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March/April 2016

Columns

CEO Perspective: Reject the Politics of Scarcity AKA Distributive Justice

by Barbara Merrill, Esq.

The Medicaid unsustainability "fact" has taken such root that we now routinely accept that the overall Medicaid pie will not get bigger, and we either must fight to keep our share of the pie, or accept the new reality of scarcity.

Whether you are *Feeling the Bern* or not, the Presidential candidate's message that it's preposterous that the wealthiest nation on earth can't do better by its citizens is resonating with a lot of people – for good cause.

For years we've been told that Medicaid is unsustainable. Years of flat funding and exhausting advocacy campaigns just to stay afloat have left us believing it. We even repeat it to policy makers – as we plead to manage our own services and try to get out from under some of the regulatory burdens that strangle our ability to achieve efficiencies – only to be told that we now need to do more with less. The Medicaid unsustainability "fact" has taken such root that we now routinely accept that the overall Medicaid pie will not get bigger, and we either must fight to keep our share of the pie, or accept the new reality of scarcity. It pits advocates seeking greater resources for self direction against providers; populations against each other; employees against employers; even providers against providers.

Unless you've been living under a rock, or dialed down your receipt of the ANCOR Connected Community notifications, you've seen the explosion of postings about the utilization of the Supports Intensity Scale (SIS) as a resource allocation tool. With indefatigable ANCOR member Bonnie Brooks leading the charge, ANCOR members have been posting at a furious clip about how the use of the SIS and other needs assessment tools are being used to ratchet down services and slash rates. Providers are angry, unsure of who, what, or how many to blame, and lashing out at the tools, private consultants and state decision makers.

We saw this coming during the Great Recession: in the beginning states cut provider rates – some "across the board", others more surgically. Perpetrating the perception that the IDD system is spending too much on too few, and that Medicaid funding is unsustainable, states began to cut funding for services much more effectively.

If you set out to design a "systems change" to serve more people without adding more dollars, and you wanted to minimize the ability of stakeholders to mount an effective defense, you couldn't do much better than to link a credible needs assessment tool with resource allocation.

Those who followed the flurry of SIS-related postings noted that on three different occasions we cautioned members that the ANCOR Forum is fairly public – what may seem like an intimate conversation is really one with about four thousand of your closest friends – and every posting is only a click away from being forwarded. I obviously worried about an ANCOR member writing something that could bite them in a legal action, but I want to validate the feelings that were expressed.

The anger, specifically. I also feel it. I think we are all fed up with what seems like perpetual buck-passing, in a thinly disguised effort to abdicate responsibility. Thus the use of terms like "rate rationalization", or "right sizing". I really get frosted when the response is a patronizing "oh yes, change is difficult" – like this is just a change challenge. The HCBS community settings rule is and will be a legitimate change challenge – but when providers do not have the funding to give people the hours they need to be successful in their communities, and we continue to pay our DSPs poverty level wages – that's more than just resistance to changing. It's short changing the neediest among us.

States hire firms like Burns and Associates, Mercer, etc, to solve a problem – they want to spend less money, serve more people.

Maybe the SIS is used, maybe the ICAP or a home grown tool. The brilliance of the resource allocation strategy for states is that it lacks the transparency of a straight across the board cut – it's hard to fight something when you don't have access to the algorithms used to back into the rates. Those are the types of state legislative and legal challenges that need to be examined – what is reachable by a freedom of information request? What is legitimately "proprietary" information, and should disability advocates push for state legislation that ensures people impacted have full access to interviews, and providers have access to the algorithms used to establish rates per tiers? These are the questions we'll be examining in the next ANCOR webinar dedicated to this topic, questions we'll be asking Burns & Associates at a session during our annual conference in Chicago May 1-3, and questions providers should be asking at the state level.

Obviously not all states are hiding the ball, or misusing tools never originally designed for these purposes. But this is what we as providers know to be true: overall rates aren't even coming close to keeping up with demands, DSP turnover rates are between 40-50% nationwide, our efforts to loosen regulatory constraints are almost never successful and our system is at breaking point.

That's why it's our responsibility to reject that we must accept that we have an economy of scarcity – and to serve more people we have to do by giving others less service. That attitude simply perpetuates the marginalization of disability, and as service providers, it's our job to advocate for what people need, not to settle for what we're given.

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President's Corner: The Evolution of Disability Services

by Chris Sparks

If we analyze the evolution of disability services, there are at least four factors that have driven change over the last 40 plus years: customer expectations, funding, regulatory changes, and staffing.

"Bill Brown would be turning over in his grave," shared one long-time stakeholder during a recent telephone conversation. Bill Brown was the founding (in 1957) Executive Director of Exceptional Persons, Inc. (EPI) and this mother and I had been talking about the numerous, significant changes going on in our organization and service environment. I resisted my impulse to be offended by her remark (no, it wasn't easy.) Instead, I invested in understanding her perspective and shared again the change drivers to which we were responding.

Over the last couple of years here at EPI, I have found myself in similar situations, explaining to invested stakeholders the changes we and they are experiencing, and why. I believe it is intellectually dishonest to frame our response to change factors as if we are simply victims of policy makers and funders. The truth is much more complex than that.

What are the changes challenging our long-term stakeholders? Broadly speaking, people with disabilities and their loved ones are finding their voice and demanding the opportunity to direct their own services. They are expecting a say in where they live and with whom, a chance to work in real jobs they like and that pay a fair wage, and to have access to friendships and activities in the community. That may not sound revolutionary, but if you track back to the late 1950's as a starting point, it is.

If we analyze the evolution of disability services, there are at least four factors that have driven change over the last 40 plus years: customer expectations, funding, regulatory changes, and staffing.

Our customers, people with disabilities and those that care about them, have grown increasingly savvy and appropriately discerning as they have expected more in terms of quality, innovation, and personalization. This has resulted in the transition from large, segregated “group homes” to apartments and homes in preferred locations and with roommates of one’s choice, as just one example.

As funding has evolved from largely county- or state-based to predominantly Medicaid, this has driven service changes. Funding, or the lack thereof at times, has motivated changes - from the deinstitutionalization movement to the funding flexibility and individualization needed to develop service settings that are fully inclusive. It’s important to note the pressure of inadequate funding has created serious problems in the past, and these problems continue.

On the regulatory front we have a myriad of state and federal regulations to follow. Two recent ones, the HCBS Community Rule and the proposed DOL overtime threshold change are sweeping in their impact. The former supports the self-direction and inclusion of people with disabilities while the latter threatens to make it impossible for many organizations to operate successfully as we will be required to pay overtime to large segments of management staff that were previously exempt from such payment.

Worse still, spending money to comply with this rule without access to rate increases on the revenue side, further imperils our commitment to pay direct support staff more and erodes our ability to attract and retain these critical workers.**It is a true catch-22 because we would love to pay all staff better, but we must have access to additional revenue to do so.**

Finally, DSP turnover rates are still incredibly high. Additionally, many organizations are running double digit staff vacancy rates. Beyond DSP positions, it is becoming more challenging to attract staff in to key management positions. This trifecta of trends is unmistakable and clearly national. It is going to require us all working together to find solutions to this overwhelming problem. With some discomfort, we are adjusting to the reality of service delivery solutions that require less staff.

For organizations that provide community services to people with disabilities, ANCOR is a unifying and galvanizing force as we work to accomplish our mission. I deeply appreciate the public policy work and the educational offerings, but I often get the most value from ANCOR as a community of practice. By sharing experiences and working together, tirelessly looking for novel solutions to ongoing challenges, we all become more effective. And it helps to be able to confer with supportive others when we are simply tired from wrestling with intractable problems. I urge you to take full advantage of this aspect of membership.

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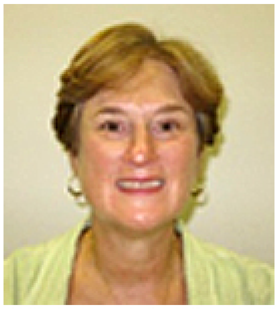
State Association View: The Rate Setting Hullabaloo

by Diane McComb
Assessment tools, rate-setting algorithms and stakeholder input - our State Association Liaison Diane McComb weighs in.



The first months of 2016 are proving onerous for states engaged in rate-setting strategies. Our ANCOR Connected Community (ACC) has been afire with back and forth over assessment tools, rate-setting algorithms, and states ignoring stakeholders' input. Our members were quick to blame the assessment tool for reducing rates; yet, the SIS, ICAP and InterRAI were never developed for that purpose. Nonetheless, states are doing just that – using these tools to set rates for services and supports.

CMS requires states to use a uniform assessment tool so states are scurrying to figure out which one they will use. States are also under enormous pressure to figure out how to minimize waitlists AND do a better job providing equal access to their dwindling resources. The SIS is used in a majority of states, followed by the ICAP, and a number of state specific tools. Half of the states use their assessment tool to develop a service plan, while half do not. Seventy percent of our members polled think the assessment tool used does NOT do a good job addressing issues of challenging behavior; and, 80% DO NOT think it adequately accounts for medical complexity.

We know rate setting algorithms have at least 25 data variables including levels of disability, levels of quality, geographic indicators, and more. There are two or three dealing with the amount of money a state has available for all those they want to serve. Assessments tell them what people need presumably, cost reports tell them what they are currently spending presumably, but in the end, the states must decide what they can afford to buy with the funding available. The bottom line is state government cannot print money. They must work within the allocation granted by their legislature. It is rare for a state's rates to truly pay for 100% of the services being provided. It is also rare for a state to acknowledge their rates fail to cover the full cost of regulatory compliance and an individual's plan.

The assessments, cost report data, available state and federal funds, and other variables inform states as to what they can do with rate reconfiguration. It is from these variables that algorithms are built to more equitably disburse funds across a subset of people to pay for supports and services. Ideally, states undertaking this effort will enhance the funding pool so resources aren't drawn away from anyone in the process of equalizing access. In years past, successful rate adjustment strategies were implemented concurrently with the closure of a large state institution, or an influx of new dollars. Agencies are finding the impact of rate-setting without new funding can wreak havoc on an already fragile system.

In several states, rate setting has successfully been challenged by focusing on the state's lack of adherence to their policies governing due process. Essentially, any time states propose reducing services and/or funding to beneficiaries (i.e. the people we support) notice must be given along with an opportunity to file an appeal (due process). Implementing a new rate-setting methodology without providing for proper due process violates the individual's rights.

As with any change proposed by a state, agencies must arm themselves with data and actively work to inform people with disabilities, families, government officials, and legislators as to the impact a shift in rates will have on individuals being served. Looking at State of the State data (D. Braddock) one can quickly determine rates paid by states are all over the place. One can only imagine people with disabilities and families have accepted dramatically differing levels of funding from one state to another along with dramatically different settings for supports. Some states rely primarily on in home supports and supported living, while others have come to expect 24/7 staff supervision in group homes for individuals with the same level of need as those in lesser settings.

All states must grapple with the expectations held by individuals and families. Convincing them they will be fine with fewer hours of supervision is challenging when done as part of a rate setting modification. Sometimes people will be just fine with fewer staff hours, sometimes not – but any state reducing hours would be well advised to transition people over time to “test the waters” so to speak.

ANCOR has launched a series of webinars to assist agencies in better understanding the dynamics of rate setting, assessment tools, and advocacy strategies for stakeholders. States must be held accountable to a transparent and fair process. It is our roles to make certain people with disabilities receive the right supports, in the right amount, and at a reasonable price. Agencies must partner with states to insist on adequate funding.

The recording of the first webinar, The Skinny on Rate Setting Re-Design - What’s Really Behind Those Assessment Tools can be located here. Details on the second webinar in the series are coming soon.

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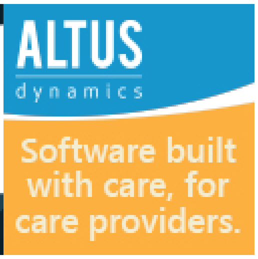

Notes from the Foundation

by Chris Stevenson

ANCOR Foundation President Chris Stevenson gives an update of recent Foundation activity and a preview of what's to come.

You’ve seen it in print, you’ve heard us say it…heck, you’ve probably even worn a pin stating it at recent ANCOR conferences. What am I talking about? It’s the ANCOR Foundation’s “Every Member Counts!” annual giving campaign. It’s the slogan from which our Foundation Board members derive passion for our many initiatives – initiatives that focus on providing members with innovative leadership training opportunities and mentoring possibilities.

Over the years, the ANCOR Foundation has sought out and offered training opportunities that we heard our members needed. Our partnership with the National Leadership Consortium on Developmental Disabilities at the University of Delaware stretches back ten years with the inaugural class of the 2006 Summer Leadership Institute and continues to go strong in 2016. Another key partnership that we have enjoyed for several years is with FranklinCovey. Together, ANCOR Foundation and FranklinCovey offered annual training opportunities in *The 7 Habits of Highly Effective People* to nurture ANCOR Foundation Lighthouse Leader agencies who have committed to build an agency-wide culture of principle-centered leadership embodied in *The 7 Habits*. And more recently, the ANCOR Foundation launched the Emerging Leaders Program to identify and support the growth of the next generation of leaders in our community.

In 2016, after considerable contemplation, the Foundation Board of Directors made a decision to focus on leadership initiatives that our members are requesting, in light of today’s challenges. Our leadership initiatives, such as the Emerging Leaders Program, the Renee L. Pietrangelo

(RLP) Leadership Forum and our Legacy Leaders Program boldly uphold our key value that, indeed, Every Member Counts! The ANCOR Foundation will continue to be a proud sponsor of the National Leadership Consortium on Developmental Disabilities and encourages you to consider applying for the 2016 Summer Institute. At the same time, the Foundation decided to sunset the Lighthouse Leaders Program associated with *The 7Habits* framework. We will be recognizing our Lighthouse Leaders partner agencies at the spring conference that have transformed their internal leadership through *The 7Habits* framework.

At the conference, we will recognize the accomplishments of our past leaders who have made ANCOR the organization that it is today at the Legacy Leader Award presentation on Sunday, May 1st. And, if you are attending the spring conference, I encourage you to participate in the Foundation's Auction. It will be loads of fun and the proceeds will go toward our leadership initiatives through the "Every Member Counts!" Campaign.

If you've made a contribution to the ANCOR Foundation, thank you! If you haven't, I encourage you to reach out to the Foundation Board of Directors and learn more about what the Foundation is doing to bring innovative leadership practices to ANCOR so that we can obtain your support to help our ANCOR member agencies thrive.

Take care – and have a happy spring!

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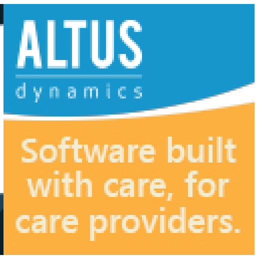

Articles

Keeping Pace with PACE

by Esme Grant Grewal, Esq.

The PACE pilot for people with disabilities is on its way to becoming a reality very soon.

Last year, ANCOR was invited to partake in a stakeholder discussion with the Centers for Medicare and Medicaid Services (CMS) and national health and disability organizations around a pilot model being considered by CMS that would apply the Program of All-Inclusive Care for the Elderly (PACE) program to a population under age 55 with disabilities. ANCOR has long been involved in conversations expanding this model from the aging population to adults with disabilities thanks to the participation of ANCOR leadership such as VOA's Angela King. However, last spring's stakeholder meeting launched an entirely new level of involvement on the issue.

The PACE model has long existed and was created with the goal of enabling older Americans age 55 and older that are eligible for nursing home care to instead receive coordinated care within their own neighborhoods while allowing them to live in their homes for the entirety of their lifespan. One notable success from this model included the creation of an interdisciplinary team of doctors, nurses, social workers and other specialists that work together to provide quality and person-centered care to each individual.

When ANCOR attended the stakeholder discussion last spring, we were intrigued by the idea of coordinated care creating the opportunity of better person-centered care delivery and independence, but were also challenged by how to adapt the PACE model to a population that would require not only health services but other integrated services throughout the lifespan. We left not knowing who the disability population being targeted was, what roles would make up the interdisciplinary team, and what a PACE center would look like to ensure integration and coordination with the HCBS rule.

The evolution of policy discussion and collaboration since that meeting a year ago has been a true vision of what the national disability community is capable of. It all began when ANCOR recommended bringing together key national disability stakeholders, all with different perspectives on the pilot, with the National PACE Association (NPA) to share variances in ideas and thoughts around the pilot model. This collaborative group now includes national organizations of self-advocates, providers, representatives of I/DD populations as well as behavioral health and physical disabilities, and it even includes state operational perspectives. Together we are all crafting a thorough disability protocol that a PACE pilot for people with disabilities should follow in order to meet expectations within the law but also to provide a truly quality innovative model.

The PACE pilot for people with disabilities is on its way to becoming a reality very soon. The legislative changes needed to permit CMS to begin demonstrating pilots passed the Senate and House easily and were signed into law this past November (See the PACE Innovation Act here) CMS is aware we are working on a disability protocol to accompany their pilots and we look forward to concluding our work on it soon so that we can deliver our work product to them. NPA will be presenting at ANCOR's Annual Conference in Chicago in May and discussing next steps for the pilots as well.

The process ANCOR has been involved in leading the creation of a disability protocol for the PACE pilot has not been an easy one as many different opinions and expertise have had to reconcile in order to create guidelines that will impact many peoples' lives. Yet it has been a rewarding and educational experience as we have all come together to focus on what innovation means in our field and how to ensure we continue to move the needle forward on provision of services. We are so pleased to be part of this work and we look forward to continuing it.

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The New EEOC NPRM: Stick, Carrot or Something Else?

by Katherine Berland, Esq.

In February, the EEOC issued a Notice of Proposed Rulemaking that will require federal agencies to adopt a goal of having at least 12% of their workforce consist of people with disabilities, and of that at least 2% consist of people with targeted or severe disabilities. But what if agencies fall short?

Although progress has been made since the passage of the Americans with Disabilities Act in ensuring that people with disabilities are granted reasonable accommodations to remain in a job, overall employment of people with disabilities remains a challenge. Recent statistics out of the Department of Labor Office of Disability Employment Policy show that less than 20% of people with disabilities participate in the labor force, and have an unemployment rate more than double people without disabilities. People with disabilities face challenges at all stages of the job-seeking process.

Often low expectations from birth (or the onset of the disability) result in less access to education and other resources essential to job readiness. When applying for a job, a person with a disability that self-identifies as such risks being bumped from consideration without ever getting an interview. The same is true during the interview process - a person with a disability may face discrimination from the potential employer without ever knowing if his or her disability was the reason for being passed over. Though such discrimination is illegal under the ADA, it is nearly impossible to prove prior to employment beginning, which means many qualified applicants never get a chance to demonstrate their ability to work.

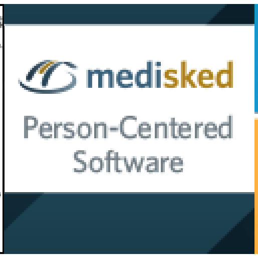
Given the challenges people with disabilities face beyond those of other populations, the Equal Employment Opportunity Commission (EEOC) requires federal agencies to engage in affirmative action employment for people with disabilities. In February, theEEOC issued a Notice of Proposed Rulemaking (NPRM) that will require federal agencies to adopt a goal of having at least 12% of their workforce consist of people with disabilities, and of that at least 2% consist of people with targeted or severe disabilities.

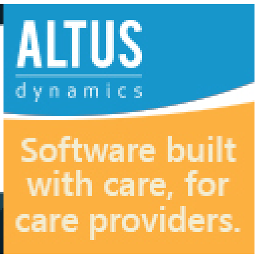
While the goal is a good one, it is aspirational. The rule requires that the agency set a goal, formulate an action plan on how to achieve that goal, and report back on how it is progressing towards it. However, if the agency falls short of the goal, the only real consequence is that they must continue working on it.

Federal laws and regulations tend to be a mix of sticks and carrots. "Sticks" include requirements that, if not met, will land the rulebreaker in hot water with the Department of Justice or other agencies with prosecutorial authority, resulting in fines or worse. "Carrots" usually take the form of tax deductions, tax credits, or other financial incentives designed to encourage a person or business to make decisions that, while not required by law, will advance policy in a way the government thinks right. **Mixed in between sticks and carrots are a different type of regulation - the aspirational goal.** Aspirational goals are requirements without teeth. They dictate actions rather than outcomes. In the case of this proposed rule, the action dictated is to create a plan to get to an outcome, but if the outcome never comes to pass, there is no meaningful way to enforce it.

The EEOC's proposed rule is unquestionably well-intentioned. And it probably will help lead to the outcomes it seeks. Perhaps the EEOC determined that it would be stepping beyond its bounds to require the outcomes rather than dictate actions. Perhaps it determined that, given the current administration, aspirational goals would be sufficient to advance policy. But administrations change, and with them, the goals to be aspired to, and the focus of where to best allocate resources. Time will tell if this rule results in more people with disabilities getting and remaining in meaningful employment. If not, it may be time to break out plumper carrots, or sharper sticks.

Author LINK: ***Katherine Berland*** *is the Director of Public Policy at ANCOR. She can be reached at kberland@ancor.org.*





The SOS Campaign: Funding the Future of Disability Services, One Action at a Time

by Doris Parfaite-Claude

With the Department of Labor's proposed changes to the overtime rule now in the final stage of review, we think it is important to take a moment to celebrate our membership's contributions.

ANCOR members have risen to the challenge with our Save Our Services (SOS) campaign, sending out 2346 emails to their Congressional delegations at the time of this writing through the www.disabilitySOS.org website, and even flying into Washington, D.C. with two days' notice! While our work is far from done from this issue – and with the Department of Labor's proposed changes to the overtime rule now in the final stage of review, the clock is ticking more than ever – we think it is important to take a moment to celebrate our membership's contributions.

Government Relations staff were lucky to have ANCOR Board Member Paula Hart come from Minnesota to join them on March 7 for an in-person meeting with U.S. Representative Collin Peterson (D, MN-7). ANCOR Board Members Julie Manworren and Dave Toeniskoetter also joined that meeting by phone. Their insights went a long way towards securing that office's receptiveness to our message and ultimately secured the office's cooperation. Paula also had a chance to stop by the offices of U.S. Senators Al Franken (D, MN) and Amy Klobuchar (D, MN), opening the door to email communications with key staffers. Paula had a productive day with us – and got to enjoy a sunny day on Capitol Hill! We hope you will be able to educate your Members of Congress as well, because each time they hear about the SOS Campaign they will move closer to lending their support to our legislation.

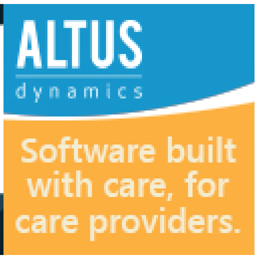
We understand not all of you can come to D.C., but through your sheer dedication to your work each and every one of you are compelling advocates and there are many ways you can reach out to Members of Congress:

- If you have not done so yet, use our **Action Alert to personalize an email** and send it to your whole delegation. Please feel free to share this alert with your networks – the more, the merrier!
- **Call your Members of Congress** to discuss the Department of Labor's overtime rule on your services - you can identify them through our ANCOR Amplifier (look to the menu on the right side of the screen for the Find Your Elected Official button). ·
- **Get into their newspapers** – please contact Gabrielle Sedor, Chief Operations Officer, at gsedor@ancor.org to discuss publishing an op-ed in your local newspaper(s).
- **See if you are in any of the districts of Members of Congress we have visited**, listed below. These offices were strategically chosen for their influential committee positions, blue-dog affiliations, ties to our membership or the IDD community. Upon your request, we will send you the contact information for the specific staff we have met in in your district so they can hear a perspective that is closer to home:
    - U.S. Representative Marcia Fudge (D, OH-11)
    - U.S. Representative Steve Stivers (R, OH-15)
    - U.S. Representative Bob Latta (R, OH-5)
    - U.S. Representative Bobby Scott (D, VA-3)
    - U.S. Representative Mark DeSaulnier (D, CA-11)
    - U.S. Representative Katherine Clark (D, MA-5)
    - U.S. Representative Jared Polis (D, CO-2)
    - U.S. Representative Susan Davis (D, CA-53)
    - U.S. Representative Mark Pocan (D, WI-2)
    - U.S. Representative Suzanne Bonamici (D, OR-1)
    - U.S. Representative Frederica Wilson (D, FL-24)
    - U.S. Representative Loretta Sanchez (D, CA-46)
    - U.S. Representative Jim Cooper (D, TN-5)
    - U.S. Representative Cheri Bustos (D, IL-5)
    - U.S. Representative Daniel Lipinski (D, IL-3)
    - U.S. Representative Jim Costa (D, CA-16)
    - U.S. Representative Brad Ashford (D, NE-2)
    - U.S. Representative Paul Tonko (D, NY-20)
    - U.S. Representative Joe Courtney (D, CT-2)

If you have any questions or want more specific information to help you with your outreach, please reach out to Doris Parfaite-Claude, Government Relations Manager, at dparfaite-claude@ancor.org or (703) 535 7850 ext. 108. Please add her email to your contacts, because she will be sending out communications for more opportunities to advocate, including a potential summer fly-in Advocacy Day.

Members of Congress need to hear from their constituents directly to put faces to policy issues, otherwise they will keep seeing those issues as abstract problems with no human consequences. Hearing from you can make a world of difference in a Member of Congress' attitude, and we need Congress to act to give support to providers immediately. The sooner you take action, the sooner we can Save Our Services!

*Author LINK: **Doris Parfaite-Claude** is the Government Relations Manager at ANCOR. She can be reached at dparfaite-claude@ancor.org.*



The Power of "Side-by-Side"

by Aaron Bishop, Commissioner, Administration on Disabilities

It is not only people with and without disabilities who are stronger working side by side. This simple, yet powerful idea also applies to all of us working *within* the disability community.

This post originally appeared on the Administration for Community Living Blog.

Every March we celebrate Developmental Disabilities Awareness Month and the many contributions people with developmental disabilities (DD) make to our society. This year, the National Association of Councils on Developmental Disabilities, Association of University Centers on Disabilities, and National Disability Rights Network chose the theme “Side by Side” to highlight the principle that everyone benefits when people with and without disabilities live, learn, and earn “side by side” in the community.

This idea of true inclusion and integration is the backbone of our work at ACL, and we are proud to work with our DD network partners to make it a reality for all people.

However, it is not only people with and without disabilities who are stronger working side by side. This simple, yet powerful idea also applies to all of us working *within* the disability community.

Historically, we have often worked within our individual spheres. DD advocates all knew each other and worked together, the independent living community did the same, and so forth. We were each doing great work, and we occasionally came together to accomplish great things such as the passage of the Americans with Disabilities Act, but we also missed some opportunities to achieve more by working together.

Fortunately, that is starting to change, and I can tell you that we are stronger as a result.

Last year, following the transfer of the TBI programs from the Health Resources and Services Administration to ACL and passage of the Workforce Innovation and Opportunities Act, which transferred several disability programs from the Department of Education to our family, ACL created the Administration on Disabilities (AoD). AoD brought together—for the first time—federal DD, independent living, and other disability programs. While we are still learning about each other’s work, we’ve already begun benefitting from our collective knowledge.

And the same thing is happening in the states. Earlier this month, I visited Sacramento, CA where I saw many examples of the power and potential of collaboration within the disability network.

With funding from an AIDD Partnerships in Employment Systems Change Grant, the California Employment Consortium for Youth and Young Adults with Intellectual and Developmental Disabilities (CECY) is bringing together more than 45 representatives from 23 state agencies, centers, and organizations along with families and self-advocates to increase the number of youth with DD in integrated competitive employment. Together they are working to tackle bureaucratic barriers and create innovative new models.

At the DD Public Policy Conference hosted by the California chapters of The Arc and United Cerebral Palsy, I led a panel that included Disability Rights California, three University Centers on DD, the California Foundation for Independent Living Centers, and California's independent living and DD councils. Each of these programs have their own unique histories, models, and culture, yet as they spoke the connections between their programs became clear and the opportunities for collaboration seemed endless.

I also met directors from two independent living centers who are working closely with colleagues in the aging network. A majority of the people served by both centers are older adults, and the centers are working with the aging network to connect those people with services such as home modifications and meals.

Of course, bringing together aging and disability work is the reason ACL was created. Together, the disability and aging communities have a larger voice and more influence. We can be more successful advocates, more easily share expertise across our networks, and bring the partners we work with, at all levels, together.

We also benefit from collaboration beyond the aging and disability spheres by advocating for each other's issues, building genuine coalitions across movements, and having each other's backs. One person who is living out this principle is Frances Gracechild. Over 35 years at Sacramento's Resources for Independent Living (RIL) she has worked in coalition with everyone from faith leaders, to labor unions, to anti-poverty groups to advance common goals.

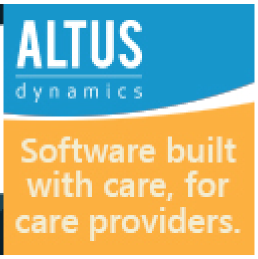
And there are always new frontiers for collaboration. For example, the UC Davis MIND Institute is helping the next generation of doctors become better allies to people with DD with a month-long training module introducing fourth year medical students to the experiences of people with disabilities, disability culture, and community-based services and supports.

Of course, collaboration doesn't mean we lose the unique elements of our individual missions. At ACL, we really are a multicultural organization. There are a lot of commonalities between the needs of older adults, people with intellectual and developmental disabilities, and people with physical and sensory disabilities. So it's important that we all develop a better understanding of each other's programs and issues so we can look for opportunities to work together where it makes sense. But it is just as important that we preserve, and continue to develop, the deep specific expertise we brought to the table as separate organizations.

That multicultural mindset reminds us of the critical importance of cultural and linguistic competency. Here again, our state network partners are leading the way. Disability Rights California is undertaking organization-wide efforts to include people with DD from underrepresented communities. This includes dedicated staff responsible for outreach to underserved communities, comparing client and staff demographics to Census figures, and advocacy to ensure individuals receive notices and programs plans in their native languages.

Whether working across movements or across generations, listening is essential to a "side by side" approach. Barbara Wheeler of the University of Southern California UCEDD shared an example of the dangers of not listening when organizing youth with disabilities. She notes that within the disability community, youth and adults often prioritize issues differently. Youth-organizing initiatives can falter when youth are expected to mobilize around the priorities of the adult organizers and not the issues that matter most in their own lives.

These are just a few examples of some of the great work happening in just one state and I could tell many more stories of the "side by side" approach in action all over the country.Working side by side, across differences, won't always be easy. It can take energy, time, and resources. And even with the best of intentions, not every attempt will lead to a resounding success.But overall, we are strongest when we find alternatives to segregation, break down silos, and abandon our single-issue boxes.



Members in The News

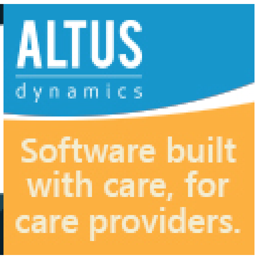
Aquaponics at the Arc Meriden-Wallingford Inc

The Arc Meriden-Wallingford, Inc. Invests in Innovation.

ANCOR Member **Arc Meriden-Wallingford, Inc**. was featured in a Hartford Courant article earlier this year on Sustainable Aquaponics Farming. Here is a quick excerpt:

> *Anyone can have an aquaponic garden. The concept is rather simple. An aquafarmer needs fish — the best are koi, Spencer said, because of the waste they produce — and a large aquarium or tank. That water is pumped and circulated into nearby grow beds filled with small shale rocks. (The size of the tank and number of fish depends on how large of a garden is planned.) The waste is broken down by bacteria into nutrients and fertilizer for the plants and the fertilized water saturates the bed of shale and a layer beneath it called the underdeck, where there is about a foot of water, and where roots dangle like tentacles of a jellyfish.*
>
> *In an ARC facility in Meriden — an organization that works with people with disabilities — strawberries, jalepeno peppers, swiss chard, microgreens, lettuce and nasturtiums grow in the beds with LED lights glowing above them. The people behind this company believe aquaponics is the future, in particular because no pesticides or herbicides are used, as is common on commercial farms. The company finds natural ways to deal with pests like using ladybugs....*
>
> *Pamela Fields, executive director of Arc Meriden-Wallingford Inc., said FRESH Farm took an underachieving aquaponics system at her facility and improved it so that it's usable. "Each of them bring their own expertise to the program," Fields said. "But they also have the personalities to work with our guys. It's hard to have both in the right mix, but they do. They are constantly coming up with new ideas and trying to grow ideas. They've really launched it and got it going.*

The full article can be found here.



UCP Wheels for Humanity Receives Grant from Google.org

ANCOR congratulates UCP Wheels for receiving a grant from the Google Impact Challenge: Disabilities!

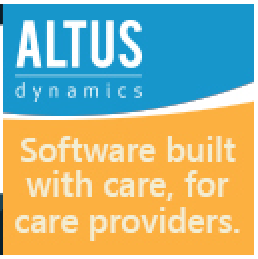
Launched in May of 2015, the **Google Impact Challenge: Disabilities** put $20 million in Google.org grants behind nonprofits using emerging technologies to increase independence for people living with disabilities.

“At Google.org, we support organizations that offer innovative solutions to complex challenges. We’re thrilled to back **UCP Wheels for Humanity** as they help build a world that works for everyone,” states Brigitte Gosselink, Head of the Google Impact Challenge: Disabilities. With a $1 million, three-year grant from Google.org, UCP Wheels for Humanity (UCP Wheels) will bring the voice of people with disabilities to the forefront in policy and philanthropy decisions.

Ronald Cohen, CEO of UCP Wheels states, “We are excited to be aligned with Google.org as we work together to make dynamic strides in connecting individuals with disabilities to innovative resources that will bring them independence and integration in our global community.” UCP Wheels is interested to know what really makes a difference in wheelchair users' lives. Data from less-resourced countries on the performance, usage and benefits of wheelchairs provided by donors, aid agencies, and governments is difficult to collect and not broadly available. Since different chairs and clinical services are needed to accommodate the varying needs of people with disabilities, this data is crucial to ensure users have the best chair to maximize their health and independence.

UCP Wheels is developing a system for gathering both subjective and objective data from users in less-resourced settings all over the world. UCP Wheels will use sensors to collect data on wheelchair usage patterns and environment, as well as SMS surveys to learn about user satisfaction and impacts on education, income, community participation and health. The combined data will provide key insights into which chairs are most effective in a range of conditions, users’ preferences and overall impacts. Because thousands of wheelchair users in many countries will be involved, the project will reach an unprecedented scale. Through SMS surveys, even remote users will be able to submit a review of their chair in their own words - bringing their voice directly into the conversation on how best to serve their needs. This global wheelchair performance project aims to answer basic effectiveness questions and drive future funding to a problem that affects 70 million people worldwide.

UCP Wheels for Humanity is a subsidiary of ANCOR member **United Cerebral Palsy of Los Angeles, Ventura & Santa Barbara Counties.** UCP Wheels for Humanity was founded in 1996 to increase access to mobility for children and adults with physical disabilities who live in developing countries. UCP Wheels provides mobility, therapy and empowerment programs to globally and acts as an advocate and capacity-building partner to local organizations, creating sustainable, community-based systems that support long-term change.



Comings and Goings

News and updates about ANCOR Member Executives.

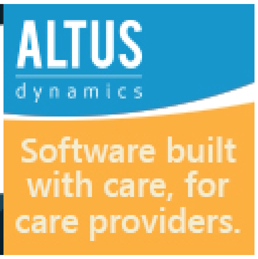
On April 15th, **Kim Opsahl** will step down from her role as **President/CEO for Indiana's provider trade association – INARF.** Kim has been with INARF for over twelve years, beginning as Director of Membership Support and culminating in her most recent role serving the past three years as the Association's third President/CEO. During that time, she helped lead the Association in many successful advocacy efforts, including working with the Indiana General Assembly in 2015 to secure the necessary resources to restore rates that were cut during the most recent economic decline. Kim also completed her law degree, while working at INARF – graduating summa cum laude from Indiana University Robert H. McKinney School of Law in May 2014. She also greatly enjoyed being a part of the ANCOR Family by participating in the State Association Executive group, Government Relations Committee, and National Advocacy Campaign. She is leaving to pursue opportunities to put her legal education into more direct use on behalf of providers and the individuals they serve.

As the INARF Board works to select a permanent replacement, **Jim Van Dyke will serve as INARF's Interim President/CEO.** Jim has most recently been a consultant in the health care field. Prior to that, Jim was the CEO of INARF Member New Hope of Indiana for 15 years during which he led New Hope's successful spinoff from St. Vincent Health. Before New Hope, Jim was the CEO of then-INARF Member REM-Indiana for seven years prior to its becoming part of the Mentor Network. Jim has experience assisting the state of Indiana in closing several large institutions for persons with developmental disabilities. He is also very familiar with rate setting and rate reform efforts, having been deeply involved in Indiana's last three changes to Medicaid Waiver rate setting. Jim is well-respected by his colleagues with a demonstrated commitment to the Association, its members, and their collective success. As INARF's Interim President/CEO, he will provide continuity and proven leadership to the INARF team.

Ian Paragol was recently named the new **State Association Executive** for the **District of Columbia.** Ian replaces Arthur Ginsberg, who left the position a few months ago to lead Community Residences, Inc. an ANCOR member agency in Virginia.

Ian has a history of advocacy, negotiating, building leadership teams, and providing vision and support in his prior roles. He has almost 17 years of experience in serving at-risk populations including as General Counsel to a Maryland-based for-profit organization of residential group homes and a non-public school for emotionally disturbed adolescents, as well as directing advocacy at state and county levels. Ian was the Chief Operations Officer, and most recently the Executive Director of the nonprofit Community Services for Austic Adults & Children (CSAAC) for the last ten years. His strategic and organizational abilities led CSAAC to attain improved efficiency of operations, enriched quality of services and an exceptional reputation as a national leader in lifespan autism services.

ANCOR members at the executive level are encouraged to contact
Jerri McCandless *(jmccandless@ancor.org)*
about their comings and goings.



Member Benefits

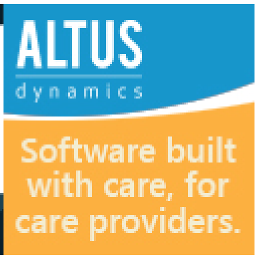
The ANCOR Marketplace Benefits You!

The ANCOR Marketplace gives ANCOR members special insight into new products and services as they appear in the I/DD marketplace — products and services that will help grow providers' businesses.

The **ANCOR Marketplace** (www.ancormarketplace.org) is an easy to navigate site that gives ANCOR members a special insight into new products and services. The various offerings are conveniently categorized, which makes shopping for I/DD products, such as software systems, housing solutions, merger and acquisitions prospects, insurance services and more, a smooth browsing experience.

The ANCOR Marketplace also features customer reviews and testimonials by other I/DD executives, thereby helping providers evaulate their choices.

Find out more about the **ANCOR Marketplace** — contact ANCOR's Development Director, Marsha Patrick (mpatrick@ancor.org).



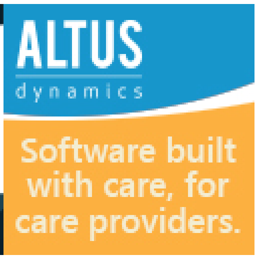
Did You Know: Medline and Sears?

Check out these special offers for ANCOR members!

"Did You Knows" feature vendors in the ANCOR **Services Corp.'s** ***Shared Resources Purchasing Network!***

Did You know that Medline offers savings on housekeeping items, homecare beds, walking aids, bath safety items, latex gloves, diapers, aids for daily living and a full line of bariatric products? Click here to find out more information.

Did You know that Sears has ANCOR's Best Values Program for appliances and household goods. As an ANCOR member, you have the opportunity to purchase major appliances and other whole-house products at special affiliate pricing combined with personal shopping and order assistance? Click here for details...

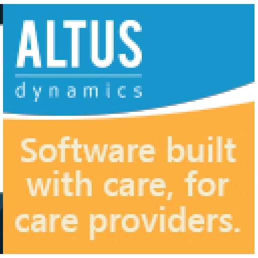


SRPN: What Members Are Saying...

The Shared Resources Purchasing Network (SRPN) partners with national companies to provide significant savings to ANCOR Members.

The Shared Resources Purchasing Network (SRPN), administered by the *ANCOR Services Corporation,* partners with national companies to provide significant savings to ANCOR Members and supports ANCOR programs. Members who use the SRPN enjoy savings and leading purchasing practices, and can rededicate their savings to needed programs. The SRPN discounts with selected vendors also apply to Members' employees, persons served by the organization and their families.

For more information, including a list of SRPN vendor partners, visit [ANCOR Services Corporation]() or contact Marsha Patrick at [mpatrick@ancor.org]()



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