



Annual Report April 4, 2019

President's Message



Joanne Bergin

When individuals with intellectual and developmental disabilities, and their families, are overwhelmed by the daunting maze of the service delivery system, The Arc of New Jersey is there to support them. Through every step of the way, our knowledgeable and caring staff provide information, resources and a compassionate shoulder to lean on. As president of this organization, I am always impressed by the sheer number of individuals we reach. We are able to “touch” so many lives and redirect people out of a crisis and onto a path toward help. You will see from this Annual Report just how many residents of New Jersey we came into contact with this year and the ways in which we were able to support them and ease their journey. I am however most uplifted by the stories

of families and self-advocates who seek out The Arc of New Jersey for assistance but from that experience turn into lifelong advocates. Whether it's my fellow board members, the dedicated volunteers who sit on our numerous committees, or the amazing self-advocates who testify before the legislature, many of our most committed advocates began as the very individuals or family members they now work to assist. That theme of paying it forward, and of helping others who have experienced challenging times, is the hallmark of our past and what makes The Arc of New Jersey stand apart. Thank you to everyone who has played a role in this year's successes. I look forward to the next chapter ahead.

Executive Director's Message

Thomas Baffuto



The ongoing overhaul of services and systems for people with intellectual and developmental disabilities and their families has been lengthy and exhausting. The shift to fee-for-service and the impacts of this tremendous change has touched everyone who relies on supports. Though the process came along with a number of challenges, I am proud to say that through it all, The Arc of New Jersey remained and continues to remain the constant. Although no easy task, our organization has lead individuals and families into this new way of life and as the state finishes the transition to fee-for-service in the coming months, I am confident that The Arc of New Jersey will continue to be a guiding force for those we represent. In addition to our consistent presence for individuals and families, The Arc of New Jersey used this year to break new ground. I want to specifically note our June Summit to address sexual violence against people with intellectual and developmental disabilities. A complicated but incredibly important topic, our organization brought this issue to the forefront, assembled stakeholders, and then authored a subsequent white paper with recommendations to fight back against the terrible sexual violence statistics facing people with I/DD. This is truly groundbreaking work and something that I believe will set the stage for change moving forward. But that is only one major highlight from a very full year of accomplishments. Our programs continued to grow and thrive, providing thousands of hours of direct services, as well as valuable training for individuals, families and professionals. And our dedicated staff provided an unprecedented level of individual advocacy to individuals with I/DD and families. It's been an outstanding year and I know there are many more successes ahead.

Human Resources, Finance & Operations

Michael Prendergast,
Assistant Executive Director
Anna Scruggs,
Coordinator, Financial Services
Helen Rivera,
Coordinator, Administrative Services

- The FY 2018 audit of The Arc of New Jersey financial statements was completed. No findings were discovered.
- The FY 2018 audit of NJ Camp Jaycee financial statements was completed. No findings were discovered.
- 2018 Finance Manual was reviewed by the Internal Committee and updated as needed.
- 2019 Personnel Policies were reviewed by the Internal Committee and updated as needed.
- The Arc of New Jersey employs 57 full-time staff members and 6 part-time staff.

Board of Directors



Executive Committee

Joanne Bergin, President
Kevin Sturges, First Vice President
Karen Murphy, Second Vice President
Elspeth Corrigan Moore, Secretary
Pamela Corrigan, Treasurer

Members-at-Large

Bruce Bird
James Gallagher
Carolyn Hayer
Bruce Humphreys
S. Paul Prior
Kevin K. Walsh
Robert Hage, Immediate Past President

Activities of the Board

- 7 Executive Committee meetings and 4 Board meetings; DHS Assistant Commissioner Jonathan Seifried and Aubrey Powers, Executive Director, DCF Office of Family Voice, as guest speakers
- Board policies reviewed, revised and approved; Personnel policies reviewed and approved
- Represented The Arc of NJ at The Arc National Convention and Disability Policy Seminar
- Regular meetings of all Committees – Governmental Affairs, Development/Awards, Internal, Audit, Investment, and the Family Advisory Council
- Development of slate of officers for FY 2020-2022 by Nominating Committee



Connect With Us!

985 Livingston Avenue,
North Brunswick, NJ 08902
(732) 246-2525

Visit us at: www.arcnj.org

Email: info@arcnj.org

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Governmental Affairs

Sharon Levine, Director

Over the past year, The Arc of New Jersey advocated on a number of priority public policy initiatives, weighed in with legislators and state departments on regulatory proposals, engaged our grassroots networks and kept in close contact and communication with our stakeholder community.

Budget

In year two as Chair of the Coalition for a DSP Living Wage, we secured a \$20 million appropriation, which was built into the rates, to address the ongoing DSP workforce crisis. This year-long effort involved months of advocacy, action alerts, meetings with legislators and mobilizing of our grassroots networks. The Arc of New Jersey also played an integral role in how the funds were distributed following the budget signing. In addition, funding we advocated to remain in the final budget was maintained in the final document. This included \$19.8 million for home and community-based services and \$8.5 million towards implementing comprehensive Autism Spectrum Disorder (ASD) services for Medicaid-eligible youth. In FY19, The Arc of New Jersey remains a very active member of the Coalition for a DSP Living Wage as more funds are needed and new complications have arisen in light of the newly signed minimum wage law.

Legislation

Earlier this year, Lt. Governor Oliver signed the New Jersey Caregiver Task Force bill into law. The Task Force is charged with evaluating support services that are available to caregivers. The Arc of New Jersey is a named member of the Task Force and will provide recommendations and insights from the family's perspective. The Arc of New Jersey was also successful this year in amending legislation aimed at eliminating one-time use plastic straws and another bill that would create a Task Force on the Prevention of Sexual Violence Against Persons with Developmental Disabilities. We monitored more than 125 pieces of legislation throughout the year and submitted oral or written testimony on more than 25 bills.

Regulation & Federal Policy

In the past year we issued comments to various state

departments on topics such as use of person-first language, the Paid Sick Leave regulations, the state plan amendment to include Autism Spectrum Disorder related services for EPSDT eligible individuals, and the implementation of the Stephen Komminos' Law. On a federal level, we continued to support advocacy efforts by The Arc US and participated in action alerts on pending legislation, such as the EMPOWER Care Act. We also attended the Disability Policy Seminar and advocated with members of New Jersey's Congressional delegation.

Communication & Get Out the Vote

The Arc of New Jersey kept families, self-advocates, and Local County Chapters of The Arc informed with ongoing "Updates from Trenton." In addition, a monthly Governmental Affairs Update was included in every monthly newsletter and in The Arc of NJ Family Institute newsletter. In the fall, a Get Out the Vote Guide and corresponding website was created to inform stakeholders about disability-related issues as they related to candidates and Election Day. This Guide was distributed widely to self-advocates and sent out electronically to families and Chapters.

Relationship Building & Advocacy Presence

We continued to foster relationships with legislators, their staff, and members of the Administration. This included ongoing working relationships with high-ranking officials at the Departments of Human Services, Children and Families, Health and Labor. We also supported families at the State House at their National Family Caregiver Month event in November and we assisted Self-Advocates at their Developmental Disabilities Awareness Month event in March.



The Arc of NJ Family Institute

Lisa Ford, Director

Cheryl Crick, Coordinator

The Arc of New Jersey Family Institute has become the “Go To” place for families in need of support when navigating the system. Through our comprehensive website, The Family Institute works tirelessly to share the most up to date information with families.

Webinars:

• **14** webinars with **760** attendees. Some of the topics included: Accessing After School Programs, Inclusion: Working Together To Include Children With Disabilities and The Importance of Wills and Trusts in Planning For A Secure Future and Understanding the Sibling Experience.

Lunch and Learn: Safety Series

This free webinar safety series includes a variety of safety topics to help caregivers and professionals identify areas of concern and ways to protect children and adults with intellectual and developmental disabilities. Topics included:

- Community Safety & Wandering Prevention for Children and Adults with I/DD
- Emergency Preparedness for People with I/DD
- Investigating and Prosecuting Financial Crimes Against People with I/DD
- People with Intellectual and Developmental Disabilities Growing Old: Understanding and Supporting Age-Related Health Changes
- How Caregivers Can Work Effectively With Law Enforcement and Emergency Responders
- Supporting the Village: Helping Parents and Caregivers to Support Youths’ Healthy Sexual Development Part 1: Kindergarten - 6th grade, Part 2: 7th - 12th grade, Part 3: Adults 18+

Total podcasts archived this year: 24

Total Listeners: 795 (The number of listeners quadrupled this year)

Highlight Podcast: Get To Know Your Support Coordination Agency
This podcast series consists of 10 questions in 10 minutes. It is designed to provide families with a better understanding of the different services provided by Support Coordination Agencies. Our goal is to interview each and every Support Coordination Agency listed on the Division of Developmental Provider List and archive them on our website.

College Tours at **7 locations** with a combined total of **more than 300 families**. **Sibshops:** Sibshops provide brothers and sisters of children with intellectual and developmental disabilities opportunities to share and connect with peers who “get it.” Attending a Sibshop allows siblings a chance to meet one another in a relaxed setting. The Family Institute hosted **6 Sibshops** and offered support to more than **20 siblings**.



Planning for Adult Life

Jerisa Chiumbu-Maseko, Director



Now in its 5th year, Planning for Adult Life assists and supports students in special education, age 16-21, to make a plan for their life after high school. The Program also works with the students' families so that they are well prepared for their child's transition to adult life. Activities focus on eight core areas including: Post-secondary Education/Employment; Housing; Legal/Financial Planning; Entitlement Programs and Eligibility; Self-Direction; Health/Behavioral Health; Building/Maintaining Community Ties and Friendships; and Planning/Visioning a Life Course. This year PFAL has concentrated its efforts on reaching out to students, families and professionals in new schools, while maintaining relationships with current schools.

Highlights of the Year:

- The MAPs Clubs for students (Making Action Plans for Life and Career) continue to run strong in **69 schools serving all 21 counties. This is an increase of 5 new schools and more than 200 students.**
- The HOW Series (Hands on Workshops) provided valuable information Planning for the Future, SSI and Medicaid, Exploring Employment Options, and Guardianship Basics to **more than 1,200 participants.**
- This year PFAL presented parent workshops and staff trainings in **29 schools** that currently do not have the MAPs program.
- The Planning for Adult Life website welcomed **more than 12,000 unique visitors** who have viewed our information pages, watched archived videos and asked helpdesk questions.
- The helpdesk has received **more than 2,000 requests for assistance** on IEPs, SSI and Medicaid, DDD, and a host of other issues regarding transitioning from school to adult life.
- The FREE Parent Forums have been held in two new counties with **more than 80 new registrations.**
- The COMPASS e-newsletter is now distributed to **more than 5,500 individuals per month.**

By the Numbers in the 2017-2018 School Year:

- Grad Bags distributed: **937**
- Community Site Tours: **30**
- MAPs Clubs conducted: **1,902**
- Students participating in MAPs: **5,227**
- HOW Series Workshops: **178**
- # of Participants in HOW series: **1,264**
- Website Visitors: **12,641**
- Webinar Attendees: **1,070**
- Help desk: **2,183**
- Parent Forums Conducted: **6**



Mainstreaming Medical Care

Beverly Roberts, Director

The Mainstreaming Medical Care Program promotes quality health care for people with developmental disabilities throughout New Jersey.

Highlights of the Year:

- Responded to **935** requests for assistance from families and staff, including support coordinators. Some of the requests for help occurred when families received a notice of Medicaid termination, which, understandably, caused panic -- if Medicaid is terminated then the individual's DDD services are also terminated. Families also contacted us when the Medicaid managed care organization (MCO) reduced or terminated Personal Preference Program (PPP) or private duty nursing hours; when appropriate, a referral is made for pro bono legal representation for a Medicaid fair hearing. Our program also responded to many questions on Medicaid eligibility; DAC status; Supplemental Security Income (SSI); Social Security Disability Insurance (SSDI); dual eligibility for both Medicare and Medicaid; and how to get DDD services if the individual with I/DD is not eligible for Medicaid.
- Our **29th Annual Conference** on Medical Care for Persons with Intellectual and Developmental Disabilities was held on June 1, 2018. It was a huge success, with **315 attendees**.
- Developed and distributed a fact sheet explaining continuing disability reviews for persons who receive SSI or SSDI.
- Updated and distributed our program fact sheet on Dual Eligible Special Needs Plans (D-SNPs).
- Most of the program director's **12** presentations this year focused on helping families and school personnel understand the importance of SSI and Medicaid for students with I/DD who will apply for services from the NJ Division of Developmental Disabilities. She also held a webinar on the changes in Medicare Part D for families and staff of individuals with I/DD who are dually eligible for both Medicare and Medicaid.
- Continued to serve as a Governor's appointee on the Medical Assistance Advisory Council (MAAC), with participation at meetings that are held quarterly.

Feedback:

- From a grateful mom after the program director was able to have her son's Medicaid HMO reinstated following a Medicaid "glitch."***"You are an Angel who cares and we are so blessed to be referred to you. Thanks to my support coordinator for giving me your name."***
- From a support coordinator who is also the mom of a child with I/DD: ***"I truly appreciate your dedication to families in resolving these issues related to Medicaid...I remember when the state made the move to transition everyone to an HMO and you traveled around the state to provide information to families who were not happy about the transition. You said then that you would be available to families and you have kept your promise."***
- From a social worker who is a Transition Coordinator at a high school: ***"I got so much out of your presentation last night. So much great information that I can pass on to parents."***



Project HIRE



Adam Kubler, Director

Project HIRE experienced many changes in the Supported Employment arena over the last year. True to Project HIRE's goal of continuing to be a leader in the field, the program continues to adapt to these changes to ensure continued success. These are some of the highlights from the past twelve months.

The Supported Employment industry experiences a higher than average turnover rate for the direct support staff members that provide the services. Some figures report an industry average turnover rate as high as 44%. Over the past year, Project HIRE remains a stable program and reported a turnover rate of 16%, far

lower than the industry average. Project HIRE **employed 38 field staff members with an average of 4.8 years with the Program.** Project HIRE staff enjoy the work they do and are passionate about serving individuals living with disabilities. Administrative staff help to train, administer the program and assist staff with day to day operations in the field. On average, the supervising staff members have been with the company for **almost 10 years**, further strengthening the program.

Project HIRE's work with Union County Project SEARCH again proved successful with the 2018 cohort, which included approximately 9 students, completing the program and meeting all required benchmarks. Additionally, the 2019 cohort, also with approximately 9 students, was selected and is expected to experience the same, excellent outcomes when they graduate this summer.

Project HIRE was approved for Pre-Employment Transition Services funded by the Division of Vocational Rehabilitation Services. At the time of this writing, Project HIRE is providing these services in **5 counties** and will continue to grow in this area.

Lastly, Project HIRE selected and implemented a new electronic case monitoring and documentation system statewide. This new program will improve the staff ability to notate activities and meet funder standards for documented services. The benefits will also enhance the services which participants receive in the field by providing easily accessible electronic tools for staff to use. These tools include a database of employers complete with site/task analysis, digital mapping functionality and a completely electronic filing system. These electronic tools work to reduce the time spent on documentation, while increasing the time spent and services provided to individuals across the state.



The NJ Self-Advocacy Project

Ashley Ritchey, Director

The New Jersey Self-Advocacy Project team take their cues from the 2,100+ members of the affiliated New Jersey Statewide Self-Advocacy Network (NJSSAN). Members of NJSSAN are most proud of the many educational and outreach events that have amplified awareness throughout the year.

A Timeline of Events:

On April 7, NJSSAN hosted their 13th Annual Awards Luncheon. More than **300** NJSSAN members attended this event which featured an awards ceremony attended by Heroes Award recipient Senate President Stephen Sweeney. The NJSAP team also attended the 3-day Abilities Expo at the New Jersey Convention & Expo Center in May and shared resources with **more than 7,500** community members. In July, NJSSAN members hosted their 7th annual event on Point Pleasant Beach Boardwalk to celebrate the 28th Anniversary of the Americans with Disabilities Act. More than **250 community members** visited the booth and learned about the importance of the protections included in The Americans with Disabilities Act. September 29, marked the 35th Annual NJSSAN Fall Conference, which was held at The Westin Princeton. This educational and networking event drew a crowd of **more than 350 advocates** and staff members and featured 5 educational workshops, more than a dozen vendor displays, as well as a cadre of speakers and presentations by members of the NJSSAN.

In preparation for the November election, the NJSAP team presented **21** voting rights and responsibilities workshops throughout the state. Legislative advocacy opportunities were shared with members of the Network via Constant Contact e-mail blasts and targeted outreach to members of the Governmental Affairs Ambassador Program, which gained **101 additional members** this year. In March, a group of **more than 40 advocates and Direct Support Professionals** attended the annual Developmental Disabilities Awareness Month outreach event at the State House in Trenton. Legislators and Department of Human Services Commissioner Carole Johnson visited the display to meet with advocates and to discuss current NJSSAN initiatives. Members of the New Jersey Statewide Self-Advocacy Network received a proclamation from Commissioner Johnson on behalf of Governor Murphy and were presented with a ceremonial joint resolution from Assemblywoman Downey and Assemblyman Houghtaling.

Highlights of the Year:

- The Advisory Board of the NJSSAN worked on several critical issues during the year, including a letter writing campaign to raise awareness about the need for accessibility improvements to public transportation systems and the ongoing initiative to raise wages for Direct Support Professionals.
- The NJSAP team expanded their training to include **8 school-based programs** throughout the state. Training topics included self-advocacy skill building, healthy relationships, effective communication, stress management and many more.
- Through a grant generously provided by the Horizon Foundation for New Jersey, self-advocates continued to learn about living a healthy lifestyle. This year, our HLP program was expanded to include monthly community-based activities in each region of the state, including art therapy sessions, accessible hiking events, music therapy, rock climbing, and yoga.



Criminal Justice Advocacy Program

Jessica Oppenheim, Director

This was a particularly exciting year as we assisted in the implementation of the Addressing Sexual Violence Against People with I/DD: Blueprint for an Empowered Future Summit which was held on June 14. As a result of the Summit, a White Paper was produced and in order to begin to implement the recommendations of the White Paper, we have reconvened the New Jersey Partners in Justice, a multidisciplinary group of professionals, families and self-advocates from across NJ to work together to end sexual violence against people with I/DD and improve all facets of community life. In addition, we are helping The Arc of the United States with bringing the Pathways to Justice training to New Jersey. On April 3, we welcomed The Arc of the United States National Center on Criminal Justice and Disabilities to Warren and Sussex Counties, where we hosted a one day training for police, prosecutors, attorneys, judges, victim service providers, self-advocates and others, which we hope will spread to other counties.

The program caseload is routinely more than 100 cases and is, as of March 2019, at 129 clients receiving services statewide. The Program monthly Level of Service averages between 700 and 1,000, well above expected services. CJAP's overarching goal is to educate professionals in the criminal justice system about the unique problems and needs of individuals with intellectual and developmental disabilities. To accomplish this, each of the three Community Resource Coordinators work with service providers, family members, DDD staff, court personnel and the client to locate and access services that can help keep a client successfully in the community. These services are memorialized in a Personalized Justice Plan, which is provided to the court and the attorneys and provides specific services for the client, intended to allow each person to remain successfully in the community. As of March 2019, **27 PJPs** had been provided to courts throughout the state in both superior and municipal court. This year, CJAP has continued to assist the Administrative Office of the Courts with training for municipal judges and staff, as well as newly appointed superior court judges, at trainings held in February and March. As a result, we have provided Americans with Disabilities Act training, in conjunction with AOC staff, in every vicinage (county) in the State, for well over **500 judges and staff**.

Finally, training for law enforcement, the legal community and direct service providers has become an ever burgeoning part of our mission. We have trained in **6 counties** for their Crisis Intervention Team Training for law enforcement and mental health providers, and continue to work with the statewide CIT Program to ensure that issues related to developmental disabilities are included in every county. Including all training for law enforcement, judges and direct support providers, we conducted **23 trainings, reaching more than 1,500 attendees** throughout the State.



Training and Consultation Services

Wesley E. Anderson, Director

Training and Consultation Services (TCS) provides guidance to supported employment providers in an effort to improve employment services and outcomes for people with disabilities in New Jersey. TCS staff utilizes a myriad of formats for disseminating current industry best practices, including; classroom style training, webinars, consultation services, information & referral, and advocacy. TCS has retained its standing as the authority on matters related to Employment First, providing **more than 300 hours of trainings and consults to DDD funded providers** throughout the state. Some of the topics covered have included:

- Documentation & Record Keeping
- Implementing Interventions

- Organization Tools for Job Coaches
- Employment First
- Fee for Service
- Job Development
- Job Coaching

Some additional highlights included:

- Member of National & NJ APSE Boards
- Ongoing partnership with Rutgers' Boggs Center
- Assisted in the revision of DDD's monitoring tool for Supported Employment
- Conducting presentations for the Mental Health Association in New Jersey- Career Connections Employment Resource Institute (CCERI)
- Presented at NJ APSE Conference, ACCSES NJ Conference, National APSE Conference.

Communications and Development

Céline Fortin, Associate Executive Director Sharon Levine, Director of Governmental Affairs and Communications

- Support of **14 local county chapter walkathons**
- Monthly e-news: **1,130 subscribers**

- Website – **36,803 visitors, 90,227 viewed**
- Facebook – **2,788 page likes**
- Twitter – **3,082 followers**
- **\$25,000 grant** for the Healthy Lifestyles Program from the Horizon Foundation for NJ
- **\$32,529 grant** for Year 2 of the DD Training Resources Databank Project from the NJ Council on Developmental Disabilities
- **\$7,500 grant** for The Arc of NJ Family Institute from Provident Bank Foundation

- October 18, 2018 Awards Dinner; 11 awardees, 147 attendees, **net \$25,500**
- Exceeded fundraising goals for FY 2018 and already for FY 2019
- Successful annual appeal netting **\$8,500**.
- The Arc of New Jersey is celebrating its **70th anniversary** in 2019!



The Arc of NJ serves on the following Boards, Committees and Workgroups

- American Association on Intellectual and Developmental Disabilities
- APSE's National Board of Directors
- Boggs Center Consumer Advisory Committee
- CMS Medicare Partners
- Coalition for a DSP Living Wage
- County Children's Interagency Coordinating Council
- Developmental Disabilities Advocacy Network
- DDD Leadership Committee
- EI Part C Steering Committee
- ESSA Stakeholder Focus Group
- Family Support Coalition
- Health Care Advocates Group
- Horizon NJ Health, Managed Long-Term Services and Supports, Advisory Committee
- Justice-Involved Services Statewide Coordinator Committee
- Medical Assistance Advisory Council
- Middlesex County Behavioral Health Task Force
- National Association of Social Workers - NJ Chapter
- National Conference of Executives of The Arc (NCE)
- NJ APSE Board of Directors
- NJ APSE Conference Committee
- NJ APSE Steering Committee
- NJ APSE Professional Development Committee
- NJ Business and Industry Association
- NJ Coalition for Special Education Funding Reform
- NJ Conference of Executives of The Arc (NJCEArc)
- NJCEArc Development Directors Group
- NJCEArc Finance Directors Group
- NJ Council on Developmental Disabilities, Health Committee
- NJ Council on Developmental Disabilities, People & Families, Editorial Board
- NJ Jewish Federations
- Special Needs Work Group
- New Jersey Alliance for Children, Youth and Families
- NJ Pathways to Justice Task Force
- NJ Task Force on Abuse of Persons Who are Elderly or Disabled
- Office of Special Education Stakeholder
- Protection and Advocacy for Developmental Disabilities (PADD)
- Regional Family Support Planning Councils
- Restraint and Seclusion Stakeholder Group
- SHA Grant Partner Advisory Committee
- SPAN Community of Care Consortium
- SPAN Family to Family Health Information Resource
- SPAN Parent Training Information Stakeholder Advisory Council
- Statewide Crisis Intervention Team Training Task Force
- Supportive Housing Association of NJ
- The Arc @School
- The Arc of Union County's Medical Advisory Board
- The Arc's Center for Future Planning Chapter Workgroup
- The Arc of the US Planned Giving Workgroup
- Transition Leadership Network

