



# 2018 Annual Report





# Our. Mission

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.



## Dear friends,

### **Equity. Opportunity. Access. Inclusion. Community.**

These are more than just words – they are some of the ideals we live by throughout The Arc’s network.

This year’s annual report highlights the array of ways we are promoting and protecting the rights of people with intellectual and developmental disabilities (I/DD).

Through our programs, our powerful chapter network, and our public policy and advocacy efforts, we are working alongside people with I/DD and their families to make a more inclusive society a reality in all aspects of life.

Our work has been going strong for nearly 70 years. We’ve made great progress, and proudly share with you our 2018 accomplishments. Thank you for being a part of our past, present, and future as we strive to fully achieve our mission.

**Fred Misilo**  
President  
The Arc’s Board of Directors

**Peter V. Berns**  
Chief Executive Officer  
The Arc



## Advocacy in Action: Facing Challenges and Advocating for Our Rights

The Arc has a long, successful history of public policy and grassroots advocacy leadership, and has been involved in every major development that has advanced the rights and addressed the needs of people with I/DD and their families.

The major challenges we faced in 2018 included threats to Medicaid, proposed cuts to basic food assistance, and discrimination in the immigration process.

The threats to **Medicaid** took shape with the Administration allowing states to propose in plans for how their Medicaid program would run to include work requirements in order for people to be eligible for Medicaid. The Arc opposes this approach because many people with serious health conditions require access to health care services to treat those health conditions, and to maintain their health and function. Furthermore, Medicaid specifically covers services, such as attendant care, that are critical to enable people with significant disabilities to have basic needs met, to get to and from work, and to do their jobs. Requiring individuals to prove each month that they meet complicated work rules, or are exempt, just makes it harder for people to qualify for these programs and to access the services they need to be employed. These requirements are being challenged in the courts.

Work requirements were also a major issue during the yearlong fight over cuts to the **Supplemental Nutrition Assistance Program**, or SNAP. Out of the gate, the House of Representatives considered a bill that would have cut the program and expanded SNAP's existing work requirements, among other proposals harmful to people with I/DD. As the underlying bill, known as the Farm Bill, moved through the process in the Senate and reconciling differences between the two chambers, The Arc called on Congress to work together on a bipartisan approach to reauthorization that protected and preserved SNAP. The Arc's network was active throughout this fight, advocating with Members of Congress through meetings with legislators, submitting letters to the editor in local news outlets, and speaking out on a video that was promoted on social media about the impact of SNAP on the lives of people with disabilities. Finally, the version of the bill that was passed and signed into law rejected cuts to SNAP, which

### #HANDSOFF: SHARING STORIES OF IMPACT

The Arc's #HandsOff blog series features stories from individuals and families across The Arc's network about how some of today's key policy issues impact their day to day lives. From access to Supplemental Security Income (SSI), to Medicaid, to community living, to SNAP, to why it's important to be an advocate, this platform elevated the experiences of people with disabilities and family members. Check it out at [blog.thearc.org](http://blog.thearc.org)!





more than 11 million people with disabilities across the United States rely on to help them eat.

In 2018, The Arc pushed back on the Department of Homeland Security's proposed expansion of the existing **"public charge" rule**. The rule would exclude people from this country simply because they have a disability and might need some assistance in an expanded number of circumstances and programs. Someone is called a "public charge" if the government thinks they might depend on government benefits to meet their needs — directly discriminating against people with disabilities and chronic health conditions. If the new rule is put into practice, it will hurt many more immigrants and immigrant families, including people with disabilities, and make it harder for families to stay together.

The Arc's public policy team monitors and acts on a wide range of issues. Among other activities, we worked to block advancement of proposals to cut **Social Security**, including SSDI, and Supplemental Security Income in the President's budget proposal; legislative attempts to undermine the **Medicaid Home and Community Based Settings Rule** and administrative action; and legislation in the Senate that would weaken the **Americans with Disabilities Act**.

While much effort went into fighting against proposals harmful to people with I/DD, The Arc was on offense for many positive programs and legislation for our community. Two highlights include the reauthorization of the **Children's Health Insurance Program**, or CHIP; and ongoing work to reauthorize the **Money Follows the Person** program, which moves people with disabilities from institutions into the community by paying for programs not normally covered by Medicaid such as employment and housing services.



## PAID FAMILY AND MEDICAL LEAVE: ADVANCING THE DISABILITY ANGLE

Nearly all of us will need paid leave at some point — to care for a family member's or our own serious medical condition, or to welcome a new child. Without paid leave, workers often face a cruel and unnecessary tradeoff: health and family, or work and making ends meet.

The Arc continues to advance the disability angle on this issue, working on research to highlight the intersection of the need for paid leave and workers with disabilities and families that include a person with a disability; seeking media opportunities to draw attention to this issue; and sharing personal stories from families impacted by the need for paid leave.

Visit [thearc.org/paidleave](https://thearc.org/paidleave) to see these stories and learn more about our work in this important policy area.



## The National Center on Criminal Justice and Disability®: Promoting Access to Justice

The Arc's National Center on Criminal Justice and Disability (NCCJD®) is a nationally-recognized leader in promoting access to justice for people with I/DD, whether as suspects, defendants, incarcerated persons, victims, or witnesses.

One of NCCJD's flagship initiatives is the Pathways to Justice® program, which is designed to prepare criminal justice professionals to more effectively interact with and serve people with I/DD and build lasting relationships between the criminal justice and disability communities. This award-winning program has provided 15 trainings to over 1,250 professionals since the program's inception in 2015. In 2018, staff provided two Pathways to Justice trainings, reaching 185 criminal justice professionals and disability advocates. NCCJD also piloted a new Pathways to Justice Trainer Certification Course, a train-the-trainer version of Pathways, in partnership with the University of Cincinnati Center for Excellence in Developmental Disabilities. As part of this project, three Disability Response Teams provided three additional Pathways trainings in different regions of Ohio.

Staff also delivered 28 conference and webinar presentations on various topics, including sexual assault, false confessions, and Supreme Court updates, reaching over 1,800 people. NCCJD responded to over 150 information and referral requests from people with disabilities and their supporters. The program also provided technical assistance to law enforcement agencies and prosecutors' offices as part of a new initiative called, "Serving Safely," funded by the Bureau of Justice Assistance, that creates a national training and technical assistance center on mental health and developmental disabilities. Further, NCCJD worked with the WITH Foundation to expand the scope of its Talk About Sexual Violence project to include sexual violence against men with disabilities.

In 2018, NCCJD managed more than \$500,000 in grant funds and greatly expanded the power of The Arc's chapter network to engage in criminal justice advocacy by launching a national community of practice, with over 120 members to date.

**TALK ABOUT  
SEXUAL  
VIOLENCE:  
KECIA'S STORY**

**Individuals with disabilities are seven times more likely to be victims of sexual assault than those without disabilities.** Kecia, a sexual assault survivor-turned-advocate, is one of those individuals. She was raped, but justice was denied to her because of the failings of the criminal justice system. This is her story.

Kecia met a man at a self-advocacy meeting and, after discovering that they shared a love for chess, invited him to her home for a friendly game. As soon as Kecia and her newfound friend arrived at her home, however, he assaulted Kecia.

Kecia contacted the police, who dismissed the case on the basis that it was her word against her attacker's. Kecia then appealed to her social services agency, who filed a Special Incident Report but then offered no further support. Kecia tried in vain to obtain a copy of the report from her case manager, but her request was met with silence.

With little help from the justice system and no support from her social services agency, Kecia was forced to face the traumatic aftermath of her assault alone, which caused her to become depressed and suffer other negative effects. It was only through her enrollment in an in-patient program with specialized therapy and a structured follow-up program that Kecia emerged from her depression and is now in recovery.

Today, Kecia has found her strength and her voice in telling her story and empowering other victims of sexual abuse to come forward and seek justice. Kecia is an Abuse Awareness Prevention Advocate and is working with The Arc's Talk About Sexual Violence program to share her story with medical professionals and criminal justice professionals to raise awareness of sexual abuse in the I/DD community and prepare these first responders to support survivors of sexual assault.



## Legal Advocacy to Advance the Mission



The Arc is actively involved in disability rights impact litigation as plaintiff, counsel, and *amicus* to advance The Arc's mission and ensure that people with I/DD can lead full lives in the community, free from discrimination.

*Amicus* (friend of the court) briefs allow The Arc to offer its expertise to the court in cases in which it is not a party or counsel, thereby broadening the reach of The Arc's influence on cases across the country that impact the lives of people with I/DD in every aspect of life. In 2018, The Arc filed *amicus* briefs in cases relating to community integration, criminal justice, health care, parental rights, and the importance of class action lawsuits in disability civil rights litigation.

The Arc also filed a new civil rights lawsuit, *Seth v. D.C.* (D. D.C.), on behalf of a young African-American man with intellectual disability found incompetent to stand trial but languishing in federal prison. He is frequently placed in solitary confinement since Washington D.C.'s disability services agency will not serve him in the community, where the agency's experts agree he belongs. The lawsuit alleges violations of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, the D.C. Human Rights Act, and D.C.'s Citizens with Intellectual Disabilities Act.

We continue our participation in a class action lawsuit, *Georgia Advocacy Office v. Georgia*, challenging Georgia's segregated and inferior "school" system for students with disability-related behaviors. The Arc was involved in garnering a feature length piece in *The New Yorker* on this case, which shed light on this punitive and harmful program. Titled "The Forgotten Ones: Georgia's Separate and Unequal Special-Education System," the article raised the profile of the litigation—catching the attention of former Georgia gubernatorial candidate Stacey Abrams and documentary filmmaker Ava DuVernay—and educated the general public about a statewide shadow "school" system for students with disabilities that few knew existed.

The Arc came out in opposition to Judge (now Justice) Brett Kavanaugh's appointment to the United States Supreme Court due to several troubling decisions on cases involving self-determination, education, and employment, and his stances on the Affordable Care Act and school choice. Prior to this, The Arc had not opposed a presidential Supreme Court nominee in over three decades.

Our legal advocacy work is strengthened and made possible by our partnerships with law firms (via *pro bono* support\*) and other non-profit advocacy organizations as well as the generous donors to our Legal Advocacy Fund. Thanks to all who joined The Arc in this critical work in 2018.

\*A list of the law firms providing *pro bono* support is available on page 20.



# The Arc@Work and Walmart Foundation Exceed Expectations in National Employment Initiative

The Arc@Work and Walmart Foundation have successfully completed the second year of the “Innovative Approaches to Community-Based Employment Initiative”, during which the 12 participating chapters far exceeded projected employment outcomes and expectations set at the beginning of the fiscal year. This initiative is a competitive subgrant program, supported by the Walmart Foundation that provides subgrants to chapters of The Arc that demonstrate innovation, ingenuity and sustainability in their community-based employment programs.

Since its inception in 2016, the Innovative Approaches to Community-Based Employment Initiative has consistently exceeded projected outcomes, placing nearly 1,000 individuals into jobs and providing job-readiness training to an estimated 2,500 job seekers with intellectual and developmental disabilities. The program entered its third year in June 2018, leveraging \$325,000 in grants to 18 chapters across the country.

## PEOPLE TRAINED



## PEOPLE EMPLOYED



## RETENTION RATE



## PATTI'S STORY: FROM STUDENT TO TEACHER

Patti M. was about to graduate from high school in Stonington, CT in 2015. As she planned the next step in her life, school officials felt she would benefit from a school to work transition program. Her school's Special Education department worked with The Arc of New London County (CT) to place her at The Arc's Employment Transition Center (ETC) in Groton, CT. She began at ETC with a curriculum of life skills and general vocational training before moving onto The Arc's Culinary Arts program.

During her two years of vocational training, Patti excelled in many areas, demonstrating her attention to detail and capacity to lead others in tasks. Once her two years of training were complete, Patti was hired onto The Arc of New London County's staff as a full-time employee! She is now a Job Coach, receiving supervision from the head Job Coach and Culinary program coordinator. She oversees the participants and teaches the same kitchen techniques that she mastered during her time as a student learner.

She has become a role model in the kitchen — and an example of what someone with I/DD can accomplish if provided with the right tools and encouragement. In a short time, and with the supports and coaching from The Arc's staff, Patti has transformed from a shy young student to a confident and knowledgeable staff member.



## New Data Reveals Our Nation is Failing to Support People with Intellectual and Developmental Disabilities and their Families

In 2018 The Arc released the 2017 Family & Individual Needs for Disability Supports (FINDS) Community Report. The intent of this one-of-a-kind survey conducted by The University of Minnesota's Institute on Community Integration in collaboration with The Arc is to understand the experiences of families who provide supports to a family member with I/DD. This is the second FINDS Report that The Arc has released; the first was conducted in 2010 and released in 2011.

An estimated 7.3 million people with I/DD live in the United States, with the majority living in their family home and receiving support from a family member. The report includes survey responses from over 3,000 caregivers and provides information on the economic implications, logistical challenges, and major gaps that exist in caregiving infrastructure.

The FINDS Survey revealed that, despite the current levels of availability of resources and public funding to provide supports for caregivers and individuals with disabilities, many critical challenges remain that impact the wellbeing of caregivers day to day:

- A vast majority of caregivers are stressed (94%), stretched thin, and lack time to complete personal tasks (51%); and
- On average, caregivers provide 57 hours of care a week to their loved ones with disabilities.

For employed caregivers, high levels of stress and the time commitment of providing care translates, in many cases, to performance issues in the workplace:

- 75% reported meeting work responsibilities is a problem, including 33% for whom this is a major problem;
- 55% reported shifting to part-time or reducing hours;
- 33% passed on a promotion; and
- 24% received a warning for attendance or performance issues.

Learn more about the FINDS study and the results on topics such as education, employment, future planning, and more, at [thearc.org/FINDS](http://thearc.org/FINDS).



**1,286** PEOPLE

reached through 17 in-person trainings and webinars, including trainings for human services professionals in Arizona, Illinois, and Wisconsin, and financial literacy trainings for families in Indiana, Maryland, Michigan, New York, and Oregon.

**50** FAMILY MEMBERS

trained in Spanish on future planning in Arizona and Wisconsin.

## Planning for the Future

While many people with I/DD were once confined to institutions, today the vast majority live in the community: about 75% of adults with I/DD live with their parents or other caregivers.

However, far too many families don't have a plan for how to ensure their family member is supported in the future. The Arc's Family and Individual Needs for Disability Supports (FINDS) survey found that 52% of respondents didn't have a future plan. The Arc's Center for Future Planning continues working to ensure more families know about future planning and have the tools to create a future plan.

In 2018, the Center continued educating families through in person trainings and webinars, and increased efforts to reach Spanish speaking families. We also created several new resources for families and those working with people with I/DD, including a paper on the needs of older caregivers of people with I/DD, a detailed guide and plain language brochure on talking to older people with I/DD and their families about dementia, and an online training for information and referral professionals on working with people with I/DD.

Finally, we facilitated a national survey, working groups, and story-telling sessions with 156 people with co-occurring I/DD and mental illness, their families, and professionals, to better understand the needs of individuals with a dual diagnosis.

Future planning can be daunting, but it's necessary. The Center for Future Planning provides people with disabilities and their families tools and resources to help start the conversation. Learn more at [futureplanning.thearc.org](http://futureplanning.thearc.org).



IN 2018, THE ARC'S WINGS FOR AUTISM/WINGS FOR ALL TEAM WORKED WITH...

**40** chapters of The Arc, **10** airlines & **30** local branches of TSA.

TO ORGANIZE...

**34** events at **32** airports across the country.

MORE THAN...

**1,600** individuals with I/DD and over **2,600** family members

BENEFITED FROM WINGS EVENTS IN 2018.

## Wings for Autism®/ Wings for All® Makes Air Travel Accessible

While there are many unique advantages that air travel has over other modes of transportation, the fact remains that traveling by air can be a stressful and even frustrating process. Large crowds, bright lights, loud noises, and high stress situations impact all travelers as they navigate airports. For travelers with I/DD and their families, this type of environment can be particularly difficult to navigate.

Since 2014, the Wings for Autism/Wings for All program has provided thousands of individuals with I/DD and their family members with the opportunity to practice all the steps involved in air travel in a controlled, but realistic, environment. This "rehearsal" helps to alleviate some of the stress families experience when traveling by air. Each event allows attendees to partake in every stage of the airport journey — from check-in to buckling their seatbelt on the aircraft. The program also offers vital training and education for TSA, airport, and airline staff on how to better serve and interact with individuals with autism and I/DD.

Additionally, The Arc partnered with TSA to develop a public service announcement to help better prepare individuals with I/DD and their families for the security screening process prior to arriving at the airport.



## **Bridging the Digital Divide: The Arc's Tech Programs & Comcast NBCUniversal**

Technology is playing an increasingly important part of our daily lives — whether it is to socialize, hunt for jobs, order groceries or read the news — yet many in the disability community continue to be left out of these virtual spaces. People with disabilities face several barriers in becoming digital citizens, such as poor web accessibility, unaffordable technology products and services, and risks of online bullying or exploitation. Greater than any of these challenges, however, is the overall lack of access to basic digital literacy instruction for the disability community, especially those with I/DD.

Since 2014, The Arc and Comcast NBCUniversal have partnered together to create opportunities for people with I/DD to learn basic computer skills by establishing Tech Coaching Centers (TCC) at chapters of The Arc across the country. The TCC initiative was created to give people with I/DD access to the latest technology and to provide them with individualized instruction and support so that they can pursue their personal and professional goals.

In 2018, 489 individuals with I/DD signed up for tech coaching. Of that group, 120 individuals gained at least one new tech skill with the support of 56 tech coaches who conducted 288 tech coaching sessions or workshops.

Mickey J. Dower, a 35 year-old man from Fitchburg, Massachusetts who attends a day program at The Arc Opportunity, lives with congestive heart failure — largely due to his weight. With the help of a tech coach, Dower has been learning the necessary skills to use his laptop and smartphone to track his food intake and implement healthy habits. He has since lost 120 pounds and his health has greatly improved.

Kelly Sullivan came to The Arc of Carroll County's Tech Coaching Center with a special project — she wanted to help a friend of hers who had communication challenges better express themselves by creating a custom communication board. She started out by taking pictures of objects or people her friend regularly interacts with and uploaded the pictures on to the computer. She then learned how to insert pictures into a document and crop/resize them to print. Once she had printed the pictures, she used a laminator to laminate them and, with them, fashioned a communication board.

Kelly saw a need in the life of one of her friends and decided to do something about it. Because of the coaching session, she was able to not only have the idea, but the ability to do something to better the life of someone else. Not only did her efforts help the life of someone who was non-verbal, they also gave her a more meaningful and purposeful time at The Arc.

The TCC initiative is part of the national partnership between The Arc and Comcast NBCUniversal. From their efforts together to promote Comcast's Internet Essentials program to volunteer opportunities through Comcast Cares Day, the partnership enables both organizations to achieve their shared goals of expanding technology resources for people with intellectual and developmental disabilities to ensure everyone has the tools to reach his or her greatest potential.

## The Arc@School: Carrying on The Arc's Tradition of Advocating for the Rights of Students with I/DD



Since its founding, The Arc has been a staunch advocate for the rights of students with I/DD and supporter of greater access to educational supports and services. Over the years, The Arc and our network of chapters have been on the front lines of promoting and protecting the rights of individuals with disabilities in our schools. The Arc played an important role in bringing one of the landmark lawsuits in education access for students with disabilities, challenging the state of Pennsylvania's right to deny a public education to children with I/DD. This victory was followed by the passage of the Individuals with Disabilities Education Act (IDEA) in 1975, which legally required schools to educate all students with disabilities for the first time.

The Arc carries on its education advocacy today through The Arc@School. This program's mission is to build the capacity of our nationwide network of chapters to provide individual advocacy that helps students with I/DD and their families navigate the special education system.

The program launched an online Advocacy Curriculum with eight modules to provide non-attorney special education advocates the basic information and training that they need to advance the rights and secure supports for students in need of special education services. Family members can access the curriculum to learn how to advocate for their children, and educators can access the curriculum to better serve students with disabilities, build relationships with families, and comply with disability laws. The Curriculum officially launched in 2019.

In 2018, The Arc@School launched a Community of Practice to promote collaboration, knowledge sharing and dialogue among The Arc's chapters on topics related to special education advocacy. The group garnered 140 members from 99 chapters across the country and covered over 20 different topics in special education. The Arc@School also hosted three webinars for chapters on behavioral supports for individuals with I/DD, publicly available special education resources and the online Advocacy Curriculum. Learn more at [thearcatschool.org](http://thearcatschool.org).

## The Catalyst Awards: Recognizing Impact Across Society

The Arc presented the prestigious Catalyst Awards to six honorees, all of whom have made extraordinary contributions in the lives of people with I/DD. The 2018 Catalyst Award winners hail from a wide swath of our society, including one of the most admired fashion brands in the world, the lead cast and writer behind a hit Broadway show, a nationally recognized self-advocate, a non-profit that is paving the way for inclusion of disability in the fashion industry, and one of the nation's premier special education lawyers, all of whom continue to endeavor toward changing how society perceives and treats people with disabilities.

### CORPORATE ADVOCATE OF THE YEAR:

**Tommy Hilfiger**

### SELF-ADVOCATE OF THE YEAR:

**James Meadours**

### ENTERTAINMENT INDUSTRY EXCELLENCE:

**Amy and The Orphans**

### LEGAL ADVOCATE OF THE YEAR:

**Jack D. Robinson**

### EMPLOYER OF THE YEAR:

**Levy Restaurant Group**

### MARKETING INFLUENCER OF THE YEAR:

**Runway of Dreams Foundation**

The Catalyst Awards Ceremony was dotted with stars, such as international model Mama Cax and CMT Hot 20 Countdown Host Katie Cook. Cook and her husband, songwriter and producer Adam Shoenfeld, also performed their new single "Hey JoJo" for the first time on the Catalyst stage. The duo wrote "Hey JoJo" as a tribute to Katie's sister Joanne who passed away in early 2018 and pledged the song's proceeds to The Arc. Joanne had I/DD and was a huge part of Katie and Adam's life, she also embodied the mission of The Arc — living a meaningful life of her choosing in the community. Support The Arc by downloading "Hey JoJo":

<https://apple.co/2ROx9y2>



2018 Catalyst Award Winners (left to right): **Mindy Scheier**, President & Founder, Runway of Dreams; **Jamie Brewer**, Actor, Amy & the Orphans; **Greg Costa**, Director of Operations, Levy Restaurant Group; **Edward Barbanell**, Actor, Amy & the Orphans; **James Meadours**, Self Advocate; and **Jack D. Robinson**, Founding Partner, Spies, Powers and Robinson, P.C.



## Inclusive Volunteering: The Ultimate Win-Win

### *Martin Luther King Jr. Day of Service*

For The Arc, the quote from Martin Luther King, Jr. — “Everybody can be great because everyone can serve” — has a special meaning. Many perceive people with disabilities as the ones in need of service — but in reality, they are an important part of civic engagement at the state, local, and national levels. The Arc was honored to have been selected for a third year by the Corporation for National and Community Service to execute volunteer projects for the annual Martin Luther King, Jr. Day of Service.

Inclusive volunteering is a win for people with and without disabilities and for the community as a whole. It gives people with and without I/DD the opportunity to interact, learn from each other, and establish friendships, all while helping those in need. The projects also have helped people with I/DD build soft skills and job skills that can help as they find employment and build a career.

**In 2018, subgrantees collectively supported 987 volunteers to contribute 24,704 hours of service during 339 events.** These events fed over 64,000 meals to people in the community. Events included sandwich-making competitions, food drives and delivery, food recovery from restaurants, and food bank volunteer events. Each chapter’s creative and engaging project helped further our mission of community inclusion and participation for people with intellectual and developmental disabilities.

Inclusive volunteering doesn’t just help the volunteers: organizations that work with our grantees to promote inclusive volunteering also benefit greatly from these projects. Participating in community-based volunteering projects helps organizations develop partnerships with other community organizations, school groups and service sororities, and businesses. These projects also increase participating organizations’ name and brand recognition in local communities, which has led to additional funding and participation in their activities by students and professionals in their local communities.

Truly, when we support inclusive volunteering, everyone wins.

Danielle, the Director of True Blue Neighbors at the University of Tulsa, has been instrumental in the success of TARC’s MLK Day Service grants. Over the past three years, Danielle and True Blue Neighbors have helped TARC recruit volunteers without disabilities to take part in service projects. Danielle also volunteers herself at most of TARC’s service projects. Danielle has taken the next step in serving and has now joined TARC on their board of directors. Thank you, Danielle, for making TARC’s volunteer work successful and for becoming more engaged in the I/DD field!

## Health and Fitness for All: Helping Individuals Become Healthier!



Living a healthy and active life is a challenge that everyone faces regardless of who you are or your background. Individuals with I/DD are at an increased risk for obesity compared to the general population. There are many factors that can contribute to this increased risk — lack of healthy food options, mobility limitations, lack of physical activity opportunities, difficulty chewing, food sensitivities, and absence of role models. Unhealthy weight can lead to many secondary health issues such as heart disease, high blood pressure, diabetes, and stroke. As part of The Arc's mission to support individuals with I/DD to live independent and fulfilling lives, our Health and Fitness for All program trains staff at chapters of The Arc and other organizations to implement a 12-week healthy living program to adults with I/DD. The goal of the program is for individuals with I/DD to walk away with more knowledge on how to eat better and lead more active lives.

Thanks to the Anthem Foundation's support, the Health and Fitness for All program worked with eight chapters of The Arc in Kentucky, Wisconsin, and Texas to help improve health outcomes for the individuals they serve. Two-hundred and twenty-three individuals participated and lost a combined 316 pounds at the completion of the 12-week program, and 25 percent of individuals attained or maintained a healthy weight by the program's end. In addition, 90 percent of participants increased their knowledge of healthy foods and nutrition. This improved knowledge of healthy foods and incorporating a regular workout routine helped participants lose weight throughout the program.

One participant from The Arc of Kentucky, Nyketa, lost an astonishing 30 pounds throughout the 12-week program and actually started to enjoy working out once she incorporated biking into her routine. After the program ended, she joined a local fitness center to continue to stay active and has maintained her weight loss. The Arc of Kentucky said field trips to the grocery store helped Nyketa and other participants learn to read nutrition labels and plan healthier meals and snacks, which contributed to their weight loss success.



# 2018 Annual Report Donor List

## **ACTIVIST'S LEAGUE** **(\$200,000 AND ABOVE)**

Anonymous Foundation  
Estate of Ehler O Gregory\*  
Mrs. Joan Wister\*  
May and Stanley Smith Charitable Trust  
Walmart Foundation

## **ACTIVIST'S ALLIANCE** **(\$40,000 - \$199,999)**

Anthem Foundation  
Comcast NBCUniversal  
Corporation for National and Community Service  
Ford Foundation  
Mitsubishi Electric America Foundation  
Open Society Foundations  
Estate of Karen Staley\*  
Norman E. Foisy\*  
New Venture Fund  
The Center on Budget and Policy Priorities  
The Retirement Research Foundation  
The Sixteen Thirty Fund  
The Taft Foundation  
University of Illinois at Chicago  
University of Massachusetts Boston  
Vera Institute of Justice  
WITH Foundation

## **ADVOCATE'S LEAGUE** **(\$15,000 - \$39,999)**

United Healthcare Community Plan of Wisconsin  
Mr. Douglas\*\* and Mrs. Glenys Church  
Mr. Tom and Ms. Carol Wheeler\*\*

## **PROTECTOR'S CIRCLE** **(\$5,000 - \$14,999)**

Mr. Quincy\*\*\* and Mrs. Zelia Abbot  
Mr. Peter V. Berns and Ms. Melissa Zieve  
Mr. Charles E. Binder and Ms. Nancy G. Shor  
Estate of Howard Winters Carr\*  
Mr. Eric and Mrs. Laura Dreiband  
Fred A & Barbara M Erb Family Foundation  
Mr. Hugh Evans III\*\*  
Dr. Neil\*\* and Mrs. Annmarie Hawkins  
Mr. Timothy\*\* and Ms. Pat Hornbecker  
Mr. Howard and Ms. Trudy Jacobson  
Mr. David and Mrs. Patricia Kepler  
Mr. John J. Lyons III  
Mr. Tom and Mrs. Elise\*\*\* McMillan  
Mr. Frederick Misilo, Jr.\*\*\*  
Mr. Randall Patrick\*\*  
People with Disabilities Foundation  
Public Welfare Foundation  
Skadden Foundation  
Mr. Rick Stamberger  
Mr. John and Mrs. Julene Stellato  
Ms. Faye Tate\*\*  
Mr. Robert and Mrs. Nancy\*\*\* Webster

## **NATIONAL SUPPORTER** **(\$2,000 - \$4,999)**

Mr. Lawrence and Mrs. Emily J. Chu  
Dr. Kruti Acharya\*\*  
Mr. Ronald\*\*\* and Mrs. Judy Brown  
Mr. John Bryant  
Mr. Wilfred Cooper, Sr.  
Mr. Kristopher Dawsey  
Mr. Jack Davies and Ms. Kay Kendall

Ms. Maureen Del Duca  
Monsignor Thomas Dolina LPC  
Eta Phi Beta Sorority Foundation, Inc.  
Dr. Grace L. Francis\*\*  
Ms. Constance Garner\*\*  
Ms. Mary L. Gonzales\*\*  
Mr. Lewis Greenbaum, Esq.  
Mr. Jonathan Haines  
Mrs. Carrie Hobbs Guiden\*\*  
Ms. Patricia Hollobaugh  
Ms. Sari R. Hornstein  
Mrs. Miriam Hunt  
Mr. Rocco and Ms. Deborah Landesman  
Ms. Alexis Leyman  
Mr. James Mauer and Mrs. Jennifer Richter Mauer  
Mr. Robert McDowell  
Ms. Rebecca Milkman  
Mr. John P Miller  
Mr. Andrew and Mrs. Shanna Milman  
Ms. Bridget Morse  
Mr. Frank and Ms. Kelly\*\* Piacenti  
Ms. Elise S. Reeder  
Mrs. Elizabeth Sansone  
Dr. Jeffrey B. Schwamm and Ms. Marty Ford  
Mr. Clifford Sloan  
Ms. Kathleen A. Stauffer\*\*  
Ms. Martha Elaine Sweeney  
Mr. Jose H. Velasco\*\*  
Mr. Kenneth I. Wirfel  
The Dorsey & Whitney Foundation

\*Bequest gift

\*\*National board member (Members as of November 2018, when the most recent term ended)

\*\*\*Current/past national president



## Pro Bono Spotlight

The Arc of the United States appreciates in-kind contributions of service. We would like to extend a heartfelt thank you to **Comcast NBCUniversal** for airtime provided for public service announcements and Xfinity.com placement of \$1,639,188. Additionally, we are grateful to the following law firms that provided pro bono legal services: **Skadden, Arps, Slate, Meager & Feld LLP** valued at \$1,452,219; **DLA Piper, LLP (US)** valued at \$561,685; **Latham & Watkins** valued at \$441,600; **Jones Day** valued at \$107,000; **Lowenstein Sandler** valued at \$68,365; **Venable** valued at \$49,346; **Epstein Becker Green** valued at \$40,038; **Katten Muchin Rosenman** valued at \$31,907; **Akin Gump Strauss Hauer & Feld LLP** valued at \$26,481.

## THANK YOU TO THE FOLLOWING CHAPTERS OF THE ARC FOR THEIR CONTRIBUTION IN ADDITION TO THEIR ANNUAL DUES

AHRC Nassau  
Arc Herkimer  
Arc Lucas County  
Bronx Developmental Center  
Clinton County Arc  
Communitas, Inc.  
Developmental Services of Dickson County  
Stone Belt Arc  
The Arc Brockton Area  
The Arc Eastern Shore  
The Arc El Paso  
The Arc for the New River Valley  
The Arc Jefferson - St. Lawrence  
The Arc New London County

The Arc of Bergen and Passaic Counties, Inc.  
The Arc of Adams-Clay  
The Arc of Ashtabula County  
The Arc of Atlantic County  
The Arc of Decatur County Inc.  
The Arc of Dodge County  
The Arc of Greater Boone County  
The Arc of Greater Pittsburgh  
The Arc of Greater Prince William INSIGHT, Inc.  
The Arc of Greater Williamsburg  
The Arc of Jackson County, Inc.  
The Arc of Jackson County, Inc.  
The Arc of Mid-Columbia  
The Arc of Midland

The Arc of New Jersey  
The Arc of New Mexico  
The Arc of Opportunity  
The Arc of Pueblo  
The Arc of San Antonio  
The Arc of San Diego  
The Arc of Shelby County  
The Arc of Southwest Colorado  
The Arc of Sunflower  
The Arc of the Bay  
The Arc of Washington County  
The Arc of Washington State  
The Arc of Wayne County  
The Arc, Ocean County Chapter  
The Charles River Center

Thank you  
to our  
Sponsors:

CHAMPION



ADVOCATE



SUPPORTER



FRIEND





# Auditor's Letter

To the Board of Directors  
The Arc of the United States  
The Foundation of The Arc of the United States  
Washington, D.C.

## REPORT ON THE FINANCIAL STATEMENTS

We have audited the accompanying combined financial statements of The Arc of the United States (The Arc) and The Foundation of The Arc of the United States (the Foundation), collectively the Organizations, which comprise the combined statement of financial position as of December 31, 2018, and the related combined statements of activities and change in net assets, functional expenses and cash flows for the year then ended, and the related notes to the combined financial statements.

## MANAGEMENT'S RESPONSIBILITY FOR THE FINANCIAL STATEMENTS

Management is responsible for the preparation and fair presentation of these combined financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation and maintenance of internal control relevant to the preparation and fair presentation of combined financial statements that are free from material misstatement, whether due to fraud or error.

## AUDITOR'S RESPONSIBILITY

Our responsibility is to express an opinion on these combined financial statements based on our audit. We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the combined financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the combined financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the combined financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation

and fair presentation of the combined financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the combined financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

## OPINION

In our opinion, the combined financial statements referred to above present fairly, in all material respects, the combined financial position of the Organizations as of December 31, 2018, and the combined change in their net assets and their combined cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

## REPORT ON SUMMARIZED COMPARATIVE INFORMATION

We have previously audited the Organizations' 2017 combined financial statements, and we expressed an unmodified audit opinion on those audited combined financial statements in our report dated April 12, 2018. In our opinion, the summarized comparative information presented herein as of and for the year ended December 31, 2017, is consistent, in all material respects, with the audited combined financial statements from which it has been derived.



April 7, 2019

# Combined Statement of Financial Position

As of December 31, 2018

With Summarized Financial  
Information For 2017

	2018			2017
	WITHOUT DONOR RESTRICTIONS	WITH DONOR RESTRICTIONS	TOTAL	TOTAL
<b>Revenue and Support</b>				
Contributions	\$ 692,100	\$ 1,723,827	\$ 2,415,927	\$ 3,461,413
Affiliation and chapter fees	2,869,978	—	2,869,978	2,652,475
Contributed services	4,496,222	—	4,496,222	1,951,014
Bequest income	526,077	198,395	724,472	132,901
Registration fees	928,758	—	928,758	947,241
Grants	547,457	—	547,457	584,055
Program service fees	370,661	—	370,661	169,810
Investment (loss) income, net	(376,277)	(303,903)	(680,180)	1,634,375
Royalty income	84,145	—	84,145	103,550
Other income	20,616	751	21,367	114,298
Loss on sale of land	(56,807)	—	56,807	—
Net (loss) gain in perpetual trust	—	(151,591)	(151,591)	130,887
Net assets released from donor restrictions	2,683,695	(2,683,695)	—	—
<b>TOTAL REVENUE AND SUPPORT</b>	<b>12,786,625</b>	<b>1,216,216</b>	<b>11,570,409</b>	<b>11,882,019</b>
<b>Expenses</b>				
<b>Program Services:</b>				
Chapter Leadership and Development	2,157,217	—	2,157,217	1,762,232
Public Education	1,947,051	—	1,947,051	1,616,262
Public Policy	4,275,107	—	4,275,107	2,454,508
Program Innovation	3,621,728	—	3,621,728	3,773,568
Total program services	12,001,103	—	12,001,103	9,606,570
<b>Supporting Services:</b>				
Management and General	1,037,507	—	1,037,507	869,234
Fundraising	822,319	—	822,319	905,579
Total supporting services	1,859,826	—	1,859,826	1,774,813
<b>TOTAL EXPENSES</b>	<b>13,860,929</b>	<b>—</b>	<b>13,860,929</b>	<b>11,381,383</b>
Change in net assets	(1,074,304)	(1,216,216)	(2,290,520)	500,636
Net assets at beginning of year	3,276,636	12,138,974	15,415,610	14,914,974
<b>Net Assets at End of Year</b>	<b>\$ 2,202,332</b>	<b>\$ 10,922,758</b>	<b>\$ 13,125,090</b>	<b>\$ 15,415,610</b>

# Assets

	2018	2017
<b>Current Assets</b>		
Cash and cash equivalents	\$ 1,659,601	\$ 1,609,933
Investments	10,234,434	11,977,282
Accounts receivable, net of allowance for doubtful accounts of \$52,000 and \$65,000, for 2018 and 2017, respectively	530,982	637,716
Grants receivable	97,061	83,653
Due from related party	135,327	49,335
Prepaid expenses	69,012	64,688
<b>TOTAL CURRENT ASSETS</b>	<b>12,726,417</b>	<b>14,422,607</b>
<b>Fixed Assets</b>		
Land	—	238,755
Furniture and equipment	1,805,618	1,730,824
Website	885,215	826,363
Subtotal	2,690,833	2,795,942
Less: Accumulated depreciation and amortization	(1,855,121)	(1,548,150)
<b>NET FIXED ASSETS</b>	<b>835,712</b>	<b>1,247,792</b>
<b>Other Assets</b>		
Security deposit	40,054	40,054
Investments held for beneficial interest in perpetual trust	1,122,742	1,274,333
Deferred compensation investments	135,398	126,498
<b>TOTAL OTHER ASSETS</b>	<b>1,298,194</b>	<b>1,440,885</b>
<b>Total Assets</b>	<b>\$ 14,860,323</b>	<b>\$ 17,111,284</b>

## Liabilities and Net Assets

	2018	2017
<b>Current Liabilities</b>		
Accounts payable and accrued liabilities	\$ 847,934	\$ 701,079
Deferred revenue	9,005	3,000
Deferred rent, current	138,659	56,830
<b>TOTAL CURRENT LIABILITIES</b>	<b>995,598</b>	<b>760,909</b>
<b>Long-Term Liabilities</b>		
Deferred rent, net of current portion	604,237	808,267
Deferred compensation	135,398	126,498
Total long-term liabilities	739,635	934,765
<b>TOTAL LIABILITIES</b>	<b>1,735,233</b>	<b>1,695,674</b>
<b>Net Assets</b>		
Without donor restrictions:		
Undesignated	1,592,650	2,666,954
Board designated	609,682	609,682
Without donor restriction net assets	2,202,332	3,276,636
With donor restrictions	10,922,758	12,138,974
<b>TOTAL NET ASSETS</b>	<b>13,125,090</b>	<b>15,415,610</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 14,860,323</b>	<b>\$ 17,111,284</b>

## Senior Management



**Peter V. Berns** CEO



**Marty Ford**  
Senior Advisor



**Trudy Jacobson**  
Senior Advisor,  
Development &  
Partnerships



**Jonathan Lucus**  
Senior Director,  
Workforce Strategy



**Kristen McKiernan**  
Senior Executive  
Officer,  
Communications &  
Marketing



**Abe Rafi**  
Senior Director,  
Technology Strategy  
& Programs



**Shawn Ullman**  
Senior Director,  
National Initiatives



**Julie Ward**  
Senior Executive  
Officer, Public Policy



**Karen Wolf-Branigin**  
Senior Executive  
Officer, Chapter Growth  
& Affiliate Relations



**Feng Zhang**  
Senior Director, Finance

## Board of Directors

### OFFICERS

**Fred Misilo, Jr.**, *President*  
Northborough, MA

**Carol Wheeler**, *Vice President*  
Washington, D.C.

**Doug Church**, *Secretary*  
Oak Hill, VA

**Hugh Evans**, *Treasurer*  
Baltimore, MD

**Elise McMillan**, *Immediate Past President*  
Nashville, TN

### DIRECTORS

**Dr. Kruti Acharya**  
Chicago, IL

**Dr. Grace Francis**  
Fairfax, VA

**Connie Garner**  
Burke, VA

**Elise McMillan**  
Immediate Past  
President  
Nashville, TN

**Dena Gassner**  
West Hempstead, NY

**Mary Gonzales**  
Chicago, IL

**Dr. Neil Hawkins**  
Midland, MI

**Carrie Hobbs Guiden**  
Old Hickory, TN

**Hussain Ismail**  
Brooklyn, NY

**Laura Kennedy**  
Staten Island, NY

**Dr. Christopher Metzler**  
West Palm Beach, FL

**John Muller**  
Milwaukee, WI

**Ken Oakes**  
Philadelphia, PA

**Kelly Piacenti**  
Chester, NJ

**Chloe Rothschild**  
Sylvania, OH

**Mitch Routon**  
Manitou Springs, CO

**Karen Shoemaker**  
Allentown, PA

**Kathleen Stauffer**  
Mystic, CT

**Faye Tate**  
Denver, CO

**Jose Velasco**  
Austin, TX

## In Memoriam

Cecil and David Rosenthal were murdered in the shooting that took place at the Tree of Life Congregation in Pittsburgh, PA in October 2018. Cecil and David were served in the residential program of ACHIEVA/The Arc of Greater Pittsburgh.



