

Believe It or Not?

How Reliable is the Information You Read on the Internet?

Many things have changed with the advent of the Internet. Parenting is one of them — especially parenting a child with exceptional needs. Now there are many resources to draw from, and the willingness to question conventional wisdom and even professional opinions has increased.

When parents want to educate themselves in order to make informed decisions they turn to the Internet.

Along with increased availability of information, the Internet has brought increased availability of inaccurate information. The ease of copying and repeating comments, articles, links and more made much information



from the Internet unreliable. Without oversight or monitoring, unverified information can appear frequently and spread quickly between blogs, bulletin boards, websites, social media conversations and other forums.

A third of consumers use social media sites to search for medical information, discuss symptoms and express opinions about providers and treatments reported the Los Angeles Times in April.

Alex Duggan, Executive Director of DSNetwork recently noted, “Social media today offers immediacy of receiving or giving personal recommendations and connecting with a network of individuals. From questions about occupational therapists, to summer camp offerings, to advice, there is a world of information shared in our Yahoo discussion board and other social media forums.”

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“When we received the first diagnosis, we went on the Internet and did a lot of searching. It was frustrating to find conflicting information. Before you knew it three hours would go by and we still had not found what we were looking for. What we read online was not giving us hope.”

— Parent of three children with special needs.

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Staff Spotlight

Neil Wintle, Family Support Specialist

In the span of a couple hours Neil went from happily sharing a typical family dinner with his wife and 6-year-old son to facing life and death choices for his unborn child. There had been no cause for alarm during the pregnancy, but after Michelle's sudden distress sent them rushing to the hospital, doctors informed the couple their baby could be born any minute despite not yet having reached the "viability cutoff" of 24 weeks.



Tristan's birth the next day began a 104-day saga in the neonatal intensive care unit dealing with heart surgery, brain hemorrhages and efforts to encourage their son's lungs to develop sufficiently. In a characteristic understatement, Neil remembers it was "tricky" to balance the emotional drain of daily medical challenges while trying to juggle practical needs and maintain strength and support for his wife and older son.

Then, while Tristan was still attached to a monitor and receiving oxygen, it was time to bring their new baby home. "It was scary all over again with just us taking care of him," said Neil. The couple knew their baby would need extra help and therapies, but they faced a future of uncertainty as no one seemed to know what services Tristan would be qualified to receive.

Amidst a mountain of papers that accompanied them home from the hospital the couple discovered information about Raising Special Kids. With the first call Michelle found someone who shared her experience of surviving NICU and could understand their fears and challenges. Further assistance helped Neil and Michelle find appropriate services and resources and slowly their family life moved toward a steadier routine.

Later Neil was seeking a career change and recalled "that really good organization that helped us after Tristan was born." Neil is now helping other families as he had been helped. "When you are in that kind of situation, if you can find someone to take even one small thing off your plate for you, it is so helpful," he explained. "When I've helped a family overcome an obstacle, it's a really good feeling."



**Raising
Special Kids**®
families helping families

Connecting is published by
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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in both Spanish and English. Services are provided at no charge to families in Arizona.

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

Experts caution readers to regard information from the Internet with healthy skepticism. Arlene Fink Ph.D. notes in her book *Evidence-Based Public Health*

“Misinformation on the Internet is, and will always be, a problem. One of the attributes of the Internet — the fact that nearly anyone can publish on it — creates an environment of freedom and simultaneously an environment that lacks quality control. That lack of quality control often requires the Internet user to perform the filtering done for us transparently in magazines, newsletters, journals, encyclopedias, books, and so on. The array of agents, editors, publishers, and professional readers that scrutinize the majority of published text is often absent from Internet content.”

— *Better Read That Again: Web Hoaxes and Misinformation* by Paul S. Piper, Librarian, Western Washington University

Practice, “Assessing the reliability of health information that you come across in discussion groups is at least as important as it is for any online site. Most Internet service providers do not verify what is discussed in these groups, and you have no way of knowing the qualifications or credentials of the other people online.”

In a recent Health Resources and Services Administration presentation for health center communicators, John Richards, MA, AITP, a Research Instructor at Health Information Group and Maternal and Child Health Library at Georgetown University said, “American Academy of Pediatrics studies show that 58% of parents actually

trust what they read online more than their pediatrician — which is scary.”

A tutorial on research from University of California Berkeley Library notes, “The burden is on you — the reader — to establish the validity, authorship, timeliness, and integrity of what you find. Documents can easily be copied and falsified or copied with omissions and errors — intentional or accidental.”

The nature of information sharing on the Internet can affect readers by making any piece of information seem accepted as truth simply by frequent repetition. The more often a story or statement appears, the more valid it may seem to be.

For a parent seeking proof that a specific technique, treatment or therapy would be appropriate for their child, it is important to be aware of the difference between individuals’ perceptions of what seemed to happen, and what has been proven to happen in controlled studies. Daniel B. Kessler, MD, FAAP, Medical Director at Southwest Human Development has discussed diagnoses and treatment for children with developmental disabilities with many families. “If parents search for an answer (usually online) they are likely to come across individuals who are absolutely sure they know the answer.” He recommends, “Look for help through highly reputable resources with real science behind them.”



What Do You Want?

How can family members seeking answers about their child’s health, education, and parenting issues determine the value of information they read online? A good place to start is to clarify what type of information is desired. Parents of children with special needs may need different kinds of resources,

so it is helpful to be clear about the goal. Some examples may include:

- An understandable explanation of a diagnosis or data on treatment options

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Tips for Evaluating Websites



1. **Check the URL** (the address of a website). The extension at the end can give a clue as to what type of entity published it (some examples include .com = business, .org = organization, .edu = university). Be careful of fake websites — some use a URL that mimics the address of a popular site with just a minor difference such as an alternate extension.
2. **Consider the source** — is it reputable? In determining whether a source is high quality, consider the type of information it delivers. If you are looking for the results of a scientific study, then look for peer reviewed articles. If you are seeking firsthand experience of someone who has dealt with a particular situation, a peer support network may be a better choice.
3. **What type** of publication or site is it (scholarly journal, popular e-zine, social discussion group)?
4. Is **information about the website's owner** readily available? Look for pages labeled About Us, Privacy Policies, or Contact Us for information. If tabs to those pages are not obvious, look for a Site Map for guidance in finding the links.
5. **Identify the author and credentials** — is this person considered authoritative in the subject area?
6. **Follow the money** — who is funding the website, the study, the organization, etc? Is there anything for the source to gain by convincing the reader of something?
7. Is information presented in an **objective** manner or is the language inflammatory?
8. Are facts or claims **attributed** to a traceable source?
9. **When** was the source published? How old is the information the source reports? Is it too new to be verified? Is it out of date for the topic being researched?
10. What is the **potential for harm** or risk to the child from following the advice?



Resources Online:

UC Berkeley - Finding Information on the Internet: A Tutorial: <http://bit.ly/C9FiX>

How Internet Search Engines Work / HowStuffWorks.com: <http://bit.ly/MmXTjg>

U.S. National Archives and Records Administration: <http://1.usa.gov/LcseDp>

Associated Press published **statement of News Values and Principles**: <http://bit.ly/H9s7no>

Emily Center Health Library: includes skilled nurses to conduct individualized research for families and professionals: www.theemilycenter.com

— continued from page 3

- Empathy from someone else who understands your challenges and needs
- Instructions for navigating state systems or clarifying legal rights
- Assurance of confidentiality

Each of these would require a different approach in determining what information is reliable.

Best practices have been identified for peer support networks such as the Parent to Parent Program at Raising Special Kids. New parents are mentored by a parent with training and experience for eight weeks.

“We train our parent mentors to describe, not prescribe when they are helping another parent of a child with a disability,” said Janna Murrell, Director of Family Support. Parent mentors listen, provide emotional support, and share their experiences, but refrain from dictating what another parent should do. “By sharing your experiences and what worked well for your family, you are providing valuable information for parents to consider when making decisions for their own family. When parents make decisions on their own, they become more empowered as advocates for their children.”

Tools for Online Research

Information about a website: **Alexa** - Find traffic data and contact information for a website: <http://www.alexa.com>

Whois - Find information in the registration record of a domain name: <http://www.internic.net/whois.html>

Link command – find out what other websites provide a link to the site you are viewing. type “link:www.website.com” into your browser – (this tool is not complete or foolproof, but it can provide some helpful information)

Current Awareness Service to keep up-to-date with the most recently published information; one e.g.: <http://www.library.cornell.edu/resrch/current#social>

Agency for Healthcare Research and Quality: <http://www.ahrq.gov> - type a keyword into the search box and choose tools

Web of Knowledge: research platform for information in the sciences, social sciences, arts, and humanities <http://wokinfo.com>

PAIS International Peer Reviewed Journals List: <http://www.csa.com/factsheets/supplements/paispeer.php>

PubMed Central® (PMC) is a free archive of biomedical and life sciences journal literature at the U.S. National Institutes of Health's National Library of Medicine (NIH/NLM). <http://www.ncbi.nlm.nih.gov/pmc>

Medline Plus directory of health libraries: <http://www.nlm.nih.gov/medlineplus/libraries.html>

Institute of Educational Sciences, What Works Clearinghouse: <http://ies.ed.gov/ncee/wwc>

The **WebGuide** is a directory that evaluates, describes and provides links to hundreds of sites containing child development research and practical advice. <http://www.cfw.tufts.edu>

Better Business Bureau: <http://www.bbb.org>

Snopes.com: Reference source on urban legends, folklore, myths, rumors, and misinformation. <http://snopes.com>

List of tools and directories: <http://www.virtualsalt.com/search.htm>



Raising Special Kids Calendar

Register through our online calendar or call 602-242-4366 or 800-237-3007.

Our office location is a fragrance-free environment, please avoid wearing fragrances.

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

IFSP Basics

For parents of children birth to 3. Learn the basics of the process for developing an Individualized Family Service Plan.

Sat. 8/18/12, 1:00 – 3:00 pm

Thu. 10/4/12, 10:00 – 12:00 noon

Turning 3, What's Next?

AzEIP to Preschool Transition

Learn how to transition your child from AzEIP services to preschool services provided by the school district.

Wed. 8/22/12, 10:00 – 12:00 noon

Thu. 10/4/12, 1:00 – 3:00 pm

Positive Behavior Support

Training on effective techniques for behavior management.

Thu. 7/19/12, 6:00 – 8:00 pm

Thu. 8/16/12, 6:00 – 8:00 pm

Sat. 9/15/12, 9:00 – 11:00 am

Thu. 10/11/12, 3:00 – 5:00 pm

Understanding 504

Learn about the rules and regulations of a 504 Plan and how it differs from the IEP (IDEA).

Sat. 7/14/12, 2:00 – 4:00 pm^{SS}

Wed. 9/26/12, 2:00 – 4:00 pm

Tues. 12/4/12, 6:00 – 8:00 pm

Parent/Professional Collaboration

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

Wed. 8/22/12, 1:00 – 3:00 pm

Thu. 10/25/12, 11:00 – 1:00 pm

IEP Basics

Learn about the purpose of IEPs, parents' role in the process, and how to prepare for meetings.

Thu. 8/9/12, 6:00 – 8:00 pm

Sat. 9/15/12, 11:30 – 1:30 pm

Thu. 10/25/12, 2:00 – 4:00 pm

Thu. 11/15/12, 6:00 – 8:00 pm

Advanced IEP Training

Receive an in-depth view of the IEP and strategies to help maximize the potential of each student. (Recommended: First attend IEP Basics.)

Thu. 8/30/12, 3:00 – 5:00 pm

Sat. 10/27/12, 12:00 – 2:00 pm

The Journey to Adulthood

Provide young adults and parents with information about physical, emotional and social changes that adolescence and puberty bring to every child.

Thu. 7/19/12, 12:30 – 2:30 pm

Wed. 9/5/12, 10:00 – 12:00 pm

Thu. 11/8/12, 3:00 – 5:00 pm

Getting and Keeping the First Job

Assist young adults and parents with identifying the importance of employment for youth with disabilities and special needs.

Thu. 9/6/12, 6:00 – 8:00 pm

High School Transition

Learn how the transition plan in a student's IEP in high school can prepare for higher education, employment, and life in the community. Resources discussed.

Sat. 7/14/12, 10:15 – 12:00 noon^{SS}

Wed. 8/15/12, 1:00 – 3:00 pm

Tues. 10/9/12, 4:00 – 6:00 pm

Bully-Free Environments

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

Sat. 7/14/12, 8:00 – 10:00 am^{SS}

Thu. 9/13/12, 1:00 – 3:00 pm

Thu. 10/11/12, 5:30 – 7:30 pm

Guardianship

Turning 18, What's Next?

Making the decision; understanding the process. Learn what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

Sat. 7/14/12, 12:15 – 1:45 pm^{SS}

Wed. 8/15/12, 10:00 – 12:00 noon

Thu. 9/6/12, 3:00 – 5:00 pm

Tue. 10/9/12, 1:00 – 3:00 pm

Organizing Your Child's Records

Bring your child's special education, ISP, therapy and medical records to this "make and take" session to create your own filing system.

Sat. 8/18/12, 10:00 – 12:00 noon

Resilient Relationships

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

Sat. 10/27/12, 9:30 – 11:30 am

IEP 1-to-1 Consultation

Bring your child's IEP for review, as well as your questions and concerns.

Call for an appointment:

602-242-4366 or 800-237-3007

Attendance at all workshops is at NO COST. For Southern Arizona workshops please call 520-324-3150 or visit www.pilotparents.org

SS = Offered at the Summer School for Parents.
See page 7 for details.

CALENDARIO EN ESPAÑOL

Por favor llamar al 602-242-4366 o 800-237-3007 para confirmar su asistencia a los talleres.
Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034.
Somos una oficina libre de fragancias.

El Comportamiento Positivo

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

Viernes 8/17/12, 10:00 – 12:00 pm

Viernes 10/12/12, 11:00 – 12:30 pm

Conceptos Basicos del IEP

Aprender acerca del propósito del IEP a través de una visión general del documento y reunión.

Viernes 8/17/12, 1:00 – 3:00 pm

Viernes 10/19/12, 11:00 – 1:00 pm

Organizando los archivos de sus niños/as

Aprenda modos efectivos para organizar sus archivos. Los materiales son proveídos gratuitamente

Lunes 8/20/12, 10:00 – 12:00 pm

Destrezas para ser un Padre Defensor Eficaz

Usted aprenderá: Qué es ser defensor; Cómo mejorar sus destrezas de Abogacía; Cómo hacer una contribución significativa

Viernes 9/14/12, 1:00 – 3:00 pm

Conceptos Basicos del IFSP

Para padres de niños de 0 a 3 años de edad. Aprenda los pasos basicos del proceso para desarrollar un plan familiar de servicios individualizado.

Viernes 10/12/12, 1:00 – 3:00 pm

Es su Hijo Blanco de Burlas?

Estrategias de Intervención para Padres de Niños con Discapacidades.

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

Sabado 7/14/12, 8:00 – 10:00 am *

Lunes 11/12/12, 2:00 – 4:00 pm

Transición de Escuela Secundaria (High School)

Aprenda como el plan de transición en el IEP de su estudiante de Escuela Secundaria (High School) puede prepararlo para una educación superior, empleo, vida en la comunidad y recursos disponibles.

Sabado 7/14/12, 10:15 – 12:00 pm*

Viernes 12/7/12, 11:30 – 1:00 pm

Al cumplir los 18 años, que sigue?

Tutela: Tomando la Decisión y Entendiendo el Proceso Aprenda lo que la Tutela implica y sus alternativas antes de que su adolescente cumpla los 18 años de edad.

Sabado 7/14/12, 12:15 – 1:45 pm *

Viernes 9/14/12, 11:00 – 12:30 pm

 = One Life Unlimited, 1650 N Dysart Rd Goodyear Az, 85395

* = Escuela de Verano para Padres



Entrenamiento Para Padres Líderes

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

Martes 7/10/12, 9:30 – 11:00 am

Familias Resistentes

La estructura más básica para una relación de familia saludable, la habilidad de volver de un trauma o una situación difícil.

Lunes 7/23/12, 9:30 – 11:00 am

Para descripciones de talleres y más información, llame a nuestra oficina al 602-242-4366 o al 800-237-3007 o vea el Calendario en español en nuestra pagina web: www.raisingpecialkids.org
Por favor llámenos para confirmar su asistencia a los talleres.



Summer School for Parents

Saturday July 14, 8 am to 4 pm

Disability Empowerment Center

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

Workshops will be presented in English and Spanish

Bully Free	8:00 – 10:00 am	Guardianship	12:15 – 1:45 pm
High School Transition	10:15 – 12:00 pm	Understanding 504	2:00 – 4:00 pm

Lunch provided. No child care.

Space is limited, please register by contacting Raising Special Kids at 602-242-4366 or online at www.raisingpecialkids.org.

www.raisingpecialkids.org

Parent Resource Manual

A new guide titled the NICU Parent Resource Manual for families of newborns is available at no cost to parents of babies who have been placed in neonatal intensive care units.

Paired with support from parent leaders, the guide is designed to help families deal with the emotions of having a child with special health care needs and provide them with information on how to partner with doctors and others on their child's health care team in order to be an effective advocate for their child.

Raising Special Kids participated in the project as Arizona's Family to Family Health Information Center through a grant funded by the Maternal and Child Health Bureau.

Additional Funding for collaboration between Raising Special Kids, POPSICLE, and Southwest Human Development was provided by Dignity Health through St. Joseph's Hospital.

The book can be customized for each family's needs. In addition to advice and information, it provides parents with tools to organize medical records, keep notes, track contact information on providers and community resources, and log important dates and the child's development.



FREE Collaborative Therapies Conferences For Parents of Children with Disabilities

Gain greater understanding of therapies and techniques you can use with your children. Parents who have "been there" will share their experiences.



Show Low

Saturday, July 21, 2012

9 am - 2 pm

Whipple Elementary School

1350 N. Central, Show Low, AZ

Yuma

Spanish interpretation available

Saturday, August 4, 2012

9 am - 2 pm

Yuma Regional Medical Center

2400 South Avenue A, Yuma, AZ 85364

Breakfast and lunch included. No child care; adults only should attend. To register: 1-800-237-3007 or 602-242-4366 or online at www.raisingpecialkids.org

We are being discharged! But, now what?

Your excitement is building at the thought of bringing your baby home from the NICU. Here is a list of a few of the simple, but critical, things you should take care of as you plan for life at home with a new baby:

- Clean your house to protect your baby from dust, smoke, animal hair and germs.
- Make sure you have a car seat. Visit the American Academy of Pediatrics at www.aap.org for tips on how to choose the proper one for your newborn. Your nurse can also help you decide what kind of car seat is best for your baby and will make sure that your baby is safe in the seat before you leave the hospital.
- Have a crib, diapers, thermometer, clothing, and blankets available.
- Start using a breast pump, if planning to breast-feed, or buy several weeks' supply of formula.
- Make appointments with your baby's healthcare provider for follow-up checkups and immunizations.

The manual includes practical resources such as this excerpt from "Your Preemie in the NICU" — a selection reprinted with permission from preemievoices.com.

"A critical component of this resource is the personal support for parents from trained volunteer mentors who have been through the NICU experience. Parent to Parent mentors assist families in becoming familiar with the book, providing guidance on resources and lending emotional support and reassurance," explained Neil Wintle, a member of the development team.

The manual will be available to download and print for free in English and Spanish on Raising Special Kids' website: www.raisingpecialkids.org.

What is that?

Special Education Terminology

If you are confused about some of the terms you've encountered in an IEP meeting or while communicating with your child's school, you are not alone. Here are some terms we have frequently received questions about from parents:

Prior Written Notice

Because this form often appears at IEP meetings, it is sometimes assumed that it is a notice to inform parents about meetings. The word "prior" actually refers to a proposed *action*. This form is required to be issued from the school to parents any time the school proposes to take (or refuses to take) certain actions with respect to a student. The school must provide parents with prior written notice each time that it:

- refuses or proposes to initiate or change the identification, evaluation, or educational placement of your child; *e.g.: A Parent requests an evaluation of their child and the school accepts. The school documents the decision in a Prior Written Notice and provides a copy to the parents.*
- refuses or proposes to initiate or change the provision of free appropriate public education (FAPE) to your child; *e.g.: The school wants to decrease a student's speech services. The final team decision is documented in a Prior Written Notice and a copy is provided to the parent.*

Multidisciplinary Evaluation Team (MET)

A Multidisciplinary Evaluation Team (MET) comprises educators, administrators, evaluators, agency staff and parents as equal team members. This team reviews data and results of evaluations **to determine if a student is eligible for special education services.**

If the child is determined to be eligible, then the Individual Education Program (IEP) team will meet within 30 days to determine what services are needed and how they will be delivered to the student. Often, but not always, these two meetings are held on the same occasion. It can be useful to plan your schedule to accommodate the possibility of both meetings.



FREE

Lake Havasu

Transition Workshops

For Parents and Teens with Disabilities

Presented in partnership with Lake Havasu Unified School District #1

Thunderbolt Middle School

695 Thunderbolt Ave., Lake Havasu, AZ

Saturday, August 18, 2012

9 am - 4 pm

Positive Behavior Support

9 am - 12 noon

- Why kids behave the way they do
- Effective techniques for dealing with difficult behaviors
- Feel like you're always saying "No"? Explore new options.

High School Transition

12:45 pm - 2:30 pm

- How the transition plan in a high school student's IEP can prepare for higher education, employment and life in the community
- How students can explore options and make choices
- Resources

Getting and Keeping the First Job

2:30 pm - 4 pm

- Importance of work
- Need to know about employment & career planning
- Accommodations, Disclosure & Interviewing

Registration required for EACH workshop. No child care. Light breakfast and lunch included. To register: 1-800-237-3007 or 602-242-4366 or online at www.raisingpecialkids.org

¿Crear o no crear?

¿Qué tan confiable es la información que lee en Internet?

Muchas cosas han cambiado con la llegada de Internet. El cuidado de los niños es una de ellas, en especial, cuando se trata de niños con necesidades especiales. Actualmente, existen muchos recursos disponibles y la tendencia a cuestionar las creencias populares y hasta las opiniones profesionales es mucho mayor.

Cuando los padres quieren informarse para tomar decisiones bien documentados consultan Internet.

Si bien es cierto que hay más información disponible gracias a Internet, se debe tener presente que también hay más información errónea. La facilidad para copiar y repetir comentarios, artículos, enlaces, entre otros, hace que gran parte de la información que se encuentra en internet no sea confiable. Sin supervisión o control, es muy probable que aparezca información sin verificar y que se disemine rápidamente a través de blogs, secciones de boletines, sitios web, conversaciones en redes sociales y otros foros.

Según un artículo publicado en abril en Los Angeles Times, un tercio de los consumidores utilizan las redes sociales para buscar información médica, discutir síntomas y expresar su opinión sobre proveedores y tratamientos. Alex Duggan, Director Ejecutivo de la organización DSNetwork, explicó hace poco que “las redes sociales hoy en día ofrecen la posibilidad de dar y recibir recomendaciones personales de forma inmediata y conectarse con una red de personas. Desde preguntas sobre terapeutas ocupacionales, pasando por ofertas de campamentos de verano, hasta consejos; existe todo un mundo de información compartido en nuestro grupo

de discusión de Yahoo y otros foros de redes sociales”.

Los expertos le advierten a los lectores que deben evaluar la información de Internet con cierto escepticismo. En su libro Evidence-Based Public Health Practice, Arlene Fink (Ph.D.) señala que “evaluar la fiabilidad de la información relativa a la salud que encuentra en grupos de discusión es, cuando menos, tan importante como evaluarla en cualquier otro sitio de Internet. La mayoría de los proveedores de servicios de Internet no verifican qué se discute en estos grupos y usted no tiene forma de saber cuáles son las calificaciones o credenciales del resto de las personas conectadas”.

En una reciente presentación sobre recursos sanitarios y servicios administrativos para comunicadores de centros de salud, John Richards, MA, AITP, Instructor de investigación del Grupo de Información de Salud y Biblioteca de Salud Infantil y Materna de la Universidad de Georgetown, indicó que “los estudios de la Academia Estadounidense de Pediatría muestran que 58% de los padres confía más en lo que lee en Internet que en lo que le dice el pediatra, lo cual es alarmante”.

En un seminario sobre investigación de la Biblioteca Berkeley de la Universidad de California se señaló que “es su responsabilidad –como lector– establecer la validez, autoría, actualidad e integridad de lo que encuentra. Los documentos se pueden copiar y falsificar con facilidad o pueden copiarse con omisiones y errores, intencionales o por descuido”.



La forma en la que se comparte información en Internet puede afectar a los lectores, puesto que los datos podrían parecer aceptados como válidos simplemente porque se repiten. Mientras más se repite una historia o afirmación, más válida podría parecer.

Para un padre que busca pruebas de que una técnica, tratamiento o terapia específica podría ser la indicada para su hijo, es importante tener presente la diferencia entre la percepción que una persona tiene de lo que pareció ocurrir y lo que se demostró que realmente ocurrió mediante estudios supervisados. Daniel B. Kessler, MD, FAAP, Director Médico de la organización Southwest Human Development ha discutido diagnósticos y tratamientos para niños con discapacidades relativas al desarrollo con muchas familias. “Si los padres buscan una respuesta (usualmente en Internet) es muy probable que encuentren personas que están completamente seguras de que saben la respuesta”. Su recomendación es “buscar ayuda utilizando recursos con excelente reputación y estudios científicos que los avalen”.

do de su hijo determinar el valor de la información que leen en Internet? Un buen punto de partida es aclarar el tipo de información que se desea. Los padres de niños con necesidades especiales pueden necesitar diferentes tipos de recursos, así que es útil tener claro el objetivo. A continuación, algunos ejemplos:

- Un explicación comprensible de un diagnóstico o datos sobre opciones de tratamiento
- Empatía con alguien que comprenda sus dificultades y necesidades
- Instrucciones para desenvolverse en los sistemas estatales o aclarar derechos legales
- Garantía de confidencialidad

Cada uno de los puntos anteriores ameritaría un enfoque diferente para determinar qué información es confiable.

Se han determinado prácticas recomendables para redes de apoyo para personas en condiciones similares, tales como el Programa de padres a padres (Parent to Parent Program) de la organización Raising Special Kids (Criar Niños Especiales). Los

padres son entrenados por un padre con capacitación y experiencia durante ocho semanas. “Le enseñamos a nuestros padres mentores a describir –en vez de prescribir– cuando están ayudando a padres de niños con discapacidades”, explicó Janna Murrell, Directora de Apoyo Familiar. Los padres mentores escuchan, brindan apoyo emocional y comparten sus experiencias, pero no le dicen a los padres lo que deben hacer. “Al compartir sus experiencias y contar lo que funcionó en sus familias, proporcionan valiosa información que los padres pueden considerar cuando tomen decisiones en su núcleo familiar. Cuando los padres toman

decisiones por sí mismos adquieren más poder como representantes de sus hijos”, agregó Murrell.



¿Qué es lo que quiere?

¿Cómo pueden los miembros de una familia que busca respuestas sobre la salud, educación y cuida-

Consejos para evaluar sitios web



1. Revise la dirección URL (la dirección de un sitio web). La extensión al final puede darle una pista sobre el tipo de entidad que publica la información [por ejemplo, .com (comercial), .org (organización), .edu (universitario)]. Tenga cuidado con los sitios web falsos, algunos utilizan una URL que imita la dirección de un sitio conocido y sólo se diferencian por un detalle mínimo, como una extensión diferente.

2. Considere la fuente, ¿tiene buena reputación? Para determinar la calidad de la fuente, evalúe el tipo de información que ofrece. Si está buscando los resultados de un estudio científico, busque artículos con evaluaciones de otros especialistas. Si lo que busca es experiencia personal de alguien que

haya lidiado con una situación específica, una red de apoyo para personas en condiciones similares podría ser una mejor opción.

3. ¿De qué tipo de publicación o sitio se trata (publicación académica, revista electrónica, grupo de discusión social)?
4. ¿Se puede acceder con facilidad a información sobre el propietario del sitio web? Busque enlaces como “Sobre nosotros”, “Políticas de Privacidad” o “Contáctenos” para informarse. Si tiene dificultades para encontrar esos enlaces, busque un mapa de sitio (Site Map) como guía para encontrar los enlaces.
5. Identifique el autor y sus credenciales. ¿Es respetado en el área de interés?
6. ¿La fuente gana algo si convence al lector de algo en particular? Hágale un seguimiento a los recursos: ¿Quién financia el sitio web, el estudio, la organización, etc?
7. ¿La información está presentada de forma objetiva o el lenguaje empleado es incendiario?
8. ¿Los hechos o afirmaciones se le atribuyen a una fuente fácil de ubicar?
9. ¿Cuál es la fecha de publicación? ¿Qué tan antigua es la información que reporta la fuente? ¿Es tan reciente que no puede verificarse? ¿Está desactualizada?
10. ¿Cuál es el daño o riesgo potencial para el niño si se sigue el consejo?



Recursos de Internet:

Visite La Biblioteca Familiar The Emily Center en Español:

<http://www.phoenixchildrens.com/espanol/emily-center/about-the-emily-center/>

Bienvenidos a los Archivos Nacionales y Administración de Documentos (NARA) de los Estados Unidos de América: <http://www.archives.gov/espanol/>

Community Notes

6th Annual

Dandelion Golf Classic

All proceeds
to benefit
Raising
Special Kids

Sponsored by CareScape, Inc.
Saturday, September 29, 2012

Tuscany Falls at Pebble Creek Golf Resort

16262 W. Clubhouse Drive, Goodyear, Arizona 85395



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

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

8:30 am - Shotgun Start

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

Sponsorships available from \$300 to \$7500
Individual players \$150, Team Early Registration Package \$600
Must sign up by August 31, 2012

For details visit: www.dandeliongolfclassic.com

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

Partners in Policymaking

Free Leadership Training for Self-Advocates and Parents of Children with Disabilities
Pilot Parents of Southern Arizona announced applications for the 16th class of Partners in Policymaking are now being accepted. This six-month training program for parents of children with special needs and for young adult self-advocates will begin in Phoenix in October. Applications are due by August 31, 2012. For more information contact: Karen Kelsch at (520) 324-3158, or Toll Free 1-877-365-7220 or visit www.pilotparents.org

Arizona's Twelfth Annual Transition Conference

"Facing the Future: Who's In Your Network?"
Making a commitment to the successful transition to adult life for Youth and Young Adults with Disabilities
October 15th - 16th, 2012 for youth and families (additional day for professionals: October 17th)
9:30 am - 5:00 pm
Talking Stick Resort,
9800 E. Indian Bend Rd., Scottsdale, AZ 85250

Special Thanks to

John Michalakes, All Tech Computers

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Scott Sacherer, Salesforce.com Foundation

for your kind contribution to assist families of children with special needs.

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Find links on the home-
page of our website.
While you're there, sign
up for our weekly
Monday Memo email.
www.raisingpecialkids.org



Raising Special Kids News

Special Day for Special Kids



Thanks to the volunteers from the Scottsdale Sunrise Rotary Club, Phoenix El Puente Rotary and Scottsdale Unified School District Service Learning Classes for a fabulous time for families. Free food, face painting, a petting zoo, games and appearances by Ronald McDonald, the Cardinal's Big Red and cheerleaders, Suns Gorilla, and Coyotes Howler were just some of the highlights.

Mark your calendars now for another great day on March 23rd, 2013 for the 28th Annual Special Day for Special Kids at McCormick-Stillman Railroad Park in Scottsdale.



Special thanks to Jeff Lang of All in the Family Photography for providing free portraits to more than 60 families!!

Visit from Nevada Parent Center

The Nevada Parent Center, Family Ties, requested technical assistance from Raising Special Kids to assist them in building and improving the capacity of their organization. Their site visit team was composed of three representatives who traveled to Phoenix to spend two days gathering information about family support programs

and practices, financial management, and fund development activities.

“We couldn’t have chosen a better organization to learn from. The amount of information we came away with was astounding. We feel we learned from the best.” said Melanie Kauffman, Executive Director, Family TIES of Nevada.

Conference a hit with families

Parents learned therapy techniques from the pros

Raising Special Kids presented a conference for family members of young children to learn about therapy techniques they can use at home, effective advocacy, communication with professionals, and resources. The fourth annual Collaborative Therapies Conference was hosted by Phoenix Children’s Hospital in May. During the free event therapists and a pediatrician presented with translation for Spanish-speaking parents.

Two more conferences are being held in Yuma and Show Low this summer (see page 8).



Attendees chat with therapists between presentations.

We gratefully acknowledge our conference sponsors and presenters

Phoenix Children’s Hospital
Arizona Early Intervention Program
Del Monte Fresh Produce Company
Chick-fil-A Mesa Riverview
Hachette Book Group
Rhonda Gerchak
Southwest Human Development
CareConnect at Phoenix Children’s Hospital
POPSICLE Center
HopeKids
Hanger Clinic
Aspire Therapy
Emily Center
Neurological Music Therapy of Arizona

In The Spotlight

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

February - April, 2012

A New Leaf
Aid to the Adoption of Special Kids
Alhambra Developmental Preschool
Christina Carolan
Alhambra School District
Elizabeth Johnson-Heston
Arizona Autism United
Paulina Tiffany
Arizona Center for Disability Law
Judy Tyler
Arizona Department Of Education
Jill Castle
Amy Dill
Arizona Department Of Health Services / Office of Children with Special Health Care Needs
Ralph Fiueroa
Marta Urbina
Arizona Department of Economic Security
Arizona Early Intervention Project (0-3)
Jenine Cook
Courtney Parker
Becky Stark
Arizona's Children Association
Jane Lord
Anna Longoria, MSW
Joanna M. Prusa
Elizabeth Urtuzuastegui
Banner Desert Medical Center
Deb Humphreys
Cardon Children's Medical Center
Cindy George
Heidi Solak
CareConnect Arizona at MPH
Antoinette Martinez
Carol Rae Ranch School
Catholic Charities
Cave Creek School District
Centapico Behavioral Health
Diane Taylor
Centro de Amistad
Adriana Arola-Sierra
Maria Hernandez
Elva Torres
Child and Family Resources
Nubia Garcia
Children's Action Alliance
Matt Jewett
Children's Rehabilitative Services
City of Phoenix Early Headstart
Lori Solares
City of Phoenix Head Start
Sylvia de Leon
Sylvia Rangel
Creighton School District
Kelly Risner
Crisis Nursery
Karla Carzares
Crisis Nursery Early Head Start
Joanna Martinez
Deer Valley School District
Division Of Developmental Disabilities
Andrea Adams
Carmen Aguilera
Whitney Barclay
Maritsa Beltran
Ruben Bernal
Lois Brooks
Renee Brown
William Byers
Kathleen Calder
Maggie Carbajal
Robin Chanto
Rita Chavez
Chelle Colton-Rutledge
Annie Converse
Wanda Copeland
Teresa Cromer
Rebecca Cummings
Adonis Deniz
Flor Erickson
Tanya Goltia
Jade Guerrero
Kathi Guildig
Julia Harris
Claudia Hart
Esther Hasz
Susan Hawley
Tatum Hemmeger
Billy Henderson
Joanie Henderson
Kristen Heninger
Amy Jaques

Jill Keyes-McClements
William Kilgore
Valerie Krasevic
Vanessa Kruse
Laura Kushemba
Phillip Leavitt
Maria Mangiameli
Elynn Manzo
Lucia Marquez
Chelsie Martin
Betty McAuley
Martha Mills
Armando Molina
Marta Monyer
Laura Moore Smith
Jonathan Newby
Kelly Norris
Kelly O'Brien
Shawn Padilla
Courtney Parker
Carla Pate
Charlene Pinango
Elva Rama
Yuriana Ramirez
Lisa Rennells
Alma Reyes
Amanda Reynolds
Lynn Rhodes
Richard Schloe
Dana Southworth
Lola Summers
Cortney Tipton
JoAnn Valdez
Marietta Valdez
Patty Walters
Megan Wiley
Elizabeth Williams
Dysart School District
EMBRACE Palliative Care Foundation
Dana Southworth
Impact CPS Stabilization
Andrea Dinardo
Estes Elementary
Estrella Pediatrics
Imelda Ojeda
Family Learning Center
Maritsa Beltran
Four Directions
Adela Urbano
Fuerza y Esperanza Support Group
Lydia Seise
GALA
Alberto Serpas
GANE
Gabby Orozco
Gilbert Parent Council
Glendale District
Wendy Collison
Grand Canyon University
Healthy Families
Jasmin Hernandez
Imagine School
Interfaith Counseling
Lucy Vasques
Joni & Friends
Pam Baldwin
Kids Foster and Adoption Center
Michelle Lunka
Kyrene School District
La Casa de Cristo MOPS Group
Luke Air Force Base Exceptional Family Member Program
Judy L. Pierson
Lutheran Social Services of the Southwest - Refugee Services
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Mesa Community College Red Mountain Branch
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Mountain Park Health Care
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Kim Williams
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Judie Walker
Washington Elementary School District
Katie Anderson
Washington School District
West Valley Family Development Center
Dr. Valerie Kemper, PsyD
Wilson Elementary School
Luz Muñoz

Kristina Blackledge
Dr. Robin Blitz
Zelmor Danford
Brooke DeCora
Dr. Elaine Ellis
Erin Gunderson
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Angel Mullins
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Dr. Ron Serbein
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Paula Serries
Hannah Spain
Terry Sutter
Dr. Kathy Thomas
Robin Thompson
Lori Tilbury
Kim Yamamoto

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

February - April, 2012

Apache Junction
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2011 Report to the Community

7,287 parents were helped

314 Parent to Parent matches were made

98% reported being better prepared to make decisions about their child's needs and services

3,050 Professionals received assistance and training

Over 90% reported being better prepared to work with families



Help Raising Special Kids serve more families

Please make your donation today through our secure online system at www.raisingpecialkids.org

Thank you!



www.raisingpecialkids.org