Dear Friends,

The mission of The Arc reaches across the lifespan and touches every aspect of the human experience. Uniting our efforts is the core belief that people with intellectual and developmental disabilities (I/DD) can and should have a life like yours.

Over our nearly 70-year history, we have achieved a lot working alongside people with I/DD and their families and are proud of our accomplishments in 2019. We hope you enjoy learning about the impact of The Arc and our network.

Reflecting on the past is important as we chart a course for the future. The Arc is on the verge of breaking down more barriers to true inclusion across the board — in schools, in the workplace, online, and in communities large and small. But as we look ahead to a new decade, the biggest change must happen in the hearts and minds of people across our nation.

When you read Dillon’s story, you may wonder — how can we be putting kids into padded rooms and call that an education?

When you learn about James’ experience as a sexual assault survivor, you may ask yourself — why hasn’t society woken up to the fact that people with intellectual disability are seven times more likely to be a victim of sexual violence?

When you marvel at Delores’ work to help families plan for the future — the future that is knocking on their door — you may wonder, who is helping all of the other families that don’t have a plan in place for the future of their loved one with I/DD when a parent passes away?

There is no doubt that over the last 70 years, big changes have happened for people with I/DD and their families in this country. But there’s a lot more work to be done. And The Arc, our chapters, the individuals and families they serve, donors, volunteers, and community partners are ready for the next decade of change.

Join us. Join our movement, and be a part of changing hearts and minds, as we chart a course through the next decade to achieve the vision of people with I/DD being fully included, valued members of their communities.

Peter Berns
CEO, The Arc

Frederick Misilo, Jr.
President, The Arc’s Board of Directors
The Arc’s Origins

In 1950, little was known about intellectual disability and developmental disability, or their causes. There were virtually no programs or activities to assist in the development and care of people with intellectual and developmental disabilities (I/DD) or to support families. It was common for doctors to tell parents that the best place for their child was in an institution. But these advocates wanted more. Fulfilling lives in the community. An end to dark institutions and isolation.

Emboldened by their collective desire to raise their children at home and their refusal to accept that institutionalization was the only option, The Arc was born.

Seventy years later, The Arc still carries out its mission of protecting and promoting the rights of people with I/DD and their families through public policy advocacy, grassroots organizing, and innovative programs. Our initiatives touch almost every aspect of life in the community. Our programs help connect communities and inform efforts to broaden inclusion across the country. Our chapters are the heart and soul of The Arc.
132,265 staff working at more than 600 chapters in 46 states and the District of Columbia provided significant supports and services to people with intellectual and developmental disabilities to help them enjoy full lives in their communities.

Services vary by chapter and include but are not limited to:

- Individual and public policy advocacy
- Residential, educational, and vocational services
- Person-centered and financial planning
- Recreational activities
- And other supports that meet the unique needs of people with disabilities in their community
IN 2019, WE TACKLED BIG CHALLENGES ALONGSIDE PEOPLE WITH DISABILITIES AND THEIR FAMILIES.

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TOGETHER, WE ENGAGED...

INDIVIDUALS to chart a course for success.

We launched The Arc@School’s new online Advocacy Curriculum, training parents, educators, and advocates to help students with disabilities receive the services and supports they need and deserve from the special education system.

At Tech Coaching Centers at select chapters of The Arc across the country, we helped people with I/DD learn to use new devices, access the internet, and gain new online skills that can lead to employment, social connection, and more.

FAMILIES to plan for and access a secure present and future.

Families are seeking out resources to help plan for the future of a loved one with a disability. In 2019, The Arc reached more than 1.5 million people with our future planning materials, with more than 61,000 people engaging with our Center for Future Planning.

You contributed to groundbreaking research on paid family and medical leave that examines how workers with disabilities and working caregivers of people with disabilities use, need, and benefit from it to build the case for a national paid leave policy that includes everyone.
TOGETHER, WE ENGAGED...

**ADVOCATES** to participate in our democracy and influence decision makers.

Advocates around the country are preparing for the 2020 Presidential election—registering to vote, engaging with candidates in person and online, and for the first time in a major Presidential debate, candidates were asked how they would support the disability community.

We are building upon The Arc’s long legacy in legal advocacy, with active litigation in 2019 in Georgia, West Virginia, and Washington, DC enforcing the rights of people with disabilities in schools as well as those entangled in the criminal justice system to receive the supports and services they need to thrive in the community.

We participated in 13 amicus briefs, advocating for the rights of people with disabilities in courts across the country—including the U.S. Supreme Court—on topics including health care, immigrants’ rights, the death penalty, effective communication, education, affordable housing, and self-determination.

You joined us online by the thousands in pushing back on President Donald Trump’s call to create new institutions for people with mental illness. With 37 states still operating institutions for people with I/DD, we need to move forward with closures, never backward.

We improved access to justice for people with disabilities, delivering our signature Pathways to Justice® program in nine states and reaching more than 600 criminal justice professionals.

**THE COMMUNITY** to broaden understanding of disability.

With our longtime partner, Walmart, The Arc trained approximately 600 of the corporation’s leadership and staff on the history of the disability rights movement and the core issues affecting today’s disability community.

Volunteers like you helped 5,995 families and individuals with disabilities break down barriers to air travel with 42 Wings for Autism/Wings for All events in 39 cities across the country. These air travel dress rehearsals for families and aviation professionals make the skies friendlier for everyone.

We expanded our work addressing sexual violence against people with I/DD by reaching 330,000 people with new brief videos with written information on the sexual assault of men with disabilities, who are twice as likely as those without disabilities to experience sexual violence.

Volunteers like you participated in Martin Luther King, Jr. Day of Service projects—1,694 people with disabilities volunteered side-by-side with people without disabilities at 324 events across the country. They contributed more than 22,500 hours of their time, served 64,410 meals, and made impacts big and small in the lives of neighbors in need.
People with disabilities and their families continue to face tough challenges—some decades old—and some new in our path.

Institutions, which warehouse people with I/DD, still exist in 37 states. Dollars and mindsets need to shift fully to supports and services in the community.

Medicaid and Social Security are the programs that people with I/DD and their families rely on for health, wellbeing, modest income, and access to the community. Yet these programs are often targeted in Congress for cuts and changes that would have a disastrous impact on the lives of people with disabilities. We must advocate to both protect and expand these programs.

Direct support professionals help people with disabilities with very personal tasks and support them with day to day needs such as bathing, dressing, preparing meals, grocery shopping, managing money, and interactions in the community. But they aren’t paid enough and there is a shortage of workers and qualified employees in the field. We have to provide training, compensation, and respect for this critical workforce.

The stakes are high. Independence, health, and dignity are on the line.

So, we are unrelenting in our advocacy.

We tackle these challenges through our vast network of local chapters that are on the ground in communities, serving people with I/DD and their families.

We advocate through our state chapters for state policy to meet the needs and desires of people with I/DD, today and into the future.

We tell our stories to elected officials at every level and to the media to help people understand the lives of people with I/DD and their families.

We work in concert with all kinds of national organizations in Washington, DC and beyond to amplify the message that disability rights are human rights.

As we enter a new decade, we have made so much progress...but we need you in our corner as we continue to take on old injustices and new challenges.

Our Challenges, Covered in the Media

The New York Times
Justice Department Investigates Experiments on People with Disabilities
December 13, 2019

Forbes
Not a Unique Case: 87-Year-Old Murdered Disabled Grandson with Overdose
September 26, 2019

Los Angeles Times
Costco shooting is worst nightmare for families of developmentally disabled children
June 22, 2019

The Washington Post
Trump proposes big cuts to health programs for poor, elderly and disabled
March 11, 2019

The Washington Post
‘Warehousing at its worst’: Rights groups say W.Va. school system gives inferior education to special-needs students
July 22, 2019

Politico
Trump Wants to Bypass Congress on Medicaid Plan
January 11, 2019

Congressional Testimony: The Direct Care Crisis
"The one thing I’d love to have every member of Congress really see is the life of a family, the life of an individual with disabilities, and make the connection to what they’ve agreed to provide funding for, and how it helps them live each day fully."

Leo Sarkissian, Executive Director, The Arc of Massachusetts

"We have power to continue our advocacy work and to make our lives so much greater!"

Martha Haythorn, self-advocate from Decatur, Georgia

"The only way to make a difference and a change is to speak up, making others aware of what our needs and desires are, just like any average person."

Steve Grammer, self-advocate from Roanoke, Virginia

"What happens when you leave here?"

That’s the question Delores Sallis asks her families. Sallis, founder of resource center Parent University in Milwaukee, Wisconsin, says that single question often leads mothers, fathers, siblings, and caregivers of people with disabilities to the striking realization that planning for the future can’t wait. Sallis has committed her life to guiding families in planning future needs and wishes.

Sallis’ inspiration is her son Albert, her “pride and joy.” Albert, 30, has I/DD and lives at home with his mother. Helping other families navigate their personal journey has always been Sallis’ passion. In 2017, the mother of five attended a training session co-hosted by The Arc’s Center for Future Planning and The Arc Wisconsin. Sallis became extraordinarily inspired to share the knowledge with her caregiver group in the Milwaukee area.

After years of informally supporting families, Sallis opened Parent University in the Wisconsin African American Women’s Center in 2017. Sallis adapted The Arc’s resources to fit the needs of her families.

She invites them to “Tea and Talk” to sit down one-on-one to share their stories and build trust. Sallis, appointed to the Governor’s Task Force on Caregiving, also holds monthly sessions with caregivers and prides herself in relating to families in a uniquely authentic way:

“I start at the bottom where they’re at and we climb a ladder together,” Sallis said. “Sometimes people think they have failed. The problem is they just didn’t know how to do something.”

The Arc’s Center for Future Planning supports and encourages adults with I/DD and their families to plan for the future. The Center’s online Build Your Plan tool has guided more than 2,000 individuals and families to create customized plans and to think through some of life’s most important decisions. For example, documenting wishes for the future, deciding where to live and how much support is needed, getting a job and finding daily activities, and developing friendships and good relationships.

Build Your Plan resources are free on the Center’s website, which also includes a video gallery to see how others have planned.

In addition to utilizing her modified resources from The Arc, Sallis encourages her families to create a vision board. Watching them chart a path to the future brings her tears of joy.

“I have a happy cry every time we have a session,” said Sallis. “I love helping people.”

If something happened to me – if he can have the same familiar life, then he can make it in this world.

— Delores Sallis
Employers and The Arc Leading the Way

What does a job mean to you? A paycheck, a career, social connections, ongoing learning? People with I/DD can be employed in the community alongside people without disabilities and earn competitive wages. But too many barriers exist that lead to people with I/DD being unemployed or underemployed.

Slowly but surely, corporate America is taking notice of this talent pool, and leveraging The Arc’s expertise to meet their business needs.

Meet Kevin. He will be the first to tell you that he is a people person, and it’s easy to see why. His sense of humor, high energy, and positivity are hard to miss in National Geographic’s Food Court, where he works both behind the scenes and in a public-facing role to ensure that the center’s employees are well taken care of during their lunch breaks.

“I love my job. I especially like speaking with our customers and making sure that they have what they need to be happy. My job is to make the customers happy and I take pride in that,” said Kevin.

Kevin is one of several employees with disabilities who were hired at Sodexo’s site at National Geographic’s headquarters in downtown Washington, D.C. through a partnership between Sodexo and The Arc.

Laura Monto, General Manager of Sodexo’s site at National Geographic, was inspired to create the program from the personal experience of being an aunt of a young man with autism.

“The first step to addressing the epidemic of sexual assault against people with I/DD is to talk about it. Sexual assault and violence disproportionately affect people with I/DD.” – Kecia

In 2019, in partnership with The Board Resource Center, The Arc expanded TASV with a grant from the WITH Foundation. We grew the project from its focus on women who are survivors to men who are survivors too. Efforts to address sexual violence, such as the #MeToo movement, have typically focused on women as victims. We are changing that.

We brought attention to the fact that 14 percent of men with disabilities will experience violent victimization compared to four percent of men without disabilities. And, men with I/DD may be less likely to disclose an assault because of additional challenges they face if they do speak out or report it.

TASV introduced us to James, a man with a disability and survivor of sexual assault. After working on healing, he felt compelled to tell his story, advocate for other victims with disabilities and to support survivors.

We created training videos to prepare health care professionals, who are on the frontlines, for sensitive conversations and to equip them with tools to educate patients with disabilities about sexual violence and prevention.

This was the beginning of my journey to become an advocate to support others with disabilities who have suffered with sexual assault. I am now a national advocate and speaker at many conferences sharing my story and recommending changes so others can find healing.
Dillon was restrained and dragged into the “blue space”—a walled and padded area, with a small opening with a pad cover to keep a child from leaving the space—again and again in kindergarten and first grade.

It happened far too many times, and when the situation escalated to the point where 9-1-1 was called, if Dillon’s parents didn’t arrive before the ambulance, he would be taken to the hospital—alone.

The repeated trauma of restraint and seclusion, the threat of going to the hospital, and continued interruptions to his education were having a major impact on Dillon and his family.

Dillon’s story was shared by his mom, Rhode Island advocate Renee Smith, with the U.S. House Education and Labor’s Subcommittee on Early Childhood, Elementary, and Secondary Education at a hearing on the use of restraint and seclusion in schools. The Arc recruited Renee to testify on this topic on behalf of families across the country whose children were facing similar outrageous treatment in schools across the country.

When Dillon, who has autism spectrum disorder, was in kindergarten and first grade, he and his parents struggled with the school administration for proper positive supports for him. Restraint and seclusion were repeatedly used to manage Dillon’s behavior. Yet his parents knew other positive methods would lead to a better outcome, and positive reinforcement was a part of Dillon’s documented Individualized Education Program (IEP) with the school.

“Dillon’s work avoidance, we now know was in direct reaction to the restraint and seclusion he was experiencing. The more he was restrained and secluded, the less he was interested in schoolwork, which resulted in more restraint and seclusion—a constant downward spiral. It broke my heart when Dillon told us that he no longer trusted any of the adults in that school,” said his mom Renee.

Dillon’s family was very fortunate to have another public school nearby that utilized “positive behavioral intervention and supports.” Dillon started at this school, where the behavior program allows children to float between a special education classroom and a regular education classroom for work. There are several cool down spaces and one open space within the office of the school behaviorist. Teachers provide positive reinforcement in their classrooms and one-on-one with their students. Within only two weeks of the new placement, Dillon was in a regular education classroom 100% of the time with supports.

There are thousands of Dillons in schools across the country who suffer emotionally and academically due to restraint and seclusion. Every day, trauma is inflicted despite the fact there is no evidence of therapeutic or educational value. That’s why we advocate for federal legislation to end seclusion and restraint and provide schools with proven effective alternatives to these harmful practices. Without it, the future of thousands of kids like Dillon will be left up to schools that sometimes get it wrong, and they’ll wind up in a “blue space”—with no way out.
PRO BONO SPOTLIGHT

The Arc of the United States appreciates in-kind contributions of service. We would like to extend a heartfelt thank you the following law firms that provided pro bono legal services: Akin Gump Strauss Hauer & Feld LLP valued at $30,837; DLA Piper valued at $588,82; Skadden valued at $520,673; Burns & Levinson valued at $181,520; Latham & Watkins valued at $159,000; Katten Muchin Rosenman valued at $24,952; Epstein Becker Green valued at $2,925; Crowell & Moring valued at $1237,500; Whittaker Hall valuated at $521,520; Buckley Sanders valued at $25,282; Kirkland Ellis valued at $59,5210; Chapman & Cutler valued at $12,240; Clinton & Peed valued at $91,895; Munger Tolles Olsen valued at $34,576; Blank Rome valued at $25,565; Dentons valued at $98,779 and Miller Chevalier. We will also like to extend a thank you to Comcast NBCUniversal for airtime provided for public service announcements and Xfinity.com placement of $1,270,476.

Thank you to the following chapters of The Arc for making voluntary contributions to The Arc’s national office in addition to their annual Dues

AHRC Nassau
Arc of Denver, Inc.
Bronx Developmental Center
The Arc Brockton Area
The Arc Eastern Shore
The Arc Genesse Orleans
The Arc Jefferson - St. Lawrence
The Arc Northland
The Arc of Adames-Clay
The Arc of Atlantic County
The Arc of Calhoun-Cleburne Counties
The Arc of Gillespie County
The Arc of Greater Williamsburg
The Arc of Indiana
The Arc of Iroquois County
The Arc of Lawrence County

The Arc of Marshall County
The Arc of New Mexico
The Arc of Oregon
The Arc of Putnam County, Inc.
The Arc of Rush County
The Arc of San Antonio
The Arc of San Diego
The Arc of Shelby County, Inc.
The Arc of Southington, Inc.
The Arc of Wayne County
The Arc of West Central Colorado
The Arc, Ocean County Chapter
The Association for Community Living in Boulder County
The Enrichment Center, an Affiliated Chapter of The Arc

** National Board Member
* Bequest gift
** National Board Member (Members as of November 2019, when the most recent term ended)
*** Current/Past National President
**** Total of all contributions made through Facebook fundraising in support of The Arc

2019 ANNUAL REPORT DONOR LIST

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INDEPENDENT AUDITOR’S REPORT

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

We have audited the accompanying consolidated financial statements of The Arc of the United States and Affiliates (the Organizations), which comprise the consolidated statement of financial position as of December 31, 2019, and the related consolidated statements of activities and change in net assets, functional expenses and cash flows for the year then ended, and the related notes to the consolidated financial statements.

MANAGEMENT’S RESPONSIBILITY FOR THE FINANCIAL STATEMENTS

Management is responsible for the preparation and fair presentation of these consolidated 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 consolidated 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 consolidated 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 consolidated financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the consolidated financial statements. The procedures selected depend on the auditor’s judgment, including the assessment of the risks of material misstatement of the consolidated 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 consolidated 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 consolidated 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 consolidated financial statements referred to above present fairly, in all material respects, the consolidated financial position of the Organizations as of December 31, 2019, and the consolidated change in their net assets and their consolidated cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

OTHER MATTER

Our audit was conducted for the purpose of forming an opinion on the consolidated financial statements as a whole. The Consolidated Schedule of Financial Position on pages 20 – 21, and Consolidated Schedule of Activities and Change in Net Assets on pages 22 – 23 are presented for purposes of additional analysis and are not a required part of the consolidated financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the consolidated financial statements. The information has been subjected to the auditing procedures applied in the audit of the consolidated financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the consolidated financial statements or to the consolidated financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the consolidated financial statements as a whole.
### Consolidated Statement of Financial Position

#### Current Liabilities
- **Contingency accrued liability**: $160,000
- **Deferred revenue**: $40,659
- **Grants receivable**: $196,313
- **Investments**: $11,767,831
- **Deferred compensation investments**: $188,756
- **Deferred compensation**: $188,756
- **Deferred rent, net of current portion**: $448,695
- **Accounts payable and accrued liabilities**: $1,142,417
- **Investments held for beneficial interest in perpetual trust**: $2,817,766

#### Fixed Assets
- **Furniture and equipment**: $1,909,686
- **Vehicles**: $21,859
- **Website**: $886,221
- **Cash and cash equivalents**: $1,030,490
- **Less: Accumulated depreciation and amortization**: ($2,799,192)

#### Other Assets
- **Security deposit**: $49,257
- **Investments held for beneficial interest in perpetual trust**: $1,320,372
- **Deferred compensation investments**: $188,756

#### Total Current Assets
**Total Current Assets**: $13,892,622

#### Total Assets
- **Total assets without donor restrictions**: $13,892,622
- **Total assets with donor restrictions**: $11,464,886

#### Total Liabilities and Net Assets
**Total Liabilities and Net Assets**: $16,089,581

### Change In Net Assets

**Change in net assets before other items**: $2,468,775
- **Forgiveness of debt**: $2,202,332
- **Program Services**: $725,055
- **Grants**: $4,328,647
- **Investment income, net**: $1,337,658

**Revenue and Support**: $4,580,247
- **Royalty income**: $107,815
- **Other income**: $52,381
- **Total revenue and support**: $4,937,155

**Expenses**: $2,642,545
- **Fees and services**: $2,202,332
- **Program Services**: $725,055
- **Investment income, net**: $1,337,658
- **Management and General**: $876,867
- **Fundraising**: $823,240
- **Total net assets at end of year before other items**: $13,892,622

**Change in net assets from other items**: $209,683
- **Net assets released from donor restrictions**: $2,979,877
- **Contributions**: $4,292,547
- **Investment income, net**: $1,005,407
- **Total expenses**: $209,683

**Net assets released from donor restrictions**: $2,755,740

### Other Items
- **Transfer of net assets from The Arc of the District of Columbia, Inc.**: $(491,883)
- **Forgiveness of debt**: $351,974
- **Total other items**: $(449,909)

**Net assets at the beginning of year**: $13,125,090
- **Change in net assets**: $209,683
- **Net assets at the end of year**: $13,393,761

**Total liabilities and net assets**: $16,089,581
Join With The Arc

Join us. There are so many ways to support the rights of people with intellectual and developmental disabilities.

Learn how at thearc.org/get-involved.

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