



# empower

Real People, Real Progress

Issue 12 | Winter 2012

Announcing The Arc's HealthMeet<sup>™</sup>:

## *Health Promotion for People with Intellectual Disabilities*

The Arc is launching a new health promotion project, thanks to a new three-year cooperative agreement with the Centers for Disease Control (CDC)! This new effort, which kicked off in August, will aim to raise awareness of and reduce the significant health disparities often experienced by people with intellectual disabilities (ID), including those with autism. The Arc aims to do this through offering free health screening events for people with ID, collecting and evaluating the health screening data, and launching an amazing array of evidenced-based and best practices training for key stakeholders, including people with ID.

The Arc has one million dollars to work with in this first year of the project. And, one year to make an incredible impact.

Imagine someone with an intellectual disability going through a health screening to discover that they have an undetected health issue, like high blood pressure, an



Jennifer Dresen, Director, The Arc San Francisco Center for Health and Wellness, checks a client's blood pressure at a recent screening.

infected tooth, or an untreated issue on the bottom of their foot. Or maybe it's a hearing problem or blurry vision that shows up in the screening. Health professional volunteers conducting these screenings will help identify areas of concern, and staff from selected Chapters of The Arc will be on site to provide information, referrals, and linkages to local doctors. This effort will be among the first to collect HIPAA-compliant health data on this population, data that

will help bring more awareness and solutions to health issues that they face.

So what is our plan? Our goal: to move more than 6,000 people with ID of all ages through a basic, free, non-invasive health screening that is conducted by volunteer health professionals such as nurses or medical students. The CDC helped The Arc to shape the plan that focuses on five selected states/regions in which to work on implementing HealthMeet<sup>™</sup> initiatives in this first year.

Working in a pilot phase with an eye towards replication opportunities, The Arc will be working with The Arc of Massachusetts, The Arc San Francisco, The Arc New Jersey, ACHIEVA in Pittsburgh, PA, and The Arc of North Carolina. Together, we will implement and evaluate five different models and the work has already begun.

We are working with some amazing national partners – the Association of University Centers on Disabilities (AUCCD), the American Association on Intellectual and Developmental Disabilities (AAIDD), Autism Speaks, the National Down Syndrome Congress, and the National Association of County and City Health Officials. Therap LLC is helping us to collect the data using state of the art technology, and the Elizabeth Boggs Center in New Jersey is helping with the data evaluation. We are in discussions with major corporations to see how they can lend a helping hand to this important initiative. The Arc's

*Achieve with us.*

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# The Presidential Campaigns – *On the Record on Disability Issues*



**W**ith an historic election guaranteed to impact issues that people with intellectual and developmental disabilities (I/DD) care about, The Arc joined approximately 80 other organizations in sponsoring the National Forum on Disability Issues on September 28 in Columbus, Ohio.

The non-partisan forum was the only national event that brought together representatives from President Barack Obama's and former Massachusetts Gov. Mitt Romney's campaigns and provided them with a platform to present their candidate's policy positions on disability issues.

Both campaigns sent representatives to speak on their behalf – President Obama sent Edward M. "Ted" Kennedy, Jr., and Governor Romney dispatched U.S. Rep. Cathy McMorris Rodgers (R-WA).

Kennedy and McMorris Rodgers both spoke about helping

people with disabilities find jobs and educational opportunities, and Medicaid was a focus of discussion. While the two surrogates did not appear on stage together, they did take tough questions from moderator Frank Sesno, director of the School of Media and Public Affairs at the George Washington University, and former CNN White House correspondent, anchor and Washington bureau chief. One unifying question Sesno asked of each campaign was: "If you could ask the Presidential candidates any question about how to support people with disabilities, what would you ask?"

The Forum was held in front of 500 attendees in the room, and thousands watched online. The Arc was involved in organizing this event in conjunction with our "We've Got The Power" voter engagement campaign leading up to the 2012 elections. ■

## 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.

## Upcoming Events

Join The Arc for one or both of our largest national events in 2013.

### 2013 Disability Policy Seminar

April 15-17, 2013

Washington, D.C.

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

### 2013 National Convention

*Achieving Momentum*

Bellevue, Washington (near Seattle)

August 2-5, 2013

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

Hotel and registration information will be available online soon.

The Arc wants to thank the many professionals, donors, and advocates that worked on behalf of our mission throughout 2012. We wish you a happy holiday season and look forward to continuing our relationship in 2013!

# The Arc, Walmart Foundation Team Up to Put People with Disabilities to Work and Clean Up the Environment

The Arc's new "eXplore eRecycling" initiative, funded by a \$465,000 grant from the Walmart Foundation, is off to a great start in 10 communities across the country! Through the program, 10 chapters of The Arc have been awarded funds to help develop or enhance electronic waste management programs that offer community-based employment opportunities for people with I/DD.

"The eXplore eRecycling initiative is a wonderful chance to show how individuals with intellectual and developmental disabilities can excel in cutting-edge jobs while earning competitive salaries. By bringing together the disability and the e-recycling communities, we hope to create more employment opportunities for individuals with disabilities," said Peter Berns, CEO of The Arc.

Each chapter's grant will allow them to start or expand their electronic waste recycling program. They will also have the unique opportunity to interact with



A worker with Genesee ARC's Trash and Recycling Center helps recycle e-waste.

members of an Expert Advisory Committee made up of leaders from the e-recycling, environmental, disability, and business fields. These experts will provide their knowledge and perspectives to identify practice and policy recommendations that further electronic waste conservation efforts and competitive employment outcomes for people with I/DD.

Genesee ARC in Batavia, New York has been in the trash and recycling business

for nearly 30 years. Since 1983, this chapter has been the exclusive provider of this service to the 16,000 residents of Batavia.

Over the years, Genesee ARC has continually employed as many as 20 people with disabilities through this successful work program, and quality satisfaction surveys conducted over the last quarter century have consistently rated their service exceptional!

Recently, the Genesee ARC

Trash and Recycling Center has moved to a larger, more modern facility. The move coincides with increased marketing efforts to expand the amount of recyclables collected, and the news that they were selected to receive an eXplore eRecycling Grant from The Walmart Foundation and The Arc. And as New York begins the implementation of a new law requiring e-recycling in their communities, Genesee ARC is poised to be a leader in the field.

"The eXplore eRecycling Grant will allow us to expand on this success and plans include offering an e-recycling drop off service to residents in each of our County's 13 towns and six villages. We are currently in the process of developing the E-Waste Apprentice position and designing a marketing plan to help guide our eXplore eRecycling initiatives. This grant is already making an impact on the lives of people with I/DD in our community, and reducing e-waste in our landfills," said Shelley Falitico, Genesee ARC. ■

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own National Council of Self Advocates is involved in getting their growing network of people with intellectual disabilities involved.

We're going to need your help! As these Chapters of The Arc work within their states to implement HealthMeets™ early in 2013, we want our network and our national partners to activate a HealthMeets™ movement. There's going to be online training that you can register for, learn from, and pass along to someone else. There might be someone you can help by getting involved yourself as a volunteer.

You'll be hearing more and more about HealthMeets™ as we advance this project. We can all take part in activities that lead to being healthy. Join us!

For more information about HealthMeets™, please contact The Arc of the United States at 202-534-3700 or at [info@thearc.org](mailto:info@thearc.org). Or, visit our website at [www.thearc.org](http://www.thearc.org) for project information.

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## An Incredible Legacy from a Lifelong Advocate

# What Is Your Contribution to our Movement?

Prevention and Peter Leibert are synonymous. Peter initially got involved with The Arc in the late 1960s when his son, Pat, was served by a local chapter. When Peter's wife Virginia heard that the local chapter needed some help fixing their Volkswagen buses, and Peter drove a Volkswagen, she volunteered his handiwork. A month later, he was asked to serve on the board of directors! Then his commitment to The Arc led him to be President of The Arc of California in 1973 and 1974, and on the national board from 1980 to 1985. Peter is retired now, but his passion for prevention and his continued support of The Arc at

the local, state and national level are obvious.

Peter knew his early involvement in our movement would pay off, and as we grew in strength, so did awareness of the issues nearest to his heart. For example, Fetal Alcohol Spectrum Disorders, a preventable form of intellectual and developmental disabilities, has become a well-known issue for pregnant women and in society. Peter's emphasis on prevention raised its profile. It undoubtedly had an impact on people who might have chosen to drink, but did not with the awareness The Arc created.

Prevention is Peter's legacy. What will yours be?

Peter's journey included exhaustively reviewing all the literature he could get his hands on regarding prevention – books, journals, medical research. Years ago, he learned that I/DD was often thought to be the result of major causes like genetics, brain damage, disease, nutrition deficiencies or toxins (lead, alcohol, drugs, etc.). Imagine if the internet had been available when Peter and his fellow volunteers got their start?

Peter secured a place in history by working with other advocates on legislation requiring vaccinations for children before they began school. That legislation contributed to the near eradication of diseases which were too common during Peter's youth like Diphtheria, Measles, Mumps, Whooping Cough, and Rubella, to name a few. Today, almost every state in the nation has adopted similar inoculation requirements.

Also, Peter was involved in looking for ways to prevent injuries that can lead to I/DD, such as head trauma or oxygen deprivation. Something we now take for granted – helmets – have clearly reduced the number the injuries resulting in intellectual disabilities.

Today, we are seeing progress in the areas of genetics and toxins. For those of us who had children after 1973, we can remember our newborns having their heels pricked. The work of two doctors, research microbiologist Dr. Robert Guthrie



Peter and Virginia Leibert

and pediatrician Dr. Richard Koch, both of whom worked with The Arc, led to the creation and validation of the test that now makes Phenylketonuria (PKU), a metabolic disorder which occurs as frequently as one in every 15,000 births, clearly detectable and treatable.

We should all be aware of and appreciate the passion of extremely dedicated volunteers like Peter Leibert that made such an incredible difference for people with intellectual and developmental disabilities and the lives they lead today. We thank him for the work he did to make sure The Arc was on the forefront of prevention.

Peter's lifelong dedication to helping The Arc emphasize prevention is his legacy. What will be your legacy with The Arc? Make an impact in our movement by making a donation – of funds, your time and, your expertise – today. Thank you Peter.

Together, we can achieve!

If you are interested in exploring how to establish your legacy with The Arc, contact Chief Marketing and Development Officer Trudy Jacobson, [Jacobson@thearc.org](mailto:Jacobson@thearc.org) or 202-534-3714. ■

**It's great to have a website that actually has REAL IDEAS that I can immediately PUT TO USE.**  
- Tisha, Kentucky

*Autism NOW is a community of experts, people on with autism and other developmental disabilities and their families providing you with resources, quality information and connections. Visit [www.autismnow.org](http://www.autismnow.org) today!*

 **autism NOW**  
you, empowered.

 **AIDD**  
ADVANCEMENT IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

 **The Arc**

*Autism NOW is part of The Arc, and is funded in part by AIDD.*

# *Inspirational Advocacy in Virginia will Lead to the Closure of Four Institutions*

The Arc has long believed that individuals with disabilities should be empowered to live in accessible and affordable housing similar to those without disabilities. The closure of institutions has been and will remain a priority of The Arc until all individuals with I/DD have the supports needed to live in the community. As of 2009, more than 92,000 individuals with disabilities were living in public and private institutions across the country.

The Arc's chapters are the heart of our cause. Living our mission through grassroots efforts and advocacy at the local level, they help promote inclusion in communities across the country. This year, The Arc of Virginia's advocacy efforts were rewarded with a huge victory for individuals with I/DD in Virginia.

On January 26, 2012, the Commonwealth of Virginia and the U.S. Department of Justice (DOJ) announced an historic settlement (U.S. v. Virginia Settlement Agreement) requiring the state to provide community-based services for thousands of individuals with I/DD.

The next step in the process, a judge's approval, was granted in late August, and advocates across Virginia celebrated this milestone. The signing of the court order means that Virginia will finally move from a system that is reliant on large, segregated institutions to one that is focused on safe, integrated community-based services. The court acknowledged that moving towards a community-based system will enable the state to not only serve more people, but to serve them better.

The agreement requires Virginia to provide 4,170 new Medicaid Waivers to individuals who are living in institutions or at risk of institutionalization over the next 10 years. The agreement also requires the state to develop a community-based crisis system, opportunities for competitive employment, integrated housing and a robust system of quality assurance. These services will help thousands of individuals with I/DD, including those with the most complex support needs, receive the services they need to live in the community. As a result of the agreement and its provisions, the Commonwealth plans to close four of its five institutions, with the first closure scheduled to take place in 2014.

"The settlement incorporates the mandates of the American with Disabilities Act by ensuring that people with intellectual and developmental disabilities, including those



Tom Perez, Assistant Attorney General for the Civil Rights Division of the U.S. Department of Justice, and self advocate Linda Whitlow at the announcement of the settlement.

with the most complex needs, have access to supports and services in integrated, community-based settings. We look forward to working with all stakeholders to help ensure transitions to the community are safe and person-centered," said Jamie Liban, Executive Director of The Arc of Virginia.

The Arc of Virginia has been a tireless advocate so that people in institutions could live in more integrated settings and so that people on Virginia's long waiting lists could receive services. Like all civil rights victories, there were many advocates working for a common cause leading up to this historic settlement. For its advocacy work, The Arc of Virginia was presented with The Arc's Advocacy Matters! Award during this year's convention.

Jamie Liban accepted the award with two members of her board of directors in October. During a concurrent session with officials from DOJ, Liban shared The Arc of Virginia's advocacy experience over the course of the DOJ investigation, negotiations and litigation, as well as The Arc of Virginia's plans to continue its advocacy work throughout the implementation phase. The session provided an overview of activities related to the U.S. v. Virginia Settlement Agreement and advice for chapters on how they can support DOJ in their enforcement of the Americans with Disabilities Act and the Supreme Court's Olmstead decision, a ruling that requires states to eliminate unnecessary segregation of people with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. ■



# The Arc Audi Racing Program at the Finish Line for 2012



Don and Laurie Istook

This year, The Arc had an exciting opportunity to partner with Istook's Motorsports, Volkswagen Group of America and the Pirelli World Challenge Series to open up the world of racing to individuals with I/DD.

Professional race team owner Don Istook and his wife Laurie have a unique personal connection to the I/DD community. Two of Laurie's brothers, Mark and Tyson, have

Fragile X, but this hasn't stopped them from being an active part of Don's professional race team pit crew. Inspired by their success, Don and Laurie contacted the national office of The Arc to propose a program to connect members of The Arc with one of the events in which Don and his crew would be competing across the country. While there, they would enjoy the opportunity to be an integral part of one of five races in 2012. By hosting different chapters of The Arc at Pirelli World Challenge Series races across the country, they gave dozens of individuals with I/DD the chance to be crew members for a day and cheer on Don.

Don and Laurie's work with The Arc this year was honored at our 2012 National Convention, where the couple received The Arc's prestigious Image and Inclusion Award for their efforts to promote including people with I/DD in the racing experience and demonstrate to racing fans across the country that they should be fully included in society.

We're already making plans for the 2013 race season, so look for news about more victories as we move forward with this effort to empower people with I/DD! ■



Take a look at a few of Don's honorary crew members hard at work!

# Help Make a Meaningful Connection this Holiday Season

Do you know someone who would enjoy being connected to the nation's leading and largest organization for people with intellectual and developmental disabilities? Would this person or organization benefit from the connections they could make with experts, professionals in the field, families, and others with I/DD who share their point of view? If so, why not take the first step for them? Give the gift of mem-

bership in The Arc this holiday season! The Arc has special rates for individuals with I/DD and families and the cost of a membership more than pays for itself with complimentary trial subscriptions to *Apostrophe* and *ABILITY* Magazines, discounts of \$50 or more to attend The Arc's annual events and access to a host of discounts and services from our partners. Find out more about The Arc's national membership and sign

up a friend or family member at [www.thearc.org/become-a-member](http://www.thearc.org/become-a-member). We'll send them a new member packet in the mail explaining what membership means and you can feel good knowing that your gift membership not only contributed to the work of The Arc on behalf of people with I/DD but connected a friend or family member to our amazing community. ■

## On the Road with The Arc

The Arc hit the road this year, holding conversations across the country in New York City, San Francisco, Chicago and a fourth, planned for Palm Beach, Florida to enlist the ideas and voices of supporters of The Arc to join a discussion about what it will take to make The Arc the national powerhouse organization people expect us to be. Each "parlor meeting" was hosted by national members of The Arc's Board of Directors in their local communities. Each

meeting was organized to enable selected supporters and board leadership from local and state chapters with the President of The Arc's national Board of Directors as well as its CEO, Peter Berns, to openly discuss the important work The Arc is doing to protect the rights of those with I/DD and strengthen The Arc as a national movement. The primary goal of these intimate meetings was to get influential local stakeholders around the table to discuss the work The Arc needs to do to strengthen its ability to advocate for people locally and at the state level and nationally through our federal public policy work as well as our national initiatives such as School to Community Transition, eXplore eRecycling, and our newest initiative, HealthMeet™.

The main focus of each meeting was to discuss the commitment The Arc has to achieving its rightful place as one



Advocates gather in San Francisco to discuss strengthening and growing The Arc.

of the leading charities in America. Emphasizing the importance of synergy between the national, state, and local offices, each event demonstrated how we are stronger and more influential standing as one unified organization. These conversations were the first building blocks to energizing our powerful momentum not only at the national level but through grassroots in every corner of our nation. And, how a stronger national organiza-

tion can pay rewards at every level.

The Arc's national office also learned from these meetings questions that local leaders have about the work of The Arc and how it benefits them. We learned that too many people in chapters across the country are unaware of all of the work of The Arc's national office and how it pays dividends in their local communities through our expert public policy staff through the hard work we do to stave off cuts to federal programs such as Medicaid, and how our growing national initiative programs have been established nationally but implemented locally.

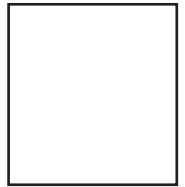
The Arc's national office is already beginning plans to host four to six parlor meetings in 2013. Would you like one in your community? If so, contact Trudy Jacobson, Chief Marketing & Development Officer, at [Jacobson@thearc.org](mailto:Jacobson@thearc.org). ■





For people with intellectual  
and developmental disabilities

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

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## 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! ■

## Let 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](http://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. ■



## 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! ■