



# empower

Real People, Real Progress

Issue 16 | Fall 2013

## *The Arc Earns Two Exciting New Grants*

### *The Arc Launches New National Resource Center on Criminal Justice and Disability*

The Arc is thrilled to announce a new two-year grant for \$400,000 by the U.S. Department of Justice, Bureau of Justice Assistance (BJA) to develop a national center on justice and intellectual and developmental disabilities (I/DD). This is the first national effort of its kind to bring together both victim and offender issues involving people with I/DD under one roof. According to the National Crime Victim Survey of 2010, the victimization rate is twice as high for individuals with disabilities as compared to those without disabilities. And we don't have to look far for examples where law enforcement and people with I/DD could have benefited from this kind of work, including the tragic death of Robert Ethan Saylor in Frederick, Maryland, who died earlier this year after three off-duty deputies attempted to remove him from a movie theater over a misunderstanding over a ticket.

The goal of this project is to create a national clearinghouse for research, information, evaluation, training and technical assistance for justice and disability professionals and other advocates that will build their capacity



The Arc of Aurora's Balancing the Scales of Justice for Children and Adults with Disabilities Conference

to better identify and meet the needs of people with I/DD, whose disability often goes unrecognized, and who are overrepresented in the nation's criminal justice system – both as victims and offenders.

"When individuals with I/DD become involved in the criminal justice system as suspects or victims, they often face miscommunication, fear, confusion and prejudice. This new center will play a critical role in improving first response and communication between people with I/DD and the justice system. No similar center on this topic exists, nor are there sufficient resources to address the gap in expertise in the field, and so this effort is long overdue," said Peter Berns, CEO of The Arc.

**DOJ Grant** continued on page 6

### *The Arc Taking Lead on Educating Medical Professionals on Preventing Fetal Alcohol Spectrum Disorders with New Federal Grant Award*

**B**uilding on The Arc's long history working on Fetal Alcohol Spectrum Disorder (FASD) prevention and providing services to people with FASD, The Arc is pleased to announce it has been awarded a cooperative agreement valued at more than \$1.3 million over three years from the federal Health Resources and Services Administration's (HRSA) Maternal and Child Health

Bureau to increase the education of medical professionals regarding alcohol-exposed pregnancy and change clinical practice to better prevent FASD.

Drinking while pregnant can cause FASD, a preventable form of intellectual and developmental disability (I/DD). Yet according to HRSA, 22.5% of pregnant women drink alcohol and

**HRSA Grant** continued on page 7

***Achieve with us.***

# Built to Last...

By Nancy Webster, President, The Arc's National Board of Directors



Nancy Webster

**T**he Arc IS built to last. For over 60 years, The Arc and many of our chapters have been supporting and sustaining the services we provide for people with I/DD and their families. We have made tremendous progress in creating the strong national organization we know today, and we are determined to continue to grow and broaden our reach to more communities. Recently, we have been focusing on just how to continue doing this, and have been engaging in conversations

with the national Board of Directors, our Executive Directors, and our State Presidents and, in meetings at different sites across the country that we're calling Parlor Meetings.

These Parlor Meetings are an opportunity for the national organization to go out to meet our chapters on their home turf, to get to know their friends and supporters, and listen to feedback from you, the core of our movement, about how to build The Arc into a nationally recognized, high-profile organization. So far we have met in eight different cities: New York, Chicago, San Francisco, West Palm Beach, Nashville, Boston, Houston and Birmingham. Each of these events was hosted by one of our national board members and attended by Peter Berns, our CEO, either Mohan Mehra (immediate Past President) or myself, and Trudy Jacobson, Senior Executive Officer, Development & Marketing.

These have been interesting and exciting events – I have enjoyed the chance to share the current success of our organization and our chapters and share our collective vision for the future. And, they have provided an opportunity to hear our guests' ideas about how The Arc can increase its visibility and success and develop a strong brand and a real fundraising ability. One topic of discussion that has cropped up in my travels to our chapters recently has been The Arc's further exploration of a planned giving program. When setting up a will, many people designate charities such as The Arc to receive a portion of their estate. Unless The Arc sets up a formal program to make people more aware of this option, we may miss opportunities to connect people to this optional way to support The Arc in the long run. Stay tuned for more on this in 2014.

As you can see, we are tapping into unique perspectives across the country and hearing from people with a wealth of ideas. But communication is a two-way street. While we are hearing from supporters and stakeholders, we are also taking the opportunity to gauge just how much the general public knows about The Arc and how we can increase that awareness.

I am constantly asking myself the question, "Why should people care about The Arc?" I know why I care and I am pretty sure I know why you care, but the question challenges me to put myself in shoes of folks outside of our circle. It makes me think of ways to explain The Arc to others and to tap into the support they might offer if they only knew and understood more about what we do. This challenge is not unique to The Arc. Growing our brand in a cluttered marketplace of charities and other organizations competing for attention is a challenge, but it is vital to the continued success of The Arc. There are many "natural partners" out there – the faith community, community organizers, educators – who are already inclined to support The Arc's mission but may not know as much about us as they do other highly visible organizations such as Feeding America or Habitat for Humanity.

Young families who are new to the I/DD movement and our organization are another segment of the population we need to reach by making our brand more visible. But they are also difficult to reach and engage. Young families these days are so entrenched in their day-to-day lives. While they may seek connection via social media, they don't always know about offline resources like our services and supports in their local communities. Making this connection is absolutely critical to the future of The Arc, and I welcome your input on how to improve our reach to this generation. I would like for you to be part of a "virtual" parlor meeting of *Empower* readers who can give us additional ideas. For instance, could we do more with social media? You tell me. I invite you to contact me at [president@thearc.org](mailto:president@thearc.org) and let me hear your ideas for taking The Arc into the future. With the creativity and energy of the people connected to our chapter network across the nation, The Arc is built as we are – built to last. ■

## empower

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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**

**1-800-433-5255**

# A Chapter of The Arc Promoting Health and Nutrition in Schenectady County, New York

A few years ago, Schenectady County Public Health Services and Schenectady ARC formed a unique partnership to address the high rates of chronic disease and obesity among people with I/DD in Schenectady County through the Strategic Alliance for Health. Schenectady ARC, a provider of residential, vocational, clinical, and adult day services in New York State's Capital Region, recognized that among its 1,480 participants, nearly 10 percent were diagnosed with cardiovascular disease, obesity, or diabetes and wanted to do something to address the needs of those they served.

While nationally-based research showed individuals with I/DD were more prone to incidence of chronic disease, Schenectady ARC had confidence that they could help their participants by improving their diet and educating them about healthy eating habits. Further research found that children who participated in a "seed to table" nutrition education

program tended to increase their consumption of fruits and vegetables. Through this program, children participated in a variety of regularly scheduled activities such as vegetable taste-testing, hands-on gardening, and recipe preparation. Based on these studies, Schenectady ARC created Know, Grow and Eat Your Vegetables, a garden-based nutrition education program for people with I/DD. The agency's horticulture coordinator oversaw the new program which was located at Schenectady ARC's commercial-sized greenhouse in Rotterdam, NY. The



Schenectady ARC participants tend to a raised vegetable planter outside the agency's greenhouse in Rotterdam, New York.

coordinator assessed awareness of and preference for 15 vegetable types and, worked alongside 70 participants to plant and cultivate seedlings.

While the vegetables were being grown, nutrition educators from Cornell Cooperative Extension of Schenectady County (CCESC) conducted a six-week program adapted to the specific needs of individuals with I/DD. This training provided participants and staff with strategies regarding healthy meal preparation

practices and how to incorporate vegetables into daily meals and snacks.

This remarkable program continues to flourish and provide nutrition and education for individuals with I/DD in Schenectady County. Since the program began, participants have harvested approximately 1,000 vegetables. Vegetable packets, along with recipes, were distributed for consumption in group home or family home settings. Last year, this program was named by The National Association of County and City Health Officials (NACCHO) as a model practice and an implementation guide can be found on the U.S. Centers for Disease Control and Prevention website! Also, during The Arc's national convention, Schenectady ARC and NACCHO presented together, giving chapters of The Arc the opportunity to learn from the success of this program. ■



Schenectady ARC participants proudly display packets of vegetables grown through the Know, Grow and Eat Your Vegetables Program.

*"The Know, Grow and Eat program has been a great opportunity for individuals at Schenectady ARC. The partnership with the community has provided new educational tools and a personal awareness of health and eating habits that have spread throughout Schenectady ARC. It's been an exciting new venture, one that we are hoping to enhance and grow in the future." said Kirk Lewis, Executive Director, Schenectady ARC.*



# Honoring Our Champions this Holiday Season

*Champion: "A person who fights tirelessly for a cause or on behalf of a cause."*

A respected tradition for the end of the year is to take the time to reflect on the accomplishments and trials of the past 11 months, while looking ahead to the coming year with optimism and hope.

Despite the challenges and opportunities each New Year brings, we remain resolute in our dedication to the individuals we serve. This year we want to begin a new tradition, to show our appreciation for the real champions that help The Arc fulfill our mission on a daily basis.

You can find these champions in Congress, in your state government, within state and local chapters of The

Arc, in your local community, and in your own family. From a U.S. Senator who has been on the frontlines fighting for disability rights and supports in the halls of Congress, to our chapter leaders and amazing grassroots advocates, to Ricardo Thornton, a successful champion and self-advocate who shares his inspirational story in his local community and across the nation.

2014 is right around the corner, and The Arc is gearing up for a new year filled with challenges and opportunities. Without champions, The Arc could not continue its important work. Won't you help us identify those who are our champions of the future?

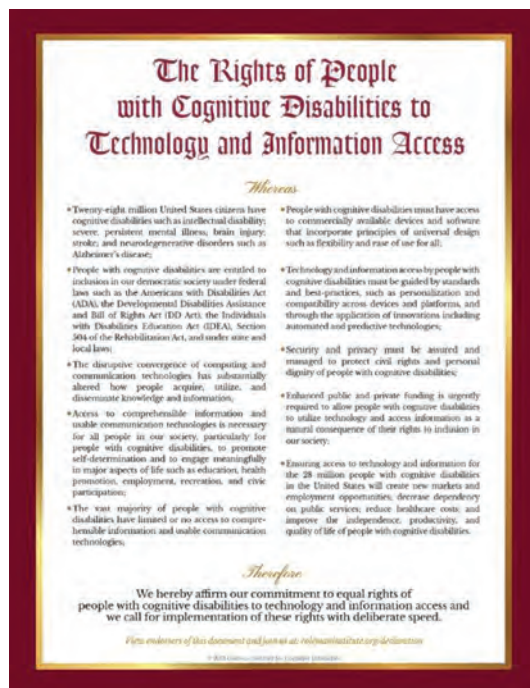
Champions are everywhere and deserve our thanks – perhaps you know a teacher, friend or family member who has been a champion and you could acknowledge their commitment to you, your family and our cause, by recognizing them with a gift to The Arc in their honor today! During this time of year when we all look back and give thanks, please start a new tradition and thank the champions in your life.

Our supporters are our champions too! Please become a champion for The Arc and help people with I/DD live the life they deserve with an end of the year tax-deductible gift today! ■

## Endorse Equal Access to Technology for Individuals with Disabilities

Do you benefit from technology on a daily basis? Can you imagine life without your tablet, smart phone, or computer? People with cognitive disabilities are estimated to comprise over 60% of the world's total population of people with disabilities, yet the vast majority of people with cognitive disabilities have limited or no access to comprehensible information and usable communications technologies.

The Arc has joined more than 100 other organizations in supporting a declaration on the rights of people with cognitive disabilities to have an equal right to technology and information access. The Rights of People with Cognitive Disabilities to Technology and Information Access is a statement of principles: the rights of ALL people to inclusion and choice in relation to technology and information access.



"Technology can expose individuals with intellectual and developmental disabilities as well as those with cognitive disabilities to a new world. The advantages of technology are something that every individual deserves to have equal access to, which is why The Arc supports the Declaration on the Rights of People with Cognitive Disabilities to Technology and Information Access. Technology can be particularly beneficial to individuals with disabilities as it can serve as a communication device, assist in education, and overall promote independence," said Peter Berns, CEO of The Arc.

To join The Arc in endorsing the declara-

tion visit the Coleman Institute website at <http://www.colemaninstitute.org/declaration-endorse>. ■

# Your Old Car Can Help People with Intellectual and Developmental Disabilities

Every day, state and local chapters of The Arc are on the front lines providing advocacy and vital services for people with I/DD and their families. And they depend on your donations. But not everyone can make a cash donation, so The Arc has developed other ways individuals can support its mission that are just as impactful if not more. One of those is The Arc's Car Donation Program. With a simple phone call or through an online form, you can donate any car, boat, motorcycle or other titled vehicle to your chapter of The Arc.

Greg LaRue, the Facilities and Donations Manager with The Arc of the Greater Twin Cities in Minnesota, points out that his chapter sees between \$30,000 and \$35,000 of additional revenue each year from car donations – money that can make a tremendous difference in the chapter's ability to serve people with I/DD. To illustrate the impact of car donations on their charity, he points out to the employees of the chapter's four thrift stores that they would have to sell shirts to 60 to 100 different customers to raise the amount of money that can be generated from just one car. And, he is quick to remind potential donors that The Arc accepts vehicles in any condition. Even cars that can only be sold for scrap metal still yield some money – possibly more than an individual might be able to give in cash.

The key to the success of the program is how easy it is to use. In the case of The Arc of the Greater Twin Cities, it only takes about 15 minutes at one of their thrift store

locations to drop off a car and fill out paperwork. Or donors can simply call 1-877-ARC-CAR-0 or fill out an online form at [www.thearc.org/donate-my-vehicle](http://www.thearc.org/donate-my-vehicle) and a representative will make arrangements to pick up or tow a vehicle, sell it at auction and deliver the cash proceeds directly to The Arc. The Arc even makes sure you get the proper paperwork to take a deduction for your donation at tax time. The program is so streamlined that The Arc is able to use very minimal resources to run it, allowing a greater portion of the donation to go directly to funding the work we do on behalf of people with I/DD. Do you have an old car that you need to get rid of? Consider donating it to The Arc before the end of the year so you can take a tax break and help people with I/DD at the same time. ■



## There's More for Our "Friends" Online

Are you following The Arc or your local chapter on social media? More than 400 of our chapters are using Facebook to keep in touch with their friends and fans and nearly as many are using Twitter as well. You can find The Arc of the United States at [facebook.com/thearcus](https://facebook.com/thearcus) or on Twitter by using the handle @thearcus. Join in the online conversation today. We're always sharing news, information and fun, feel-good stories about the I/DD movement. ■



## Save the Dates!

Plan to join The Arc in 2014 for two big events. April 7-9, the I/DD community will head to Washington, D.C. for the annual Disability Policy Seminar to go in-depth on public policy issues and meet with their elected representatives. Registration opens in January and we are already booking rooms at [www.disabilitypolicyseminar.org](http://www.disabilitypolicyseminar.org). And from September 30 - October 2, 2014, The Arc's National Convention will convene in festive New Orleans, LA for educational sessions, enlightening speakers and social events designed to keep you informed and connected. Registration will open in May, so save the date and check [www.thearc.org/convention](http://www.thearc.org/convention) this Spring for program details. ■

# Top Five Reasons the Affordable Care Act Will Help People with Disabilities

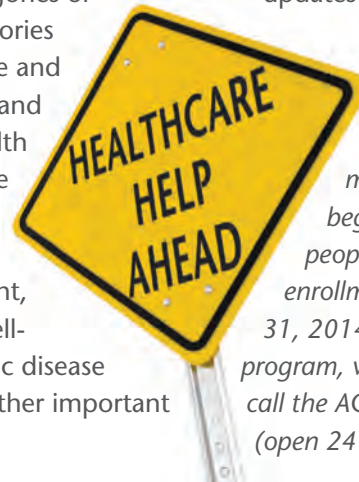
The Affordable Care Act (ACA) marked one of the most significant laws for people with disabilities since the enactment of the Americans with Disabilities Act (ADA) in 1990. This year, implementation is moving into high gear and we want to highlight the top reasons this landmark legislation will help individuals with intellectual and developmental disabilities!

- 1. Eliminates pre-existing condition exclusions:** Health insurance companies are not allowed to deny enrollment or specific benefits based on pre-existing conditions.
- 2. Medical underwriting no longer allowed:** Beginning in 2014, health insurance companies will only be able to base premium amounts on age, smoking, size of family and geographic location. Insurers will no longer be able to take into account health status when setting premiums. Premiums are the amount people pay to purchase insurance.

- 3. Provides affordability provisions:** Tax credits and cost-sharing reductions will make private health insurance more affordable for low and moderate income individuals. To qualify for help individuals and families can earn up to 400% of poverty, or \$45,960 for an individual, and \$94,200 for a family of four in 2013.

- 4. Health plans sold in the marketplace must cover key services:** The law requires that plans sold to individuals, small employers and Medicaid Alternative Benefit Plans must cover 10 categories of services. Key categories include rehabilitative and habilitative services and devices, mental health and substance abuse disorder services including behavioral health treatment, preventative and wellness services, chronic disease management and other important health care services.

- 5. Allows states to expand Medicaid coverage:** States can now expand Medicaid coverage to adults with incomes up to 133% of the federal poverty level and receive a generous federal match - 100% for the first 3 years and gradually declining to 90% in 2020. Find out if your state is taking advantage of this option by visiting the Kaiser Family Foundation's website: <http://kff.org/state-category/health-reform/medicaid-and-health-reform-health-reform/> and clicking "news and updates".



*In October 2013, enrollment began in the new private health insurance marketplaces and coverage begins January 1, 2014, for people who enroll in time. Open enrollment will continue until March 31, 2014. To learn more about this program, visit [www.healthcare.gov](http://www.healthcare.gov) or call the ACA helpline 1-800-318-2596 (open 24 hours a day). ■*

## DOJ Grant continued from page 1

The Arc will work closely with several other national partners within the criminal justice, legal and victim advocacy communities to research, analyze and replicate evidence-based solutions to the problems of injustice and victimization that have gone on for far too long within the I/DD community. For example, people with I/DD are often unable to report crimes or are not seen as credible witnesses. They are also vulnerable to becoming perpetrators of crime, including sex offenses, and used by other criminals to assist in law-breaking activities. And with many forms of mild I/DD not being easily identifiable, justice personnel may not recognize that someone has a disability or know how to work effectively with the individual. Although organized training is available for criminal justice professionals on mental illness, few resources on I/DD exist. Many law enforcement and other justice professionals do not know the difference between mental illness and I/DD and often think they are

synonymous.

"When our chapters work with their local law enforcement agencies, they hear time and time again that training is provided for mental health issues, yet that doesn't encompass millions of people with I/DD living in our communities. Through this grant, The Arc's center will become a national focal point for the collection and dissemination of resources and serve as a bridge between the justice and disability communities," said Berns.

The center will consist of a resource library, directories of expert witnesses, attorneys, forensic interviewers, and victim advocates, a database of relevant state laws, and hands-on technical assistance and training. Additionally, The Arc will create a Justice and I/DD Certification program using training curriculum authored by Leigh Ann Davis, M.S.S.W., M.P.A., and hold five trainings (beginning in August 2014) around the country and web-based trainings (beginning in January 2014).

Stay tuned to The Arc's website, [www.thearc.org](http://www.thearc.org), to see the Center take shape in the coming months! ■



many health care providers advise women that light drinking is safe. Providers need education on drinking during pregnancy, screening tools and interventions that can prevent FASD. The Arc, with the support of its national partners, will develop trainings including webinars, peer learning communities, and continuing medical education (CME) courses for allied health professionals, and create and disseminate culturally appropriate materials.

“This grant is a tremendous opportunity for The Arc to make a real difference in how the medical community views the risk of drinking while pregnant. Working with key players in the medical sector, we expect to dramatically change the conversations happening in doctors’ offices,” said Peter Berns, CEO of The Arc.

The Arc will work with The Association of Reproductive Health Professionals, and the National Association of City and County Health Officials to carry out this grant. The goal of this project is to increase provider knowledge of the risks alcohol poses during pregnancy and encourage prevention by:

- Conducting a comprehensive needs assessment on the educational needs of providers;
- Developing an educational plan for increasing provider knowledge of FASD prevention;
- Working with national professional associations to create culturally and linguistically appropriate educational materials for a range of health care providers;
- Disseminating materials to providers via national organizations’ networks and other channels; and

*“This grant is a tremendous opportunity for The Arc to make a real difference in how the medical community views the risk of drinking while pregnant. Working with key players in the medical sector, we expect to dramatically change the conversations happening in doctors’ offices.”*

— Peter Berns, CEO of The Arc.



- Assessing the impact of educational efforts on provider knowledge, practice, and prevention.

This award to The Arc comes at a particularly opportune time to capitalize on important changes in our health care system. Thanks to the Affordable Care Act, starting in 2014, all health insurance marketplace plans and many other plans must cover select preventive services, including alcohol misuse screening and counseling, without charging a copayment or coinsurance when these services are delivered by a network provider. According to guidance from the Department of Health and Human Services, alcohol misuse includes any alcohol consumption by women who are pregnant or trying to get pregnant.

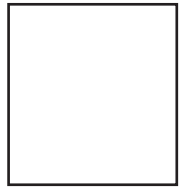
And starting in October of 2014, the new edition of the International Classification of Diseases (ICD), the standard diagnostic tool for epidemiology, health management, and clinical purposes, will go into effect. For the first time, there will be specific codes for FASD prevention and intervention. These welcome and long sought additions to the ICD are expected to yield greater interest in prenatal alcohol exposure by medical professionals and encourage clinical interventions by creating billing codes for such services.

*The project will be 100% funded by this cooperative agreement, funded by HRSA, grant # U1HMC26371. ■*



For people with intellectual  
and developmental disabilities

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[www.thearc.org](http://www.thearc.org)

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## *The Arc Racing Program Crosses the Finish Line*

The Arc Racing Program closed out the 2013 race season at the Streets of Houston Grand Prix in Texas October 5 with members of The Arc of Greater Houston and the RS Werkes race team. Over the course of the season, The Arc was represented by local chapters at eight events in the U.S. and Canada where we raised awareness about intellectual and developmental disabilities among race fans. Twenty individuals with I/DD at each chapter were treated to race-day experiences which included serving as honorary pit crew members, attending autograph sessions with drivers and cheering on driver and team owner Don Istook racing under The Arc's banner. Look for The Arc Racing Program to start our engines up again in March 2014! ■

## *Workplace Giving Season is Here!*

Indicate your support for The Arc of the United States by writing in our Combined Federal Campaign (CFC) number on your payroll deduction form: 11296. Thank you for participating! ■



[bbb.org/charity](http://bbb.org/charity)

## *Meeting High Standards!*

The BBB Wise Giving Alliance National Charity Seal carries a lot of meaning for both donors and charities. After undergoing a rigorous evaluation by the BBB Wise Giving Alliance, The Arc is proud to have received their seal for meeting the Standards for Charity Accountability again this year! ■