

empower

Real People, Real Progress

states slash medicaid: hard choices for people with disabilities

"Amidst all the budget cuts in South Carolina, The Arc of South Carolina is hard at work advocating for our families who have had a reduction in their services." — Suzanne Yankowitz, Executive Director, The Arc of South Carolina

The Arc of South Carolina is on the frontlines in pushing back against deep cuts to critical supports and services for residents of the State. Suzanne Yankowitz, Executive Director of The Arc of South Carolina, knows first-hand the crisis faced by her State and others, and in response, chapter advocacy is even stronger.

"Amidst all the budget cuts in South Carolina, The Arc of South Carolina is hard at work advocating for our families who have had a reduction in their services. As a local service provider in the state, several of our families who have adult children with intellectual disabilities and who have had their Personal Care Services reduced were able to get an increase in respite hours in order to supplement their lost hours and ensure continuity of care," Yankowitz said.

Though for other families who do

not have services in place due to not having a MR/RD (Mental Retardation and Related Disabilities) Waiver or Community Supports Waiver, The Arc has utilized The Community Long Term Care Waiver.

"It is our hope to successfully work with state agencies to affect some meaningful systems change to service delivery. The Arc has been extremely creative with obtaining services and this has resulted in our families being satisfied with the level of services that are in place," Yankowitz added.

At The Arc of South Carolina, several new families recently changed service coordination to The Arc so they can get help advocating for their services. "While cuts for the future are a possibility," Yankowitz said, "The Arc of South Carolina continues to advocate for families and continues the 'out of the box' thinking to help

families obtain services. The Arc, in partnership with the South Carolina Department of Disabilities and Special Needs (DDSN) continues to advocate for the services that are desperately needed in our State."

As in South Carolina, families across the nation face harsh and increasingly painful realities of Medicaid budget cuts affecting people with disabilities, especially those with intellectual and developmental disabilities. A recent story in *The Wall Street Journal*, "Disabled Face Hard Choices as States Slash Medicaid" focused on residents of South Carolina, including Barbara Hickey of Florence, S.C. "Born with cerebral palsy, Ms. Hickey, now 67 years old, is confined to a motorized wheelchair. She lives alone and relies on certified nurse's assistants to get her in and out of bed, bathed, clothed, and fed."

Ms. Hickey received a letter in December from the South Carolina Department of Special Needs and Disabilities, saying her weekly 50

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— Suzanne Yankowitz,
Executive Director,
The Arc of South Carolina

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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.

the arc@60 national convention: glee cast members joining celebration!

The Arc's National Convention is an opportunity to empower everyone in our cause—individuals with I/DD, self-advocates, families, volunteers, staff members, professional service providers, experts, and advocates. Come to reaffirm our commitment, show our strength and celebrate this year as we move forward in Orlando, Florida, November 3 -6, 2010.

In celebration of The Arc's 60th anniversary, Convention will include many special guests. Actors Lauren Potter and Robin Trocki, from the hit show *Glee*, who will be honored with The Arc's *Inclusion & Image Award* in recognition of their achievements in television for breaking down barriers, increasing awareness and challenging stereotypes. Jane Lynch (coach Sue Sylvester on *Glee*) will appear at Convention via video from Los Angeles delivering a message to attendees.

Marking six decades of unparalleled service and support for Americans with intellectual and developmental disabilities (I/DD) is cause for joyous remembrance. What better place to celebrate The Arc@60 than in sun-drenched Orlando at the Hilton in the *Walt Disney World*® Resort, just steps from Downtown Disney? Convention will offer plenty of opportunities to play and visit some of Disney's most popular attractions.



Lauren Potter

Actress Lauren Potter of *Glee* plays Becky Jackson, a William McKinley High School special education student with Down syndrome who is accepted onto the cheerleading team.

Glee underscores inclusion for people with disabilities as coach Sue Sylvester treats Becky like she treats every other cheerleader, pushing her to her absolute limits, never once going easy on her because of her disability.

Actress Robin Trocki plays Jean, the sister of coach Sue Sylvester (played by Jane Lynch) on the popular FOX program *Glee*. Robin, who has Down syndrome, is pivotal in the show's storyline to understanding Sue's most often hidden positive qualities as the show's lead character and nemesis.

Through Robin's portrayal of Jean, who lives in a residential home for people with disabilities, viewers of *Glee* experience a personal perspective on relationships between siblings and on independent living.



Robin Trocki

fernald to close at last?

controversy surrounds what's best for residents

by Leo V. Sarkissian, Executive Director, The Arc of Massachusetts

The state of Massachusetts' plan to close the Fernald Development Center in Waltham in late June is ringing alarm bells in some quarters. The plan to close Fernald is a component of Governor Deval L. Patrick's Community First initiative to shutter sprawling, decrepit institutions and move their residents into community-based living.

Two months ago, it had been feared that when Fernald finally shuts its doors, the Tufts Dental School clinic housed on Fernald's grounds would close too. The clinic's dentists and hygienists provide essential oral health services to more than 2,000 people with intellectual and developmental disabilities (I/DD).

However, Tufts University announced that the clinic would remain open another year while State officials craft a plan to accommodate patients at six other dental facilities operated by Tufts.

From the outset, those who oppose closing Fernald have tried to make political hay over the status of the dental clinic arguing that the dental clinic would be collateral damage from Fernald's closure. This was another reason to spare the archaic institution its overdue fate according to opponents. Their argument fails to recognize the likelihood that the clinic's services would be made available at other Tufts clinics. More importantly, it ignored the fact that overall health care, shelter, food, employment, and other services for people with disabili-



Governor Deval L. Patrick and Leo V. Sarkissian, Executive Director, The Arc of Massachusetts

ties is of superior quality and improved efficiency when delivered through a network of state-sanctioned, community-based homes and program settings.

Now the foes of shutting down Fernald and three other institutions in the Commonwealth are pressing their case at the State House. A budget amendment, filed by Rep. Anne M. Gobi (D) representing Spencer, MA, would delay the closing of the Waltham facility and three other similarly outdated and under-populated institutions.

Sadly, the House of Representatives has approved the amendment, undermining the commitment of the Legislature at large to community-based housing, as well as to the wise use of taxpayer dollars at a time of severe fiscal constraints.

In late May, several passionate supporters of the closure delay visited senators to push for the same language in the State budget. What these supporters don't realize is that stalling institution closures will mean further cuts in community services. The FY'2011 budget depends on more than \$11 million in savings from institution closures, most of this attributable to Fernald. There are 81 individuals left at Fernald and less than 800 hundred at the remaining institutions, which were originally designed for 10,000 people.

The Arc has weighed the arguments for and against closing Fernald and three other such facilities in Massachusetts by the 2013 deadline set by Governor Patrick. The State has concluded that the evidence in favor of closing them far

outweighs the notion that their residents would be ill-served by placement in community-based homes.

One argument advanced in favor of maintaining the institutions derives from the belief that their residents are 'too disabled' to live in the community. The reality is that when such facilities have been closed in the past (Belchertown State School in 1992 and Dever Developmental Center in 2002, to name just two), more than 95 percent of the residents were found to have made successful transitions to community settings.

According to K. Charlie Lakin, a disability policy researcher, those who moved showed significant improvement in "overall adaptive behavior," self-care, academic ability, communication, socializing, and other skills. By contrast, those who resided in large institutions, Lakin reported, "received habilitative experiences that were substantially and consistently inferior to those of people living in community settings."

Perhaps the most persuasive proof is to be found in the numbers. A budget analysis of maintaining the institutions has shown that the average cost of serving an institutionalized individual with a disability is nearly double (\$501-\$548 per day) the cost of serving

spotlight on donor susan mills: “inspired by my brother”

Like so many who are a part of The Arc movement, Susan Mills and her husband support the organization as relatives of people with intellectual disabilities. Susan Mills' late brother, Edward (Ted) Lee Sheley III, had an intellectual and developmental disability, and she and her husband support The Arc in his memory. Susan and her husband Gary have also made gifts to The Arc on behalf of Gary's Aunt Vera, who has severe developmental disabilities.



Edward (Ted) Lee Sheley III

Families of people with intellectual and developmental disabilities face tough challenges and hard decisions around the care of their family member. For nearly two decades, Ted Sheley lived both with his father as well as part time in an assisted care home run by a foundation. As

Ted's health problems mounted, the assisted living facility determined that they could no longer care for him. Susan recalls receiving an e-mail from their father about “the most difficult decision he had to make in his life.”

As is the case with many siblings, when their father passed away, the difficult decisions around her brother's care fell largely to Susan and her husband.

Placement in another assisted living home “didn't work out” for Ted, and Susan, “by the grace of God, met a social worker at a day program who found housing for him in Maryland.” Ted flourished in his new home, enjoying the company of the other residents and the live-in staff and

obtaining a scholarship for a day program. But sadly illness struck Ted suddenly on his first bus trip to the day program and he passed away at age 56.

Susan recalls her brother touching many lives, adding that he was “a great guy!”

“He was an important member of our family and he loved joining in family events, especially sports. We played games as kids such as naming the states, and he was better than me! Ted loved the Redskins, he bowled and he was a big fan of the Baltimore Orioles. He read the newspaper every day,” Susan said.

As a loyal donor, Susan makes giving to The Arc a funding priority. She's connected locally and on the state level in Maryland where she and her family reside. Susan is dedicated to giving to The Arc on a national level to support opportunity for people like her brother and their families. To donate to The Arc visit <https://www.thearc.org/NetCommunity/SSLPage.aspx?pid=349> ■

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hours of personal-care help was being cut back to 28 hours.

Peter Berns, CEO of The Arc said, “we are hearing and experiencing hundreds of stories of lives being disrupted due to these cuts with states putting no viable alternatives in place. There are countless thousands of individuals like Ms. Hickey across the country.

These disruptions in many cases create life-threatening situations for the individuals that need critical personal supports to live, work and derive satisfaction from their lives. Drastic cuts such as these upend the lives of individuals and families who rely on a systematic network of support.”

Cuts to Medicaid services to people with disabilities result in a withdrawal of essential supports to engage in fundamental life activities that many of us take for granted, activities such as not being able to get out of bed or not being able to feed or toilet oneself. It is nothing short of a violation of the civil and human rights of these Americans.

Cuts in funding further destabilize the economic health of families that are doing all they can to support their loved ones. This will have an unprecedented domino effect for states, which if left unchecked, will exacerbate the already crushing effects of Medicaid cuts. These families have saved state governments millions of dollars by

providing care to their family member in their homes and in their communities.

“With the Health Care Reform Act recently enacted, we are deeply concerned that the promise of health care reform will be compromised significantly by states' decisions to not partner with the federal government as we seek to improve health care and long-term care services and supports, while at the same time minimizing the costs and maximizing outcomes,” Berns said. To learn about Medicaid and The Arc's Public Policy visit <http://www.thearc.org/NetCommunity/Page.aspx?pid=209> ■

IEP guide for parents:

10 tips for ending the school year

As another school year comes to a close and parents shift into the summer phase of activities for their children, it's an ideal time to assess whether the Individualized Education Plan (IEP) charted out for your child was successful during the school year.

Parents, in conjunction with educators and others involved in creating an IEP for a student, commit their combined energy toward crafting a school plan to address the specific needs of a child.

This team's work to develop a course of action should also include the most important player: your child. Your son or daughter's participation in the IEP process is critical to ensuring his or her ongoing success.

The close of the school term offers an excellent opportunity to determine if goals were met, benchmarks were reached and if the IEP fit the child's needs. Did the educators and the school meet your expectations? Would you say your child's school experience for the year was productive and successful? We know that each time you meet for an IEP the "experts" advise on a defined scale if each goal was reached, but you live with your child: do you see, feel, experience the aforementioned improvements?

Don't wait until 'back to school' in the fall to consider these questions. If you evaluate the IEP process while the school experience is still fresh, you'll be better prepared to plan the success of your child's upcoming school year. Plan ahead!

Pat Howey, an advocate with the Upside of Downs of Cleveland, shared these IEP tip and tools:

1. Visit the new school or classroom.

Will your child make a major transition next fall? Will your child be moving from preschool to kindergarten, from elementary to middle school, or from middle school to



high school? Plan to take your child to visit the new school or classroom before the first day of school.

2. Review your child's IEP and progress.

Did your child make progress this school year? Did the school properly implement the IEP? Does the IEP adequately address your child's needs? Do your child's goals prepare your child for further education, employment and independent living?

3. Don't be afraid to ask for an IEP Team meeting if necessary.

Did you answer "No" to any of the questions above? Ask for an IEP Team Meeting to resolve these concerns. Do not let another year go by with an inappropriate IEP.

4. Prepare for the IEP Team Meeting.

With your child prepare a list of your child's present levels of performance. The list includes your

child's strengths and the areas that are challenging. Look carefully at this list and you will better understand what your child needs. Add these needs to your list of present levels of performance. You can also add goals, related services, assistive technology, and anything else that your list justifies as an educational need. Don't let the resources of the school guide whether or not these resources should be added to the list. If resources ever change your IEP will reflect what you already asked for in it.

5. Say "thank you" to those who helped.

Did your child have a great school year? Was this success due to a wonderful teacher, a helpful classroom aide or a thoughtful bus driver? Say "thank you" to those who helped your child succeed. Look at what made this a good year for your child. Add that information to the list of your child's present levels of performance.

6. Give your information list to the IEP Team before the meeting.

Do not surprise other members of the IEP Team. At least one week before the meeting, give a copy of your list to each member of the IEP Team. Take extra copies to the meeting for anyone who forgets to bring their copy. Your IEP Team Meeting will go faster and smoother if everyone has your list ahead of time.

7. Ask for a copy of any information that has been given to other members of the IEP Team.

You do not want to be surprised. Ask for copies of all information

the IEP Team will discuss. You cannot be a full team member if you are left out of the loop. Ask for things like copies of teacher reports, evaluation reports and group achievement testing.

8. Ask the IEP Team to address Extended School Year (ESY).

Ask the IEP Team to address ESY early in the second semester. If there is disagreement about whether your child needs an ESY, you will need enough time to resolve this with one of the due process procedures available.

9. Find out what summer educational resources are available for your child.

An ESY is not the same as summer school. Summer school is usually a generic program that is not designed to meet your child's individual needs. An ESY program is intended to meet the specific educational needs of your child as identified in his or her IEP. Make sure you know what services the school is offering!

10. Determine whether your child needs a new evaluation.

Does your child need new evaluations? Are you unsure whether your child has made adequate progress? Achievement testing at the beginning and end of every year will give objective answers about your child's progress.

To read more about The Arc and education visit <http://www.thearc.org/NetCommunity/Page.aspx?pid=1369> ■

the new health care reform law: state level planning for medicaid home and community-based services (HCBS) starts now

The law contains new options for states to provide long term services and supports that will become effective over the next few years. Advocates should begin to work with states to utilize these new options:

- The Community First Choice Option provides a 6% increase in the federal share of Medicaid for providing comprehensive Home and Community-based Services including hands-on assistance, supervision, and cueing.
- Removal of Barriers to Providing Home and Community-Based Services makes improvements (e. g., offers more types of services) to an existing program for serving people who do not need an institutional level of care.
- Rebalancing Incentives provide states with increased federal share of Medicaid (up to 5%) for increasing the proportion of HCBS.

Eligibility for these programs will be based on functional need, rather than diagnosis or age. Working with disability and aging coalitions will be essential to ensure that Governors, state legislatures, and other state level officials take full advantage of the improvements for our constituents. Learn more about health care reform at <http://www.thearc.org/NetCommunity/Page.aspx?pid=209> ■

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them in the community (\$314 per day, including state- and privately operated homes and day/transportation expenses). Those findings are all the more dramatic when one considers that 81 people now live at Fernald, a multi-building, 180-acre spread that, from its beginnings in 1848, grew to be home to 2,600 people by the 1960s.

Indeed, Fernald originally was known as the Massachusetts School for Idiotic and Feeble-Minded Youth, and treatment of its "students" was truly deplorable. It has been well documented that physical and sexual abuse of the residents was widespread; some of them were treated as guinea pigs, subjected to "scientific" testing that involved being fed irradiated oatmeal. Conditions at Fernald were so bad that from 1972 to 1993 oversight of the facility was in the hands of the federal court in Massachusetts.

Those who argue that Massachusetts is rushing to close Fernald and other institutions fail to acknowledge that 140 such institutions nationally have closed since 1970 while Massachusetts has shut down only three; nine states and the District of Columbia have closed all their institutions. Per capita, Massachusetts has the 15th highest percentage of individuals living in institutions in the nation.

As a part of The Arc, The Arc of Massachusetts are the first to acknowledge that change can be exceedingly difficult in a society without full inclusion. But, as advocates for people with I/DD, we would be remiss if we did not sound an alarm of our own—that the era of Dickensian, deservedly maligned institutions housing those who are least able to voice their objections must come to an end, beginning this June 30 at Fernald. ■

welcome ann cameron caldwell: the arc's new chief research and innovations officer

Ann Cameron Caldwell, Ph.D., has joined The Arc as the new Chief Research and Innovations Officer. AC (as she likes to be called) will advance The Arc's mission at national and local levels through innovative growth and outcome opportunities in partnership with public agencies and foundations, while implementing effective organizational metrics and knowledge management practices.

"Ann Cameron is widely respected in the disabilities field; she brings a wealth of experience in forging partnerships with philanthropic organizations, public agencies and others on behalf of people with disabilities. Her background in these areas and in academia will serve to strengthen and support The Arc's continuing growth and momentum," said Peter Berns, CEO of The Arc.

Prior to joining The Arc, Dr. Caldwell was Assistant Vice President for Grant Development at Easter Seals, Inc., a post she held since early 2007. Previously, Dr. Caldwell was an independent consultant to nonprofit organizations in strategic development and program evaluation.

She obtained her doctorate in Disability Studies from the University of Illinois at Chicago, where she was also project coordinator of the Rehabilitation and Research



Ann Cameron Caldwell

Training and Technical Assistance Center on Aging with Developmental Disabilities, funded by the National Institute of Disability Rehabilitation Research. Dr. Caldwell received her Master's degree from The University of Chicago. She is also the parent of a teenager with Down syndrome. ■

Join The Arc's Online Community

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

liz savage to join department of justice

In July, Liz Savage, Director of Health and Housing Policy for the Disability Policy Collaboration, (DPC) a partnership of The Arc and UCP, will be leaving The Arc to join the Civil Rights Division in the United States Department of Justice. A recognized leader in the disability community, Liz serves as the co-chair of the Consortium for Citizens with Disabilities Health and Housing Task Forces.

For almost nine years, Liz has spearheaded The Arc's advocacy efforts on health and housing policy for people with intellectual disabilities. Along with Marty Ford, Director of Legal Advocacy for the DPC, Liz was instrumental in ensuring that key provisions of importance to people with intellectual disabilities, such as the prohibition of pre-existing condition exclusions in health insurance, were included in the historic health care reform legislation. She also played an instrumental role in the expansion of Housing and Urban Development housing programs for people with intellectual and developmental disabilities.

Prior to joining The Arc, she served as Counsel to the Assistant Attorney General for Civil Rights during the Clinton Administration where she directed the Justice Department's enforcement of the Americans with Disabilities Act (ADA). The Arc wishes Liz well in her new position and is grateful for her contributions to our movement. ■



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network, learn and recharge: register today for nce summer leadership institute

Are you an executive with a chapter of The Arc? If so, join us and your fellow chapter executives at The National Conference of Executives of The Arc (NCE) Summer Leadership Institute in Reno, Nevada, from July 29 to August 1, 2010. Only at this year's conference will you hear from strategic planning consultant Allan I. Bergman, who will share how to align your organization's values and activities in a manner that strategically advances your mission. You'll also hear from Jonathan Paisner, Brand Director with CoreBrand, our award-winning branding consultant; he'll share the latest on The Arc's rebranding efforts and what it will mean to your chapter. To learn more about these and other program sessions—and to register, visit www.ncearc.org.

when you have a will, you have a way to help change lives

When you have a will, or other estate plan, in place, you can protect your loved ones and create a lasting legacy that continues your profound commitment for the work done at The Arc.

- ☐ Yes! I know that estate planning is very important! And,
___ I have included The Arc in my estate plans.
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Or, please contact, Trudy Jacobson, Chief Development & Marketing Officer at 202 534 3714 or jacobson@TheArc.org

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