



The Arc[™]
of New Jersey

Report to the Annual Meeting

April 7, 2011

President's Message

'Achieve with us!'

The new tagline of The Arc - '**Achieve with us**' - says a whole lot in just three simple words.

It *invites* - it *ignites* - it *embraces* - it *challenges*. It *celebrates* our capacity as an organization to help individuals with intellectual and developmental disabilities achieve their highest potential and create lives rich with meaning and joy, and it *recognizes and honors* the inherent ability of those individuals to create and maintain such lives.

The new tagline as well as the new logo and brand identity of The Arc, launched on **March 1, 2011**, also give an outward appearance of being "simple". Yet this belies an enormous amount of work over the past two years that included painstaking research, ongoing national conversations with staff from hundreds of state and local chapters of The Arc, and deep reflection on what the core essence of The Arc is and how best to convey that through rebranding. Not an easy task by any means - and certainly not complete, as many chapters across the country still work toward embracing the organization's new identity. I am confident, however, that the new brand will do just what it set out to do: *unify* and *energize* The Arc internally, and spread that energy outward as we communicate our unwavering belief in the dignity and potential of every person living with a disability.

Walter Bender

Executive Director's Message

Talent. Teamwork. Results.

These ideas are what drive our internal organizational compass, and are at the heart of what it means to be a member of The Arc Family in a larger sense. Volunteers, boards, staff, professionals, self-advocates, families - all bringing their own unique and valuable piece to the table we all share. Across the board, The Arc of New Jersey maintains a hard and fast commitment to excellence and we expect nothing less for the individuals with intellectual and developmental disabilities who we are proud and humbled to represent.

Of course, results are what counts and this year was another amazing year. Whether it was passing legislation, helping someone find employment, resolving issues or educating the public, The Arc was involved, effective and successful on a number of critically urgent issues.

Advocacy is our *number one priority*, and we are grateful for the strong and consistent support from our families, self-advocates, board members and local chapters. Truly, You make all the difference; and when "the rubber hits the road", so to speak, I am always amazed at how many of you are right there with us. My staff here at the state office are well familiar with my age-old motto to always "fight the good fight". That good fight is sometimes won and sometimes lost (temporarily), but is always worth it because of the invaluable contributions that each staff person, each volunteer, each Self Advocate, each family member and each and every local county chapter share.

Thomas Baffuto

Family Advocacy

■**e-Action Networks:** Launched by our **Family Advocacy Program** in 2006, the e-Action Network has truly become the cornerstone of our grassroots advocacy efforts. Generating massive statewide response to Action Alerts and other calls to action, it began with the **Families Network**, which is now nearly **1000 members strong!** In May 2010 the **Friends Network** was launched as a complementary component of the Families Network, with the goal of engaging friends and supporters who may not be directly impacted by our issues but still have a desire to be “part of the **ACTION!**”

■**Survey of Families’ Needs:** The Program distributed and then compiled data from Families’ Needs Survey; key results were published in *What Matters Most: A Survey of Families’ Needs*, and were also shared with The Arc of New Jersey staff and Board of Directors, members of the Family Advocacy Program, local county chapters of The Arc, and Human Services Commissioner Jennifer Velez. With a remarkable **517 respondents**, important discussion and advocacy has resulted around many of the systems issues specifically identified by families in the survey.

■**Individual Advocacy and Family Support:** The Program has spent significant time and energy assisting individual families, who are finding it increasingly difficult to get the assistance they need and are struggling with the lack of responsiveness from the systems designed to support them. The Program has also spent a considerable amount of time working on issues related to **Family Support**. The Director of our Family Advocacy Program serves as the **Vice President of the Family Support Coalition** and sits on the **Division of Developmental Disabilities Family Support Task Force**. The Division has been working on a Medicaid Waiver for family support services and we have been deeply involved in that issue. The Arc of New Jersey has been working with other advocates to ensure that federal funds realized by any new waiver will be **reinvested into the developmental disabilities service system**.

Self Advocacy

■**Ending the R-word:** After the rousing Rally for Respect in March, 2010, a huge part of the agenda for New Jersey Self Advocates over the next several months became passage of R-word legislation. **Dozens of community outreach/public awareness events** (walkathons, shredding events, pledge signing at high-volume locations, presentations at schools) were held and attended by members of the New Jersey Statewide Self Advocacy Network and staff from the New Jersey Self Advocacy Project; compelling personal testimony was provided by **5 Self Advocates** before the Assembly Human Services Committee and/or the Senate Health and Human Services Committee regarding the denigrating use of the R-word; and to date, **2500 signed pledges** to stop using the R-word have been collected. The massive effort was rewarded when the R-word bill was unanimously passed by both Houses in June and was signed into law by Governor Christie on August 16, 2010, mandating replacement of the R-word with the term “intellectual disability” in all state documents and statutes.

■**Annual Events:** The **5th Annual Self Advocacy Spring Into Action Luncheon** was held in May, with nearly 250 Self Advocates in attendance, and four awards presented: the Jane Miller Leadership Award, the Heroes Award, the Group Achievement Award, and the Advisor of the Year Award. In October the **27th Annual Self Advocacy Conference, I’m a Person First, My Disability Comes Last**, welcomed approximately 450 Self Advocates and caregivers.

■**Statewide Self Advocacy:** There are **thousands of Self Advocates** in the New Jersey Statewide Self-Advocacy Network. Approximately 20 Self Advocates are fully participating members of a number of coalitions, task forces, and committees statewide, including Seeking Ways Out Together, Partners In Justice, TASH, the Protection and Advocacy for Persons with Developmental Disabilities Program of Disability Rights NJ, the Community Planning and Advisory Council, the Consumer Advisory Council, the Olmstead Steering Committee.

Education Advocacy

■ **IEP Advocacy:** The Arc of New Jersey's Education Advocacy program is *unique in New Jersey*, with an Education Advocate who attends IEP meetings with parents at no cost to the family. In our experience, **the impact is enormous**: parents feel empowered and many families have expressed appreciation at having an advocate to rely on during often contentious interactions with school districts.

■ **Building Blocks of a Good IEP:** A comprehensive parent training workshop developed by the Education Advocacy Program and presented to parent groups in several counties. Covered topics include: how to prepare for the IEP meeting; what to look for in the IEP draft; how to make sure the present levels of academic and functional performance really capture the student's strengths and weaknesses; how to formulate annual goals; and how to determine what interventions are needed to help a student succeed.

■ The Numbers:

Parent calls fielded: **1700** | IEP meetings attended: **150**

School programs observed: **45** | Parent workshops and **Ask the Advocate** sessions: **16**

■ Recurring Issues / Themes:

What is the Least Restrictive Environment? ...What is an appropriate education? ...How do you read an evaluation and make sense of it? ...How can my child's needs be documented? ...Do 504 plans really work? ...What are reasonable accommodations? ...How do I get my child services during the summer?

Citizen Advocacy

■ **4,446:** The incredible number of contacts (information, referrals, direct support) made by the social work staff of our **Citizen Advocacy Program** this year. The social work component of this program provides intensive case advocacy services for individuals in Burlington, Camden and Gloucester Counties who are not able to protect their own interests and whose needs are not adequately met by the existing service system. Of the **105 consumers** currently on the Citizen Advocacy caseload, **19** received Crisis Intervention Services.

■ **Volunteer Advocacy Services:** The **28 Volunteer Advocate-Consumer** matches currently managed by the Citizen Advocacy Program provide ongoing friendship, support and community involvement for individuals with developmental disabilities in Burlington, Camden and Gloucester Counties. The inestimable value of this unique **one-to-one relationship** is evident in consumer comments like these: *"My volunteer is a wonderful guy; great to talk to. I love him like a brother."* | *"CAP gave me the keys to unlock a whole new world....introduced me to new perspectives on many aspects of life...for me it has been an incredible experience."* The program maintains a presence on **8 Volunteer Recruitment Websites**, regularly does presentations on college campuses, distributes literature to libraries, colleges, churches, educational fairs and other community gatherings.

■ Issues Confronting Consumers:

Inability to meet basic food needs (reduction in food stamp benefits, shortages at local food banks); **Lack of reliable, consistent transportation**; **Dual Diagnosis** - many of the consumers Citizen Advocacy works with are dually diagnosed with a developmental disability and a mental health issue, making it difficult to receive appropriate services. The Citizen Advocacy Program assisted consumers with all of these issues.

Health Care Advocacy

■ **Medicaid Managed Care:** Major changes are anticipated for all New Jersey Medicaid beneficiaries, including a requirement that, as of **July 1, 2011**, everyone who receives Medicaid must be in a **Medicaid HMO**, and all medication will be "carved-in" to the HMO system. The Director of The Arc of New Jersey's **Mainstreaming Medical Care Program** has been appointed by the Department of Human Services Commissioner to two of four new Workgroups, to provide detailed suggestions and safeguards for the transition. The Program received **445 requests** from families and agency staff for assistance and advocacy with Medicaid, as well as Medicare and other private health insurance issues.

■ **The Dual Diagnosis Issue:** The Program continues its individual and systems advocacy on behalf of people with a dual diagnosis of a developmental disability and a mental health disorder - a largely inadequately-served population in New Jersey and nationwide. The Program Director sent a **Letter to the Editor** of the Star-Ledger on this urgent issue, published on December 28, 2010.

■ **Outreach/Education:** Another highly successful health care conference was held in May, 2010, bringing the most current and relevant medical, dental and mental health information regarding people with developmental disabilities straight to the families and caregivers who need it. The **21st Annual Conference on Medical Care for Persons with DD, Promoting Quality Health Care**, welcomed **300 attendees** and **two keynote speakers**, and offered **11 workshops**. The Program has also developed (a) Cancer Detection and Prevention materials, (b) Diabetes Prevention and Maintenance materials, and (c) Women's Health materials, distributed as follows: **517 Cancer Prevention materials; 316 Diabetes Prevention materials; 105 Women's Health materials.**

Prevention Advocacy

■ **25 Years of Prevention:** In 2010 The **New Jersey Coalition for Prevention of Developmental Disabilities** celebrated **25 years** of enhanced public education and awareness regarding *preventable* intellectual and developmental disabilities. The Program received a Proclamation from the New Jersey State Assembly; The Arc Board of Directors enjoyed a 25-year Overview presentation from Coalition Chair, Patti Lucarelli; and on the occasion of the 75th anniversary of the enactment of the Title V program, the Coalition was recognized, along with 22 other organizations throughout the state, by the New Jersey Department of Health and Senior Services for its contribution in furthering the goals of the Title V Program under the Social Security Act, which focuses on maternal and child health services.

■ **Outreach/Education:** The Program co-sponsored and served as administrator for the April, 2010 statewide conference, **Lead and Beyond: Progress in Eliminating Lead Poisoning and New Opportunities for Collaboration in New Jersey**, with **300 attendees**. Also, the **NoWrongDoorNJ.org** website was launched.

■ **The Numbers:** The cornerstones of the Coalition's activities are its targeted prevention initiatives, which included the following: **20 Pregnant Pause** events held in 17 counties; ***Am I a Safe Kid?*** presentations provided to over **400** children; **5** Fetal Alcohol Spectrum Disorders (FASD) presentations; **4** quarterly issues of ***Prevention Counts*** newsletter; and **Lead Prevention Toolkits** distributed all members of The Arc of New Jersey Board of Directors.

Criminal Justice Advocacy

■ **Individual and Systems Advocacy:** The Arc of New Jersey's **Developmentally Disabled Offenders Program** remains **the only program in New Jersey** and **one of a handful nationwide** to identify and coordinate services for criminal offenders who have a developmental or intellectual disability. The Program seeks to provide a viable alternative to incarceration that can be implemented as a condition of probation or parole. Through **advocacy and case management**, staff intervenes at every stage of the criminal justice system to identify appropriate non-custodial alternatives, which are presented to the court system through the comprehensive **Personalized Justice Plan**. Currently the Program has an active caseload of **75 clients**. **Levels of service** have been consistently high, reaching **5,392** by the end of February 2011, including **correspondence** to counsel and the court, **information** to families of defendants, **training** for law enforcement and the defense bar. The Program **opened 83 cases** this year. In addition, technical assistance is provided in many cases where interaction with the legal system is less serious and can be resolved alternatively.

■ **Outreach/Education:** In April 2010 The Program coordinated its Annual **Equal Justice Conference**, with 200 attendees. The morning keynote theme was *Enforcement of Safety and Personal Rights for People with Intellectual and Developmental Disabilities*, while the afternoon keynote was centered around *Continuity of Care for Offenders with Developmental Disabilities*.

Employment Advocacy

■ **Supported Employment:** **Project HIRE** celebrated its **25th Anniversary** in 2010 and continues to be the oldest, largest, and one of the most reputable supported employment programs in New Jersey. In 2011, the Program underwent a **CARF re-accreditation survey**, receiving high praise for its performance and practices; a full re-accreditation decision is anticipated. Through a Division of Vocational Rehabilitation Services initiative launched this year, Project HIRE has been granted state funding to provide **Long Term Follow Along** services. There are **489 individuals** receiving supported employment services, with nearly **23,000 service hours** having been logged this year.

■ **School to Work Transition:** Our School to Work program has reached a high point with **58 contracts** for the first 3 quarters of the fiscal year. Nearly **75 students** are receiving transition and vocational services from Project HIRE in areas such as community based vocational assessments, classroom sessions, and paid part-time work with job coach support.

■ **Training and Consultation:** Housed within Project Hire, The Arc of New Jersey's **Training and Consultation Services (TCS)** assists supported employment providers and professionals in improving employment outcomes for people with disabilities through **classroom style training, hands-on technical assistance, consultation services, information and referral, and advocacy**. TCS continues to work collaboratively with Division of Developmental Disabilities, Division of Vocational Rehabilitation Services, and Region 2 Technical Assistance and Continuing Education (TACE) Center. TCS continued its partnership with the Region 2 TACE Center by providing **17 training opportunities** throughout the state. TCS also conducted **10 presentations** in New Jersey and nationally on a number of topics. The TCS Director was elected **Chair of the National APSE Delegate Council** and became a member of the **National APSE Board of Directors**; co-chairs the **APSE Employment First Committee**; represents NJ APSE as the **Legislative Liaison**; and became a part of the **Alliance for Full Participation**.

Legislative Advocacy

■ **Legislative Priorities:** (1) **Data Bill:** A major public policy goal for The Arc of New Jersey for two years, this legislation mandates that the Division of Developmental Disabilities (DDD) collect and disseminate critically-important data on individuals with developmental disabilities in New Jersey. We drafted the initial legislation and have been the primary advocates; the bill has been through committee in both houses and final passage is expected soon; (2) **Deinstitutionalization:** The Arc of New Jersey worked as part of large coalition of DD advocates to press the Governor to announce the **closure of a developmental center**, which he did in his recent budget proposal, proposing the closure of Vineland Developmental Center; (3) **School Choice:** The Arc of New Jersey succeeded in getting critically-important amendments for several school choice bills to make them more protective of students in special education; and (4) **Transparency and Communication:** The Executive Committee, with support from several staff of The Arc of New Jersey, worked closely with the Department of Human Services on major issues of transparency and communication at DDD, and toward improving DDD regulations in several key areas.

■ **The Numbers:** The Arc of New Jersey monitored over **250** pieces of legislation, provided testimony on **43** pieces of legislation, requested and succeeded in getting amended language on over **25** pieces of legislation. We also did a great deal of work this year educating legislators about **unintended negative consequences** to proposed legislation, and **clarifying and amending** legislative language.

Communications and Public Relations

From the Rally for Respect in March 2010 and the launch of the months-long **End the R-word! Campaign** to the **Open House and Rebranding Celebration** in March 2011, this has been a full and exciting year.

▶ In 2010 two of our programs - **Project HIRE** and the **New Jersey Coalition for Prevention of Developmental Disabilities** - celebrated **25 years** of advocacy and service.

▶ In 2010 two of our staff received awards for their exceptional work and contributions: Associate Executive Director Celine Fortin received the National Conference of Executives of The Arc's **Outstanding Professional Achievement Award**; and Beverly Roberts, Director of the Mainstreaming Medical Care Program, received the **Lifetime Achievement Award** from the New Jersey Council on Developmental Disabilities.

▶ A statewide **Get Connected with The Arc** initiative was coordinated in May 2010.

▶ Another successful season of **Step Up For The Arc Walks** was held, with well-attended events in every county. **Hinkle, Fingles and Prior, Attorneys at Law**, generously stepped into the role of 2010 Statewide Sponsor.

▶ Two issues of the statewide newsletter, **Progress**, were distributed; and our internet and social media presence continue to grow by leaps and bounds, with an impressive **409 friends** on Facebook and **722 followers** on Twitter.

▶ And of course we also enjoyed our **Annual Awards Dinner and Celebration**, not to mention a stellar **National Convention** at the Disneyworld resort.

EXECUTIVE COMMITTEE OF THE BOARD OF DIRECTORS

| | | | |
|-------------------|---------------------------------|------------------------|------------------------|
| Walter Bender | <i>President</i> | Mitchell Bell | <i>Member-at-Large</i> |
| Bruce Humphreys | <i>First Vice President</i> | Elsbeth Corrigan Moore | <i>Member-at-Large</i> |
| Donna Gruter | <i>Second Vice President</i> | Robert Hage | <i>Member-at-Large</i> |
| Pamela Corrigan | <i>Treasurer</i> | John O'Brien | <i>Member-at-Large</i> |
| Carmen Bannon III | <i>Secretary</i> | S. Paul Prior | <i>Member-at-Large</i> |
| Bruce A. Bird | <i>Immediate Past President</i> | Kevin K. Walsh | <i>Member-at-Large</i> |

EXECUTIVE STAFF

| | |
|---------------------|-------------------------------------|
| Thomas Baffuto | <i>Executive Director</i> |
| Celine Fortin | <i>Associate Executive Director</i> |
| Michael Prendergast | <i>Assistant Executive Director</i> |
| Elizabeth Shea | <i>Assistant Executive Director</i> |
| Stella Natale | <i>Executive Secretary</i> |

PROGRAMS AND DEPARTMENTS

♦**CITIZEN ADVOCACY PROGRAM, since 1972:** Ensuring that consumers have equal access to services and supports that help them to be independent and integrated members of their community; individuals living in Burlington, Camden and Gloucester Counties are provided with case advocacy services and/or volunteer advocates.

Lorraine Travaglione, Director

♦**DEVELOPMENTALLY DISABLED OFFENDERS PROGRAM, since 1982:** Supporting and assisting youth and adults with developmental disabilities who become involved with the New Jersey criminal justice system, and educating criminal justice professionals and service providers about working effectively with these individuals.

Jessica Oppenheim, Director

♦**EDUCATION ADVOCACY, since 2002:** Empowering New Jersey families of students with developmental disabilities in the special education process through information and advocacy. **Natasha Schneider, Director**

♦**FAMILY ADVOCACY, since 2005:** Engaging and assisting New Jersey families of children and adults with developmental disabilities in advocating for service and policy changes that will improve the lives of their loved ones. **Denbigh Shelton, Director**

♦**MAINSTREAMING MEDICAL CARE PROGRAM, since 1986:** Helping individuals with developmental disabilities and their caregivers access quality medical, dental and mental health care, and educating health care professionals to become effective allies in meeting the complex health care needs of these individuals. **Beverly Roberts, Director**

♦**NEW JERSEY SELF-ADVOCACY PROJECT, since 1983:** Supporting individuals with developmental disabilities as

they advocate on their own behalf and assisting them to become organized on the local and state levels and thereby increasing their effectiveness. **Dennis Donatelli, Director**

♦**NEW JERSEY COALITION FOR PREVENTION OF DEVELOPMENTAL DISABILITIES, since 1985:** Educating community providers and the general public about preventive measures that, when implemented, can reduce or eliminate the incidence of disabling conditions.

Jerisa Chiumbu Maseko, Director

♦**PROJECT HIRE, since 1985:** A CARF-accredited supported employment and school-to-work transition program. **Michael Prendergast, Assistant Executive Director**

♦**TRAINING AND CONSULTATION SERVICES:** Providing comprehensive training on topics related to supported employment and transition from school to work, and consultation and technical assistance to supported employment providers in New Jersey.

Jennifer Joyce, Director

♦**HUMAN RESOURCES AND FINANCIAL MANAGEMENT:** Maintaining the viability of the organization by balancing the programming and human resource needs against actual and anticipated revenue.

Michael Prendergast, Assistant Executive Director

♦**LEGISLATIVE ADVOCACY:** The governmental affairs arm of The Arc of New Jersey, overseeing budget and legislative advocacy efforts. **Elizabeth Shea, Assistant Executive Director**

♦**COMMUNICATIONS AND PUBLIC RELATIONS:** Working to create a consistent and appropriate print, internet, media and community presence and reputation for the organization. **Celine Fortin, Associate Executive Director**

The Arc of New Jersey is represented on the following Boards, Committees and Workgroups

Administrative Office of the Courts ADA Committee
American Academy of Bereavement
American Association on Intellectual and Developmental Disabilities-New Jersey Chapter
AMERIGROUP HMO Advisory Committee
Boggs Center Consumer Advisory Committee
Camden County Community Linkages
Coalition for Healthy Communities
Coalition for a Moral Budget
Coalition on Special Education Funding Reform
Community Health Charities of New Jersey
Community Organizations Active in Disasters of Burlington County
Crossings Disabilities and Addictions Task Force
DDD Contracted Services Committee
DDD Dialogue with the Division
DDD Family Support Task Force
DDD Olmstead Advisory Council
DDD Olmstead Advisory Council, Self-Advocacy and Family Partnership Workgroup
Developmental Disabilities Coalition
Direct Support Professionals Workforce Coalition Steering Committee
Directors of Volunteer in Associations in Southern NJ Disabilities and Addictions Task Force
Disability Advocates Group, Legal Services of NJ
Disability Issues Committee of Burlington County
Disability Rights NJ Advisory Council for Persons with Developmental Disabilities (DD)
Division of Vocational Rehabilitation Services Professional Advisory Committee
Early Intervention Workgroup
Employment Task Force
Family Support Coalition
Federal Legislative Task Force
Gloucester County Healthy Mothers/Healthy Babies Coalition
Governor's Advisory Council Against Sexual Assault
Governor's Council on the Prevention of Developmental Disabilities
HealthFirst HMO Advisory Committee
Housing Alternatives Board of Directors
Housing and Community Development Network of NJ
Housing Authority of Union County
IDEA Roundtable
Medical Assistance Advisory Committee
Middlesex County Department of Transportation Advisory Committee
Middlesex County Educational Services Advisory Committee
Middlesex County Transportation Task Force
Military Family Support 360 Advisory Committee
National APSE Board of Directors
National APSE Delegate Council
National APSE Employment First Committee
National Association of the Dually Diagnosed
National Association of Social Workers
National Association of Social Workers NJ HIV/AIDS Committee
National Conference of Executives of The Arc (NCE)
National Council on Alcoholism and Drug Dependence
NJ Alliance for Full Participation
NJ Alliance for Full Participation Task Force
NJ APSE
NJ APSE Board of Directors
NJ Association of County Disability Services
NJ Association of Mental Health and Addiction Agencies
NJ Attorney General's Prisoner Reentry, Medicaid Related Issues Committee
NJ Breathes
NJ Business and Industry Association
NJ Chapter American Academy of Pediatrics, Children with Disabilities Advisory Committee
NJ Coalition for Bullying Awareness and Prevention
NJ Conference of Executives of The Arc (CEArc)
NJ Council on Developmental Disabilities Education Subcommittee
NJ Council on Special Transportation
NJ Dental Lifeline Network
NJ Department of Human Services Medicaid Managed Care Workgroups
NJ Fetal Alcohol Spectrum Disorders Task Force
NJ Health Care Quality Institute Consumer Advisory Committee
NJ Interagency Task Force on Lead Poisoning Prevention
NJ Medicare Consortium (chaired by the Federal Centers for Medicaid and Medicare)
NJ Special Education Practitioners
NJ State Disability and Addictions Task Force
Practice Group on DD and Mental Illness
NJ TASH
NJ Transit ADA Task Force
NJ Workability
No Wrong Door NJ Collaborative
Parent Advocacy Network Advisory Group
Partners in Justice NJ
Regional Family Support Planning Council Community Outreach
SPAN Family to Family Health Information Resource Advisory Committee
State Rehabilitation Council
Statewide Interagency Coordinating Council
Statewide Employment and Training Commission, Disability Issues Subcommittee
TACE Advisory Committee
The Arc/Mercer Health Care Advisory Group
The Arc of Union County's Medical Advisory Board
The Arc of the United States Marketing and Resource Development Committee
The Integrated Employment Coalition
United Healthcare Community Plan Advisory Committee
Volunteer Center of Burlington County Board of Directors



For people with intellectual and developmental disabilities

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