

Achieve with us.



Report to the Annual Meeting

April 12, 2012

PRESIDENT'S MESSAGE

The Arc has your back

One of the biggest highlights of the year was February's **policy briefing at the White House**. Organized by The Arc of the U.S., more than 150 leaders of The Arc from around the country came together for a productive, informative (not to mention *exciting!*) day at the White House. An impressive lineup of speakers addressed our group and responded to our questions and concerns, but nothing could have prepared us for the surprise visit from President Barack Obama! His inspirational message and his rare appearance at such an event **truly underscores the power of The Arc and its mission**, and the President eloquently closed his remarks with the words "I've got your back".

Powerful stuff. And it got me to thinking about the unique nature of this organization, with its consistent record of achievement driven in large part by the strong relationship between the state chapter and the local county chapters - a relationship in which, in so many ways, we've got each other's backs. Our collaboration has resulted in tremendous advocacy, public relations and, most importantly, direct service successes; and working together, we have created major paradigm shifts at both the systems level and the human level, affecting the lives of thousands of individuals with intellectual and developmental disabilities and their families in deeply meaningful, positive and lasting ways. I truly am so grateful to count myself as a member of The Arc family, and both proud and humbled to work alongside so many talented and caring professionals, self advocates and family members. As the President of this exceptional organization, and as the dad of a beautiful daughter with disabilities, I thank all of you for having my back.

Walter Bender

EXECUTIVE DIRECTOR'S MESSAGE

Challenging Times, Extraordinary Effort

In some respects, in terms of The Arc's mission and history, there have never really been *unchallenging times*. Indeed, we exist and *thrive* - as an organization, as individuals, as families - because we are willing to name and to meet the challenges of living in a society that does not easily extend acceptance to those who are perceived as "different". And so in that sense, The Arc's effort - *your effort* - has been extraordinary from day one.

This past year presented a landscape replete with challenges - and yet regularly punctuated with successful effort on the part of self advocates, family advocates, and local county chapter staff and volunteers. A record-breaking **Step Up For The Arc Walk** in 2011; a massive statewide collaboration to **close Vineland Developmental Center** and to begin to look at closure of many of the state's other developmental institutions; passage of the **Data Bill**, mandating the state to collect and disseminate critical information about the individuals it serves; and most recently, an extremely well-received and well-broadcast **Developmental Disabilities Awareness Month** campaign, **Someone To Get To Know**, which included presentation to The Arc of an official Governor's Proclamation. Internally, representatives from local county chapters and from the state chapter put forth great effort drafting a new **Strategic Plan** for The Arc of New Jersey that will take us into 2015; and reviewing, discussing and drafting responsive comments to The Arc of the U.S.'s new **Bylaws and Affiliation Agreement**.

Yes, challenging times call for extraordinary effort. I don't think I overestimate the power and viability of The Arc - its members, its families, its professionals - when I say that those two stand side by side for us almost daily.

LEGISLATIVE ADVOCACY

- ■The Data Bill: On January 5, 2012, the Data Bill was signed into law, requiring the Department of Human Services to collect and disseminate critically needed data about the individuals they serve. The Arc of New Jersey has long understood that any effective advocacy on behalf of individuals with intellectual and developmental disabilities is contingent upon accurate and up-to-date information from both the Department of Human Services and the Division of Developmental Disabilities. We spent over three years working to create, draft and amend the Data Bill and are confident that, as a result of this law, our advocacy efforts will be strengthened.
- Deinstitutionalization issues including the 2013 closure of Vineland Developmental Center, the Legislative Review Panel, and implementation of the Developmental Center Closure Task Force
- ■Advocacy related to the New Jersey Department of Human Service submission and implementation of the Comprehensive Medicaid Waiver and the Supports Waiver, as well as monitoring and advocacy around the shift to mandatory managed care
- ■Advocacy for the development of **self directed services regulations** and for the implementation of appropriate regulations on the **waiting list**, **community care residences**, and **family support**
- ■Budget Advocacy: In FY2012 The Arc of New Jersey supported the Close Vineland Initiative and advocated for the continuation of Medicaid Wrap Around funding; in FY2013 we are advocating to keep the funding for affordable housing, for Olmstead funding, funding to serve people waiting for services, and a 3% true cost of care increase. We also coordinated the statewide Don't Cut Our Lifeline campaign to stave off proposed federal Medicaid cuts.

PUBLIC POLICY AND FAMILY ADVOCACY

- ■Public Policy and Family Advocacy: In his FY20122012 budget address, Governor Christie included funding to close the Vineland Developmental Center and move its residents into the community or into one of the state's six other developmental centers. While the disability community applauded this provision, there was strong opposition from labor unions, many Cumberland County residents and politicians, and some family members whose loved ones reside at the center. The Close Vineland Initiative, a collaboration of several disability rights organizations, was led by The Arc of New Jersey and included:
 - ⇒Development of Close Vineland website, Fact Sheet, Statehouse exhibit, and informational email messages
 - ⇒Distribution of Action Alerts to Families Network, Friends Network, and collaborative partner members
 - ⇒Planning/implementation of *May Flowers Campaign*: delivery by **Self Advocates** of a single white carnation, with alternating messages attached, to the Governor, Lt. Governor, Senate President, and Assembly Leader each day during May 2011
 - ⇒Coordination of **testimony** by staff, family members and Self Advocates

Although funding for the closure was ultimately not included in the FY20122012 budget, a Task Force on Developmental Center closings has since been formed by the Governor.

■Budget Initiatives: Two major campaigns were undertaken. *Don't Cut Our Lifeline* originated at the national level and sought to stave off proposed cuts to Medicaid. Action Alerts were targeted for the Governor and Commissioner of Human Services; and The Arc of New Jersey, along with family members and local chapter representatives, met with *all but two* of New Jersey's federal legislators. *Restore Our Safety Net* was the message to the Governor prior to his FY20122013 budget address, requesting that appropriate funding for community-based supports and services be included. Action Alerts were distributed to the Families and Friends Networks, and testimony at budget hearings was coordinated.

SELF ADVOCACY

■Anti-Bullying Campaign: Closely related to the End the R-word campaign, the Anti-Bullying Campaign speaks a similar message, advocating for respect and an end to verbal, emotional and physical bullying. Self Advocates provided testimony and supported New Jersey's Anti-Bullying Bill of Rights. The bill, considered the toughest in the nation, passed and was signed into law in January, 2011, but was ruled unconstitutional by the Council on Local Mandates as an "unfunded mandate". It has since been revised to include \$1 million in state funding, which essentially keeps the legislation in tact. Self Advocates continue to present the End the R-word and Anti-Bullying message to K-12 and post-secondary education audiences.

■Governmental Affairs Ambassador Program, a program for Self Advocates modeled after the Family Advocacy Ambassador Program, is in its beginning stages. Self Advocates can apply to become an Ambassador, to learn more about how the State government operates and how they can get involved to affect systems change by engaging with their legislators on issues that affect people with disabilities.

■Annual Events: The 6th Annual Spring Into Action Luncheon was held in April, 2011 with over 300 attendees, and the 28th Annual Self Advocacy Conference, Equality for All, welcomed over 400 attendees.

■Outreach: The New Jersey Statewide Self Advocacy Network Advisory Board President serves on The Arc of the U.S. Board of Directors and is a Co-convener of the National Council on Self Advocacy. Locally, five new groups have been formed; staff attended over 135 self advocacy meetings, averaging 13 meetings per month and serving approximately 440 self advocates monthly.

EDUCATION ADVOCACY

■One-to-One 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. Equally as important, this type of personalized education advocacy enables us to engage young families, and has resulted in more than 75 new memberships.

■Outreach/Education: Developed by the Education Advocacy Program, *Building Blocks of a Good IEP* is a comprehensive parent training workshop that was presented to parent groups in 4 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: 1980 | IEP meetings attended: 200

School programs observed: 60 | Parent workshops and Ask the Advocate sessions: 11

■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

- ■The Citizen Advocacy Program (CAP) is different from other programs because it actually walks people through the social service system. CAP staff spend hours with consumers working to resolve issues, and routinely assist them in attending medical appointments, completing medical forms, appearing in court, initiating agency appeals, applying for government benefits, and organizing a budget. Despite having just celebrated its 40th anniversary in 2011, The Arc of New Jersey was sadly informed by DDD that the program will close in June due to state funding cuts. We are so proud of CAP's highly respected track record of providing a broad range of intensive case advocacy services to consumers, and of establishing numerous volunteer advocate/consumer matches, as well as CAP's development of other programs that were later transitioned to local agencies (for example, CAP served as an alternative for the new pre-trial intervention program for offenders with developmental disabilities, working closely with judges and public defenders to develop a community rehabilitation plan for consumers; and CAP developed a recreational program that was taken over by the Gloucester County Parks and Recreation Department).
- ■CAP provided **4320 units of information, referral and support services** this year, served **105 consumers**, and maintains **30 volunteer advocate/consumer matches**, consistently receives glowing feedback, like the excerpts below from a social service professional and a consumer:

"There are so many clients that would have fallen through the cracks if Citizen Advocacy was not there to help...We can honestly say that [CAP's] intervention has made a noticeable difference in our clients. Clients that felt helpless and lost now feel a sense of security and stability in their lives due to [CAP's] support and caring efforts."

"You have helped me not to be taken advantage of...Thank you for your help, we couldn't do without your help."

HEALTH CARE ADVOCACY

- ■Medicaid Managed Care: In 2011, New Jersey Medicaid beneficiaries, including the dual eligibles (those who receive both Medicaid and Medicare) were required to enroll in a Medicaid HMO. Families and agency staff reported massive confusion about these Medicaid HMO changes, and our Mainstreaming Medical Care (MMC) program was deluged with nearly 850 requests from families and agency staff for assistance, including concerns about Medicaid managed care, Medicare, and the new Medicare Advantage (HMO) Special Needs Plans (SNPs). The MMC program developed an eform for families and staff to document the pertinent details of the problem.
- ■Behavioral Health: The New Jersey Department of Human Services (DHS) is planning to develop a new service delivery system for adults who receive Medicaid and need behavioral health services -- including individuals with intellectual disabilities who need these services. The Program Director was appointed to serve on the DHS Steering Committee for the development of an Administrative Services Organization (ASO)/Managed Behavioral Health Organization (MBHO), and she also participated on the Access workgroup, which provided recommendations to be incorporated into the Request for Proposals (RFP). The State will select one organization to provide the ASO/MBHO services.
- ■Outreach/Education: The MMC program welcomed more than 300 attendees to its 22nd Annual Conference on Medical Care for Persons with Developmental Disabilities, *Promoting Healthy Aging*, with two keynote speakers and 11 workshops. In addition, the program conducted 17 presentations, 3 conference calls, and a Webinar on the Medicaid managed care changes; and a Webinar on the Medicare Part D changes for the dual eligibles. The program also distributed 82 diabetes materials; 90 cancer prevention materials; 25 women's health materials; and 108 listserv emails covering a wide variety of topics.

CRIMINAL JUSTICE ADVOCACY

■Individual and Systems Advocacy: The Arc of New Jersey's Criminal Justice Advocacy Program (previously the 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 intellectual and developmental disabilities. 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 Personal Justice Plan. The Program opened **61 cases** this year, and has an active caseload of **90 clients**. Levels of service have been *at an all time high*, reaching **5,785** by the end of January 2012, including correspondence to counsel and court, information to families of defendants, training for law enforcement and the defense bar. **Technical assistance** is provided in cases where interaction with the legal system is less serious and can be resolved alternatively.

■Outreach/Education: In April 2011 the Program coordinated its annual Equal Justice Conference, Improving Outcomes for Juvenile Criminal Defendants with Intellectual and Developmental Disabilities. In addition, the Program provided trainings at the County Prosecutors Association Annual Conference and the Probation Association of New Jersey Conference, as well as a training on the criminal justice system for all Division of Developmental Disabilities regional offices.

EMPLOYMENT ADVOCACY

- ■Supported Employment: Project HIRE is in its 27th year of operation and continues to be the one of the largest and most reputable supported employment programs in New Jersey. Project HIRE is CARF accredited and in May, 2011 was re-accredited for a three-year term, receiving high marks from CARF surveyors for performance, administration, service delivery, and outcomes. Many adjustments have been made this past year to streamline operations while continuing to provide excellent service, including consolidation into three field offices; adjustments in staffing to meet changing needs of participants; and investment in new technology. There are 589 individuals receiving supported employment services, with more than 27,000 service hours having been logged this year.
- ■School-to-Work Transition: Now in its 20th year, Project HIRE's School-to-Work program supports students with disabilities with community-based assessments, life-skills training related to vocational needs, and job placement into paid work as part of the school day. Project HIRE staff regularly attend IEP meetings with students and parents and remain an important part of transition planning. There are 63 school service contracts so far this year, several of which included services during summer months (extended school year).
- ■Training and Consultation: Project HIRE's Director of Training and Consultation Services is a Job Coach trainer for Region 2 TACE Center (Technical Assistance and Continuing Education), and provides job coach certification training for provider agency staff throughout the state. In December, the Director facilitated a first-ever workshop for job coaches on social media, *Using Social Media Technology to Help People with Disabilities Find Employment*, and is a presenter at this year's National APSE Conference, *Employment First: A Capitol Idea!*, being held in June in Washington D.C.

PREVENTION ADVOCACY

■Outreach/Education: The New Jersey Coalition for Prevention of Developmental Disabilities launched its redesigned e-Newsletter, *Prevention Counts*. The new format has increased sharability of the prevention message and, as a result, more than **500 new network members** have been added to the Coalition listserv, with **6 bi-monthly issues** distributed.

With a strong emphasis being placed on community partnerships, the Coalition has become a member of 15 new Coalitions/Committees/Task Forces and has attended 52 Coalition building meetings. In terms of community education the Coalition has exhibited in 23 health fairs; presented 8 Lead Free Kids for a Healthy Future seminars and 5 Am I a Safe Kid? workshops; and conducted 7 of its newly-developed FASD: When 'Just One' is Too Many trainings. Pregnant Pause continues to be a highly successful public event for the Coalition, with events held in all 21 counties, and over 3000 in attendance. In an effort to expand the reach of the Pregnant Pause message, organizers have also been able to collaborate with more than 35 agencies.

Internet-based social media is another venue being successfully tapped to spread the prevention message. The Coalition authored **42 posts** on its *Think Prevention* blog, **350 posts** on its Facebook page, and **480 tweets** on Twitter.

■Recall Monitoring: The Coalition monitors items recalled by the Consumer Product Safety Commission and the Food Safety Commission due to high levels of lead, fire hazard and fall hazards. Using this information 12 Recall Alerts were sent to our network members.

PUBLIC RELATIONS AND OTHER ADVOCACY EFFORTS

- ■Public Relations: Our Annual Awards Celebration and Dinner was held in November, 2011, with 14 awards presented. Two issues of Progress have been mailed to members, while our internet presence is steadily gaining momentum with an increase of interactive capability on our website; a newly-launched e-newsletter, e-News from The Arc of New Jersey; a total of 555 followers and more than 82,000 page views on Facebook; and 1130 followers on Twitter. In March 2012, we launched an extremely successful Developmental Disabilities Awareness Month campaign, Someone To Get To Know, including a Statehouse exhibit staffed by Self Advocates who greeted countless legislators and other visitors; and profiles of people with I/DD posted throughout the month on Facebook and Twitter.
- ■Other Advocacy Efforts: The Arc of New Jersey maintains involvement with the Statewide Interagancy Coordinating Council (SICC), which advises the Department of Health and Senior Services regarding the Early Intervention system, including holding a seat on the SICC; chairing the SICC Administrative Committee; acceptance of an invitation to represent provider agencies during the federal monitoring visit from the U.S. Department of Education; acceptance of an invitation to work on the RFP for the Central Management Office data system; analysis of the amended federal regulations; and review of the State's Part C application.

The Arc of New Jersey also sits on the **Steering Committee** of the **Direct Support Professional Workforce Development Task Force**, where issues have included use of the College of Direct Support (CDS) for mandatory preservice trainings; enrollment of all provider organization in the CDS; engagement of county colleges in ongoing training initiatives, and renewal of the CDS contract with the Department of Human Services. And finally, The Arc of New Jersey has management contracts to oversee the operations of **New Jersey Camp Jaycee**, and **The Arc of Hudson County.**

EXECUTIVE COMMITTEE OF THE BOARD OF DIRECTORS

Walter Bender Bruce Humphreys Robert Hage Pamela Corrigan Carmen Bannon III Bruce A. Bird President
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EXECUTIVE STAFF

Thomas Baffuto Celine Fortin

Executive Director
Associate Executive Director

Michael Prendergast Stella Natale Assistant Executive Director

Executive Secretary

PROGRAMS AND DEPARTMENTS

Citizen Advocacy Program: 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

Criminal Justice Advocacy Program: 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: Empowering New Jersey families of students with developmental disabilities in the special education process through information and advocacy. *Natasha Chase, Director*

Family Advocacy: 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, Public Policy and Family Advocacy

Mainstreaming Medical Care Program: 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: 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: 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: A CARF-accredited supported employment and school-to-wok 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. *Kirk Lew, Director*

Human Resources/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

Public Policy Advocacy: THE governmental affairs arm of The Arc of New Jersey, overseeing budget and legislative advocacy efforts.

Denbigh Shelton, Director, Public Policy and Family Advocacy Jacy Lance, Coordinator, Advocacy Services

Communications/Public Relations: Working to create a consistent and appropriate print, internet, media and community presence and reputation for the organization. *Diane Flynn, Coordinator, Communications*

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

AMERIGROUP HMO Advisory Committee

Anti-Poverty Network of NJ

Boggs Center Consumer Advisory Committee

Camden County Community Linkages

Coalition for Healthy Communities

Coalition on Health and Long-Term Care Reform for

People with Intellectual and Developmental Disabilities

Coalition on Special Education Funding Reform

Community Health Charities of NJ Board of Directors

Community Organizations Active in Disasters of

Burlington County

Crossings Disabilities and Addictions Task Force

DDD Dialogue with the Division

DDD Family Support Task Force

DDD Leadership Committee

DDD Olmstead Advisory Council

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

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

National Association of the Dually Diagnosed

National Association of Social Workers - NJ Chapter

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 Association of County Disability Services

NJ Association of Mental Health and Addiction Agencies,

Practice Group on Developmental Disabilities and Mental

Illness

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 DD Education Subcommittee

NJ Council on Special Transportation

NJ Dental Lifeline Network

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

NJ TASH

NJ Transit ADA Task Force

NJ Workability

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 Integrated Employment Coalition

United Healthcare Community Plan Advisory Committee

Volunteer Center of Burlington County Board of Directors



Achieve with us.

For people with intellectual and developmental disabilities

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