

empower

Real People, Real Progress

Issue 5 | Spring 2011

The Arc – Achieve With Us

You probably noticed that this issue of Empower looks dramatically different: meet the new face of The Arc! Our dynamic new logo and new brand identity represents the energy with which The Arc works on behalf of people with intellectual and developmental disabilities (I/DD) and their families.

The Arc's more than 700 affiliated chapters nationwide are embracing, determined and experienced in promoting and protecting rights of people with I/DD.

Collectively, as The Arc, our chapters provide a variety of needed services and supports across the arc of a lifetime and across diagnoses such as Down syndrome, autism, and many other intellectual and developmental disabilities. And in doing so, they provide opportunity, which is the cornerstone of The Arc's new brand; opportunity for hope, for growth, for change.

The Arc knows a thing or two about change. We have been on the front lines of a movement that has ushered in dramatic changes in the law, in



Former President of The Arc's national board Lynne A. Cleveland with Peter V. Berns, CEO of The Arc.

schools, in health care, in communities and often on a very personal level in individual's lives.

Our new identity will take us forward as a movement and command the kind of respect and recognition on a national basis that our organization deserves. That respect and recognition, in turn, will allow us to continue to achieve our goals for people with I/DD. We invite you to *Achieve With Us*. ■

march is our month

Thousands of self-advocates, parents, siblings and volunteers will band together during the month of March to commemorate Developmental Disabilities (DD) Awareness Month with events, activities and celebrations across the nation.

The Arc's advocacy efforts were crucial to President Ronald Reagan's signing of a proclamation in 1987 affirming that "Americans are becoming increasingly aware that such disabilities need not keep individuals from realizing their full potential in school, at work or at home, as members of their families and of their communities."

This national declaration generated renewed respect for people with intellectual and developmental disabilities (I/DD) and increased awareness of the issues faced by individuals and their families. DD Awareness Month is an opportunity to recognize the more than 7 million people with I/DD and their families for whom this respect has been hard-won.

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Achieve with us.

meet The Arc's new president



Mohan Mehra

As the newly elected President of the Board of Directors of The Arc, I would like to introduce myself and share some thoughts with you. It is an honor to take on this leadership role at such a transformative time in the organization's history. I have been active in The Arc movement in the local and state levels for over twenty years, and nationally since 2004.

I initially came to volunteer with the Westchester Arc in New York when I was asked to help them with their strategy and raise the visibility of the organization. As a business manager with Kraft Foods with experience in business strategy, marketing and sales, I endeavored to help them make an impact on the community.

My affinity for The Arc and my commitment to empowering people with intellectual and developmental disabilities is also very personal. I am the parent of Brian, a young man with Down syndrome. I am proud that Brian is productively employed in the community. He is supported by the chapter in his employment as well as participating in the various recreational programs.

This is both an exciting and challenging time for The Arc.

There is tremendous energy and "buzz" as we begin to implement The Arc's new brand identity. This will help raise

public awareness of The Arc and translate to greater support at both the local and national levels. I am especially invested in the new brand and have been involved since the start of the process. I know from my professional experience that a new brand can make a real difference.

For an organization of our size and diversity, we had virtually no name recognition. In part this was due to each chapter creating its own unique identity while the national organization never branded a common identity across our network. A survey of our chapters demonstrated widespread support to rebrand and create a more compelling vision for The Arc.

I envision The Arc, with over 700 affiliated chapters across the nation, sharing a more similar look and purpose, and determined in promoting and protecting the rights of children and adults with intellectual and developmental disabilities.

I envision The Arc where our chapters are focused on providing opportunity, the cornerstone of our new brand; the opportunity for hope and growth for people with intellectual and developmental disabilities, and the needed change in public attitudes. I encourage you to ask your chapter leaders how your chapter will be a part of this.

Cuts in state and federal budgets pose significant challenges to maintaining the supports and services at the local chapter level. States are cutting Medicaid spending, a key source of funding for services. Advocacy by families and advocates at the local, state and national levels will be critical in the coming year. But, this is what we in The Arc movement do best. I ask you to continue your advocacy in State houses as well as in Washington. This personal commitment and involvement of families is what makes The Arc unique. I know I will be doing so in New York. And we at the national level will support your efforts in every way we can.

I am reminded of what Joseph Weingold, the first Executive Director of New York State Arc, said over fifty years ago. "While there may be some doubt as to how much we may be able to change our children for the world's sake, there can be no doubt about how much we must change the world for our children's sake."

I hope that we can engage in an ongoing dialogue on issues that matter to you. Please feel free to share your thoughts and ideas with me at president@thearc.org. ■

Mohan Mehra

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Mission Statement

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

SAVE THE DATE

Achieving New Heights

National Convention

September 16-19, 2011

Denver, CO

www.thearc.org

justice prevailed? the posthumous pardon of Joe Arridy

Leigh Ann Davis, Project Associate, Chapter Excellence Group, The Arc

Seeking justice for Joe Arridy and others like him, comes through tireless advocacy and a hunger for truth. A number of dedicated advocates worked throughout Joe's life, and after his death, to bring his compelling story to light.



January 7th, 2011 is a day many thought would never come. Joe Arridy, a man with intellectual disabilities convicted of the murder and rape of a 15-year-old girl in 1937 and executed just two years later, was granted a posthumous pardon.

Although innocent, he was coerced into confessing to the crime, then wrongly executed in Canon City, Colorado. He too was murdered, not by a villainous perpetrator, but by a “justice” system that was unable or unwilling to correct the mistake that had been made in imprisoning him in the first place. Seventy years later justice finally prevailed with his name being cleared of the crime—seventy years too late to save his life.

Seeking justice for Joe Arridy, and others like him, comes through tireless advocacy and a hunger for truth. A number of dedicated advocates worked throughout Joe's life, and after his death, to bring his compelling story to light. These same champions for justice, notably author and advocate Robert (Bob) Perske, uncover other similar cases. Perske is at the heart of a movement to reform the criminal justice

system and its treatment of people with intellectual and developmental disabilities. As a widely-known and much admired advocate within The Arc and beyond, Perske reached out to attorney David Martinez for his help, ultimately resulting in Arridy's pardon.

As chapters of The Arc and as individual advocates, we have much to learn from Joe Arridy's life and death. We can honor his life and memory by committing to do something when a similar case or injustice is brought to our attention. Consider the following ideas:

- **Action:** Don't assume there is nothing that can be done. Even one small act can be a catalyst for a wave of advocacy that could change a person's life. Be vigilant and prepared when cases like Joe Arridy's surface in your community. Make a phone call to the defendant's attorney, find out the facts of the case and organize a “Circle of Friends” to support the defendant so that no one advocate is going it alone. Change may happen much slower than expected, but it can happen.

1. Joe giving his trains away.
2. Joe meeting with Warden Roy Best.
3. Joe saying good-bye to his mother.

- **Education:** Establish strong ties and relationships with your local law enforcement, attorney general, public defender and victim assistance agencies. Offer to provide training and assist on tough cases that cross their desks. Be available when they need your advice. The Arc's *Justice Advocacy Guide* can help you get started whether the person you are advocating for is a victim or suspect. You can find it on The Arc's website at www.thearc.org/page.aspx?pid=2461
- **Teamwork:** Begin building alliances with other nonprofit and disability-

related agencies in your community that share a similar interest in serving this population. Consider forming a multi-disciplinary team (MDT) to address these types of cases. (MDTs are groups of professionals from diverse disciplines who come together to provide comprehensive assessment and consultation in criminal justice-related cases.)

To learn more about Joe Arridy's story, and hear the Colorado public radio interview with Robert Perske and attorney David Martinez, visit www.friendsofjoearridy.com/ and www.cpr.org/article/A_Gubernatorial_Pardon ■

civil rights/ADA enforcement update

The new issue of a Department of Justice (DOJ) publication features a summary of recent Olmstead actions by the DOJ. The January 2011 edition of “Disability Rights Online News” is now available online. To read the latest issues visit www.ada.gov/disabilitynews.htm. ■

charitable remainder trusts: benefiting family and The Arc

Ross Charkatz, Institutional Consulting Director

Graystone Consulting, a business of Morgan Stanley Smith Barney LLC

For those who are able, making a financial contribution to The Arc for long-term support is a means to strengthen the organization's lasting sustainability.

One concern that many donors have in gifting significant assets to charity is that the assets will no longer be available for the safe care of their family member with an intellectual or developmental disability. Did you know that effective personal financial planning can benefit the donor and family in the immediate and long-term, while also providing meaningful support to The Arc?

One commonly used tool is a Charitable Remainder Trust (CRT). A CRT is a tax-exempt trust that enables a donor to give to charity, diversify assets, and receive annual payouts. By establishing a CRT, the donor continues to receive income from the assets while living, and the named charity receives the principal after a specified period of time. Immediate benefits to the donor may include an income tax deduction based on the

transfer of assets into the CRT as well as tax benefits by removing assets from the estate. Plus, such a financial plan may be more appropriate for someone in your income or assets level than you might imagine.

The donor determines the term of the trust, which can last for the life of the donor and/or spouse, or for a fixed term of up to 20 years. The donor can also choose the level of annual payouts to be paid by the trust. Typically, the maximum payout rate depends on the length of the trust or the life expectancies of the income recipients, but it cannot exceed 50%. The minimum payout is 5%. When the donor's payout term ends (often at death), whatever is left in the trust is distributed to the charity (or charities) of the donor's choice.

Donors will experience dramatic savings in taxes as well as an enhancement of retirement benefits and wealth passing to heirs can be achieved by using tools such as the CRT. Thoughtful

and strategic personal financial planning can be mutually beneficial to the donor and family in the immediate and long-term, while also providing significant support to The Arc. The Arc would be happy to help you with some of your preliminary questions to make sure that you get the guidance you need from an attorney/investment manager. Many families with The Arc have already set up CRT's to meet the needs of their long term financial planning.

Ross Charkatz is an Institutional Consulting Director with the Graystone Consulting business of Morgan Stanley Smith Barney in Washington, D.C. The information contained in this article is not a solicitation to purchase or sell investments. Any information presented is general in nature and not intended to provide individually tailored investment advice. The strategies and/or investments referenced may not be suitable for all investors as the appropriateness of a particular investment or strategy will depend on an investor's individual circumstances and objectives. Investing involves risks and there is always the potential of losing money when you invest. The views expressed herein are those of the author and may not necessarily reflect the views of Morgan Stanley Smith Barney LLC, Member SIPC, or its affiliates. For information on planned giving options contact Trudy Jacobson at jacobson@thearc.org.

Your Donation Counts — Achieve With Us

- ☐ Yes! I want to support The Arc.
☐ \$50 ☐ \$100 ☐ \$150 ☐ \$_____ Other ☐ \$_____ Monthly
- ☐ Yes! I want to become a monthly sustainer.
- ☐ Yes! Count on me to work to improve the lives of those with I/DD.
- ☐ Yes! I want to receive e-updates with the latest news from The Arc.
My e-mail address is: _____
- ☐ I support The Arc because I have a child, grandchild, sibling, friend, co-worker or _____ with I/DD.

- ☐ Check or money order enclosed
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*Registration with any state agency does not imply endorsement, approval or recommendation by the state.

managing a special needs trust



Since the Fall of 2010, The Arc has assisted DisABILITIESBOOKS* in getting the word out about *Managing a Special Needs Trust: A Guide for Trustees*. We wanted to learn more

about Barbara Jackins, the lead author, and why she created this book.

Most parents of children with disabilities are aware of the importance of a special needs trust. But for many, trusts can be mysterious—if not downright intimidating.

As the parent of a young adult with developmental disabilities and an attorney with over 30 years experience writing and managing special needs trusts, Barbara has a foot in both worlds. As a parent, she routinely advised her family and friends to carefully plan for their children's financial future. She felt

that a special needs trust was an important piece of planning because it could assure a good quality of life beyond government benefits.

But in her law practice, Barbara noticed that many trustees were not using the trust funds for maximum advantage. Many were afraid to spend the money for fear of getting into trouble with the government. The benefits the trust was meant to provide were being lost.

In 2004, Barbara and four other Massachusetts attorneys wrote the first edition of this book. Its purpose was to help trustees use a trust fund as it was intended—to help people with disabilities lead fuller lives. That edition focused primarily on Massachusetts rules and procedures. In 2010, the authors completely revised, updated, and expanded the book to cover all 50 states.

The result—*Managing a Special Needs Trust*—is a comprehensive guide to using a special needs trust. It covers the

different kinds of trusts, public benefits, investments, taxes, opening the trust, closing the trust, distributing the remaining funds, and much more.

The book is written in plain English, free of jargon and “legalese.” Barbara reports that many parents buy multiple copies of this book—one for their attorney, one for their son or daughter who will be managing the trust, and one for themselves.

* When members/friends of The Arc purchase the book online (www.disabilitiesbooks.com/managing_snt/index.html) or by mail (DisABILITIESBOOKS, 33 Pond Ave., #919, Brookline, MA 02445), The Arc receives a portion of the proceeds as long as the purchaser enters The Arc in the “Redeem Coupon” space online or writes The Arc on the check when ordering by mail (cost of book is \$24 plus \$4.50 for postage and handling).

If you have already purchased the book but neglected to mention The Arc, contact DisABILITIESBOOKS via email (stan@disabilitiesbooks.com) or regular mail. ■

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There's a lot you as an individual can do to raise awareness about intellectual and developmental disabilities (I/DD) in your community!

- Help celebrate the contributions of all people with I/DD by copying and posting March is Developmental Disabilities (I/DD) Awareness Month on your Facebook page as your status during March. Get more information about I/DD at www.thearc.org.
- Go to www.thearc.org to check out the latest in the I/DD world on The Arc's blog. Share interesting posts with family and friends.
- Many people with disabilities rely on publicly funded services to fully participate in their communities; policy makers need to know you are concerned about continuing those services in the face of budget cuts during tough economic times. Contact your legislator today and let them know you expect them to enact public policy to assist people with I/DD. Visit The Arc's Action Center to join sign up for action alerts, legislative updates

and get contact information for your state and local elected officials.

- Contact your local chapter of The Arc to contribute time or money. Local chapters are on the front lines of advocacy efforts and provide the services and supports essential to people with I/DD and their families. Often they are lifelines for struggling families and they need your help to accomplish their goals.
- Watch movies and TV shows that positively portray actors with disabilities and discuss them with your friends and family. Two actresses with Down syndrome are featured on the hit TV show *Glee* and were recently awarded The Arc's *Inclusion and Image Award* for their positive portrayals. Tell us about positive, realistic portrayals of people with I/DD that you've seen in films, TV or online; drop us a line at communications@thearc.org
- Talk to your employer about their practices for recruiting and hiring people with I/DD. Many employers



don't realize just how much an employee with I/DD can contribute to the workplace.

- Support businesses that employ people with I/DD and make sure they know you noticed.
- Comment on The Arc's Facebook page and Twitter profile about what you are doing to raise awareness of I/DD.

March is a month to promote and encourage changing attitudes and creating opportunity by educating the public about the needs, issues and concerns of people with intellectual and developmental disabilities. Join The Arc in celebrating I/DD Awareness Month! ■

helping families cope: what works?

Ann Cameron Caldwell, Ph.D., Chief Research and Innovations Officer, The Arc

Families are the bedrock of support for their children – of any age – with intellectual and developmental disabilities (I/DD), including autism. In fact, families are the unsung heroes in making it possible to help our loved ones achieve their goals and live a quality life. How do families cope with the challenges and the stresses of raising a child with diverse needs?

First, understanding the kinds of stresses families face may be helpful. In a longitudinal study of parental stress, researchers have found that the time of diagnosis was the most stressful event for parents, followed by the time when the child entered school, and then when they encountered the transition from school to work. What is interesting is that parents of children with autism, in contrast with parents of children with other kinds of devel-

opmental disabilities, maintained high levels of stress in between the two time points – an important distinction.

Parents have reported that facing the permanency of the diagnosis is tough. Reconciling an unanticipated reality with other parenting expectations is challenging at different points across the lifespan. Also, parents report that the lack of social acceptance of biological and behavioral diversity is difficult. Other challenging issues include low levels of support, economic burdens relating to caring for disability needs, disruption of parents' career and/or income, concern for the future, and perceptions of loss of control in constructing solutions. While mothers and fathers share parenting roles, mothers typically assume a larger part of the responsibility of meeting their child's needs. So – how do families cope?

The short answer is that many do – and do it well. There are different ways to cope with situations - some try to deal with a particularly stressful issue by seeking information about it, monitoring it, and trying to resolve it. Sometimes a person tries to solve the issue or change the situation. Others avoid the issue altogether by ignoring, denying, or minimizing the issue, or try to manage emotional reactions to the issue. Of these, those that try to understand what is going on or problem-solve tend to cope better and experience lower levels of stress and higher levels of family

cohesiveness – but at certain times, all of these coping strategies may be helpful. We do what we have to do to get through tough times.

The Arc knows that families connected to intellectual and developmental disabilities are amazing. The research backs it up. Studies show that families connected to autism – and I would argue these strengths apply to families connected to other intellectual and developmental disabilities as well – display powerful resilience and are overall stronger family units as a result of disability in the family.

Specifically, families are exceptional at pulling together resources and being connected, making meaning out of challenging situations, affirming internal strength attributes and being more compassionate, and are often more spiritual. When asked, many families report that having a child with intellectual and developmental disabilities is a positive experience.

Families connected to autism that receive informal support from their social networks, such as friends and relatives and quality formal support from agencies and health care providers tend to show lower levels of stress. Respite is one kind of formal support. Respite is a service in which another adult assumes the role of parent for children with disabilities for short periods of time on a consistent basis.

This kind of support for parents of children with

I/DD, including autism, reduces stress, reduces emotional distress, and allows parents to engage in “down time” together or individually. Sometimes, just being able to go for a walk by yourself, go to a movie with your spouse or partner, or get in the car and go to the grocery store by yourself without having to coordinate the pressure of managing your child with a disability can be a relief.

Sometimes respite can give parents three or four hours of much-needed sleep, knowing that a responsible, caring, and trained adult is ensuring the safety of our child. It doesn't mean we don't love our child or love being with them. It means that we are deserving of our own time and space. Taking care of ourselves is the best thing we can do so that when our children need us, we have the physical and emotional reserves to care for them.

If you are a parent and you feel stressed, you're not alone. There are ways to get help. If you feel like you need a break from the day-to-day pressures of parenting, call your local Chapter of The Arc to see what respite services or other supports might be available. One more thing – be good to yourself today. You deserve it.

Research information provided was summarized from Meadan, Halle, and Ebata's article, "Families with Children who have Autism Spectrum Disorders: Stress and Support," published in Exceptional Children, Volume 77, No.1., pp. 7-36, 2010. ■



Geoffrey Mikol Caldwell with his mom Ann Cameron Caldwell

chapters in the news

The Arc of Pennsylvania

The Arc of Pennsylvania is included in a prestigious study of 13 nonprofits that helped improve their communities and are notable for amplifying the voices of underserved residents through the democratic process and policy engagement. These nonprofits leveraged foundation grants that generated a \$122 return for every dollar spent.

"Strengthening Democracy, Increasing Opportunities: Impacts of Advocacy, Organizing and Civic Engagement in Pennsylvania" was produced by the National Committee for Responsive Philanthropy (NCRP), an independent watchdog of foundations, based in Washington, D.C. The study is a part of NCRP's Grantmaking for Community Impact Project (GCIP) to encourage more funders and other grantmaking institutions to increase or start funding advocacy and community organizing.

Other organizations that are a part of the study are the AIDS Law Project of Pennsylvania, Asian Americans United (AAU), Consumer Health Coalition (CHC), Pennsylvania Partnerships for Children (PPC) and Youth United for Change (YUC).

"This report shows the supreme value that these organizations bring

to communities in Pennsylvania," said Aaron Dorfman, director of NCRP. "The nonprofits often work with shoestring budgets to help and give voice to those people who are overlooked by the system."

The report, "Strengthening Democracy, Increasing Opportunities," is available online at www.ncrp.org.

The Arc of Baton Rouge Says No to Transit Cuts

When The Arc Baton Rouge Executive Director Barry Meyer learned that the Baton Rouge Metro Council was considering a vote to cut services and raise prices, he was stunned. Meyer knew that cuts would severely impact people with intellectual and developmental disabilities. Cuts to services and raised fares would hit those that relied on these services most.

For those that depend on the Capital Area Transit System (CATS) system, like Lynette Williams, a resident of Baton Rouge with cerebral palsy who uses a wheelchair, a change in fare and services would significantly change how she gets to work.

Bobby Martin, who works with Wil-

liams at Metro Enterprises in Baton Rouge, where he's been employed for 38 years, said without CATS, he would lose his job. Martin's aide noted that, "Bobby's parents are both in their 80's and they can't drive him."

CATS faces a \$1.2 million budget shortfall. After three decades of providing transportation to Baton Rouge, CATS said it has no choice but to cut services and raise prices.

Thanks to advocates like The Arc Baton Rouge and other citizens, CATS bus fares will not be increased and routes will not be eliminated in February. While the service will continue for the short term, rejecting the money-saving measures means that the CATS bus system may shut down in October.

The Metro Council recently voted 7-5 in support of a motion to reject the service changes. Meyer knew there would be hardship for those that rely on the bus, especially for employment, medical appointments and more. When he first learned of the proposals, Meyer said, "I was thinking maybe as much as 20 percent, but the initial proposal was a 128 percent increase in current rates," he said.

Currently, a one-way ticket on CATS is \$1.75 for individuals covered under the Americans with Disabilities Act. Under the new proposal, the price would be \$4 for the same ticket. ■

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disabilities" for the term "mental retardation" in many federal laws.

The stakes are high this year with disability programs facing serious budgetary and political challenges. This year's record number of participants was spurred to action in this current climate and was briefed on the 'hot' issues facing people with disabilities, including the Affordable Care Act, Budget and Appropriations, Developmental Disabilities Act, Employment, Housing, Medicaid/Medicare and more.

Colleagues and friends gathered to honor and celebrate the career of Paul Marchand, who for 38 years has been

one of the most ardent and successful disability policy advocates working on behalf of The Arc, United Cerebral Palsy and the entire intellectual and developmental disability community. The event kicked-off The Paul Marchand Internship Fund to support the next generation of difference-makers in the world of public policy and advocacy for the intellectual and developmental disability community.

The 2011 Disability Policy Seminar was hosted by The Arc, United Cerebral Palsy, the American Association on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, and Self Advocates Becoming Empowered. ■



Peter V. Berns, CEO of The Arc, Sen. Barbara Mikulski (D-MD) and Betty Williams, President, Self Advocates Becoming Empowered



For people with intellectual
and developmental disabilities

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remainder trusts*

*chapters in the
news*

*helping families
cope*

special needs trusts

disability policy seminar: speaking truth to power

The 2011 Disability Policy Seminar (DPS) – Cultivating New Champions on Capitol Hill – educated and empowered attendees to fight for our issues on Capitol Hill in mid-February.

Attendees were emboldened and inspired at the gathering, especially with the awarding of the Distinguished Leadership in Disability Policy Award to the Honorable Barbara Mikulski (D-MD), United States Senate. The award was presented to Sen. Mikulski by Betty Williams, President, Self Advocates Becoming Empowered and by Peter V. Berns, CEO of The Arc.

Sen. Mikulski told a cheering audience of hundreds of advocates: “We all have to stand up together for the disability advocacy community adding that the Distinguished Leadership in Disability Policy Award is “a challenge for the future.”

Peter V. Berns said “We are honoring Sen. Mikulski as a long-standing champion of disabilities issues and for her outstanding role in the passage of Rosa’s Law which is a great step forward in full inclusion.” Rosa’s Law is legislation that substitutes the term “intellectual

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meeting high standards!



bbb.org/charity

The BBB Wise Giving Alliance National Charity Seal carries a lot of meaning for both donors and charities. It is a clear and concise sign that the charity meets the Alliance’s Standards for Charity Accountability. Before national charities can even apply to use the seal, they must undergo evaluation by the BBB Wise Giving Alliance, the nation’s most experienced charity evaluator. And the evaluation process is anything but superficial. It involves rigorous scrutiny of a charity’s governance, effectiveness, finances, and solicitations and informational materials. The standards go beyond what government regulators require. We are proud to meet their standards!