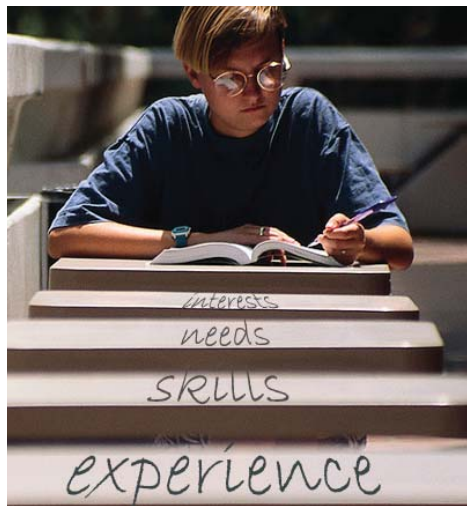


Preparing for the future

A checklist for parents

With their attention focused on providing for their child's immediate needs, many families have been startled to discover something has been missed in preparing for their child's transition to adulthood. A number of guidebooks and other tools are available to help teens and young adults through stages of transition, but parents also need guidance to be effective in their many roles including caretaker, financial provider, and educator.

Quite a few families of children with disabilities have found a surprise or two in the various systems and processes their child encounters as he or she proceeds through transition. Some families have reported finding out too late about services or deadlines for application, or being taken unaware that they no longer are legally entitled



to obtain information or to make decisions regarding their child's medical care. Others may never become aware of benefits or resources for which their child could be eligible.

"Teaching advocacy skills is huge," said Leanne Murillo, Youth Transition Coordinator at Arizona Bridge to Independent Living. "When young people turn 18 and go to the doctor or proceed into college or enter the job market, the decisions become theirs, not their parents. It is critical to help parents understand how essential it is to train their child to advocate for themselves and then to let go and let that child do it on their own."

Families need open, honest discussion about options. The best

defense against the unexpected is discarding assumptions and becoming educated. Seek out information from multiple sources and ask for clarification of anything that is not clear to you. Educate your child by including them as much as possible in decisions and processes that affect their future.

This issue highlights important milestones, services, benefits, procedures and more that families have experienced as areas of concern.

— continued on page 3

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**DON'T MISS ANY FUTURE ISSUES OF
CONNECTING
Sign up for our e-list today!**

"So often when I talk to parents about transition issues, their eyes just gloss over and they say 'I would have never thought of that!'"

Debbie Weidinger, Co-founder and President of AZ ASSIST, a support group for parents and their teens or young adult children with autism spectrum diagnoses.

azassist.com

From the Director...

As I sat down to write this, I had just completed a journey of 1500 miles driving a moving van and hauling a piano. One hour into the journey, feeling good about being on our way, we were forced to pull off the road and wait for assistance to change a damaged tire.

There were "blind spots" — times when we just couldn't see very well and had to be exceptionally cautious. The truck was buffeted by strong winds, and at one location the roadway was closed because of wind and dust conditions, adding another day to our trip.

Driving was tiring, seats were uncomfortable, and we changed drivers often to keep from wearing out. Keeping the fuel tank full was expensive.

At the end of the trip, we were tremendously relieved and ready to celebrate. The piano, our precious cargo arrived safe and in good condition. It was ready to be an instrument for its intended purpose, enriching our family life with its music.

This metaphor of setting out on a long trip, facing the unexpected, experiencing disruptions and delays, needing support, and not always being sure you're seeing everything clearly, might be one way to describe the journey taken by parents of children with disabilities. We navigate through some difficult times and carry our hopes and dreams for reaching the right destination.

Have a safe and enjoyable summer, and take heart in knowing there are many of us out there on the same road.



**Raising
Special Kids**®
families helping families

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 both Spanish and English. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)3 non-profit organization.

Planning for the future

Financial Planning

- ❑ Families should be aware of how their child's ownership of assets could affect eligibility for benefits from social security, Medicaid (AHCCCS in Arizona), and other services. Identify how financial support your child may receive impacts other benefits.
- ❑ Consult with a legal professional who specializes in estate planning for families of children with special needs. Ask about special needs trusts, education savings plans, wills, and life insurance.
- ❑ Learn about Social Security – Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), community services for adults with disabilities, Social Security Administration work incentives: PASS, Ticket to Work, 1619a and b.



- ❑ What services will your child need to re-apply for at age 18?

18 - The Age of Majority

- ❑ When a child turns 18, under law, their rights and responsibilities change regardless of the presence of a disability. Consider options well in advance if there is a need for someone to act in a decision making capacity for your child after they turn 18.
- ❑ *Before your child turns 18, learn about guardianship (various types), conservatorship, power of attorney, and other options. This information is addressed in Raising Special Kids' Guardianship and Other Legal Options Workshop.*
- ❑ At age 18, students receive a Transfer of Rights notice from school—at this point parents no longer have the right to the child's records unless their child signs a release.
- ❑ An Individual Education Program (IEP) ends when a student exits high school, it does not extend into post secondary education (such as college or trade school.)
- ❑ All males must register for Selective Service (regardless of disability or special health needs.)

- ❑ Transfer to adult health care – Most children will be required to transfer out of a pediatrician's care. Many more children with severe disabilities or chronic health problems are now surviving into adulthood, and a lack of qualified adult health providers may, in some cases, necessitate retaining care from a pediatrician. Not all pediatricians or pediatric specialists will allow a child over 18 to continue to be treated in their practice. Pediatric physicians should have a transition plan in place for their patients who have disabilities or special health care needs.

A Job and/or Secondary Education

- ❑ Identify the child's strengths, interests, and needs.
- ❑ Is post secondary education a goal? Consider the options (university, community college, vocational training, personal development classes, or other options.) Contact the preferred school at least two years ahead for information on admission requirements and the availability of disability services.
- ❑ Is a job after graduation a goal? Vocational assessment should be done in high school. Contact Vocational Rehabilitation Service (they may become involved in the IEP process); learn about One-Stop Career Centers and other employment assistance for people with disabilities.
- ❑ Incorporate college preparation or vocational training into IEP transition planning.
- ❑ Assemble documentation of disability with most recent evaluation results.
- ❑ Explore financial aid resources.
- ❑ Be aware that at the college level parents need written consent from the student to obtain access to the student's records.
- ❑ Know the difference between the laws that govern education at the secondary level (IDEA) and at the college level (ADA).
- ❑ 504 plans may follow an individual into college or the workplace.
- ❑ Help your student find opportunities to gain experience through work or volunteer activities.

Planning for the future

Housing

- Learn about possibilities for independent living.
- Consider various housing options e.g.: living by oneself, finding a roommate, entering a group home, or staying with family.
- Research types of group homes in the area the child wants to live in, or consider beginning a co-op with other families.
- Examine funding options.
- Learn about housing rights (Fair Housing Act).

Daily Living Skills

Identify areas of need and means for acquiring needed skills in:

- Transportation
- Managing finances
- Maintaining a household (cooking, shopping, laundry, keeping house)



- Social, communication, and self advocacy skills
- Self knowledge regarding disability, health and medications, sexuality, available support network
- Obtaining health care, dealing with insurance. Creating a medical journal can be useful; include lists of providers, medications, instructions for Durable Medical Equipment upkeep and repair and general health history.
- Recreation and leisure options
- Planning for emergencies

Resources:

- http://www.dol.gov/odep/documents/creating_path_to_Employment.pdf
- http://www.dol.gov/odep/documents/essential_job_skills.pdf
- <http://www.medicalhomeportal.org/living-with-child>
- <http://www.nsttac.org/> • www.hrtw.org • www.ncset.org

Other

- Obtain a drivers license or state ID
- Register to vote

Developmental checklist for health behaviors

Adapted from checklist developed by Kentucky Commission Children Special Health Care Needs

- Is building understanding of condition/special needs and treatments
- Can describe condition to others
- Can determine when condition is worsening
- Is active/exercises to maintain physical fitness
- Knows basics of nutrition
- Has someone to talk to about concerns
- Working with parents/caregivers in doing self-care related to meds and treatments
- Has plan for emergencies
- Carries list of medications, list of health care providers
- Carries copy of insurance/medical card & summary medical information
- Answers questions from medical providers about condition
- Knows how condition and treatment affects physical, mental, sexual development
- Knows how smoking, drinking, chewing, drugs affect body and condition
- Understands sexuality, pregnancy, and birth control
- Sees doctor for some time privately
- Manages own medication and treatment regime; notifies caregiver of need for med refills
- Knows what equipment does and how to fix minor problems
- Knows side effects of medication and interactions with food, alcohol, etc.
- Family explores guardianship if needed (age 18 is age of majority when youth legally makes own decisions); assent to consent; health surrogate
- Has plans for adult health care providers (primary, specialty, dental, DME, pharmacy, therapy, mental health)
- Has plans for adult health insurance
- Knows how to use health insurance/medical card
- Has adult health care providers
- Has signed release to transfer records
- Has copy of own records



Special Education Forum FREE for Parents

Presented by Attorneys Who Practice Special Education Law

Saturday, August 7th, 2010

8:00 a.m. to 12:00 noon

Disability Empowerment Center

The Nina Mason Pulliam Conference Center
5025 E. Washington St., Phoenix, AZ 85034

Topics covered will be:

- Child Find
- Evaluations
- Eligibility
- IEPs (Individual Education Plans)
- Procedural Safeguards
- FBA (Functional Behavior Assessment)
- BIP (Behavior Intervention Plan)
- Short-term suspensions and other consequences
- Long-term suspension and expulsions
- Procedural Safeguards
- Panel of experienced parents who've "been there" will share their experiences

Refreshments will be provided. No child care available.
Space is limited, please register by contacting Raising Special Kids at 602-242-4366.

Therapies Conference

Raising Special Kids' conference on therapies in May, the first of a series of parent trainings funded by a grant from Virginia G. Piper Charitable Trust, was a tremendous hit with parents.

80 attendees learned hands on techniques that can be implemented at home to help their children.

"Thank you!! For a wonderful conference today!! I learned so much and got a lot of resources that I did not have before!"



Live translation was available for Spanish speaking families.



Attendees had opportunities for one-on-one questions with therapists and presenters.



Raising Special Kids gratefully acknowledges our generous donors of goods and services:

Phoenix Children's Hospital
A Bridge Between Nations
ABIL
Joni and Friends
Kellogg's
OZMO, LLC

Southwest Human Development
The Doll Market
United Way – Valley of the Sun Chapter
Williams & Associates
Wist

Raising Special Kids Calendar

Call 602-242-4366 or 800-237-3007 to register

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

Positive Behavior Support

Training on effective techniques for behavior management.

Sat. 6/26/10, 12:30 – 2:00 p.m.

Wed. 7/14/10, 6:00 – 7:30 p.m.

Wed. 8/18/10, 6:00 – 7:30 p.m.

(Catholic Charities)

Sat. 8/21/10, 10:00 – 11:30 a.m.

(Highlands Church, Scottsdale)

Wed. 9/15/10, 6:00 – 7:30 p.m.

Resilient Relationships

Create and maintain a healthy couples relationship through the journey of raising a child with special needs.

Fri. 9/17/10, 1:30 – 3:00 p.m.

Can you hear me now?

Techniques for effective advocacy. What to ask, how to ask it.

Wed. 6/16/10, 6:00 – 7:30 p.m.

(Highlands Church, Scottsdale)

Sat. 7/17/10, 8:30 – 10:00 a.m.

Wed. 8/4/10, 6:00 – 7:30 p.m.

Sat. 9/25/10, 10:00 – 11:30 a.m.

Guardianship Workshop

Learn about what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

Sat. 6/26/10, 2:30 – 4:00 p.m.

Tue. 7/20/10, 6:30 – 8:30 p.m.

Sat. 8/21/10, 2:00 – 4:00 p.m.

Thu. 9/16/10, 10:00 – 12:00 p.m.

IEP Basics

Learn about the purpose of IEP's through an overview of the document and meeting.

Sat. 6/26/10, 8:30 – 10:00 a.m.

Thu. 7/8/10, 6:00 – 8:00 p.m.

(Lodestar, Phoenix)

Thu. 7/15/10, 10:00 – 12:00 p.m.

Thu. 9/30/10, 10:00 – 12:00 p.m.

Advanced IEP Training

Learn about the requirements for IEP's and how to actively participate in team meetings.

(Recommended: first attend *Understanding the IEP.*)

Thu. 9/9/10, 10:00 – 12:00 p.m.

Understanding 504

Learn about the intent and requirements of Section 504, responsibilities of schools, and samples of 504 accommodations.

Tue. 7/27/10, 1:30 – 3:00 p.m.

AzIEP to Preschool Transition

Learn about the requirements for transition and tips for a smoother process.

Sat. 7/17/10, 10:00 – 11:30 a.m.

Wed. 8/11/10, 10:00 – 12:00 p.m.

Sat. 9/25/10, 12:00 – 2:00 p.m.

High School Transition

Learn how to prepare youth for transition from high school to higher education, employment, and life in the community.

Wed. 8/4/10, 4:00 – 6:00 p.m.

Bully-Free Environments

Learn how to recognize bullying, effectively Respond, and build positive solutions.

Mon. 6/14/10, 6:00 – 8:00 p.m.

(Lodestar, Phoenix)

Sat. 6/26/10, 10:30 – 12:00 p.m.

Wed. 8/18/10, 7:30 – 9:00 p.m.

(Catholic Charities, Phoenix)

Wed. 9/15/10, 4:00 – 6:00 p.m.

Parent/Professional Collaboration

Learn ways for parents and professionals to develop working relationships.

Wed. 8/25/10, 10:00 – 12:00 p.m.

www.raisingpecialkids.org

Notice our

ALTERNATE LOCATIONS

(workshops listed in red at left)

Highlands Church

9050 E. Pinnacle Peak Rd.
Scottsdale, AZ 85255

Catholic Charities/Arizona Partnership for Children

4747 N. 7th Ave.
Phoenix, AZ 85013

Lodestar Family

Connections Center

2320 N. 20th St.
Phoenix, AZ 85006

Evaluations & Assessments

Learn about the types of tests and what they measure, scoring results and what the bell curve means in formal assessments.

Wed. 9/29/10, 10:00 – 12:00 p.m.

Volunteer Training

Your skills count! Become a parent volunteer for Raising Special Kids and share what you've learned as a parent of a child with special needs.

Thu. 6/10/10, 10:00 – 12:00 p.m.

Mon. 7/26/10, 6:00 – 8:00 p.m.

Sat. 9/4/10, 10:00 – 12:00 p.m.

IEP 1-to-1 Consultation

Bring your child's current IEP as well as your questions and concerns. We will privately address your individual issues and offer solutions and strategies to help you advocate more effectively for your child.

Call for an appointment:

602-242-4366 or 800-237-3007.

Attendance at all workshops is at NO COST.

NORTHERN ARIZONA WORKSHOPS

Call 928-523-4870 to register

Unless noted*

Time: 4:30 – 6:00 p.m.

Location:

Flagstaff Family Resource Ctr
1806 E US-66, Flagstaff, AZ
86004, (928-774-1103)

Organizing Your Child's Records

Tue. 6/8/10

Special Education Overview

Tue. 8/17/10

Understanding the IEP Process

Tue. 9/14/10

* Special Education Overview & Understanding the IEP Process

Tue, 7/13/10 3:00 p.m. - 5:00 p.m.
Kykotsmovi Community Center
Hwy 264 mile post 373
Kykotsmovi, AZ 86039-0123

NEW

* Getting and Keeping the First Job

The importance of disability self-awareness, how families can help youth with career planning, and strategies to navigate resumes, job interviews, and job accommodations

AND

* The Journey to Adulthood: What Parents Need To Know (Sexuality)

Promote the independence, personal safety, healthy lifestyles, healthy relationships, and social inclusion of youth with disabilities

Sat., 6/19/10, 10:00 a.m. - 3:00 p.m.
Location TBA (in Flagstaff)

Foster Care additional education hour/certificates will be provided.

2 Workshops
1 Day!

CALENDARIO ESPAÑOL

Por favor llamar al 602-242-4366 o 800-237-3007 para confirmar su asistencia a los talleres

Disability Empowerment Center
5025 E. Washington St., #204, Phoenix, AZ 85034

Somos un oficina libre de fragancias.

El Comportamiento Positivo

El vínculo entre las familias y las intervenciones y el apoyo conductual positivo es muy importante

Miércoles, 9/8/10, 6:00 – 7:30 p.m.

(Catholic Charities)

Viernes, 9/10/10, 1:30 – 3:00 p.m.

Organizando su niño/a's archivos

Aprenda modos efectivos para organizar sus archivos

Viernes, 5/21/10, 1:30 – 3:00 p.m.

Entrenamiento Para Voluntarios

Acompañenos a un entrenamiento para voluntarios y así desarrollar su liderazgo ayudando a otras familias a aceptar y sobrellevar el diagnóstico de un hijo (a) con necesidades especiales de salud.

Viernes, 6/18/10, 10:00 – 12:00 p.m.

Viernes, 7/23/10, 1:30 – 3:00 p.m.

Viernes, 9/3/10, 10:00 – 11:30 a.m.

Derechos de padres en educación especial

Aprenda alrededor de los derechos y las responsabilidades de padres en la educación especial.

Viernes, 8/20/10, 1:30 – 3:00 p.m.

Transición de AzEIP (Intervención Temprana) al Preescolar

Aprenda sobre los requerimientos para la transición e ideas para lograr un proceso más fácil.

Miércoles, 7/28/10, 10:00 – 12:00 p.m.

Es su Hijo Blanco de Burlas?

Estrategias de Intervención para Padres de Niños con Discapacidades.

*Una forma de abuso en la escuela a través de la intimidación, tiranía y aislamiento.

Viernes, 8/6/10, 1:30 – 3:00 p.m.

Miércoles, 9/8/10, 7:30 – 9:00 p.m.

(Catholic Charities)

Viernes, 9/24/10 10:00 – 11:30 a.m.

Familias Resistentes

La Estructura más Básica para una Relación de Familia Saludable La habilidad de volver de un trauma o una situación difícil.

Viernes, 8/13/10, 1:30 – 3:00 p.m.

Para descripciones de talleres y más información, llame nuestra oficina en listas de 602-242-4366 o 800-237-3007 o cheque en el Calendario español en nuestro sitio web: www.raisingsspecialkids.org/ Por favor llamar al 242-4366 o al 800-237-3007 para confirmar su asistencia a los talleres.



www.raisingsspecialkids.org

Arizona's Tenth Annual Transition Conference

Designing the Future Be Anyone You Want to Be

Addressing the Needs of Youth and Young Adults with Disabilities

September 20-22, 2010

Talking Stick Resort, 9800 E. Indian Bend Rd., Scottsdale, AZ 85250

- Sessions for youth and young adults with disabilities and their families on topics including transition planning, assistive technology, guardianship, advocacy, social skills training, vocational guidance and more
- Early registration discounts May 11 - July 2
- Scholarships available

Online registration at <http://www.ade.az.gov/> under Hot Topics
For more information call Jeannette Zemeida at 602-542-3855.

Artist graduates



Congratulations to Clark Demland, a long time Family Faculty volunteer in Raising Special Kids' Community Medicine Program.

Clark graduated from Camelback High School.

With a scholarship awarded by the school Alumni Association, he is looking forward to studying digital photography and graphic arts at Phoenix College.

An accomplished artist, Clark's digital photo collage was selected for the cover of the program for Arizona's 2010 Transition Fair. Clark has Duchenne's muscular dystrophy and is currently seeking an eye gaze control system to help him interact with his computer.

Insurance coverage for young adults

New rule released

The Department of Health and Human Services released a rule on the health care reform provision allowing children up to age 26 to get insurance through their parents' family coverage. Both married and unmarried children qualify for this coverage.

A highlight from the Fact Sheet follows:

Access to Insurance:

What Young Adults and Parents Need to Do:

- **Check for Immediate Options:** Private health insurance companies that cover the majority of Americans have volunteered to provide coverage earlier than the implementation deadline for young adults losing coverage as a result of graduating from college or aging out of dependent coverage on a family policy. This stop-gap coverage, in many cases, is available now. Ask your employer and insurer about this option.
- **Watch for Open Enrollment:** If early coverage is not an option with your employer or insurance company, then young adults will qualify for an open enrollment period to join their parents' family

plan or policy beginning on or after September 23, 2010. Insurers and employers are required to provide notice for this special open enrollment period. Watch for it or ask about it.

- **Expect an Offer of Continued Enrollment:** Insurers and employers that sponsor health plans will inform young adults of continued eligibility for coverage until the age of 26. To get the coverage, young adults and their parents need not do anything but sign up and pay for this option.

Information on the rule/provision — including a fact sheet, Q&A, and the rule itself can be found at http://www.hhs.gov/ociio/regulations/index.html#dependent_coverage. The Fact Sheet and Q&A both include a list of the insurance companies that have volunteered to make this coverage available before the required 9/23/10 implementation date.

The public can comment on the rule until August 9 via [regulations.gov](http://www.regulations.gov).

Paying for hearing aides for your child

Excerpt from a new publication by the The Arizona Early Hearing Detection and Intervention program (AzEHDI)

Hearing aids are a significant expense. Many families find that they need assistance, and there are several programs available.

Check with your audiologist about loaner hearing aids. Loaner hearing aids are available to any family, living in Arizona, through the EAR Foundation of Arizona's HEAR for Kids program. Generally loaners are available for up to six months. Longer loan periods are possible for extenuating circumstances such as assessment for cochlear implantation. The program is funded through grants and donations.

You should begin the process of finding out how you will pay for permanent hearing aids as soon as possible. It may take several months to determine eligibility for some programs. The answers to some of the questions below may help you find the assistance that is right for your family.

Download full document: http://aznewborn.com/pdf/parents/Options_for_Funding_Hearing_4%202010.pdf
Hear for Kids: please contact Lylis Olsen, program manager: (602) 690-3975
ADHS Office of Newborn Screening (602) 364-1409.

Health issues and IEPs

Excerpt from a Parent Brief, May 2006 (by PACER & NCSET)

Family involvement generally contributes to better school and medical outcomes. Because it is not yet common practice, families may find they have to bring health-care concerns to the attention of the IEP team in order for their son or daughter's health needs to be addressed. It can also be very difficult for parents to give full responsibility for health issues to a young adult because of the obvious dangers of mismanagement.

Starting at an early age, planning ahead and identifying safety



nets and emergency plans are important.

Physicians can help youth and families solve problems in these areas. It is beneficial to clearly identify concerns and discuss best- and worst-case scenarios. Support and emergency plans can be developed, and youth can become aware

of the impact of certain behaviors on their health in order to make informed choices. This approach has been successful in alleviating some fears and providing teens with a better understanding of how to maintain their health. These and other healthcare issues can be addressed in the statement of transition services in a student's IEP.

The full text of this document is available at:
http://www.ncset.org/publications/parent/NCSETParent_May06.pdf
or call *Raising Special Kids* at 602-242-4366 or 800-237-3007

QUOTED

“Great job in presenting the Guardianship seminar. Nicely done with a variety of viewpoints — a good presenter who clearly understands the issues of special needs families. This is a “must” workshop for parents who have children coming to the end of the teen years.”

Preparándose para el Futuro

Una Lista de Comprobación para Padres

Con su atención enfocada en proveer para satisfacer las necesidades inmediatas de sus hijos, muchas familias se han asustado al descubrir que algo ha faltado en la preparación para la transición de sus hijos a la edad adulta. Varias guías y otras herramientas están disponibles para ayudar a los adolescentes y jóvenes adultos a pasar a través de las etapas de transición, pero los padres también necesitan una guía para ser eficaces en sus muchos papeles, como cuidador, proveedor financiero y educador.

Muchas familias de niños con discapacidades han encontrado una o varias sorpresas dentro de los variados sistemas y procesos con los que sus hijos se topan, mientras avanzan a través de la transición. Algunas familias han reportado que descubrieron demasiado tarde servicios o fechas límite para hacer ciertas solicitudes, o que no sabían que ya no tenían el derecho legal de obtener información o tomar decisiones con respecto al cuidado médico de sus hijos. Otros tal vez nunca se enterarán de los beneficios o recursos para los cuales sus hijos podrían ser elegibles.

“Enseñar habilidades de abogacía es algo muy importante”, dijo Leanne Murillo, Coordinadora de Transición de Jóvenes de la Organización Bridge to Independent Living. “Cuando los jóvenes cumplen 18 años de edad y van al doctor o pasan a la universidad, o entran al mercado laboral, las decisiones se vuelven tuyas, y ya no de sus padres. Es muy importante ayudar a los padres a entender lo fundamental que es el capacitar a sus hijos para defenderse por sí mismos, y después dejarlos ir, y permitir que se valgan por sí mismos.”

Las familias necesitan hablar abierta y honestamente sobre las opciones. La mejor defensa contra lo inesperado es deshacerse de suposiciones y prepararse. Busque información de múltiples fuentes, y pida que le aclaren cualquier duda que tenga. Eduque a su hijo/a incluyéndole lo más posible en las decisiones y los procesos que afectan su futuro. Los siguientes son algunos aspectos destacados de sucesos importantes, servicios, beneficios, procedimientos y más, que las familias han experimentado como áreas de inquietud.

Planeación Financiera

- Las familias deberían estar conscientes con respecto a cómo la propiedad de bienes de su hijo/a podría afectar su elegibilidad a beneficios del Seguro Social, Medicaid (AHCCCS en Arizona), y otros servicios. Identifique cómo el apoyo económico que su hijo/a pueda recibir afecta otros beneficios.
- Consulte a un profesional en leyes especializado en la planeación de bienes raíces para familias con necesidades especiales. Pregunte acerca de fideicomisos para necesidades especiales, planes de ahorros para la educación, testamentos y seguros de vida.
- Aprenda sobre el Seguro Social – Ingreso Suplementario de Seguridad (SSI por sus siglas en inglés), Seguro por Discapacidad del Seguro Social (SSDI), servicios comunitarios para adultos con discapacidades, incentivos de trabajo de la Administración del Seguro Social: PASS, Boleto para Trabajo “Ticket to Work”, 1619a y b.
- ¿Qué servicios necesitará volver a solicitar su hijo/a a la edad de 18 años?

18 – La Mayoría de Edad

- Cuando un/a niño/a cumple 18 años, bajo la ley, sus derechos y responsabilidades cambian a pesar de la presencia de una discapacidad. Considere opciones con mucha anticipación si existe la necesidad de que alguien actúe en un papel de toma de decisiones para su hijo/a después de que cumpla los 18 años de edad.
- Antes de que su hijo/a cumpla los 18 años de edad, aprenda acerca de la tutoría (varios tipos), la tutela (conservatorship), el poder notarial, y otras opciones. Esta información es tratada en el Taller de Tutoría y Otras Opciones Legales de la organización Raising Special Kids.
- A la edad de 18 años, los estudiantes reciben un aviso de Transferencia de Derechos de la escuela—en este punto los padres ya no tienen derecho a los registros de sus hijos, a menos que sus hijos firmen una liberación.

Español

Preparándose para el Futuro

Una Lista de Comprobación para Padres

- Un Programa de Educación Individual (IEP por sus siglas en inglés) termina cuando un estudiante sale de la secundaria, y no se extiende en la educación post secundaria (como colegio, universidad o escuela vocacional).
- Todos los varones deben registrarse para el Servicio Selectivo (a pesar de cualquier discapacidad o necesidades especiales de la salud).
- Transferencia a cuidado de la salud para adultos— A la mayoría de los niños se les pedirá que se transfieran del cuidado de un pediatra. Muchos más niños con discapacidades severas o problemas crónicos de la salud están sobreviviendo ahora en la edad adulta, y la falta de proveedores del cuidado de la salud calificados para adultos puede, en algunos casos, necesitar el retener cuidado pediátrico. No todos los pediatras o especialistas pediátricos permitirán que los niños de más de 18 años de edad continúen siendo tratados en su práctica. Los doctores pediatras deben tener un plan de transición disponible para sus pacientes con discapacidades o necesidades de cuidado especial para la salud.
- Reúna documentación sobre la discapacidad con los resultados de la evaluación más reciente.
- Explore recursos de ayuda financiera.
- Esté consciente de que a nivel universitario, los padres necesitan el consentimiento por escrito del estudiante para obtener acceso a sus registros.
- Conozca la diferencia entre las leyes que gobiernan la educación a nivel de secundaria (IDEA por sus siglas en inglés) y a nivel universitario (ADA por sus siglas en inglés).
- Los planes 504 pueden continuar con un individuo a la universidad o al lugar de trabajo.
- Ayude a su estudiante a encontrar oportunidades para obtener experiencia a través del trabajo o actividades como voluntario.

Trabajo y/o Educación Secundaria

- Identifique las fortalezas, los intereses y las necesidades del/la niño/a.
- ¿Es la educación post secundaria una meta? Considere las opciones (universidad, colegio comunitario, capacitación vocacional, clases de desarrollo personal, u otras opciones). Llame a la escuela preferida por lo menos con dos años de anticipación, para información sobre requisitos de admisión y disponibilidad de servicios para la discapacidad.
- ¿Es un trabajo después de la graduación una meta? Deberá hacerse la evaluación vocacional en la secundaria. Llame al Servicio de Rehabilitación Vocacional (ellos podrían participar en el proceso IEP); infórmese sobre los centros de carreras One-Stop Career Centers y otras ayudas para encontrarles empleo a personas con discapacidades.
- Incorpore la preparación universitaria o capacitación vocacional en la planeación para la transición IEP.
- Infórmese sobre las posibilidades de una vida independiente.
- Considere varias opciones de vivienda, por ejemplo: vivir solo/a, encontrar un/a compañero/a de vivienda, entrar a un hogar en grupo, o permanecer con la familia.
- Investigue los tipos de hogares en grupo en el área en la cual su hijo/a desea vivir, o considere empezar una cooperación con familias.
- Examine opciones de financiamiento.
- Aprenda sobre los derechos de vivienda (Decreto de Viviendas Equitativas).

Vivienda

Habilidades para la Vida Cotidiana

Identifique las áreas de necesidad y los medios para adquirir habilidades necesarias en:

- Transporte.
- Administración de finanzas.
- Mantenimiento del hogar (cocinar, hacer las compras, lavandería, trabajo doméstico).

Español

- Habilidades sociales, de comunicación y auto defensa.
- Autoconocimiento acerca de la discapacidad, la salud y los medicamentos, sexualidad, red de apoyo disponible.
- Obtener cuidado de la salud, tratando con los seguros. Crear un diario médico puede ser útil; incluya listas de proveedores, medicamentos, instrucciones para el mantenimiento y reparación del Equipo Médico Duradero, e historial general de salud.
- Opciones de recreación y ocio.
- Planeación para emergencias.

Otros

- Obteniendo una licencia de conductor o identificación del estado.
- Registrándose para votar.

20 Years!

Come celebrate the Anniversary of the ADA

The Americans with Disabilities Act

Saturday, July 24th, 2010

6:00 - 10:00 pm

Tempe Mission Palms Resort

60 East Fifth Street, Tempe, AZ 85281

Sponsored by



Positive Action for a Better Tomorrow

602-503-6593

602-364-0990 (TTY)

<http://www.azdac.org>

7:00 pm Cocktail Hour

7:00 pm Dinner and ADA Awards

8:30 pm Entertainment, Music and Dancing

Tickets - \$35 each

Table of 8 - \$280

Sponsorship and Scholarship opportunities available

Purchase Tickets by July 12 at www.azdac.org/gala

Wear your finest and join us for this fun, festive celebration!

Please do not smoke or wear scented products when attending this event.

Disability fitness center breaks ground

Ground was broken in April for a new 45,000-square-foot sports, fitness and aquatics center for persons with disabilities.

The first of its kind in the Western United States, the Virginia G. Piper Sports & Fitness Center is located at the Disability Empowerment Campus at 5025 E. Washington St. in Phoenix. The center will feature accessible sports courts, a runners' track, a pool, fitness equipment, locker rooms, showers and dressing areas for people with physical and sensory disabilities.

More info at: <http://disabilitysportscenter.com>



Donors and staff of the Arizona Bridge to Independent Living (ABIL) gather to break ground on the new center.

Bookshare

Accessible books for students

The world's largest online library for accessible materials, Bookshare® (www.bookshare.org) is a federally funded program that provides digital text and software applications to people with print disabilities. School-age students who meet certain criteria qualify for free membership. The intent of Bookshare is to:

- Help schools to comply with IDEA '04 requirements regarding accessibility and timelines of instructional materials
- Equalize educational experiences for students with print disabilities and encourage independent reading and studying
- Provide access to the general education curriculum for students with print disabilities
- Reduce the burden and cost of scanning books

Bookshare is funded by the U.S. Department of Education, Office of Special Education Programs (OSEP) to expand the availability of accessible electronic books and to provide related software.

Ryan House

Respite for families

“A new and valuable pediatric resource for families opened its doors in Phoenix just before March drew to a close. The first facility of its kind in the Southwest, Ryan House offers respite and hospice care for children with life-limiting conditions.

The house serves children and families, regardless of ability to pay, and is a cheery place for children to come for short-term stays to relieve their parents of the often overwhelming responsibilities of day-to-day care.

Respite—short breaks from the continuous strain of round-the-clock care—is essential for families to remain intact, and for their children to enjoy a higher quality of life.

Inspired by a facility in England that helped a couple who now live in Arizona, Ryan House was conceived by Jonathan and Holly Cottor and named for their son. Ryan, now 9 years old, was diagnosed at 9 months with spinal muscular atrophy.

A team of caregivers, including the medical director, registered nurses, certified nursing assistants, child life specialists, social workers and others, emulate the care provided at home, offering reassurance as well as a deserved rest to parents. They also provide continuing support for families and end-of-life care, as needed.

The cheerful, home-like environment of the facility includes eight bedrooms for children each with an extra bed for a parent or

sibling, and three family suites. Amenities include comfortable common areas, an outside accessible playground, a hydrotherapy room, and a soundproof music room. Ryan House also offers family-focused activities including arts and crafts, pet and music therapy, advocacy, consultation as well as emotional and spiritual support.

Ryan House provides Sibshop® workshops, allowing siblings to meet, talk and gain support with other kids whose brothers and sisters have similar needs.



A cheerful cafe.



Fully accessible playground.



One of uniquely themed children's bedrooms.

For more information visit ryanhouse.org or call 602-200-0767.

Pilot Parents of Southern Arizona Partners in Policymaking

**A FREE Leadership Training
for self-advocates & parents of children with disabilities**

Partners in Policymaking is an innovative leadership training program for parents of children with disabilities and for adults with disabilities. The program is designed to provide information, training, resources and skill building to people with a disability and the parents of children with disabilities so that they can become better advocates for themselves or their children. Partners in Policymaking provides participants with opportunities to meet and talk to national and state leaders in the disability advocacy field.

Participants will have an opportunity to meet and unite with others who have similar concerns to create a powerful voice on important issues. Participants learn how the legislative process works at the local, state and national levels. The goal of the training is to develop productive partnerships between people who need and use services and those in a position to make policy and law. Monthly weekend sessions begin in October.

APPLICATION DEADLINE IS August 31 2010. To receive an application contact: Pilot Parents of Southern Arizona 1-520-324-3150, Toll Free 1-877-365-7220, or log on to <http://www.pilotparents.org/>

Raising Special Kids News

Profile of Excellence

Jeannie Bremerkamp, Volunteer

After her daughter was diagnosed at the age of 10, Jeannie Bremerkamp found a place to turn to for help in raising a child with an emotional disability: Raising Special Kids.

Ten years and tons of experience later, Jeannie is turning skills she has learned into an important source of support for other families. “Jeannie has really gone above and beyond,” said Janna Murrell, Director of Family Support. “Her willingness to reach out and do whatever is needed has made a huge difference for families she has mentored.”

Jeannie was originally drawn to volunteering after reading about other families in the newsletter. The classes and workshops she attended helped her gain the confidence to be able to help parents find resources and make decisions that are good for their families.

“I wanted to volunteer for an agency that specifically helped families with children with special needs. Because I am an eager learner I jumped in and took almost all the workshops Raising Special Kids offered. After that I felt ready to participate in Parent

to Parent support, Parent Panels and outreach events. Raising a child with special needs has given me the understanding and knowledge that only a parent that has been through it would have,” said Jeannie.

“This is *sooo* needed in the emotional disability area; because families with children with unseen disabilities many times feel lost or helpless, and they don’t know what to do. If I can assist another parent that has a child with special needs to access benefits and become an advocate for the child, it makes me feel good that I am able to help another family through difficult times.”

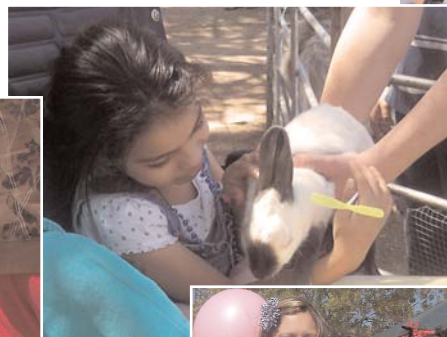
One of the moms Jeannie mentored found the parent to parent support to be invaluable. “Jeannie has been a life saver,” she said. “I don’t know how I would have survived these last few weeks without Jeannie and her daughter. I was struggling through what, for me and my child, were uncharted waters. They gave me insight and filled that emotional support gap in ways that I had not thought of previously. She is a wealth of knowledge!”

Special Day for Special Kids

Scenes from an amazing day of free fun for families, March 27, 2010.

“My 2 1/2-year-old baby boy (who has Down Syndrome) had a blast at the Special Day for Special Kids event at the McCormick-Stillman Railroad Park..That was our first trip ever, and we loved it. “

**Special thanks to
Scottsdale Sunrise
Rotary Club**



In The Spotlight

Making a Difference in the Lives of Children Thank You for referring families to Raising Special Kids

February 2010 - April, 2010

Organizations

A Place to Call Home
ABIL
Lisa Purdy
Aid to Adoption of Special Kids
Airman and Family Readiness Flight
Stephanie Games
Ameripsych
Arizona Child Study Center
Daniel B. Kessler, MD
Arizona Children's Association
Anita Carter
Arizona Partnership for Children, LLP
Ofelia Malsach, MSW
Arizona Reading Clinic
Dr. Rupperecht
Arizona State University West
Juliet Hart
Association For Supportive Childcare
AT Stills Dental School
Augustus H Shaw School
Alexandra Harris
Aurora Behavioral Health
Lillian Jones
Az Dept Of Education
Miriam Podrazik
Az Dept Of Education - PINS
Amy Dill
Allison Meritt
Banner Behavioral Health
Banner Cardon Childrens Hospital
Marcia Bluth, MSW, LCSW
Heidi Solak
Tracie Baker, MSW
Banner Copper Basin Medical Clinic
Dr. Jacqueline Gray
CARE Partnership
Patty Zowada
Cartwright School District
Casa de los Ninos
Casa Grande Head Start
CASA Leader
Cenpatico
Diane Taylor
Child & Family Resources
Jenine Cook
Nubia Garcia-Shinagawa
Maria Pimentel
Children's Rehabilitative Services
Dr. Chapman
Christian Family Care Agency
City of Peoria
City of Phoenix
City of Surprise ADA Summit
Cordova Primary School
Brenda Carrillo
Crisis Nursery
Crossroads Professional Counseling, LLC
Ginger Myers, LMFT
Deer Valley School District
Ginger Pottenger
Desert Voices
Linda Malmberg
Devereux Arizona
Pam Bove
Division Of Developmental Disabilities
Carmen Aguilera
Kimberly Becker
Ruthann Blikey
Dawn Bird
Ellie Bowen
Sarah Bravo
Lois Brooks
Kathleen Calder
Robin Chanto
Annie Converse
Cindy Cooper
Loretta Curles
Anita Decker
Rose Fabris
Maria Fernandez
Ralph Figueroa
Denise Garcia
Jessie Gilliam
Jan Gilmore
Jade Guerrero
Kathi Guildig
Christina Harri
Lynn Headrick
Kristen Heninger
Nachol Henson
Monica Joe

Tina Johnson
Jill Keyes-McClements
Jeannie Kildoo
William Kilgore
Dorothy Knox
Carly Konieczny
Vanessa Kruse
Nadine Laman
Juanita Martinez
Diane Martinez
Sonia Navarro
Gina Niccum
Courtney Parker
Karen Patten
Judy Puckett
Lisa Rennels
Liza Roman
Ramona Sands
Adina Scortea
Kizzy Sepulveda
Dana Southworth
Carla Spector
Jade Stevens
Ernestine Thompson
JoAnn Valdez
Marietta Valdez
Down Syndrome Network
Karla Phillis
Janet Romo
Dysart Elementary School
Eileen Holub
Ebony House Children's Services
Lizzette Novelo
Etipsr LLC
Family Resource Center
Florence Unified School District
Donna Riffel
For Success Schools
Foundation for Blind Children
Jeanette Manley
GANES
Getz School
Gail Hales
Golden Gate Theological Seminary
Leslie Dodrill
Governor Jan Brewer's Office
Patti Cordova
Grand Canyon University
Lisa Aaroe
GRIC Defense Services
Jessica Turk
Head Start Casa Grande
Hispanic Outreach Alliance
Hope Group
Horizon Human Services Employer
Hydrocephalus Association
Jane Andren
Jewish Family & Children's Service
Bertha Alvarez
Joni & Friends
Kinship Kare of Northern Arizona
Kyrene School District
Kyrene SEPAC
Shari Dukes
La Casa De Cristo
Maricopa Medical Center
Leslie Carnahan, MD
Melmed Center
Raun Melmed, MD
Mercy Care
Beverly Johnson
Mountainview Elementary School
Murphy School District
Jenna DelCostello
Northern Arizona Autism Society of America
Office for Children with Special Healthcare Needs
Marta Urbina
One Step Beyond
Ginger Barnhart
Paradise Valley Community College
Amber Torda
Debbie Voll
Paradise Valley SEPAC
Allison Cahill
Peoria Elementary
Jodi Brigham
Phoenix Children's Hospital
Julie Biaggi, LCSW
Julie Dougan
Cynthia Nakamura

Annamarie Ricci, MSW, LCSW
Jennifer Stalleri
Phoenix Interfaith
Pilot Parents of Southern Arizona
Pinal County Public Health Services
Pinal Gila Community Child services
Katrina R Mueller
Quality Care Network
Rhodes Middle school
Maria Huntington
RISE
Ashley Blunt
Laura Demick
Alma Espinoza
Lacey Novak
Raven Reed
Jena Scott
Amy-Lee Verfaillie
SARRC
Salt River & Gila Social Services
Scottsdale Healthcare
Scottsdale SEPAC
Seeds of Hope Cenpatico
Diane Taylor
South Phoenix Healthy Start
Chinur Kanu
Southwest Behavioral Health
Erin Stone
Southwest Network
Cameron Cobb
Springville Head Start Program: St Johns
Nester Montoya
St. Joseph's Hospital
Niwle Curtis, LMSW
Lindsey Kern, MSW
Sunshine Acres
Ted Huntington
TASK
Jennifer Ruiz
The Guidance Center, Inc.
Cathy Uno
Touchstone Behavioral Health
Tourette's Syndrome Network
Karen Miller
United Cerebral Palsy of Central Arizona
Kim Phillips
Unity, LLC
US Dept of Education - Office of Special Education Programs
Dwight Thomas
Valle Del Sol
Sabrina Nelson
Westside Head Start
Anne Andrade
Youth Evaluation & Treatment Centers

Individuals
Heidi Christensen, MSW
Lisa Aaroe
Ann-Marie Alameddin
Dr. Bingham
Kevin Bonner
Nanette Bowles
David Carey
Margoth Carrasquilla
Barbara Dow
Miriam Doyle
Jodi Feuerhelm
Martha Garza
Jennifer Hamblin, MSW, LCSW
Anne Homan
Dorothy Kzaerncki
Dr. Magalnick
Beth Ann Maloney
Claudia Martinez
Maureen Mills
Gayle Nobel
Tanya Noth
Becky Raabe
Beata Rasicz
Carolyn Sechler
Mary Slaughter
Ellen Stein
Steve Watkins
Teri Weeks
Janelle Westfall

Volunteers are the heart of Raising Special Kids

Thank You!

February 2010 - April, 2010

Anthem

Kristina Blackledge

Cave Creek

Jill Pearnis

Chandler

Marty Baio
Beth Maloney
Marsha Rosser
Noelle White

Gilbert

Janet Kirwan

Glendale

Dawn Kurbat
Danielle Martinez
Marci Monaghan
Keri Parker

Laveen

Beatriz Acosta

Mesa

Colleen Martinez

Peoria

Steve French
Tricia & Mark Mucklow

Phoenix

ABIL Peer Mentor Program
Rebecca Bailey
Paula Banahan
Hermelinda Barrios
Renee Behl
Jeannie Bremerkamp
Lisa Case
Inilda Christensen
Patty Coe
Jim Cole
Elaine Ellis
Blanca Esparza-Pap
Nancy Gunderson
Sharon Hayes
Vickie Herd
Karen Hinds
Shirley Kaufman
Nancy Licht
Kathy McDonald
Stacie Mellen
Maureen Mills
Migdalia Morales
Thanh Nguyen
Madeline Papazian
Ched Salasek
Suzanne Simms
Hannah Swearingin
Susan Vohr
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Scottsdale

Chris Atherton
Jodi Feuerhelm
Jackie & Steve Lee
Chris Linn
Shauna Mattson
Lynn Michels
Katie Petersen
Mary Quinsler

Sun Lakes

Philip Sanabria

Surprise

Ron & Terri Nelson
Laura Riddle

Tempe

Theresa Devine

Tolleson

Kristie Amator

Our sincere thanks go to
**Perkins Coie
Brown and Bain**
for their gift of baseball tickets
to see the Arizona Diamondbacks.

Raising Special Kids
5025 E. Washington, Suite #204
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4th Annual

Dandelion Golf Classic

**All proceeds
to benefit
Raising
Special Kids**

Sponsored by CareScape, Inc.

Saturday, October 2nd, 2010

Tuscany Falls at Pebble Creek Golf Resort

16262 W. Clubhouse Drive, Goodyear, Arizona 85395, Pro Shop 623-536-2491

Golfers will receive:
18 holes of golf with cart, range balls, golf shirt,
breakfast, lunch, player tee prize bag, one drink
ticket, one door prize ticket

6:30 am - Registration, Breakfast, & Driving Range

8:30 am - Shotgun Start

1:30 pm - Lunch, Auction, Door Prizes, & Awards

Sponsorships available from \$300 to \$5000
Individual players \$150, Team Early Registration Package \$600

For details visit: www.dandeliongolfclassic.com

or contact: Marcy DeChandt at CareScape 623-583-8700 or dandeliongolf@carescape.com

www.raisingpecialkids.org