



Raising Special Kids

Families Helping Families

Poster design by Brittany Hewardine as part of the AIGA civic engagement initiative Design for Democracy. Learn more at aiga.org/vote

Let **your**
voice be
heard.



VOTE

Connecting
Summer 2016

Staff Spotlight

Dolores Rios Herrera Family Support Specialist



Dolores Rios Herrera was first introduced to Raising Special Kids seventeen years ago when she was admitted to the hospital a month prior to the birth of her son, Rodolfo. Dolores had just learned that her fourth child was going to be born with Spina Bifida. A hospital social worker recognized Dolores' unease about having a child with a disability and suggested Raising Special Kids would be able to help her. She recalls, "I was scared, and couldn't find any information about Spina Bifida in Spanish. I called Raising Special Kids and they sent a whole packet of information, and all of it was in Spanish."



Dolores and Rodolfo

Dolores was also connected with a parent mentor who had a child with Spina Bifida, and she appreciated the comfort and advice from an experienced parent.

Dolores is a dedicated and engaged community leader. She heads her neighborhood watch association, helped establish GANE (a support group for Spanish-speaking families of children with disabilities), served on the board of the Spina Bifida Association and the Developmental Disabilities Advisory Council. She is an invaluable resource for families who contact Raising Special Kids with questions ranging from homelessness to immigration and domestic violence. She shared, "To me it's not a job. I really like what I do. I like to provide support and information to parents. But mostly, I think about the children. Because in all the children I see my son and think, 'what if?' What if I didn't receive all that priceless information when he was born? I know how impactful it is for me to help them see things in a positive light."

Connecting is published by

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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.

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Can Young Adults with Intellectual Disabilities Vote?

How one young man in AZ helped answer that question

When Americans turn 18 years old, among other things, they gain the right to vote. Unlike obtaining a driver's license or entering college, this rite of passage does not require passing any type of test or exam.

When Americans with intellectual disabilities approach the age of 18, they and their families face decisions about possible legal actions regarding their rights, including the right to vote.

Years before Clinton Gode turned 18 he knew he wanted to vote. His father, Art Gode, remembers Clinton's reaction when he was told he would not be able to vote once his parents were awarded guardianship. "He didn't understand. He agreed that he needed help in some areas but that didn't mean he should be kept from voting. So, we decided to work on this so he could vote." When asked how he knew what steps to take, Art humbly replied, "These things just come up and you shotgun it till you get it right."

If a judge finds that an individual is 'incapacitated', the rights of that person, now called the ward, are removed. The ward's guardian becomes responsible for making decisions in the best interest of the ward.

At the time Clinton expressed an interest in voting, Art was a member of the Governor's Council on Developmental Disabilities (now known as the Arizona Developmental Disabilities Planning Council). After bringing Clinton's plight to the Council, the members worked to get a bill before the legislature. Art recalls that in addition to gaining voting rights, there was another focus of their effort. "The way the law was worded was pretty derogatory. It was written as if they [people under guardianship] were prisoners. It meant a lot to Clinton to have the wording changed to be more respectful, as well as for him to be able to vote."

Clinton recalled meeting with legislators. "I told them why I wanted to vote and talked about the

things that were important to me." His self-assurance was no accident; his father had been modeling good advocacy skills for Clinton throughout his entire life.

The Council's first attempt to change the law was unsuccessful, by the 2012 election season, Clinton was back visiting legislators and testifying at hearings. As always, Art was by his side. And, in the second week of April 2012, Governor Jan Brewer signed HB 2377 which states:



Clinton on the floor of the AZ House of Representatives

"In cases of limited guardianship only, a person is not deemed an incapacitated person for purposes of voting if the person files a petition, has a hearing and the judge determines by clear and convincing evidence that the person retains sufficient understanding to exercise the right to vote."

Clinton said, "It felt awesome when I found out the bill passed!" But changing the law was only the first hurdle. The following August, Clinton had his day in court. After being sworn in, Clinton spent about 30 minutes answering the questions of Mohave Superior Court Judge Lee Jantzen before the judge ruled Clinton had provided "clear and convincing evidence" and should be the first person under the new law to have his right to vote reinstated.

Clinton may have been the first to vote, but you or

"I told [the legislators] why I wanted to vote and talked about the things that were important to me."

~Clinton Gode

someone you know with an intellectual disability may be interested in voting.

Here are some resources:

- **Arizona Secretary of State** <http://www.azsos.gov/elections/voting-election/register-vote-or-update-your-current-voter-information>
- **Self Advocates Becoming Empowered (SABE)** <http://www.sabeusa.org>
- **The National Technical Assistance Center for Voting and Cognitive Access** <http://www.sabeusa.org/govoter/voting-info/>
- **Help America Vote Act Fact Sheet** http://www.acl.gov/NewsRoom/Publications/docs/HAVA_factsheet.pdf
- **The Americans with Disabilities Act and Other Federal Laws Protecting the Rights of Voters with Disabilities** http://www.ada.gov/ada_voting/ada_voting_ta.htm

Which Federal Laws Protect the Voting Rights of People With Disabilities?

- **The Americans with Disabilities Act (ADA)** requires state and local governments to ensure people with disabilities have a full and equal opportunity to vote. The ADA's provisions apply to all aspects of voting, including voter registration, site selection, and the casting of ballots, whether on Election Day or during an early voting process.
- **The Voting Rights Act of 1965 (VRA)** requires election officials to allow a voter who is blind or has another disability to receive assistance from a person of the voter's choice (other than the voter's employer or its agent or an officer or agent of the voter's union). The VRA also prohibits conditioning the right to vote on being able to read or write, attaining a particular level of education, or passing an interpretation "test."
- **The Voting Accessibility for the Elderly and Handicapped Act of 1984 (VAEHA)** requires accessible polling places in federal elections for elderly individuals and people with disabilities. Where no accessible location is available to serve as a polling place, voters must be provided an alternate means of voting on Election Day.
- **The National Voter Registration Act of 1993 (NVRA)** aims, among other things, to increase the registration rates of persons with disabilities.
- **The Help America Vote Act of 2002 (HAVA)** requires jurisdictions responsible for conducting federal elections to provide at least one accessible voting system for persons with disabilities at each polling place in federal elections.

No Cost Workshops & Training

Register online at www.raisingsspecialkids.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

Sat, Aug 6, 1 - 3pm
Sat, Sep 10, 1 - 3pm
Sat, Oct 15, 10am - 12pm

Positive Behavior Support

Sat, Aug 6, 10am - 12pm
Sat, Sep 10, 10am - 12pm
Sat, Oct 15, 10am - 12pm

The Road to Employment:

Sat, Aug 6, 1 - 3pm
Sat, Sep 10, 1 - 3pm

Transition Institute

Sat, Jul 16, 8:30am - 4:30pm

Turning 18 - Legal Options

Sat, Aug 6, 10am - 12pm

Sat, Sep 10, 10am - 12pm

Sat, Oct 15, 1 - 3pm

Working Through Challenging Behaviors at School

Sat, Oct 15, 1 - 3pm

FLAGSTAFF

Raising Special Kids
3100 N West Street #300
Flagstaff, AZ 86004

IEP Training

Sat, Aug 27, 10 am-12pm

Positive Behavior Support

Tue, Sep 13, 5:30-7:30pm

Turning 18 - Legal Options

Tue, Oct 11, 5:30-7:30pm

PINETOP

Hon-Dah Conference Center
777 AZ 260

Pinetop, AZ 85935

Early Childhood Education

Wed, Aug 17, 10am - 12pm

YUMA

ACTS

2573 S Arizona Ave, Ste D
Yuma, AZ 85364

IEP Training

Thu, Jul 21, 6 - 8pm

Yuma Public Library

2951 S 21st Dr
Yuma, AZ 85364

Positive Behavior Support

Sat, Jul 23, 10am - 12pm

Turning 18 - Legal Options

Sat, Aug 6, 10am - 12pm

Call or check our website for updated training dates.

2,500 PARENTS AND CHILDREN HAD FUN AT SPECIAL DAY FOR SPECIAL KIDS!

MARCH 19, 2016



Getting Down to Business

A story of decisions and determination

There's no lack of intensity in the Banahan family. When asked what had prepared her daughter, Julia, for post-secondary education, Paula Banahan replied without hesitation, "Nothing— except for determination." She then clarified that Julia's social experience in high school was very positive saying, "She had all kinds of friends and they helped her incredibly. She was the 'belle of the ball.'" But Paula went on to describe her daughter's academic experience as "a total drudge uphill." When I met with the psychologist in Julia's junior year, he looked at me and said, 'Mrs. Banahan, your daughter has Down syndrome and you need to understand she has reached her limit and she's probably not going to college.' At that point I stopped the meeting, saying I would be happy to reconvene when everyone agreed that the sole purpose of the meeting would be how to get Julia into community college." Julia's twin brother, Bobby, said Julia was the single most important influence in his life by proving time and time again that she can do things everyone thought to be impossible.

A few years later, there was a very different school meeting. Julia's first attempt to pass the Certified Nursing Assistant (CNA) program at Brookline College was not successful. Julia, Paula, and an administrator sat discussing the possibility of allowing Julia to repeat the CNA course a second and possibly a third time if necessary. It was Julia who stopped that meeting, declaring, "I am not doing this a third time. I will pass the second time." And she did. Out of 13 students, Julia was one of five who successfully went on to complete the clinical portion of the program. Through hard work, good coaching from Paula and appropriate accommodations, Julia was able to complete her clinicals and become a Certified Nursing Assistant. Julia still faces some challenges in

the process of obtaining her license, but with Paula's help, Julia is working through it.

For now, Julia maintains her interest in the medical field by volunteering at Phoenix Children's Hospital in the Down Syndrome Clinic run by Developmental Pediatrician Dr. Robin Blitz. When she talks about her duties at the hospital, Julia brightens, "I like being around kids. Sometimes I read to them, and some of them have what I have: Down syndrome." She does acknowledge the job is not without some challenges, "It's hard for me to see kids hurt. Sometimes I care too much."

When Julia was approaching 18, her parents considered the legal options available and concluded that guardianship was not the right choice. Paula and Jim recall thinking, "For us to go into a court of law and say that Julia is incompetent to decide if she wants to get married or have kids, we can't say that. We won't take that away from her but we will help her. And she's fine with us having power of attorney. We felt it would be more difficult



Julia, Jim and Paula Banahan

to reverse guardianship."

Julia recently started her first job as a hostess at Aunt Chilada's restaurant in North Phoenix and she's looking forward to voting in her second presidential election. Although she says it is too soon for her to decide who she'll be voting for, she'll be doing her research, "I want to see how they stand on the issues I'm for. I find out by reading newspapers, watching television and having discussions with family about issues." And what are Julia's hopes for her volunteer position at Phoenix Children's Hospital? She offers, "It might turn out to be a paying job."

If Julia's determination to succeed is any guide, it seems very possible that it will.

Integrating Health Care in the IEP

Tips for Youth, Caregivers and Professionals

Students with disabilities who have health care needs that need to be taken care of while at school. If necessary, a student's IEP can address health issues and as students move towards post-secondary transition, health care can also be incorporated into their transition planning. Here are some tips on how to incorporate health care into an IEP:

Identify Health Care Needs in the Present Levels of Academic Achievement and Functional Performance (PLAAFP)

The PLAAFP can be thought of as a snapshot of where the student is at the time the IEP is written. Health care concerns that affect participation in school and extracurricular activities should be identified clearly. It is also important to document the extent a student can participate in their own health care routines and the levels of support, if any, they require.

Addressing the Needs Identified in the PLAAFP

The IEP that may contain health-related information, goals, and activities in any of the following sections:

- Annual Goals
- Accommodations
- Curriculum Modifications
- Services for the Student
- Related Services
- Supports for School Personnel

The Transition Age Student and the IEP

The IEP that is in effect when a student turns 16 should link the PLAAFP and other appropriate IEP sections to the student's Measurable Post-Secondary Goals (MPSG) as identified in the their transition plan.

For a student with health concerns, their program should be geared toward reasonably enabling the student to achieve as much self-care and independent management of health conditions as possible across all work and living situations. Some areas where youth may need assistance are:

- Understanding their own condition and treatment(s)
- Explaining their condition & needed treatment to others and asking for guidance
- Monitoring their health status on an ongoing basis
- Learning about the systems that will apply to

them as adults

- Managing their own health, health care, and health insurance/healthcare financing
- Interacting with healthcare providers
- Advocating for their health and healthcare
- Social Security
- Health Care Power of Attorney/Guardianship
- Understanding formal and informal advocacy services and supports

For transition age students who receive related services, the Coordinated Set of Activities in the transition plan must support the achievement of the MPSG and may require assistance from related services providers.

Collaboration in IEP Development

Collaboration is essential in developing a comprehensive and effective IEP. Students, parents, and others, including outside providers working with a student, must be involved in the process. With prior parental permission, schools can reach out to providers involved in the success of the transitioning student and invite appropriate staff to the IEP meeting.

Parents can help facilitate interagency collaboration by:

- Providing consent for appropriate outside providers and coordinators to attend the IEP meeting
- Requesting the school include outside providers and service coordinators involved with the student to attend the IEP meeting
- Asking specific staff to attend the IEP meeting
- Requesting a written report on the student's progress from a service provider if an invited provider or service coordinator is unable to attend the IEP meeting

Incorporating health care goals and supports in a student's IEP at any age is clearly supported in the Individuals with Disabilities Education Act. However, it is important to include health care goals and supports in the IEP of a transition-aged student to reflect the increased independence in their life beyond high school.

¿Pueden votar los jóvenes con discapacidades intelectuales?

Cómo un hombre joven en AZ ayudó a responder a esa pregunta

Cuando los estadounidenses cumplen 18 años, entre otras cosas adquieren el derecho a votar. En contraste a como cuando se va a obtener la licencia de conducir, o al ingresar al colegio, este rito de paso no exige pasar ningún tipo de examen.

Cuando los estadounidenses con discapacidades intelectuales están cerca de cumplir sus 18 años, ellos y sus familiares encaran decisiones legales acerca de sus derechos, incluyendo el derecho a votar.

Años antes de cumplir los 18 años, Clinton Gode sabía que él quería votar. Art, el papá de Clinton, recuerda la reacción que tuvo Clinton cuando le anunciaron que no podría votar una vez que a sus padres les otorgaran su tutela. “Él no podía entenderlo. Él estaba consciente de que necesitaba ayuda en ciertas áreas, pero eso no significaba que se le debería excluir de votar.”

Si se está tramitando la tutela y un juez falla que el individuo es ‘incapacitado’, los derechos de esa persona, ahora llamado legalmente custodiado, se eliminan. El tutor se convierte en la persona responsable de tomar decisiones que favorezcan más al custodiado.

En Arizona, cuando se solicita la tutela ante el tribunal, se tiene la opción de pedir al juez que se otorgue una tutela limitada solo concerniente a ciertas áreas. Una forma de limitar la tutela es permitiéndole al individual con discapacidades que retenga su derecho al voto. Solo un juez puede decidir si un individuo puede retener sus derechos. Pero esto no ha sido siempre así.

En abril del 2012 la gobernadora Jan Brewer firmó la propuesta de ley HB 2377, que reza:

“Solo en casos de tutela limitada, a una persona no se le considerará incapacitada para los propósitos del voto, si la persona

solicita una petición, tiene una audiencia y el juez determina por medio de pruebas claras y convincentes, que la persona retiene suficiente entendimiento para ejercitar el derecho a votar.”



Clinton en el piso de la Cámara de Representantes AZ

Clinton expresó que, “ise sintió formidable cuando la propuesta de ley pasó!” Pero el cambio de la ley fue solo el primer obstáculo. Clinton iba a tener su audiencia en el tribunal en el mes de agosto. Una vez juramentado, Clinton pasó 30 minutos respondiendo las preguntas del juez Lee Jantzen del Tribunal Superior de Mohave, al concluir el juez falló que Clinton había proveído “pruebas claras y convincentes” y que debía ser la primera persona bajo esta ley a quien se le reintegrara

su derecho a votar.

Quizás Clinton haya sido el primero en votar, pero es posible que usted o alguien a quien usted conozca que tenga alguna discapacidad intelectual esté interesado

“¡Se sintió formidable cuando la propuesta de ley pasó!”

~Clinton Gode

en saber acerca del voto.

A continuación se ofrecen varios recursos:

Self Advocates Becoming Empowered (SABE) Hoja Informativa <http://www.sabeusa.org/wp-content/uploads/2014/02/FactSheetSelfAdvocatesEspanol.pdf>

Ley de Accesibilidad al Voto para los Ancianos y los Discapacitados https://www.ada.gov/cguide_spanish.htm#anchor63814

Acerca de la Comisión de Asistencia Electoral <http://www.eac.gov/translations/spanish/>

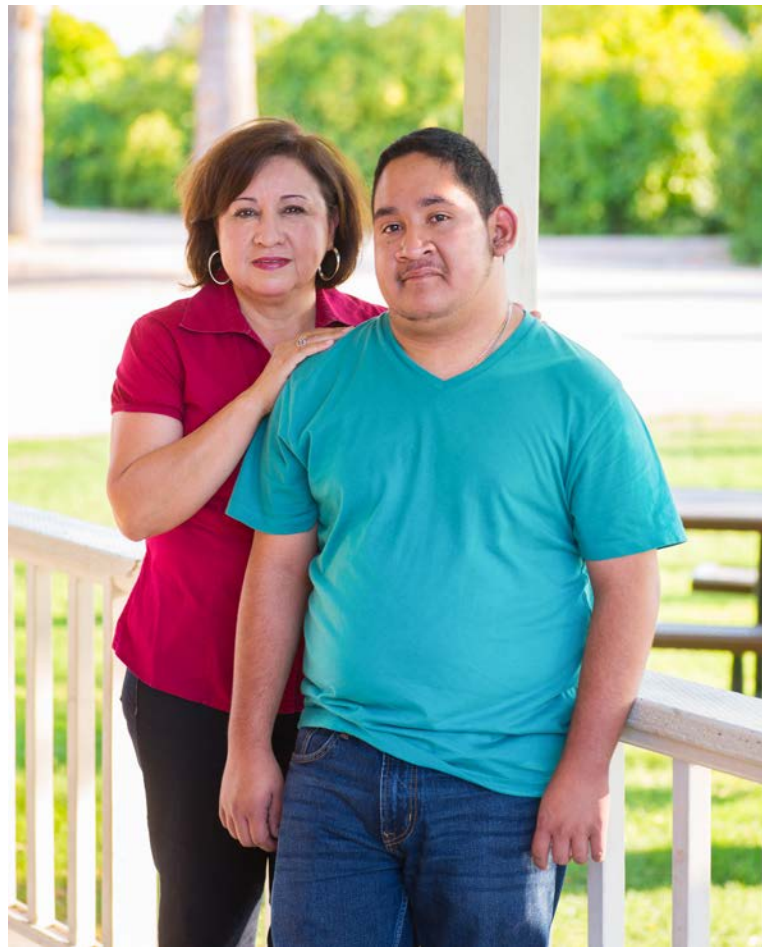
Personal Destacado

Dolores Rios Herrera - *Especialista en Apoyo Familiar*

Dolores Ríos Herrera supo de Raising Special Kids hace diez y siete años, cuando fue admitida al hospital un mes antes del nacimiento de su hijo Rodolfo. Dolores se acababa de enterar de que su cuarto hijo iba a nacer con espina bífida. Una trabajadora social del hospital reconoció la inquietud de Dolores, lo que sería tener un hijo con discapacidades, y le dijo que Raising Special Kids podría ayudarla. Ella recuerda, "yo estaba aterrada, no podía conseguir información sobre la espina bífida en español. Llamé a Raising Special Kids y me enviaron un paquete completo de información, y todo estaba en español".

A Dolores la pusieron en contacto con un mentor, padre/madre de un niño con espina bífida, y por muchos años recibió el consuelo y los consejos de estos padres con experiencia.

Dolores se convirtió en una líder comunitaria dedicada y comprometida. Ella dirige la asociación de vecinos en vigilia (neighborhood watch association), y jugó un papel importante en la creación de GANE (un grupo de apoyo para familias hispanohablantes con niños con discapacidades); colaboró con la Asociación de Espina Bífida y en la Comisión Asesora sobre Discapacidades del Desarrollo (Developmental Disabilities Advisory Council). Ella es un recurso con un valor incalculable para muchas familias que contactan a Raising Special Kids, con preguntas acerca de asuntos de desamparo (estar sin hogar), hasta asuntos de inmigración y de violencia intrafamiliar. Hace poco nos comento, "para mí esto no es un trabajo. De verdad me gusta lo que hago, disfruto apoyar e informar a los padres. Pero sobre todo, pienso en los niños. Porque



Dolores y Rodolfo

en todos los niños veo a mi hijo, y pienso, '¿y qué tal si?' ¿Que habría sucedido si no hubiera recibido toda la información tan valiosa que recibí cuando él nació? También sé el impacto que tiene que les haga ver las cosas de una forma positiva".

Talleres y Entrenamientos

www.raisingpecialkids.org o llame al 800-237-3007

PHOENIX

Ability360 Center
5025 E Washington Stret
Phoenix, AZ 85034
edificio libre de fragancias

Cumpliendo los 18 años - Opciones Legales

15 de octubre, 10am - 12pm

El Comportamiento Positivo

6 de agosto, 10am - 12pm
10 de septiembre, 10am - 12pm

Entrenamiento del IEP

6 de agosto, 1 - 3pm
10 de septiembre, 1 - 3pm
15 de octubre, 1 - 3pm

SAN LUIS

Rio Colorado Elementary School
1055 N Main St,
San Luis, AZ 85349

Prevención de Burlas

21 de septiembre, 10am - 12pm

YUMA

Yuma Main Library
2951 S 21st Dr
Yuma, AZ 85364

El Comportamiento Positivo

27 de julio, 6 - 8pm

Para obtener una lista actualizada de los talleres en español, visite <http://bit.ly/1XD1Cws>

KidsCare - Arizona's Children's Health Insurance Program (CHIP)

For eligible children (under age 19) who are not eligible for other AHCCCS health insurance

AHCCCS offers health insurance through KidsCare for eligible children (under age 19). For those who qualify, there are monthly premiums.

Applications for KidsCare will be accepted beginning July 26, 2016 for coverage that will begin September 1, 2016.

Who Can Receive Services?

An applicant may qualify for this program if the applicant:

- Is an Arizona resident
- Is 18 years old or younger
- Is a United States citizen or a qualified immigrant
- Has a Social Security number or applies for one
 - To apply for a Social Security number visit the U.S. Social Security Administration



- Make a copy of the form submitted as confirmation of applying for a Social Security Number

- Is under the income limit
- Is not currently covered by other health insurance
- Does not qualify for coverage through a state agency employee
- Is not eligible to receive AHCCCS (Medicaid) coverage
- Is a member of a household that is willing to pay a premium

Please visit <https://www.azahcccs.gov/Members/GetCovered/Categories/KidsCare.html> for information about How to Apply, programs, covered services, available health plans, and additional resources.

Parent Leaders

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

March - June 2016

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TRANSITION INSTITUTE FOR PARENTS, YOUTH & YOUNG ADULTS

(Youth & young adults aged 14-26 invited. If under 18, must be accompanied by a parent or guardian)

SATURDAY, JULY 16, 8:30 AM - 4:30 PM

This Institute will give you an overview of what to plan for and ideas of what you can do NOW that will contribute to a successful transition.

- Learn about National and Arizona initiatives that support transition of youth from school to life as a young adult
- Learn about Vocational Rehabilitation Services to help develop employment opportunities
- Explore options for further education including college.
- Learn practical things you can do while still in school to prepare for transition (e.g., begin to develop your own resume and portfolio.)
- Hear from young adult self-advocates.
- Learn practical ways to approach employment and independent living.

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