



empower

Real People, Real Progress

Issue 10 | Summer 2012

The Arc Brings Issues Facing People with Disabilities to the White House

President Obama Tells Disability Community “I’ve Got Your Back”

In February, The Arc had a unique opportunity to bring 150 leaders from chapters across the country to the White House for a day-long series of briefings with top officials from the Obama Administration. The session, dubbed a *Community Leaders Briefing* and held just for The Arc, included an unannounced visit from President Barack Obama. The President addressed issues of critical importance to people with intellectual and developmental disabilities (I/DD) and their families, ending simply with, “I’ve got your back.”

This surprise appearance by the President of the United States was the highlight of the day for many attendees, along with the opportunity to interact with high level government officials about how they can support people with I/DD to live in the community. Over the course of the day, leaders of chapters of The Arc were briefed on topics ranging from Medicaid to education to community living and em-

ployment for people with I/DD. Many of the speakers, including President Obama, referenced the impact advocates made during budget negotiations to protect Medicaid, and encouraged The Arc and others to continue these efforts.

Are you on our action list? It’s easy to stay engaged and take action with The Arc – visit www.capwiz.com/thearc to sign up.

Another unannounced speaker was White House Chief of Staff Jack Lew, who reiterated the President’s opposition to turning Medicaid into a block



grant. He also took questions from the audience, including Barbara Coppins, a member of the national board of directors of The Arc and a self-advocate who helps lead The Arc’s new National Council of Self Advocates. Barbara took the opportunity to speak about the importance of self-advocacy by people with disabilities.

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Matthew Grafton, self-advocate from Alabama: “I felt very shocked when I met the President – it was a thrill! After a tour of the East Wing of the White House, I attended a meeting about the budget cuts of Medicare and Medicaid. I was able to voice my opinion on the matter to senior White House staff.”

Achieve with us.

So, What does The Arc Do for My Family?

By Mohan Mehra, President of The Arc's National Board of Directors



I often hear- what does the national organization of The Arc do for my family? So, I thought it may be helpful to share with you a snapshot of what we accomplished in the past several months.

The Arc was successful in many public policy arenas, including preventing massive cuts in the federal Medicaid program during the 2011 Congressional budget battle.

Medicaid is the lifeline for people with I/DD and provides over 75% of the funding for all long term services and supports. Thanks to advocates like you and our federal public policy team in Washington, we implemented the "Don't Cut Our Lifeline" grassroots campaign to flood Congress with phone calls and emails, and brought a number of families to talk with senior White House officials during tense budget negotiations in July about the importance of Medicaid to their family. In the end, Medicaid was spared significant cuts, and our efforts were noticed at the highest level of our government, including President Obama (see cover story).

The Arc worked as part of a coalition to secure passage of the Combating Autism Reauthorization Act, which autho-

rizes \$695 million in funding for another three years for screening of Autism Spectrum Disorders and training for professionals in the field.

We played a key role in successfully advocating for additional federal resources for housing for people with I/DD – \$165 million for the Section 811 Supportive Housing program – for next year. It was one of the few federal housing programs that saw an increase in funding.

We are also well on our way to raising the public profile of The Arc as one of the nation's leading charities. In the last year, we successfully launched a dynamic new brand identity, and in less than a year, nearly half of our 700+ chapters have signed on – exceeding our expectations for this effort. We have public service announcements running in over 100 television markets and so far airing more than 22,000 times, and The Arc was featured in a *TIME Magazine* special section reaching 19 million readers. And validating this forward momentum, a number of independent organizations, such as GuideStar and the American Institute on Philanthropy, rated The Arc as one of the most effective, financially responsible national organizations serving people with disabilities.

You told us you wanted to build The Arc into an even stronger force, and that is the road we are on together. - Mehra

We completed the first major national survey of family members and caregivers regarding the needs of people with I/DD and their families, called FINDS, or Family and Individual Needs for Disability Supports. This has resulted in media coverage across the country, and our chapters are using the information in their advocacy efforts.

And, we continued to establish The Arc as a major resource for individuals with Autism Spectrum Disorders and their families by winning a \$2.6 million grant from the Administration on Developmental Disabilities, and launching Autism NOW: The National Autism Resource and Information Center, which you can find at www.autismnow.org. This innovative project provides resources and information on supports and services through the web, webinars, e-newsletters and social media. In 2011 alone, we reached over 1 million people through the activities of Autism NOW.

You told us you wanted to build The Arc into an even stronger force, and that is the road we are on together. As always, I welcome your comments. You can reach me at president@thearc.org. ■

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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.

Start Your Engines!

The Arc is embarking on an exciting new partnership with Istook's Motorsports that exposes people with I/DD to employment in the exciting world of professional race car driving.

You may be wondering – how did The Arc end up on the hood of a race car? In the fall of 2011, Don Istook and his wife Laurie were looking for ways to open the doors to people with I/DD to the race car industry. Two of Laurie's brothers, Mark and Tyson, who have Fragile X, have become an active part of Don's professional race car crew. Don and Laurie have been so thrilled with their involvement on the team that they want to expose more individuals with I/DD to the possibility of meaningful employment in the race car industry and beyond, and show the public that people with I/DD are capable of doing anything, including working on a professional race pit crew. With those goals in mind, the Istooks contacted The Arc's national office with this exciting idea to develop a program for chapters of The Arc to be a part of seven races across the country in 2012!

The newly created The Arc Audi Race Program a team of professional race car drivers competing in the Pirelli World Vision Challenge with the Sports Car Club of



Mark and Tyson (photo, left) and the Istook's Race Car

America – check out their schedule for a race near you at www.thearc.org.

Chapters of The Arc are provided 20 tickets to the race, along with the opportunity for individuals with I/DD to gain hands-on experience in the paddock area and potentially be a part of ceremonies at the race. This is an incredible opportunity for our chapters to be the face of The Arc in front of race car fans across the country and to promote employment opportunities for people with I/DD in a unique setting. To follow The Arc on this adventure, keep an eye on our blog, www.blog.thearc.org. ■

The Arc Partners for a New State Chapter in Montana

For the first time in a decade, The Arc will have a statewide presence in Montana – thanks to a new affiliation with AWARE, Inc.

Founded in 1976 as a non-profit corporation, AWARE delivers services for people with challenging mental health, emotional, and in some instances, physical disabilities, who otherwise would be served in a more restricted setting or perhaps would not be served at all.

With more than 900 employees in 26 communities across Montana, AWARE has been providing homes and training for adults with developmental disabilities and services for adults and children with mental illness for more than 30

years. Among AWARE's services are group home living, supported independent living, supported employment and center-based employment.

In becoming a state chapter, AWARE will be able to tap into the many resources The Arc's National Office can provide. Larry Noonan, CEO of AWARE has expressed his interest in expanding the policy work that is being done in Montana. Noonan and his team are already very active with Montana's Congressional delegation and in local politics throughout the state. The Arc will serve as an additional resource to them with support from our national office's

experienced federal public policy team, a number of publications, newsletters and alerts about disability policy, and important updates straight from Washington, DC.

"Our affiliation with The Arc gives us the opportunity to be involved with folks from all over the country who are dealing with the same issues and problems we deal with in Montana," said Noonan.

The Arc welcomes AWARE to our

family over of 700 chapters, and looks forward to serving Montana for years to come! ■



It's An Honor

Life's milestones are often marked with certain distinction – candles to blow out on a birthday cake, or the tossing of the cap at a graduation. But some choose to mark the occasion in a different way – with a tribute gift to an organization, like The Arc.

Meet Dr. Sheila Natbony, who first got involved with The Arc when she made a tribute gift several years ago to mark one of her daughters' college graduations. Sheila has two girls, and the graduating senior shared many of the same values of The Arc – she was passionate about respecting the rights of people with disabilities. This passion flowed from her love for her sister, who has Tourette Syndrome. So Sheila honored one daughter's rite of passage with a gift that honored the whole family.

Tribute gifts are a special way for someone who may or may not have a connection to The Arc's work or our movement to simply give back. It can be a one-time show of support, or an

ongoing relationship. Sheila continues to support The Arc, even recently asking that in lieu of gifts for her own birthday, that donations be sent to The Arc.

For Sheila, this way of supporting a charity like ours is personal. It demonstrates her beliefs – Sheila believes that people with I/DD deserve respect and to be included in the community. By asking others to donate on her birthday or by marking her child's graduation with a gift to The Arc, it pays a special tribute to whomever the gift is made in honor of. From Sheila's experience, it is much more meaningful and gives more satisfaction, no matter if you can donate \$1 or \$1 million, if you believe in the cause.

From The Arc, we can't say thank you enough, for allowing tribute gifts to help us continue our work. Every year, The Arc is fortunate that hundreds of people think to make gifts to us to remember someone special or to mark a

milestone in life. Birthdays of all ages, anniversaries, and graduations are used as an occasion to make a tribute gift through The Arc.

And it's easy! Go to The Arc's website (www.thearc.org/donate), to make your tribute contribution to The Arc's national organization. When completing all of the requisite donor information, you will also fill out the tribute gift section of the form, including the type – honor or memorial. When a gift is made, the donor receives an acknowledgement for tax purposes and the honoree or the family of the honoree being memorialized receives a special notification in the mail. This personalized message will let the recipient know that a gift to The Arc has been made in their honor.

So thank you Dr. Natbony, for making The Arc a personal part of your family's journey. And thanks to all of our readers who make this special gift too. ■

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"I tell other self-advocates – you've got to get out there and advocate for yourself because you can't rely on other people to make change for you," said Coppens to Chief of Staff Jack Lew.

The Arc heard from Cecilia Muñoz, Director of the White House Domestic Policy Council, who spoke of their commitment to providing services and supports to all in need. Other speakers included high-level representatives from the Federal Housing Administration, Centers for Medicare and Medicaid Services, the Office of Management and Budget, and the Department of Justice.

Tom Perez, Assistant Attorney General for Civil Rights, Department of Justice, discussed the recent federal settlement with the Commonwealth of Virginia regarding people with I/DD who live in any of its five institutions who could live in the community. He spoke about the bipartisan work going on across the country to implement the *Olmstead* decision, which states that under the Americans with Disabilities Act (ADA), unnecessarily institutionalizing a person

with a disability who, with proper support, is capable of and who wants to live in the community can amount to discrimination.

After a tour of the East Wing of the White House, advocates from The Arc took part in policy breakout sessions that allowed for more detailed discussions on certain issue areas, like community living, family caregiving, education, and Medicaid. The purpose of these briefings was to allow White House and administration officials to engage in a dialogue with leaders of The Arc about how government policies affect the lives of people with I/DD and impact their ability to live full, independent lives.

"This unique, face-to-face opportunity to speak directly to people in positions to make change from within the government allowed leaders of The Arc to make the voices of the millions of people with I/DD heard at the White House. Our network seized on this opportunity, and we left the White House feeling a sense of accomplishment and inspiration for continued advocacy that we will take back to our communities to help grow our movement," said Peter V. Berns, CEO of The Arc. ■

Empowering Self-Advocates Across the Country!

In March, The Arc officially launched the National Council of Self Advocates of The Arc (NCSA). The first national council of its kind, the NCSA will allow individuals with I/DD to join a network of leaders representing the full spectrum of ages and abilities across The Arc's national chapter network. While promoting the active involvement of individuals with I/DD in the work of The Arc, this Council will give self-advocates the chance to support each other and provide learning opportunities as they grow as advocates in their community.

The primary purpose of the Council is to empower persons with I/DD to voice their opinions about what is important to them and to ensure that they are afforded the same opportunities as everyone else to have a meaningful

life in the community. By joining the Council, members will be able to network with others who are involved in advocacy work, educate the public about the issues that are important to people with I/DD, and become active leaders in their communities. This Council will allow self-advocates to share their unique perspective and to truly make an impact in their communities.

The NCSA is co-convened by Barbara Coppens, Joe Meadours, and Kurt Rutzen, who are all members of The Arc's National Board of Directors. They each have a deep personal interest in this Council and are looking forward to creating a strong network of self-advocates across the country. Learn more at www.thearc.org/national-self-advocate-council. ■



"This is an opportunity for us to voice our opinions and show what self-advocates across the country care about."

*Joe Meadours, The Arc's
National Board of Directors*

We've Got the Power! Make Your Mark in 2012!

Election Day 2012—it's closer than you think! In this time of rapid change and challenges at all levels of government, the importance of action and engagement in the political process by people with I/DD, their families, and everyone who cares about our issues, has never been more important.

The Arc is pleased to provide resources for advocates and community partners for the upcoming 2012 elections. As people who care about the dignity, civil rights and access for people with I/DD at all levels of society, it is our role to promote civic responsibility and participation in our democracy. The Arc's "We've Got The Power!" campaign is meant to provide support to amplify the voice of people with disabilities as active participants in the political pro-



cess, and in their communities. Through partnerships with Nonprofit VOTE, a national, nonpartisan organization that partners with America's nonprofits to help the people they serve participate and vote, and SABE's Project VOTE, The Arc is offering access to webinars and other materials for advocates and members across the country. Information is available to assist advocates in:

1. **Voter Registration**—information on how to register in your state, as well as data on limitations for people with I/DD, is provided.
2. **Voter Education**—voters need to be up to date on the issues of importance in this election season. Information on what issues will impact people with I/DD and their families is included.

3. **Candidate Education**—candidates for elected office, at national, state and local levels, need to understand the importance of issues that impact people with I/DD and their families. The Arc is providing talking points and data for use when communicating with candidates.
4. **Voter Mobilization**—being registered and educated about the issues isn't enough—we have to get to the polls! Information on early voter, absentee voter, and polling place access will be provided.

The Arc encourages everyone to get involved this election season by going to www.thearc.org for ongoing information and support. It's time to Make Our Mark in 2012!

For more information, contact Dee Dee Eberle, Director of Chapter Organizing & Advocacy at eberle@thearc.org or 202-534-3700. ■

The Arc Connects with the Global Community

Every year, The Arc hosts a National Convention for the intellectual and developmental disability community which is widely attended by people from across the country. This year, however, we're expanding our audience by partnering with Inclusion International, a global federation of family-based organizations advocating for the human rights of people with intellectual and developmental disabilities, to bring a National Convention and International Forum to Washington, D.C. this October.

Together, we'll explore the implications of Article 19 of the Convention on the Rights of Persons with Disabilities: Living independently and being included in the community. Inclusion International is involved in an extensive campaign to promote Article 19, which will culminate at this event with the release of a Global Report. Also, we'll focus on national issues related to advocacy, employment, and public policy, all with an international flair.

Make plans now to join us for this unique four-day event filled with informative and inspiring sessions from experts in the field, fun social events, networking opportunities and The Arc's annual business meeting. And take advantage of



the opportunity to gain an international perspective on living and being included in the community. The National Convention and International Forum, "Achieving Inclusion Across the Globe," will be held at the Grand Hyatt in downtown Washington, D.C. October 25-28. Find out more and register now to attend at www.thearc.org. ■

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Autism on the Rise – CDC Releases New Data

The prevalence of Autism Spectrum Disorders (ASDs) is rising, according to new data released by the Centers for Disease Control and Prevention (CDC) in March. The CDC is reporting that one in 88 children has autism or a related disorder, a 23% increase since the last report in 2009 and a 78% increase since the first report in 2007.

"The data signal an impending crisis in America's safety net system for people with autism and related disorders. We may be facing a 'perfect storm' as the rapid rise in the prevalence of autism comes at the very same time the federal government is proposing to cut hundreds of billions of dollars from the Medicaid program – the single largest funding source of services and support for autism – while slashing funding for public health programs," said Peter V. Berns, CEO of The Arc.

ASDs are a group of developmental disabilities that are often diagnosed in early childhood and can cause significant social, communication, and behavioral challenges over a lifetime. There are three subtypes of ASDs: autistic disorder, Asperger disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). Chapters of The Arc serve

people with autism and their families across the country, supporting their efforts to live and succeed in the community.

According to the CDC, medical costs for children with ASDs are estimated to be six times higher than for children without ASDs. In addition to medical costs, intensive behavioral interventions for children with ASDs can cost \$40,000 to \$60,000 per child per year.

Early identification and intervention can have a significant impact on a child's ability to learn new skills. CDC's "Learn the Signs. Act Early." health education campaign promotes awareness among parents, health professionals, and child care providers about healthy developmental milestones, the importance of tracking each child's development, and acting early if there are concerns. CDC offers free online resources, including checklists of developmental milestones, at www.cdc.gov/ActEarly.

Autism NOW: The National Autism Resource and Information Center, a federally funded project of The Arc, is another resource for people with ASDs and their families. The online center aims to help people searching the web separate fact from fiction when it comes to autism. Learn more at www.autismnow.org. ■



In Our Nation's Capital, "Navigating the Future"

What's next for people with I/DD when the school bus stops? That's an exciting and daunting question for many families served by chapters of The Arc. Guided by The Arc's core belief that individuals with I/DD have the right to be part of the community and live as independently as possible, The Arc is helping to guide this transition across the country so that people with I/DD can take advantage of post-secondary education, employment opportunities, and community living while supporting families as they deal with uncertainty, face fears, and overcome bias.

In July of 2009, The Arc received a \$3 million grant from the Walmart Foundation to support efforts to improve outcomes for youth through innovative best practices in transition services nationwide. Since then, The Arc has been working in conjunction with employers in communities across the country to improve transition outcomes for these individuals. And through state and local chapters, The Arc is promoting employment programs, post-secondary education opportunities, and independent community living. Through the grant as well as additional funding, The Arc has developed this initiative to include 49 chapters from across the country.

One shining example of the success of this program comes from The Arc of the District of Columbia (The Arc of DC). Their project "Beyond High School: Navigating the Future," took off in a big way during 2011. The project aims to increase transition outcomes for students with I/DD and autism through training and support in the District of Columbia Public Schools (DCPS).

The Arc of DC implemented a one year training model for 34 youth and families that included benefits training, transition planning, referrals for post-secondary education, connections to government agencies, and family support meetings to guide students

and family beyond high school. During the 2010-2011 school year, The Arc of DC convened a Community Advisory group to guide and direct the mission of this project. In addition, they created a Family Guide to Transition Services and a Student Transition Planning Book that is being used throughout the city.

Due to the great success of this project and the need for transition services, DCPS contracted with The Arc of

DC to expand the project to continue their efforts into the 2011-2012 school year. The Arc of DC is now working with more than 100 students in 8 schools throughout the Washington area. This project has blossomed into an opportunity beyond The Arc of DC's initial expectations, proving once again that The Arc is on the cutting edge of providing a service to fulfill the needs of families and individuals with I/DD at this crucial point in life's journey. ■



Beyond High School: Navigating the Future's Class of 2011-2012

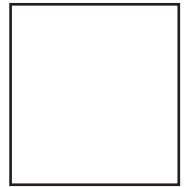
Ashley Lucas loves music – her dream is to one day become a music producer and she is working towards making that dream a reality. Ashley is one of the many students who completed an eight week transition planning program at The Arc of DC.

Her participation in The Arc of DC's transition program, "Beyond High School: Navigating the Future," has been incredibly positive. Ashley is currently a senior at Mamie D. Lee School and is already preparing for her future. Through the program, Ashley has created a resume, completed a Transition-to-Work Inventory, participated in mock interviews, and completed applications for employment – all important steps to making her dreams come true. She is now enrolled with the District of Columbia Rehabilitation Services Administration which provides services and supports for individuals who want to further their career path or pursue college options. ■



For people with intellectual
and developmental disabilities

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Let's Us Take That Clunker Off Your Hands

Donate a used vehicle to The Arc's Car Donation Program today and give someone with intellectual and developmental disabilities the key to their independence. Proceeds benefit your local chapter of The Arc. Just call toll free 1-877-ARC-CAR0 or donate online at www.thearc.org/donate-my-vehicle. We'll take care of everything, including towing and the paperwork you'll need to take advantage of your tax break. ■



Meeting High Standards!



The BBB Wise Giving Alliance National Charity Seal carries a lot of meaning for both donors and charities. It is a clear and concise sign that the charity meets the Alliance's Standards for Charity Accountability. Before national charities can even apply to use the seal, they must undergo evaluation by the BBB Wise Giving Alliance, the nation's most experienced charity evaluator. We are proud to meet their standards!

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!