



For people with intellectual
and developmental disabilities



empower

Real People, Real Progress

Issue 21 | Winter 2015

Future Planning: It's Possible and Necessary

Future planning is important for all families. Yet, thinking about the future can be challenging and emotional. Last year, The Arc launched the Center for Future Planning to encourage and support individuals with intellectual and developmental disabilities (I/DD) and their families as they plan for the future.

Having a plan is important especially after the parent or caregiver can no longer provide support. With an estimated 600,000 – 700,000 families in the

"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."
~ CEO of The Arc

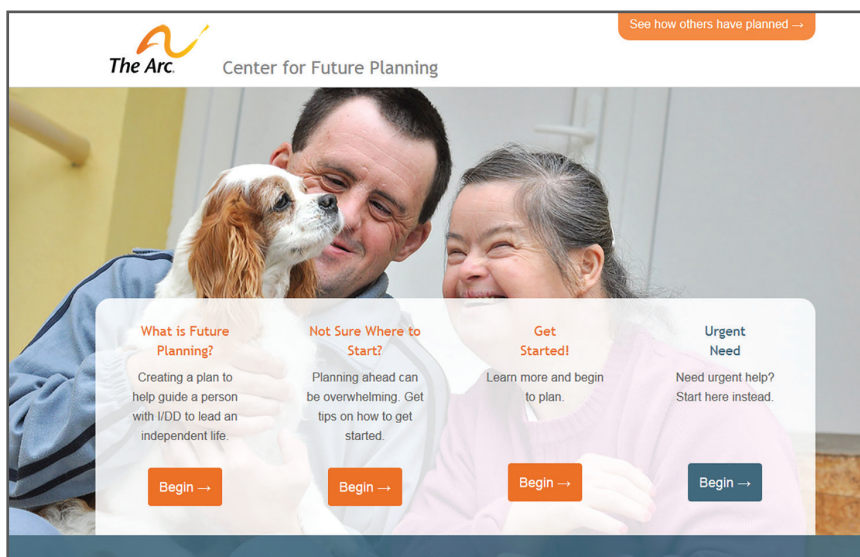
United States where an adult with I/DD is living with aging family members and there is no plan for the individual's future, the need for this resource was clear.

The Arc's Center for Future Planning website is now live and ready to guide families as they take the first steps to plan for the future. The Center's website provides reliable information and assistance to

individuals with I/DD, their family members and friends, chapters of The Arc and disability professionals on:

- person-centered planning
- supported decision-making and guardianship
- housing options
- financial planning
- employment and daily activities
- making social connections

The Arc's Center for Future Planning launches new website! Visit the site today for the tools you need to begin planning for the future:
<http://futureplanning.thearc.org>



In addition, the Center's website features stories of people and families who have created future plans or who are in the planning process. These stories may help families get an idea about what to include in their plan or in some cases modify an existing plan.

The Center also offers webinars to chapters of The Arc and other professionals who support people with I/DD to help them learn how to assist families in the future planning

process. Planning ahead can be difficult, but it's possible and necessary. You can learn more about the resources and training opportunities the Center for Future Planning provides at futureplanning.thearc.org. Please contact The Arc's national office at (202) 202-617-3268 or futureplanning@thearc.org for more help. ■

Achieve with us.

Invigorating Relationships that Propel The Arc Forward

Greetings and welcome to 2015! As I reflect back on 2014, it was a year of impressive growth for The Arc at all levels. From the national perspective, our programmatic reach into areas that are important to people with I/DD expanded, providing many new opt-in opportunities for our chapters to increase service in their communities. We also faced many challenges – particularly in public policy and with state and federal funding not nearly meeting the needs of our constituency. Going forward, I see so many opportunities in which to expand our work and our influence, and I look forward to achieving great things with all of you in this New Year.

I started my journey as the President of the board at The Arc's 2014 National Convention this past fall in New Orleans, which was a rousing success with over 800 people in attendance! More than 64 years after the birth of The Arc, we continue to be the preeminent organization dedicated to assisting parents and advocating with



Ronald Brown

and for people with I/DD. At our roots, we are first and foremost a grassroots family based organization, and when our network gathers together, the passion of our mission becomes the pulse of the city we are in. The setting was warm and inviting, a vibrant energy surrounded all aspects of convention and there was a sense of community that can only be felt when our chapters and members join together for this annual event. With ideas flowing, networking opportunities available at every turn, and experts in the field on hand as participants and speakers – the environment was invigorating. New relationships were formed and connections made which are so important to the growth of The Arc at all levels.

Those relationships will be what propel us forward into 2015 and beyond.

As I begin my role as President of The Arc, I'm ever mindful of the fact that this is a role of service and I remain dedicated to doing all that is in my power to fulfill our mission. We will persevere in our effort to move the organization forward! Ongoing national initiatives such as Wings for Autism, the Center for Future Planning, the National Center on Criminal Justice and Disability (NCCJD), the Fetal Alcohol Spectrum Disorder Prevention (FASD) Project, and The Arc's Committee on Diversity are flourishing as more new initiatives are being ramped up.

As The Arc continues to grow and more opportunities emerge to engage us, we will work collectively to meet the needs and support the mission of The Arc. The invitations for our internal committees will soon be released. If you are interested in committee work at the national level, please email me at, president@thearc.org. These committees give you the opportunity to be more hands-on and help shape the future of The Arc – and we need your expertise.

We also need your support in our advocacy work – without your calls and emails to Congress, we won't be the force we have been for the past 64 years. You can join our action e-list by going to www.thearc.org and clicking on the Take Action tab.

I look forward to working with many of you as I begin my journey as President of The Arc and hope we are able to learn, grow and achieve success together! ■

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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.

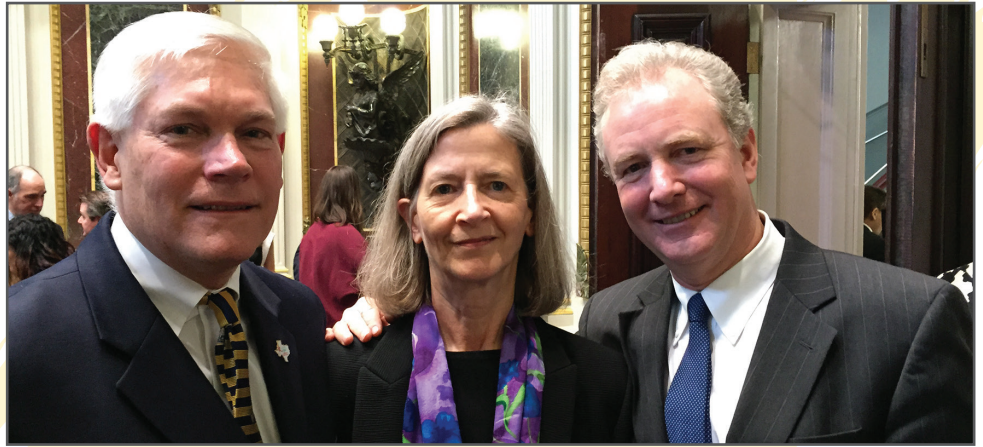
The Arc

1-800-433-5255

The Arc Celebrates the ABLÉ Act Becoming Law

As the clock wound down on 2014, Congress passed and President Obama signed an important bill for people with I/DD and their families – the Achieving a Better Life Experience Act (ABLE Act).

The ABLE Act changes the tax code to allow for tax advantaged savings accounts for individuals with disabilities for certain expenses, like education, housing, and transportation. Similar to existing “Section 529” education savings accounts, ABLE accounts will let families save for disability-related expenses on behalf of qualified beneficiaries with disabilities that will supplement, but not replace, benefits provided through the Medicaid program, the Supplemental Security Income program, the beneficiary’s employment, and other sources. If properly managed, funds in the ABLE accounts would not jeopardize eligibility for critical federal benefits. With full understanding of its features, individuals and families could use the ABLE accounts as another tool in planning for the lifetime needs of an individual with long term disabilities. The version of the bill that was signed into law includes age limitations and a cap on contributions, added in July by the House Committee on Ways and Means to reduce the costs of the bill. The Arc



From Left to Right: House Rules Committee Chairman Pete Sessions (R-TX) with Marty Ford, The Arc’s Senior Executive Officer for Public Policy, and Congressman Chris Van Hollen (D- MD) at the ABLE Act celebration at the White House in February.

recently released two fact sheets – a short summary and a more detailed document – about the law, which can be found at www.thearc.org. Stay tuned as The Arc will provide further updates as details will come through the federal regulatory process in the coming months.

“We are pleased that the Achieving a Better Life Experience Act has been signed into law. We appreciate the untiring work of the chief sponsors of the bill and the support of a large and broad representation in both chambers of Congress.

“While the legislation was narrowed due to the constraints from the cost

analysis, the approved bill will provide an instrument for some families and people with intellectual and developmental disabilities to save for the future, depending on their own circumstances. Our efforts are unfinished – The Arc will continue to work with the leadership and chief sponsors in Congress to expand this program in the future to ensure that everyone in need can get the maximum benefit from this legislation,” said Peter V. Berns, CEO of The Arc.

Chief sponsors of this bill were: Congressman Crenshaw (R-FL), Congressman Van Hollen (D-MD), Senator Casey (D-PA), and Senator Burr (R-NC) ■

Register Now for the 2015 Disability Policy Seminar

Make your plans to attend the 2015 Disability Policy Seminar in Washington, D.C. April 13-15 and take advantage of special early registration and hotel rates until March 11th. This event is your best opportunity this year to cultivate new champions on Capitol Hill and advance the grassroots movement for people with intellectual and developmental disabilities. This unique platform offers you the opportunity to come together with other advocates, learn about the issues of common concern, and speak with your elected officials about what is important to you.



Get the best rates and availability for the event at the Renaissance Washington, D.C. Downtown Hotel and find out more about this year’s program at www.disabilitypolicyseminar.org. (Please note: this year our event will be taking place at a new hotel.)

Hosted by: The Arc, United Cerebral Palsy (UCP), Association of University Centers on Disabilities (AUCD), American Association on Intellectual and Developmental Disabilities (AAIDD), National Association of Councils on Developmental Disabilities (NACDD), and Self-Advocates Becoming Empowered (SABE).

Promotional Partners for this event are the Sibling Leadership Network and the American Association of People with Disabilities (AAPD) ■

Your Philanthropic Support Helps Us Achieve Greatness

The Arc's tag line "*Achieve with us*" came to life in 2014 with the financial support received from our annual donors. Contributions ranging in size from a few dollars to several thousand dollars are all essential, and combined, they ensure that The Arc will continue to make progress on our mission.

We thought you might appreciate how your generous philanthropic investments are being put to work. Here are a few examples of our accomplishments in 2014, in addition to the national initiatives we launched last year including the Center for Future Planning, Wings for Autism, and The National Center on Criminal Justice and Disability (all of which are featured in this edition of *Empower*).

We know you expect us to continue to make an impact in the lives of people with I/DD, and we take the trust you have in us seriously. It fuels our passion to perform with results.

Again, thank you for your support and generosity to make all of The Arc's efforts possible. Regardless of how you give, we thank you. Your support at the local, state and national level ensures that we will continue achieving greatness in 2015.

If you are looking for a way to make your giving to The Arc even easier in 2015, you should consider becoming a monthly donor. Many donors have opted to spread their giving over the course of the year, making it an affordable way for some individuals to increase their support while lessening the impact on end of the year cash flow. If you are interested in becoming a monthly donor please contact Laura Schroeder at schroeder@thearc.org. ■

A Return on Your Philanthropic Investment – A Few Highlights from 2014

- The Arc was able to raise the profile of our organization and people with I/DD by interacting with the media and building relationships that inform our national dialogue on the issues that matter most to you. We successfully worked with *The Washington Post*, *USA Today*, the *Huffington Post*, *Exceptional Parent* magazine, to name just a few, to achieve our goals.
- The Arc's brand continues to grow inside our network of chapters, which will make us more recognizable by the broader general public. As of the end of 2014 we have 439 (66%) of our chapters signed on to use the updated brand identity.
- In 32 states, more than two-thirds have signed on (15 states are at 100%).
- Working with several chapters and thanks to the generosity of an independent television producer, in 2015 we will be launching a new public service announcement via Comcast/NBCUniversal's continued commitment to provide us \$1 million in broadcast time this year (and again in 2016).

The Arc's network is always strengthened when we come together to network, improve, and lead. In 2014:

- The annual Disability Policy Seminar was attended by 1,000 advocates who learned about the latest trends in public policy and took our message to Congress.
- The National Council of Executives of The Arc (NCE), the leadership and professional development arm of The Arc, had one of the largest training events they have had in recent years, with 84 chapters represented.
- And to close out the year, The Arc's National Convention in New Orleans, Louisiana was one of the best in a long time, with over 183 chapters sending board, staff and volunteers contributing to an attendance of over 800 people!

Achieve with us.

ACTIVATE HERE! Self Advocacy Training Video in Collaboration with The Arc Available Now

The Arc and Academy Award®-nominated documentary filmmaker Alice Elliott bring you ACTIVATE HERE!, a free and downloadable training video in seven modules designed to help refresh people with intellectual and developmental disabilities on their self-advocacy skills.

Many people with intellectual and developmental disabilities wish to participate more actively in decisions about their own lives and advocate for policy changes. However, sometimes they haven't had the experience of standing up for themselves and speaking out. The ACTIVATE HERE! video series will be used as a tool to develop or remind burgeoning self-advocates of their self-advocacy skills and serve as a resource for training. Five self-advocates star in the video, and show how to help each other prepare for local, state, or national legislative conversations. As a movement we want to reawaken all of our grassroots advocates, and our self-advocates have the greatest passion when they can



Bernard Carabello, life-long activist, led the closure of the institutions in New York state. speak for themselves about their own needs.

Script consultant Emily Perl Kingsley has won 17 Emmy Awards® for her writing on *Sesame Street* and has introduced people with disabilities to television through her innovative writing. Kingsley is the mother of a man with Down syndrome.

We encourage chapters of The Arc and other organizations, especially self-advocacy groups, to make use of this tool. It is available free online in the For Chapters section of The Arc's website, and DVDs will be sold on www.welcomechange.org. Elliott and the

self-advocates in the film are available to speak at events, trainings, and at chapters of The Arc – contact Elliott at info@welcomechange.org. ■

For Chapters of The Arc

Don't miss out on all the materials that are available to you and your staff! Just login to the "For Chapters" section on www.thearc.org to gain access to tools developed to assist you with marketing, branding, fundraising, professional development, and chapter governance. Here are some helpful resources:

- The New NCE of The Arc Chapter Leadership Development Program which includes The Arc Connection, Special Interest Groups (SIGs), Summer Leadership Institute, Pre-Convention, and Standards for Excellence®
- Full image gallery that you can download or browse through
- Easy to use brochure, flyer, and newsletter templates
- Information on brand trademark licensing and resources to help you implement the brand
- Yearly development calendar and opportunities to fundraise for your chapter
- Chapter governance materials, which include sample policies
- A variety of other useful materials

Staff members and volunteers of chapters of The Arc can login or create an account by visiting - <https://www.thearc.org/for-chapters/login>

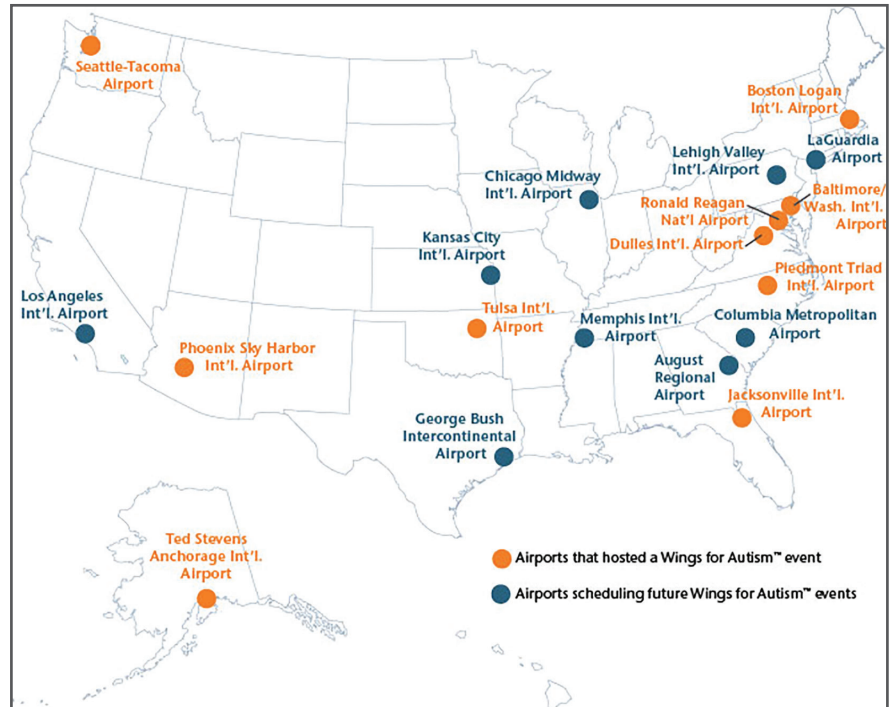


The cast of ACTIVATE HERE! prepares for another take on the set.

Wings for Autism Soars Across the Country

Last year, The Arc expanded the national initiative Wings for Autism® to ten major airports across the country. Local chapters of The Arc partnered with their regional airports and Transportation Security Administration (TSA) personnel in order to conduct the “airport rehearsal” program for families with children with disabilities. Thanks to the hard work and dedication of our wonderful chapters, partnering airports, and sponsors, over 1700 participants were able to go through the process of entering the airport, obtaining a boarding pass, going through security and actually boarding a plane.

Programs like Wings for Autism® provide families with the opportunity to prepare their children for travel across the country, or around the world. Children with I/DD are able to become acquainted with security procedures, airport personnel, and boarding processes so that when the time comes for them to travel, they have experience and their parents can be at ease. In 2015, The Arc is looking forward to expanding into more airports and bringing the program to other chapters of The



Arc. If you would like more information about the Wings for Autism® program, please visit www.thearc.org/wings-forautism, or contact Phuong Nguyen, Program Assistant, at 202.600.3483, or nguyen@thearc.org. ■

We wanted to let you know that we took a flight to Fort Myers, FL from Detroit, MI last week with Tushar. We are EXTREMELY happy to tell you that Tushar not only flew but enjoyed both laps of the flight. This is an amazing transformation in him and this could not have been possible without all of your team's help. He was very comfortable going through TSA security and had absolutely no issues waiting for boarding at the gate. Once in the plane he happily settled down, fastened his seat belt and started looking out of the window and was giggling looking at the clouds. He in fact did not want to come off the plane and wanted to fly more. His grandparents and other relatives in India are very excited about this development and are eagerly waiting to see Tushar in India.

We would like to express our heartfelt thanks to all you wonderful people who gave him a chance to settle down and understand the concept of flying



Tushar boarding the plane



Tushar on the plane

without any pressure. Please keep up the great work you are doing and I am sure there are many more children with special needs who will be benefited like Tushar.

Thanks,

Ram and Upasna Palakodaty

(The Palakodaty family participated in a Wings for Autism event at Dulles Airport outside of Washington, D.C. on November 1, 2014)

Case Dismissed: National Center on Criminal Justice and Disability Provides Critical Support to Bring Justice in Illinois

The Arc's National Center on Criminal Justice and Disability (NCCJD) fields calls from all over the country regarding people with disabilities in the criminal justice system. From first encounters with law enforcement to time behind bars, the horrors people with disabilities face are shocking and appalling. A blatant disregard for human rights sets off a chain of events that denies people with I/DD justice. However, every so often, a case comes to our attention and events unfold in a way that looks a little bit more like "justice."

In August, an Illinois family contacted NCCJD – their son, Jack¹, who has I/DD, had been charged with felony assault at his new group home. After a verbal altercation between Jack and another resident, a third resident called the police. Jack

was arrested and, in the process, struck a police officer who grabbed him by the hoodie from behind as he attempted to exit the situation. As Jack lay on the ground, the officer threatened to taze him if he did not cooperate.

Jack spent 24 hours in jail without support or access to his medication. His parents called the supervisor of the Adult Detention Center to inform them of Jack's needs. Jack's parents were told that their son should be able to tell the nurse himself about his needs and pharmacy information. Jack was unable to do that, leaving him at risk and without access to his medications. Although Jack was read his Miranda rights without assistance, due to his disability he did not understand them.

Jack was assigned a public defender the day he went to bond court. The judge initially put a large bond on Jack because he struck a police officer. However, the public defender argued for low-no bail because of Jack's disability. The judge reduced bond from \$30,000 to \$10,000, after asking Jack's parents if they could afford the \$1,000 on a \$10,000 bond. Jack was out on bond when, as part of the legal process, his competency was evaluated and he was found unfit to stand trial. The state attorney refused to dismiss charges and the public defender was forced to send Jack for a sanity evaluation. Jack was found not sane at the time of the incident.

These sets of circumstances are all too common for people with disabilities. Thankfully, Jack had a public defender that insisted on competency and sanity evaluations. And Jack's parents contacted NCCJD and The Arc of Illinois Life Span Program in an effort to secure support. Working together

with family members, Jack's service providers, The Arc of Illinois Life Span Program, and NCCJD, advocates were able to put together a Personalized Justice Plan for Jack. The plan outlined resources and possible alternatives for assisting Jack in the community and was supported by the Director of Illinois Department of Human Services, Division of Developmental Disabilities. The report was submitted to Jack's public defender, which allowed him to demonstrate that Jack

had appropriate services in the community and that there were additional supports being made available as needed. The case was dismissed.

Jack was arrested in mid-March of 2014 and the case was finally dismissed in mid-October 2014. There were almost monthly hearings throughout the ordeal, causing

stress to everyone involved. When the case was finally dismissed, the family felt Jack had been misunderstood by the legal system from the beginning. They believe the court did not understand the difference between mental illness and developmental disability. Despite all the shortcomings in this case, the public defender took the necessary steps to ensure dismissal of the case, and the Judge was open to reading the personalized justice plan and making a dismissal.

When asked how he felt when he was arrested, Jack said: "My heart was racing 290 because I was in the back of a squad car, handcuffed." [At the police station] "I pretty much felt like a nervous wreck." [When I went to the Adult Detention Center] "I felt sick to my stomach because I was around people I didn't know." [A couple of days before court] "I felt scared and nervous." [At court] "I felt scared I was going to jail." [On the last day of court] "the judge calmly talked to me and explained what would happen the next time I got in trouble." [When the court case was dismissed] "I was still edgy." "I feel more calmly now" [that it is over.]

The Arc's National Center on Criminal Justice and Disability, working with our chapters, self-advocates, families, and legal professionals, is an invaluable resource that can make a significant difference in the outcomes of cases like Jack's. Visit www.thearc.org/nccjd to learn more or request assistance. ■

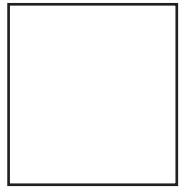
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¹Names have been changed to protect the privacy of those involved.



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Save the Date:



Don't miss an amazing event! You know you want to go to Indy!

The Arc's 2015 National Convention
October 3 – 5, 2015 | Indianapolis, Indiana
convention.thearc.org

Meeting High Standards!



bbb.org/charity

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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