



The Arc

For people with intellectual
and developmental disabilities



empower

Real People, Real Progress

Issue 8 | Winter 2011

Achieve with us Contest Winner Takes on Washington, DC

On November 1st, The Arc welcomed Tyler Smothers of Cedar Rapids, Iowa to Washington, DC to meet with members of Congress. In August, Tyler won The Arc's *Achieve with us* social media contest by garnering the most votes for his incredible story of achievement as an individual with an intellectual and developmental disability (I/DD).

Out of 119 contestants with more than 25,000 votes cast, Tyler was selected for his impressive achievements in his community, which had been devastated by floods in 2008. To help his community and his local chapter, The Arc of East Central Iowa, get back on their feet, Tyler established the "Tour de Flood" bike riding fundraiser. Tyler leads the now annual event using an adaptive bike. Tyler's entry was submitted by his older brother Josh Smothers.

The Arc arranged for Tyler and his family to travel to Washington, DC and meet with national office staff before descending on Capitol Hill to talk budget cuts with Iowa Senators Tom Harkin and Chuck Grassley, and Congressman Dave Loebsack. In addition to his meetings, Tyler and his family toured the White House and U.S. Capitol, and visited the Holocaust Museum.

During his meetings, Tyler shared the challenges of living with a disability. He

also told Congressman Loebsack how the services he and his friends receive allow them to remain active in the community and how that is important to him. Tyler's mother Cindy spoke to the Members of Congress about how Medicaid is a lifeline for her family. Without Medicaid, Cindy would not be able to work and Tyler would not be able to be the active and included member of his community that he is.

"Tyler exemplifies what The Arc stands for and we were honored to host him and his family during their trip to Washington, DC. Tyler is an inspiration to his friends and neighbors in Iowa, and he

brought his message to leaders in Washington to demonstrate why in particular the Medicaid lifeline is so important," said Peter V. Berns, CEO of The Arc.

We're thrilled that Tyler turned out to be the perfect embodiment of The Arc's *Achieve with us* tagline! Check out his winning entry and other great stories of achievement from people with I/DD on The Arc's blog at www.thearc.org, and go to facebook.com/thearcus to see photos of Tyler with Senators Harkin and Grassley and Congressman Loebsack on Facebook! And, look for Tyler in an upcoming issue of *ABILITY Magazine*, which co-sponsored the contest. ■



From left to right, Cindy, Tyler, J.J., and Josh Smothers at The Arc of the United States in Washington, DC.

Achieve with us.

Autism Law Renewed in Washington

In late September, President Obama signed into law the Combating Autism Reauthorization Act. This law will continue the programs established by the Combating Autism Act of 2006 - screening and surveillance of autism spectrum disorder (ASD) and educating professionals about proper screening, diagnosis, and intervention for children with a range of developmental disabilities. The bill authorizes \$231 million a year from Fiscal Year (FY) 2012 through 2014 for these efforts.

One of the law's most important programs for families of children with developmental disorders is Leadership Education in Neurodevelopmental & Related Disabilities (LEND). LEND is the only federal program that supports professional education on screening, identification and treatment of developmental disabilities, including ASD. Over the years, it has helped to train thousands of health care providers, educators, and other community providers who regularly work with children. The training program is particularly important for older professionals who have had very limited coursework on developmental disabilities as part of their professional training.

Sadly, many parents of children with ASD and other developmental disabilities spend years seeking proper diagnoses and treatments for their children. Such delays can have adverse

long term effects, particularly for young children as the most critical stage of brain development takes place in the first 3 years of a child's life, according to Dr. Kathryn McVicar, a pediatric neurologist at the LeBonheur Children's Hospital who provides LEND training in Tennessee. "I had one particularly compelling example recently after a doctor I trained referred one of his young patients to me. This child had been placed in foster care because, due to his many bruises and scrapes, the mother had been suspected of child abuse. After the doctor learned about the self-harming behavior that some children with Autism engage in, he referred the child to me. Our team eventually determined that the child's injuries were self-inflicted and he was placed back in the home with his mother. He continues to receive behavioral interventions and medication therapy and his functioning has improved significantly since he first came to our attention."

With the Centers for Disease Control estimating that 1 in 110 children have ASD, the reauthorization of the Combating Autism Act is crucial. The Arc thanks our large network of advocates who helped ensure its enactment by reaching out to their Senators and Representatives. We celebrate this victory and look forward to working with Congress in 2014 to revise the law to include ASD services and research across the lifespan. ■

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Mission Statement

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

**The Arc's Board of Directors has accepted the resignation of Immediate Past President Lynne Cleveland due to personal reasons. Lynne has been a tireless advocate since the early 1990s for people with intellectual and developmental disabilities in Texas and across the country. As a Board member, Lynne has been very supportive of our mission and her positive attitude and spirit have always left an impression on those of us fortunate enough to work with her over the years. We thank Lynne for her many years of service to The Arc.*

Medicaid, State by State

The Arc is excited to announce a valuable new resource available at www.thearc.org to help guide people with intellectual and developmental disabilities (I/DD) and their families through the complexities of Medicaid benefits, services and supports. The Medicaid Reference Desk offers detailed, state-by-state information about Medicaid benefits, a glossary of terms, answers to frequently asked questions, person-centered planning resources and a blog from The Arc's training specialist about issues related to Medicaid, self-advocacy and planning.

Medicaid is the largest source of financing for disabilities services in the United States. For people with disabilities and for those who provide their care, Medicaid serves as a valuable safety net. Often the only source of financial assistance for health care, Medicaid plays a critical role for people with disabilities in providing coverage and access to care. Medicaid is, however, extremely complicated. At least half of the funds for Medicaid programs come from the Federal government with the remainder coming from state funds. Federal law contains detailed requirements and limitations on eligibility, services, and financing. But, state law varies widely.

This project was made possible by a grant from the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (Grant No. 90 DN0215). We encourage you to explore the Medicaid Reference Desk on www.thearc.org under What We Do – Resources. ■

Exciting News in Nevada!



Nicole Schomberg, The Arc's new Project Coordinator in Nevada

The Arc is happy to announce the launch of the "Growing a Grassroots Advocacy Movement" project in Nevada! This exciting new opportunity is being funded by the Nevada Governor's Council on Developmental Disabilities as well as The Arc of the United States. The Arc in Nevada will work to de-

velop long-term capacity for advocates to have input and impact on issues of importance to people with intellectual and developmental disabilities (I/DD) and their families.

With the launch of this new program, The Arc will have a statewide presence in Nevada for the first time since the mid 1990s. The project will train individuals with I/DD and family members on how to affect disability policy at the local, regional and state levels, culminating in a grassroots campaign.

The training, called Partners Plus, will be conducted across the state, targeting graduates of previous Nevada Partners in Policymaking™ classes. This project will work to train people with

disabilities and their families (parents, siblings, grandparents, other family members), primarily those who have previously completed the original Partner in Policy-making classes. Participants from The Arc in Nevada's programs will develop a legislative advocacy agenda and a specific action plan to promote it during the 2013 Nevada legislative session. To ensure lasting impact, some participants will work to train others in their local communities, involving advocates at all levels in the execution of the legislative platform and advocacy agenda.

In addition to the Partners Plus program, The Arc in Nevada will expand efforts to support individuals with I/DD and their families through

new chapter recruitment, grassroots advocacy development, and collaborative efforts with communities across Nevada.

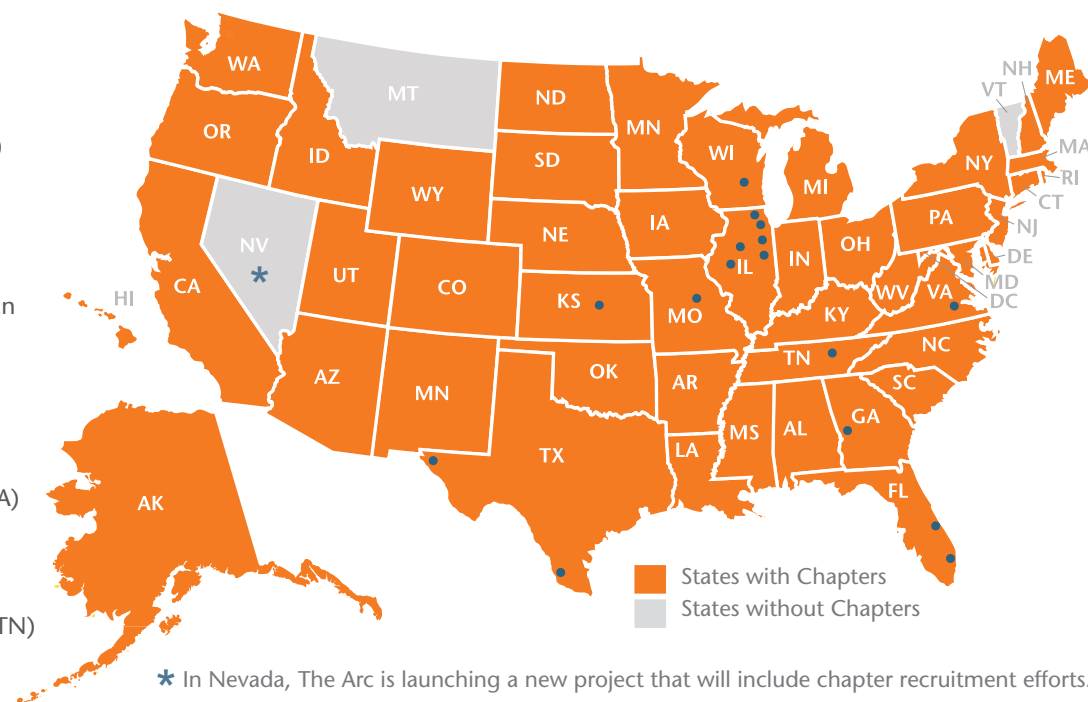
This project will be staffed by a new member of The Arc team, Nicole Schomberg. Nicole has expertise in advocate engagement and community outreach. Most recently, Nicole worked to coordinate previous Partners in Policymaking programs in the state. Additionally, Nicole is a parent of a child with developmental disabilities, and has extensive experience working with families and self-advocates in Nevada. If you are in Nevada and interested in participating in The Arc's project, we encourage you to contact Nicole at schomberg@thearc.org. ■

Growing Strong

The Arc continues to grow our strong national network of more than 700 Chapters. Here are 17 new Chapters we added to our family in 2011. You can find their contact information at www.thearc.org under the Find a Chapter tab, which is organized by state.

17 New Chapters:

- Aspire (IL)
- Central Illinois Service Access (IL)
- Gateway Services, Inc. (IL)
- SouthSTAR Services (IL)
- PACT, Inc. (IL)
- Avenues to Independence (IL)
- Abilities Resource Center of Indian River County (FL)
- Victory Living Programs (FL)
- The Arc Del Paso (TX)
- The Arc of South Texas (TX)
- The Arc South of the James (VA)
- The Arc of Greater Columbus (GA)
- The Arc of Boone County (MO)
- The Arc of Dodge County (WI)
- The Arc of Island & Skagit (WA)
- The Arc of Cumberland County (TN)
- The Arc of Sunflower (KS)



A Successful 2011 Convention in Denver



Temple Grandin signs copies of her book for convention attendees.

In September, The Arc hosted its 60th Annual National Convention in Denver, Colorado. This year's theme, "Achieve new Heights" resonated through each session on the agenda. Working together all attendees were able to find new and innovative ways to grow as a movement, as an organization, and as individual advocates.

One of the most memorable parts of the convention was Dr. Temple Grandin's keynote address. Dr. Grandin was also presented with The Arc's Image and Inclusion Award. Her presentation gave remarkable insight about what it is like living with autism. She shared stories

about her life offering both advice and inspiration for all those who attended. Though world renowned for her work as a scientist and advocate, Dr. Grandin still took time to sign books and speak with convention attendees.

Attendees enjoyed an exciting presentation by an expert and legend in the disability community Dr. David Braddock, including personal copies of



Hundreds of convention attendees enjoyed bowling on Saturday night.



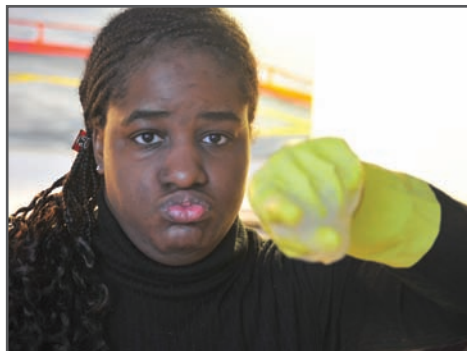
Lauren Potter greets fans and signs autographs.

the most recent State of the States in Developmental Disabilities 2011 as well as insightful breakout sessions where dozens of topics including Standards for Excellence™ in chapters and marketing were discussed, and finally the closing plenary where attendees were given a crash-course in community organizing by Don Elmer.

Next year, The Arc will be partnering with Inclusion International for its 61st Annual Convention in Washington, DC. For more information about next year's convention (October 25-29, 2012) and how to participate visit our website at www.thearc.org. ■

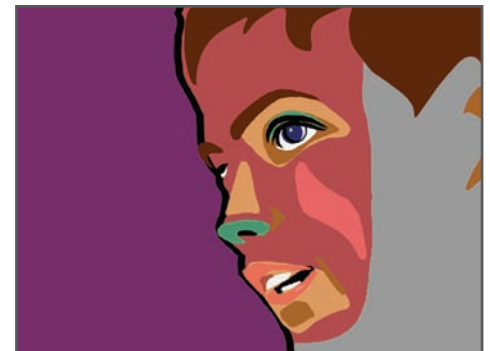
The Arc Launches National Film Festival

The Arc has partnered with Sprout, a nonprofit organization which develops films about and by people with intellectual and developmental disabilities (I/DD), to launch a national touring film festival at Chapters of The Arc throughout the country. Anthony DiSalvo, a filmmaker and co-founder of Sprout, has worked for many years to cultivate and create a collection of shorts, documentaries and other types of films that explore the aspects of and issues related to I/DD. Sprout presents an annual film festival in New York City and has a touring film festival which he has brought to Chapters of The Arc on occasion over the years.



Still images from films screened by The Arc & Sprout National Film Festival at The Arc's recent National Convention in Denver.

Those local collaborations between Sprout and Chapters of The Arc coalesced into a formal entity now called The Arc & Sprout National Film Festival in 2011 and was formally announced



at The Arc's National Convention in Denver in September. Through this partnership, The Arc's national office can offer a level of marketing support

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Fighting for Our Rights in California

The Arc of California is taking the needs and rights of people with intellectual and developmental disabilities (I/DD) to the courts in a new lawsuit against the state. The lawsuit against the California Department of Developmental Services and the Department of Health Care Services claims that the state is violating federal law by failing to adequately fund services needed by individuals with I/DD. The lawsuit asks that laws requiring the State to provide necessary funding to ensure adequate care for individuals with I/DD be enforced.

In its case, The Arc of California lays out how the State has not been providing sufficient support for people with I/DD because of economic woes. Over the last decade, there have been rate freezes, program closures, and budget cuts that have shut down many com-



Tony Anderson, Executive Director of The Arc of California

munity-based services, leaving more than 240,000 Californians with disabilities in dire situations.

"It's illegal to slash basic support services that allow Californians with I/DD to live safely in their communities," said

Tony Anderson, Executive Director of The Arc of California. "These basic civil rights cannot be compromised or bargained away as part of a budget deal. The State of California must follow the law and honor its commitment to serve and protect the rights of Californians with intellectual and developmental disabilities."

In early October, the U.S. Supreme Court heard oral arguments in a case that The Arc and the disability community are watching very closely. The case, *Douglas v. Independent Living Center of Southern California, et al*, concerns whether individuals and providers can sue states to block cuts to Medicaid rates. California maintains that only the federal government can enforce the portion of the law concerning payment rates. This case may impact The Arc of California's lawsuit as well.

So far, the response from the community has been overwhelmingly positive including a few families who are moved to tears at the thought of someone standing up for them and fighting for the futures of their sons and daughters. ■

"These cuts have hurt my daughter and I believe we have to fight for what's right. I'm so glad The Arc and UCP are fighting for us. Keeping people in their homes is just morally the right thing to do. Everybody deserves to live safely in their homes and have a good life."

- Sandy Waterbury, parent from Ventura County, CA

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and organization to take this exciting initiative to a much broader audience on a truly national scale.

"The Arc & Sprout National Film Festival fits so perfectly with our mission," said Shelly DeButts, Marketing Associate for The Arc's national office. "First and foremost, attending a film festival is an activity almost anyone, regardless of disability, can enjoy. Plus, it allows actors and other performers an opportunity to express themselves through film. Film is the epitome of inclusiveness."

Peter Berns, CEO of The Arc, added, "not only is this good for the I/DD community, but it can be an entertaining

experience for those who like films, but don't necessarily know anything about intellectual and developmental disabilities. It's also a great opportunity for companies interested in supporting this new national event. The films we'll show are entertaining, thought-provoking and inspiring, allowing us to connect with the public in a meaningful way to help raise awareness about I/DD."

The Arc presented a sampling of the types of fare people can expect to see at upcoming film festivals at a luncheon at The Arc's National Convention in Denver, including music videos by an artist with Down syndrome and a band of people with various disabilities, a series of animated shorts explaining

Asperger's Syndrome from the perspective of the individuals who have it and a series of shorts featuring poetry composed by people with I/DD then recited by actors with I/DD.

The Arc & Sprout National Film Festival will bring these entertaining events to Chapters of The Arc throughout the country in 2012 and beyond, so check with your Chapter to find out if a film festival is coming to your community. We are anticipating approximately 25 events in such geographically diverse areas as Idaho and Maryland in 2012. Also, you can find out more about Sprout and the programs and films they create at www.gosprout.org. ■

These are our issues, too

MMeet John and Julene Stellato, parents of three children (ages 13, 11 and 8). None of their children or anyone in their immediate family has an intellectual or developmental disability (I/DD) – nonetheless, they are generous supporters of The Arc. For John and Julene Stellato, The Arc's cause resonated. They have been touched in particular by the plight of families dealing with the day-to-day stress and challenges of having a member with I/DD, especially as they and their children grow older and support services are harder to find.

Why do John and Julene care to support us? Was it growing up with fond memories of playtimes with neighbors with I/DD, or the perspective given to them by a health scare for their oldest child when he was just days old? They support The Arc simply because they feel it's the right thing to do. As members of a community, they feel a responsibility to help because The Arc's issues are their issues too. Real progress for The Arc depends on people like the Stellatos, who don't themselves have a direct connection with I/DD, becoming educated and involved in the cause.

A few years ago, John read an article



The Stellato family

in the Wall Street Journal showcasing a family with an adult child diagnosed with Autism Spectrum Disorder. The article detailed the issues of aging parents and their anxiety as they wondered who would care for their son when they passed. How would he live comfortably, safely, happily, independently?

After reading the article, John took an extraordinary step. He contacted the reporter and asked how he could learn more about helping families like the one featured. Those questions eventually led him to The Arc. John and Julene educated themselves about The Arc's work on a national level to advocate for and protect this vulnerable population, and they discovered our broad national

network of state and local chapters.

Intrigued by the work The Arc has done to establish a new national brand, John and Julene wondered what could be accomplished if our new color (orange) could become as ubiquitous as the shade of pink associated with breast cancer awareness. Could we get more of America's strong corporate citizens to understand the role they could play in hiring more people with I/DD? How could increased employment opportunities improve the lives of not only individuals with disabilities, but also family members who worry and give up so much to support them?

We like the way John and Julene think! The news story that inspired John could have a happy ending if The Arc had the resources it needs to gain the awareness level of other top national nonprofits. We hope the example of the Stellato's generosity will spur many prospective supporters, whether or not they themselves have a personal connection to The Arc. Nearly 70% of most annual philanthropic support is given between November and December, and we need your support. Please consider making a gift to The Arc today. ■

Your Donation Counts — Achieve With Us

- ☐ Yes! I want to support The Arc.
☐ \$50 ☐ \$100 ☐ \$150 ☐ \$_____ Other ☐ \$_____ Monthly
- ☐ Yes! I want to become a monthly sustainer.
- ☐ Yes! I want to learn more about The Arc's planned giving program.
- ☐ Yes! I want to receive e-updates with the latest news from The Arc.
My e-mail address is: _____
- ☐ I support The Arc because I have a ☐ child, ☐ grandchild, ☐ sibling,
☐ friend, ☐ co-worker or _____ with I/DD.
- ☐ Check or money order enclosed
- ☐ Please charge my ☐ VISA ☐ MasterCard ☐ AMEX ☐ ArcVISA
Card # _____ Exp. Date _____
- Signature _____
- ☐ My company will match my gift

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*Registration with any state agency does not imply endorsement, approval or recommendation by the state.

How Self-Advocacy Changes Lives – From Victims to Survivors

By James Meadours & Leigh Ann Davis

A well-known, passionate leader within the self-advocacy movement, James Meadours is a staunch supporter of The Arc and has volunteered and worked for The Arc at the local, state and national levels for 21 years. About ten years ago, he began speaking out about the high rate of victimization in the lives of people with intellectual and developmental disabilities (I/DD), and with great courage took the risk of “putting himself out there” to reveal what is secretly going on behind closed doors.

Over the years, James has learned that self-advocacy must include victim advocacy, and that people with disabilities and their families need to face what statistics have proven - victimization is a very real threat to people with I/DD. People with I/DD are not only more likely to be victimized compared to people without disabilities, but they are also more likely to be victimized repeatedly. Consider James’ experience:

- At 15 years old, as a freshman in high school, James was first attacked in someone’s backyard by two teenage girls who continued sexually assaulting him multiple times after the initial attack. He was afraid to say anything because he thought his parents and teachers would say it was his fault.
- James’ family moved to Oklahoma where he began using over-the-counter drugs like Nyquil as a way to deal with the death of his mother and the pain of victimization. In a public restroom, a member of the school’s Board of Directors fondled James - but he was too afraid to tell, thinking no one would believe him since the offender was a powerful person in the school system.
- James moved to a group home in Oklahoma in 1987. While visiting a friend at an independent living center, a resident fondled him and he was, again, afraid to tell anyone. In 1990, a speaker from the rape crisis center spoke at a self-advocacy meeting

“I’m sharing my story to bring about changes to the system that will help other people, both with and without disabilities, obtain healing and justice after victimization occurs.”

– James Meadours, Self Advocate

James attended, and for the first time he talked about his experiences of victimization. James felt better after telling the truth, and believed that part of his life was over.

- In 2003, James befriended a deaf man at a local church who offered to teach him sign language. The so-called friend raped him while in his own apartment, even though James signed “NO!” several times. It was hard for James to tell anyone at first, but within days, James told the church pastor, then staff at the local chapter of The Arc where he worked. With the active support of people at the local rape crisis center and The Arc, the offender was eventually prosecuted for the criminal charge of rape.

If a victim with I/DD who is so well-connected to supports and services and well-versed in the world of self-advocacy was afraid to speak up, how much harder is it for those with disabilities who have little or no supports, or expe-

rience with self-advocacy? Even when victims try to report crimes against them, the seriousness of the crime may be minimized, or worse, victims are not believed. Research has found that crimes against people with disabilities are less likely to be prosecuted, but thanks to advocates within his local rape crisis center, and local chapter of The Arc, James fought those statistics and won when the so-called friend-turned rapist was finally brought to justice.

James Meadours and Leigh Ann Davis, Project & Information Specialist with The Arc who is also a survivor of sexual assault and understands first-hand challenges victims face, share a passion to educate others about the realities of victimization among people with disabilities. They will be speaking at the National Center for Victims of Crime “National Training Conference on Responding to Crime Victims with Disabilities” December 13-15, 2011 in Orlando, Florida. The conference brings together people from all over the country who work in victim services, disability services, law enforcement, and other professions to enhance the skills of professionals and advocates in reaching out to and supporting people with disabilities who are victims.

The Arc can help people with I/DD who are victims of crimes and their families. Visit www.thearc.org to find fact sheets about this topic and to find a chapter near you. Silence won’t heal the pain of being a victim of a crime. Let The Arc connect you to the resources you need to move from being a victim to a survivor. ■

More About Leigh Ann Davis, The Arc’s Project & Information Specialist

Issues of victimization and how the criminal justice system intersects with the intellectual and developmental disability community are two areas of focus for Leigh Ann Davis and her work with The Arc. She recently contributed to a special issue of the noted Journal of Psychiatry & Law which was focused on victimization issues related to individuals with Fetal Alcohol Spectrum Disorder (FASD). You can find this publication at www.federallegalpublications.com/journal-of-psychiatry-law

Leigh Ann is also an expert on FASD and serves on the Substance Abuse and Mental Health Services Administration (SAMSHA) FASD Center for Excellence Expert Panel. Leigh Ann holds a Masters of Science in Social Work and a Masters of Public Administration, and regularly lends her expertise in developing The Arc’s fact sheets on various issues as well as special projects. Leigh Ann can be reached at ldavis@theac.org or 202-534-3727. ■



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California*

The Stellato Family

*From Victims to
Survivors*

National Film Festival

We Moved!

The Arc's national headquarters has moved to new digs in Washington, D.C. You can still reach us online at info@thearc.org and www.thearc.org and via our toll-free phone number 1-800-433-5255, but our new mailing and shipping address is:

**1825 K Street NW, Suite 1200
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Give to the Best

Have you ever wondered what national experts in our field think of the effectiveness of The Arc? Philanthropedia, a subsidiary of GuideStar, named The Arc one of the top nonprofits working for people with disabilities (check us out at <http://www.myphilanthropedia.org/top-nonprofits/national/people-with-disabilities>). Philanthropedia is a nonprofit organization working to make you aware of the highest impact nonprofits in a cause. The Arc was selected as one of eleven high-impact nonprofits in the disability field by a group of 79 experts, including foundation professionals, nonprofit senior staff, academics, and researchers. Philanthropedia evaluated each organization based on their ability to carry out their mission, organizational strengths and, most importantly, evidence of the impact they achieve, demonstrating that money given to The Arc truly makes a difference. You can support a high impact nonprofit by joining The Arc or donating today. Look for a donation form on page 6 in this issue or visit www.thearc.org for more information about membership and what we do. ■