

An **ANCOR** publication of private provider practice and federal policy issues.

Medicaid Cuts Imperil State Economies, Study Finds

As states face fiscal crises and consider big cuts to their Medicaid programs, a new report documents that those cuts would significantly harm each state's ailing economy.

The report, issued by the health care consumer watchdog organization Families USA, indicates that states cutting their Medicaid programs would cause large reductions in their states' jobs, wages, and business activity.

According to the Families USA report, states stand to lose an average of 37 jobs for every million dollars cut in the Medicaid program in 2003. Such job losses would vary considerably from state to state—with Mississippi losing 72 jobs for each million-dollar cut while Delaware would lose 17 jobs.

The report indicates that states would face large reductions in business activity for each million dollars in Medicaid cuts. On average, each million-dollar reduction in Medicaid spending would cause a loss of \$3.4 million in business activity. Reductions in business activity would also differ substantially from state to state—with Mississippi losing \$6.25 million in business activity for each million-dollar Medicaid cut while Delaware would lose \$1.96 million.

In California, Gov. Gray Davis has proposed a Medicaid cutback of \$1.3 billion for 2003. According to the Families USA report, this proposed cut would result in a loss of 27,994 jobs, \$1.2 billion in lost wages, and \$3.2 billion in lost business activity. In Michigan, the state legislature is considering a Medicaid cut of \$60 million that, according to the new report, would result in a loss of 1600 jobs, \$56 million in

lost wages, and \$151 million in lost business activity.

"When states slash their Medicaid programs, they hurt everyone through losses in jobs, wages, and economic activity," said Ron Pollack, executive director of Families USA. "This harm is in addition to the many difficulties faced by low-income families when their Medicaid lifeline is cut."

Among the findings in the Families USA report are the following:

- The 10 states that would experience the greatest job loss per million dollars in Medicaid cuts in 2003 are Mississippi (72 jobs), New Mexico (67), Arkansas (65), Montana (64), Oklahoma (62), Utah (60), West Virginia (57), Idaho (56), Louisiana (55), and Alabama (55).

- The 10 states that would lose the most state business activity per million dollars in Medicaid cuts in 2003 are Mississippi (\$6.25 million), New Mexico (\$5.72 million), Arkansas (\$5.41 million), Utah (\$5.27 million), West Virginia (\$5.16 million), Oklahoma (\$4.98 million), Alabama (\$4.93 million), Montana (\$4.90 million), Louisiana (\$4.87 million), and South Carolina (\$4.78 million).

"Cuts to the Medicaid program are short-sighted," continued Pollack. "Medicaid is a powerful stimulus to state economies, and Medicaid cutbacks will exacerbate states' economic problems."

The Families USA report also focused on how state money invested in the Medicaid program in 2001 translated into new jobs, additional business activity, and increased wages for all 50 states:

- State Medicaid spending in 2001 generated over 2.9 million jobs—approximately 58,785 jobs on average per state.
- The 10 states with the largest number

of jobs generated by state Medicaid spending in 2001 were New York (300,352), California (291,439), Texas (187,901), Pennsylvania (143,110), Florida (132,215), Ohio (132,028), North Carolina (100,353), Michigan (98,754), Illinois (98,435), and Tennessee (81,675).

- The 50 states spent nearly \$98 billion on Medicaid in 2001, but this investment generated an almost three-fold return (\$279 billion) in new business activity.

- Employee wage increases attributable to state Medicaid spending ranged from \$11.7 billion in New York to \$114 million in Wyoming.

The report indicates that a significant factor in states' improved economic activity due to Medicaid spending arises because the federal government provides matching funds for each state's Medicaid program. The matching rate varies from state to state, ranging from \$1.00 to \$3.27 in federal funds for each state dollar.

Families USA used the RIMS II input-output economic model created by the U.S. Department of Commerce, Bureau of Economic Analysis to determine the impact of Medicaid spending on each state's economy. Through this model, Families USA was able to capture the specific economic conditions in each state and then calculated the new economic activity that would be generated by Medicaid spending in the areas of business activity, number of new jobs created, and wage and salary income associated with these new jobs.

RESOURCE LINK For a copy of this report, and to compute how present Medicaid cut proposals will affect each state's business activities, jobs, and wages, visit the "Medicaid cuts calculator" at www.familiesusa.org.

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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Strength in Partnership and Collaboration

Renée Pietrangelo

One of ANCOR's goals three years ago when I began my tenure was to shift the perception of ANCOR from an after-thought—oh yeah, we should have included the provider perspective—or no thought at all, to a fore-thought.



I believe events over the past year support the fact that we've made great progress in this effort.

- In October ANCOR was invited to participate with

The Council on Quality and Leadership in a two-day conference on building social capital for both consumers and direct support staff. The result was a series of action strategies. A second conference is planned for fall 2003 in New Orleans.

- In November ANCOR was invited to participate in the National Foundation of Women Legislators' annual meeting. At that conference we had an opportunity to raise awareness regarding our issues to numerous policy and like-minded constituency groups, and to speak directly with Department of Health and Human Services Secretary Tommy Thompson.

- In December ANCOR was invited to participate in the Vermont Department of Aging and Disabilities summit on workforce leading practices, sharing data from the ANCOR-commissioned BDO Seidman research study and the goals of our National Advocacy Campaign.

- In January, ANCOR cosponsored, along with 24 other national organizations, "Keeping the Promises," a national, invitational collaborative conference to set national goals, assess state-of-the-art knowledge and create a national agenda for research, evaluation and dissemination of information, and applied practices regarding the development, inclusion, self-determination and well-being of citizens with intellectual and developmental disabilities. It's important to note that a predominate, across-the-board theme from Administration, federal agency, congressional, state, advocacy and academic organizations represented at the conference was person-centered choice, with funding following the individual.

- Finally, ANCOR is a founding member of the Alliance for Full Participation, which is currently working toward the development of a 2005 summit meeting to share information, increase collaboration at state and local levels, and develop a national policy agenda for the developmental disabilities community.

We also continue to share information at state provider association and other meetings across the country. I have had the privilege of speaking in 17 states over the past 36

months; and, together with other ANCOR leaders, we have shared our story in 35 states.

The strength of a rope is directly associated with the individual strands of fiber braided to form it. As a single strand, we are gravely limited in the impact we can make. As a vital part of a larger whole, our strength increases proportionately. To that end, and as evidenced above, ANCOR is committed to continuing its tradition of partnership and collaboration in order to broaden and strengthen the import of our message. ■

President's Corner

Living in Challenging Times

Fred Romkema, President

"If there is any lesson from history, it is that small powers with everything to lose are often more stubborn than big powers.... The lesson, too, is that if it is worth fighting for, you had better be prepared to win." (Condoleezza Rice, 2000)

As we proceed into legislative sessions (in most states), many providers of services are looking ahead with some degree of trepidation due to the serious budget issues being faced by nearly all



states. With the opening of the 108th Congress in Washington, DC, issues directly or indirectly affecting providers include: prescription drug coverage, economic stimulus pack-

ages, reauthorization of IDEA, and the Rehabilitation Act and appropriation bills. It has become a time of planning—at least for budget cuts—with the perennial problems of associated cuts of staff and benefits.

Once again, ANCOR is anticipating the challenges with various events being planned. ANCOR participated in the Administration on Developmental Disabilities (ADD) Commissioners Forum held in Washington, DC, during February, 2003. Some of our member agencies pre-

sented. One of the themes was the support of the direct-support professional workforce, an issue ANCOR has been addressing for some time. The ADD will be issuing a summary report—stay tuned.

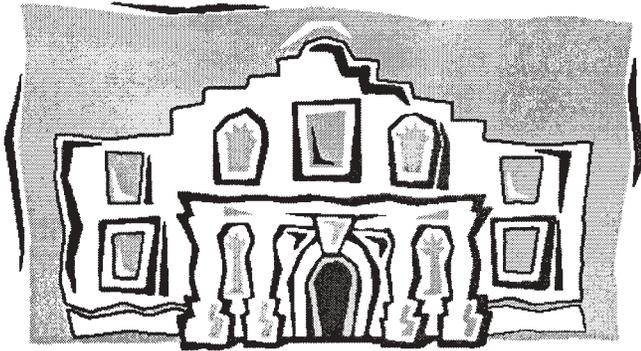
Additionally, ANCOR is formulating a summit to be held addressing survival in the environment of budget deficits with concomitant strategic issues. Who would have thought *survival*?!?!? We thought we were beyond that. Just throw in a few terrorists, some saber rattling with possible war, the burst of the tech bubble, and *voila!* Now we have some tremendous budgetary issues and our survival is at stake.

Once again it comes down to allocating resources. We are doing the right thing for the right people. We must get our message out. We must be the squeaky wheels. We must convince policy makers that we are indeed worthy of support! ANCOR is doing its best to accomplish that deed!!!

To a great extent, our success will depend on our ability to present our story and work with new and old allies in that story presentation. The ANCOR Partnership Building Initiative is another example of reaching out for new allies as well as our ongoing effort to attract new members. Please do your part and invite a colleague to join. Public policy and appropriations are largely made for the benefit of those who make themselves heard. Remember—*"...if it is worth fighting for, you had better be prepared to win."* ■

ANCOR's Winter Conference

Building the Future, Today



ANCOR's Winter Conference

BUILDING THE FUTURE TODAY

MARCH 16-18, 2003

**Mark Your Calendars for the Conference
Providers Shouldn't Miss!!**

A sampling of topics include:

- Navigating in a Stormy Policy Environment
- Quality Assurance
- National Advocacy Campaign
- Cultural Shifting
- Leadership
- Fiscal Intermediaries
- Transforming Your Agency With Innovative Software
- Legal Liability/Self Determination
- Workforce Recruitment/Retention Strategies
- Employment/Vocational Issues

Don't miss this opportunity to network with providers from around the country!

Visit www.ancor.org for further details or contact jmccandless@ancor.org.

**Join ANCOR in San Antonio, Texas
Adams Mark Riverwalk Hotel
For Hotel Reservations Call 210-354-2800 and
ask for the ANCOR room block.**

Join other agency executives at ANCOR's annual winter conference, *Building the Future, Today*, March 16-18th at the Adams Mark Hotel located on the Riverwalk in San Antonio, Texas. Interesting, informative sessions; great opportunity to network with peers from across the country; and San Antonio where the sun shines 300 days a year, what more can you ask for!

The keynote speaker is **Al Condeluci, CEO, United Cerebral Palsy of Pittsburgh**. Al, an award winning author and one of America's leading consultants on human services and community issues will discuss *Cultural Shifting, Building Social Capital*. He'll take a look at the reasons why our systems haven't been successful in these goals and will offer a community building perspective designed to shift the culture to be more inclusive.

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AGENDA

Saturday, March 15th

- | | |
|----------------|---|
| 8:00 a.m.-noon | Committee Meetings |
| noon-1:00 p.m. | Executive Committee Session |
| 1:00-2:30 p.m. | Board Orientation Sessions for Reps/Board Members |
| 2:45-5:45 p.m. | Board of Directors Meeting |

Sunday, March 16th

- | | |
|---------------------|--------------------------------------|
| 8:00-11:00 a.m. | Reconvene Board of Directors Meeting |
| 11:00a.m.-1:00 p.m. | Board of Representatives Meeting |
| 1:00-2:00 p.m. | State Association Executives Forum |
| 1:00-4:00 p.m. | Pre-Conference Workshops |
| 4:30-6:00 p.m. | Keynote Address |
| 6:00-7:30 p.m. | Welcome Reception |

Monday, March 17th

- | | |
|---------------------|--|
| 7:30 a.m.-4:00 p.m. | Exhibits |
| 8:30 a.m.-4:00 p.m. | Conference Sessions |
| 11:00-4:00 p.m. | CEO Roundtable |
| 2:00-4:00 p.m. | National Advocacy Campaign Task Forces |
| 4:00-6:00 p.m. | State Share |
| 7:00 p.m. | Optional Social Event |

Tuesday, March 18th

- | | |
|---------------------|--------------------------------------|
| 7:30 a.m.-4:00 p.m. | Exhibits |
| 8:30 a.m.-4:00 p.m. | Conference Sessions |
| 4:30-5:30 p.m. | Winter Conference Planning Committee |

Wednesday, March 19th

- | | |
|---------------------|------------------|
| 8:00 a.m.-3:00 p.m. | ANCOR Foundation |
|---------------------|------------------|

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 \$557,230.78.

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ARCA

ARRM

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Nebraska Association of Private Resources

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New Avenues to Independence

New Hope Community, Inc.

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ANCOR Meets with New Office of Disability Employment Policy Assistant Secretary Grizzard

By *Charlie Harles and Kara Freeburg*

ANCOR along with representatives of other national disabilities organizations met with Assistant Secretary of Labor for the Office of Disability Employment Policy (ODEP) Roy Grizzard Thursday, January 9, 2003 to discuss the Department of Labor's new office, its plans for the future, and to discuss issues regarding the employment of individuals with disabilities. The Office of Disability Employment Policy was established by Congress as part of the FY 2001 budget and designated that the Office to be headed by an Assistant Secretary. Dr. W. Roy Grizzard nominated and confirmed as ODEP's first assistant secretary in July 2002.

To open the meeting, Dr. Grizzard provided background on the new office, including its mission and the issues that ODEP will be addressing over the next year. The Assistant Secretary stated that he is *humbled with a sense of purpose* in given the responsibility for the new agency and noted that the new agency did not really start to gear up until he was appointed last July. He noted that ODEP had subsumed the old President's Committee for Employment of Persons with Disabilities (PCEPD) and had also taken up the issues that were under the purview of the President's Task Force on the Employment of Adults with Disabilities (PTFEAD), which disbanded in August 2002 under its sunset provision. He said that while many of the employees of PCEPD and the President's Task Force were now working for ODEP, they are still hiring. ODEP will have approximately 65 full time employees when fully staffed.

In describing the organization of the new office, Grizzard stated that ODEP has

been set up as a matrix organization, with "policy teams" targeting youth issues, adult issues, assistive technology, education and outreach, and research. He expects new policy teams to be added as ODEP hires additional staff with expertise in other areas and as new ideas are generated.

ODEP to Focus on Research and Development, Plans Work with Other Federal Agencies

In keeping with ODEP's mission to provide and enhance opportunities for persons with disabilities to become employed, employment of people with disabilities is the main focus of the office. Much of ODEP's work will be research and development. While it will not be the job of ODEP to regulate, enforce, or investigate Federal employment programs, Grizzard stated that ODEP will be to provide best practices for employment, provide grant funding, and develop policy recommendations for programs and agencies within the Department of Labor. ODEP does not have funding to provide direct case services, although they have been making grants to develop model programs, including a series of customized employment grants to identify ways One Stop Centers can better work with persons with disabilities.

An important aspect of ODEP will be to work with other Federal departments and agencies. Grizzard expects ODEP to work on other issues—for example, housing, transportation, and Medicaid—that impact people with disabilities and have a tangential relationship to employment. Grizzard also stated that ODEP to act as an ombudsman to other Federal agencies, providing expertise and offering policy recommendations to remove barriers to employment. He stated that ODEP also wants to work with state and local agencies and private entities to assist people with disabilities who want to work.

WIA, Rehab Reauthorizations, Transition of Youth with Disabilities to Work Among ODEP's 2003 Priorities

Among the priorities identified by Grizzard for ODEP over the next few years include reauthorization of the

Workforce Investment Act and the Rehabilitation Act. Accessibility of One Stop Centers and the development and distribution of a checklist for accessibility of One Stops will also be priorities. He also noted that ODEP was involved with the Social Security Administration in funding "Navigators" in One Stop Centers to assist people with disabilities and people on welfare to deal with getting appropriate services through the One Stop Centers (see *LINKS* January 2003 issue). ODEP will continue its work with SSA to monitor the progress of the Navigator program. Another priority identified was implementation of the Olmstead decision with regard to employment. He indicated that ODEP would have additional grants available in the future to address this priority. Finally, Grizzard stated that ODEP would be involved in discussions with the Department of Education on reauthorization of Individuals with Disabilities Education Act (IDEA), which is scheduled for 2003. In particular, ODEP is interested in the issue of transitioning youth with disabilities to work.

After the meeting, it was still not entirely clear what role ODEP will play in the development of Federal policy with regard to programs for persons with disabilities. Grizzard acknowledged several times that ODEP does not have any authority over other Federal agencies. As such, ODEP will need to sell their policy recommendations. Grizzard likened himself as a door-to-door salesman going up and down the National Mall in Washington, selling ODEP's ideas to other agencies. He said ODEP is eager and willing to be a "bully pulpit" to share ideas with other Federal agencies to advance the employment of disabilities. He closed the meeting by encouraging ANCOR and other organizations to submit their ideas and suggestions to him. *We have to move forward together. My door is always open. I want to hear what you want to say*, Grizzard stated.

RESOURCE LINK Harles & Associates provides consulting services to ANCOR on employment and training-related issues.

ANCOR's Fax-On-Demand is available 24 hours a day, 7 days a week at 1-888-715-5501 INFORMATION IS JUST A PHONE CALL AWAY!

Five Steps for Successful Succession Planning

Leave a Legacy of Leadership

When you give a gift to the ANCOR Foundation, you leave a legacy to the field of private providers. By designating the ANCOR Foundation as a beneficiary in your will or insurance policy, you directly support the continuation of the critical work needed to assure the success of the next generation of leaders in the field.

For more information on the ANCOR Foundation, contact Renée Pietrangelo at (703) 535-7850
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A successful organization leadership succession plan maps the landscape, prepares for contingencies and minimizes disputes.

Simultaneously, an organization needs to enable an orderly transition, ensure continuity and build a legacy. How can it achieve these goals?

More and more nonprofit organizations, including the Maryland Association of Nonprofit Organizations and San Francisco's Support Center for Nonprofit Management, are beginning to offer services to help organizations better manage executive transitions with the long-term goal of strengthening operations through fine-tuned leadership succession structures.

The following five-step process can provide a strong framework for effective organization leadership succession.

Step 1. Build a Solid Foundation

One key to a successful succession plan lies in building a solid, foundation of financial stability and growth for the organization.

Step 2. Co-developing the Leader's Exit Strategy

Leaders should begin with the end in mind. Any sound and successful strategy begins with a goal or vision of the desired outcome. A road map is needed to successfully navigate the exits and integrations of outgoing and incoming leaders. The organization's board and senior management must be involved with and support this process. Succession planning also must be "owned" in part by all staff.

Board should define a clear vision for future leadership, including setting up a board-appointed search committee that could include staff representation. The search committee should reexamine the organization's defined vision, as well as identify major issues the organization is likely to face in the next 10 years, including the qualities required of the new chief executive to lead toward that vision.

Step 3: Minimizing the Organization's Risk

In many cases, illness, serious injury or even death of an organization leader can be devastating and lead to peril for an organization. The risk-related component of the succession plan ensures that the organiza-

tion, its key constituencies and staff are protected in the event of the executive's incapacitation. Proper legal documentation, insurance policies for key persons and business and financial plans must be in place.

Step 4: Strengthening Systems and Processes

Critical factors that create value at the end of the day for any organization are continuous organizational improvement, customer focus, high quality services, and finding, recruiting and training the best possible staff. Essential competencies implicit in these are:

- Building the successor's business and leadership skills
- Planning the retention and development of key persons
- Creating an effective organizational structure
- Developing management systems for peak performance
- Documenting systems and procedures to create efficiencies and support the effective transfer of knowledge
- Implementing a proper strategic planning process that includes leadership transition
- Hiring and training the best possible staff
- Having accounting and financial controls and a comprehensive marketing plan

Step 5. Transitioning the Leadership

Identify gaps between the required leadership and the existing talent pool. The organization must decide if a new leader can be promoted from within or if an external search is required. It must also ensure that the future vision is fresh and vital, so the selection of the new leader is based on choosing the right person to lead the organization to the new vision. Also important is ensuring a good fit between a potential leader and the organization's culture. Matching the leader to the desired culture is critical. ■

Resource LINKS:

- *ESOP Workbook: The Ultimate Instrument in Succession Planning* by Robert A. Frisch (John Wiley & Sons, 2002)
- *Effective Succession Planning: Ensuring Leadership Continuity and Building Talent from Within* by William J. Rothwell (AMACOM, 2000)
- www.entreworld.org
Related topics: Succession Planning (November 2002 feature)
- www.employment-studies.co.uk/summary/summary.php?id=372
- www.cuttingedgeinfo.com/FLReports/FL52_Succession_Planning.htm
- www.benchmarkingreports.com/humanresources/hr50successionplanning.asp

Wage and Hour Questions Clarified

By *Joni Fritz, Labor Standards Specialist*

Questions generated at Wage and Hour Workshops or over the phone sometimes require clarification by federal Wage and Hour Division personnel. It often helps to get two heads together when looking at the regulations in *29 Code of Federal Regulations* (the volume that contains Labor Department rules) to determine how these apply to specific situations. The results of a couple of the discussions with Wage and Hour Analysts follow.

- *It is not necessary to pay employees who have been suspended because of allegations of abuse or neglect when they come into an agency's offices to respond to questions about the incident.* This is true whether the investigator is an agency employee or a state official.

Section 785.7 of *29 CFR* informs us that the Fair Labor Standards Act requires employers to pay employees for working; however, there is no definition of "work" in the Act. The U.S. Supreme Court has ruled that employees must be paid not only



for "physical or mental exertion" for all hours "which the employee is *required* to give his employer." (Emphasis ours.) Suspended employees are not mandated to help with an investigation—and in actuality, many do not show up for interview. Suspended employees are considered to have been *invited* to participate. In this case, they need not be compensated for the time spent in the interview.

If the agency is interested in having the participation of the employee in the investigation, however, payment of the time the employee spends at the agency may be advisable as an incentive to the employee to show up to join in the process.

- *Training time that is not directly related to an employee's job is not considered "hours worked" and need not be compensated.* Therefore, a clerical employee who asks to take a medication administration course would not have to be paid for time spent in that class, *provided that it is given outside of his or her regular work hours.*

Federal rule *29 CFR*, Sec. 785.29 also states that: "Where a training course is instituted for the bona fide purpose of preparing for advancement, through upgrading the employee to a higher skill, and is not intended to make the employee more efficient in his present job, the training is not considered directly related to the employee's job even though the course incidentally improves his skill in doing his regular work." The example given in *29 CFR* is of a stenographer who need not be paid for voluntarily taking a bookkeeping course, since this course is not directly related to his job "even though it may incidentally improve his skill in doing his regular work."

- *Travel from home to work to respond to an emergency on an employee's day off generally need not be compensated.* The applicable regulation (Sec. 785.36) requires the payment of travel time "if an employee who has gone home after completing his day's work is subsequently called out at night to *travel a substantial distance* to perform an emergency job for one of his employer's customers." (Emphasis ours.)

The discussion of the rule further states that *the Labor Department has taken "no position on whether travel to the job and back home by an employee who receives an emergency call outside of his regular hours to report back to his regular place of business to do a job is working time."* Since there is no rule requiring compensation of such time, there is nothing for Labor officials to enforce. Payment is at the discretion of the employer unless the travel involves a "substantial distance."

As a result of earlier *LINKS* articles, many readers have phoned requesting further guidance regarding the exempt status of specific employee positions. When seeking suggestions from the U.S. Department of Labor, the Wage and Hour Analyst to whom we spoke declined to express an opinion about whether certain employees meet the requirements for exemption. She suggested that agencies contact a local wage and hour office for their interpretation of the position in question so that all of the duties can be described in detail. However, she also indicated that exemption can only be fully determined in an investigation when all of the conditions of employment as understood by both the employer and employee can be accurately determined. Unfortunately, there is no very definitive guidance available from the Labor Department beyond the language of the regulations themselves. ■

RESOURCE LINK For a thorough description of federal labor requirements applied to agencies that offer community residential supports and in-home services, you can obtain a copy of the *ANCOR Wage and Hour Handbook*. This publication of more than 100 pages is available at a cost of \$35 to ANCOR members and \$50 for non-members. To order your copy, send a check or money order in the appropriate amount to ANCOR, 1101 King Street, Suite 380, Alexandria, VA 22314; phone 703-5355-7850.

AUTHOR LINK For further information, author Joni Fritz can be reached at her home office in Arizona, phone 928-203-0618, or by writing 11 Elice Circle, Sedona, AZ 86336. Her phone guidance is free to ANCOR members and is available to others at a cost of \$55 for up to the first one-half hour.

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Down the Garden Path of Self-Determination

John Ashbaugh

Some years ago I moved from the world of public policy and administration in developmental disabilities at the Human Services Research Institute to the world below—the world of front-line agencies actually serving people with developmental disabilities and others in need of publicly-funded services and supports. I have come to appreciate, more than ever, the critical and difficult role these providers play in the resource-starved human services industry. It is this heightened appreciation, in contrast to the marked decline in appreciation among outspoken devotees of the self-determination movement, that has given rise to this writing.

Lunching with a respected colleague last month, I was taken back at her vision of developmental disabilities systems of the future. One that I've been hearing more and more often in the preachings of self-determination. Support coordinators will help consumers, families and others concerned choose among different self-employed support workers and locate the natural and generic

resources integral to inclusion in their communities. "Fiscal" Intermediaries will take care of the fiscal and administrative details involved. There will be little place for "specialized" providers "as we know them" in the world of self-determination. This, to me, is a frightening scenario as it should be for most consumers and families who need services and supports upon which they can depend.

I'll tell you why by painting the dark side, some might say 'jaundiced view' of the self-determination picture. Historically, governments in the US and other democratic countries take on about as much as public revenues allow. Abundant resources give life to new programs, i.e., constituent obligations; as resources dwindle, governments look for politically palatable ways to reduce these obligations. In the public health and human services arena, the pattern is for the higher-levels of government to pass the responsibility for fiscally untenable programs to entities further down "the program food chain." In order to make the responsibility more fiscally tenable and acceptable, the entity

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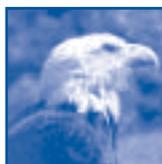
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accepting responsibility is given more control / freedom over how the resources will be managed and expended. Federal categorical programs become block grant programs in the hand-off to the states. State Fee for service arrangements become capitated programs in the hand-off to "preferred" service providers or self-determination programs in the hand-off to consumers and families and the communities in which they live.

No matter how you cut it—excuse the pun—in the end there are fewer resources available per person served and to those serving them. The danger with the self-determination hand-off particularly, is underestimating the front-line organization and infra-structure necessary and over-estimating the capacity of consumers, families, and communities to manage in resource-thin situations.

Faced with years of under-funding, repeated payment delays, and a myriad of stifling regulations and ever-changing certification, reporting and billing requirements, providers have had to master a lot of survival skills. They've had to become adept at fund raising, at attracting and

using volunteers, at recruiting from low-wage labor pools, and at coordinating cadres of part-time individuals in order to cater to the schedules of secondary wage earners and avoid paying full benefits. They've devised cooperative purchasing arrangements, shared training arrangements, and shared staffing arrangements. And despite an environment increasingly respectful of consumers and increasingly distrustful of providers, they have had to sustain staff morale and retain the core staff necessary to provide reasonably stable and safe environments.

Maintaining quality services and supports for most individuals with developmental disabilities requires a level of organization and resourcefulness that loose affiliations of support coordinators, fiscal intermediaries and natural supports simply cannot muster.

Call it self-determination, call it choice, but call it less. That creative service coordinators can do a more with less given enough flexibility is an attractive but fanciful notion when presented as a system-wide solution. The idea has been over sold through the use of success stories featuring

higher functioning individuals with exceptionally supportive families, friends and / or communities. The bulk of the population in public service, lower functioning adults with less supportive families, few friends and disinterested communities are conveniently forgotten except by providers long left to their support.

Let's be real. Self-determination, like any movement that secures a place for itself in the perennially under-funded world of developmental disabilities, is sure to have an economic underpinning. The benefits of self-determination for consumers and payers are substantial for those able to do more with less. Most consumers can't. For them self-determination is nothing more than a cover for cutbacks in funding where it can be least afforded—among the front-line agencies upon which they so heavily depend. ■

AUTHOR LINK John Ashbaugh is currently the Vice President, Director U.S. Operations for Danic Technology, Inc. in Needham, MA. He can be reached at (781) 400-1110 or by e-mail at jashbaugh@danic.com.

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Vermont Gems on Recruiting and Retention Practice

The Vermont Department of Aging and Disabilities sponsored a state-wide best practices conference in early December. The various presentations surfaced some very astute recruiting axioms, which are shared here. These points may seem simple; but simple is not easy.

- The main thing your agency has to “sell” in distinguishing itself as an employer of choice is *values*.
- Your organization’s mission statement must be readily “quotable”.
- Critically important is extensive support in the first 30 days of employment from other direct support staff who can paint a realistic picture of day-to-day challenges of the job.
- You can’t change your culture until you’re aware of what it is.
- Make it personal by communicating to prospective candidates the vulnerability we all share to at some point in our lives needing additional support.
- With regard to retention, good training is not enough. Attitude modeling in the context of training is critical.
- It’s important that your agency build social capital in the community through proactive involvement with churches, high schools, local universities and colleges, technical schools, VFW, and Lions, Rotary and Kiwanis clubs. Consider positioning/branding your agency by advertising on the back of grocery slips.
- Use exit interviews with *current* staff to assess challenge points.
- Consider as a value-added to staff no-interest loans up to \$250.00 with scaled payroll deduction for reimbursement.
- What drew you to this work and what wears you down is the same from the top down and bottom up. Unfortunately, individuals deal with these issues in isolation, thus perpetuating an us/them dichotomy. Create a supportive culture for dialogue about them.
- Consider inviting prospective candidates to a casual coffee session at a service delivery location and hosted by direct support staff. Use the opportunity to describe the role, responsibilities and challenges of direct support work, in context, alongside the individuals supported. ■

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Crisis—Danger or Opportunity?

Catherine Hayes

The recent ANCOR Governmental Affairs Conference was titled “Crisis in Long Term Care: Marshalling America’s Resources”. It reminded me of the Chinese symbol for “crisis” that was used at a counseling center where I volunteered many years ago. This symbol represents both danger and opportunity. The danger was that we might not find the right words to help the person move forward. The opportunity being that by listening and “tuning in to the music behind the words” we might indeed help the person out of their crisis. The crisis in the service delivery system for people with developmental disabilities also presents both danger and opportunity. This article addresses a unique opportunity we have to review and suggest changes for the two major funding programs for residential services.

There has been a major shift in developmental disability services during the last 25 years, when private providers were first allowed to enter the ICF/MR program. Homes are smaller and more integrated into the community, funding tighter and those wanting services have grown in numbers and need. The system has shifted from a focus on large settings to emphasizing people living in their own homes, controlling their own lives and truly being included in their communities. The concept of quality enhancement has broadened

to include a focus on the desires of individuals served. Individuals, families and the providers should all be an integral part of planning which evolves around these desires.

New Regulations—Soon, we will all have an opportunity to provide input to the Center for Medicare and Medicaid Services (CMS) on both the Home and Community Based Services (HCBS) waiver program and the Intermediate Care Facilities for people with Mental Retardation (ICF/MR) regulations. CMS is publishing updated regulations for comment in the Federal Register for both programs in the next few months. Now is a good time to step back and ask what have we learned and how can better we work together to overcome the challenges that still face us. We need to look at a range of issues: how we deliver services, where we deliver them and the range of services and settings available. Each of these has changed since the ICF/MR and HCBS programs were created.

Some History—Congress created the ICF/MR program in 1971. In 1977 private providers were allowed to become ICFs/MR. It was 1981 before the HCBS program was created and 1993 before a majority of ICF/MR beneficiaries were served in private settings. Since that time, the model for service delivery has changed. Initially, the large settings of the past were supported by the medical model, with an emphasis on professional control and care. Twenty years ago, we moved to the developmental model, with the emphasis on the team and “Active Treatment”. We are now in the era of individual supports and services, tailored to the needs of each individual.

The values that support these service models also evolved, driving the changes forward. The medical model reflected a parental, “taking care of” value system. The developmental model was based on community integration and promoting rights. The individual support model emphasis is on self-determination, real choice and person-centered outcomes.

Throughout the recent evolution from developmental to self-determination, there have been two major funding mechanisms available, the ICF/MR and HCBS programs. Both were created by Congress under the Social Security Act and reflected the thinking of the era in which they were created and their regulations promulgated. For example, the current ICF/MR regulations were developed in the mid-1980’s and published in 1988. They reflected the developmental model, representing a step forward in service delivery philosophy. Consumers, advocates and providers welcomed the change at that time. However, since then, leading thinkers and advocates in the developmental disabilities arena have pushed forward to embrace a new individual support approach. The HCBS program grew as a result.

Both programs are tied to federal regulations and oversight but the HCBS offers greater flexibility to the states. The two programs are linked by statutory requirements and whom they serve. There are many differences as well, but the focus of this article is on the commonalities, and the challenges we face as a system.

Several things are clear; the ICF/MR program is serving fewer people today than 10 years ago and the settings are smaller. On the

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other hand, the HCBS program has grown dramatically over the last 20 years. In 1982 only six states had waivers, today there are over 262+ wavier programs throughout the country and over 260,000 people are served through them. Both programs are serving an aging population, having multiple disabilities, with an increasing need for health care.

Current Challenges—Several critical challenges face us in providing quality services: serving a population that has increasing health care needs on shrinking funds, figuring out what to do about those who need more intensive supports for behavior while reducing the use of restrictive procedures, and making sure we protect people from abuse and neglect in an increasingly diverse and dispersed system—and doing all of this while promoting client choice and self-determination!!

What Lies Ahead—Issues for Discussion Key issues for discussion include eligibility for program services, the governments' oversight role, the tension between assuring consumer safety and respecting consumer choice, and serving individuals who have engaged in dangerous criminal behavior.

Eligibility—As both the ICF/MR and HCBS waiver regulations are being reviewed by CMS, providers should use this opportunity to bring up several tough issues for discussion, including how best to revise the regulatory definition of who can be served in the ICF/MR program. The definition of whom the program is designed for and the definition of active treatment will also have a profound impact in the HCBS program, due to its statutory link to the need for institutional care. Resolution of the dilemma may require a statutory “delinking” of the ICF/MR and HCBS program, enabling each program to target a specific population. One question is whether to revise the regulations and definitions to permit people with less severe functional deficits and conditions, unrelated to mental retardation, to be served.

Another challenge to be addressed is services for individuals with mental retardation and other developmental disabilities, who are also guilty of dangerous criminal behaviors such as murder, rape, and assault. Recognizing that this population is at risk if admitted to the criminal justice system at large, strategies must be developed to determine how these individuals can best be

served. Some states have addressed the problem by using the ICF/MR facilities to house court-ordered individuals together in “locked down”, fenced units replicating a forensic or prison environment. Whether the ICF/MR benefit should be used to isolate people from their community, withhold their rights as citizens and restrict their freedom of movement, requires analysis and discussion by stakeholders.

Oversight—Along with dramatic changes in philosophy, have come major conflicts between various groups on how services should be provided, and which setting best meets the needs of individuals with developmental disabilities. Most consumer and advocate groups are opposed to “institutional” care and have a great fear of individuals being forced back into nursing home or custodial care settings. At the same time, some parent and advocate groups are concerned about a perceived lack of oversight and protections in the community setting. Both the HCBS and ICF/MR programs have seen an increase in CMS oversight in the last two years, primarily due to these concerns.



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Safety vs. Consumer Choice—One of the most challenging issues when writing regulations is defining the regulatory role, ensuring that health and safety requirements are met, and still promoting consumer choice. Several critical questions face us as we look at revising the regulations:

- How can regulations be framed and implemented that do not interfere with individual choice and self-determination?
- Where is the balance point between regulatory safety and individual choice?
- Whose choice takes precedence?
- What is the responsibility of the agency that receives funding to provide certain services?
- What is the role of the paid professional whose “judgment” differs from the individual’s “choice?”
- What if the person makes a choice that is not in the “norm” or harms his or her health?

Planning for the Future, Learning from the Past

There is no doubt that choice and self-management play a critical role in the “quality” of one’s life. However, as we struggle with the changes in our system, we should revisit several concepts.

Inclusiveness—We do not want to return to the days of segregation from the community. Yet we sometimes isolate folks by integrating them into the community, but failing to help them fully access that community. Loneliness is as big a possibility in a small setting as it was in large, segregated settings.

Real Choice—A home can mean many different things. It can be an apartment with one person; a small home with one or two roommates, and for some, home is the group home they have shared with several others for many years. Real choice respects that people may want something different than what we would want, and supporting them in creating that reality.

Full Range of Services—A range implies more than a choice between big and small, between the old and the new. A spectrum of services is needed to allow both for real choice and to create a system that allows for flexibility to adapt as needs change.

Need for Collaboration—In closing, I want to emphasize the need for collaboration. Given the magnitude and variety of issues, it is essential that collaborative bonds

be formed across constituency groups and across service settings. Labor, management, providers, self-advocates, families and other advocacy groups, professional organizations, regulatory bodies and lawmakers must all join forces to address the new challenges and future directions that affect the lives of people with disabilities. We have a unique opportunity to review and have input into the future direction of our service system. This challenge presents opportunities and dangers. Only by working together can we devise creative solutions that will improve the quality of life for the individuals being supported as well as those still waiting for services and supports. ■

RESOURCE LINK Parts of this article are adapted from Chapter 10: “Federal Policy and Practice In Transition: A Look Ahead at the ICF/MR Program” For Quality Enhancement In Developmental Disabilities: Challenges and Opportunities in a Rapidly Changing World 2003 update. Paul Brookes Publishing. Co-authored Catherine Hayes, Linda Joyce & Elizabeth Couchoud. (November 2002).

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Gizmo House Sparks New Era of Independence

Matt Fletcher

The house of the future is here. It's a user-friendly abode, "Jetson-like" in the computerized, remote access it allows to appliances, phones and even doors. No, it's not the home of a celebrity, billionaire dealmaker or software industry giant. The residence, "Gizmo House", is home to six people with developmental and physical disabilities.

Aptly named, Gizmo House is an innovative breakthrough for the Ann Storck Center in Ft. Lauderdale, FL. The single-family residence affords a new level of independence for its residents who live virtually assistance-free in their home. Everything in the house has been modified to be remotely operated through a computer touch screen mounted to each occupant's wheelchair. A project ten years in development, the genesis for Gizmo House came from the realization that the Ann Storck Center's consumers could be assisted through a combination of custom software and newly available "smart home" technology. "We began to understand they could do more if they had the right technology to assist them," said Jim McGuire, executive director of the Ann Storck Center. The Gizmo House is one of five group homes that the Ann Storck Center operates in the Broward County area.

The heart of the remote system is a \$30,000 "smart home" computer that is capable of controlling all the automated features of the house. Everything but the kitchen sink has been fitted with adaptive technology to allow for wireless operation via the special touch screens. Actually, the kitchen sink can be operated too via an infrared sensor.

Residents use their wheelchair-mounted touch screen to choose from a multitude of Gizmo icons that represent appliances, facets and faucets of the house. Operation of the touch screens is

intuitive and easy to use. A green button allows for movement through the various menus, while a red button will stop the screen on the icon currently pictured. Voice cues have been added to the program to make for even easier operation. McGuire explained that, "They can adjust the lights, adjust the drapes, get a snack from the pantry or something to drink from the refrigerator."

The tables and countertops in Gizmo House have adjustable surfaces for each resident; and special induction cook-tops allow for safe preparation of food. "It empowers people. They get to do their own thing when they choose to," McGuire pointed out. Even the phone numbers of family and friends have been programmed into the system, and residents use the touch screens to select a photograph or name of the person they wish to call.

The Ann Storck Center raised \$800,000 to develop Gizmo House and partnered with gifted local technology designers, architects and contractors to complete the project. "We consider it a standard by which all people with disabilities should have an opportunity to live," McGuire explained.

For the consumers who call Gizmo House their home, the gizmos have made a big difference. "It's all about giving people control and self confidence, and in that respect, it went beyond our expectations," McGuire stated. One resident, who used to be very shy, has newfound confidence. McGuire indicated that the resident, who used to have difficulty talking to even small numbers of people two years ago, recently spoke for 30 minutes to an audience of 500 nurses at a convention in Orlando and received a standing ovation. "We built it (Gizmo House) as a values statement," McGuire continued, "a statement of empowerment."

The Ann Storck Center has a long history of innovative care in Florida. The organization was formed more than forty years ago by a local nurse, Ann Storck, who believed in quality community care for children with multiple disabilities. The center flourished over the past four decades, expanding to provide programs and services such as an early intervention preschool, adult training, residential programs and specialized group homes. The Ann Storck Center's philosophy is that "despite the presence of disabilities, there is ability to be discovered".

The Ann Storck Center has plans to add to the success of Gizmo House. The organization is in the process of raising \$500,000 for a second automated house, "Project HOPE", that will be home to six teenage residents. McGuire expects the Ann Storck Center to break ground on Project HOPE within three years. ■

RESOURCE LINK For more information about Gizmo House, please contact the Ann Storck Center at (954) 584-8000, or visit them online at www.annstorckcenter.com.

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To use our hands and legs for their hands and legs

To use our eyes, our voices, our ears for them, but not take these away from them

To never expect more than they can give

To never take away from them the dignity, love and respect they deserve

To never use the words can't, don't, or won't in a derogatory manner

Remember always, we have days we can't, don't and won't too

Remember our down days can make them have down days

Keep, hope, cherish, be a friend

Always one day at a time

—Submitted by Dora Ratzlaff, home manager for the Hozhoni Foundation in Flagstaff, AZ; 928-526-7944

In The News

ANCOR Endorses NADSP Code of Ethics At its retreat session in November 2002, the ANCOR Board of Directors officially endorsed the National Alliance of Direct Support Professionals' (NADSP) Code of Ethics. As a member of the NADSP Board of Directors, ANCOR was involved with the development of this document, which is accessible on the ANCOR web site at <http://www.ancor.org/dev/Activities/NADSPCodeofEthics.doc>. Copies of the Code of Ethics brochure, which is distributed at every ANCOR exhibit, is available in alternate formats on request. Contact NADSP Code of Ethics, POB 13315, Minneapolis, MN 55414.

Cash and Counseling Teleconference The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services (HHS) recently held two teleconferences to build on what has been learned from the Cash and Counseling programs operating in Arkansas, Florida, and New Jersey. The ninety-minute long teleconferences, held on October 28th and November 4th, opened a dialogue with state policymakers and investigated

possible opportunities for partnership. The agenda included an invitation for states to take part in an individualized "Environmental Assessment" to provide more background that could help inform a possible expansion of Cash and Counseling. This assessment will help determine how many states are seriously interested in pursuing individualized budget approaches with or without *Independence Plus* 1915c or 1115 waivers, and what kind of start-up funding and technical assistance interested states needed in order to move forward.

The organizers invited state officials who might be involved in authorizing or developing consumer directed options involving individualized budgets to take part in these calls to discuss what states see as the benefits and limits to cash and counseling-like models, and what states believe that they would need to move forward in implementing such models.

RESOURCE LINK For more information on these teleconferences, or on the RWJF/ASPE "Environmental Assessment for Possible Expansion of Cash and Counseling" e-mail or call Kristin Simone, Deputy Project Director at simonek@be.edu (617) 552-0620.

ATTENTION MEMBERS & CONSULTANTS

We need your input!

If you know a consultant—or are a consultant—to private providers and have an interest in being a part of the special LINKS 2003 Supplement featuring the services of industry consultants, please contact

Marsha Patrick, patrick@ancor.org.

State Representative Profile



Dick Farnsworth
Maine State
Representative

As I look back on my career, it is hard to believe that I have bounced around so many times and in so many places. But, even more fascinating is the enormous change that has taken place in the way in which services are provided for people with special needs and the fact that the state of the art is not stagnant.

Like so many of my colleagues, I started out in the field of mental health services, completing an internship in residential treatment at Judge Baker Guidance Center in Boston during my last year in graduate school at Boston University in 1966-67. But it wasn't until I took a social work position with Wrentham State School in 1971 that I began to catch the excitement around the potential of people with disabilities and how the institution stifled that potential. It became clear at that point

that the action was taking place in the community and the real hope for those we served was:

- To develop the capacity in the community.
- To keep people *out* of the institution.

My first stint in Maine was as a part of the state system. Not only was I the regional administrator for the then Bureau of Mental Retardation, I also had a chance to develop and open a small community-based residential program. The area served was Aroostook County, a large rural area (Maine potatoes), and a place where many children could not get adequate educational programs in their local schools. Our residence was opened five days a week and the residents all went home on the weekend. We functioned as an extension of family, not as a replacement.

As regional administrator, it was exciting to work with local provider agencies to develop the various programs that were needed. Wow!!! Those were good times with lots of creative juices flowing as the idea of community-based services really took hold.

Alas with a change of governors, I was lured to the mid-Atlantic area and, after more administrative work, I took a position as assistant professor at Temple University's School of Social Administration teaching courses related to developmental disabilities.

The exciting times were helping students see the potential of people with disabilities, their role in helping to achieve that potential, and working with them in various field placements as they grew to their own professional maturity. This was tempered by trips to Pennhurst to see the transition as the institution prepared to close down. These experiences inspired the students to make life better for those they served in the community.

One of the things I used to share with students was the concept that more progress had been made for people with disabilities in the previous 30 years than in all of recorded history. What a moment of truth that was to these students who were just becoming aware of the possibilities in our field.

From Temple, I went to work with COMHAR Inc., a Philadelphia community MH/MR center. Here is where the real work was to be done. Building a service system that started with infants and served a geriatric population. Challenging, exciting, sometimes frustrating, still a great experience. A tough neighborhood, but great families committed to good service in their community. Working with Steve Eidelman, we took some of the last residents from Pennhurst and had the opportunity to celebrate the closing of that venerable institution. What an honor.

In 1992 I came back to Maine to become the executive director of Woodfords Family Services because this is where my heart is. In spite of the challenging time, the spirit was strong and the people, many whom I had known when I left in 1976, were still fighting the good fight. These were the people involved with ANCOR-Maine, actively advocating for disability services and supporting the self advocacy movement in our state. These were also the people leading the charge to close our state institution, Pineland Center. We achieved that goal in 1998.

The ANCOR connection became stronger and stronger as I realized the network of communication and support at the local and national level. The collaboration between ANCOR and other organizations (AAMR, the ARC, UCP, etc.), is a great strength and resource that I have grown to value, and our ANCOR national staff is great, well respected for their expertise.

In 1999, ANCOR Maine and the Maine Association of Rehabilitative Services (another statewide provider group) felt that the strength of merging would outweigh the value of separation, so we merged into the Maine Association for Community Service Providers. The real value, however, is the ongoing connection with ANCOR national and the ability to tie into the valuable information and advocacy network, the educational opportunities, and the goodwill and good counsel of our fellow members across the nation. ■

AUTHOR LINK Dick Farnsworth works for Woodfords Family Services and can be reached at 207-878-9663 or rfarnsworth@woodfords.org.

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Conference

continued from page 4

Another distinguished speaker is **Bob Gettings, Executive Director National Association of State Directors of Developmental Disabilities Services**. Bob will explore the implications of the current federal-state financing picture and identify steps that state/local DD services system can take to adjust to the new funding realities. **Norm Davis, Principal, William M. Mercer, Inc.**, and a panel of providers will also discuss the provider perspective on dealing with budget deficits and reimbursement reform.

The conference will also feature a compelling *Executive Summary* of the significant progress made toward achieving the goals of our National Advocacy Campaign. You'll hear from senior Bush Administration officials (**both President Bush and HHS Deputy Secretary Claude Allen have been invited**), and campaign consultants.

Val Bradley, Executive Director, Human Services Institute, will also review recent CMS initiatives regarding quality assurance and enhancement.

Other sessions include discussions by

representatives of major software companies and agency executives regarding innovative technologies they've implemented that have been successful in cutting costs, improving services and streamlining agency operations.

Sessions are too numerous to list in any detail but a limited sampling of topics/sessions include: *Transforming the Client File through Web-Based Technology; Shaping a Fiscal Intermediary that Works for You; Business Development that Encourages Choice; Immersion Training Model for Direct Support Staff; Litigation: The Best Defense is a Good Defense; 360 Feedback in the Human Services Field; The Secret of Keeping People; Employees: Finding 'em and Keeping 'em; How's Your Marketing These Days; Ticket to Work: The Provider Perspective; and, Collaborative Public Relations Strategies.*

Extended Pre-Conference sessions include *Building Community for Natural Supports* and *Leadership: The Key to Hurdling.*

Building the Future, Today promises to be a terrific conference, one that you can't afford to miss. See www.ancor.org for complete details or contact Jerri McCandless (703) 535-7850, jmccandless@ancor.org. ■

ANCOR Calendar

2003

- Feb. 18** **Audio Conference**
Survival & Growth Depends on Talented Supervisors
- Feb. 18-20** **ADD Commissioner's Forum**
Mayflower Hotel
Washington, DC
- March 16-18** **ANNUAL WINTER CONFERENCE**
Building the Future, Today
Adam's Mark Riverwalk Hotel
San Antonio, TX
(Board meetings 3/15-16)
- Sept. 7-9** **ANCOR's 2003 Governmental Activities Seminar**
Washington Court Hotel
Washington, DC

ANCOR Mission:

To promote and assist private providers who offer services and supports to people with disabilities and their families.

ANCOR Vision:

To be the premier association providing advocacy, services and resources to private providers.

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