



Raising Special Kids

# TEAMING UP

for effective early intervention

Connecting  
*Fall 2019*

## Staff Spotlight

Ceci Hartke, Bilingual Director of Programs



When Ceci Hartke's middle son, Roman was diagnosed with autism, she reached out to Raising Special Kids for guidance on learning about special education rights, navigating health care systems, and to connect with other families on similar journeys. She found the experience so helpful that once she felt more settled and confident, she volunteered to be a parent leader with Raising Special Kids so she could give to other families the same measured guidance

she'd received when her family needed it most.

Parent leadership at Raising Special Kids was just the beginning for Ceci's involvement and advocacy in the disability community. She participated in the Arizona Partners in Leadership program and was selected for a seat on the state Special Education Advisory Panel. It was on SEAP that Ceci met Christopher Tiffany who encouraged her to join the Raising Special Kids team as a Project Coordinator for the 52 DDD & Raising Special Kids Family Member Forums held during the first half of 2019.

One comment Ceci received from a community member especially resonated with her as it reflects her own experience with Raising Special Kids as well as the purpose of the organization:

*"I am thankful for the experienced families who paved the way ahead of families like mine. My blue sky is seeing those families talking to and engaging younger families."*

Ceci is excited to continue the work of Raising Special Kids in her new position as Director of Programs.

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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.



## Teaming Up

For effective early intervention

The Individuals with Disabilities Education Act is familiar to most people as the law ensuring students with disabilities are provided with a Free Appropriate Public Education tailored to their individual needs. It may surprise some to learn that early intervention is one of the four-parts-- Part C to be specific-- of the IDEA. In Arizona, the Part C program is called the Arizona Early Intervention Program or AzEIP. Services are provided for infants and toddlers with disabilities through agencies who are contracted by the Division of Developmental Disabilities or the Arizona School for the Deaf and Blind.

Any child from birth to 36 months who is developmentally delayed or who has an established condition which has a high probability of resulting in a developmental delay, may be found eligible for AzEIP. When a child is referred to AzEIP, the family is contacted and given information about early intervention services and eligibility. If interested in the program, arrangements are made to meet with the family to begin the initial planning process which includes assessment, eligibility determination, and, for eligible children, the development of an Individualized Family Service Plan (IFSP).

A child may stay enrolled in AzEIP until they turn three or no longer need early intervention. As they near two and a half years of age, their Service Coordinator will help the family determine the next steps which may include a preschool



program for children with special needs offered by the local school district, a Head Start program, or a local childcare center.

Prior to 2007, early intervention services in Arizona were provided using a clinical model. Clients would go to a center for a set appointment where a therapist would work with a child on identified skills in isolation. The child might then go to a different center for a different therapy and perhaps a third and even a fourth depending on the child's needs as identified in their Individualized Family Service Plan.

Maureen Mills remembers running from office to office with her son Conor, now 21, who has Down syndrome. "It was pretty overwhelming. Not only did he have weekly Occupational Therapy, Physical Therapy and Speech Therapy; the Developmental Special Interventionist would also come to our house for their

appointment. Then, he also had doctor's appointments with the cardiologist, the neurologist, the gastroenterologist and the ophthalmologist. Conor also has an older brother and sister so trying to fit in everything for everybody was stressful! I never felt like I was doing a good enough job for anyone."

It wasn't just calendar juggling that was an obstacle for families. More and more evidence was coming to light showing that teaching young

**By working within teams, families and providers coordinate services and strategize the best way to help the child develop in the environments in which they already participate.**

children skills in their natural environment was a much better approach.

As AzEIP Liaison Alicia Sharma

shared, “For children under the age of three, the natural learning environment, or activity-based approach, is much more effective. The team supports children where they actually use the skills they’re working on. We work with children at home, at daycare, the park, the grocery store-- just so we’re not practicing skills outside of their typical environment. We know children that young can’t really generalize. We can’t teach an 18-month old a skill in one place, give them homework and tell them

specialists are included as needed to address areas such as behavioral concerns, vision and hearing. One member serves as the team lead and coordinates services with the family. The teams meet at least monthly and each team member is expected to be skilled in evidenced-based strategies appropriate to address the needs of the child. Team members coach each other and the family taking into account the child’s real-life situation. Alicia explained, “Coaching is an evidence-based adult learning strategy. We

the other team members including the family, how things work within the environment and may adjust the intervention incorporating the team’s input.”

By working within teams, families and providers coordinate services and strategize the best way to help the child develop in the environments in which they already participate. Repetition is minimized; conflicting interventions are avoided, time is saved and, most importantly, outcomes improve.

However, not all AzEIP experiences are perfect. If families find they do not agree with the identification, evaluation, placement, or the early intervention services provided, or they have other complaints about their experience, there are procedures for resolving concerns. It’s always best to work to resolve disputes informally by addressing them with the team lead and, if necessary, working up the chain of command. Always put concerns in writing. A simple email will suffice. More formal dispute resolution options are available if necessary. (See link to Child and Family Rights in AzEIP in the resource list.)

The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child’s and family members’ preferences, learning styles and cultural beliefs.



practice in different places. It just doesn't work well.”

In 2007, AzEIP began providing services using the team-based model which assigns each family a core team consisting of a DSI, and a licensed OT, PT and SPT. Other

use reflective questions. We use modeling, observation, practice-- all of the components of coaching. What it boils down to is a team member does not assume they know everything because they're an expert in their field. Rather, they ask

## RESOURCES:

**Individuals with Disabilities Education Act**  
<https://sites.ed.gov/idea/about-idea/>

**Arizona Early Intervention Policy Manual**  
[http://bit.ly/AzEIP\\_Policy\\_Manual](http://bit.ly/AzEIP_Policy_Manual)

**Team-Based Early Intervention Information and Materials**  
[http://bit.ly/AzEIP\\_Team\\_Based\\_EI](http://bit.ly/AzEIP_Team_Based_EI)

**Child and Family Rights in AzEIP**  
[http://bit.ly/AzEIP-Parent\\_Child\\_Rights](http://bit.ly/AzEIP-Parent_Child_Rights)

**AzEIP Mission and Key Principles**  
[http://bit.ly/AzEIP\\_Mission\\_Key\\_Principles](http://bit.ly/AzEIP_Mission_Key_Principles)

**6 Things to Do If You’re Denied Early Intervention**  
[http://bit.ly/What\\_to\\_do\\_if\\_denied](http://bit.ly/What_to_do_if_denied)

**Transition from Part C to Preschool**  
[http://bit.ly/Transition\\_to\\_preschool](http://bit.ly/Transition_to_preschool)

# Exactly Where We Needed to Be

## Raising Special Kids Symposium: Systems and Strategies for Managing Behavior



*Stacey Gordon: Habilitator, Parent & Puppeteer*

In her presentation at the Third Annual Raising Special Kids Symposium: Systems and Strategies for Managing Behavior, Stacey Gordon, whose alter ego Julia is the loveable Sesame Street-dwelling Muppet with autism, shared some of many times throughout her life she's found herself exactly where she needed to be. She punctuated her endearing and educational presentation with images and succinct observations she's made as a parent of a child with autism. Most, if not all, brought nods of recognition, appreciation and some chuckles from the crowd of more than 200 family members and professionals in attendance from around Arizona and beyond.

Well before Stacey took the stage, attendees began the day hearing an update on AHCCCS from Shelli Silver and insights on the healthcare integration from a panel of executives from UnitedHealthcare, Mercy Care and the Division of Developmental Disabilities.

In his keynote address, Dr. Michael Gurian shared fascinating research and insights on the difference in male and female brains and how those differences affect learning (spoiler alert: in general, male brains like movement more than female brains).

As the crowd made their way to the morning breakout sessions which were repeated in the afternoon, one participant remarked, "I'm so glad I found this. I will be sharing what I learned with my son's team and will encourage them all to attend next year." Sessions topics, all with a focus on behavior, ranged from exploring the role of implicit bias in child care centers, to strength-based strategies in movement; from trauma informed school practices to bi-polar disorder and self-advocacy; from exploring a framework for treating challenging behavior in family contexts and to special education conflict resolution. In each session, presenters echoed the premise of

Dr. Dan Davidson's presentation which is how being your best can bring out the best in others when supporting people with challenging behaviors.

During the luncheon, Susan Voirol, program manager for Arizona's Employment First Initiative and Transition at the Sonoran University Center for Educational Excellence at the University of Arizona, was presented with the Families First Award for her exemplary support for Arizona families raising children who have disabilities. About her selection, Chris Tiffany shared, "Susan's work in systems change through collaboration and participation, her commitment to Arizona's Employment First Initiative, and her compassion for the family experience made this year's unanimous decision an easy one for the committee."



*Susan Voirol, receiving the Families First Award from Christopher Tiffany*

Before breaking for afternoon sessions, Howard Glasser introduced the crowd to The Nurtured Heart Approach and



his dedication to awakening and recognizing the greatness in all children, particularly intense and challenging children. Dr. Velia Leybas Nuño shared some of her research into the efficacy of The Nurtured Heart Approach and its promise for the future.

It was only through the generosity of our symposium sponsors that we were able to provide the highest caliber presenters with such terrific information in an environment so conducive to learning. Many thanks to First Things First, the Arizona

Developmental Disabilities Planning Council, Arizona Department of Health Services-Office for Children with Special Health Care Needs, Ability360, Kile & Kupiszewski Law Firm, UnitedHealthcare Community Plan, Mercy Care, Williams Express, The Menta Group, Phelps Law, Hopebridge, Trumpet Behavioral Health, DMG Children's Rehabilitative Services, DES/DDD Arizona Early Intervention Program, Southwest Human Development and Banner Health.

When plans begin for the next

symposium, information will be announced in our weekly newsletter, The Monday Memo, and through social media.



The Monday Memo:  
<http://bit.ly/subscribe2mm>



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## Raising Special Kids Training & Workshops

Register online at [www.raisingspecialkids.org](http://www.raisingspecialkids.org) or call 602-242-4366 | 800-237-3006



### IEP Training

Gain a better understanding of the special education process and the Individualized Education Program (IEP).



### Turning 18 - Legal Options

Learn about the different legal options families will need consider when their child becomes an adult at the age of 18.



### Positive Behavior Support

Learn how to reduce unwanted behavior and increase preferred behavior by using Positive Behavior Supports in your home and in the community.



### Early Childhood Education

Information and guidance for families with children birth through kindergarten with information on IFSPs and IEPs and skills to work on at home.



### Parent & Professional Collaboration

Understand the parents' role in special education, how to communicate effectively, and help students self-advocate.



### Talking to Your Child About Sexuality

Acquire knowledge and skills in communicating about sexuality with young and grown children with disabilities.

# Building the Habits of Learning

How Early Intervention helped 'light up' this Skye

Mallory Lee was trying to be patient. She was waiting for the “light to turn on” in her daughter Skylar’s brain. That light, her pediatrician has assured her, would turn on like ‘flipping a switch’ and Skylar would begin communicating. But, by two and a half years old, she was not doing the things Mallory saw her friends’ children doing. Not only was Skylar not speaking, she wasn’t meeting other milestones and her behavior was becoming very challenging. “None of my friends or my mother had ever experienced anything like these tantrums before; screaming for hours,” she explained. “I’ve never experienced anything like it and I didn’t know what to do.” Mallory was worried. “How long should we wait for the light to go on?”

Mallory has a friend who works at Raising Special Kids. Like many of us, Mallory had a vague idea of the work her friend does. “I just knew she worked with families who needed help,” she shared, “and I needed some help.” So, Mallory reached out to see what advice, if any, her friend could offer.

Quickly, Mallory was guided on how to get Skylar evaluated by the Arizona Early Intervention Program and it wasn’t long before Skylar began receiving weekly early intervention services. A month or so before the end of that school year, she began attending developmental preschool.

For the rest of that school year and for the next two, Skylar attended preschool three days a week riding the bus to and from. With a smile in her voice, Mallory



*Mallory's Family*

recalls, “She began developing this independence. She really enjoyed the structure of school and things just started progressing. It wasn’t all of a sudden overnight, it was little changes. And then she started getting words!” Once Skylar started communicating with words, Mallory started to see a decline in her challenging behavior and tantrums.

For Kindergarten, the IEP team decided the appropriate placement for Skylar was in a general education class with daily pull-out for speech services. She excelled.

This year, in first grade, Skylar meets with her speech therapist just once a week. “She loves school!” Mallory exclaimed. “It really is this crazy change. She is such a happy sweet girl who loves reading and writing and all of the things in school. We don’t have any of those behavioral issues we had when she was having communication challenges.”

Mallory shared, “If Skylar hadn’t started building habits of learning through her experiences with early intervention and preschool, she would not be enjoying the success she is now!”



# Intervención Temprana en Arizona

Trabajar en equipo para obtener resultados efectivos



La mayoría de las personas conocen la Ley de Educación de Personas con Discapacidades (IDEA) como la ley que asegura que los estudiantes con discapacidad reciban la educación adecuada pública gratuita y adaptada a sus necesidades individuales. Algunas personas podrían sorprenderse al saber que la intervención temprana es una de las cuatro partes—la Parte C, específicamente—de la ley IDEA. En Arizona, el programa de la Parte C se llama Programa de Intervención Temprana de Arizona o AzEIP. Se proveen servicios para recién nacidos y niños pequeños con discapacidades mediante agencias que son contratadas por la División de Discapacidades del Desarrollo o la Escuela de Arizona para los Sordos y Ciegos.

Cualquier niño desde el nacimiento hasta los 36 meses que presente retraso en el desarrollo o que tenga una condición establecida con una alta probabilidad de resultar en un

retraso del desarrollo podría ser considerado elegible para el AzEIP. Cuando se deriva a un niño al AzEIP, se contacta a la familia y se le da información sobre los servicios de intervención temprana, así como sobre la elegibilidad. De estar interesados en el programa, se pueden hacer los arreglos para reunirse con la familia y empezar con el proceso de planeación inicial, que incluye la evaluación, la determinación de la elegibilidad y, en el caso de los niños admisibles, el desarrollo de un Plan de Servicio Familiar Individualizado (IFSP).

Los niños pueden seguir inscritos en el AzEIP hasta que cumplan tres años o hasta que ya no necesiten intervención temprana. Conforme un niño inscrito se acerque a los dos años y medio de edad, su Coordinador de Servicio ayudará a la familia a determinar los siguientes pasos, que podrían incluir un programa preescolar para

niños con necesidades especiales ofrecido por el distrito escolar local, un programa de inicio temprano (Head Start) o un centro local de cuidado infantil.

Antes del 2007, los servicios de intervención temprana en Arizona se brindaban mediante un modelo clínico. Los usuarios iban a un centro a una cita establecida, en la que un terapeuta trabajaba con un niño en habilidades identificadas en aislamiento. Después, el niño podía ir a un centro diferente a una terapia diferente, y quizás a un tercero y hasta un cuarto centro, dependiendo de las necesidades que se le hubieran identificado en su Plan de Servicio Familiar Individualizado.

Maureen Mills recuerda que corría de un centro a otro con su hijo con Síndrome de Down, Conor, que ahora tiene 21 años. "Era bastante abrumador. No solo tenía terapia ocupacional, fisioterapia y terapia del lenguaje cada semana, sino que el Interventor Especial del Desarrollo también iba a nuestra casa para su cita; además, tenía citas médicas con el cardiólogo, el neurólogo, el gastroenterólogo y el oftalmólogo. Conor también tiene un hermano y una hermana mayores. Era mucho estrés con tres hijos y tratar de hacer todo. Sentí que nunca lograba ser nada bien para nadie"

Y el obstáculo para las familias no era nada más hacer malabares con el calendario: cada vez salía a la luz más evidencia que mostraba que enseñar a los niños pequeños las habilidades en su entorno natural



era un enfoque mucho mejor. Tal como lo compartió el Enlace del AzEIP, Alicia Sharma, "para los niños menores de tres años, el entorno de aprendizaje natural, o enfoque basado en actividades, es mucho más efectivo. El equipo apoya a los niños en donde en verdad usan las habilidades en las que están trabajando; trabajamos con niños en la casa, en la guardería, en el parque, en la tienda de víveres—tan sólo para no practicar habilidades fuera de su ambiente típico. Sabemos también, que los niños muy pequeños no pueden generalizar realmente; no podemos enseñarle a un bebé de 18 meses una habilidad en un lugar, dejarle tarea y decirle que practique en lugares diferentes. Simplemente no funciona bien".

En el 2007, el AzEIP empezó a brindar servicios mediante el modelo basado en equipos, que asigna a cada familia un equipo central que consiste en un Interventor Especial del Desarrollo, un terapeuta ocupacional autorizado, un fisioterapeuta y un terapeuta del lenguaje. Se incluyen otros

especialistas según se requiera para tratar áreas como preocupaciones del comportamiento, vista y oído. Uno de los miembros funge como líder de equipo y coordina servicios con la familia. Los equipos se reúnen por lo menos cada mes, y se espera que todos sus miembros dominen estrategias basadas en evidencia adecuadas para atender las necesidades del niño y que actúen como coaches entre ellos y con la familia, tomando en cuenta la situación de la vida real del niño. Alicia explicó que "el coaching es una estrategia de aprendizaje para adultos basada en evidencia. Empleamos preguntas reflexivas. Utilizamos el modelado, la observación, la práctica: todos los componentes del coaching. A lo que se reduce es a que un miembro del equipo no da por hecho que sabe todo por ser experto en su campo, sino que pregunta a los demás, incluyendo a la familia, cómo funcionan las cosas dentro del entorno y puede ajustar la intervención incorporando las aportaciones del equipo".

Al trabajar en equipos, las familias

y los proveedores coordinan servicios y crean estrategias sobre la mejor forma de ayudar al niño a desarrollarse en los ambientes en que ya participan. Se disminuye la repetición, se evitan las intervenciones conflictivas, se ahorra tiempo y, lo más importante, mejoran los resultados.

Sin embargo, no todas las experiencias con el AzEIP son perfectas. Si las familias se encuentran con que no están de acuerdo con la identificación, la evaluación, la colocación o los servicios de intervención temprana brindados, o si tienen otras quejas sobre su experiencia, hay procedimientos para resolver los problemas. Siempre es mejor trabajar por para resolver las controversias de manera informal abordándolas con el líder del equipo y, de ser necesario, llevándolas más arriba en la cadena de mando. Siempre ponga sus inquietudes por escrito, un simple y sencillo correo electrónico basta. En caso de requerirse, existen opciones más formales para la solución de conflictos.

## Talleres y entrenamientos

Por favor vea nuestra página de web para el horario y los lugares más actuales, [www.raisingsspecialkids.org](http://www.raisingsspecialkids.org), o llame al 800-237-3007



**El Comportamiento Positivo**



**Cumpliendo los 18 años -  
Opciones Legales**



**Entrenamiento del IEP**

# Flu Information for Parents

## What is the flu?

Flu is a contagious respiratory illness caused by influenza viruses that infect the nose, throat, and lungs. Flu viruses cause illness, hospital stays and deaths in the United States each year.

## How serious is the flu?

Flu illness can vary from mild to severe. While the flu can be serious even in kids who are healthy, it can be especially dangerous for young children and children of any age who have certain long-term health problems.

## What are the symptoms of the flu?

Symptoms of the flu can include:

- Fever\* or feeling feverish/chills
  - Cough
  - Sore throat
  - Runny or stuffy nose
  - Muscle or body aches
  - Headaches
  - Fatigue (tiredness)
  - Some people may have vomiting and diarrhea, though this is more common in children than adults.
- \* It's important to note that not everyone with flu will have a fever.

## Protect your child

The first and best way to protect against flu is to get a yearly flu vaccine for yourself and your child.

Ask your health care provider which flu vaccine is right for your child.

- Everyone 6 months of age and older should get a flu vaccine by the end of October, if possible.
- Children 6 months through 8 years of age may need either 1 or 2 doses of vaccine.
- Children younger than 6 months are at high risk of serious flu illness, but are too young to be vaccinated. Parents, siblings, and people who care for infants should be vaccinated instead.

In addition to getting a flu vaccine, you and your child should take everyday actions to help prevent the spread of germs.

- Stay away from people who are sick, cover your cough and sneezes, wash your hands often with soap and water, do not touch your eyes, nose, and mouth, and clean and disinfect surfaces and objects that may be contaminated with flu viruses.

## If your child is sick

### What can I do if my child gets sick?

Talk to your doctor right away if you are worried about your child's illness.

- Make sure your child gets plenty of rest and drinks enough fluids. If your child is at high risk for flu complications, call your doctor or take them to the doctor right away if they develop flu symptoms.
- If your child becomes sick with flu illness, CDC recommends that they stay home for at least 24 hours after their fever is gone. (The fever should be gone without the use of a fever-reducing medicine.) A fever is defined as 100°F (37.8°C)\* or higher.

\*Many authorities use either 100 (37.8 degrees Celsius) or 100.4 F (38.0 degrees Celsius) as a cut-off for fever, but this number can vary depending on factors such as the method of measurement and the age of the person.

### Is there medicine to treat the flu?

Yes. Antiviral drugs are prescription medicines that can be used to treat flu illness. They can make people feel better and get better sooner. Antivirals can mean the difference between having milder illness instead of very serious illness that could result in a hospital stay. These drugs can be given to children and pregnant women.



For more information, visit  
[www.cdc.gov/flu/protect/children.htm](http://www.cdc.gov/flu/protect/children.htm)  
or call 800-CDC-INFO

#FIGHT FLU



U.S. Department of  
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Thank you! Parent Leaders are the heart of our mission.

June - August 2019

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