



empower

Real People, Real Progress

Issue 22 | Summer 2015

Looking for Technology for People with Intellectual and Developmental Disabilities?

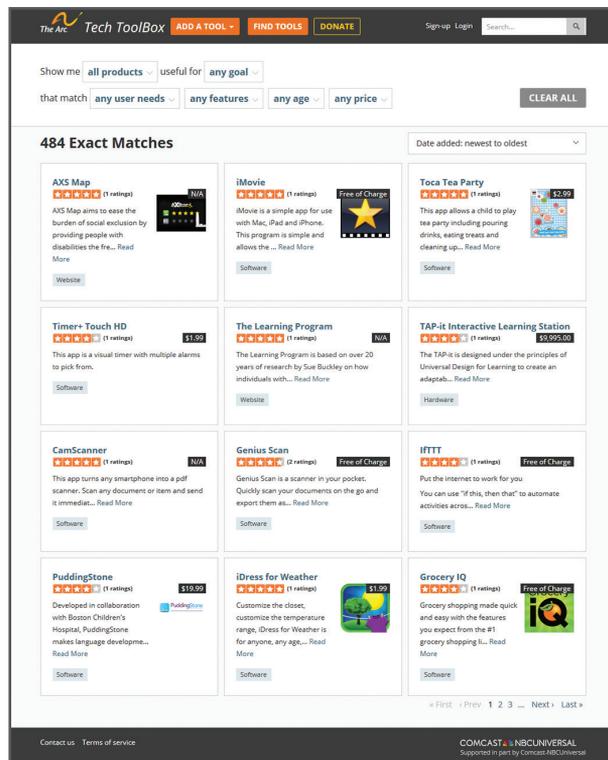
The Arc Has the Resource for You!

The need for a service that helps people with intellectual and developmental disabilities (I/DD) access technology has long been apparent and The Arc decided to step in to help centralize resources in this field. Through a partnership with the Comcast Foundation, The Arc was able to create the Tech Toolbox.

Staff from across The Arc's chapter network came together to design a one-stop-shop, peer-reviewed directory of technology products that are effective for people with I/DD. Through this directory, which can be found at <http://toolbox.thearc.org>, chapter staff, people with I/DD, and the general public can find, review, and post examples of technology tools that work well for them.

When this project first launched, people had a number of questions:

Achieve with us.



In the Tech Toolbox, you can find devices or apps that are searchable according to the unique needs of people with I/DD. Products are sorted by tags, such as:

User needs:

- Voice commands/spoken text
- Body gestures
- Simple language text
- Symbols or pictures (no text)
- High contrast images
- Large print/screen magnification

Features:

- Touch screen
- Easy to grip and hold
- Durable if dropped
- Mounts on wheelchair
- Word prediction
- Mounts on table

I heard about an app that might help me communicate better or live more independently—is it a good fit for me? What kinds of devices might work for me if I don't read or can't use a keyboard or mouse? The Arc listened, and is proud to introduce its newest national initiative, Tech Toolbox!

There are already over 500 apps and devices in Tech Toolbox, and the list will continue to grow with your input! Each product is rated by other users of the site. You can read stories of how people have used each product, and their judgment of the products'

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In It For the Long Haul — A Lifelong Advocate's Ask of Families To Speak Up

Ginger Pottenger has been a member of The Arc – at either the local, state, or national level – since the early 1970s. She lives in Arizona, near her daughters, Kandi and Kristi. Her daughter Kandi, who will soon turn 51, was diagnosed with “mental retardation”, as it was known then, when she was 3 years old.

You have been both a “professional advocate,” serving as an executive director of chapters of The Arc and on boards and other positions, and a parent to Kandi. How have those experiences shaped how you advocate?

I have seen the power of the personal, nitty gritty story, on public policy. People are too scared to get on the phone or get in front of their elected officials, and tell them the consequences of their policy decisions. Or people will think they don't have time to advocate. And I understand raising a family, including a child with special needs, maintaining a



Kandi, Ginger, Ginger's grandson Austin, and Ginger's husband Don

career, a marriage, a life – it all takes time. But you're in it for the long haul as a parent. Share your hopes and dreams for your family, the struggles, your fears.

What's your biggest concern today for the future of Kandi and other people with I/DD?

What is going on at the federal level with funding and the structure of Medicaid scares me to death. And it should scare others into action. The threat to our funding is real and if we lose the supports that Kandi has, our

options are bleak. Chapters of The Arc should be the place they go for training on how to advocate, for encouragement from chapter leaders and other families.

How do you suggest presenting your story?

I don't sugarcoat it – I just met with my state senator recently, and I told her – I can't die not knowing that the supports will be in place for Kandi. I've worked too hard for it to all go away when I'm not here. Right now, she's in a good place, living in a townhome, with some supports, and has supported employment in the community. But what does the future hold for her if public policy decisions change the way the money flows? I want them to understand and remember that our lives are impacted by their policy decisions.

Any final thoughts to share?

Families can't wait for the crisis to think about the future. It blows my mind how many people with disabilities the same age range as Kandi, whose families haven't considered what's going to happen when they die. The Arc's Center on Future Planning (www.futureplanning.thearc.org) is going to be a great resource to them, and so will their local and state chapters of The Arc. These families need to face reality – so much has changed for people with I/DD in society. We can't go backwards, and they've got to step up. ■

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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

Learn about the important policy issues facing our community and take action by signing up for The Arc's Action List –
<http://cqrcengage.com/thearc/home>

The Arc Needs You to Advocate Now!

Advocacy Toolkit Available from The Arc

The Arc created the “Don’t Cut Our Lifeline Medicaid and Social Security Toolkit” to help individuals across the country advocate with their Members of Congress during August recess. This toolkit explains why it is important to engage with your Members of Congress, and provides information to share in your calls, e-mails, or in person.

Why is it important to advocate now? Lifeline programs which are critical to people with I/DD, such as Medicaid and Social Security Disability Insurance (SSDI), are currently under attack:

- Majorities in the House and Senate have voted for deep cuts to Medicaid and fundamental structural changes that would eliminate the entitlement to services and undo the system of supports and services for people with I/DD.

- Congress must act by the end of 2016 to prevent a 20 percent across-the-board cut in SSDI benefits – but instead, on day one of the 114th Congress the House passed a rule creating hurdles to making the financial adjustment needed to prevent benefit cuts. And in both the House and Senate, Members have proposed bills to cut SSDI and create new barriers to work for SSDI beneficiaries.

In the coming months, Congressional leadership plans to write legislation to implement the Medicaid cuts, and decisions will move forward about SSDI and other serious threats to our lifeline programs. We must make our voices heard now! Visit The Arc’s website (<http://www.thearc.org/dont-cut-our-lifeline>) and check out the toolkit today! ■

Don't Cut Our Lifeline
What Can You Do to Help Protect the Lifeline?

Connect with Your Chapter(s) of The Arc
The Arc has more than 665 chapters in 48 states and the District of Columbia. We are a network of a volunteer-led chapter of individuals with I/DD and their families. Reach out to your local chapter to find out what activities they have planned to engage with your Member of Congress. If you do not have a chapter of The Arc in your area, consider contacting your Member of Congress directly, or reach out to The Arc to learn more about how you can help.

Participate in The Arc's Action Alerts
The Arc has a long record of advocating across the country that may interest and engage you on the issues by signing up on our website, other ways to get involved, or an issue hearing in Congress. The people that sit on the committees that will be making the decisions on the bills that will be passed in Congress. You will also receive information on other important issues in Congress and federal agencies that impact people with I/DD.

Attend a Public Event Hosted by Your Member of Congress
When Members of Congress are back home in their districts, they often hold town hall meetings, office hours or group events in person, or attend large community events so that they can hear from their constituents. Find out if there are any opportunities available in your area. Sign up for these events on Facebook and Twitter to see they post updates on events on the social media feeds. There don't have to be town meetings - some of the most important and influential discussions a Member of Congress can have are when they are out in the community and by their constituent's voices with a disability. Join an event.

Attend a Public Hearing in the House or Senate
We are currently in the middle of August. We can get out on any given issue. Additionally, the House and Senate are currently in recess. We can get out on any given issue. We can get out on any given issue. We can get out on any given issue.

Write a Letter to Your Member of Congress
We can get out on any given issue. We can get out on any given issue. We can get out on any given issue.

Call Your Member of Congress
We can get out on any given issue. We can get out on any given issue. We can get out on any given issue.

Ask a Question Key Message:
I have your personal care or services to I/DD.

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Dates to Remember

House of Representatives:
July 31 – August 7

Senate:
August 10 – September 7

Fetal Alcohol Spectrum Disorders Prevention Day

September 9th marks Fetal Alcohol Spectrum Disorders (FASDs) Prevention Day, and we want to empower individuals to join the national efforts to help educate everyone about FASDs. We encourage you to visit our website and download our toolkit (<http://www.thearc.org/FASD-Prevention-Project>) to see how you can be involved in FASDs Prevention Day.

Here are a few ways you can get involved:

- **Join the conversation online:** Post on Twitter or Facebook using the hashtag #FASD or tweet @TheArcUS.
- **Talk to your friends:** Have a conversation with your friends about FASDs and share knowledge or questions.
- **Write a letter to your local paper:** Write a letter to the editor about FASDs Prevention Day to spread the conversation in your community.

In 2013, The Arc was awarded a cooperative agreement from the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) and created the FASDs Prevention Project. The goal of the FASDs Prevention Project is to increase health care professional/provider knowledge of the risks alcohol can pose to a fetus and encourage the use of prevention strategies and provide educational opportunities to health care professionals and community health representatives. ■



The key fact to remember: FASDs are 100% preventable. The only way to protect your child from possible brain damage associated with alcohol use is to not drink any alcohol if you are pregnant or if you could be pregnant.

Many Ways to Give, Which Will You Choose?

There are many ways The Arc is carrying out its mission in your community and throughout the country. The Arc's important work includes over ten national initiatives, our expert public policy and advocacy, as well as the services and supports through our state and local chapter network. It is dedicated supporters like you that enable us to continue this important work! There are many ways you can contribute to

our cause, and we wanted to share a few with you!

Please check out the updated "Ways to Give" section of our website by visiting www.thearc.org/get-involved/ways-to-give to learn about all the easy ways you can contribute to make a difference in the lives of individuals with I/DD!

However you choose to make a gift to The Arc, you will change the life of a child, teen, adult or family member of

someone with I/DD. Additionally, your gift will help us strengthen the work we do across the country. Make a donation today by using the enclosed envelope or by visiting www.thearc.org/donate.

Of course – we welcome you to learn more about our national initiatives, and designate your support to one of them directly! To learn about our national programs, go to www.thearc.org/what-we-do/programs-and-services. ■

Donate Today!

www.thearc.org/donate



Monthly Giving: Increase your impact and even out your payments by giving monthly.



Tribute Gift: Honor someone special by making a gift in their name.



Car Donation Program: Donate your car, van, truck, boat or recreational vehicle.



Planned Gift: Protect your financial future and your family's legacy, while sustaining The Arc's future.

Calling All Siblings!

Are you a sibling of someone with I/DD? Visit www.thearc.org/siblings to access resources, sign up for our new For Siblings e-newsletter, and see past newsletters.

Exciting Additions to The Arc's National Convention Program



Don't miss out on the premier event for the disability community – The Arc's National Convention! This year's program will feature an array of speakers and events:

- An opening session by Tim Shriver, Chairman of the Special Olympics
- The Arc & Sprout National Film Festival, which will be free to all attendees
- The National Conference of Executives of The Arc (NCE) Silent Auction
- The Arc 65 Derby
- An exciting tailgate inspired event hosted by our local host committee (The Arc of Indiana), complete with food and games



Derrick Feldmann

And, we are thrilled to announce our closing general session keynote, Derrick Feldmann! Feldmann is the lead researcher and creator of the Millennial Impact Project, an oft-cited, multi-year study of how the next generation supports causes. Feldmann's extensive expertise on understanding the next generation of donors, activists, and employees who are redefining causes will help strengthen your

organization, grow your advocacy work, and sustain The Arc as a national powerhouse. ■

Affordable Care Act Survives Challenge, Get Ready for 2016 Insurance Enrollment

This summer, The Arc celebrated the 6-3 *King v. Burwell* decision, when the U.S. Supreme Court held that federal tax subsidies are being provided lawfully in those states that have decided not to run marketplace exchanges for insurance coverage. This is a huge win for the Affordable Care Act (ACA) and people with disabilities throughout the country.

This legal challenge could have weakened the law overall, threatening all the protections that people with disabilities gained in this landmark law. The ACA is important to people with disabilities. It expanded coverage and reformed insurance practices to end discrimination against people with disabilities and enhance access to health care. The private health insurance marketplaces allow individuals or small businesses to shop for coverage and potentially receive subsidies to help offset the cost

of insurance. The subsidies are key to ensuring affordable coverage. The health insurance reforms, the protections from high premium increases or out-of-pocket costs, and the coverage of "essential health benefits", including mental health care and rehabilitative/habilitative services and devices, help ensure that people with disabilities have affordable health care that meets their needs.

After the end of the second enrollment period earlier this spring, about 22 million people had enrolled in plans through the health insurance marketplaces or had newly enrolled in Medicaid. The majority of those enrolled in the marketplace had premium tax credits and or cost sharing reductions to help make the health insurance affordable. Too many people remain uninsured and unaware that there is help to make the insurance more affordable.

Important dates to remember:

- **November 1, 2015:** Open Enrollment starts — first day you can enroll in a 2016 Marketplace plan
- **January 1, 2016:** First date 2016 coverage can start
- **January 31, 2016:** 2016 Open Enrollment ends

Remember, if you have already have health insurance through the Marketplace, you must re-enroll every year or you will be automatically re-enrolled without the option to change your existing plan. It is also important to report any changes to your income to the marketplace.

If you don't enroll in a 2016 plan by January 31, 2016, you can't enroll in a health insurance plan for 2016 unless you qualify for a special enrollment period. To learn more about special enrollment periods visit www.health-care.gov. ■

Champions of The Arc's Chapters

The Arc grew from a grassroots organization to the largest non-profit federation in the country because of the amazing advocates and leaders that comprise our network. Our strength lies in our reach, and our power is made possible by our nearly 700 chapters and the stellar work they are doing to support our mission.

While we remain inspired by their tireless efforts, we know they are only as strong as their supporters as well. Recently, we asked our chapters to share with us who they were honoring on the local and state level. The results were overwhelming, and we wanted to take the opportunity to recognize the people making the work our chapters do possible. Award recipients varied from businesses, volunteers, and employees of chapters showing the variety of support needed to succeed. We wish we could recognize all of the amazing honorees our chapters shared!

If your chapter would like to share information about your award winners with us, we will send them a letter from the national office congratulating and thanking them for their efforts on behalf of people with I/DD. Please email communications@thearc.org.

The Arc of Monmouth (New Jersey)

Volunteer of The Year — Mollie Giamanco and Francine Acquaviva

Mollie Giamanco and Francine Acquaviva have been best friends for over 25 years, and started their service to The Arc in 1990. Together, they've been a moving force behind The Arc of Monmouth's largest annual fundraising, the Winter Glow Ball (www.arcofmonmouth.org/winterglow). No aspect of the event is out of their reach – auctions, entertainment, décor, sponsorships – together, they do it all!

Beyond 25 years of service to this event, last year, they chaired a new wine tasting fundraiser, which in their hands became a signature event. These two special ladies go above and beyond, and always put the needs of The Arc and individuals with I/DD first.



Mollie Giamanco and Francine Acquaviva

The Arc of Northern Chesapeake Region (Maryland)

The Rob Dare Unsung Hero Award — Yota Dermatis

The Rob Dare Unsung Hero Award is given annually to an employee or foster parent of The Arc Northern Chesapeake Region (The Arc NCR) in Aberdeen, Maryland. The 2015 winner was Psych Support Specialist Yota Dermatis. Yota works tirelessly to assist staff and clients, supporting on average 40 different teams each month at The Arc NCR, their employment sites and in their residential homes to support people in times of sorrow and crisis with a calm and positive attitude. Yota goes above and beyond to take the time to teach direct care staff counseling skills and provide in-person support.



From left to right: Award winner Yota Dermatis; Director of QA & Psych, Cindy Lindgren; and Executive Director of The Arc Northern Chesapeake Region, Shawn Kros, share a smile at The Arc Northern Chesapeake's Annual Meeting awards presentation

SHC/The Arc of Medina County (Ohio)

The Arc President's Award — Jeni Gray

The President's Award was established in 2013 to start a tradition of recognizing staff who go above and beyond to help SHC/The Arc of Medina County achieve its mission. Jeni Gray, Operations Manager of Residential Services, was the recipient of the 2015 award. Jeni has been with The Arc of Medina County for 21 years and her caring nature and passion continues to shine through in all she does. Her work is vital to the success of the organization and over the years she has created systems that save time, assure standards are met, and most importantly enable staff to focus on their primary goal of providing quality services to individuals with I/DD.



Chris Ruf, SHC, The Arc of Medina County's Board President, presents the prestigious President's Award to Jennifer Gray, SHC/The Arc of Medina County's Operations Manager, for exceptional performance.

Happy 25th Birthday to the Americans With Disabilities Act!

Last month, on July 26th we celebrated the 25th anniversary of the Americans with Disabilities Act (ADA). The ADA affirms the rights of citizens with disabilities by prohibiting discrimination in employment, public services, public accommodations and services operated by private entities, and telecommunications. It is a wide-ranging law intended to make our society accessible to people with disabilities.



The Arc played a leadership role in the passage of the ADA. Our volunteer leadership, state chapters, local chapters, and public policy staff worked closely with others in the disability community to make the ADA a reality. Elizabeth Boggs, was a founder of The Arc and served as the Association's first female President. Throughout her career, she had continually been involved with The Arc's Governmental Affairs Committee. With Justin Dart, Elizabeth co-chaired the congressionally appointed Task Force on the Rights and Empowerment of People with Disabilities, an important impetus to the development of the Americans with Disabilities Act. The task force traversed the country holding public hearings which were attended by thousands of people with disabilities, friends, and families documenting the injustice of discrimination in the lives of people with disabilities. State and local chapters of The Arc participated in these activities

and were a critical part of the grassroots voice.

The public policy staff of The Arc was actively involved in the negotiations leading to the passage of the law as well as mobilizing the grassroots, and educating the public, Members of Congress and staff. Paul Marchand, the staff director of The Arc's public policy team, was also the longtime chairman of the Consortium for Citizens with Disabilities (CCD), a coalition of national disability groups working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. Paul chaired CCD during the years leading up to and including passage of the ADA. He was an integral part of the leadership in determining and implementing strategy for passage.

As we celebrate this monumental achievement and the 25 years of implementation of this law, we can't help but reflect on what the ADA really means to individuals with I/DD and their loved ones.

We invite you to visit our social media channels, on Facebook(The Arc US) and Twitter (@TheArcUS) and share with us what the ADA means to you. We want you to be part of the conversation so be sure to use the hashtag #ADA25. ■

TOOLBOX continued from page 1



"By learning how to get online, people with I/DD are in a better position to gain employment, expand their social circle, and be a part of the increasingly growing community that exists online," said Peter Berns, CEO of The Arc.

strengths and weaknesses. Many of the reviewers of the products are staff from chapters of The Arc, who are experienced in helping a range of people with I/DD find and use technology. However, anyone can add their products and evaluations—people with I/DD, their family, teachers, support staff, and more! We hope that this information will equip individuals across the country to find products that are most useful for their specific situation.

In addition to providing an online directory for you and the public, we

have selected a group of Technology Navigator Fellows from across the country who are developing knowledge resources and coaching services to help people with I/DD better learn to use technology that supports them in all areas of their lives. We look forward to sharing more about the results of the Fellows' work in coming months.

Our world has been changed dramatically by technology, and we believe that it should be accessible to everyone. The Tech Toolbox can help people learn, work, and live more inclusively. ■



For people with intellectual and developmental disabilities

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Do you know about TalentScout?

Vist TheArc@Work's website to learn more — <http://www.thearc.org/thearcwork>



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! ■



PHILANTHROPEDIA
GIVE TOGETHER, DO MORE BETTER
A Division of GuideStar

