



TULSA ADVOCATES FOR THE RIGHTS OF  
CITIZENS WITH DEVELOPMENTAL DISABILITIES

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OK AIM and ARCCorps  
VOLUNTEER NEWSLETTER

# CaringVoices

SPEAKING OUT FOR OKLAHOMANS WITH DEVELOPMENTAL DISABILITIES

Winter  
2016

## I/DD Resource Fair to be held in Tulsa on April 2

TARC will host a resource fair on Saturday, April 2, for individuals, families, volunteer guardians, and groups who are interested in Intellectual/Developmental Disability (I/DD) services and programs available in the Tulsa area.

The fair will take place from 10:30 a.m.-12:30 p.m. at the Rudisill Library, 1520 N. Hartford, in Tulsa.

If you know of an organization that serves individuals with I/DD and their families, please invite them to join us as an exhibitor.

There is no fee and a table and two chairs will be provided.

To register as an exhibitor or for more information, call Kate Fitzpatrick at 582-TARC (8272) or email

kfitzpatrick@ddadvocacy.net.

Space is limited and registration will be on a first-come-first-served basis.

Complimentary refreshments will be provided by Topeca Coffee and The Bramble Bakery.



KOTV's LeAnne Taylor and OK AIM Volunteer Shelby Hard

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## OK AIM monitor Shelby Hard receives 'Courage In Advocacy' Award

A very special award was presented to a very special person in January on the "6 In The Morning" show on KOTV.

Shelby Hard was presented the TARC Courage in Advocacy Award by "6 In The Morning" personality LeAnne Taylor and TARC Executive Director John Gajda during the closing segment of the program.

Prior to the presentation, Shelby's mother, Iva, said, "Shelby is very excited to receive this award from LeAnne, who she considers her cancer buddy."

Shelby was chosen to receive the Courage in Advocacy Award because of her positive attitude and bravery in battling her disease while she continues to be an advocate for herself and others

with developmental disabilities. Shelby and her mother are long-time OK AIM volunteers.

Sean Lewis, Tulsa People First President, his mother Kyle, and several TARC staff also attended the presentation.

Shelby was born in 1989. Her parents were told she would never walk, talk, run,

*(Continued on page 3)*



An affiliated chapter of



## 21<sup>st</sup> Annual Shot In The Dark Golf Tournament Set for May 6



The 21<sup>st</sup> Annual Shot In The Dark Golf Tournament is scheduled for Friday, May 6,

2016 at LaFortune Golf Course, 5501 S. Yale.

Registration will begin at 6:30 p.m. and the tournament will begin at 9 p.m. Participants will also enjoy a BBQ dinner, putting contest, live music, silent auction, and more.

This unique tournament is played at night with glow-in-the-dark balls and glow sticks marking tee boxes and holes. Golfers will tee off in teams of four at the 9 p.m. shotgun start.

All holes are reset to par

three and the golfers navigate the course playing nine holes. Players can register online as individuals (\$100) or four-somes (\$300).

For more information

about the tournament as well as sponsorship opportunities, contact Barry Maxwell at 918-582-TARC (8272) or by email at bmaxwell@ddadvocacy.net.



The 2015 tournament team champions: (left to right) Jordan Elam, Damen Hershberger, Nick Landon, and Matt Kupke who were sponsored by D & L Oil Tools.

## New TARC website with added features now online

TARC's website has had a makeover! We are very excited about our new online look and functionality.

During the next few months, additional features will be added as we continue to bring you useful content and easier navigation tools.

We would greatly appreciate your feedback in making our new website even better and more responsive to your needs.



Please email your comments and suggestions to [cthompson@ddadvocacy.net](mailto:cthompson@ddadvocacy.net).

Among the features available on the new website will be a more complete selection of TARC publications including brochures, annual reports, and newsletters.

And don't forget to visit the TARC Volunteers Facebook page that also has a new look. We invite our volunteers and others to post comments as well as ideas for volunteer recruitment and training.



## OK AIM Activity Gauges July 1 - December 31, 2015



## Easy as 1-2-3!

### Join

Become a TARC Member and add your voice as an advocate for those with developmental disabilities.

### Volunteer

Learn how you can personally affect an individual's life by becoming an OK-AIM or ARCCorps volunteer.

### Donate

Your tax-deductible donation helps fund the many programs and services that TARC provides.

Find out how to do all three by going to the TARC website — [www.ddadvocacy.net](http://www.ddadvocacy.net)



Like us on Facebook  
TARC Volunteers

## TARC supports two legislative disability advocacy efforts

### ABLE Act for Oklahomans with disabilities

Oklahoma legislators are currently considering eight different bills that would allow the establishment of tax-free savings accounts similar to Oklahoma's College 529 plan for individuals with disabilities.

For the federal legislation to benefit Oklahomans, the Legislature must pass changes to the state's existing 529-fund law.

Eleven states have already done so, and 29 others are considering changes.

TARC actively supports

passage of legislation to establish what are known as ABLÉ Accounts in Oklahoma.

Congress passed the Achieving Better Life Experience (ABLE) Act years ago but Oklahoma has never followed suit.

The law allows eligible individuals with disabilities the ability to establish "ABLE accounts" for qualified beneficiaries that resemble the qualified tuition programs, often called "529 accounts", that have been established under that

section of the tax code since 1996.

The new ABLÉ accounts will allow more individual choice and control over spending on qualified disability expenses and limited investment decisions, while protecting eligibility for Medicaid, Supplemental Security Income, and other important federal benefits for people with disabilities.

Without these accounts, many people with disabilities have very limited avenues to save and allow for further independence.

### Autism insurance reform

The Oklahoma Legislature is currently reviewing HB 2962, which would require insurance coverage for evidence-based treatments for autism that currently are routinely denied by health insurers.

Forty-three states have passed similar legislation. According to the CDC, autism now affects 1 in 68 children (1 in 42 boys) in the U.S. More children will be diagnosed with autism than AIDS, diabetes, and cancer combined.

Currently, more than one million Oklahomans with

state regulated private health insurance do not have meaningful autism insurance coverage in their plans.

HB 2962 requires coverage for the diagnosis and evidence-based treatment for autism spectrum disorder for individuals under the age of 18 years when prescribed by a licensed physician or licensed psychologist as medically necessary.

This includes:

... Behavioral health treatment (applied behavior analysis up to \$36,000 per year)

... Pharmacy Care, Psychiatric Care, Psychological Care)

... Therapeutic Care (speech, occupational and physical therapy)

According to the Harvard School of Public Health, the incremental cost of caring for someone with autism over their lifetime is \$3.2 million.

TARC is actively supporting passage of HB 2962 through community meetings for Tulsa-residents who are interested in insurance reform for the treatment of children with autism.

## TARC awarded grant from The Arc for MLK volunteer initiative

In conjunction with Martin Luther King, Jr. Day of Service, TARC, in partnership with University of Tulsa True Blue Neighbors, Tulsa People First, and the Bridges Foundation, brought together people with and without developmental disabilities to participate in a

variety of volunteer service projects in January and February.

The federal agency that leads the national Martin Luther King, Jr. Day of Service, the Corporation for National and Community Service (CNCS), selected The Arc of the United States

and five other organizations as grantees to plan and execute volunteer projects that will unite Americans in service.

The 2016 MLK Day of Service took place on January 18 and The Arc, through Tulsa-based nonprofit TARC and nine other chapters nationwide, were involved in service events throughout January and February.

During these events, people with intellectual and developmental disabilities (I/DD) volunteered alongside people without disabilities in service projects related to access to healthy food.

Service projects in Tulsa included: volunteer service at the Community Food Bank of Eastern Oklahoma, food drive at the University of Tulsa for the Kendall Whittier Food Pantry Feb. 1-26, collection of canned food at the TU and University of Connecticut women's basket-



(left to right) Liz Murrell and Connie Dearman participate at the food bank service project.

ball game on Jan. 27, and serving meals on multiple days in February to approximately 140 students at Kendall Whittier Elementary School as part of their after-school program sponsored by TU True Blue Neighbors. #TheArcMLK #MLKDay



Volunteers from TARC, Tulsa People First, the Bridges Foundation, and TU joined together to collect food items brought by people attending the TU women's basketball game on January 27.

## Shelby Hard

(Continued from page 1)

or have the capability to be sociable. They were advised to place her in an institution. But with great determination, she overcame all of



An avid fan of the Duck Dynasty television show, Shelby shows off some of the items sent to her by the Duck family.

these negative prognoses.

She can walk (slowly), talk (leaves a few words out here and there), run (slowly), and she is *very* sociable.

During her senior year in high school, she was diagnosed with colorectal cancer. She started radiation therapy and soon thereafter started a three-month round of chemotherapy.

After a couple of years of remission, the cancer started growing again. She started another six-month round of chemotherapy. She went into remission again. In November 2013, the cancer progressed to stage IV.

She began chemo treatments again which were working in the spring, but the cancer stopped responding in June.

Shelby then decided not to



Shelby with LeAnne Taylor and Sean Lewis (front row) and supporters from TARC with Iva Hard (back row, center).

do any more chemotherapy. She says she just wants to enjoy life and be happy.

She continues to have blood work done at Tulsa Cancer Institute, where she is a joy to the other chemo

patients who interact with her.

Her mother said, "She is always Happy, Happy! She always brings stuffed animals with her on treatment day or to doctor visits.

**2016 TARC Board of Directors announced**

Officers:

**Kurt Webber**,  
President & VP Human Resources and Membership  
**Dawne Stafford**,  
President Elect  
**Kent Garrett**,  
Past President  
**Lisa Burlingame**,  
VP Legislative Affairs and Public Policy  
**Megan Henderson**,  
Treasurer  
**Sara Johnson**,  
VP Programs  
**Julie Kenderdine**,  
VP Public Relations and Development  
**Ronda Marfechuk**,  
Secretary

Members:

**David Clutter**  
**Bob Cole**  
**Jean Cook**  
**Laura Farris**  
**Charity Gillman**  
**Allen Johnson**  
**Debbie McClellan**  
**Dalawna O'Guin**

Board Interns:

**Mary Anne Ahluwalia**  
**Mark Hargis**

**2015 Advocacy Awards**

The 25<sup>th</sup> Annual Advocacy Awards & Volunteer Recognition event was held Dec. 3, 2015 at the Tulsa Marriott Southern Hills Hotel. More than 200 people enjoyed an evening of dining, entertainment, a special keynote speaker, and, most importantly, an opportunity to join TARC in recognizing outstanding volunteers and supporters of TARC programs.



John Gajda presents the Catalyst of Change Award to Donna Nigh.

Keynote speaker at the awards ceremony was Pulitzer Prize-winning journalist and best-selling author Ron Suskind, who related his family's journey of connecting with his son Owen, who has autism, through Owen's obsession with Disney movies. The special 25<sup>th</sup> edition of the TARC Advocacy Awards & Volunteer Recognition also included a seated dinner and entertainment by the Pathways Choir from Kirk of the Hills Presbyterian Church in Tulsa, whose choir members include several individuals with developmental disabilities. Also performing was the Green Country Shining Stars – a cheerleading squad for special needs athletes ages 5 and older.



Ron Suskind describes his family's experiences with their son's autism.

Awards were presented in 12 categories including a new Catalyst of Change category. This award was given to individuals, groups or organizations that have been catalysts for significant

Green Country Shining Stars cheer group performs.



positive change in improving the lives of Oklahomans with developmental disabilities.

In addition to these awards, OK AIM and ARCCorps volunteers who have served for 5, 10, 15, and 20 years were recognized for their dedication and service to Oklahomans with developmental disabilities.

**2015 Advocacy Award Winners**

Advocate – Board Member:  
**Wanda Felty**

Advocate – Case Manager:  
**Darla Hill-Myers**

Advocate – Direct Care Provider:  
**Marie Hamilton**

Advocate – Educator:  
**Shanda Moody**

Advocate – Professional Provider:  
**Kelly Piper**

Advocate – Volunteer:  
**Ellyn Novak Hefner**

Elected Official:  
**Rep. Jon Echols**

Self-Advocate:  
**Jennifer Karner**

Media Advocate:  
**Mike Averill**

Parent Advocate:  
**Kodey Toney**

Special Achievement in Advocacy:  
**Camp Fire Green Country**

Catalyst of Change Award winners:  
**Michelle Hoffman**  
**Homeward Bound Parents**  
**Donna Nigh**  
**Partners in Policymaking**

President's Award:  
**The Anne & Henry Zarrow Foundation**

Lifetime Achievement Award:  
**James Nicholson**

**— A Night to Remember!**



(left) Advocacy Awards Master of Ceremonies, KTUL-TV personality Burt Mummolo .



(right) Pathways Choir from Kirk of the Hills Presbyterian Church performs.



(above) Dana Lawson presents the Educator of the Year Award to Shanda Moody.



(below) Rebecca Thompson interprets for Self-Advocate of the Year nominee Betty Falk.



John Gajda presents the Lifetime Achievement Award to Jim Nicholson.



David Pitts presents the Direct Care Provider of the Year Award to Marie Hamilton.



**Homeward Bound Parents Honored at Advocacy Awards**

In 1985, a group of parents, with children in Hissom Memorial Center, under the name of Homeward Bound Inc. filed a class-action lawsuit against the Center and various state agencies.

Two years later, Judge James Ellison ordered Hissom to shut down and the residents be transitioned into community-based care.



Brenda Garrett, ARCCorps Volunteer Coordinator (left) who accepted the award on behalf of Mary Ann Duncan, stands next to award winner Susie Paulson.

Their action spurred the community-based services movement in Oklahoma and created the community-based service system that exists today.

These pioneering parents are: Mary Ann Duncan, John and Sharon Berry, John and Sharon Brasier, Paul and Susie Paulson, and Barbara Thompson.



### John Gajda appointed to OCCJ Board

TARC Executive Director, John Gajda, has been appointed to The Oklahoma Center for Community and Justice (OCCJ) Board of Directors.

OCCJ is a nonprofit human relations organization dedicated to achieving respect and understanding for all people through education, advocacy, and dialogue.

Founded as a volunteer movement in Tulsa in 1934 as a chapter of the National Conference of Christians and Jews, OCCJ has a proud legacy deeply rooted in the community.

It became independent of the national organization in 2005. OCCJ is now better prepared and equipped to define and address issues in which Oklahomans want to be involved.

"I feel very honored to be asked to serve on the OCCJ Board of Directors. Their efforts to ensure the well being and inclusion of all people into society fit perfectly with the mission of TARC and its efforts on behalf of Oklahomans with developmental disabilities," said Gajda.

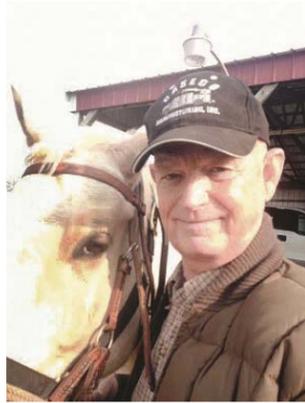
## ARCCorps volunteer adds equine therapy to advocacy role

In 1987, Bob and Alice Burnett founded All-star Therapy Group, a therapeutic horseback riding program between Tulsa and Bartlesville for individuals with special needs.

Therapeutic horseback riding is the use of horses and equine-assisted activities in order to achieve goals that enhance physical, emotional, social, cognitive, behavioral, and educational skills.

In 2000, the couple was introduced to TARC when they were awarded TARC's Advocate Professional Care Provider of the Year award.

Their involvement with TARC was limited until 2010, when Elaine Jeffy, a former ARCCorps Volunteer Recruiter, approached Bob. She asked him to serve as a



Bob Burnett, owner of All-star Therapy Group and ARCCorps volunteer.

volunteer advocate for a DDS consumer who had just begun the riding program at All-star.

Bob quickly agreed, became trained as an advocate, and was assigned power of

attorney over the individual's medical care.

A few months later, Bob agreed to become a guardian for another young DDS consumer living in Pawhuska. Bob was already familiar with him, as he was also already riding in the program.

Later that year, TARC shot a promotional video featuring these men at All-star Therapy Group.

In 2015, Bob Burnett was nominated for the TARC Volunteer of the Year award. Many DDS consumers continue to work, volunteer, and ride at All-star.

Bob's relationships with his two matched individuals, Larry and Ray, has blossomed. He sees both men, separately, twice weekly for riding and volunteer

ARCCorps volunteer Bob Burnett stands behind his two matched individuals, Larry and Ray, at the All-star Therapy Group facility he operates with his wife Alice.



vocational activities at the farm.

He has invited them into his life, hosting sleepovers, facilitating visits with their families, and inviting them to his own family's holiday celebrations.

Larry and Ray had not met until one of them was hospitalized last year. Since their initial visit in the hospital, Bob has scheduled them to ride thirty minutes apart, so they see each other each week.

Bob began volunteering in therapeutic horseback riding as a board member and instructor in 1988 with the English Equitation Group of Washington County.

In the early nineties, he was a founder and original board member of Bluestem Therapeutic Riding (BTR).

While developing that program, he became the first certified therapeutic riding instructor in Oklahoma and a short time later, an Advanced-level Instructor.

Bob and Alice are parents to nine children ranging in age from seven to 50 years. They also share and enjoy nine grandchildren and five great-grandchildren.

They are active in their church and in the special-needs and deaf communities.

They have been, and continue to be, strong voices in advocating for individuals with intellectual/developmental disabilities, and are constantly seeking the best options for a high quality of life for Larry and Ray as well as the many others they serve. ❧



Larry rides "Cisco" at the All-star Therapy Group facility near Ramona.



### Nominations now accepted for 2016 Advocacy Awards

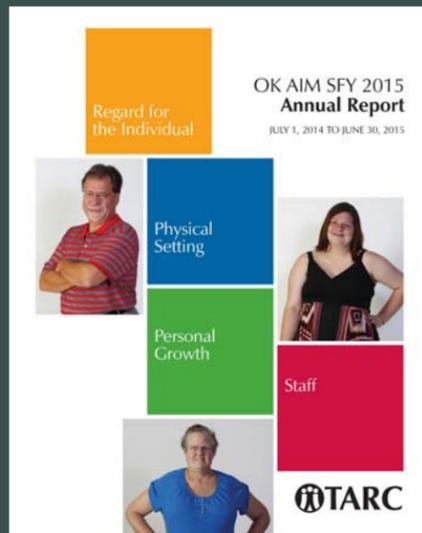
Nominations are now being accepted for the 2016 Advocacy Awards.

This is your opportunity to nominate a person, agency, civic group, or business that has made an outstanding contribution to the field of developmental disabilities.

Nominations can be submitted online by going to the TARC website at [www.ddadvocacy.net](http://www.ddadvocacy.net).

Please take time to let someone you know how much their service is appreciated by nominating them for this important recognition award.

## 2015 OK AIM Annual Report now available online



TARC volunteers will soon receive copies of the OK AIM SFY 2015 Annual Report in the mail. Volunteer monitors in the OK AIM program ensure that the focus of residential programs remains on the individuals being served.

Their visits to individuals in their homes throughout Oklahoma evaluate the quality of the lives of individuals being served from the perspective of four building blocks that form the foundation of a good life for most individuals.

Those four building blocks are: regard for the individual, physical setting, personal growth and staff. Each contributes part of what determines the quality of life for individuals served in residential programs and are the framework volunteer monitors use to access the homes they visit.

This report documents the work of OK AIM volunteer monitors during State Fiscal Year (SFY) 2015 that began on July 1, 2014 and ended on June 30, 2015. Who they saw, what they said, and what became of their findings tells the story of one of the ways Oklahoma strives to ensure a quality life for those individuals with developmental disabilities who entrust their lives to the formal system of residential services operated by DDS.

The eyes and ears of OK AIM volunteer monitors assure that quality of life remains an important element of the overall quality assurance system that oversees services.

The 2015 OK AIM Annual Report also is available for viewing online at [www.ddadvocacy.net](http://www.ddadvocacy.net).

## ARCCorps Activity Gauges July 1 - December 31, 2015



### Has Your Address or Phone Number Changed?

Please contact your OK AIM or ARCCorps Coordinator with your correct information or call 918-582-8272 or 800-688-8272.