

Advocacy Network News

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Effective Advocacy – Our Only Service

Nov/Dec 2003

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Comments about our newsletter? Need to contact us with a question or concern?

Please write: *Advocacy Network*, P.O. Box 2071, Amherst MA 01004-2071.
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Advocacy Network
All volunteers
advocating for
all retarded persons

President’s Message

Americans with Disabilities Act Provides Important Protection

AR (fictional initials) arrived at his annual Individual Service Plan (ISP) meeting and said he wanted to use his tape recorder. You see, AR has a reading disability. He often uses the tape recorder to make up for this disability. AR’s new service coordinator, Lorna Green, phoned Area Director William Zimmer’s office. Zimmer (or his agent) denied AR the use of his tape recorder. AR said he felt humiliated and upset following this denial.

Can Department of Mental Retardation bureaucrats stop reading-disabled people from recording their ISP meetings? NO! This denial violates the Americans with Disabilities Act (ADA). The law requires agencies such as DMR to provide assistive technology for people with disabilities. The ADA is an important and well-publicized law.

The Americans with Disabilities Act prohibits state and local agencies from discriminating against parents and friends of people with mental retardation.

Zimmer’s office violated AR’s federal rights. They may not have realized that this violated AR’s protected rights. Regional Director Terry O’Hare certainly understood the issue. Her response was clear. AR will no longer face this form of humiliating denial.

The ADA covers relatives and friends of persons with mental retardation. The law prohibits state and local agencies

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President, cont.

from discriminating against parents and friends of people with mental retardation. But what if agency officials treat people with disrespect? Is this simply bad manners? It could be more than that. Disrespectful and obstructionist behavior can discourage people from supporting the rights of a loved one with mental retardation. When agency people discriminate against parents and friends in this manner, such actions can rise to the level of an ADA violation.

I will have more to say about the ADA in future issues of *Advocacy Network News*. For example, when DMR and its vendor agencies deny mentally retarded people adequate mental health services, or fail to properly monitor such services – and this leads to injury and/or premature death – where does the liability lie? Is this an ADA matter for the U.S. Department of Justice to pursue?

– Dr. William Knaus
President



State Official's Remark Unacceptable

We all remember from our childhoods, the phrase, “Sticks and stones can break my bones, but names can never hurt me.” That was a line we often heard from our parents, teachers, or other adults when, as kids, we complained that some bully had made a hurtful remark.

While this piece of advice may be true, we still recognize the power of names or words to hurt, whether intentionally, or by accident. And we certainly recognize the power of words to influence public opinion.

An incident recently reported by the Associated Press in *The Herald News* (Boston), *The Worcester Telegram*, and *The Republican* (Springfield) illustrates that power. During an October address to the Greater Boston Chamber of Commerce, Eric Kriss, Governor Romney’s Secretary of Administration and Finance, referred to Medicaid recipients as “takers,” that is, people who receive more benefits through state services than they pay in taxes.

Individuals afflicted with mental retardation comprise a significant portion of those who receive free health care as Medicaid recipients in Massachusetts, and it's true that they receive more benefits than they pay in taxes.

But there's a world of difference in tone between the word "recipient" and the word "taker." "Taker" conjures up an image of selfish opportunists running amok, grabbing everything in sight. Whether his word choice was deliberate, or merely unfortunate, Mr. Kriss has come under considerable fire, and rightly so.

News reports indicate that John E. McDonough, Democratic leader of the Legislative Health Care committee, and executive director of an advocacy group called Health Care for All, was particularly critical: "It is so demeaning to cast people in that light and deeply troubling ... It's important and it matters that the state's chief financial officer views people this way."

The use of the word "taker" in this context cannot be ignored.


Senator Richard T. Moore, Democrat of Uxbridge, is reported to have called Kriss's remarks "disingenuous and divisive ... blaming the victim." Senator Moore is further quoted: "The kind of divisive rhetoric that was used in the State of the State address earlier in the year, and in Secretary Kriss's comments ... needs to be tempered if the governor truly supports care reform."

Governor Romney, offering no apology for Kriss's word selection, reportedly asked those involved to "tune the rhetoric down in the building." The governor recognizes a potentially volatile issue when he sees one. But while Governor Romney is right to ask that cooler heads prevail, the use of the word "taker" in this context cannot be ignored.

One measure of a caring society is how it perceives its most needy and vulnerable citizens. And labeling individuals with mental retardation "takers" because they receive Medicaid benefits is simply not acceptable from a high-ranking state official.

– Edward Orzechowski,
Advocacy Network Board of Directors

Reader Participation

 We know from many phone calls and letters that the current condition of the Massachusetts economy is having a direct impact on the services being provided to the mentally retarded. But we realize there are situations we haven't yet heard about that may need addressing. We invite you to respond to the following **Reader Participation Question:**

Have the latest state budget cuts affected the care being provided to your family member or friend with mental retardation? If so, how?

Please let us know. We've made it even easier to contact us, either by sending a letter, giving us a call, or now through e-mail. Thank you for your response.

US Mail

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Preventive Health Standards for Adults With Mental Retardation: Recommendations for Community Practitioners

[**Ed. note:** The information on this page is a portion of a brochure compiled in May of 2002 by the Center for Developmental Disabilities Evaluation and Research at the Shriver UCDD at UMass Medical School. It is re-printed here, formatted to fit this newsletter, with permission of the Massachusetts Department of Mental Retardation. The entire brochure is available by contacting DMR.]

The Periodic Health Review

This brochure was designed to assist the clinician and other caregivers in assuring quality preventive health care to adults with mental retardation. Many adults with mental retardation are involved in their own health care and are able to make decisions regarding their own health. The following suggestions may assist the clinician in supporting persons with mental retardation and improve any health care encounter.

PREPARATION

Many adults can be helped to feel more comfortable at a medical visit if they feel adequately prepared for the event. Family or support staff can be encouraged to introduce unfamiliar items such as a stethoscope or a blood pressure cuff at home to allow the instrument to become more familiar, and facilitate cooperation during an exam.

During the exam, it is helpful to prepare patients for procedures by explaining them well, or allowing patients with sensory impairments to explore the instruments that are about to be used. Performing simple examinations in an office or quiet waiting room may reduce a person's anxiety.

If someone is particularly anxious, or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment. In some cases, multiple procedures can be performed while the patient is sedated

(dental work, or routine blood work, for example) to reduce the number of times a person is exposed to the risks of sedation.

COMMUNICATION

First direct your questions to the patient to determine their own perception of their health care status and needs. If communication is a problem, clinicians may have to rely on a family member or support staff to provide information relating to signs or symptoms of health concerns. Questions regarding changes in the individual's behavior and adaptive function can bring underlying physical and mental health issues to light.

ADULT PREVENTIVE CARE RECOMMENDATIONS

Based on Massachusetts Health Quality Partnership (MHQP) Adult Preventive Care Recommendations 2001. <http://www.mhqp.org/> Guidelines and discussion of risk factors are for the general population. Modifications to meet the health concerns of the population with mental retardation are below. Risk factors remain the same as the general population unless specified.

Health Maintenance Visit
Recommend Annually for all age groups.

CANCER SCREENING

Mammography

Follow MHQP recommendations. If procedure is difficult to complete for behavioral or body habitus reasons, recommend every two years when annually was recommended.

Pap Smear

Every 1-3 years at physician discretion. Risk factors outlined in MHQP standards. Women will likely need considerable preparation for examination. For women who will require conscious sedation or general anesthesia:

- If unlikely to have been sexually active, withhold testing until other invasive testing done.
- For women with prior sexual activity, every 1-3 years, depending on risk factors.

Colorectal Cancer Screen

Annual fecal occult blood testing recommended beginning at 50 unless high risk. If endoscopy considered important, recommend colonoscopy if need for general anesthesia is likely. For high risk clients, follow MHQP recommendations.

Prostate Cancer Screen

Not routine until age 50 and then at physician/patient discretion after consideration of risks and benefits.

Skin Cancer Screen

Periodic total cutaneous examinations targeting populations at high risk for malignant melanoma.

OTHER RECOMMENDED SCREENING

Hypertension

Recommend yearly screening and at all acute visits.

Cholesterol

Five year intervals or at physician discretion.

Diabetes (Type II)

Fasting Plasma Glucose screen for high risk individuals with minimum five year testing interval for all.

Osteoporosis

Consider risks of medications and in all patients with hypothyroid, mobility impairments. Screen as appropriate.

INFECTIOUS DISEASE SCREENING

Chlamydia and STDs

Screening should be done on same schedule as PAP smears. See above.

HIV

Periodic testing of individuals defined as increased risk.

Hepatitis B and C

Periodic testing of individuals defined as high risk.

Tuberculosis

Skin testing performed on individuals every 1-2 years according to MHQP standards and identification of risk factors.

SENSORY SCREENING

Glaucoma

At least every 3-5 years. More frequent with risk factors. Screening likely to be more successful using Tonopen.

Hearing and Vision

Careful history regarding observed changes in behavior. Screen annually when possible.

MENTAL AND BEHAVIORAL HEALTH

Depression

Recommend screening for sleep, appetite disturbances, weight loss, general agitation. Ask questions appropriate to developmental level with less emphasis on subjective verbal explanations of internal states.

Dementia

In persons with Down Syndrome, recommend annual screening for dementia beginning at age 40.

GENERAL COUNSELING AND GUIDANCE

Recommend appropriate counseling to individual and support staff regarding healthy lifestyle at annual visit and acute visits. Annually counsel caregivers to be alert to ways to prevent household injuries (fall prevention, choking prevention, fire/burn prevention). On all visits be alert to behavioral signs of abuse of neglect. Routinely ask patients direct, specific questions about abuse, including sexual abuse. Sexuality counseling should include genetic counseling, assessment and discussion of parenting capability, as well as folic acid supplementation as appropriate.

COMMONLY UNRECOGNIZED HEALTH PROBLEMS

(Adapted from Tyler, C.V. [1999] Medical Issues for Adults with Mental Retardation. High Tide Press, Homewood, Illinois)

Gastrointestinal Problems:

Dysphagia, esophagitis, constipation, bowel impaction, gastroesophageal reflux disease (GERD)

Sensory Impairments

Visual and Auditory

Chronic/Recurrent Infections

Most commonly sinusitis and otitis media.

Oral Disease

Infected teeth, periodontal disease. Referred pain may affect behavior or function.

Respiratory Diseases

Chronic obstructive pulmonary diseases (COPD).

Musculoskeletal Conditions

Degenerative joint disease, osteoporosis. Long-term polypharmacy may contribute to

Neurological Conditions

Compressive neuropathies from contractures or use of walkers, seizure disorders.

Approximately 30% of adults with MR/DD have syndromes and unique health problems requiring additional screening.

DOWN SYNDROME

Hearing concerns (up to 50%), ocular problems (up to 50%), hypothyroidism (15%), seizure disorders (5-10%), atlantoaxial instability (10%), premature senescence (increased rate), other musculoskeletal problems.

CEREBRAL PALSY

Strength and ROM should be monitored regularly. Particular attention to areas of swallowing, bowel and bladder function in people who are not independent for mobility.

OTHER SYNDROMES

Clinicians are advised to gather necessary information regarding health issues for syndromes that are known to be associated with an individual.

OTHER SOURCES OF INFORMATION

General Internet Resources

Developmental Disabilities: Resources for Health Care Providers

<http://www.ddhealthinfo.org/ggrc/index.asp?ParentID=2835>

Family Village

<http://www.familyvillage.wisc.edu>

Alliance of Genetic Support Groups

<http://www.geneticalliance.org>

National Organization for Rare Disorders

<http://www.rarediseases.org>

Resources for Specific Conditions

In addition to the general sites listed above, many organizations created for individuals with specific conditions disseminate and publish their own valuable health related materials.

Health Care Guidelines for Individuals with Down Syndrome

<http://www.denison.edu/dsq/health99.shtml>

National Fragile X Foundation

<http://www.fragilex.org.html/intervention.html>

Prader-Willi Syndrome Association

<http://www.pwsausa.org/support/medalert.html>

[Ed. note: The actual DMR brochure excerpted above also includes a helpful Health Screening Guidelines Wall Chart which depicts the ages at which recommended procedures and screenings should occur.]

Advocacy Network's **2003 Honor Roll of Donors**

Advocacy Network could not continue to function without your financial support. We are an all-volunteer organization, funded by the dues and donations of individuals who care about the well-being of the mentally retarded. Our Board of Directors thanks both the people listed below, and those many others who wish to remain anonymous, for their generous donations during 2003. The help of such caring contributors strengthens our efforts to advocate for all of our relatives and friends. On behalf of all those who suffer from mental retardation, ***thank you all for your generosity!*** The following individuals contributed beyond the basic membership fee.

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Membership Dues Unchanged

At our June meeting, the Board of Directors voted to maintain annual membership dues at \$20, instead of instituting the increase previously announced in the May/June edition of *Advocacy Network News*. While state budget cuts are certainly having an impact on DMR services for the retarded, we also recognize the impact of current economic times on our members. Please help us to continue to be your advocacy group by renewing your membership now, or by joining as a new member. Please clip and fill out the form below and mail it with your check to the address at the top of this page. *Thank you for your continuing support!*



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