



# empower

*Real People, Real Progress*

## ca, fl, va battle budget cuts: “rebirth of the movement,” advocates say



### California

Across the country, disability rights advocates are taking to the streets to fight paralyzing state budget cuts that would impact the quality of life and safety of their clients. The Arc of San Francisco, The Arc of Florida and The Arc of Virginia are mobilizing in their states

to defend what Tim Hornbecker, CEO of The Arc of San Francisco, calls “cuts to services and supports that leave our most vulnerable citizens—and their families—without the critical services we’ve worked for decades to guarantee.”

The Arc of San Francisco opposes California Governor Arnold Schwarzenegger’s drastic cuts to close a projected \$21 billion state budget gap; it is trying to keep services available—particularly for those with acute medical needs.

For a second year in a row, California added a 3% cut to funding services for people with intellectual and developmental disabilities. They are also facing a 30% cut in federal fees for Supported Employment from the Department of Rehabilitation. In-home Support Services have been limited only to those with the most severe disabilities and Medi-Cal has stopped funding dental, vision and psychiatric services.

[budget cuts](#) continued on page 2

## coming in may: look for the arc’s new website

Along with *empower*, a new e-newsletter and other exciting communications efforts, The Arc is also introducing a redesigned website. Our website address is not changing, and by late spring at [www.thearc.org](http://www.thearc.org) you will find more relevant, reliable and topical information for everyone who cares about intellectual and developmental disabilities.

Parents, siblings, self-advocates, chapter leaders, and others will find the new site to be intuitive and easy to navigate. The website redesign will advance The Arc as the “go-to” resource. Additionally, our chapters will have a greater presence so you will be up-to-date on activities in chapters where you live.

The website will also serve to reinforce our strong and growing community by providing links to discussion boards and social media sites such as Twitter and Facebook where our presence is growing. ■

“The Arc is a strong organization built on the promise of empowering people with intellectual disabilities and their families.”

## empower

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### Mission Statement

The Arc of the United States 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 lifetime.

## progress & power: the arc@60

2010 marks 60 years that The Arc has been on the front lines in the fight for the human and civil rights of people with intellectual and developmental disabilities. This is an apex in our history and a moment of great progress.

The Arc is strong. While countless nonprofits are on the financial brink in the midst of an economic downturn, The Arc has emerged in the “black” for the first time since FY05.

It is our shared commitment and fierce dedication to envisioning a day when our children and our siblings with intellectual disabilities live fully in the community. For some this is a dream made real, but despite our progress our work will not be done until “some” becomes ALL.

In looking to the future, we have charted a path that

echoes in our 2010 convention theme: “A Clear Way Forward.” This also resonates in our new mission statement: The Arc of the United States 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 lifetime.

The blueprint to The Arc’s continuing advancement is our new Strategic Framework: a visionary and concrete plan to achieving the goals of

the organization on each front—advocacy, development, communications, membership; and on every level—national, state, local; and in every community, including yours.

There is much work ahead for us in realizing the basic rights of education, employment and housing for people with intellectual disabilities—the fundamental claim of every American. The Arc is a strong organization built on the promise of empowering people with intellectual disabilities and their families. ■

### budget cuts continued from page 1

Self-advocates, families and friends of The Arc of San Francisco testified recently at City Hall to protest an increase in monthly bus passes for seniors, youth and people with disabilities. They also joined with more than 15,000 other students, educators and families for a Rally for California’s Future in San Francisco’s Civic Center.

In the fall, The Arc of San Francisco will lose teachers from City College who have taught Life Skills and Job Preparedness courses at the chapter for over 30 years. The cuts are also impacting the staff of The



Arc of San Francisco who are resorting to drastic measures, including taking unpaid furlough days and unpaid holidays and a

reduction in health care benefits, as well as cutting the hours of Direct Support Professionals.

[budget cuts continued on page 5](#)



## words & action

by Peter V. Berns

In recent months, our movement has been forced on the offensive, again demanding respect for people with intellectual and developmental disabilities.

If you haven't heard by now, I am referring to White House Chief of Staff Rahm Emanuel's use of the "r-word" in a meeting of Congressional leaders. In response to a health care reform strategy with which he disagreed, "That's f-ing retarded," he said.

I joined other disability rights activists, self-advocates and family members in a meeting at the White House with Emanuel, who sat down with us in the wake of national outrage from all quarters of our constituency. He seemed genuinely surprised by the furor he generated, apologized sincerely and even said he would discuss the situation with his three children so they too could learn from his mistakes. He also promised to explore whether the Administration could be of assistance in securing passage of Rosa's Law—legislation proposed in Congress that will take the phrase "mentally retarded" out of federal health, employment and labor laws.

On the heels of this productive meeting in which advocates were able to establish a personal relationship with a key member of the Administration, talk show titan Rush Limbaugh wasted no time in doling out cheap shots all around. "So now there's going to be a meeting, there's going to be a 'Retard' Summit at the White House, much like the Beer Summit between Obama and Gates and that cop in Cambridge," Limbaugh bellowed.

I recall that it was a brisk and sunny day in Washington as I walked to the White House, just three blocks away from The Arc's national offices. I was struck by the sense that this was a key moment of activism and energy within our movement—as disability activists we stood ready to speak truth to power! Until...Limbaugh's ridiculous and shameful comments about the meeting called to mind the old cliché about taking one step forward and ten steps back...

This feeling passed, however, as The Arc pivoted and responded by writing a letter to Limbaugh inviting him to meet with individuals with intellectual and developmental disabilities and their families for a candid conversation on how the "r-word" negatively impacts their lives.

Disability activists can and should continue to speak out and condemn the use of epithets like the "r-word." Until we can gain ground in fighting the negative attitudes, stereotypes and misconceptions about people with I/DD, and the reprehensible language that seems tied to them, our constituents will continue to be viewed as leading lives that are of lesser value.

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### Join The Arc's Online Community

To receive The Arc's e-newsletter and other e-publications please visit [www.thearc.org](http://www.thearc.org). Not a member? It's easy to create an account and login to join The Arc's Online Community.

A CLEAR WAY FORWARD



NATIONAL CONVENTION

NOVEMBER 3-6, 2010 – ORLANDO, FL

3

dates to remember

## calendar of events

### Disability Policy Seminar

April 12 - 14, 2010

Washington, D.C.

[www.disabilitypolicyseminar.org](http://www.disabilitypolicyseminar.org)

Join us in educating policy-makers and their staff about the national disability issues that affect you and those you love.

### NCE Summer Leadership Institute

July 29 - August 1, 2010

Reno, NV

[www.ncearc.org](http://www.ncearc.org)

Come to Reno and join fellow executives of The Arc and other professionals for valuable training and networking opportunities that'll help you carry out the mission of The Arc.

### National Convention

November 3 - 6, 2010

Orlando, FL

[www.thearc.org](http://www.thearc.org)

Families, volunteers and staff of The Arc are invited to join us in Orlando to celebrate the national organization's 60th anniversary. Help us look to the future as we define "A Clear Way Forward" that ensures another 60 years of advocacy and service.

## spotlight on donor quincy abbot: “it’s only the arc that can get us there”



“The Arc has been there for 60 years when there were no other organizations fighting for the rights of people with intellectual disabilities and for the services for them. If you have a child, you can’t just be concerned with what is going on today but about what will happen in the future,” says Abbot. “If you want to ensure your child’s future, you want to be a part of The Arc on the state, local and national level,” he says.

Abbot is father to Becky, who was born with brain damage in 1963; he attributes The Arc with ensuring that Becky received a monthly supplemental security income beginning at age 18.

Before retiring, Abbot headed the tax department at Connecticut General. He has experienced first-hand the tenuous structure of services for a child with an intellectual disability. After his company merged to become CIGNA, “the headquarters moved

In the over forty years that Quincy Abbot has been connected with The Arc, he has been an active force for change in the lives of people with intellectual and developmental disabilities. Abbot, a long-time volunteer and leader with The Arc of Connecticut, has served as President of The Arc of the United States and The Arc of Connecticut, in other leadership positions at all levels of The Arc and as a generous financial supporter.

to Philadelphia. I learned that there was a ten-year wait list simply to put her name on a separate waiting list for services in Pennsylvania; I was the only senior corporate staff member to get permission to remain in Connecticut.”

Abbot is currently involved in The Arc of Connecticut’s 15-year long legal battle for quality care and community placement for the residents of the Southbury Training School. As Chair of the litigation committee of The Arc of Connecticut, he has spearheaded efforts to give the residents at the institution a real opportunity to relocate into the community. He is presently participating in U.S District Court hearings as a first step in determining appropriate remedies.

Abbot’s role in the disability rights movement has helped shape policy and resulted in tangible impact, such as the closing of institutions. After the settlement of a similar case regarding Mansfield Training School in Connecticut, Abbot helped found and served on the board of the Corporation for Independent Living, a housing developer. That organization is celebrating its 30th year and now has assets of over \$100 million. He

chaired the Connecticut Governor’s Council on Mental Retardation from 1988-1994. Since the Olmstead decision of the Supreme Court in 1998, Abbot has represented The Arc of Connecticut on cross disability activities, including Steering Committees for federal grants for Nursing Facility Transitions, Money Follows the Person and Medicaid Infrastructure Changes to increase the employment of persons with disabilities.

Abbot takes a long view on the role an organization like The Arc plays in society. “There is certainly a lot of momentum now. Sixty years ago when The Arc was formed, no one could have foreseen what life for people with disabilities would be like today,” he says.

“The ideal that we’re working toward may take longer than another 60 years. I look forward to a day when people with intellectual and other disabilities won’t need The Arc or any other organization because all people will be recognized for their gifts and just lead lives as people like everyone else. That’s the ultimate goal—to put yourself out of business. As an organization, it’s only The Arc that can get us there,” Abbot says. ■

## Florida

Florida is facing a \$1.5 to \$2 billion dollar state deficit this year. "Cuts like these are nothing new but this year is a particularly bad one," says Deborah Linton, Executive Director of The Arc of Florida.

This year, The Arc of Florida is advocating for multiple pieces of legislation. One of these bills includes a college tuition plan called the Prepaid Services Plan, which is aimed at young families to jump-start their planning for the future needs of children with a developmental disability. For more information on the prepaid plan, go to [www.floridagapplan.com](http://www.floridagapplan.com).

The Arc of Florida is also pushing for a special lottery scratch-off ticket to benefit individuals on the wait list. Revenue from ticket sales would create a 'win-win' situation for families on the wait list and would help to increase the State coffers.

A third bill currently

working its way through the Florida Legislature would allow Florida citizens who are renewing their driver's licenses or motor vehicle registrations to make a voluntary contribution to The Arc of Florida. The monies collected from these donations would then flow back out to local chapters for services and supports in their communities.

Michele Poole, President of the Board of The Arc of Florida, said that increased support was evidenced by attendance at their annual Advocacy Day at the State capitol, where approximately 400 parents, professionals and self-advocates rallied. Some of these advocates had the opportunity to testify before the Senate Health and Human Services Appropriations Committee. A member of that committee has introduced legislation to delete the term "mental retardation" in all State statutes and replace the term with



"intellectual disabilities."

"Members of The Arc assured their local legislators on Advocacy Day that we were also working on our Congressional delegations to pass legislation to continue the increased FMAP (Federal Medical Assistance Percentages) to the states," Poole says.

## Virginia

Like California and Florida, Virginia is facing budget shortfalls and unprecedented cuts to services. "By dismantling the community-based safety net and promoting a policy of institutionalization, Virginia's budget proposals truly jeopardize the civil rights of people with intellectual and developmental disabilities," says Jamie Liban, Executive Director of The Arc of Virginia.

Virginia was hit with former Governor Tim Kaine's proposal to eliminate more than \$270 million in home-and-community-based waiver services. In February 2010, Governor Bob McDonnell proposed an additional cut that would eliminate self-directed services all

together. In the same budget, Virginia proposes spending \$47 million to rebuild and renovate large, segregated, state institutions, a shocking retreat from a 40-year commitment to community-based services.

The budget will be sent to Governor McDonnell for action and "it appears some services will be saved due to the extension of the enhanced federal Medicaid match, another reminder why The Arc's national network is so critically important," Liban says. "However Virginia's legislature still plans to eliminate more than 900 I/DD Waivers that were promised to families on the waiting lists last year," she added.

Liban observes that "the policies proposed in the budget are reigniting the civil rights movement on behalf of Virginians with intellectual and developmental disabilities. Every day, we are seeing more and more people with developmental disabilities and family members get-





ting connected with The Arc for the first time. Families are finding their voice and the movement is becoming stronger.”

On President’s Day 2010, people with developmental disabilities and their families held a march for civil rights on Capitol Square, 50 years after the first Richmond lunch counter sit-in protesting the segregation of African Americans. Hundreds traveled from across the State calling for Governor McDonnell and members of the Virginia General Assembly to eliminate cuts to community-based services and stop plans to rebuild large, segregated state institutions. Protestors also held vigil in the hallways of the General Assembly for 47 minutes, in protest of the \$47 million being invested to segregate people with developmental disabilities.

Liban reflected on the budget protests in Virginia and across the nation saying, “budget challenges remind us that it is often through adversity that we grow stronger. Now, more than ever, we see The Arc is so much more than an organization—we are a civil rights movement.” ■

## inventing parlerai: a tool for communication

As parents to their daughter Karly, Kristin and Jon Erickson face the challenges of many parents of children with a disability. So Kristin, a community business leader, and Jon, an internet technologist, combined their skills to co-found Parlerai, the world’s first Augmentive Collaboration Service to help family’s track and share information about their child’s life with teachers, aides, therapists, babysitters, relatives, friends, and others. Parlerai, French for “shall speak,” is a new way of communicating through an Internet site.

The Arc and Parlerai have partnered to build a bridge to assist these families and ultimately empower them. To register for a Parlerai account, and get a discount, enter the promo code “TheArc” and a portion of the proceeds will go to The Arc of the United States (once members use Parlerai for at least three months.)

When they co-founded Parlerai, the Erickson’s vision of a communication interface to help their daughter Karly have a voice merged with their desire to positively impact the lives of individuals with disabilities and their families.



“Never before have parents had access to such a powerful and necessary tool. It will have a tremendous impact on a parent’s ability to influence the outcome of IEP (individualized education plan) meetings and medical and clinical reports,” Kristin says.

While their daughter was the inspiration for the Erickson’s when they co-founded Parlerai, they also saw it as a means for all people with special needs. “Our desire,” Kristin says, “is to improve quality of life for people with special needs.”

For more information, visit [www.parlerai.com](http://www.parlerai.com). ■

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## words & action continued from page 3

Our advocacy on behalf of people with intellectual disabilities makes us shepherds in protecting their basic human and civil rights. We have an opportunity through the passage of Rosa’s Law to drive home the point that language plays a crucial role in how people with intellectual disabilities are perceived and treated in society.

This legislation would replace the terms “mental retardation” and

“mentally retarded” with “intellectual disability” and “individual with an intellectual disability” in federal health, education and labor policy statutes.

While The Arc will keep fighting the good fight through words and in action, we do so with the understanding that the issue is larger than changing language. To paraphrase the mother of Rosa, an eight-year-old with Down syndrome after whom the legislation

is named, “you cannot separate what you call people from how you treat people.”

Oh, and in case you were wondering, The Arc is still waiting for a response from Rush Limbaugh.

Use The Arc’s Grassroots Action Kit on Rosa’s Law. Join the effort <http://www.thearc.org/NetCommunity/Page.aspx?pid=2254>. ■

# choosing the right one: summer camps for children with i/dd

by Howard Blas, MSW, MA. Blas is the director of the Tikvah Program at Camp Ramah in New England ([www.camprahamne.org](http://www.camprahamne.org); [www.howardblas.com](http://www.howardblas.com))

Summer camp—both day camps and overnight camps—offer opportunities for children to learn new skills, form friendships, experiment with new interests, and learn new things about themselves. Children with intellectual disabilities are increasingly participating in these programs. But truly succeeding in a camp requires parents to be good consumers, advocates and partners.

## Be a Smart Consumer

In considering a camp for your child, do your research. There are many types of camps: day and overnight, specialty camps (sports, horseback riding and drama), separate camps for children with various special needs, and camps with inclusion programs for which The Arc advocates.

Ask how the day is structured. What activities are offered? Are campers required to participate in all activities or can they opt out of some? Is there a “free choice” period? What about children who need breaks? What are the background and ages of staff? Is English their first language or are they proficient in English? How are meals run and supervised? How is medication administered and monitored?

## Be a Good Advocate/Be a Good Partner

Build on the countless hours you have spent advocating for your child in the school system and use these advocacy skills on behalf of your camper. What modifications is the camp willing to make for your child? Explain the types of programs where he/she has been successful. Speak to the inclusion specialist, division head or head counselor.

Provide school evaluations, therapist reports, occupational therapy and physical therapy reports. This will help the camp assess whether they are a good fit for your child and assure the camp truly understands your child as they strive to meet his/her unique needs.



## Challenges and Opportunities for Success at Camp

Once your child is accepted, the opportunities for friendships and social growth are unparalleled: interactions and opportunities for verbal and nonverbal interactions and instant feedback, discovering other children with common interests and developing enduring friendships.

While your child will not be in an academic setting, some of the same issues experienced in school may surface perhaps from frustration with and difficulties in social situations. Living in a bunk with ten or more peers can also lead to misunderstandings. Being away from home can be an opportunity for growth, but it can also lead to periods of homesickness. Sharing tight quarters means little privacy and little personal space. Your child will have to keep his/her possessions contained, learn to shower, dress and undress modestly and quickly, and he/she will have to carefully navigate and negotiate many social situations. ■



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## this month's success story: house passes the “keeping all students safe act”

In a great victory for disability and civil rights advocates, the House of Representatives passed the Keeping All Students Safe Act (formerly, the Preventing Harmful Restraint and Seclusion in Schools Act), by a vote of 262-153. The bill, which would set the first federal safety standards on restraint and seclusion in schools, will put significant restrictions on schools restraining children, confining them in seclusion rooms and using aversive interventions that could harm them. The legislation stems from a congressional report last year citing hundreds of cases of alleged abuse and death from restraint and seclusion in public and private schools in the past two decades. The Government Accountability Office report said the majority of students in the study were students with disabilities. The legislation awaits Senate action.

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### be part of the progress™: donate to the arc

Your generosity helps The Arc continue our vital work. Together we are protecting the human and civil rights of people with intellectual and developmental disabilities by continuing to improve the systems of supports and services, connect families, inspire communities, and influence public policy. Please visit <http://www.thearc.org/netcommunity/SpringList> to see a list of recent generous supporters. If you would like to speak to someone in Development, call Trudy Jacobson at 202.534.3714 or Molly Farrell at 202.534.3713. ■

