



**REPORT ON IMPLEMENTATION OF THE  
*STRATEGIC FRAMEWORK FOR THE FUTURE OF THE ARC, 2010 – 2019***

**YEAR THREE: JANUARY 1 – DECEMBER 31, 2012**

This report summarizes The Arc’s progress in 2012 in implementing the new *Strategic Framework for the Future of The Arc, 2010-2019*. The information is presented with reference to the relevant goals and strategies, although many of the activities are cross-cutting. Where no specific activities or accomplishments are listed that is not intended to suggest that there was no action taken in support of the particular strategy. Rather, in many cases that strategy was likely advanced through The Arc’s general communications and public relations activities, including information distributed through The Arc’s website, blogs, social media, as well as through educational programming at the annual convention, NCE summer leadership institute and other activities.

**Goal I: Infants, children and youth with I/DD have access to the supports and services they need to live in their family homes, to succeed in school and to partake in all of the experiences of childhood.**

- Met extensively with Members of Congress and/or their staff in leadership, in the Senate “Gang of Eight” and on Committees of jurisdiction over key entitlement and discretionary programs in the Senate (Finance; Budget; Health, Education, Labor and Pensions; Banking, Housing and Urban Affairs) and the House (Energy and Commerce; Ways and Means; Financial Services; Education and the Workforce) to advocate for adequate funding of critical programs. PubPol also met with White House officials on the need for a balanced approach to deficit reduction and protecting critical programs for people with I/DD.
- Successfully advocated for Medicaid, Supplemental Security Income (SSI), and Social Security disability programs to be held harmless in budget negotiations regarding the fiscal cliff.
- Successfully advocated to protect SSI for children, including presenting as part of a Brookings panel on the future of children with disabilities with panelists and audience of Capitol Hill and other key policy influencers.
- Advocated for adequate FY 2013 funding for both entitlement and discretionary programs.
- Arranged for attendance of 150 chapter leaders at Community Leader Briefing attended by President Barack Obama.
- The Arc’s budget advocacy is referenced throughout this document using the phrase Don’t Cut Our Lifeline (“DCOL Advocacy”); DCOL includes advocacy on Medicaid, Medicare, Social Security and SSI.

***Strategy 1: Increase the availability of early intervention services that are provided in naturally occurring environments.***

- DCOL Advocacy

***Strategy 2: Increase the inclusion, participation and integration of students with proper accommodations in their neighborhood schools, as well as in other public and publicly general educational settings***

- Advocated for restrictions on the use of restraints and seclusion in schools; regarding requirements for highly qualified teachers; for funding for the national Center for Special Education Research; and regarding computer adaptive testing.
- Dynamic Learning Maps - conducted focus groups with families on IEP testing alternatives.

***Strategy 3: Promote best practices in school-to-community transition.***

- Advocated for federal legislation supporting effective transitions for students from school to work.
- School-to-Community Transition (STC) Project.
  - Closed out year 3 of grant with Walmart Foundation.
  - Of the 55 funded projects, ten (10) emerging models were selected as particularly promising programs that demonstrate results that indicate success in producing positive transition outcomes for youth with I/DD. Staff began the process of analyzing data to isolate the key components of projects that appear to be correlated with successful transition outcomes for youth with I/DD. This information is being used to develop three models in the following areas: (1) Transition to Post-Secondary Education, (2) Transition to Employment, and (3) Maximizing Self-Determination in the IEP and Transition Planning Process
  - The Online Community Resource Database shared approximately 103 resources and information with people with I/DD, families, educators, employers, and other stakeholders to advance the field of transition. The OCRD (<http://resources.thearc.org>) is in blog format.
  - Submission of 47 articles by sub-grantees in The Arc's chapter e-newsletter Fusion highlighting participant's successes and sharing resources about the projects.
  - Successfully launched five (5) Peer Learning Community webinars in 2012.
    - "Transition for Youth with I/DD" PLC offered for chapters who were interested in developing transition programs within their chapters. 14 chapters registered with a total of 68 participants.
  - Presented information about the project at relevant conferences and events, including the National Transition Conference and The Arc National Convention.
  - Prepared and submitted end of grant report to Walmart Foundation and interim grant to May and Stanley Smith Charitable Trust.
  - Cultivate relationship and secured \$250,000 grant from AT&T Foundation to support replication at additional sites of model focused on transition to post-secondary education.
  - Distribution of \$510,000 in subgrants.
- The STC Project serves many other goals and strategies in the Strategic Framework and is referenced with the notation "STC Project" where applicable.

***Strategy 4: Eliminate the use of seclusion, aversive interventions and non-emergency restraint of children in schools.***

- Advocated for restrictions on the use of restraints and seclusion in schools.

***Strategy 5: Increase the involvement of students with I/DD in the IEP process, including in transition planning.***

- STC Project.

***Strategy 6: Increase the quality and accessibility of lay and professional advocates to support people with I/DD and their families, including the development of parent advocate and youth self-advocate groups.***

- Advocated for inclusion of families of children with disabilities, parents with disabilities, and respite in the annual application process and program instruction for the Community-based Child Abuse Prevention Program.

***Strategy 7: Reach out to and empower parents, siblings and other family members of infants, children and youth with I/DD and provide them access to the information they need, when they need it, across multiple media and modalities***

- DCOL Advocacy.
- Autism NOW - the National Autism Resource and Information Center
  - Website enhancements include an interactive map for locating national/state/local services and supports, discussion forums, YouTube videos, mobile version of site, and a website feedback to track customer satisfaction and ideas for improvement.
  - Successfully held 53 webinars with 3082 attendees.
  - 62,863 visits to the website
  - The Autism NOW Facebook received 8357 “new likes” during 2012 for a total of 9,362 up from 1005 in December of 2011.
  - Disseminated more than 20,000 brochures, posters, and marketing materials to collaborative partners, disability organizations, and individuals.
  - Attended and exhibited at Autism Society of America National Conference, Kennedy Krieger Autism Conference, The Arc of Maryland, West Virginia State Autism Society Conference, The National Down Syndrome Congress Conference, and The Arc of Illinois State Conference.
  - Autism NOW Center and the Autism NOW Call Center (powered by Autism Society of America up until October 2012) assisted and linked over 900 families and self-advocates to important resources such as: counseling services, family support funding, resources on financial assistance, therapeutic behavioral in-home-supports, mentoring programs, and health care access.
  - Autism NOW, in collaboration with The Arc, collaborative partners, and other national organizations reached over 350,000 individuals seeking resources and information.
  - Autism NOW viral reach during this reporting period is over 2,820,000 individuals who have engaged the Facebook page, posted one of our stories, or liking the page, posting on a wall, commenting on or sharing one of the page posts, answering a question posted, RSVP’ing to one of the events, mentioning the page, or photo tagging on our web page.
  - Center activities advance multiple goals and strategies are referenced below with the notation “Autism NOW” where applicable.
- Communications and public education to a broad audience are ongoing with The Arc’s website, blog, quarterly print newsletter, *Empower*, and quarterly e-newsletter, *The Arc’s e-Newsletter*.
- STC Project
- Secured \$100,000 in funding from Autism Speaks to pilot replication of Wings for Autism Program developed by Charles River Arc and began implementation.

- NM Down Syndrome Grant Program supported planning process and attendance of ten families/self-advocates at The Arc's national convention.
- Established trade agreement with Apostrophe Magazine – including exposure in every issue (which as of 2013 will be distributed nationally)

***Strategy 8: Actively involve, collaborate with and support other family support/service organizations.***

- Sibling Leadership Network – collaborated on joint programming and activities, including new National Sibling Leadership Council within The Arc.
- National Organization on Fetal Alcohol Syndrome – collaborated on SAFA project
- The Association for Successful Parenting – sponsorship of their annual conference, session at The Arc's National Convention, eLearning webinar
- American Bar Association Continuing Legal Education Program on FASD – sponsorship
- Parent to Parent USA – session at The Arc's National Convention and discussions of formal partnership
- Autism Now - sub-grants provided to Autism Society of America, Autism Self Advocacy Network, and Self Advocates Becoming Empowered
- HealthMeet® - subcontracts to national dissemination partners: National Down Syndrome Congress, and the American Association on Intellectual and Developmental Disabilities
- Wings for Autism – collaboration to include local Autism Speaks chapters

**Goal II: Adults with I/DD have the opportunity to lead lives of their own choosing, free from poverty, to be employed, to reside in the community, and to live independently with ready access to whatever services and supports they need.**

- DCOL Advocacy
- Provided ongoing support for state chapters involved in advocacy on dual eligibles and managed care, including regular emails, periodic conference calls and half-day session on managed care at state executive directors meeting.

***Strategy 1: Increase opportunities for integrated employment at fair wages, and self-employment, for people with IDD.***

- Advocated extensively for preserving the Work Incentives Planning Assistance (WIPA) and Protection and Advocacy for Beneficiaries of Social Security (PABSS) programs.
- Collaborate with and support Governor Jack Markell of Delaware, Chairman of the National Governor's Association, in his Chairman's Initiative on Employment of People with Disabilities, including outreach and information gathering with chapters.
- eXplore eRecycling Project
  - Secured \$465,000 grant from Walmart Foundation
  - Recruited and convened an Expert Advisory Council, and successfully conducted an RFP process, including 33 letters of inquiry and 21 full applications, resulting in 10 chapters being awarded grants totaling \$275,000 to develop new or to strengthen existing e-recycling programs
  - Successfully launched Peer Learning Community and Peer Learning Community Course Series.
  - Launched Sub-Grantee website for peer-to-peer networking.
  - Planned and Implemented October Thought Leadership Summit for Sub-Grantees Chapters and Expert Advisory Committee.
  - Presented eXplore eRecycling Project at National Board of Directors Meeting.
  - Implemented Concurrent Session on eXplore eRecycling at The Arc's National Convention. eXplore eRecycling article published in The Arc's *Empower*.
  - The eXplore eRecycling Project serves many other goals and strategies in the Strategic Framework and is referenced with the notation "eXplore Project" where applicable.
- Initiated dialogue with U.S. Office of Personnel Management, and convened ad hoc work group of chapter leaders, on increasing employment of people with I/DD in Federal government. (hereinafter "Federal Employment Initiative")

***Strategy 2: Increase services and supports necessary for people with IDD to be gainfully employed or self-employed.***

- eXplore Project
- STC Project

***Strategy 3: Build the capacity and readiness of employers to recruit, hire and retain individuals with I/DD as employees.***

- Successfully advocated in support of extending the Work Opportunity Tax Credit (WOTC), which was accomplished (1-year extension) as part of the end-of-year "fiscal cliff" legislation.

- Attended U.S. Business Leadership Network, an association of employers committed to expanding competitive employment for people with I/DD. Began follow-up cultivation of relationships with multiple companies.
- eXplore Project
- STC Project

***Strategy 4: Identify and promote best practices in services and supports for people with IDD relating to housing, employment, recreation and other aspects of community participation.***

- STC Project
- eXplore Project
- Autism NOW Project
- HealthMeet® Project – see additional information under Goal 5, Strategy 2, below.
- Justice and Disability Project - Research and planning for new project to provide education and training (possibly offering an accreditation program) to chapters who will provide training to criminal justice-related personnel in community settings.
- Ad Hoc Work Group on Planned Communities and Other Residential Alternatives continues to explore housing options and trends for people with I/DD.

***Strategy 5: Increase the availability of affordable and accessible rental housing and home-ownership, including supported housing.***

- Advocated in support of adequate FY 2013 funding for the Section 811 Supportive Housing for Persons with Disabilities program and for Department of Housing and Urban Development (HUD) programs overall.
- Advocated for implementation of the Frank Melville Supportive Housing Investment Act.
- Advocated for reforms to the Section 8 Housing Choice Voucher program and successfully advocated for amendments to benefit people with disabilities.
- Worked extensively with the office of Management and Budget on funding issues and with Department of Housing and Urban Development officials regarding supportive housing and fair housing issues and submitted comments on numerous issues.

***Strategy 6: Increase the availability of personal supports.***

- Advocated for preserving the CLASS Program; monitored House efforts regarding repeal; (quietly) supported the establishment of a long term services and supports commission as an alternative to repeal; and supported Hill staff on policy arguments.
- Worked with other advocates to develop set of principles to guide CMS and states in move to Medicaid managed care and shared with Hill staff.
- Supported legislation which would have created a home and community-based waiver option to psychiatric residential treatment centers for youth and changed language in the Social Security Act from “mental retardation” to “intellectual disability.”
- Advocated for expansion to all developmental disabilities in the military health care program’s coverage of behavioral health therapies for dependents with autism spectrum disorders.

***Strategy 7: Encourage, assist and support chapters of The Arc to transition from group homes to providing supported living, as well as to assist people with I/DD to live in their own homes in the community with the appropriate supports.***

- Produced NCE Summer Leadership Institute plenary session, “Supporting People to Lead Lives They Choose: moving from Programs to Support” presented by Lynne Seagle board member of The Arc of VA and Ex. Dir of Hope House.

***Strategy 8: Encourage, assist and support chapters to transition from segregated day programs and employment to providing support for integrated, community based employment and activities***

- Produced NCE Summer Leadership Institute plenary session, “Supporting People to Lead Lives They Choose: moving from Programs to Support,” and Leadership Forum “State Trends in Self Directed Services and Employment.”

***Strategy 9: Support chapters of The Arc to facilitate the community change process necessary to replace the remaining state institutions with community based services and supports.***

- Presented the 2012 Advocacy Matters Award to The Arc of Virginia for their role in securing and upholding the DOJ settlement which will result in institutional closures in that state.

***Strategy 10: Promote and support the growth of self-determination and self-advocacy.***

- Established and facilitated planning of new National Council of Self-Advocates (NCSA) with the vision of creating a constituency of leaders that represent the full spectrum of ages and abilities across our national chapter network.
  - NCSA members presented on self-advocacy at NCE Summer Leadership, National Convention, Reinventing Quality, and eLearning series.
- Self Advocates with an FASD in Action (SAFA) Project grew with an additional 11 members for a total of 21.
  - Held second annual Self-Advocacy track at the Building FASD State Systems conference.
  - Created dedicated website pages on The Arc’s website.
  - Secured funding through SAMSHA to hold an additional face to face training focused on developing personal self-advocacy skills and defining safe boundaries between members.
- Easter Seals Transportation Project - Conducted 13 interviews to create and support meaningful self-advocacy involvement in the development and implementation of coordinated transportation systems (on-going).
- Autism NOW – support ASAN and SABE with sub-grants
- [www.selfadvocacyonline.org](http://www.selfadvocacyonline.org) – The Arc and The University of Minnesota – Institute on Community Integration, Research and Training Center on Community Living (RTC) entered into a Memorandum of Understanding to collaborate on content and marketing a web-based interactive portal known as Self-Advocacy Online ([www.selfadvocacyonline.org](http://www.selfadvocacyonline.org)) that offers training on issues, a directory of self-advocacy groups in the US, research translation specifically for persons with I/DD and a story wall of video interviews with self-advocates. During the National Convention and International Forum 24 video interviews were conducted to be used on the website and in other ways to be determined.
- Completed integration of the Medicaid Reference Desk into The Arc’s website.
- HealthMeet® - working with University of Minnesota’s Research and Training Center on Community Living to create two health related modules for their Self Advocacy Online website.

***Strategy 11: Rebalance the Medicaid program so that home and community based services, and family support are mandatory and readily available with consistency and portability from state to state.***

- DCOL Advocacy
- Opposed efforts to remove the maintenance of effort on eligibility for Medicaid contained in the Affordable Care Act; opposed block grants, per person spending caps, and other threats to the program; and joined with coalition partners to send letters to the Hill supporting Medicaid.

- Submitted comments on proposed regulations on the definition “home and community” for waiver and other non-institutional services.
- Met with key Senate staff regarding concerns about mandatory managed care for people who are dually eligible for Medicaid and Medicare.
- Advocated regarding concerns about the treatment of habilitation in the NPRM on essential health benefits in the ACA.
- Submitted comments on numerous regulations to implement the Affordable Care Act.

***Strategy 12: Improve basic income support systems for people with I/DD and their families, and change requirements applicable to benefits eligibility, to reduce the incidence of poverty.***

- Recruited additional sponsors for the ABLE Act and worked with staff to address details regarding the legislation to create tax-exempt savings accounts for families of people with I/DD. Former board member, Joyce Lipman, appeared at spoke on behalf of The Arc at press conference in support of the legislation.
- Advocated unsuccessfully against repeal of the Community Living Assistance Services and Supports (CLASS), which as part of the Affordable Care Act established a voluntary system of private insurance for long term home and community based services. The Act was repealed as part of ATRA 2012.
- Advocated for passage of the Achieving a Better life Experience (ABLE) Act; worked with sponsors regarding strategy and refinements to the language; and supported The Arc grassroots and chapters to help achieve broad bipartisan co-sponsorship by over half of the 112<sup>th</sup> Congress.
- Worked extensively with Hill staff to prevent cuts to Social Security and keep reform separate from deficit reduction; to oppose the chained CPI; and to preserve Social Security during deficit reduction negotiations.
- Supported several bills to strengthen Social Security’s long-term finances; met with key Hill staff to protect Supplemental Security Income (SSI) benefits for children and adults; sent letters/statements to the Hill on key topics including proposed House cuts to SSI and a Government Accountability Office report on the children’s SSI program; and testified at Congressional hearing on Disability Insurance reform. Submitted written testimonies for the record of hearings on: the future of the SSDI program; stay-at-work and return-to-work strategies; the Social Security appeals process; testified at Congressional hearing on the use of technology and SSI nonfinancial eligibility criteria; and presented at a Hill briefing.

**Goal III: People with I/DD have the opportunity to participate in civic activities, volunteerism and community service, religion, arts, culture and recreation alongside their peers without disabilities.**

***Strategy 1: Build the capacity and readiness of civic, cultural, religious, governmental, business and other community organizations to include and support the participation of people with I/DD in their programs and activities.***

***Strategy 2: Increase services and supports necessary for people with IDD to participate in civic, cultural, religious and other community organizations.***

- Developed Memorandum of Understanding with National Inclusion Project to promote awareness and use of Let's ALL Play program. Concurrent session offered at Convention. Full implementation of the activities will begin in 2013.
- Advocated extensively in support of the Convention on the Rights of Persons with Disabilities (CRPD).
- Advocated in opposition to several bills that would have put limits on individuals' rights to file ADA lawsuits, rolled back regulatory rights, and diminished the ability of DOJ to enforce the ADA.
- Advocated in opposition to a bill that would have created a separate rule for individuals residing in intermediate care facilities for individuals with I/DD allowing them to opt out of class action litigation.
- Supported a self-advocate to testify before the Senate HELP Committee on "Olmstead Enforcement Update: Using the ADA to Promote Community Integration."

***Strategy 3: Increase voting by people with I/DD and their participation in the political process.***

- We've Got the Power – developed and implemented non-partisan election year activities, including:
  - Dissemination through Fusion (6x), Empower (4x) and e-Newsletter (2x)
  - Website pages – main page received 2,444 visits
  - Distribution of training materials to all chapters
  - 3 webinars
  - Breakout session at Disability Policy Seminar (200 attendees)
  - Produced a comparison of the 2012 Democratic and Republican party platforms on disability-related issues.
- Co-sponsored National Forum on Disability Issues for 2012 Presidential candidates. (500 in person, and 2000 web attendees)
- Advocated for continued funding of the protection and advocacy for voter accessibility programs.

***Strategy 4: Increase the availability of family support, including respite services.***

**Goal IV: Individual members of the public value, respect and accept people with I/DD as equal members of society.**

***Strategy 1: Publicize the high rate, as well as specific incidents, of bigotry, discrimination, and victimization of people with IDD.***

- Conducted webinar on victimization of individuals with an FASD.
- Staff wrote a Blog post in response to Fortin v Connecticut where a woman with significant disabilities was sexually assaulted.

***Strategy 2: Develop and support chapters of The Arc in implementing testing programs to identify discriminatory practices in housing, employment and instances of unlawful failures to provide accommodation.***

***Strategy 3: Promote increased public awareness of people with I/DD, their needs issues and concerns.***

- Issued thirty (30) press releases
  - Average open rate – 15.18%
  - Interesting data to note:
    - 1/20/2012 - Change in Autism Definition – Sent to 295 with 11.73% open rate
    - 1/26/2012 – VA DOJ Settlement Statement – Sent to 73 with 16.44% open rate
    - 6/21/2012 – Danish Alcohol Study on consuming alcohol while pregnant – Sent to 129 with 16.28% open rate
    - 10/3/2012 – NCD Report on Parents with disabilities – Sent to 89 with 19.1% open rate
    - 10/16/2012 – Image and Inclusion Award – Sent to 95 with 16.84% open rate
- Developed and implemented The Arc Audi Racing Program, including crafting blog posts and e-newsletter stories to promote events. Also, worked closely with Marc Istook on his filming of the first race, and with Heidi Reinberg on her film backed by Audi.
- Arranged for Bob Hage (The Arc of New Jersey) to participate in lunch meeting with Vice President Biden regarding the impact of the nation going over the “fiscal cliff” and the resulting tax increase.
- Empower and E-News
  - Successfully put out 4 editions of Empower (129,000 – 161,000 circulation) and 6 editions of The Arc e-Newsletter (41,000 circulation)
  - Generated \$20,527 from the 4 editions this year, compared to \$ 12,930 in 2011.
- Produced 2011 Annual report.
- Produced two issues of National Policy Matters one on the implementation of the Affordable Care Act, and the second on Deficit Reduction.
- Produced special section in Time Magazine.
- White House Community Leaders Briefing - organized briefings and provided support for chapters in publicizing participation, including creating a sample press release, and generating local media coverage. More than 20 media outlets picked this up nationwide.
  - The White House used some of the stories we collected in their press release - <http://www.whitehouse.gov/the-press-office/2012/02/09/white-house-host-arc-part-community-leaders-briefing-series>
- Capitol Insider and Action Alert Data/Lifeline Campaign
  - We executed 23 national action alerts on a variety of topics, including elements of the Don't Cut Our Lifeline campaign.

- Collaboration with CDC on New Autism Data, including co-hosting a live Twitter chat for The Arc, experts from the CDC, and other organizations.
- Autism NOW's – developed new YouTube series; disseminated Autism Awareness Month kit; developed and coordinated during Autism Awareness month a social media campaign to help the public find resources and information on the Autism NOW website.
- HealthMeet Project

***Strategy 4: Monitor the media for negative portrayals and descriptions of people with I/DD in the media and promote more accurate, respectful and positive coverage***

- Monitored coverage relating to Newtown, CT shooting involving suspect with Asperger's and Monitored coverage of National Federation for the Blind boycott of Goodwill for their use of the subminimum wage, and prepared talking points for use as needed.
- Provided background for New York Times columnist Nicholas Kristof on social security disability programs.
- Developed and released an open letter to Dr. Phil in response to an episode concerning a mother's desire to euthanize her two adult children with disabilities.
  - <http://blog.thearc.org/2012/05/18/an-open-letter-to-the-dr-phil-show-people-with-disabilities-have-a-voice/>

***Strategy 5: Promote appropriate education and training of medical professionals, legal professionals, law enforcement officials, teachers, clergy, human resources professionals and others whose conduct impacts the lives and opportunities of people with I/DD.***

- Participated as amicus curiae (“friend of the court”) briefs in cases with issues of significance to The Arc. Most of the cases in 2012 were related to the various challenges to the constitutionality of the Affordable Care Act. The Arc participated in additional cases regarding a false confession (Louisiana) and a death penalty case (Georgia).
- Staff participated in a VERA Institute of Justice Roundtable on Sexual Abuse of Children with Disabilities related to a project on child victims with disabilities.
- Staff oversaw implementation of action plans developed at the National Center for Victims of Crime (NCVC) conference on Crime Victims with Disabilities. Held teams of criminal justice-related personnel accountable to providing education and training in their respective communities per their action plans.
- Staff reviewed National Association on Dual Diagnosis's (NADD) new law enforcement curriculum.
- Healthmeet trained 12 people on the HealthMatters curriculum, a health promotion education program for people with I/DD. Trainers can then replicate the program in their local areas.
- HealthMeet provides several training activities for medical professionals and medical students focused on working with people with ID/D.
- Wings for Autism Project – will provide education for airline, airport and transportation security officials to educate them on meeting the needs of children with autism and their families.
  - Initiated relationship with Airline Pilots Association

***Strategy 6: Educate people with I/DD, and their family members, about their rights and provide them the tools and supports to protect their rights where such are being unlawfully denied.***

- DCOL Advocacy
- Autism NOW - several webinars have focused on family and individual rights and how to be self-advocates.

- Ongoing preparation and dissemination of public policy publications (e.g Capitol Insider, National Policy Matters, Policy Alerts!) and website content.

***Strategy 7: Showcase the positive role and contributions of people with I/DD in society.***

- The Arc gave the 3<sup>rd</sup> Image and Inclusion Award at the 2012 National Convention.
- Launched new blog, [www.wearethearc.org](http://www.wearethearc.org).
- Ongoing preparation and dissemination of content via website, print and electronic newsletters, and social media.
- SAFA Project - website includes bios and photos of each member highlighting their accomplishments and advocacy effort in their communities.
- Self-Advocacy Online – website includes stories and photos of self-advocates
- The Arc & Sprout Disability Film Festival - 15 national film festival events held in 2012 with 5 additional events booked already for 2013; highly successful film festival held at Convention with nearly 300 paid attendees and overwhelmingly positive feedback

**Goal V: Quality health education, health promotion and health care are widely available and accessible, enabling individuals to avoid known environmental causes of I/DD and to prevent secondary health problems for people with I/DD.**

***Strategy 1: Educate the public to avoid environmental agents and behaviors known to cause of intellectual and developmental disabilities.***

- Met with the Office of Management and Budget (OMB) and the Director of the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDD) regarding the administration's efforts to consolidate disability programs within the Center and efforts of the Friends of NCBDD coalition.
- Participated in Safe Chemicals Coalition efforts in support of the Safe Chemicals Act.

***Strategy 2: Increase the availability and accessibility of quality routine and preventative medical, dental, vision and mental health care for people with I/DD.***

- Continued to advocate to prevent repeal of Affordable Care Act.
- HealthMeet - obtained award of new grant from CDC (\$1 million/year for 3 years) for project which will pilot health screening, health education and health professional education at multiple sites throughout the U.S. Screening planned in 5 states/6000 people.

***Strategy 3: Make public and private health insurance universally available to people with I/DD.***

- Met several times with key Administration staff on the importance of defining the essential health benefits required by the law and of the non-discrimination provisions of the ACA.
- Submitted comments to HHS on Notices of Proposed Rulemaking (NPRM) on:
  - Multi-state health insurance plans
  - Defining essential health benefits
  - Health insurance market reforms
  - Essential Health Benefits and Actuarial Value Working Group Comments on Data Collection
  - General Guidance from HHS on Federally-facilitated Exchanges
  - Eligibility in the Medicaid and health exchange programs (final rule with interim final language for comment)

**Strategy 4: Prevent discrimination against people with I/DD in the delivery of health care services**

- HealthMeet - training activities for medical professionals will help prevent discrimination against people with I/DD in the delivery of health care services.
- Affordable Care Act advocacy.

**Strategy 5: Build the capacity of medical professionals, and health care organizations, to provide health care services to people with I/DD, including by expanding relevant specialized training.**

- HealthMeet - in partnership with AUCD will develop new curricula for medical students and will expand the use of UIC's Health Advocacy training curriculum for health care professionals.
- Affordable Care Act advocacy.

**Goal VI: The Arc is a powerful advocate for people with I/DD, leading a vibrant, engaged and growing movement of people with I/DD, their family members, friends and colleagues, and the nonprofit organizations that serve them, committed to the full inclusion of people with I/DD in society.**

- Worked closely with the White House and The Arc's Chapters in developing the highly successful February 10 Community Leaders Briefing for The Arc. In addition to a strong list of high level federal officials who came to speak to the leadership of The Arc, we were also honored by a surprise visit and address by President Obama and his Chief of Staff Jack Lew.
- Worked closely with the White House to secure a place for Bob Hage, member of The Arc from NJ, to meet with Vice President Biden over lunch regarding the potential impact of a tax increase on the Adrian-Hage family, including his daughters with I/DD.
- CEO served on the President's Committee on People with Intellectual Disabilities.
- Staff served on the Board of Directors of CCD and as co-chairs of the following CCD Task Forces: Social Security, Long Term Services and Supports, Health, Housing, Fiscal Policy, Financial Security, and Developmental Disabilities. Staff also served as members of the CCD Task Forces on Autism, International, Emergency Management, Education, Employment and Training, Medicaid, Prevention, Rights, Technology and Telecommunications, Transportation, Child Abuse Prevention, and TANF.
- Staff also served on the Boards of Directors of: Advance CLASS, the Long Term Quality Alliance, NISH, and the National Academy of Social Insurance (and chaired NASI's Membership Committee).
- Staff represented disability community interests on the American Bar Association Commission on Law and Aging, the Social Security Advocates Group, the Strengthen Social Security Campaign, the SSI Children's Program Coalition, the Coalition for Housing and Community Development Funding, the Department of Housing and Urban Development Disability Task Force, the National Fair Housing Advocates' Group, the NISH National Nonprofit Agency (NNA) Public Policy Group, the Work Opportunity Tax Credit Coalition, the Friday Morning Collaborative (long term services and supports/disability and aging), the National Guardianship Network, the Medicaid Coalition, the Chronic Illness and Disability Health Care Reform Partnership, the Habilitation Coalition, the ITEM Coalition, the Waiver Task Force, APRAIS, the Coalition to Preserve Rehabilitation, the Coalition for Sensible Safeguards, the ad hoc Medicare Advocacy group, the Campaign for Better Care, the Friends of the National Center on Birth Defects and Developmental Disabilities, the Human Services Assembly, the steering committee of the Americans for Tax Fairness coalition and the advisory committee for the National Respite Network and Resource Center.
- Presented to or represented The Arc at the following advocacy-related national and international meetings:
  - Coleman Institute Conference on Cognitive Disability and Technology
  - Bethesda Lutheran Communities
  - Brookings Institute, Panel on Children with Disabilities
  - Inclusion Interamericana meeting, Mexico City
  - Inclusion Europe and Inclusion International, Brussels, Belgium, including presentation on inclusive employment
- Conducted chapter visits in 10 states.
- In 2012, The Arc's National Convention was attended by 979 people, including 141 from 43 foreign countries and 197 self-advocates. Gross surplus was \$120,968, up from \$53k in 2011.

***Strategy 1: Build the capacity of all chapters of The Arc to engage in both public policy advocacy and individual advocacy for people with I/DD***

- DCOL Advocacy
  - Capwiz alerts resulted in 630 advocates responding with 959 messages to Congress regarding important federal alerts. 282 advocates promoted those messages via social media.
  - Specific to Lifeline campaign messaging, 297 advocates responding with 484 messages to Congress regarding protection of Medicaid and other lifeline programs. 127 advocates promoted those messages via social media.
  - DCOL highlighted via Empower, Fusion & e-News in 2012.
- Held one-day community organizer training prior to annual Disability Policy Seminar for 17 chapter advocates from 5 states.
- Exhibited at annual NCSL State Legislator Summit, promoting DCOL message to 1000+ attendees; follow up letter restating DCOL messaging sent to all attendees; included contact information for state chapters where appropriate.
- Hosted two webinars on Medicaid for advocates.
- NCE Summer Leadership Institute sessions on Growing Grassroots Activities through chapters. Approximately 50 people in attendance.
- Continued to conduct semi-monthly briefings for chapter leaders via telephone conference call and to regularly disseminated public policy information via weekly distribution of Capitol Insider.
- Disability Policy Seminar - achieved 2% growth in attendance; 628 paid attendees, including 250 first time attendees and 64 self-advocates. Gross surplus divisible among the six co-sponsors was \$54,434, down from \$62,600 in 2011.
- Continued to convene state chapter advocacy staff for periodic telephone conference calls, regular email communications and a face-to-face meeting at the National Convention.
- Recognized advocacy efforts of individuals or chapters with Advocacy Matters! Award. 2012 Award given to The Arc of VA for their exemplary grass roots advocacy efforts to successfully close institutions in their state and advocate for community living options for people with I/DD
- Began an exhaustive refresh of our Public Policy section on the website (to launch 2013)
- In addition to regularly disseminating Capitol Insider, issued 23 Action Alerts on a broad range of topics.

***Strategy 2: Assure and sustain a state office or chapter in every state or a combination of state and regional offices that provide a presence in all 50 states.***

- New state chapter affiliated in Montana, with \$12,500 in new revenue.
- Continued operations of state office in Nevada with continuing grant from NV DD Council
- Continued efforts to develop new state chapters and state offices, including:
  - Applied for grant with VT DD Council that would have mirrored NV structure; we were not awarded the grant
  - Proposed state office structure and management to The Arc of AZ; pending.
  - Proposed state office structure and management to The Arc of MO; chapter board decided to decline offer.

***Strategy 3: Dramatically expand the number of members and activists, including obtaining greater participation of families of younger children and people from diverse ethnic and cultural backgrounds***

- Finalized development of new Bylaws and Standard Terms and Conditions for Affiliation, which were adopted at the 2012 Business Meeting.
- Launched an unsuccessful direct mail campaign to drive new individual membership (especially younger more ethnically diverse members)
- Researched and purchased new stock images to address diversity gap in promotional materials

***Strategy 4: Promote and support the development of people with I/DD as leaders, advocates and spokespersons on issues of their concern.***

- See results listed under Goal 2, Strategy 10, above.
- Autism NOW - co-director has taped a series of YouTube videos that include her personal experiences as an individual on the autism spectrum
- National Council of Self-Advocates of The Arc
  - Barbara Coppens represented NCSA as a panelist on self-advocacy groups at the Reinventing Quality Conference.
  - NCSA co-sponsored (with Inclusion International's self-advocacy movement) a full day pre-conference at the National Convention and International Forum. 125+ attendees at the preconference shared their passion regarding the rights and responsibilities as an advocate.
- SAFA Project - Successfully completed a 18 month contract with SAMSHA to establish the SAFA Network – Self-Advocates with an FASD (Fetal Alcohol Spectrum Disorder) in Action. Some SAFA members are already members of their local chapters, or employed by the chapter. Others provide training on FASD to community agencies, including chapters of The Arc.
- National Convention - 20+ self-advocates in key roles as session presenters, plenary keynotes, panelists, and speakers.

***Strategy 5: Actively collaborate with and support self-advocacy organizations and involve them in all aspects of the work of The Arc.***

- See results listed under Goal 2, Strategy 10, above.
- See results listed under Goal 6, Strategy 4, above.

***Strategy 6: Develop a network of well-trained, empowered and informed self-advocates.***

- See results listed under Goal 2, Strategy 10, above.
- See results listed under Goal 6, Strategies 4 & 5 above.
- ACTIVATE Here! – Provided small grant to sponsor a video series with Alice Elliott, Film Director (The Collector of Bedford Street and Body & Soul: Diana & Kathy) for self-advocates to learn and “activate” their advocacy skills. Production will happen in 2013.
- SAFA Project - provided effective training for its 21 network members, and three SAFA members have formed their own local SAFA groups to continue reaching out to others with FASD in their own communities.

***Strategy 7: Build the capacity of board and staff leaders of state and local chapters, as well as individual members and volunteers, to engage in advocacy.***

- See results listed under Goal 6, Strategy 1 in this section, above.
- DCOL Advocacy
- Continued to provide support and provide information to state chapter CEOs involved in state efforts to integrate and coordinate care for individuals who are dually eligible for Medicare and Medicaid (“duals”) and Medicaid Section 1115 Waivers. Arranged meeting with staff from the Centers for Medicare and Medicaid Services (CMS) and state chapter CEOs concerning

integrated coordinated care for individuals dually eligible for Medicare and Medicaid.  
Presented at NCE on Medicaid managed care.

- Developed individual webpages for 25 priority disability-related discretionary programs which include results of survey of state and local chapters that have received funding from each program.
- Provided state chapters with a technical assistance document on designing the essential health benefit packages for rehabilitative and habilitative services and devices.
- Provided state chapters with background material to use in reacting to the Supreme Court decision on the constitutionality of the Affordable Care Act.
- Developed a National Policy Matters describing why the Affordable Care Act is important to people with disabilities.

***Strategy 8: Collaborate with culturally focused groups to increase awareness of The Arc in communities of color, as well as the accessibility of advocacy, supports and services for people with I/DD.***

***Strategy 9: Develop benchmarks and compile state-specific rankings of the accessibility and quality of supports and services for people with I/DD and their families.***

***Strategy 10: Empower people with I/DD and their families to tell their stories***

- White House Community Leader Briefing.
- Bob Hage, lunch meeting with Vice President Joe Biden.
- Self-Advocacy Online Project
- Developed and administered a questionnaire for parents, self-advocates, and family members about Medicaid, Social Security, and SSI. Over 400 people have provided information for The Arc to use in support of the Medicaid, SSI and Social Security programs.
- Actively seeking appropriate/relevant personal stories of self-advocates to be placed in The Arc's fact sheets (both current and new).

***Strategy 11: Position The Arc as the leading resource for the media and the general public about intellectual and developmental disabilities.***

- Provided interviews with radio, TV, cable and print journalists, generating coverage including: MSNBC, [www.disabilityscoop.com](http://www.disabilityscoop.com)
- Produced and disseminated toolkits:
  - Disability Awareness Month Chapter Toolkit
  - DCOL Toolkit
  - Autism Awareness Month Toolkit
- Responded to approximately 1000 inquiries via [info@thearc.org](mailto:info@thearc.org), plus 750-1000 inquiries received via telephone or thru other staff.
- See additional results under Goal IV, Strategy 3.
- Autism NOW Project
- School to Community Transition Project
- Updated the Think Before you Drink brochure and posted.
- The Arc's Self-Determination Scale re-posted.
- Placed a letter to the editor in Marty's name in the New York Times in response to an op-ed about the SSI program.
- Placed a letter to the editor in Marty's name in the Washington Post about the fiscal cliff and the chained CPI threat to Social Security in the negotiations.



**Goal VII: The Arc is a catalyst advancing best practices among all community-based service providers and the preeminent provider of inclusive services and supports for people with I/DD and their families.**

***Strategy 1: Establish a knowledgebase of best practices in supports and services for people with I/DD, as well as of the specific programs, services and supports offered by chapters of The Arc.***

- Continued to disseminate results of Chapter Profile Census Survey to chapter network via electronic communications, board presentation, and webinar for chapter leaders.
- Autism NOW Project
- School to Community Transition Project
- eXplore eRecycling Project
- HealthMeet

***Strategy 2: Conduct or commission research to assess the quality of outcomes attained by people with I/DD served by chapters of The Arc in comparison to other community-based service providers.***

***Strategy 3: Set clear direct service standards for what are best practices in services and supports for people with IDD and their families and a system of education, training and support to promote organizational improvement consistent with the standards.***

***Strategy 4: Provide ongoing professional development and education for program staff of chapters of The Arc, promoting best practices in programs, services and supports for people with I/DD.***

- National Convention
- NCE Summer Leadership Institute – 15 sessions
- NCE Pre-Conference – Achieving through Leadership, with Kathy Davis
- e-Learning Series - offered a yearlong webinar based series. Nearly 500 attendees participated in webinars in 2012. 83 completed evaluations. 78% of those responding indicated that the information presented was helpful in their day to day work/operations of their chapter. 14.5 said that while they may not use the info themselves, they would pass on to those that could. Presenters included national staff, chapter staff, self-advocates, The Arc Board members and professionals in the field.
- Peer Learning Communities - *During 2012 there were 3 PLC's*
  - *eXplore eRecycling Peer Learning Community (10 participating chapters)*
  - *Transition for Youth with I/DD Peer Learning Community (14 chapters, 68 participants)*
  - *Planning for Sibling Programs and Supports for Chapters (registration began in 2012 and launched mid-January 2013)*

***Strategy 5: Develop and implement mechanisms for promoting continuous quality improvement in the supports and services provided by chapters of the Arc.***

***Strategy 6: Develop and implement processes to effectively address complaints from the public about programs, supports and services provided by chapters of The Arc, or other evidence of conduct that is incompatible with the best interest of people with I/DD and their families.***

- Received and reviewed 17 complaints about chapters received in 2012 (compared to 25 in 2011). No disaffiliations resulted from complaints.

**Goal VIII: The Arc is a household name, well known and respected as an effective, responsive, well managed and responsibly governed, and sustainable nonprofit federation.**

- Launched group purchasing website for chapter use in procuring goods, [www.purchasingpoint.org](http://www.purchasingpoint.org)
- Secured \$103,000 in annual savings through competitive procurement of health insurance benefits for staff.

***Strategy 1: Rebrand The Arc to establish its position as the leading advocacy and service nonprofit for people with I/DD in the United States, including supporting chapters in implementing the new brand identity.***

- Continued to support chapters to adopt and implement new brand. As of 12/31/12, 371 or 53% of chapters have signed on to use the new brand identity, including 37 of 41 state chapters and at least one chapter in 47 of the 50 states and territories where The Arc has a presence.
- Revamped DesignOnline service for chapters.
- Provided chapters additional branding resources.
- See Goal IV, Strategy 3.
- Time Magazine special section
- Finalized Chapter Trademark Licensing Agreement with NYSARC to provide multiple options for local chapters.
- Compiled and provided chapter information necessary to:
  - Maintain listing in Forbes list of 200 Top Charities
  - Maintain listing in Chronicle of Philanthropy top 400 charities
  - Maintain status as BBB Accredited Charity
  - Obtain recognition with [www.myphilanthropedia.org](http://www.myphilanthropedia.org) as one of the most effective disability nonprofits

***Strategy 2: Reaffirm The Arc's relevance and role on behalf of all people with intellectual and developmental disabilities, regardless of diagnoses, at all stages of life.***

- The branding initiative, described immediately above, supports this strategy.
- Autism NOW Project
- School to Community Transition Project
- See results under Goal IV, Strategy 3.

***Strategy 3: Develop a collaborative approach to fundraising, among national state and local, that maximizes philanthropic resources***

- Piloted member acquisition mailings; results largely unsuccessful.
- Obtained \$250,000 in support from AT&T Foundation to support \$150,000 in subgrants to chapters for school to community transition project.
- Obtained \$465,000 in support from Walmart Foundation to support \$260,000 in subgrants to chapters for eXplore eRecycling project.
- Obtained \$100,000 in support from Alcoa Foundation to support \$60,000 in subgrants to chapters for eXplore eRecycling project.
- Distributed \$510,000 to chapters participating in School to Community Transition Program; \$85,000 to The Arc New Mexico under The Arc Down Syndrome New Mexico grant program.
- Attained 25% increase in number of chapters participation in The Arc vehicle donation program, from 145 to 181 chapters, generating \$199,442 in donations.

- Implemented major donor parlor meetings in four cities leveraging relationships with local chapters in New York, San Francisco, Chicago & West Palm Beach FL
- Further work on a future planned giving program – including planning with Morgan Stanley/Smith Barney, and a well-received breakout at the 2012 NCE (and some parlor meeting attendees signaled interest in its development as a cooperative venture with chapters)

***Strategy 4: Strengthen and expand the depth and breadth of the network of local chapters, including: (i) Directly recruiting new local chapters in states where there is no state chapter, (ii) Support and coordinate with state chapters to recruit new local chapters, and (iii) promoting mergers and consolidation where necessary and appropriate to advance the mission of The Arc.***

- Obtained commitment from NYSARC to increase affiliate dues investment by \$44,000 in 2012.
- Successfully resolved affiliation dues issues with Mobile Arc.
- Developed new bylaws and standard terms and conditions for affiliation.
- 8 chapters affiliated or re-affiliated (\$26,800); 21 chapters were disaffiliated, merged with other chapters, or dissolved (\$44,150).

***Strategy 5: Establish a nimble, seamless, state of the art model for involving parents, family members and interested individuals as members of The Arc that is educational, mission driven, flexible, rewarding and high impact.***

- New Bylaws and Standard Terms and Conditions for Affiliation provide framework for new approach to membership development.
- Developed and began beta testing of an online portal for chapters to transmit membership information.
- Tested a combination email and direct mail acquisition program mailed to about 250,000 names purchased using two different creative strategies to grow national individual memberships. It was a complete flop and we did not pursue the full mailing to the 75,000 and saved further expense.

***Strategy 6: Recruit and involve businesses, professionals, consultants, government agencies, associated nonprofits and other organizations in The Arc.***

- Corporate and organizational membership revenue increased from \$17,850 in 2011 to \$27,650 in 2012
- Corporate and business contributions increased from \$76,416 in 2011 to \$86,558 in 2012.
- Corporate sponsorship revenue increased from \$64,250 in 2011 to \$98,432 in 2012.
- Exhibit and advertising revenue increased from \$23,831 in 2011 to \$32,515 in 2012.
- Established new government funding relationship with US HHS, CDC.

***Strategy 7: Develop dynamic partnerships with major corporations to promote inclusion, as well as to provide ongoing support for The Arc at all levels.***

- Ongoing cultivation of relationship with Walmart Foundation and Walmart corporate.
- Established new project funding relationships with Alcoa Foundation, Audi/Volkswagen and AT&T Foundation.
- Staff attended US Business Leadership Network and met representatives of major national corporations; began follow-up cultivation of relationships with those companies.
- Cultivating relationships with corporations, including: Walgreens, Rest Assured, Hasbro, CH2M Hill, Starbucks, Amerigroup.

**Strategy 8: Provide ongoing professional development and education for executive and program staff of chapters of The Arc, promoting best practices in programs, services and supports for people with I/DD.**

- See results under Goal 7, Strategy 4.

**Strategy 9: Develop the Board of Directors to be composed of a majority of parents, family members and people with disabilities themselves on the Board, while also including leaders from the business, philanthropic, media, academic and others capable of providing resources and expertise necessary for the success of The Arc at the national level.**

- New class of board members elected.

**Strategy 10: Increase use of technology, including social networking, in all aspects of the organization's work.**

- Autism NOW - used Facebook to increase awareness of the program, resulting in an over 200% increase of visits to the website in 2012.
- Created a HealthMeet® section on The Arc website.
- Established the first challenge match from a major donor to secure new support from online donors (\$2500 match secured \$6465 in online contributions)
- Increased Facebook audience by 2,085 through special end of year campaign to grow fans and increased overall engagement on social media channels and blog (2400 total actions – such as likes, shares and comments) for a CPM of only .83¢ Total impressions = 1.4 million with 3,500 clicks through to our blog, donate pages or other website pages from Facebook. Overall – we grew from end of year 2011 at 4997 to 8663 (a 57% increase in one year).
- Launched new chapter blog on Tumblr to help chapters connect and share with other chapters on their local marketing and event priorities (especially for those that are working to grow their overall social media presence)
- Completed a site refresh of our main website, emphasizing the organization's main goals (online actions): joining The Arc; Taking Action (Capital Insider sign up); Donating
- Compiled an exhaustive list of our chapters website URL's, and Facebook/Twitter pages
  - Added FB links to chapter pages in our directory
- Built website sections for two peer learning communities (eXplore eRecycling & Transition)
- Launched a new blog devoted to chapters
- Launched website for The Arc of Nevada
- Began an exhaustive refresh of our Public Policy section on the website (to launch 2013)
- Held our first interactive chat online using the social network Twitter
- Broadcast President Barack Obama addressing The Arc during a Community Leaders briefing live on the social network Twitter