OPEN WIDE...
Dental Care for Children with Special Needs

Raising Special Kids
Families Helping Families

Connecting
Summer 2015
Staff Spotlight
Trudy John - NAZ Family Support Specialist

Raising Special Kids has a new team member in Northern Arizona. Trudy John has joined our staff as a Family Support Specialist and will be spending much of her time in Tuba City where she was born.

Trudy’s native language is Navajo, her maternal clan is Deer Spring (Biih Bitoodnii) and her paternal clan is Red Bottom (Tl’aaashchii’i). Raising Special Kids is grateful to have her assistance to help our organization serve the native population with understanding and respect.

Trudy earned her BS in Public Health from Northern Arizona University after which she coordinated several health and wellness programs on Western Navajo. She then took a research position for Johns Hopkins University Center for American Indian Health focusing on Behavioral Health and Nutrition.

When her oldest son was diagnosed with a brain stem tumor in early 2013, she chose to stay closer to home and took a position as the manager of a food bank. “As tough as the diagnosis and treatment was, it really brought our family closer,” said Trudy, adding, “It helped us decide what was important to us as a family.”

Trudy is anxious to help other families navigate their own journey by sharing her experience and knowledge of healthcare systems and special education.

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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 English, Spanish and other languages. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)(3) non-profit organization.
Dental Care for Children with Special Needs
Considerations and Tips for Success

If your child has a developmental disability, a behavioral issue or a physical limitation, it’s important for you to find a dentist who can provide dental care while accommodating your child’s unique needs. Children with mild anxiety disorders, Down syndrome, autism and cerebral palsy may need extra time or support when seeing a dentist.

SUPPORTS FOR SPECIAL NEEDS AT THE DENTIST
Finding the right dentist for your child requires clearly identifying your child’s needs. Call or visit the dentist’s office to find out if the dentist is familiar with your child’s condition and how it could affect his or her oral health. Describe the special supports your child may need and ask whether the dentist can provide them. When looking for a dentist, think about these special supports and qualifications:

Pre-Appointments:
Does the dentist offer pre-appointments? A pre-appointment would give your child a chance to meet the dentist and see the exam room and equipment. This could help your child feel more comfortable and be more cooperative during the actual dental appointment.

Accessibility:
Are the areas inside and outside the dentist’s office accessible for your child? If your child uses a wheelchair, you’ll want to find a dentist’s office where the wheelchair will fit through the front door and in the examination room.

Experience:
Dentists and their staff who have already cared for children with special needs may have developed strategies that could help support your child. They may also be able to give you advice on oral health home care, like tips for brushing teeth.

Specialized Clinical Training:
Some general dentists and most pediatric dentists have completed special training to treat children with special needs. Before scheduling an appointment, find out whether the dentist has had such training.

Sedation:
Some children may need general anesthesia, while others may need some mild sedation, which can be given by mouth or from an IV drip. Speak with the dentist about your child’s options, and find out what he or she recommends for your child.

STEPS TO FINDING THE RIGHT DENTIST
These resources can help you find a dentist who can meet your child’s special needs:
• Use the Insure Kids Now Dental Locator on www.Insure-KidsNow.gov to find nearby dentists that accept Medicaid coverage. Enter your child’s state, Medicaid plan name, and ZIP code or address. Hit “Search.” Under the “More Information” column, look for the dentists that “Can Accommodate Special Needs.” Before you make an appointment, call or visit the dentist’s office to talk about your child’s special needs.
• Family Voices is a network of experienced family members of children with special needs. Connect with Family Voices at www.FamilyVoices.org/states to find information on a variety of topics, as well as referrals and support from other families.

Reprinted from InsureKidsNow.gov
Think Teeth
Keep up good dental habits at every age.

You can help your child prevent cavities! Here’s how:

- Get regular dental check-ups, starting at age 1.
  Ask about dental sealants that prevent tooth decay.

- Brush twice a day for 2 minutes using fluoride toothpaste.

- Limit foods and drinks with sugar.

Your child could be eligible for dental care through Medicaid. Services include teeth cleanings, check-ups, x-rays, fluoride, dental sealants and fillings.

To enroll or find a dentist, call 1-877-KIDS-NOW or visit InsureKidsNow.gov.

Visit HealthCare.gov to learn more about affordable health coverage for your family.
My passion used to be fish. I loved them and wanted to spend my life working with them. Then, one day on a train ride home from working at the Shedd Aquarium in Chicago, a family I had never met changed my life. Noticing my aquarium uniform (and fishy smell), they realized I worked at the Shedd and commented about how much fun it must be feeding sharks and riding dolphins at work. I smiled and said the majority of my job was actually a little different.

When I asked if they liked to visit the aquarium, their answer was no. Never. They would love to visit, but their son had autism and it was too stressful and overwhelming to go to a place like the Shedd Aquarium, where the sights, smells, sounds, and crowds made the experience difficult for their son and negative for the entire family. In fact, they said, there weren’t many places they could go and have a positive experience. I remembered this feeling. Growing up with uncles who had muscular dystrophy, I was often frustrated when the zoo or pizza place did not have physical accommodations, and our family missed out.

Thanks to the Americans with Disabilities Act, public facilities now provide appropriate access to their buildings. But the boy on the train did not need these tools, he needed something else. This was the beginning of my journey to create PAL Experiences, a Phoenix-based non-profit organization that helps our community become accessible for individuals with intellectual and developmental disabilities. Everyone deserves to go to the aquarium.

I knew there must be a way to help, so I started to learn more about autism and other types of developmental disabilities. By spending time with experts, I got to know individuals and families and read every Temple Grandin book I could find. Just as people with physical disabilities are assisted by tools like wheelchair ramps, individuals with developmental disabilities like autism can thrive when supported appropriately. Reliably simple things can make a world of difference. Video social stories help foreshadow the sensory elements that make new experiences overwhelming for those with developmental disabilities. Guides and pamphlets can help with logistics and by reinforcing the elements presented in the social story. Training for facility staff members can help build a community of awareness, understanding, and compassion for all types of guests.

Using this knowledge, I worked with the Shedd Aquarium to pilot the first PAL Experience, a set of customized tools that helped make the aquarium more predictable, approachable and enjoyable for individuals like the boy I met on the train. Since then, six additional PAL Experiences were created.

Now, my passion is making experiences more accessible for folks with intellectual and developmental disabilities. There are fewer fish in my life, but more smiling faces as I see families sharing new experiences together. Also, my husband says I smell better.

Melanie Isaacs is the founder and Director of PAL Experiences www.palexperiences.org. Photos courtesy PAL Experiences.
Celebrate Dedication and Excellence in Caregiving
DDD accepting nominations for Direct Support Professional & Direct Support Supervisor of the year

Each year the Arizona Department of Economic Security, Division of Developmental Disabilities and its partners seek nominations for excellence in caregiving.

Direct Support Professionals and Direct Support Supervisors will be honored for superior services and/or exemplary work for individuals with developmental disabilities.

Division partners include: Arizona Bridge to Independent Living, the Arizona Autism Coalitions, Arizona Association of Providers for People with Developmental Disabilities, Arizona UCEDDs, Arizona Planning Council for Developmental Disabilities, Raising Special Kids and the provider community for Direct Support Professionals.

Nomination Rules and Requirements

- The nominee must spend 100% of their work time in the delivery of direct care. This includes habilitation, attendant care, day treatment, employment, or other related services. DDD Services can be provided in an individual’s home, group home, day program, employment or after school program, etc. For nominated supervisors, work time must be 100% supervision of direct care.
- The nominee must be currently employed in the field (although they may now be working for another company or serving different consumers).
- Nominee must have been employed in the field for three or more years.
- Nominee must be employed with a contracted agency, work as an independent provider, or be a state employee.
- Nominations must be received by Thursday, August 3, 2015.

Nominations forms are available online and are due by August 3, 2015. For additional information contact Nicolina Chavez at 602-542-6850 or NChavez@azdes.gov

Top 10 Tips to Improve Parent to Professional Communication

These tips are suggestions and techniques from advocates from PACER Center to help parents address some concerns and improve communication with school staff. You may already use some of these approaches while others may be new ideas to consider:

1. If school staff presents a new idea that you may be interested in, you may want to ask, “What will it take to make that happen?”
2. If a school IEP team member expresses something that you think may be an opinion, you may want to ask, “Is that an opinion or do you have data I can see to support it?”
3. If you are uncertain about something in your child’s school day, you may want to ask, “What does this look like in Johnnie’s day?”
4. If a school IEP team member says, “Your son refuses to ____,” you may want to ask, “Is that something he can’t or doesn’t know how to do rather than refuses to do?”
5. If a school staff member says, “We don’t have the money to do that,” you may say, “I understand that the school district has financial concerns. However, we are here to talk about what my child needs for a free, appropriate public education.” Or you might say, “Please put that in writing for me.”
6. If you are trying something new, you may want to ask, “How will we know that it is working?” and “How will data on success be collected?”
7. If you want input from all team members, you may want to ask, “What is your professional opinion?”
8. If an important agreement, decision, or promise is made,
ask to have it put into writing.

9. If you are bringing a problem to the IEP team that needs solving, try to clearly present the problem and then brainstorm solutions with the team.

10. If a school staff member says, “We don’t know (the answer to a particular question, concern, problem, or issue)” without offering a way to find the answer, you may want to ask, “Who can we invite to the meeting to help find the answer?”

Visit www.pacer.org for bonus tips and more information.

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No Cost Workshops & Training

Register online at www.raisingspecialkids.org/events or call 800-237-3007

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Disability Empowerment Center
5025 E Washington St, Ste 204
Phoenix, AZ 85034
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Thu, Sep 24, 6-8pm

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Thu, Sep 24, 6-8pm

High School Transition
Thu, Aug 20, 6-8pm

IEP Training
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Thu, Aug 20, 6-8pm

**Sat, Sep 12, 10am-12pm**

Positive Behavior Support
Thu, Jun 25, 6-8pm
Sat, Jul 18, 10:30am - 12:30pm
Sat, Aug 8, 1-3pm
Sat, Sep 12, 1-3pm

Turning 18 - Legal Options
Sat, Jul 18, 1:30pm - 3:30pm
Sat, Aug 8, 10am-12pm
Thu, Sep 10, 3-5pm

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**IDEA**
Tue, Aug 4, 12-1:30pm

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Arizona Loan$ for Assistive Technology (AzLAT)

Assistance for people with disabilities to borrow money for assistive technology devices

With services available statewide, the Arizona Technology Access Program (AzTAP), a program of Northern Arizona University’s Institute for Human Development (IHD), is expanding their financial loan program, the Arizona Loan$ for Assistive Technology (AzLAT).

AzLAT provides affordable loans to persons with disabilities who need a range of assistive technology devices. Need a loan to buy hearing aids or that scooter you really want but is not covered by your health care plan? Need adaptive software for your computer or other devices that could make living with your vision, hearing or mobility disability easier? AzLAT is a federally funded program that can provide loans to people with disabilities that might not be able to find funding any other way. Payment arrangements are reasonable for people on fixed incomes. New funding will allow AzLAT to increase the number and size of its loans (from $500 to $20,000), enhance outreach efforts to increase consumer awareness of the program beyond Maricopa County, and develop credit building resources to help potential loan applicants manage finances and improve their credit.

AzTAP also has the SEED Loan$ program that provides affordable business loans to persons with disabilities who telework, or as a self-employment opportunity for those who need assistive technology and business equipment.

For information, call 1-800-477-9921, or visit the website: http://aztap.org/at-funding/azlat.
Si su hijo o hija tiene dificultades de desarrollo, problemas conductuales o impedimentos físicos, es importante buscar un dentista que proporcione un cuidado dental de acuerdo a la situación particular del niño o niña. Los niños y niñas con necesidades especiales, tales como trastorno de ansiedad leve, síndrome de Down y parálisis cerebral, requieren tiempo y atención especial a la hora de visitar al dentista.

ATENCIÓN DE NECESIDADES ESPECIALES EN EL CONSULTORIO DEL DENTISTA

Para buscar un dentista adecuado para su hijo o hija usted debe tener en cuenta sus necesidades y la experiencia del profesional. Llame o visite el consultorio para verificar que el profesional está familiarizado con la enfermedad de su hijo o hija y conoce los posibles efectos sobre la salud dental. Describa las necesidades especiales de su hijo o hija y averigüe si el dentista está en condiciones de atenderlas. Para elegir un dentista, tenga en cuenta los siguientes aspectos y cualidades especiales:

Citas Previias:
¿El profesional concede citas previas? La cita previa le brinda a su hijo o hija la posibilidad de conocer al dentista y familiarizarse con el consultorio y los equipos. Esto puede contribuir a que el niño o niña se sienta más cómodo y se muestre más dispuesto a cooperar durante la consulta con el dentista.

Accesibilidad:
¿Son las áreas dentro y fuera del consultorio accesibles? Si su hijo o hija está en silla de ruedas, es importante verificar que el consultorio tenga las dimensiones necesarias para que la silla pase por la puerta de entrada y que pase dentro del consultorio.

Experiencia:
Es frecuente que los dentistas y sus equipos de trabajo con experiencia en la atención de niños y niñas con necesidades especiales desarrollen estrategias para facilitar la atención de su hijo o hija. Además, pueden hablarle acerca del cuidado dental diario, como por ejemplo, darle consejos para el cepillado.

Entrenamiento clínico Especializado:
Algunos dentistas generales y la mayoría de los pediatras cuentan con entrenamiento especializado para la atención de niños y niñas con necesidades especiales. Antes de hacer una cita, averigüe si el profesional elegido tiene esa clase de entrenamiento.

Sedación:
Ciertos niños o niñas pueden requerir anestesia general, mientras que otros pueden tratarse con una sedación suave, administrada por vía oral o intravenosa. Consulte con el dentista las distintas opciones y conozca su opinión acerca del método más recomendable para su hijo o hija.

PASOS PARA ELEGIR EL DENTISTA ADECUADO

Los siguientes recursos pueden ser útiles en la búsqueda de un profesional adecuado para atender las necesidades especiales de su hijo o hija.

- Use la herramienta Insure Kids Now Dental Locator, disponible en www.Insure-KidsNow.gov, para obtener la localización de los dentistas cercanos que aceptan la cobertura de Medicaid. Ingrese el estado, el nombre del plan Medicaid, el código postal o el domicilio de su hijo o hija. Haga clic en “Buscar”. En la columna “Más información”, seleccione los profesionales que “Atienden pacientes con necesidades especiales”. Antes de hacer una cita, comuníquese por teléfono o visite el consultorio para hablar sobre las necesidades especiales de su hijo o hija.

- Family Voices es una red de familiares de niños y niñas con necesidades especiales. Comuníquese con Family Voices en su estado de residencia a través de www.FamilyVoices.org/states, para obtener información acerca de distintos temas, recomendaciones y asistencia de otras familias.
Gracias a las familias que nos acompañaron en el Disability Empowerment Center el sábado 6 de junio para nuestra Conferencia en Español. Fue un día lleno de talleres sobre temas que cubrían la intervención de conducta, la educación especial, el cuidado de la salud, la transición, seguro social y más. El objetivo es que la conferencia se celebrará en Tucson el próximo año, y en Yuma el año después.

Para obtener una lista actualizada de los talleres en español, visite http://www.raisingspecialkids.org/events-training/register-for-a-workshop/?category=spanish

Piense en sus dientes
Mantenga buenos hábitos dentales a cualquier edad.

¡Usted puede ayudar a su hijo a prevenir las caries! Haga lo siguiente:

- **Realice chequeos dentales regulares**, a partir de 1 año de edad. Pregunte sobre los selladores dentales que previenen la caries.
- **Cepille los dientes dos veces al día durante 2 minutos** usando una pasta con fluoruro.
- **Limite los alimentos y bebidas con azúcar**.

Su hijo podría ser elegible para recibir cuidado dental a través de Medicaid. Los servicios incluyen limpiezas dentales, exámenes, radiografías, fluoruro, selladores dentales y relenos.

Para inscribirse o encontrar un dentista, llame al 1-877-KIDS-NOW o visite InsureKidsNow.gov.

Visite CuidadoDeSalud.gov para más información sobre la cobertura de salud a bajo costo para su familia.
I recently had a ‘friend’ go on a rant, and he chose to use the word ‘R-word’ over and over in his communication with me. Each time that word was used, it was like a sword taking another stab at my heart.

Now, I’m not an overly sensitive guy, but with a 3-year-old child with Down syndrome, these particular words were hurtful towards me, and ultimately towards my child.

For myself, I have one very simple rule as it relates to the words that I use. I ask, “Is what I am telling myself, or saying to my child empowering or disempowering?” This makes it very simple, and very clear.

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