



empower

Real People, Real Progress

Issue 20 | Fall 2014

Homes for Life

Freedom. Independence. A home of your own. Those dreams apply to people with and without disabilities. And in Wilmington, Delaware, they have become a reality for three individuals with disabilities, thanks to The Arc of Delaware and the Homes For Life Foundation.

The Arc of Delaware recently received two new condominiums thanks to a generous donation from the Homes For Life Foundation. The two furnished condos, in Wilmington's revitalized riverfront area, will house a total of four individuals with intellectual and developmental disabilities (I/DD), and are valued over \$420,000.



Dayon Stevens settles in to his new home, complete with a new kitchen to meet his needs.

Jeff Jones, Alexandra Jahn, and Dayon Stevens moved in recently to the new Justison Landing building, and have

truly made it their home. They have explored their new neighborhood, which includes restaurants, small businesses, parks, and even a minor league ballpark. Jones has cooked dinner for everyone, and Stevens is looking for a job in the area. Jones and Jahn currently work for Bank of America, and Jahn is looking for a roommate to share her new place.

The Justison Landing acquisition brings to life new regulations from the U.S. Centers for Medicare and Medicaid Services (CMS), which governs how and where federal support for home and community based ser-

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Sign the Pledge to Stop Violence, Abuse, and Bullying



Over the last few months, there have been several high profile cases of violence, abuse, and bullying against people with intellectual and developmental disabilities (I/DD). These incidents, particularly in Ohio and Delaware, grabbed the attention of

the media and the public. While the authorities are pursuing charges in both cases, too many instances of violence, abuse, and bullying of people with I/DD go unreported, unnoticed, and unresolved.

The Arc is launching a pledge to rally our chapters and the public to stop this kind of behavior before it starts. We need you to:

- Sign the pledge at <https://www.causes.com/campaigns/84605-stop-violence-abuse-bullying-of-people-with-disabilities> to show your support for this effort.
- Share the pledge with your contacts – your members, staff at your chapter, community partners, and the public.

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Achieve with us.

Affordable Care Act Update: What You Need to Know About Open Enrollment

If you are uninsured or seeking affordable health insurance, now is the time for you to look! During “open enrollment” you can purchase private health insurance through the marketplace in each state.

Depending on your income, you may be eligible for assistance with your health insurance costs.

If you currently have insurance through the marketplace, you should look at your current plan and determine if it will continue to meet your needs, or select a better plan. If

you do not take action, you will be automatically re-enrolled in your current plan. Re-enrollment provides an important opportunity to report any changes to your income.

2015 Open Enrollment

November 15, 2014
open enrollment begins

December 15, 2014
Enroll before this date to have
coverage January 1, 2015

February 15, 2015
open enrollment ends

- Even if your income has not changed, you could be eligible for more financial assistance.

If you have a disability or a health condition, pay attention to possible changes:

- Are a broad range of health care providers included in the health plan’s network of providers?
- Are there enough medical specialists in the network to meet your needs?
- Are needed medications included in the plan’s list of covered drugs?
- Is there adequate access to non-clinical, disability-specific services and supports?
- Does the plan have service limits, such as caps on the number of office visits for therapy services?
- Are mental health services covered to the same extent that other “physical” health benefits are covered?

Where to get help?

Health insurance can be complicated. If you or your family member needs assistance with understanding the options, healthcare.gov can help. This website has information about seeking assistance in local communities, explanations of health insurance terms, enrollment information and much more. There is also a 24-hour phone line for consumer assistance at 1-800-318-2596 to call for help. ■

Why you should check your coverage:

- Even if you like your health plan, new plans may be available and premiums or cost sharing may have changed since last year.

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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

1-800-433-5255

Enrollment for Medicaid and the Children’s Health Insurance Program (CHIP) is open anytime. Open enrollment is not limited for these publically funded health insurance programs for low income individuals. Medicaid also provides long term services and supports to people with disabilities.

stop

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- Alert The Arc’s national staff when a case of violence, abuse, or bullying of a person with I/DD occurs in your area. Too many instances are going unreported and unnoticed in society. We need to bring these issues to light and the national office of The Arc is leading the charge to stop this kind of behavior before it starts. Contact The Arc at NCCJInfo@thearc.org.

This pledge is The Arc’s first step in leading the charge to stop this kind of behavior before it starts. Look for more resources and activities from the national office in 2015. ■

The Arc's 2014 National Convention – A Rousing Success!



❶ The Arc's network marching in their own parade; ❷ Ron Suskind meets with one of his biggest fans; ❸ Chip Warren chatting with Leigh Ann Davis about the documentary film *Children of the Dumping Ground*; ❹ Chris Engler and Joe Jelinski of Eruption Athletics; and ❺ Barry Meyer, Nancy Webster, Kelly Serrett, and Peter Berns having fun at the local host event

Thank you to all of the nearly 800 attendees who made it to New Orleans for The Arc's 2014 National Convention. We could not have pulled it off without the support from our sponsors, as well as chapter staff, self-advocates, family members, and professionals in our network. You all help us make this event bigger and better every year. A lot of work went into designing a program that featured not only educational opportunities and inspiration, but also the passion that brings The Arc's mission to life.

The convention got started with an engaging and captivating opening session. Award winning author Ron Suskind gave an impassioned speech about his new book, *Life Animated*, that details the remarkable journey that his family went on to reconnect with Owen, their son with autism. His speech brought the audience to tears and to their feet. Ron truly felt at home in The Arc's network and spent more than an hour signing copies of his book, speaking to each person in line, and sharing hugs.

Fred Maahs, Director of National Partnerships for Comcast/NBCUniversal, spoke about his desire to use his position to bridge corporations and the non-profits that service communities.

Thanks to our 2014 Convention Sponsors!

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Fred also shared his personal story of his physical disability and how it has impacted his career and the goals he has for Comcast/NBCUniversal. Comcast/NBC Universal is a national corporate partner of The Arc, supporting our programs and helping grow awareness of our organization.

Throughout the convention, at-

tendees were able to network and interact with chapter staff, sponsors, and national initiative partners. Self-advocates showcased their products and services in Entrepreneur Alley. This year featured our biggest showing of self-advocate entrepreneurs yet!

But the convention wasn't all work and no play. Early risers were able to "Wake and Shake" with Eruption Athletics. Chris Engler and Joe Jelinski of Eruption Athletics (EA) bring physical fitness to people with intellectual and developmental disabilities through informative workout sessions that feature the EA patented Volcano PADD and specially designed music to help inform participants of the specific exercises they have to complete.

With the convention going off without a hitch, everyone was thrilled to participate in the local host event, which involved a "second line parade" from the hotel to The Presbytere. Onlookers from neighboring stores and restaurants waved the parade on, as everyone marched through The French Quarter. At The Presbytere, everyone was able to enjoy jazz music, light refreshments, and view the ongoing exhibits on Hurricane Katrina and the

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Getting to Know a Champion: Follow Carol's Lead in 2015

This holiday season, we all want to stop, breathe and appreciate what we have and what works in our lives. For Carol Wheeler, a member of The Arc's national Board of Directors, that means working hard, being very generous and still wanting to do more. For The Arc, she is a true champion.

Over the course of this past year, we have introduced you to three champions: David Dassau from Tennessee, a sibling and personal care attendant who has made sure that his brother Ben will achieve all that he can; Kim Resh from Pennsylvania, a mother who is educating not just her daughters (one of whom has a disability) about what inclusion really means, but her whole community; and Joe Meadours from California, a self-advocate who knows from experience how crucial it is to train and encourage the next generation of self-advocates. As 2014 comes to a close, we want to make sure you get to know Carol, a parent of a young adult with Williams Syndrome who has come to appreciate the impact of The Arc. In selecting an organization with which to develop a close relationship, she chose The Arc because she knew that our unparalleled track record in assisting parents and advocating with and for people with intellectual and developmental disabilities (I/DD) would benefit not only her family, but the thousands like them who are looking

"Part of The Arc's message is that if you're trying to address a community problem... and you ignore the population that The Arc is serving, you're leaving millions of people behind." ~ Carol Wheeler



Max and Carol

for support, opportunity, and answers in communities across the country.

While some champions in our movement are often high profile for their work in the halls of Congress, or their efforts to change systems at the state and local level, too often we overlook the champions who behind the scenes, give both their time and their resources and in return, seek only the assurance that their efforts are making a difference. Recently, Carol opened her home to host a parlor meeting for The Arc's national office. The Arc has been hosting these intimate gatherings in cities across the country to give people the opportunity to get to know us better and start a dialogue about how to sustain the organization for the next 60 plus years. Carol invited a mixed group of friends, most of whom (even though many had a personal connection to the I/DD sector) had little knowledge about The Arc locally and or its capacity to be a national powerhouse.

We shared The Arc story with Carol's guests and just as importantly, we had

a chance to hear theirs. Conversations were begun about issues of mutual interest and new connections were made, already resulting in several generous contributions to our work. As Carol has said: "Part of The Arc's message is that if you're trying to address a community problem—be it affordable housing or employment, health care or criminal justice – and you ignore the population that The Arc is serving, you're leaving millions of people behind. And if you're determined to see that they're included, you find yourself asking your friends for help."

2015 is right around the corner, and The Arc is again gearing up for a new year filled with challenges and opportunities. Please follow Carol's lead and ask your friends to consider supporting our work now.

You and your friends can become champions for The Arc and help people with I/DD live the life they deserve with an end-of-the-year tax-deductible gift today! ■

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vices will be provided. The new regulations emphasize settings like the condos donated at Justison Landing – in the community, with supports as needed, but plenty of freedom for people with I/DD to make their own decisions day to day. In this living arrangement, the tenants have signed their own leases, with The Arc of Delaware as landlord, and another local agency provides services. The state government is involved to verify eligibility and provide case management services.

Homes For Life was founded in 1999 by Micki Edelson and her husband Dr. Lanny Edelson. Through the

foundation, they have raised the funds, constructed, and furnished a total of 25 group homes in New Castle County and donated 21 of them to The Arc. The Edelsons have an adult son with an intellectual disability who lives in one of The Arc's group homes.

"The revitalized Riverfront area where these condominiums are located offers an incredibly rich mix of cultural, recreational, employment and other community integrated opportunities," said Terry Olson, Executive Director, The Arc of Delaware. "We believe that the persons with intellectual disabilities

who choose to live in these condominiums will enjoy an incredible quality of life. We are extremely grateful to Homes For Life for the gift of these condominiums and their continuing support of The Arc of Delaware and the persons with disabilities and their families who it is our mutual mission to serve. We are also extremely grateful to the state's Division of Developmental Disabilities Services for their partnership with The Arc and for funding the cost-effective services which will be provided within these beautiful new condos." ■

A Powerful Film, Conveying the Value of the Lives of People with Disabilities

Film is a powerful vehicle for a message, and a short film called *Menschen* packs a punch. The movie *Menschen* highlights a dark time in history. During World War II, Adolf Hitler enacted the T-4 program. This program's purpose was to eliminate – murder those deemed “incurably ill” – people with mental illness, physical disabilities, or intellectual and developmental disabilities. Throughout the course of the war, from 1940-1945, approximately 200,000 people with disabilities were killed under the T-4 program.

Menschen tells the story of an Austrian captain, who takes under his wing a boy with a developmental disability, bringing the loyalty of his men to the test as a secret from his past comes to light. Throughout the filming, filmmaker Sarah Lotfi strived to convey the seriousness of the film's subject matter, alongside the profound humanity of the characters.

One of the lead characters is played by Connor Long, an actor with Down syndrome. And the film's director, Lotfi, is a sibling of a brother and sister with Down syndrome, whose connection to the issues made writing and directing this film very personal.

At the the same time *Menschen* is under consideration in the film industry's current award season, an evolutionary biologist, Richard Dawkins, has made headlines recently

for advising women who learn they may have a child with Down syndrome that abortion is the best option. People with Down syndrome and their families across the globe are echoing the same message – this can't happen again. The outdated notion that the life of a person with Down syndrome is somehow less worthy than anyone else defies decades of progress to expand the rights of people with disabilities and showcase their ability, not their disability.

The Arc is partnering to promote this film while it is under consideration in the film industry's current award season because it showcases why this can't happen again. Long and Lotfi exemplify what people with disabilities can do when people are open to the ability, not the disability, of all people.

Chapters are encouraged to contact The Arc's national office to arrange a screening of *Menschen* in their community. This is a fantastic opportunity to educate about what people with I/DD can do, and support a great film and filmmaker! For more information, contact Monica Sanjur, Marketing Associate, Sanjur@thearc.org. To learn more about the film visit www.menschenthemovie.com. Or you can connect through social media with Facebook (<https://www.facebook.com/menschenmovie>) and Twitter (@menschenmovie). ■



Learn more about this film, reviewed by blogger Kari Wagner-Peck - <http://atypicalson.com/2014/10/31/not-all-history-is-remembered-equally-why-you-must-see-the-film-menschen/>

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history of Mardi Gras.

The convention drew to a close on Thursday afternoon with a sneak preview of the documentary film *Children of the Dumping Ground*, followed by a discussion with the film's producer, Chip Warren, led by The Arc's Program Manager for Justice Initiatives, Leigh Ann Davis. Board President Nancy Webster presented the President's Award to Dr. David Braddock for his research regarding long-term care, health promotion and disease prevention, and public policy toward people with intellectual and developmental disabilities, and Jim Ellis was presented with The Arc's 2014 Advocacy Matters Award.

One of the highlights for many of the participants were the powerful self-advocates who shared their stories. During the opening session, Betty

Williams of Indiana spoke about the importance of employment for individuals with I/DD and how The Arc has given her meaningful employment. Shaun Bickley of Texas had the crowd cheering as he spoke about his personal journey as an individual with autism. In fact, his speech was so powerful he has already

been booked for another speaking gig. And finally, during the closing general session, James Meadours, a nationally-known leader in self-advocacy and a sexual assault survivor, shared his personal story of multiple instances of abuse and how his local chapter of The Arc supported him along the way. ■

If you attended convention and are interested in having Shaun, Betty or James speak at an event, you can find their contact information below:



Shaun Bickley
sbickley@thearcoftexas.org
or 800-252-9729 ext. 7747



Betty Williams
317-977-2375



James Meadours
jetstr31@aol.com

Understanding a Child's Right to Special Education

By Mary T. Schmitt Smith, CELA, Special Needs Alliance

Pioneering efforts by staunch parent advocates led to enactment of the Individuals with Disabilities Education Act (IDEA). This law guarantees students with I/DD a “free and appropriate education in the least restrictive environment possible.” But the language in the law and regulations is often vague, leaving details to be worked out by states and school districts.

With budget cuts and a growing, diverse population of children needing services, tensions can build between families and local schools. Parent advocacy is as important as ever, but there is a learning curve full of acronyms. The special education process is complex and varies significantly among states. This process can be intimidating, so it's important to know your child's rights.

Federal law requires that all school districts:

- identify children entitled to receive special education services;
- develop and implement an Individualized Education Program (IEP) for each eligible student;
- pay for necessary services to be delivered elsewhere if they cannot provide them.

Evaluation and IEP

Schools must pay to have an assessment of a child's physical, social, psychological and behavioral development. Families can also provide any outside evaluations. Together, a determination is made whether the student is entitled to receive special ed services. If so, then an IEP team — including the parents — is developed. The IEP outlines written goals for the school year and how they'll be measured and achieved. It addresses academics, physical education, and social and life skills. Consideration must be given to delivering services in a mainstream classroom (inclusive), and/or goals better met in a separate, more intensive environment. A student's eligibility for special education must be assessed every three years. Special education students may receive services from the public school system until graduation or age 22 (26 in Michigan).

Family Rights

Parents are entitled to attend all IEP meetings and to receive a written copy of the IEP, which must be evaluated at least annually. Parents must be notified of all plans to evaluate a student or change an IEP, and they can call an IEP meeting at any time to address concerns about the plan.

If the parents disagree with the IEP, they are entitled to an impartial hearing. Since such proceedings can be daunting, they may find it helpful to work with a professional advocate such as a special needs attorney. If necessary, they can carry their grievance to the federal courts and, if successful, are entitled to reimbursement of attorney fees. Other advocacy resources for parents include chapters of The Arc, state protection and advocacy agencies, parent information and resource centers, and private educational consultants.



Special needs require special attorneys.

Transition Planning

By the time a student is 14, the IEP should address “transition planning,” skills needed in adulthood. Since the child's personal goals should shape the curriculum, his/her involvement becomes increasingly important. Considerations include employment options, housing and independent living skills. Nutrition, travel skills, handling of money, appropriate behavior around strangers and much more should also be addressed, with the goal of becoming as independent as possible.

Upon the student's 18th birthday, he/she is considered a legal adult, so parents need to determine whether a power of attorney or other legal authorization is needed to keep participating in the student's education and other aspects of their lives such as health care and personal finances.

Community-based vocational initiatives should be investigated as early as possible during the transition process. Many localities coordinate job fairs where special ed students can explore opportunities. Local chapters of The Arc can be a useful source for available employment supports.

While the special education system can be both confusing and frustrating, its goal is building the foundation for a self-directed, fulfilling life. Knowing how to effectively work with the school district can make all the difference.

SNA (www.specialneedsalliance.org) is partnering with The Arc to provide educational resources, build awareness, and advocate for policies benefiting people with I/DD. The author is the founder of the Theresa Law Center (www.theresalaw.com). ■



Wings for Autism® Taking Flight Across the Country

In January, The Arc began national expansion of Wings for Autism® one of The Arc's newest national initiatives. Wings for Autism®, is an airport "rehearsal" specially designed for individuals with autism spectrum disorders and other intellectual and developmental disabilities, their families and aviation professionals.

This year alone, Wings for Autism has landed in Washington state, Florida, Alaska, Oklahoma, North Carolina, Arizona, Virginia, Washington, DC, and Maryland (scheduled for December). There are a number of events scheduled for 2015, and even more in the works. To learn more about this program visit, www.tharc.org/wingsforautism or contact Karen Wolf-Branigin, Senior Executive Officer, National Initiatives at wolf-branigin@tharc.org.

Upcoming events with tentative dates in 2015:

- Memphis, TN (Memphis International Airport) – Winter 2015
- West Columbia, SC (Columbia Metropolitan Airport) – Spring 2015
- Chicago, IL (Chicago Midway International Airport) – Spring 2015
- Lehigh County, PA (Lehigh Valley International Airport) – Spring 2015
- Augusta, GA (Augusta Regional Airport) – Spring 2015
- Los Angeles, CA (LAX) – Spring 2015
- New York, NY (LaGuardia) – Spring 2015



Wings for Autism® would not be possible without the commitment from our airport and airline partners. The Arc currently has several airports that are eager to bring Wings for Autism® to their communities. If your local chapter is interested in partnering with the airports listed below to host a Wings for Autism event, please contact Karen Wolf-Branigin at wolf-branigin@tharc.org.

- Hartsfield-Jackson Atlanta International Airport (Atlanta, GA)
- Bill and Hillary Clinton National Airport (Little Rock, AR)
- Kansas City International Airport (Kansas City, MO)
- Denver International Airport (Denver, CO)
- Mobile Regional Airport (Mobile, AL)
- George Bush Intercontinental Airport (Houston, TX)
- San Francisco International Airport (San Francisco, CA)

The Path to Diversity

In our current global society, there is no longer the luxury of believing we already know the needs of a diverse I/DD population, a community that varies by race and ethnicity as well as gender, sexual orientation, religion, age and socio-economic status to name a few. The knowledge, skills and abilities that are now needed to be effective require an expansion to a broader pool of candidates who can understand and manage the diversity in their organizations and also within the diverse communities they are operating. For The Arc and its chapter network to realize their potential, and maximize their impact, there must be recognition that diversity is everywhere and that it is inevitable and beneficial.

To realize the benefits from diversity, The Arc is looking to expand its current organizational practices to reflect greater diversity and cultural competency. Creating a workforce that will support and enhance the work of chapters of The Arc requires the energy and input of the entire organization. In addition, a successful diversity strategy is needed to ensure the goals of your diversity initiative stay aligned with those of the organization. This strategy will define what success looks like for The Arc and its chapter network and put actions in place to help the organization achieve its mission and objectives.

Introducing diversity to a chapter is a process that can produce just as many challenges and fears as found in any

organizational change initiative. And as with any other change process, the rewards and benefits far outweigh the perceived safety of maintaining the status quo. Building a diverse workforce, however, is just one step in the process. When your workforce is diverse, you need to ensure that you have an environment that values inclusivity, commitment and accountability, fully utilizes the talents and skills of all employees, and maintains organizational viability by meeting stated goals and objectives.

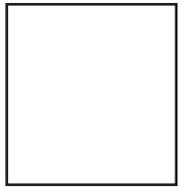
As part of the work of The Arc's Cultural Diversity Initiative, we look to help our chapters identify how diversity can best help them, recognizing that the impact will vary from organization to organization. For The Arc, diversity is the key to moving our organization forward, because without diversity at every level of our organization we will not be able to advance our mission. Diversity is an asset in developing and implementing long-term programs and solutions for our members and those who are served by our chapters, who come from a wide variety of cultural, ethnic and religious backgrounds.

If you have thoughts on how The Arc can better reflect the communities in which we serve, please contact Dawn Cooper, Manager, Diversity and Cultural Competence at cooper@tharc.org. ■



For people with intellectual
and developmental disabilities

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Donate that Clunker!

Do you have an old car that you need to get rid of? Consider donating it to The Arc before the end of the year so you can take a tax break and help people with I/DD at the same time. Simply call 1-877-ARC-2270 or fill out an online form at www.thearc.org/donate-my-vehicle and a representative will make arrangements to pick up or tow a vehicle, sell it at auction and deliver the cash proceeds directly to The Arc.



Save the Date – Disability Policy Seminar!

The 2015 Disability Policy Seminar will take place April 13-15, 2015 at a new location – at the Renaissance Washington, DC. Stay tuned for more details on registration at www.thearc.org

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! ■



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