



empower

Real People, Real Progress

Issue 7 | Fall 2011

Federal Spending and Debt Bill Clears Congress before Economic Default

Fight to Protect Programs for People with I/DD Will Continue

After a long and unusually arduous process, Congressional leaders and President Obama reached a deal to avoid defaulting on the Nation's debt.

On August 2nd, President Obama signed a bill into law to create a three step process to raise the debt ceiling and place spending caps on discretionary programs, reducing spending by \$840 billion over ten years in the first step. These cuts must be balanced between security and non-security spending, (which could include important disability-related programs like housing, education, employment, and transportation.) Entitlement programs, including Medicare, Medicaid, Social Security, and Supplemental Security Income (SSI), are protected from cuts in this first step.

Then this fall, Congress is charged with finding an additional \$1.5 trillion in deficit reduction over 10 years. The second step of the process will be initiated by a twelve-member bipartisan Congressional "super committee" that

proposes specific spending cuts by November 23rd. The Committee's plan must get the support of at least 7 of its members to be voted on. Congress will then hold an up or down vote, with no amendments allowed, on the spending cuts legislation by December 23rd. Cuts to important disability-related entitlement and discretionary programs could be proposed by the

Committee and enacted by Congress at this time.

If this Committee fails to obtain agreement from at least 7 of its members to cut \$1.2 trillion or if Congress fails to enact it, then automatic, across-the-board spending cuts will be triggered for 2013-2021. However, any automatic, across-the-board cuts would

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Javi and Linda Guzman Tell Washington, "Don't Cut Our Lifeline!"



Javi Guzman

Linda Guzman and her son, Javi, came to Washington D.C. with several other families from across the country with a mission: to fight for the future of Medicaid.

Though Linda has been to the nation's capital a number of times, this was Javi's first trip and it was a memorable journey to the White House to meet with senior officials to share his story of achievement and advocate against cuts in the Medicaid program.

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Draw the Circle Wide

By Mohan Mehra, President, The Arc Board of Directors

In March of this year, we took the first step towards raising the public profile of The Arc and making it one of the leading charities in the country with the launch of our new brand. It clearly defines who The Arc is and the difference we make in the lives of people with intellectual and developmental disabilities (I/DD). We advocate for their rights and create opportunities to help them achieve their life goals.

Our next task is to grow our base of members and supporters. That's where you come in.

We currently have 160,000 members nationally. Membership is important for our advocacy at both the state and national levels. It is estimated that we serve over 1 million people with I/DD and their families through our chapters. So, if we had one person join as a member of a local chapter, be it a family member, relative, or friend, for each person we support, we would have one million members nationally. States like New York, Pennsylvania, Tennessee



Mohan Mehra, President of The Arc's Board of Directors

and Virginia are having good success growing their membership. Let's make this a priority for all chapters of The Arc.

Social media, including Facebook, is a major tool to help people engage with us and grow our network. We just wrapped up a social media contest called *Achieve with us* which is our new brand tagline. We invited people with I/DD to share their stories of achievement

on Facebook. We garnered 119 entries and over 30,000 votes and counting as of this writing. This is a great example of the power of social media.

Today, many people who are passionate about a cause and eager to bring about change connect through social media. It is becoming the preferred method of communication with a person's circle of trust. This is especially true for younger people. Also, people support and give to causes that their friends and family recommend. According to Facebook, 48% of Americans have a Facebook page, and the average user has 130 "friends." If The Arc is to grow, and continue to serve this population in years to come, we need to engage more people through social networks. For example, currently 4,450 people "like" The Arc of the United States' Facebook page and are fans. As a comparison, Make a Wish Foundation has 271,000 fans, Goodwill has 33,000, Autism Society has 285,000 and Special Olympics has 520,000. Given the size of our membership and the number of people we serve, we should increase our numbers dramatically. And, it's easy. So, I ask those of you who use social media to do the following - go to The Arc of United States Facebook page at www.facebook.com/thearcus and become a "fan" by liking it. Then, share what The Arc posts with your friends, tell them why you support The Arc, and ask them to become a fan too. This is how we will get more people to engage with us. It is that simple.

Let's set a goal to get 100,000 fans of The Arc of the United States page in 2012. With your help, I know we can do it.

As the words of the inspirational song, Draw the Circle Wide by Gordon Light, go, "Draw it wider still, Let this be our song, No one stands alone, Standing side by side." ■

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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.

In the Media Spotlight –

The Arc Releases Groundbreaking New Data on Status of People with Disabilities

Last year, The Arc broke new ground by conducting the Family and Individual Needs for Disability Supports (FINDS) survey to find out if we as a nation have been keeping our promise to give people with intellectual and developmental disabilities (I/DD) opportunities to lead productive, quality lives. The results were shocking, showing that efforts have plateaued and not nearly enough progress has been made.

The findings warranted The Arc undertaking a major media push to get the word out to the public, while simultaneously introducing our new brand. So the FINDS survey results were compiled in a report released on June 14th, “Still in the Shadows With Their Future Uncertain.” That morning, The Arc’s CEO Peter V. Berns

and Lauren Potter, star of the hit FOX show “Glee,” participated in more than twenty back-to-back satellite television and radio interviews across the nation, to talk about what needs to be done to improve the lives of people with I/DD. Then Berns and Potter were joined at a press conference at the National Press Club in Washington, DC with The Arc’s President of the Board of Directors Mohan Mehra and Dr. K. Charlie Lakin, who was the Director of the Research & Training Center on Community Living at the University of Minnesota at the time of the survey. Media outlets across the country picked up the story, putting The Arc and people with I/DD in the spotlight!

Here are just a few of the most dramatic findings from the survey:



From left: Dr. Charlie K. Lakin, Mohan Mehra, actress Lauren Potter, Peter V. Berns

- Fewer than one-third of students with I/DD are being fully included in primary/middle (29%) or high school (32%).
- 72% of family respondents provide direct financial support to their family member with disabilities and 52% of families are paying for care out of their own income.
- More than 80% of families reported not having

enough retirement savings for their future as a result of using personal funds to compensate for the lack of services available to their loved one.

These startling results are a reminder of the work we have ahead of us. To view the full FINDS survey report visit thearc.org, and click on “Read About The FINDS Report.” ■

The Arc Continues to Grow – Now In Idaho!

Earlier this year, The Arc of Boise in Idaho contacted the National office to discuss opening a state chapter. Idaho has not had a state chapter for a number of years, and so this was an exciting opportunity to expand The Arc’s reach to more communities in this state!

The Boise chapter worked tirelessly with the National office for months to set up a framework and plans to start the state chapter. Having already embraced the new brand of The Arc, some of the transition to a full state chapter was made easier. Finally, in July the chapter board voted and the transition to becoming The Arc of Idaho is now moving forward.



Having a state chapter in Idaho will create many opportunities to provide local services and supports to people throughout the state, as well as to reach out to underserved communities. The local chapter currently operates a number of services including developmental therapy, RAVE (a recreational and social program for adults and children with disabilities throughout Southwestern Idaho), and residential supports. With a state chapter structure, these programs can be expanded, and advocacy and outreach to additional areas of the state can be realized.

The Arc’s movement in Idaho is growing, thanks to the hard work and support in Boise! Welcome aboard! ■

Book Corner

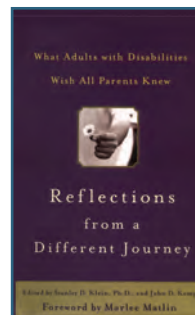
Trusts 101



Managing a Special Needs Trust: A Guide for Trustees is a valuable reference guide for anyone who is managing a special needs trust for a person with a physical or mental disability. In a clear, user-friendly way, the authors explain how special needs trusts relate to the many complicated public benefit programs that assist people with disabilities. The book answers the questions like what are my responsibilities to the beneficiary with a disability, and what expenses can I safely pay without risking SSI benefits.

Poignant Essay Collection from Adults with Disabilities

What do adults with disabilities wish parents knew? *Reflections from a Different Journey*, a book from editors Stan Klein, Ph.D. and John Kemp, explores this question with a collection of essays from people who have lived the disability experience, including several with developmental disabilities, who offer their perspective on what all parents of children with disabilities should know as they guide their children into adulthood.

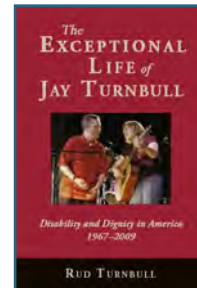


Both books are available online at www.disabilitybooks.com and a portion of sales benefits The Arc. If you order, please enter The Arc into the "Your comments" space on the Payments page.

To order by mail, send \$29 for one book (\$24 + \$5 shipping) or \$54 for both books (\$48 + \$6 shipping) to: DISABILITIESBOOKS, Inc., 44 Washington Street, #913, Brookline, MA 02445. Be sure write The Arc on your check. ■

Another Hot Read

"The Exceptional Life of Jay Turnbull"



The Arc invites you to delve into "The Exceptional Life of Jay Turnbull," a new memoir which illustrates the possibilities for a person with multiple disabilities to live a dignified

life. Written by Rud Turnbull, Jay's father, this explores disability, dignity and ultimately death as it chronicles how Jay's life and passing impacted those around him. Proceeds from the book will benefit The Jay Turnbull Fellowship set up at Kansas University to support the education and research of doctoral students at The Beach Center on Disability which was founded and is co-directed by Rud and Ann Turnbull and which employed Jay for 21 years. The book is available at www.amazon.com/gp/product/B005FFFUEDB for \$24.95. Contact Rud Turnbull at rud@ku.edu for more information or to make a direct contribution to The Jay Turnbull Fellowship. ■

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Unsure what they were in store for, Linda and Javi made their way to the White House and walked the same halls that President Obama and his team walk every day. Medicaid is a part of Javi's and Linda's daily lives as Javi, age 17, has autism and a debilitating connective tissue disorder called Ehlers – Danlos Syndrome, type 3. They came to Washington to speak with President Obama's senior staff about how Medicaid has changed both of their lives.

In the White House, officials asked Linda what probably seemed like a simple question, but what so many know doesn't have a simple answer: "What has Medicaid done for you?" What is more telling is what Linda and

Javi wouldn't have if their Medicaid benefits were cut. Without community based waivers, Javi wouldn't be at home – he would most likely be in an institution to receive the care he needs. Or Linda wouldn't be able to work at The Arc of North Carolina, pay taxes, and be the citizen and mother that she is.

Like so many other people and families served by The Arc, Medicaid is Linda's and Javi's lifeline. With the services Medicaid provides, not only are Javi's medical needs taken care of, he is learning important skills that will enable him to have the most independent and productive life possible.

Medicaid has improved the lives of countless families and given so many

individuals new hope and opportunities. While we live in an ever-changing

world, the needs of individuals with I/DD do not go away with waves of economic stability or shifting political majorities. We have a responsibility to protect the lifelines of all the people that Medicaid serves.

To learn more about Linda's and Javi's visit to the White House, and see videos of other families who are fighting to protect Medicaid, please visit our blog: <http://blog.thearc.org/>. ■



Think Before You Drink!

By Leigh Ann Davis, Project and Information Specialist for The Arc

The Arc has a strong history and deep roots in the prevention of intellectual and developmental disabilities (I/DD), especially when it comes to Fetal Alcohol Spectrum Disorder (or FASD), so I was thrilled to see my friend and colleague's son in a recent issue of *PEOPLE Magazine*. Dillon Ohlemiller is 18 years old and the adopted son of Melinda Ohlemiller, a staunch advocate for people with FASD who worked for St. Louis Arc for 17 years. She knows first-hand the ins and outs of raising a child with a FASD, and the importance of early detection and providing intervention. That's why The Arc called on her when we secured funding from the Centers for Disease Control and Prevention to write a curriculum educating others about the secondary disabilities of FASD and how to prevent it. Melinda and I worked together on this project and today are both members of SAMHSA's (Substance Abuse and Mental Health Services Administration) Expert panel on FASD.

Dillon is a shining example of how early supports and services can make the defining difference in the life of someone with an FASD. He has received support from the St. Louis Arc since he was 8 months old, and just finished their summer program. At that time, The Arc had a collaborative



Image of pages from *People Magazine's* July 11, 2011 issue featuring a story on Our Little Haven.

arrangement with Our Little Haven (the agency featured in the *PEOPLE* article) to provide intervention and therapy services during Dillon's early years, and the family also received respite and summer services throughout his childhood and adolescence.

With all The Arc and many other organizations, like SAMHSA and CDC have done in the area of education, some people still don't realize that FASD is 100 percent preventable.

Abstaining from alcohol during pregnancy is the surefire way to prevent a child from having an FASD. To learn more, see our fact sheet on FASD available on www.thearc.org. This is one of many fact sheets The Arc makes available online to educate the public about a variety of topics related to I/DD. We invite you to explore and make use of all of the online resources available at www.thearc.org. ■

The Arc in Action - Upcoming Events

September 16-19, 2011

The Arc's Annual Convention
Denver, CO
www.thearc.org

November 17-19, 2011

Alliance for Full Participation Summit: Real Jobs. It's Everybody's Business
Washington, D.C.
www.allianceforfullparticipation.org

April 23-25, 2012

2012 Disability Policy Seminar
Washington, D.C.
www.disabilitypolicyseminar.org

The Arc's Online Community Continues to Expand

The Arc's online community has been growing for the last year. From the launch of the new brand and our new website to active participation with our members through social networks, The Arc has expanded its online presence.

One of the newest additions to our online community is The Arc Resource Blog. This Intellectual and Developmental Disabilities (I/DD) Resource Blog is an online catalogue of resources for

self advocates, parents, caregivers, and anyone interested in I/DD resources. Frequently, members will ask us for additional information and resources and we decided to create a blog so that it is at everyone's fingertips. Users will be able to pose questions and post responses to information, and even submit resources for consideration in the future.

The Arc Resource Blog is optimized for all viewing on all devices so you can access the site just as easily from your smart phone or tablet as you can from your computer. Right now, there are over 30 resources on the blog and we are excited to be adding more each week. We invite you to check out the blog at www.thearc.org (under the Resources tab), and share your thoughts! ■

Planning Ahead

Want to ensure The Arc's important work will continue for future generations but can't make a substantial contribution right now? Why not give a planned gift to The Arc? It's as simple as including a gift to The Arc when you are putting your estate plans together.

A gift by will to The Arc can be unrestricted or designated to a specific program by the donor. By combining philanthropy with financial planning, you may be able to give more than you ever thought possible while taking advantage of tax savings. A planned

gift enables The Arc to continue its important work. When planning for the future, think of The Arc! For more information, please contact Trudy Jacobson, Chief Development & Marketing Officer at Jacobson@thearc.org or 202-534-3714. ■

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 learn more about The Arc's planned giving program.
- ☐ 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
- ☐ Please charge my ☐ VISA ☐ MasterCard ☐ AMEX ☐ ArcVISA
- Card # _____ Exp. Date _____
- Signature _____
- ☐ My company will match my gift

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Use this card and the attached envelope for your gift. Thank you for your generosity.



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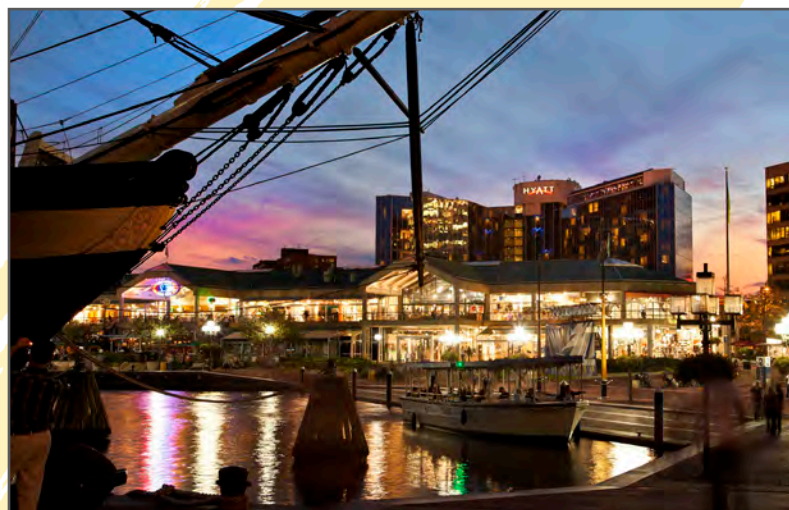
The Arc of the United States is a non-profit organization located at 1660 L Street, NW, Suite 301, Washington DC 20036. The information enclosed describes one or more of The Arc's activities. Your gift is very much appreciated and is tax-deductible as a charitable organization to the fullest extent allowed by law. A copy of The Arc's current audited financial statement may be obtained by writing to The Arc at the above address, by calling 1-800-433-5255, or via email at donorsupport@thearc.org. If you are a resident of the following states, you may obtain information directly by contacting: *Florida—a copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling toll free within the state 1-800-HELP-FLA. Florida registration #CH1140. Maryland—for the cost of copies and postage, documents and information submitted by the organization are available from the Secretary of State. *Mississippi—the official registration and financial information of the organization may be obtained from the Mississippi Secretary of State's office by calling (888) 236-6167. *New Jersey—information filed with the Attorney General concerning this charitable solicitation and the percentage of contributions received by the charity during the last reporting period that was dedicated to the charitable purpose may be obtained from the Attorney General of the state of New Jersey by calling (201) 504-6215 and is available on the Internet at www.state.nj.us/lps/ca/. New York—a copy of the latest annual report may be obtained from the organization or from the Charities Bureau, Department of Law, 120 Broadway, New York, NY 10271. *North Carolina—financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at (898) 830-4989. *Pennsylvania—the official registration and financial information of The Arc of the United States may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, (800) 732-0999. Virginia—a financial statement is available from the State Division of Consumer Affairs. Washington—additional financial disclosure information may be obtained with the Secretary of State at (800) 332-4483. *West Virginia—residents may obtain a summary of the registration and financial documents may be obtained from the Secretary of State, State Capitol, Charleston, West Virginia 25305.

*Registration with any state agency does not imply endorsement, approval or recommendation by the state.

NCE Summer Leadership Institute Navigates Through Challenging Times

Over a scorching hot August weekend, leaders of The Arc and members of The Arc's National Conference of Executives (NCE) came together in Baltimore with professionals and experts in the field for the 2011 NCE Summer Leadership Institute to learn, share, connect and get creative. Under the banner "Navigating Through Challenging Times" attendees were offered tools and resources for creative leadership that they can take back to their local organizations to better serve people with intellectual and developmental disabilities and their families.

Executives of The Arc gathered August 5-7 from as far away as Alaska to attend sessions on such topics as grassroots advocacy to community employment options to the current Medicaid crisis. However, even with such great sessions, much of the educational value of this annual conference stems from the networking and sharing that occurs between attendees throughout the weekend. Laurie Ertz, The Arc's Director of Chapter Excellence and organizer of the conference remarked that she witnessed several "a-ha" moments as leaders from diverse chapters shared their best practices with one another. "The lightbulbs just kept going off! They're taking away new ways of doing things or a new ways of looking at something and that can't help but make



Baltimore's Inner Harbor

their local chapter stronger."

Laurie also pointed out that the conference allows chapters of The Arc a chance to feel a sense of belonging in a national organization with common values and goals. "This mutual support is priceless. Chapter leaders can go back to their local communities with a renewed energy and sense of purpose!" ■

Join the Conversation Online



The Arc
for people with intellectual and developmental disabilities

... Different Deficit Reduction Efforts, Same Result for Medicaid? ... Achieve with Us and Grow Yourself in ABILITY Magazine ...

Groundbreaking FINDS Report Picked up by National Media

Posted on June 24, 2011 by Shelly DeBolt

The Arc recently released the results of its groundbreaking Families and Individual Needs for Disability Support (FINDS) survey and media across the country have been covering the startling statistics. A major goal for this project has been to raise awareness of The Arc and the urgent, unmet needs of people with intellectual and developmental disabilities (I/DD), and the media has responded by reporting findings from the survey to the general public and highlighting the work of local chapters.

We know that while we have come a long way in promoting and protecting the human rights of people with I/DD, there is still much more work to be done. Throughout our efforts to bring about greater awareness, two findings from this survey have struck a nerve – one-third of parents and caregivers (potentially 1 million families) reported that they are on waiting lists for government-funded services, with the average wait more than five years. And in this recession, 52 percent of caregivers reported a decrease in services for their family member with a disability, leaving them financially vulnerable.



The Arc
for people with intellectual and developmental disabilities

... Meet Sam Jenkins ... The Arc Makes a Statement on Employment ...

The Arc's New Brand is Sweeping the Country

Posted on March 9, 2011 by Shelly DeBolt

It's an exciting time for The Arc's national office as well as nearly 200 Chapters of The Arc nationwide that are rolling out our new brand identity in March. The Arc has already attracted considerable attention for the new brand through the efforts of our Chapters in their communities. The Arc of Baltimore, The Arc of Colorado County and The Arc of Kentucky are just a few Chapters who are sporting the new brand on their websites. And, those Chapters plus The Arc of Palm Beach County and The Arc of Atlantic County among others received favorable press upon announcing the new brand to the media. Many Chapters launched the brand in conjunction with the promotion of Developmental Disabilities Awareness Month such as The Arc of York County and The Arc of the Mid South.

The Arc of New Jersey held an Open House attended by New Jersey State Senator Bob Smith and proudly showed off Sam Jenkins and the Adrian-Hage family who are the viral stars of The Arc's new PSA (check them out on our Website, www.thearc.org), and The Arc of the St. Johns kicked off a broad ad campaign in northeast Florida. Disability Scoop and Ability Magazine both covered the national announcement. And, our brand consultants, Corebrand, even attracted attention for us within the design industry with www.designer.com covering the work they did on our behalf.

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exempt the low income entitlement programs, such as the Medicaid and SSI programs. Small Medicare cuts are allowed but will fall on the providers.

In the coming months, The Arc's national office will be vigilant in monitoring and aggressively advocating to protect Medicaid and the programs on which people with I/DD rely on. If you aren't already signed up, please join our Action Alert list by going to <http://capwiz.com/thearc/mlm/signup/> so that you can stay informed and take action. Now, we must redouble our efforts as more grave threats lie ahead, so please join us so that your voice is heard in the debates in Washington! ■

Thank you for reading Empower, The Arc's official newsletter for our membership. But you don't have to wait for the next issue to get the most up-to-date news and information from The Arc. Check out our blog at <http://blog.thearc.org> or become a fan on Facebook at www.facebook.com/thearcus. Follow us on Twitter (@thearcus). You can even watch videos about The Arc on YouTube! ■





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We're Moving!

As of October 2011, The Arc's national headquarters will have new digs in Washington, D.C. You can still reach us online at info@thearc.org and www.thearc.org and via our toll-free phone number 1-800-433-5255, but our new mailing and shipping address will be:

**1825 K Street NW, Suite 1200
Washington, D.C. 20006**

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!