staffer Maureen Mills to present at the Arizona Department of Education's 2018 Transition Conference

The Parent Leaders listed above participated in leadership activities from August through October 2018. We appreciate each of our 300 Parent Leaders, but we do not have room to list all of their names.

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Parent to parent
Information and support



Health care information
and resources

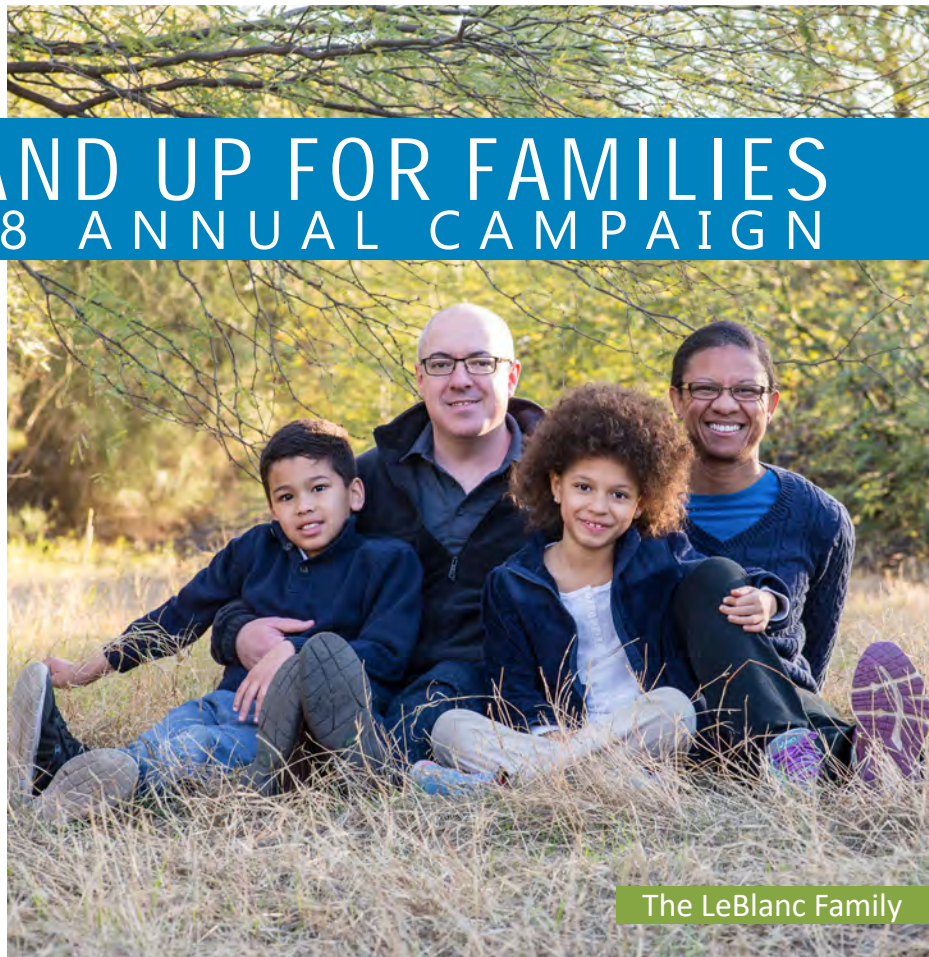


Special education
consultation and training



Help with managing
challenging behavior

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The LeBlanc Family