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The National Consumer Voice For Quality Long-Term Care

ADVOCATING FOR RESIDENTS WITH MENTAL HEALTH NEEDS: ENGAGING AND CHANGING THE SYSTEM

SESSION SUMMARY AND RESOURCE GUIDE

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PRESENTER

Dr. Susan Wehry has generously shared her time and expertise with long-term care ombudsmen to improve their advocacy skills and knowledge on behalf of individuals with mental health needs. For many years, Dr. Wehry has continued to work with ombudsmen on the state and the national levels. This document is based on her 2008 presentation to state long-term care ombudsmen. Her leadership and personal commitment to advocacy is an inspiration to the ombudsman network.

ADVISORS

This document was refined and improved by the contributions and careful review of several ombudsmen. Their experience, interest in this topic, and time is appreciated. They are: Joanne Chuslo, Ombudsman, Holyoke, Massachusetts; Mark Miller, New York State Long-Term Care Ombudsman; Kelly Moore, Montana State Long-Term Care Ombudsman; Louise Ryan, Washington State Long-Term Care Ombudsman; and Sharon Wilder, North Carolina State Long-Term Care Ombudsman.

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ABOUT THE SESSION SUMMARY AND RESOURCE GUIDE

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Advocating for Residents With Mental Health Needs: Engaging and Changing the System

Session Summary and Resource Guide

Susan Wehry, M.D., Presenter

Prepared by Sara S. Hunt, NORC Consultant

At the 2008 Annual State Long-Term Care Ombudsman Training Conference, Dr. Wehry¹ challenged ombudsman assumptions and offered suggestions for improving ombudsman advocacy on behalf of residents with mental health needs. Her presentation focused on systems issues. The Session Summary of this document is based on the information presented by Dr. Wehry. It is followed by Examples of State Activities and Resources. The Appendix contains supplemental information.

The purpose of this Session Summary and Resource Guide is to:

- inform long-term care ombudsman (LTCO) advocacy and
- provide a list of resources that may be useful in teaching ombudsmen and caregivers and in advocating for individuals and for systems change.

Although tackling mental health systems issues may be intimidating for ombudsmen, they already have applicable skills and knowledge. Dr. Wehry made several key points throughout her presentation that parallel traditional ombudsman advocacy approaches. The challenge is to use these approaches with a different, and perhaps larger, network to address issues that may not be publicly acknowledged. A list of similarities between a few of Dr. Wehry's points and typical ombudsman approaches follows. The Session Summary contains more information about these points as well as additional information. Refer to *The Changed Face of Long-Term Care, Advocating for All Residents: Tips for Ombudsmen* and *What helps an individual stay on medication?* in the appendix for additional points on advocating for individual residents.

Key Points in Addressing Mental Issues from Dr. Wehry	Parallels to Typical Ombudsman Knowledge and Approaches
"Behaviors" are communication.	Ombudsmen know this from working to eliminate restraints, working with individuals with dementia, and dealing with involuntary transfer/discharge issues.
"I can't care for those people, they don't fit."	Ombudsmen frequently encounter this attitude, particularly related to involuntary transfer/discharge issues.
Be prepared to engage others in dialogue about issues and solutions.	Ombudsmen frequently engage others to resolve problems for an individual or to achieve systems change.

¹ Refer to the appendix for Dr. Wehry's biography submitted for 2008 Training Conference.

Key Points in Addressing Mental Issues from Dr. Wehry	Parallels to Typical Ombudsman Knowledge and Approaches
Talk with the individual with a mental illness diagnosis to help define the problem and identify solutions and desired outcomes.	A primary Ombudsmen tenant is to begin with the resident. The desired outcome to complaint resolution is resident satisfaction. Ombudsmen seek to empower others to engage in self-advocacy. Ombudsmen also encourage and support residents in participating in their care planning meetings.
While mental illness does have an impact, it does not make the individual an entirely different person. We must get around the notion that mental health is what we take care of when we've finished taking care of "the body."	Ombudsmen know that quality of care is more than just "body work". Quality of care and quality of life are interconnected. Through working to implement the Nursing Home Reform Law and participating in culture change and other initiatives, ombudsmen have embraced the importance of a holistic approach to meeting an individual's needs.

SESSION SUMMARY:

Background and Context

To understand where to begin with advocacy, it is important to have an overview of changes that led to some of the issues ombudsmen encounter. Historically, individuals with mental health needs received treatment in mental health hospitals. These facilities typically had a large number of beds and were operated by the state.

In the first wave of de-institutionalization in the 1960's and 1970's, young and middle-aged people with serious mental illness were discharged into their communities and older, frailer people with major mental illness in need of nursing home care were left behind². Dr. Wehry encountered them in the 1980's as state hospitals tried to "clear them out" and shut down their state hospital-based nursing homes.

Her journey began with trying to help nursing home operators understand that this population actually made "good" nursing home residents because, in fact, their institution-learned behaviors made it "easier" for them to adapt to being in a nursing home. They were more accustomed to following a facility's routine than a frail elderly individual coming into facility life after a lifetime of independence. Part of that persuasion was also trying to help nursing home operators see these individuals not so much as normal, but as *people*. Their needs for nursing care very closely resembled the needs of other residents without mental illness.

Today, there is a new context that is more complicated. When mental health resources began to dry up in the 1980's, the process of re-institutionalization - only this time into nursing homes and prisons - began.

² Case law decisions such as Wyatt (1971), Donaldson (1975), ultimately community care for residents.

What we currently have is a situation where young people with psychiatric disabilities and with marginal medical or activities of daily living needs are being placed in nursing homes. They would agree “they don’t fit” – not so much because of having a mental illness per se, but because they don’t have the needs for the kind of maintenance long-term care that facilities have evolved to provide.

Dr. Wehry hopes that the new emphasis on person-centered (strengths and wishes based), individualized (consumer’s needs and goals) care planning provides a process for making facilities *work* for each individual.

Now we see increasing numbers of individuals with dementia and individuals with “behaviors” in nursing homes and other community settings. These “behaviors” are communication and research now backs up this basic tenet of Dr. Wehry’s. At least in the case of people with dementia, Jiska Cohen-Mansfield and colleagues have nicely demonstrated that the “problem” behavioral symptoms associated with dementia are “expressions of unmet need” and Cohen-Mansfield has written rather extensively about what so-called “agitation” and “aggression” may mean. Having mental health needs is an additional stigma and label for an individual.

In many states there is a push to develop facilities for “those” people, to separate them into other facilities apart from “normal” individuals. Advocates are always encountering the attitude of “I can’t care for those people, they don’t fit.” There is resistance from providers to making any changes in how I provide care or how I staff my facility.

The focus needs to shift from the provider to the consumer. The consumer’s care needs including mental health needs, should be the focus of attention, even if the person is older and frail.

Attitudes and Assumptions

It is important for every ombudsman to do a self-check on where they are with certain issues. What comes to mind when you hear “the mentally ill?” What are your stereotypes or biases? What is your comfort level?

While mental health does impact an individual, it does not change the individual into someone who is an entirely different person. We must get around the notion that mental health is what we take care of when we’ve finished taking care of “the body.”

Definition of Serious Mental Illness and Access to Services

Access to services for individuals with serious mental illness varies from state to state. Access depends upon the definition the state uses, which often is based on the classification of certain types of mental illness. Sometimes there are battles regarding whether to include individuals with Alzheimer’s in a mental illness class.

In recent years, there has been a growing emphasis on allowing individuals with serious mental illness

to live in board and care homes. We are taking a huge step backward if we begin asking, “Do we move people into facilities for the mentally ill because the community services for support are not in place?” This is the equivalent of segregating individuals based on diagnoses, not on individual abilities and needs.

Current Issues

In recent years there are some new factors influencing policy and service delivery decisions.

- Public Policy Changes: Long-term care services are shifting from nursing homes to home and community based services at an accelerated pace. There are some implications of this change.
 - This shift is resulting in more empty beds within nursing homes and a push to identify new markets for nursing home providers. Finding places for people to live based on available space instead of needs and preferences, is not a good way to develop policy. The needs of the individual are not considered on par with the state’s desire to find placement and the providers’ desire to fill empty beds.
 - In general, nursing home providers are ill-equipped to care for younger people with disabilities, or for individuals who are experiencing depression or psychosis (severe break with reality) due to a dementia syndrome or a serious mental illness.
 - There is a shortage of community housing for individuals with mental illness.
- Olmstead: Olmstead plans have the potential for including mental health needs in the care options that are developed. *The Olmstead Decision³ is being seriously underutilized in addressing needs of individuals with mental illness.*
- Non-compliance with medical treatment: “Non-compliant” typically means that someone is not doing what I want them to do. Think about your ombudsman role. Would you tell a senior who is exercising choice that he or she is non-compliant? As an ombudsman, your role is informing individuals about their rights and supporting them in exercising those rights. Imagine saying, “You take that bath at 7:00 in the morning or you’re being non-compliant.” Dr. Wehry has yet to meet someone who is on a court ordered medication who doesn’t resent it, even if the medication means that the individual no longer hears voices. Is “non-compliance” with taking medication for mental illness different from being “non-compliant” with taking medication for any other condition? Is there a different standard for an individual with mental illness to exercise the right to refuse treatment? Values bump up against each other in some situations. In the mental health field, practitioners are now beginning to re-examine their approach to helping individuals stay on medications. Increasingly, and more successfully, the approach is to use motivational techniques to encourage medication adherence.

³ In its landmark decision of June 1999, *Olmstead vs. L.C. and E. W.*, the United States Supreme Court ruled that the Americans with Disabilities Act (ADA) grants consumers new rights to live in something other than an institution when health or supportive services are needed. The decision applies to all governmental-funded programs and to all people with disabilities, without regard to age or the kind of disability. The Olmstead decision and resulting guidance from the Department of Health and Human Services (DHHS) construct both a federal legal foundation for nursing home alternatives and a process for the creation of the augmented non-institutional services. For more information, go to http://www.ltombudsman.org/ombpublic/49_369_1111.CFM.

As ombudsmen, you could try to engage the recovery movement⁴ in your community to help tackle motivation issues OR use some of the techniques yourself. See “what helps an individual stay on his or her medication” under resources.

- Preadmission Screening and Resident Review (PASRR): “The purpose of PASRR is to assess, through progressive screening, whether applicants for nursing facilities have mental illness or retardation, and if the nursing facility is an appropriate placement.”⁵ The 2006 report of the PASRR program found that the Level II screen, which more accurately identifies mental illness and assesses the need for specialized services, is where the process is falling down. If there is a change in the person’s mental or physical condition, PASRR must be repeated. Less than 10% of facilities were doing this. The report identifies several other issues and opportunities for advocacy.

- The oversight of PASRR is different in different states. The responsibility for PASRR is not clearly assigned in many states; therefore, the oversight slips. For individuals needing specialized services there may be limited services: for example, most states define specialized services as hospitalization. Who oversees PASRR in your state? Any discussion about what to do to meet the mental health needs in your state will involve a discussion of PASRR.

- The report makes several recommendations including that the Centers for Medicare and Medicaid Services increase its guidance to the states, clarifying the regulations. There are many recommendations to states, such as the need for more oversight, especially in the quality of the reviews and the follow-up. Recommendations to facilities include more training on PASRR and its implementation.

- Minimum Data Set (MDS), Resident Assessment Protocols (RAPS) and PASRR: The regulators have said that when an MDS reassessment is triggered, conduct another PASRR. However, the lack of oversight of PASRR leads to 10% or less of facilities actually repeating the PASRR.

- Quality Indicators: Twelve of the quality indicators link to mental illness and mental health. Quality Indicators were developed for use by the Centers for Medicare & Medicaid Services. The indicators are currently used in nursing homes and by surveyors to indicate areas of care that may be a potential concern within the facility. The indicators are derived from information submitted by the nursing staff on the MDS.⁶

Paradigm Shift

It is time for a shift in the paradigm for addressing health issues. The mental health approach has tended to be: diagnose, treat, manage. We need to start applying public health approaches to mental health policy. A public health approach means:

⁴ The recovery movement began as a mostly grassroots initiative based on the belief and goal that individuals with mental illness can recover. It encourages individuals to have hope, to trust their thoughts and choices, to enjoy the environment, and to feel alert and alive. Mental Health Ombudsman Training Manual. Module II. Susan Wehry. March 2004.

⁵ PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents. Linkins, K., Lucca, A., Housman, M. & Smith, S. U.S. Dept. of Health and Human Services. Substance Abuse and Mental Health Services Administration. Center for Mental Health Services. March 2006. p. 1. <http://download.ncadi.samhsa.gov/ken/pdf/SMA05-4039/SMA05-4039.pdf> or www.samhsa.gov

⁶ For more information, refer to *Nursing Home Quality Initiative Training Curriculum Manual For Long Term Care Ombudsman Programs*. Hunt, S. NASUA. December 2002. Available from NASUA (202- 898-2578).

- 1) looking at groups and not just individuals (addressing the health of a community or a population),
- 2) early identification through screening,
- 3) early intervention and treatment,
- 4) prevention (primary, secondary and tertiary), and
- 5) health promotion (including embracing the recovery movement).

It would be a big change in the culture of nursing homes for them to see themselves as a “health promotion environment.”

Underlying Assumptions for Advocacy

Dr. Wehry’s assumptions that may be useful guidance for ombudsman systems advocacy.

- Regulations build floors.
- Education raises ceilings.
- Individual action modifies the immediate environment.
- Quality improvement incentives work.
- Engagement gets results.

Action Tips

- **Learn the definition of serious mental illness.**

Find out the definition of serious mental illness that is used in your state. Know what you’re up against in advocating for individuals and in accessing services based on your state’s definition of illness and access to services. Identify mental health advocacy services in your state such as a mental health ombudsman or related mental health advocacy services.

- **Be specific about the mental health issues you want to address.**

When you sit at the table with others to talk about a systems approach to mental health issues, make sure that everyone knows: (a) whose needs you are discussing and (b) what needs you want to be the focus. For example, are you focusing on individuals with Alzheimer’s disease or individuals who have had a stroke? Young adults with psychiatric disabilities? Individuals who are “non-compliant?” homeless? isolated? without family support? Individuals at risk for suicide? Who are depressed? Anxious? All of these individuals are often lumped together under the phrase “mental health issues.”

- **Focus on how to meet the needs through collaboration.**

Focus on how we, *collectively*, deal with the needs of individuals with mental illness. Avoid arguing

about who “those people” belong to: mental health system, nursing homes, department of health, or to some other agency.

- **Engage the individual with a mental illness diagnosis in problem-solving.**

Is the individual amenable to developing a plan? Talk with the individual to help clarify his or her goals,

identify his residual strengths and usual coping strategies, and to define solutions to a given problem. In other words, try to engage the person as a partner in problem-solving. This is more do-able than it might be with a person with an advanced dementia. Ask how a particular medication affects daily functioning or what services or outcomes he or she wants. Learning from the individual is the same thing that helps us define solutions to a bigger problem related to groups of individuals, or to systems change.

- **Partner with others to advocate for solutions.**

Identify and connect with groups to partner with in advocating for solutions. Look to groups such as Psychiatric Survivors, National Alliance on Mental Illness, National Mental Health Association, and recovery groups in your area for potential partners. Move beyond provider organizations and state government agencies to connect with consumers.

What Ombudsmen Can Do

- Be prepared to engage others in dialogue about issues and solutions.
- Know your state's:
 - definition of serious mental illness and access to services.
 - resources such as the community mental health centers, designated agencies to oversee PASRR and the state's mental health authority, availability of waiver services specific to individuals with serious mental illnesses, and the organizations or groups in the self-help community.
 - Olmstead Plan and provisions that may apply to individuals with mental health needs.
- Give facility administrators and owners the benefit of the doubt. Assume that everyone has some good intentions.
 - Use data to compare facilities such as the data available on Nursing Home Compare⁷ and look for ways to use the Advancing Excellence Campaign⁸ to promote quality improvement activities.
 - Become better informed about issues, specific diagnoses, and services by using some of the resources included in this paper.
- Engage others to address issues on behalf of an individual.
 - Reach out to residents, work with resident councils and say, "I can be there if a problem comes up and you want me to be there."
 - Make a proactive offer to be present in the care plan meeting when a person has a mental health need. Participate in care planning upon request of the resident or provide information to enable the individual to be better prepared for his or her care plan meeting.

7 <http://www.medicare.gov/NHCompare>

8 <http://www.nhqualitycampaign.org/>

- Be sure that the resident attends and participates.
 - Facilitate discussion between the resident, the facility, and family. Try to lessen the dichotomous, “us, them” way of thinking.
 - Gain the perspective of the individual resident regarding issues and outcomes.
 - Establish, or confirm, a common language and use of terms.
 - Be specific.
 - Identify individualized community mental health resources such as compeer programs, mental health day treatment programs or drop-in centers.
 - Advocate for the development of an individualized “crisis plan” or self advocacy plan to promote a consumer driven plan and personal choice during times of an illness.
 - Acknowledge the broader systems issues such as the need for training, increased or consistent staffing, or for participation by a qualified mental health professional.
- Know the community resources or other resources that may be applicable such as a listing of local mental health therapists, mental health services, or a mental health crisis line.
- Participate in local or statewide training provided by your state National Alliance on Mental Illness (NAMI) chapter or Mental Health Association chapter such as, In our Own Voice or NAMI Basics.
- Engage others to address issues to improve systemic approaches and resources.
- Advocate for:
 - improved curriculum, at all levels,
 - better access to mental health networks, and
 - state legislation to create quality jobs and to conceive a housing strategy.
- Engage elected officials and regulators.
- Focus the dialogue on questions such as:
 - What should we do?
 - What housing options with services are available for individuals with mental health needs?
 - How should the institutions change? (This is not a question of who goes away and who stays.)
 - What alternatives do we need?
 - What barriers will be encountered?
 - What resources will be needed? (Consider using existing resources differently instead of assuming that all new resources are needed.)

Develop an Advocacy Strategy

- Objectives: What change do you want?
- Audiences: Who can make it happen?
- Message: What do they need to hear?
- Messengers: From whom do they need to hear it?
- Delivery: How can we get them to hear it?
- Resources: What is available?
- Gaps: What do we need to develop? Consider the use of technology in your strategy.
- First efforts: How do we begin? How do we lay the groundwork?
- Evaluation: How do we tell if it's working?
- Pick one issue and get to work!

EXAMPLES OF STATE ACTIVITIES:

New York

Mental Health Ombudsman Training Manual, developed by Susan Wehry, M.D., for the New York State Long-Term Care Ombudsman Program in partnership with the New York State Commission on Quality of Care for the Mentally Disabled. March 2004: The goals of the training program are: to increase the personal comfort and confidence of ombudsmen in their ability to work effectively with residents living in adult homes who have multiple, chronic health problems (both mental and physical); and by doing so, to increase the ombudsman's ability to advocate effectively *for* and *with* residents living in adult homes. The six hour training program consists of five modules designed for the adult learner. Each module includes a well-defined set of objectives, suggested strategies for presenting the material; a Power Point presentation; exercises; homework and supplemental reading. Dr. Wehry conducted a series of training programs, including a train the trainer session, for ombudsmen at their statewide conference. All State Ombudsmen received a copy of this training manual on a CD-Rom. It has a blue label and is titled, "Mental Health Ombudsman: Training Video." The manual is available from the National Long-Term Care Ombudsman Resource Center, www.ltcombudsman.org.

North Carolina

Long-Term Care Public Policy Conference and Long-Term Care Advocacy Day, 2007: One of three areas of focus for this day was current policy issues related to addressing the needs of persons with mental illness in long term care facilities. The North Carolina State Office of Long-Term Care Ombudsman and the North Carolina AAA Regional Ombudsman Association provided staff support, planning and coordination, along with other stakeholders, for the Friends of Residents' in Long-Term Care Education Committee that developed this conference and advocacy day. *Source: 2007 Annual Report, North Carolina State Long-Term Care Ombudsman Program.*

Study of Rules and Regulations Regarding Housing Individuals with Mental Illness in the Same Facility Vicinity as Individuals without Mental Illness. March 2008: This report was developed in response to a General Assembly law and was produced by an interdepartmental work group within the Department of

Health and Human Services. The State Long-Term Care Ombudsman was a member of the work group. Two regional long term care ombudsmen participated in a smaller work group that was convened to focus on training for direct care staff. The report covers three areas.

<http://search.nc.gov/DHHS/query.html>

1. Rules and regulations of North Carolina and other states regarding the provision of appropriate care and housing of individuals with mental illness in the same facility vicinity with individuals without mental illness, with recommendations relating to the housing of these individuals.
2. The need for training direct care workers in adult care homes to provide appropriate care to facility residents with mental illness and facility residents without mental illness, with recommendations for training, including fiscal impact.
3. Findings and recommendations pertaining to 1. and 2. above, along with any required statutory or rule changes.

Washington

The State Long-Term Care Ombudsman Program convened three training programs conducted by Dr. Wehry from September 29 – October 1, 2008. Each day targeted a different audience.

Day 1: Train the Trainers: An intensive for regional ombudsmen

Day 2: Bad Reps and Bum Raps: Why some residents seem harder to serve and how you can help (ombudsmen and regulators)

Day 3: Retooling Homes to Better Serve Residents with Complex Needs (providers)

The goals and objectives of each training day are in the appendix.

Wyoming

Several states have mental health ombudsmen. With advocacy and guidance from the State Long-Term Care Ombudsman, Wyoming was one of the first states to develop this position. It has responsibilities that are similar to those of the long-term care ombudsman, providing services to individuals with mental illness and their families, professionals, and other people advocating on behalf of individuals with a mental illness.

<http://www.wyoguardianship.org/WGC.html>

RESOURCES:

Curriculum for Long-Term Care Ombudsmen

Mental Health Ombudsman Training Manual, developed by Susan Wehry, M.D., for the New York State Long-Term Care Ombudsman Program. Refer to the preceding section (New York) for a description and information on how to obtain this curriculum.

Mental Health Advocacy for Ombudsmen, a DVD and Self-Study Guide. The goal of this self-study tool is to increase ombudsman confidence in effectively responding to residents who have multiple, chronic health problems (both mental and physical); and by doing so, to increase ombudsman ability to effectively advocate for residents with mental health needs. The DVD contains excerpts of Dr. Wehry's presentations to the New York LTCO in two parts. Worksheets and a resource guide are included to assist viewers in following the key points and principles presented. An answer sheet for each worksheet is also included as a tool for viewers to check their work. The DVD and self-study guide were distributed by the National Long-Term Care Ombudsman Resource Center to state and local ombudsmen in June, 2006. Contact NORC for more information, (202)332-2275.

Curriculum for Caregivers

North Carolina Interventions (NCI). The Division of Mental Health's training program aimed at preventing the use of restraints and seclusion. NC Interventions© (NCI) is a standardized training program to prevent the use of restraints and seclusion, created and supported by DMH/DD/SAS and used in all DMH/DD/SAS state facilities. The NCI Quality Assurance Committee oversees the integrity of the training program by training and monitoring Instructor Trainers and reviewing/ approving any changes or additions to the curriculum. <http://www.ncdhhs.gov/mhddsas/training/nci.htm>

Care with Confidence. The Wyoming Department of Health Mental Health and Substance Abuse Division in collaboration with the Wyoming Geriatric Education Center (WyGEC) at the University of Wyoming have developed an educational curriculum for certified nursing assistants (CNAs) who serve older adults in long-term care facilities. The training curriculum, Care with Confidence, was written by Rita Van Norman, LCSW of the Northern Wyoming Mental Health Center. This curriculum was developed for mental health practitioners to use in teaching CNA's about "behavioral problems" that are related to depression, dementia, delirium and anxiety. The focus is on non-medical interventions. Once the mental health practitioners have completed a "train the trainer" course, they are available, upon request, to conduct 1 to 3, four hour sessions for CNAs in nursing homes across the state. <http://www.uwyo.edu/geriatrics/>

Key Resources Identified by Dr. Wehry for Ombudsmen

Depression

Depression Toolkit. An educational resource that helps nursing homes conduct a self-assessment on where they are with their current policies and shows them step-by-step how to implement a depression screening, treatment and prevention program. It was developed by TMF's Health Quality Institute and the Mental Health Association in Texas. <http://nursinghomes.tmf.org> Click on "Other, Clinical," then "Depression."

Recovery

Boston University's Center for Psychiatric Rehabilitation. Information is available on how to register for trainings to learn and teach recovery techniques, how to sign up on-line to receive the Mental Health and Rehabilitation eCast and how to order printed materials such as Leroy Spaniol's Recovery Workbook. Contact information: Center for Psychiatric Rehabilitation, Boston University, 940 Commonwealth Avenue West, Boston, MA 02215. phone: (617) 353-3549, fax: (617) 353-7700. <http://www.bu.edu/cpr/>

National Empowerment Center. A consumer/survivor/expatient-led organization offering resources including a newsletter and information on an alternative to the P/ACT programs called PACE, Personal Assistance in Community Existence. <http://www.power2u.org/>

Reports

Administration of Mental Health Services by Medicaid Agencies. Report by: Verdier, J., Barrett, A., & Davis, S. for the U.S. Department of Health and Human Services. Substance Abuse and Mental Health Services Administration. Center for Mental Health Services. 2007. DHHS Publication No. (SMA) 07-4301 <http://mentalhealth.samhsa.gov/publications/allpubs/sma07%2D4301/>

PASRR Screening for Mental Illness in Nursing Facility Applicants and Residents. Linkins, K., Lucca, A., Housman, M. & Smith, S. U.S. Dept. of Health and Human Services. Substance Abuse and Mental Health Services Administration. Center for Mental Health Services. March 2006. <http://download.ncadi.samhsa.gov/ken/pdf/SMA05-4039/SMA05-4039.pdf> or www.samhsa.gov

Resource Guides: Several states have developed mental health resource guides for older adults. Two examples are listed.

Mental Health Services in Nursing Homes. An information sheet with seventeen questions to ask of every skilled nursing facility about providing for mental health needs. Mental Health/Aging Advocacy Project, Mental Health Association of Southeast Pennsylvania. Philadelphia, Pennsylvania. <http://www.mhaging.org/help/find-nh.html>

A New Hampshire Guide to Mental Health and Healthy Aging for Older Adults and Their Caregivers. National Alliance on Mental Illness, New Hampshire Chapter. Concord, New Hampshire. http://www.naminh.org/documents/GuideBk_OA.pdf

National Organizations with Numerous Resources

Advancing Excellence in America's Nursing Homes is an ongoing, coalition-based campaign concerned with how we care for the elderly, chronically ill and disabled, as well as those recuperating in a nursing home environment. www.nhqualitycampaign.org

National Mental Health Information Center. Substance Abuse and Mental Health Services Administration. Center for Mental Health Services. U.S. Department of Health and Human Services. Lists of mental health resources by state as well as other resources and information. Use this site to link to Action Plan for Prevention and Recovery, A Self Help Guide. <http://mentalhealth.samhsa.gov/>

National Alliance on Mental Illness (NAMI). The website contains information and resources. NAMI is

the nation's largest grassroots organization for people with mental illness and their families. Founded in 1979, NAMI has affiliates in every state and in more than 1,100 local communities across the country. <http://www.nami.org/>

Network of Care, recognized as a model program by the President's New Freedom Commission on Mental Health, provides vital information to help link consumers to support groups and personal advocacy resources in the community. The site also provides a repository of evidence-based practices – successful, creative ways for communities to respond to their behavioral-health needs. <http://networkofcare.org/home.cfm>

National Mental Health Consumers' Self-Help Clearinghouse. A consumer-run national technical assistance center serving the mental-health consumer movement. It helps connect individuals to self-help and advocacy resources and offers expertise to self-help groups and other peer-run services for mental-health consumers. <http://www.mhselfhelp.org/>

Older Women's League (OWL): Older Americans' Mental Health Week, an annual opportunity to spread the message that mental illness is not a normal part of aging, is a project of OWL. Older Americans' Mental Health Week is May 24-30, 2009. In 2008, OWL partnered with the National Network of Career Nursing Assistants (NNCNA) to conduct train-the-trainer sessions and training sessions for nursing assistants. Resources and additional information are available: <http://www.mentalhealthweek.org/Welcome.html> or via www.owl-national.org

UPENN Collaborative on Community Integration and the Bazelon Center have many resources. One publication, *In the Driver's Seat*, includes advocacy strategies and examples of existing programs' approaches to self-directed care. Fact sheets summarize important aspects such as financing. Ombudsmen may find the tips and checklist for advocacy to achieve a self-directed care approach very useful. *In the Driver's Seat* is available as a free download document. <http://www.bazelon.org/publications/index.htm>

Wellness Recovery Action Plan: A focus from "symptom control to prevention and recovery" Materials include a crisis plan. <http://www.mentalhealthrecovery.com/>

Susan Wehry

Susan Wehry, M.D, is a board-certified geriatric psychiatrist with added qualifications in geriatric psychiatry and a former Deputy Commissioner of Health. She is currently a consultant to the Vermont Department of Disabilities, Aging and Independent Living.

Dr. Wehry is a nationally recognized speaker and advocate for seniors. She has trained physicians, ombudsmen, administrators and direct care workers from Maine to Louisiana and was a featured speaker at the 2003 and 2006 National Citizens' Coalition for Nursing Home Reform's annual meeting. In 2002 and 2007, she assisted CMS in the development of national web-casts on mental health needs and individualized care planning in nursing homes. For the past two years, Dr. Wehry has been working on workforce development and stabilization with nursing homes hardest hit by Hurricanes Katrina and Rita.

Susan is honored to have received the 2002 Paul Dana Vanas award, presented by New York State Office for the Aging Long Term Care Ombudsman Program for her commitment to excellence in long-term care.

http://web.me.com/swehrymd/Susan_Wehry_MD/Home.html

The Changed Face of Long-Term Care ADVOCATING FOR ALL RESIDENTS: Tips for Ombudsmen

Joanne Chuslo, Long-Term Care Ombudsman

The human face of the long-term care environment has changed. It is no longer the exclusive domain of the now almost mythic frail, disabled older adult. Many nursing homes are also home to younger adults with complex needs due to traumatic brain injuries, serious and persistent mental illness and to older adults with challenging behavioral syndromes associated with dementia.

The ombudsman may find this increasingly complicated world intimidating. These tips were written to help you tackle this world. Let's look at three basic fundamentals of ombudsman work used in nursing homes and see how different scenarios might play out.

1. Resident's Rights
2. Interviewing and Problem-Solving
3. Access to Services

1. Residents' Rights

Suppose a facility wants to limit a resident's phone calls. This could be because the resident is calling his or her family at all hours of the day or night thus affecting their rights to privacy and comfort. A resident may ask for your help to make calls whenever she or he wants.

The resident's ability to negotiate or reason may be hampered by a brain injury, a stroke, dementia, a serious mental illness or a personality disorder. The diagnosis really needn't matter to the ombudsman. In this case, your first step is to understand, what is this resident's behavior trying to tell us? Why so many calls? Is the resident lonely, perhaps missing his family? Angry and trying to annoy someone? Forgetful and disoriented? Doesn't know that he's calling frequently or what time it is? Is the resident simply bored? What do you do?

Steps you could take to advocate, with the resident's permission, might be:

- 1) Ask the resident and family to agree on good times to call.
- 2) Ask the nurse or certified nursing assistant to facilitate calls during those times and to offer reminders about not calling at other times. Agree on how the staff will "prevent" calling at other times.
- 3) Request a special individualized care planning session to address the underlying unmet need (communication). Is a family meeting needed to address angry feelings? Are more meaningful activities needed to address boredom?

2. Interviewing and Problem-Solving

We all have our preferred ways of communicating. Some of us are direct. Some of us exaggerate. Some of us are indirect. All of us present problems from our own point of view –after all –it's usually the one that

is most important to us!

However, most of us can also step outside our point of view and see things from another's perspective. We can wait our turn to speak. We can listen to others even when we do not agree. This may not always be the case for individuals with traumatic brain injuries, major mental illness or serious personality disorders.

When interviewing any resident it helps to listen carefully and non-judgmentally. It also helps to ask for clarification if you're not sure what an individual means. Sometimes, it is helpful to tell the resident you'd like to get staff's perspective on a situation and ask if that is all right with the resident. If it is, invite the resident to join you as you talk with staff. For a resident who is unable to listen or to let another speak, you may have to tell the resident you'd like to speak with staff alone to get their perspective.

If the problem you're trying to help solve involves several people, the appropriate problem solving may include a group meeting putting all the pieces of the story together so that everyone has the same information.

Remember that a resident with any brain problem (mental illness or a brain injury) may find it harder to think, pay attention, process information, or speak up. The ombudsman plays a critical role in making sure there is enough time to address the resident's concern and that the information is presented and reviewed in a way the resident can understand. Writing down agreed upon solutions may also help.

Environmental solutions can help a resident with a need for more "travel" space: in one nursing home, the staff enlarged the room of one resident who liked to walk about by placing an easy chair outside his room at the end of the corridor. This became additional space for him. The near-by resident rooms had ribbons across their doors to remind him to stay out and to remind them to proceed carefully, allowing extra space between themselves and the other resident.

3. Access to Services

Since there are neither non-nursing home specialty facilities nor appropriate community housing, the nursing home is frequently the home of last resort for many younger persons with psychiatric disabilities and brain injuries. The goal should always be to help younger persons move toward recovery and discharge into the community.

What helps an individual stay on medication? Adapted from the New York State Ombudsman Curriculum Recovery Module

Susan Wehry, M.D.

Individuals who feel as though their concerns are heard and who feel they are truly partners in their own care are more likely to take their medication than those who don't. Individuals need support from all the members of their team and easy access to information that is easy to understand.

An ombudsman can help in this regard by reminding the staff and the person with mental illness, that mental illness is just like other medical illnesses. For example, if a resident says to you, "I don't want to take this medication for my voices", the ombudsman can respond first with, "why?" If the individual says, "I just don't want to", the ombudsman may say, "I understand that but it's sort of like diabetes isn't it? People with diabetes may not like taking insulin everyday but know they need to, to keep their sugars in control. Being free of voices is the same thing."

An ombudsman can also acknowledge that residents have a right to treatment as well as a right to refuse.

There are many understandable reasons an individual may not want to take psychoactive medications. Here are some that I have heard:

I feel funny when I take them.

I think they make me look funny.

I'm sick of people asking me about my medications.

I'm sick of being sick.

I want to see if I can do it on my own.

I have too many side effects.

I can't sit still.

They make me stiff.

They make me gain weight.

Despite these legitimate reasons, many individuals take the medications because they don't want their symptoms to re-emerge and because they make the connection that taking medications may help them reach other goals. Always remember: getting someone to adhere to a medication regimen is NEVER a goal unto itself. It is always a means to helping the individual reach his or her goal.

There are several ways to help individuals adhere to their program.

Suppose a resident says: "I don't want to take my medications. I have too many side effects. My doctor doesn't listen. I don't know what to say." One way to respond is to say, "Would you like me to tell the doctor for you?" Another way would be to say, "Have you told your doctor? How about if I help you learn how to talk to the doctor in a way he'll listen? I'll be your coach. We can practice."

If an ombudsman takes on this role of coach or partner in advocacy, here are the key questions to be sure the resident asks:

- What is the name of this medication?
- What is it supposed to do for me?
- What specific symptoms will this help with?
- How and when do I take it?
- Should it be taken with food or on an empty stomach?
- Are there any other medications I should avoid when taking this medication?
- Are there any foods I can't eat or beverages I can't drink on this medication?
- Is it safe to drink alcohol while on this medication?
- What are the most significant advantages of taking this drug instead of something else?
- How will I know I am experiencing a side effect?
- What should I do if I'm having side effects?
- How will I know if it's working?
- How long will it take me to feel the effects?
- When do I stop taking it?

APPENDIX D:

Washington State Long-Term Care Ombudsman Training Conference
Sept. 29, 30 and Oct. 1, 2008
Clarion Inn Conference Center - Yakima, Washington

DAY 1

Train the Trainers: An intensive for Regional Ombudsmen

Faculty: Susan Wehry, M.D., Consultant

Goals: At the end of this session, trainers will be better able to:

- 1) Address questions and concerns raised by staff, volunteers concerning clients who pose particular challenges
- 2) Train using adult learning principles

Objectives: Trainers will be able to:

- 1) Utilize and modify a curriculum for volunteers that addresses
 - a. The 4Ds
 - b. How to assist the self-defeating, help-rejecting, anxious or paranoid client
 - c. Personalities: why some people push our buttons
 - d. The need for intimacy in long term care settings and the rise of mislabeling residents as sexual predators
- 2) Identify resources for use in their trainings
- 3) Present a topic for volunteers on Day 2 or 3 of this intensive

DAY 2

Bad Reps and Bum Raps: Why some residents seem harder to serve and how you can help

Faculty: Susan Wehry, M.D., Consultant and Regional Ombudsmen

Goals: At the end of this session, ombudsmen and regulators will be better able to:

- 1) Engage and serve clients who challenge them, especially those with mental health needs
- 2) Know where and how to obtain additional resources
- 3) Help prevent involuntary discharges

Objectives: At the end of this session, volunteers will be able to:

- 1) Discuss the 4Ds and their relevance to long term care
- 2) Discuss recovery as it pertains to mental health and describe its importance to your work
- 3) Engage residents who are self-defeating, anxious, help-rejecting or push your buttons

DAY 3

Retooling Homes to Better Serve Residents with Complex Needs

Faculty: Susan Wehry, M.D., Consultant and Regional Ombudsmen

Goals: At the end of this session, providers will be better able to:

- 1) Engage and serve residents who challenge them, especially those with mental health needs
- 2) Avoid unnecessary discharges

Objectives: At the end of this session, providers will be better able to:

- 1) Discuss the 4Ds and their relevance to long term care
- 2) Strategize for obtaining mental health resources
- 3) Describe gaps in staff training and create a plan to deal with them
- 4) Discuss the challenges related to intimacy needs, sexual desire, diminished capacity and maintaining a safe environment for all.