RISING to the Occasion
2 Stories of Post-Secondary Success
Janna Murrell first contacted Raising Special Kids when her son, Tucker, was 7 years old. Tucker is now 20, and one of the biggest decisions he and his family have faced recently is determining whether guardianship would be appropriate. For now, Tucker and his family have decided not to pursue guardianship.

When asked if she could point to anything specific that helped guide their decision Janna recalled, “I think the pivotal moment for me came shortly after Tucker turned 18. I took him to the Social Security office to apply for benefits. The agent addressed Tucker directly saying, ‘Tucker, do you want your mom to have her name on your checks and help you manage the money you’ll be getting?’ Tucker looked at me and then back to her and nodded. I realized Tucker had just given informed consent. It was that simple. The agent helped him understand the situation and he told her what he wanted.” Continuing, Janna said, “Our family is very close and Tucker has a strong support system. We know we can help him understand the decisions he’s faced with. We’ve also worked hard to cultivate relationships with the professionals in his life so we can all work together to support him. For now, that’s what seems right for our family and for Tucker.”

Janna joined the Raising Special Kids staff in 2008, and is now Director of Family Support and Education. Janna’s role is focused on the importance of providing quality programs and services, and helping families find the solutions and strategies they need to become effective advocates for their children.
What do you want to be when you grow up? It’s a question kids are probably asked hundreds of times. The choice is not simple and may be fraught with indecision and false starts. For young adults with disabilities, there may be added challenges for achieving goals. But, not all challenges are insurmountable.

Matt Cottle first thought he wanted to work on a search and rescue team. Danielle Baldwin thought she would be a Kindergarten teacher. After some growth, exploration and trials, each found their true passion. After learning some self-advocacy skills and enlisting the assistance of their supportive families, each have found their niche.

Matt recalls a career presentation he attended during his senior year in high school, “This gentleman was representing a culinary school and all he had was a cutting board, a knife and an apple. He was cutting away, just talking to the class about the opportunities these skills will give you, and right when he was done with the lecture, he had a made swan! Just with his bare hands and a knife!”

The combination of precision and creativity struck a chord with Matt. After discussing his new interest in becoming a baker with his parents, Peggy and Dave, they searched for ways for Matt to gain necessary skills and explore his talents. As an individual with autism, Matt found the traditional routes of classroom learning or on-the-job training in an entry-level position were not conducive to his learning style. With Matt’s determination and Peggy’s creative thinking, Matt connected with pastry chef Heather Netzloff, founder of Rumpelstiltskin Granola. For three hours every Monday for three years, Matt baked new recipes with Heather. Through the week, Matt would repeat the recipe on his own, perfecting his craft and sharing his creations with Peg and Dave.

But baking is only one part of owning a bakery. The Cottles also had to gain experience with the business end of the enterprise. For assistance in that arena, Matt was accepted to SeedSpot, a small business incubator. Peggy recalls, “SeedSpot was a really good intro into how business is done.” She added, “It helped us understand that this is a real business and we now needed to act like it.”

Matt opened The Stuttering King Bakery in 2012 operating out of his home kitchen. He named his business after King George VI, made famous by Colin Firth in the 2010 film The King’s Speech. Peggy was concerned about the name her son chose but Matt explained, “He overcame his disability and I thought, I’m going to overcome mine.”

Danielle Baldwin is no stranger to overcoming a disability. Danielle was in third grade when she first received an Individualized Education Program (IEP). After the eligibility meeting, her mom Pam recalls sitting down with her to explain about IEPs and what having one meant; essentially giving her first lesson in self-advocacy. “I told her ‘you just learn differently,” said Pam, continuing, “I could see the relief in her face as she looked at me and said ‘so there is nothing wrong with me!’”

By the time Danielle got to high school, she was leading her own IEP meetings. She explained, “I’ve always liked slide shows so I made one about what I wanted and what worked for me. It was easier than sitting down and trying to explain.”

From the time she was in elementary school, she thought being a Kindergarten teacher was going to be her calling. It took until high school for her to realize her true interest was in cosmetology. She was accepted into the Maricopa Skills Center’s Cosmetology Program in her senior year. The program was very hands-on and fit well with Danielle’s learning style. However, not everything was hands-on. She knew she needed her tests read to her and for the test to be administered in a separate room so she spoke with her teachers to ensure those accommodations were available for her.
The biggest hurdle was taking her state licensing exam which is given in two parts; one practical exam and one written exam. Although nervous, she wasn’t too concerned about the practical aspect of the exam.

For the written exam, Pam was ready to jump in to assist with requests for accommodations but heard a firm, “I’ve got it” from Danielle who contacted the state licensing board and made the request herself. The board contracted with someone to read Danielle her exam and made sure the test was given in a room separate from others. Despite nicking her finger with her scissors during her practical exam, she passed both sections on her initial attempt.

Danielle is now a cosmetologist at Innerlooks salon in Glendale. She enjoys color consultations and Pam is a frequent visitor to her chair, self-advocating for her perfect shade.

Although there is no one formula for success that will work for every person, Danielle and Matt’s stories do have a few themes in common: self-determination (see box), self-advocacy and support. Raising Special Kids can help families learn about and practice all three.

Call RSK at 602-242-4366 or 800-237-3007

Help for Transitioning Youth

Resources from the Web

Education to Employment Transition

- Transitioning out of High School
  http://www.parentcenterhub.org/repository/transitionadult/

- Disability Benefits 101 - learn how work and benefits go together
  https://az.db101.org/

- The National Secondary Transition Technical Assistance Center ( NSTTAC )
  http://nsttac.org/

Health Care Transition

- Medical Home Portal
  http://bit.ly/1GPM5oN

- Health Care Transition
  http://www.gottransition.org/youthfamilies/index.cfm

- The National Alliance to Advance Adolescent Health
  http://www.thenationalalliance.org/index.cfm

Self-Determination

What is it?

**Self-awareness** to understand one’s own:
- Needs
- Interests
- Strengths
- Limitations
- Values

**Self-advocacy** to express in an assertive manner one’s:
- Needs
- Wants
- Rights

**Self-efficacy** or self-confidence
- The belief that one will attain their goal

**Independent performance**
- To start and complete tasks through self-management strategies

**Self-evaluation**
- Assess performance
- Determine when goal/task has been satisfactorily completed

**Adjustment**
- Revising goals and plans to improve performance or success

**Decision-making**
- Setting goals
- Planning actions
- Identifying information to make decisions
- Choosing best option to reach goal

*Martin and Huber Marshall (1995)*

raisingspecialkids.org
It is important to find your adult doctors early. You should begin seeing an adult doctor around age 18 to 21. If possible, have your first appointments and send your records to your new doctors while you are still being seen by your old doctors in case there are questions about your condition or treatment.

**HOW TO FIND ADULT PROVIDERS**

- Ask your current doctor for a referral
- Consider your parents’ doctor
- Call your insurance company
- Check with your local support groups
- Call large medical and specialty rehab hospitals and ask for referral line.
- Ask your Care Coordinator or Case Manager for suggestions
- Ask friends and family for suggestions

**Check the Arizona Medical Board Doctor Search at** https://www.azmd.gov/GLSPages/DoctorSearch.aspx.

### QUESTIONS TO ASK

**It is important to find a doctor who makes you feel comfortable and can meet your needs. Before you choose your new doctor, call his/her office and ask to speak with a staff member who has time to answer your questions, or make an appointment to meet the doctor and staff in person.**

**Ask the office:**

- Does the doctor accept your insurance coverage? Is he/she taking new patients?
- Is the office accessible (easy to reach and easy to get around inside the building or clinic area)?
- What are the office hours? How can the doctor be reached after hours?
- How will the doctor exchange information with your specialists?
- Will the office be flexible to meet your health needs (allow service dog, schedule visits so you will not miss a meal, or schedule at quiet times if you are sensitive to noise)?

**Ask the doctor:**

- Is the doctor willing to discuss your health history and special needs with your pediatric doctor?
- Does the doctor currently see patients with health conditions similar to yours?
- At what hospital does the doctor schedule procedures?
- Where did the doctor get his/her medical school and specialty training? Is he/she board certified?
- Does the doctor have any special interests or more advanced training?

**Ask yourself:**

- Does the doctor listen to your questions or is he/she constantly interrupting you?
- Can the doctor explain information so that you can understand it?
- Does he/she take enough time to answer your questions?
- Does the doctor treat you with respect?

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**Shift!**

**A Future of New Possibilities**

The Shift Project is a partnership between PEAK, the Parent Training and Information Center (PTI) for the State of Colorado, and Raising Special Kids, Arizona’s PTI.

Shift is designed to help youth with disabilities and their families get information and learn to navigate systems so they transition to adulthood in positive, productive ways.


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**Celebrating 40 Years of the IDEA**

OSEP wants to hear from you!

The Office of Special Education Programs wants to hear from children and youth with disabilities, teachers, parents, researchers, and other stakeholders about the impact the Individuals with Disabilities Education Act (IDEA) has had. Please share your art, photographs, and writing with them for possible use during the upcoming 40th Anniversary events.

[Read more about how to participate at http://bit.ly/1RgOl3B](http://bit.ly/1RgOl3B)
Parent to Parent USA
2015 Directors’ Leadership Institute Held in Scottsdale

Raising Special Kids was the host site for the national Parent to Parent Leadership Institute with P2PUSA.

Parent to Parent (P2PUSA) is a national non-profit organization committed to promoting access, quality and leadership in parent to parent support across the country. Member programs must demonstrate a commitment to implementing evidence-based P2PUSA endorsed practices in providing Parent to Parent support. Raising Special Kids was a founding member of P2PUSA.

Over 80 directors and staff from Parent to Parent programs, representing 30 states, attended. The Institute was held at Talking Stick Resort in Scottsdale, where participants experienced three days organized around the conference theme of learning, sharing and connecting. Woven into the institute were topics like: Collaboration at a Systems Level, Evidence Based Best Practices for Parent to Parent, Implementing Life Course Framework Tools, Engaging Diverse Communities, and others.

Janna Murrell, Director of Family Support and Education at Raising Special Kids, serves on P2PUSA Board of Directors. Janna, along with Kathy Brill, Executive Director of P2PUSA, worked with a planning committee to implement this year’s institute. The next Leadership Institute is planned for 2017 in a location yet to be announced.

“Such a wonderful opportunity to network and learn from each other.”

“Thank you for the presentation on Tuesday which opened my eyes to ‘blended funding’. As a program solely funded and never growing, this gives me some good ideas for further exploration.”

“I loved the presentation on collaboration at a systems level. I so needed that and want more! Excellent organization of materials – great wisdom. Loved the information.”

No Cost Workshops & Training
Register online at www.raisingspecialkids.org/events or call 800-237-3007

PHOENIX
Ability360 Center
5025 E Washington St, Ste 204
Phoenix, AZ 85034
This building is fragrance-free

IEP Training
Tue, Nov 17, 6pm-8pm
Sat, Dec 5, 10am-12pm

Positive Behavior Support
Thu, Nov 5, 6-8pm
Sat, Dec 5, 12-3pm

Turning 18 - Legal Options
Thu, Nov 12, 3-5pm
Sat, Dec 5, 1-3pm

ACCEL Tempe Campus
1430 E Baseline Rd
Tempe, AZ 85283

Turning 18 - Legal Options
Mon, Nov 9, 5-7pm

Care1st Avondale Resource and Housing Center
328 W Western Ave
Avondale, Arizona 85323

IEP Training
Sat, Nov 21, 9-11am

Positive Behavior Support
Sat, Nov 21, 11am-1pm

FLAGSTAFF
3100 N West St
Flagstaff, AZ 86004

Turning 18 - Legal Options
Thu, Nov 5, 10am-12pm

TUBA CITY
Moenkopi Day School
US-160
Tuba City, AZ 86045

Preschool to Kindergarten Transition
Wed, Nov 18, 5-8pm

YUMA
3250A 40th St
Yuma, AZ 85365

Turning 18- Legal Options
Thu, Nov 12, 10am-12pm
Tona TreeTop described finding out her 5 month old son Mateo had sustained a Traumatic Brain Injury (TBI) as “Life-altering. You don’t ever think something like that is going to happen. Then, it was like being in a tornado of all the legal and medical issues. It was overwhelming. I was trying to understand what the doctors were saying and I thought, ‘I don’t know enough!’ I didn’t have time to sit back and think; there was too much I had to do for my son.”

Tona’s research into Mateo’s injury indicated his outcome was probably going to be bleak. She recalls, “I did everything in my power to help Mateo regain as much as possible, but he is the one who never stops trying. Even when he was a baby getting OT, PT, and Speech, he would always persist.”

Five years after his initial diagnosis, Tona and Mateo moved from Idaho to Phoenix. Tona searched for local support for families of children with disabilities and connected with Raising Special Kids.

In the ensuing years she attended several workshops and, when Mateo was in junior high, she worked with a family support specialist to review his IEP. It was an event she describes as “...a turning point. It was crucial in terms of Mateo’s academic development, the wealth of knowledge make available to me. Every time I needed help, Raising Special Kids has been there to help us along this journey.”

Mateo continues to beat the odds having recently graduated from high school and participated in the Statewide Independent Living Council’s Arizona Youth Leadership Forum. He is currently enrolled at Scottsdale Community College (SCC) studying to be a Tribal Librarian. He works with the SCC’s Disability Resource Center to ensure he has testing accommodations and assistive technology in place.

*Mateo, a member of the Lakota Tribe, documented the history of his TBI experience. See the description of his winter count at: http://bit.ly/1KIS61G

CareScape Continues Their Commitment to Families

2015 Dandelion Golf Tournament

For the eighth year in a row, CareScape landscaping company selected Raising Special Kids as the beneficiary for its annual Dandelion Golf Classic.

Guests at this year’s sold-out event were shown a ‘through the years’ slide show depicting the impact CareScape’s generosity has had on Raising Special Kids’ ability to help families.

Since 2009, CareScape has donated over $325,000 to Raising Special Kids. It’s no surprise that the tagline for CareScape is “We care. It’s our nature.”

Thank you CareScape! This year’s donation will help us support hundreds of families throughout our state.
Es importante que usted encuentre médicos de adultos lo antes posible. Usted debe comenzar a consultar un médico de adultos entre los 18 y los 21 años de edad. Si es posible, tenga sus primeras consultas y envíe sus registros a sus nuevos médicos mientras todavía está siendo atendido por su médico anterior en caso de que haya preguntas sobre su condición o tratamiento.

CÓMO ENCONTRAR PROVEEDORES DE ATENCION MÉDICA PARA ADULTOS

- Pida a su médico actual que le dé una referencia.
- Considere al médico de sus padres
- Llame a su compañía de seguro
- Consulte a sus grupos de apoyo locales
- Llame a los hospitales médicos y de especialidades
- de rehabilitación grandes y
- pregunte por la línea de referencia
- Pida sugerencias a su Coordinador de atención
- médica o a su Administrador de caso
- Pida sugerencias a sus amigos

Consulte Arizona Junta Médico

PREGUNTAS QUE DEBE HACER

Es importante encontrar médicos que le hagan sentir cómodo y que puedan atender sus necesidades. Antes de elegir un médico nuevo, llame a su consultorio e indíquele que desea hablar con un integrante del personal que pueda dedicar tiempo a responder sus preguntas, o pida una cita para reunirse en persona con el médico y el personal

Pregunte en el consultorio:

- ¿Acepta el médico su cobertura de seguro? ¿Acepta pacientes nuevos?
- ¿Es el consultorio accesible (fácil de llegar y fácil de encontrar dentro del área del edificio o la clínica)?
- ¿Cuáles son los horarios del consultorio? ¿Cómo se puede comunicar con el médico fuera de horario?
- ¿Cómo intercambiará información el médico con sus especialistas?
- ¿Tendrá el consultorio flexibilidad para atender sus necesidades médicas (permitirá entrar a su perro de servicio, programará las consultas de forma que usted no tenga que quedarse sin alguna comida, o programará sus citas en horarios tranquilos si usted es sensible al ruido)?

Pregunte al médico:

- ¿Está el médico dispuesto a hablar sobre su historia clínica y sus necesidades especiales con su médico pediatra?
- ¿Atiende el médico actualmente a pacientes con condiciones médicas similares a la suya?
- ¿En qué hospital realiza el médico los procedimientos?
- ¿Dónde obtuvo el médico su educación universitaria en medicina y la formación en su especialidad?
- ¿Tiene certificación oficial?
- ¿Tiene el médico intereses especiales o formación más avanzada?

Pregúntese a usted mismo:

- ¿Escucha el médico sus preguntas o le interrumpe constantemente?
- ¿Puede el médico explicar la información de forma que usted la entienda?
- ¿Se toma el médico suficiente tiempo para responder sus preguntas?
- ¿Le trata el médico con respeto?

Recursos para la Transición de la Juventud

- Transición a la Vida Adulta
  http://www.parentcenterhub.org/repository/transicion-adulta/
- Disability Benefits 101 - le ofrece herramientas e información sobre cobertura de salud, beneficios y empleo.
  https://az-es.db101.org/index.htm
- Preguntas más frecuentes sobre la transición de los cuidados médicos
  http://www.gottransition.org/youthfamilies/indexES.cfm
Talleres y Entrenamiento
www.raisingspecialkids.org o llame al 800-237-3007

PHOENIX
Ability360 Center
5025 E Washington Street
Phoenix, AZ 85034

Cumpliendo los 18 años – Opciones Legales
vie, nov 13, 10-11:30 am
vie, dic 5, 10-11:30am

El Comportamiento Positivo
jue, nov 5, 6-8pm
Entrenamiento del IEP
mar, nov 17, 6-8pm
sab, dic 5, 10am-12pm

YUMA
3250A E 40th St
Yuma, AZ 85365
Cumpliendo los 18 años - Opciones Legales
jue, nov 12, 1-3pm

Marketplace Open Enrollment
Nov 1, 2015 - Jan 31, 2016
Arizona residents can sign up for health insurance through the Arizona Healthcare Exchange at https://www.healthearizonaplus.gov.


La hoja informativa De Cobertura a Cuidado por parte de La Colaborativa Nacional del Navegador de Recursos de Discapacidad (NDNRC por sus siglas en inglés) [National Disability Navigator Resource Collaborative], ayudar a familias con discapacidades que tienen cobertura de seguro médico nuevo a entender sus beneficios en cuanto consigan seguro. Acceso a la hoja informativa en http://bit.ly/1NIleCu

Los consumidores tendrán hasta el 31 de enero para registrarse, pero si desean que su cobertura se renueve o comience el 10 de enero, tendrán que completar su solicitud antes del 15 de diciembre del 2015.

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

Avondale
Veronica Acosta
Guevara
Rosa M. Barroso
Teenaen Curtin
Claudia Lizarraga
Luis Lizarraga
Gabriela Sanchez
Orozco
Casa Grande
Margarita Ayala
Cashion
Juana Perez
Martinez
Margarita Zaragoza
Chandler
Gilbert Alonzo
Susan Alonzo
Marti Baio
Martha Burrer
Samantha Flores
Kristina Hunt
Beth Kaib
Lisa Myers
Gilbert
Sarah Greene
Heather Monica
Louise Murphy
Aimee Patton
Dona Prouty
Glendale
Pam Baldwin
Isabel Dorame
Luis Mendoza
Marisol Mendoza
Jose Luis Moreno
Aimee Patton
Dora Angelica
Ramirez
Goodyear
Maria Elena Avalos
Stephanie Culbreth
Laveen
Bonnie Carroll
Chanel Mauzy
Mesa
Domonique
Colunga
Maria Colunga
Phoenix
Flora Amaya
Ana Arjona
Sasha Diaz
Nora Calvillo
Brianna Carreras
Lisa Case
Inilda Christensen
Mykl Cook
Yesenia Escarrega
Michelle Faudskar
Juan Manuel Flores
Claudia Gamez
Sarah Greene
Marissa Huth
Elizabeth Keltzler
Naughton
Maura Knoell
Rebecca Masterson
Maria del Carmen
Nuñez
Juana Lida
Ontiveros
Damita Radtke
Margarita Ramirez
Maria Elva
Retamaza
Maria Mercedes
Luci Rivera
Josefina Romero
Ines Rosas
Ched Salasek
Olga A. Scott
Sherri Scruggs
Paulina Serna
Chuck Smith
Dana Wayne
Queen Creek
LaTasha Whitaker
Scottsdale
Elizabeth Freeburg
Steve Lee
Lynn Michaels
Katie Petersen
Ellen Wilson
Sun City
Melissa McQueen
Taylor
Anna Merrill
Tolleson
Eufemia Martinez
Tucson
Wendy Swartz
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