



Raising Special Kids

Families Helping Families



Connecting

Spring 2014

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Guardianship and Self-determination

Supporting Decision-making and Competence

By Marissa Huth

Age 18 marks the threshold of a child's entry to adult life. It's a milestone that many parents of children with developmental and other significant disabilities find difficult.

Every individual acquires the rights and responsibilities of an adult on their 18th birthday unless specific legal actions prevent it. Often, parents struggle with decisions about how to

support their child in adulthood, and they may wonder what choices are available and appropriate to provide adequate protection for their child. For parents of a child who has challenges in handling money, making important medical decisions, or knowing whom to trust, this transition presents several options. In the educational environment, the right to make decisions about

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Staff Spotlight

Gabi Parra - Family Support Specialist

Gabriela “Gabi” Parra, originally from Juarez, Chihuahua Mexico, is a single parent of two boys with special needs. Her oldest son received the diagnosis of autism at age three. Her youngest was diagnosed with ADHD just two years ago. “It has been a difficult journey with both of my boys, but I feel that it has helped me. Not only did I become a better teacher and pro-active parent, it has made me a better person. We celebrate all the



triumphs in my boys’ lives, big or small. I certainly don’t take things for granted.”

In addition to her work and family responsibilities, Gabi earned a master’s degree in education and is working toward a doctorate.

Gabi credits her resilience to the great support she receives from her family. “I couldn’t do what I do without my parents’ support, my siblings’ understanding and acceptance, and everyone’s unconditional love.”

Gabi first learned of Raising Special Kids in her search for community support and training at an autism conference. “I wished I had known about Raising Special Kids sooner. I did the best that I could with the information and knowledge that I had at the time. If Raising Special Kids had been a part of my support system earlier, it would have been so much easier to navigate the different systems of care.”

Now that Gabi has joined the Raising Special Kids staff, she provides bilingual support to families. “Being a Family Support Specialist is very rewarding. There’s a warm feeling in my heart when a parent expresses how grateful they are to have found someone who knows exactly what they are going through. I feel that I have found my purpose and I know that I am in the right place.”



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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 Spanish and English. 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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Raising Special Kids Announces Partnership with SRPMIC

Raising Special Kids is pleased to announce a new partnership with the Salt River Pima Maricopa Indian Community. Through a generous \$10,000 grant from Casino Arizona, Raising Special Kids will offer an enhanced network of education and services to members of the Salt River Pima Maricopa community.

- Two mini-conferences offering a full day of educational workshops for parents
- Arizona Early Intervention Program overview workshops



- Information at community outreach events
- In-service trainings for teachers, ESS coordinators and IHS staff
- Two scholarships for the Epics annual Native American Conference on Special Education

Raising Special Kids gratefully acknowledges Casino Arizona and the Salt River Pima Maricopa Indian Community for creating opportunities for parents to gain the information, training, and leadership skills to become more effective advocates for their children.

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school transfers from parent to child (see page 5 for Transfer of Parent's Rights).

Sher, the parent of a young adult with disabilities, faced this critical decision for her daughter. In high school, some students had subjected Whitney to financial manipulation, and her family was concerned about her ability to make health care decisions. "As Whitney was approaching 18, we needed to start thinking about these things. We wanted to explore every option, and guardianship was something we considered," said Sher.

After consulting a lawyer, the family discovered that guardianship meant their daughter would lose the right to vote, have her own bank account, choose to get married, and more. "We found this very distressing. How could we strip Whitney of her rights? We felt there were other options, but if those did not work out, we could revisit the idea of guardianship." They saw full guardianship as an "all or nothing" approach that did not provide flexibility for their daughter to exercise her abilities or participate in choices.

Guardianship is a legal action taken by a court in which the power and obligation to make decisions for an individual, or "ward," is assigned to another party, often a relative or trusted friend. Many parents consider guardianship

as a way to provide security and long-term continuity of care. Some families fear that if they do not go through guardianship proceedings their child may be taken away from them, lose important services, or be forced to live in an institution. Some parents wrongly assume that guardianship is an automatic process for a child with a developmental disability. Guardianship must be requested and legally granted through a formal court process. Another common misconception is that guardianship costs thousands of dollars. It is not necessary to pay high fees—the guardianship process can involve a minimal cost if family members file court documents themselves instead of hiring an attorney.

Options

Different forms of guardianship, as well as effective alternatives to guardianship have become available, and parents may choose to combine options to achieve the most beneficial situation for their child.

Greater awareness of individual capabilities, plus an improved understanding of effective methods of support for people with disabilities has emerged in recent years. These options are prompting a push to enhance opportunities for

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independence, autonomy, and inclusion. Sher notes that her daughter “knows she is of age, and knows she is entitled to make these decisions. Whitney opted to give us power of attorney for her health. She has a bank account. She is registered to vote, and we assist her in understanding the voting materials so she can make her own decisions.”

Changing Expectations

Research shows people who have more control over their lives have better outcomes in quality of life measures. In one study, students who were able to exercise greater self-determination had better experiences with employment, access to health care and other benefits, financial independence, and independent living. Recognition of the need to promote self-advocacy and avoid restricting individual choice is gaining ground. When a person has limitations in one area, sometimes assumptions will be made about the person’s abilities in other areas. However, individual capabilities are not “all or nothing.” Support may be needed only for making certain decisions and enhancing specific capabilities. This “assisted competence” can honor an individual’s preferences, choices, and abilities.

Supported Decision-making

Decision-making is a learned skill, and skill levels may change over time. Sher said, “We made our daughter a partner in these decisions. She has grown into a confident, capable young woman. We have never regretted our decision.” Views of social obligations for people with disabilities are changing from traditional ideas of providing “benign protection” by assuming control over an individual’s choices to helping that individual retain civil rights and responsibilities. Changing views have led to a shift from an emphasis on just ensuring health and safety to enhancing self-determination through practices such as supported decision-making. With supported decision-making, individuals receive help tailored to their unique needs enabling them to make informed decisions.

Does My Child Need a Guardian?

The primary test for determining the need for guardianship focuses on the ability to make decisions, and to communicate the decisions once made regarding living arrangements, medical care, vocational and educational services, and managing finances.

Questions to ask:

- Does the individual understand that a decision needs to be made?
- Does the individual understand the options available in making a decision?
- Does the individual understand the potential consequences of the decision and options?
- Can the individual direct the decision to appropriate parties?

(From: National Guardianship Association, Inc. http://www.guardianship.org/pdf/Question_Answers.pdf)

Person-Centered Planning

Person-centered planning is a process that focuses on the interests and desires of an individual in helping to plan that person’s future. Using person-centered planning is an effective way of choosing the most meaningful options for a young adult. This process can help parents preserve their child’s rights and dignity through balancing safety and protection with self-determination, and basing decisions on the unique needs of their child.

Parents planning for their young adult’s well-being in adulthood, must have access to accurate information and know all the options available. Sher suggested, “The most important thing is to know your child. You can only do what is right for you and your family.”

When Your Child Turns 18

Transfer of parental rights to the young adult

Happy 18th birthday! Guess what? Your child is now an adult and legally responsible for making all decisions and living with the results of those decisions. For parents of young adults with disabilities, a child's 18th birthday has added significance and impact.

For special education purposes, the "Transfer of Parental Rights at the Age of Majority" is the Arizona terminology used to describe how the rights formerly held by the parents automatically transfer to the student. After the age of 18, the student can agree to sign over their educational rights to their parents. The student must be informed of and understand both the advantages and disadvantages of delegating this responsibility. Students may revoke this delegation at any time.

The Individuals with Disabilities Education Act (IDEA) requires schools to notify students that the transfer of rights is going to take place. Often, the IEP document has a checkbox for schools to indicate whether they have made the notification. The IDEA simply requires schools to provide notification of the transfer of educational rights, and document that they provided notification.

tion.

The Legal Options Manual produced by the Arizona Center for Disability Law is an excellent resource for parents. The manual contains the form "Delegation of Right to Make Educational Decisions". The form needs the signatures of the student and the student's representative, and the signatures must be notarized. Download a copy at www.raisingpecialkids.org

If no other options are appropriate, parents may decide to petition for guardianship prior to the young adult turning 18. When a judge makes the determination prior to age 18 that guardianship is in the best interest of the young adult, there is no need for the student to delegate their educational rights. Educational rights are included with all the other

rights that the judge decides the guardian should assume for the child.

For more information about options to consider when an individual is approaching the age 18, register for Raising Special Kids' Turning 18 – Legal Options workshop. Find a list of our trainings at <http://www.raisingpecialkids.org/events-training>.



For more information or to attend workshops on legal options for adults with disabilities, call Raising Special Kids at 602-242-4366 or visit raisingpecialkids.org



MAKE A DIFFERENCE by joining the Compass Club today!

You're invited to take a leadership role in building stronger families by pledging to make a monthly contribution to Raising Special Kids. Compass Club members help us provide information and training to empower families to create better outcomes for children with special needs.

Visit www.raisingpecialkids.org/compassclub to join today!

No Cost Workshops & Training

Talleres y Entrenamiento Sin Costo

Register online at www.raisingsspecialkids.org or call 800-237-3007
Regístrese en línea en www.raisingsspecialkids.org o llame al 800-237-3007

Phoenix

Disability Empowerment Center
5025 E. Washington St. #204
Phoenix, AZ 85034
Our office is a fragrance-free environment.

Bullying Prevention

Tue. 4/15/2014, 6:00pm - 8:00pm

Turning 18 - Legal Options

Sat. 3/15/14, 10:00am - 12:00pm
Thu. 4/10/14, 6:00pm - 8:00pm

High School Transition

Sat. 3/15/14, 1:00pm - 3:00pm

IDEA: What You Need To Know

Thu. 2/13/14, 6:00pm-8:00pm

IEP Training

Sat. 3/15/14, 1:00pm - 3:00pm
Thu. 3/27/14, 6:00pm - 8:00pm
Thu. 4/15/14, 6:00pm - 8:00pm

Positive Behavior Support

Sat. 3/15/14, 10:00am - 12:00pm
Thu. 4/10/14, 6:00pm - 8:00pm

Understanding 504

Thu. 3/27/14, 6:00pm - 8:00pm

Flagstaff

Exceptional Student Services
3100 N. West St. Suite 300
Flagstaff, AZ 86004

Positive Behavior Support

Thu. 3/13/14, 10:00am - 12:00pm
Thu. 3/13/14, 5:30pm - 7:30pm

Turning 18 - Legal Options

Thu. 4/10/14, 5:30pm - 7:30pm

Tucson

Eckstrom-Columbus Library
4350 E. 22nd St.
Tucson, AZ 85711

IEP Training

Wed. 3/12/14, 10:30am - 12:30pm

Understanding 504

Thu. 4/9/14, 10:30am - 12:30pm

Conferences

Multiple workshops in one day

Pinal County

Special Education Conference

Sat. 3/1/14, 9:00am - 3:15pm
Mary C. O'Brien
Elementary School
1400 N. Eleven Mile Corner Rd.
Casa Grande, AZ 85194

- IDEA: What You Need to Know
- IEP Training
- High School Transition

Ganado

High School Transition Conference

Sat. 3/8/14, 9:00am - 3:30pm
Ganado Unified School District
Administration Conference Room
Hwy 264, Ganado, AZ 86505

- Partners for Transition
- Getting & Keeping the 1st Job
- Turning 18 - Legal Options

Entrenamiento en Español

Disability Empowerment Center
5025 E. Washington St. #204
Phoenix, AZ 85034
Somos una oficina libre de fragancias.

Cumpliendo los 18 – Opciones Legales

Viér. 3/7/14, 10:00am - 11:30am
Viér. 4/11/14, 10:00am - 11:30am

Entrenamiento del IEP

Sáb. 3/8/14, 10:00am - 12:00pm
Sáb. 4/26/14, 1:00pm - 3:00pm

El Comportamiento Positivo

Sáb. 3/8/14, 1:00pm - 3:00pm
Sáb. 4/26/14, 10:00am - 12:00pm

Familias Resistentes

Lun. 3/17/14, 10:00am - 11:30am

Conferencias

Condado Pinal

Conferencia de Educación Especial

Sáb. 3/1/14, 9:00am - 3:15pm
Mary C. O'Brien
Elementary School
1400 N. Eleven Mile Corner Rd.
Casa Grande, AZ 85194

- IDEA: Lo Que Usted Necesita Saber
- Entrenamiento del IEP
- Transición de Escuela Secundaria

Recent Advances in the Treatment of Cerebral Palsy Conference

March 8, 2014 7:30am to 12:30pm

Free Admission • Free Parking

Phoenix Children's Hospital

Melvin L. Cohen Conference Center • Rosenberg Children's Medical Plaza
1920 E. Cambridge Ave. • Phoenix, AZ 85006

Register at:

www.phoenixchildrens.org/recent-advances-treatment-cerebral-palsy



Tutela (guardianship) y Autodeterminación

Apoyar la toma de decisiones y las capacidades

Los 18 años son cruciales y le causan gran ansiedad a muchos padres de niños con discapacidades del desarrollo.

Todas las personas adquieren derechos y obligaciones al cumplir 18 años salvo que se tomen medidas para evitarlo. Para quienes tienen un hijo con dificultades para manejar las finanzas, elegir en quien confiar o tomar decisiones médicas importantes, ese momento trascendental puede implicar tener que tomar decisiones particularmente complejas. En algunos casos, los padres tienen problemas para decidir cómo apoyar mejor a sus hijos en la adultez y se preguntan qué opciones tienen y cuáles son las más adecuadas para proteger a sus hijos.

Algunos padres asumen que la Tutela (guardianship) es un proceso automático para los niños con discapacidades del desarrollo, pero no es así. Debe solicitarse y debe ser otorgada legalmente tras un proceso formal en tribunales.

Muchos padres piensan que la Tutela es una forma de ofrecer seguridad y mantener los cuidados a largo plazo. Algunas familias temen que les quiten a sus hijos o los obliguen a vivir en una institución si no obtienen la Tutela.

Muchos tienen la idea equivocada de que obtener la Tutela cuesta miles de dólares. No es necesario pagar honorarios elevados, pues el proceso puede llevarse a cabo por un costo mínimo si los familiares presentan los documentos en los tribunales en vez de contratar a un abogado para los trámites.

Opciones

Tener una discapacidad no significa que automáticamente se requiera la Tutela total. Ahora existen distintos tipos de Tutela y alternativas efectivas a la misma y los padres pueden combinar opciones para que su hijo esté en la situación

más beneficiosa posible.

En los últimos años, han mejorado tanto el grado de concientización en torno a las capacidades individuales como la comprensión hacia

métodos de apoyo efectivos para personas con discapacidades. Esta situación promueve el fortalecimiento de oportunidades para la independencia, la autonomía y la inclusión.

Si una persona tiene limitaciones en un área, se tiende a hacer conjeturas sobre las capacidades de esa persona en otras áreas,

pero las capacidades individuales no son cosa de “todo o nada”. Se puede apoyar a una persona mediante asistencia específica, por ejemplo, se le puede ayudar a tomar decisiones, para fortalecer capacidades específicas, según sea necesario. Esta “capacidad asistida” respeta las preferencias, elecciones y habilidades individuales. Tomar decisiones es una habilidad aprendida y el nivel de destreza puede cambiar con el tiempo.

Planificación centrada en la persona

La planificación centrada en la persona es un proceso enfocado en los intereses y deseos del individuo para ayudarlo a planificar su futuro. Es un método efectivo para elegir las opciones más significativas para los jóvenes. Este proceso puede ayudar a los padres a preservar los derechos y la dignidad de sus hijos combinando seguridad y protección con autodeterminación y basando las decisiones en las necesidades únicas de sus hijos.

Cuando los padres planifican para el bienestar de sus hijos en la adultez, deben tener acceso a información precisa y conocer todas las opciones disponibles. Si requiere mayor información o talleres sobre curatela (guardianship), llame a Raising Special Kids o ubique los talleres en raisingspecialkids.org/events-training/.



Family Story

When Laurie and her husband adopted Adilynn, they anticipated a few minor medical issues. What they couldn't have anticipated was the hospitalizations, medical procedures and over a dozen specialists necessary to meet Adilynn's medical needs. "We have been hospitalized a total of four times and with every stay we would leave with more doctors, tests, and stress to come," Laurie said.

"We were bombarded with paperwork, insurance issues, and the feeling that we were drowning and couldn't catch up."

In addition to Adilynn, the Shooks have a two year old foster son who also has special needs. "I felt overwhelmed, stressed, sad, and even hopeless at times. I would sit at the hospital and cry some days because I wasn't sure how to move

forward or where to begin."

Following Adilynn's surgery, Laurie received a call from Raising Special Kids. "They helped me cope with her new feeding tube and the best help of all was that I got pointed in the right direction on how to get Long Term Care set up! I finally felt like I could breathe again!"

Through Raising Special Kids' Parent-to-Parent Connection program, Laurie

was connected with another mom who also has a child with complex medical needs. "I could talk to someone who understands and someone who is a few steps ahead of where we were at the time. I now know just how important Raising Special Kids is to those who have kids with special needs."



Parent Leaders are the Heart of Raising Special Kids Thank You!

Cave Creek

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Chandler

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Dawn Bailey
Karin Smith
Lisa Myers
Marti Baio
Rigo Lopez
Samantha Flores

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May - November 2013

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Quality Child Care

By Neil Wintle

The search for a quality child care provider is an anxiety-inducing task for any parent. When my wife and I began our search, we had all the usual worries plus additional concerns regarding our son's special developmental and physical needs.



We started the process by writing down our list of features and qualities that were essential to us from a child care provider. Next, we asked our friends with

kids about their experiences and recommendations. Finally, we turned to the internet to find locations, read amenities lists and reviews written by other parents.

We scheduled visits with providers in our

immediate vicinity, asked a lot of questions, and explained our son's needs. After a few visits we expanded the area of our search. We decided that a little extra driving was okay if it meant finding the right provider.

Over 40% of parents of children with disabilities report difficulty in finding child care

Finding the right provider takes time, research and access to good information. Experiences like ours are not uncommon. Arizona data suggests that **1 in 5 parents of young children are trying to find day care services and over 40% of parents of children with disabilities report difficulty in finding child care.**

There are many excellent resources in Arizona for finding child care. Parents can find this information by visiting www.raisingpecialkids.org/resources or by calling 602-242-4366.

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Questions? Contact Raising Special Kids (En Español) 602-242-4366 or 800-237-3007