

Family participation

Improving therapy services for children



The value of family involvement in a child's development is well documented and has long been recognized by professionals in many fields of practice. More than ever, parent participation is being encouraged in educational and academic activities based on numerous studies showing the positive benefits for children.

Some professionals in physical therapy, occupational therapy and speech therapy have traditionally focused specifically on the interactions between the provider and the child. Parents who feel overwhelmed by the prospect of another responsibility, or unsure of how effective their efforts might be, may be hesitant to become active participants.

A better understanding of the positive benefits of involving families and caregivers in delivering therapy services is growing, and families are learning what a critical role they have in all areas of their child's development.

"Participating" in therapy can reflect a wide range of commitment on the part of the family. Some therapy techniques may require little more than a small change in the way a parent interacts with their child. Others may entail an extensive commitment to receiving training and following a complex program. Successful involvement of family members in a child's therapy depends on the family's interest and acceptance as well as the provider's approach.

Providers must be sensitive to families' priorities and available resources (including time, finances, and support network) to arrive at a service plan that will be followed.

Parents who are eager to be involved have sometimes met with resistance from providers. "All therapists are different," said Frankie Rosenberger, mother of four children who receive therapy services. "I'm hands on—I want to be involved. If the therapist does not include us, it is not a good fit." When asked if providers usually consult with her or her husband

Contents

Family Participation	1
From the Director	2
Calendar	3
Conference for families	5
Community news	6, 7, 10
Highlights of 2009	11

Contenido

Participación de la familia	8
Calendario	10

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

— continued on page 4

From the Director...

After hearing that a child has a disability or special health condition, many parents begin seeking information about treatment, intervention, and therapy. Knowing how to work with a variety of professionals in planning and implementing effective strategies to support a child's development takes some skill and practice. Meeting this new role and expectation is like anything we encounter for the first time; there is a learning curve. (This issue contains information about free workshops on working with professionals and improving your advocacy skills.)

Parents sometimes feel ineffective or left out of the loop in knowing how to help their children. Fortunately, there are a few tips to support good relationships between parents and professionals, and most veteran parents would agree with these basic principles for promoting a successful partnership.

- Recognize both of you have areas of competence and expertise. This acknowledges the importance of partnership as a reciprocal effort and avoids creating a dependency role. The principle of "mutual competence" places a value on the different perspectives and contributions that each bring to the effort.
- Keep the focus on your child: Parents and professionals work together most effectively, and are more likely to resolve differences, when they identify and share a common goal — achieving good results for the child.
- Find effective ways to communicate. What form your communication takes is only one consideration. Be thoughtful and considerate in expressing your views and opinions. Take time to say thank you when it's appropriate, and acknowledge accomplishments and suggestions that have helped your child.
- Include other family members and support their participation. Your family members have many opportunities during the day to help your child "practice" skills in language, social interaction, behavior control, motor skills, and other areas. Family members and caregivers are a tremendous asset, and their participation may help to lessen any feelings they have of being left out or excluded.

Most parents find they need to put forth a little effort to create the conditions for an effective partnership with professionals. If you set out with this goal in mind, and make decisions on this basis, you'll be better prepared to help your child and even make a few new friends and allies along the way.



Connecting is published by
Raising Special Kids
5025 E. Washington St., #204
Phoenix, AZ 85034
602-242-4366 • 800-237-3007
Fax: 602-242-4306
www.raisingpecialkids.org

STAFF

Joyce Millard Hoie
Executive Director

Marissa Huth
Editor

Peggy Storrs
Director Business Operations

Vickie French
Director of Family Support

Veronica Castillo,
Kathleen Collins, Peter Graf,
Dolores Herrera, Rita Kenison,
Lydia Martinez, Janna Murrell,
Jane Nguyen, Vicky Rozich,
Nannette Salasek, Heather Snider,
Carrie Swearengin, Alice Villarreal

BOARD OF DIRECTORS

Kevin Bonner, President
Elaine Ellis, MD, Vice President
Vickie Herd, Secretary
Elizabeth Freeburg, Treasurer
Heather Buchta
Jim Cole
Bob Cox
Blanca Esparza-Pap
Jodi Feuerhelm
Karen Hinds
Shirley Kaufman
Michael Remus
Gabriela Sanchez Orozco
Susan Voirol
Tim Watters

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.

Our office location is a fragrance-free environment: 5025 E. Washington St., #204, Phoenix, AZ 85034

Positive Behavior Support

Training on effective techniques for behavior management.

Wed. 4/14/10, 10:00 – 12:00 noon

Tue. 5/4/10, 6:30 - 8:30 pm

(North Bible Church)

Sat. 6/26/10, 12:30 – 2:00 p.m.

Resilient Relationships

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

Tue. 3/16/10, 6:30 – 8:30 p.m.

(Peoria Community Center)

Sat. 4/24/10, 9:00 – 10:30 a.m.

(United Cerebral Palsy)

Can you hear me now?

Techniques for effective advocacy.

What to ask, how to ask it.

Thu. 3/25/10, 6:30 – 8:00 p.m.

Wed. 4/21/10, 10:00 – 11:30 a.m.

Guardianship and other options

It's not too soon to start— even before your teen turns 18! Learn about guardianship, and other options available for young adults with disabilities.

Tue. 4/13/10, 6:30 – 8:00 p.m.

Sat. 6/26/10, 2:30 – 4:00 p.m.

IEP Basics

Learn about the purpose of Individual Education Programs and how to actively participate.

Wed. 4/7/10, 10:00 – 12:00 noon

Thu. 4/22/10, 6:30 – 8:30 p.m.

(Peoria Community Center)

Sat. 6/26/10, 8:30 – 10:00 a.m.

Advanced IEP Training

Learn about IEP requirements SMART goals, and how to measure progress.

(Recommended: attend

IEP Basics first.)

Thu. 5/6/10, 4:00 – 6:00 p.m.

Special Education Overview

Learn what the special education evaluation, IEP, and placement processes include and tips for active participation in all decisions.

*Calendario Español - página 7
Spanish workshops - pg. 7*

Understanding 504

Learn about the 504 requirements, responsibilities of schools, plus samples of 504 accommodations.

Tue. 2/16/10, 1:30 – 3:00 p.m.

Transition from AzIEP to Preschool

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

Thu. 3/18/10, 6:00 – 8:00 p.m.

(Peoria Community Center)

Tue. 4/20/10, 6:30 – 8:00 p.m.

(Scottsdale Bible Church)

Wed. 5/5/10, 10:00 – 11:30 a.m.

High School Transition

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

Thu. 3/11/10, 6:30 – 8:30 p.m.

Tue. 4/13/10, 4:00 – 6:00 p.m.

Organizing Your Child's Records

Learn effective ways to tame that pile of papers.

Thu. 4/15/10, 6:30 – 8:30 p.m.

Bully-Free Environments

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

Wed. 3/10/10, 1:30 – 3:00 p.m.

Sat. 4/24/10, 10:45 – 12:00 noon

(United Cerebral Palsy)

Sat. 6/26/10, 10:30 – 12:00 p.m.

Evaluations & Tests

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

Wed. 3/24/10, 10:00 – 12:00 noon

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.

Saturday workshops are back!!

www.raisingpecialkids.org

Notice our NEW

ALTERNATE LOCATIONS

(workshops listed in red at left)

United Cerebral Palsy (UCP)

1802 W. Parkside Lane

Phoenix, AZ 85027

North of the 101 off of I-17

Peoria Community Center

8335 W. Jefferson St.

Peoria, AZ 85345

2 blocks south of Peoria Ave.

North Bible Church

15678 N. Greenway Hayden Loop

Scottsdale, AZ 85260

Scottsdale Bible Church

7601 E. Shea Blvd.

Scottsdale, AZ 85260

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.

Wed. 4/28/10, 10:00 – 12:00 p.m.

Thu. 5/6/10, 1:00 – 3:00 p.m.

Sat. 5/22/10, 1:00 – 3:00 p.m.

Summer school for parents 4 Workshops - 1 Day!

IEP BASICS

Sat. 6/26/10, 8:30 – 10:00 a.m.

Bully Free Environments

Sat. 6/26/10, 10:30 – 12:00 p.m.

Positive Behavior Support

Sat. 6/26/10, 12:30 – 2:00 p.m.

Guardianship

Sat. 6/26/10, 2:30 – 4:00 p.m.

Parents as Collaborative Leaders Improving Outcomes for Children with Disabilities

Saturday, May 22th, 2010

9:00 a.m. to 12:30 p.m.

see pg 5 for more info

when planning therapy activities, she said, “You have to kind of beg for that sometimes.” She continued, “what is frustrating for me is that there is no true understanding of the parent’s role...especially after the child is 3 years old—then they tend to focus only on the child with special needs, not on the family unit.”



Initial advances in family involvement were seen more frequently in Early Intervention practices with infants and toddlers. Ideas are now spreading into care for all ages of individuals with special health care needs. In a 2006 article, Robert J. Palisano, a physical therapist and professor at Drexel University, noted “Family-centered service is an approach to service delivery that is considered best practice in pediatric rehabilitation. The focus is on services that address child and family needs, priorities, and preferences in settings where children live, learn, and play. Collaboration between the family and service providers is integral to establishing goals and the plan of care.”

Daniel Openden, Ph.D., Clinical Services Director at The Southwest Autism Research & Resource Center (SARRC) said their training programs emphasize helping parents learn how to interweave techniques into daily parent/child activities so that “every interaction becomes therapeutic.” He noted, “everything we do (other than services offered in schools)

involves parent training in some capacity.” The intention, he explained, “is not that parents replace the therapist—instead they complement them.” The amount of time a therapist typically spends with a child can’t compare with the time parents are interacting with that child, Openden pointed out, and the interaction techniques are beneficial for children with all types of disabilities.

Arizona’s position on service delivery supports the concept of family involvement. Miriam Podrazik, Director of Policy and Program Development at DDD noted, “The Division of Developmental Disabilities does require that a family member or caregiver be present when therapy occurs in the home, clinic or any natural setting. The Division believes that when families and caregivers are taught how to do the activities or strategies, the child

“The therapist’s role is to write a home program and teach the family and caregivers how to incorporate appropriate activities into the daily routine of the family.”

has multiple opportunities to practice the skills and will be able to meet their goals. The therapist’s role is to write a home program and teach the family and caregivers how to incorporate appropriate activities into the daily routine of the family.”

Increasing the role of caregivers in providing children with therapeutic opportunities within their natural environment has been enthusiastically embraced by some

providers. “I have been practicing physical therapy for over 35 years and teaching parents has always been part of what I do,...The point is not to do therapy ‘on’ the child, but to develop ideas WITH the caregiver on ways to embed activities throughout their day.” said Barb Womack, a physical therapist in the Phoenix area who is helping facilitate training in a new approach for therapists called

“The therapeutic use of daily life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community, and other settings...”

excerpt from The American Occupational Therapy Association’s definition of occupational therapy

Participation Based Service for Children and Youth with Disabilities (see page 6 for more information).

This approach for service delivery is based on a model advanced by the World Health Organization (WHO) that focuses on the ability of an individual to participate within the context of her community. Using the International Classification of Functioning, Disability and Health this perspective “takes into account the social aspects of disability and does not see disability only as a ‘medical’ or ‘biological’ dysfunction.” As more countries choose to develop standards of practice based on WHO recommendations, a new approach for addressing the needs of persons with disabilities is emerging. Greater emphasis is being placed on improving the ability of an individual to function within her environment, and taking into account cultural perspectives and family

Free conference for parents of children birth to five



Phoenix Children's Hospital

Saturday, May 1, 2010

8:30 a.m. - 4 p.m.

Practical therapy techniques you can use at home



Sessions facilitated by

- Developmental Pediatrician
- Speech Therapist
- Occupational Therapist
- Physical Therapist
- Panel of experienced parents who've "been there" will share their experiences

Topics covered

- How to work with your doctor and therapist
- How to recognize and encourage communication, including basic baby sign language
- Coping with sensory issues
- Interactive hands on physical therapy techniques.

Breakfast and lunch are included

Space is limited, please register by contacting Raising Special Kids at 602-242-4366

No child care available

priorities when planning services. The trend focuses on what needs an individual has within a particular environment, rather than on practicing isolated skills.

"Provide culturally sensitive care distinguished by trust, respect, and an appreciation for individual differences."

from the The American Physical Therapy Association's (APTA) Vision Statement for Physical Therapy 2020

The family participation approach complements the ideals of Family Centered practices advocated by Family Voices, a national organization that promotes family-centered care for children and youth with special health care needs and/or disabilities. Their publication titled *Families Partnering With Providers** has tips to help parents increase

involvement in their child's care. (Downloadable - see box.)*

Increasing family participation in children's services calls for active engagement on the part of families and caregivers as well as providers. For parents who may not be comfortable asking providers for information or instruction, a new workshop called *Parents as Collaborative Leaders, Improving Outcomes for Children with Disabilities* offered by Raising Special Kids can help families in developing positive and assertive advocacy and leadership skills. The free workshop will be on Saturday, May 22 from 9:00 a.m. to 1:00 p.m. (see box for details). Call Raising Special Kids at 602-242-4366 to register.

Parents as Collaborative Leaders

Improving Outcomes for Children with Disabilities

Saturday, May 22th, 2010

9:00 a.m. to 12:30 p.m.

Raising Special Kids

FREE

Have successful meetings with your children's school, doctors, and other professionals. Advocate for systems change by serving on policy committees or focus groups.

This is for you! Come and learn:

- Your Leadership Style
- Evaluate Your Conflict Management Style
- Collaborative Decision-Making
- How to tell your story to policy makers

Call 602-242-4366 to register.

Follow up on line:

- *Families Partnering With Providers: <http://www.familyvoices.org/pub/general/PartneringWithProviders.pdf>
- Questions to ask professionals: <http://www.Idonline.org/article/6023>

www.raisingpecialkids.org

New program for therapists

Continuing Education Opportunity for Participation Based Services for Children and Youth with Disabilities

This 30 hour continuing education project will use information created by a federal grant. There will only be 12 participants selected for this project, 4 from each therapy discipline. This is a pilot project, which offers participants an excellent opportunity to learn the *Participation Based Services Approach* while earning free CEUs. **Join us to learn more about embedding therapy strategies into the daily routine for individuals with disabilities and how to teach the family and caregivers how to do these activities to help the individual meet their outcomes.**

Participant's responsibilities:

- Complete modules prior to teleconference dates and participate in all scheduled teleconferences
- Identify 3 families you are serving to participate in the project and administer the initial interview (approximately one hour per family)
- Provide your therapy services to your identified families for 16 weeks
- Bring short video clips for brainstorming and discussion

Trainer:

Dr. Jeanne Wilcox, *Arizona State University*

Facilitators:

Barbara Womack, *Physical Therapist*

Amy Heck, *Speech Language Pathologist*

Teresa Ray, *Occupational Therapist*

Application deadline is May 7, 2010. Participants selected will be notified by May 20, 2010.

Project period: August-December, 2010

To download an application or for more information, visit: http://icrp.asu.edu/arizona_pbs after March 15.

Advocacy training for future leaders

The Arizona Disability Advocacy Coalition (AzDAC) is sponsoring a **FREE** webinar training on effective advocacy.

Thursday, March 25, 2010, 6:00 p.m. – 7:30 pm

Attend online from the comfort of your own computer

To register, email contact@azdac.org before March 24.

- Gain insight into the state legislative process
- Learn more about the power of your perspective and voice, and
- Advocate for issues impacting the disability community at the State Legislature, or from your own home.

The webinar is great preparation for...

AzDAC's Day at the Capitol

an introduction to the Arizona Capitol.

Tuesday, April 6, 2010 8:30 a.m. - 2:00 p.m.

State Capitol: 1700 W. Washington St., 2nd floor conference room

Who should attend?

Individuals committed to their communities and to provide the advocacy training for others.

The event and luncheon are **FREE**.

APPLICATION IS REQUIRED AS SPACE IS LIMITED.

Program will include:

- Learn how to advocate to your legislators from home
- Learn about budget issues that impact the disability community
- Meet with legislators
- Lunch provided
- Overview of AZDAC supported bills & issues
- Group recognition in the House & Senate galleries



Positive Action for a Better Tomorrow

Visit AzDAC's new website:
<http://www.azdac.org>

For an application, contact:
Phone: 602-503-6593,
TTY: 602-364-0990
or email contact@azdac.org

Application deadline is
Thursday, March 25, 2010.
If you are selected as an attendee
you will be notified by April 1, 2010.

Family cost participation for birth to 3

Implementation delayed

The Department of Economic Security, Division of Developmental Disabilities (DDD) has delayed the implementation of its new Family Cost Participation program for recipients of early intervention services.

Families were to begin sharing in the cost of their early intervention services effective March 1, 2010. The program is being delayed a minimum of 60 days. As a result, families who have been determined responsible to share in the cost of their services will not be charged for their current array of services until May 1, 2010 at the earliest. To clarify, this means families will *not* be billed for their services for the months of March and April but *may* be expected to share in the cost of services beginning May 1st.

Families will be notified of the new program standards prior to implementation. Families whose children are Arizona Long Term Care System (ALTCS) eligible will continue to be excluded from the Division's Family Cost Participation program. The Department is using this time to further evaluate program implementation, including income standards,

and procedures. If you have questions, please contact 602-364-1379 or e-mail your question and phone number to DDDHotline@azdes.gov.

Points to remember:

While the Family Cost Participation program has been delayed, families should *not* experience any reduction in services.

Before the new process of cost-sharing is implemented, families will receive advance notice from the Department of Economic Security, through AZEIP or DDD, describing the program and income guidelines. Families will retain the right to some services at no cost: Child Find, Evaluation, Assessment, Development of the Individual Family Service Plan (IFSP), Service Coordination and Dispute Resolution. Families have the right to request a meeting of their IFSP team to consider changes in their services before the cost-sharing program takes effect.

Help assess needs in Arizona

OCSHCN needs your input

The Office for Children with Special Health Care Needs, (OCSHCN) is conducting an assessment of what is working and what is needed to improve service in Arizona. Families of children and youth with special health care needs are invited to participate in a public input session about problems, needs, assets and strengths of

Arizona programs and services for children and youth with special health care needs.

A session is scheduled for **Monday, April 26, 2010 at 5 p.m. at the Disability Empowerment Center** Conference Room, 5025 E. Washington Street in Phoenix. Raising Special Kids will host a light dinner. This event is free for families.

Please contact Raising Special Kids by calling 602-242-4366 to register.

This needs assessment is being conducted by OCSHCN under the Maternal and Child Health Services (MCH) Title V Block Grant, a federal program that focuses on improving the health of all mothers and children.

Just Vote Arizona Disability Coalition

The Just Vote Arizona Disability Coalition (JVADC) was recently formed to establish and sustain a statewide network of grassroots, disability related organizations and interested individuals that will promote and support voter participation activities across Arizona.

The website at <http://jvadc.org/> gives visitors an opportunity to register to vote, find out who their legislators are and learn about information important to voters with disabilities. In addition, visitors can **sign up for the Action Alert Network**, to be alerted to what's happening at the state legis-

lature, receive the Ballot Buzz Newsletter and learn about voter registration events. In the voter assistance section, voters may request assistance filling out a voter registration form, filling out their absentee (mail-in) ballot and transportation to a polling place.

Participación de la familia

Cambiado la interfase de la terapia

El valor de la participación de la familia en el desarrollo de los niños está bien documentado y ha sido reconocido desde hace mucho tiempo por profesionales en varios campos de la práctica. Más que nunca, se está alentando la participación de los padres de familia en actividades educativas y académicas basados en numerosos estudios que muestran los beneficios positivos para los niños.

Algunos profesionales en terapia física, terapia ocupacional y terapia del lenguaje tradicionalmente se enfocaron específicamente en las interacciones entre el proveedor y el/la niño/as. Los padres que se sienten abrumados ante la perspectiva de otra responsabilidad, o inseguros sobre qué tan efectivos podrán ser sus esfuerzos, pueden estar dudosos de convertirse en participantes activos.

Está aumentando una mejor comprensión de los beneficios positivos de la participación de las familias y de las personas proporcionando cuidado en la entrega de servicios de terapia, y las familias están aprendiendo qué papel tan importante tienen en todas las áreas del desarrollo de su niño/a. “Participando” en la terapia puede reflejar un amplio ámbito de dedicación por parte de la familia. Algunas técnicas de terapia pueden requerir un poco más que un pequeño cambio en la manera en la que un padre de familia interactúa con su niño/a. Otras pueden implicar una extensa dedicación recibiendo capacitación y siguiendo

un programa complejo. La participación exitosa de los miembros de la familia en la terapia de un/a niño/a depende del interés y la aceptación de la familia, así como del enfoque del proveedor. Los proveedores deben ser sensibles a las prioridades de las familias y los recursos disponibles (incluyendo tiempo, finanzas y red de apoyo), para llegar a un plan de servicio que se seguirá.

Los padres de familia que están ansiosos de participar, algunas veces se encontraron con la resistencia de los proveedores. “Todos los terapeutas son distintos”, dijo Frankie Rosenberger, madre de cuatro niños que reciben servicios de terapia. “Yo soy práctica—yo quiero participar. Si el terapeuta no nos incluye, no funcionará.” Cuando se le preguntó si los proveedores usualmente la consultan a ella o a su esposo cuando planean las actividades de la terapia, ella dijo, “En ocasiones tienes casi que suplicar por ello.” Ella continuó, “lo que es frustrante para mí es que no hay un verdadero entendimiento del papel de los padres de familia...especialmente después de que el/la niño/a cumple tres años de edad—luego tienden a enfocarse sólo sobre el/la niño/a con necesidades especiales, no sobre la unidad familiar.”

Avances iniciales en el enfoque de la participación de la familia se vieron más frecuentemente en las prácticas de Intervención Temprana con infantes y niños menores de dos años. Las ideas

ahora se están esparciendo dentro del cuidado de individuos de todas las edades con necesidades especiales para el cuidado de la salud. En un artículo de 2006, Robert J. Palisano, un terapeuta físico y profesor en la universidad Drexel University, señaló “Los servicios centrados en la familia es un enfoque de entrega de servicios considerado como una mejor práctica en la rehabilitación pediátrica. El centro de atención son los servicios que atienden las necesidades, prioridades y preferencias del/la niño/a y la familia, en aquellos ambientes en los que los niños viven, aprenden y juegan. La colaboración entre la familia y los proveedores de servicio es integral para establecer las metas y el plan de cuidado.”

El Dr. Daniel Openden, Ph.D., Director de Servicios Clínicos del Centro de Investigación y Recursos para el Autismo del Suroeste (SARRC por sus siglas en inglés), dijo que sus programas de capacitación enfatizan el ayudar a los padres de familia a aprender cómo intercalar técnicas en las actividades cotidianas de padres/hijos, para que “toda la actividad sea terapéutica.” Señaló, “Nada de lo que hacemos (diferente de los servicios ofrecidos e las escuelas) no envuelve la capacitación de los padres en alguna capacidad.” La intención, explicó, “no es que los padres de familia reemplacen al terapeuta—en lugar de ello lo complementan.” La cantidad de tiempo que pasa típicamente un terapeuta

Participación de la familia Cambiado la interfase de la terapia

con un/a niño/a se vuelve insignificante en comparación con el tiempo que los padres de familia están interactuando con dicho/a niño/a, Openden señaló, “y las técnicas de interacción son benéficas para los niños con distintos tipos de discapacidades—o sin discapacidades.”

La posición de Arizona sobre la entrega de servicios apoya el concepto de la participación de la familia. Miriam Podrazik, Directora of Normas Desarrollo de Programas en DDD señaló, “La División de Discapacidades del Desarrollo requiere que un miembro de la familia o persona proporcionando cuidado esté presente cuando ocurre la terapia en el hogar, la clínica o en cualquier otro ambiente natural. La División cree que cuando a las familias y las personas proporcionando cuidado se les enseña cómo realizar las actividades o estrategias, el/la niño/a tiene múltiples oportunidades de practicar las habilidades y podrá alcanzar sus metas. El papel del terapeuta es el de redactar un programa para el hogar y enseñar a la familia y las personas proporcionando cuidado cómo incorporar actividades apropiadas dentro de la rutina diaria de la familia.”

El aumentar el papel de las personas proporcionando cuidado para que provean a los niños oportunidades terapéuticas dentro de su medio ambiente natural, ha sido acogido entusiastamente por algunos proveedores. “He estado practicando la terapia física durante más de 35 años y enseñar a los padres de familia ha sido siempre

parte de lo que yo hago,...El punto no es hacer terapia ‘sobre’ el/la niño/a, sino desarrollar ideas CON la persona proporcionando cuidado, sobre formas de incorporar actividades durante todo su día.” dijo Barb Womack, una terapeuta física en el área de Phoenix, quien está ayudando a moderar la capacitación en un nuevo enfoque para terapeutas llamado Servicio para Niños y Jóvenes con Discapacidades Basado en la Participación (vea la página 6 para más información).

Este enfoque para la entrega de servicios está basado en un modelo avanzado propuesto por la Organización Mundial de la Salud (OMS) que se enfoca en la capacidad de un individuo para participar dentro del contexto de su comunidad. Usando la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud, esta perspectiva “toma en cuenta los aspectos sociales de la discapacidad y no ve la discapacidad sólo como una disfunción ‘médica’ o ‘biológica.’” A medida que más países eligen desarrollar estándares de práctica basados en las recomendaciones de la OMS, un nuevo enfoque de atender las necesidades de las personas con discapacidades está emergiendo. Se está poniendo mayor énfasis en mejorar la capacidad de un individuo para que funcione dentro de su medio ambiente, y tomar en cuenta perspectivas culturales, así como las prioridades de la familia cuando se planean los servicios. La tendencia se enfoca en cuáles son las necesidades que tiene un individuo

dentro de un medio ambiente en particular, en lugar de practicar habilidades aisladas.

El enfoque de la participación de la familia complementa los ideales de las prácticas Centradas en la Familia recomendadas por Family Voices, una organización nacional que promueve el cuidado centrado en la familia para niños y jóvenes con necesidades especiales del cuidado de la salud y/o discapacidades. Su publicación titulada Familias Asociándose con Proveedores (Families Partnering With Providers)* tiene consejos par ayudar a los padres de familia a aumentar su participación en el cuidado de su niño/a. (Descargable – vea la caja.)*

Una creciente participación de la familia en los servicios de los niños exige una dedicación activa por parte de las familias y las personas proporcionando cuidado, así como de los proveedores. Para los padres de familia que pueden no sentirse cómodos pidiendo a los proveedores información o instrucción, un nuevo taller llamado Padres de Familia como Líderes Colaborativos, Mejorando los Resultados para Niños con Discapacidades ofrecido por Raising Special Kids, puede ayudar a las familias a desarrollar habilidades asertivas de abogacía y de liderazgo. El taller gratuito se llevará a cabo el sábado 29 de mayo, de 9:00 a.m. a 1:00 p.m. (vea el calendario en la Página 3 para detalles). Llame a Raising Special Kids al 602-242-4366.

CALENDARIO ESPAÑOL

POR FAVOR TOME NOTA
NUEVA DIRECCIÓN :
5025 E. Washington St. #204
Phoenix, AZ 85034

IEP/504

Jueves 3/4/10, 5:30–7 p.m.
(Getz School – Tempe)
Viernes, 5/7/10, 3:00 – 5:00 p.m.

El Comportamiento Positivo

Sabado 3/6/10, 10:30–12 p.m.
Viernes 4/9/10, 1:30–3 p.m.

Organizando su niño/a's archivos

Jueves 4/15/10, 6:30–8:30 p.m.

Entrenamiento Para Voluntarios

Viernes 2/26/10, 10–11:30 a.m.

Derechas de padres en educación especial

Martes 3/9/10, 1:30–3 p.m.

Es su Hijo Blanco de Burlas?

Sabado 4/24/10, 10:45–12 p.m.
(UCP – Phx)

Familias Resistentes

Viernes 3/19/10, 1:30–3p.m.
Sabado 4/24/10, 9–10:30 p.m.
(UCP – Phx)

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.raisingpecialkids.org/ Por favor llamar al 242-4366 o al 800-237-3007 para confirmar su asistencia a los talleres.

Somos un oficina libre de fragancias.

Northern AZ Workshops Flagstaff Family Resource Center

1806 E US-66
Flagstaff, AZ 86004
928-774-1103

Understanding the IEP

Tue., May 18, 4:30 – 6:00 p.m.

Organizing Your Child's Record

Tue., June 15, 4:30 – 6:00 p.m.

Health and Wellness Fair

Saturday, April 10, 2010

10:00 a.m. to 3:00 p.m.

Disability Empowerment Center (DEC)

5025 E. Washington Street, Phoenix, AZ 85034

Come visit the 11 agencies of the Disability Empowerment Center of Arizona (DEC) during their Community Health & Wellness Fair with information on issues surrounding chronic illness and disability. The fair will feature presentations on:

- mental health
- wellness
- pharmacology
- natural therapies
- healthcare appeals process
- fitness demonstrations
- health screenings
- expo of community partners
- 911 technologies for the deaf

For more information and updates, visit <http://www.abil.org/wellness>

Please park only in the four-story garage designated for the DEC. Food & beverage will be available for purchase

No fragrances please!

To accommodate those with allergies, breathing conditions or multiple chemical sensitivities please do not smoke or wear scented products when attending this event. This event is accessible and in compliance with ADA guidelines.

CITT Sibshop

Sibshops offered by Child Improvement through Therapy (CITT) are designed just for brothers and sisters age 5-13. The workshops are designed for siblings of children with special needs ranging from developmental to life-limiting conditions. They are fun, lively experiences that provide siblings the opportunity to interact with peers and make new friends.

Workshops are co-facilitated by professionals from CITT, Raising Special Kids, and Ryan House. Cost: \$15.00

Our next workshop is scheduled for **Saturday, April 10th from 10-2 pm. at Hospice of the Valley 1510 E. Flower St. Phoenix.** For more information, please contact Karen Lukas at karen@cittkids.org or log on to : <http://www.cittkids.org/>

PAC needs you!

The Children's Rehabilitative Services Parent Action Council (PAC) is made up of past and present CRS families. The PAC meets monthly to share ideas and resources for improving health

care. Meetings are held at 10:00 a.m. at the CRS Clinic (124 West Thomas Road, Phoenix). For more information please contact Adriana Molina at 602-406-5041.

www.raisingpecialkids.org



Highlights of 2009

- **Raising Special Kids celebrated 30 Years of serving Arizona Families.**
- In the past year **9,042** families of children with disabilities and professionals who serve them were supported with training, information or individual assistance—an average of **753** each month.
- Over **360** families were provided with a Parent to Parent “match,” for one-on-one support from trained parent volunteers.
- 100% follow-up and evaluation of Parent to Parent contacts revealed that **96%** reported excellent or very good results in obtaining needed information and assistance.
- **84%** of parents who participated in training reported feeling better prepared to make decisions regarding a child’s education, services or care.
- **29** parents were recruited and trained as Parent to Parent volunteers, Family Faculty, and for other leadership activities.
- **320** workshops or training programs were presented on a wide variety of topics.



*Celebrating 30 Years
at D-Backs game*



Families



Community Outreach

- **14** Spanish-speaking parent volunteers were trained to provide family support.
- Our **1st Annual Therapies Conference** for families was a huge success in meeting the immediate needs of families and planting the seeds for future programs. **100%** of parents attending said they want to attend another conference on therapy topics.
- Tribal Liaisons for the Navajo and Hopi Nations supported **63** families in northern Arizona.
- **97** physicians in pediatrics and family practice residency programs completed training in family centered care in the Family and Community Medicine Program. **51** Family Faculty hosted **194** hours of home visits.

Participating hospitals include:

**Maricopa Medical Center
 Phoenix Children's Hospital
 Banner Good Samaritan
 St. Joseph's Pediatrics
 St. Joseph's Family Medicine
 Phoenix Baptist Hospital
 John C. Lincoln
 Scottsdale Healthcare
 Northwestern University**

- **2,762** Arizona educators, student teachers, school personnel and other professionals received training and information on how to work effectively with families. **87%** of the professionals who completed training reported feeling better equipped to work more effectively with families.
- **141** Community organizations, state agencies, and medical centers referred families to Raising Special Kids.



Presenting to physicians at St. Joseph's Hospital



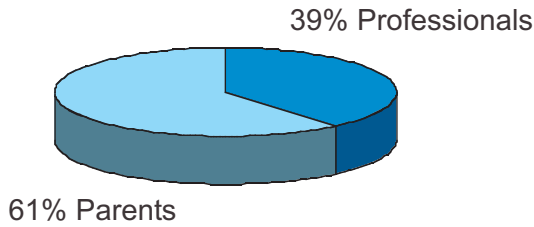
Therapies Conference for parents



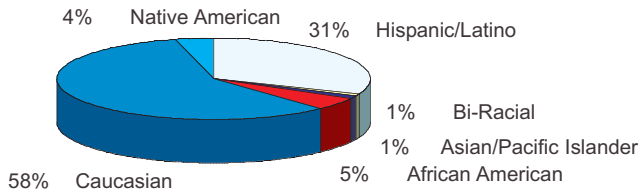
Parents forum with Division of Developmental Disabilities



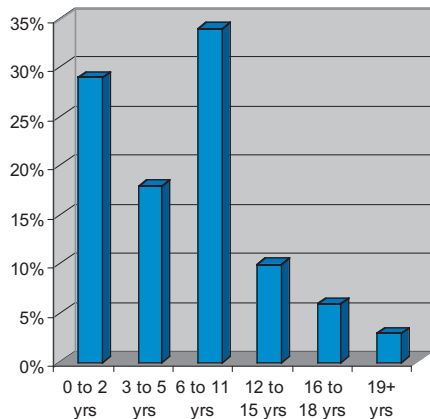
Who We Serve



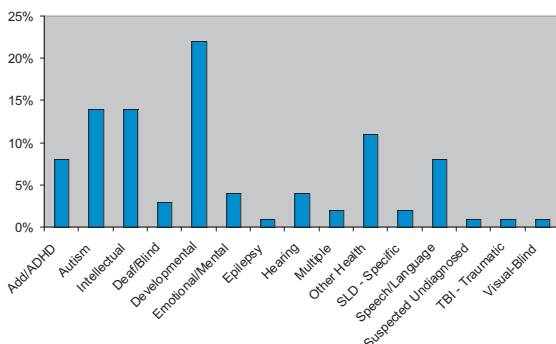
Families: diverse language and culture



Children's Ages



Children by Disability



MENTIONED

"Your organization is the best! I appreciate your unique ability to pinpoint the best resource for the situation my son and I are facing."

— Parent

"I was very impressed with the presentation I attended and was wondering how more parents can hear this type of information. It was very organized, professional, and well-done. The presenter was excellent, and I liked how she was able to illustrate her points with anecdotes and elicit examples from her audience to help everyone better understand each point discussed. Very well done!"

— Special Education Teacher

"I am so glad that my friend pressured me into calling you. I had been putting it off thinking your organization would be just like everyone else I called. You are definitely different. You gave me so many resources and such good information. I feel strong and more capable because of you."

— Parent

It's my pleasure to acknowledge Raising Special Kids staff and volunteers for the exemplary work they do on behalf of parents and children throughout Arizona. As a recipient of your support and services for the past twenty-three years, I appreciate the ongoing effectiveness and sincerity of your efforts to improve the quality of life for individuals with disabilities and their families."

— Becky Raabe, PINS Director, Arizona Department of Education

"I am so happy I found you. You gave me the tools I need to be able to help my children."

— Parent

Raising Special Kids News

Board of Directors

It is with a sense of loss that we say farewell to Board members Heather Buchta, Jim Cole, and Jodi Feuerhelm who served as Board President for the past three years. Each of these individuals has contributed immeasurably to the mission of Raising Special Kids with unique insight and talents that have helped our organization thrive and serve families. We are grateful they will not go far, as all are moving on to our Advisory Board.

We are looking forward to the addition of two new members to the board: Bob Cox, president of Nothing But Net information technology services company, and Gabriela Sanchez Orozco, a long time volunteer, mother and president of Grupo de apoyo para niños especiales (GANE) a West Valley organization for Spanish speaking parents and professionals.



Bob Cox and Gabriela Sanchez Orozco

Grant from Virginia G. Piper Charitable Trust

New parent workshops being developed

We are pleased to thank Virginia G. Piper Charitable Trust for an award of \$40,000 to Raising Special Kids to develop and pilot new training workshops for parents of children with disabilities.

Piper Trust president and CEO Judy Jolley Mohraz said "Raising Special Kids is known for excellent training and this grant will add new training topics that parents have said they needed."

The topical workshops will focus on family support, parent education, collaboration with professionals, and effective self-advocacy. The goal of the project is to provide parents with knowledge and skills to resolve problems, become better advocates for their children, and improve their ability to work with professionals.

Welcome new staff

With the addition of Carrie Swearingin to our staff, Raising Special Kids has gained a valuable new source of insight and a strong connection with the foster care community. Carrie is Project Coordinator for programs developed under the new Virginia G. Piper grant. She has also just been appointed to the Foster Care Review Board of Maricopa County and will be reviewing foster care cases.

"I believe that every child deserves to have a family that will care for, nurture and support them unconditionally," Carrie said.

Celebrating 10 years

Executive Director



Joyce Millard Hoie
Executive Director

Your skills count!

Share them as a volunteer for Raising Special Kids

- 1) Fill out a volunteer orientation and training application
- 2) Attend volunteer orientation and training
- 3) Get started right away as a Parent-to-Parent volunteer talking to families or professionals about what you know best—raising a child with special needs!

The staff and Board of Directors recently recognized Joyce Millard Hoie for her ten years of service as Executive Director. Reflecting on the organization's long history of family advocacy efforts and achievements, Joyce remarked, "As a parent volunteer, past Board member, and now Executive Director, it has been an extraordinary privilege to serve Raising Special Kids. You and the families we serve have given me so much."

In The Spotlight

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

November 2009 - January, 2010

Individuals

Cathy Bermingham
Allison Cahill
Margot Carrasquilla
Anne Dennis
Miriam Doyle
Barbara Forman
Stephanie Garnes
Sue Glascoe
Dr. Melanie Griffin
Melissa Herb
Dr Jordan
Cami Lane
Dr. Harold Magalnick
Beth Ann Maloney
Dr Raun Melmed
Josie Moncada
Donna O'Brien
Lyne Peterson
Dr. Karlsson Roth
Mike Swearingin
Patty Widomski

Organizations

AASK
Area Agency on Aging
Julie Ngiriyi
Arizona Center for Disability Law
Arizona Children's Association
Anita Carter
Maria Rodriguez
Arizona State University
Cathy Bacon
Association for Supportive Child Care
ASU West
Juliet Hart
Az Dept Of Education
Tabitha Fisher
Valerie James
Banner Behavior Health
Banner Cardon Childrens Hospital
Marcia Bluth, MSW, LCSW
Jenenne Redd, LMSW
Heidi Solak
Banner Children's Hospital
Jen Hamblin
Banner Good Samaritan Hospital
Center for Autism and Related
Disorders
Cardon Children's Medical Center
Tracie Baker, MSW
Cenpatco Behavioral Health Diane
Taylor
Child and Family Resources
Nubia Garcia-Shinagwa
Maria Pimental
Children's Rehabilitative Services
Dr. Chapman
David Karrigen
Judy Tyler
City of Phoenix Head Start
Ruby Rios
Cordova Primary School
Brenda Carrillo
CPS
Andrew Marzowi
Deer Valley Unified School District
Michael Remus
Department of Education
Amy Dill
Devereaux School
Lauren Blast
Division Of Developmental Disabilities
Carmen Aguilera
Kathy Bahamonde
Kimberly Becker
Ruthann Bilkey
Ellie Bowen
Sarah Bravo

Lois Brooks
April Butler
Kathleen Calder
Tina Chaffin
Robin Chanto
Annie Converse
Cindy Cooper
Anita Decker
Laura Denali
Rose Fabris
Maria Fernandez
Jan Gilmore
Jade Guerrero
Kathi Guildig
Denice Hammons
Christina Harri
Kristen Heninger
Rhonda Hugo
Monica Joe
Jill Keyes-McClements
Jeannie Kildoo
William Kilgore
William Kilgore
Carly Konieczny
Vanessa Kruse
Renee Lamphear
Sonia Navarro
Gina Niccum
Shawn Padilla
Courtney Parker
Nicki Passielli
Carla Pate
Karen Patten
Julie Quesada-Conner
Lisa Rennels
Adina Scortea
Kizzy Sepulveda
Deanna Siedel
Dana Southworth
Ernestine Thompson
JoAnn Valdez
Marietta Valdez

Down Syndrome Network

Karla Phillips

Family Involvement Center

Vanessa Herrera

First Southern Baptist Church at

Sahuaro Ranch

Steve French

For Success Schools

Foundation for Blind Children

GANE

Garcia Elem School - Head Start

Program

Getz School Tempe

Gail Hales

Gilbert District

Emily Haskell

Gilbert School District

Glendale Community College

Governor Jan Brewer's Office

Patti Cordova

Hopi Health Care Center

Rhonda Talaswaima

Human Resources Training, Inc.

Integrated ABA

Jennie D Cook

Integrated/Nadaburg School District

Jenine Cook, OTR/L

International Dyslexia Association

Marjorie Schmidt

Jewish Family & Children Services

Lina Jimenez

Joni and Friends

Pam Baldwin

Kyrene School District

Chris Epper

Kyrene SEPAC

Shari Dukes

La Casa De Cristo Lutheran Church

Luke Air Force Base

Maricopa Medical Center

Dr. Leslie Carnahan

McClintock High School

Jessica Hogg

Medtronic

Mercy Care

Mercy Gilbert Medical Center

Kristen Curtis, MSW

Mesa Public Schools

Jan Umhay

Mountain Park Health Center

Dr. Perez

Murphy School District J

Jenna DelCastello

New Leaf

Office of Children with Special Health

Care Needs

Marta Urbina

Peoria Elementary

Jodi Brigham

Phoenix Children's Hospital

Julie Biaggi

Annamarie Ricci

Maritsa Saucedo-Graham

Jennifer Stalteri, LMSW

Dr. Robin Wetherland

RISE, Inc

Ashley Blint

Laura Demick

Amylee Verfallie

SARRC

Sherri Doyle

Scottsdale Fiesta

Scottsdale Healthcare

Sevilla Primary Elem School

Dr. Michael Jaime

Sharing Down Syndrome

Gina Johnson

Sharp School

South King Early Intervention Program

Sandy Carlson

Southwest Behavioral Health

Martha Sainz

Southwest Human Development

Southwest Network

St. Joseph's Hospital

Kristen Samaddar

Statewide Independent Living Council

Tony DiRienzi

Sunshine Acres

Ted Huntington

Tempe Elementary District

Laura Hauer

Tempe Union High School District

Sharon Gilbert

Terros Behavioral Health Services

United Cerebral Palsy of Central Arizona

USDOE/OSEP

Dwight Thomas

Valle Del Sol

Sabrina Nelsen

Valley of the Sun United Way

Washington Elementary School District

Gayle Wynam

Wilson Elementary School

Luz Rios

Youth Evaluation and Treatment Center

Susan Cano

Volunteers are the heart of Raising Special Kids

Thank You!

November 2009 - January,
2010

Avondale

Gabriela Sanchez-Orozco

Chandler

Brenda Crockett

Beth Maloney

Shelby Willa

Gilbert

Carol & Chad Boyd

Paul Lucas

Derrill Wolkins

Glendale

Dawn Kurbat

Marci Monaghan

CeeCee Tassineri

Kingman

Art Gode

Mesa

Jennifer Adler

Evangeline Buckley

Kim Cohill

Cindy Floyd

Nancy Garner

Peoria

Steve French

Mark Mucklow

Tricia Mucklow

Niccole & Jason Swim

Phoenix

Julie Atkinson

Rebecca Bailey

Paula Banahan

Renee Behl

Inilda Christensen

Nancy Gunderson

Sharon Hayes

Maureen Mills

Claudia Olivas

Ched Salasek

Lori Stuart

Leslie Williams

Scottsdale

Chris Atherton

Shaunai Miller

Katie Petersen

Mary Quinsler

Sun Lakes

Philip Sanabria

Surprise

Margie Yaw-Mehlos

Tempe

Mike Doherty

Waddell

Candace Ann Floyd

Our sincere thanks go to
Salesforce.com
Foundation
for their generous gift of software

Raising Special Kids
5025 E. Washington, Suite #204
Phoenix, AZ 85034

NONPROFIT ORG.
U.S. POSTAGE
PAID
PHOENIX, ARIZONA
PERMIT NO. 2017



Mark your calendar for the 25th Annual

A Special Day for Special Kids!

Sponsored by Scottsdale Sunrise Rotary Club,
Phoenix El Puente Rotary, Raising Special Kids &
Scottsdale Unified School District Service Learning Classes

Saturday, March 27, 2010
10 am - 2 pm

McCormick-Stillman Railroad Park, Scottsdale
(located on the southwest corner of Indian Bend and Scottsdale roads)

Please join us for **FREE** train rides, carnival activities, carousel rides, games, activity booths, clowns, face painting, petting zoo, plus lots of food and ice cream...all for **FREE!**

Register on the day of the event.

Questions? Contact Dan McAuliffe 480-624-2338 or Al Chaves (En Espanol) 480-314-4729

www.raisingpecialkids.org