Nannette Salasek recalls the day her daughter was born, “I sat in the Newborn Intensive Care Unit, cradling my baby, completely overwhelmed and paralyzed with fear. Annie had some very difficult health challenges ahead of her and for a mama who prided herself in being very organized and in control, I fell apart under the weight of the unknown.”

A nurse in the NICU recognized the fog Nannette was in, and suggested Raising Special Kids might be able to help. When Nannette arrived home with Annie, Raising Special Kids did call.

“At first, I turned down their offer or help. I felt so inadequate. I couldn’t take care of my baby. I didn’t understand the medical terminology or anything about the services that would eventually make our lives better. I was frozen. I couldn’t move forward.”

The Family Support Specialist did not give up and persisted in offering support. When she shared with Nannette how she could connect with another mother through a Parent to Parent Connection, Nannette cried with relief! She recalled, “Finally, I could talk with someone who understood what we were going through.”

After experiencing the help of Parent-to-Parent support, Nannette wanted to be that ‘lifeline’ for parents. She volunteered with Raising Special Kids for six years and eventually joined the staff working to provide bilingual family support, recruit and train parent volunteers, and train medical residents on the principles of Family Centered Care and how to best care for families that have children with special healthcare needs. Nannette continued her professional development and is now a licensed social worker.

When asked about her job, Nannette shared, “I am so passionate about providing support to families, and letting them know they are not alone in the journey of advocacy for their children with special needs.”

CONTENTS
What’s That You Say? 12 Teacher Terms Demystified . . . 1
Workshops .................. 3
Severe Combined Immune Deficiency (SCID) ............... 5

ESPAÑOL
12x: Hablar con las familias sobre la educación .................. 7
Talleres ...................... 8

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.
Developmentally appropriate? Scaffolding? Your child’s teacher might use language other educators understand but may be new to you. This list of commonly used early childhood terms can help you understand what the teacher means when she talks about what and how your child is learning.

1. **Approaches to learning:** How children become curious about learning new things. It is also how children respond to learning situations. Curiosity about the world, initiative and problem solving, and focused attention and persistence are just a few approaches to learning teachers and families hope to foster.

   A teacher might say: “Your child has some wonderful approaches to learning. She’s very persistent when working on puzzles.”

2. **Cognitive development:** How children learn to think, make decisions, and solve problems.

   A teacher might say: “We want to build the children’s cognitive development, so today we conducted a science experiment, and the children tried to predict the result.”

3. **Constructive play:** When children use blocks, LEGOs, or other materials to make buildings or towers.

   A teacher might say: “Rebekah made a pretty complicated castle during her constructive play today!”

4. **Developmentally appropriate practice (DAP):** Teaching strategies that are based on knowledge of how young children develop and learn, what makes each child unique, and the child’s community and family culture and home language. DAP activities are neither too difficult or too easy, but just right.

   For example, in most cases it is developmentally appropriate to introduce a 4-year-old to the letters in his name, with the expectation that over time he will learn to write his name on his own. On the other hand, it is not developmentally appropriate to ask 4-year-olds to write letters over and over again on worksheets.

   A teacher might say: “In this classroom, we don’t believe that worksheets are developmentally appropriate.”

5. **Dramatic play:** When children pretend to be someone else, such as a firefighter or doctor, and they make up scenes and dialogue.

   A teacher might say: “We’d love to have you bring a few items related to going to work for the children to use in their dramatic play.”

6. **Exploratory play:** When children discover how materials work. For example, when playing with water or sand, children explore how to fill and empty buckets.

   A teacher might say: “Today Andre discovered how to use a bucket to build a sand castle during his exploratory play!”

7. **Environmental print:** The words that are all around us, such as store signs, a menu board, or a poster with the daily schedule.
A teacher might say: “Your child can learn a lot about reading and writing just by seeing environmental print.”

8. Physical and motor development:
How children use their bodies to make large movements with their legs and arms (gross motor) and small movements with their fingers and hands (fine motor). Children learn with their legs and arms when they run, climb, or ride a tricycle. They learn with their fingers and hands when they cut with scissors, use a pencil, or construct a puzzle.

A teacher might say: “We need to support children’s fine motor development so we are using playdough to strengthen fingers.”

9. Print awareness:
When children understand how print works. For example, after listening to lots of stories, children notice that letters make words, words make a story, and reading goes from left to right in English.

A teacher might say: “Maritza’s print awareness is developing. She’s picking up books right-side up and is starting to turn the pages of the book herself.”

10. Self-regulation:
How children learn to control their feelings and their bodies. For example, if a child wants to play with a toy her friend is using, she asks for a turn rather than grabbing it.

A teacher might say: “Robert is almost ready to climb up the slide ladder on his own, but not quite. I’ve been helping him by holding his hand and scaffolding his climbing skills until he’s able to do it without my help.”

11. Social and emotional development:
How children learn about feelings. It helps them feel good about themselves and helps them understand the feelings of other people.

A teacher might say: “We are supporting children’s social and emotional development by reading books about friendship.”

12. Scaffolding:
When an adult helps children learn at a faster rate and more than they would on their own. For example, when an adult holds a child’s hand as he goes up the slide ladder, the adult is scaffolding his learning to climb.

A teacher might say: “Robert is almost ready to climb up the slide ladder on his own, but not quite. I’ve been helping him by holding his hand and scaffolding his climbing skills until he’s able to do it without my help.”

RESOURCES:
- National Institute for Early Education Research: http://nieer.org/
- National Association for the Education of Young Children (NAEYC): http://www.naeyc.org/
- Early Childhood Technical Assistance Center (ECTA): http://ectacenter.org/
- Council for Exceptional Children - Division for Early Childhood (DEC): http://www.dec-sped.org/
- Understood: https://www.understood.org/
- Zero to Three: https://www.zerotothree.org/
No Cost Workshops & Training
Register online at www.raisingspecialkids.org or call 602-242-4366 | 800-237-3006

CENTRAL ARIZONA
Ability360 Center
5025 E Washington St, Ste 204
Phoenix, AZ 85034
This building is fragrance-free
Early Childhood Education (Birth-K)
Sat, Mar 18, 10AM-12PM
High School Transition
Sat, Feb 18, 10AM-12PM
IEP Training
Sat, Jan 14, 10AM-12PM
Sat, Feb 18, 1-3PM
Sat, Mar 18, 1-3PM
Positive Behavior Support
Sat, Jan 14, 1-3PM
Sat, Feb 18, 10AM-12PM
Sat, Mar 18, 10AM-12PM
Turning 18 - Legal Options
Sat, Jan 14, 1-3PM
Sat, Feb 18, 1-3PM
Sat, Mar 18, 1-3PM
New Diagnosis; What’s Next?
Sat, Jan 14, 10AM-12PM
Dysart Unified School District
15802 N Parkview Pl
Surprise AZ, 85374
Positive Behavior Support
Thu, Jan 26, 5:30-7:30PM

Road to Employment
Thu, Mar 9, 6-8PM

NORTHERN ARIZONA
Raising Special Kids
3100 N West St, #300
Flagstaff, AZ 86004
IEP Training
Thu, Feb 9, 5:30-7:30PM
Positive Behavior Support
Wed, Mar 1, 5:30-7:30PM
Turning 18 - Legal Options
Sat, Jan 28, 10AM-12PM
Sat, Apr 15, 10AM-12PM
Holbrook Unified School District
1000 N 8th Ave
Holbrook, AZ 86025
IEP Training
Thu, Feb 2, 5-7PM

SOUTHERN ARIZONA
Catalina Family Resource Center
3645 E Pima
Tucson, AZ 85716
Positive Behavior Support
Thu, Jan 26, 5:30-7:30PM

Emily Meschter Early Learning Center
4605 N La Cholla Blvd
Tucson, AZ 85704
IEP Training
Wed, Jan 25, 5-7PM
Positive Behavior Support
Fri, Mar 31, 9-11AM
Turning 3: What’s Next?
AzEIP to Preschool Transition
Wed, Apr 5, 5-7PM
Vail Unified School District
13801 E Benson Hwy
Vail, AZ 85641
IEP Training
Wed, Mar 30, 5:30-7:30PM

Call or check our website for updated training dates.

Talleres y Entrenamientos
www.raisingspecialkids.org o llame al 800-237-3007

CENTRAL ARIZONA
Ability360 Center
5025 E Washington Street
Phoenix, AZ 85034
edificio libre de fragancias
Cumpliendo los 18 anos - Opciones Legales
18 de febrero, 1-3PM
18 de marzo, 1-3PM
El Comportamiento Positivo
14 de enero, 1-3PM
18 de marzo, 10AM-12PM
Entrenamiento del IEP
14 de enero, 10AM-12PM
18 de febrero, 10AM-12PM

TUCSON
Catalina Family Resource Center
3645 E Pima
Tucson, AZ 85716
Apoyo de Comportamiento Positivo
26 de enero, 5:30-7:30PM

Wakefield Family Resource Center
101 W 44th St
Tucson, AZ 85713
Apoyo de Comportamiento Positivo
26 de enero, 9:30-11:30AM

SAN LUIS
Gadsden School District
1055 N Main St
San Luis, AZ 85349
Transición de la Escuela Secundaria
8 de marzo, 10AM-12PM

Para obtener una lista actualizada de los talleres en español, visite http://bit.ly/1XD1Cws

raisingspecialkids.org
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or visit www.CoverAZ.org/Connector
When Angel Cortez-Pirie was born in 2015, he appeared to be a perfectly healthy 7lb. 14oz. little boy. His mom Rachael Pirie and dad Alfonso Cortez brought Angel home to what they thought would be the typically chaotic life of a family of five.

At his two-month well check, Angel weighed almost a pound less than his birth weight. After some monitoring, the pediatrician diagnosed him with failure to thrive.

But it wasn’t long before he was repeatedly admitted to the hospital, first, with an ear infection, then with a cough and eventually with pneumonia. Each time, the antibiotics were ineffective and Angel was getting sicker. He continued to lose weight and Rachael was taking him to the pediatrician every two days to monitor his weight.

When his weight fell to six pounds and Angel began using supplemental oxygen, Rachael decided to travel from their home in Williams, AZ, to Phoenix Children’s Hospital to look for answers.

Within 10 hours of arriving, Angel was placed in isolation in a room with special circulation to keep the infection levels low. “The suite,” as it was nicknamed, was double-doored. Rachael had to scrub her hands and arms, put on a gown, gloves and mask before she could enter the room to be with Angel. Rachael soon learned that Angel had Severe Combined Immune Deficiency, and would need a bone marrow transplant before his first birthday. He was three months old.

Estimates are that 72 -100 babies are diagnosed with SCID per year in the U.S. and many infants are not identified until they develop repeated life-threatening infections.

If undetected and untreated, SCID typically leads to death before the baby’s first birthday.

Arizona is one of only three states with no current plans to include SCID in their newborn screening.
¡COBERTURA DE SALUD KidsCare está disponible!

CoverAZ puede ayudarle a encontrar seguro de salud para su familia de bajo costo

LLAME AL 1.800.377.3536

para hacer una cita con un representante en su área que le pueda ayudar con una solicitud
Como en todas las profesiones, los maestros de preescolares usan términos que son conocidos por todos los demás educadores infantiles, pero que quizás son desconocidos para las familias de los niños. Quizás este glosario pueda ayudarlos a hablar con las familias sobre lo que sus hijos están haciendo y aprendiendo en el programa.

1. **Enfoques del aprendizaje:**
   Forma en que se genera la curiosidad de los niños para que aprendan cosas nuevas. También es la forma en que los niños reflexionan sobre lo que aprendieron.

2. **Desarrollo cognitivo:**
   Forma en que los niños aprenden a reflexionar, tomar decisiones y resolver problemas.

3. **Juego constructivo:**
   Utilización de bloques o ladrillos Lego para construir edificios o torres.

4. **Texto ambiental:**
   Palabras y textos que nos rodean, como, por ejemplo, carteles de las tiendas, carteleras con menús o pósteres con el programa de actividades del día.

5. **Juego exploratorio:**
   Descubrimiento de la forma en que funcionan los materiales. Por ejemplo, al jugar con agua o arena, los niños exploran cómo llenar y vaciar cubos.

6. **Juego dramático:**
   Simulación de ser otra persona, como, por ejemplo, un bombero o un médico, y representación de escenas y diálogos acordes.

7. **Percepción del lenguaje escrito:**
   Comprensión del funcionamiento de los textos. Por ejemplo, luego de escuchar muchos cuentos, los niños notan que las letras forman palabras, que las palabras forman un cuento y que en inglés la lectura transcurre de izquierda a derecha.

8. **Desarrollo físico y motor:**
   Forma en que los niños usan su cuerpo para realizar movimientos grandes con sus piernas y brazos (motricidad gruesa) y movimientos pequeños con los dedos y las manos (motricidad fina). Con sus piernas y brazos los niños aprenden a correr, trepar o andar en triciclo; con los dedos y las manos, aprenden a usar una tijera para cortar, un lápiz para escribir o las piezas con que arman un rompecabezas.

9. **Práctica apropiada al nivel de desarrollo:**
   Utilización de estrategias docentes que se basan en los conocimientos sobre el desarrollo y el aprendizaje de los niños pequeños, las características distintivas de cada niño, y la comunidad, cultura familiar y lengua materna del niño. Las actividades de la práctica apropiada para el nivel de desarrollo no son ni muy difíciles ni muy fáciles; son exactamente lo que deben ser. Por ejemplo, desde el punto de vista del desarrollo, no es apropiado que a un niño de cuatro años se le pida que escriba letras una y otra vez en una planilla.

10. **Autorregulación:**
    Forma en que los niños controlan sus sentimientos y su cuerpo. Por ejemplo, si un niño con buena autorregulación desea jugar con un juguete que está usando un compañero, se lo pide por un rato en vez de arrebatárselo.

11. **Desarrollo social y emocional:**
    Forma en que los niños aprenden acerca de los sentimientos. Cuando tienen un buen desarrollo socioemocional, se sienten bien con ellos mismos y comprenden los sentimientos de otras personas.

12. **Andamiaje:**
    Ayuda que un adulto le da a un niño para que aprenda más y con mayor rapidez que si lo hiciera solo. Por ejemplo, cuando un adulto le sostiene la mano a un niño que está trepando a un tobogán, le está brindando un andamiaje para que aprenda a trepar.


raisingspecialkids.org
In November 2015, the team found a donor for Angel. In an effort to clear the adenovirus which was causing so much difficulty for him, Rachael signed consent for an experimental t-cell infusion. Angel was injected with donor t-cells that had been treated with adenovirus. Rachael shared, “There was only 1 in 10 chance it would work but it was our only choice or the adenovirus was going to continue to cause complications.”

Transplant day finally arrived on February 22, 2016. Angel was still feeling the effects of chemotherapy, but on the fourteenth day after transplant, tests showed the transplanted donor cells were creating a new immune system for Angel. After 8 months in the hospital, Angel was able to go home.

Angel now crawls everywhere and has started taking some tentative steps. He still has a high risk of infection and is on a lot of medication, some of which will be needed long-term, and he makes frequent doctor visits.

To regain some of the skills he had lost during his illness, Angel is receiving services through the Arizona Early Intervention Program. He receives speech therapy every other week and his physical therapists are helping him develop walking skills.

Angel spends most of his time inside but when they go out, Rachael makes sure he wears a mask and his stroller is protected with a weatherproof cover. Angel’s sister knows to change her clothes as soon as she gets home from kindergarten to make sure she keeps the risk of infection low for her brother.

Family and friends also know the rules when they visit: No shoes in the house; get a flu shot; stay away if you’re not feeling well or if you’ve been sick; and wash your hands--a lot.

Rachael has become active in efforts to increase awareness about SCID and the importance of including SCID in Arizona’s newborn screening tests. “If Angel was diagnosed at 10 days old with the newborn screening, he may not have caught the viruses. He would have had his bone marrow transplant much sooner and the cost of Angel’s care would have been so much less.” Even so, she says, “He was so lucky to have a transplant at 10 months old. Most kids [with SCID] have so many complications by that time, and no ability to fight it off.”

Rachael explained, “I have found the best way for me to heal is by talking it out and the only people I can talk to are parents who have gone through this. It makes me realize I’m not alone.”

Newborn screening is the process of testing newborn babies for some serious, but treatable, conditions. NBS can include a heel stick, hearing screen, and pulse oximetry.

Angel’s medical team and family hoped to see the treated t-cells multiplying rapidly but his daily blood draws showed that wasn’t happening. Thinking they might have depleted the t-cells with their frequent blood draws, the doctors gave Angel a second infusion. And then, he caught respiratory syncytial virus. “We thought it was going to be a huge setback,” said Rachael, “but we caught it quick, and he cleared the RSV virus in one week! By the end of January 2016, Angel was infection free.”

Angel was almost ready for his bone marrow transplant. The donor was ready and the procedure was scheduled, but before it could take place, Angel would need a week of chemotherapy.

“That’s when everything went south,” recalls Rachael. “Up until the chemo, Angel was happy and social and no one could believe he was so sick. He just didn’t look sick.” She continued, “Once he had chemo, he started to look like a sick baby. He developed respiratory complications and stopped eating. He needed a feeding tube and he didn’t want to move. His development took a step back.”

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The Secretary of the U.S. Department of Health and Human Services and the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children work together to create the Recommended Uniform Screening Panel. The RUSP is a list of conditions, including 34 core conditions (SCID included) and 26 secondary conditions which the Committee recommends every baby should be screened for. Arizona screens for 30 disorders.

www.aznewborn.com
Parent Leaders

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

The following Parent Leaders participated in leadership activities during September - November 2016. We appreciate our 300 Parent Leaders who have been trained to volunteer, but we do not have room to list their names.

Avondale
Jennifer Priddy
Buckeye
Jill Nico
Chandler
Susan Alonzo
Dawn Bailey
Marti Baio
Samantha Flores
Aimee Johnson
Noelle White
Chino Valley
Jody Brigham
Gilbert
Holland Hines
Sonya Kanidis
Karen
McLoughlin
Stephanie
Michelle
Louise Murphy
Heather Prouty
Kim Updegraff
Glendale
Bethany Alcorn
Becky Getz
Tina Wildoner
Michelle
Wolfson
Goodyear
Krista Hill
Kingman
Art Gode
Lake Havasu City
Christy Rail
Laveen
Bonnie Carroll
Mesa
Carrie Aranda
Cynthia Elliott
Brittany Miller
Paradise Valley
Karen Barr
Peoria
Sharon Blanton
Brittany Johnson
Heather Joy
Magdelano
Maria Del
Carmen Nuñez
Margarita
Ramirez
Chuck Smith
Gissela Welle
San Tan Valley
Jacqueline Tate-Tafoya
LaTasha
Whitaker
Scottsdale
Amber Bailey
Maura Knoell
Steve Lee
Carol
Levenseller
Gina Merola
Laura Michael
Katie Petersen
Amy Stroth
Heidi
VanderMolen
Sun City
Melissa
McQueen
Kris
Ohannessian-Dean
Tempe
Syed
Atikuzzaman
Crystal Leon
Janet Romo
Tolleson
Sasha Diaz
Tucson
Mindy Kellogg
Melissa Ward
Yuma
Brenda Higuera
Whitney Kala

Special thanks to Steve Lee for his many recent parent-to-parent connections

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The Camby Hotel
Phoenix

information and registration at www.partnersincare2017.com