ANCOR LINKS
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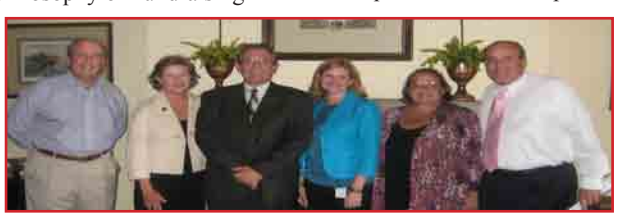
Cedar Lake: Revenue Growth Through Partnership

By Jim Evans

Cedar Lake's mission is to offer highly compassionate, capable care for people with intellectual and developmental disabilities so they may experience a life of abundant possibilities. That statement brings with it a commitment to do whatever it takes to fund the mission.

Everyone knows that Medicaid reimbursement is inadequate to the task of providing the funding necessary for quality care and services. While many are working to rectify that, the challenge for me is to find a way to bridge the gap. This is a task I love, and that I pursue passionately, comprehensively and unapologetically.

Cedar Lake has a philosophy on fundraising that can best be characterized as "partnership development." Through concentric "Circles of Friends", we work to bring everyone we touch into a sense of partnership with our mission. Families are not just served, they are partners in care, and they are asked to support us financially. Board members are challenged to provide not just governance, but financial support. Employees are asked annually to give a gift through payroll deduction to help indigent residents and clients. Companies we do business with are approached with the concept that we want more than a business relationship, we want a partnership that includes financial support, volunteer opportunities, and referrals. More, this is a two-way street. We support them as well, with referrals to other nonprofits and businesses where we have connections.



Corporate Partner volunteers work on a Golf Tournament Committee. (L-R) Bill Wagner, COO, Kaden Companies; Sherry Varner, Commonwealth Bank & Trust; Jim Evans, Cedar Lake; Christine Gandara, Commonwealth; Martha Bennett, Cedar Lake; Mark Kennedy, EVP, Commonwealth.

The result is that fundraising is an extension of all other relations. People in every level of the circles of friends receive information and encouragement to help them come to know that we are passionate about our work and the people we serve, and as such we will invite them to invest in Cedar Lake at their pace. And, as an added benefit, it gives people in every level and area of our organization an opportunity to be part of the fundraising effort.

A good example of this approach is the way we handled an RFP (Request for Proposal) to manage our endowment funds. The RFP was sent out to about 20 banks and financial management companies. Our philosophy was explained, and we asked them to respond, not just about fund management performance and fee structure, but also about how they would become partners in our mission.

One question was *"Our partnership expectations assume that managing Cedar Lake's investments is a desired goal for you, and as such, you would desire to respond—(1) through charitable dollars in support of the on-going mission, (2) in support of "First Light", Cedar Lake's signature annual fundraising Gala, and (3) in support of capital campaigns that necessarily will occur every four or five years. Please specify how you would prefer to provide funding, and in what amounts and frequencies we might expect your donations to come."* A follow-up question addressed introductions. *"Partnership assumes that you would be willing to introduce Cedar Lake*'s mission to others that you know and/or do business with. This is not "selling" Cedar Lake, but "opening doors" for us to present our mission, t*aking the role of one who says 'We partner with Cedar Lake, and you may find you, too, would be interested in their mission.'"*

The RFP process produced one firm that stood above the rest, Commonwealth Bank and Trust Company, which has now been a true corporate partner for the last four years. They support us financially, they open doors with other clients and friends, and they volunteer in many projects. And we have also brought new business contacts to them. Their partnership has been a crucial component in our growth in the community. A mini-RFP identified a new second manager, JP Morgan Chase, who has enthusiastically embraced Cedar Lake in every way a partner should.

This up-front approach may not work for every nonprofit provider of services to people with disabilities. It requires a commitment to have the forthright conversations, and a willingness to have the "hard talks" with would-be vendors. And it will not be received by everyone we present it to, but it works for us to tie our fund development with our circles of friends. In the end, we simply believe that Cedar Lake brings value to our community and to the life of every person who receives our services, or gives them, and who is willing to hear our story and respond to it. So, we continue to tell the story, we continue to ask people to join us in our mission and we continue to develop partners in funding the mission, bridging the gap between inadequate government funding and acutely needed supports and services to people with intellectual and developmental disabilities. ●

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Inside this Issue of LINKS:

Answers Left Unquestioned

By Renee Pietrangelo
ANCOR CEO

One of the speakers at ANCOR's recent Leadership Summit characterized the present as a threshold moment for providers. I concur; and in fact believe we are at a threshold moment for our country in determining the future role of government. To be sure, we find ourselves in the position of political exigencies versus collaborative change. Implicit in that is assuring we're at the table and not on the menu as the future of Medicaid funding is considered. ANCOR is responding to that imperative in multiple ways, including the October 1-2 leadership summit on funding and financing; our highly praised Funding Reform Checklist for use in your state, and the ANCOR Medicaid Values People initiative recently launched under the auspices of ANCOR's National Advocacy Campaign.

The environment is unpredictable for everyone. And, faced with this level of uncertainty, many of us try to avoid it, which can actually increase the occurrence of the shocks and stresses that we try so desperately to avoid. Does this make us even more fragile?

Author Nassim Nicholas' advice in his new book, *Antifragile*, is to expect and embrace randomness, noting that economies, cultures, evolution and organizations benefit from the occasional shock. In fact, organic systems gain from disorder. So to become antifragile, Nicholas suggests that we be more open-minded and mistake-prone; success being the result of excessive tinkering and improvisation.

To do that we must be up-front in addressing the answers left unquestioned. If it's true that we on some level know the answers to the questions facing us, but because of fear and uncertainty leave them unconsidered, then I enjoin you learn about ANCOR's Sustainable Medicaid Project, the purpose of which is to take up this challenge. We need fresh thinking and the benefit of a broader range of thoughts, opinions and perspectives. (To find out more about the Sustainable Medicaid Project, contact Barbara Merrill at bmerrill@ancor.org.)

There's no question that given the current economic climate, many leaders have little appetite for risk and are most comfortable sticking to what they know and what has proven effective in the past. That makes being open to change challenging. Certainly

Renee Pietrangelo

we need to be confident in our convictions. But we also need to be more collaborative (assuring a diversity of thinking) in examining alternatives, examining problems, identifying weaknesses and making decisions about envisioning a robust future. ⬣

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The Power of Collective Action

By Dave Toeniskoetter
ANCOR President

I am honored to have been elected by the Board of Representatives as ANCOR's President for the next two years. By way of introduction, let me share with you some thoughts about how and why I became involved with ANCOR, and why I believe so strongly in the value of ANCOR to support my organization, and yours.

I am the President and CEO of Dungarvin, a multi-state provider based in St. Paul, Minnesota. Founded in 1976, Dungarvin has been a member of ANCOR for most of its history. My active involvement with ANCOR began about 15 years ago, when I had a problem, and turned to ANCOR to solve that problem.

A small percentage of the people served by Dungarvin are supported in "host home" settings, in which a person with a disability resides on a long-term basis in the family home of the individual support provider. In these arrangements, the individual provider is an independent subcontractor, rather than an employee of Dungarvin. In the 1990s, we had a problem with the income tax treatment of the payments we made to our individual host home providers. I won't bore you with the details, except to say that the IRS applied a confusing patchwork of rules to the host home arrangement. The situation was so confusing that every local IRS office seemed to have a different interpretation of the law. Neither agency providers nor host home providers had clear guidance, and host home providers were increasingly being subjected to IRS audits, with frightening results.

I had no idea how to solve this problem on my own, so I picked up the phone and called ANCOR's Executive Director, Joni Fritz. Joni was the first person who fully understood the challenge Dungarvin faced. Better yet, she was able to direct me to three or four other providers, scattered across the nation, who were wrestling with the same problem. Joni arranged a conference call to get us talking to each other, and she offered the assistance of ANCOR's governmental affairs staff. The Foster Care Tax Task Force was born.

As an individual provider, it never occurred to me that I could change the Internal Revenue Code. My initial objective was much more modest: to get clarification of the law and educate the provider community. However, emboldened by our numbers and with the encouragement of ANCOR staff, we decided to set a more aggressive target. We set a goal of amending the Internal Revenue Code so that substantially all payments to individual family foster care providers could receive the same beneficial income tax treatment (exclusion from taxable income) that already applied to traditional foster care arrangements.

It took us four years, but ultimately we achieved our objective: in 2002, Congress amended Section 131 of the Internal Revenue Code in order to allow payments from government-sponsored foster care programs to be non-taxable income to the family foster care provider, regardless of the age of the person served or the involvement of an intermediary agency provider. ANCOR capped this achievement by obtaining a legal opinion letter confirming the effects of the new law. The IRS audits ceased, and family foster care programs for people with disabilities have consistently benefited from the change we wrought.

ANCOR's Foster Care Tax Task Force taught me a great deal about how to effect change in Washington. About two dozen ANCOR members were actively involved in various ways in the task force. With the help of a professional lobbyist, we refined our "ask" (what we wanted changed). We identified the Members of Congress who had particular influence over the tax laws, and the ANCOR members who were their constituents. Then we got down to work, finding sponsors for our legislation, and visiting with Members of Congress to request their support and co-sponsorship of our bill. Gradually we built a level of bi-partisan support for our bill, to the point that the leaders in Congress couldn't ignore us, and in 2002, the effective language of our bill was incorporated into a larger bill that was approved by both houses of Congress, and subsequently signed into law by President George W. Bush.

For me, perhaps the most memorable moment in the foster care tax effort was a session in the office of the Speaker of the House around 2001. We had recruited an ANCOR member from the Speaker's home district in Illinois to come to Washington with his young daughter with a developmental disability. Sitting in the Speaker's office in the Capitol, this member told the Speaker's Chief of Staff about the importance of the family foster care option to support people with disabilities, and how he personally hoped Congress would act to keep that option viable for his daughter, when her parents would someday no longer be able to care for her. At that moment, I believe a personal connection was made, a light came on, and I like to think that visit was perhaps the final nudge needed to get our foster care tax bill through Congress.

Dave Toeniskoetter

The point of my story is that, as daunting as it seems to change federal laws, we can accomplish such outcomes with the collective effort of the ANCOR membership.

Not every change in federal law is as simple and achievable as our foster care tax objective. The objectives of ANCOR's National Advocacy Campaign (NAC) are much broader and larger. I'm proud to say that Dungarvin is a founding member and continuing supporter of NAC, and I've been personally involved at various times with the work of NAC. This is a different kind of advocacy project, that goes directly to the heart of the most important financial issue for services to people with intellectual and developmental disabilities: the Medicaid program. NAC was all about Medicaid when it started in 2001, and it is still all about Medicaid, but the approach has changed as the economic and political climates have changed.

During the early years, the primary focus of NAC was on a direct support provider wage enhancement bill. By 2008, ANCOR members had obtained more than 130 Congressional co-sponsors for a bill that would have added millions of dollars of new federal money into the federal match of Medicaid expenses, on the condition that states would inject additional funds into their Medicaid programs to improve DSP wages.

Could the NAC's DSP wage bill have been passed into law? We'll never know, because the severe economic recession that began in late 2008 made it impossible to continue with that "ask." Instead, the focus of the NAC has shifted to raising awareness of the critical importance of Medicaid to support people with I/DD. We are in the fight of our lives

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to preserve Medicaid as the key source of financial support for services for people with intellectual and developmental disabilities. I believe that if they fully understand the role Medicaid plays in the lives of people with I/DD, a large majority of Members of Congress will act to preserve the most important aspects of Medicaid as we know it, for the people we serve.

The DSP wage bill didn't pass, so was that a wasted effort? I don't think so. ANCOR members and the people we serve have a visibility problem; we are a small part of Medicaid-supported services, so we can simply get lost in the political debate about Medicaid. NAC and the DSP wage bill campaign have gone a long way toward raising the profile of the services ANCOR members provide, and telling the personal stories of the people we support and the DSPs who support them. That is an important investment we must continue to make.

What keeps you awake at night concerning your agency and the services you provide? For me, it is the belief that the challenges facing Medicaid are serious and "structural;" which means they won't go away when our national economy improves. What I've learned through ANCOR is that Medicaid is in trouble because of structural issues of demographic trends (particularly the aging of the baby boom population) and continuing high inflationary trends in the cost of medical services. The disabilities world didn't create those problematic trends, but we may be run over by them.

At the ANCOR Leadership Summit on Funding and Financing on October 1 and 2, we heard again from Matt Salo, Executive Director of the National Association of Medicaid Directors. Matt forcefully made the point that the challenges of operating the Medicaid program will be daunting for state Medicaid directors in the coming years – and that's before any cuts are made in the federal Medicaid match. Mr. Salo strongly urged ANCOR members to get involved with the Medicaid debate at the federal level, because in the next Congress, we will either be "at the table or on the menu." Mr. Salo commented on the continuing movement of state I/DD programs in the direction of managed care and fee for service, and observed that "fee for service" may be another way of saying "fend for self."

As a provider, I'm struggling like everyone else to cope with the drum beat of reductions in payment rates and individual service authorizations, and the steadily increasing pace of change in expectations from our governmental customers. It isn't easy to budget for the cost of being an ANCOR member, attending conferences, and serving on the Board of Directors (which is not subsidized by ANCOR), but in these challenging times, I can't imagine that Dungarvin would not be "at the table" with our fellow providers, doing our best to assure we are not "on the menu" in the next session of Congress.

What do you and your agency need and want from ANCOR now, and over the next several years? If you think we are missing the mark, or you just wish to share a request or a new idea, I'd like to hear from you. My contact information is available through the ANCOR Connected Community. Let's engage. ⬣

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Are you connected?

Join the conversation -- ask, discuss, share -- on the ANCOR Connected Community.

Start something here.

Hills & Dales: Fundraising Through Community Outreach

By Marilyn Althoff

Hills & Dales, located in Dubuque, Iowa, has been building meaningful lives for children and young adults with disabilities for nearly 40 years. It is really not that long ago that Hills & Dales was considered the "best kept secret" in Dubuque. As the identified need for services began to grow, and typical Medicaid funding challenges became evident, our Board leadership and management team began to think about the future in terms of capital needs, growth of facilities and expansion of community-based services. With this decision and the commitment to provide the necessary financial resources and development staff, Board volunteers began educating and sharing our mission with the community.

Many of these presentations occurred externally, but it did not take long for us to realize the importance and effectiveness of bringing people to our Residential Center to see the mission in action. Through this process, the Board began to acknowledge that they needed to be active participants in the initiative and not casual bystanders.

The work of creating a greater community presence did not happen overnight. The process was strategic every step of the way, and it is now an expectation of the Board to continue growing, sharing our niche in services, and setting ourselves apart from the over 400 non-profit organizations operating within a 30 mile radius from Hills & Dales.

Through a futures planning session, we realigned our mission to embrace the role we have in assuring inclusion of persons with disabilities. We were able to expand on this focus and responsibility when we acquired our Community Center, which became the hub of multiple human service agencies that were independent of our mission – but served as the access point in reducing barriers for people we served – by including our mission with several other vulnerable populations. The Center was home to a senior meal and activities program, the local Project Concern agency which supports and administers numerous human needs programs, an off-site public school program for Life Skills Training, the vocational worksite for Hills & Dales, a for profit hardware store, and public meeting and conference space as well as a Summer Group Respite Camp. Not only did we create social enterprises, we created new stakeholders and supporters of our mission. We were becoming part of the community and awareness of who we are and what we do grew exponentially. We have continued to evolve and assure that we create opportunities to have meaningful partnerships, which is why we opened a licensed Childcare Center in the space vacated by the hardware store. It is now another community relations venue that attracts many organizations and volunteers to support our mission.

A festive holiday event at Hills & Dales also generates revenue.

Because of the efforts of many people and the community, a recent five year fundraising

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Inside the Back Room

By Barbara Merrill

Beyond the pale!!! I loved his speech and was once again scared by its content - yet came away hopeful.

Fantastic!

He made sense!!

What struck me about Rodney's presentation this time is the emphasis on the lifespan model, which makes more sense than talking about carving out specific populations

Has Rodney Whitlock let a genie out of a box? Those comments were in response to his presentation in October at ANCOR's Leadership Summit: Funding and Financing – From Crisis to Sustainability – and people are still talking about it. In a nutshell, Rodney is asking us to envision a long term services and supports system for people with disabilities that is based on a life span model – one that encourages independence, dignity and work, and does not contain the inherent inconsistencies of the Medicaid program. (Does this sound somewhat familiar? *LINKS* readers may remember that ANCOR's then-president Peter Kowalski made the same case in a two-part column in the June and July 2007 issues of LINKS.)

Rodney's questions were simple yet went right to the heart: why do we spend billions of dollars encouraging people to gain independence and get a job, only to penalize them once they start becoming successful? Does a program that needs to be there for people throughout their lives really fit within the same program that provides long term care to people who are in the last years of their life? Staffer to Senator Chuck Grassley (R-IA), and one of the most highly respected health policy analysts on Capitol Hill, Mr. Whitlock is making the rounds on the Washington conference circuit, and people in the disability community are listening.

It also appears that Rodney has the ear of Congresswoman Cathy McMorris-Rodgers (R-WA). Co-chair of the House Congressional Disability Caucus and founder of the Down's Syndrome Caucus, she is one of the rising stars in the Republican party – Governor Romney's campaign sent her to speak for him at the National Forum on Disability Issues in Ohio earlier this fall. Near the end of her presentation, after responding to a number of tough questions from moderator Frank Sesno, this little revelation slipped out:

> *Medicaid is being asked to do a lot as we move forward. And one of the thoughts I want to explore is whether or not we should pull even the disability portion out of Medicaid and make sure that we have some kind of a program long-term that is clearly protecting those with disabilities and making sure that a program continues over a longer period of time, and that those with disabilities and the important funding that is needed to serve those with disabilities in the home, in the community, is not taken away in order to meet the needs that are being added to Medicaid as we move forward…*

But two people do not a trend make – and certainly do not pass what would amount to such fundamentally radical reform. Despite McMorriss-Rodger's comments in the highest profile disability issues forum this election cycle, this idea has not taken sufficient form to be vetted through the political process. Mr. Whitlock knows that – that is why he challenged ANCOR conference participants to share thoughts with him of what a lifespan model would look like, and how it would work.

Barbara Merrill

Notably, elected Democrats are not talking about this idea – at least not publically – and such a potential change could be seen as inconsistent with current policy trends emphasizing function over diagnosis, and of breaking down silos. The question of what happens to people when they reach age 65 is a big issue – as the current dual eligibles state-by-state experience illustrates. State demonstration projects are all over the map – some include both acute care and LTSS for people with I/DD, others include only acute care, many other states carve I/DD out entirely. Then there is the ultimate strategy question for disability advocates - are services for people with lifespan disabilities safer as part of the larger Medicaid entitlement community, in the big tent that includes the political power of the elderly, hospitals, and nursing homes? Or does the safer course really only guarantee perpetuation of the poverty model, and prevent people with disabilities from realizing the full promise of true integration?

It behooves us to continue to participate in this dialogue, because it could represent the seeds of change – but remember, our political framework encourages incremental change and is structured to discourage big change. But this idea may prove difficult to get back into the box. Tell me what you think.

Author LINK: Barbara Merrill is ANCOR's Vice President of Public Policy. She can be reached at bmerrill@ancor.org.

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period review shows revenue increased 351%. Our outcomes are best measured by the increased fundraising and partnerships that have occurred through our vision of building meaningful lives through enhanced inclusion. A few examples of this would be receiving a three year Federal grant with a local sexual and domestic violence agency to promote access and empower survivors of sexual abuse/violence with disabilities, to recently receiving an anonymous $25,000 donation recognizing the efforts of a local woman who organizes an annual Christmas event at Hills & Dales supported by emergency service groups throughout the area, to various community groups holding smaller fundraising events on our behalf.

While the pathway to increased friend-raising and fundraising certainly requires hard work, Hills & Dales and the people we support have benefitted tremendously. What sets Hills & Dales apart is how – through social enterprise, stakeholder and relationship building, and revenue development – we can truly help provide for a meaningful life. We do not settle for meeting the very basic service requirements, they are just not enough to fulfill our mission. ⬣

Marilyn Althoff is Executive Director of Hills and Dales in Dubuque, IA. She can be reached at malthoff@hillsdales.org or 563-556-7878. Visit the Hills and Dales website at www.hillsdales.org.

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– Renee Pietrangelo, ANCOR CEO

Six Keys to Effective Fundraising

By Sandra Gerdes

Fundraisers are an important part of achieving your mission. Done well, they generate brand awareness, build goodwill among supporters and create the momentum for revenue cycles for your organization. Here are 6 key elements to consider when planning a new event or rejuvenating an old one:

1. **Organize!**

When selecting your committee, select key donors whose interests align with the event. Don't ask the president of your local golf club to chair your gala unless you know for a fact they love dressing up fancy and going to parties. Ask your chair to invite key peers of theirs to round out the committee. These are successful people who are used to meeting goals: give them a goal and watch them go.

2. **Create!**

Do some research. What other events are going on at that time of year? Don't plan your event to coincide with a fishing or hunting opening weekend if most of your golf committee members are hunters. Focus on what makes your organization unique—and communicate that in as many ways as you can imagine throughout the event. At a domestic abuse prevention event, there was an empty chair at each table symbolizing a victim from that year, with a story.

3. **Be Our Guest!**

This is the time to build momentum. Create a plan for each committee member to recruit sponsors, auction items and guests. It is effective to tie sponsorship to guests—"a Gold Sponsorship includes 8 guests"—then the sponsor helps fill your event. Have your key volunteers create the invitation list. Follow up invitations with personal phone calls or face to face visits. Involve your clients as guests as much as you can—greeters, servers, speakers, ticket sellers. Plan an advertising campaign that creates a sense of urgency—"tickets are going fast—call today"

4. **Harvest!**

Deliberately create ways to capture guest information- email sign up, raffle tickets that include contact info. Be prepared for the many contacts and ideas that will come in conversation at this event—coach your key volunteers to pass along these nuggets.

5. **Reward!**

Is this an annual event for your organization? Why not create an award that recognizes outstanding contributions by a volunteer or donor? Make the presentation at some point during the event, and publicize it. Thank your volunteers and guests without spending your precious resources on lavish thank-you gifts. Can your clients create a thank you note given to each guest? Can you make a small blank notecard with client artwork so guests can use that to send to a friend? How about a sticker they can wear at some later date that recognizes their support? "I Voted" stickers leverage this effectively.

6. **Cultivate!**

Based on your results, have a wrap-up meeting, congratulate your team, show them the results, demonstrate how they achieved their goal, and celebrate that. Identify new friends made, and start that committee list for next year. Start a cultivation process for both old and new friends. Develop those relationships. Before you know it, it will be time to start organizing again. ⬣

Author LINK: Sandra Gerdes is Executive Director of the Laura Baker Services Association in Northfield, MN. She can be reached at sandi@laurabaker.org.

2013 Direct Support Professional Recognition Awards -- Call for Nominations

To honor the long term supports and services workforce, ANCOR is pleased to announce the 7th Annual Direct Support Professional Recognition Award competition. There's no question that direct support professions (DSPs) constitute the backbone of community supports and services and without whom we could not function.

By nominating the star of your DSP staff for this coveted award, you have a unique opportunity to bestow deserved national recognition, while fueling advocacy initiatives on behalf of direct support professionals (DSPs) nationwide. We invite you to showcase the best and brightest within your organization's DSP community. Recognize this invaluable workforce by answering the call for nominations today!

Background

In 2007, ANCOR awarded its first national Direct Support Professional Recognition Awards in conjunction with the National Advocacy Campaign (NAC). Since then, ANCOR has recognized more than 150 state and national direct support professionals and members of the long-term supports and services workforce. The campaign's mission is to enhance the lives of people with disabilities by obtaining the resources to recruit, train and retain a sustainable direct support workforce. The awards honor and recognize the dedicated individuals who continually enrich the lives of the people with disabilities they serve.

2012 DSP Recognition Award recipients at the ANCOR conference in Washingotn, DC

Through its landmark National Advocacy Campaign, ANCOR continues to provide a strong voice in Washington for the direct support workforce on issues that affect their ability to provide quality supports to millions of Americans with disabilities. In addition, ANCOR has led the way to increasingly high standards for quality, inclusion and individual choice.

Why Submit a Nomination?

In addition to advancing the goals of the NAC, your nomination provides an opportunity to spotlight the critical value and importance you place on your dedicated direct support staff while educating your local media, elected officials and supporters about the value DSPs bring to their communities. Each nominee is considered a "finalist" and acknowledged accordingly by ANCOR.

Nomination Process

Only nominations submitted online through ANCOR's website will be eligible for consideration. Nominations must be received no later than 5 p.m. (EST) on Wednesday, **January 9, 2013**.

Please nominate only one person from each organization. For multi-state organizations, you may submit three nominations for each state in which you provide services.

Please read carefully and follow the instructions on the nomination form.

Only nominations accompanied by a clear digital photograph of the nominee (preferably with the person(s) they serve or in a work environment) will be eligible for consideration.

All state and national award recipients will be announced at ANCOR's 2013 Conference, which will take place April 28-30 in Washington, DC. The national winner will be invited to attend the conference at ANCOR's expense.

2012 National DSP Recognition Award recipient Lynda DiPressi (r) with ANCOR president Wendy Swager.

Questions?

Please direct any questions to Mary Pauline Jones at mpjones@ancor.org.

Thank you for your continued commitment to the direct support workforce and the delivery of quality long term supports and services to those with disabilities.

All nominations are confidential. ANCOR will secure release forms from nominees before using their name or likeness in any public communications.

Click here to nominate a deserving DSP today!

ANCOR Leadership Summit: Funding and Financing -- From Crisis to Sustainability

By Diane McComb

October got off to a bang as ANCOR members gathered in Washington for the fall Leadership Summit: *Funding and Financing – From Crisis to Sustainability*. The program was packed with the most current information available regarding the states' implementation of the Affordable Care Act, Medicaid reform, the latest trends in managed long term services and supports across the nation, and a close up look at what is happening in three states – Oregon, Kansas, and New York.

Participants heard high level national experts discuss the implications of the current fiscal and political climates and their potential impacts on ANCOR members. Topics ranged from Medicaid reform, to managed long term services and supports (MLTSS), to employer mandates under the ACA.

The program opened with Matt Salo, CEO of the National Association of State Medicaid Directors, telling us huge changes within Medicaid are occurring at both the state and federal levels. Increasingly there is an urgent sense that health care is dysfunctional. So we ask ourselves – what is in the broader mix that needs fixing in the systems supporting people with disabilities? Certainly the US health care system is among the biggest broken systems we have. We have terrible outcomes even though we spend 17% of our GDP on health care. Switzerland also spends a similar amount on health care, yet their outcomes are among the best. The countries with healthcare outcomes similar to the US are El Salvador and Ghana.

Health care is re-organizing around care coordination, care management and paying for outcomes. Currently, we pay for volume rather than quality under fee for service. The solution is moving toward some kind of managed care or other capitation structure. Not like the managed care of the 90s, where only cost was managed, but in terms of focusing on quality. Arizona and Tennessee are both doing good work in this area. Seventy percent of Medicaid recipients are in some form of managed care today. State Medicaid directors are confident that the end result of all of this change is going to be better care overall.

There are 9 million people nationwide who are dually eligible for both Medicaid and Medicare. Medicaid spends 42% of its budget on these 9 million, in addition to Medicare costs. There are multiple projects states are creating to integrate these two systems. Currently, each program shifts cost to the other, which results in unnecessary hospitalizations, medications, and institutionalization. Current projects beginning in early 2013 include MA, OH, and CA.

Now that the election is over, the lame duck Congress must resolve the sequestration issues. Entitlement reform is on the table, social security, Medicare and Medicaid. Medicaid is looking at potentially $80 – 100 billion in cuts. It's hard to find that level of cut in Medicaid. Some want to cap the federal exposure through block grants, which is not as likely as the implementation of a per capita cap. Everyone is suggesting a cut to provider taxes and possibly the delay of the implementation of the ACA to 2015, rather than 2014, which will allow the new congress to deal with some of the decisions.

Nancy Klimon from CMS and Paul Saucier of Truven Health shared the definition of managed long term services and supports as the capitation of all service arrangements between state Medicaid programs and contractors using capitated payments and accountability for quality, cost, and other standards. Of the states currently using MLTSS, Arizona is the oldest, having begun in 1989 and Delaware, the most recent, began in 2012. There are 389,000 people in MLTSS across the country and of those, 60-80,000 have I/DD. Most large states have mandatory enrollment. Most states include some form of self-direction with fiscal management service variations. MCOs are not opposed to using self-direction, especially when they can use family members as personal care staff. Money follows the person (MFP) also works well with managed care, with states building the MFP payment into their rate structures.

Quality measurement is achieved by looking at the person centeredness of the plan. States need to start with a good contract and then provide good monitoring. The big MCOs doing MTLSS right now include United Healthcare, Amerigroup, Centene, and Aetna. States using MTLSS include WA, WI, AZ, PA, MI, NC, DE, HI. States using community boards acting as MCOs include MI and NC. Arizona uses the state DD agency acting as the MCO. Delaware does not include I/DD waiver services. It is projected that 26 states will be using MLTSS by 2014, including states with proposals pending in CA, ID, IL, KS, MA, MI, NH, and NY.

States can propose MLTSS under multiple authorities including 1115 demonstration waivers or a combined 1915 b/c waiver. Different authorities allow different provisions. States should be asked to release contracts to anyone who asks to assure transparency and scrutiny that the contracts include important provisions for performance measures and quality assurance.

Dave Chandra, of the Center for Budget and Policy Priorities, presented on the impact of the implementation of the State Exchanges. Full-time work will now be defined as 30 hours per week and employers must provide coverage for all full-time employees. States can implement their own exchanges. If they don't, the federal government will set up an exchange for people to purchase health insurance. There are also partnership models shared between states and the federal government.

Merrill Friedman spoke about Amerigroup's presence in 30 states, many of which are pursuing MLTSS. She emphasized that they were de-medicalizing managed care to support people with disabilities. Their new MLTSS package is defined as transparent, flexible, person-centered, person-driven, and self-advocated. Amerigroup is incorporating the principles of Olmstead, Money Follows the Person, Community First Choice and the new definition of community proposed by CMS as a place to anchor supports and focusing on people's abilities. She acknowledged increased oversight and accountability for MCOs is needed in monitoring MLTSS. Amerigroup wants MLTSS to mirror best practices in community supports.

She stressed that quality of life must be measured using performance outcomes that go beyond medical outcomes – including re-integration into community for a person that includes the provision of technology and durable medical equipment that enhances a person's independence – and are not based solely on medical necessity. She said Amerigroup has not gotten it right in some of the early states and they want to partner with stakeholders early on to get it right in future states. She emphasized that if we look at managed care as a vehicle to drive Olmstead compliance and self-direction, we can get this right. Some essential services cited as non-medical included respite, transportation, day habilitation, and education in some instances. ANCOR members are primary stakeholders who should be at the table with input on benefit design.

She also affirmed Amerigroup's sense that when people choose the services they want

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and need, when they need them, and with staff they choose – people generally get what they want. Capitated models should allow a person with a disability to move through an array of services to accommodate changing needs. They should be flexible enough to achieve the desired result. Good outcomes on which to focus include self-directions, jobs, improved coordination, expanded accessibility, empowering people to participate in the mainstream of community, and investing in technology.

Ari Ne'eman from the National Council on Disability said they've made looking at the ACA a high priority as it relates to closing health disparities. Managed care is one of their priorities and they are engaged in meaningful conversations with managed care companies about what MLTSS should and should not look like. There is an acknowledgement that there will be little cost savings with the I/DD population in the immediate future, but that over time, better health and self-direction will present lower costs eventually.

NCD identified a new performance measure as the number of service coordinators who have been trained in self-direction and the number of people who are self-directing services. Their priorities also include shifting away from sheltered workshops and toward integrated employment. He talked about creating a responsible pathway to change sub-minimum wages paid to people with disabilities. He elaborated that, under MLTSS, states could create incentives for integrated employment options for people with disabilities by prioritizing supported employment over congregate vocational training or other day supports. He suggested a way to do this is for CMS to pay 100% of the federal match to states that do this. Some states are paying for the number of hours a person works, not just the number of hours of supported employment provided.

MaryBeth Musumeci from Kaiser and Judy Solomon from the Center on Budget and Policy Priorities provided insight on the Supreme Court decision regarding the implementation of the ACA citing 15 million uninsured adults could now be eligible for health care (11.5 million of which have incomes below the federal poverty level). The Supreme Court decision ruled that the individual mandate is legal; however, it also gave states the option of expanding Medicaid eligibility to this new group.

For states that expand Medicaid the federal government will pay 100% of the costs for the new enrollees for the first three years. This match will decrease to 90% by the year 2022. The Congressional Budget Office estimates that this Medicaid expansion will increase state spending by about 2.8% with the federal government picking up the rest. The current lack of coverage for this group costs the states already in uncompensated care for things such as mental health, substance abuse, and more. The exception to the federal match is for those individuals who currently are already eligible for Medicaid but have not enrolled. The feds will only pay their current match for state Medicaid for those individuals and states fear the woodwork affect the new push for enrollment might bring.

Summit participants also heard from Rodney Whitlock, Health Policy Director for Senator Grassley of Iowa. For an overview of his remarks, see the article "The 'Holy Grail' – Medicaid and Medicare Together" on page 16.

Eileen Quenell and Crag Jannino of Towers Watson provided much needed expertise regarding the requirements our members will face as employers under the full implementation of the ACA. They emphasized how agencies respond is dependent upon their business model and employees base profile. The individual mandate kicks in in 2014, requiring all individuals to have health care coverage or pay a fine of $95 per year or 1% of income, whichever is less.

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Individuals will have the ability to purchase health coverage through either a state or federal exchange and federal subsidies will be available for families earning up to 400% of the federal poverty level (about $92,000/year).

Benefits of the new coverage include expanded coverage for women's health, no underwriting, 100% payment for preventive care, no exclusions for pre-existing conditions, and no annual or lifetime limits on coverage among others.

Employers will be required to provide coverage for all full-time employees or face non-deductible penalties of $2,000 per employee. They estimate that 23 states will not be ready to start their exchanges by 2014. Several have done nothing waiting for the outcome of the Supreme Court decision and even after that, many have decided to wait until after the November election.

ANCOR will host a follow up webinar with Towers Watson, "Beyond Pay or Play: Healthcare Reform and Its Implications for Employers on November 28. Click here for more information

ANCOR member Dennis Felty, CEO and President, Keystone Services provided the closing plenary discussing a harrowing year of crises and resolution for Pennsylvania agencies. He talked about what his agency has done to pull people into a common mission, despite adversity, and look forward with a positive "can do" attitude. The very positive outcomes of their Adult Community Autism Program, which is funded through a capitated PACE model, reinforced his vision for the potential of funding reform under capitation and how he lives that vision every day. ⬣

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The ANCOR Benefits Team, You and Your Agency

By Richard Farnsworth

So much of what we do in our business is based on teams and teamwork. Whether at the clinical level with person centered planning that includes the many professionals and support staff that work with the individuals we serve or at the organizational level with management teams and department teams that are responsible for the smooth and efficient operation of the agency and sustain the delivery of quality services and supports to persons served. This is the core of how we do what we do.

ANCOR, through the ANCOR Services Corporation (ASC), has taken the same team focused approach that affects its many members in several ways. It is beneficial to our members who choose to participate, it benefits ANCOR as an organization and it benefits the people we serve through the quality of the goods and services that can be made available to those we support and staff. A happy workforce makes for a stronger team.

How is this happening, you ask?

ANCOR, as you know, has selected a substantial number of vendors that provide quality goods and services to participate in the ASC Shared Resources Purchasing Network program. This program gives our members access to significant discounts or rebates and also provides ANCOR with additional support that helps to keep the share of operating costs of ANCOR, that are paid through membership dues, under control.

For the past six months, I have had the pleasure of working with the ANCOR staff and some key providers to introduce the opportunities the goods and services of key vendor partners offer to our members. As the Benefits Representative, I have been working with Aflac, U.S. Bank and Medline with the goal of opening the doors of our members to learning about the benefits that they can offer. This has been a great opportunity for me to reestablish old friendships that I had made when I was the C.E.O. of Woodfords Family Services in Maine and an ANCOR member. It has also given me a chance to make new acquaintances that share the same commitment to providing quality services, in an efficient and cost effective manner, as I had worked to do when I was at Woodfords.

How are we doing?

Yes, we have made progress. We have not only been able to initiate conversations with new customers but also to expand where we have already been doing business. This has

Richard Farnsworth

been great in that, once again, it helps our member agencies, it helps ANCOR and it helps our vendors to maintain their commitment to providing quality goods and services to our members. That is the *teamwork* that makes the difference for us all.

So, should you get a call from me over the next few months, it is as a member of the *team* that is here to help you and ANCOR.
I will be calling!! ●

Author Link: Richard (Dick) Farnsworth is ANCOR's Benefits Representative and can be reached at omc@maine.rr.com. Dick encourages you to contact him to find out more about the valuable discounts and savings that are yours because you are an ANCOR member.

Pennsylvania First to Adopt CDS Curriculum Statewide

By Peter Schilling

For nearly a decade, Pennsylvania's Department of Public Welfare Office of Developmental Programs (ODP) has continued to provide self-advocates, families and direct support staff with access to DirectCourse/College of Direct Support. Pennsylvania became the first state in the country to adopt the DirectCourse/College of Direct Support (CDS) online curriculum as a method for uniform education across the entire state.

Seeking a convenient, cost-effective, accessible, and around-the-clock tool for Pennsylvania's direct support community, the ODP first discussed purchasing a statewide license to administer online courses through the CDS at the Reinventing Quality Conference back in 2002. CDS representatives worked with members of the ODP and its stakeholders, who were impressed with the course flexibility, affordability, and especially by its content, which they felt was some of the best in the world.

"The content was developed by national *and* international experts," said Jacqueline Epstein, Training and Communications Director for the Office of Developmental Programs. "And it was managed through the University of Minnesota, who already had an excellent reputation in the field of intellectual disabilities. How can you replicate that?"

Epstein continues, "One constant in our licensing regulations is that the provider must be able to meet the individual needs of the person. CDS has such a wide variety of topical areas that it helps to address that issue."

She also noted that, at the time of the conference in 2002, DirectCourse/College of Direct Support was the leader in the field, being the first and, at the time, only online training system specifically geared toward direct support professionals working in the field of intellectual disabilities. Now DirectCourse offers curricula for employment services and personal care assistance with another curriculum under development.

DirectCourse/College of Direct Support is a nationally recognized online curriculum developed by both national and international experts, updated frequently, based on best practices, and is accessible 24 hours a day, 365 days of the year. In Pennsylvania, as with the rest of the United States, direct support professionals work varying hours, have increased responsibilities and face geographical challenges, such as working in rural areas, far from sites that might be ideal for training. The CDS proved to be an ideal fit for Pennsylvania's training program, as the web-based curriculum gives learners the freedom to work at any hour of the day, in any location, and at their own pace.

Even better, Pennsylvania's CDS curriculum was tailored to meet that state's particular regulations. The staff at ODP and community stakeholders from every corner of the state—including self-advocate, family members, disability advocates, providers, and county representatives, among others—worked diligently with DirectCourse/College of Direct Support, to customize the content. The state of Pennsylvania also encourages learners to periodically weigh in on the coursework, and the feedback is closely monitored by ODP to enhance the learners' use of CDS. It is a constantly evolving process.

Furthermore, the DirectCourse/College of Direct Support staff also took a hands-on role in helping to administer the curriculum for its clients, working closely with the state to make sure its varying needs were met. "One of the most critical things for us in making the decision to adopt The College of Direct Support is how engaged the interested parties were right from the very beginning. CDS came out, showed us what they were developing, and there was a total buy-in from the start, as they were represented in the decision-making."

Funded at both the state and national levels, the learner's cost of enrolling in the CDS is shared, with the state absorbing the licensing fee and the agency absorbing the learners' administrative costs.

As of this writing, Pennsylvania has seen over 30,000 learners registered with the CDS online program, from over 200 enrolled individuals and organizations. These numbers include, of course, direct support professionals, but also self-advocates and family members who use the courses in the state's self-determination initiative.

Peter Schilling

Ms. Epstein is emphatic when discussing the merits of the CDS for direct support professionals. "Why would we want multiple providers creating overlapping training, when we can draw from training developed by the leaders in the field? This creates consistency of knowledge development."

From a letter welcoming learners to Pennsylvania CDS, the goal of this program is stated perfectly: "We hope that by using the College of Direct Support curriculum, we will begin to build a common language, which will enhance communication and help us better support the people we serve." ⬣

Author LINK: Peter Schilling works at DirectCourse. For more information about the DirectCourse/College of Direct Support curriculum call 1-888-526-8756 or email directcourse@elsevier.com.

The Holy Grail -- Medicaid and Medicare Together

By Diane McComb
ANCOR Liaison to State Associations

(Inspired by Shirley Walker, President and CEO Pennsylvania Advocacy and Resources for Autism and Intellectual Disabilities)

It is important from time to time to reflect upon the powerful advocacy within ANCOR. Working together on common causes, and maintaining solidarity even when there are peripheral differences, gives us hope we will prevail. The system supporting people with disabilities, created over the last four decades, won't look the same in five years; but, supports to people with disabilities and others with long term service needs will undoubtedly continue. The door is opening to extend the work we do so well to other populations, as we expand our capacity to support people in their own homes regardless of age or disability.

Having just returned from ANCOR's Leadership Summit: *Funding and Financing – From Crisis to Stability,* some are saying they now see clearly that the national focus of Medicaid reform is on creating systems putting people who are dually eligible for both Medicare and Medicaid together into one system – then from that core to wrap all other supports that they need around them - such as housing, employment, behavioral health supports, acute care, and whatever it takes to keep someone in their home.

Aging services are being pushed to develop community supports, and it comes to mind that we may have a role in this. ANCOR members are expert at providing community supports in homes, through shared living, and other community living opportunities for people, no matter their age. Collectively, we are the experts supporting people with intellectual disabilities – even those who are very difficult to support -- in the community. It is no different with aging.

The opening keynote at last month's Leadership Summit was Matt Salo, Executive Director of the National Association of Medicaid Directors. He shared that state Medicaid directors collectively acknowledge that putting Medicaid and Medicare together is the "Holy Grail." As states grapple with Medicaid reform, this knowledge will create a force so strong that it will happen in a powerful way. I also listened to Rodney Whitlock, Health Policy Director for Senator Grassley of Iowa and one who is very outspoken regarding our issues in Congress. He framed the discussion around two competing models of care - the medical model of the traditional aging program verses the person-centered lifespan model to which ANCOR members adhere. He emphasized the importance of educating elected and public policy officials as to the differences.

He also cautioned us to be wary of people who say "no" to every innovative idea that we have. He said those people simply want to adhere to an ideology that cuts services until there is nothing left. He said the goal for Senator Grassley and many others is for an individual to have one point of contact where all of the services s/he needs can be pulled together, without the layers of bureaucracy currently in our existing federal and state programs that are barriers to services for individuals and their families. It is these layers which create much of the cost. He alerted us that, as the systems are currently structured, many in government see no other way to reduce costs than to take from provider rates or from beneficiaries – both of which are completely unsatisfactory options because both will hurt the individuals we support.

Government systems have been built up around each other without regard to what the other is doing or what the impact to people with disabilities and families might be. Eligibility criteria and programs do not provide streamlined access to people with disabilities enabling them to quickly get the services needed. The services are there – all across several systems -- but accessing them for a family is a nightmare and many policies along with the misalignment of incentives defy common sense.

We have an extraordinary opportunity to advise elected and public policy officials how to best realign incentives in ways that will improve our ability to support people in the ways they really need. Our current system does not reward for providing supports in the ways we now know work best for families and people with disabilities. The system is geared to support a person in a group home rather than provide funding for home modifications, respite care, and other supports that would enable a family to keep their family member at home. That needs to change.

There is both risk and opportunity in the future of services and supports to people with disabilities, but this is nothing new. The difference is that the changes are moving faster than we are accustomed to. We can never know where the tipping points will be and who among us will have the right ideas at the right time that will take hold.

Diane McComb

ANCOR is our lifeline at the national level, providing us collectively a strong voice in Washington. We must advocate relentlessly to sustain the values important for people with disabilities. That is the purpose of our immediate future - to keep moving forward by learning, by thinking strategically, and by advocating – to insure that all people with disabilities and their families get what they need. ⬣

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Be Careful When Complying With Requests of Employees -- It Could Cost You

By Joni Fritz
Labor Standards Specialist

I believe that employers in the disability field—in particular—are anxious to accommodate requests of their employees. When these involve changes to the schedules of staff who sleep overnight at group living arrangements, and who are not paid for sleep time, these can be particularly dangerous. Requirements of the U.S. Department of Labor (DOL) are very tricky and even a slight deviation can result in a requirement that all sleep time be paid!

The DOL issued an enforcement policy on June 30, 1988 (88.48) that is still being used today. One sentence in this policy defines what it means to reside on the premises "for an extended period of time:" *the employee* must be *on duty at the group home and . . . compensated for at least eight hours in each of five consecutive 24-hour periods; and the employee* must sleep *on the premises for all sleep periods between the beginning and end of this 120-hour period.*

If all of the requirements of this sentence are not complied with, unless the employee actually makes the home or apartment his or her "legal residence," the sleep time must be compensated.

In the real world of group living, these requirements usually build in more than 40 hours a week, meaning that there will be some hours of overtime pay. The only way to avoid overtime is to have two employees cover some of the time the people who are served are in the home, while **making certain that the employee who sleeps there is working in the home a minimum of eight hours in each of five consecutive 24-hour periods.**

An employee may come to a mid level managerial employee at some future date and ask for a permanent shift change that will violate these minimum DOL requirements. If the mid-level employee is unaware of these DOL requirements, the change might be approved, putting the agency at risk of later paying sleep time due for a two-year period. An example of such a request would be to work for only four days a week rather than five.

It may be time to review your agency staffing patterns to assure that all employees who are not paid for sleep time are working schedules that comply with DOL policy 88.48. If you are uncertain what is required to comply with this

Joni Fritz

DOL enforcement policy, we suggest that you obtain a copy of the ***ANCOR Wage & Hour Handbook*** which contains the policy and sample staffing patterns. ⬣

Author LINK: Joni Fritz is a Labor Standards Specialist whose guidance is free to ANCOR members and to those who attend a Wage and Hour Workshop or participate in a teleconference that she has conducted. Any ANCOR member who wishes to make arrangements for consultation or workshops with Joni must first contact Barbara Merrill, ANCOR Vice President for Public Policy, for a referral at (703)535-785, ext. 103 or bmerrill@ancor.org.

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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