MEDICAID: NCSL Medicaid Reform Proposal

The National Conference of State Legislatures (NCSL) adopted its Medicaid Reform proposal on December 11th, 2003, during its winter meeting, making suggestions to improve the state-federal partnership underpinning state Medicaid programs. The central feature of this NCSL Medicaid Reform proposal is to increase the flexibility that the states have for innovation with the Medicaid program. According to the proposal, additional state flexibility would:

- Facilitate more state experiments in meeting the needs of uninsured and under insured people;
- Allow states to cut costs with minimal loss of services; and
- Reduce long-term care costs.

Shifting items for which the states must now seek waivers to options the states may choose as part of their state Medicaid plans would give the states the right to implement these choices rather than asking permission from the Centers for Medicare and Medicaid Services (CMS). The NCSL proposal urges that the joint federal/state program with state financial participation in and management of individual programs be maintained and reinforced. The states would like to experiment with specific reforms individually so that if an experiment fails—as some will—it would be a local problem locally fixed and not a national disaster.

In addition to increased flexibility, the NCSL proposes including an explicit counter-cyclical element in the funding formula so the states are not forced to make cuts in the program during hard times when it is needed most. This would increase the federal financial participation (FMAP) in bad times and return it to normal in good times.

Although NCSL does not expect to be able to stop increases in Medicaid costs due to rising health care costs and the aging of the population, the states expect to pay their share and to get more for their dollar. However, the NCSL also believes the structural cost increases due to rising health care costs and the nation’s aging population should continue to be shared between the states and the federal government as it always has been.

According to the NCSL proposal, a key to the success of the Medicaid program is the continuing sharing of the financial burden between states and the federal government. Although the shares will vary, NCSL believes each party should continue to bear its percentage share of any program increases. NCSL believes this to be especially important in giving each party the proper incentives to deal with the cost increases that the aging population and increasing health care costs will bring.

To this end, NCSL proposes:

- Congress should forbid the new practice of requiring the federal share for large segments on the Medicaid program be capped as a condition of receiving a waiver—a practice which defeats traditional cost sharing and discourages state flexibility and innovation. Any capping associated with waivers should be limited to the specific expenditures under the waiver and should extend to both federal and state shares.
- The federal government should eliminate the current capping of the Medicaid program in Puerto Rico and the territories and develop a distribution mechanism that more adequately reflects the need and is more comparable to what the states receive.

The need for the Medicaid program is growing both because of the economic downturn and because rising health care costs are forcing many employers to drop health coverage or greatly increase the employee’s share of its costs. At the same time, the Medicaid program is a major contributor to state budget deficits.

NCSL Executive Summary, Medicaid Reform Proposal

NCSL applauds the wisdom of Congress in providing fiscal relief for the state Medicaid programs in the recently passed tax cut legislation. NCSL proposes we learn from this experience and make such relief a permanent feature of the Medicaid program in hard economic times…

See MEDICAID, page 15
Contents

Public Policy Update
MEDICAID: NCSL Medicaid Reform Proposal..................1
President Names New HUD Secretary..........................6
SSA Proposes Simplifying SSI Income and Resource Eligibility Rules
Public Comments Due by March 8..........................7
AAMR Releases New Assessment Tool......................9
CEO Perspective
Open Dialogue Is Vital As We Move Toward New Ways of Thinking and Doing..................3
President’s Corner
Look for More in 2004..........................4
Contributing Editor
The Sense and Nonsense about Choice..................10

Leading Practices—Management Practices
Open Books, Open Minds........................................11

ANCOR Member Highlight
ResCare of WV Thanks Rep. Capito for DSP Resolution.........................13

State Representative Profile..........................14

ANCOR Foundation Update..........................20

ANCOR Monthly Updates
ANCOR Honor Roll.................................................9

ANCOR Welcomes New Members........................10

ANCOR National Advocacy Campaign Contributors..........................16

ANCOR Calendar...........................................20

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2 Links/February 2004

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Open Dialogue Is Vital As We Move Toward New Ways of Thinking and Doing

Renee Piatrangelo

I love to get feedback. Regardless of its tenor, feedback implies that I’ve struck a nerve and opened a venue for dialogue. Since I believe unequivocally that dialogue is the key to progress, I’m always happy to hear from providers—who too often are diffused and distracted by crises at home—who express strong viewpoints regarding certain issues. I was pleased to get the following response to my January Bridges communication to ANCOR members:

“Well put! You stated: ‘Every crisis is an opportunity, however, and the current storm may encourage, even force, legislators to consider creative solutions and structural reforms, and we as providers must be poised to seize those opportunities as they arise.’

Your assessment is right on. There is truly rising and falling in America’s priorities. Right now, we are not a strong priority, and you could argue that the war is unneeded, that national security spending is too high, that the president has a poor worldview, and that our economy needs to spend tax cuts on our programs.

This however is not the place in which we find ourselves...about two-thirds of the country views social spending as excessive. With fewer being born...and a growing aging population, we are moving toward a nation with a workforce population that cannot support our seniors and other needy groups.

Being that is where we find ourselves, what are our choices? That is the key question. We will soon, I believe, find ourselves in a situation where public support for our valuable programs will continue to diminish as boomers retire and want the benefits for themselves, and the younger workers do not want to support any of it as their tax burden will escalate.

Our choices, however, are not limited. Our options are not few. But we need to change; we need a pyridine shift. We need to not simply desire to provide our services at an ever-increasing rate. ...The ‘goal’ of the human services system is...to see the people we serve well supported and growing and retaining dignity. Folks, ‘this’ is doable! It will require innovative delivery options and may have to be done with truncated funding, but it can be done.

1. We need to advocate for an elementary school agenda that teaches children all through their 13 years of education the value of caring for others; to view people with disabilities as okay; to nurture a spirit of volunteerism. Mandatory weekly time helping with the elderly, the disabled, hospitals, clinics, grandma, the neighbor lady...are all options. We need to system that rewards and values people who help people as much as those who hit homeruns and score touchdowns. Education can shape a generation.

2. We need to make it possible for the working American to save more. We need to reduce taxation for people who are willing to save for retirement. We need to have a better tax incentive for those who give to charitable organizations by removing the standard deduction for charitable contributions and allowing people to document their giving to get a larger tax break and also allow for hours volunteered to qualify as a tax deduction. We need to get governmental requirements for volunteerism eased and funding allocated to train volunteers.

3. Another key to increasing the funds Americans have to use for family and/or give to worthy causes is to get us out of debt. Ironically, I believe that driving up the cost of borrowing by raising the interest rate on all non-secured (credit card) borrowing by an additional 5% would discourage people from using cheap credit.

4. We need the government to give families huge incentives to care for their own “in need” family members, and even non-family members. This is an age-old world-value that we narcissistic Americans have gotten away from—caring for your own. Instead we institutionalize.

5. The poor or under-educated would benefit greatly if communities required employers—especially small businesses—to mentor the unskilled, using a graded wage scale (as apprenticeships and guilds used to do). Business people could band together to establish such a system and share the burden. The organization that employees me is currently running an ad campaign that says, ‘Give a person a fish, he eats for a day, teach them to fish and they eat for a lifetime.’ Well said! Philanthropists, employers and families that learn to see those in need as future fishermen instead of burdens will get excited about teaching them rather than resenting them.

There are endless possibilities to meet our ultimate goal—supporting and helping grow ‘at need’ people. Much of it can be done without ‘us’ being the main provider of services. Our type of programs will always be needed. There are poor and dysfunctional families who cannot care for their own as well as people without able-bodied family support.

Both my wife and I derive our living working for human service organizations. ...A nation where we value those at risk—the needy, the elderly, the disabled—and demonstrate that value through our actions, our educational system, and our government showing its commitment...would be the best outcome. We can take the ‘perfect storm’ and navigate to a land where we can make it organically better than where we were before.”

On another issue, I received the following communication recently from former ANCOR Board member Amy Gerowitz:

“Renee, as you know, in Ohio we received funding for the PATHS work-force project. We are running into some resistance from providers regarding their becoming apprenticeship sites. We are trying to determine if other states are having difficulty as well. We’re especially concerned that people either think that it is a prelude to unionization, or those with unions think it’s impossible to enter into...”

See CEO PERSPECTIVE, page 14
Once again, I feel it appropriate to highlight the accomplishments of ANCOR (see sidebar). Those accomplishments are very important as they have formed the foundation for an eventful 2004 and beyond.

An exciting event now in the planning stages is a 2005 summit meeting sponsored by the Alliance for Full Participation, of which ANCOR is a member. The summit is intended to set the public policy agenda for people with developmental disabilities and DD support services and to proactively address public perception of people with disabilities. The Alliance for Full Participation (AFP) has been meeting for some time. I had the privilege of meeting with the executives and Board members during the September Governmental Affairs Seminar (GAS) held in DC. I was impressed not only with the leadership present in the room, but also with the diversity and perhaps cross-purposes (at times) of some of the organizations represented.

At the time, I wondered who was going to lead this group. I should not have been concerned as our own ANCOR CEO, Renée Pietrangelo, was elected as the initial chair! Congratulations and best wishes to her as we progress in ‘04 and beyond.

I believe Renée's selection was at least partially the result of her leadership abilities. For, to take on this unique opportunity - certainly the first ever and one fraught with risk - takes a great deal of courage, the primary characteristic of a great leader. ANCOR is fortunate to have such a leader who has been able to inspire and motivate people to achieve their greatest potentials through various means – be it passion, mission, or vision. I, for one, am proud to be on the illustrious ANCOR team. I hope that you are as well!

To that end, the leadership of ANCOR is convening a facilitated retreat session in January to assess and shape future direction for ANCOR. Once again, superb leadership that inspires and motivates people to do their individual best for the cumulative good is what will continue to propel this organization to success. ANCOR will continue to provide relevant leadership in the field. Just watch us . . . or better yet, why not get on board . . . and help make things happen in 2004!!!

Fred Romkema, President

2003 Highlights of ANCOR Accomplishments:

- ANCOR played an important role in the passage of FMAP legislation. In total, $20 billion in state fiscal relief was directed to the states in the form of a temporary increase in the federal medical assistance percentage (FMAP) and state and local general revenue sharing.
- ANCOR's National Advocacy Campaign achieved passage in both houses of Congress of the Direct Support Professional Recognition Act. In the House, this victory was a resounding vote tally of 382-0. ANCOR also secured budget appropriations language in both the House and Senate budget versions directly referencing fiscal support to address the direct support workforce crisis. And, the Department of Labor proposed directly to ANCOR specific initiatives DOL will undertake in support of workforce development and training.
- ANCOR convened a Medicaid Reform summit in June, once again laying the foundation for future events. Those who participated received support and resource materials critical to provider understanding of how Medicaid works and heightened concern over proposed changes. To that end, ANCOR has developed a set of principles for Medicaid reform.
- ANCOR doubled its program of audio conferences to address key subject areas and to reach more agencies and their individual staff members.
- ANCOR's customized HIPAA Compliance Manual was used by nearly half of ANCOR's membership, providing real-time answers to specific compliance queries. This included ongoing technical assistance to members who purchased the manual.
- ANCOR participated as a founding member of the Alliance for Full Participation (AFP), a coalition of ten national disability organizations that plan to host a national summit in 2005 to formulate policy and other outcomes for the future. ANCOR hosted the AFP's retreat sessions in September, which included leadership representatives from each organization.
- ANCOR enhanced its Web site and interactive capability to LINKS content and to the content of our conferences. This year's Governmental Affairs Seminar, for example, exceeded all previous attendance totals with over 225 participants and excellent feedback on content and opportunity for interactive dialogue.
ANCOR’s Kickin’ It Up in New Orleans!

2004 Management Practices Conference

“Renewing and Regenerating for Tomorrow”

March 14-16, 2004
(Committee/Board of Directors Meetings March 13th)

A Brief Sampling of Topics Includes:

• National Advocacy Campaign: Moving Beyond Congressional Recognition
• Direct Support Professionals: What’s Happening Across the Nation
• Development for Your Agency: No Money-No Mission
• Leadership—Sayings of the Chairman—Guiding Your Organization Into the Future
• Using Open Book Management for Business Development and Quality Improvement
• Implementing Self-Directed Services: What You Need to Know
• W198 and Active Treatment—Are You Meeting the Needs of the Person Served?
• Best Practices Standards/Measurements
• Innovative Technology for Today’s Provider
• Workforce: Training, Recruitment and Retention

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

Sheraton Hotel (Canal Street)
For Hotel Reservations call 888-627-7033 and ask for the ANCOR Room Block—$157 single/double.

Visit www.ancor.org for further details or contact jmccandless@ ancor.org.
Braddock 2004 Report on State of States in Developmental Disabilities

This new December 2003 monograph presents the results of the 2004 State of The States in Developmental Disabilities study of financing and programming trends in the United States and extends the longitudinal analysis of financial and programmatic trends in the states through fiscal 2002. The monograph is divided into two parts: Part One describes the structure and financing of MR/DD services in the states and nationally and Part Two presents individual state profiles. The monograph is a supplement to the AAMR publication entitled Disability at the Dawn of the 21st Century and the State of the States published in October, 2002.

The monograph is authored by David Braddock, Mary C. Rizzolo, Richard Hemp, and Amy Pomeranz-Essley and is funded in part by the Administration on Developmental Disabilities, with financial assistance provided by the Department of Psychiatry of the University of Colorado School of Medicine and by the Coleman Institute.

During 2000-2002, the number of individuals served in all types of out-of-home residential settings in the U.S. advanced 7%—from 429,093 to 460,455. The number of people living in settings for 6 or fewer people grew by 15% and settings for 7 to 15 persons increased by 2%. In contrast, residents in the nation’s public and private institutional facilities for 16 or more persons declined by 6%.

The rapid growth from 1960 to 2002 in the number of individuals served in community residential settings in the U.S. for 6 or fewer persons is especially noteworthy. The total number of individuals served in group homes, supervised apartments, and supported living settings that serve 6 or fewer individuals grew from an estimated 3,727 in 1960 to 298,375 persons in 2002.

Costs By Setting

The nationwide cost per resident for reporting states ranged from $19,211 in supported living to $134,619 in state institutions.

ICFs/MR: The average annual cost of services in state-operated 16+ institutions ranged from less than $100,000 in Arkansas, Georgia, Mississippi, Nebraska, South Dakota, and Texas to more than $200,000 in Connecticut, Idaho, Minnesota, New York, Oregon, and Tennessee. The average annual cost per resident in the 35 states funding private ICFs/MR for 15 or fewer persons was $67,348, ranging from below $40,000 in Alabama, Colorado, and Oklahoma to more than $100,000 in Connecticut, Iowa, Kansas, Maine, New York, Tennessee, Vermont, and Virginia. The average annual cost of care in private institutions serving 16 or more persons was $52,585 in California, Connecticut, and Washington to more than $150,000 in Arizona, Delaware, Oregon, and Rhode Island.

In 2002, eight states (Alaska, Maryland, Massachusetts, Michigan, Montana, Oregon, South Dakota and Wyoming) funded no private ICFs/MR of any size nor public ICFs/MR for 15 or fewer persons. Georgia, Maryland, New Jersey, and Wyoming had never funded public or private ICFs/MR for 15 or fewer persons.

HCBS Services:

In 2002, 367,456 participants were supported by the HCBS waiver. The HCBS waiver has been an essential part of community services expansion—including development of supported living and personal assistance, family support, and supported employment. In 2002, the average state institutional ICF/MR cost $134,619 per resident—contrasted with an annual HCBS cost per participant of $35,215.

In the 21 states in which federal-state-funded HCBS cost per participant is $35,215.

President Names New HUD Secretary

On December 12, 2003, President George W. Bush announced he will nominate Alphonso Jackson, to become the 13th Secretary of the Department of Housing and Urban Development. Jackson was nominated by President Bush on March 3, 2001, to become HUD’s Deputy Secretary and was unanimously confirmed by the Senate on June 3, 2001. Acting Secretary Jackson was most recently the President of American Electric Power-Texas, a $13 billion utility company, located in Austin, Texas.

As the Chief Operating Officer and Deputy Secretary of HUD, Jackson managed the day-to-day operations of the $32 billion agency with a core mission of providing affordable housing and promoting community and economic development. He has almost 20 years of experience running public housing authorities in St. Louis, Washington, D.C., and Dallas.

If confirmed, Jackson will replace Secretary Mel Martinez who resigned his post to seek the seat of retiring Senator Bob Graham (D-FL).
SSA Proposes Simplifying SSI Income and Resource Eligibility Rules
Public Comments Due By March 8th

The Social Security Administration (SSA) January 6th announced proposed revisions for determining income and resources under the Supplemental Security Income program (SSI). The proposed changes are designed to streamline the SSI eligibility determination process and make SSA’s financial eligibility more consistent with those of other Federal programs.

SSA is seeking public comment by March 8th on three proposed changes:
- Eliminating clothing from the definition of income and in-kind support;
- Excluding goods and personal effects from countable resources; and
- Excluding one automobile used for transportation from countable resources.

Clothing, Household Goods Would Not Be Counted When Determining SSI Eligibility

The Social Security Act—the law governing the SSI program—provides for SSI cash payments only to people who have income and resources below a specified amount. Current SSI rules state that income may include anything received in cash or in-kind to meet an individual’s need for food, clothing, and shelter.

SSA’s proposal would eliminate clothing from the definition of income, and from the definition of in-kind support and maintenance. As a result of the change, gifts of clothing would be disregarded when applying the rules for valuing in-kind support and maintenance when determining SSI eligibility. The only exception to this change would be when an individual receives clothing from an employer, which must still count as wages and be reported as in-kind earned income.

SSA is also proposing to exclude household goods and personal effects as countable resources. Currently, SSA totally excludes an engagement ring, a wedding ring, and household goods and personal effect items required because of person’s physical condition from the definition of countable resources. SSA also excludes household goods and personal items to the extent that their total value does not exceed a reasonable amount, which is $2,000; the amount in excess of $2,000 would be disregarded when determining SSI eligibility.

See SSA, page 8

The Samantha Blanchard Music CD and bonus Music Video has arrived! This CD contains "Music of Our Lives," the ANCOR National Advocacy Campaign theme song. Show your family, friends, employees and consumers that you are part of a campaign that is making a difference.

Celebrate the music of our lives and contribute to the ANCOR National Advocacy Campaign. Many of you have had the opportunity to view the video in September at our Governmental Activities Seminar in Washington, DC. We have had many requests to purchase the video so here is your opportunity! (The Music CD can be played in any music CD player. To access the music video, insert the cd into your computer cdrom drive.)

Download an order form at: http://www.ancor.org/eimages/samanthaorder.doc
Braddock Report
continued from page 6

HCBS waiver spending constituted 50% or more of total MR/DD long-term care spending, waiver cost per participant did not exceed $70,000. In most states, the HCBS waiver costs ranged from $21,000 to $40,000 per participant.

Maine, Minnesota, Rhode Island, and Vermont had the largest HCBS waiver programs in 2002 on the basis of federal spending per person of the state general population—ranging from $72 to $79 per capita. In terms of the absolute number of participants served, large HCBS waiver programs in 2002 were in the populous states of California, Florida, New York and Pennsylvania.

All states but Kansas provided supported living or personal assistance in 2002. Spending per participant in supported living and personal assistance ranged from below $2,000 in Mississippi and West Virginia to over $50,000 in Maine, New Mexico, Ohio, Oklahoma, Rhode Island, and Tennessee. The combined annual costs for supported living and personal assistance.

Dr. Braddock will be providing information on these trends as well as the advances in technology at ANCOR’s March 2004 Management Practices Conference in New Orleans.

To download a copy of The State of the States in Developmental Disabilities (2004), go online to www.cusys.edu/ColemanInstitute/stateofthestates/.

SSA
continued from page 7

counts against SSI’s resource limits, which are $2,000/individual and $3,000/couple. SSA’s proposal would eliminate the total dollar value limit and exclude all household goods that are items of personal property, used on a regular basis, or items needed for maintenance, use, and occupancy of the home from countable resources. Such items may include furniture, appliances, personal computers, televisions, dishes, and cooking and eating utensils. Personal effects that are personal property that are ordinarily worn or carried by the individual or have an intimate relation to the individual would also be excluded. Examples include personal care items, educational or recreational resources such as books or musical instruments, and items of cultural or religious significance.

However, items that are acquired or are held for their value or as an investment—for example, investment property other than the individual’s home, gems, and collectibles—would continue to be considered countable resources and be subject to the applicable SSI resource limitations.

Exclusion of One Automobile for Transportation from Countable Resources

Current SSI program rules permit an automobile to be excluded from resources if it meets one of four criteria, such as a necessity for employment or because it is necessary for the medical treatment of a medical problem. If the automobile cannot be excluded because of its use, it is excluded as long as its current value does not exceed $4,500. The value above the $4,500 limit is counted against the SSI resource limit.

SSA research has concluded that vast majority of automobiles owned by SSI recipients are excluded from countable resources based on one of the four criteria. Therefore, SSA is proposing to totally exclude from resources one automobile—regardless of its value—if it is used to

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**Independent Skills Assessments**

**Independent Skills Assessment Scale 2004**

<table>
<thead>
<tr>
<th>Scale Category</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping</td>
<td>10 for $20.00</td>
</tr>
<tr>
<td>Personal Medications</td>
<td>25 for $40.00</td>
</tr>
<tr>
<td>Money Management</td>
<td>50 for $75.00</td>
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</tbody>
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**Clinical Nursing Care Needs**

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

**Personal Strengths and Needs**

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

**Nutritional Needs**

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

**Sexuality Assessment**

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

**Sexuality Assessment/Curriculum Guide:**

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

**Sexuality Assessment Worksheet:**

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

**Sexuality Kit:**

- Includes 20 Sexuality Assessment Worksheets.
- Sexuality Assessment/Curriculum Guide, 18 line drawings, anatomically correct male and female dolls, sanitary pads, condoms, an artificial penis and a soft carry bag.
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transport an individual or a member of his/her household. If it is not used for transportation or if additional automobiles are owned, the current rules would still apply.

Comments Due to SSA by March 8th

ANCOR members who would like to offer their comments on these proposed changes must provide SSA their comments by March 8th. Comments will be received via Internet at http://policy.ssa.gov/npnpublic.nsf or via letter addressed to Commissioner of Social Security, PO Box 17703, Baltimore, MD, 21235-7703.

A copy of SSA’s proposed changes are available from the January 6th Federal Register at SSA web site at http://policy.ssa.gov/npnpublic.nsf/LawsRegs. (Follow instructions at the ‘Open Proposed Rulemaking’ link.) Public comments will also be posted at this site.

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**ANCOR Honor Roll**

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

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

Please send supporting documentation of the surveys.

**Arizona**

A.I.R.E.S.
Shasta Group Home
Calle Vista setting
Martin setting
Plaza Oro Loma “A” setting
Plaza Oro Loma “B” setting
Plaza Oro Loma “C” setting
Merito “A” setting
Merito “B” setting
Barona “A” setting
Barona “B” setting

**Minnesota**

**Dakota Communities, Inc.**
Victoria Road
3801 Broadway

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**AAMR Releases New Assessment Tool**

On January 6th, the American Association on Mental Retardation released the Supports Intensity Scale (SIS), paving the way for a major shift in the way services and supports are delivered to persons with intellectual disabilities. The SIS is a unique planning tool that enables professionals to assess the daily needs and life goals of a person with an intellectual disability and identify practical support strategies to fulfill them.

According to AAMR, the SIS breaks away from the traditional approach towards assessment, taking the needs—as opposed to deficits—of the person with an intellectual disability as the point of departure for planning supports and services. The positive, direct, and person-centered focus of the Scale makes it a breakthrough in disability services.

The SIS evaluates the needs of a person with mental retardation in 57 key activities through a one-on-one interview process between a qualified professional and the individual with a disability and those close to him or her. The professional glean a comprehensive overview of the type and frequency of support needed to fulfill required and desired life activities in the areas of home and community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. This information is then used by the individual providing supports to create personalized support plans for the individual with mental retardation.

In addition to serving as a tool that brings attention to the needs of each individual with mental retardation to live a life of his or her own making, two other features contribute to the uniqueness of the Supports Intensity Scale. The SIS:

- Evaluates how certain pre-existing medical and behavioral conditions commonly associated with mental retardation affect the overall support requirements of a person with mental retardation—combining for the first time the assessment of medical conditions and daily support requirements.

  - Assesses the help a person with an intellectual disability requires to advocate for his or her own rights. Sample tasks evaluated in category include managing personal finances, obtaining legal services, and protecting oneself from self-exploitation.

The Supports Intensity Scale was developed over a period of five years by a team of 10 experts in mental retardation: Definition, Classification and Systems of Supports.

The 128 page person-centered manual is available for $95 ( manual and 25 interview forms for $125). To order, contact AAMR by calling 301-604-1340 or go online at www.aamr.org.
The Sense and Nonsense about Choice

Jim Gardner, Ph.D.

Since introducing the Personal Outcome Measures in 1993, The Council has recognized the complexity and ambiguities related to the issue of choice. The Council continues to focus on the importance of choice even as it begins work on a new set of quality measures that will integrate concepts and indicators related to social capital, individual and community quality of life, and the promotion of health and safety through community relationships.

As The Council explores new quality measures and indicators, we restate the importance of choice and the context for its consideration. In this regard, three aspects of choice merit our attention.

1. The cultural context for choice. Individual choice and autonomy are evident in much western political and social discourse. Concern for individual rights, the democratic imperative of “one person—one vote” and personal autonomy and responsibility are manifest in contemporary society. However, there are other traditions that emphasize the social dimensions of choice, be it “families,” the clan or the community. As such we need to recognize the understanding and application of choice within cultural and historical boundaries.

2. The support context for choice. The Council’s field test experience with the Personal Outcome Measures in the early 1990s resulted in development of a three-part test for the meaningful exercise of choice. In making decisions about personal outcomes, The Council asks three questions:

a.) Does the person have a range of experiences and opportunities for trying options in making a choice? There can be no meaningful choice if there are not options from which to choose. In addition, choice requires some experience with the options. Asking people with significant disabilities to make choice without the opportunity to learn about or experience the options makes the “choice” meaningless.

b.) Has the family, provider or community exercised real creativity in searching for and creating alternative choices? Disability and human service systems frequently define choice as “picking either A or B” when the person is interested in neither. Or, the person wants A and the family wants B, which results in dead-end conflict. The Council maintains that creating alternatives, being innovative, and learning to negotiate can lead to the possibility of agreement on choices.

c.) Have we provided the person with necessary supports while they make decisions and experience new alternatives in their lives? Choice often brings doubt, anxiety, and the need for support and encouragement. Personal and social supports are necessary requirements for making choices.

It is unacceptable to offer the simplistic excuse that “it was their choice” when we allow people to engage is dangerous or unhealthy behavior. At a minimum, the decision process that results in people making such difficult choices should include ongoing support and dialogue with the individual about the consequences of choice; possible consideration by a human rights committee; active attention to the ethical, legal and moral dimensions of allowing such choice, and a lot of self-doubt on our part.

3. The temporal context of choice. Choice does not exist as an isolated event in time and space. Instead, choice creates the potential for new possibilities. Choice is not about choosing A or B. Instead, choice is selecting A and all the future roads, alternatives, detours and possibilities that A affords us.

Modern science and, in particular, complexity science stresses the importance of emergence. Fundamentally, emergence is about the possibility of choices, opportunities, and alternatives that didn’t exist yesterday and that can’t be identified or predicted for tomorrow. Life flows from, and is maintained through, a series of unfolding and unpredictable opportunities and alternatives. Our choices today directly influence our options, alternatives and choices in the future.

Closed systems (whether they are labeled institutions, group homes or community ALUs) limit the opportunities and alternatives for the future and the support systems to pursue those opportunities and alternatives. These closed systems deny the possibility of emergence and choice. The result is a mistaken focus on a right to make one choice rather than creating the possibility of a world of choice over time.

Hence the importance of social capital, natural support networks and close friends that prevent closed systems. The connected world of family, friends, community and accumulated social capital provides all people with the support and encouragement to pursue opportunities and alternatives in an unfolding life.

ANCOR Welcomes New Members

Great Lakes/East Region
Carol Mitchell, Regional Director
Anderson School
Neil J. Pollack
Staatsburg, NY
neilpollack@andersonschool.org
Lifespire, Inc.
Mark van Voorst
New York, NY
mvanvoorst@lifespire.org

AUTHOR LINK: James Gardner, Ph.D. is currently the president and chief executive officer of The Council on Quality and Leadership. Contact Jim by phone 410-583-0060 or email at jfgardner@thecouncil.org.
Most of us struggle to successfully address the challenges of a limited workforce, fiscal deficits and increasing demands from regulators and insurers. Even the needed emphasis on individual/family choice can create a stress, albeit very positive. Each of these challenges demands some financial literacy that is shared among all parties, especially if we are to strengthen the decision-making skills of our co-workers and the individuals/families we support.

The approach that we have embraced in this quest is called open book management (OBM). What is OBM? According to John Case, a noted OBM author, it is when employees “learn to follow the numbers and help make decisions” and when they “learn to think and act like owners (Open Book Management, p.xvii).”

Probably the most famous proponent of OBM, Jack Stack, wrote a management bestseller, The Great Game of Business (1983), that chronicles the efforts of a small group of determined workers to save Springfield Remanufacturing Company (SRC), that was to be shut down by International Harvester. The workers banded together with very few resources, offered company financial information to all employees, and asked for everyone to participate in the “game.” The result has been remarkable at SRC and many other organizations that have undertaken OBM. SRC has a subsidiary, The Great Game of Business (GGOB), which promotes this approach internationally through consultation and training.

Some of the essential elements include:
- Sharing basic organizational financial information with all employees and teaching them how to understand how the organization operates.
- Involving as many employees as possible in creating budgets and financial plans, including organizational growth.
- Identifying the “critical numbers” that drive organizational success and rewarding employees for their efforts when they reach their “mini-game” goals.
- Creating a sense of ownership by celebrating success together and providing some stake in the outcome for larger organizational success.

How do you incorporate this approach in non-profit and for-profit organizations supporting individuals with disabilities? From our experience, the principles are the same. The implementation will differ given the nature of what we do and our unique relationships to individuals/families and taxpayers who fund our services. We believe that it is our responsibility to be good at financial management as we focus on service quality and

See OPEN BOOKS, page 12
Open Books
continued from page 11

the preferences of people we serve, as well as their families.

Some potential implementation examples include:

• Taking a “critical number” like vehicle repair expense and rewarding employees when they keep the expenses in check while providing regular transportation.

• Offering a bonus or variable compensation (“stake in the outcome”) program for all employees who target certain goals, while not allowing employees to trim the food expense.

• Encouraging line supervisors to be actively involved in budget development for their services and “defending” this budget throughout the year.

• Developing “scoreboards” that focus on quality-related issues such as employee turnover, creating strategies to reduce turnover and monitor success over time.

We have discovered that this openness actually improves quality on objective indicators of performance. We have also found that family members appreciate this approach because they learn more about what it takes to operate services with the challenges familiar to each of us. Through our work at CPES and Salience Consulting, we believe there is tremendous potential to liberate the process of providing services and managing the related business activity.

In a provocative 2003 Harvard Business Review article, “The Nonprofit Sectors $100 Billion Opportunity,” Bradley, Lester and Silverman studied organizations across the country and found that substantial savings (equaling more services to clients) could be generated by more effective operations and management. We believe that OBM, particularly the GGOB approach, is one significant strategy that can help achieve these savings, while generating other benefits such as increased employee retention, better quality of service, and more faith in the ethical conduct of senior managers.

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AUTHOR LINK
Tom Schramski, Ph.D. is President/CEO, CPES, and President, Salience Consulting of Tucson, AZ.
If you have any questions about Open Book Management, Tom can be contacted at 520-884-7954 or tschramski@cpes.com

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ResCare of WV Thanks Rep. Capito for DSP Resolution

ResCare West Virginia, a provider of supports and services to people with developmental disabilities, recently honored and thanked Representative Shelley Moore Capito (R-WV) for endorsing House Concurrent Resolution 94 to recognize direct support professionals. The ultimate passage of the Direct Support Professional Recognition Resolution by both houses of Congress was a major victory for the ANCOR National Advocacy Campaign.

Representative Capito visited a group home on Charleston's Maxwell Street, where six adults live with support from ResCare staff. During the visit, she told the group home staff, “This is how it ought to be for everyone who has developmental disabilities.”

“We are pleased that Reps. Capito and Rahall supported the resolution. We are honored to have Shelly Moore Capito visit with our employees and the people we serve,” said Steve Hendricks, state director for ResCare.

ResCare West Virginia has provided community-based services in West Virginia since 1987. The West Virginia operations provide supports and services to approximately 600 individuals and has over 1,600 employees.

Other ANCOR agency members who have recognized the support of their senator(s) and/or representative are encouraged to submit their story to ANCOR Member Highlights.

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Reference OFFER CODE # JLINKS134 and contact us at 419-335-1280 ext. 11 or email info@mrddsolutions.com (please provide mailing address)

www.mrddsolutions.com info@mrddsolutions.com
I graduated from Washington State University in 1996 with a Bachelor of Science degree in Kinesiology. After spending some time in Mount Vernon, Washington, assisting with the special education program I began looking at job opportunities in my hometown of Boise, Idaho. I discovered a position working with adults with disabilities in a vocational training program.

I had never heard of the program before but something sparked my interest. I was called for an interview in November 98 and once I toured the facility of Western Idaho Training Company, Inc., I never looked back. The feeling that I received walking through the facility gave me a direction in life and built a sense of excitement inside of me that I couldn’t believe.

I am currently the director of marketing and production. WITCO has provided me with a wonderful opportunity to work with great individuals. I love to go out into the community looking for production opportunities with companies. I enjoy being able to share with them what an immense benefit employing people with disabilities can be. I know the value that work brings to the individuals with whom I work; I see their excitement, their dedication and their pride in what they do. I am personally grateful to have this opportunity to provide opportunities to everyone who attends our program.

People comment on how excited I am and how much enthusiasm I have, but I give all the credit to the consumers of the Western Idaho Training Company, Inc. They are my energy, and I am so proud of what they have done and what they will be able to do in the future.

I became involved with ANCOR three years ago while reading LINKS. I further became involved when I was notified that I would be the State Representative for Idaho and was very surprised to find that our CEO had nominated me. I was very excited to take on the responsibilities, but have not been able to participate as much as I would like. I feel that ANCOR provides great information regarding national issues and helps providers to become more familiar with issues that will impact their state. Our company is very involved on the state level regarding issues that affect individuals with disabilities and would look forward to receiving additional information that could help further our legislative impact.

National involvement is critical for the population we serve. I believe that we have a responsibility to be an active voice in our communities to ensure that the people we serve receive the appropriate representation and services. Without our advocacy, policies would not change and opportunities would be lost for those who need the most assistance.

So with GREAT enthusiasm I look forward to seeing what ANCOR has to offer and hopefully become more involved with the other State Representatives.

Jennifer Ramon with Brian “Eddy” Sproul, who works at the WITCO workshop and attends developmental programs.

an apprenticeship development program with an existing union because it would require renegotiating contracts and agreements, etc. Since we’ve received a rather significant grant from The Ohio State Apprenticeship Council to support our PATHS project, we are especially concerned. We need to address these barriers to participation and respond to questions and concerns that providers might have.”

Amy’s concern is important in light of ANCOR’s ongoing dialogue with the Department of Labor as part of the National Advocacy Campaign and its partnership with the National Alliance of Direct Support Professionals (NADSP). The NADSP achieved apprenticeship status for the job title of “direct support specialist” in 2001. That designation and official recognition by DoL opened opportunities to tap into DoL funds—which are extensive—for training and development apprenticeship programs for DSPs. Funding has already supported the College of Direct Support and we’re seeking additional funding to complete the College’s curriculum and to support other programs, such as PATH.

The concept of apprenticeship programs for workforce development should not be a threat to us as we explore every conceivable opportunity to build a qualified, stable direct support workforce. We’ve been advised repeatedly that inherent in raising the wage structure for DSPs is increasing the perceived “value” of the job—part and parcel of accomplishing that is raising the standard of education and training required to obtain the position—apprenticeship programs like PATH can help us accomplish that objective.

Let’s keep the dialogue running! ■

Heads Up!!

LINKS is being distributed in both electronic (pdf) and hard copy formats. If you prefer one over the other, please let us know. If you have no preference, you’ll receive it electronically.

Questions?
Contact Marsha Patrick at mpatrick@ancor.org or 703/535-7850
Highlights of Specific Proposals

Some of the specifics of the NCSL Medicaid Reform proposal include the following:

- Allow states to modify their state Medicaid programs by plan amendment instead of using the waiver process in many areas. With respect to existing and future waiver and demonstration programs, NCSL urges the federal government to work with states to develop an expedited waiver process and to require prior state legislative authorization when any waiver requires long-term commitment of state appropriations.

- States should be allowed to establish and set the size of the programs that provide for home and community based care as an alternative to nursing homes. As a cost control technique, states should continue to be allowed to limit this program to a specific number of slots and additionally should be allowed to provide this service without providing the full range of additional Medicaid services.

- NCSL urges the federal government to give states more flexibility to streamline and simplify the Medicaid eligibility process, reducing the hassle factor for recipients and reducing administrative costs. States should be allowed to give families and individuals eligibility for the program based on their low-income even if they do not otherwise fit the categorical eligibility. This would make the program a more explicit program for low-income people and simplify the eligibility process.

- States should be allowed to impose enhanced deductibles and copayments for recipients with incomes above the minimum federal requirements for program eligibility.

- NCSL proposes an addition to the current Medicaid financial formula applied uniformly across all states.

- NCSL supports the development of a formula that would automatically provide additional relief in bad economic times and revert to the normal federal state cost sharing in good economic times. NCSL recognizes that other formulas are possible but suggests that the federal cost share for Medicaid be increased by one percentage point for every ¼ of a percentage point the national unemployment rate is above 4.5 percent.

- NCSL urges Congress to authorize the elimination of the current cost neutrality requirement for many classes of waivers—especially for waivers with prior legislative approval.

- NCSL urges the federal government to provide more flexibility for state with regard to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program, given that some procedures or services are not covered on the state's Medicaid plan even when a treatment is required due to the screening.

- States should be authorized by statute to use provider-specific taxes, voluntary donations, and intergovernmental transfers. NCSL believes the law establishing guidelines for the development and implementation of these programs to be too restrictive.

As any Administration or Congressional Medicaid reform proposals come forward this year, ANCOR will provide information in future electronic transmissions of ANCOR’s Washington Insiders’ Club Updates and alerts.
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 $879,297.93.

**AGENCY CONTRIBUTION $40,000 AND ABOVE**

- American Habilitation Services
- Mosaic (Bethphage/Martin Luther Homes Society, Inc.)
- ResCare, Inc.
- The Mentor Network (REM, Inc./The Mentor Network)

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- Volunteers of America of Oklahoma, Inc.
- WCI
- Woodford's Family Services
- Willows Way Inc.
- Zachary House, Inc.

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- The Council on Quality and Leadership
- The National Alliance of Direct Support Professionals
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- Kim Wynkoop, Employment Specialist
PrimeCare, Inc., www.PrimeCare.org

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The ANCOR Foundation is looking forward to participating in the ANCOR's New Orleans Conference – Renewing and Regenerating for Tomorrow – March 14 – 16.

The ANCOR Foundation is participating in two major conference events. The first is the pre-conference CEO roundtable on March 14 from 1 to 4 PM. Peter Bina and Bill Tapp will present, No Money, No Mission.

Development Strategies for a New World. Participants in this three hour round table will learn practical and proven processes for telling their agency’s stories and designing fund raising strategies with a long-term focus. We are asking registrants to complete a brief questionnaire about their experiences with fund raising practices. These practices will be compiled into a booklet and shared with the participants.

The ANCOR Foundation will present the first Community Builder Award on March 15 at the Awards Luncheon. We will be announcing the winner of this national competition and hear about how their work builds inclusive communities for all. We look forward to seeing all of you at this major event.

Of course we'll be there with our fashionable and reasonably priced logo material so please bring, cash, check or credit card. Please come and meet our board of trustees and find out how you can become involved in the ANCOR Foundation.

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Foundation Update

Amy Gerowitz, President

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ANCOR Calendar

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<tr>
<td>February 26</td>
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<th>March 14-16</th>
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<tr>
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<th>Sept. 19-21</th>
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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.