



empower

Real People, Real Progress

Issue 11 | Fall 2012

Wings for Autism – A Test Run

As parents of children with autism spectrum disorders are well aware, everyday tasks can sometimes prove to be far more difficult for their child. Parents of children on the spectrum have a lot to take into consideration before making travel arrangements, from how they will respond to the lights at the airport, will they be comfortable with airport security talking to or touching them, to how the noise on the plane will affect their child.

To address these and other concerns, The Charles River Center (a chapter of The Arc), in collaboration with Massachusetts Port Authority, JetBlue, and the Transportation Security Administration (TSA), has created a new program called Wings for Autism. The program sets up simulations of airport travel and security at airports across the country, giving families an opportunity to see how their loved one on the spectrum will deal with the many aspects of airline travel.

In May, Wings for Autism held a workshop at Logan International Airport in Boston, MA. This was an opportunity for airport officials, airlines and TSA staff to learn about the program and how each of their orga-



Cameron is on the autism spectrum and was completely non-verbal until a Wings event in November at Logan Airport where he said “airplane” while sitting on the plane. That was the first word that he had ever spoken at 5 years old. His mother Nancy reassured him with “yes Cameron, you are on an airplane.” Nancy says: “It is a moment I will never forget and I will always be grateful to the Wings for Autism program for that.”

nizations can create a successful Wings for Autism event at their local airport. The event gave parents and children a “test run” where they went through every step of traveling on a major airline. With volunteers from JetBlue including flight attendants and pilots, staff from United Airlines, TSA officials, ticket counter agents, and collaboration with other airlines and their staffs, the simulation truly prepared parents and children for what to expect when traveling. The simulation required families to clear security, board the plane, fasten their seatbelts, and prepare for take-off. The exercise even included a tour of the cockpit given by a pilot.

For children who had issues with the various steps of the simulation, behavioral specialists were on hand to help parents and children work through the exercise.

While the program’s primary goal is to help children and parents, there is also an orientation process for TSA and airline staff. Jennifer Robtoy, Director of Autism Support for The Charles River Center, provided a brief training for the staff in Boston before the start of the simulation which included what to expect, encouraged questions, and taught them that parents are their best resource with a child on the spectrum.

Achieve with us.

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The Arc's Turnaround

By Mohan Mehra, President of The Arc's National Board of Directors



This is my last column in Empower as I finish my term as President of the Board of Directors in October.

It has been a privilege and an honor to serve you in the past two years. During this period, you have invited me to join in your State conventions or meetings in eleven states. I have benefitted greatly by meeting with your boards, families, self-advocates, and the

staff of your chapters and learning about your accomplishments and challenges. I thank you from the bottom of my heart. Most importantly, I have learned that the greatest strength of The Arc is our network of more than 700 chapters and a national leadership that truly recognizes this.

The Arc is on a path for significant achievements on behalf of people with intellectual and developmental disabilities (I/DD) and their families. In the past few years, we built a foundation for and better defined the role of the national organization. This will help The Arc solidify its place as one of America's leading charities. As Alan Sampson, the first President of The Arc said, almost sixty years ago, "Yes our ambitions are mighty, but our program is not for today, nor tomorrow, but for years to come."

So, what are the key elements of this foundation?

A New Brand Identity: This more clearly defines what The Arc brand stands for and how we communicate that to the public. About half of our chapters have adopted it so far with more coming on board daily. This will unite our chapters, better harness our collective power, and help raise public awareness. We further strengthened our network with new state chapters in Idaho, Montana and a state office in Nevada.

A New Set of National Bylaws and Terms and Conditions for Chapter Affiliation: This will help make The Arc a more unified federation. These will be presented to the chapters for approval at the Convention later this year.

Integration of The Arc's Public Policy Team: With the end of our policy collaboration with United Cerebral Palsy, The Arc's national staff – including public policy, community organizing, media relations, and social media – are working in tandem under one roof in one office. A major accomplishment was protecting Medicaid against significant cuts during the 2011 Congressional session. This was accomplished with the "Don't Cut our Lifeline" campaign during which we flooded Capitol Hill with our message as well as arranged personal visits by families to the Administration staff. President Obama himself commented on this when the leaders of The Arc were invited to the White House in February 2012 to a briefing by the Administration. And the newly formed National Sibling Council will further engage siblings and strengthen our advocacy efforts.

Improving our Understanding and Response to the Changing Needs of People with I/DD: The Arc established Autism NOW: The National Information and Resource Center with a \$2.6 million grant from the Administration on Developmental Disabilities. It served over one million people last year through webinars, e-newsletters and social media. We also broke new ground by conducting the Family and Individual Needs for Disability Supports (FINDS) survey to find out how the nation is meeting its promise of productive, quality lives for people with I/DD. The survey showed that there is much more to be done. To further engage people with I/DD in shaping service delivery and advocacy, we established the National Council of Self Advocates of The Arc.

Supporting State and Local Chapters with New Resources: We secured a \$3 million grant from Walmart Foundation to support the School-to-Community Transition project, funding programs at 49 chapters across the country. And we have other exciting opportunities on the horizon for chapters and those they serve.

It has been an honor to be a part of the leadership team of The Arc at this exciting time. *Achieve with Us!* ■

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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 Reacts to the U.S. Supreme Court's Decision on the Affordable Care Act

By Marty Ford, Director of Public Policy for The Arc

People with intellectual and developmental disabilities have been waiting for generations for the insurance reforms put in place by the Affordable Care Act. The Supreme Court's ruling removes any doubts that the law Congress enacted should stand and will benefit millions of people with and without disabilities. It ends discriminatory insurance practices and makes health coverage more affordable and accessible – important protections which too many people with disabilities have been deprived of

for too long. Go to blog.thearc.org for the top reasons why The Arc supports the law.

But the ruling is not perfect for people with I/DD. The Arc is concerned that disallowing the federal government the ability to withhold Medicaid dollars from states that don't expand their program to cover more of the uninsured might mean that people with I/DD who would have benefitted from the expansion could be left behind. Medicaid is an incredibly important lifeline for people

with I/DD, providing health care and long term services and supports.

We will carefully watch how states react to this development and encourage our advocates across the country to put pressure on their state leaders to do the right thing and expand their Medicaid program. And keep an eye on our website, www.thearc.org, for additional analysis. To get involved with our legislative advocacy efforts, sign up for our Action List at <http://capwiz.com/thearc/home/>. ■

Growing Their Network, Speaking Up in Congress — Self Advocates with FASD in Action!

The Arc, together with the federal Substance Abuse and Mental Health Services Administration (SAMHSA) the Fetal Alcohol Spectrum Disorder (FASD) Center for Excellence, is leading an innovative initiative for self-advocates that has had an exciting year.

Since its launch in the spring of 2011, the Self-Advocates with FASD in Action, or SAFA Network, has built and supported a network of people with FASDs to take on leadership roles in the disability movement. The main effort over the last year has been to organize, attend, and help facilitate a self-advocacy track at an annual SAMHSA-funded meeting on FASD.

Throughout its first full year of operation, the SAFA Network promoted its efforts and recruited new members at conferences in Colorado, Washington, DC, Georgia, and Virginia. And the group took the opportunity to network with and educate participants about the need for services and supports for people with FASD at state level at conferences in Arizona and Virginia.

Jean Searle, a SAFA member and the Co-President for The Pennhurst Memo-



rial and Preservation Alliance, is a long-time self-advocate and a force within the disability rights movement. Jean has experienced the trauma of institutionalization first-hand. Encouraged by advocates and friends, Jean moved out to assisted living arrangements in 1984. Jean recently connected with the SAFA Network, and shared her experience: "When I was in Virginia I was a little scared because I did not know anyone and wonder if I was going to fit in with other people and as soon as I told my story about Pennhurst and being a Co-President with my friend Jim, people just open up to me and I felt very wel-

comed with open arms and people was happy to hear my story. I like talking to strangers and making them think about how hard it is for a person like me to be disabled and talking to the whole world and feel very proud of it. I'm happy to be in SAFA so I can tell my story."

Throughout the year, the group stayed in contact with regular conference calls and web-based meetings, as well as an in-person gathering in Fort Lauderdale, Florida for SAFA Network members and their support persons to discuss their mission and vision.

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Disability Issues in the National Spotlight – Coming to Ohio and Streaming Online

By Nancy Ward, The Arc's Training Specialist



"I have a dream."

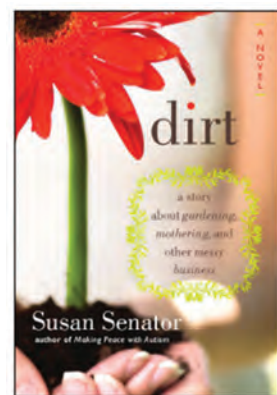
When Martin Luther King, Jr. made this famous speech, he was talking about the civil rights movement. Today, many self-advocates and their families also have a dream where people with disabilities will come together to exercise their rights as citizens of this great nation. People with intellectual and developmental disabilities can be a powerful force as informed voters who will make changes in people's lives by supporting candidates with views that reflect their values and the policy changes they want to see. The American Association of People with

Disabilities, The Arc, Association of University Centers on Disability, National Council on Aging, National Council on Independent Living, Self Advocates Becoming Empowered, United Cerebral Palsy and Ohio Disability Vote Coalition are helping make this dream a reality by organizing the second National Forum on Disability Issues.

The forum will be at the Hyatt Regency Hotel in Columbus, Ohio on September 28. The last National Forum, held during the 2008 elections, brought over 80 local and national organizations from a broad and diverse disability community together. President Barack Obama and his presumptive opponent in this November's election, Governor Mitt Romney, will be invited to voice their opinions on issues that affect people with disabilities. The program will cover a wide range of topics like health care, long-term community-based supports, transportation, housing and education. In addition to engaging self-

advocates and their families and supporters and informing them about the candidates' platforms, the forum is an opportunity to make society more aware of the issues people with intellectual and developmental disabilities face and how powerful they can be when they cast their ballots.

The forum will be the only national event to focus specifically on disability issues during this election. A live internet stream of the event will be broadcast nationally, with organized viewing parties taking place across the country. Please join us at this exciting event to learn about the candidates' opinions on issues that affect people with disabilities, and share this information with others so they become informed voters too. Keep an eye on The Arc's website, www.thearc.org, for updates. And get involved with The Arc's "We've Got The Power" voter engagement campaign at www.thearc.org to make a difference in this election season! ■



Dirt: A Novel by Susan Senator

This novel follows the life of Emmy, a typical suburban mother. Trying to raise her three sons as a single mother she is faced with many challenges. Her oldest, Nick, is profoundly autistic and increasingly frustrated with the world around him. Henry, her normally dependable middle child seems to be drifting away from her, and then there's Dan, her eight-year-old who seems perpetually angry at everyone in his family.

Susan is the successful author of *The Autism Mom's Survival Guide* and *Making Peace with Autism*. She is also a blogger and has been published in *The New York Times*, the *Washington Post*, and *Education Week*, among many other publications. *Dirt* is Susan's first fictional work. ■

Our Friend Mikayla Arrives in Pennsylvania Elementary Schools

The Arc of Pennsylvania, in partnership with Mikayla's Voice, recently mailed copies of *Our Friend Mikayla* to every one of Pennsylvania's 1,800-plus public elementary schools. The book details Mikayla's school days through the eyes of her third-grade peers and is a valuable resource that teaches the meaning of diversity and unconditional friendship in a language that speaks to students of all ages. Mikayla, a third-grader when the book was written, is now a 10th-grade student. Mikayla has never spoken a word, yet her friends have found a way for her voice to be heard across the Commonwealth. The book's printing was funded through a \$10,000 grant from the Walmart Foundation, with mailing costs funded by Air Products. Learn more on our blog, <http://blog.thearc.org/>. ■

Advocates in Action—Fighting Budget Cuts in Pennsylvania

In this tough economic climate, many states are facing cuts to important programs, including those that serve people with I/DD. In Pennsylvania, the threat of 20% cuts to community mental and behavioral health services, programs that individuals with I/DD rely on, motivated hundreds of advocates to take action.

Rallying their troops, The Arc of Pennsylvania joined other advocacy organizations from across the state at the Capitol rotunda in Harrisburg, PA in early May to fight for their rights. Together almost 2,000 advocates lined the white marble steps and chanted “Keep Your Promise,” while others waived their signs high to remind Governor Tom Corbett and other lawmakers of promises they made and that constituents were not about to forget. The Arc’s “Don’t Cut our Lifeline” campaign logo was on display as advocates carried signs and wore pins bearing the slogan throughout their efforts at the Capitol.

At the rally, Maureen Cronin, Executive Director of The Arc of Pennsylvania, spoke of how family members built The Arc of Pennsylvania and its many local



Advocates join together on the stairs of the Pennsylvania State Capitol.



chapters over the years. She emphasized how important it is for families to have access to services, because so many parents are struggling to support their son or daughter with disabilities. One by one, all the passionate speakers echoed concerns about providers not being able to support those in need if these cuts are signed into law.

“Right now, without these major cuts, people with I/DD aren’t getting all the services and supports they need. This budget proposal would be a major setback in our efforts to live up to our

commitment to people with I/DD, and have real impacts on their quality of life,” said Cronin.

Last month, Governor Corbett signed a budget that included \$150 million in cuts. Thanks to the efforts of The Arc of Pennsylvania there were victories for individuals with I/DD in the final budget. The Office of Developmental Programs Budget for Home and Community Based Waivers will receive an increase of nearly 8% above the level of funding originally recommended by the Governor. ■

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“I think that exposing our officers to people with different needs, different abilities, and disabilities is invaluable. And letting us have a one-on-one with these families and learning what we can do to make it easier for them is always going to be beneficial to all of us,” Robin Zandt with the Transportation Security Administration.

The Arc’s national office is working with The Charles River Center to expand Wings for Autism. If you are interested in the program and want to find out how to bring a workshop to an airport near you, please contact Tonia Ferguson, Director of National Initiatives, ferguson@thearc.org. ■



“Bringing a program like this to the area was profoundly valuable to families containing a member with intellectual challenges. Our family alone is comprised of multiple members with special needs, so we were very thankful to have had the opportunity as it calmed some of our deepest fears and concerns about airline travel,” Wendy Agudelo, Mother of Abigail (6), Aramis and Alec (5).

“My dream is for this to be in every state. I know that I can’t change every child with autism to make them fit into our world but I can teach the world to learn how to be accepting of kids with autism. That’s what this program is doing,” Jennifer Robtoy, Director of Autism Support Services, The Charles River Center.



Early Intervention – Giving Children Across Disabilities a Chance to Shine



Shawn Dacey on a recent trip to Italy.

Every child is different, from their unique personalities to their likes and dislikes – no two children are the same or have the same needs. The same is true of children with I/DD, though in the case of children with I/DD there is one universal truth that can be beneficial to every child despite their level of need – early intervention.

The Arc strongly believes that all children who have been identified with I/DD should have access to high-quality, affordable developmental services in the community. These services will benefit not only children but their families by helping them understand the needs of their loved one. It is also essential that these services start early in a child's life to promote inclusion at a young age.

Examples of the benefits of early intervention can be seen across all diagnoses. Look at Shawn Dacey – he began early intervention services at his local chapter of The Arc when he was just 2 years old. Shawn was diagnosed with Asperger's Syndrome when he was very young, which is why his mother enrolled him in Carousel Children's Services, an early intervention program run by The Arc of Delaware County. Through the program, he worked to achieve a level of social, physical, and speech proficiency that allowed him to excel in a public school setting.

"I do not mean to boast my personal achievements, but without the early intervention I am confident I would not be the same person that I am today. This is why I owe The Arc and its entire professional staff (especially Honeybee) a heartfelt thank you. It is my hope that this letter will show other parents that even though their children may be diagnosed with certain disorders, it does not mean they are out of the race for a productive and successful life. By taking advantage of the early intervention programs at The Arc, my parents were able to ensure that I would lead the life I am today," Shawn Dacey.

For Gabbi Poole, the benefits of early intervention benefited not only her, but Gabbi's family as well. At 4 months

old, Gabbi was diagnosed with Shaken Baby Syndrome. After she was shaken, she suffered severe brain hemorrhaging that affected 60% of her brain. Doctors told her grandmother Michele Poole, President of The Arc of Florida, that her granddaughter had very little chance of survival. Overcoming the odds Gabbi survived, and today she is a beautiful teenager. Unfortunately, due to the severity of her injury Gabbi cannot walk or talk, and she suffers from seizures. Following her diagnosis, Gabbi's family was in shock trying to cope with the news and how to care for her. Michele turned to Easter Seals and began early intervention with Gabbi to learn how to support her and deal with the emotional shock of the situation.

"Early intervention was so helpful for healing the family and helping us learn how to care for a child like Gabbi (Gabriela). Gabbi benefitted from the one on one that she received in physical therapy, occupational therapy and speech therapy, and I know it made a big difference in her joints and ligaments because of all the stretching and correct positioning that she received in those first 3 years. Unfortunately, because of the damage to her brain from the shaking, her ability to learn has been greatly compromised," Michele Poole. ■

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The big event capping off SAFA's first year in existence was a visit to the U.S. Capitol in May. SAFA Network members had the chance to meet with U.S. Representative Dean Heller (R-NV), and they spoke passionately about their personal stories of both struggles and successes, and their ongoing need for supports and services.

Amanda Oliver-Blaine, a 19-year-old from Nevada, participated in the meeting with Rep. Heller. When

Amanda was 20 months old, her birth mother placed her and her 8-month-old sister in foster care so she could enter rehab. After two months, the foster parents said it was too difficult for them to care for Amanda, and so she was placed for a weekend with another family before being moved into a home for people with I/DD. That second family intervened, raising Amanda and formally adopting her in 2009.

Reflecting on her trip to the nation's capital, Amanda said: "Representative Heller invited me to Washington, DC. It was great to meet and talk with someone from my state and for all of the SAFA group to talk to them about our issues."

Are you interested in learning more and getting involved with the SAFA Network? Contact The Arc's Project & Information Specialist Leigh Ann Davis, 202.534.3727 or ldavis@thearc.org. ■

What Does It Mean to Live and Be Included in the Community?

We'll explore that question and other important issues facing the intellectual and developmental disability community this October in Washington, D.C. We invite you to join The Arc and Inclusion International – a global federation of organizations advocating for the rights of people with I/DD – for “Achieving Inclusion Across the Globe” October 25-28 at the Grand Hyatt in Washington, D.C. This National Convention & International Forum features keynote speaker Judy Heumann, a lifelong advocate for people with disabilities who contributed much to the development of human rights legislation and policies while extending the reach of the independent living movement. Sessions will include “Creating Change: How Advocacy and Policy Can Come Together” and “Key Issues for Living in the Community: Choice, Support and Inclusion.” Plus, we'll be tackling crucial elements of The Arc's governance in three annual business meetings and celebrating contributions to the field with our annual Advocacy Matters, Research and President's Awards.

On the fun side, attendees will enjoy an opening event with a dash of Hollywood

glamour at The Arc & Sprout National Film Festival. We'll screen several short films created by or about and starring people with I/DD and offer everyone the chance to stroll our “red carpet.” And, we'll close out the weekend with a celebration of hand dancing, a form of dance also known as “D.C. Swing.” Check out more details about

this year's program and registration information in a special insert in this newsletter or visit www.thearc.org. Register now, before September 3, and take advantage of early bird discounts on the event and accommodations. Members

of The Arc are entitled to special discounts as well. If you're not already a member of The Arc, you can purchase a national membership at www.thearc.org or through your local chapter now. If you need assistance with travel arrangements, check out our exclusive travel sponsor, Hammer Travel, at www.hammertravel.org. They specialize in comprehensive travel packages for people with intellectual and developmental disabilities and their families. ■



Convention Bookstore

The Arc and American Association on Intellectual and Developmental Disabilities (AAIDD) will be joining forces at the 2012 National Convention and International Forum to stock a bookstore in the Convention Marketplace. It seemed like a natural fit to combine AAIDD, a sister organization that teams with The Arc on advocating for quality of life and rights for those with I/DD.

AAIDD is known for publishing high-quality books and publications for professionals in the disability field and related human services professions. Each title published by AAIDD has been vetted as a best-in-class resource geared toward keeping working professionals and family members informed of the latest information trends in the field of I/DD.

After the success of last year's Marketplace Bookstore, we were looking to ensure that our bookstore would once again be a successful attraction. We aim to give attendees the opportunity to purchase compelling and educational books that discuss a range of topics in the disability field. Let us know if you have any favorites by emailing info@thearc.org — we plan to have books for everyone from siblings, to self-advocates, from professionals to policy wonks. We hope you will come to Convention and check out The Marketplace Bookstore! ■

The Market to Debut at Convention!

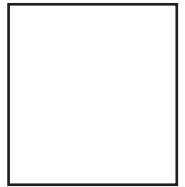
T-Shirts, Greeting Cards, and more! The Arc's National Convention & International Forum is offering an exciting new opportunity to promote entrepreneurs with I/DD. Last year's *Entrepreneur Alley*, a section of *The Marketplace* exhibit hall set up for people with I/DD to showcase their businesses, was a big hit, so we're adding *The Market* to allow even more entrepreneurs to participate.

The Market is an avenue for those self-advocate entrepreneurs who are unable to travel to the event or staff a booth in *Entrepreneur Alley* to market their products. The Arc wants to encourage participants in *The Market* to have their goods or promotional items sent to the event, where staff and volunteers with The Arc will sell or distribute materials on their behalf. A small portion of the proceeds will go to The Arc. *The Market* is another way The Arc is continuing to carry out our mission to promote what full participation can look like. We're sure *The Market* will be a big draw for the hundreds of attendees at this year's event. Are you a self-advocate entrepreneur? Or do you know a self-advocate with a great micro-business to promote? Contact Wendy Katz at 202-534-3720 or katz@thearc.org for all the details about *The Market* today! ■



For people with intellectual
and developmental disabilities

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*What Does it Mean
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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! ■



Look for The Arc in your October issue of TIME Magazine

The Arc hopes to again be featured in a special advertising section introducing *TIME*'s 19 million readers to the work of The Arc and our national network of 700+ chapters. Plan to pick up a copy of the October 15, 2012 issue of *TIME Magazine*.

The Arc thanks the corporate supporters who are helping to make this section possible. If you are part of a national company or organization that might want to support The Arc in its mission, please contact Trudy Jacobson at jacobson@thearc.org or 202-534-3714. ■

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!