



## The Arc of the United States Annual Report 2008

### **Mission**

The Arc of the United States advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with our network of members and affiliated chapters, we improve systems of supports and services, connect families, inspire communities, and influence public policy.





The Arc of the United States  
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info@thearc.org  
www.thearc.org

## Dear Friends:



Lynne A. Cleveland

In 2008, The Arc of the United States (The Arc) experienced an unprecedented wave of change—ushering in a new and exciting era for The Arc and underscoring the importance of ensuring a strong and robust organization.

In July, Peter V. Berns joined The Arc as the new executive director; he was selected after a nationwide search conducted by Transition Guides based in Silver Spring, MD. Peter previously served nearly 17 years as executive director of the Maryland Association of Nonprofit Organizations, a group he built from a start-up to a position of national prominence.

We are grateful to John Foley, who served as acting executive director from November 2007 through Peter's official start in the summer. John has been an integral part of The Arc family for over four decades and during that time he worked both at the regional and state level, including serving as executive director of The Arc of New Mexico. As acting executive director, John steered the organization through a smooth transition with his commitment, experience and wisdom.

2008 included many catalysts that spurred The Arc into the future:

**Economic Downturn**—spiraling federal and state budget deficits, rising unemployment and the banking crisis threatened the developmental disabilities service system and heightened the importance and raised the profile of our federal policy advocacy;

**Tropic Thunder**—through mobilizing for action around the issue of respect, The Arc created a sense of movement within our network;

**Grant Thornton**—our ongoing strategic planning process and change initiative are grounded in the research and recommendations provided by Grant Thornton, including a national stakeholder survey;

**Membership**—restructuring of chapter and member services as the Chapter Excellence group focused on delivering value to state and local chapters, including the *Standards for Excellence*<sup>®</sup> program; and

**Development**—explored and developed potential new revenue streams for The Arc, including foundations, corporations, government, and philanthropic.

2008 is significant for being a turning point when collective momentum took hold of The Arc in moving toward a future that fulfills the purpose, promise and vision for people with intellectual and developmental disabilities and their families.

Sincerely,

Lynne A. Cleveland  
President

Peter V. Berns  
Executive Director

Officially founded in 1950, today The Arc has more than 140,000 members affiliated through more than 730 state and local chapters across the nation. We continue to advance and enhance supports and services for people with intellectual and developmental disabilities, advocate for their human and civil rights, and alter perceptions about people with disabilities. In 2008, we accomplished many of these objectives, which serve to empower these individuals and their families.



## National Public Policy

The Arc's two greatest legislative achievements in 2008 took the form of restoring lost civil rights protections and preventing significant cuts to the Medicaid program. Listed below is the enacted disability-related legislation from 2008 in which The Arc played an instrumental role.

### Medicaid

In a huge victory for The Arc and other disability groups, six proposed Centers for Medicare and Medicaid Services regulations were put on hold or stopped altogether. These proposed rules would have significantly reduced Medicaid services to children and adults with developmental and other disabilities. More than \$7 billion worth of cuts over five years would have resulted from the following three key regulations: 1) the Rehabilitation Services Option Regulation that would have cut day habilitation such as communication and skills training; 2) the School-Based Administration and Transportation Services Regulation that would have prohibited Medicaid from covering school-based administration costs and services such as occupational, physical and speech/language therapy; and 3) the Case Management and Targeted Case Management Regulation that would have restricted coverage of transitional case management such as assistance for persons moving from institutional care to independent living.

### Civil Rights

The ADA Amendments Act is expected to restore the workplace protections of the Americans with Disabilities Act (ADA), which has been eroded by several court decisions. The law redefines "major life activities" in ways that make it easier for people with disabilities to qualify for employment protections under the ADA.

After a 13-year crusade, the Genetic Information Non-Discrimination Act (GINA) was signed into law. GINA will prevent employers from engaging in prejudicial practices



such as refusing to hire or paying lower wages based on genetic information. Similarly, this bill will also prohibit insurance companies from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information.

### Higher Education

The Higher Education Opportunity Act is the most significant federal effort to date that helps students with intellectual disabilities access and succeed in postsecondary education programs. It includes groundbreaking provisions regarding inclusion, enrichment, socialization, independent living, and person-centered planning in course selection. The law also bolsters teacher training in special education.

### Mental Health Parity

The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act mandates that commercial insurers set mental health insurance co-payments and treatment limits equal to those for coverage of physical conditions. It also bans cost-sharing requirements that only apply to mental health or substance abuse disorder benefits.

### Housing

The National Affordable Housing Trust Fund Act will develop 1.5 million new units of rental housing affordable to very low- and extremely low-income households. This law creates the first new federal housing production program specifically targeted to extremely low-income households since the Section 8 Housing Choice Voucher program of 1974.

### Family Support

The Diagnosed Conditions Awareness Act will increase the provision of scientifically sound information and support services for parents receiving a positive test diagnosis for Down syndrome or other prenatally and postnatally diagnosed conditions for their children.

### Transportation

The Over-the-Road Bus Transportation Accessibility Act provides the U.S. Department of Transportation with additional tools for ensuring accessibility of all buses and "curbside" operators, many of whom have a poor record of meeting ADA standards.

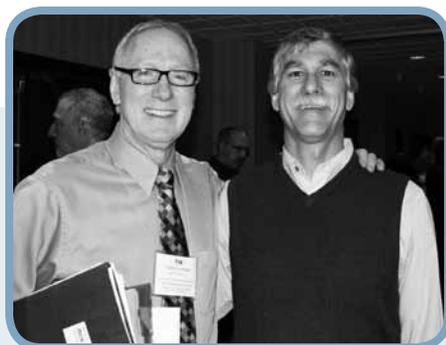
The Federal Railroad Safety Improvement Act requires Amtrak to report to Congress how they intend to meet the 2010 ADA deadline to have all their stations fully accessible. It also authorizes funds to help Amtrak finance the accessibility improvements.

### Obama Administration

Senior staff of The Arc met with several of the transition teams that were developing policy strategies and priorities for the incoming Obama Administration.

### Chafee Award

Senator Jeff Bingaman (D-NM) was the recipient of the John. H. Chafee Leadership in Public Policy Award. As a key member of the Senate Finance and Health, Education, Labor, and Pensions Committees, Senator Bingaman has championed several key laws providing vital benefits, services and supports for The Arc's constituents.



### Disability Policy Seminar

Nearly 600 disability advocates traveled to our nation's capital to participate in the annual Disability Policy Seminar co-hosted by The Arc and five partner organizations. More than 300 Senate and House offices were visited by the participants, educating policy makers and their staff about priority disability issues. During the Seminar, House Majority Leader Steny Hoyer (D-MD) received the Leadership in Disability Policy Award for his outstanding role in passing the ADA Amendments Act.



- Strengthen our affiliation model with an efficient, effective organizational structure that has democratic governance and administrative systems to support it.

## Chapter Excellence Highlights

An exciting year for chapters of The Arc, 2008 saw the national office working to restructure their support to better reflect the needs of chapters and help them serve their membership. Some of these highlights include:

- **Membership Processing Went Green.** In an effort to streamline and standardize the way memberships are processed and tracked, the national office rolled out a fully paperless system whereby chapters could submit all pertinent information electronically. As a result, the Chapter Excellence department is able to devote more time and energy to providing services and benefits to chapters;
- **Online Credentialing Launched.** In 2008, The Arc utilized an online credentialing module for chapters to register their delegates for our annual meeting. The new system has created a more efficient credentialing process;
- **State President & Executive Director Dialogue Opened.** This year, the national office reestablished monthly communications with state presidents and executive directors. These monthly calls are providing a venue for chapter leaders to share ideas, offer feedback and ask questions peer-to-peer. They also provide the executive director and president of The Arc of the United States with valuable insight into needs and activities at the state and local levels; and
- **Standards for Excellence® Offered.** In the fall of 2008, The Arc announced an important partnership with the *Standards for Excellence®* Institute. This contractual agreement allows The Arc to offer affiliated state and local chapters access to indispensable information and materials on governance and management for nonprofit organizations.

While these highlights are only a sampling of the changes underway for Chapter Excellence, they represent our ongoing efforts to revamp what and how support is provided to all of our chapters and members of The Arc at every level.

## Charting the Future of The Arc

For nearly 60 years, The Arc has been a tireless advocate and service provider for individuals with intellectual and developmental disabilities and their families. In 2008, The Arc's Board of Directors determined it was time to assess the organization's current status and develop a plan for the future—one that would build on our decades of experience to have an even greater impact in the disabilities community. We want to lead the way from sheltered workshops to competitive employment, microenterprise and small business; from congregate housing to supported housing, independent living and then homeownership; and from segregated classrooms to integrated schools, community colleges and beyond.

To this end, our Board of Directors established a Task Force on Affiliation and Growth that would guide the development of a strategic plan. The task force hired the internationally recognized management consulting firm, Grant Thornton, to conduct a thorough assessment of The Arc and provide recommendations for the future of the organization. The firm collected and analyzed results from thousands of surveys and dozens of in-depth interviews with leaders, volunteers and stakeholders before presenting their recommendations to the Board. Based on the results of their assessment, we are moving forward with a plan that will:

- **Transform The Arc image** with a compelling brand and message that influences public opinion and inspires families to join our network;
- **Develop a nimble, state-of-the-art family involvement model** that is easy to join, educational, mission-driven, flexible, and rewarding;
- **Ensure The Arc brand represents exceptional quality** by applying a rigorous, evidence-based approach to identifying programs, services and supports that produce the desired results and then upholding those practices and supporting broader implementation of them across our network;
- **Provide state and local chapters with the tools and supports needed to be more successful** in advocating on behalf of and serving people with intellectual and developmental disabilities and their families;
- **Define the role membership plays** in our organization and develop a clear, meaningful value proposition for members that will resonate with families;
- **Organize local chapters to be more influential** in gaining access to services, protecting civil rights and making organizations responsive to the needs of people with disabilities; and

## Tropic Thunder Mobilizes The Arc

In August 2008, DreamWorks and Paramount Studios were poised to release the comedy/action film, *Tropic Thunder*. Prior to the nationwide release of the movie, disability activists were made aware of the film's negative portrayal of a person with an intellectual disability.

The Arc joined with other national disability rights organizations in condemning the offensive and demeaning representation, urging people to stay away from the movie and instead join the organization's national "Rally for Respect" campaign. Hundreds of members, volunteers, self-advocates, family members, and chapter representatives from across the country

banded together to assail the offensive portrayal in the film. Utilizing a "Tropic Thunder Action Kit" and other resources on our website, chapters of The Arc were able to mobilize protest efforts.

The national outcry resulted in a meeting of disability rights advocates from numerous organizations and Hollywood executives, led by The Arc's executive director, Peter V. Berns. The Arc continues to have a meaningful dialogue with producers at DreamWorks and to build relationships with the entertainment industry in enforcing accurate depictions of people with intellectual and developmental disabilities.

## 57th National Convention



The 57th National Convention of The Arc of the United States was held in Albuquerque, New Mexico, from November 5-8, 2008. With a focus on "Telling Our Story—Weaving Our Future," each day of Convention was structured under three overarching themes—supporting families, creating real community and building dynamic chapters. Presentations and workshops were offered on a wide range of topics—self-advocacy, eligibility for Medicaid and Social Security, housing, and more.

Convention also provided an opportunity to look forward in a town hall meeting on "Defining a Vision for the Future of The Arc." Representatives from Grant Thornton, a highly regarded management consulting firm, presented an analysis of the state of the organization and Executive Director Peter V. Berns moderated a discussion about future goals and priorities among Board members, staff, individual members, volunteers, and supporters of state and local chapters.

The highlight of Convention, however, was award-winning veteran journalist Geraldo Rivera, who addressed a group of more than 650 self-advocates, family members, volunteers, and others in his plenary presentation, "Telling Our Story—From Shadow to Light." Rivera discussed his investigative exposés on the conditions at the Willowbrook institution, which led to the



facility's closing. Attendees shared with him the current crisis facing people with disabilities—waiting lists and access to services. Calling waiting lists "the new institutions," Rivera pledged to produce a nationally televised program focusing on these issues. "The Waiting List: America's Healthcare Crisis" aired nationwide on "Geraldo at Large" in December and featured The Arc's executive director, Peter V. Berns, and representatives from The Arc of New Jersey, The Arc of Northern Virginia and The Arc of Westchester, New York.





National Conference of Executives of The Arc

## National Conference of Executives of The Arc

The National Conference of Executives of The Arc (NCE) provides training for executives and professionals in the field, offering valuable guidance and support. NCE serves more than 250 members representing nearly 220 chapters of The Arc.

Their 2008 Summer Leadership Institute in New York focused on “Challenge, Change and Opportunity on the Horizon.” Thanks to the hard work of Barry Meyer and the planning committee, the conference was attended by more than 160 participants and covered a broad range of topics—from ways to identify, share and replicate best practices to strategies for recruiting new members, developing a board of directors, fundraising, and motivating staff. The conference opened with a reception hosted by The Arc of Westchester and, before it concluded, attendees had the opportunity to enjoy an inspiring presentation by the Enrichment Center Percussion Ensemble, one of the world’s few professional performing groups whose members have disabilities.

NCE also hosted a Topical Conference at The Arc’s National Convention in New Mexico. The conference, put together by Peggy Terhune and the Convention Planning Committee, was attended by more than 70 NCE executives. Participants left excited about implementing new strategies for effective leadership and advocacy at the state level, as well as motivated to participate in the Real Economic Impact Tour and the Money Follows the Person Rebalancing Demonstration.



## GELMAN, ROSENBERG & FREEDMAN CERTIFIED PUBLIC ACCOUNTANTS

### INDEPENDENT AUDITORS’ REPORT

To the Board of Directors  
The Arc of the United States  
Silver Spring, Maryland

We have audited the accompanying statement of financial position of The Arc of the United States (The Arc) as of December 31, 2008, and the related statements of activities and change in net assets, functional expenses and cash flows for the year then ended. These financial statements are the responsibility of The Arc’s management. Our responsibility is to express an opinion on these financial statements based on our audit. The prior year summarized comparative information has been derived from The Arc’s 2007 financial statements and, in our report dated July 16, 2008, we expressed an unqualified opinion on those statements.

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of The Arc as of December 31, 2008, and its change in net assets and its cash flows for the year then ended in conformity with accounting principles generally accepted in the United States of America.

*Gelman Rosenberg & Freedman*

July 18, 2009

## Statement of Financial Position as of December 31, 2008 and 2007

### Assets

<b>Current Assets</b>	<b>2008</b>	<b>2007</b>
Cash and cash equivalents*	\$671,861	\$386,808
Investments*	\$1,601,386	\$2,196,017
Accounts receivable and advances, net of allowance for doubtful accounts of \$175,580 and \$206,367 for 2008 and 2007, respectively*	\$146,169	\$117,511
Grants receivable	\$55,702	\$235,545
Inventory	\$3,618	\$14,268
Prepaid expenses	<u>\$48,928</u>	<u>\$57,369</u>
Total current assets	\$2,527,664	\$3,007,518
<b>Furniture and Equipment</b>		
Furniture and equipment	\$915,345	\$907,229
Less: accumulated depreciation	( <u>\$824,124</u> )	( <u>\$759,506</u> )
Net furniture and equipment	\$91,221	\$147,723
<b>Other Assets</b>		
Deposits	\$10,020	\$10,020
Investment held for beneficial interest in perpetual trust*	\$925,834	\$1,032,273
Total other assets	<u>\$935,854</u>	<u>\$1,042,293</u>
<b>Total Assets</b>	<b>\$3,554,739</b>	<b>\$4,197,534</b>
<b>Liabilities and Net Assets</b>		
<b>Current Liabilities</b>		
Account payable and accrued expenses	\$270,950	\$454,909
Grants payable	\$6,456	\$6,456
Accrued vacation	\$106,222	\$111,031
Due to related parties*	\$28,775	\$204,203
Deferred revenue	<u>\$71,900</u>	<u>\$1,400</u>
Total current liabilities	\$484,303	\$777,999
<b>Net Assets</b>		
Unrestricted net assets:		
Undesignated	\$35,407	\$47,451
Board designated*	<u>\$740,457</u>	<u>\$829,613</u>
Total unrestricted net assets	\$775,864	\$877,064
Temporarily restricted*	\$648,002	\$789,462
Permanently restricted*	<u>\$1,646,570</u>	<u>\$1,753,009</u>
Total net assets	<u>\$3,070,436</u>	<u>\$3,419,535</u>
<b>Total Liabilities and Net Assets</b>	<b>\$3,554,739</b>	<b>\$4,197,534</b>

\* Explanatory notes included in the full 2008 audited financial statement for The Arc of the United State are available at [www.thearc.org](http://www.thearc.org).

## Statement of Activities for Year Ended December 31, 2008 and 2007

<b>Revenue</b>	<b>2008</b>	<b>2007</b>
Contributions*	\$737,173	\$519,034
Grants from governmental agencies	\$133,725	\$454,725
Affiliation and chapter fees	\$2,056,192	\$1,927,542
Registration fees	\$366,946	\$319,761
Program service fees	\$334,489	\$300,742
Investment income*	\$59,089	\$122,549
Net gain (loss) in perpetual trust*	(\$324,456)	\$46,696
Sub-contract revenue	\$7,140	(\$23,019)
Advertising	\$18,300	\$22,760
Royalty income	\$95,844	\$73,697
Other (loss) income	(\$2,069)	\$19,135
Net assets released from donor restrictions*	<u>\$0</u>	<u>\$0</u>
<b>Total Revenue</b>	<b>\$3,482,373</b>	<b>\$3,783,622</b>
<b>Expenses</b>		
Program services:		
Chapter Excellence	\$1,083,638	\$359,189
Public Education	\$658,724	\$457,475
Public Policy	<u>\$992,144</u>	<u>\$2,341,980</u>
Total program services	\$2,734,506	\$3,158,644
Supporting services:		
Management and general	\$815,157	\$846,692
Fundraising	<u>\$281,809</u>	<u>\$446,476</u>
Total supporting services	<u>\$1,096,966</u>	<u>\$1,293,168</u>
<b>Total Expenses</b>	<b>\$3,831,472</b>	<b>\$4,451,812</b>
<b>Change in Net Assets</b>	<b>(\$349,099)</b>	<b>(\$668,190)</b>
<b>Net Assets at Beginning of Year</b>	<b>\$3,419,535</b>	<b>\$4,087,725</b>
<b>Net Assets at End of Year</b>	<b>\$3,070,436</b>	<b>\$3,419,535</b>



\* Explanatory notes included in the full 2008 audited financial statement for The Arc of the United States are available at [www.thearc.org](http://www.thearc.org).

## 2007-2008 OFFICERS AND DIRECTORS

October 12, 2007 to November 6, 2008

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Every donation, large or small, makes a difference in the intellectual and developmental disabilities community throughout the United States. Thank you for helping us make a difference.

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*We would also like to thank our donors who wish to remain anonymous. We are equally grateful for your support.*

*Note: Donors listed are for the period January 1, 2008, to December 31, 2008. Although we make every effort to ensure the accuracy of our annual report, from time to time we may overlook someone. If we have done so, please accept our sincere apologies and contact us as soon as possible. We regret any oversights.*

## Pro-Bono Spotlight



The Arc of the United States appreciates that, instead of monetary support, some organizations provide a contribution of services. We would like to add a heartfelt thank you to DLA Piper who, in 2008, provided more than 900 hours in pro-bono legal services—a contribution valued at \$418,413.98. Thanks to their generosity, we were able to review the status of waiting lists and access to services for people with intellectual and developmental disabilities in all 50 states and Washington D.C., as well as obtain legal counsel and advice on estates and trusts and intellectual property matters. We look forward to sharing the results from our comprehensive study in the months to come.

## Corporate Collaborations

The Arc of the United States develops relationships with other national organizations in order to offer our members and more than 730 local chapters the benefit of expert resources, support and fund-raising. In 2008, we were proud to work with and encourage your support of the following:

### Endorsed Vendors:

Main Mobility  
Met Desk\*  
Mutual of America\*

### Affinity Partners:

Hartford Insurance  
Liberty Mutual  
US Bank

### Service provided by

### The Arc of the United States:

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