



# empower

Real People, Real Progress

Issue 15 | Summer 2013

## HealthMeet<sup>®</sup> in Action – Changing Lives in Five States

By Ann Cameron Williams, Ph.D., Senior Executive Officer, Research and Innovations and Karen Wolf-Branigin, Senior Executive Officer, National Initiatives

Many of us at The Arc at local, state, and national levels get up and go to work every morning to make a positive difference for people with intellectual and developmental disabilities (I/DD). It's not only what we do, it's who we are.

When we have the opportunity to visit local and state Chapters, we are usually stunned by the creativity and sheer genius that is activated on behalf of people in need of a better solution. In May, The Arc of the United States invited five Chapters from five states that are engaged in our *HealthMeet: Promoting Health for People with Intellectual Disabilities* project that is funded by the Centers for Disease Control and Prevention (CDC), to share their approaches to improving health in their communities. As we listened, once again, we found ourselves marveling at the depth of understanding and quality of response that our Chapters deliver.



The Arc San Francisco in the news for HealthMeet (left) and The Arc North Carolina at a screening event.



For example, The Arc of Massachusetts is working in collaboration with the health providers from the Boston Medical Center, the Developmental Disabilities Nurses Association, and Simmons College to conduct health assessments. They translated a promotional HealthMeet flyer into Portuguese and engaged in specific outreach efforts in Boston's Portuguese community. In addition, The Arc of Massachusetts is coordinating a four-week Health and Nutrition program for people with I/DD.

In Pennsylvania, ACHIEVA, The Arc of Greater Pittsburgh, recruited physicians, medical residents and students, nurses, retired nurses, nursing students, paramedics, physical therapists and speech/language pathologists to conduct health assessments at ACHIEVA programs, community recreation events, and community health fairs. They even have a partnership with a local fitness business, Eruption Athletics, which sends fitness experts to screenings to get participants moving and teach them about the importance of exercise. At one screening, a sibling of a person with I/DD who had been concerned about her sister's weight and overall health was thrilled to make the connection with Eruption Athletics so that her sister could get some tips on how to take charge of her health and wellness through exercise. And

**HealthMeet is...** yoga, healthy eating tips, blood pressure checks, webinars, in your home, with your friends, recipes, BMI checks, gardening lessons, dental health giveaways, plus at your chapter too ...**on the move!**



**Achieve with us.**

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# Journeys to Chapters Are My Inspiration

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



Nancy Webster

Since being elected President of The Arc's national board of directors, I have had the privilege of meeting and visiting with many of you as I have traveled around the country. At big and small chapters, in tiny communities and large cities, I have been intrigued by the delightful personality of each. Since November, I have visited nine different states, sometimes twice. I hope you are as impressed by our energetic, powerful network as I am. Let me give you just a few examples of the programs I have been able to experience in my travels:

- Successful School-to-Community Transition projects - in Oregon, I attended a triumphant luncheon where the students confidently demonstrated the strengths they have learned that they will bring to an employer.
- Exciting technological enhancements at The Arc of Delaware County in Pennsylvania impressed me by how extensive and personalized they are for each individual, enabling and growing communication and outreach, encouraging artistic and musical participation, exploration and composition. I loved how proud these individuals were to "use an iPad just like everyone else" – they are as hooked on this cutting edge technology as I am!
- Siblings shared and taught each other (and me) in Nashville, Tennessee. As a sibling myself, I was honored to be a part of their conference, connecting on issues we grapple with and celebrating this special relationship.

- At Easter Seals Arc of Northeast Indiana, Inc. in Fort Wayne, Indiana, I enjoyed a gala celebration for all those who shine.
- In Austin, Texas, I joined self-advocates from The Arc of the Capital Area as they learned about car racing and talked with "real" race car driver, the wonderful Don Istook and his wife, Laurie, who are the heart of The Arc Audi Racing Program.
- Our chapters are the best at finding long-term employment solutions for people with I/DD, as I witnessed at the Staten Island Ferry Terminal.
- At the Leadership Conference in Illinois, I learned of the tremendous efforts that have brought about successful closure (finally) to institutions.

Everywhere I go, our chapters are simply fantastic! As I visit our chapters and see our brand proudly being used in many ways, I know we are telling the world "we are commitment, excellence and innovation for people with I/DD." At The Arc of Oregon's Leadership Conference and Annual Meeting, because every chapter in the state has adopted the brand, it is evident through all of the materials and each of the presentations that each organization adheres to the same standards of excellence; you know when you see our logo that you can count on The Arc.

As always, I enjoyed the opportunity to join many of you during our national convention. I look forward to hearing from you because what is clearer and clearer with each chapter I visit and each family or individual whose life is touched by The Arc, that it's you that inspires me and families across the country! ■

## 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.

## HealthMeet

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ACHIEVA created and produced an e-newsletter, *Your Health Matters*, with articles on policy, applied research, services, and training related to HealthMeet events and health and I/DD.

The Arc of North Carolina is building the HealthMeet program within their local chapters with eight sites across the state. Their goals are to work in both rural and urban areas, serving as a catalyst to build and strengthen partnerships, bringing value to the membership and letting chapters shine. The Arc of North Carolina's Wilmington Office's first screening went "viral" as people with I/DD unexpectedly spread the word on the spot via texting and social media, encouraging their friends to stop by. The result was one third of the screenings were people who just walked in without an appointment. In fact, one individual was connected to multiple services through HealthMeet. He was able to get a referral to vocational rehabilitation and get important information about the local managed care organization. Additionally, a nurse supervisor assisted him in

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# The Arc of Indiana – One Idea Turns Into a “Teaching Hotel” for Career Development

Jobs are hard to come by, and sadly even harder for individuals with I/DD in many cases. While members of The Arc know that individuals with disabilities deserve to work in integrated work settings and earn competitive wages, the harsh reality is only about 20.7% of people with disabilities are employed.

The Arc of Indiana has worked for years to promote equality for individuals with I/DD, and now they are taking it one step further by proactively creating employment opportunities for individuals in their state. In 2012, The Arc Development Group, LLC (ADG) was established by The Arc of Indiana after Jeff Huffman, a parent and member of The Arc of Indiana, came up with a creative, proactive idea to train and employ people with I/DD in the hotel business. The purpose of the LLC is to invest time and resources in business ventures that provide employment opportunities for I/DD.

Earlier this year, ADG received a \$5 million grant from the State of Indiana to be used for the construction of a hospitality training institute and hotel in Muncie, Indiana. They also received a grant from the Ball Brothers Foundation in Muncie to be used for startup expenses. This venture will provide the first statewide hospitality training institute where individuals with I/DD will receive training in the hospitality industry. In addition to serving as a training facility, the hotel will be staffed by individuals with and without disabilities full time. This will provide an integrated work setting where individuals with disabilities will be earning competitive salaries, benefits, and participating in a retirement program.

The hotel will offer a series of training programs for individuals to choose from, including departments like concierge services and catering. At the



Jeff, Jan and Nash Huffman are very committed to the mission of The Arc. While driving through Muncie, Jeff began to think about his son and the lack of post-secondary options in Indiana. Through his creativity and innovative thinking, the idea for the hospitality training institute was born.

end of the training program, participants will receive a certificate that they can take back to their community to seek employment. They will also be encouraged to return and seek additional training after working for a few years to help move up in their careers and to explore other post-secondary options.

To complement the hotel and promote independence, this project will also include multiple entrepreneurial ventures within the hotel that are owned by people with disabilities.

These could include a flower shop, news stand, shoe shine stand and other related ventures.

In addition to the benefits for individuals with I/DD, ADG also offers training to human resource professionals on topics like the benefits of hiring individuals with I/DD and how to easily make accommodations for employees with disabilities.

The “Teaching Hotel” concept will create a modern economic development project that demonstrates the strength of private and public investments. Additionally, it will provide a positive economic impact for the City of Muncie through additional convention business for the Horizon Convention Center and property taxes to the city.

Local government officials including the Mayor of Muncie, Dennis Tyler, are excited about this proposal. Mayor Tyler began his relationship with The Arc of Indiana during his tenure as a state representative. “I’m excited about this economic development opportunity. I look forward to continuing my work with The Arc at the local level and improving the quality of life for the residents of Muncie and the great state of Indiana,” Mayor Tyler stated.

Planning continues for this project. The next steps are securing a management company to run the day-to-day operations of the hotel. ADG hopes to be ready to break ground in early 2014. The hospitality training institute and hotel are slated to open in the summer of 2015.

To learn more about ADG’s work and this project, contact Jill Vaught, Director of Organizational Advancement for The Arc of Indiana at: [jvaught@arcind.org](mailto:jvaught@arcind.org), or Kim Dodson, Associate Executive Director for The Arc of Indiana at: [kdodson@arcind.org](mailto:kdodson@arcind.org). ■



# A Legacy Continued, Through Dance

Spreading The Arc's important message can happen in many different forms. Across the country, The Arc's passionate advocates are working together to promote and protect the human rights of individuals with I/DD. Shannon Quinn is one of those dedicated supporters spreading The Arc's message in a unique way. Shannon is the daughter of a much-beloved member of The Arc family and past Executive Director of The Arc Northern Chesapeake Region, Tim Quinn, who passed away in 2010. An activist, Tim was an authentic agent of change and his involvement in disability issues was evident at The Arc on every level. Tim's work has left a lasting mark on our movement and Shannon is honoring that legacy and creating her own in the process.

Shannon carries on her father's legacy of understanding, respect, integ-



*"Growing up with my father, I was inspired from an early age to work with individuals with intellectual and developmental disabilities. I was inspired by his kind heart and genuine interest in every person he came in contact with." ~ Shannon Quinn*

rity, and commitment to ensuring people with I/DD live full and inclusive lives through teaching dance to children and adults with I/DD. Since her father's passing, Shannon has spent much time thinking how the word "inclusion" shouldn't even exist, because every

human being has the right to live a fulfilling and engaged life, no matter what their ability. It should be a given. As an artist, Shannon turned these thoughts into movements, and from there "Just Be" was born.

This past April, Shannon, along with ReVision dance company, performed "Just Be" for an audience in Washington, DC at the company's home theater, Dance Place. The performance included students from The Arc of Northern Chesapeake Region. Following this inspirational performance was a VIP reception with a portion of the proceeds benefiting The Arc of the United States.

"Just Be" was more than a dance performance - it was a testament to how one person's passion can motivate and inspire others in creative ways to continue to build The Arc's

movement and spread our message.

Without dedicated supporters like Shannon, we would not be able to continue our important work for those individuals with I/DD and their families. Whatever your passion may be, we hope you will help build The Arc's legacy. By helping individuals with I/DD express themselves and find joy in dance, Shannon was able to tie her passion to The Arc's mission. Together we can continue empowering individuals with I/DD in unique ways through unique programs, but we need your support, innovation and most importantly, passion. Please consider making a gift or hosting an event with proceeds shared with The Arc today!

To learn more about hosting an event for The Arc, contact Laura Schroeder, Development Manager at: [schroeder@thearc.org](mailto:schroeder@thearc.org) or 202-534-3713. ■



Shannon and other dancers from ReVision dance company with students from The Arc of Northern Chesapeake Region during a dance class.

# The Affordable Care Act Matters for People with Disabilities

The Arc has been a leader of the health insurance reform charge in the disability community, calling for the elimination of coverage exclusions for pre-existing conditions, ending discrimination in health care, expanding Medicaid eligibility, and universal health care coverage. While progress toward these goals has been achieved over the years, comprehensive health insurance reform was an elusive goal until the passage of the Affordable Care Act (ACA). Today we enjoy benefits such as:

- Kids can access health insurance now that was previously denied because of a pre-existing condition (extends to adults in 2014);
- Young adults can stay on their parents private health insurance plan until they turn 26;
- Access to free preventive care – like mammograms, colonoscopies, and other testing; and
- Health insurance companies can no longer arbitrarily place a life time limit on health insurance coverage and annual limits are being phased out.

In 2014, the health insurance landscape will dramatically change as reforms to health insurance practices will mean that companies cannot deny coverage or charge more to provide insurance coverage to people with health conditions. New health insurance coverage options will be available as states decide whether to expand Medicaid to 133% of the federal poverty level (in 2013, 133% of federal poverty level is \$15,282 for an individual and \$31,322 for a family of four) and private health insurance marketplaces (formerly known as exchanges) begin operating for consumers to find the best insurance for them. These private insurance marketplaces will allow small businesses and individuals in need of affordable health insurance to easily find coverage that can fit in their budgets. Low and moderate income families will have help in affording the insurance.

The plans sold in the marketplaces will include doctor visits, lab work, prescription drugs, hospitalization, and other benefits that

- help people with disabilities including:
- children's dental and vision services;
  - rehabilitative and habilitative services and devices for all ages (includes services such as physical occupational and speech therapy, durable medical equipment, etc.); and
  - mental health and behavioral health services.

As we approach the next milestones in ACA implementation, The Arc will continue to develop materials and update our website to explain key provisions of the ACA in order to help people with I/DD, their family members, our chapters, and our supporters understand how the law can benefit them. Stay informed by visiting our website <http://www.thearc.org/>, or The Capitol Insider Blog <http://insider.thearc.org/category/health-care/>. ■

## Insurance Marketplace Timeline

**October 1, 2013: Enrollment begins**

**January 1, 2014: Coverage begins**

**March 31, 2014: Initial open enrollment ends**

## HealthMeet continued from page 2



The Arc San Francisco performs health screenings (left) and Eruption Athletics staff gets people moving at ACHIEVA's screenings in the Pittsburgh area.

scheduling a doctor's appointment, to ensure he continues taking care of his health needs.

The Arc of New Jersey is working with The Arc of Atlantic County, The Arc of Camden County, The Arc of Essex County, The Arc Gloucester, and The Arc of Monmouth to implement HealthMeet events. The chapters complete assessments as part of their day program services and at ambulatory care centers. Publicity efforts have included print and broadcast media, including guest appearance on a local radio show, podcasts and interviews with local television stations.

And, in California, The Arc San Francisco hosts Wellness Wednesdays, an organized drop-in health assessment for the people they serve. The program is held on site so it's easily

accessible to individuals, allows for private screenings, and is easy to quickly set-up and breakdown. The Arc San Francisco developed their own registration system and uses nurses and volunteers to conduct the assessment. In addition, they are developing processes to identify potential health issues on an ongoing basis by training Direct Support Professionals to be aware of hidden health issues.

In each state, Chapters are facilitating life-changing events that are helping people with I/DD identify health concerns and training medical health professionals and students to become more familiar with interacting with people with disabilities. Each Chapter has developed a customized approach, which is one of the hallmarks of our responsive network. The Arc of the United States is also helping with systems level changes through innovative and timely training via our HealthMeet webinars, partnering with the University of Minnesota to advance self-advocacy training in health promotion and other essential life areas at [www.selfadvocacyonline.org](http://www.selfadvocacyonline.org), and advancing in-community health promotion program training.

This effort is bringing into clear relief the chronic and often unattended health care needs of the people we serve.

The thing is, health is – and should be considered – a civil right. Chapters of The Arc are helping to get this word across to many who may be hearing this message for the first time. ■



# Tax Free Savings for People with I/DD – Encourage Congress to Act



Joyce Lipman of Rockville, Maryland speaks on Capitol Hill about the ABLER Act, which would help her daughter Elise (seated) have more financial independence.

A big obstacle facing the families of people with I/DD when preparing for their future is how little can be set aside in savings without jeopardizing access to Medicaid, Supplemental Security Income, and other lifeline programs.

So for the past few years, The Arc has been one of the leaders working with Members of Congress to pass the Achieving a Better Life Experience Act (ABLE) Act. This bipartisan legislation could make a big difference in the lives of people with I/DD by giving them additional financial security and in turn, independence.

## What is the ABLER Act?

The ABLER Act aims to change the federal tax code to allow for tax advantaged savings accounts for individuals with disabilities for certain expenses, like education, housing, and transportation. Similar to existing "Section 529" education savings accounts, ABLER accounts would let families save for disability-related expenses on behalf of qualified beneficiaries with disabilities that will supplement, but not replace, benefits provided through the Medicaid program, the Supplemental Security Income program, the beneficiary's employment, and other sources.

If properly managed, funds in the ABLER accounts would not jeopardize

eligibility for critical federal benefits. In return, at death, any funds left in the account would go first to pay back the state Medicaid program for services provided to the individual. With full understanding of its features, individuals and families could use the ABLER accounts as another tool in planning for the lifetime needs of an individual with long term disabilities.

## Who supports the ABLER Act?

This legislation has bipartisan support in the U.S. House of Representatives and the U.S. Senate, and the effort is being led by U.S. Senators Bob Casey (D-PA) and Richard Burr (R-NC), and U.S. Representatives Ander Crenshaw (R-FL), Cathy McMorris Rodgers (R-WA), and Chris Van Hollen (D-MD). Last year, before Congress adjourned for the year, there were 235 Members of the House and 40 U.S. Senators who had signed on as cosponsors. But the bill was not passed in time, and so now, in 2013, we are starting the process of garnering support and cosponsors all over again.

## How can you help?

We need you to contact your U.S. Senators and Members of the U.S.

House of Representatives today and let them know that the ABLER Act must be a priority. As of early July, there are 183 cosponsors in the House and 36 cosponsors in the Senate, but we need to keep the momentum going! To connect with your federal elected officials, go to <http://capwiz.com/thearc/home/> and take action!

## Take Action on the ABLER Act

- ✓ Contact your member of the U.S. House of Representatives and U.S. Senate and ask them to support the ABLER Act.
- ✓ This bill will change Section 529 of the tax code to allow for savings accounts for individuals with disabilities for certain expenses, like education, housing, and transportation.
- ✓ This is important legislation for people with intellectual and developmental disabilities across the country and their families.
- ✓ Sign up for The Arc's Action List to stay informed – <http://capwiz.com/thearc/mlm/signup/>

## A Parent Advocates for Her Daughter and Millions More to Be ABLER to Save

By Joyce Lipman of Rockville, Maryland, former member of The Arc's national Board of Directors

I got involved with The Arc when my daughter Elise, who is now 45, was about 12, at the time when a parent of someone with a disability starts to think, "Oh my gosh, what does the future hold for my child? How do we plan for her needs? She's going to need supports and services, but we also have such dreams for her future! Are we going to be forced to let the dreams die in order to get her services?"

We are like all families in that we want to protect our children's future, plan for educational opportunities and unforeseeable health needs down the road. But because of our child's disability, we must deal with the added challenges and prospective financial commitments necessary to secure a full and independent life for our child.

I spoke on Capitol Hill because the ABLER Act could help solve that problem for—and thus relieve the stress on—many families. With ABLER accounts, some families could have the ability to finance things like an apartment, or a ride to work, or post-high school education, without jeopardizing other necessary services provided by federal programs like Medicaid.

ABLE Act continued on page 7

# Advocacy in Action in Washington State – Eric Matthes In His Own Words

Our chapters are filled with amazing men and women working to promote inclusion for individuals with disabilities. One of the most powerful things our grassroots possess is the strength of self-advocates who are employed at our chapters and are working to promote The Arc's mission. Take Eric Matthes, a remarkable young man empowering self-advocates in his community in Washington State.

Eric joined The Arc of King County as a member of the board of directors in 2008, and in 2010 he was hired as the Advocacy Coordinator and he left his position on the board. In his role as Advocacy Coordinator, Eric organizes multiple trips a year for individuals with I/DD to the State Capitol where they lobby their State Legislators.

This year, Eric has also been very involved in planning The Arc's 2013 Convention in Bellevue, WA (which took place from August 3-5). As the Chair of the Host Committee for the Self-Advocacy Pre-Conference, Eric assisted The Arc's national staff in all steps of planning and brainstorming. As if he doesn't have enough on his plate, Eric still finds time to serve on the Advisory Group for The Arc's National Council of Self-Advocates (NCSA).

Read in Eric's own words what he does for The Arc of King County and why it brings him such satisfaction.

## What is your job with The Arc of King County?

My job is Advocacy Coordinator. What I do in my job is so many things.

So many things in spreading the word for people with developmental, and intellectual disabilities, and for professionals too. I do presentations on different things.

## What are some of the things you do as Advocacy Coordinator that make you proud?

In one of the programs I work with another coordinator, it is "School to Work." Where I give students the experiences and excitement of employment and talk to their parents and give them hope for their sons and daughters. I even go to different school districts and talk to them. I talk to them about one day being independent enough to work, being on their own, and happy. That is one of the things I do.

## Do you enjoy the work you do?

I enjoy it when I can relate to the (high school) students with my presentations and seeing how cool it is to get the students excited about work. They hear from me my message and I hope they want a job, to have money, be independent, and enjoy their life. Have their dreams!

## How do you describe self-advocacy?

I know that a lot of people have a super-hero in them they believe in.

## Why is it important for you to work?

I think it's important for me to carry out the things that I do in spreading the word to end the word, and have people to be more respected in their life. The reason I have my job is because I advocate for my job and I really



Eric at The Arc's Convention 2012 in Washington, DC – extending an invitation to come to convention in Bellevue, WA in 2013.

enjoy what I do. I have had a passion for this job for many years, before I moved here from Utah to Washington. It is a great part in my life to be part of the self-advocacy movement in Washington State. I like being an activist advocate for myself.

## Why do you like working for The Arc?

I like to give back to the community, it is a thing I'm involved with. Having people use The Arc and me as the advocacy coordinator and knowing what we are – I can help and I can have a big part in providing that resource to them. People feeling good that they are getting the right kind of resources for their loved ones. Being part of the local community is important and giving back. Believing in something more than just themselves. ■

## ABLE Act continued from page 6

We are fortunate that Elise has had wonderful services and supports over the last few years. But we are always scared that she will not have enough money to continue living in her home because her expenses are so tight. After paying for food and regular, as opposed to unexpected, household expenses, she has less than \$200 a month

left. The scariest problem is her extra medical costs – for example, a long list of un-reimbursable medications prescribed by her doctor and a necessary third dental visit each year.

The ABLE Act won't necessarily be right for everyone, but it will offer a planning opportunity that many families can choose if it works for them.

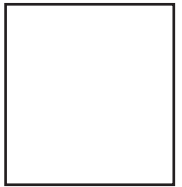
If we can allow an ABLE-like savings account for the future of our children without disabilities, why not for my child, my Elise, who happens to have a disability?

The ABLE Act is the right thing to do for people with disabilities, it's the right thing to do for their families, and it's the right thing to do for our economic future. ■



For people with intellectual  
and developmental disabilities

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

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**empower**  
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*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! ■



*Get Apostrophe Magazine!*

Have you heard of *Apostrophe Magazine*? This full-color, glossy, quarterly publication is designed specifically for, about and by people with intellectual and developmental disabilities with features dedicated to advocacy, news, lifestyle and other topics of interest to the I/DD community.

The magazine is published each January, April, July and October and frequently features editorials from The Arc’s national office on vital issues such as federal public policy along with articles about interesting happenings at chapters of The Arc across the country. You can subscribe for only \$19.99 at [www.apostrophemagazine.com](http://www.apostrophemagazine.com) for one year and a portion of the proceeds from your subscription will go directly to The Arc. ■



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