



THE

# Navigator

FALL

Pilot Parents of Southern Arizona

Volume 17 Issue 3

Providing Information and Resources to Families and Professionals in Southern Arizona

## CHANGES: TO THE CHILDREN'S CLINIC AND TO PILOT PARENTS OF SO. AZ

In April of this year, the Clinic renovated the second floor of the Clinic. This may not have effected many of you and maybe you didn't even realize it happened.

It changed the second floor of the building, for the better. Pilot Parents of Southern Arizona now has a new suite of offices. We are still located in the same general area, but the entrance to our offices is down the south hallway instead of directly across the hallway from the elevator. Our offices are all new and shiny and you should stop by and visit. The office is generally open from 9 am to 5 pm Monday through Friday.

In addition to our office space, our staff has changed. Most of you know that Robert Snyder is no longer with us in the Education Department. Now, we have Amanda Heyser. Amanda MS. Ed, works along with the Clinic staff in many of the Clinics downstairs and is available to everyone through her voice mail. Amanda's direct line is 520-324-3157. She is available to help with IEP/504'S and other school issues and will help you figure out the best course to take to solve your school education issues.

Amanda supports individuals and families with research based educational resources and information for special education from birth to adult. Amanda graduated with a Bachelor of Science in Elementary

Education from Texas Christian University and has received a Master's of Science in Education for Special Education Instruction from Arkansas State University. She holds an endorsement for Early Childhood Special Education. Amanda enjoys finding strategies that help individuals and families facing challenges so that they may enjoy educational and personal success. Amanda is the President of the Board of Directors for the National Organization of the Disorders of the Corpus Callosum and was appointed to serve on the Special Education Advisory Panel for Arizona's State Board of Education.

In addition to Amanda, Pilot Parents has a new Coordinator for our Partners in Policymaking program Marianne Scott. Partners in Policymaking is a free leadership training program for young adult self-advocates and parents of children with disabilities. Please check Partners on our website: [www.pilotparents.org](http://www.pilotparents.org).

Marianne received her Bachelor's degree from Boise State University in Early Childhood Education with a blended certificate in Special Education. While her husband attended graduate school, she taught in the local school district and also was a home tutor for the same school district in New York. Since then, she has been at home raising their three children, one who has significant disabilities. She is passionate about advocating for those with disabilities and is happy to be working with Pilot Parents of Southern Arizona to help other families with children with special needs.

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Pilot Parents of Southern Arizona 2600 N. Wyatt Drive, Tucson, AZ, Phone 324-3150



# Partners in Policymaking

## Exciting News from Pilot Parents

Pilot Parents will be consulting with the New Hampshire Leadership Series through the Institute on Disabilities, University of New Hampshire to enhance and expand the Arizona Partners in Policymaking program.



Upcoming session dates and the application deadline have been changed to accommodate this new relationship.

### 2014 *NEW* Session Dates

January 10-11, 2014

February 7-8, 2014

March 7-8, 2014

April 11-12, 2014

May 9-10, 2014

June 6-7, 2014

*NEW* Application Deadline: **November 15, 2013**

Pilot Parents is seeking participants who are highly motivated to become well informed about, and active in, policymaking and systems change for individuals with disabilities in Arizona. We are accepting nominations from past program graduates, agencies and community members.

To learn more, download an application, or nominate someone you know visit [www.pilotparents.org](http://www.pilotparents.org)

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*“Life isn’t about waiting for the storm to pass.  
It is about learning to dance in the rain.”*

## Teen with Down Syndrome stars in Wet Seal campaign

Karrie Brown got to live out every teenager's dream in August when her favorite clothing company, Wet Seal asked her to model for them. But the 17 year old high school junior from Collinsville, Ill. Isn't like most other models: She has Down Syndrome.

Wet Seal flew Karrie and her mother to the company's headquarters in California, put them up in a hotel, gave Karrie a full fledged fashion shoot and sent them on a shopping spree at Wet Seal and a trip to Disneyland.

"It was really fun," Karrie, who describes her style as "biker chick" told the TODAY show.

For the full story go to <http://www.today.com/style/teen-down-syndrome-stars-wet-seal-campaign>.

## Affordable Care Act

### Frequently Asked Questions:

**1. What is the Affordable Care Act (Obama Care)?**

The Affordable Care Act (Obama Care) is a new healthcare law that takes effect on January 1, 2014, with the goal of making affordable health care available for all Americans, regardless of their medical history or ability to pay.

**2. Where can I buy health insurance?**

A new way to buy insurance is available as of October 1, 2013. You will still be able to purchase insurance on your own from an insurance company or through a broker. You will also be able to use the *new, state-based health insurance marketplaces*, also called exchanges which can be accessed online.

**3. Who is eligible?**

Most American who do not receive insurance through their employers are eligible, including people who buy coverage themselves (such as those who are self-employed or retired early), and people who cannot afford to buy health insurance but do not qualify for Medicaid.

*(Continued on page 4)*

## Wrights Law Special Education Law & Advocacy Training

Friday, November 15, 2013  
9 am to 4:30 pm

Casino del Sol Resort  
5655 W. Valencia Road  
Tucson, AZ 85757

Speaker, Pete Wright, Esq. presents this one-day Wrightslaw Special Education Law and Advocacy workshop designed to meet the needs of parents and professionals serving children and teens with disabilities.

For more information go to:  
[www.autismsocietygreatertucson.org](http://www.autismsocietygreatertucson.org)  
or email  
[events@autismsocietygreatertucson.org](mailto:events@autismsocietygreatertucson.org)  
or  
call 520-324-3284

*Caring for the Caregiver  
You take care of everyone else,  
who takes care of you?*

WEDNESDAY,  
NOVEMBER 6TH, 2013  
FLORENCE MANNING  
Children's Clinic  
2600 N. Wyatt Dr.  
11:30-12:30  
Register at 520-324-3153

?????????

DID YOU KNOW

**Sensory Friendly Storytime at  
Martha Cooper Branch Library  
beginning October 5th, 2013.**

**DID YOU KNOW?????????**

*(Continued from page 3)*

**4. Who is not eligible?**

There are three groups of people that are not eligible: People living in the United States Illegally, Native American Tribe members, and prisoners.

**5. What if I do not obtain health insurance?**

If you do not have adequate health insurance in 2014, you could face a penalty on the taxes you file in 2015. There is no penalty for a gap of less than three months. Enrolled members of Native American tribes are exempt, as are groups that do not pay into Social Security, such as the Amish.

**6. What is a "Market Place" ?**

The Market Places have web sites that offer one-stop shopping for new health insurance. There is an eligibility application you must fill out to see if you qualify for financial assistance and see what insurance policies you can buy.

If you have questions about the Health Market Place, you can call 1-800-318-2596, 24 hours a day, seven days a week. TTY users should call 1-855-889-4325.

**7. When does open enrollment start?**

**October 1, 2013 through March 2014**, with coverage to start **January 1, 2014**.

**8. If I have AHCCCS health plan, do I need to do anything?**

No, you will continue to enjoy that coverage.

**9. If I have Medicare, do I need to do anything?**

No, you will continue to enjoy that coverage.

**10. How much will it cost?**

The cost varies with deductible choices, copays, and out-of-pocket maximums, and can vary by state. Arizona's Medicaid (AHCCCS) will now be open to anyone who earns less than 133 percent (133%) of the federal poverty level (\$15,282.00 for a single person this year). To get more information on the Market Place, go to [Healthcare.gov](http://Healthcare.gov).

*Health and Wellness Workshop*

**Learn how good nutrition, physical activity, and mindfulness can help you achieve your independent living goals!**

**November 13th 1:00 to 3:00 pm**

**UA RISE Health & Wellness Center  
1030 N. Alvernon Way, Tucson, AZ 85711  
Jenny Goeckel, (520) 624-6452  
DIRECT, Center for Independence**

- \* The stories we read are geared towards the age group of 3-5 years old, but enjoyable for anyone! We encourage any age.
- \* We use 1/2 lb. beanbags, juggling scarves, bubbles and Therabands. The books are interactive and it is about having fun!
- \* Storytime is in a meeting room with closed doors. There will be some fidget toys and a weighted blanket available in the room.
- \* There will be no judgments and no worries. This storytime is for your family.
- \* As with any storytime, if it isn't working that moment, that day or at all, there will be no hurt feelings when you step out for a minute, the day or long-term!

For more information:

Jennifer Whitt

Martha Cooper Library/ Assistant Manager

Pima County Public Library

1377 N. Catalina Ave, Tucson, AZ 85712

Jennifer.Whitt@pima.gov

520-594-5322

**SATURDAY, NOVEMBER 2, 2013**

Child & Family  
RESOURCES  
Where Great Things Start Small  
PRESENTS THE

**26TH ANNUAL**



**Lobster Pick-up 9am-2pm**

**Crustacean Celebration 11am-2pm**

**\$45 in advance  
\$60 day at the door**

**Windmill Inn at St. Phillip's Plaza  
4250 N. Campbell Avenue**

**Purchase a lobster for a party in your home!**

**[www.lobsterlandingtucson.org](http://www.lobsterlandingtucson.org)**

# October 1, 2013 Changes to Your Children's Rehabilitative Services (CRS) Program

- CRS members will have one of the 4 new CRS coverage types
- Depending on the coverage type, you or your child may get other types of health care
  - This might be **primary care and/or behavioral health (BH) services**
  - Members will be able to get primary care and BH services in the MSIC clinic, or
  - Have a choice of seeing a CRS contracted primary care physician (PCP) or BH provider in the community
- You will get a **new CRS ID card**
- **ALTCS (EPD) members** right now in CRS will be moved into their ALTCS plan, they will not stay in CRS as of October 1, 2013
- CRS members enrolled in the program prior to age 20 will be given a **one-time option** at age 21 to remain in CRS

## Description of the 4 CRS coverage types:

### Fully Integrated 010115

For AHCCCS (Medicaid) and CRS eligible members; they will receive all of their AHCCCS covered benefits from UnitedHealthcare Community Plan and:

- CRS specialty services
- Primary Care services
- Behavioral Health services

*This category applies to the majority of CRS members*

### Partially Integrated-Acute 010145

For American Indian members; they will receive these benefits from UnitedHealthcare Community Plan:

- CRS specialty services
- Primary Care services

Members will receive behavioral health from a Tribal RBHA.

### Partially Integrated-BH 999125

For CMDP (foster care) or DDD members; they will receive these benefits from UnitedHealthcare Community Plan:

- CRS specialty services
- Behavioral Health services

Primary care comes from the member's CMDP or the member's DD health plan.

### CRS Only 999135

For American Indian members; they will receive these benefits from UnitedHealthcare Community Plan:

- CRS specialty services

These members receive primary care from the primary program of enrollment and behavioral health services from:

- CMDP AI members from a Tribal RBHA
- DDD AI members from a Tribal RBHA
- AI Fee for Service members from a Tribal RBHA

Questions? Call 866-275-5776 or ask your MSIC  
Email [CRS\\_SpecialNeeds@uhc.com](mailto:CRS_SpecialNeeds@uhc.com)



Contract services are funded in part under Contract with the State of Arizona.

## WE NEED TRAINED PARENTS TO HELP OTHER PARENTS.....

The original concept of Pilot Parents has been to provide encouragement and support to families who have children with special needs. This is our #1 priority and to reach this goal, we have a number of parents (Pilot Parents) who are willing to talk with other families who contact us with questions or concerns about their child. As years pass and children grow older, families move away and sometimes we just lose touch.

We are looking for families who are interested in sharing their knowledge on their child's disability and perhaps community resources, with other families. We provide a short training course, either individually or in a small group and then contact you when a family calls us looking for support. This is called a match. We match you with another family who is new to disabilities and needs some help making sense of all of the obstacles we face daily raising a child with special needs.

We are now in the process of updating our database of trained Pilot Parents. And we are searching for parents who would like to assist other families through the maze of having a child with a disability. If you would like information on how to become a trained Pilot Parents, or are currently one of our Pilot Parents but need to update your information we currently have for you, please contact the office so we can either send you a form to update your information, or sign you up for a brief training to get you started helping other families. **Call 520-324-3150.**



### Did you know that October is:

National Down Syndrome Awareness  
Month

National Domestic Violence Awareness  
Month

National Bullying Prevention Month

Breast Cancer Awareness Month

Spina Bifida Awareness Month

Dwarfism Awareness Month

National Disability Employment Awareness

## HAPPY HALLOWEEN



# Pilot Parents of Southern Arizona &



Partner to offer the community a Free Workshop:

## Guardianship & Special Needs Trusts

**Guest Speaker; Jane K. Larrabee, Attorney**

**Date: Wednesday, January 15<sup>th</sup>, 2014 6-8 pm**

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

**2600 N. Wyatt Drive**

**Registration Required;**

**Please call Pilot Parents (520) 324-3150**

**or email [joann@pilotparents.org](mailto: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?**

**And, what if something catastrophic happens to you? Will your family know how to support your child?**

**You might need a Guardianship or a Special Needs trust or both. And you need an emergency plan.**

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

- What is a Guardianship?
- What is a Special Needs Trust?
- What is an emergency plan?
- 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?

**Jane Larrabee, Attorney**, 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 proper 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 received her law degree from the University of Arizona and was awarded as Masters of Law in Taxation from the University of Washington in Seattle. Her practice focuses on estate & legacy planning, especially for families with children or adults children with special needs. Law is her third career. She was formerly an education specialist (Masters in Education) and directed training programs for franchisees and international licensees for a US based quick print franchisor.

**Jane K. Larrabee, Esq. ,333 N. Wilmot Rd., Suite 340 Tucson, AZ 85711 Direct: 520.829.0571 [Jane@jlaw.com](mailto:Jane@jlaw.com)**



# PILOT PARENTS OF SOUTHERN ARIZONA BROWN BAG LECTURE SERIES

## Visual Care Map/Story Tree:

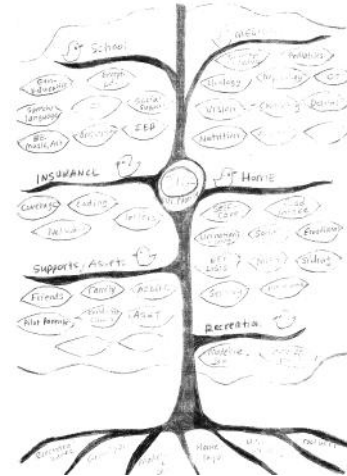
A Story Tree is a visual map of all the different elements a family of a child with special needs has to manage on a daily basis.

It helps parents graphically explain their child's story.

**WEDNESDAY, NOVEMBER 13, 2013**

**FLORENCE MANNING**

Children's Clinic  
2600 N. Wyatt Dr.  
11:30-12:30



\*\*\*\*\*



Kay Aldridge, PhD

Presents: Assessments:

Why do we do them?  
When should we ask for them?  
What do they tell us?

**WEDNESDAY,**  
**November 20, 2013**  
**FLORENCE MANNING**  
Children's Clinic  
2600 N. Wyatt Dr.  
11:30-12:30

\*\*\*\*\*

### UPCOMING WORKSHOPS:

**NOVEMBER 6TH CARING FOR THE CAREGIVER 11:30-12:30 FLORENCE MANNING**  
**JANUARY 15, 2014 GUARDIANSHIP - JANE LARRABEE 6-8 PM FLORENCE MANNING**

**PLEASE REGISTER TO ATTEND.** 324-3150, OR EMAIL JO ANN [joann@pilotparents.org](mailto:joann@pilotparents.org)  
HAVE A TOPIC YOU WOULD LIKE US TO DO A PRESENTATION ON? CONTACT JO ANN WITH RECOMMENDATIONS. ALL WORKSHOPS ARE FREE UNLESS OTHERWISE NOTED.





**The Children's Clinics  
Has a new Child/Life specialist**

Lori Mitts left the Clinics to go to the University of Arizona Medical Center as their new Child/Life Specialist.

Melinda Rowe is the new Child Life/Volunteer coordinator at Children's Clinics. She has a B.S in psychology and a M.Ed. in counseling. Both of her degrees are from Texas Christian University in Fort Worth, TX. She has completed a practicum in school counseling and a child life internship. Melinda is excited to be at Children's Clinics. She hopes that during her work at the clinic, she will be able to support the patients served so that they can be successful participants in their own medical care. Before coming to Children's Clinics, she was the surgical child life specialist at Tucson Medical Center.



**Staff Members:**

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

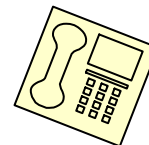
**Cheryl McKenzie**— Receptionist/Secretary  
324-3150

**Karen Kelsch**— Director Partners in Policymaking, L.E.A.P. 324-3158

**Amanda Heyser**— Education Coordinator  
324-3157

**Marianne Scott**— Partner's in Policymaking Coordinator 324-3154

**Jo Ann Spencer**— Special Projects— Sibshop, Editor *The Navigator*.  
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)

Funding is made available by the Arizona Developmental Disabilities Planning Council through contract NO. ADDPC-FFY-11-1112-00-CY3.

**LEAP**

**Year 2 in Review**

Pilot Parents is pleased to report the successful completion of Year 2 of the LEAP program. During the program year (October 1, 2012 – August 30, 2013) Pilot Parents received 58 applications from around the state to attend various local, state-wide and national educational events. We are pleased to report that we were able to grant 40 scholarship requests. The LEAP program awarded \$29,294.42 in scholarship funds.

With continued funding from the Arizona Developmental Disabilities Planning Council, Pilot Parents has launched year 3 of the LEAP program. We continue to provide financial support 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. New educational opportunities are posted weekly on the calendar page of the website.