



**Raising
Special Kids**
families helping families

Connecting

Connect

Family Support is the Heart of our Mission.

April - June, 2008

Volume 13, Number 2

Identification

To label or not to label

Many parents view the moment they learn the name of their child's disability or special health condition as a life changing event.

Giving a name to a set of troubling symptoms, or having an explanation for puzzling and unusual behavior can serve to define the circumstances for family members, and provide a "thing" at which they can target their feelings. Relief, guilt, fear, and anger are normal reactions. The expression of these feelings are highly varied and grounded in the unique perspectives and life experiences of each person.

Some parents experience feelings of relief and renewed determination. Knowing what they are facing, and planning how to take the next steps provides a goal and a focus for their efforts. If the parents previously felt something was wrong, and were seeking information, finding the answer might provide reassurance and have a stabilizing effect.

Other parents react with grief and fear stemming from a profound sense of loss. They may feel their vision for their child's or family's future is suddenly taken away. The experience can be a

shock — "like the rug was yanked from under my feet" or "our world turned upside down" are often-heard descriptions.

If there is any question about a child's diagnosis or evaluation results, seeking a second opinion is prudent. Some parents and professionals believe certain diagnoses, such as Attention Deficit Disorder, are used inappropriately in response to behavior management problems. Determining whether a child has a disability due to a biological cause, or is reacting to not having needs met in an appropriate environment can be crucial

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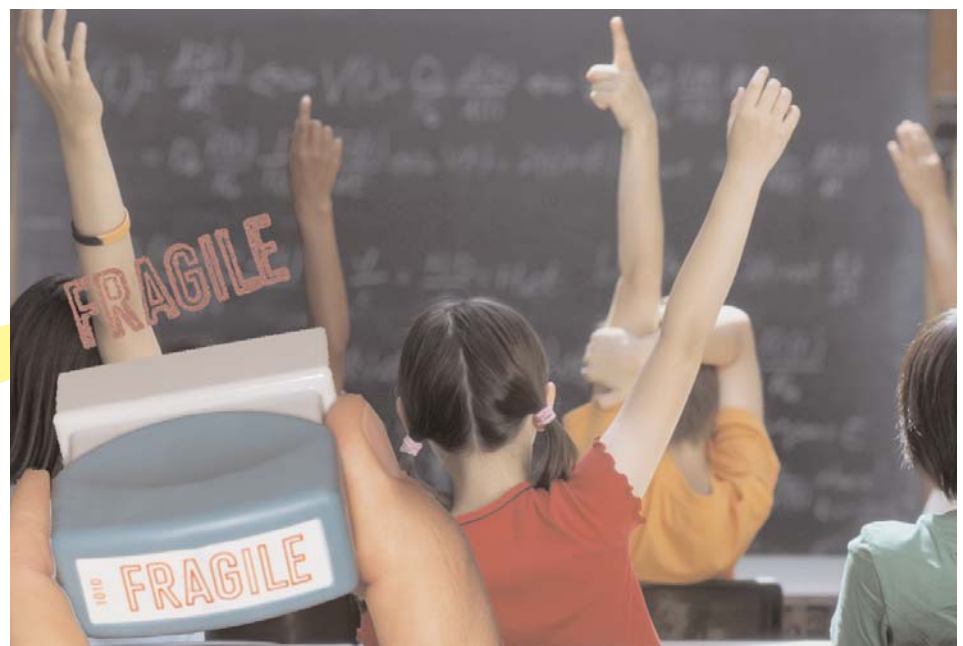
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in determining the best course of action.

"Sometimes misdiagnosis can occur even though the provider may be doing their best," acknowledged June Siegel, a Licensed

— continued on page 4



Director's Column

"What's in a name? That which we call a rose, by any other name would smell as sweet."

Shakespeare's words ring true. A child by any other label, diagnosis, or identification is still a child. A formal medical diagnosis carries with it a range of assumptions, fears, and expectations. While a diagnosis has certain practical value in making available various forms of treatment, medication, therapy and educational programs, it specifically focuses on describing a problem. A formal diagnosis has very limited value in raising a happy, healthy child who will develop his own unique and special capabilities.

In the years since I experienced hearing the news that our son had a significant and life-long disability, I learned it is the creative, intuitive, loving care and attention which brings forth the best in a child, and this process enriches our lives as well as those of our children. If I could return to the day I first heard the distressing news, I would tell myself some of the following things:

Don't project the current situation into the future. Dire scenarios born of panic and desperation are negative influences that rob you of needed energy and inspiration. Realize that childhood is a precious time and passes much too soon. It may take time to learn to operate on your child's timetable.

Listen to your parent's intuition. You will learn things about your child no one else can know with the same degree of depth and understanding. This practical wisdom is a necessary and valuable tool for parenting your child.

Early intervention is essential. I subscribed to the "chaos theory" of parenting (my family would interpret this differently!), but it means sensitive dependence on initial conditions, or the "butterfly effect", the idea that something as small as the movement of a butterfly's wings can affect global weather patterns. Early consistent, purposeful, therapeutic interventions provided by parents as well as clinicians, may yield enormous benefits. Small and seemingly inconsequential efforts to train, reinforce, and encourage your child can result in amazing things.

Advocate for your child as a key member of the decision-making team. Learn to work well with professionals. Inform, educate, and listen to the experts with whom you consult. Occasionally someone may need to be "fired", but the many conscientious professionals who forged partnerships with us helped to provide the optimum interventions for our son. They deserve and receive my deepest respect and appreciation.

Visualize where you need to be in two years. Your goals and objectives will become clearer to you. When I took time to objectively evaluate the situation, we found new goals and new ways to measure performance and progress.

Find ways to encourage your child's independence. As essential as you are in the life of your child, it reinforces respect and responsibility when you build feelings of confidence and competence in your child.

Parenting a child with a disability is never easy; it's demanding, exhausting, and the outcome is uncertain. The art of parenting requires the best from us, no matter what we choose to call it.



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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 central and northern Arizona.

Raising Special Kids is a
501(c)3 non-profit organization.

Raising Special Kids Calendar

For a complete listing of calendar events, please visit our website at www.raisingpecialkids.org. If you require special accommodations to attend a Raising Special Kids sponsored activity, please notify us at least 48 hours in advance. Unless otherwise noted, all Raising Special Kids workshops and trainings will be held at 2400 N. Central Ave., Suite #200, Phoenix. For more information please call 602-242-4366 or 800-237-3007.

Raising Special Kids Hosted Events, Training & Workshops

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

All workshops at Raising Special Kids are free of charge, but you must call and sign up if you wish to attend. If no one has signed up for a workshop, we will cancel it.

IEP/504

An overview of special education and 504 plans for parents and professionals.

Thu., Apr. 3, 10 am-12noon
Wed., Apr. 23, 10 am-12noon
Tue., May 6, 1:30-3:30 pm
Thu., June 12, 10 am-12noon
Tue., July 1, 1:30-3:30 pm
Thu., Aug., 14, 10 am-12noon

Special Education and the IEP Document

Learn about the details of IEPs and the documentation required.

Thu., May 29, 10 am-11:30 am
Fri., July 18, 10 am-11:30 am
Mon., Aug., 15, 9:30-10:30 am

Section 504

Learn about the Section 504 and get accommodation ideas that work.

Mon., Apr. 14, 3-4 pm
Wed., June 4, 10:30-11:30 am
Fri., Aug., 1, 10:30-11:30 am

Advanced IEP

A more in-depth look at special education law for families who want to go beyond the overview.

Wed., May 21, 1-4 pm
Mon., June 23, 1-4 pm
Mon., July 28, 1-4 pm

Self Advocacy for Youth

Discussion of advocacy with youth and parents

Thu., Apr. 10, 2-4 pm
Mon., Apr. 28, 10am-12noon
Mon., June 16, 10am-12noon
Wed., July 23, 4-6 pm
Wed., Aug., 20, 4-6 pm

Positive Behavior Support

Tips and positive techniques for families of children who have behavior issues.

Wed., Apr. 2, 10:30 am-12 noon
Thu., Apr. 24, 2-3:30 pm
Wed., May 7, 10:30-12noon
Thu., May 22, 10:30-12noon
Mon., June 9, 10:30-12noon
Wed., July 9, 10:30-12noon
Wed., July 24, 10:30-12noon
Thu., Aug 7, 10:30-12noon
Mon., Aug 25, 10:30-12noon

Resilient Families

Learn ways to help your family "bounce back" and thrive in the face of challenges.

Tue., Apr. 8, 1-3 pm
Sat., Apr. 12, 2-3 pm

Resilient Relationships

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

Wed., Apr. 8, 1-3 pm
Thu., June 26, 6:30-8:30 pm
Thu., Aug. 7, 6:30-8:30 pm

Understanding Evaluations

Develop a better understanding of the numbers on an evaluation and how to put the results to work in your child's IEP.

Mon., Apr. 7, 10-11am
Fri., June. 20, 1:30-2:30 pm

Extended School Year

What is ESY? How does your child qualify?

Thu., Apr. 24, 10-11 am
Wed., May 16, 10:30-11:30 am

Preschool Transition

Learning about the process of entering and moving beyond preschool.

Fri., Apr. 11, 1:30-2:30 pm
Wed., Apr. 23, 1:30-2:30 pm
Mon., May 5, 10:30-11:30 am

Parents Rights

Learn about rights and responsibilities of parents with a student in special education.

Mon., Apr. 14, 1:30-2:30 pm
Mon., May 19, 10:30-11:30 pm
Tue., June 10, 1:30-2:30 pm
Fri., July. 18, 1-2 pm
Tue., Aug., 5, 1:30-2:30 pm

Parent/Professional Collaboration

Learn tools for clear and effective communication with service providers.

Mon., Apr. 7, 11am-12noon
Wed., May 14, 10:00-11:00 am
Wed., June 11, 10:00-11:00 am
Thu., July 10, 10:00-11:00 am
Tue., Aug., 19, 10:00-11:00 am

High School Transition

Preparing youth for transition from high school to post-secondary education, employment and life in the community.

Thu., Apr. 10, 4-5:30 pm
Mon., Apr. 28, 1 -2:30 pm
Fri., May 16, 4-6 pm
Wed., May 21, 4-6 pm
Thu., June 10 am-12noon
Wed., June 18, 10 am-12noon
Wed., July 30, 10 am-12noon
Wed., Aug 6, 4-6 pm
Thu., Aug 28, 4-6 pm

Clinical Social Worker and parent of a child with a disability. “Parents need to trust their own judgment and their gut. Utilizing what they know as a parent and an expert on their child is an essential part of the process of finding appropriate treatment. It’s necessary to receive a competent diagnosis in order to determine proper services.”

Faced with new and possibly disturbing information, some parents reject what they perceive as a “label” for their child and the frightening prospects they associate with it. “I’d love to chuck the stinkin’ labels,” commented a mother in a blog for families of children with autism. Adding to parents’ confusion are anecdotes that abound in the media, on Internet groups, or shared by word-

For children with learning disabilities, accepting those problems may be the most important step toward finding success and happiness as adults, according to a long-term study of LD students in Southern California. Through extensive evaluations and interviews of 41 former students of the Frostig Center in Pasadena, researchers found that **self-awareness, positive attitudes** toward overcoming or adapting to LDs and **seeking support from outside sources** were more accurate predictors of success than IQ or academic achievement.

—<http://www.schwablearning.org/articles.aspx?r=622>

Denial

Parents sometimes react to a label with denial, explained Kristina Blackledge, M.S., a family counselor. “Denial may be a useful coping mechanism and has helped people manage through that period of adjustment. If denial persists too long, it could interfere with accessing proper supports that can lead to positive outcomes.”

relationships when a diagnosis is revealed. Others find they need to insist on setting high expectations for their children with educators and other professionals following the disclosure of a diagnosis.

Guilt

To some degree, many cultures view individuals as a reflection of the family. If there is a negative connotation associated with disability, parents may feel it is in some way their fault. Is the child’s situation a result of something the parent did or somehow deserved? Kelly Morris MAPC, LAC specializes in counseling for marriage and family issues and has worked with many families of children with disabilities. She noted “Parents sometimes think ‘It’s as though I’ve been labeled—my family has been labeled. What does this define me as?’ Some see their child’s health needs as a reflection on them.”

Fear

Unanswered questions may lead to increased anxiety and fear of the unknown for parents of a child with a new diagnosis. Parents face the uncertainty of not knowing about prescribed treatment or therapy, how treatment will be paid for, and how their child will respond. Questions about the child’s and family’s future life are difficult. Morris explained, “The

Invisible disabilities such as behavioral, neurological or mental health may be among the most stigmatized.

“It may feel embarrassing and uncomfortable to talk about problems with your child’s emotions and behavior. But mental health problems are illnesses, like diabetes or asthma. And like those illnesses, mental health problems are often chronic and need ongoing care; they may get better or worse over time. Most children do get better with the help of medication and/or psychotherapy. Diagnosing and treating mental health problems early can keep them from getting worse and reduce problems at school and with peers.”

— from *Finding Help and Working with Schools: Tips for Parents of Teens with Mental Health Problems* developed by Education Development Center available on line: http://www.urbancollaborative.org/pdfs/mental_health.pdf

of-mouth about the wrong diagnoses resulting in delayed or inappropriate services for children.

“The reality is that for your child to get the services he or she needs, our health and education systems require these labels in order to provide appropriate care,” Siegel continued. “Sometimes the more diagnoses the child has, the more services are available.”

Stigma, defined as a mark of shame or discredit, can influence a parent’s feelings about the disability. Parents may reject needed treatment and services for the child based on their fears about the reactions of family members and the community. These fears are not without some justification. Some parents of children with disabilities have seen changes in their personal

number one issue I think families face is a feeling of powerlessness. They want to do something, but they don't know what. They may react by thinking 'If I accept this label, that makes it so.'"

Many parents express concern that information entered in their child's health and education records may affect future opportunities. Privacy laws, including The Family Educational Rights and Privacy Act (FERPA), and HIPAA (Health Insurance Portability and Accountability Act) provide safeguards against releasing or sharing information contained in these records without permission.

Sometimes parents feel they must treat their child with a disability "just like everybody else" to help them learn how to be successful. It may help to consider that we treat people differently—whether that is due to differences in ability, personality, personal preferences or just circumstances. Helping a child learn to cope with a disability starts with acceptance of the disability, and acceptance that disability is a normal part of the human condition.

Siegel noted, "Sometimes parents need to get the labels in order to fully advocate for their children. It is important to remember that a child isn't just a diagnosis. Kids are resilient and often exceed expectations. Never settle or stop raising the bar for your child."



The **Family Educational Rights and Privacy Act (FERPA)** is a federal privacy law that gives parents certain protections with regard to their children's education records, such as report cards, transcripts, disciplinary records, contact and family information, and class schedules. As a parent, you have the right to review your child's education records and to request changes under limited circumstances. To protect your child's privacy, the law generally requires schools to ask for written consent before disclosing your child's personally identifiable information to individuals other than you.

Schools are generally prohibited from disclosing personally identifiable information about your child without your written consent, subject to the following:

- Disclosures made to school officials with legitimate educational interests;
- Disclosures made to another school at which the student intends to enroll;
- Disclosures made to state or local education authorities for auditing or evaluating federal- or state-supported education programs, or enforcing federal laws that relate to those programs; and
- Disclosures including information the school has designated as "directory information."

More at: <http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

NOTE:

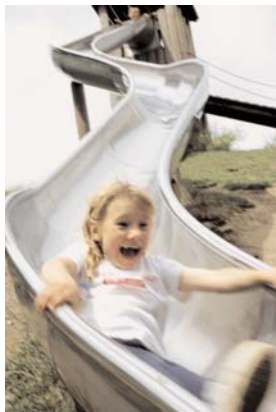
The Federal Register recently posted a notice of proposed rulemaking (NPRM) regarding FERPA. According to the NPRM, the revisions are needed because of recent Supreme Court cases, and amendments to FERPA contained in the U.S. Patriot Act and the Campus Sex Crimes Prevention Act. These changes would clarify various aspects of permissible disclosures. Comments on the proposed regulations are due on or before May 8th. To access the Federal Register notice, go to: <http://a257.g.akamaitech.net/7/257/2422/01jan20081800/edocket.access.gpo.gov/2008/pdf/E8-5790.pdf>

The **Health Insurance Portability and Accountability Act (HIPAA)** The U.S. Department of Health and Human Services ("HHS") issued the Privacy Rule to implement the requirement of HIPAA. The Privacy Rule protects all individually identifiable health information held or transmitted by covered entities such as health plans, health care clearinghouses, and health care providers. It establishes national standards that address the use and disclosure of individuals' health information and for individuals' privacy rights to understand and control how their health information is used. *More info is available at <http://www.hhs.gov/ocr/hipaa/>*

Summer Slide

Increasing student success

Students' school skills can decline during summer vacation without intervention according to research from Johns Hopkins University. In fact, up to 25% of what a student learned during the previous school year is in danger of being lost. This loss is known as “summer slide” or summer learning loss. The Center for Summer Learning found that students scored lower on standardized tests at the end of summer vacation than they did on the same tests at the beginning of vacation.



Summer slide does not end at the end of summer it can continue into the following school year, typically up to six weeks. For students in special education, Extended School Year (ESY) should be considered (*see box on following page*). According to a study by the University of Missouri-Columbia, reading and math are the two subjects where summer slide occurs the most.

Summer Reading & Math Activities

- Read a book with your child about a summer activity (e.g. camping, vacation destinations, etc.)
- Track daily temperatures
- Play card games
- Visit the library to take advantage of books and activities
- Swap or share reading material over the summer with friends or family

Free reading & math websites

www.starfall.com
www.edhelper.com
www.mathplayground.com

Research confirms that summer learning activities improve academic performance and can, over several years, increase the likelihood that a child will maintain more skills, graduate from high school and be better prepared for college. Maintaining school skills while getting ready for the next academic year does not have to consist of traditional summer school, nor does it have to be hard on your wallet. When looking at summer activities, camps, or summer school classes, be sure to **plan** and **enroll early** because many programs and activities fill quickly.

If you are planning for a student with an IEP or 504 Plan, consider the following: Will you be looking at an activity supported specifically for students with disabilities? Will he/she be joining an inclusive activity or camp? Do you need to arrange for additional supports or training to help your child access the activity or program? Activities don't always have to happen outside the home—partner with other families to make a play/social group and create fun activities that all will enjoy.

Summer Ideas:

- Summer camps are often available through your local schools, recreation centers, universities, community-based organizations, DDD, YMCA, Boys and Girls Club, Parks and Recreation, local churches and disability specific agencies/support groups.
- Take an educational trip to different parks, museums, zoos and nature centers. When planning vacations, consider those with educational themes.
- Get out and play. Intense physical activity programs have positive effects on academic achievement including increased concentration, improved mathematics, reading and writing test scores, and reduced disruptive behavior.
- Do good deeds. Students learn better and “act out” less when they engage in activities that aid in their social-emotional development, such as community service.

Comments? Questions? Contact Kristina Blackledge, M.S. via email at kristinab@raisingspecialkids.org or telephone 602-242-4366 ext.206.

Extended school year (ESY)

For a child on an Individual Education Plan (IEP), the IEP team should determine if the child is eligible for Extended School Year (ESY). ESY means special education and/or related services provided beyond the normal school year for the purpose of providing a Free and Appropriate Public Education (FAPE).

ESY services are provided to a student when the educational benefits gained during the regular school year are significantly jeopardized by a break in service. ESY is necessary to enable a student to benefit from instruction received during the regular school year when the lack of ESY services would thwart the goal of maintaining the meaningful progress gained during the regular school year.

ESY services are a result of an individual determination of the IEP team and focus on critical skills. Critical skills are those academic, social, functional, and behavioral skills that are related to IEP goals and are critical to the student's overall school and community functioning.

A child's involvement in ESY services one year does not automatically guarantee services in the following years. Similarly, the fact that no ESY services were provided in a prior year does not mean ESY services are not needed in the current year. **The decision is made on an annual basis, no less than 45 days prior to the end of the school year.** While the need for ESY services is the exception rather than the rule, it is the responsibility of the IEP team to consider the need for ESY for every student.

Arizona Department of Education

More for summer on the web:

http://phoenix.about.com/od/campeducation/Educational_Camps.htm

<http://www.azcentral.com/ent/calendar/summercamp/summercampindex.html>

http://www.kidscamps.com/summer_camps/arizona-summer-camps.html

<http://www.ceao.arizona.edu/child/index.html>

<http://www.asdb.state.az.us/parent/summer.html>

<http://www.mysummercamps.com/camps/arizona-after-school-programs.html>

<http://flagparents.com/summer.htm>

Calendar cont.

(from page 3)



Parents as Advocates

Advanced exploration of effective advocacy techniques with focus on special education.

Fri., Apr. 18, 2-3 pm

Volunteer Training

Too busy or too far to come to our office? We'll come to you! Use your talents to help other parents. **Call today for an appointment: 602-242-4366.**

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 appointment.**

Weekend Workshop Special

Education & Positive Behavior Support

Join us for an overview of the IEP process from 12-1:30. Positive behavior techniques will be shared for families who have children with behavior issues from 10-11:30.

Sat. May 3, 10 am-1:30 pm

Sat. June 7, 10 am-1:30 pm

QUOTED

"I didn't even know the schools had to accept my son with visual impairments. Thank you for changing my son's future in high school!"

— Parent after receiving information on special education.

New Health Care Fact Sheets

To help families connect to health care resources, we're developing more fact sheets to add to the state agency profiles available on our website.

Fact sheets about other programs and diagnoses, as well as Spanish versions of all materials will be available soon. As a sample, the Social Security Income (SSI) fact sheet is on the following page.

New topics:

- [Supplemental Security Income \(SSI\)](#)
- [Social Security Disability Income \(SSDI\)](#)
- [Early Intervention](#)
- [Vision Impairment](#)
- [Epilepsy & Seizure Disorder](#)
- [Resources for Dads](#)
- [Resources for Adoptive & Foster Families](#)

Copies of the health care fact sheets can be downloaded and printed from our website at www.raisingpecialkids.org, click on Resources, then Materials for Download.

Who are Arizona's Children with Special Needs?

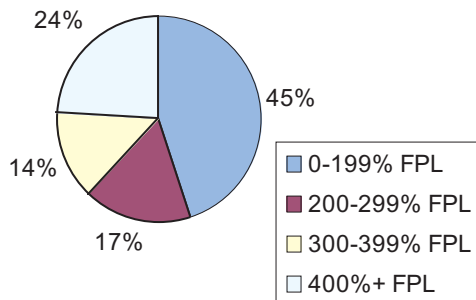
A detailed profile of Arizona's children with special health care needs (CSHCN) is now available on an interactive website <http://cshcndata.org>. The site, created by the Data Resource Center for Child and Adolescent Health (DRC), includes information about insurance coverage, access to care and how a child's disability or special health need affects the family. The website makes it easy to compare Arizona to other states and the nation. Statistics are helpful to family advocates, healthcare providers, educators, policymakers and others in improving healthcare systems and services for children with special needs.

The data on the DRC site are from the 2005-06 National Survey of Children with Special Health Care Needs, sponsored by the Maternal and Child Health Bureau (MCHB) of the U.S. Dept of Health and Human Services. Telephone interviewers asked approximately 800 families of CSHCN in each state in-depth questions about their children's health, services and family life.

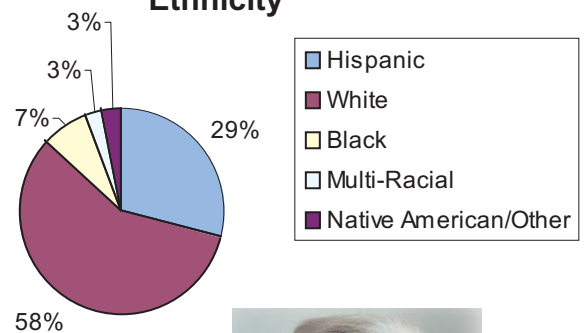
Based on the survey responses of families in Arizona, here's an overview of our state's children and youth with special health needs:

A Profile of Arizona's Children with Special Health Care Needs

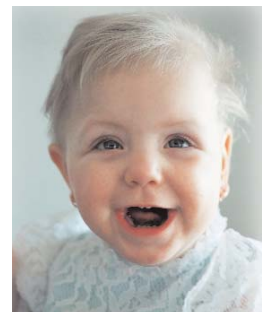
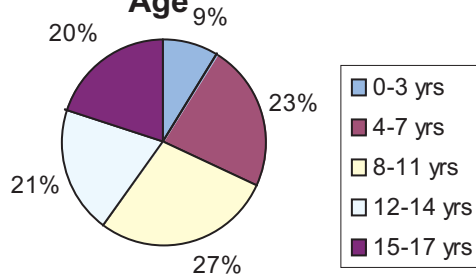
Income
(FPL=Federal Poverty Limit)



Ethnicity



Age



Ages**0-2****3-5****6-17****18-20****21+**

SSI Supplemental Security Income

Supplemental Security Income (SSI) is a Federal program through the Social Security Administration that provides monthly income to people who are age 65 or older, or are blind or disabled, and have limited income and financial resources, who meet the living arrangement requirements, and are otherwise eligible. SSI is a Federal income supplement program funded by general tax revenues (not Social Security Taxes). The monthly payment varies up to the maximum federal benefit rate, which may be supplemented by the state or decreased by countable income and resources. As of January 2008 the SSI payment for an eligible individual is \$637 per month and \$956 per month for an eligible couple.

WHO is Eligible?

- Persons 65 or older
- Persons who are blind or disabled
- Have limited income and financial resources
- Who meet the living arrangement requirements

For Children:

- A child from birth to age 18 or is under age 22 and is a student regularly attending school (as determined by Social Security)
- Must have a physical or mental condition(s) that very seriously limit activities, **and**
- The condition(s) must have lasted, or be expected to last, at least 1 year or result in death. A state Social Security agency makes the decision from information provided by parent/guardian, medical and school sources and other people who know about the child. If the state agency needs more information to make a decision, they will arrange an examination or test for the child, which the agency pays for. Eligibility based on the income and resources of the parent(s) and child within the allowed limits.

WHAT Services Are Covered?

Financial assistance/to meet basic living expenses (food, clothing, shelter). Monthly payment varies depending on eligibility requirements.

For those who are blind or disabled: You may be able to receive SSI payments while you work. As you earn more money, your SSI payments may be reduced or stopped, but you may be able to keep your Medicaid coverage. You also may be able to set aside some money for a work goal or school. In this case, the money you set aside will not reduce the amount of your SSI. Also, those with blindness or disabilities may get free special services to help them work, in-

cluding counseling, job training and help in finding work. The Social Security Department provides more information regarding these services in ***Working While Disabled – How We Can Help*** (Publication # 05-10095) available at the Social Security website (see below) or local office.

HOW MUCH Does it Cost?

No cost, but SSI income may increase or decrease, or even cease, depending upon change in income of person/parent/child or change in health condition.

HOW Are Services Provided?

Monthly checks can be mailed or directly deposited. Funds are received at the beginning of each month.

WHAT DOCUMENTS Do I Need?

Make an appointment at the nearest Social Security office. Info to bring to your appointment:

- Social Security card (or record of SS number)
- Birth certificate or other proof of age
- Information about the home you live in (mortgage or lease and landlord's contact info)
- Payroll slips, bank books, insurance policies, burial fund records, and any other information about your income and things you own (such as cars, land, etc.)
- Names, addresses & phone numbers of your doctors, hospitals and clinics if you are blind or disabled
- Proof of U.S. citizenship or eligible non-citizen
- Checkbook, bank statement with account number to set up direct deposit for SSI monthly benefits.

WHERE Do I Apply?

- **Via the Internet** at the Social Security website: www.socialsecurity.gov
- **Call** toll-free at **1-800-772-1213**, TTY **1-800-325-0778** to make an appointment.

Identificación Etiquetar o no etiquetar

Muchos padres de familia ven al momento en el cual se enteran del nombre de la discapacidad o condición especial de salud de sus niños como un evento que les cambia la vida.

El darle un nombre al conjunto de síntomas inquietantes, o tener una explicación para algún comportamiento desconcertante o inusual puede servir para definir las circunstancias para los miembros de la familia, y proveer una “algo” hacia lo cual pueden enfocar sus sentimientos. Alivio, culpa, miedo o ira son reacciones normales. La expresión de estos sentimientos es muy variada, y se basa en las perspectivas y experiencias particulares de la vida de cada persona.

Algunos padres de familia experimentan sentimientos de alivio y una renovada determinación. El saber a qué se enfrentan y poder planear sus siguientes acciones provee una meta y un enfoque a sus esfuerzos. Si los padres de familia previamente sintieron que algo estaba mal y estaban buscando información, encontrar la respuesta puede darles consuelo y tener un efecto estabilizador.

Otros padres de familia reaccionan con profunda pena y miedo como resultado de una profunda sensación de pérdida. Pueden sentir que de pronto se perdió lo que esperaban para el futuro de sus niños o sus familias. La experiencia puede ser un choque — “como si te jalaran la alfombra bajo los pies” o “nuestro mundo se puso de cabeza”, son descripciones que se escuchan frecuentemente.

Si hay alguna pregunta sobre el diagnóstico del/la niño/a o los resultados de una evaluación, es prudente buscar una segunda opinión. Algunos padres de familia y profesionales creen que ciertos diagnósticos, como el Trastorno de Déficit de Atención, se usan inadecuadamente como respuesta a problemas de manejo del comportamiento. Determinar si un niño tiene una discapacidad debido a una causa biológica o si ésta está relacionada con la no satisfacción de sus

necesidades en un ambiente apropiado, puede ser decisivo para determinar el mejor curso de acción.

“En ocasiones puede haber un diagnóstico equivocado, aunque el proveedor pueda estar haciendo su mejor esfuerzo”, reconoció June Siegel, Trabajadora Social Autorizada y madre de un niño con una discapaci-

De acuerdo a un estudio a largo plazo de estudiantes con discapacidades del aprendizaje en el sur de California, para los niños con discapacidades de aprendizaje, aceptar esos problemas puede ser el paso más importante para encontrar el éxito y la felicidad cuando sean adultos. Por medio de exhaustivas evaluaciones y entrevistas a 41 ex-estudiantes del centro Frostig Center de Pasadena, los investigadores encontraron que la autoconciencia, las actitudes positivas para superar o adaptarse a la discapacidad del aprendizaje, y el buscar apoyo de fuentes externas fueron indicadores más exactos del éxito que el coeficiente intelectual o los logros académicos.

—<http://www.schwablearning.org/articles.aspx?r=622>

dad. “Los padres de familia necesitan confiar en su propio juicio y su percepción. El usar lo que saben como padres de familia y expertos sobre su niño/a es una parte esencial del proceso de encontrar el tratamiento apropiado. Es necesario recibir un diagnóstico competente para poder determinar los servicios apropiados.”

Enfrentados a una nueva y posiblemente inquietante información, algunos padres de familia rechazan lo que perciben como una “etiqueta” para su niño/a y las aterradoras perspectivas asociadas con la misma. “Me encantaría tirar las horribles etiquetas”, comentó una madre en un blog en la Internet para familias de niños con autismo. Agregándose a la confusión de los padres de familia están las anécdotas que abundan en los medios, en los grupos de la Internet, o compartidos de persona a persona sobre los diagnósticos equivocados que resultan en el retraso de servicios o servicios inapropiados para los niños.

“La realidad es que para que su niño/a reciba los servicios que necesita, nuestros sistemas educativos y de salud

requieren las ‘etiquetas’ para poder proveer el cuidado apropiado”, siguió diciendo Siegel. “A veces, mientras más diagnósticos tenga el niño, más servicios hay disponibles.”

Negación

Los padres de familia a veces reaccionan a una etiqueta con una negación, explicó Kristina Blackledge, M.S.,

consejera familiar. “La negación puede ser un mecanismo útil para enfrentar situaciones, y ha ayudado a las personas a arreglárselas durante ese periodo de ajuste. Si la negación persiste por demasiado tiempo, podría interferir con el acceso a los apoyos apropiados que pueden llevar a resultados positivos.”

El estigma, definido como marca, vergüenza o descrédito, puede influir los sentimientos de los padres de familia hacia la discapacidad. Los padres de familia pueden rechazar los tratamientos o servicios necesarios para el/la niño/a, basados en sus miedos a las reacciones de los miembros de la familia y la comunidad. A estos miedos no les falta cierta justificación. Algunos padres de familia de niños con discapacidades, han visto cambios en sus relaciones personales cuando les dan a conocer un diagnóstico. Otros, encuentran que después de recibir un diagnóstico, tienen que establecer altas expectativas para sus niños con los educadores y otros profesionales.

Culpa

En alguna medida, muchas culturas ven a los individuos como reflejo de la

Identificación

Etiquetar o no etiquetar

familia. Si hay una connotación negativa asociada con la discapacidad, los padres de familia pueden sentir que es de alguna manera su culpa. ¿Es la situación del/la niño/a resultado de algo que hicieron los padres de familia o que de alguna manera se merecen? Kelly Morris MAPC, LAC, quien se especializa en dar orientación para problemas matrimoniales y familiares, y ha trabajado con muchas familias de niños con discapacidades, señaló que “Los padres de familia a veces piensan que ‘Es como si yo he sido etiquetado/a—mi familia ha sido etiquetada. ¿Como qué me define esto?’ Algunos ven las necesidades de salud de su niño/a como un reflejo de sí mismos.”

Miedo

Las preguntas sin respuesta pueden resultar en mayor ansiedad y miedo a lo desconocido para los padres de familia de un niño con un diagnóstico nuevo. Ellos se enfrentan a la incertidumbre al no saber sobre el tratamiento o la terapia prescritos, cómo se pagarán, y cómo responderá su niño. Las preguntas sobre el futuro del niño y la familia son difíciles. Morris explicó, “El principal problema al que creo se enfrentan las familias, es al sentimiento de impotencia. Quieren hacer algo, pero no saben qué. Pueden reaccionar pensando ‘Si acepto esta etiqueta, eso se convertirá en realidad.’”

Muchos padres de familia expresan inquietud con respecto a que la información ingresada en los registros educativos y de salud de su niño/a pueda afectar oportunidades futuras. Los decretos de privacidad, incluyendo al Decreto de Derechos de Educación y Privacidad de la Familia (FERPA por sus siglas en inglés), y al Decreto de Transferibilidad y Responsabilidad del Seguro de la Salud (HIPAA por sus siglas en inglés), proveen defensas contra la liberación o el compartir información contenida en estos registros sin permiso previo.

En ocasiones los padres de familia sienten que deben tratar a su niño/a con una discapacidad “como a cualquier otra persona”, para ayudarlos a aprender a ser exitosos. Puede ayudar el considerar que tratamos a las personas de distinta manera—ya sea que se deba a diferencias en su capacidad, personalidad, preferencias personales o sólo a las circunstancias. El ayudar a un niño a aprender a enfrentarse a una discapacidad empieza con la aceptación de la discapacidad, y la aceptación de que la discapacidad es una parte normal de la condición humana.

Siegel señaló, “A veces los padres de familia necesitan obtener las etiquetas para poder abogar plenamente por sus niños. Es importante recordar que un/a niño/a no es sólo un diagnóstico. Los niños son resistentes y frecuentemente

sobrepasan las expectativas. Nunca decida dejar o deje de elevar sus expectativas para su niño/a.”

CALENDARIO ESPAÑOL

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.

Viernes, 4 de Abril, 10:30-12:00

Viernes, 9 de Mayo, 1:30-3:00 pm

Viernes, 25 de Julio, 1:00-2:30 pm

El Comportamiento Positivo

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

Viernes, 25 de Abril, 10:30-12:00

Martes, 20 de Mayo, 1:30-3:00 pm

Viernes, 27 de Junio, 1:00-2:30 pm

Martes, 29 de Julio, 10:00-11:30 am

ENTRENAMIENTO PARA VOLUNTARIOS

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

Viernes, 16 de Mayo, 10:00-11:30 am

Viernes, 20 de Junio, 1:00-2:30 pm

Martes, 15 de Julio, 10:00-11:30 am

Grupo de apoyo para padres (hombres)

Grupo de padres (hombres) con hijos con necesidades especiales. Para más información, lláme al 602-242-4366, Lugar: La Oficina de Raising Special Kids (Criando Niños Especiales) EN ENTRENAMIENTO SERA EN Español

Las discapacidades invisibles, como la salud del comportamiento, neurológica o mental, pueden estar entre las más estigmatizadas. “Puede ser embarazoso e incómodo hablar sobre los problemas con las emociones o el comportamiento de su niño/a. Pero los problemas de salud mental son enfermedades, como la diabetes o el asma. Y al igual que esas enfermedades, los problemas de salud mental son frecuentemente crónicos, requieren atención permanente, y pueden mejorar o empeorar con el tiempo. La mayoría de los niños mejora con la ayuda de medicamentos y/o psicoterapia. El diagnosticar y tratar los problemas de salud mental de manera temprana puede evitar que empeoren, y reduce los problemas en la escuela y con los compañeros.”

— Tomado de *Encontrando Ayuda y Trabajando con las Escuelas: Consejos para Padres de Adolescentes con Problemas de Salud Mental* “Finding Help and Working with Schools: Tips for Parents of Teens with Mental Health Problems” desarrollado por el Centro de Desarrollo Educativo. Disponible en línea en: http://www.urbancollaborative.org/pdfs/mental_health.pdf

Worth Noting

New program from Special Olympics

Arizona Young Athletes

Fun, flexible activity groups for children with intellectual disabilities.

- Free!
- Ages 2 ½ to 7
- Great exercise and physical development
- Introduction to sports skills
- Led by trained volunteers with parent participation
- Connect with other parents of special needs children
- Groups meet weekly at various locations
- New groups forming statewide

For more information about Young Athletes activity groups in your area, visit www.soaz.org, click on “Athletes” and fill out an Athlete Interest Form.

The Young Athletes program is fun, flexible and assists a child in developing the necessary building blocks such as walking, running, balancing and jumping, trapping and catching, throwing, striking and kicking, just to name a few. These building blocks result in notable improvements in the development of a child’s motor, cognitive, social, emotional, adaptive

and communication skills. The ultimate goal of the SOAZ Young Athletes program is for the next generation of Special Olympics

athletes to be better prepared for a lifetime of healthy and safe lifestyles.

Arizona Spina Bifida Association

Free cycles & new support group

A program to supply cycles to children and adults with Spina Bifida is available through the Arizona Spina Bifida Association. Hand or foot-powered styles are offered. Applications are posted on the website <http://www.azspinabifida.org> or available by calling their office at 602-274-3323.

A support group for families is also forming and is welcoming new members. Meetings are the 3rd Wednesday of each month beginning on April 16 at 7pm at 1001 E. Fairmont, Phoenix, AZ. For more information, contact Michelle Miller at 623-533-4615 or Dolores Herrera (habla español) 602-242-4366. Meetings are child-friendly.

Community Development

Family Leadership Conference

The Conference will bring families, agency staff and community partners together to learn how to apply the principles of asset-based community development to build stronger communities and foster healthier families.

May 13 & 14, 2008 • Black Canyon Conference Center, Phoenix

- Tools for developing family leadership at the individual, community and state levels;
- How to recognize opportunities for family leaders to partner with state agencies to strengthen services, policies and systems; and
- How to establish Community Action Teams—a mechanism that connects families, agencies, non-profits and others to build stronger, more self-reliant communities
- Hear Keynotes from national experts John (Jody) Kretzmann, PhD, co-director of Asset-Based Community Development Institute, and Donna Beegle, EdD, President, Communication Across Barriers
- 28 content-rich workshops

Registration materials available online at www.pcaaz.org.

Cost: \$150 for professionals; **scholarships available for families**



Rodolfo Martinez shows off the new bike he received from the Arizona Association for Spina Bifida.

QUOTED

“I just wanted to thank you for talking with me last week. It made me feel so much better, like I have made the right decision. I got my packet from DDD, and I am hoping to send that out today. I really think (my son) qualifies for services...Your organization is great. Sometimes it is so frustrating as a parent of a special needs child to know who to contact. Thanks so much!”

— Parent

Around Arizona

Flagstaff Workshops By Raising Special Kids

(Descriptions on Calendar: pg 3)

Positive Behavioral Support
Cottonwood Public Safety Bldg
March 7th, 10 am-12 pm

504 plans
Flagstaff Family Resource Cent
March 18, 5:30 pm-7 pm

Parents as Advocates
Flagstaff Family Resource Cent
April 15, 5:30 pm-7 pm

Positive Behavioral Support
Flagstaff Family Resource Cent
May 13, 5:00 pm-7 pm

Please register by calling
928-523-4870 or 1-800-237-3007

Northern Arizona

Life Planning Workshop

By Margaret "Midge" White, M.Ed., CCD
The Cutty Legacy Foundation Administrator

Location: **Flagstaff Medical Center**
McGee Auditorium, FMC 1200 North Beaver, Flagstaff

Time: **Saturday May 31, 2008**
3:00 to 6:00 P.M.

How to Provide for Your Family Member with a Disability:
Overview of Wills, Trusts, Power of Attorney, Guardianship,
Conservatorship, Maps and Government Services
(Free booklets including information on all areas listed, etc.)

To Sign up, please call or e-mail Kathleen Collins:
kathleenc@raisingspecialkids.org
Phone: 928-523-4870 or 1-800-237-3007

*Workshop and "Life Planning" booklets are free, but
please call ahead so we have enough materials.*

Arizona TASH proudly presents:

Everyone Belongs Together!

The 4th Annual Arizona Inclusive Schools Conference

Co-sponsored by Raising Special Kids, Arizona Department of
Education/Exceptional Student Services, Institute for Human
Development/Project ImpACT, NAU Educational Specialties Program,
NAU and IHD: Project SKIES, National Institute for Urban School
Improvement, Northern Arizona Chapter of the Autism Society of America,
Southwest Autism Research and Resource Center

June 13-14, 2008
Northern Arizona University
Flagstaff, AZ

For educators, administrators, parents, self-advocates, students,
and agencies providing services to individuals with disabilities.

Online early registration begins April 1, 2008.
Early registration fee will be \$140, then \$150 after May 15.
For updated information please check <http://arizonatash.org>.
Questions? Contact Susan Marks: susan.marks@nau.edu

KEEN

Kids Enjoy Exercise Now (KEEN), is a nonprofit, volunteer-led organization that provides free one-to-one recreational opportunities for children and young adults with mental and physical disabilities. KEEN announced the launch of their Phoenix program in March of 2008.

At each KEEN session, a participating athlete is paired with a volunteer coach for a variety of age-appropriate recreational opportunities. Since its inception in the United States in 1992, KEEN has served several hundred children and young adults with severe and profound disabilities who, because of their need for individualized attention, have experienced difficulty participating in existing programs. For more information visit www.keenphoenix.org

Raising Special Kids News

Parent Presentations

Our volunteer parent speakers have had a busy season this winter and spring presenting their perspective on raising children with a disability or special health need. They have been a hit with varied audiences including students and professionals in education and health fields whose feedback has been tremendously positive.

One dental student commented, *“Wonderful presentation! I learned a lot, and I really appreciate the honesty and sharing of their experience. This workshop with the personal experiences from parents will help me to better communicate with special needs patients, their parents and caregivers.”*



Judy Gates, volunteer parent speaker, presenting to dental students at A. T. Still University's Arizona School of Dentistry & Oral Health.

Legislative Awareness

Consumers, families and organizations gathered in front of the capitol to share ideas and show support for issues and legislation related to disability on Legislative Awareness Day. Legislators were able to tour through the information tables, chat with individuals and become better educated about community concerns. Representative families from throughout the state participated in making their voices heard.

If you would like to participate in our state's legislative process, you can keep up-to-date on the progress of bills related to disability issues as they move through the legislature, log on to view the **Bill Tracking Chart** at http://www.azgcd.org/public_policy_update.asp



Consumers and Legislators stopped by Raising Special Kids information table during Legislative Awareness Day at the state's capitol.

Scenes from sibshop



Siblings of children with disabilities had a terrific time sharing their experiences at our last sibshop at Hospice of the Valley in Phoenix. The next sibshop is scheduled for April 12. Call 602-242-4366 for info.



Head Start

Workshops on transition for children entering Kindergarten are now being offered through select Headstart locations in the Phoenix area. Presentations in English and Spanish are available for families of preschoolers with disabilities and professionals who serve them. A professional translator and headsets will be available in addition to materials in Spanish and English.

Locations include Central Phoenix, Glendale, Avondale, and Tolleson. Call 602-242-4366 for more information.

In The Spotlight

Volunteers are the Heart of Raising Special Kids Thank You!

January-February, 2008

CHANDLER

JUNE SIEGEL

COTTONWOOD

JULENE COLE

GILBERT

MARIA DAVIS

GLENDALE

MARGE DALEN
DANIELLE MARTINEZ
MARCI MONAGHAN
CEE CEE TASSINARI

LAKE HAVASU CITY

JULIE DECKER

PARADISE VALLEY

JENNIFER LANSKY

PHOENIX

REBECCA BAILEY
PAIGE CAMPBELL
KATHY MOSCHIONI
JOSEPH & JUDITH SMITH
LORI STUART

SCOTTSDALE

MICHELLE NAGEL

SUN LAKES

PHILIP SANABRIA

WILLIAMS

JENNIFER EVERETT

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

January-February, 2008

ORGANIZATIONS

ARIZONA AUTISM UNITED

AARON BLOCKER RUBIN

ARIZONA BUSINESS BANK

ANDREA MCNEELEY

ARIZONA CHILD STUDY CENTER

THERESA RIMER

ARIZONA COUNSELING CENTER

ASU

LISA AAROE

MARTHA COCCHIARELLA

AURORA BEHAVIORAL HEALTH

ALLISON NIELSON, MSW

AZEIP

MINDY HEDT, MA, CC-SLP

MAXINE PIPER

BANNER CHILDREN'S HOSPITAL

AMIRA EL-AHMADIYYAH

ANN STEFFEN

BANNER MEDICALCENTER

TRACIE BAKER

COMMUNITY ALLIANCE TO PREVENT

ABUSE

CRS

MELISSA ABBITT

DR. ROBIN BLITZ

JUDI TYLER

DDD

CARMEN AGUILAR

TAWNIA BEASLEY

BILKEY BILKEY

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TINA BRUMMER

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AMY WATERS

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LISA YAZZIE

EASTER SEALS

ROSEMARY GARZA

FIESTA PEDIATRICS

FRESH START WOMEN'S CENTER

GANE

GROWING IN BEAUTY

VERNA J HARVEY

HEAD START-CITY OF PHOENIX

MARIANNE KRIVAN

HIGHLANDS CHURCH

JEWISH LEAGUE

LOS NINOS HOSPITAL

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MESA PUBLIC SCHOOLS

MIKID

NEW WAY LEARNING ACADEMY

PHOENIX CHILDREN'S HOSPITAL

MORITSA SAUCEDO-GRAHAM

SARRC

SARAH DENNO

SOUTH CENTRAL FAMILY HEALTH CENTER

MELISSA BARBOA

NUBIA DOMINGUEZ

SOUTHWEST BEHAVIORAL HEALTH

LINA MACIA

ST JOSEPH'S HOSPITAL

MANDY CORNELIUS

ELISA SIMPSON

INDIVIDUALS

JANICE DAY

SHERRI WALTON

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Connecting is available by email. Visit our website to sign up or send an email to info@raisingspecialkids.org

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2nd Annual *Dandelion Golf Classic*

Sponsored by CareScape, Inc.

All proceeds to benefit Raising Special Kids

Saturday, September 27, 2008

Eagles Nest at Pebble Creek Golf Resort

3645 Clubhouse Drive, Goodyear, AZ 85395

Sponsorships available from \$500 to \$7500

Individual players \$150

Team Early Registration Package \$600

Golfers will receive:

**18 holes of golf with cart, range balls, golf shirt,
breakfast, lunch, player tee prize bag, one drink ticker, one door prize ticket**

For details visit: <http://www.dandeliongolfclassic.com>

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

www.raisingpecialkids.org