



THE

# Navigator

Winter 2013

Pilot Parents of Southern Arizona

Volume 17 Issue 2

Providing Information and Resources to Families and Professionals in Southern Arizona

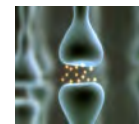
## THERAPY? WHAT DOES IT MEAN??????

Early Intervention, DDD services, therapy, what is all of this stuff? You have entered a new world of experiences, definitions and topics you never expected to discover. Discover them you will.

Let's start with Early Intervention (EI). Early Intervention services are for children birth to three, who have disabilities or delays, in order for them to learn key skills to allow them to catch up in their development. Research has shown, that those children with disabilities or children born pre-maturely greatly benefit from these services. There have been various models throughout the years. The newest model for early intervention is starting March 1st. The new "team-based" model will include professionals from a variety of disciplines who will meet regularly and share information on both the child's progress and family concerns and questions. One member will act as lead for the group and coordinate services and carry recommendations to the family. The group will receive support from an IFSP (Individual Family Service Plan) team, which includes service coordination, the Team Leader, others identified on the IFSP, other core team members (*Physical Therapist (PT)*, *Occupational Therapist (OT)*, *Speech Language Pathologist (SLP)*, *Developmental Special Instructionist (DSI)* and as needed, psychologist, social worker, and ASDB Vision/Hearing Specialist. Many of you will already know about the various types of therapy available. For those of you who have not yet had experience with the different

therapies, I am going to try to make therapy easier on everybody. I will give you the basic definition of the type of therapy, why we perform the type of therapy we do on or with a child and what we hope the outcome or benefits of each therapy might be.

**Physical Therapy (PT):** physical therapists diagnose, manage and treat disorders and injuries of the musculo-skeletal system (bones and joints). Bones and joints make movement possible. PT focuses on large muscle mass, as well as, soft tissue systems that stabilize the bones and joints and allow them to move. Parts of soft tissue are muscles, ligaments, tendons and fascia (web-like tissue throughout the body similar to the clear membrane under the skin of a chicken). Pediatric physical therapy assists in early detection of health problems as well as the diagnosis, treatment, and management of infants, children, and adolescents with a variety of injuries, disorders and disease that affect the muscles, bones, and joints. Treatment focuses on gross and fine motor skills, balance and coordination, strength and endurance. Walking, rolling, balance, strengthening muscles, sensory processing and cognitive issues. Children with developmental delays, cerebral palsy and spina bifida are a few of the patients treated by pediatric physical therapists. PT can be used to reduce pain, increase mobility, reduce tone, re-train neurotransmitters to work properly, restore length to soft tissue, to increase strength, and can be completed through manual manipulation, electrical stimulation, heat and cold, stretching, etc.



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**Occupational Therapy - OT** - Occupational Therapists concentrate on fine motor issues. And, yes, they do re-train people to do a job. Your child's job is to play. So, the OT is helping your child learn to play effectively with toys, and interact with their environment appropriately, and they also work with sensory issues. Tactile (feel or touch) how various objects feel and having the child interact with lots of textures to help them overcome an aversion to particular ones. Your child may play with shaving cream, sand or sand paper, water, various materials like corduroy, velvet, etc., corrugated cardboard, etc. They will also work on the vestibular system ( the body in space and movement). Swinging helps children locate their place in space and become familiar with the sense of movement needed to walk, crawl, etc.. As the child matures and goes to school the OT assists with writing and communication. How to work with a pencil, computer, etc. OT's also work on dressing skills, buttoning buttons, zipping zippers, etc.. Daily living skills - cooking, washing and folding clothes, dressing, tying shoes, combing hair, etc.. And, coming up with alternatives if the above skills will not be possible.

**Speech Language Pathologists (SLP)** - speech therapists help children learn receptive and expressive language. Receptive is the ability to understand what is said to you and expressive is the ability to speak your wants and needs to other people. It also deals with articulation, pitch, fluency, and volume. Many children need help with speech and the various areas that help improve understanding, as well as the volume of their speech.

There are many other types of therapy available. Some are thought to be experimental and others have been around for many, many years. Do research to see what might be the best for your child. In any case, prior to your child receiving services, they will go through an evaluation procedure and goals will be set so progress may be measured. See if there are exercises you can do with your child at home to reinforce what the therapist does during their sessions. Repetition and practice work well in succeeding with therapies.



## HOW TO COMMUNICATE EFFECTIVELY WITH EARLY CHILDHOOD PROFESSIONALS

Children with disabilities also have a lot of abilities. By communication both your child's needs and strengths to early childhood professionals, you can help them select services that will be most appropriate for your son or daughter.

You and this team of professionals will create your child's Individualized Family Service Plan (IFSP). Or Individualized Education Plan (IEP). Their role is to listen to your concerns and develop goals based upon your child's strengths and needs.

Your role is to help the team understand your child. Here are some ideas that can help you do that effectively.

### Know Your Child's Strengths and Needs

While all children develop in their own way and at their own rates, general guidelines show the skills and behaviors children *typically* have at certain ages ( *order a free development wheel at [www.health.state.mn.us/divs/fh/mcshn/wheel.htm](http://www.health.state.mn.us/divs/fh/mcshn/wheel.htm) ). These guidelines can help you think about where your child is developing typically and where some support might be helpful.*

#### STRENGTHS MY CHILD CAN :

- \*Smiles back at me & others
- \*Follows movement of an object by turning her or his head.
- \*Reaches for objects
- \*Makes sounds, babbles, or talks
- \*Understands common words Such as "no", "bye"
- \*Likes to play with other children
- \*Sometimes uses two to three word sentences.
- \*Talks and usually is understood By others.

#### NEEDS MY CHILD:

- doesn't smile back
- doesn't follow moving objects
- doesn't reach
- seldom makes sounds
- doesn't seem to understand "no", "bye"
- likes to play alone
- uses only single words
- talks but is not understood.

**Share** information, **ask** questions, and **remember you are the expert on your child**. By sharing information you are allowing the professionals to determine how to help your child reach his or her potential.

PACER Center \action Sheet :PHP-c159. 2008



Mealt ime Connections is a pediatric clinic that offers occupational therapy, speech therapy, nutritional counseling and developmental support for children with a wide variety of feeding challenges.

Mealt ime Connections is offering an informative class for parents/caregivers who are transitioning their babies to solids called, "Baby's First Tastes". This class is beneficial to parents/caregivers that are ready to introduce their babies to solid foods, or those who have introduced solids and are experiencing struggles and need some guidance and support. This class is offered monthly with both day and evening options. For additional information, please see below or give them a call.

#### Baby's First Tastes Class Information:

Learn how to...

Determine when your child is ready for solid foods.

Create opportunities for baby to enjoy food tastes, textures, colors and smells.

Build confidence in a loving and nurturing mealtime.

Develop your baby's palate.

Set up mealtimes for success.

#### Upcoming Classes:

Friday, March 15th 10:30 am -12:00 pm

Monday, April 8th 6:00 pm - 7:30 pm

Cost: \$25.00

Location: 1601 N. Tucson Blvd, Suite 6  
Babies in arms welcome!

Space is limited so please register in advance.

**(520) 829-9635**



## Pilot Parents & The Down Syndrome Connection

Partner to offer the community a Free Workshop:

### Introduction to Guardianship & Special Needs Trusts

**Guest Speaker; Jane K. Larrabee J.D., L.L.M.**

**Date: THURSDAY, APRIL 25TH, 6-8 pm**

**Where: Florence Manning Room, Children's Clinic**

**2600 N. Wyatt Drive**

**Light refreshments provided**

**Registration Required;**

**Please call Pilot Parents (520) 324-3150 or email joann@pilotparents.org with special needs as subject line**

**At age 18, children become legal adults. But what if your child doesn't have the capacity to handle this role? What If your child needs you to continue to make his or her educational, financial and medical decisions?**

**You might need a Guardianship or a Special Needs trust or both**

**At this free workshop, you will learn:**

- What is a Guardianship?
- What is a Special Needs Trust?
- When are they needed? What other options might be open?
- What steps do I need to take to put them into place?
- How do they protect my child with a disability regardless of age?
- How do I maintain my child's eligibility to continue to receive State and Federal benefits?

**Jane Larrabee, J.D., L.L.M.,** is a trusted advisor who helps clients make the best legal, financial and business decisions throughout their lifetime. Estate planning isn't just about money. That's not the half of it. A properly delineated estate plan will preserve your independence, protect assets from creditors predators and divorce, keep kids safe, and preserve your legacy as well as promote charitable endeavors and minimize tax and other expense.

Jane K. Larrabee, Esq.  
333 N. Wilmot Rd., Suite 340  
Tucson, AZ 85711  
Direct: 520.829.0571

**THIS IS A DUPLICATE EVENT  
THE MARCH WORKSHOP WAS  
OVER BOOKED.**

# GROW UP STRONG

## BABIES NEED FREQUENT CHECKUPS

By age 2, your child should have had 10 well-baby visits. Well-baby visits make sure your baby is healthy. They are also a good time to ask questions. Well-baby visits include:

- \* **GROWTH CHECKS:**  
Your child will be weighed and measured.
- \* **TESTS:**  
Your child will get needed tests. This includes blood  
Lead tests by ages 1 and 2.
- \* **SHOTS:**  
By age 2, your child will get shots for 14 diseases.

From Health TALK- United Healthcare Community Plan  
Winter 2013

### KidsCare II Re-Opens

November 16, 2012

On November 1, 2012, AHCCCS reopened enrollment in the KidsCare II program and all applications are being considered for eligibility. Eligibility requirements for KidsCare II remain the same. Additionally, children on the wait list that was started Sept 7, are being automatically enrolled into the program if they meet the eligibility requirements for KidsCare II and do NOT need to reapply at this time. AHCCCS will continue to consider all applications for KidsCare II until the program reaches maximum enrollment based on available funding. More information about the KidsCare II program is available on the link below or call the toll free hotline (operated by a Community Partnership) at: 1-800-377-3536.

### **KidsCare Eligibility Requirements**

Beginning June 25, 2012, a child may qualify for KidsCare II if the child:

Is an Arizona resident

18 years old or younger

Is a United States citizen or a qualified immigrant

Has a Social Security number or applies for one

To apply for a Social Security number visit the U.S.

Social Security Administration

- Make a copy of the form submitted as confirmation of applying for a Social Security Number
- Is under the income limit
- Is not currently covered by other health insurance
- Does not qualify for coverage through a state agency employee
- Is not eligible to receive AHCCCS (Medicaid) coverage
- Is a member of a household that is willing to pay a premium

### **Income Limits**

If the child's income is too high for AHCCCS Health Insurance, the child may qualify for KidsCare II at a low monthly premium if they are at or below 175% FPL. This chart shows how much money a person can receive each month before taxes (gross monthly income) and other deductions are subtracted.

<b>Income Limits at 175% of FPL *</b>		
<b>Family Size</b>	<b>Monthly Family Income</b>	<b>Annual Family Income</b>
1	\$1,629.00	\$19,548.00
2	\$2,207.00	\$26,484.00
3	\$2,784.00	\$33,408.00
4	\$3,362.00	\$40,344.00

**\*income limits change every April 1.**

### **Premiums**

KidsCare II will cost no more than \$40 a month for one child or no more than \$60 a month no matter how many children are in the household. The application must indicate that the household is willing to pay the premium for coverage. If a child received KidsCare before and money is owed for past premiums, families will be notified with the amount due and ways to pay. Children will not be enrolled in KidsCare II until all past due premiums are paid in full. Per federal law, Native Americans enrolled with a federally recognized tribe and certain Alaskan Natives do not have to pay a premium. To get KidsCare II at no cost, you must give us proof of tribal enrollment.

Should you have any questions or challenges with the application process or accessing health care services your child needs, please contact our office.

### **Office for Children with Special Health Care Needs/ADHS/BWCH**

**602-542-1860 (Receptionist)**

**602-364-1480 (Direct Line) Rita Aitken**

**1-800-232-1676 (Toll Free)**

**602-542-1200 (TDD)**



## MY TEAM TRIUMPH

My team triumph is a thing for kids that have wheelchairs and they have a special racing wheelchair that they use to race with. The people who push are angels the people in the wheelchairs are the captains. The team triumph managers are Steve and Denise King. They let kids who can't run feel like they can run. They help them feel like winners. My brother Marco is in this activity. He is happy for what they can do. And their son Lucas does my team triumph. They have done this for years and they hope they can keep on doing it! I am an angel in training and it would mean the world to me if I were an angel and when I am one I will push my brother. So' that is what my team triumph is all about.

By Isaiah Fernstaedt 3<sup>rd</sup> grade

Cragin elementary.



### MY TEAM TRIUMPH SOUTHERN AZ

My TEAM TRIUMPH is an athletic ride-along program created for people with disabilities who would normally not be able to experience road races.

Children, teens, adults and veterans with disabilities are able to experience endurance events such as triathlons and road races.

The who's who....The participants with disabilities are known as "Captains," and the athletes who have the honor of pushing and pulling the Captains on the course are called their "Angels."

Triathlons, 10Ks, 5Ks, Marathons, Half marathons. We provide all necessary equipment.

For more information call:

520-293-9280

## DID THEY ADOPT, OR WERE THEY ADOPTED?

Recently our family had the privilege of adopting Claire, a German shepherd mix, from the Humane Society of Southern Arizona. While many adopt pets, our adoption was, “unique”, in that we were not looking for a pet. We were in search of a companion for my son Marco, a dog who, with the right training could become a service dog.

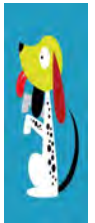
Marco is blind, hearing impaired and has a number of medical diagnosis...all of which affect his ability to be just another 12 year old. Due to this, while he has friends in school, he does not have out of school interaction with them; his abilities to participate in many events are limited or due to poor health, he isn't able to participate. He also needed someone who would understand him, not judge him. So, as any boy would do, he asked for a dog.

I chose the humane society to begin our search, as I felt confident, they could help me to understand what breed of dog may or may not be best, we would have the opportunity to spend time with the dog in a yard there and they are a trusted agency. So, in we went. After discussing a couple of other dogs, we came to Claire's name on the list. They told us a bit about her and we went to meet her in the yard. They had explained, she was shy around new people situations and out of anxiety would probably not react to us right away....this is when Claire “chose” Marco to adopt. As soon as they brought her to the yard, she went directly to him and was not leaving his side. As I had truly not been prepared to adopt a dog that day (I was ready for this endeavor to take more time considering our needs), we did have to return the next day to pick her up and bring her home. When Claire and Marco saw each other, it was like best friends reuniting after a lengthy separation; smiles, hugs and “dog” kisses!

To this day, they are inseparable, unless necessary. And now they are beginning service dog training. It is important to understand what a service dog is and/or does. A service dog is not just a companion or therapy dog. A service dog actually does something for the owner which is disability related. Some examples: retrieving items such as a phone from another room, opening a door, picking up items when the owner is unable to, pulling/pushing a wheelchair. This type of training, allows those with disabilities, to train their own dogs to work as service dogs. While Marco and Claire are going through Top Dog, Inc; there are other organizations in the Tucson area. This type of program requires at least a year commitment and may take up to 2 years and is no guarantee the dog will become a service dog. Some owners are just not able to train their dog, while sometimes the dog is just not able to do what is required whether it be temperament, age, illness or any other cause. There is a financial investment; which can range from \$300 up to \$1600, depending on the program.

While Claire and Marco continue to bond and grow together, I marvel at the difference she has made in Marco's life. I am seeing more smiles, there is more energy in his voice when he talks and the stress during rough days is a lot lower.

Cynthia Fernstaedt Martinez



Children and dogs are as necessary to the welfare of the country  
as Wall Street and the railroads. Harry S. Truman

## SERVICE VS THERAPY DOGS

So, everyone knows that a dog is man's best friend. If you happen to be the parent of a child with disabilities and you frequent clinics and hospitals, you may have been exposed to therapy and service dogs and maybe thought about getting one for your child.

Before you do, do your research. Don't go off without checking on where you are getting a dog, where you are getting training, etc. You might even check with the Better Business Bureau. There are people out there that enjoy taking advantage of the emotionality of parents with children with special needs. You need to be careful. Go slowly. Ask questions. Make sure this decision is the right one for you.

A **service dog** is a dog that helps you perform activities of daily living, that you may not be able to do for yourself. A service dog may go with you wherever you go. The ADA requires that a service dog *be trained to do work or perform tasks* that assist you in making your disability less of a burden on you and make you more independent. Just being a companion or providing comfort is not enough to qualify a dog for consideration for being a service dog.

First, the person must be disabled. The federal definition of disability is as follows: Disability means, a physical or mental impairment that *substantially limits one or more of the major life activities* of such individuals; a record of such an impairment; or being regarded as having such an impairment. Major life activities means functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.

You then decide what the dog is going to be expected to do for you. Is a Service Dog right for you? A Service Dog must be able to handle situations that most dogs find very stressful or frightening. Choosing the dog is very important. It will be assessed for appropriate temperament

It must be physically sound and capable of performing the tasks asked of it. It must have proof of health and required vaccinations and be have at least 6 years of working life after completing training. Generally this means a dog no older than 4 years of age.

Your dog will not be free. Good dogs are expensive. There are programs that may be able to assist you. Know also, that there is a fee for training your dog and you. You are the one who trains the dog, as the dog must respond to you - the handler.

In Tucson there are several groups who may be able to assist you. Look in the phone book or google service dogs Tucson. Handi-Dogs assisted me with this article, to reach them call 520-326-3412, or email [service@handi-dogs.org](mailto:service@handi-dogs.org) Their website is <http://www.handi-dogs.org>.

**Therapy dogs** are pets that love to interact with people and be petted. They visit hospitals, clinics and healthcare facilities, as well as participate in "Read to a Dog" programs at schools and libraries. Therapy dogs do not have universal public access rights. They can only enter facilities for which they have prior approval.

There are training classes for your dog to qualify as a therapy dog and you and your dog are trained as a team. After the training you will need to become a registered Pet Partners Therapy Animal Team. All of this is a commitment of time and there are fees for training.

For more information on these trainings, and what type of dog is best, how to find them, etc. contact Handi-Dogs. 520-326-3412.





Miscellaneous this and that.....

### Public Meetings on AHCCCS Coverage

Want to know more as Arizona's legislature considers Governor Brewer's proposal to accept federal funding to expand AHCCCS coverage? AHCCCS will be holding public hearings to provide information and receive public input on future coverage. You can review documents related to the Governor's proposals on the AHCCCS website, [Medicaid Coverage page](#). See schedule below for times and locations. If you wish to speak, you can email a speaker slip or bring it to the hearing.

You must RSVP. Space is limited.

### Tucson

Thursday, March 14

1:00 - 3:00 pm

Joel D. Valdez Main Public Library, 101 N. Stone Avenue, 85701

Space is limited.

### HB 2161 - Waiver for License Fees for Service Dogs

Permits the members of the Board of Supervisors of each Arizona County to not charge a license fee to a person with disability and who uses a service animal.

## IT'S NOT TOO EARLY TO REGISTER!



**CHALLENGER LITTLE LEAGUE IS FOR CHILDREN AND YOUNG ADULTS WITH VARIOUS PHYSICAL AND/OR MENTAL CHALLENGES.**



**GIRLS AND BOYS WITH SPECIAL NEEDS**

**PLAY CHALLENGER BASEBALL!**

**GROUPED BY DIVISION: AGES 5-20**

- EMPHASIS ON FUN
- MAKE FRIENDS
- SEASON: MARCH-JUNE
- CHALLENGER IS FLEXIBLE AND ACCOMMODATING
- LEARN AS THEY PLAY
- SOCIAL SKILLS
- BUDDYS ALLOWED TO ASSIST/HELP



FOR INFO OR REGISTRATION:  
[WWW.TUCSONCHALLENGER.ORG](http://WWW.TUCSONCHALLENGER.ORG)

OR

520.298.3639 OR [KGETMAN@COX.NET](mailto:KGETMAN@COX.NET)





## PILOT PARENTS IS MOVING!!!!SORT OF

I think some of you may be confused and think that Raising Special Kids (RSK) replaced Pilot Parents in So. Arizona.

**UNTRUE.** We are still very much here. RSK is providing some additional education services in this area, but we are **still here** offering one to one support, Partners in Policymaking, Sibshops, LEAP and general information. CALL PPSA today! 520-324-3150.

The Clinic is remodeling the second floor of the Square and Compass Clinic. We are on the 2nd floor and will be relocated within the clinic to another location during renovations. We will still have our

### Staff Members:

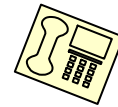
Lynn Kallis— Executive Director—Pilot Parents of Southern Arizona  
324-3151

Cheryl McKenzie— Receptionist/Secretary  
324-3150

Karen Kelsch— Partners in Policymaking, Coordinator /L.E.A.P.  
324-3158

Robert Snyder— Education Coordinator 324-3157

Jo Ann Spencer— Coordinator Special Projects— Sibshop Coordinator, Editor, *The Navigator*, L.E.A.P.  
324-3153



You can now view or download *The Navigator* from our web page. Go to [pilotparents.org](http://pilotparents.org) and click on *The Navigator*. If you no longer wish to receive *The Navigator*, please contact the office.

*The Navigator* is published quarterly; winter, spring, summer and fall. You may e-mail notices, articles, etc. to [joann@pilotparents.org](mailto:joann@pilotparents.org), fax them to 520-324-3152 or mail them to: PPSA, 2600 N. Wyatt Drive, Tucson, AZ 85712 attn: Jo Ann Spencer, editor, at any time. Submissions will be used based upon space availability and will be used if the date of the activity falls within our publishing schedule.



**Leadership Education Advocacy Partnership**  
a program of Pilot Parents of Southern Arizona

Financial support is available for self-advocates and family members of individuals with developmental disabilities to participate in conferences, workshops and other training opportunities.

Trainings must meet eligibility requirements as outlined on the Pilot Parents website. Information on how to apply, the application and supporting information is available on-line at [www.pilotparents.org](http://www.pilotparents.org)

Partial funding is made available by the Arizona Developmental Disabilities Planning Council through contract NO. ADDPC-FFY-11-1112-00-CY2.

## L.E.A.P.

### (Leadership Education Advocacy Partnership)

Pilot Parents of Southern Arizona received a renewal on our contract from the Arizona Developmental Disabilities Planning Council (ADDPC) for a self-advocacy development project. Upon approval, PPSA will provide reimbursement for conferences, workshops and other training opportunities for individuals with developmental disabilities and their families. Trainings must meet eligibility requirements outlined on the PPSA website. This project will be known as LEAP.

Information on how to apply is available on our website. If you know of a conference or are having a workshop that we might be able to help individuals attend, please contact me, Jo Ann at 520-324-3153 or at [joann@pilotparents.org](mailto:joann@pilotparents.org), or Karen at 324-3155, [Karen@pilotparents.org](mailto:Karen@pilotparents.org). Use LEAP as subject.

We have a list of upcoming conferences on our website, but are always looking for other programs to place on our community calendar.