

National Coalition on Mental Health and Aging
Meeting Minutes
March 10, 2011

Alix McNeill, Chair of the National Coalition on Mental Health and Aging (NCMHA) and Vice President of the National Council on Aging (NCOA) called the meeting to order and reviewed the proposed agenda. There were 23 members present onsite and 12 via conference call. The meeting began with member introductions. The theme of the meeting was Family Caregiving.

NCMHA Business

The minutes of the October 2010 meeting were adopted.

Stephanie Reed, Deborah DiGilio and Willard Mays, agreed to serve as the Nominating Committee to develop the slate of offices for 2011-2013 NCMHA Executive Board. They will present the nomination slate at the next meeting.

Policy Update

James Finley, National Association of Social Workers (NASW) and Stephanie Reed, American Association of Geriatric Psychiatry (AAGP) representatives provided the policy update.

Department of Health and Human Services Secretary Kathleen Sebelius and others have expressed concern about the sustainability of the CLASS Act in its current form. She has the ability to tweak eligibility and make other changes necessary to sustain the program. They have been given a very short time frame – only one year - to get the program up and running. To receive program benefits, beneficiaries have to pay premiums for three years prior to drawing those benefits. One must have multiple functional impairments to be eligible. Persons with mental health disabilities would be highly unlikely to receive benefits if they have no other functional limitations. CLASS Act provides a cash benefit. To have the critical mass necessary to support it, rates need to be established that are attractive for lower income persons to also buy into the program. The Republicans would like to repeal this legislation. There is also talk of initiating new legislation to take all mandatory spending and make it discretionary. From the advocates' perspective, there is concern that implementation of many of the new provisions will not move forward, as there is concern that some provisions will be repealed.

The Medicare Sustainable Growth Rate (SGR) payment 12-month extension expires at the end of this year. The problem with a big deficit like we have now is that often Medicare amendments can be added when the budget is opened up for discussion. Medicaid budgets are putting a severe strain on the states. The deficit hold on the states is extraordinary. Sixteen million new beneficiaries are coming into Medicaid under Health reform. In addition, Community Health Centers were severely cut in the House version of the 2011 budget.

Medicaid 1915(i) State Plan Home and Community Based Services (HCBS) Benefit

Kathryn Poisal who is with the Centers for Medicare and Medicaid Services (CMS), Center for Medicaid, CHIP, and Survey & Certification, Disabled and Elderly Health Programs Group, Division of Long Term Services and Supports described the key features of the 1915(i) State Plan HCBS. It was established by the Deficit Reduction Act of 2005 and was effective January 1, 2007. It gives the States the option to amend their state plan to offer HCBS as a state plan benefit. It breaks the "eligibility link" between HCBS and institutional care now required under 1915(c) HCBS waivers. The 1915(i) was modified through the Affordable Care Act (ACA) with the changes that became

effective October 1, 2010. Statutory 1915(c) services include: case management, homemaker, home health aide, personal care, adult day health, and respite care. For individuals with chronic mental illness, services also include day treatment or partial hospitalization, psychosocial rehabilitation and clinical services. 1915(i) does provide an opportunity for mental health as it does not include an institutional level of care nor does it have a cost neutrality requirement. Due to the ACA changes, States can also offer “other” services.

In order to receive services, State plan HCBS individuals must be eligible for medical assistance under their State plan, States must provide needs-based criteria to establish who can receive the benefit, and individuals must reside in the community, and have income that does not exceed 150% of the Federal Poverty Level. Through changes included under the Affordable Care Act, States also have the option to include individuals with incomes up to 300% of SSI Federal Benefit Rate and who are eligible for a waiver.

The 1915(i) Needs-Based Criteria is determined by an *individualized* evaluation of need (e.g., individuals with the same condition may differ in ADLs). The criteria may be functional criteria such as ADLs and may include State-defined risk factors but does not include descriptive characteristics of the person, or diagnosis, population characteristics or institutional levels of care. The lower threshold of needs-based eligibility criteria must be “less stringent” than institutional level of care (LOC). However, there is no implied upper threshold of need. Therefore the universe of individuals served must include some individuals with less need than institutional LOC and may include individuals at institutional LOC (but not in an institution). Eligibility criteria for HCBS benefit may be narrow or broad. HCBS eligibility criteria may overlap all, part, or none, of the institutional LOC. Under 1915(i), States have the option to not apply income and resource rules for the medically needy and can determine its direction (e.g. what 1915(i) services are offered, may offer budget and/or employer authority, and specific requirements for the service plan).

Under the ACA changes to 1915(i), States may offer HCBS to specific, targeted populations for a 5-year period with option to renew with CMS approval; and can have more than one 1915(i) benefit in their State Plan. However, States may no longer limit the number of participants who may receive the benefit and the benefit must be offered state-wide.

In terms of quality assurance, as a State plan service, no review and renewal is needed as in HCBS waivers unless a State includes the new option added to 1915(i) under the Affordable Care Act to target populations (5 year periods with option to renew). But unlike other State plan services, there is a quality assurance requirement that States must ensure that HCBS meets Federal and State guidelines. Under 1915(i) States are to provide: independent evaluation to determine program eligibility; individual assessment of need for services; individualized plan of care; projection of the number of individuals who will receive State plan HCBS; and a payment methodology for each service. The differences between HCBS under 1915(i) State plan & 1915(c) Waivers are: institutional care requirements, length of time for operation, an option to limit number of participants, an option to limit statewide, and financial estimates.

As of March 2011, there are five states using the waiver to provide 1915(i) benefits: Iowa, Nevada, Colorado, Washington, and Wisconsin. Wisconsin and Iowa focus on mental health issues and offer mental health benefits. There will be a proposed rule on 1915(i) probably near end of year in the Federal Register which everyone should keep an eye out for. A question was raised regarding how this option works with states moving to managed care and ACOs. The response was that states can pull the 1915(i) option into their managed care authority. For more information about 1915(i) see: CMS Regional Office Representative or CMS Central Office representatives: Damon Terzaghi at Damon.Terzaghi@cms.hhs.gov or Kathy Poisal at Kathryn.Poisal@cms.hhs.gov. Also, more information is available at:
http://www.cms.hhs.gov/MedicaidGenInfo/08_Medicaidregulations.asp.

Family Caregiving Efforts at the National Level - The National Family Caregiver Support Program, the Year of the Family Caregiver, and the Lifespan Respite Care Program

Greg Link, Aging Services Program Specialist of the U.S. Administration on Aging and the Federal Program Officer for the National Family Caregiver Support Program began his presentation with a discussion of the National Family Caregiver Support Program (NFCSP). It was created in the 2000 reauthorization of the Older Americans Act. It focuses on caregivers instead of the care recipient. The NFCSP offers a range of services to support family caregivers. Under this program, States provide five types of services: information to caregivers about available services, assistance to caregivers in gaining access to the services, individual counseling, organization of support groups, and caregiver training, respite care, and supplemental services, on a limited basis.

Since 2006, NFCSP has served the following populations: family caregivers (18+) of older adults (60+), grandparents and relative caregivers (55+) of children (18 and under), caregivers of persons with Alzheimer's disease or related dementias (of any age), and relative caregivers (55+) of adult children (18-59) with a disability. Of the 675,000 caregivers served, 1/3 work full time, they are primarily women (73%), and older themselves (54% age 60+; 22% age 75+). Of the grandparent caregivers, 81% are female and 84% are age 60-74. Seventeen percent live in rural areas.

Recipients of NFSCP receives includes: 84% receive respite, 45% said respite was most helpful, 75% reported less stress, 85% reported caregiving was easier, 95% reported service quality as good to excellent.

Greg then described plans for the 10th Anniversary NFCSP. A celebration was held on November 17, 2010 at which 2011 was named The Year of the Family Caregiver. Look at their website, www.celebratingfamilycaregivers.org for a calendar of national, state and local events, tools, resources, and video testimonials on caregiving.

Greg next described respite and the Lifespan Respite Care Program. Respite is the foundation of caregiver support. It is the provision of temporary relief for caregivers that strengthens family systems and protects the health and wellbeing of caregivers. It is defined by the Lifespan Respite Care Act of 2006 (PL 109-42) as: "planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that adult or child."

The Lifespan Respite Care Programs are coordinated systems of accessible, community-based respite care services for family caregivers of children or adults with special needs. Its objectives and characteristics are to: enhance and expand respite services; improve coordination and dissemination; improve access; fill service gaps; improve overall service quality; volunteer recruitment, training and retention; and raise public awareness.

The Lifespan Respite Care Program was authorized in 2006 and funded in 2009 and 2010 at \$2.5 million. The President's FY 11 Request is for \$5 Million. It is a competitive grant award process through which 12 States were funded in FY 2009 (Alabama, Arizona, Connecticut, District of Columbia, Illinois, Nevada, New Hampshire, North Carolina, Rhode Island, South Carolina, Tennessee, Texas) and 12 States funded in FY 2010 (Delaware, Kansas, Louisiana, Massachusetts, Minnesota, Nebraska, New York, Oklahoma, Pennsylvania, Utah, Washington State, Wisconsin). Funding is up to \$200,000 for three year projects. Technical assistance is provided to the 24 states receiving funding by the ARCH National Respite Network & Resource Center. Eligible entities are state units on aging, state Medicaid agencies, and other state agencies. The majority of state applicants engage AAAs. The recipients work in concert with the Aging and Disability Resource Centers (ADRCs) and State Lifespan Respite Coalitions.

There are a number of key stakeholders involved in program development including the state agencies, respite coalitions, the ADRCs and others including consumers, providers and advocacy groups. The role of the state agencies is to provide program administration and implementation program oversight, contracting to local entities, coordination of respite information, and coordination of statewide respite databases. The role of the state respite coalitions are advocacy, networking, provider recruitment and training, information and referral, fundraising, and voucher programs. The role of ADRCs are outreach, serving as a clearinghouse for respite information dissemination, maintaining the respite registries and hotlines, caregiver training and in an advisory role for program administration.

Looking ahead, there are 2011 Respite Summits planned in Georgia, Montana, Ohio and Virginia and the 2011 National Respite Conference will be held in Glendale, AZ on November 1-4, 2011. There is also the 2nd Annual Grantee Meeting coming up. Since The Lifespan Respite Act does not specify roles for stakeholders, different roles have emerged. For example, in Tennessee they partner with the university to train students as respite providers. The Summits bring together essential stakeholders in providing lifespan respite to share strategies and learnings. There are a number of informational resources available on family caregiving at the national level including:

- Lifespan Respite Care Act Public Law 109-442, <http://www.archrespite.org/PublicLaw.pdf>
- The House Energy and Commerce Committee Report on the bill, <http://www.archrespite.org/PublicLawHouseReport.pdf>
- The Technical Assistance Centers for Caregiver Programs and Lifespan Respite, www.caregiver.org
- ARCH Lifespan Respite Training and TA, <http://chtop.org/ARCH/Lifespan-T/TA.html>
- Information on each respite care program, www.aoa.gov

Look for the FY 2011 Program Announcement for states that will be coming out in a number of weeks. Also input of NCMHA and its member organizations would be welcomed as reauthorization is coming up.

New Studies of the National Alliance for Caregiving

Gail Hunt, Executive Director of the National Alliance for Caregiving (NAC) and member of the NCMHA Executive Committee provided an overview of NAC and their two newest studies. NAC is nonprofit coalition of 40+ national organizations focused on family caregiving issues. It was established in 1996 to support family caregivers and the professionals who work with them. NAC activities include conducting research and policy analysis; developing national programs; strengthening coalitions; increase public awareness; and working internationally.

One of their more recent studies is *Caregivers of Veterans: Serving on the Homefront*. Its purpose was to assess the experiences and challenges of family caregivers of veterans as well as the impact of caregiving on their lives and what programs and services would support and assist them.

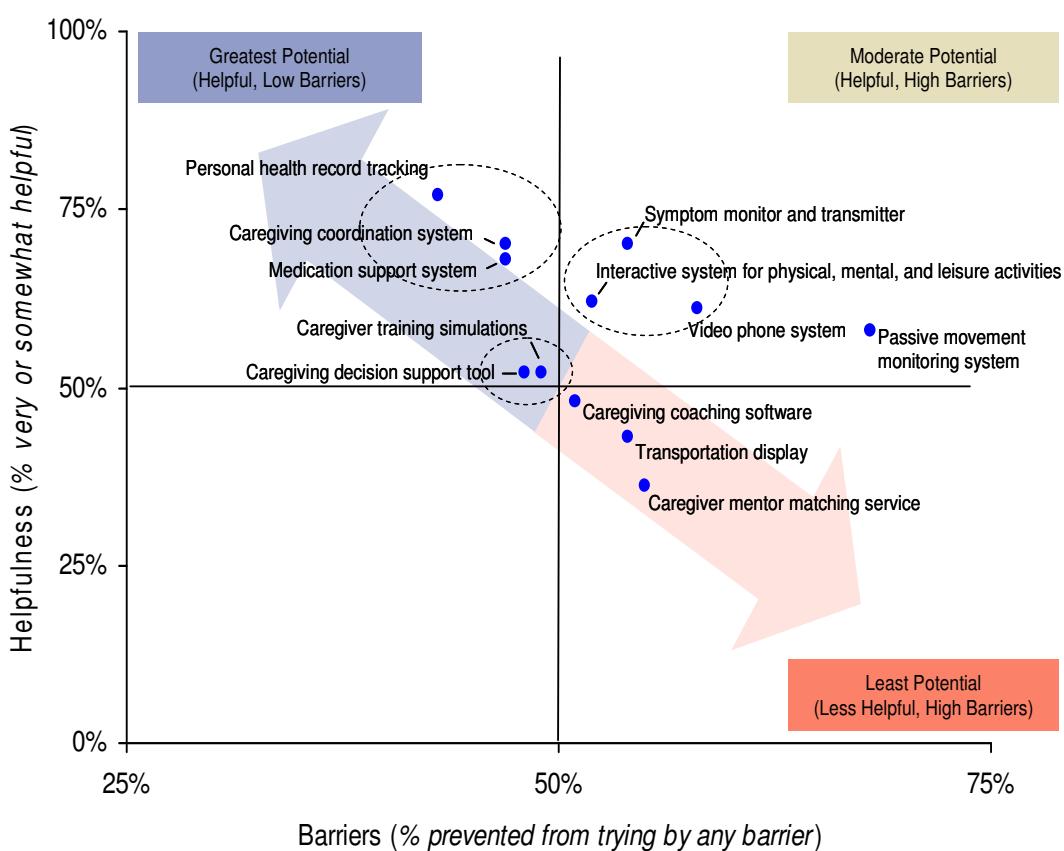
The research was funded by the United Health Foundation. They conducted six focus groups in Bethesda, MD, San Antonio, TX, and San Diego, CA and had in-depth interviews with 42 caregivers of veterans supplemented by an online and paper survey of 462 additional caregivers of veterans.

The top reasons stated by caregivers of veterans for why their recipients need care were: Comorbidity (80%), Mental Illness (70%), PTSD (60%), Traumatic Brain Injury (29%), Diabetes (28%) and Paralysis or Spinal Cord Injury (20%). Sixty-five percent are in a high burden caregiving situation versus 31% nationally reported. This is due to the need for assistance with all Activities of Daily Living (dressing, bathing, feeding, toileting). Most caregivers of Veterans report spending at least 21 hours per week helping the veteran.

The particular challenges of caregiving included: not knowing what to expect medically with the Veteran's condition; not being aware of VA services that could help; not knowing how to address PTSD or mental illness; difficulties getting through the bureaucracies in order to obtain services; not knowing where to obtain financial assistance; not knowing where to turn to arrange a break from caregiving; and, not knowing where to obtain specialized care.

The second study, *The e-Connected Family Caregiver: Bringing Caregiving into the 21st Century*, utilized an online survey of 1,000 Tech-Using Family Caregivers. It was funded by United Healthcare. The purpose of the survey was to learn how receptive family caregivers are to 12 specific technologies as well as sources of technology information that they trust. The definition of caregiver used was an individual age 18+ spending at least 5 hours per week caring for another.

Seventy percent of caregivers have used the Internet to find information, participated in online blog or used electronic devices. The three technologies they thought would be especially helpful are: personal health records tracking (77%), a caregiving coordination system (70%) and a medication support system (70%). Sixty-nine percent were receptive to smart phone apps. The perceived benefits of technology were: saving time, improving logistics, increasing effectiveness and reducing stress. Eighty-three percent of long distance caregivers thought technology will make them feel more effective. Perceived barriers to using technology were that it was, too expensive (although conversely, 46% believed it would save money), did not address needs, and that the care recipient would resist. Caregivers would be more Likely to Try Technology if a health professional that they utilized would explain it to them, if they received a "how-to" explanation showing how easy it was to install and use, and if there were three-year warranties. The following graph provides more insight into caregivers opinions on technology.



To find these and other NAC studies, go to: <http://www.caregiving.org/research/general>

AARP Public Policy Initiative: Professional Partners Supporting Family Caregivers

Rita Choula, Project Administrator, AARP Public Policy Institute described their Professional Partners Supporting Family Caregivers initiative. They are leading and coordinating a national three year initiative to improve the capacity of nurses and social workers to meet the needs of family caregivers. The project's second phase targets Latino and African American family caregivers. They are working in four New Jersey counties with the Family Caregiver Alliance and AARP. Care mangers in ADRD are receiving the training. More information is available at: <http://www.aarp.org/relationships/caregiving/info-11-2009/091104-caregiving.html>. Rita also distributed three fact sheets: Professional Partners Supporting Family Caregivers, Physical and Mental Health Effects of Family Caregiving, and an editorial related to caregiving, How Are You Doing?

National Association of Social Workers' Standards for Social Work Practice with Family Caregivers of Older Adults

Chris Herman, NCMHA Executive Committee Member and National Association of Social Workers representative discussed their new *Standards for Social Work Practice with Family Caregivers of Older Adults*. They are designed to enhance social work practice with family caregivers of older adults and to help the public understand the role of professional social work in supporting family caregivers. These standards and other practice-related standards are available at:

<http://www.socialworkers.org/practice/default.asp>

American Psychological Association's Family Caregiver Briefcase

Deborah DiGilio, NCMHA Executive Committee Member and Director and APA representative walked the Coalition through the online APA Family Caregiver Briefcase. It is a resource for those who work with family caregivers, the Briefcase can help professionals recognize, anticipate, and reduce the stresses on family caregivers across the life span. Segments of the briefcase are also useful for family caregivers. It includes: caregiving facts and figures, strategies for reaching family caregivers, caregiving interventions, assessment tools, variations in practice for culturally diverse groups, practical aspects of providing services, research opportunities and considerations, teaching about caregiving, advocacy on behalf of family caregivers, and resources for diverse populations and ages. Available at: <http://www.apa.org/pi/about/publications/caregivers/index.aspx>

NCMHA Online Survey of State and Local Mental Health & Aging Coalitions

Kimberly Williams NCMHA Executive Committee Member and The Geriatric Mental Health Alliance of New York representative initiated a survey to identify and learn about the structures, activities, areas of need, and contact information for state and local coalitions on mental health and aging. Our information was sorely outdated. Kim reported that she had received 56 responses. She is currently tabulating the data and update the Coalition when it is complete.

Member Updates

American Society on Aging (ASA) – Anita Rosen reminded the group that the 2011 NCOA/ASA Aging in America Conference is April 26–30 in San Francisco, CA. The Mental Health and Aging Network (MHAN) will present its Mental Health and Aging Award recognizing outstanding programs and services in mental health and aging to Judy Schultz. The MHAN Leadership Council will meet on April 28th. NCMHA will once again sponsor the Coalition track. This year, one session will be a panel presentation of Targeted Capacity Expansion (TCE) grantees. Another will be on evidence based practices and the TCE programs. Alixe McNeill, Anita Rosen and Robyn Golden will present

the annual NCMHA Update session. For more information is available at:
<http://www.asaging.org/aia11/>

National Association of State Mental Health Program Directors – Marcia Marshall reported on their SAMHSA/CMHS Community Support Resource Center. They provide technical assistance to the SAMHSA's 10 Targeted Capacity Expansion (TCE) grantees. They are convening a TCE grantees meeting on May 23rd and 24th. If any NCMHA members are interested in evidence based practices or in providing citations, or if anyone has a solid contact at CMS Office of Dual Eligibles, please contact her. memb7. BCE A power point presentation describing their activities is available at:
http://docs.google.com/viewer?a=v&q=cache:qBolalQMIA4J:www.nasmhpd.org/general_files/TH%2520201%2520Marshall%2520SAMHSA%2520TCE%2520grants%2520Overview%2520v2.pdf+SAMHSA/CMHS+Community+Support+Resource+Center&hl=en&gl=us&pid=bl&srcid=ADGEESiP0zb_wXDFTaZ9yE8kAXYsH7QvLLnluXkyhBK6yNa8L5z_THW302YW55LPMXQdIANmsHgFh526IZzNLhd07-3icsON0IK8un2RbeErxsLDM-me3MF0MnFA5LiiepApcwXFC8JB&sig=AHIEtbRe2AU2srEMIzHnF4MAqXDBWATIgg

Administration on Aging – Shannon Skowronski discussed the National Strategy for Suicide Prevention. She also mentioned that in the President's budget, implementation of CLASS Act, and the Senior Employment program will be administered by AoA. Also the StateHealth Insurance Program (SHIP) that offers counseling is coming from CMS to AoA.

Virginia Alcohol and Aging Awareness Group or Virginia Center on Aging -Constance Coogle reported that The Gerontological Society of America's publication, *The Gerontologist*, has issued a Call for Papers on Boomers' Mental Health: Across the Continuum of Healthy Aging, Vulnerability, and Frailty. Manuscripts are due October 1st and are submitted via their journal Manuscript Tracking System at <http://mts.hindawi.com/>.

In closing, Alixe noted that NCMHA's next meeting will focus on the Affordable Care Act (ACA) both from the national and state perspectives. Members are encouraged to provide ideas for agenda items for upcoming meetings. To do so, send a note to Alixe at alixe.mcneill@ncoa.org.

The meeting was adjourned at 12:30 p.m.