Links

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SPECIAL CONFERENCE ISSUE

Leadership and Innovation Are Watchwords at ANCOR Winter Conference

The ANCOR 2003 Winter Conference, held in San Antonio, Texas, was marked by an engaged and focused attendance of nearly 300. This year's program featured several new features, including a day-long CEO Roundtable and a topical luncheon dialogue that focused attendees on strategies for leading and managing in a turbulent fiscal environment.

Leadership

A pre-conference workshop addressed the need for top-down, bottom-up leadership skills development in your organization, and the impact of a strong values-driven culture on minimizing risk and liability in your agency. Benchmarking and dynamic communications techniques were shared by a panel of accomplished agency CEOs, who also shared their personal stories regarding leadership strategies in the face of daunting agency challenges.

Attorney Michael Komoll discusses the correlation between leadership and liability risks.

A full-day CEO Roundtable led by accomplished consultants Yo Bestgen and Ed Ryan focused on leadership survival skills in times of stress, and human resource development, topics selected in a comprehensive survey of ANCOR agency leaders. The CEO Roundtable programming format will continue as a dynamic feature of future ANCOR conferences and regional programs under the direction of the ANCOR Foundation's Center for Leadership.

Consultant Ed Ryan leads discussion at CEO Roundtable.

Keynoter and workshop leader Al Condelucci.

Building Community

Keynoter Al Condelucci, noted author and national speaker on building social capital and the process of cultural shifting, set the tone for the meeting with an intelligent and impassioned presentation on viable strategies for inclusion and solidly connecting people with disabilities into the mainstream of the community. His keynote was coupled earlier in the day with an extended seminar featuring a four-step process to cultural shifting.

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ANCOR

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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The Great Turning

Renée Pietrangelo

In spiritual new age jargon, "The Great Turning" is the act of courage we make when we dare to see our world as it is and commit to making it different. It entails both the perception of danger and the means to act. That's what we've done as the collective "ANCOR" in initiating and supporting the National Advocacy Campaign (NAC). We have, in fact, enhanced our *response-ability* by focusing our message and taking it beyond the borders of our traditional feedback networks. I commend each of our contributors on that effort.

But in our present environment, The Great Turning may not be a simple one. The perils facing us are so massive and unprecedented that they have overwhelmed many of us. The state of the general WILLPOWER to effect change is also compromised by the distractions of terrorism and the war in Iraq.

The very danger signals that should rivet our attention, summon our courage and energy, and bond us in collective action can have the opposite effect. They may make us want to hunker down, pull down the shades and busy ourselves with crisis management. There's no question that sounding the alarm and sermonizing tend to make us pull the shades down even tighter, stiffening our resistance to what appears to be too daunting and complicated a task; or capitulating because of circumstances too out of our control.

What we are dealing with here is akin to the original meaning of compassion: "to suffer with." It is the distress we feel on behalf of the larger whole of which we are a part—the hundreds of thousands of direct support professionals and people with disabilities we work with and serve.

The situation for providers is unprecedented. The states' collective current-year budget shortfall is estimated to be $80 billion—described as the worst deficits since WWII. Forty-nine states have planned or are implementing Medicaid cuts in FY 2003, with 32 of these states already having made a second round of Medicaid cuts. States have already reduced or frozen provider reimbursement rates in 37 states, restricted eligibility in 27 states, reduced benefits in

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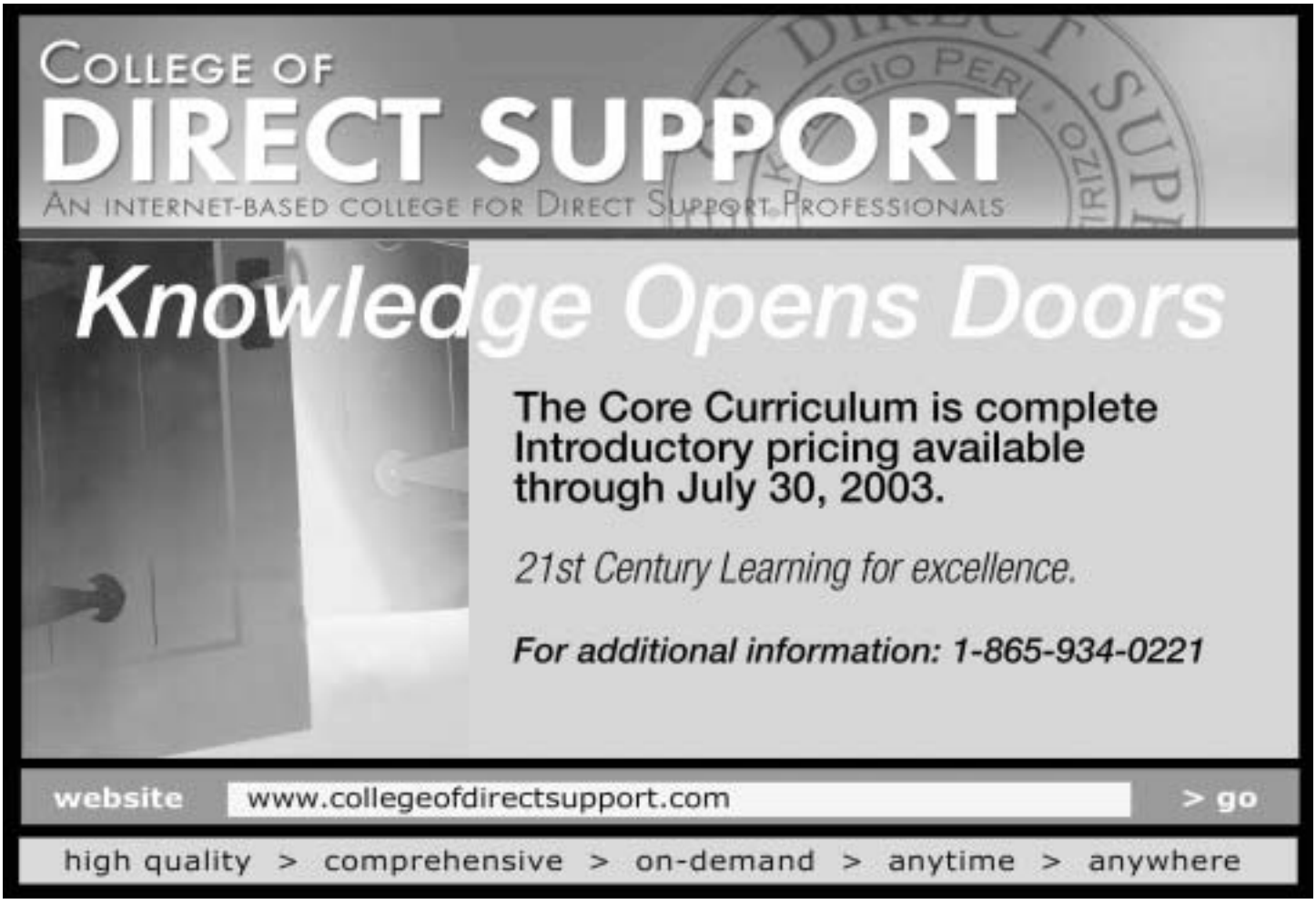

45 states, increased co-payments in 17 states, and 17 states have taken action to reduce spending on community and institutional long-term services. Certainly this is a major blow—and possibly a knock-out punch—to realizing the vision of choice and implementing the Administration's New Freedom Initiative.

As we announced in a recent communication to all ANCOR members, we have released the first of our public service announcements (PSA) to raise awareness regarding the wage issue and the critical role direct support professionals play in enhancing the lives of people with disabilities. The PSAs were previewed at the recent ANCOR Winter Conference, and the response was overwhelmingly positive. Many ANCOR members committed to getting the PSAs aired on their local television networks. They also appreciated the tremendous value of the PSAs as morale builders among direct support staff, consumers and family members.

As part of the PSA launch, ANCOR has also gone live with our National Advocacy Campaign *public* web site at www.supportnac.org. You can view both the 30-second and 15-second public service spots on this web site. The PSAs' call to action is to visit the public NAC web site. I strongly encourage you to share the spot with your direct support staff, families and consumers and ask that you make a commitment to work with your local media to get the PSA aired in your local television market. Contact ANCOR for a copy of the announcements.

As you'll remember, a Congressional Resolution was introduced at our September meeting regarding the direct support professional workforce crisis. On Friday, March 14, the resolution was reintroduced in the House and introduced in the Senate, sponsored by Senators Jim Bunning (R-KY) and Blanche L. Lincoln (D-AR).

We succeed one achievement at a time; we fail one commitment at a time. The National Advocacy Campaign has succeeded one achievement at a time. Let's commit ourselves today to not allowing it to fail one commitment at a time. The commitment of every ANCOR member is critical to our success.

Get involved and join the campaign today. Specifically, we ask that you share the names of corporations or organizations within your centers of influence that could assist us with our grassroots campaign or provide financial support. If your agency is not a contributor, please join the campaign today. If you're already a contributor, consider increasing your support and, if you haven't already, implement a grassroots initiative with your staff, family members, provider colleagues, and community networks. Our grassroots kit is included on the NAC CD-Rom that was mailed to every ANCOR member in early March.

In these troubling times, I am reminded of the inspiring words of Margaret Mead: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." We are doing just that! ■

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Winter Conference

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SABE President Chester Finn confers with Suellen Galbraith.

Another first for ANCOR was the permanent addition of the self-advocacy perspective on the conference program. This year, ANCOR was privileged to have Chester Finn, president of Self Advocates Becoming Empowered (SABE), a national organization numbering thousands of self advocates. Mr. Finn shared SABE's mission and the imperative for effective collaboration among providers and self advocates, praising ANCOR's initiative in actively seeking partnership opportunities with SABE.

National Advocacy Campaign

A preview of the first in a series of national public service announcements (PSAs) on the direct support professional workforce crisis, met with enthusiasm and strong approval.

Midge Soderbergh (center) poses with ANCOR members at National Advocacy Campaign contributors' briefing.

The PSAs feature Midge Soderbergh, mother of Peter, who is developmentally disabled, and Steven, Academy-Award-winning director. Mrs. Soderbergh also presented an impassioned directive to ANCOR members to get families and staff involved in the national campaign, which is aimed at raising public awareness regarding the value and dignity of the direct support profession. *(See page X for a complete text of Mrs. Soderbergh's remarks and preview the PSAs on either the ANCOR and NAC websites: www.ancor.org; www.suportnac.org.)*

Also featured in the update session was advocacy consultant Lanny Griffith, COO of Barbour Griffith and Rogers, the consulting firm engaged by ANCOR to focus on Administration and Congressional efforts to ameliorate the direct support professional staffing crisis. Of note is the reintroduction of the Direct Support Professional Recognition Resolution in the House of Representatives by Representatives Pete Sessions (R-TX) and Lois Capps (D-CA), and the introduction of the resolution in the Senate by Senators Jim Bunning (R-KY) and Blanche L. Lincoln (D-AR). Copies of the resolution and a draft letter enjoining congressional support can be found on the NAC web site www.supoprtnac.org.

The adoption of these resolutions, which will lead the way to Congressional hearings and future legislation, is incumbent on a massive grassroots letter-writing campaign by providers, consumers, family members and centers of influence in your community. A draft letter you can customize to your organization and staff are included on the web site.

Administration senior official Dr. Margaret Giannini, director of the recently created Office on Disabilities, shared Administration initiatives relevant to the needs and concerns of the private provider community. Several very tangible plans and other creative proposals for addressing workforce, regulatory and funding issues were presented.

Innovation

Many of the panel and breakout sessions focused on quality improvements and cost savings through the application of innovative technology. A panel of consultants and providers shared how software technology applications streamlined operations, saved money and enhanced the quality of supports and services. Of particular note were very affordable applications for small- to mid-sized agencies.

Specific business development and transitional strategies were shared that encourage consumer and family choice while supporting an agency's continued growth and success.

Collaborative public relations strategies and state-of-the-art practices in screening, interviewing and retaining staff were also shared in interactive workshop environments.

continued

Lanny Griffith, Dr. Margaret Giannini and NAC Chairman Peter Kowalski at National Advocacy Campaign contributors' briefing.

An exclusive briefing luncheon was held for National Advocacy Campaign contributors. Both Lanny Griffith and Dr. Giannini fielded questions from the audience regarding impending Medicaid reform initiatives, workforce issues and funding woes.

NAC contributors enjoy animated exchange at contributors' briefing luncheon.

Gale Bohling (pictured here) and Tom Schramski lead workshop on innovative business development strategies.

Dr. Margaret Giannini is the director of the newly created Office on Disabilities. She shared many of the issues, creative plans and ideas either underway or being considered with regard to implementation of the President's New Freedom Initiative. Her complete remarks can be read on ANCOR's web site, www.ancor.org, as well as on the National Advocacy Campaign site, www.supportnac.org.

Active participation by workshop attendees was a pervasive conference dynamic.

State Share

ANCOR's traditional State Share environmental scan was characterized by animated discussion regarding funding cutbacks, legal actions and liability issues facing providers across the nation. A final State Share report will be posted on the ANCOR web site in April.

ANCOR New Jersey representative Mercedes Witowsky joins dialogue, sharing her state's perspective in State Share environmental scan session.

Public Policy

Industry leader Bob Gettings explored the implications of the current federal and state funding crisis and identified steps state and local DD services systems could take to adjust to this stormy and challenging environment. A compelling panel of participants discussed cutbacks and changes in reimbursement strategies, focusing on recommendations for reimbursement reforms. And Val Bradley, executive director of the Human Services Research Institute, highlighted leading practices and emerging issues with respect to quality assurance and enhancement.

ANCOR Foundation

ANCOR Foundation President Amy Gerowitz shared the vision and mission of the ANCOR Foundation and the creation of two major centers for research, education and training—the Center for Leadership and the Center for Information and Innovation.

Bob Gettings.

Val Bradley.

Wendy Sokel moderates discussion on innovative software applications with speaker Steve Bernat.

Exhibitor Sebastian Triscari explains his firm's services.

ANCOR Foundation

Mission

To build the capacity and commitment of communities to improve the quality of life for people with disabilities.

Vision

People with disabilities living meaningful, productive, personally satisfying and well supported lives in communities of their choice.

ANCOR Foundation President Amy Gerowitz introduces bold plans for ANCOR Foundation.

Thought-provoking panel tackles reimbursement reform. (*left to right:* Norm Davis, Gale Bohling, Dave Toeniskoetter, Ken Lovan, Bob Getting and Marty Lampner).

Remarks by Midge Soderbergh

Thank you for inviting me to San Antonio to speak to all who are assembled here at the annual ANCOR winter conference. I wish these were happier times that mark our meeting today. Soon, many young Americans, fully deserving of their hopes and dreams, will no doubt be sacrificed for what we as a nation hold dear. The problem is, what exactly is it that we hold dear? What is it we are fighting for? And how is all of this so terribly relevant to our mission in human services?

As a war veteran, I know what it is to be ready to put everything on the line. That is why I can stand before you today, fearing for what will happen to the quality of life for individuals with disabilities, like my son Peter, if the human service community fails to protect its own quiet heroes. After all, isn't it the direct support professionals across America who make it possible for our talk about respect and dignity to have any integrity at all?

We must be willing to wage our own war and stand up for what we know is right and just. It's one thing to talk a good game about equal opportunity and respect for all Americans. As a movement, we never seem to be short on talk. It's quite another, however, to make the necessary sacrifices and take the necessary personal action to ensure that our values have meaning for all Americans, not the least of which are our own workers who are fighting the good fight on the "front line" every day of their lives.

Known for being something of a boat rocker, taking no for an answer isn't exactly my specialty. If I'd accepted everyone else's pre-conceived notions of what was right or even appropriate, I never would have become a Marine.

I certainly wouldn't currently be working on my masters degree at the age of 73; my son Steven Soderbergh might never have become an award-winning film director; my other children and grandchildren would not now be achieving their true potential as they work to better the world around them; and perhaps most important, my son Peter, who was born with severe developmental disabilities, might not be leading the extraordinarily rich and fulfilling life he enjoys today.

Indeed, none of us can remain on the road less traveled without being confronted by extraordinary challenges. I have faced many. Thankfully, however, I've also enjoyed many blessings—my children, my health. But there is only one singular blessing In my life that could ever rate as pure or as inspiring as mothering my children, and that was having written communication with Mother Theresa through a series of letters we exchanged over two years.

It was Mother Theresa who most clearly reaffirmed my own moral necessity to work to achieve the unthinkable. Now let's think about that for a minute—the moral necessity to work to achieve the unthinkable. Consider how Mother Theresa moved mountains when everyone around her saw only insurmountable avalanches of pain and misery. She took her zeal into the slums of Calcutta without an ounce of material support, and emerged as a beacon of hope to thousands upon thousands of despairing and abandoned souls. I always felt that my relationship with Mother Theresa provided a moral and spiritual compass for me.

Now it is 2003, and our mission isn't feeding and uplifting the poor, but empowering those most directly responsible for professional and compassionate human support. Who are we to trifle with Mother Theresa's moral mandate, not to mention the moral mandate upon which our great nation was founded? If Mother Theresa, a fiercely driven but frail wisp of a woman, could move mountains and gain worldwide attention without political or social support, then who's to say we cannot muster enough resources and public sympathy to once-and-for-all sway an unjust social policy? I ask you, if we don't believe it is possible and show it through our own actions, who will?

I believe we are involved in a just war. I've looked at the National Advocacy Campaign's current roster of supporters, the hundreds of you who have already proven your sincere commitment to our urgent workforce agenda. I would be remiss without publicly thanking Carol Mitchell for the instrumental role she has played in the campaign, and specifically in my being here today. It was Carol's tenacity and Renee Pietrangelo's leadership, coupled with the talents of Lisa Ramirez, Sebastian and Jacqlyn Triscari that have facilitated the success we can celebrate to date.

I also want to thank every provider

Career Opportunity

Vice President Programs and Services

Ability Beyond Disability, formerly Datahr Rehabilitation Institute, a leading health and human services provider with a 50 year history, is seeking an experienced individual to oversee the residential, supported living, employment, and vocational programs for 800 persons served in NY and CT. Reporting to the President as a vital member of the senior management team, the V.P. is responsible for budget, quality, management development, staff competency and satisfaction, and community outreach. Qualified candidates will have a bachelor's degree with strong preference given to advanced degree I human services, healthcare or management. Must have at least 10 years of progressive supervisory experience, preferably in related field and/or not-for-profit environment with a record of constructive relationships with third party payers. Must have strong leadership, team building, communication, interpersonal and negotiation skills with demonstrated success in creating innovative consumer services that lead to independence and dignity.

Please visit our website at AbilityBeyondDisability.org for more information. Fax resume with salary requirements to (203) 740-7129 or e-mail: jobs@abilitybeyonddisability.org.

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and contributor from the bottom of my heart on behalf of the thousands of parents and families whose loved ones are ultimately at grave risk. Your vision and conviction will go down in the annals of the community service movement at a very critical juncture in our besieged history.

Now it is up to the rest of us. The workforce crisis isn't anybody's without first being yours. ANCOR's National Advocacy Campaign is your National Advocacy Campaign. Our advocates in Washington will never achieve equity if we insist on being bystanders. Even beyond giving money, each of us in the human service family must fertilize the ground, talk to our neighbors, and speak publicly and passionately to our circles of Influence.

We must take our message to America's churches, synagogues and mosques; to civic groups and community organizations. In the end, we must win public sympathy for more respectful treatment for those providing compassionate support, or face the prospect of understaffed services, overtaxed workers and decreasing regard for those we have fought so hard to empower.

The theme of the National Advocacy Campaign reads, "By empowering Individuals with disabilities, direct support professionals strengthen all of America." If you believe this as I do, then it is up to each of us to give from the heart, take to the streets, and convince our fellow Americans that our collective well-being rests with the fate of those who are most vulnerable, including those who support them.

America wasn't founded as the land of the free for just those most politically connected. So in essence, I ask you: Are we going to war simply to protect the rights of those most advantaged? Or are we losing sight of the very reasons for which our forefathers, not to mention our professional ancestors, fought and sacrificed?

This campaign is a war just like any other. If we don't risk fighting for what we know is fair and just, then we risk establishing a permanent underclass of service workers who will more closely resemble the caste systems of old than the democracy we so cherish today. Equal opportunity is just that, equal and sacred opportunity for all Americans, including those who give so much of themselves daily, and who in return receive so little.

We talk so passionately about direct support professionals making a difference. So why is it less incumbent on us to make a difference in their lives? Throughout our history, we've accused society of talking the talk without walking the walk. Well I ask you, isn't it now your turn to walk the walk and wage war against inequity while making peace with your own conscience?

The destiny of so many rests on what you as leaders are willing to do today. I implore you as a mother, educator, volunteer, war veteran, and as an impassioned admirer of Mother Theresa to reach into your pockets, speak out against injustice, and take whatever initiatives are necessary to generate widespread support for this moral and worthy cause.

My son Peter, his direct support staff, and the hundreds of thousands like them across America thank you for being boat rockers and proactive believers at heart. There is no room on this journey for bystanders. Our painful legacy in the institutions, our sacred quality of life in the community, and the promise of a secure and honorable future demands that we all participate now! ■

ANCOR National Advocacy Campaign Contributors

We wish to extend our sincere appreciation to the following members, who have made a contribution in support of the ANCOR National Advocacy Campaign launched in September 2001. Their contributions to date total $603,259.78.

Agency Contribution $40,000 and Above

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As April 15th Tax Day Approaches, Providers Can Help Workers Boost Their Paychecks

In 2002, over 19 million low- and moderate-income workers claimed Earned Income Credits (EIC) worth more than $31 billion. And, for the first time last year, many working families also were able to claim Child Tax Credit (CTC) refunds, providing an additional boost to their paychecks. The Earned Income Credit—and now the Child Tax Credit—continue to be vital work supports for employees in low-wage jobs.

This year the EIC can boost workers' paychecks higher than ever. It is worth as much as $4,140 for some families. The EIC is a special tax benefit for working people who earn low or moderate incomes and help to reduce the tax burden on these workers, help supplement wages, and help to make work more attractive. Workers who qualify for the EIC and file a federal tax return can get back some or all of the federal income tax that was taken our of their pay during the year. *They may also get extra cash back from the IRS. Even workers whose earnings are too small to owe income tax can get the EIC. What's more, the EIC offsets any additional taxes workers may owe, such as payroll taxes.* And many families can also qualify for the Child Tax Credit, worth up to $600 for each child.

However, millions of eligible workers risk missing out on these important federal tax benefits because they do not know they qualify, do not know how to claim the credits, and do not know where to find free tax filing assistance.

In addition to low-wage workers, some of the families who may be eligible, but may not realize it, include:

- Foster parents
- Disabled adult SSI recipients who live with their families
- Custodial parents

Who Can Get the EIC and How Much Is It Worth?

Single or married people who worked full-time or part-time at some point in 2002 can qualify for the EIC, depending on their income.

- Workers who were raising one child in their home and had family income of less than $29,201 (or $30,201 for married

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Boston — 18-19
Albany — 20-21
Philadelphia — 20-21
New York City — 24-25

APRIL
Chicago — 7-8
Minneapolis — 9-10
Indianapolis — 14-15
St. Louis — 21-22

MAY
Columbus — TBA
Pittsburgh — TBA

In-House Workshops Available Call for Details

TO REGISTER CALL STAFF TRAINING ASSOCIATES
(410) 266-5915
$249 per person—Discounts available for 3 or more attending from same organization

workers) in 2002 can get an EIC of up to $2,506.

• Workers who were raising more than one child in their home and had family income of less than $33, 178 (or $34,178 for married workers) in 2002 can get an EIC of up to $4,140.

• Workers who were not raising children in their home, were between the ages of 25 and 64 on December 31, 2002, and had income below $11,060 (or $12,060 for married workers) can get an EIC of up to $375.

The children that qualify for the EIC include: sons, daughters, stepchildren, grandchildren and adopted children; brothers, sisters, stepbrothers or stepsisters—as well as descendants of such relatives—if they were cared for as a member of the family; and other children may qualify as foster children, but only if they are placed with the worker by an authorized government or private placement agency. Qualifying children must live with the worker for more than half of the year. However, as of 2002, a full year is no longer required for foster children—only six months of the tax year. They must be under age 19, or under age 24 if they are full-time students. *New rules beginning in 2002 changed the definition of a foster child for purposes of the EIC (and Child Tax Credit). Children of any age who are totally and permanently disabled and are placed with the worker by an authorized placement agency may be qualifying children.*

There is also something called the Advance EIC payment option. *Workers raising children can even get part of their EIC in their paychecks throughout the year and part in a check from the IRS after they file their tax return.*

You don't have to be a tax expert to promote EIC

Each year, community organizations, human service providers, businesses, government agencies, and other employers find effective ways to incorporate EIC outreach activities into their routine operations. Many find ways to successfully alert working families and individuals about this critical tax benefit and direct them to free tax filing assistance. And, the result is that millions of working families and individuals get a significant boost to their paychecks.

Excellent resources include:

• Facts About the Earned Income Credit (26 pages)

• Facts About the New Child Tax Credit (15 pages)

• *Helping Workers Boost Their Paychecks: How to Promote the EIC and the New Child Tax Credit* (30 pages)

• *Linking Workers with Free Tax Filing Assistance* (22 pages)

• These and other materials—including forms from IRS site—are available online at http://www.cbpp.org/eic2003/index.html. ■

HHS Publishes Final HIPAA Security Rule

The Department of Health and Human Services (HHS) published its long-awaited final HIPAA Security Standards (Security Rule) on February 20, 2003, establishing national standards to protect individually identifiable health information maintained or transmitted electronically. The new Security Rule is required as part of the Administration Simplification requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

HIPAA covered entities—most health plans, health care clearinghouses, and providers who transmit health information electronically in connection with one or more HIPAA-covered transactions—must comply with the Security Rule by April 21, 2005. *ANCOR providers who must comply with HIPAA's Privacy Rule and the Standards for Electronic Transactions and Code Sets must also comply with the Security Rule by April 21, 2005*. Small health plans will have an extra year to comply, as required by HIPAA.

This final Security Rule is drastically different from the proposed rule HHS issued in 1998. The Security Rule offers covered entities greater latitude in how to implement the rule in their organizations. Unlike the Privacy Rule, which specifically states how standards must be implemented, the Security Rule offers more generic guidance—in the form of high-level direction about how covered entities should implement the rule. In essence, the rule focuses on *what needs to be done, not how it should be accomplished.*

Another significant difference is that the new *Security Rule applies only to electronic protected health information (ePHI)*. Thus, only individually identifiable health information that is received, stored, or transmitted in electronic form is subject to this new rule. This is different from the Privacy Rule, which applies to all protected health information in any medium, whether electronic, paper, or oral.

The Centers for Medicare and Medicaid Services (CMS) will be responsible for implementing and enforcing the Security Rule. CMS is responsible for all Administrative Simplification regulations.

General Security Rule Provisions

The Security Rule requires covered entities to meet four general requirements:

(1) Ensure the confidentiality, integrity, and availability of all electronic protected health information (ePHI) the covered entity creates, receives, maintains, or transmits;

(2) Protect against any reasonably anticipated threats or hazards to the security or integrity of ePHI;

(3) Protect against any reasonably anticipated uses or disclosures of ePHI that are not permitted under the HIPAA Privacy Rule;

(4) Ensure compliance with the Security Rule by all members of the covered entities workforce.

To meet these general requirements, covered entities must implement specific standards for administrative, physical, and technical safeguards, business associate contracts, and policies and procedures and documentation.

The Security Rule offers providers and other covered entities a flexible approach in determining how they implement these specific standards. First, the new rule is *scalable*. When covered entities are determining how to meet the standards, they may take into account their size and capabilities, their technical infrastructure, hardware, and software capabilities, the costs of the security measures, and the probability of potential risks to the entity's ePHI. Second, the rule is *technology neutral*; the standards do not specify any particular technology. In addition, the new rule dovetails with the Privacy

Rule, working in concert by using the same concepts and definitions in order to make it easier for covered entities to comply with both regulations.

Standards for Administrative, Physical, and Technical Safeguards

The Security Rule has standards for administrative, physical, and technical safeguards all covered entities must implement. These safeguards are designed to protect ePHI at rest and in transit. The administrative safeguards focus on the management of the selection and execution of security measures. There are nine separate administrative standards. The four physical safeguard standards protect electronic systems, related building, and equipment form environmental hazards and unauthorized intrusion.

The technical safeguards focus on automated processes to protect data and control access to it; there are five separate technical safeguard standards. (See box below.)

Within many of theses standard sets, there are implementation specifications that are either *Required or Addressable.* Required implementation specifications must be implemented by the covered entity. If the specification is addressable, the covered entity must determine if the specification is reasonable and appropriate for that particular entity. If it is reasonable and appropriate, the covered entity must implement that specification. If it is not reasonable, the covered entity must document why it is not reasonable to implement, and then implement an equivalent alternative measure. In instances where there are no implementation specifications, the general standard must be met.

For example under the Administrative Safeguards, the Security Management Process Standard has four *required* implementation specifics addressing risk analysis, risk. management, sanction policies, and activity review. Under the Security Awareness and Training Standard, there are four *addressable* implementation specifics regarding security reminders, log-in monitoring, and password management. For the Assigned Security Workforce Standard, there are no implementation specifications. The standard simply states that the covered entity must identify the security official who is responsible for developing and implementing the covered entity's required policies and procedures.

[Note: The Security Rule includes a matrix detailing the standards and the implementation specifications.]

Additional Standards

The Security Rule also contains organizational requirements and policies and procedures and documentation requirements. Under the standards for organization requirements, covered providers and clearinghouses who have business associate contracts must meet the requirements stated in the rule. Essentially the contracts must ensure business associates implement the administrative, physical, and technical safeguards in the rule to protect ePHI that it creates, maintains, or transmits on behalf of the covered entity.

All covered entities are required to implement reasonable and appropriate policies and procedures to comply with the Security Rule's standards. Policies and procedures may be changed at any time, as long as the changes are documents and they must be maintained in written (which may be electronic) form. If the covered entity must document any actions, activities, or assessments as part of its compliance, such documentation must be maintained in a written record, retained for 6 years from the date it was created (or the date it was last in effect), and must make the documentation available to those persons responsible for implementing the procedures to which the documentation pertains.

Role of Faxing, Telephoning Clarified

ANCOR members will be pleased to learn that the Security Rule clarifies the issue of faxing. There have been many questions about whether faxing is considered *electronic* and whether ANCOR members who fax protected health information (PHI) in connection with a HIPAA covered transaction are HIPAA covered providers. The final Security Rule states that *[c]ertain transmissions, including of paper, via facsimile, and of voice, via telephone, are not considered to be transmissions via electronic media, because the information being exchanged did not exist in electronic form before the transmission.*

With this clarification, paper faxing from a stand-alone fax machine—regardless of how the fax is received on the opposite end—is not considered "electronic". This means that *private providers who*, in connection with a HIPAA covered transaction, *only fax PHI from a stand-alone fax machine* —and who in no other way conduct electronic transactions—*are not HIPAA covered entities* and are not required to comply with HIPAA's Privacy, Security, or other regulations.

However, faxes send via computer would be considered "electronic" and are protected by the Security Rule. Providers transmitting PHI in connection with a HIPAA covered transaction via computer faxes would be considered HIPAA covered entities. are required to comply with the HIPAA Privacy and Security Rules, as well as the Standards for Electronic Transactions and Code Sets.

What to Do Now

ANCOR members who must comply with the Security Rule are encouraged to become familiar with the Rule and its requirements. A copy of the February 20th final rule is available at www.ancor.org.

Although compliance is not until

Security Standards

Administrative Safeguards
Security Management
Assigned Security Responsibility
Workforce Security
Information Access Management
Security Awareness & Training
Security Incident Procedures
Contingency Plan
Evaluation
Business Associate Contracts

Physical Safeguards
Facility Access Control
Workstation Use
Workstation Security
Device and Media Controls

Technical Safeguards
Access Control
Audit Controls
Integrity
Person/Entity Authentication
Transmission Security

April 21, 2005, it is important to get started on compliance early. Depending on your organization, the Security Rule may be time-consuming to implement. ANCOR members are encouraged to compare the regulation's requirements with their own operations and current policies and procedures to gain a better understanding of how much time and effort will be involved to achieve compliance with the Security. Keep in mind, that like the other HIPAA standards, there are civil penalties for failure to comply.

According to many security consultants, some beginning steps covered entities can take to ensure compliance include:

• Conduct a HIPAA security assessment—This will help you identify existing gaps in security relative to the Security Rule and identify changes necessary to close gaps.

• Establish a security management program—What to include in such a program is part of the Administrative Safeguards.

• Begin to train staff on the Security Rule's requirements and your policies and procedures.

• Develop a contingency plan—Begin discussing how to access any PHI that may be necessary during an emergency.

For more information about the Security Rule and other HIPAA regulations, go to ANCOR's web site at www.ancor.org or to the CMS web site at http://www.cms.gov/hipaa/hipaa2/default.asp. ■

OCR Publishes Addresses for HIPAA Privacy Compliant Submissions

OCR Publishes Addresses for HIPAA Privacy Compliant Submissions

The Department of Health and Human Services (HHS)' Office for Civil Rights (OCR) has developed a Privacy Complaint Submission Form and has published a notice listing addresses for filing a complaint with the Secretary of HHS for non-compliance with the Privacy Rule by a covered entity. The notice was published in the March 20th *Federal Register.*

As required by the Privacy Rule, a person who believes a covered entity is not complying with the Rule's requirements may file a compliant with the Secretary. Complaints may be filed in writing (either on paper or electronically) and must name the entity that is the subject of the compliant and the alleged violation(s). Complaints must be filed within 180 days of when the complainant knew or should have known that the violation occurred (unless granted a waiver

INDEPENDENT SKILLS ASSESSMENTS

Independent Skills Assessment Scale 2003

Designed for persons receiving or being considered for fewer than 24 hours of staffing time. Key indicator areas are:

- Meal Planning and Preparation
- Personal Appearance and Hygiene
- Apartment/Home Maintenance and Upkeep
- Personal Safety/Use of Emergency Resources
- Civil Rights and Responsibilities
- Social/Recreation/Transportation
- Shopping,
- Personal Medications
- Money Management
- First Aid and Health,
- Telephone and Other Utilities
- Coping Skills and Behavior

Independent Skills Assessment Scale	10 for $20.00 25 for $40.00 50 for $75.00

Clinical Nursing Care Needs

The scale assists in determining the level of Clinical Nursing Services and suggests a number of Clinical Nursing hours (RN or LPN) necessary for individual consumers as well as entire group facilities.

Personal Strengths and Needs

A quick, 100 item, two-page assessment designed to show skills and abilities, as well as programming and health needs, for persons of all ability levels and ages.

Nutritional Needs

Aids in determining nutritional needs for the individual, developing individualized skill training goals for food shopping and preparation, supplying health related information to the physician, planning pertinent staff training, arranging staffing patterns during meal times, and in screening referrals to the agency or program

Clinical Nursing Care Needs Personal Strengths and Needs Nutritional Needs	20 for $10.00 50 for $20.00

Sexuality Assessment

Helps determine an individual's social/sexual vulnerabilities and supervision needs. Identifies individual program objectives in the area of sexuality, prioritizes sexuality goals and objectives, and establishes homogeneous social skills groups.

Sexuality Assessment/Curriculum Guide:
The guide is to be used in conjunction with the Sexuality Assessment Worksheet. Describes how each assessment item should be answered and provides information that can serve as a basis for training and program development. Included with the guide are 18 line drawings in a three ring binder, helpful in both assessment and training.

Sexuality Assessment Worksheet:
100 questions designed to address knowledge and performance in such areas as privacy and ownership, basic anatomy, relationships, positive touch, sexual expression, birth control, victimization and sexually transmitted diseases. It can be used with individuals of varying levels of knowledge and abilities.

Sexuality Kit:
Includes 20 Sexuality Assessment Worksheets, a Sexuality Assessment / Curriculum Guide, 18 line drawings, anatomically correct male and female dolls, sanitary pads, condoms, an artificial penis and a soft carry bag.

Sexuality Kit – includes guide and 20 worksheets:	$200.00
Sexuality Guide – Includes 20 worksheets:	$20.00
Sexuality Assessment Worksheet:	20 for $10.00 50 for $20.00

Add 8% to the above prices for shipping & handling, MN residents should include sales tax or a tax exempt number.

For an order form, or to order, write or call

Bald Eagle Assessments
111 11th Ave. N. E., Austin, MN 55912
507-437-2074
wbaldus@yahoo.com fax 507-433-4597

by OCR for good cause).

Complaints may be files only with respect to alleged violations occurring on or after April 14, 2003.

OCR will be responsible for receiving and investigation complaints. Written complaints may be filed with OCR by mail, fax, or e-mail. Complaints may be filed using OCR's Health Information Privacy Complaint Form, available at www.hhs.gov/ocr. Complaints may be submitted via e-mail at CRComplaint@hhs.gov. Complaints submitted via e-mail or fax should be submitted to the OCR Regional Office that covers the state where the covered entity is located. The Regional Office addresses and phone and fax numbers are available at http://www.hhs.gov/ocr/hipaahealth.pdf. ■

Attention ANCOR Members:
HIPAA Privacy Compliance Deadline is April 14th

ANCOR members who must comply with the HIPAA Privacy Rule are reminded that the compliance deadline is Monday, April 14th.

If your organization must comply and you haven't yet ordered ANCOR's HIPAA Privacy Compliance Manual, orders are still being accepted. The manual includes a CD-ROM with the necessary template policies, notice of privacy policies, and forms needed for compliance. Price for ANCOR members is $675. Order forms available at www.ancor.org.

Governors Announce Medicaid Reform Task Force

The National Governors Association (NGA) announced March 20th the ten governors named to a task force to help the Administration work on its Medicaid reform proposal.

The bipartisan task force will be headed by NGA Chairman Paul Patton (D-KY) and Dirk Kempthorne (R-ID) and will include the following governors: Jeb Bush (R-FL), Frank O'Bannon (D-IN), John Rowland (R-CT), Tom Vilsack (D-IA), Robert Ehrlich (R-MD), Bob Holden (D-MO), John Hoeven (R-ND), and Bill Richardson (D-NM).

The task force will conduct its Medicaid reform negotiations during weekly conference calls, as well as travel to Washington as needed to meet with Administration officials and Congress. The governors will work to fashion an agreement that is based on NGA's Medicaid reform principles that were adopted in a new NGA policy at the NGA Winter Meeting.

> The nation's governors are ready to move forward on the important task of reforming Medicaid so that we can continue to provide the safety net that so many of our citizens have relied upon for nearly 40 years. Medicaid's 47 million enrollees include over 23 million children, 5 million seniors and 8 million adults with disabilities—these are the people we need to remember as we embark upon this process to improve the delivery of health care services within the Medicaid program.
>
> Kentucky Governor Paul Patton, NGA Chairman

The governors concluded their winter meeting in late February without endorsing the Administration's plans to overhaul the Medicaid program. Instead, the NGA adopted its own set of principles for Medicaid reform and decided to set up a task force to address Medicaid reform.

The principles include:

• The Medicare and Medicaid programs are interrelated and any change made to Medicare, whether to strengthen its solvency, address its financing, or for other purposes, should be considered in conjunction with reforms to Medicaid.

• The federal government should assume full responsibility for the acute, primary, long-term, and pharmaceutical care of the dual eligibles, individuals who are enrolled in the Medicare program, but because of their low-income, are also eligible for the Medicaid program.

• It is also unacceptable for Medicaid to be the only long-term care program in this country. Other sources of coverage, whether federal, employer-based, personal, familial, or community-based, must be developed.

• States must have greater ability to manage the Medicaid program with respect to eligibility, benefits, cost-sharing, and coordination with private sector insurance.

• Medicaid reform proposals that provide states broader Medicaid program authority should weigh fiscal and health policy implications of the current financing structure, or an alternative approach.

• Efforts to reduce fraud and abuse by Medicaid beneficiaries and providers are essential to safeguarding limited health care resources, but any effort to develop error rates to measure state performance should be strongly opposed.

• To the extent possible, all current waivers should be replaced with clear statutory authority.

• The federal government should pay 100 percent of the cost of any new Medicaid mandates imposed under an act of Congress, federal regulation, or court decision based on federal laws and regulations.

• The federal cap on the commonwealths and territories should be removed and a federal contribution for commonwealths and territories should be implemented that is comparable to that of the states.

It is ANCOR's understanding that the governors have been asked to submit their recommendations to the Administration by May 1st and that the reform proposal will be wrapped-up by Memorial Day. ■

A Show of Unity: ANCOR and Citizens for Long Term Care Hold Press Conference on Medicaid Match

Responding to worsening state budget conditions, Citizens For Long Term Care (CLTC), a diverse coalition of national long term care provider, consumer, insurance and worker groups representing over 40 million Americans called upon President Bush and Congress February 21, 2003, to provide an immediate infusion of federal assistance to bolster state Medicaid programs. The call to protect America's most vulnerable citizens' access to quality long term supports came on the eve of the nation's governors arrival in Washington for their annual Winter Meeting.

> As our nation's Governors arrive in Washington to sound the alarm about the worst state fiscal conditions since World War II, we are here as a diverse, collective voice to support their plea for immediate federal Medicaid assistance.
>
> Dale Thompson, Vice Chair of CLTC

ANCOR CEO Renee Pietrangelo was joined with other top leaders of AARP, American Health Care Association, American Association of Homes and Services for the Aged, Alzheimer's Association, and The Arc at the National Press Club event in Washington, D.C. The organizations pointed to recent studies by Families USA and the Kaiser Commission on Medicaid and the Uninsured on the serious, negative impact on the ability of states to finance long term supports and services.

As ANCOR pointed out in its statement, states are facing total budget shortfalls exceeding $60 to $85 billion for fiscal year 2004—the worst since World War II. States have already reduced or frozen provider reimbursement rates in 37 states, restricted eligibility in 27 states, reduced benefits in 45 states, increased co-payments in 17 states, and taken action to reduce spending on community and institutional long-term services. Medicaid spending in 2001 generated over 2.9 million jobs—approximately 58,785 jobs on average in each state. Furthermore, investment in Medicaid in 2001 generated an almost threefold return in new business activity throughout the states. ANCOR also joined with CLTC partners in calling for at least $20 billion in temporary fiscal relief to states to stop cutbacks that jeopardize health and safety for people with disabilities.

The coalition partners have been supporting bipartisan legislation (S. 138) introduced by Senators Collins (R-ME), Rockefeller (D-WVA), Smith (R-OR), and Nelson (D-NE) that would provide $20 billion in

> Congress and the Administration must take immediate action to prevent the hemorrhaging in the states' Medicaid programs….The current unprecedented crisis facing the states and their low-income citizenry obliges the Federal government to step in and help—shouldering its responsibility to preserve the health, well-being and long-term security of our nation's most vulnerable individuals, the job security of hundreds of thousands of direct support workers, and the economic security of state and local communities.
>
> Renee L. Pietrangelo, ANCOR CEO

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If you ask what the underlying issue is in our nation, on the care of the frail, elderly, and the disabled, is that we have no strategy, and that we have put together a piecemeal program that is budgetarily driven rather than requirements of the people who are entitled to the social contract that we have made over many, many years….Let me break this down for you. You are about to see the cardiopulmonary arrest of long term care in our nation…. We now face a moral test as a nation on what it means to be an American, and, quite frankly, I see us failing that moral test, and this coalition is here to say, that is not acceptable.

Charles H. Roadman II,
AHCA President and CEO

fiscal relief to the states—$10 billion for Medicaid and $10 billion for the Social Services Block Grant program. The issue got a lift when the Senate adopted by 80 to 19 an amendment to provide $30 billion in federal assistance, at least half of which would come to the states through increased federal funding of their Medicaid programs. The amendment was offered by the four Senators March 24th during the debate on the Senate budget resolution. At press time, the final differences in the House and Senate budget resolutions had not been ironed out and awaited a final vote by both chambers.

To view the complete CLTC and ANCOR statements, to view a webcast of the press event, and to download a transcript, go online at www.ancor.org.

NOTE: Thanks to ANCOR members who contacted their Senators regarding the several alerts on the increased Medicaid match. Their voices were heard and made the difference! ■

Citizens For Long Term Care believes that in the short term an immediate, temporary infusion of federal assistance is necessary to help bring stability to long term care; provide economic stimulus to states, preserve jobs, and most importantly, ensure access to quality care and services for millions of people in need. We need Congress and the President to act immediately.

Former U.S. Senator David Durenberger
(MN, 1978-1995)
CLTC Chairman

CMS Conference and Response to State Budgetary Crisis

The Centers for Medicare and Medicaid (CMS) sponsored its second annual systems change conference March 4-5, 2003 in Baltimore, Maryland. More than 700 participants from all 50 states, the District of Columbia, Guam, and the Northern Mariana Islands registered for *The Living and Working in the Community 2003 Conference*. The two-day conference featured a variety of topics, including sessions on housing, Ticket to Work, fiscal intermediary, workforce shortage, Olmstead, quality assurance, Medicaid services, Independence Plus Waiver, person-centered planning, consumer-direction, transportation services, and employment issues.

Participants included Medicaid grantees, consumers, providers, consultants, academics and Federal and State representatives. The event utilized workshops, roundtables, plenary sessions, Federal panels, and a poster session to facilitate discussion and information sharing. *ANCOR Vice President for Membership Ken Lovan of ResCare presented a very successful and busy exhibit at the poster session on ANCOR's National Advocacy Campaign.*

As part of the Olmstead session, Mary Jean Duckett of CMS provided information on the agency's continuing efforts to improve the quality of home and community-based services and furthering the commitment to community integration. Some highlights include the following:

• New Hampshire and South Carolina have completed work on a 1915(c) Independence Plus Waiver and Florida has completed work on an 1115 Independence Plus Waiver. (As a reminder, information on the Independence Plus Waiver is available at go online at http://cms.hhs.gov/independenceplus/.

• Nebraska is the first state to include transition services (i.e., security deposits, essential furnishings, moving expenses, and utility deposits) in a home and community based waiver (1915(c)). Louisiana, New Jersey, Oregon and Wisconsin have also received approval to provide transition services. (As a reminder, the May 9, 2002 letter to Medicaid Directors on transition services is available at www.ancor.org/dev/issues/Medicaid_Medicare/CMSTransitionsLetter.htm.)

• CMS is in the beginning stages of looking at the 1915(c) home and community-based waiver (HCBS) regulations to clarify and update the regulations to reflect changes in service delivery, reduce the burden on states, and further the commitment to community integration.

• CMS is hosting a series of monthly New Freedom Open Door Forums beginning March 2003, to provide for discussion on a variety of topics, including self-directed services, quality of HCBS services, housing, employment, and workforce issues. The first two sessions will be on the President's 2004 budget and "Money Follows the Individual." (As a reminder, you can view the agendas for the New

ANCOR Calendar

2003

May 8	**Audio Conference Challenges in Leadership: The Field of Disabilities in Change**
June 10	**Audio Conference Guidelines for Supporting Sexual Activity: Legal, Ethical and Practical**
Sept. 7-9	**ANCOR's 2003 Governmental Activities Seminar** Washington Court Hotel Washington, DC

Freedom Initiative forums through December and register to phone in for forum discussions by going online at http://www.cms.gov/newfreedom/nfiforums.pdf.

CMS Response to State Budgetary Crisis

Given the current budgetary climate, Duckett provided information that states are requesting approval under HCBS waivers (1915(c)) to do the following:

- Impose eligibility thresholds related to costs for purposes of admission to the waiver (for example, cost limitation of a waiver applicant does not exceed $10,000 per person).
- Eliminate waiver capacity that has not yet been used (for example, waiver approval is for 1,000 people, but are only serving 750 individuals).
- Eliminate waiver services.
- Reduce the scope of waiver service through cost caps (reduce amount, duration and scope of services through a cap).

Although the budgetary climate presents challenges to states in using the Medicaid HCBS waiver in the most efficient manner and to serve people with the most severe disabilities, *it is important to keep in mind that* ***states are not relieved of their responsibility under the Americans with Disabilities Act and the U.S. Supreme Court's decision in Olmstead.*** *In addition, in eliminating or reducing services,* ***states still have the statutory responsibility to ensure the health and welfare of waiver beneficiaries.*** *It is important for providers to keep these state responsibilities in mind as states seek to reduce or eliminate eligibility, capacity, scope and services under the HCBS waiver.*

The CMS response to the above requests include:

- The eligibility threshold must be based on a comparison of the individual's estimated cost of Medicaid services in the community to 100% of the cost of Medicaid services in the institution. There are two ways the state can do the cost comparison: (1) person-specific or (2) average per capita (on the basis of all levels of care or same level of care).
- Reductions in the size of a waiver cannot result in eligible individuals being terminated.
- Reductions in the size of a waiver do not relieve the state from meeting its responsibilities under the ADA, and may be counter productive.
- Services under the waiver and the Medicaid state plan must continue to be sufficient in order to enable an individual to remain in the community and avoid institutionalization.
- States must have an acceptable process/methodology for ensuring the health and welfare of individuals on the waiver when the service limit is reached. This process methodology may include: prior authorization process, development of crisis intervention/crisis support services, and transition to another waiver or state funded services and supports.

To view the agenda and gain access to many of the presentation materials for the CMS conference, go online at www.nashp.org/CMSconference2003. ■

TRAINING SPECIALIST

Emmaus Homes, Inc. seeks an individual to train employees to work with individuals with developmental disabilities. Requires BA in related field and 2 yrs direct exp. in MR/DD field. Must have excellent oral and written communication and organizational skills; able to work independently; willing to work 1-2 evenings per week and 1-2 Saturdays per month. Light travel in metro area involved 25 hours per week.
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ANCOR Welcomes New Members

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George Suess
Walton, NY
Dan Berkowicz, Representative

Great Lakes/West Region

Tom Lewins, Regional Director
Michiana Resources, Inc.
Michael Horton
Michigan City, IN
Nicole Lazzell, Representative

Mid-Atlantic Region

Bill Loyd, Regional Director
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Jack Wall
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Wendy Sokol, Regional Director
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In The News

Social Capital and Personal Outcomes The personal outcomes associated with social capital are among the most difficult to facilitate. Consider the following percentages of people with disabilities attaining outcomes on the following:

- 45% choose where and with whom they live
- 34% choose where they work
- 34% live in integrated environments
- 30% perform different social roles
- 58% have friends
- 69% interact with other members of the community

These six outcomes are very frequently associated with achieving other personal outcomes and may be an indication of the positive influence that personal support networks have in our lives.

These personal outcomes associated with developing networks of trust and reciprocity are also the most difficult to facilitate for people with the most challenging disabilities. This data suggests that we may need to rethink and redefine our strategies for promoting social capital for people with significant intellectual disabilities by focusing on each person's unique capabilities. We need to identify each person's unique role as a co-producer of social capital and in providing reciprocity for our supports and services. *Reprinted from November 2002* Council Dispatch, *published by The Council on Quality and Leadership.* ■

Workforce Tools is a series of publications specifically targeted to people concerned with improving the quality and stability of the home and community-based direct support workforce. It is produced by the Paraprofessional Healthcare Institute for the Centers for Medicare and Medicaid Services project *Research on the Availability of Personal Assistance Services.* These resources are available on-line at: www.directcareclearinghouse.org/practices.html. The Right People for the Job, which synthesizes promising recruitment practices, is available on-line at www.directcareclearing house.org/pas.html. ■

ANCOR Honor Roll

The following agencies have submitted the names of homes that have succeeded in having deficiency-free surveys, which qualifies them for appearance on the ANCOR Honor Roll.

ANCOR congratulates all of the staff who make these honors possible. Send your submission for the Honor Roll to: Attn: Barry Noel, ANCOR, 1101 King St., Suite 380, Alexandria, VA 22314.

Please send supporting documentation of the surveys.

Delaware

Martin Luther Homes
The Sherwood Program

New Hampshire

Great Bay Services
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(3 years)

Ohio

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