



empower

Real People, Real Progress

Issue 18 | Spring 2014

Wings for Autism[™] Taking Off Nationwide!

This year, Wings for Autism[™] began national expansion with events in Seattle, Washington; Jacksonville, Florida; Anchorage, Alaska; and Tulsa, Oklahoma, with more in the planning stages across the country. Wings for Autism, one of The Arc's newest national initiatives, is an airport "rehearsal" specially designed for individuals with autism spectrum disorders, their families and aviation professionals. Originated by the Charles River Center, a local chapter of The Arc in Massachusetts, and the Massachusetts Port Authority, Wings for Autism is designed to alleviate some of the stress that families who have a child with autism experience when traveling by air. The program provides families with the opportunity to practice entering the airport, obtain boarding passes, go through security, and board a plane.

Wings for Autism also gives airport, airline, Transportation Security Administration (TSA) professionals and other personnel the opportunity to observe, interact and deliver their services in a structured, learning environment. This experience is equally useful for families that have a member with other intellectual or developmental disabilities



(I/DD) who are concerned about the ability of their family member to travel.

One of the most powerful parts about this program is the fact that everyone involved benefits, from participants to airline personnel.

Ray Prentice, Director of Customer Advocacy for Alaska Airlines, which was a partner for the event at SeaTac Airport in Seattle and at Ted Stevens Airport in Anchorage, was thrilled to share how beneficial he found the training, "I

didn't realize until this event that a little bit of additional training and guidance, combined with our great caring employees, could totally change people's lives. Speaking on behalf of Alaska Airlines' volunteers I can openly share that we had a blast. We felt a close connection with everyone at the event."

The program's first few events have been extremely successful, with 445 participants in total. One mother who participated in an event at the Ted Stevens Airport in Anchorage, Alaska shared her personal experience with staff of The Arc's national office in a

The Arc, Breaking New Ground!

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



Nancy Webster

Welcome to spring, an especially uplifting thought this year after many of us are eager to feel warmer weather and to see new sprouts breaking ground.

The Arc too is breaking new ground: 2013 was rich in new initiatives that support our chapters and our families – initiatives like HealthMeet, Wings for Autism, the National Center on Criminal Justice and Disability, and the Fetal Alcohol Spectrum Disorders (FASD) Preven-

tion Project. And we are pleased to begin 2014 breaking ground on more growth and opportunity. The Arc is thrilled that it has been awarded a grant for \$100,000 from the MetLife Foundation to make the programs, services, and supports offered by The Arc nationwide more accessible to culturally diverse populations with I/DD and their family members, and to ensure that our chapters are addressing the needs of the different cultures in their communities.

As you know, in 2013 The Board of Directors and staff of The Arc committed to making diversity a priority initiative. Last May, the Committee on Diversity was created, and it IS

diverse, consisting of 23 people with I/DD, parents, siblings, staff and volunteer leaders, as well as experts on diversity from large national businesses and academic centers. Because of this wonderful grant from the MetLife Foundation, we will be able to achieve our goal to have The Arc grow to include more diverse populations so that we continue to promote inclusion and civil rights for truly all individuals with I/DD and their families.

As part of this initiative, The Arc has already begun a comprehensive assessment of the cultural competence within our network of nearly 700 chapters. This assessment will include substantial input from The Arc's chapters as well as from current and potential stakeholders in ethnically and culturally diverse communities across the country. In the course of the assessment, The Arc will collect information about best practices in serving diverse populations (including health care, social services and other non-profit and for-profit industry segments that serve individuals with I/DD).

As a result of this assessment, The Arc will report and identify the challenges professionals and volunteers face when serving people with I/DD from many diverse backgrounds. The Arc expects to develop an action plan defining specific tactics that can and will be undertaken by our chapters to achieve greater cultural competency.

This is exciting work for us to be doing – learning, understanding, reaching, growing, breaking new ground – so The Arc will be able to better serve all communities across the country.

Getting started is always challenging with an initiative of this nature and we need your active participation to make it successful. Are you or your chapter working in or with diverse communities and want to share successes, challenges and best practices? Are you looking to understand more about the impact of culture on your advocacy, services, and supports? Are you a self-advocate, family member, volunteer or staff member who would like to share your insights or experiences with discrimination? Would you like to help The Arc realize our full potential by effectively leveraging diversity and cultural competence? If you answered yes to any of these questions, then we want to hear from you. Please call or contact Dawn Cooper, our new Manager, Diversity and Cultural Competency at 202-600-3487 or at cooper@thearc.org and share your experiences, questions, stories, and ideas today! We look forward to hearing from you. ■

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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

The Arc to Launch New National Resource Center for Future Planning

The Arc is excited to announce it has been awarded \$800,000 over two years by the May and Stanley Smith Charitable Trust to develop a National Center on Future Planning for families and individuals with I/DD.

The goal of this project is to support the estimated 600,000-700,000 families in the United States where an adult with I/DD is living with aging family members and there is no plan for the individual's future. The Center will empower aging caregivers to take the important first steps to plan for the future of their adult son or daughter with I/DD, providing families with information, resources, and practical assistance in person-centered planning; guardianship and supported decision-making; housing and residential options and supports; special needs trust and representative payee services; financial planning; and personal care and independent living supports.

The Arc's new Center for Future Planning will have a robust online presence, with an interactive and user-friendly website geared toward older learners,

"There is a silent crisis facing our country that desperately needs a solution – what happens when there is no plan for how an individual with an intellectual or developmental disability will live life to the fullest when the loved one they live with is no longer with them? In the last twenty years, people with disabilities have made great strides to live independently, be a part of their community, and experience all they want in life. But too many people are facing the next chapter in their lives without a plan, and The Arc is seeking to provide help to families and people with disabilities looking for that roadmap."

~ Peter Berns, CEO of The Arc.

with extensive, vetted content. The website will include a database of sources for local and state-based information, people, and related organizations, and a searchable provider database. The Arc will also operate a telephone and online information and referral system, connecting people to help in their communities.

Chapters of The Arc will play a critical role in this Center, as they will be able to access best practice protocols when providing future planning resources in their local communities. The Center will also feature a National Pooled Special Needs Trust, develop

protocols and business infrastructure to provide private trust companies with outsource assistance in servicing existing and future beneficiaries under individual special needs trusts, create training and networking opportunities for families and professionals in the field, and establish a volunteer action network. This new network will pair self-advocates with volunteers without disabilities to visit people with I/DD in community settings and monitor their satisfaction and quality of life.

Stay tuned on The Arc's website, www.thearc.org, as this project launches later in 2014. ■

Wings continued from page 1

beautifully worded letter. In her letter, Katherine detailed her family's experience and the benefit for her son Jack, who is on the autism spectrum.

"Jack still has worries about taking off/landing, and getting sick on the plane. We will cross those hurdles as they come. Yet, this experience with Wings for Autism gave us something we normally could never obtain, which was practice in an airport and on a real aircraft. Who gets to have that?! I don't think I can fully punctuate how important and valuable this experience was to our family and to Jack; all I can say is thank you, and hope it is a program that can be repeated so more families can benefit like we did."

Nothing sums up the experience better than hearing directly from children who participated and benefitted from the program. Mariah Jarvis attended the event in Jacksonville with her three children Emma-Lee, Kathleen, and Ross.

Kathleen and Ross are both on the spectrum and Emma-Lee serves as a right hand for her mother helping to support her siblings.

For Kathleen the inclusive nature of Wings for Autism made the event special, "I liked that we weren't judged for who we are, they supported us." As for her brother having some of the comforts of home like TV with a familiar show made the experience enjoyable.

For information on bringing Wings for Autism to your community, contact Karen Wolf-Branigin, Senior Executive Officer, National Initiatives for The Arc at wolf-branigin@thearc.org. ■



Ross and big sister Emma-Lee buckled in and ready to go.

What Do You Think It Takes To Make A Champion?

Depending on the scenario, there are plenty of answers that spring to mind: hard work, dedication, inspiration, or selflessness. While the term “champion” is used in many contexts, for The Arc someone who defines the term perfectly is David Dassau.

For the past five years, David has not only been Ben’s brother, he has also been his full-time professional caregiver. For David, there is no greater calling than helping his brother live independently and fulfill his dreams. The joy it brings David led him to put his own career on hold to provide Ben with the highest quality of life possible. That is why David is a champion.

Without David’s passion and dedication, Ben’s goals and dreams would be much more difficult for him to attain.

“Ben has challenges around every corner,” his brother says, “but he doesn’t let them stand in his way. He accomplishes his goals, no matter



David and Ben Dassau

what. I remind myself of this every day, and try and live my life like my brother.”

For personal support and guidance, David regularly communicates with his local chapter of The Arc. One of our

nearly 700 chapters, The Arc of Davidson County in Nashville, Tennessee is a tremendous resource for David, supporting his life as a caregiver.

“Working with The Arc is nothing short of amazing, with the services and insight they provide, the real value is in the collaboration to help me plan out Ben’s short and long-term goals so they can be realized,” David says.

From Davidson County, to our nation’s capital, and right in your own city, The Arc is working to promote inclusion and provide support through a number of programs, as well as public policy and advocacy at the local, state and national levels. The Arc helps champions like David to better support their siblings.

Just like David and Ben, our supporters are our champions too! Please become a champion for The Arc and help people with I/DD live the life they deserve with a tax-deductible gift today! ■

Two New Programs of The Arc Launch Web Resources:

The National Center on Criminal Justice and Disability (NCCJD)

<http://www.thearc.org/NCCJD>

NCCJD is a national clearinghouse on criminal justice and disabilities, funded by the Bureau of Justice Assistance (part of the U.S. Department of Justice). NCCJD is unique to other resources because it covers both victim and suspect/offender issues in one convenient location, empowering criminal justice and disability advocates with the information and tools they need to provide meaningful support for people with disabilities in the criminal justice system.

The Fetal Alcohol Spectrum Disorder Prevention Project

<http://www.thearc.org/FASD-Prevention-Project>

Fetal Alcohol Spectrum Disorder, or FASD, is the single most common cause of I/DD that is 100% preventable. The goal of the FASD Prevention Project is to increase health care provider knowledge of the risks alcohol can pose to a fetus and encourage the use of FASD prevention strategies and provide educational opportunities to health care providers, specifically family practitioners, internists, pediatricians, obstetrician/gynecologists, physician’s assistants, midwives, nurse practitioners, registered/licensed practical nurses, mental health therapists, substance use therapists, and community health representatives.

The Fetal Alcohol Spectrum Disorder Prevention Project is a national initiative of The Arc funded by the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA).

Providing Employment Opportunities and Promoting the Importance of Recycling

Over the last few years, The Arc's recycling initiatives have created environments in which individuals with I/DD who want to work, receive the training and support they need to provide valuable recycling services to businesses and their communities. Last year, thanks to generous funding from the Alcoa Foundation, The Arc expanded these recycling initiatives to three new chapters. Each chapter's program supports employment and skill development for individuals with I/DD and takes us closer to our goal of promoting the importance of recycling as a means for environmental sustainability in local communities. Here's how they're doing it:

The Arc of Knox County –



Ricky, Robert, Kimica, Nick and Mark pose in front of the cardboard baler they were trained to use.

In Tennessee, The Arc of Knox County decided to leverage an existing relationship with Second Harvest Food Bank to create a new recycling program that both provides employment opportunities for individuals with I/DD and helps Second Harvest recycle the large amount of plastic and cardboard materials they take in from boxes of donated food.

The satisfaction of having a job and earning a competitive wage doing work for an organization like Second Harvest can mean a lot to someone with a disability. For Robert Harb, that joy comes from getting ready for work each day - putting on his work pants and going to his job evokes a great sense of pride. Last year when the program began, Robert showed interest in the opportunity and agreed to visit the site with his job coach. After seeing the work first hand he decided he wanted the job, but was informed that his usual sweat pants weren't appropriate work attire. He agreed with this requirement and embraced this change in his daily routine. He was provided with several pairs

of khakis and blue work pants and he now arrives each morning wearing the appropriate pants and with a great attitude. Overall, Robert has shown an increased awareness of the importance of good hygiene as well as a renewed dedication for doing his very best work. He is even saving money to expand his work wardrobe, as his career with Second Harvest continues to grow.

Ulster-Greene Arc –



Team Member Craig Nickerson, Team Leader Theo Raddice, and Team Member Sharon Robertin take a break from sorting products to smile for the camera.

In the spring of 2011, Theo left Ulster-Greene Arc's sheltered work center to work at a neighborhood bottle and can redemption center. The job was a good fit for him and allowed him to earn a decent paycheck, but unfortunately the center closed and Theo was left jobless. Undeterred, Theo began exploring the idea of creating a bottle and can redemption center within Ulster-Greene Arc, showing tremendous initiative. In January 2012, the agency proudly opened Theo's Bottle and Can Return, and with additional funding from The Arc through its recycling initiative, the program was able to expand.

The business currently employs eight individuals with I/DD at minimum wage or above and collects approximately 38,880 refundable items (aluminum, glass and plastic containers) weekly. From the time the products enter into the recycling centers, employees with I/DD are involved in every aspect of the job including the sorting and packaging of materials for shipment. Ulster-Greene Arc has created an environment in which customers can be helped quickly and efficiently, while workers with and without disabilities work side by side showcasing their talents and contributing to their community.

Opportunities continued on page 7

The Arc and Special Needs Alliance Forge a Strategic Partnership

The Arc and Special Needs Alliance (SNA) have formed a strategic partnership to collaborate at the local, state and national levels on issues of mutual interest. We will explore wide ranging opportunities to provide educational resources to families, build public awareness, and advocate for legislative and regulatory change.

SNA is a national non-profit comprised of attorneys who assist individuals with disabilities, their families and the professionals who serve them.

The average SNA attorney has nearly two decades of legal experience relating to public benefits, guardianships and conservatorships, special needs planning and special education. Many of them have family members with disabilities, enriching their work with personal insight. They understand how daunting it can be to navigate government programs with a bewildering array of eligibility regulations and to plan for the long-range security of a loved one.

Many SNA members are already active within The Arc and its chapters, and many more plan to volunteer their services in the coming months. Brian and Benjamin Rubin are prime examples. Brian, who is an SNA board member, currently

serves as president for The Arc of Illinois. He has been a board member for this chapter for the past decade, in addition to serving as a board member for his local chapter of The Arc. As father to Mitchell, an adult with autism, he has long advocated for improved services to support individuals

with intellectual disabilities and has represented The Arc of Illinois on many State of Illinois commissions.

Another son of Brian's, Benjamin, who is an affiliate SNA member, is president of the Illinois chapter of the Sibling Leadership Network and will soon begin a three-year term on

The Arc of Illinois board. Benjamin's sibling perspective has proven invaluable to both clients and the many volunteer activities to which he devotes himself. Father and son regularly speak about future planning at workshops hosted by chapters of The Arc throughout the state.

SNA attorneys are community activists who are deeply familiar with the daily complexities faced by self-advocates and their families. They have striven for change at every level of government and understand how much remains to be done. For more information, visit www.specialneedsalliance.org. ■



New Affordable Care Act Resources from the National Disability Navigator Resource Collaborative

The Arc has worked with the National Disability Navigator Resource Collaborative (NDNRC) to develop resource materials aimed at helping people with disabilities enroll in

private health insurance available through the marketplaces created by the Affordable Care Act (ACA). As part of this work, The Arc assisted in developing a "Guide to Disability for

Healthcare Insurance Marketplace Navigators" designed to inform "navigators" and other enrollment specialists about special considerations people with disabilities face as they shop for healthcare coverage. The Arc encourages chapters and members to share the availability of the guide and other

resources with ACA navigators in their community – <http://www.nationaldisabilitynavigator.org/>.

The NDNRC is comprised of seven national disability

organizations representing unique cross-disability experiences including The Arc, American Association on Health and Disability (AAHD), American Association of People with



Disabilities (AAPD), Disability Rights Education and Defense Fund (DREDF), National Alliance on Mental Illness (NAMI), the National Multiple Sclerosis Society (NMSS), and United Spinal Association. The NDNRC is funded through a grant from the Robert Wood Johnson Foundation. ■

Fulfilling Dreams as Big as Texas

The Arc of Bristol County in Massachusetts is well known for supporting many individuals with big dreams... some might say dreams as big as the state of Texas! One big dream for several of the chapter's clients was to go to an authentic Texas dude ranch.

Striving to make this dream a reality, The Arc of Bristol County's CEO Michael Andrade reached out to Hammer Travel, a nonprofit organization providing customized travel experiences for people with I/DD. Hammer Travel's Give Back Program was designed as an ideal way for those supported by organizations such as The Arc to have big dreams come true. The Give Back Program focused on supporting The Arc of Bristol County in planning all aspects of travel plus providing support to the chapter through a donation if eight or more people registered for this trip.

Along with Hammer Travel's trip leaders, The Arc of Bristol County was able to send along a few of their direct support professionals to help the dreams, support needs and desires of each of the individual travelers to make the trip a success.

In October of 2013, the dreams of 14 people with I/DD became a reality. Hammer Travel provided staff to assist The



Arc's staff with navigation through the Providence, Rhode Island airport on their way to Bandera, Texas. After a day of travel, the group arrived at a dude ranch and settled into their cabins. While at the ranch, travelers took therapeutic horseback rides and participated in sing-a-longs, campfires, hay rides and much more. Hammer Travel's staff, working with the staff of The Arc, was able to ensure each individual traveler's needs and expectations were being met. And following the trip, The Arc of Bristol County received a donation from Hammer Travel to support their mission.

Find out more about Hammer Travel and the Give Back Program at www.hammertravel.org. Hammer Travel is a member and sponsor of The Arc's national organization. ■

Opportunities continued from page 5

The Arc Montgomery County –

The Arc Montgomery County, in Maryland, has been involved in recycling since 2005. Since then, the chapter has trained and supported both paid and volunteer workers with I/DD and has fostered inclusive work environments. Thanks to funding from The Arc the Textile Recycling & Collection Program ("TRCP") expansion began in January 2013, utilizing various capabilities of The Arc Montgomery's Thrift Store and document destruction business.

After several meetings with its senior executives, Asbury Methodist Village decided to launch a TRCP Multi-Day Container Collection Program for their entire community and agreed to host a permanent drop-off location for textile

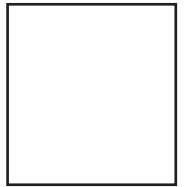
donations. With 823 independent living units, 122 assisted living units and 285 nursing supported units, Asbury Methodist Village, is the 12th largest Senior Living Community in the country.

Asbury Methodist Village has also asked individuals with I/DD to volunteer as collection helpers which led to them expressing an interest in hiring workers with I/DD to serve meals and arrange tables in their cafeteria and to assist recreational and social activities for seniors. Asbury Methodist Village is one of Montgomery County's largest employers, generating economic growth and opportunities for philanthropic involvement – and now generating opportunities for people with I/DD as well. ■



For people with intellectual
and developmental disabilities

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inside:

*Wings for Autism™ Taking
Off Nationwide!*

*The Arc, Breaking New
Ground!*

*The Arc to Launch New
National Resource Center
for Future Planning*

*What do you think it takes
to make a champion?*

*Two New Programs of The
Arc Launch Web Resources*

*Providing Employment
Opportunities and
Promoting the Importance
of Recycling*

*The Arc and Special Needs
Alliance Forge a Strategic
Partnership*

*New Affordable Care Act
Resources from the National
Disability Navigator
Resource Collaborative*

Calling Self-Advocate Entrepreneurs!

Are you an individual with an intellectual or developmental disability who owns a small business? Spots are available in Entrepreneur Alley for self-advocates to showcase their business enterprises at The Arc's National Convention, this year in New Orleans September 30-October 2. We offer a highly reduced rate of only \$100 per exhibit for those who sign up before June 30. And, for those self-advocates who can't travel to New Orleans, we also offer "The Market" – an opportunity for us to sell or promote items for you. Contact Sarah Kennedy at skennedy@thearc.org or at 202-534-3720 for more information or to sign up today. ■



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! ■