ANCOR Providers Leading The Way

20 Year Celebration: Historic Supreme Court Housing Decision A Result of ANCOR Provider Determination

This year marks the 20th anniversary of the U.S. Supreme Court’s Cleburne decision. The case first made local then regional and finally national news. It made news because of the “David and Goliath nature of the suit” as one reporter expressed it—and because it highlighted the struggle between public policy and public fear. Follow the details of that struggle, the victory that followed, and reflections on the lasting effects as told by one of the providers who made the five year journey – Jan Hannah of the Cleburne Living Center (now known as Community Living Concepts).

It was a hot August night in 1980 in the sleepy little town of Cleburne, Texas. The Planning and Zoning Commission had just denied the request of the newly formed corporation, Cleburne Living Center, to open a small group home for people with mental retardation in a turn-of-the-century home in a historic section of that small town. Although disappointed, CLC’s David Southern, Bobbie Northrop, and I were not deterred. We began immediately to plan our strategy for the next step, the City Council meeting.

A little band of supporters that included Bobbie, David, and myself, among others, had been working to educate the council members, had marshaled support from people all over the city and had secured the support of the members of the local Association for Retarded Citizens (now The Arc). While the zoning commission had caved to pressure from the neighbors to deny the Special Use Permit, we believed the City Council would have to take the broader view—after all, they were the elected officials and had to answer to the residents of the whole town, not just a few frightened ill-informed neighbors.

Fearing that the City Council would deny or refuse the permit, we contacted several local attorneys. Our query: See Celebration page 19

Appellate Court Strikes A Blow in Sanchez Case

Advocates Decry Decision Regarding Wages and Wonder: If Rights Are Unenforceable, Are They Still Rights?

The Ninth U.S. Circuit Court of Appeals ruled August 2nd that Medicaid providers and beneficiaries, including individuals with disabilities, cannot sue the state to enforce the equal-access and quality-of-care provisions in the federal Medicaid law governing California’s Medi-Cal program. The ruling came in the Sanchez v. Johnson lawsuit brought against California officials seeking to increase funding for community-based services to prevent unnecessary institutionalization.

It is not enough for Medicaid recipients to show merely a violation of federal law or the denial of a benefit, the court stated. In addition, plaintiffs must show that Congress clearly intended to allow individuals to go to court to enforce the law.

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ANCOR at the Crossroads

Renee Pietrangelo

“ANCOR at the Crossroads” was the theme selected for the June 27-29 CEO Summit and Board retreat. The summit was the fourth annual invitation-only leaders summit, which included ANCOR board members, board of representatives, state provider association executives and founding supporters of the ANCOR National Advocacy Campaign.

Over 40 agency leaders and state association executives engaged in a day and a half of facilitated discussion and information sharing by industry leaders, regulators and consultants. Reflective of the overall feedback we received are the following attendees comments:

“I found each section and their respective topics informative and helpful to my understanding of national issues and trends.”

“Washington minds representing advocacy organizations as well as lobbyists, public policy reps and ‘think tank’ folks made for a diverse, information and yeasty discussion that provided insight to those present.”

The summit discussion was wide-ranging. The focus of both the CEO summit and the ANCOR Board retreat was to think to the future in assessing current trends and the direction of service delivery models; providers’ role in shaping public policy to support the changing service delivery landscape; and ANCOR’s role in supporting its members in advancing public policy, transitioning service delivery models, and helping to shape the future. The context of discussion included the impact of consumer choice and control; innovations in service delivery; efficiency and cost effectiveness; pay for perform-

See CEO page 23

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Imagine 500,000 people converging on a small South Dakota community of 10,000 during a week in August — all for the purpose of engaging in what has been described as an adult “spring break”, or the world’s largest costume party! These numbers are even more impressive when one considers that the entire population of South Dakota is only 760,000. Most of these revelers have a vision of fun, frolicking, fellowship and fanfare accompanied by the roar of the American icon, the Harley Davidson motorcycle. I paint this picture because I have lived it for some 30 of its 65 years and have been a casual observer as it has grown into an international event. Are there commonalities between this event and the international event? Are there common interests? People with disabilities movement’s many voices together? What brings these Many Voices together in Sturgis is the ownership of or interest in Harley Davidson motorcycles and the accompanying riding, racing and revelry.

What brings the enlightened disabilities movement’s many voices together? Like the Sturgis Rally, we too have a common interest — people with disabilities. We are going to D.C. to find solutions to the challenges and barriers facing full participation. People from all walks of life, including self advocates, family members, service providers, researchers, public policy gurus and other leaders collectively will seek to remove the barriers to equality that are present in our society.

The enlightened disabilities movement has its origins with the Willowbrook exposé, when Geraldo Rivera was given a key and he surreptitiously filmed neglect and squalor in the halls of the institution. This 1970s exposé sparked the de-institutionalization movement, which is still going on with improvements in the quality of life for people with disabilities that continues today. ANCOR has been a part of the movement for some 35 years.

For the good of the cause, it will be necessary to form a critical mass to move our agendas forward, for we have assembled Many Voices — with One Vision. It is imperative we clearly articulate that vision and convey it to the elected officials and others of influence. We are certainly worthy of support.

As Congress debates the worthiness and affordability of Medicaid, we appear to be at a crossroads with the delivery of affordable health care for people with disabilities who have low incomes. It is vitally important that we form a cohesive andSee President, page 18
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I n June of 2004, Renee Pietrangelo introduced us to the concept of “communities of practice” (CoP) in her Links “CEO Perspectives” column. The term and her description sounded interesting, but like many other things that come across our desk, there never seems to be enough time to look into it in depth. However, our association with the American Society for Quality and the data collection pilot activity being coordinated as part of ANCOR’s Performance Excellence initiative bring ANCOR members to a unique participation opportunity organized around practices in our field of supports for people with disabilities.

Let's look at this “critter” again. Renee referenced a book by Etienne Wenger entitled Cultivating Communities of Practice (Wenger, McDermott and Snyder, Harvard Business School Press – 2002), which has become a standard reference in the field.

Briefly, “Communities of Practice involve people who share a concern, a set of principles, a passion about a topic, and who deepen their knowledge and expertise in it by interacting on an ongoing basis.” Several web references at the end of this article will lead you to more examples and understanding.

To bring this home, ANCOR members will soon be invited to participate by sharing and interacting through the gracious hosting of a CoP (there’s a new word to impress your friends during party conversations!) by our colleagues at the American Society for Quality.

One of the more interesting things about the concept may be the dynamic of the activity itself. It is described as something that starts on a topic in general terms—Performance Excellence Markers, for example. As people join the dialogue, threads of sub-topics of interest to a more specialized group may form, and new CoPs spin off to have a life of their own. Thus we may see discussions of general practice guidelines and experience evolve into the sharing of quite specific service suggestions, resources, techniques, strategies, pitfalls, and encouragement.

Why is all this important to us now? The work of the Performance Excellence Taskforce was to create a framework of quality markers—currently posted for review on the ANCOR web site. The next step in the plan and charge is to identify resources that support these markers in ANCOR member organizations. The developing CoP may be one of the most accessible forums for the development and transfer of that information.

ANCOR Member Showcases Art on Capitol Hill During Alliance Summit

I n conjunction with “Summit 2005 - Alliance for Full Participation”, an exhibit of thirty- five original paintings will be displayed in the U.S. Senate Russell Office Building Rotunda from September 19th - 23rd, showcasing the works of fifteen Wyoming artists with developmental disabilities. The art exhibit entitled, Wyoming, The Wild West and Beyond features artists from the creative arts program of Ark Regional Services, Laramie, Wyoming. This exhibit is of national significance for the opportunity it creates for artists with developmental disabilities to present their art to on Capitol Hill.

Four featured artists from the Creative Arts program will represent the fifteen artists contributing to the exhibit. Each of these artists desire to create and find a voice through artistic expression and show their true colors in this vibrant depiction of the Wyoming west, and beyond to penguins and pop art. The exhibit is sponsored by the creative arts program at Ark Regional Services in Laramie, Wyoming, VSA Arts of Wyoming, The Wyoming Arts Council, and hosted by Wyoming Senator Mike Enzi.

Everyone is invited to enjoy the exhibit. The show is open from 7:00 a.m. to 7:00 p.m. from September 20th-23rd in the U.S. Senate Russell Office Building Rotunda. The most direct access to the art show is to enter the Senate Russell building at Constitution and Delaware Avenues. There will be guided tours from 12:00-1:30 p.m. and 5:00-6:30 p.m. daily. Four of the featured artists will be available to talk about their art on Thursday from 3:00-7:00 p.m. and Friday afternoon from 12:00-3:00 p.m.

“I look forward to an America which will reward achievement in the arts as we reward achievement in business or statecraft. I look forward to an America which will steadily raise the standards of artistic accomplishment and which will steadily enlarge cultural opportunities for all of our citizens.”

—President John F. Kennedy
Medicaid Commission Adopts
Recommendations for $11 Billion in Cuts

The newly appointed federal Medicaid Commission held its first meeting July 27th in Washington, DC., spending the day to introduce themselves to one another and the public and organize for future meetings. Commissioners also heard from a number of experts on Medicaid spending, trends, and structure. The 13 voting members and 15 nonvoting members set up a two-day meeting in August to determine recommendations to meet the first part of their charge from HHS Secretary Leavitt—recommendations to reduce Medicaid by $10 billion over five years. (See previous LINKS for initial information on the Commission.)

Chairman Don Sundquist (former Governor of Tennessee) and Vice Chair Angus King (former Governor of Maine) met August 17-18 discussing a series of 33 recommendations to reduce Medicaid spending. The recommendations included some from the National Governors Association and the Administration. Commissioners heard again from experts including CMS Medicaid Director Dennis Smith and representatives from the Congressional Budget Office, the National Governors Association, and the National Community Health Plans.

Six recommendations were presented to the Commission on August 18th as the Chairman’s mark with the remainder of the day spent on discussion of the recommendations and any substitutions. The Commission voted to approve $11 billion in program cuts over five years with the following recommendations:

- change Medicaid’s reimbursement formula for prescription drugs for estimated savings of $4.3 billion;
- extend the Medicaid drug rebate program to Medicaid managed care plans;
- change the start date of the penalty period to the date of Medicaid application for individuals who transfer assets to qualify for Medicaid with $1.5-$1.6 billion in savings;
- increase the Medicaid eligibility look back (asset and resource transfers) period from three to five years with estimated savings of $100 million;
- allow states to create tiered copayments for preferred prescription drugs; and
- reform the Medicaid managed care organization provider tax requirement.

Perhaps some clarity in where some of the Commissioners stood in regards to these and future recommendations regarding Medicaid changes occurred in the afternoon session that culminated in a vote on final recommendations. Although the group collectively agreed to give states the ability to create tiered copayments for prescription drugs, a number of commissioners expressed concern that the proposal could have unintended consequences for certain groups, mostly those that rely on psychotropic drugs, epilepsy drugs, and other classes of drugs for people with disabilities or chronic illnesses. Many Commissioners were clear that they did not support cost-sharing measures that shifted cuts to beneficiaries or major changes to provider tax and intergovernmental transfers (IGTs) as recommended by the Administration. Commissioner King stated that he was not for beneficiary cost-sharing either and framed the recommendation as a price discount measure.

Chairman Sundquist and Vice
U.S. Surgeon General Issues First Call to Action on Disability

U.S. Surgeon General Richard H. Carmona, M.D., M.P.H., FACS, released The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities on July 26th. Developed by the Surgeon General in collaboration with the HHS Office on Disability, the Call to Action describes the particular challenges to health and well being faced by persons of all ages with disabilities. It also identifies four goals that must be achieved and barriers that must be overcome.

This Call to Action is based on what is known and what has been observed about disability, health and wellness. It touches on the costs of inaction, in both human and dollar-and-cent terms. It is based on the following principle: Good health is necessary for persons with disabilities to have the freedom to work, learn and engage actively in their families and their communities.

To make this happen, the Call to Action looks to meeting the following goals:

• Increase understanding nationwide that people with disabilities can lead long, healthy, and productive lives.
• Increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity.
• Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle.
• Increase accessible health care and support services to promote independence for people with disabilities.

According to the Surgeon General and the Call to Action: The health and wellness for persons with disabilities today is a matter of public health concern. Everyone needs to be made aware of the health issues for persons with disabilities. Swift action needs to be taken to ensure that these matters are brought to the attention of those who can help. Without such action, the quality of life for 54 millions Americans will be lessened. To that end, the principle and goals that define this Call to Action must be acted upon. Barriers must be identified and solutions must be found and, more importantly, set into motion.

The “Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities” is available at http://www.surgeongeneral.gov/library/disabilities/calltoaction/index.html

ANCOR Partner
Colonial Insurance Agency Selects ANCOR Foundation As Designated Charity

The Colonial Insurance Agency LLC has selected the ANCOR Foundation as its team’s designated charity in the final round of the Chubb Charity Challenge Golf Tournament at the Ritz Carlton Resort in Half Moon Bay, CA the end of September. The event is sponsored by the Chubb Group of Insurance Companies.

Forty-five teams from around the country will be competing for a total purse of $560,000. Depending on the final results, the Colonial team will be awarded between $5,500 to $50,000 with the ANCOR Foundation the ultimate beneficiary.

ANCOR Partner
Colonial Insurance Agency Selects ANCOR Foundation As Designated Charity

This Call to Action is a call to caring. Every life has value and every person has promise. The reality is that for too long we provided lesser care to people with disabilities. Today, we must redouble our efforts so that people with disabilities achieve full access to disease prevention and health promotion services.
Why accreditation with The Council on Quality and Leadership (CQL)? “Experience”, “meaningful data”, “proven solutions” and a “revitalized organization” – just a few words that our customers use about their experience with CQL Accreditation.

CQL Accreditation promotes real person-centered solutions to the challenges facing service providers today. For years our methods have led the field, and as our customers will tell you, CQL Accreditation is more than just a one-time event, it’s an ongoing journey to excellence. Grounded in person-centered outcomes, CQL Accreditation measures your direct impact on the lives of people receiving services and offers:

- An objective, external measurement of the quality of services
- Support and direction for ongoing quality enhancement
- Recognition of excellence

The benefits of CQL accreditation are clear: a tangible marker of your commitment to providing supports that improve outcomes in people’s lives; increased accountability to funders, the public and stakeholders; evidence that you protect the health, safety and welfare of people receiving services; and strategies for individualizing services and supports and maximizing fiscal and human resources.

The only accreditation offering an Integrated Quality Management approach. Why choose anything but the best?
The Centers for Medicare and Medicaid Services (CMS) released its Quality Improvement Roadmap Executive Summary in late July. The 19-page document states the agency’s aims in focusing on opportunities to influence both the health care system and the care it delivers.

CMS Administrator Mark McClellan has stepped up the agency’s efforts regarding quality improvement throughout the agency. According to McClellan: What our Agency does about quality in Medicare and Medicaid is fundamentally important for the future of health care. Because of our size, it is very difficult for all of the other stakeholders in our health care system to make care better if we are not moving with them and with the current of quality improvement and biomedical science.

By first providing a vision regarding care for the agency, McClellan’s roadmap lays out a set of system strategies designed to link specific, clear steps to achieve transformational improvements in health care. CMS expects that these strategies, implemented with partners throughout the health care system, will help promote changes in the culture of health care organizations that can lead to transformational improvements in health care quality. The second part of the quality roadmap links these system strategies to some particular areas for improving quality and avoiding unnecessary health care costs.

Implementing the quality roadmap will feature focused, collaborative breakthrough projects to demonstrate the feasibility of major health care improvement, according to the summary. And, to implement these initiatives, CMS has redesigned its Quality Improvement Roadmap Executive Summary.
Social Security Turns 70 Years Old!

President Franklin Delano Roosevelt signed the Social Security Act on August 14, 1935, establishing the nation’s compact between generations: younger workers would contribute payroll taxes, and retired workers would have a more secure retirement. Since then Presidents Eisenhower to Reagan have signed landmark Social Security reforms to expand Social Security to provide disability insurance (1954), index Social Security benefits so people would not become poorer as they grew older (1972), and reform Social Security to add decades to its life (1983).

This fall, policy-makers in Washington may start work on major reforms in Social Security. As they contemplate changes, they and you should keep in mind 10 important facts about the program:

Fact #1: About half of the elderly have incomes that, without Social Security, leave them below the poverty line. Social Security lifts 13 million elderly Americans above the poverty line.

Fact #2: Social Security does more to reduce poverty among children than any other government program.

Fact #3: Social Security is more than just a retirement program: one-third of Social Security beneficiaries receive survivors benefits or disability insurance benefits. 10 million beneficiaries are adults below the age of 65, and 4 million are children.

Fact #4. For two-thirds of the elderly, Social Security provides the majority of their income. For one-third of the elderly, it provides nearly all of their income.

Fact #5. Social Security provides benefits to 48 million Americans, with the average beneficiary receiving $10,500 per year.

Fact #6: Social Security is especially beneficial for women.

Fact #7. Social Security is particularly important for African Americans.

Fact #8. Social Security provides an especially good deal for Hispanics.

Fact #9: Social Security provides a progressive benefit that keeps up with increases in the cost of living.

Fact #10: Social Security is an extremely efficient program, with administrative costs equality only 0.6 percent of retirement and survivors benefits.

For more information on the Top Ten Facts on Social Security’s 70th Anniversary released August 11th by the Center on Budget Policy and Priorities, go online at www.cbpp.org/8-11-05soc-sec.htm. For specific information on Social Security and individuals with disabilities, see the Consortium for Citizens with Disabilities Social Security Fact Sheets online at www.ancor.org/2004/issues/socialsecurity.

McClellan continued from page 11

Council—now chaired by CMS Administrator Mark McClellan—and has created workgroups to achieve specific progress in such areas as health information technology, performance measurement and pay-for-performance, technology and innovation, prevention, Medicaid and SCHIP, long-term care, cancer care, and methods for breakthrough improvement. These workgroups, with membership drawn from across CMS, report to the Quality Council which reviews, approves, tracks and supports their work in each component of the agency.

Payment Part of the Problem

McClellan identified part of the problem as stemming from CMS’ payment and coverage policies. He states that Medicaid benefits are also out of date. For example, the Medicaid statute entitles beneficiaries with a disability to care in a nursing home, not to modern long-term care services, which include much more than nursing home care, may actually be best for their needs and is often less expensive. More generally, Medicaid pays more when states spend more, not when Medicaid programs get better results for more people who need help.

CMS is working with states on Medicaid waiver and demonstration programs that provide better information and financial support for improvements in quality, beneficiary outcomes, and costs. One such example cited is with the states of California, Michigan, and New York. They have implemented Performance Based-Auto Assignment Programs that reward Medicaid health plans with superior performance. The programs create an incentive to improve Medicaid quality and preserve the safety net by increasing enrollee volume and payment to those plans that provide a consistent level of quality improvement.

ANCOR CELEBRATES MEDICAID TURNING 40! (Part 2)
Saluting the Difference That Medicaid Has Made in the Lives of People with Disabilities

It is an honor to participate in the 40th birthday celebration of Medicaid. Medicaid is an example of a compassionate, successful state/federal program. An example of the giving, caring attitude of the American citizenry. An example of an ever evolving program that looks to enhance the freedom of citizens with disabilities. Happy Birthday Medicaid! Than Johnson is CEO of CRSI in Urbana, Ohio, ANCOR’s immediate past president, and currently President of the Ohio Provider Resource Association.

You are truly amazing! Unfortunately, you have usually been taken for granted and now you are being unfairly criticized. The fact is, most of us would simply not be here, if it were not for you. It is hard to image how different our lives, and those we serve, would be without your existence these past 40 years. Since I know you well, a couple of words of ‘friendly’ advice to you on your birthday. You have just taken on more than you can handle and done the work others should be doing, Take some time and reflect on what is really important to you and focus your priorities. Finally, please understand that not all who ‘want to be your friend and help you, have your best interests in mind.’ Thank you and I am confident you will take the necessary steps that enable you to continue being a vital resource for our most vulnerable citizens. Ken Lovan, Vice President of Government Relations for ResCare, ANCOR’s Vice President for Government Relations, and a 20-year member of ANCOR.

On its 40th birthday, Medicaid continues to be the best program that ever happened for people with disabilities, providing them with essential supports that allow them to live in and be part of their communities. We are at a crossroads regarding our national priorities and whether or not we will maintain this important program that is the life-blood for the nearly 300 people our organization supports. There is not likely a person in this country that does not know someone who depends on Medicaid for his or her day-to-day supports. Medicaid works, and maintaining Medicaid is a moral issue! Rod Braun is Executive Director of Christian Opportunity Center in Pella, Iowa, a former ANCOR Board member, whose agency has been a member of ANCOR for 20 years.

Medicaid’s anniversary comes at an especially crucial time as Congress faces a requirement to make up to $10 billion in cuts to the program over the next five years. It seems to me that most of the news I tend to read about Medicaid is negative, when, in reality, Medicaid, more than any other government program, has improved the lives of millions of persons with severe mental retardation and other developmental disabilities. I believe it is vital for me, and other ANCOR members, to share ‘good news’ stories about Medicaid so that others can hear that Medicaid makes a tremendous difference in the lives of individuals with disabilities. Jim Richardson is President of Cedar Lake in Louisville, Kentucky, serves as ANCOR’s Medicaid Subcommittee Co-chair, and has been an ANCOR member since 1978.

For thirty years I have seen the journey of the Medicaid program for people with disabilities...through the times of NAPRFMR to ANCOR. The journey has resulted in new opportunities for people with disabilities. In the 70’s Medicaid staff came from Washington to Minnesota and we “walked the talk” about people living in 1-6 person homes in the community, being involved with their family, going to workshops and participating in life more fully than it was possible in an institution. Today we are working to continue that journey of inclusion. Bob Wardwell, former HCFA Medicaid Director, would come to ANCOR meetings and encourage us as providers to keep on the journey. He shared his passion for people with us and we knew that there was a chance that our ideas would be heard and change was possible. Life is better today for people with disabilities because Medicaid was a philosophy of supports and not a fixed method that had to be unchanged through the decades. Therefore people, one at a time, could participate more fully in life. May we never lose the ability to innovate so all Americans can participate in living the American dream. Wayne Larson is Executive Director of Mount Olivet Rolling Acres, Inc. in Victoria, Minnesota, a current member of the ANCOR Board of Directors, and a member of ANCOR for 30 years.

For those of us in the MR/DD community, who have been with Medicaid almost from it’s beginning, we recognize Medicaid as the cornerstone of the progress that we have made. Medicaid forced strict standards of care in the ICFs-MR in the 1970s which, in large measure, prompted the first wave of deinstitutionalization. The lack of funding to support individuals in the community then generated the support for the initial phase of Home and Community Based Waivers. Advocates, providers such as ANCOR members, and state officials have led and been led by Medicaid to change the landscape and possibilities for individuals with MR/DD. It has been a productive partnership for 40 years—we look forward to the next 40 years and the potential that we will realize. Jennifer Fidura, previously Deputy Commissioner of Virginia’s Department of MH/IMR/SAS, is currently President/CEO of Fidura and Associates, and serves on ANCOR’s Board of Representatives.

Thanks to Tammi and Scott for sharing their photo with us. Both live in the community due to Medicaid supports. Thanks and happy birthday Medicaid!

More Birthday Greetings and Well Wishes from ANCOR Providers
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ANCOR and UCP Form Strategic Partnership

Joining forces to raise public awareness and drive grassroots support for the ANCOR National Advocacy Campaign, ANCOR and United Cerebral Palsy (UCP) have entered into a partnership agreement to launch www.WhoWillCare.net, an internet-based campaign to build additional grassroots support for Direct Support Professionals and those that depend on them. WhoWillCare.net does not replace any of ANCOR’s existing initiatives, it complements them.

WhoWillCare.net provides a quick, easy avenue for supporters to get information and take action. In just its first two weeks, WhoWillCare.net has generated more than 20,000 letters to members of the U.S. House of Representatives asking them to co-sponsor H.R. 1264, The Direct Support Professional Fairness and Security Act of 2005.

This is a strong start, but we need your help to sustain the momentum. Because WhoWillCare.net is internet-driven, you can lend the campaign significant support in minutes.

Please consider doing the following activities:
• Send an email about WhoWillCare.net to your friends, family and neighbors;
• Add a story about WhoWillCare.net to your next newsletter;
• Tell your local media outlets about WhoWillCare.net and how the Direct Support Professional crisis is impacting your community;
• Tell the state-based associations and coalitions you are involved with about WhoWillCare.net; or
• Promote WhoWillCare.net with a story, link or banner ad on your Web site.

Please contact Catherine Dunkelberger if you would like materials or draft language for these activities at 703-535-7850, Ext. 110; cdunkelberger@ancor.org.
Thank You, Mr. Sproll!

More support for fairness, security and quality care

Denise Patton-Pace

The opportunity to spread the word about ANCOR’s National Advocacy Campaign often comes at unexpected times, this was one of them. “Hello, my name is Claus Sproll. I am the publisher of LILIPOH magazine.” Clearly, this was not your everyday phone call and this conversation certainly had an intriguing beginning.

In the course of our discussion, it was evident that Mr. Sproll’s awareness of ANCOR was quite personal. As the father of a special needs child, he is intensely interested in social ideals. He serves on myriad boards of directors that further an anthroposophical approach to life and education. He is also an administrator of the Camphill Special Schools which provide community-care for children “with the full spectrum of mental retardation, from borderline to severe and profound….Children categorized as learning disabled, brain injured, autistic, emotionally disturbed, neurologically impaired, and multiply handicapped…”

And the magazine? Publisher Sproll called to explore story ideas for LILIPOH, a witty use of the abbreviation for Life, Liberty and the Pursuit of Happiness. The magazine positions itself as “a unique quarterly wellness magazine dedicated to The Spirit in Life.” It is geared to a wide readership, and specializes in the “anthroposophical approach to life as it is brought forth through health, homeopathy and naturopathic medicine, Waldorf education, biodynamic agriculture, nutrition, the arts, community life and more!”

ANCOR was well-prepared for Mr. Sproll’s call. For the past year, ANCOR’s story collection has been growing. Easily accessible at www.supportnac.org, the stories posted online include the contact and agency information to expedite media inquiries. The NAC Web site also includes a comprehensive look at the status of the National Advocacy Campaign and issues an urgent plea to sign a petition to alert state governors of the need for direct support workforce wage reform.

LILIPOH carried the ANCOR National Advocacy Campaign message to its readers in its Summer 2005 issue. More outreach and more support for the ideals of fairness, security and quality care. Thank you, Mr. Sproll.


Denise Patton-Pace is a member of the ANCOR Public Relations Committee and can be reached at dpatton.pace@verizon.net or 703-845-1152.
A recent compilation of performance factors in Harvard Business Review included differing prescriptions for high performance derived from a who’s who of the business literature over the past ten years. Considered in total, they certainly offer a thought-provoking overview, which is shared herein.

- Having a bias for action
- Staying close to the customer
- Fostering autonomy and entrepreneurship
- Hands-on, values-driven management
- Sticking to the knitting
- Having simple form and lean staff
- Demanding leadership from managers at all levels
- Seeking consistent alignment
- Becoming clock builders, not time tellers

Emphasizing-
- Collective decision-making
- Communication of core purpose and values
- A guiding vision and stretch goals
- Development of new competencies
- Global benchmarks of excellence
- Employee empowerment

Consistently pursuing——
- Mission and values
- Process and metrics
- Entrepreneurial spirit
- Individual achievement
- Recognition and celebration

- Creating a collective state of mindfulness
- Creating new businesses
- Abandoning outdated structures and rules
- Adopting new decision-making processes, control systems and mental models.

The ANCOR Foundation has been accepted into the national Buyers Port program, which provides an opportunity for everyone to earn rewards for ANCOR while doing their everyday shopping. Buyers Port created an online marketplace consisting of more than 500 name brand merchants including Dell computers, Barnes & Noble, Lands End, Staples, JCPenney, The Gap and Home Depot, who along with hundreds of others have agreed to donate a portion of every dollar you spend for the benefit of worthy non-profits. This program creates the opportunity for the ANCOR Foundation to benefit from the ecommerce boom while you shop for the items you regularly buy. There is no additional cost to you to participate. The merchants are contributing a share of their profits on your purchases back to the ANCOR Foundation.

Whether you are buying office supplies for your regular operations from Staples or buying items for your latest home improvement project at Home Depot, your purchases can help the ANCOR Foundation meet its goals. Be sure to look for the Buyers Port demonstration at the ANCOR booth at the Alliance For Full Participation Summit exhibit program. You’ll be able to see Buyers Port in action right in the exhibit hall. Don’t miss the chance to see how the dollars you spend can deliver results for the ANCOR Foundation without costing you a penny!
ANCOR Marketing Partnership with Philadelphia Insurance

We continue to encourage ANCOR members to consider Philadelphia Insurance (PI) as they assess their general, property and casualty and professional liability insurance needs. As another revenue stream, funds from marketing partnerships like the one with PI help support ANCOR’s expanded programs and services and offset reliance on membership dues as a sole income source.

In a recent interview, PI Vice President Cole Henry stated that “We’re strictly a niche carrier. We don’t try to be all things to all people. …We want to be experts in our chosen fields,” highlighting expertise in the non-profit social services segment of the market.

Did You Know?
• That Philadelphia Insurance was ranked fifth nationally in profitability by the respected National Underwriter in profitability. This is an important and clear indicator of long-term strength and reliability as well as stable pricing.
• Philadelphia provides clients with access to a wealth of education programs and learning materials; resources and other supports through its loss control on-line web service at www.losscontrol.com.

ANCOR CEO Renee Pietrangelo receives first marketing partnership check from Philadelphia Insurance, delivered by marketing representative Richard LaClair.

ANCOR Tech Bits

Website – Heads Up!! ANCOR has moved its website to a new provider. As with all technology updates and moves there have been a few bumps and bruises along the way. If you experience any problems with the ANCOR website, be sure to send them in to tyu@ ancor.org so that we can be sure that they are taken care of!

Adobe Acrobat Reader – You will need Adobe Acrobat Reader if you want to view LINKS in its electronic format. It is free and available for immediate download at http://www.adobe.com/products/acrobat/readstep2.html.

Keyboard Shortcuts – Your computer mouse is a great tool for getting around your programs but it is not always the quickest or easiest way to get things done. Knowing a few simple keyboard shortcuts can save you time and frustration everyday. Through each of our “Tech Bits” columns we will give you one or two shortcuts you can use to make your work on the computer easier.

• Alt-Tab – When you are working in several different programs at the same time, you can quickly tab between them without lifting your hands off the keyboard. Simply hold down the “Alt” key and then hit the “Tab” key, it will bring you up a screen of all of the programs you have open. Tab to the one you want to switch to and voila, quick and easy switching between programs without loosing your momentum!

President continued from page 5

coherent vision to take to the public policy makers. This is but one issue on which we need a clear vision. There are many others.

The message from so many diverse quarters must be forwarded in an irresistible manner so the power brokers will most certainly see things our way. After years of making strides in public acceptance in housing and employment, it is time to solidify the gains and assure opportunities for others.

I submit that the Alliance has a much different vision than the Sturgis Rally, but they are similar in the passion displayed by participants. As for the Alliance, it is up to the collective body of people who care about service and opportunities for people with disabilities to rouse the passion of the general public, which, in turn with our assistance, will persuade the policy makers to do the right thing. It is first necessary to define a clear set of goals, which every one may agree upon and take forward.

There are many players with many agendas in the “big tent”. We must establish some common goals and go after them with vigor!! With time, perhaps, we may be as large as the Sturgis Motorcycle Rally. See you at the AFP Summit “Rally” in September!!!

Give it! Wear it! Live it!

Make A Difference Wristband
Show your support for the difference Direct Support Professionals play in the lives of individuals with disabilities. Contribute to receive your Make A Difference wristband.

Visit ANCOR’s National Advocacy Campaign website and get yours today!

ANCOR—A national network of providers offering quality supports to people with disabilities.—www.ancor.org
The case, originally titled Cleburne Living Center vs. the City of Cleburne, was filed in the District Court for the Northern District of Texas on November 26, 1980. It would take two years, several briefs, depositions, arguments and testimony before Judge Robert Porter of the Northern District of Texas ruled in favor of the City of Cleburne on October 4, 1982. Then CLC filed an appeal on behalf of the plaintiffs in the Fifth Circuit Court of Appeals in New Orleans, LA on October 22, 1982.

During the next year and a half legal briefs flew back and forth culminating in 1983 in oral arguments before a 3-judge panel. Finally on March 5, 1984 the decision came from the Court of Appeals. We won! And the win was not only on the zoning issue; it was on more technical and in some ways more important issues—those that dealt with constitutional protections and the granting of people with mental retardation with quasi-suspect class status or special status. The latter being a necessary finding to determine discrimination. Those were the issues that everyone was truly excited about—and CLC could proceed with plans to open the Cleburne home.

As was to be expected, the city filed their appeals, first petitioning the court to rehear the case, then petitioning for the full court—all 15 judges—to rehear it. With both of the City’s requests denied, CLC began putting finishing touches on the house and began notifying the people on its waiting list that their new home was near to opening.

On the planned opening day, August 27, 1984, as the first person was settling into his room and unpacking his clothes, CLC received a call from the Advocacy attorneys stating that CLC would not be able to open. The person who was moving would have to go back to the group home where he had been living. In their last attempt to stop CLC, the Court yielded to the City’s request to recall the mandate and stop the enforcement because the City was filing its case with the U.S. Supreme Court.

On to Washington

It’s said that first impressions are the strongest. If this is true then the first impression one has of the U.S. Supreme Court building and courtroom is one of simplicity and beauty. It stood in stark contrast to the courtroom of the Fifth Circuit Court of Appeals with its tall ceilings, heavy, dark paneling, and carving of rattlesnakes on the paneled, lighted pillars. The appellate court, with its air of solemnity and foreboding, was very different from the Supreme Court, which seemed small, intimate, light and hopeful. The white stone walls and crimson drapes were pleasing to the eye yet dignified and regal and it was with expectation and hope that the audience seemed to watch the justices part the drapes behind their dais and take their seats.

In preparing for its case, CLC gained additional support from organizations who were certified as amicus curiae (friends of the court). These organizations included the National Association of Private Residential Facilities for the Mentally Retarded (now ANCOR), National Association of Protection and Advocacy Systems, American Civil Liberties Union, the Association for Retarded Citizens (now The Arc), the American Association on Mental Deficiency (now AAMR), the American Psychiatric Association, the American Psychiatric Association, and the states of Connecticut, Arkansas, California, Colorado, Illinois, Louisiana, North Dakota, Rhode Island, Tennessee, West Virginia, Maryland, and Texas are just a few. In all, over 50 different groups supported the arguments made by CLC’s attorney and added arguments of their own.

With only eight justices seated instead of the usual nine members of the court, the case was heard by the U.S. Supreme Court on March 18, 1985. Then the waiting began again. However, something that has happened only about a dozen times in the history of the Court, happened in this case. CLC received a call on April 1st from the Court’s clerk. The attorneys had to argue the case again because the Court wanted the ninth justice—absent from the oral arguments because of surgery—to participate in the decision.

The case was reargued April 23, 1985 with the highest court in the land rendering its decision 10 weeks later on July 1, 1985.

See Celebration, page 20
It was finally over! After five years, CLC had finally won the right to open the home on Featherston Street in Cleburne, Texas.

Epilogue and Lasting Change

Not everything about the case was successful. The Supreme Court overturned the lower court ruling that people with mental retardation constituted a quasi-suspect class. If this designation had been upheld, it would have made it easier for individuals with this disability to prove discrimination. However, the case was a landmark case and the written opinion affirmed what the attorneys had argued in the briefs. And just as important, it served as the catalyst for many cities changing their zoning ordinances, for several states changing their laws of how cities could zone for group living and things that could not appear in deed restriction, and finally in 1988 in the amendments to the Fair Housing Act giving persons with disabilities rights to housing.

Both policy about and the way services are delivered have changed since then. Group home living is now only one of the many services available to people with disabilities and one that is used less and less often as a wide array of other service options and supports are available to more and more people. As a nation we have passed laws such as the 1988 amendment to the Fair Housing Act, the Americans with Disabilities Act, IDEA and others that offer protections and allow people to take advantage of opportunities like all other Americans.

We as advocates and providers can only hope that other cases such as the “Cleburne case” will never have to happen again. Court battles do not represent the best in our society. They represent conflict not cooperation, take too long to come to resolution, are too costly (indeed the City counted on CLC’s not surviving either the time it would take for the case to be resolved or the cost of the battle), and the results are often limited in scope. The best possible future for people with disabilities is in the cooperation between lawmakers, advocates, providers, and the people who need services to assure the development of services and supports that utilizes the strengths and abilities of us all.

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AUTHOR LINK
three-judge circuit panel cited a 2002 U.S. Supreme Court decision that said a federal statute may be enforced against a state by a private entity only if the right to do so has been “unambiguously” written into the statute by Congress.

The decision also reversed a ruling by another federal judge that kept the state from cutting by 5 percent its reimbursements to physicians and other providers of health care. Hearing both cases that reached split decisions at the lower court level, the appellate court ruled in both cases

heard in December 2004, that the text and structure of the Medicaid statute simply do not focus on an individual recipient’s or provider’s right to benefits, nor is the broad and diffuse language of the statute amendable to judicial remedy. We conclude, therefore, that Congress has not spoken with an unambiguous, clear voice that would put a state on notice that Medicaid recipients or providers are able to compel state action.

Situation Worsens

This stinging decision is part of a multi-year struggle that ANCOR member Ron Cohen, CEO of UCP of Los Angeles, Ventura, and Santa Barbara Counties, and five other providers undertook with seven individuals and their families to force California to improve community supports on behalf of people with developmental disabilities. The Sanchez v. Johnson lawsuit, filed in District Court in May of 2000, challenged the State of California’s failure to increase wages of direct support professions for people with disabilities residing in the community. According to plaintiffs, California has made only one inadequate increase in 15 years. Workers in community facilities are paid 54 percent of what similar workers in California’s institutions are paid. Only one state, Mississippi, spent less per person than California for Medicaid’s home and community based services.

Five years ago the Bureau of State Audits warned that the quality of community services was threatened by high turnover and low wages. Providers point to a turnover rate in excess of 50 percent, when the average turnover rate in other industries is under 15%.

Specifically, the lawsuit alleged that California has established and maintained highly differential payment and wage and benefit structures between institutional and community based components of California’s developmental disabilities services programs, which has the effect of subjecting them to unnecessary institutionalization and segregation. In fact, the lawsuit demonstrates the ineffective use of resources in the state: the average per person Medicaid home and community-based services expenditures in California in FY 2004 was $19,229 while the national average was $37,486.

See Sanchez Case, page 22
Sanchez Case  
continued from page 21

The three-judge panel decision in Sanchez asserts that the Medicaid statute’s (Title XIX of the Social Security Act) requirement—that payments by states ensure quality of care in the community—is not enforceable. The decision, if it stands, would be a severe defeat for accountability in federal programs, according to one of the attorneys for the plaintiffs. No other Court of Appeals in the country has held that this provision of the Medicaid Act is not enforceable by intended recipients of services. Indeed, the Ninth Circuit court identified four other Courts of Appeals which had previously upheld the enforceability of this provision.

2002 Supreme Court Sea Change Ruling Leaves Entitlements Hanging By Thread

While the decision may seem to be a technical one, it is critically important. The court’s decision will make it impossible for millions of people who rely on Medicaid to enforce provisions about quality or availability of health and long term services.

In 2002 the U.S. Supreme Court ruled in Gonzaga University v. Doe that a federal law cannot be enforced through a private lawsuit unless Congress speaks with a clear voice and manifests an unambiguous intent to confer individual rights. Previously, federal judges ruled that Medicaid recipients and health care providers could sue to enforce many provisions of the Medicaid law. Those rulings were based on a 19th century civil rights law known as Section 1983 that allowed individuals to sue state officials who violate rights secured by federal law or the U.S. Constitution. However, since the 2002 decision in which the Supreme Court created a more stringent federal right to sue, some lower court decisions have become reluctant to find individually enforceable rights where Congress did not explicitly state such rights.

According to Sara Rosenbaum, professor of health law and policy at George Washington University: ‘The idea of Medicaid as an enforceable entitlement is hanging by a thread. Some of Medicaid’s most important provisions cannot be enforced. Increasingly the courts are saying, “Don’t come to us any more unless you can show that you have an absolutely crystal-clear right.”’

ANCOR applauds Ron Cohen and other California providers who lead the way in advancing the lives of people with disabilities, who continue the struggle on their behalf, and whose passion has not waned in their mission to ensure the rights of people with disabilities. Thank you for your sacrifices over the past five years, Ron, and all at UCP of Los Angeles, Ventura, and Santa Barbara Counties, California Coalition of UCP Associations, Easter Seals of California, California Rehabilitation Association, Systems Reform, Inc., Tierra Del Sol, and United Autism Alliance.
ance; and systems and infrastructure needs and funding.

Pat Wear II, commissioner of the Kentucky Department for Mental Health and Mental Retardation Services and a nationally recognized advocate for people with disabilities, said he was honored to have had the opportunity to participate in the summit dialogue as an invited speaker. He stated that “This summit will allow national leaders the opportunity to discuss and develop ideas and creative solutions as we work toward excellence in the services we provide. It is my hope that those ideas and solutions will ultimately lead to the development of significant public policy at both the federal and state level that will greatly improve the lives of people with disabilities.”

The following “sound bites” offer a sense of the content and tenor of the CEO summit.
• Agility/flexibility key success factor for service providers.
• The fuel of inevitability is intent; so how can providers shape the future?
• Marketing and communications will grow in importance for providers locally and on the state and national levels. We must keep the message simple and put a face on it—make it personal.
• Providers must become “obsessed” with customer needs and satisfaction.
• Critical importance to providers of public relations, marketing and messaging strategies and expertise. Need to design and continually revise messages to be simple and fit with values and issues priorities of various publics, e.g., voting public.
• Service providers must move toward empowerment of front-line staff and to flatten organization structures.
• Providers must advance the most cost effective ways of supporting people with disabilities.
  1. Capitalization of economies of scale; administrative roll-ups; regional training provided by single provider.
  2. Learn once, pay once
• Consumers and family members will work with more than one provider.
• Emerging customers are more educated on options and will demand to control dollars.
• Emerging markets for providers: autism, forensic populations, highly institutionalized states moving to community-based services.
• Nonprofit service providers must prepare for increased scrutiny/audits by states attorney generals and the IRS.
• We must move beyond DD on national, state and local levels to create coalitions, collaborations and partnerships with stakeholders that share common values system.
• Resource distribution is inequitable, i.e., most of the money available is spent on 20% of people with disabilities with greatest needs. Future will bring triaging of services and using available dollars to serve as many people as possible.
• There will be heightened tensions between states and feds.
• Increasing focus on family care model.
• CMS to focus on leading practices and quality management.
• Systems change prompted by CMS:
  1. Maximize independence, choice and flexibility.
  2. One system to serve all ages and disabilities
  3. Single point of entry for long-term supports; one-stop options

Critical trends/factors for service providers:
• Family and consumer satisfaction/personal outcomes
• Decentralization
• Downsized government
• Do it for less money
• Consumer employment
• Workforce

See CEO, page 24

ANCOR Calendar

2005

Sept. 22-23 Disability Summit
Alliance for Full Participation
Washington, D.C.
(Takes the place of ANCOR’s 2005 Governmental Activities Seminar)


2006

March 19-21 ANCOR’s 2006 Management Practices Conference
New Orleans, LA

Mark Your Calendar

2005
Management Practices Conference
and Trade Show

Achieving High Performance through People Centric Cultures

March 19-21, 2005
New Orleans, LA
4. Consumer-directed system
   • Systems change prompted by states
   1. Development of fiscal intermediary systems
   2. Shifts to in-home supports, supported and companion living, supported employment, choice and personal budgets.
   3. Self-employment and small business ownership are solidly on the radar screen in most states and in the federal Department of Rehab and ADD.
   • International perspectives and partnerships will grow.
   • In addition to protecting Medicaid, need funds for infrastructure development to support systems change at all levels.

The ANCOR Board retreat piggy-backed on much of the discussion from the summit to dialogue on how best to translate trends and discussion into tangible strategic outcomes. Specifically the Board focused on the following:

1. Determine how best to initiate, implement and coordinate ANCOR activity with regard to consumer choice/self-determination; changes in service delivery models; overall systems change and funding supports.
2. Determine strategies to position the provider community and communicate with varied stakeholder groups. Establish partnerships that effectively support a transitioning field.
3. Effectively identify and showcase promising practices for enhanced performance excellence.
4. Effectively support provider members in transitioning to new service delivery models and funding supports.
5. Advance public policy to support items two and three above.
6. Determine business and other partnership opportunities to enhance membership value-added and provide additional support funding to achieve established outcomes.

No strategists worth their salt will stop at understanding how the world is revolving around them. The important follow-up questions and the ones we focused on at both the summit and the retreat were:

• How much influence do we have over the outcome?

These questions can only be answered by engaging in constant dialogue with key stakeholders, including policymakers and others who influence the marketplace.
ANCOR must continually work at springing us from entrenched mental models and move us toward innovative, strategic creativity, i.e., to think in terms of solution to the challenges we face. This is the best way to shape the terms of the debate and get people thinking about a different framework, new lenses and fresh vocabulary. We definitely made progress toward that end at the conclusion of the CEO summit and Board retreat.
As the operator of a group home that offers mentally challenged adults the opportunity to live within the mainstream community, you have the best interests of people like Alice at heart. But you can look after your own best interests at the same time, with a Community Living Loan through Irwin Mortgage.

A Community Living Loan allows qualified buyers to more easily purchase group housing. It features:

- Fixed interest rates lower than you’d pay for mortgages at a bank
- Higher loan-to-value ratios (up to 90%) that minimize down payment on purchase or re-finance
- Pre-qualification valid for one year

Irwin Mortgage is one of only about 10 lenders nationwide to provide Fannie Mae Community Living Loans. So call us to learn how this program can help you to better look out for Alice’s interests – and your own.

For information, contact:

Sally Vail, Director of Community Living
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State Representative Profile

State Representative Mercedes Witowsky – New Jersey

It didn’t take long to realize that working in the social service field was the right match for me. I had shifted the focus of my desire to help people from working as a Certified Teacher of Special Education to providing supportive services for adults with disabilities living in apartments in the community.

The field was in the midst of tremendous change when I began 23 years ago, and I never realized what a wonderful opportunity I faced when I became part of this social service movement.

Once I graduated, I accepted a full-time position at Community Access Unlimited, Inc. (CAU) in a supervised apartment program as the assistant manager. It wasn’t long before I was offered a position at the main office where I was given the opportunity to develop supports for people with disabilities one person at a time. Person Centered Planning was not a buzzword in the early 1980s, but it was what I learned to do. It was also what came naturally. It just worked so much better for people when they could tell you what they needed and wanted in order to become more independent. Looking back over the years, hundreds of individuals with disabilities and their families have been able to build their own support services. Even now as the associate executive director of a $16 million dollar organization, I still get to see every day how people’s lives have developed and how the people we support are living real lives as part of their community.

As an administrator, I often look for resources to assist me in managing a multifaceted social service agency. Finding ANCOR was by far the best find yet. I never imagined there would be a one-stop resource for navigating the complicated maze that is this field. When CAU first joined ANCOR, the benefits were immediate. The ANCOR website offers such a broad range of resources and an unlimited wealth of information. The ANCOR staff are knowledgeable, dedicated, welcoming, and committed to helping in any way they can, and the members of the ANCOR network are eager to share their experiences. This combination makes for a truly great organization, one to which I am proud to say I belong.
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ANCOR—A national network of providers offering quality supports to people with disabilities.—www.ancor.org
**ANCOR Mission:**
To empower providers and people with disabilities to celebrate diversity and effect change that ensures full participation.

**ANCOR Vision:**
To be the premier provider association creating a world that values the full participation of all stakeholders.