



Raising Special Kids

Families Helping Families

# What's that you say?

12 Teacher Terms  
Demystified

# Connecting

Winter 2016

## Staff Spotlight

**Nannette Salasek** *Family Support Specialist*

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.”



*Annie and Nannette*

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.”



Connecting is published by

### **Raising Special Kids**

5025 E. Washington St., #204

Phoenix, AZ 85034

602-242-4366 | 800-237-3007

Fax: 602-242-4306

[www.raisingpecialkids.org](http://www.raisingpecialkids.org)

[info@raisingpecialkids.org](mailto:info@raisingpecialkids.org)

### **Flagstaff**

928-444-8834

### **Sierra Vista**

520-441-3411

### **Tuba City**

928-444-8687

### **Tucson**

520-441-4416

### **Yuma**

928-444-8803

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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.

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*This publication is partially supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the Family to Family Health Information Centers, CFDA No. 93.504. The information, content, and conclusions should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.*



# What's That You Say?

## 12 Teacher Terms Demystified

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."*

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.

### 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: "I've seen so much growth in children's self-regulation. At the beginning of the year children sometimes just take a toy they want even if another child is using it. Now I hear them ask if they can use it."*

### **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."*

*12 Teacher Terms Demystified. NAEYC For Families. Adapted from "Talking About Education With Families," by Angele Sancho Passe. Teaching Young Children, Vol. 6, No. 4. pp. 6-7. Copyright© 2013 NAEYC®. Reprinted with permission.*

### **RESOURCES:**

- **Arizona Department of Education-Early Childhood Special Education (ECSE):** <http://www.azed.gov/early-childhood/preschool/preschool-programs/ecse/>
- **US Department of Education-Early Learning Resources:** <http://www.ed.gov/early-learning/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.raisingsspecialkids.org](http://www.raisingsspecialkids.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, 1-3PM

Turning 18 - Legal Options

Sat, Jan 14, 1-3PM

Sat, Feb 18, 1-3PM

Sat, Mar 18, 10AM-12PM

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 19, 6-8PM

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

Direct Center for Independence

1001 N Alvernon Wy

Tucson, AZ 85716

Turning 18 - Legal Options

Wed, Jan 18, 10AM-12PM

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.raisingsspecialkids.org](http://www.raisingsspecialkids.org) o llame al 800-237-3007

## CENTRAL ARIZONA

Ability360 Center

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Phoenix, AZ 85034

*edificio libre de fragancias*

Cumpliendo los 18 años - 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>*



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## Severe Combined Immune Deficiency

### Will Arizona include SCID in their newborn screening?



*Nikolas, Alfonso, Angel, Arayla and Rachael*

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.

Rachael had planned for a week away from home, but it was clear a week was not going to be enough. She recalled those first weeks, "I would never leave the hospital room. The first time I did leave to go downstairs to get something to eat, I came back and they said we'd almost lost him. His oxygen level had dropped below 60."

Angel was fighting off three viruses; rhinovirus, adenovirus,

and coronavirus. The viruses that cause the common cold were life threatening for him.

About a month after Angel was hospitalized, Alfonso moved the rest of the family to Phoenix. Rachael stayed by Angel's side trading shifts with Alfonso and other adult family members when they were available. While Angel was in the hospital, his siblings were not allowed to visit due to age restrictions.

No one in Angel's family was a match for the bone marrow transplant, so his name was placed on the donor registry and the search was on.

For several weeks Angel was treated with experimental medications in an effort to clear the viruses and prepare him for the transplant. During that time, Rachael recalled, "Angel started having problems with his liver and kidneys and developed high blood pressure."

**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.**

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para hacer una cita con un representante  
en su área que le pueda ayudar con una  
solicitud



## 12x: Hablar con las familias sobre la educación

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, en la mayoría de los casos es apropiado que a un niño de cuatro años se le muestren las letras de su nombre con la expectativa de que, con el tiempo, aprenderá a escribir solo su propio nombre. Sin embargo, 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.

*"12x: Hablar con las familias sobre la educación." NAEYC Para Familias. Adaptado de "Talking About Education With Families," by Angele Sancho Passe. Teaching Young Children, Vol. 6, No. 4. pp. 6-7. Copyright © 2013 NAEYC®. Reimpreso con permiso.*

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.”

**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.”

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.”

**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](http://www.aznewborn.com)**



## Parent Leaders

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

September - November 2016

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

Mickelsen

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



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

Lisa Thomas

### Phoenix

Angela

Christensen

Patricia Dean

Claudia Gamez

Marissa Huth

Nicole Kauffman

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

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Syed

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