



THE

# Navigator

FALL/WINTER

Pilot Parents of Southern Arizona

Volume 19 Issue 2

Providing Information and Resources to Families and Professionals in Southern Arizona

## Jessica Cox a profile of independence; and a role model for everyone

Jessica was born with a birth defect. She was born with no arms. Her mother grieved about this disorder originally and wondered what she had done wrong to cause Jessica's disability. Like many of us, she thought she had done something during her pregnancy to cause this disorder. It was during this time that she contacted Pilot Parents and received support. Once over this misconception, and it took some time, she rallied behind Jessica encouraging her to do anything she wanted. Today Jessica drives a car, flies a plane, plays the piano, surfs, dresses herself (all except for fixing her pony tail), and continues training in taekwondo which she started at 10. Additionally, she is a motivational speaker and has traveled to at least 20 countries spreading her message of overcoming obstacles and maintaining a positive attitude. She is the subject of a documentary, "Right-Footed" directed by Emmy Award winning filmmaker Nick Spark. The documentary speaks of her life, mentorship, and her humanitarian trips to Ethiopia and the Philippines. She has written a book [Disarm Your Limits](#) an autobiography.

Jessica was born in Sierra Vista, went to the U of A and majored in psychology with a minor in communication, and graduated in 2005 with a

Bachelor's degree in both.

She holds the Guinness World Record for being the first armless person in aviation history to earn a pilots certificate.

When I spoke with her on the phone, I found her to be delightful. She is articulate, inspirational and very, very interesting. Her perseverance has helped her inspire others to make devices to help people with upper body extremity issues. She is truly amazing.



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

# JESSICA IN ACTION



  
**JESSICA COX**



# 'Sesame Street' Unveils Character With Autism

by Michelle Diamant Oct. 21, 2015  
Disability Scoop

The makers of "Sesame Street" say Elmo, Abby Cadabby and Grover are getting a new friend with autism as part of an effort to reduce stigma and help those on the spectrum learn life skills.

Sesame Workshop said Wednesday that it is introducing a new character named Julia, a preschool girl with autism who "does things a little differently when playing with her friends."

Julia is part of the nonprofit's "See Amazing in All Children" initiative, which is designed to teach kids about autism and offer tools for those with the developmental disorder.



Sesame Workshop is introducing a character with autism named Julia, center, as part of its new "See Amazing in All Children" initiative. (Marybeth Nelson)

The website, <http://autism.sesamestreet.org> includes tips for parents and siblings, as well as guides to help kids on the spectrum learn everyday basics like brushing teeth and going to the grocery store, Sesame Workshop said. In addition, the initiative includes an iPad app and printed storybooks.

"Sesame Workshop is uniquely positioned to play a meaningful role in increasing peoples' understanding about autism," said Sherrie Westin, executive vice president of global impact and philanthropy at Sesame Workshop. "This project is an extension of the belief we've always promoted: 'we are all different, but all the same.'"

Sesame Workshop said it collaborated with more than a dozen organizations including The Arc, Autism Speaks, the Autism Society and the Autistic Self Advocacy Network to produce the content.

In addition, the nonprofit said it engaged Exceptional Minds, a nonprofit animation studio staffed by young adults on the spectrum, to assist with video editing.



# A LITTLE BIT OF THIS AND THAT.....

## NATIONAL AWARENESS

### OCTOBER

**Down Syndrome Awareness Mo.**  
**Dwarfism Awareness Mo.**  
**Domestic Violence Awareness Mo.**  
**Nat'l Bullying Prevention Mo**  
**Nat'l Disability Employment Mo.**

### NOVEMBER

**Epilepsy Awareness Mo.**  
**World Diabetes Awareness Mo.**  
**Great American Smokeout 19th**

### DECEMBER

**International Day for People with  
Disabilities Dec. 3rd**  
**6-14 Hanukkah**  
**25 Christmas**  
**31 New Year's Eve**

## WORKABILITY

Providing individualized training and employment for people with disabilities

From Vanessa Zuber  
Director of Employment Services  
(520) 344-8250

We are proud to announce that UCP of Southern Arizona's WorkAbility program will receive the Linkages Arizona Project of the Year Award at The Eighth Annual Building Bridges Awards luncheon on November 3, at the Westin La Paloma Resort and Spa. This award is in recognition of our commitment to educating and supporting Tucson businesses and families, and to preparing people with disabilities for integrated and sustainable employment.

Congratulations to Sprouts Farmers Market, as they will receive the Linkages Arizona Employer of the Year Award! Sprouts has hired eight individuals from the WorkAbility program, as well as from other various agencies in Tucson. We encourage other Tucson businesses to follow their lead.

## ANALYSIS RANKS BEST STATES FOR DISABILITY SERVICES

By Michelle Diamant July 16, 2015 Disability Scoop  
The Grand Canyon State is number one in a 50 –state ranking of services for people with intellectual and developmental disabilities. (Mel Melson/Los Angeles Times/TNS)

A diverse group of states spanning the nation came out on top in an annual ranking of services for people with intellectual and developmental disabilities.

The analysis released Thursday by United Cerebral Palsy looks at Medicaid services offered across the 50 states and the District of Columbia.

For the fourth year in a row, Arizona took first place in the listing. Other states leading the pack include Maryland, Missouri, New York, Hawaii, Colorado, Minnesota, the District of Columbia, South Carolina and Ohio.

The ranking is largely based on data from 2013 and assesses a number of factors including how easily services are accessed, what types of environments people with developmental disabilities live in and how much they participate in the community.

Nationally, the report found that 4 states had no institutions, but the number of states where at least 80 percent of people and dollars are allocated to community-based settings fell to 32.

At the same time, waiting lists for home and community-based services grew to 322,000 people.

Top states included those that are both big and small as well as those with high and low taxes. The level of per-person spending on home and community-based services also did not appear to affect a state's odds of faring well in the ranking.

Mississippi came in dead last for the ninth year in a row. In addition, the report calls out Arkansas, Illinois and Texas for consistently falling at the bottom of the list since 2007.

*Do you my poppet feel  
infirm? You probably  
contain a germ! ~ Ogden Nash*

Influenza (the flu) is a serious disease...  
Make sure your child is protected!

**What is influenza?** It is a serious disease caused by a virus. The flu can make your child miserable. Fevers, coughing, shaking chills, body aches, and extreme weakness.

**Is it serious?** Yes. Every year infants, children, teens, and adults die from influenza. You can catch flu from people around you sneezing or coughing, or even talking. It is very contagious.

**How can I protect my child and myself?**  
Wash your hands frequently, get plenty of rest and eat healthy foods. Sneeze or cough into your sleeve and try to avoid high use areas that could be coated with germs. Also, get a flu shot. Everyone 6 months of age or older should get a flu shot against influenza every year.

From  
Immunization  
Action coalition  
Immunize.org



# VOTE

NOT REGISTERED? IT'S EASY!

Go to [servicearizona.com](http://servicearizona.com)

Click on Voter Registration tab

Follow the instructions

And you are registered

Or

Visit the Motor Vehicle Department

And register to vote

Remember if you  
don't vote, you give  
up your voice.

ACDL Arizona Center for Disability Law

## I want to Vote

### Free training on your voting rights

Wednesday, January 13, 2016

2:00 pm to 5:00 pm

Viscount Suite Hotel

4855 E. Broadway, Tucson, Arizona

If you are a person with a disability and you want to learn about your voting rights: Learn how to register to vote: Learn where to vote: Have a guardian and want to vote: Live in a group home and want to vote: Learn how to use a voting machine

#### Come and learn about your right to Vote

This training is designed for persons with disabilities who are interested in learning about their voting rights. The training will provide you with information on registering to vote, casting your vote and polling place accessibility. You will have an opportunity to learn and practice how to use the accessible voting machine. In addition, the training will provide you with information on developing self-advocacy skills regarding your right to vote.

Training presented by the Arizona Center for Disability Law, People First of Arizona, SABE Voter Project, Youth Action Council of Arizona and Pima County Elections

**Register online for this Tucson training at Eventbrite:**

<http://iwanttovotetucson.eventbrite.com>

For more information or to register for the training, please contact the Center, at (520) 327-9547 ex. 326 (voice) or 1-800-922-1447 (toll free), or e-mail

[cgutierrez@azdisabilitylaw.org](mailto:cgutierrez@azdisabilitylaw.org). Please notify the Center as soon as possible if you need any special accommodations or are unable to keep your reservation. The training is subject to cancellation if minimal registration is not achieved; you will be contacted as soon as possible if the training is cancelled. The training is limited to 65 participants.

#### Come early to browse our vendor exhibits!

For more information about the Center, please visit our website at [www.azdisabilitylaw.org](http://www.azdisabilitylaw.org)

Funding for this training is provided by the United States Department of Health and Human Services, Administration on Developmental Disabilities



DID YOU?

# DOWN SYNDROME

October is Down Syndrome (DS) awareness month.

Down syndrome is a chromosomal disorder that includes a combination of birth defects. Individuals with DS have some degree of intellectual disability, characteristic facial features and, often heart defects and other health problems.

Down Syndrome is one of the most common genetic birth defects. According to the National Down Syndrome Society, there are more than 400,000 individuals with Down syndrome in the United States.

For centuries, people with Down syndrome were alluded to in art, literature and science. But it wasn't until John Langdon Down, an English physician in 1866, published an accurate description of a person with Down syndrome.

Individuals with Down syndrome once had a short life expectancy. But the outlook is much brighter than it once was. Most of the health problems connected with Down syndrome can be treated. Life expectancy now is 60 years.

Individuals with Down syndrome are more likely than unaffected individuals to have one or more of the following health conditions:

- ◆ Heart defects: almost half of babies with Down syndrome have heart defects. Some defects are minor and may be treated with medications, while others require surgery. All babies with Down syndrome should be examined by a cardiologist. They should also have an echocardiogram, a special ultrasound of the heart, in the first 2 months of life so that defects can be detected and treated, if necessary.
- ◆ Intestinal defects: about 12 percent of babies are born with intestinal malformations requiring surgery.
- ◆ Vision problems: more than 60 percent of children with Down syndrome have vision problems, including crossed eyes (esotropia), near or far-sightedness and cataracts. Most issues can be improved with surgery, glasses or other treatments. Children with Down syndrome should be checked within the first 6 months of life and have regular vision exams after.
- ◆ Hearing loss: About 75 percent of children with DS

have some hearing loss.

- ◆ Infections: Children with Down syndrome tend to have many colds and ear infections, as well as bronchitis and pneumonia. They should receive all childhood immunizations, which help prevent some of these infections.
- ◆ Thyroid problems: about 1 percent of babies with DS are born with congenital hypothyroidism, a thyroid hormone deficiency that can affect growth and brain development.
- ◆ Leukemia: fewer than 1 in 100 children with DS develop leukemia (a blood cancer) that can be successfully treated with chemotherapy.
- ◆ Memory loss: individuals with DS are more likely than unaffected individuals to develop Alzheimer's disease.

## What Can a Child with Down Syndrome do?

A child with Down syndrome can usually do most things that any young child can do, such as walking, talking, dressing and being toilet-trained. However, they generally start learning these things later than unaffected children.

The exact age that these developmental milestones are achieved cannot be predicted. However, early intervention programs beginning in infancy can help these children achieve their developmental milestones sooner.

Children with Down syndrome can go to school, live on their own and get jobs. Today, an increasing number of adults with Down syndrome live semi-independently in community group homes where they take care of themselves, participate in household chores, develop friendships, partake in leisure activities and work in their communities.

Information from March of Dimes, [www.marchofdimes.org](http://www.marchofdimes.org) and ndss [www.ndss.org](http://www.ndss.org) (National Down Syndrome Society).

## Resources that can Help:

If you are a parent of a child diagnosed with Down syndrome, you may at first feel overwhelmed by feelings of loss, guilt, and fear. Talking with other parents of kids with DS may help you deal with the initial shock and grief and find ways to look toward the future. Many parents find that learning as much as they can about DS helps ease some of their fears. Pilot Parents of Southern Arizona can help match you with another family who will speak with you and help you through the tough times. Call us 520-324-3150 and ask for support. That is why we are here. Also, there are several really good support groups in Tucson and Arizona for families with children who have Down syndrome.

Experts recommend enrolling kids with DS in early-intervention services as soon as possible. Physical, occupational and speech therapists and early-childhood educators can work with your child to encourage and accelerate development.

Once your child is 3, he or she is guaranteed educational services under the Individuals with Disabilities Education Act (IDEA). Under IDEA, local school districts must provide “a free and appropriate education in the least restrictive environment” and provide the child with an individualized education program (IEP).

Some organizations in Arizona:

Down Syndrome Connection  
Down Syndrome Network of Arizona  
Leti Foundation  
Santa Cruz Parent Love Connection  
Sharing Down Syndrome Arizona! Inc.  
Southern Arizona Network for Down Syndrome (SANDS)

# THE BUDDY WALK 2015

SUNDAY NOVEMBER 15TH  
REID PARK TUCSON, AZ  
1PM - 5PM

MEET NEW FRIENDS  
GET SOME EXERCISE AND FRESH AIR  
VISIT COMMUNITY RESOURCE TABLES

The worst thing  
about a disability  
is that people see  
it before they see  
you.

Easter Seals

meetville.com

### Staff Members

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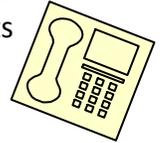
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# LEAP

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

*The LEAP Program provides financial support for self-advocates and family members to participate in local, state-wide and national conference, workshops and other training opportunities. Applications are available at [www.pilotparents.org](http://www.pilotparents.org)*



## PILOT PARENTS PROVIDES:

- ONE TO ONE SUPPORT
- DISABILITY INFORMATION
- RESOURCE INFORMATION
- EDUCATIONAL SUPPORT
- FREE TRAININGS ON A VARIETY OF TOPICS
- PARTNERS IN LEADERSHIP
- LEAP SCHOLARSHIPS
- SIBLING SUPPORT

COME VISIT US ON THE 2ND  
FLOOR OF THE CHILDREN'S  
CLINICS