



empower

Real People, Real Progress

Issue 13 | Winter 2013



The Arc's CEO Peter Berns greets President Barack Obama at a meeting at the White House regarding the budget in November. (Official White House Photo by Pete Souza)

Partial Fiscal Cliff Deal Enacted

Paves the Way for Another Showdown

After weeks of tense negotiations, both the Senate and House ended 2012 and ushered in 2013 by passing a measure to address the series of harmful tax increases and spending cuts that had been set to take effect January 1, known as the "fiscal cliff." Most of the tax cuts that had been scheduled to take effect have now been permanently extended, while the automatic spending cuts (originally \$1.2 trillion over 10 years) for discretionary programs have been slightly reduced and put off for a two month period.

The measure represents a partial victory for both the Obama Administration and House Republicans who have been at odds over tax increases and spending cuts to entitlement programs in order to reduce federal deficits. The law will bring in only about \$750 billion in new tax revenue over the next decade, rather than the \$1.6 trillion sought by The Obama Administration. Meanwhile, House Republicans succeeded in raising the threshold on household incomes to \$450,000 that

showdown continued on page 3

"Bob, Would You Like the Chance to Meet with Vice President Biden?"

By Bob Hage, parent and advocate with The Arc

December 1, 2012 — it was a typical Saturday for our family — I was shuttling our 13-year-old son Vann from a hockey game, while my wife Odette Adrian was home with our girls, Annika and Maya. My cell phone rang, and it was Marty Ford with The Arc's national office. What she said was anything but typical...

"Bob, would you like the chance to meet with Vice President Biden?"

biden continued on page 5



Vice President Joe Biden has lunch with Americans to discuss the importance of middle class tax cuts, at Metro 29 diner in Arlington, Virginia, Dec. 7, 2012. (Official White House Photo by David Lienemann)

Achieve with us.

We Are All The Arc!

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



Welcome to 2013! I'm thrilled to be writing as your new national president of The Arc! This is an exciting time to be leading our organization. As you can see in this edition of *Empower*, The Arc is being seen as the go-to resource for information about the needs, issues and concerns of people with disabilities and their families at the highest level of our government in these critical times. Because our families, chapter leaders and advocates (like you) have been contacting their Members of Congress and the White House to tell the real stories of how our families live and depend on Medicaid, Social Security and other programs, we are the source for information. You are

helping our public policy team, and The Arc as a whole, with your contacts and your stories — we need you to continue to provide us with stories, anecdotes, issues, and solutions! Parents, siblings and people with intellectual and developmental disabilities (I/DD) themselves are the most effective in explaining about critical supports — we make all the difference!

As a sibling, my sister, Martha, and I depend on Medicaid and Social Security to enable her to live and work in the community of her choice, which is in a different state from mine; to live in a wonderful apartment with her friends, and to participate in the many activities they choose to do. I remember learning of The Arc as a child, when my parents and four other parents traveled to New York to hire a teacher for the new school they were starting. I am so proud that today The Arc is known as the organization that truly represents families just like ours. And as more and more of our chapters sign on to The Arc's new brand, the strength of our more than 700 chapters will be increasingly evident. We will become universally recognized.

This year we will continue to grow our initiatives: School-to-Community Transition, eXplore eRecycling, HealthMeet™, the National Council of Self-Advocates, and the National Siblings Council. We have launched The Arc & Sprout National Film Festival for implementation by our chapters, and we are making progress with our online communication and social media channels — have you seen our thriving blog: <http://blog.thearc.org/>? Are you friends with us on Facebook (www.facebook.com/thearcus)? Do you follow us on Twitter (@TheArcUs)?

New this year, our Board of Directors will be reaching out to our members to learn about diversity — and to learn how we can diversify The Arc at the national level and throughout our network. If you have thoughts about diversity, or experiences or ideas, please share them. I'd like to hear from you: president@thearc.org.

I am excited about our growth and strength.

I am proud of our chapters and the many and different ways they provide supports and services to people with I/DD and their families.

I am energized by our advocates who reach out to tell their stories to educate people everywhere.

We are all The Arc — and we are working together to build us even stronger. ■

empower

is published quarterly by The Arc located at 1825 K Street, Suite 1200, Washington, D.C. 20006.

BOARD OF DIRECTORS:

November 2012-2013

The following Board members were voted in at The Arc's 2012 Annual Convention this past October.

Officers:

Nancy Webster, President
Indian Head Park, IL

Ronald Brown, Vice President
Dallas, TX

Elise McMillan, Secretary
Nashville, TN

M.J. Bartelmay, Jr., Treasurer
Hermitage, PA

Mohan Mehra, Immediate Past President
Cortlandt Manor, NY

Directors:

Tony Anderson (NCE Rep.),
Sacramento, CA

Doug Church, Oak Hill, VA

Gary Bass, Washington, DC

Barbara Coppens, Cherry Hill, NJ

Hugh M. Evans, III, Baltimore, MD

Pat Napoliello, San Francisco, CA

Gary Horner (NCE Rep.), Pittsburgh, PA

Randy Patrick, Aurora, CO

Thomas A. Judd, Minneapolis, MN

Kelly Piacenti, Chester, NJ

Michael Mack, Silver Spring, MD

Michele Poole, Lake Worth, FL

Joe Meadours, Citrus Heights, CA

Philip Richards, Birmingham, AL

Frederick Misilo, Jr., Holden, MA

Kurt Rutzen, Minneapolis, MN

Directors-At-Large:

Margaret Lee Thompson, Redmond, WA
Carol Wheeler, Washington, DC

Pro Bono Counsel:

Stacy Taylor, San Diego, CA

Editor:

Kristen McKiernan,
Communications Director, The Arc

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.

Chapters of The Arc Coming Together in the Aftermath of Hurricane Sandy

Claiming more than 100 lives, leaving millions without power, and destroying hundreds of thousands of homes, Hurricane Sandy will not soon be forgotten. The total cost of damages in New York and New Jersey alone will likely total more than \$50 billion. Many chapters of The Arc are still coping with the aftermath of this treacherous storm.

While tragic stories filled media reports, inspiring tales of communities coming together seemed to be overlooked. The Arc's network includes more than 700 chapters in 49 states across the country, with more than 70 in the hard-hit states of New York and New Jersey. As the storm approached, these chapters were not alone; they had their chapter network to lean on.

Inspiration in New Jersey

In New Jersey, chapter staff was rushing home from The Arc's National Convention in Washington, D.C. to prep for the storm. After previous storms, chapters had plans for disaster situations and specialized training programs on emergency preparedness had taken place. While chapters were concerned about all the individuals and families they support, a priority for many was to educate individuals with I/DD living in the community about what to do and who to contact in an emergency.

The selflessness and dedication of the direct care support professionals throughout the state was truly inspiring. They went above and beyond what was expected. One employment support worker lost her home during the hurricane. Despite her loss, her priority remained locating the young man with I/DD she worked with in an evacuation shelter, and making sure he would be able to go back to work once the business he worked in was reopened. Not once did she mention her own loss; her main concern was making sure that one young man didn't get lost in the system. Her work paid off and she was able to move him into temporary housing with friends and even contacted his employer to make sure his job was secure. These

stories of compassion and generosity are plentiful in The Arc's community.

Resilience in New York

In New York, there were similar stories of resilience. Some of the most compelling stories come from NYSARC, Inc., the New York State Chapter of The Arc. Their New York City chapter, AHRC New York City (NYC), knew the key to survival was preparation. Learning from previous experiences and storms, they knew what had to be done to ensure that they could continue serving their communities even if they ended up bearing the brunt of the storm.

Despite the amazing preparation throughout New York, the aftermath of the storm did pose problems. Accounting for all individuals they supported in many urban areas proved difficult, but chapter staff used all available resources to account for everyone. In spite of severe flooding and power outages in the Wall Street area (where



Located in the South Street Seaport section of Manhattan's Financial District, one building as it appeared on the day following Sandy, and two weeks following the storm.

AHRC NYC's main office is located), staff was in the office immediately after the storm sweeping water out so that they could get back to work.

The sense of community was powerful, and AHRC NYC truly exemplified it in the aftermath of the storm. They shared their limited resources, including gas, with other chapters to make sure the work of The Arc could continue.

We at the national office commend The Arc of New Jersey, NYSARC, Inc., and all chapters that were affected by this storm for their amazing work and dedication. Contributions for disaster relief, which is shared directly with affected chapters, are still being collected by The Arc's national office. ■

showdown

continued from page 1

will see a tax increase rather than the \$250,000 that the Obama Administration wanted.

While the newly passed legislation does not include any cuts in benefits for the entitlement programs, (Medicaid, Medicare, and Social Security), this issue is expected to take center stage in the coming weeks as it becomes a bargaining chip in the upcoming debt ceiling negotiations. In the first three months of 2013, additional legislation will be necessary to address other aspects of the nation's fiscal situation, including an increase in the debt ceiling, the end of the 2-month extension of the sequester (automatic cuts), and federal funding for the remainder of Fiscal Year 2013. These deadlines will

set the stage for additional negotiations between the Congress and the White House. There will be mounting pressure to generate additional revenue and to cut Social Security, Medicaid, and Medicare, as well as the discretionary programs (such as housing, education, employment) that people with intellectual and developmental disabilities rely on to live in the community. The Arc will remain actively involved in seeking a balanced approach to deficit reduction by advocating for increased revenue and protecting critical spending programs for our constituents.

Get involved by signing up for our action list at <http://capwiz.com/thearc/mlm/signup/>. ■

Hopes and Dreams

Sharing their hopes and dreams for the future — that is what several individuals with I/DD did with The Arc and www.selfadvocacyonline.org, a project of the Research and Training Center on Community Living at The University of Minnesota. Below are just a few of the goals toward which the self-advocates we spoke with are striving.

It is The Arc's mission to help these individuals achieve their goals. We do that directly through the services provided by our national network of over 700 chapters and through our national initiatives projects such as eXplore eRecycling, HealthMeet™, and Autism NOW. And we work indirectly, advocating for the full inclusion of over 8 million people with I/DD and their families in society and making sure the appropriate supports are in place to allow that to

happen. But we can't do any of those things without your support!

Please make your gift to The Arc today and help real people with I/DD like Quincy, Wendy, Jill and David turn their dreams into reality through a donation to The Arc using the attached envelope or online at www.thearc.org. *Achieve with us!*

If you have questions about The Arc and our national efforts, contact Trudy Jacobson, Chief Development & Marketing Officer, jacobson@thearc.org or 202-534-3714. ■



Quincy:
"To settle down and have a wife and children"

Wendy: *"Honestly, what I'd really love to do right now is to be a full time self-advocate and work on these issues (related to I/DD)...organize other self-advocates. I love politics. To do stuff with grassroots organizing, I think that would be the most fun job in the world."*



David: *"My dreams and goals are to go as far as I can. My goal is to be around, maybe not always be a leader, but ensure that things happen for people with intellectual disabilities. I suppose ensuring that people with intellectual disabilities are treated the same as other people. Ideally I'd love to see them have more power."*



Jill: *"My dreams are to think big and to say that people with I/DD have a lot to offer."*

Join Us at the 2013 Disability Policy Seminar

Does what happens in Washington, D.C. really matter? Can you make a difference? You bet! As negotiations on entitlements and budget cuts potentially affect millions of Americans with intellectual and developmental disabilities, we need you to reach out to your representatives in Congress to tell them how these decisions — big and small — impact you.

Each year, hundreds of advocates from across the country attend the Disability Policy Seminar in Washington, D.C. to learn more about and discuss the hottest topics in disability public policy. We invite you to join us April 15-17 for an opportunity to advance the grassroots movement for people with I/DD and make sure your elected officials know

what's important to you.

Register now and book your room at the Grand Hyatt in downtown Washington D.C. for a special early registration rate at www.disabilitypolicyseminar.org and find out more details about the stimulating program on tap for this year's event. But act soon — special rates on rooms ends March 12. ■



Hosted by: The Arc, AAIDD, AUCD, NACDD, SAGE and UCP

Promotional Sponsorship by: Autism Society and the National Association of the Dually Diagnosed

biden continued from page 1

Our Family and the “Fiscal Cliff”

Marty had the opportunity to suggest a few names of people whose families included people with intellectual and developmental disabilities to meet with Vice President Biden about the potential impact of taxes going up in January. I'm sure you were seeing all over the news the dramatic “fiscal cliff” countdown to 2013, as leaders in Congress negotiated with the Administration on whether or not to extend tax cuts for the middle class. If they hadn't extended the cuts for the middle class, then families like mine could have seen a \$2,000 or more tax increase in 2013. And that could have had terrible consequences on our family's ability to pay for disability-related expenses.

My beautiful 9-year-old twin daughters, Annika and Maya, are the light of my life. Both my girls have severe developmental disabilities and are non-verbal and medically fragile. We've been involved with The Arc since Annika and Maya were very young — The Arc of New Jersey has given us a place to go with questions and has served as a vital link to other families like ours and resources and information that we couldn't do without.

So Marty's question had barely sunk in before I was calling Odette and we were drafting our family's biography to submit to the White House. While we have been involved with The Arc nationally, as stars of their re-branding public service an-

nouncement campaign in 2011, we had never had this kind of chance to advocate on behalf of Annika and Maya and millions of families like ours ever before. This was huge, and while Marty warned that many other organizations were responding to the White House's request and we may not be chosen, I had a feeling that this was our chance to make a big impact.

Fast forward five days, and I was on a train to Washington, D.C. for a meeting with Vice President Biden. I huddled with the staff of The Arc's national office, who gave me top-secret information about where I was to join the Vice President and the other meeting attendees. We had all assumed it would be at the White House — but it turned out that I was having lunch at a diner in Arlington, Virginia. Security is always top of mind when the Vice President is involved, so I couldn't even tell Odette where I was going!

The Big Meeting

The next day, I joined six other Americans for a candid, in-depth discussion with Vice President Biden. It's an experience I will never forget. I had brought along a photo of Vann, Annika, and Maya, and I shared it with the Vice President. He immediately smiled, as any proud father would, and connected with our family's story. Annika and Maya have defied so many expectations, and I'm immensely proud of my girls.

I shared with him that Annika and Maya go to speech therapy, which has been instrumental in moving them from being totally dependent on liquid tube feedings to eating all their nutrition from pureed foods. Currently, speech therapy's primary goal is to help Annika and Maya learn to chew so they can eat solid food.

Both girls participate in weekly music and gymnastics classes for children with special needs. While music and gymnastics is recreational for most children, it is vitally important to Annika and Maya's development. The music class focuses on building finger strength and coordination through piano and helps the girls to vocalize through singing. The gymnastics class concentrates on building muscular strength and endurance which is especially important for children with low muscular tone.

But if we were to face a tax increase in the thousands of dollars, some of their therapies and classes that help them develop could be cut from our family's budget.

Not only did Vice President Biden listen, he clearly understands the challenges families like mine face, and I walked away trusting that he would do everything he could to protect my daughters' future.

Please join me in being a strong advocate on behalf of The Arc – join The Arc's action community today at <http://capwiz.com/thearc/mlm/signup/> ■

The Arc Audi Race Team Rolls Again!

In 2013, The Arc is continuing the success of The Arc Audi Race Team by expanding to nine races covering six states and Toronto, Canada; and this year there will be two cars at each race. We're working closely with Istook's Motorsports to bring 20 individuals with I/DD, caregivers and staff from Chapters of The Arc to Pirelli World Challenge Series races to serve as "honorary crew members" for a day with the Istook's team. Istook's Motorsports employs crew members with I/DD and is working with us to raise awareness of I/DD among race fans across the country. Last year's program was a big success, with our honorary crew members participating in the experience of a lifetime in the paddock area, meeting drivers, learning about what goes on behind the scenes and then cheering on Don Istook's Audi TTRS car as he competed in each race. Watch for news and photos from the races on The Arc's blog and social media channels starting in March and find out more about the program under "Events" on www.thearc.org. ■

Schedule of Races

March 22	Streets of St. Petersburg	St. Petersburg, FL
April 19	Toyota Grand Prix	Long Beach, CA
May 17	Circuit of The Americas	Austin, TX
May 31	Detroit Belle Isle Grand Prix	Detroit, MI
July 4	Lime Rock Park	Lakeville, CT
July 12	Streets of Toronto	Toronto, Canada
August 2	Mid-Ohio Sports Car Course	Lexington, OH
August 23	Sonoma Grand Prix	Sonoma, CA
October 4	Houston Grand Prix	Houston, TX

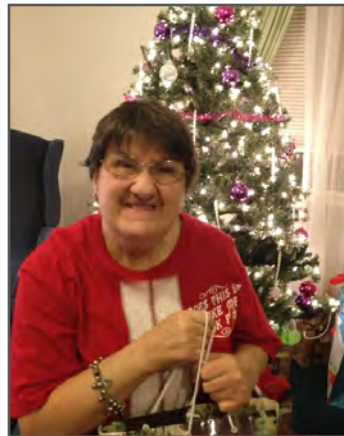
The Arc of Macon

Helping People Pursue their Dreams of Independence

Thanks to the work of The Arc's chapter in Macon, Georgia, some individuals in that community are now able to move from segregated institutions to group homes funded through new housing and urban development grants.

Across the nation, our chapters work to ensure that individuals with I/DD are given the opportunity to decide how and where they live within their communities.

The Arc has long believed that individuals with I/DD should be empowered to live in accessible and affordable housing similar to those without disabilities. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with I/DD, regardless of type or severity of disability. For this reason, The Arc supports the



Lillian stops to smile in front of the Christmas tree just after she received gifts from Santa's surprise visit to her home. The gifts were donated by Community Health Works.

move away from restrictive institutional settings to community supports.

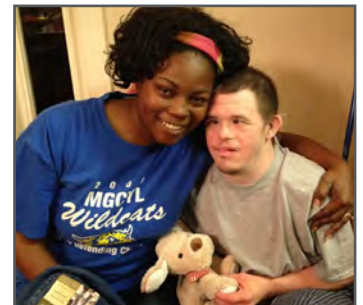
Late last year, The Arc of Macon opened two new houses. Each home houses four people with I/DD along with a staff person. The opening of these homes

came after two and half years of hard work and was made possible through a U.S. Department of Housing and Urban Development (HUD) Section 811 grant. Macon's John and Jan Saikas Builders, Inc. managed the projects that include complete accessibility for people with disabilities — from countertop height to bathrooms with state-of-the-art fire and evacuation design.

"The Arc of Macon is committed to helping people pursue their hopes and dreams which include for some the opportunity to live in a home of their own in the community. It is exciting to see these homes develop from the planning stage until they are fully operational and occupied. These homes will leave a lasting mark on the community and the people who live in them for years

to come," said Andy Harrell, Chief Administration Officer for The Arc of Macon.

The Arc of Macon owns nine other homes funded by HUD where people with disabilities reside. These homes provide an opportunity for people with disabilities to live a more integrated life in the community. The Arc of Macon has provided services to people with disabilities since 1953. ■



Brandi Mitchell and Monte share plenty of hugs in the home made possible by a federal housing grant.

Empower Yourself and Raise Awareness

This March, during Developmental Disabilities Awareness Month, The Arc would like to empower all individuals with I/DD to appoint themselves as their own advocates. Becoming a self-advocate simply means protecting one's own self-interests - demanding respect, reaching out for the services and supports needed to fully participate and making others aware of what it means to be a person with I/DD.

It is The Arc's mission to promote and protect the rights of people with I/DD to live, learn, work and play as valued and contributing members of their communities, but the real power of our message comes straight from the individuals we serve.

In the movement for people with I/DD, individuals with disabilities are really their own best advocates. No one can truly claim to speak for them

or can ever express the complexity of their thoughts and feelings. During March, The Arc will work to raise awareness about issues important to the I/DD community. We hope you will help amplify our messages by sharing with those around you. It can start with a simple question. Ask everyone you meet: **"Did you know that March is Developmental Disabilities Awareness Month?"** That may spark a conversation, a teachable moment, when you can share your experience living with a disability with someone else. Be sure to join The Arc on Facebook (facebook.com/thearcus), visit our Website and blog (www.thearc.org) and learn more about what we're doing during Developmental Disabilities Awareness Month then go out and spread the word! ■



Tyler Smothers, advocate from Cedar Rapids, Iowa, speaks at The Arc's 2012 national convention.

Introducing the Autism NOW Answer Series

The staff of Autism NOW takes pride in their ongoing engagement with the public. This interaction has guided updates to their website and helped staff better understand what people are looking for. Now, they have a whole new way for you to connect with experts and get answers to your most pressing questions about autism and other developmental disabilities.

Late last year, Autism NOW launched the "Autism NOW Answers Series!" an exciting new initiative to involve the public. Through the "Autism NOW Answer Series!" individuals can submit their own questions through an online form and get answers directly from one of Autism NOW's experts. Each month two questions are answered in a video posted on Autism NOW's YouTube page. It's that simple — ask a question and get an answer.

If you have a question that you would like to submit visit The Autism NOW



Amy Goodman, the co-director of the Autism NOW Resource and Information Center will be answering questions in the series. She is an individual on the autism spectrum, discovering she had Asperger's syndrome when she was in her 30s.

She earned her undergraduate degree from Regents College and her Master's degree from Marshall University in Special Education with a focus in autism. While working on her Master's degree, she participated in a program for students with Asperger's syndrome at the Autism Training Center at Marshall University.

website: <http://autismnow.org/ask/>. Here are a few guidelines to a good question:

- **Be specific.** Questions on broad topics may be too difficult to find a focus and suitable answer.
- **Stay on topic.** We deal with autism and other developmental disabilities

and are best suited to answer questions relating to the topics on our site.

- **Keep it concise.** Long or multiple questions may be hard to cover in our two to four minute video answers. ■



For people with intellectual
and developmental disabilities

1825 K Street, NW, Suite 1200
Washington, D.C. 20006

www.thearc.org

Achieve with us.

empower

Real People,
Real Progress

inside:

Fiscal Cliff Deal Enacted

*Would You Like the
Chance to Meet with
Vice President Biden?*

We Are All The Arc!

*Coming Together in the
Aftermath of Hurricane
Sandy*

Hopes and Dreams

*The 2013 Disability
Policy Seminar*

*The Arc Audi Race
Team Rolls Again!*

*Helping People Pursue
their Dreams*

*Empower Yourself and
Raise Awareness*

*Autism NOW Answer
Series*

Save the date!

The Arc's 2013 National Convention, "Achieving
Momentum," August 2-5 in Bellevue, Washington!



**Look for *Apostrophe*
Magazine in Barnes and
Noble Booksellers**

This publication is written for, about and by people with intellectual and developmental disabilities and often features articles and information about The Arc. As of January, 2013, it will be available in Barnes and Noble Booksellers. Visit www.apostrophemagazine.com for more information or to start a subscription. ■



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! ■