

### Performance Excellence: Its Past, Present and Future

The Performance Excellence Committee met on May 6, in conjunction with the ANCOR 2012 Conference: *Leading Cultures of Innovation & Advocacy*. In that meeting, the committee reviewed the financial status of the Performance Excellence program and determined we could no longer continue to actively operate the program via Deyta without greatly overspending our budget.

We also determined the only prudent course of action is to place the PE program on suspension for an indefinite period beginning June 1, 2012.

The PE leadership and a core group of committed participants continue to believe in the value of ANCOR sponsorship of a national performance benchmarking program, but Performance Excellence has not caught on with the majority of ANCOR's membership, and the trend suggests that won't happen soon. (Read how PE has helped organizations excel in this issue.)

#### The Beginning of PE

The Performance Excellence Initiative was developed by ANCOR in 2004, but actually began to collect data for the year 2008. We've just published PE data for 2011—our fourth year of operation. (Check out the article on page 5 for a summary of the results.)

After starting with data that represented 29,205 people receiving supports for 2008, participation reached a high-water mark of 58,349 people receiving supports for 2009, but then dropped to 36,699 for 2010 and remained stagnant at 38,610 people receiving supports by 27 provider agencies in 36 states for 2011.

#### The Present State of PE

With the current level of participation in PE, we don't have a critical mass of data in the program in order to do effective performance benchmarking. These observations suggest

that it is appropriate to redirect ANCOR's resources to other programs and suspend or terminate the program.

From program inception through the end of 2011, ANCOR's contract with Deyta for technical administration of PE called for ongoing maintenance and provider support fees, and we budgeted for that same level of expense in 2012. Unfortunately, in the last two weeks of 2011, we were surprised to receive a 2012 renewal offer from Deyta that included a very large price increase.

While there was some legitimacy to Deyta's request for a large fee increase based on the scope of work—as Deyta had been a significant participant in the revision of the PE Toolkit and development of a PE Business Plan—the timing of the request was unfortunate and left the program in a very difficult financial position for 2012.

In consultation with the CEO and Executive Committee, we made the decision to accept Deyta's final offer to continue their services through the first quarter of 2012, recognizing that we would spend our entire annual budget for PE within the first four months of this year.

As we made that decision, we expected to have a Centers for Medicare & Medicaid Services decision on our innovation grant proposal by March 30. We understood that if we received approval of the grant, it would be necessary to completely revamp PE and the relationship with Deyta.

We also acknowledged that if we did not receive CMS grant approval, we would need to make a decision to suspend or terminate the program soon after the end of the first quarter of 2012.

We received word on June 15 that ANCOR was not selected as a grant award recipient.

#### The Future of PE

Recognizing that we must cease active operation in order to prevent a more serious shortfall, the committee nevertheless doesn't want to lose the value of the work that's been completed to date. We prefer to suspend the PE program for an indefinite period of time, while we investigate alternatives for future viability of the program.

Placing PE on suspension does not mean we will end the work of the committee. Rather, we will turn our focus to the future of the program. In particular, we will examine the question of whether the Performance Excellence work product developed by ANCOR should be combined with other quality benchmarking efforts by other organizations.

While the future of PE may be uncertain, its value to both ANCOR and those who have participated in the program are undoubtable. PE has a future—it's just that the context of that future is still unknown. ●

*If you have questions or comments about any aspect of this transition of the Performance Excellence, contact Debra Langseth at [dlangseth@ancor.org](mailto:dlangseth@ancor.org).*

#### Inside this Issue of LINKS:

*For more articles on performance excellence, see pages 3-7.*

*Didn't attend the ANCOR 2012 Conference: Leading Cultures of Innovation & Advocacy? Find out what you missed on pages 9-14.*

*ANCOR welcomes Dick Farnsworth as its new benefits representative, page 17.*

## Culture Trumps Chaos

By Renee Pietrangelo  
ANCOR CEO

An organization's culture reflects its genetic makeup—its DNA, if you will. The components of culture inform and instruct how our organizations handle creativity, risk-taking and response to seismic change. It isn't something peripheral to our business; it is, in fact, our way of doing business.

Every time you examine the intersection between trends; face the brutal facts of the current reality; engage in innovation; foster creativity; maintain an aggressive solutions focus that enhances quality of supports and services to the people you serve; and consistently recognize direct support excellence, you send a clear message to the entire organization about what you value.

If we forget to do these things, we still build a culture—a culture of disengagement and mediocrity, a culture that serves as a boat anchor to any change and progress we hope to make.

In his keynote at the recent ANCOR 2012 Conference, Dr. Angelo Armenti credited the successful transformation of California Uni-

versity of Pennsylvania under his leadership as its president to creating additional degrees of freedom within an environment fraught with constraints.

We heard that theme repeated by David Leslie, who as interim CEO of National Children's Center in Washington, D.C., worked to find additional degrees of freedom within the daunting constraints of antiquated operational policies and procedures, outmoded thinking paradigms and incongruous regulatory burdens.

Both leaders saw themselves as "aligners in chief"—consistently aligning vision, goals, strategies and measureable outcomes while maintaining focus on nurturing a strong culture and establishing accountability across the board. They were both faced with the challenge of bridging the gap between today's strategies and tomorrow's problems.

There are few existing models or strategies that are sufficient in themselves to meet an increasingly complex future. We need an era of massive innovation.

These examples underpin ANCOR's reasoning in partnering with the Covey leadership



Renee Pietrangelo

group. In fostering the Covey "Leader in Me" principles through the Lighthouse Agencies pilot program launched in June 2011, we provide the tools for a solid cultural foundation that enhances and advances commitment, creativity and innovation, accountability and a laser-focus on quality supports and services that realize the potential and aspirations of the people served.

We're poised to launch our second class of pilot agencies, and it's not too late to climb on board. Contact Debra Langseth at ANCOR for more information.

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*ANCOR would like to welcome its newest members:*

*Commonwealth Case Management  
Group Main Stream  
Partnerships for People, Inc.  
Quest, Inc.*

*Continued from previous page.*

In contributing to the culture of home and community-based supports and services, ANCOR continues to play a key national role as a policy and practice expert. Our recently released *Funding Reform Checklist* provides a comprehensive guide for dialogue with state officials considering a capitated funding structure for long-term supports and services.

The checklist is just one of the ways ANCOR is helping to frame fundamental thinking about funding alternatives in important ways. The checklist starts, as it should, with principles and values and deals with all the practical aspects of capitated funding, including rates, metrics/outcomes, dealing with managed care organizations and more.

We hope you'll use this tool to engage leaders in your state, and we'd like to hear your feedback on how it went. Please contact ANCOR State Association Executives Forum Liaison **Diane McComb** with your updates.

As a final point, ANCOR recently completed an exhaustive study of communications and messaging strategies based on diverse member and stakeholder input. We're using the treasure trove of data we gleaned from this process to instruct and inform our own culture and how we communicate in response to member needs and the transformational environment in which we find ourselves.

As these examples illustrate, we understand the imperative to build a strong culture and adjust how we do business. We continue to work on multiple fronts to make those adjustments in the best and most informed ways possible. ●

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## Benchmarking: Performance Excellence for All?

*By Wendy Sokol  
ANCOR President*

**B**enchmarking systematically compares one organization's practices and standards against an industry leader in order to create new and improved business practices and standards that lead to better services.

It also builds a set of performance standards and benchmarks within our industry; provides tools and performance measures to guide decision making around capacity building; provides an opportunity for shared learning experience with other organizations that are similar to your organization; and establishes best practice models and a common database.

ANCOR's Performance Excellence Initiative is a form of benchmarking. Organizations participate so that they can improve the quality outcomes for the people they support, as well as learn best practices to improve retention and satisfaction of their employees. These are clearly the goals that would be shared by all ANCOR members. And though benchmarking has had a slow start in our industry, we know that it will inevitably become a mandate.

Benchmarking is driven by organizations and requires a system of coordinated data collection. It would be extremely difficult to implement and monitor in a self-directed model where the person served and/or his family is expected to provide oversight. Let me demonstrate this dilemma through the lives of Greg and Ann.

I met Greg and Ann 20 years ago, when both resided in local group homes. Greg was in his mid-twenties and had cerebral palsy. Extremely motivated and highly energetic, Greg was a strong advocate and volunteered on both the Governor's Council for Developmental Disabilities and was active in his local ARC. He also worked part-time at a local movie theater.

Ann had a likeable disposition, but could be extremely manipulative and would engage in inappropriate behavior such as stealing and lying. But by the time she graduated from high school, she was working full-time on a work crew shredding paper at Raytheon. At the time, Greg and Ann were healthy, happy young adults.

Under the philosophical tenets of the "least restrictive alternative" and "dignity of risk," Greg and Ann moved from licensed group home settings into their own apartments. The apartments are funded through Section 8 hous-



*Wendy Sokol*

ing and are part of the self-directed service delivery model. As Greg and Ann's guardian rent the apartments, there is no licensure or monitoring.

Fast forward to today. The last time I saw Greg, he was no longer able to use a walker and was confined to a wheelchair. He was unemployed, and his personal hygiene was extremely poor.

Ann is also unemployed and is morbidly obese. At 35 years of age, she is pre-diabetic. Her guardian restricts her access to cash in order to control her ability to purchase food, but Ann has learned to beg and do the rounds of soup kitchens and food banks. She will trade favors for food.

Greg and Ann now receive less than 20 hours per week of support. Without involved family members, they are left to advocate for themselves, but clearly lack the skills to access many basic resources. They fear that any complaint or concern could result in them being forced back into a group home.

If there was a system of benchmarking for Greg and Ann, what would it say about their quality of life? It would clearly demonstrate cost-effectiveness and perhaps even customer satisfaction—but are these promising practices? What if they were used as the tools and performance measures to guide decision-making around capacity building?

As our industry moves into performance-based measurement and payment systems, it is our responsibility to advocate for the Greg and Anns of our world. We need to ensure that any system of state or national benchmarking incorporates quality outcome measures for all people with developmental disabilities irrespective of the service delivery model. ●

*Author LINK: Wendy Sokol is CEO and co-owner of SOREO In-Home Support Services. She can be reached at [wendy@soreo.com](mailto:wendy@soreo.com).*

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# 2011 Performance Excellence Data Results

By Rebecca Guess

2011 marked the fourth year of data collection for the Performance Excellence Initiative. The data is based on self-reported data by participating agencies across the country—both ANCOR members and non-members.

Overall, the participation figures show that 36 states are described by this data representing an estimated 38,610 people receiving services. This is a figure that has varied throughout the years, with the past two years remaining consistent. (2010 represented 36,699 people receiving services.)

## Preventative Healthcare Metrics

However, 2011 was the first year that ANCOR began collecting data for the preventative healthcare metrics and has preliminary results regarding obesity/overweight. In 2011, the average body mass index (BMI) for persons served was 27.31.

For the purpose of this initiative, “obese” is defined as a person with a BMI of 30 or greater, whereas “overweight” is defined as a person with a BMI between 25 and 29. Preliminary results represent an estimate 12,087 persons served with 29.33% in the obese range and 27.69% as overweight.

## DSP Metrics

ANCOR’s PEI metrics for Direct Support Professional (DSP) stability, retention and turnover were adapted from the research conducted by Sheryl Larson from the University of Minnesota.

As in the previous years, for the purpose of this initiative, a DSP is defined as a person/employee whose primary job responsibility is to provide support, training, supervision and personal assistance to people being supported by the agency and who spends at least 50% of his or her hours in direct support tasks.

While DSPs may perform some supervisory tasks, their primary job responsibility and more than 50% of their hours are spent doing direct support work. Staff whose position would be classified as “on-call” would not be included.

## DSP Retention Rate

Retention is the tenure or the length of time a DSP has worked for a site or agency. To compute the average retention of DSPs at a particular site or agency, list each DSP and the number of months the DSP has been at the site

## PE 2011 Top Providers

When comparing the data of those top performers with the general PE participants and the disability field overall, the focus on improving quality supports is evident.

Overall Summary	2008	2009	2010	2011	2011 Top Providers
Turnover	34.5%	45.8%	47.9%	52.8%	16.6%
Stability	64.6%	62.9%	66.6%	64.9%	83.4%
Retention (in months)	38 mo	37.8 mo	44.9 mo	42.4 mo	77.7 mo

*The 2011 top providers of Performance Excellence have been notified and will conduct webinars regarding how they have used prior PE results to improve their services and supports.*

or agency. Add the number of months for each DSP at the site or agency and divide by the total number of DSPs. The result will be the average number of months DSPs have been at the site or agency.

In 2008, the reported retention rate for PE was 38.0 months; this decreased slightly in 2009 to 37.8 months. The retention rate increased to 44.9 months in 2010 and then decreased slightly in 2011 to 42.4 months.

There is not an overall consistent trend that has emerged with retention over the past four years, though the differences in the numbers have varied just slightly.

## DSP Turnover Rate

The turnover rate compares the number of DSPs who quit to the number of positions in a site or agency. To compute the turnover rate in a particular site or agency, count the number of DSPs who left the site or agency within the last 12 months. Include all DSPs who left, even if they quit or were fired one day after hire or were hired but never showed up for work. Divide this number by the average number of DSPs at the site or agency during the last 12 months.

In 2008, the reported turnover rate for PE was 34.5%, which increased notably in 2009 to 45.8%. Turnover continued to increase in 2010 to 47.9% and 2011 to 52.8%. The largest increase in turnover occurred between 2008 and 2009, though there is a trend emerging overall within turnover and the PEI benchmark.

## DSP Stability Rate

The stability rate reports longevity of DSPs working at a site or within an agency. To

compute the stability rate at a particular site or agency, count the number of DSPs working at the site or agency for one or more years. Divide this number by the total number of DSPs working at the site.

Stability is the most consistent metric within the PEI database. In 2008, the reported stability rate for PE was 64.6%. This decreased ever so slightly in 2009 to 62.9%—only to increase again in 2010 to 66.6% and decrease in 2011 to 64.9%. Although it may appear as if there is variability within the figures for stability, the fluctuation overall has only been 3.7% for the past for years, thus making this metric constant.

The past four years of data demonstrate that turnover is steadily increasing though retention appears to fluctuate year to year and stability remains consistent year to year. This allows agencies to compare their rates across specific service and support systems, states and national figures to identify trends emerging that are relevant to their particular agency structure regarding service settings and supports.

## Using the Data

Organizations have used the data to compare their performance on the specific metrics from one year to the next. Their Boards of Directors use the data to establish goals for the upcoming year and as part of the organization’s strategic planning. Participating organizations find it helpful to compare their “position” against others in their state or across the country. ●

*For more information on ANCOR’s PEI, contact Debra Langseth at [dlangseth@ancor.org](mailto:dlangseth@ancor.org).*

*Author LINK: Rebecca Guess is a senior research analyst with Deyta.*

## What PE Means to My Agency: Volunteers of America of Minnesota

By *Volunteers of America of Minnesota, Services for Seniors and Persons with Special Needs*

Volunteers of America of Minnesota has been using Performance Excellence since 2008. Our programs increase self-sufficiency, as well as promote independence and active community engagement for those with special needs and disabilities so that they may improve their quality of life and lead successful lives in their homes and community.

We have 13 corporate foster care homes that house up to four persons served in each, and we provide in-home services to 102 persons served. We also employ 144 Direct Support Professionals (DSPs) to provide that support to our consumers. Performance Excellence has helped us collect data from these individuals, their families/guardians and employees to find out areas of needed improvement and uplift the lives of those that we support.

In 2008, we began collecting and analyzing our DSP stability rates, retention rates, vacancy rates and turnover rates. This established a baseline for us to determine how we compare

with other providers statewide and nationally in our ability to retain staff.

In 2009, we were able to prepare ourselves for the next step of using the pre-formatted consumer and employee satisfaction surveys provided by PE.

In the past, we developed and implemented our own consumer satisfaction surveys annually and used our internal survey committee to address concerns noted. The PE surveys allowed us to capture more extensive information than our old consumer satisfaction survey format.

We were also able to identify whether our DSP stability, retention, vacancy and turnover had increased or decreased

within the past year, and we were able to establish our baseline for consumer and employee satisfaction.

In 2010 and 2011, we had accurate comparison data to see how we were progressing with the satisfaction level of our consumers and employees. We know that satisfaction is a significant factor in turnover, so we tried to address any areas of concern noted. As a result

of those purposeful management changes, we have seen a 4% decrease in DSP turnover from 2010 to 2011.

As a result of the data, we have been more innovative in finding ways to increase community involvement for the people we support and establish a stronger volunteer program to assist with those goals. We are also looking into other options for data collection and have put a stronger emphasis on employee recognition.

We are now ready to start implementing the preventive healthcare metric and medication error metric for the upcoming year. This will allow us to see how we can improve the health and wellness of the people we support and identify if we have adequate medication orientation and training for our employees.

The Performance Excellence system has allowed us to compare our services and employee retention to other providers in the state and nationally. The use of PE surveys also has provided us with more detail to figure out the specific areas that we can improve upon. PE provides the structure and flexibility to easily enter, analyze and utilize all collected data with the added benefit of comparison to other related service providers. ●

For more information on *Volunteers of America of Minnesota*, visit [www.voamn.org](http://www.voamn.org).

**As a result of the data, we have been more innovative in finding ways to increase community involvement for the people we support and establish a stronger volunteer program to assist with those goals.**

## What PE Means to My Agency: Langton Green

By *Kim Breton*

Langton Green joined the Performance Excellence Benchmarking program when its Board of Directors wanted data to compare its performance with other agencies. We had been collecting data for years that indicated a good retention rate, and we had anecdotal reports—i.e., “lots of stories”—but no national standard to measure by.

While we compared better with our peers locally and had just received the Maryland Association of Nonprofit Organization’s Standards of Excellence certificate, our Board wanted a larger sample of agencies to benchmark and compare—specifically companies that were doing well and others trying to address similar challenges.

There was only one national group looking at this: ANCOR. Our Board’s only reservation, which still exists, was the small number of participating companies.

As a first-time user, and new in my position, I initially felt the system was confusing. I did not understand the big picture—what PE was doing, how it would work for us and how we would be statistically compared to other agencies that flowed in and out of the PE program each year. However, after discussions with ANCOR and Deyta staff, the data submission process made sense.

The PE Toolkit was also a valuable resource. Even while reading it, I was listing things we could do differently to improve our metrics—and the supports we provide to people.

We are now in our second year and have baseline figures to compare data. While our anecdotal reports indicate we are doing great in many areas, the PE tool and process are very helpful for helping us “get the math” to support it. Changes are in progress!

We know the people we support are already receiving better supports because we’ve adjusted

some of our practices and processes. We look forward to improving quality and doing better. Having the benchmarking data to back us up and prove it to those on the outside looking in is something we value most about the process.

We have found that the information from the top performers has been very helpful in evaluating our hiring and satisfaction processes, and we have used our PE data results to explain why we are using some processes and gaining input to how we may improve outcomes over time. We believe that we will see improvement if we focus on a few things first.

While our Board is still a bit reticent due to the small sample that participates in the PE program, they congratulate ANCOR—and so do we—for promoting the use of metrics to measure and gauge quality and then coming up with suggestions on ways to improve. ●

Author *LINK*: Kim Breton is deputy director of *Langton Green* in Annapolis, Maryland.

## What PE Means to My Agency: UCP Land of Lincoln

By Kathy Leuelling

UCP Land of Lincoln finds the Performance Excellence program helpful for benchmarking with other similar organizations. It helps us identify those areas which we need to target for improvement—especially in customer and employee focus.

We use benchmarks in our strategic plan to set targets for ongoing performance improvement. We look at our survey results and determine where to focus our training, develop processes to provide additional communication with staff and provide feedback to staff regarding their individual performance. We track our turnover monthly.

Since using the results as our tool, we have had fewer voluntary turnovers and had had an improvement in results to individual targeted survey questions for both customers and staff. We feel that because of what we're learning, we're hiring more qualified people and we're doing more through a "team improvement" process.

We use the Baldrige Quality criteria and engage our customers and staff. Through this engagement, the staff is more involved in deter-

**Since using the results as our tool, we have had fewer voluntary turnovers and had had an improvement in results to individual targeted survey questions for both customers and staff.**

mining processes and realize they can make a difference. We feel the focus on engagement has played a big part in the staff leadership-making process and reduction of the voluntary turnover.

Our management team reports our score card results to our Board Committees quarterly. The Board is very interested in our trends and performance benchmarks and compares our status with industry trends.

We are beginning another three-year strategic planning process and are very glad to have our history of performance as a baseline as our future direction and goals are established. ●

*Author LINK: Kathy Leuelling is COO of UCP Land of Lincoln and can be reached at [klueelling@ucpll.org](mailto:klueelling@ucpll.org).*

## Essential Learning Coming Attractions

By Sherry Beamer

Work is in process to announce packages of online coursework that will support the ANCOR Performance Excellence Quality Framework. Highlights will include courses for Boards of Directors on personal outcome measures and courses on self-determination.

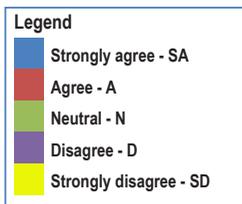
To round out the strategic planning section, the following sessions were taped at the ANCOR 2012 Conference in order to create online courses:

- "Moving Beyond Survival: Using Tech to Thrive" with David Leslie
- "Taking the Vision to Reality: Harnessing the Power of the I/DD Community" with Scott Filer
- "Succession Planning: Creating a Meaningful Transition" with Don Tebbe ●

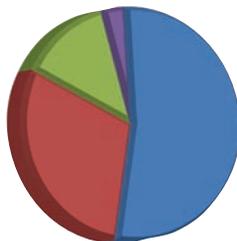
*Essential Learning partners with ANCOR to provide members with a discounted, additional online learning option. Members may contact Essential Learning for more information by phone at 1.800.729.9198 (ext. 212) or email.*

*Author LINK: Sherry Beamer is vice president of developmental disabilities services at Essential Learning.*

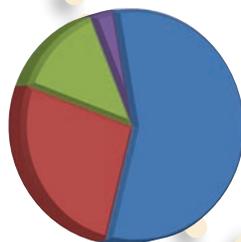
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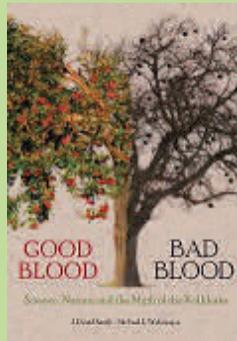
Surveys of community residential program administrators show the benefits of Rest Assured® Telecare support services for adults with developmental disabilities living in residential settings during the overnight hours. Using Rest Assured significantly helped agencies:

- provide a higher sense of privacy
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## Book Chat: Good Blood Bad Blood

Date: July 19, 2012

Time: 3:00pm EST (2p CST/1p MST/12noon PST)

Register: [aaidd.org/content\\_9116.cfm](http://aaidd.org/content_9116.cfm)

### EVENT

Join AAIDD's Director of Publications, Lisa O'Hearn as she interviews J. David Smith and Michael Wehmeyer, authors of *Good Blood, Bad Blood: Science, Nature, and the Myth of the Kallikaks*.

### AUTHORS

*J. David Smith*, EdD, is Professor Emeritus at the University of North Carolina at Greensboro. *Michael L. Wehmeyer*, PhD, is Professor of Special Education; Director, Kansas University Center on Developmental Disabilities; and Senior Scientist, Beach Center on Disability, all at the University of Kansas.

### BOOK SYNOPSIS

At the vortex of the American eugenics tragedy was the seemingly sordid tale of a “degenerate” family from rural New Jersey. Published in 1912, *The Kallikak Family* was a pseudoscientific treatise describing generations of illiterate, poor, and purportedly immoral Kallikak family members who were chronically unemployed, “feebleminded,” criminal, and, in general, perceived as threats to “racial hygiene.” Psychologist Henry Herbert Goddard invented the pseudonym “Kallikak”—from the Greek words Kallos (beauty) and Kakos (bad)—to illustrate the eugenic belief in the role of nature and heredity as unalterable forces leading to degeneracy. The starting point for Goddard’s moral tale was “Deborah Kallikak,” an inmate at The Vineland Training School, his institution for the feeble minded. Incredibly, as revealed in detail for the first time in *Good Blood, Bad Blood: Science, Nature, and the Myth of the Kallikaks*, Goddard had it all wrong. No degenerate line descended from the purported Kallikak progenitor. There were only people—some of whom had resources and access to education, others of whom were poor, uneducated, and cast into the cauldron that was urban America at the dawn of the Industrial Age. The pseudonymous “Deborah Kallikak” became the poster child for societal fears regarding immigration, heredity, and racial integration, the flames of which were fanned by a select group of scientists marching under the banner of the new “science” of eugenics.

### Questions?

Danielle Webber, Manager, Educational Programs

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## What You Missed: Government Relations

The government relations sessions at the ANCOR 2012 conference were put together based on discussions among ANCOR members and—in some cases—fights in states centered on restructuring Medicaid funded long-term supports. In addition, the ANCOR Board of Directors and ANCOR Government Relations are sharply focused on the future of the financing and funding of Medicaid, which transcends both state and federal policy.

Financing and funding may sound like the same thing, but they are indeed different. Financing is the mechanism and structure by which funds are delivered to states to fund services and supports. On the federal level, ANCOR has influence in both financing and funding.

Financing mechanisms give states the federal

**Make no mistake; no matter how the federal government balances the budget or reduces the federal contribution toward Medicaid programs, it affects you and the amount of money your state has to dedicate to your services.**

approval they need to fund certain types of service delivery models. ANCOR has an interest in working on the financing mechanisms because these options give our members the path to be creative in serving their communities. The more financing options we have, the more creative states and providers can be in providing long-term supports and services.

Funding comes into play when threats to the Federal Matching Percentage (FMAP) become part of the discussion as a means of reducing federal spending that reduces the federal deficit. This threat manifests itself in debates that center on entitlements and state flexibility. Block grants, across the board cuts to entitlements, and other reductions of federal responsibility for funding Medicaid services must be highly scrutinized.

While it seems far away and largely a federal issue—make no mistake; no matter how the federal government balances the budget or reduces the federal contribution toward Medicaid programs, it affects you and the amount of



**Lu Zawistowich of MACPAC addresses conference attendees.**

money your state has to dedicate to your services.

Providing services during a time of economic uncertainty challenges ANCOR members to examine the Medicaid financing structure in their states and the role mechanisms enacted as part of the Affordable Care Act (ACA) can play in increasing both flexibility and revenue for the purpose of providing services. This comes at a time when managed care and other capitated models have become an attractive choice for cash-strapped states.

ANCOR members need to be at the forefront of restructuring discussions in their state. The sessions at the annual conference sought to give them the tools to engage in these dialogues while giving the perspective of the federal government.

Rodney Whitlock, health policy director in the Office of Senator Chuck Grassley, gave his perspective on the role of the federal government and what ANCOR members might think

*Continued on page 10*



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**“Both Wendy’s address to us and the keynote speaker were very inspirational and informative. Thank you for your thoughtful insights.”**

**— Nancy Silver Hargreaves  
President & CEO  
WCI-WORK, COMMUNITY,  
INDEPENDENCE**

*Continued from page 9*

about as they grapple with funding issues. His ideas were thought-provoking and gave ANCOR members insight into the realities of entitlement reform discussions occurring now and following the 2012 elections.

While Whitlock talked a bit about the capitated approach to financing Medicaid, attendees had the opportunity to hear first-hand about existing capitated payment approaches and from states that are grappling with the inclusion of long-term supports and services in their plans to use Medicaid managed care to restructure their Medicaid program and reduce costs.

Attendees also heard from Lu Zawistowich, director of the Medicaid and CHIP Payment and Access Commission, about the recommendations in a recent report regarding the role of Medicaid and persons with disabilities.

The commission is important because of the tremendous changes that will be occurring in the scope of the Medicaid program for coverage as a result of health reform. Given the fiscal pressure on Medicaid and the misunderstandings surrounding the “disability population” and long-term services and supports, information to aid in entitlement reform discussions and decisions at the federal and state level is important to ensure savings do not happen at the expense of services and supports.

Attendees asked Zawistowich questions about the future direction of the commission’s work and shared areas of data collection and analysis needing further consideration, such as the availability of affordable and accessible housing options and quality measures that reflect non-medical outcomes. Additionally, Zawistowich welcomed input and expressed her desire to continue hearing from ANCOR on MACPAC’s future and current data collection efforts. ●

*Interested in more on financing and funding? Join ANCOR at the 2012 Leadership Summit: Finance and Funding — From Crisis to Sustainability. This event is available to ANCOR members only.*

## What You Missed: Leadership and Innovation

The ANCOR 2012 Conference: *Leading Cultures of Innovation & Advocacy* highlighted leadership, advocacy and innovation, which build upon ANCOR’s mega-issues.

The pre-conference included sessions on “HIPAA for Providers: What You Need to Know to Remain Compliant” by John Gililand, as well as a session on “Lighthouse Leadership: A Vision for Transforming your Organization” by Janita Anderson.

The conference officially kicked off with Angelo Armenti’s keynote address on “Achieving the End in Mind.” Taking leadership dreams to reality was a foundation for the leadership sessions throughout the conference.

David Leslie discussed his “outside” view of the disability field and how as board president and interim CEO of the National Children’s Center, he helped NCC embrace new technology in his session, “Survive and Thrive.” Leslie’s follow-up session “Taking the Vision to Reality: Harnessing the Power of the I/DD Community” presented with Scott Filer, CEO of NCC, “was worth the price of admission,” according to one conference attendee.

A common theme throughout the conference was that organizations are diversifying their services, funding streams and operational procedures as they develop greater areas of expertise. To address this theme, Melanie Herman of the Nonprofit Risk Management Center discussed risk management in her high-rated presentation, “Leading in Times of Crisis and Taking Action in the Face of Uncertainty,” and Robert Budd and Chris Long of FREE discussed the benefits of “Collaborative Relationships to Balance the Budget.”



*Melanie Herman presented one of the most well-received sessions, “Leading in Times of Crisis: Taking Action in the Face of Uncertainty.”*

**“Most excellent conference. My favorite so far is Melanie Herman—down to earth, easy to understand, very useful information.”**

**— Rebecca Carlson,  
Executive Director  
Community Connections, Inc.**

Participants also noted high value on topics such as “Mergers and Acquisitions” by Laurie Herring and Kathleen Stauffer of the Arc New London County and “Succession Planning” by Don Tebbe.

The importance of innovative programs and applications such as, “Supporting People with Autism Through a Capitated Support Model,” presented by Robert Baker of Keystone and “Using Technology to Increase Social Connectedness and Self-Direction,” by Dan Davies of AbleLink made the connection between innovation and technology.

Additionally, participants appreciated the presentations on increasing wellness through “Evidence-Based Health Promotion” by Leslie Hoelzel of ARCA and learning about the “Health Care Innovation Challenge,” which Jim Vail of Mainstay and Larry Weishaar of ResCare presented. The sessions even inspired some attendees to eat better! ●

### What Attendees Plan to Do Differently Because of the Conference:

Develop a retention plan of action

Think about technology and its advantages in providing our services

Look for more opportunities for collaboration

Continue to work to be innovative and no longer remain in a status quo mindset

Eat better

Learn more about the DOJ activities

Be more involved in the ACC; volunteer to do more for ANCOR; encourage more providers to nominate DSP’s for the ANCOR DSP awards; increase my vigilance around the consequences of the merger of elder and ID services; keep my eye, day to day, on emerging litigation in the various states

## What You Missed: ANCOR Recognizes Excellence

### Community Builder Award

On May 6, the ANCOR Foundation announced the Hope House Foundation's Community Support Program as the 2012 Community Builder Award recipient. The program offers person-directed, individualized supports that allow people with disabilities to live fully integrated in their communities.

"Hope House embodies the conviction that people with disabilities want and deserve the same things in life that everyone else does. They want to express their unique abilities and talents, they want strong supportive relationships with friends and family and they want to be an integral part of their communities," says Bill Tapp, ANCOR Foundation president. "We're very pleased to honor them with this award and hope it will be an inspiration for others to do the same."

Click [here](#) to read more about Hope House. ●



*Kim Herbourn and Taryn Subeh accept the Community Builder Award on behalf of the Hope House Foundation.*



*The 2012 Class of Legacy Leaders  
From L-R: Richard Farnsworth, Gale Bohling, Dennis Popp, Kathleen LeMay, David Ray Kiely, Gloria Quinn, Shannon Quinn, Terry Rogers  
(Note: Suellen Galbraith was unable to accept her award in person, and Gloria and Shannon Quinn accepted the award on behalf of the late Tim Quinn.)*

### Legacy Leaders' Circle

On May 7, the ANCOR Foundation announced the 2012 class of inductees into its Legacy Leaders Circle. The award recognizes long-time industry leaders and raises funds to develop leaders for the future.

The 2012 inductees are Gale Bohling; Richard R. Farnsworth; Suellen R. Galbraith; David Ray Kiely; Kathleen LeMay; Dennis Popp; Tim Quinn; and Terry J. Rogers.

"The history of de-institutionalization and the advent of community living options for people with disabilities is full of dedicated, visionary leaders like those we honor today," says Bill Tapp, president of the ANCOR Foundation. "We're very pleased to recognize this exceptional group and we hope their example is an inspiration to the leaders of the future."

Short bios of the 2012 class of Legacy Leaders can be found [here](#). ●

### Direct Support Professional of the Year

On May 8, ANCOR recognized Lynda DiPressi of New Horizons Resources, Inc., as the 2012 Direct Support Professional of the Year. DiPressi was named the national recipient among 212 nominations submitted for the competition. Forty-two additional DSPs received awards as the best of the best in their respective states.

ANCOR started the Direct Support Professional Recognition Award program in 2007 to acknowledge the commitment of the DSPs who work to ensure community inclusion and full participation for hundreds of thousands of Americans with disabilities.

"Lynda DiPressi represents all the best attributes of our DSP workforce," says Renee L. Pietrangelo, ANCOR CEO. "She is committed to supporting independence and growth for the people she serves, dedicated to continually improving her skills and a strong advocate for people with disabilities in her state. ANCOR is extremely pleased to be able to recognize her achievement."

Check out all of the 2012 DSPs of the Year and their stories [here](#). ●



*The 2012 DSPs of the Year who were able to attend the ANCOR 2012 Conference: Leading Cultures of Innovation & Advocacy*

## Gold Partners Hold the Spotlight

ANCOR's Gold Partners held the spotlight at ANCOR's 2012 Conference: *Leading Cultures of Innovation and Advocacy* in the conference breakout session, "Addressing Needs, Achieving Solutions." Before an audience of more than 30 people, they each presented the individual solutions to different provider program problems they had solved.

The session, facilitated by Chris Sparks, executive director of Exceptional Persons Inc., gave a step-by-step account of a program/business challenge experienced by a provider and the collaborative steps it took with the gold partner to achieve a positive outcome. Gold Partners presenting included Medline, Rest Assured and Scioto.



Was this session worthwhile? Comments from audience members help tell the story:

*"A very worthwhile break-out session. I look forward to more of these."*

*"I appreciated all of the information given and will utilize it for upcoming decisions I have to make."* ♦

*To learn more about ANCOR's Gold Partners and the solutions they offer, click here. For information on the Gold Partner program, please contact Marsha Patrick, Development Director, at [mpatrick@ancor.org](mailto:mpatrick@ancor.org).*

## What Exhibitors Had to Say About the Conference:

*"We appreciated your hard work and the level of ANCOR staff engagement with the exhibitors. All of our needs were met, and we enjoyed being a part of the event."*

—Rich Herold/Dan Davies, AbleLink Technologies



*"[It was] great to be part of the conference. I would not change a thing."*

—Diane Hackbarth, Bethesda Institute



*It was a great opportunity to meet new clients. I loved the new venue, and it worked out well for us."*

—Dustin Eubanks, Cerner Extended Care

*"In addition to meeting more of the ANCOR team, we were*

*able to make great connections with possible customers across the country. It was a wonderful event, and I know we will be back next year."*

—Brian White, MediSked



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## What You Missed: From an Attendee's Perspective

2012 DSP of the Year for Maine Jessica Emerson of OHI had the opportunity to participate in the ANCOR 2012 Conference as both a conference attendee and a DSP to DC attendee.

### Why did you attend both DSP and general audience sessions?

I attended every session that I could so that I could get the most out of the conference. I think the general audience sessions contained a lot of information—such as that in the breakout sessions—that, while mainly geared toward management levels of agencies, is very beneficial for everyone in an agency to know.

### What was your favorite general audience conference session and/or breakout session?

My favorite breakout session was “Taking the Vision to Reality: Harnessing the Power of the I/DD Community.” I enjoyed this session because it opened my eyes to the idea of agencies advocating for their supporting agencies to hire more people with I/DD. I think this is a great way not only to enhance the lives of a lot of the people supported by provider agencies, but also to create higher standards for those agencies we do business with.

### What was your favorite DSPs to DC conference session?

My favorite DSPs to DC session was “The DSP Code of Ethics: Live and in Living Color.” John Raffaele led a very engaging and interactive session that really showcased how DSPs can support people with disabilities that honors their individuality and independence while maintaining safety, following individual plans, teaching crucial skills and upholding the DSP Code of Ethics. Before attending this conference, I was unaware that a DSP Code of Ethics even existed, so this session was extremely informative in addition to being fun.

### What was your experience to DC like, in general?

I absolutely loved my time in DC. I found that I had ample time to attend the conference sessions, view some of DC's attractions (including many of the monuments) and network as well. I only wish that I'd had more time to meet even more people. Having the opportunity to talk to people from all levels of other provider agen-

cies throughout the nation was as enlightening as many of the conference sessions themselves. I believe we have so much to teach each other and that it is crucial to understand the struggles and achievements of our sister agencies.

### Who was the most compelling speaker?

The most compelling speaker was Dr. Angelo Armenti, who delivered the keynote address. He conveyed how there are certain principles—which are universal, timeless, objective and at work, whether we understand them or not—that govern human interactions, the same way certain principles govern nature.

Dr. Armenti really drove home how large organizations can apply these principles in order to succeed and be truly effective. I believe his message was especially compelling given the unstable economic situation that many states and agencies are currently struggling in.

### What was the most important thing you learned?

The most important thing I learned is the impact provider agencies can have on the surrounding communities, specifically that they can really push for their supporting agencies to hire more people with intellectual and developmental disabilities. I think this is crucial to helping improve the lives of the individuals we support.

### What do you wish there was more of?

I wish there was more time to network while still having all the choices of the conference sessions. I think if there had been some semi-structured time for this that attendees would have greater opportunity to share their knowledge with others.

### Did you attend the pre-conference?

I attended the pre-conference session on the Lighthouse Leadership pilot and found it to be both engaging and informative, even with the knowledge I have from being part of one of the five pilot agencies. Janita was a very effective and personable presenter.



*ANCOR President Wendy Sokol present Jessica Emerson with the 2012 DSP of the Year Award for Maine at the ANCOR 2012 Conference.*

### Did you make any connections/learn anything from other attendees?

I made several connections with attendees (both general conference attendees and DSPs) from several agencies across the nation. I learned not only about the differences between our agencies, but also about other service opportunities attendees participate in. I also learned about different legislation (in effect and being proposed) in other states.

### What was your favorite part of the entire conference?

My favorite part of the entire conference was networking with many of the attendees and hearing about their agencies.

### Why do you think DSPs should attend DSPs to DC?

I think DSPs should attend the conference because there is so much information that enhances professionalism and understanding about the field we work in. I also think that the opportunity to network with other DSPs is invaluable and that it is important for DSPs to attend the conference so they can bring back information they gain from the conference and become more involved in their agencies.

### Why do you think providers should attend the conference?

I think providers should attend the conference because the sessions are planned around the key issues many providers are facing. Providers have the opportunity not only to gain more knowledge about issues relevant to their agency, but also to network with other provider agencies and hear how they manage similar issues. ●

## What You Missed: DSPs to DC

ANCOR was proud to once again host the 2012 DSPs to DC event, May 7–8, in conjunction with ANCOR’s 2012 Conference: *Leading Cultures of Innovation & Advocacy*.

This year, ANCOR changed the format of the conference. In addition to all of the information-packed, DSP-focused sessions, Direct Support Professionals also attended joint sessions with conference attendees. Joint sessions included “Capitalizing on Change: Maintaining Productivity Through Wellness,” “Recruitment and Retention Challenges and Strategies,” “Technology, Social Connectedness and Self-Direction,” and the “Lighthouse Leader Pilot.”

To kick off the event, DSPs heard from Scott Trudo in the session “Live Your Passion.” Scott told his own life story, one that went detailed numerous struggles that led him to find his passion working as a DSP—making the point that true passion in life comes when you are living your life in service to others. He also shared some inspirational stories of others who have overcome life’s challenges and are living their passions every day.

DSPs also attended specialized training sessions, such as “Careers That Matter Most: Time to Look at Change,” “The NADSP Code of Ethics: Live and in Living Color” and facilitated DSP roundtables.

DSPs were also able to hear from “Advocacy Guru” Stephanie Vance in the session, “Use Your Voice: What DSPs Need to Do to Be Heard.” She taught DSPs how to influence elected officials with their stories and those of the people they support.

Also during ANCOR’s annual DSP to DC event, the 2012 DSP of the Year was announced in front of all of the conference participants, and the 2012 DSP of the Year state award recipients were recognized.

This is the sixth year of the National Advocacy Campaign’s successful DSP of the Year Recognition Awards. Once again, we had a wonderful opportunity to highlight the direct support workforce, thank them for their immeasurable work and advance the advocacy agenda on their behalf. ●



*John Raffaele stresses the importance of the NADSP Code of Ethics to DSPs to DC participants.*

### Here’s what DSPs had to say about the event:

**“What I found most valuable as a DSP at the 2012 ANCOR Conference was meeting other DSPs around the country who are doing good work. It felt confirming that I am in good company in providing support to people who need passionate staff to help in their life’s journey.**

**“I enjoyed Ari Ne’eman’s workshop (who was the voice for self-advocates) in letting the service system know what is important to the people being served.**

**“The National Alliance of Direct Support Professional’s presence was also very much appreciated in that I could share stories from New Hampshire as, well as hear about national issues.**

**“Lastly, it is always great to meet lots of fantastic people who are trying to make a difference in our society.”**

—Robin Carlson  
2012 DSP of the Year for New Hampshire

**“The 2012 DSPs to DC event was very inspiring. I had the opportunity to share stories and network with other DSPs from across the country.**

**“The interactive workshop, ‘The DSP Code of Ethics: Live and in Living Color,’ and the follow-up, facilitated discussion for DSPs were most valuable.... [They] gave us a chance to share stories of success and the process/challenges in which it took to get there. We were also able to brainstorm and offer or accept suggestions/strategies in ways of providing person-centered supports while working with intention.**

**“With all of the bad press in regards to the field, DSP morale is very low. Being among such dedicated, professional DSPs definitely boosted my spirit.**

**“As a representative for the Direct Support Professional Alliance of New York State (DSPANYS), I was pleased to see a focus on professionalizing the field of direct support and shedding light on the Code of Ethics and Community Support Skills Standards.”**

—Theresa Laws



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## Ability Beyond Disability DSP's Key to Success: Trust

By Tom King

There's a Direct Support Professional (DSP) at Ability Beyond Disability in Danbury, Connecticut, who summarizes success in one word: trust.

"Building trust with people over time is very important in this job," says Kendra Majette. "People need to know you and know that they can trust you and that you will be there and know what you expect. Trust makes all the difference in doing this job well."

### A Superb Role Model

Kendra has been at Ability Beyond Disability—an ANCOR member—for more than four years. She supports 12 individuals Monday through Thursday as part of the organization's Day and Work Services.

Each Friday she drives nearly 20 miles to assist two men who service the magazines and books at a grocery store in New Milford. To add to this already busy workload, on Tuesdays, Wednesdays and Sundays Kendra covers open shifts at various residential homes. This dedication means Kendra works between 50 and 55 hours a week.

"Kendra's a professional—well spoken, positive, decisive, flexible, and is a superb role model," says Diane Strom, one of the organization's community support coordinators and Kendra's supervisor. "She works great on our team, is proactive with the people she supports and manages to find the calm between everyone."

Every day, DSPs encounter countless challenges, but Kendra faces every situation with care and intelligence. "Whenever she has a problem and comes to me for advice, she also has already thought through the possible solution to the problem—and that's a rare quality," Diane explained. "It makes my job easy, and it shows how proactive she is in solving problems."

### Work Above and Beyond

When a major snowstorm hit Connecticut—knocking out the electricity, heat and water—Kendra stepped up, going above-and-beyond her duties to help a group home through the turmoil.

Arriving at the group home at 8 a.m. on that Saturday morning and working until 5 p.m. on Sunday, Kendra and another DSP supported the men throughout the ordeal until the storm eased and alternate arrangements could be carried out.

"Kendra was very assertive and took total responsibility for ensuring that the staff returned home safely," remembers Sharon Stallings, one of the organization's residential coordinators. "Kendra then stayed to assist the residents through the power outage for the evening until the next day."

Last October, Kendra was selected for the agency's "Oh My" Award, an on-the-spot recognition for work above and beyond an individual's job description.



Tom King

### A Pathway to Excellence

Ability Beyond Disability employs 900 direct care workers and of those,

174 are DSPs who have graduated from the agency's Pathways to Excellence program, a career-track program that includes the online training through the College of Direct Support/DirectCourse.

Kendra says the College of Direct Support courses were important for her. "CDS taught me a wide range of skills needed in this profession. I learned what a DSP does day in and day out and what are the best practices in the field," she explained. "It reinforced my knowledge on ethics and data privacy and helped me focus on my strengths and weaknesses."

"Kendra is a great role model and I'd like to get her into a mentoring role soon," says Diane. "She likes what she does and is concerned about making the people she supports happy, active and engaged."

Kendra is certainly a DSP with a positive attitude. Of the people she supports, she added, "I know them and they know me. We know our ups and downs, our highs and lows. In a nutshell, it's all about trust and treating each person with respect." ●

*Author Link: Tom King is a freelance writer for DirectCourse/College of Direct Support. You can reach him at 865.659.3562 or via email at tkwrites1021@gmail.com.*

*To find out about the ANCOR Foundation partnership with the DirectCourse/College of Direct Support and the ANCOR Member Buying Pool, contact Bill Tapp at 1.877.353.2767 (toll free) or email him at b.tapp@elsevier.com.*

### Kendra Majette At-A-Glance



Kendra Majette

**Name:** Kendra Majette

**Age:** 32

**Hometown:** Waterbury, Connecticut

**Organization:** Ability Beyond Disability

**Position:** Direct Support Professional

**Key Quote by Kendra:** "Building trust with people is very important in this job. People need to know they can trust you and what you expect. That makes all the difference in doing this job well."

**How Her Supervisor Describes Her:** "She is very concerned about the people she supports, and always makes sure they are happy. She keeps them active and engaged. Whenever she comes to me with a problem, she always has a suggestion to solve it as well."

## ANCOR Welcomes Richard Farnsworth as Benefits Rep

ANCOR is pleased to announce that Richard “Dick” Farnsworth has been selected as the new ANCOR benefits representative. He was recently introduced to the ANCOR Board of Directors, Board of Representatives, State Association Executives and the membership as a whole at the beginning of the ANCOR 2012 Conference: *Leading Cultures of Innovation & Advocacy* in Washington, D.C., in early May.

The position involves membership outreach and communicating the benefits of specific ANCOR partner companies. These partner companies include the following:

- **Aflac for ANCOR**, which can help ANCOR members create a more attractive employee benefits package, at no direct cost to your company—and saves you money;
- **Medline**, which provides members with quality medical supplies and equipment at lower cost;
- **U.S. Bank Purchase One Card**, which can help members reap new savings through rebates generated by using the Visa card; and
- **U.S. Bank AccelaPay Card**, a reloadable debit payroll card.



Dick Farnsworth

Dick will be calling on ANCOR members to acquaint them with the value of these partner programs on a more personal level.

### About Dick

Recently retired, Dick is no stranger to ANCOR, having been a member for many years as executive director of Woodfords Family Services in Portland, Maine. This year, Dick was honored during the ANCOR conference by being inducted into the prestigious Legacy Leaders Circle.

In 2011, Dick received a “Lifetime Achievement Award for Advocacy” from ANCOR member Maine Association for Community Service Providers. He also has been elected to the Board of the Autism Society of Maine and

is an active consultant in assisting a group of families in Pakistan to create the Autism Society of Pakistan in Rawalpindi/Islamabad, Pakistan.

Please welcome Dick Farnsworth to the ANCOR family and look for articles regarding his overview and experiences while on the job as ANCOR Benefits Representative in upcoming issues of *LINKS*. ●

Dick can be reached at [omc@maine.rr.com](mailto:omc@maine.rr.com).



### What Members are Saying about the SRPN

*“Almost one-third of my 700 employees signed on to various AFLAC plans. The demographics of the purchases cuts right across our agency—from new staff to long-term staff from hourly to salary folks... and we ended up saving \$7,000 in payroll taxes to boot...more than our dues are to ANCOR. This is a real win-win scenario that saves real dollars in these tough times. Yes, the duck has made me a believer! Thank you, SRPN.”*

—Peter Kowalski, CEO,  
John F. Murphy Homes, Inc.

[Click here to learn more about Aflac for ANCOR.](#)

## Body & Soul Cast Member, Director Visit Qatar

**B**ody & Soul: Diana & Kathy star Diana Braun and director Alice Elliott just returned from their trip to Doha, Qatar for the International Shafallah Forum of 2012, where Diana gave a very well received presentation on tornado emergency preparedness aimed at addressing this year’s topic: Crisis, Conflict and Disability: Ensuring Equality.

The Shafallah Center for Children With Special Needs is a center that provides comprehensive services to individuals with developmental and learning challenges, their families and community.

Check out the Body & Soul: Diana & Kathy Facebook page to see more photos from the trip.

If you’d like Diana Braun to present at your organization, contact Katy at [info@welcomechange.org](mailto:info@welcomechange.org). Also, please visit the brand new website: [www.welcomechange.org](http://www.welcomechange.org).

ANCOR member may enjoy a special offer (20% off) on the educationally licensed *Body & Soul: Diana & Kathy* DVD by entering the discount code R6JH2J. ●

### ANCOR Upcoming Events

#### Webinar

#### DOJ, ADA and Olmstead: What Do They Mean for You?

July 18, 2012

1:00 p.m.–2:30 p.m. EDT

[Click here](#) for more information and to register.

#### 2012 ANCOR Leadership Summit: *Financing and Funding—From Crisis to Sustainability*

October 1–2, 2012

Washington, D.C.

[Click here](#) for more information and to register.

#### 2012 ANCOR Technology Summit: *Implementing Innovative Solutions*

November 3, 2012

Westminster, Colorado

[Click here](#) for more information and to register.

## Coalition Building: The Power of Association

By Diane McComb  
ANCOR Liaison to State Associations

When we look at the most recent round of victories at the doors of State Houses around the country, they all have one thing in common: they centered around strong coalitions among state associations, people with disabilities and their families and advocacy organizations. In astonishing reversals of fortune, some states pulled back on funding cuts after demonstrations of solidarity and creativity on the part of coalitions promoting supports for people with disabilities.

When one looks at the successful efforts over the years it is easy to think, This could never happen in my state, or, We tried that, and it didn't work. If that's the case, one needs to look further to understand these successes. One needs to consider that there is a long history in these states' efforts and strong coalitions that sustain their advocacy.

Coalitions don't just happen. They require extensive commitments on the part of their members. Being part of a successful coalition is fraught with challenges; yet, they remain the single most effective way for underdogs to become champions in a highly competitive arena such as state politics. State associations are logical players in this effort.

Legislators, especially on the state level, are hard pressed to ignore constituents who come together with a common message. Even if a coalition's goals are not all met at once, over

time, the presence of a strong coalition delivering a consistent message can have an exponential impact as legislators and public officials are held accountable to the constituency.

Generally speaking, coalitions provide added credibility to an issue giving it broader support, increased access to legislators and public officials, and a greater likelihood of media attention. On the cautionary side, coalitions require members to be very disciplined regarding the public message.

The mechanics of creating a solid coalition are grounded in the group's guiding principles. Identify early on what is wanted as a result of the group's efforts. Be able to articulate in language that is unambiguous, what the coalition effort is about so that members of the coalition can educate their constituency. Get everyone on the same page. Provide materials in writing to the members of the coalition.

Members of a coalition need not agree on everything, but they must agree to disagree in private. The public persona must be one of alignment where the focus is on a unified outcome. When all members are vying for the same thing, it is difficult to challenge its relevance. Coalition members are part of a team and they must be respectful of others' points of view and willing to compromise when necessary.

Media is a critical tool in capturing public support and coalitions are cost-effective in an increasingly expensive arena of statehouse lobbying. Consolidating resources can yield



Diane McComb

greater media coverage and outreach. A broad, statewide coalition has a deeper reach than any one organization alone would have.

Social networking media can provide an inexpensive way to get the message out. Members can create videos and post to YouTube and Facebook for instant outreach to multiple constituents. The coalition should provide guidance to its members so that messaging is consistent with the guiding principles of the group.

It's never too late to form a coalition and become an active leader in shaping its direction. While some of today's successful coalitions had their beginnings years ago, others are younger. The important point is to be part of one. ●

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The American Network of Community Options and Resources (ANCOR) was founded in 1970 to provide national advocacy, resources, services and networking opportunities to providers of private supports and services. LINKS provides a nexus for the exchange of information, ideas and opinions among key stakeholders.

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