



**Raising  
Special Kids**  
*families helping families*

# Connecting

## Connect

*Family Support is the Heart of our Mission.*

March - May, 2009

Volume 14, Number 1

## Learning social skills

### *More than just having fun*

Manners, etiquette, theory of mind, and being “good with people” are terms that describe a person’s ability to start and maintain positive relationships with others. These are important aspects of human development, and are generally defined as social skills.

Teaching the fundamentals of appropriate social interaction is primarily the job of parents, but sometimes additional help is needed. Modern lifestyles often contribute to children spending increasing amounts of time away from their parents, with fewer opportunities for “teachable moments” and less time for parentally supervised practice. Social learning opportunities may be further limited by the popularity of leisure activities which involve television or electronic devices. Instead of engaging in personal interactions and play behavior which develops emotional intelligence, children may lack enough opportunities for acquiring social skills.

The presence of a disability can further impact a child’s progress in developing social skills.

Impairments in mobility, behavior, speech and language, nonverbal communication, vision, hearing, or other special health needs may affect the way a child perceives, interprets or reacts to communication and social cues.



Isolation from peers, physical communication difficulties, impaired social understanding and other factors all play a role in limiting a child’s ability to learn and demonstrate essential skills needed throughout life, and in nearly every aspect of daily living. “The importance of social competence cannot be overestimated, as it is associated with peer acceptance, academic achievement, and employment success.” commented Linda and Nick Elksnin in an LDonline.org article.

Various studies have shown that students with disabilities are more likely to have deficits in social skills—one showed 75% of children with learning disabilities exhibited social skills deficits. “What many parents and educators don’t realize is that having a learning problem can also impair a child’s social skills and prevent him from having successful relationships with family members, peers, and other adults,” notes Kristin Stanberry in an article examining connections between learning disabilities and social skills.

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**SEE PAGE 12 FOR SHARING  
PARENT WISDOM**

Are you worried about cuts in services?  
Please call us at 602-242-4366 or 800-237-3007

# Director's Column

Like many of you, my thoughts have been focused on the reality of our state's budget crisis, and the impact it's having on families of children with disabilities and special health needs. While understanding the extremely difficult task facing the governor and our legislators, some degree of moral outrage is understandable and even necessary. Systems designed and built over many years to care for the most vulnerable children and adults are far more fragile than we ever imagined. We've seen a great unmasking of some of the assumptions we've made about our systems of care, our elected representatives, and the capacity of our state to manage its fiscal responsibilities. (As a percentage of total budget, Arizona's deficit is the largest in the nation).

In some cases, infants and toddlers with disabilities will lose services because they were "assigned" to a different category of funding eligibility, one supported only by state funds. In other areas, certain essential services were never fully funded, and their continuation depended on some form of annual financial maneuvering and cost-shifting. Arizona's legislators stressed the importance of tax cuts, and now a preference for massive cuts in services, to align with their views about small government.

It reminds me that I once volunteered to work at a food bank. I was amazed when I arrived to find a 50,000 square foot warehouse stocked with salvaged food. Surely, there couldn't be many hungry people in my community. I had never known them, and they didn't live on my street, so therefore they didn't exist. After seeing all the community agencies and church pantries that depended on the food bank to help them meet the needs, I developed a new realization of the extent of hunger and poverty.

When I volunteered for a domestic violence hotline, I was amazed at the number of women turned away when there was no more room available for abused mothers and their children. I discovered a new understanding of what it means to be desperate and have nowhere safe to go. Turns out, it was my thinking that was small. Small thinking and small government; maybe it's time to ask whether these two things go together.



**Raising  
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*families helping families*

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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.

# Raising Special Kids Calendar

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

## Raising Special Kids Hosted Events, Training & Workshops

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

All trainings listed below are offered at the new office building for Raising Special Kids. If you require special accommodations to attend a Raising Special Kids sponsored activity, please notify us at least 48 hours in advance.

Please register for trainings, so we can notify you if the class must be cancelled due to insufficient registrants.

### Volunteer Training

Fri. 3/20/09, 10:00-11:30 a.m.  
Wed. 3/25/09, 1:30-3:00 p.m.  
Fri. 4/17/09, 10:00-11:30 a.m.  
Wed. 4/22/09, 1:30-3:00 p.m.  
Fri. 5/15/09, 10:00-11:30 a.m.  
Wed. 5/27/09, 1:30-3:00 p.m.

### Positive Behavior Support

Training on positive techniques for families of children who have behavior issues

Wed. 3/11/09, 10:00-11:30 a.m.  
Thu. 3/26/09, 1:00-2:30 p.m.  
Wed. 4/8/09, 10:00-11:30 a.m.  
Thu. 4/23/09, 1:00-2:30 p.m.  
Wed. 5/13/09, 10:00-11:30 a.m.  
Thu. 5/28/09, 1:30-3:00 p.m.

### Resilient Relationships

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

Fri. 3/13/09, 10:00-11:30 a.m.  
Fri. 4/10/09, 10:00-11:30 a.m.  
Fri. 5/8/09, 10:00-11:30 a.m.

### Can you hear me now?

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

Wed. 3/18/09, 10:00-11:30 a.m.  
Thu. 4/2/09, 1:00-2:30 p.m.  
Wed. 4/15/09, 10:00-11:30 a.m.  
Thu. 5/7/09, 1:00-2:30 p.m.  
Wed. 5/20/09, 10:00-11:30 a.m.

### Sibshop

Workshop for brothers and sisters of children with disabilities or special needs.

March 28th, 2009, 10-2

Location: Hospice of the Valley:  
1510 East Flower Street, PHX

Cost: \$15.00, lunch included  
Please register at 602-200-0767

### Special Education Workshops

Workshops can also be scheduled at your organization upon request (with a minimum of 5 participants) call 602-242-4366.

#### Parents' Rights in Special Education

Learn about the rights and responsibilities of parents in special education.

Thu. 3/26/09 3:00-4:30 p.m.  
Wed. 4/15/09 3:00-4:30 p.m.  
Wed. 5/13/09, 1:30 – 3:00 p.m.

#### Understanding 504

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

Thu. 3/19/09 3:00-4:30 p.m.  
Wed. 4/22/09 3:30-5:00 p.m.

#### AzIEP to Preschool Transition

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

Mon. 3/16/09 10:00-11:30 a.m.  
Wed. 4/8/09 3:00-4:30 p.m.

#### Parents as Advocates

Learn effective ways for parents to advocate for their child to receive appropriate services.

Thu. 4/2/09 3:00-4:30 p.m.  
Wed. 5/6/09, 10:00 – 11:30 a.m.

#### Parent/Professional Collaboration

Learn ways parents and professionals can develop positive working relationships.

Mon. 4/6/09 3:00-4:30 p.m.

Spanish workshops - pg. 12  
Calendario - en la página 12

[www.raisingpecialkids.org](http://www.raisingpecialkids.org)

#### Self-Advocacy for Youth

Learn how students can independently advocate for themselves.

Wed. 3/25/09 4:00-6:00 p.m.

#### High School Transition

Learn how to prepare youth for transition out of high school to post-secondary education, employment, and life in the community.

Wed. 3/18/09 3:00-5:00 p.m.  
Wed. 4/29/09 4:00-6:00 p.m.  
Wed. 5/20/09, 4:00 – 6:00 p.m.

#### Understanding the IEP

Learn about the purpose of IEPs through an overview of the document and meeting.

Thu. 4/16/09 10:00-11:30 a.m.

#### Organizing Your Child's Records

Learn effective ways to tame that pile of papers.

Wed. 3/11/09 3:00-4:30  
Wed. 5/13/09, 3:30 – 5:30 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.

#### Flagstaff Workshops

Flagstaff Family Resource Center  
5-7 pm

Advanced IEP      504 Plans  
March 18              May 20

Advocacy  
April 15

James P. Krehbiel, Ed.S., LPC, CCBT, a Scottsdale therapist who also cites 30 years experience in education explained that learning social skills is “one of the areas that is most important to look at for kids with disabilities.”

Communication or language involves more than verbal expression and words. Body language, facial expression, tone of voice, and other nonverbal cues convey far more meaning than words taken at face value. Social skills competency also involves being able to correctly interpret and respond to nonverbal communication.

Recent research on developing social skills has been focused on children with autism, ADHD, and behavioral issues, but many disabilities or perceived differences can affect a child’s interaction with others children and adults. A

mother whose teenage daughter has cerebral palsy and hearing impairment recently noted, “It’s difficult to overcome those social obstacles. For us, it is still the mom-and-daughter-show

on the weekends. Nobody is calling her to join in the typical teenage activities.”

Growing recognition of the social impacts of bullying and other factors that lead to social isolation has spurred many schools to implement programs often referred to as “character education” to address a general need for improved social skills. While these programs can be helpful in improving school environments, children with disabilities may need alternate

approaches or additional help to learn the skills needed for social acceptance.

“We get so many calls from parents looking for social skills building opportunities,” said

Vickie French, Director of Parent Support at Raising Special Kids. “They are often looking for programs or activities that

will offer their child not only a safe place to meet and socialize with peers, but one that can offer targeted support for developing specific skills their child needs.”

Programs that are effective and accessible can be hard to find.

Social skills training is offered through a variety of sources.

Providers include psychologists,

social workers, speech and language therapists, teachers, music therapists, equine therapists, and habilitation-communication providers.

Arizona’s list of providers that may specialize in social

skills training include Behavior Analysts. “There are about 19 Board Certified Behavior Analysts in Arizona at this time notes Diana

Davis of Hope Group, a statewide provider specializing in Applied Behavior Analysis (ABA).

Some schools and guidance counselors offer social groups for children determined to be at risk

due to various factors. Before participating in a social skills group, parents may want to first ask whether the activities are

following a curriculum, and how the needs of individual students are addressed. It may be difficult to judge whether a program will benefit a particular child, especially if a proven curriculum is not being used. Many children will require practice in actual social settings, and may not be able to generalize information acquired from a group and later apply it to activities of daily life. Studies have not been conclusive in showing how effective groups are in helping children with disabilities improve their overall social competence.

“For teachers, it is important to look at this with a two-prong approach,” said Krehbiel. “Schools must address the needs of kids with disabilities, and also encourage acceptance of differences by all the kids.”

This idea is echoed in Arizona’s Parent Information Network’s

“Children with poor social skills are at risk for delinquency, academic underachievement, and school drop out...”

— Anthony Kane, MD, author and specialist in parenting

“A child’s manners or social skills are appropriate topics to bring up during a pediatric visit...Social skills are necessary for school success...they affect how you do on the playground, in the classroom, in the workplace.”

— article in NY Times by Perri Klass, M.D. 1/12/09

#### More on the web:

NICHCY: <http://research.nichcy.org/MetaAnalysis.asp?ID=141>

LD Online: search for “social skills” or any article by Rick Lavoie such as: <http://www.ldonline.org/article/14910>

Wings for Kids: <http://wingsforkids.org/experience/hot-wings?gclid=CO6k0PqZuZcCFRlCawodDXMxSg>

Family Connection: [http://www.family-connection.org/social\\_skills\\_training.htm](http://www.family-connection.org/social_skills_training.htm)

Ian Community: [http://www.iancommunity.org/cs/ian\\_research\\_reports/treatment\\_series\\_social\\_skills\\_groups](http://www.iancommunity.org/cs/ian_research_reports/treatment_series_social_skills_groups)

Article on Behavior Imaging: <http://www.newswiretoday.com/news/46497/>

(PINS') publication on Positive Behavior Interventions and Support (PBIS) and the IEP which outlines the use of Functional Behavioral Assessments:

*"When the student seeks to obtain peer attention or social interaction with peers:*

- *Directly teach relevant social interaction skills, practice in context, and give positive reinforcement when skills are used.*
- *Teach all students about accepting and including others, and review these expectations frequently.*
- *Teach all students words and strategies to use if others are trying to get their attention in an unwelcome way."*



*Music Therapy can include addressing social skills development.*

Social groups can offer the benefit of being a positive environment in which kids can socialize with peers, share problems and discuss options, but whether they are successful at helping kids learn functional skills that they can or will use in other situations is not yet clear. "There is a big difference between socializing and teaching social skills," says Jessica Irwin, director of S.E.E.K. Arizona which specializes in therapy and direct care services for children with developmental disabilities. "It is important to teach kids these skills in order to have fulfilling



*Equine Therapy: "We spend time in the barn teaching body language...a horse's reaction is as good or better feedback than a person's," explained Mary Hadsall, Executive Director of Camelot Therapeutic Horsemanship.*

interactions with peers."

While best practices are not standardized in social skills training, there are some tested curricula available. Emphasis is generally placed on methods that employ positive reinforcement and take place in a natural environment or teach how to generalize skills for use in variable situations. Thomas McIntyre notes in an LDOnline article, "We must move beyond simply telling them to stop what they are doing wrong. While we might tell them which behaviors to avoid, we then need to teach them what they should be doing in those situations."

Program styles differ, and it may take some research to find which is the best approach for your child. Krehbiel has designed social group therapies to include talk time (discussion of issues), skill time (pairing participants to practice skills), and game time (focus on team building concepts).

S.E.E.K. offers a social group for boys on the autism spectrum designed to give the participants a number of sessions to become comfortable with each other while developing basic skills such as

sharing and taking turns. Then more challenging social situations are introduced under the guidance of staff to address increasingly complex skills such as negotiation, compromising and awareness of other's feelings.

Alternate resources that may be useful tools include software, videos, written curricula and age appropriate books. Each child has unique learning needs. While reading or watching a program may be a preferred method for some students to acquire knowledge, opportunities for practicing learned skills are essential. Participation in extra curricular activities, clubs, play groups, sports or other areas of interest is a critical component of any social learning program.

Finding services that address the specific needs of your child can be a challenge. Parents face difficulties in locating and affording providers, and they may need to employ creative solutions that combine varied approaches. Continuous positive reinforcement by parents and caretakers in natural social settings is one of the most important things we do for our children.

# Education

## Special Education

### Why do you need to know about state standards for learning?

Have you ever asked yourself, “How does a child get to receive special education?” or “What is the school trying to teach my child?” If so, you probably aren’t alone.

Special education decisions and services can be broken down into four steps:

1. **Evaluations and assessments** to diagnose your child’s educational or developmental learning needs and determine if your child is eligible for special education or related services;
2. If eligible, **development of an IEP** (Individualized Education Plan) to guide school staff in modifying teaching materials, methods, or the educational setting;
3. **Determination of the types of services** needed and in what learning setting your child will make the most progress toward achieving IEP goals; and
4. **Monitoring and assessments** of the progress your child is making toward meeting the IEP goals and information for revising the IEP if needed.

Both general education teachers and special education staff are expected to develop IEP goals and design their instruction to line up with the state standards set for all children. This is to ensure that children receiving special education services are making progress in the general curriculum. State standards are broken into three sets according to a child’s level of functioning and age or grade:

- *Early Learning Standards*
- *Arizona Academic Standards*
- *Alternate Academic Standards*

For preschool children, the Early Learning Standards give a range of concepts and skills that children age 3-5 would understand before entering kindergarten. The Early Learning Standards give examples of types of activities teachers might include in their lesson plans. To view them online, go to [www.azed.gov/earlychildhood/downloads/EarlyLearningStandards.pdf](http://www.azed.gov/earlychildhood/downloads/EarlyLearningStandards.pdf) or contact the Arizona Department of Education/Early Childhood Education Unit at 602-364-1530.



**Early childhood** special education teachers are expected to provide activities that build upon a child’s

own developmental learning levels and Early Learning Standards. These standards include: Social & Emotional, Language & Literacy, Mathematics, Science, Social Studies, Physical Development, Health & Safety, and Fine Arts.

Children in grades **kindergarten through 12th grade** are expected to learn the skills and concepts for their grade level in the Arizona Academic Standards.

These standards are broken into the following: Arts, Comprehensive Health & Physical Education, Foreign & Native Language, Language Arts (Reading & Writing), Mathematics, Science, Social Studies, Technology, and Workplace Skills (**including social skills.**) To view them online, go to [www.ade.state.az.us/standards/cont](http://www.ade.state.az.us/standards/cont)



[entstandards.asp](http://entstandards.asp) or contact the Arizona Department of Education/Standards & Assessment Division at 602-364-2267.

A majority of school-aged children receiving special education have IEP goals that are tied to the Arizona Academic Standards. Special education students whose present levels of functioning are at the pre-academic level will generally be expected to work on meeting Alternate Academic Standards before working on the Arizona’s Academic Standards. Alternate Academic Standards include: Mathematics, Reading, Writing, Science, Comprehensive Health, Workplace Skills, and Listening & Speaking. To view them on-line, go to:

[www.ade.az.gov/ess/SpecialProjects/aims-a/](http://www.ade.az.gov/ess/SpecialProjects/aims-a/) or contact the Arizona Department of Education/Exceptional Student Services at 602-364-2811.

The intent of special education is to assist children to make progress in both academic and functional performance (engagement, independence or social skills). State standards provide a common expectation level for schools to measure a child’s performance from preschool through high school.

If parents and teachers continue to check a child’s progress in reaching the standards, they can more specifically design IEP goals, instruction, and accommodations to enhance the child’s educational achievement.

# Health

## How does your child's care rate?

### A "Family-Centered Care Self-Assessment Tool"

A new questionnaire is now available to help families and healthcare providers learn more about family-centered care and how it can be implemented in a healthcare setting. There are two versions of the "Family-Centered Care Self-Assessment Tool" – one for families, and one for providers. The questions in these booklets describe various aspects of family-centered care in detail, with the user ratings about the level of care. The tools are not meant to score "family-centeredness" – rather, to identify current strengths and opportunities for improvement.

The tool was developed by Family Voices, a national network of family organizations that focuses on healthcare issues related to children and youth with special needs; funding for the project was provided by the federal Maternal and Child Health Bureau.

#### Sample Questions for Families:

- Does your provider:
  - *work together with your family so you can explain how your child's diagnosis might affect how she will be able to participate in school, social, community and faith-based activities?*
  - *ask your family & child/youth to share information, such as changes in daily routine or new stresses that may provide insight into the interpretation of test results or diagnostic procedures?*
  - *fully inform your family about diagnostic and treatment options in a way you can understand?*
  - *ask about your family's concerns and any stresses or successes you may experience as a caregiver?*
  - *allow your family or youth to add information into the medical record?*
  - *offer your child/youth educational opportunities to support self-care? (e.g. know how to make appointments, learn about insurance, medications, diet, and other aspects of health care)*

#### Sample Questions for Providers:

- *Do you and your staff honor families' requests for others (extended family, community elders, faith leaders or traditional healers) to participate in the process that leads to decisions about care?*
- *When deciding treatment options, do you and your staff work with the family and child/youth to decide what the desired outcomes are (e.g. improved health*

*status, better school attendance, less pain, better involvement with social or sports activities)?*

- *Do choices of diagnostic and treatment approaches take into account family and child/youth work and school schedules?*
- *Do you and your staff have a formal mechanism to identify adult health care providers for youth in transition?*

#### Tools for download (free)

Family Tool:

[http://www.familyvoices.org/pub/projects/fcca\\_FamilyTool.pdf](http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf)

Provider Tool:

[http://www.familyvoices.org/pub/projects/fcca\\_ProviderTool.pdf](http://www.familyvoices.org/pub/projects/fcca_ProviderTool.pdf)

User's Guide:

[http://www.familyvoices.org/pub/projects/fcca\\_UsersGuide.pdf](http://www.familyvoices.org/pub/projects/fcca_UsersGuide.pdf)

To receive the Tools via Mail (1st copy sent free; additional copies require payment for postage):  
Contact Family Voices national office by Phone:  
(505) 872-4774 or toll-free at (888) 835-5669 or by  
Email: [catalog@familyvoices.org](mailto:catalog@familyvoices.org)

## Principles of family-centered care for children

*Based on a partnership between families and healthcare professionals, family-centered care:*

1. *Acknowledges the family as the constant in a child's life.*
2. *Builds on family strengths.*
3. *Supports the child in learning about and participating in his/her care and decision-making.*
4. *Honors cultural diversity and family traditions.*
5. *Recognizes the importance of community-based services.*
6. *Promotes an individual and developmental approach.*
7. *Encourages family-to-family and peer support.*
8. *Supports youth as they transition to adulthood.*
9. *Develops policies, practices, and systems that are family-friendly and family-centered in all settings.*
10. *Celebrates successes.*

# Legislative Resources

From the Governor's Council on Developmental Disabilities

As a means of familiarizing individuals with disabilities, families, and community members with the legislative process and effective advocacy methods, the Council Staff is conducting Legislative Trainings throughout the state. For a complete list of Legislative Trainings that are being conducted in your area, please visit [http://www.azgcdd.org/Legislative\\_Training.asp](http://www.azgcdd.org/Legislative_Training.asp)

## Legislative Advocacy Card:

For additional supports when contacting legislators, testifying before legislative committees, and/or educating community members, the Council, in conjunction with the Self Advocacy Coalition of Arizona, has developed the Legislative Advocacy Card. The Legislative Advocacy Card will provide you with helpful guidelines when developing talking points and important information to remember when communicating with policymakers. To access the Legislative Advocacy Card, link here: <http://www.azgcdd.org/Policy%20Cards%20SAC%20of%20AZ%20-%20electronic.pdf>

## Get Free Tax Help

Certified Volunteer Income Tax Assistance Program

IRS Certified Volunteers will prepare your 2008 tax return free of charge if you have an income of \$42,000 or less! For VITA Site locations call Community Information and Referral: 1-800-352-3792

There are many credits taxpayers may take for various life events that often go overlooked. Below are just a few credits specifically for families, taken from the Internal Revenue Service website ([www.irs.gov](http://www.irs.gov)).

- *The Earned Income Tax Credit: (EITC) sometimes called the Earned Income Credit (EIC), is a refundable federal income tax credit for working individuals and families who earn low incomes.*
- *Child and Dependent Care Credit: If you paid someone to care for a child or a dependent so you could work, you may be able to reduce your tax by claiming the credit for child and dependent care expenses on your federal income tax return.*
- *Child Tax Credit: With the Child Tax Credit, you may be able to reduce the federal income tax you owe by up to \$1,000 for each qualifying child under age 17.*

## Legislative Consortium:

The Council's Legislative Consortium is designed to support advocacy efforts relative to important legislative issues impacting the lives of individuals with disabilities, family members, and community members. For more information on how to participate in the Council's Legislative Consortium, link here: <http://www.azgcdd.org/LegislativeConsortiumMeetingSchedule.asp>

## Bill Tracking Chart:

For information regarding legislation with potential impact to Arizonans with disabilities and their families in the 2009 legislative session, please access the most recent Governor's Council on Developmental Disabilities Bill Tracking Chart: <http://www.azcapitol-reports.com/webreport.cfm?webreport=397&listid=13629>

## Additional Legislative Resources:

To access additional resources relative to the legislative process, locating your legislators, researching legislation, or garnering additional supports, please reference the following Legislative Resources document: [http://www.azgcdd.org/Legislative\\_Resources\\_2009.pdf](http://www.azgcdd.org/Legislative_Resources_2009.pdf)

The following documents are needed if you decide to come to a VITA Site:

- *Proof of identification*
- *Social Security Cards for you, your spouse and dependents and/or a Social Security Number verification letter issued by the Social Security Administration*
- *Birth dates for you, your spouse and dependents on the tax return*
- *Current year's tax package if you received one*
- *Wage and earning statement(s) Form W-2, W-2G, 1099-R, from all employers*
- *Interest and dividend statements from banks (Forms 1099)*
- *A copy of last year's federal and state returns if available*
- *Bank routing numbers and account numbers for Direct Deposit*
- *Total paid for day care provider and the day care provider's tax identifying number (the provider's Social Security Number or the provider's business Employer Identification Number)*

## Profile of Excellence

### *A pioneer parent advocate*

During her pregnancy, Paula Banahan “knew in my heart” one of the twins she was expecting had Down Syndrome. But she did not expect it to be so difficult to confirm a diagnosis. One of the harder challenges she faced was just after the twins’ birth as she tried to convince her doctors to run a blood test on her new born daughter.

“They assured me repeatedly that she was normal,” explained Paula. “I said, ‘I know she is normal, but I also think she has Down Syndrome. And I am not signing the hospital discharge papers until you test for it.’”

18½ years later, Paula still loves to tell that story to the physician residents that she hosts in her home as a volunteer for Raising Special Kids. And her daughter, Julia, has enjoyed relating the story in her presentations to ASU students studying special education. She began doing presenta-

tions in 5th grade at her mother’s side, and now is a confident speaker and self advocate.

When the twins were one year old, the family moved to Arizona and Paula found Raising Special Kids (known then as Pilot Parents). She soon became a parent volunteer and has developed a lifetime of experience advocating for her daughter. And with terrific success—Julia graduated high school with a diploma alongside her twin, and she is now preparing to begin studies in a Veterinary Assistant program.

“When I have a question or when I have a difficult decision to make, I always go to Raising Special Kids’ newsletter and see if there is a seminar on the subject,” explained Paula. “I feel that I am fairly knowledgeable about most things that Julia has challenging



*Julia and Paula Banahan*

her, but that is not to say I can't learn something! The folks at Raising Special Kids are so extraordinary and never make you feel that you aren't smart, so it's a safe environment to ask any question, and I mean any question!!

“I recently attended a self-advocacy and transition workshop with Julia and felt they both provided helpful facts and tips on things I have not thought of. I especially love how staff talk with Julia and ask her opinion, instead of asking me what she thinks.”

## DDD Family Forum

Raising Special Kids hosted a Family Forum that brought 23 family members together with three senior representatives from the Division of Developmental Disabilities for constructive dialogue on delivery of services.

Parents had the opportunity to offer input and receive direct responses. DDD staff were able to get firsthand feedback in “real time.” Here are some of the comments heard at the forum:

“I thought this was an amazing idea and went very well. Thank

you for the opportunity to share my ideas and experiences! And to answer my questions.

“It was a great opportunity to share our comments with DDD representatives and I appreciate your inviting me. I hope to do this again soon, so that we can keep the positive lines of communication open.”

“It is always encouraging to share openly with others and know that they truly understand the difficulties in raising a child with special needs. “



*(Top) Spanish speaking families share their stories. (Bottom) DDD District Program Manager Al Nieto (far right) and other staff exchanged ideas and information with families members of children served by DDD.*

## Aprendiendo habilidades sociales

Más que una diversión

Los modales, la etiqueta, la teoría de la mente y de ser “buenos con la gente” son términos que describen la capacidad de una persona para iniciar y mantener relaciones positivas con otras personas. Éstos son aspectos importantes del desarrollo humano y generalmente se definen como habilidades sociales.

Enseñar los fundamentos de la interacción social apropiada es principalmente el trabajo de los padres, pero a veces se necesita ayuda adicional. Los estilos de vida modernos frecuentemente contribuyen a

que los niños pasen cada vez más tiempo lejos de sus padres, que cuenten con menos oportunidades de disfrutar “momentos de enseñanza” y menos tiempo en práctica supervisada por los padres de familia. Las oportunidades de aprendizaje social pueden ser

aún más limitadas por la popularidad de las actividades recreativas que incluyen la televisión y otros aparatos electrónicos. En lugar de participar en interacciones personales y en comportamiento que desarrolle la inteligencia emocional, los niños pueden ser privados de oportunidades esenciales para adquirir habilidades sociales.

La presencia de una discapacidad puede afectar aún más el avance de un/a niño/a dentro del desarrollo de habilidades sociales. Problemas de movilidad, comportamiento, habla o lenguaje, comunicación no verbal, vista, oído u otras necesidades espe-

ciales de salud, pueden afectar la forma en la cual un/a niño/a percibe, interpreta o reacciona a la comunicación y las claves sociales. El aislamiento de los compañeros, las dificultades físicas comunicándose, la incapacidad del entendimiento social y otros factores, juegan un papel limitando la capacidad de los niños para aprender y demostrar habilidades esenciales necesarias de por vida, y en casi cada aspecto de la vida diaria. “La importancia de la competencia social no puede ser

sobreestimada, pues está asociada con la aceptación de los compañeros, los logros académicos y el éxito en el empleo”, comentaron Linda y Nick Elksnin en un artículo de LDonline.org.\*\*\*

Varios estudios han demostrado que es más probable que los estudiantes con discapacidades tengan déficits en habilidades sociales—uno demostró que el 75% de los niños con discapacidades de aprendizaje mostraron déficits en habilidades sociales. “Muchos padres de familia y educadores no entienden que un problema del aprendizaje también puede afectar las habilidades sociales del niño e impedirle que tenga relaciones exitosas con miembros de la familia, compañeros y otros adultos”, señala Kristin Stanberry en un artículo que examina las conexiones entre las discapacidades del aprendizaje y las habilidades sociales.\*\*

James P. Krehbiel, Ed.S., LPC,

CCBT, terapeuta de Scottsdale con 30 años de experiencia en educación, explicó que el aprendizaje de habilidades sociales es “una de las áreas más importantes que deben observarse en los niños con discapacidades.”

La comunicación o el lenguaje incluyen más que la expresión verbal y las palabras. El lenguaje corporal, la expresión facial, el tono de voz y otras claves no verbales comunican mucho más significado que las palabras en sí. La competencia en habilidades sociales también incluye el poder interpretar y responder correctamente a la comunicación no verbal.

La investigación reciente sobre el desarrollo de habilidades sociales se ha centrado en niños con autismo, trastorno de déficit de atención e hiperactividad (ADHD por sus siglas en inglés) y problemas del comportamiento, pero muchas discapacidades o diferencias percibidas pueden afectar la interacción de un niño con otros niños y adultos. Una madre cuya hija adolescente tiene parálisis cerebral y discapacidad auditiva, recientemente hizo notar: “Es difícil superar esos obstáculos sociales. Para nosotros, sigue siendo el espectáculo de mamá e hija los fines de semana. Nadie la llama para que participe en las actividades típicas de adolescentes.”

Un reconocimiento cada vez mayor de los impactos sociales de intimidación escolar (bullying) y otros factores que conducen al aislamiento social han conducido a las escuelas a implementar programas frecuentemente referidos como “educación del carácter” para atender una necesidad general de mejores habilidades sociales. Si bien estos programas pueden ser de ayuda para mejorar los ambientes escolares, los

“Los modales o habilidades sociales de un niño son temas apropiados a tomar durante una visita al pediatra... Las habilidades sociales son necesarias para el éxito escolar... afectan cómo se desenvuelven en el patio de recreo, en el salón de clases, en el lugar de trabajo.” – artículo de la publicación New York Times por el Dr. Perri Klass, 1/12/09

niños con discapacidades pueden necesitar enfoques alternos o ayuda adicional para aprender las habilidades necesarias para la aceptación social.

“También recibimos muchas llamadas de padres de familia que buscan oportunidades para edificar habilidades sociales”, dijo Vickie French, Directora de Apoyo a los Padres en Raising Special Kids. “Frecuentemente están buscando programas o actividades que ofrecerán a su niño no sólo un lugar seguro dónde reunirse y socializar con compañeros, sino uno que pueda ofrecer apoyo dirigido para desarrollar las habilidades sociales que necesitan sus hijos.”

Los programas que son efectivos y accesibles pueden ser difíciles de encontrar.

La capacitación en habilidades sociales se ofrece a través de varias fuentes. Los proveedores incluyen psicólogos, trabajadores sociales, terapeutas del habla y del lenguaje, maestros, terapeutas de música, terapeutas equinos y proveedores de habilitación-comunicación. La lista de proveedores de Arizona que pueden especializarse en la capacitación en habilidades sociales incluye el Análisis del Comportamiento. “Ahora, hay cerca de 19 Analistas del Comportamiento Certificados por la Junta Directiva en Arizona, señala Diana Davis del grupo Hope Group, proveedor a través de todo el estado especializado en Análisis del Comportamiento Aplicado (ABA por sus siglas en inglés).

Algunas escuelas y asesores de guía ofrecen grupos sociales para niños a quienes se ha determinado que están a riesgo debido a varios factores. Antes de participar en un grupo de habilidades sociales, los padres de familia pueden querer preguntar primero si las actividades están siguiendo un programa de estudio, y cómo son satisfechas las necesidades individuales de los estu-

diantes. Puede ser difícil juzgar si el programa beneficiará a un niño en particular, especialmente si no se está usando un programa comprobado de estudio. Muchos niños requerirán práctica en ambientes sociales reales, y podrían no tener la capacidad de generalizar la información adquirida en un grupo y después aplicarla a actividades de la vida cotidiana. Los estudios no han sido concluyentes en demostrar qué tan efectivos son los grupos para ayudar a los niños con discapacidades a mejorar su competencia social global.

“Para los maestros, es importante que observen esto desde dos puntos de vista”, dijo Krehbiel. “Las escuelas deben satisfacer las necesidades de los niños con discapacidades, y también fomentar la aceptación de diferencias por todos los niños.”

Esta idea es repetida en la publicación de la Red de Información de Padres de Familia de Arizona (PINS’ por sus siglas en inglés), con respecto a Intervenciones y Apoyo de Comportamiento Positivo (PBIS por sus siglas en inglés) y el plan individual “IEP\*\*\*\*\*” que esboza el uso de Evaluaciones del Comportamiento Funcional:

- “Cuando el/la estudiante busca obtener la atención de los compañeros o interacción social con compañeros:
- *Directamente enseña habilidades de interacción social relevantes, practica en contexto y da refuerzo positivo cuando se usan las habilidades.*
  - *Enseña a todos los estudiantes a aceptar e incluir a otros, y revisa estas expectativas frecuentemente.*
  - *Enseña a todos los estudiantes palabras y estrategias que pueden usar, si otros están tratando de lla-*

*mar su atención de una manera desagradable.”*

Los grupos sociales pueden ofrecer el beneficio de un ambiente positivo en el que los niños pueden socializar con compañeros, compartir problemas y hablar sobre opciones, pero el que sean exitosos ayudando a los niños a aprender habilidades funcionales que podrán usar o usarán en otras situaciones no está claro aún. “Hay una gran diferencia entre socializar y enseñar habilidades sociales”, dice Jessica Irwin, directora de S.E.E.K. Arizona, quien se especializa en terapia y servicios de cuidado directo para niños con discapacidades del desarrollo. “Es importante enseñar estas habilidades a los niños para que puedan tener interacciones gratificantes con sus compañeros.”

Si bien las mejores prácticas no han sido estandarizadas en la capacitación de habilidades sociales, hay algunos programas de estudio probados disponibles. Generalmente el énfasis se pone en métodos que emplean el reforzamiento positivo y suceden en un

ambiente natural, o enseñan cómo generalizar habilidades para usarlas en distintas situaciones. Thomas McIntyre señala en un artículo de LDOnline, “Debemos ir más allá de simplemente decirles que dejen de hacer lo que están haciendo mal. Si podemos decirles qué comportamientos evitar, entonces necesitamos enseñarles qué deberían hacer en esas situaciones.”\*

Los estilos de programas son diferentes y puede requerirse hacer algo de investigación para encontrar cuál es el mejor enfoque para su niño/a. Krehbiel ha diseñado terapias de grupos sociales para incluir terapia hablando (hablando sobre proble-

“Los niños con habilidades sociales pobres están a riesgo de la delincuencia, el logro académico insuficiente y el abandono escolar,” señala el —Dr. Anthony Kane, autor y especialista en crianza de los hijos.

# Worth Noting

mas), tiempo para habilidades (formar parejas de participantes para practicar habilidades) y tiempo para juego (enfocado en conceptos para forjar equipos).

S.E.E.K. ofrece un grupo social para niños dentro del espectro del autismo, diseñados para dar a los participantes varias sesiones con el fin de que se sientan cómodos unos con los otros, mientras que desarrollan habilidades básicas como compartir y tomar turnos. Después, se van presentando situaciones sociales más desafiantes bajo la guía del personal, para atender habilidades cada vez más complejas, como la negociación, llegando a acuerdos, y estar conscientes de los sentimientos de otros.

Los recursos alternos que pueden ser herramientas útiles incluyen programas de computación (software), videos, programas de estudio por escrito y libros apropiados para la edad. Cada niño/a tiene necesidades particulares de aprendizaje. Si bien leer o ver un programa puede ser un método preferido para que algunos estudiantes adquieran conocimiento, las oportunidades para practicar las habilidades aprendidas son muy importantes. La participación en actividades extra curriculares, clubes, grupos de juego, deportes u otras áreas de interés es un componente muy importante de cualquier programa de aprendizaje social.

Encontrar servicios que satisfagan las necesidades específicas de su niño/a puede ser un reto. Los padres de familia se enfrentan a dificultades para localizar y poder pagar a los proveedores, y pueden necesitar emplear soluciones creativas que combinen enfoques variados. El refuerzo positivo continuo por parte de los padres de familia y cuidadores en ambientes sociales naturales, es una de las cosas más importantes que hacemos para nuestros niños.

## Parent wisdom

### Sharing the experience of real parents

Raising Special Kids invites families to share wisdom they've gained from the experience of raising a child with a disability or special health care need. Below are some excerpts from answers we received to the question in our last issue. To view the complete answers, log on to our website's Family Voice page at: <http://www.raisingpecialkids.org/news/familyvoice.aspx>

#### Question:

**How can I respond effectively when people comment on my child's disability in public?**

#### Answers:

- *"Humor always worked for us. My daughter's smile and twinkle in her eyes after a joke always melted the worse cynic."*
- *"Having her answer questions regarding her condition has boosted her self esteem and shown people that disabilities don't always have to limit a person."*
- *"I always tried to make this a positive experience and use this time to educate."*
- *"...Now here's the fun part – thank them for their interest in your child and suggest to them that if they are so concerned about your child's behavior they might want to make a donation to an organization (of your choice) that is dedicated to research and support..."*

**Thanks to all the parents who contributed. We hope you'll continue to our next question:**

**How do you balance time with siblings of your child with special needs?**

Please label responses with "Attention Newsletter Editor" and email to: [info@raisingpecialkids.org](mailto:info@raisingpecialkids.org) or mail to: 5025 E. Washington St. #204, Phoenix, AZ 85034

## CALENDARIO ESPAÑOL

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

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

#### IEP/504

Una perspectiva general de Educación Especial y de los planes 504.

3/27/09 10:00-11:30 a.m.

4/3/09 1:30-3:00 p.m.

5/15/09, 1:00 – 2:30 p.m.

#### El Comportamiento Positivo

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

03/20/09 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.

3/13/09 1:30-3:00 p.m.

4/17/09 1:30-3:00 p.m.

#### Derechas de padres en educación especial

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

3/31/09 3:00-5:00 p.m.

4/24/09 3:00-5:00 p.m.

5/8/09, 1:00 – 2:30 p.m.

# Around Arizona

**March 28**

Mark your calendar for the 24th 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 28, 2009**

**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 480-315-5216 or Al Chaves (En Espanol) 480-221-7259.**

**FREE**

## **Conference for parents: Learn collaborative strategies for therapy**

Has your family lost access to services for your child from DDD or AzEIP? Raising Special Kids is sponsoring workshops taught by professionals to aid families in helping their children learn and maintain skills.

Learn techniques from professionals to support your child.

Professional representatives from the fields of Occupational Therapy, Speech Therapy, Behavior Analysis and more will offer workshops to teach parents techniques they can use at home to help their child progress.

*Help your  
child  
progress.*

**Saturday, May 2, 2009**

Time to be announced (will be daytime hours)

**Phoenix Children's Hospital**

*Techniques  
you can use  
at home!*

Space is limited, please register by contacting Raising Special Kids at 602-242-4366 or [info@raisingspecialkids.org](mailto:info@raisingspecialkids.org) (please put "Conference" in the subject line) with your name, phone and email.

# Raising Special Kids News

## Board news

Raising Special Kids extends congratulations to our new Board of Directors officers:

Co-Presidents - Kevin Bonner, *Fennemore Craig*  
- Tim Watters, *Colliers, International*  
Vice President - Elaine Ellis, MD *Phoenix Children's Hosp.*

Secretary - Vickie Herd, *Extended Family Disability Serv.*  
Treasurer - Heather Buchta - *Quarles, Brady, Streich & Lang*  
And new to the Board is Blanca Esparza-Pap, *Channel 3*  
Our sincere gratitude follows recent past-president, Jodi Feuerhelm for two years of exemplary leadership.



Seen at the DEC Grand Opening  
(Left) Co-President Kevin Bonner with Board Member Michael Remus.



(Right) Co-President Tim Watters with Board Member Shirley Kaufman

## The DEC Grand Opening

The new Disability Empowerment Center recently celebrated its Grand Opening as a state-of-the-art accessible campus. Commissioned by Arizona Bridge to Independent Living (ABIL) the "DEC" is home to multiple organizations serving individuals with disabilities and their families including Raising Special Kids. Centrally located, the campus is at 5025 E. Washington St. in Phoenix.



(Left) Phil Pangrazio, Executive Director of ABIL presents the story behind the DEC's construction.  
(Below) Applause for a symbolic "breaking down of barriers" for people with disabilities.

## From Russia, to learn

Kathleen Collins, one of our staff in northern Arizona had a unique opportunity to spend an afternoon with a group of teachers and preservice teachers from Flagstaff's sister city in Siberia.

"I spent the afternoon helping them to understand our special education law, how it works, and a lot about inclusion," said Kathleen. "I feel I have learned as much as I taught in this training! They had tough questions about why and how! They really wanted a lot of information about inclusion and why we feel it is important."

## Fishing With Friends

Raising Special Kids joined Joni and Friends at the annual "Fishing With Friends" event for children with disabilities at Tempe Town Lake.



## Sign up now for our E-dition Newsletter moving in a paperless direction

Connecting is setting a goal to have our next winter edition be available only in electronic form. To receive our e-mail communications log on to [raisingspecialkids.org](http://raisingspecialkids.org) and look for "E-News Sign-Up."



## BizBash raised \$107,000

When the dust settled after the frenzy and fun of BizBash 2008, sponsors Arizona Business Bank and CoBiz Financial delivered a much appreciated gift of \$107,000 to Raising Special Kids.

"It was truly a joy to work with sponsors that were able to set such a fine example of community stewardship," said Joyce Millard Hoie, Executive Director. "They are the best!"

## Dandelion Golf Classic

*Save the date*

CareScape Inc., sponsor of the Dandelion Golf Classic to benefit Raising Special Kids, has sent the date and location for this year. Mark your calendars to join us at:

**Pebble Creek Golf Resort**  
**Tuscany Falls Course**  
**Saturday, September 26th, 2009**

# In The Spotlight

## Volunteers are the heart of Raising Special Kids *Thank You!*

November-December, 2008

### Apache Junction

Teresa Manus

### Avondale

Gabriela Orozco

### Cave Creek

Jill Pearn

Mark Trombino

### Chandler

Marty Baio

Samantha Beatty

### Gilbert

Leah Gibbs

Jennifer Kurr

### Glendale

Sue Bolton

Annette Navarro

Brandy Rogers

### Gold Canyon

Karen Perry

### Goodyear

Martha Spector

### Mesa

Angela Andreasen

Nicole Kamp

Terry & Susan Melton

### Peoria

Gillermina Martinez

Rhonda Zieba

### Phoenix

Jane Dalen

Nancy Gunderson

Chris Jones

Nancy Licht

Kathy McDonald

Stacie Mellen

Elizabeth Naughton-Ketzler

Madeline Papazian

### Scottsdale

Jill Castle

Katie Petersen

Mary Quinsler

### Snowflake

Robin Campfield

### Sun Lakes

Philip Sanabria

### Tempe

Janet Romo

### Waddell

Sharon Atwood

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

November - December, 2008

### AASK

Arizona Dept of Education

Julie

Arizona Dept Of Health Services, OCSHCN

Marta Urbina

Arizona Pediatric Clinics

Becky Alvarez, DA-C

### AZPAC

Ofelia Malsach

Chandler Unified School District

Children's Rehabilitative Services

Melissa Abbitt

### CPS

Kristen Kidd

De Colores Shelter

DES-Dept of Economic Security

Jackie Whatley

Division Of Developmental Disabilities

Carmen Aguilera

Jennifer Anderson

Kathy Bahamonde

Kimberly Becker

Ruthann Bilkey

Melanie Bissen

Tina Brummer

Robin Chanto

Lindsey Colvin

Annie Converse

Anita Decker

Laura Denali

Cheri Diefenbacher

Rose Fabris

Mariah Favela

Maria Fernandez

Michelle Ferries

Kathi Guildig

Katherine Hartnett

Susan Hawley

Lynn Headrick

Amanda Howard

Patricia Huerta Walters

Jodi Stein

Monica Joe

Jill Keyes-McClements

Traci Klein

Dorothy Knox

Linda Leslie

Alma Magana

Kim Mapes

Diane Martinez

Ellie Mendoza

Zabdy Montenegro

Amin Muhammad

Clay Muschinski

Sonia Navarro

Kathleen Nguyen

Karen Nugent

Karen Patten

Linda Poller

Lisa Rennells

Traci Robb

Nancy Rohan

Ramona Sands

Kizzy Sepulveda

Virginia Smith

Marrietta Valdez

Lisa Yazzie

Family Voices

Fiesta Pediatrics

Tami Hirasawa

### GANÉ

Gateway Academy

Robin Sweet

Homeward Bound

Paty Rethore

Jewish Family and Children's Services

David Byrne

Joni and Friends

Paty Baldwin

Listening Ear

Maricopa Children's Health Center

Lauren Pearlman, DO

Phoenix Baptist Hospital

Teresa S Garcia

Phoenix Children's Hospital

Tiffany Blick

Julie Dougan

Maritsa Saucedo-Graham

Rehab Without Walls

### RISE

Caitlan Murray

St. Joseph's Hospital

Carol Bedner

Step By Step Pediatrics

Dr Tanya Horner

### TGC

Cathy Uno

Touchstone Behavior

George George

United Cerebral Palsy

US Dept of Education - OSEP

Lisa Gorove

Tracie Bana, MSW

Dr Christiano

Mary Coontz, MD

John & March Dechandt

Darlene Franklin

Tamika Glover

Deni Nordmeyer

Dr. Karlson Roth

Jennifer Stalteri, MSW

Ann Steffen, MSW

**Did you know that you can contribute to Raising Special Kids through United Way? Just enter our agency code 314 on your form.**

**Special thanks to Shirley McPherson of Joni and Friends for extraordinary assistance to a family in need.**

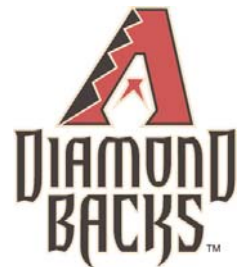
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**June 28**

*It's our Birthday!  
Celebrating 30 years of*



**Raising Special Kids**  
*with the*  
**Arizona Diamondbacks**

**Sunday, June 28th, 1 pm, D-Backs vs. Anaheim Angels**

Chase Field - located at 401 E. Jefferson Street, Phoenix

**Ticket prices discounted: \$30 prime seating, \$25, & \$15  
\$5 per ticket goes to benefit Raising Special Kids**

All Ticket Sales are handled on line at: [www.dbacks.com/specialkids](http://www.dbacks.com/specialkids)

Birthday festivities will be in the upper concourse Garden and Banquet Room.  
The sandlot, playground and batting cages are nearby.

[www.raisingpecialkids.org](http://www.raisingpecialkids.org)