




The Arc
of New Jersey
Annual Report
April 5, 2018



President's Message



Joanne Bergin

In less than three short months we will see the end of Fiscal Year 2018, and my first term as President. I am amazed at how quickly the time has passed and more astounded by how many battles we've taken on in that time to improve the lives of people with intellectual and developmental disabilities. No matter what comes our way, the one constant is that The Arc has been active and engaged on every issue. Whether it is protecting lifeline programs at the federal level, having an impact on the shift to fee for service in New Jersey, or assisting local support groups in the community, The Arc is here - to advocate, to educate, to assist and to serve. Our staff, volunteers, self-advocates and family members have joined forces and mobilized, making an incredible, lasting impact which will benefit all individuals with I/DD and their families for years to come. As we get ready for Fiscal Year 2019, and see the challenges that await us, our work becomes even more important. The Arc will never stop advocating; we will always be there for the individuals we serve and their families. It is more critical than ever before that you join us and add your voice to our advocacy efforts. Thank you to everyone who has worked so hard to protect the services and supports that individuals with I/DD and their families so desperately need. And my very special thanks to The Arc of New Jersey's wonderful Board of Directors and in particular the hard-working Executive Committee:

Executive Committee

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

Members-at-Large

Bruce Bird, PhD
James Gallagher
Carolyn Hayer
Bruce Humphreys
Paul Prior, Esq.
Kevin K. Walsh, PhD

Activities of the Board

- 7 Executive Committee meetings and 4 Board meetings; DHS Assistant Commissioner Liz Shea and DCF Assistant Commissioner Liz Manley as guest speakers
- Board 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
- Criminal Justice/Special Education lawsuit
- Planning retreat and survey to develop FY 2019-21 Strategic Plan; development and passage of the plan



Executive Director's Message

Each year as we prepare for The Arc of New Jersey's Annual Meeting, we take a look back on the challenges we have faced and the positive strides forward we have facilitated. And while each year we are overwhelmed with the number and severity of the challenges we have faced, I don't quite remember a year as difficult as this one just passed. The number of threats to the major underpinnings of the entire support and service system has been unprecedented. Every few days seemed to bring another round of actions which, taken individually, would be devastating. But together they would result in significant negative impacts on the lives of individuals with I/DD and their families. As an organization we have stood firm and spoken up, loud and clear, to ensure that the hard-won supports and services for individuals with I/DD and their families will not cease to exist. Our families, self-advocates, volunteers and staff have formed a strong, united front that has persevered through the toughest of times to ensure a better future for all individuals with I/DD and their families. This is the legacy of The Arc – stand up for what is right, don't give up, and effect lasting change. It is as true today as it was nearly seven decades ago. Thank you for your support, your advocacy and your dedication. We move forward as a better organization because of all of you.



Thomas Baffuto, Executive Director
Céline Fortin, Associate Executive Director
Michael Prendergast, Assistant Executive Director

Human Resources, Finance & Operations

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

- The FY 2017 audit of our financial statements was completed. No findings were discovered.
- The FY 2017 audit for NJ Camp Jaycee was completed by The Arc of NJ staff. No findings were discovered.
- A state audit of our 2017 financials was completed and we are currently awaiting the results.
- The 2018 Personnel Policies and Finance Policies were revised and approved by the Internal Committee.
- Implemented new electronic timesheet and payroll system.
- The Arc of New Jersey employs 58 full-time staff members and 13 part-time staff.

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FamilyAdvocacyProgram
PlanningForAdultLife
NewJerseySAP



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Governmental Affairs

Sharon Levine, Director

In the last twelve months, the Governmental Affairs Department worked tirelessly to address the Direct Support Professional (DSPs) workforce crisis, protect Medicaid from cuts on the federal level, build relationships with new members of the Administration and enhance our existing connections with legislators and decision-makers in the State Capitol.

Budget

In our first year as Chair of the Coalition for a DSP Living Wage, we successfully secured a one-time appropriation for DSPs who assist people with intellectual and developmental disabilities. This was preceded by months of advocacy, one-on-one meetings with legislators, Action Alerts, social media posts and Twitter campaigns, and a Coalition Day at the State House among other things. Our advocacy work to achieve a long-term investment to address this critical issue is ongoing for the FY19 Budget. We also successfully advocated for \$89.7 million in increased funds in the FY18 Budget to address the Waiting List, move people out of developmental centers, fund new housing vouchers, and fund general Division growth to address the needs of adults aging out of the school system, emergencies, etc.

Legislation

We had big victories this year when three bills we advocated for were signed by Governor Christie. This included legislation that will exempt community providers from paying certain motor vehicle fees, will limit the use of restraint techniques on students with disabilities, and will expand the background check process for staff who work with individuals with I/DD. In the past year we've tracked more than 100 bills and weighed in with oral or written testimony on more than 25 bills.

Get Out the Vote

We authored a comprehensive Get Out the Vote Guide (GOTV) that included a Q&A with both gubernatorial candidates and submissions from self-advocates and a family member outlining the importance of voting. A corresponding

GOTV web site was also maintained leading up to Election Day.

Relationship Building

After the new Governor and Lt. Governor were elected, we met with the new Commissioners for the Departments of Human Services, Children and Families and Labor and Workforce Development and are scheduled to meet with the Commissioner for the Department of Health.

We supported Self-Advocates during their annual Developmental Disabilities Awareness Day at the State House and spoke with freshman and veteran legislators.

Regulation & Federal Policy

On the regulatory side, we submitted comments on rule proposals related to the Personal Preference Program and Home Care Services.

Federally, we pushed back against ongoing threats to Medicaid and other federal programs that people with I/DD depend on to fund services and supports in the community. This included action alerts, outreach to New Jersey's congressional delegation, letters to the editor, etc.

Communication

We keep stakeholders informed throughout the year with Updates from Trenton and the Governmental Affairs Update in both the monthly E-newsletter and The Arc of NJ Family Institute Family Advocate newsletter.



The Arc of NJ Family Institute

Lisa Ford, Director and 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.

Highlights from the Year:

- **6 webinars** on the topics of: Early Intervention and Preschool Services, Achieving a Better Life, Grandparents: Planning for Your Grandchild, Decision Making Supports and Guardianship, The Journey to Community Housing, and Self Advocacy.
- **12 new Lunch and Learns** that focused on: The Benefits of an Inclusive Education, IEP Basics, Support Coordination: What Families Need to Know, Preparing for Fee For Service, Understanding Sexuality in Youth With I/DD, Keys to a Smooth Transition, Overview of The Catastrophic Illness in Children Relief Fund, The Dual Eligibles, Promoting Self Advocacy, Navigating the System 14-21, Understanding Supplemental Income Reporting Responsibilities, Public Policy and Advocacy - A How to Guide, and Post Secondary Options for Students with I/DD.



- **6 podcasts** listened to by more than **200 people**. Podcast topics included: The College Internship (CIP), The State Health Insurance Assistance Program (SHIP, All Metro Healthcare, Preparing For Your Next IEP Meeting, Hearts For Home Care- An Overview, 10 in 10 Get To Know A Support Coordination Agency- The Arc of Atlantic
- College Campus Tours at **3 locations** with a combined total of **more than 100 families**.
- A new **Chat Feature** was added to the website to allow us direct connection to families in need of help.
- Creation of a DD Training Databank that provides a wide range of information about trainings and support resources for individuals with intellectual and developmental disabilities (I/DD) and their families throughout the State of New Jersey. Via a grant from the NJ Council on Developmental Disabilities, the newly created Databank includes information and archived resources originating from state service systems, community providers, advocacy organizations and community resources. The trainings, resources, event calendar and archived materials address a number of areas including, but not limited to, accessing services, navigating systems, individual rights, advocacy tools and finding resources in the community. By providing information on all available sources of training, materials, advocacy and resources we empower individuals with I/DD and their families so that they can address immediate issues but also for the long term.

Mainstreaming Medical Care

Beverly Roberts, Director

Highlights of the Year:

- Developed and distributed a series of frequently asked questions (FAQs) on dual eligibles – persons who have both Medicaid and Medicare benefits.
- Revised the disabled adult child (DAC) flyer to include a link so that families can apply for Medicaid online.
- Our 28th Annual Conference on Medical Care for Persons with Intellectual and Developmental Disabilities was held on June 2, 2017. It was a huge success with more than **340 attendees**.
- Developed a “Non-DAC” fact sheet: Although everyone who receives services from DDD is required to have Medicaid, there is an exception to this requirement, known as “Non-DAC” status. However, some families had no knowledge about this exception to the Medicaid requirement, and they believed, incorrectly, that if their son/daughter was not Medicaid eligible due to receiving a Social Security benefit, that their child would be prohibited from receiving DDD services at age 21. The Non-DAC fact sheet clearly explains why some individuals with I/DD are not Medicaid eligible and how they can still receive DDD services.
- Most of this year’s presentations focused on helping families and school personnel understand the importance of Supplemental Security Income (SSI) and Medicaid in order for the student with intellectual and developmental disabilities (I/DD) to receive services from the NJ Division of Developmental Disabilities (DDD) at age 21.

Feedback:

From a parent whose daughter with I/DD has a very serious medical condition and whose private health insurance was scheduled to end. *“Thank you so much. Your attentiveness to my daughter’s insurance problems with [name of Medicaid HMO redacted] is so greatly appreciated. Her medical condition is a grave one and I don’t know what I would have done without your help. Thank you from the bottom of my heart.”*



Planning for Adult Life

Jerisa Chiumbu-Maseko, Director

Helping Students Plan for the Future

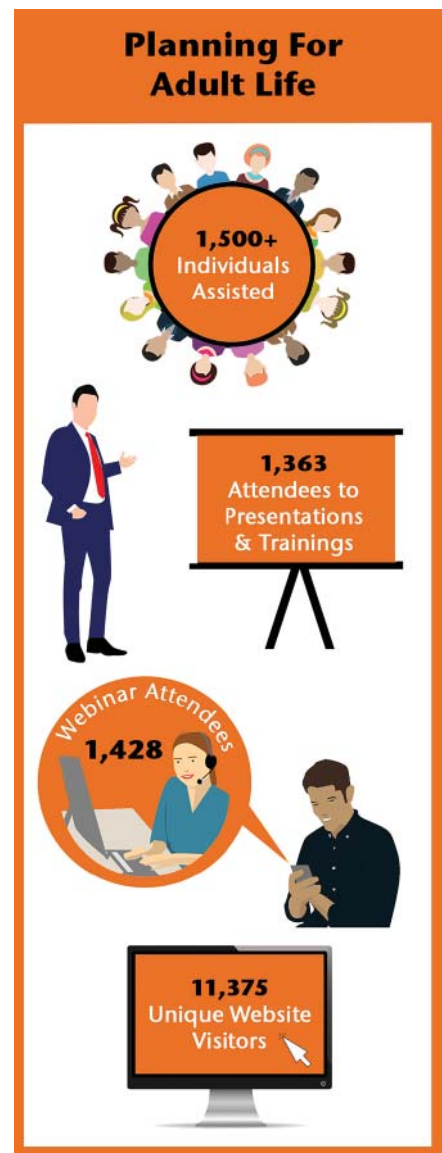
- This past summer, PFAL provided a special series on Self Determination and Self Advocacy during the extended school year programs.
- In the 2016-17 school year, PFAL launched a ‘Grad Bag’ campaign. Transition Coordinators throughout the state were given order forms to receive a “Keep Calm and Plan On” sportspack containing a student planner, maze pen, and “Got Plans” booklet to help students set goals for the road to adulthood. More than **3,000 bags** (100% increase) were distributed in the 2017-2018 school year.
- The demand for the PFAL program in schools continues to increase and staff work diligently to meet the demand.

Exposure to Employment

- PFAL hosted a number of site tours to community businesses where students were given the opportunity to tour the facility and get an overview of the business, meet with Human Resources to gain an understanding of employer expectations, and observe a variety of jobs.
- This year, PFAL brought students to manufacturing, hospitality and retail businesses to give them a better understanding of available employment opportunities in the community. This included trips to JC Penneys, the Edison Job Corps Center, the Amazon Simulation Site in Roselle Park, Dollar Tree, Acme Markets, Applebee’s, Bahama Breeze, Lowes, a Pepsi Cola plant, Build-A-Bear, Target and many more.

Connecting with Individuals and Families

- PFAL hosted 12 webinars this year that focused on topics including: How to Complete the Application for DDD services, Self-Advocacy, Support Coordination, Assistive Technology, Future Planning, and Employment



Criminal Justice Advocacy Program

Jessica Oppenheim, Director

The Criminal Justice Advocacy Program provides direct case management to individuals with developmental disabilities who become involved in the criminal justice system, at the municipal and superior court level. Our caseload is routinely **more than 100 cases** and is, as of April 1 currently at **130 clients receiving services** statewide. The average caseload among our Community Care Coordinators is **35**, which is on target for our best practices. The Program monthly Level of Service averages between 700 and 900, well above expected services.

As of March 30, 2018, **21 Personalized Justice Plans (PJP)** had been provided to courts throughout the state in both superior and municipal court. In addition to providing a PJP, the CJAP Community Resource Coordinators (CRCs) also continue to work with clients while they are on probation or in alternative disposition programs such as the Pre-Trial Intervention program, Drug Court or Mental Health Diversion programs. The CRCs maintain an ongoing relationship with probation officers and clients, ensuring that clients understand the conditions which have been imposed and are able to comply with them.

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, including speaking at the Annual Judicial College in November. 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**.

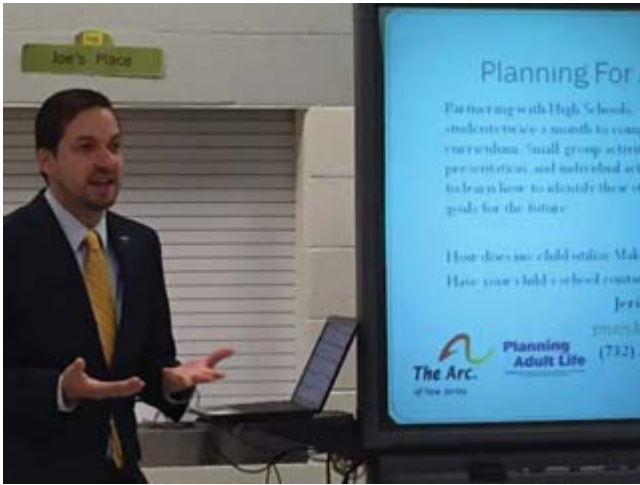
This year saw an increase in training for law enforcement, the legal community and direct service providers. We have conducted 22 Crisis Intervention Team Trainings in 6 counties for 660 law enforcement and mental health providers. We continue to work with the statewide CIT Program to ensure that issues related to developmental disabilities are included in every county

Over half of our Webinar attendees were direct service providers and DDD staff. Topics included:

- Differentiating Problematic Sexual Behavior Related to Autism Spectrum Disorders (ASD) vs Paraphilic Disorders: Part 2 ADULTS
- Involving the faith based community in helping people with sex offending behavior and developmental disabilities in living safely in the community
- Understanding Parole Supervision for Life
- Creating Effective Sexual Behavior Policies for Service Providers
- How Does Criminal Justice Reform Impact Your Client with Developmental Disabilities When Arrested In NJ
- Making the Connection & Maximizing the Results: Investigative Interviewing of People with Developmental Disabilities
- Doing the Right Thing: Making Ethical Decisions and Preventing the Abuse, Neglect and Exploitation of People with Disabilities
- How Parents and Caregivers Can Help Keep an Individual with I/DD Safe While Accessing the Internet



Project HIRE



Adam Kubler, Director

In the last twelve months, Project HIRE continued to be a leader in the Supported Employment sphere through growth in multiple new programming options. The program's strengths were also noted in one of the best CARF survey's in Project HIRE's history.

Project HIRE experienced a 22% growth in school transition services provided to districts all over the state. Due to Project HIRE's experience in both adult and transition services, the program is primed and ready to provide transition services in the new DVRS funded Pre-ETS program. The program director is

working closely with local DVRS offices and school districts to plan ways to best utilize this funding.

The agency continues to be successful in providing Trial Work Experience services and due to the increased demand has dedicated a full-time staff member to the activity. Through this position, Project HIRE aims to become *the* provider of Trial Work Experience Services in the years to come.

Referrals from the Commission for the Blind and Visually Impaired continue to increase. Due to Project HIRE's increased activity in this area several staff members were invited to participate in a comprehensive, three day training held by the Commission for the Blind and Visually Impaired which focused on job development and placement of individuals who live with visual impairments.

Project HIRE was again selected to participate in Union County's Project SEARCH after satisfactory results from the previous year's graduating class. Benchmarks were met from last year's cohort and the next cohort is expected to experience similar, if not better results.

The program participated in the mandatory CARF accreditation process and after intense, detailed review, Project HIRE was approved for the maximum, three year accreditation. The survey results were some of best ever received by the program. Specifically, Project HIRE was commended for its dedicated staff members, team environment and ability to standardize quality over such a large service area.



The NJ Self-Advocacy Project

Ashley Ritchey, Director

The Self-Advocacy Project team take their cues from the nearly 2,100 members of the affiliated New Jersey Statewide Self-Advocacy Network (NJSSAN).

Highlights of the Year:

- In April, the NJSSAN hosted the **12th Annual Awards Luncheon**. **More than 300** NJSSAN members attended this event which featured a keynote session presented by a self-advocate who has worked with medical professionals to develop and implement a comprehensive training curriculum for nurses on the topic of working with patients with I/DD.
- The Arc of New Jersey and New Jersey Self-Advocacy Project team coordinated New Jersey's second Sprout Film Festival, which was held at Middlesex County College in April. **More than 300** self-advocates, Direct Support Professionals, agency staff, and community members attended this event, which featured an array of short films featuring family members, self-advocates, and actors with I/DD.
- The NJSAP team attended the Abilities Expo at the New Jersey Convention & Expo Center in May 2017 and shared resources with more than **5,500 community members**.



- In July, NJSSAN members hosted their 6th annual event on Point Pleasant Beach Boardwalk to raise awareness about the 27th Anniversary of the Americans with Disabilities Act. Throughout the day, **more than 150 community members** visited the booth and learned about The Americans with Disabilities Act.

- Through a grant from 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, hiking, music therapy, rock climbing, and yoga.

- In October, **more than 80 advocates** participated in the 4th Annual Healthy Lifestyles Project Workshop at Watchung Reservation. The event featured a music therapy session, adaptive fitness, as well as opportunities to learn about healthy diet options for breakfast and lunch. The day culminated in a group trail walk on an accessible hiking path.

- An additional 102 interviews were recorded and posted to the Transportation Research Project (TRP) podcast website, bringing the total **number of participants to 202**. The NJSAP team conducted audio-recorded interviews which will be analyzed by Center for the Advancement of Infrastructure and Technology in an effort to quantify the challenges and opportunities related to transportation for people with I/DD and their loved ones.

- In March, 28 advocates and 20 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 Jasey.

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 784 hours** of trainings, consults, and additional assistance to DDD funded providers throughout the state. This is a 44.91%



increase from the previous year, and a 105% increase from fiscal year 2015-16.

TCS continues to push the envelope, both in the development of content and in the way it is disseminated. Some of the topics covered have included: Fading Gracefully: Using Data to Guide Services, Organizational Tools for Coaches, Advanced Intervention Strategies, Write it Right: Documentation & Record Keeping, Make it Stick: Building Staff Competency from Day One, Managing Stress & Challenging Behaviors, A.B.T: Always Be Teaching (Strategies for Coaches), How to Beat the Hidden Hiring Barrier: Applicant Tracking Systems

Highlights of the Year:

- Elected to the APSE's National Board of Directors
- Ongoing partnership with Rutgers' Boggs Center
- Development of "What is Job Coaching?" animated video
- Provided multiple trainings for DDD's provider performance unit
- Conducted presentations for the Mental Health Association in New Jersey- Career Connections Employment Resource Institute (CCERI)
- Presented 2 workshops at NJ APSE Conference
- Panelist at SJ Transition Coordinators Network

Communications and Development

Céline Fortin, Associate Executive Director

- Support of 15 local county chapter walkathons
- Monthly e-news - **981 recipients**
- Website – **38,455 visitors** with **91,599 pages** viewed (April 1, 2017 to present)
- Facebook – **2,563 likes**, with reach at **4434**
- Twitter – **2,965 followers**

Grants:

- \$25,000 grant for the Healthy Lifestyles Project from the Horizon Foundation for NJ

- \$45,378 grant for the DD Training Resources Databank Project from the NJ Council on Developmental Disabilities

Fundraising:

- October 16, 2017 Awards Dinner; 10 awardees, 142 attendees, netting \$24,000
- Exceeded fundraising goals for FY 2017 and already for FY 2018
- Successful annual appeal netting \$10,500 - more than twice the amount of previous years.

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

- Administrative Office of the Courts ADA Committee
- American Association on Intellectual and Developmental Disabilities
- AMERIGROUP HMO Advisory Committee
- APSE's National Board of Directors
- Boggs Center Consumer Advisory Committee
- Coalition for a DSP Living Wage (Chair)
- County Children's Interagency Coordinating Council
- DDD Leadership Committee
- ESSA Stakeholder Focus Group
- Family Support Coalition
- Governor's Council on the Prevention of Developmental Disabilities
- Governor's Council on Sexual Violence—Disability Rights Subcommittee
- Health Care Advocates Group
- Horizon NJ Health, Managed Long-Term Services and Supports, Advisory Committee
- Medical Assistance Advisory Council
- Middlesex County Department of Transportation Advisory Committee
- National APSE
- National Association of the Dually Diagnosed
- 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 (Secretary)
- NJ APSE Professional Development Committee (Chair)
- NJ Business and Industry Association
- NJ Chapter American Academy of Pediatrics, Children with Disabilities Advisory Committee
- NJ Coalition for Special Education Funding Reform
- NJ Conference of Executives of The Arc (CEArc)
- NJ Council on Special Transportation
- 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 Lifespan Respite Coalition
- New Jersey Alliance for Children, Youth and Families
- Developmental Disabilities Working Group
- NJ Partnership to Prevent Child Sexual Abuse
- NJ Pathways to Justice Task Force
- NJ Task Force on Abuse of Persons Who are Elderly or Disabled
- NJ Transit ADA Task Force
- NJ Workability
- Protection and Advocacy for Developmental Disabilities
- (PADD) Consumer Advisory Council (CAC)
- Regional Family Support Planning Councils
- Restraint and Seclusion Stakeholder Group
- Sexual Violence Prevention Coalition of Middlesex County
- SPAN Family to Family Health Information Resource
- SPAN Parent Training Information Stakeholder Advisory Council
- Supportive Housing Association of NJ
- SHA Grant Partner Advisory Committee
- The Arc @School
- The Arc of Union County's Medical Advisory Board
- The Arc's Center for Future Planning Chapter Workgroup
- Transition Leadership Network
- Vicinage Advisory Committee on Minority Concerns