



ANNUAL REPORT 2006

The Arc of the United States



2006 ANNUAL REPORT

The Arc of the United States

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
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910

(301) 565-3842
(301) 565-5342 Fax

info@thearc.org
www.thearc.org

The Arc: 2006



Mary V. Jordan



Sue Swenson

In 2006, The Arc of the United States made remarkable strides toward fulfilling our goal to ensure that people with intellectual and developmental disabilities enjoy equitable rights and full participation within their community. This is the birthright of every American. Hand in hand with our chapters, members and supporters, we strived to meet the needs of our constituency in providing necessary supports and effective services.

We addressed the challenges inherent in our mission on many fronts, and with the help of the foot soldiers in our movement – families, volunteers, self-advocates, professionals, supporters and others – we achieved things that years ago some may not have dreamed possible.

The Arc remains on the frontline in advocating for legislation key to providing all Americans disabilities with access to appropriate services and supports. Through the leadership of our Disability Policy Collaboration with UCP, we continue to advocate for and secured increases in federal funding and expanded the federal government's role in providing for people with intellectual and developmental disabilities and their families.

Families are the spokes in the wheels of our movement. When The Arc was founded over a half century ago, we pledged to provide families with the information and resources they needed to care for their family member. In 2006, we widened our participation in cutting edge research initiatives to enlarge our understanding of the current state of disabilities and identify the most pressing needs. We continued to provide information on a range of topics relevant to our constituency and maximized the Internet as an information tool through the Medicaid Reference Desk (TheDesk.info).

As a national leader in the disabilities movement, we redoubled our capacity building efforts in partnership with our state and local chapters to provide myriad services and supports to millions, including early intervention, access to free appropriate education, health services, group and independent living, employment opportunities, recreation and more.

We are proud of the accomplishments and achievements we have made over the course of this year. These significant benchmarks have served to embolden us and raise the bar even higher in the years to come.

Sincerely,

A handwritten signature in cursive script, reading "Mary V. Jordan".

Mary V. Jordan
President

A handwritten signature in cursive script, reading "Sue Swenson".

Sue Swenson
Executive Director

A Legacy of Connecting Families, Inspiring Communities, Influencing Public Policy

Since our founding over 55 years ago by families struggling to cope with what was then called mental retardation (now known as intellectual and developmental disabilities), we have worked to create a better life for these individuals and their families. Little was known about this condition or its causes, but now over a half century later, The Arc has improved the lives of millions, raised national consciousness and become an international voice within the disabilities movement.

The Arc today is comprised of over 140,000 members affiliated through more than 850 state and local chapters across the nation. Collectively, these chapters are dedicated to advancing and enhancing supports and services for all people with intellectual and developmental disabilities.

Through advocacy and action and by partnering with members and stakeholders, The Arc through its vast network of chapters continues to:

- Provide innovative and affordable housing and to identify new models;
- Support individuals with disabilities in employment and advocate for supportive employment programs;
- Advocate for inclusive, appropriate education with families as local education advocates;
- Ensure pay equity and fair wages for people with disabilities; ensure equitable and fair wages and job recognition for direct support staff;
- Advocate for state and federal governments to administer programs and to allocate appropriate budgets for supports and services for people with intellectual and developmental disabilities;
- Encourage self determination and an individual's right to define their own direction in life. People with intellectual and developmental disabilities deserve every opportunity afforded to others;
- Increase support for the estimated 75% of adults with intellectual or developmental disabilities who receive all or most of their supports with their families at home.

2006-2007 OFFICERS AND DIRECTORS

OFFICERS

Mary V. Jordan,
President
Johnson City, TN

Lynne Cleveland,
Vice-President
Houston, TX

William A. Catelli,
Secretary
Lincoln, RI

Michael Mack,
Treasurer
Silver Spring, MD

Leo Berggreen,
Immediate Past President
Baton Rouge, LA

DIRECTORS

Janet Albert-Herman
Mohnton, PA

Kim C. Brown
Mt. Pleasant, MI

Shirley Dove
Saugus, CA

William Dusold
Severna Park, MD

Chester Finn
New York, NY

Sam Givhan
Columbus, MS

Cindy Johnson
Woodbury, MN

K. Charlie Lakin
Minneapolis, MN

Elise McMillan
Nashville, TN

Mohan Mehra
Cortlandt Manor, NY

Barry Meyer
Baton Rouge, LA

Pat Napoliello
San Francisco, CA

Norma Reyes
La Mesa, NM

Peggy Terhune
Albemarle, NC

Nancy Webster
Western Springs, IL

DIRECTORS-AT-LARGE

Ronald Brown
Round Rock, TX

Joe Meadours
Sacramento, CA

Ann Turnbull
Lawrence, KS

KEY STAFF

Sue Swenson
Executive Director

Michael Coburn
Chief Operating Officer

Martha Hulse
Chief Financial Officer

Paul Marchand
Assistant Executive
Director – Public Policy

Laura Hart
Director of
Communications

The Arc: A Voice for Americans with Intellectual and Developmental Disabilities

Public Policy – The Arc is positioned as a leader in the disability advocacy field through its advocacy within the voluntary community and within the executive and legislative branches of government to provide Americans with disabilities access to appropriate and responsive services and supports. The Arc, in collaboration with others, works to safeguard critical legislation that provides services and supports to citizens with intellectual and developmental disabilities. The Arc addresses the significant, unmet needs of people with disabilities and their families by increasing existing federal funding and expanding the federal government's investment in people with disabilities to enable them to live and work as independently as possible in their communities with appropriate, flexible, long term individual and family supports.

Research – The Arc maintains a focus on the role of research to enhance the quality of life for individuals with intellectual and developmental disabilities. The Arc actively advocates for inclusion of individuals with intellectual and developmental disabilities in research. The Arc disseminates research results and information to help individuals and families stay abreast of research developments.

Information – The Arc is a leading resource for information to the public providing trusted information on a wide variety of topics. Individuals, families, policymakers, self-advocates, professionals and caregivers rely on information from The Arc. The ArcLink, a collaborating partner of The Arc, provides

information on the various sources of assistance available to individuals with disabilities and their families on a state-by-state basis. The Arc also provides topic-specific information through a number of outlets. For example, resources on Medicaid benefits are available through the internet-based Medicaid Reference Desk (TheDesk.info) and via published Medicaid fact sheets for every state. The Arc's website, (www.thearc.org) provides access to information, publications and referral to chapters of The Arc to millions of people who visit The Arc's website annually.

Capacity building – The Arc provides outreach and support to 41 state chapters, and it is through the collaborative partnership with the state chapters that more than 850 local chapters are providing services and supports to millions of Americans and their families. Service delivery through The Arc's network of chapters includes programs and supports across the lifespan: early intervention, access to a free appropriate public education, transition from school to work, health services and health promotion, income maintenance, group and independent living, recreation and aging issues. The Arc seeks to establish a chapter in each state, provides technical assistance, tools and guidance to chapters, and maintains affiliation agreements with each of its chapters.

Creating a movement – with a membership over 140,000 individuals, more than 800 chapters, and partnerships and alliances with the nation's leading self-advocacy, professional, governmental organizations, The Arc provides a strong voice for all individuals living with intellectual and developmental disabilities. The Arc's quarterly magazine, *inSight*, with a circulation of 100,000 readers, is among the most prominent communication vehicles linking individuals and families with current information, resource material and inspiration.



2006 In Review

- In response to humanitarian needs resulting from Hurricane Katrina and floods in New Orleans, The Arc raised and provided grants of nearly \$300,000 to chapters in Alabama, Mississippi and Louisiana to assist chapters with critical assistance for people with intellectual and developmental disabilities affected by the storms. A significant level of support was provided to The Arc of Greater New Orleans, whose operations were hardest hit by the flooding. In gratitude for the outpouring of compassion extended to people of New Orleans, The Arc of Greater New Orleans presented The Arc of the United States with its Vital Service Award.
- The Arc's 55th annual convention, "Ride the Wave", was held in San Diego, California with nearly 700 people in attendance. The convention keynote address was presented by The Honorable Rosario Marin, Secretary of the California Consumer Services Agency and long-time advocate for people with disabilities. The highly successful convention was structured around learning tracks for families, chapter leaders and advocates.
- The Arc, through its highly effective Disability Policy Collaboration with United Cerebral Palsy, partnered with its key colleague organizations to conduct the annual Disability Policy Seminar in Washington. Hundreds of advocates met with members of Congress and congressional staff.
- The Arc participated with Vanderbilt University's Kennedy Center for Research on Human Development to conduct research on the role of siblings in the life of a brother or sister with an intellectual or developmental disability. Findings of the research study will help organizations like The Arc enhance their ability to serve as a valuable resource to siblings.
- The Arc was prominently represented at The XIV World Congress of Inclusion International and worked closely with many disability organizations around the world. As a global citizen, The Arc worked closely with colleague organizations on language for the United Nations Convention on the Rights of Persons with Disabilities, to ensure that the needs of families were addressed.
- The Arc was recognized by the Internal Revenue Service (IRS) for its role in generating awareness of the Earned Income Tax Credit (EITC) which provides significant tax relief for disabled and low income taxpayers.
- The Arc published the new Justice and Advocacy Guide which serves as an authoritative reference on how to best advocate for people with intellectual disabilities who are victims or suspects of crime. The Arc also distributed more than 5,000 of the Fetal Alcohol Syndrome (FAS) awareness brochures, "Think Before You Drink" to schools, community groups and other organizations. The Arc has developed a comprehensive curriculum to this critical issue: the Fetal Alcohol Syndrome Prevention curriculum, which is designed to educate parents and professionals working in school systems, public health service agencies, and social service agencies about FAS.
- Eight state and local chapters of The Arc spearheaded efforts to address the impact of sexual violence and trauma on people with developmental disabilities. Under Project Illumination (PI), chapters initiated training on sexual violence, developed tool kits for victim assistance, created community awareness campaigns and more. Participating chapters were The Arc of St. Louis, The Arc of Aurora (CO), The Arc of Pennsylvania, The Arc of Orange County (NC), The Arc of Kent County (MI), The Arc of Multnomah/Clackamas (OR), The Arc of Weld County (CO) and The Arc of Delaware.
- The 55th National Convention of The Arc of the United States honored three self-advocates with the Bill Sackter Self-Determination Award. Beth Townsend from The Arc of Stanly County, NC opened her own business, "Celebration Gallery" selling her own gift line of products. The second pair of recipients of the Sackter Award, Brian and David Muhs of The Arc Greater Twin Cities outside of Minneapolis, were also honored for their entrepreneurial achievement with Muhs Brothers Incorporated, a vending machine concern.
- The first National Summit about Supporting Parents with Cognitive Challenges and Their Families was convened in Denver, CO. This gathering grew out of the collaborative efforts of The United Arc of Franklin and Hampshire Counties. The Arc of the United States served as a sponsor of the National Summit.
- Mary V. Jordan of Johnson City, TN was elected President of The Arc of the United States by the Congress of Delegates at the 2006 national convention. Ms. Jordan, a longtime advocate and volunteer in her local chapter and The Arc of Tennessee, had been most recently Vice President of The Arc. She is a member of the State of Tennessee Developmental Disabilities Planning and Policy Council and serves on numerous committees and task forces at East Tennessee State University where she is Special Assistant to the President for Equity and Diversity.



Looking Ahead, key programmatic priorities will require a continued support, collaboration and assistance from our chapters, donors, volunteers and friends:

Human Rights

For centuries, people with intellectual and developmental disabilities have been abused, neglected, segregated and treated as less than human. As the oldest and largest non-profit serving people with intellectual and developmental disabilities and their families, The Arc of the United States is a major defender of human rights.

Family Support

Currently in the United States, almost all children and about 75% of adults with intellectual or developmental disabilities who need significant levels of ongoing supports receive most or all of their supports in the context of the family home. Most or all of the supports are provided by a family member. Often, families do not have the information or support they need.

Family Advocacy

The Arc of the United States was the earliest voice for families of children with disabilities in the nation. As the number of disability advocacy groups has grown, we remain the strongest voice of families on Capitol Hill and in most state legislatures. Because The Arc is not a diagnosis-specific organization, our advocacy focuses more broadly than most.

Waiting Lists

More than one million Americans who have significant needs for supports due to intellectual and developmental disabilities are on waiting lists for appropriate services in their states. Many people have been on the list for more than ten years. Many states now operate “crisis waiting lists.” Medicaid provides an entitlement only to institutional care, and most families would rather struggle without the supports they need rather than allow their loved one to be sent to an institution. Families often can’t accept job opportunities that require a move to a different state because they lose their place on the list.

Building a Professional Direct Support Workforce

There is a looming crisis in the demand and supply of committed, compassionate and capable direct support workers, who are the lifeblood of The Arc’s ability to deliver individual and family supports for people with intellectual and developmental disabilities. Today more than 1 million people with intellectual and developmental disabilities are living with parents or a parent who is 65 year of age or older.

2006 Donors List

National Corporate Sponsors (\$20,000 and above)

METLIFE
MUTUAL OF AMERICA
THERAP SERVICES

Wall of Honor (\$10,000 and above)

QUINCY ABBOT
ANONYMOUS
CHARLES BINDER
ROCKLAND ARC
THE ARC OF MONMOUTH
WILLIAM M. WEISS FOUNDATION

Diamond Circle (\$5,000—\$9,999)

JENNY GASPAROTTI
THE ESTATE OF HELEN PROCTOR
JOAN WISTER

Benefactors of The Arc (\$1,000—\$4,999)

JANET R. AND MATTHEW ALBERT-HERMAN
ARC THRIFT-E-SHOP
MR. AND MRS. ROBERT BEGGIN
MR. AND MRS. LEO J. BERGGREEN
DAVID AND LAURA BRADDOCK
MR. AND MRS. ALFRED E. CAMBRIDGE
WILLIAM A. AND MARY LOU CATELLI, JR.
COLONIAL INSURANCE AGENCY LLC
SONIA DE LA CRUZ
MARK DOWD
OPAL E. AND BONNIE GENTNER
LOUIS J. AND RUTH G. HERR FOUNDATION
MARY V. JORDAN
CATHERINE M. KEARNEY
MR. AND MRS. NORMAN V. KINSEY
REBECCA L. KINSEY
MRS. ANDREA KNIGHT
DEANNA L. KOHLBRECHER
MR. AND MRS. PETER J. LEIBERT
DAVID AND YOLANDA LERNER
BRIAN MALLER
MR. AND MRS. PAUL MARCHAND
MR. AND MRS. BARRY A. MEYER
MR. AND MRS. GARY MILLS
PAT NAPOLIELLO
SHEILA AND BILL NATBONY
MR. AND MRS. EDGARDO PAPPACENA
PAM QUINTERN
RDH FOUNDATION
MARK AND HELEN RUSSELL
LORRAINE SHEEHAN
MR. AND MRS. JOHN STELLATO
SUE SWENSON

MR. ROBERT AND DR. PEGGY TERHUNE
THE ARC OF AURORA
THE ARC OF CALIFORNIA
THE ARC OF JOHNSTON COUNTY NC, INC.
THE ARC OF OREGON
THE ARC OF SAN DIEGO
THE ARC OF VENTURA COUNTY
THE CONNECTICUT INSTITUTE FOR THE BLIND
JAMES E. TUCKER
THERESA VARNET
JOY WEZELMAN
JOHN C. WILLIAMSON AND IVANA NIZICH

National Donors Circle (\$500—\$999)

ALLEGHANY ARC
ANONYMOUS
DR. AND MRS. DAVID A. BOWLIN, JR.
LYNNE CLEVELAND
MICHAEL COBURN
SHARON DAVIS
SHIRLEY DOVE
ELEANOR ELKIN
MR. AND MRS. WILLIAM G. ERVIN
FOUNDATION FOR MENTALLY RETARDED AND
HANDICAPPED CHILDREN
MR. AND MRS. JAMES B. GARDNER
MICKEY HERBST
MR. AND MRS. GILBERT F. KENNEDY, III
MR. AND MRS. MARK KEVITT
PATRICK KOCUREK
KENNETH C. LAKIN, PH.D.
MICHAEL L. AND JAN F. MACK
MOHAN AND SUZANNE MEHRA
ANDREW MILMAN
DR. JEFFREY J. MOLLIDREEM AND
M. CARMEN VINUS
NILES TOWNSHIP HIGH SCHOOL
RICHARD ROSA
BARBARA SACKETT
MR. AND MRS. TREVOR G. SMITH
KAREN STALEY
DR. H.R. AND DR. ANN P. TURNBULL
RICHARD A. VOORHEES
NANCY AND ROBERT WEBSTER
WEINGART FAMILY FUND

President's Horizon Club (\$250—\$499)

ANONYMOUS
MARILYN BAUMER
MR. AND MRS. GEORGE BABULA
MR. AND MRS. BRANDON BEGGIN
BEL AIR MIDDLE SCHOOL
BRENDA J. BENSON
MR. AND MRS. MARC BRANDT
RICHARD AND DOREEN BRANNION
MARTHA BRIGHTWELL
KIM C. BROWN

SUSAN E. BUSCH
JOHN J. BYRNE, JR.
DIANE CAREY
CASTLE POINT MORTGAGE, INC.
ANN CHMIELEWSKI
TIM C. CHMIELEWSKI
MR. AND MRS. WILLIAM COOL
MR. AND MRS. STEVE CORBETT
LARRY CROY
MR. AND MRS. THOMAS CZEPIEL
MR. AND MRS. JOHN DAHL
JEFF R. DALY
LEIGH ANN DAVIS
RANDOLPH DELFRANCO
MRS. CARLOS DEL VALLE
SHAW FODOR
MR. AND MRS. JOHN FOLEY
MARTHA FORD
RICHARD AND SUSAN GARNETT
GENESEE ARC
DR. AND MRS. THOMAS GIETZEN
SAM GIVHAN
MR. AND MRS. TIMOTHY HARRIS
MANISH HEBBAR
REGINALD HIGGS
MICHAEL HOWLAND
MR. AND MRS. BRUCE HULSE
JING YING INSTITUTE
SHANTE JONES
DR. AND MRS. STEPHEN KATZ
TOM KOMULA
STEVE LARSON
DR. AND MRS. LYLE LEHMAN
MR. AND MRS. EUGENE F. LEITEN
MR. AND MRS. JEFFREY MASNARI
MR. AND MRS. TOM MCMILLAN
DIPANKAR MUKHOPADHYAY
DORIA PANVINI
DUANE AND DELAINE PETERSEN
DR. AND MRS. RICHARD PETERSON
MRS. JOHN POPPLE
ANNMARIE PROCINO
ROBERT AND KATHLEEN PRUZNICK
LOURDES RIVERA-PUTZ AND FAMILY
WILLIAM F. ROBERT
WALTER F. ROGERS
ELIZABETH SAVAGE
JAN AND BOB SCHROTH
ANNE SCHULTE
MATHEW C. SCHWARZ
RICHARD S. SCOTT, ESQ.
PRASHANT SHANKAR
MR. AND MRS. DAN STEWART
DR. ZOLINDA STONEMAN
ARDIS SUSSELL
SARAH TUXIS RESIDENTIAL SERVICES, INC.
PETER AND KIM VANN
PHILIP WALKER
BARBARA P. WHALEY

The Arc of the US
Summarized Financial Results
Year ended December 31, 2006

ASSETS	2006	2005
Current Assets	\$3,267,408	\$3,740,630
Furniture & Equipment, net	179,436	107,227
Other Assets	1,018,804	947,805
TOTAL ASSETS	\$4,465,648	\$4,795,662
LIABILITIES AND NET ASSETS		
Current Liabilities	\$377,923	\$450,267
Net Assets		
Unrestricted Net Assets:		
Undesignated	165,102	126,236
Board Designated	571,344	887,171
	736,446	1,013,407
Temporarily Restricted	893,975	945,683
Permanently Restricted	2,457,304	2,386,305
Total Net Assets	4,087,725	4,345,395
TOTAL LIABILITIES AND NET ASSETS	\$4,465,648	\$4,795,662
REVENUES		
Affiliation and Chapter Fees	\$1,969,483	\$1,855,537
Contributions	505,580	731,837
Grants and Subcontracts	255,162	1,469,009
Program Fees	754,415	788,572
Revenue from Investments	248,977	147,553
Other	147,478	165,963
TOTAL REVENUE	\$3,881,095	\$5,158,471
EXPENSES		
Program Services:		
Public Health Education	299,124	684,087
Direct Assistance and Services	500,881	1,073,588
Services to Affiliates	2,053,352	2,152,390
	2,853,357	3,910,065
Supporting Services:		
Management and General	895,825	723,963
Fundraising	370,110	415,001
	1,265,935	1,138,964
TOTAL EXPENSES	4,119,292	5,049,029
TRANSFERS BETWEEN FUNDS	(19,473)	(8,314)
CHANGE IN NET ASSETS	(257,670)	101,128
NET ASSETS AT BEGINNING OF THE YEAR	4,345,395	4,244,267
NET ASSETS AT END OF THE YEAR	\$4,087,725	\$4,345,395

A copy of the organization's IRS 990 full financial statement can be found online at www.thearc.org or can be obtained from The Arc's national headquarters.



The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910

(301) 565-3842
(301) 565-5342 Fax

info@thearc.org
www.thearc.org