



# empower

Real People, Real Progress

Issue 14 | Spring 2013

## Achieving Momentum in Bellevue, Washington!

This summer, The Arc's 2013 National Convention will take place in Bellevue, Washington, on Seattle's East Side. This year's theme, "Achieving Momentum," reflects our continuing progress and forward movement. Utilizing new technologies and innovative programs, we are extending our reach and most importantly, making more of an impact.

This year we will focus on those elements of our movement that help us achieve momentum, whether as an individual with I/DD, a family, a chapter, or an advocate. Our program is packed with phenomenal speakers including experts from our chapters and in the field. Throughout the conference, you can pick from over 36 breakout sessions on topics ranging from practical uses for technology such as iPad applications that our chapters have integrated into their services and ad-



vocacy work, to the implementation of the Affordable Care Act. Back-to-back sessions on Fetal Alcohol Spectrum Disorders will give an in-depth look at the single most pervasive hidden disability that we know is 100% preventable. Attend sessions highlighting proven strategies for strengthening our chapter governance, advocacy and services. The full program schedule and descriptions can be found on The Arc's website – look for the Convention button on [www.thearc.org](http://www.thearc.org).

Additionally, all attendees will experience three very different plenaries described below that will provide insight, new tools, and generate a lot of great conversation.

- **Understanding and embracing cultural diversity in our communities** – As all convention attendees join together for the first time we will have an honest and open conver-

sation about true diversity. From different races, sexualities, to socio-economic backgrounds, there are unique aspects to every community. This plenary will focus on how we can not only respect every culture, but learn how to better serve them and expand our network in the process.

- **Our Families, Our Stories, Our Lives** – Families are at the heart of our cause. To truly understand what The Arc stands for, we have to understand the unique relationships of the families in our network.
- **The technology of tomorrow is here, now what?** – Technology is constantly evolving and moving forward, and so are we. This plenary will focus on how innovative technologies can improve the lives of individuals with I/DD by assisting them in school, work, recreational



**Achieve with us.**

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# Victories in Housing Policy and the Fight for Respect

With so much uncertainty in Washington, DC surrounding the federal budget and the fate of Medicaid, Social Security, and Medicare, we sometimes overlook the victories. While 2013 has been filled with concerns about the impact of budget cuts on individuals with I/DD and future threats to our lifeline programs, there have been two great victories that should empower the disability community.

## Progress in Affordable Housing for People with Disabilities

Earlier this year, the Department of Housing and Urban Development (HUD) and the Department of Health and Human Services (HHS) jointly announced the Fiscal Year 2012 awards for the new Section 811 Supportive Housing for Persons with Disabilities Project Rental Assistance (PRA) Demonstration. The new Section 811 PRA Demonstration is designed to assist state housing agencies to expand integrated supportive housing opportunities for people with the most significant and long term disabilities, and was the centerpiece of the Frank Melville Supportive Housing Investment Act of 2010. A total of 13 states will

receive \$98 million to produce 3,530 units of community-based supportive housing for people with disabilities.

Section 811 is the only HUD program dedicated to producing affordable, accessible housing for non-elderly, very low-income people with significant disabilities. The Frank Melville Supportive Housing Investment Act of 2010 modernized Section 811 to make the program more efficient and effective. These awards are the first ever under the new Section 811 PRA Demonstration model, which will create integrated housing linked with community-based services for low-income adults with significant disabilities. States receiving awards are: California, Delaware, Georgia, Illinois, Louisiana, Maryland, Massachusetts, Minnesota, Montana, North Carolina, Pennsylvania, Texas, and Washington.

There is a severe shortage of accessible and affordable housing for low-income people with disabilities. For many individuals with I/DD this announcement is the difference between life in an institution and inclusion in their communities.

*“Changing how we talk about people with disabilities is a critical step in promoting and protecting their basic civil and human rights. This is an important moment for people with disabilities because Social Security is a lifeline to so many – it allows people with ID to live in their communities and be as independent as possible. And now, the language the agency uses will reflect the respect people with ID deserve.”*

~ Peter Berns, CEO of The Arc.

## Social Security Administration’s Efforts to End the Use of the “R-word”

In an historic change for people with intellectual disability (ID), the Social Security Administration (SSA) announced its intent to stop using the phrase “mental retardation” and start using “intellectual disability” in its official Listing of Impairments.

This change, which The Arc and many other organizations advocated for, came a little over two years after President Barack Obama signed Rosa’s Law. In 2010, The Arc was very involved in efforts to end the use of the “r-word” and worked to enact Rosa’s Law, which substituted the stigmatizing word with the terms “intellectual disability” and “individual with an intellectual disability” in federal health, education, and labor policy statutes. While the legislation did not cover programs such as Medicare, Medicaid, and Social Security, it was an important stepping stone for shaping future legislation and efforts that will transform these outdated terms in all federal laws.

The proposed regulation had a 30 day comment period which closed on February 27. The Arc offered comments which can be viewed online at <http://www.regulations.gov/>. ■

## empower

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### Mission Statement:

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

# The Arc's Advocates Making an Impact!

With state legislatures in session and debating issues that can impact millions in their communities, The Arc's advocates are the go-to resource for individuals with I/DD at the local level.

Our grassroots never cease to amaze us as they continue to innovate and find new ways to advocate for individuals with I/DD in every corner of our nation. Here are two chapters that have been doing exceptional advocacy work in 2013.

## The Arc New London County Rallies in the Rain to Protect the Lifeline

Earlier this year, The Arc New London County (CT) joined many other chapters, two trade organizations and The Arc Connecticut at the State Capitol to stand up for the rights of individuals with I/DD. The north side of the



"If we don't advocate for our lives, who will?"  
- Jamie Lazaroff, Self-Advocate Coordinator,  
The Arc of Quinebaug Valley, Inc.



Advocates in Florida make an impact at the State Legislature.

Capitol was a sea of yellow shirts as over 1,000 people gathered to urge Legislators to protect lifelines essential to individuals with I/DD in their state. Prior to the rally, more than 2,700 callers flooded the Capitol switchboard to protest cuts to social services in Connecticut.

Though the skies were gray, employees, families, and consumers carried signs and chanted "Save Our Safety Net." Governor Dannel Malloy came out unannounced to address the crowd, and unveiled his plan for a new state bond pool for non-profit, community-based providers. While the advocacy day was a great success, the fight is far from over for The Arc's 17 chapters in Connecticut. They plan to keep the momentum going and continue advocating.

## The Arc of Florida Working to End the R-Word

Words are a powerful thing and The Arc of Florida is working to end the use

of a stigmatizing and offensive word sometimes used to describe individuals with I/DD. In March, Floridians with I/DD gathered at the State Capitol to support a new piece of legislation that would remove all references to "mental retardation" in state law and replace them with "intellectual disability." The Arc of Florida consulted with lawmakers to develop the Intellectual Disabilities Bill. Self-advocates, chapters of The Arc of Florida and supporters from across the state were in Tallahassee to educate lawmakers about Senate Bill 142, sponsored by Sen. Thad Altman, and House Bill 1119, sponsored by Rep. Janet Adkins.

The introduction of this bill is coupled with the launch of a state-wide campaign to end the r-word. With the new campaign, End the R-Word in Florida, The Arc of Florida is reaching into every community it can and raising awareness. Learn more by visiting <http://www.norword.org/>. ■

# A Powerful Leader On A Mission

Let us introduce you to Jill Egle. Once you meet her, you probably won't forget her. With her infectious smile, engaging personality and desire to have fun, she can really work a crowd at The Arc's national events that she attends.

Jill is a great example of the millions of people who have benefited from the work of The Arc. She has hopes and dreams for herself and others like her. Her forthright self-identification as a person with an intellectual and developmental disability leads her to pursue self-advocacy at the local, state and national level. She tells all who meet her that she is a "powerful leader." And she is.

Those who don't often engage with self-advocates may be amazed when they meet Jill and witness her poise, self-confidence and most of all, they may change their opinion about what people with I/DD can do for themselves.

Jill's advocacy career has become a testament to what people with I/DD can achieve when given a chance. She is a member of the National Council of Self Advocates of The Arc (NCSA). NCSA was founded to encourage people with I/DD to self-identify and be part of a group of leaders representing the full spectrum of ages and abilities across our national chapter network. It provides an awesome opportunity to be part of a group who unite with a clear and strong



voice to create lives that allow meaningful choices for a promising future.

The Arc is working to establish this national council to develop leadership skills, receive valuable training and work collaboratively with other self-advocacy groups.

Who will be the next Jill? The NCSA welcomes all individuals with I/DD who are members of The Arc at the local, state or national level. And anyone can support the NCSA with a contribution to The Arc.

The NCSA is an example of the strong self-advocacy which is at the core of the movement for people with I/DD. And strong self-advocacy comes from experi-

encing self-determination which instills the confidence to take action on behalf of themselves and others with I/DD. The Arc provides a structure in which powerful leaders like Jill can work to protect funding for people with I/DD, raise awareness of crucial issues like proposed budget cuts, and promote the full inclusion of people with I/DD.

To learn more about the National Council of Self Advocates of The Arc, visit our website, [www.TheArc.org](http://www.TheArc.org) and in the orange bar, click on I am A Person with a Disability. This is just one of the ways you can join in the movement and follow Jill's example. If you have the opportunity to meet her, we guarantee she will make you feel as if there is nothing you can't do. ■

## A Day at the Race Track –

# A Video That Will Make Your Heart Race

The roar of the engines. The expert pit crews working on the cars. The speed the cars travel. Does this sound like a place for people with I/DD? To Don and Laurie Istook of Istook's Motorsports and The Arc, it does and is. And award-winning film producer and director Heidi Reinberg has captured a day at the race track with people with I/DD, including a pit crew member, who is raising awareness about what people with I/DD can do when given the chance.

Mark Heitt, who is Laurie's brother and has an intellectual disability, is an important member of Don's racing crew, performing tasks like caring for the car's exterior and changing tires, alongside his coworkers.



Laurie says of her brother, Mark: "It just gives him a meaning and a purpose for his life. It gives him something to look forward to, and that's what we all want."

A partnership with RS Werkes and the Pirelli World Challenge series, The Arc Audi Racing Program invited groups

of 20 people, including individuals with I/DD, their support staff and staff from select chapters of The Arc to be honorary crew members in 2012 at seven races, giving them a unique race day experience and helping to raise awareness of The Arc and I/DD among racing fans everywhere. The program captured the attention of Heidi Reinberg, an award-winning film producer and director (Heidi Reinberg Big Idea, LLC), who immediately saw the potential to capture this exciting experience on film to show the world that people with disabilities can be a part of the racing experience. Reinberg traveled to Sonoma to follow The Arc of San Francisco at the race at the Sonoma Speedway, and

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# The Arc of Riverside, Making Respect a Priority

In March, Erin Maxwell started a mosaic mural on the parking lot wall of The Arc of Riverside County's (CA) office. When completed, the "Wall of Respect" will measure 8 feet by 40 feet and depict individuals with and without I/DD celebrating life in a backdrop of important iconic architecture and symbols of Riverside, CA.

"We were extremely fortunate to find Ms. Maxwell, who shares our vision for valuing the lives of individuals that have the same hopes and dream as everyone else," said Executive Director Jim Stream. "They deserve our respect and to be included in the life and rhythm of our community. We hope this mural will be another of the artistic treasures of our community because of its beautiful depiction of diversity and inclusion as well as our city."

The idea for the Wall of Respect came about more than three years ago. The goal was to use the wall on their property to make a visual statement that illustrated The Arc's mission. Two years ago, The Arc of Riverside began looking for the right artist to create the mural that would be seen by those visiting their location and anyone interested in



When you believe that everyone, with and without disabilities, has value and deserves respect, there's affection, and a connection.

The Arc. They were fortunate to find Erin Maxwell and her parents, a family of accomplished mosaic artists.

Erin was eager to begin.

"I am so proud to be working with

The Arc in creating the Wall of Respect. One of the most exciting aspects of this project is sharing the art of mosaic work with the community. Dignity, respect and inclusion are the words that inspire our mural. I am grateful to be working as a team with my parents on this project," said Erin.

This project isn't just a project for the Maxwell family; it is a project for the entire community.

Over the course of a few months, the Maxwell family and The Arc of Riverside conducted a series of workshops for individuals with disabilities whom The Arc supports and provided them with an opportunity to participate in this project and feel true ownership of it.

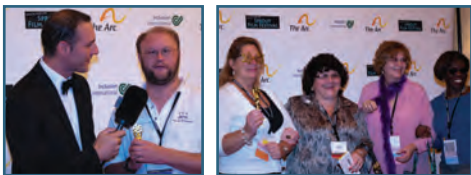
When the mural is complete, The Arc

plans to host an unveiling at the site and a celebration of their 60th year of providing support and advocacy for individuals with I/DD and their families in Riverside County. ■



Artist Greg Maxwell talks with Riverside City Council Member Paul Davis about the mosaic mural being created for a wall at The Arc of Riverside County location near St. Lawrence and Lincoln avenues in Riverside.

## convention continued from page 1



activities. The Arc can play a role to facilitate fuller inclusion in communities either through assistive technology, online educational tools, or better communications and operations systems for more effective delivery of services.

In addition to the program, we also plan to have a lot of fun! There will be a variety of daytime and evening

events to join, including The Marketplace reception. The three day event will kick off with a night of laughter and dancing brought to you by our local hosts, The Arc of Washington and The Arc of King County. Also, back by popular demand, "Red Hot on the Red Carpet" will lead in to our big closing event, The Arc & Sprout National Film Festival. After a weekend of networking, learning, and reuniting with old friends, The Arc will be rolling out the red carpet so everyone can let loose and strut their stuff. Don't worry, feather boas and sunglasses will be provided, plus a few other surprises as well! ■

### The 2013 Convention is sponsored by:

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Metlife Center for Special Needs  
Planning  
Mutual of America  
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Additional sponsorship opportunities are still available – contact Trudy Jacobson, [jacobson@thearc.org](mailto:jacobson@thearc.org).

# Entrepreneur Alley Spotlight

This year at The Arc's National Convention in Bellevue, Washington, self-advocates who own their own businesses will be exhibiting their merchandise for attendees. This is the fourth year that The Arc has focused on self-advocates promoting their entrepreneurial efforts at the marquee event. This unique opportunity gives entrepreneurs the attention of hundreds of members of The Arc and professionals in the disability community.

Entrepreneur Alley hosts a variety of talented self-advocates including artists, authors, jewelry designers, musicians, and other business ventures. We wanted to give you a little taste of what you can find in Entrepreneur Alley this year, check out a few of our amazing self-advocates!

To learn more about Entrepreneur Alley or to participate, contact Sarah Kennedy, Development Assistant at: [skennedy@thearc.org](mailto:skennedy@thearc.org).

## Meet David: Running His Own Business and Helping Others Fulfill Their Dreams



David Taylor Jr. is the owner of RaceCAR Waterboy, LLC, a business that allows him to sell ice-cold bottled water at NASCAR races, major street festivals, county fairs, and other public events. David's disabilities have never held him back from fulfilling his dream of being his own boss.

In addition to his business, David speaks at national and international conferences, self-advocacy events, and schools across the country about how he started his own company. He is also the author of a book called, *Micro-Enterprise 25 Step Business Plan, "Workbook."* His book is used in schools, Universities, by Developmental Disability Councils, and self-advocates. The book is now in Canada, Australia, Mexico, England, the Virgin Islands, Puerto Rico and New Zealand. After the last national convention of The Arc, a couple took David's book back to New Zealand and did a story on him in the news. This workbook is a tool for individuals with disabilities who want to start their own business. David continues to use his success to inspire others to follow their dreams.

## Meet Teddy: Selling with A Purpose



Teddy Fitzmaurice is a 29-year-old energetic entrepreneur with Down syndrome who promotes human rights. Teddy has been in business for 7 years. He started out selling shirts someone else designed – now he sells his own designs and makes his own buttons. His mom and his circle of friends help, but Teddy does most of the work. Teddy has traveled with his business to 14 states and mailed shirts to Japan, Sweden, Canada, and England.

Teddy's business doesn't make a profit, but Teddy isn't in it for the money. His primary goal is to promote the idea that people with Down syndrome are capable of many things and to advocate on behalf of other individuals with disabilities. His merchandise proudly displays messages such as "Label Jars, NOT People", "Shred the word – R E T A R D E D" and "Disabled, Sexy, and Proud!" Teddy uses a variety of creative methods to share his vision and passion for advocacy. ■

## The Market

For those self-advocate entrepreneurs who can't make it to Bellevue for this year's convention, The Arc offers The Market as a convenient option to sell merchandise or otherwise promote a business. The Market is a space set up inside The Marketplace and staffed by The Arc to allow self-advocates to ship in limited merchandise or promotional materials for sale or as giveaway items.

To find out more about how to participate in The Market call Sarah Kennedy with The Arc's Development Department at: 202-534-3720.

# From Institutions to Classrooms, Boiler Rooms to Playgrounds: *Safety & Justice for People with Disabilities Remain Disturbingly Out of Reach*

By Leigh Ann Davis, Project and Information Specialist, The Arc

Safety is a crucial need for all people - without it, the hope of leading full, satisfying lives within the community and within relationships is painfully out of reach. People with I/DD are most aware of this fact, and with the growth of the self-advocacy movement, more victims feel they have the permission and confidence to speak out. While advocates, reporters, concerned friends and others read and write about the grim statistics about people with disabilities being twice as likely to be victimized compared to those without disabilities, it is victims themselves who are living the nightmare every day. So many stories will never see the light of day, but those that do – like the ones below – provide a glimpse into the real world and challenges people with disabilities face:

- Concerned about a wave of rapes in California state institutions for people with developmental disabilities and mental illness, one state senator proposed legislation (supported by The Arc of California) in December 2012 mandating the immediate use of kits to collect evidence when allegations of abuse are made, as an effort to reduce sexual violence by holding criminals accountable. One report found 36 accusations of molestation and rape of residents by caretakers in the last four years at California's state institutions for the developmentally disabled.
- Two families filed lawsuits against the Colorado School for the Deaf and the Blind after school employees failed to report sexual assaults on their children to police. The youngest was 9 years old and couldn't see his attacker due to his disability and the school administrator said there was nothing he could do and made no written report. Another 15 year old victim was sexually assaulted over a period of several months. In both lawsuits, families allege that staff members were unclear about how to report sexual assaults and it wasn't clear the extent and type of training provided.
- In the first hate crimes prosecution of its kind involving victims with disabilities, defendants in Pennsylvania were charged with violating the Hate Crimes Prevention Act which criminalizes violence motivated by any person's actual or perceived disability, race, color, national origin, religion, sexual orientation, gender or gender identity. Four adults with intellectual and physical disabilities (two of whom died) were imprisoned in a dark Philadelphia boiler room, chained to the boiler, beaten, underfed and confined like zoo animals in a scheme to steal Social Security disability payments.

In addition to these crimes, bullying remains a constant threat to students with I/DD, including autism. One 2012 study from the School of Social Welfare of the University of

California, Berkley found that nearly half of all U.S. children with autism are victims of bullying and addressed this as an urgent and profound public health problem. What will it take for the victimization of children and adults with disabilities to become the exception and not the rule?

The Arc is taking proactive steps to address victimization of people with I/DD at national, state and local levels. Whether advocating for change in legislation, reaching out to families of children who experience bullying, or providing accommodations for victims with disabilities in court – there are many ways chapters are making a difference. If you or your chapter is just getting started in this area of advocacy or want to look for ways to improve outreach, read The Arc's fact sheets related to criminal justice issues, both offender and victim issues are covered, at [www.thearc.org](http://www.thearc.org). Share your knowledge and personal experience with disability issues with your local police departments, district attorney's offices, public defenders, courtroom officials and child advocacy centers. Ask if they may be interested in cross training, and be sure to invite people with I/DD themselves to be a part of the training, which can go a long way toward building solid, safe and long-term relationships between the disability and criminal justice community.

Don't be afraid to take that first step. Every effort, big or small, brings victims that much closer to experiencing the respect, dignity, equality, safety, security, justice and healing they are entitled to as equal members of society. ■

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## **racing film** continued from page 4

now you can see her film on The Arc's YouTube channel, <http://www.youtube.com/user/thearcoftheus>. (Please check it out!)

Mark's disability does not stop him from being an active part of Don's professional race pit crew. Inspired by their success, Don and Laurie contacted the national office of The Arc to propose a program to give select chapters of The Arc across the country the opportunity to be a part of the racing world.

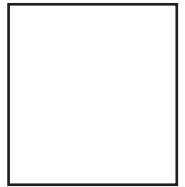
"Being a special educator, I want people to see our crew members with intellectual disabilities out here and realize they have so much potential given the opportunity," said Laurie Istook in the film. ■

We are gearing up for the 2013 racing season, and The Arc Audi Racing Program expects to be at nine races in Florida, California, Texas, Michigan, Connecticut, Ohio and Toronto, Canada, and Don has two Audis to race. Follow us on Facebook and Twitter as The Arc expands this program!



For people with intellectual  
and developmental disabilities

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

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Real People,  
Real Progress

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*Register now for*

The Arc's 2013 National Convention  
August 3-5 in Bellevue, Washington!

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

## *An Easy Way to Help*

**L**et The Arc turn your unwanted vehicles into a donation to help people with intellectual and developmental disabilities. The Arc's Car Donation Program can take any old vehicle with a title off your hands – we'll pick it up, make sure you get the necessary paperwork to claim your tax deduction and send the proceeds to your local chapter of The Arc or The Arc's national office. All you have to do is call 1-800-ARC-CAR-0 or visit [www.thearc.org/donate-a-vehicle](http://www.thearc.org/donate-a-vehicle) today! ■



## *Meeting High Standards!*

**T**he 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! ■