People With Disabilities Foundation
507 Polk Street, Suite 430 San Francisco, CA 94102
Tel: 415-931-3070 Fax: 415-931-2828 Oakland: 510-522-7933
www.PWDF.org

December 11, 2013

SENT VIA CERTIFIED MAIL, No. 7004-0550-0000-1511-8085
James. L. Madara, MD
Chief Executive Officer and Executive Vice President
American Medical Association
AMA Plaza
330 No. Wabash Ave.
Chicago, IL 60611-5885

SENT VIA CERTIFIED MAIL, No. 7004-0550-0000-1511-8108
Saul Levin, MD
Chief Executive Officer and Medical Director
American Psychiatric Association
1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209

SENT VIA CERTIFIED MAIL, No. 7004-0550-0000-1511-8115
Charles H. Norman, DDS
President
American Dental Association
211 East Chicago Ave.
Chicago, IL 60611-2678

RE: Request to Create Task Force to Address Health Disparities of Persons with Psychiatric, Intellectual and/or Developmental Disabilities

Dear Drs. Madara, Levin, and Norman:

INTRODUCTION

People With Disabilities Foundation (PWDF), a 501(c)(3) public operating non-profit based in San Francisco, CA, is seeking to create an interdisciplinary task force to address health care disparity in treating people with psychiatric, intellectual, and/or developmental disabilities, with the goal of eliminating the health care disparity that affects such individuals. We are asking the American Medical Association (AMA) and the American Psychiatric Association (APA) to create a task force comprised of mental health care and primary care professionals to develop protocols and procedures for primary health care providers (PCPs) that will address and prevent health care inequalities for people with severe mental illness (SMI), intellectual disabilities, and/or developmental disabilities (DD). A related task force was created in 2004 to determine the effect of psychotropic medication on the metabolic system, which can result in obesity and diabetes aggravation.[1] (See American Diabetes Association, American Psychiatric Association, American Association of Clinical Endocrinologists, North American Association for the Study of Obesity, "Consensus Development Conference on Antipsychotic Drugs and Obesity and Diabetes.")

BACKGROUND

Research has shown that, as a group, persons with SMI have a 13-25 year shorter life expectancy than that of the general population.[2] This shorter life span is primarily due to physical illnesses, primarily cardiovascular diseases, respiratory conditions, and metabolic dysfunction.[3] For example, multiple studies have shown an association between schizophrenia and tobacco use.[4] And it is widely accepted that smoking cigarettes causes COPD. In response, PWDF recently held a free, public seminar entitled "Overcoming Barriers to Physical Health Care Access – People with Mental Disabilities Have Shorter Life Spans." PWDF's seminar identified barriers to physical health care access and provision of service for people with mental disabilities, as well as discussed methods of overcoming those barriers.

Through this seminar, our prior work, and research into this subject, we have become aware of instances of disparity/discrimination by health care professionals in the provision of services for people with psychiatric, intellectual, and/or developmental disabilities. This includes instances in which patients with mental health diagnoses had not received medical or dental services, apparently because of their mental health diagnoses. For example, we are aware that an orthopedist intentionally avoided seeing an individual with painful scoliosis who also had schizophrenia written across the front of his chart from a S.F. county

hospital. In a second example, an individual reported that she had been refused dental treatment after informing the dentist she was taking Seroquel; the dentist told the patient he required her complete mental health chart before performing dental surgery. The dentist agreed to continue oral surgery only after the patient objected and refused to provide the chart. Over 30 years of published studies validate this anecdotal evidence of disparity in provision of services as being a factor in the poor physical health outcomes of those with mental disabilities.[5]

LACK OF ADEQUATE POLICIES, PROCEDURES AND BEST PRACTICES

PWDF has subsequently conducted extensive research and consulted with experts to determine whether relevant professional organizations or government agencies had any policies, procedures, and/or best practices in place to prevent this type of occurrence. We researched this issue from both the medical professional point of view and from the federal compliance point of view. Notably, ***none*** of the medical experts we asked knew of anything in place that would prevent or deter this type of conduct resulting in disparate access to physical health care. Thus, even if policies to prevent "discrimination" are in place, they are not so widely known so that service providers are aware of them.

Our research of AMA and American Dental Association (ADA) policies was compelling because of what was not included. One of our experts pointed out that discriminatory behavior, as mentioned above, violates several AMA Principles of Medical Ethics; e.g., lack of respect for patient rights,[6] honesty in professional interactions,[7] including most importantly the very general principle that "A physician shall support access to medical care for all people."[8] Our expert noted that these principles could be in conflict with a physician's right to "be free to choose whom to serve."[9]

We found that neither the AMA nor the ADA have rules that specifically provide guidance/protocol to preclude this lack of equal access to physical health care by those with psychiatric, intellectual, and/or developmental disabilities. The AMA Ethics Opinion that does address discrimination only specifically prohibits discrimination on the basis of race, gender, and sexual orientation.[10] Although that ethics opinion states that other bases of invidious discrimination are also barred,[11] and the AMA Code of Medical Ethics provides additional opinions addressing disparities in health care for some populations,[12] it does not have any policies, procedures or practices that address discrimination or disparity in health care for patients with *psychiatric, intellectual, and/or developmental disabilities*.

What is needed is a protocol that is reasonably calculated to put all medical doctors on notice as to what procedures should be used to prevent disparate and/or unequal health care access when treating persons with psychiatric, intellectual, and/or developmental disabilities.

At least until 2007, neither the U.S. Department of Justice nor the U.S. Department of Health and Human Services' Office for Civil Rights has any guidance to prevent health care providers from screening out persons with mental disabilities.[13]

REQUEST FOR PARTICIPATION ON INTER-DISCIPLINARY TASK FORCE

Given the significantly shorter life span of this population and the lack of concrete procedures to prevent discrimination in the provision of health care services on the basis of psychiatric, intellectual, and/or developmental disability, we propose the formation of an interdisciplinary task force to create guidance to clarify a protocol in this area for primary care providers and specialists.

Medical professionals in other parts of the world have addressed this concern and their solutions offer guidance. For example, in parts of Great Britain, a policy of integrated mental and physical health care is being pursued by using template letters in which psychiatrists communicate to the GPs (the primary care physicians) about the pertinent details of a patient's psychiatric treatment including diagnoses, medications, side effects of medications, follow-up blood panels, and other monitoring.[14] This template letter requirement has proven successful after an audit.[15] Also, Great Britain's medical health providers (GPs) are recommended to monitor the physical health of patients with psychosis at least once a year because of shorter life spans. Although the U.S. Patient Protection and Affordable Care Act of 2010 includes patient-centered medical home (PCMH) demonstration projects in which providers must "develop and implement interdisciplinary, inter-professional care plans that integrate clinical and community preventive and health promotion services for patients,"[16] we believe it is unlikely that this part of the statute will resolve these issues at this time.

In the U.S., we have not seen similar longitudinal requirements.[17] AMA policies H-90.975, "Enhancing Physicians' Interest in Medical Care for People with Profound Developmental Disabilities"[18] and H-90.976 "Medical and Dental Care for People With Developmental Disabilities"[19] are steps in the right direction but do not provide any specific guidance. AMA policy H-285.921, "Managed

Behavioral Health Organizations (MBHOs)"[20] is more specific; however, it does not go far enough. We noted that the APA and the American Diabetes Association have guidelines for monitoring metabolic risk because of the side effects of psychotropic medications; these include frequency of monitoring for BMI, blood pressure, fasting blood glucose, and fasting lipid profile, among others.[21]

The members of the AMA and ADA clearly are subject to the Americans with Disabilities Act[22] and often to Section 504 of the Rehabilitation Act of 1973[23]. We are proposing an interdisciplinary task force to create policies that will eliminate disparities in access to and provision of health care services for people with psychiatric, intellectual, and/or developmental disabilities. We propose this task force comprise PCPs, dentists, and psychiatrists/psychologists because we believe it will be the most effective way to develop a sustainable solution.

We thank you for your attention to this matter. We hope you will agree to join us in establishing a task force to address this important issue. We believe the U.S. Health and Human Services' Office of Civil Rights and SAMHSA provide free technical assistance in this area.

Moreover, if you currently use a policy, or know of one, that addresses this issue and is known (or should be known) by all doctors or a similar policy applicable to dentists in the U.S., we would appreciate if you would provide us with this information. I look forward to hearing from you within 30 days.

Sincerely,

Steven Bruce
Interim Executive Director & Legal Director
People With Disabilities Foundation

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[1] American Diabetes Association, American Psychiatric Association, American Association of Clinical Endocrinologists, North American Association for the Study of Obesity, *Consensus Development Conference on Antipsychotic Drugs and Obesity and Diabetes*, J Clin Psychiatry 65:2 (2004), *available at* http://www.psychiatrist.com/issues/diabetes.pdf.

[2] Marc De Hert et al., *Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care*, US National Library of Medicine, National Institutes

of Health, World Psychiatry 2011; 10:52-77 (2011) *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3048500/.

[3] *Id*.

[4] Joy L. Johnson, et al., Gender-specific profiles of tobacco use among non-institutionalized people with serious mental illness, BMC Psychiatry 2010, 10:101 *available at* http://www.biomedcentral.com/1471-244X/10/101; Jose de Leon & Francisco J. Diaz, A meta-analysis of worldwide studies demonstrates an association between schizophrenia and tobacco smoking behaviors, Schizophrenia Research, Vol. 76, Issue 2, Abstract (July 15, 2005) *available at* http://www.schres-journal.com/article/S0920-9964(05)00075-7/abstract.

[5] *See* David Lawrence & Stephen Kisely, *Inequalities in healthcare provision for people with severe mental illness*, J Psychopharmacol. 2010 November; 24(4_supplement): 61–68 *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2951586/ ("[D]isparities in health care provision …include[e] healthcare provider issues including the pervasive stigma associated with mental illness…" "Barriers to effective healthcare provision for the mentally ill [include] provider issues… At the provider level there are the effects of **stigma**, time and resource constraints, and the possibility of regarding physical complaints as psychosomatic symptoms.") (emphasis added) ("…there are barriers to people with SMI accessing primary care. Some primary care physicians see patients with SMI as being disruptive to their practices or feel uncomfortable treating them" (citing Goodwin et al., *Psychiatric symptoms in disliked medical patients* J Am Med Assoc 241: 1117–1120 (1979); Karasu et al., *The medical care of patients with psychiatric illness,* Hosp Community Psychiat 31: 463–472 (1980))). *See also* Mario Maj, *Physical health care in persons with severe mental illness: a public health and ethical priority*, World Psychiatry. 2009 February; 8(1): 1–2 *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2645006/ ("the quality of physical health care received by persons with severe mental illness is poorer than the general population" and "primary care providers should overcome their reluctance to treat persons with severe mental illness. They should learn effective ways to interact and communicate with these persons: it is not so much an issue of knowledge and skills; it is mostly an issue of attitudes.").

[6] AMERICAN MEDICAL ASSOCIATION, PRINCIPLES OF MEDICAL ETHICS, Principle IV (2001) *available at* http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page?.

[7] *Id.* Principle II.

[8] *Id.* Principle IX.

[9] *Id.* Principle VI.

[10] AMERICAN MEDICAL ASSOCIATION, AMA CODE OF MEDICAL ETHICS OPINION 9.12, PATIENT-PHYSICIAN RELATIONSHIP: RESPECT FOR LAW AND HUMAN RIGHTS (2008) *available at* http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion912.page ("physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, gender identity, or any other basis that would constitute invidious discrimination").

[11] *Id.*

[12] *See, e.g.*, AMERICAN MEDICAL ASSOCIATION, AMA CODE OF MEDICAL ETHICS OPINION 9.121 RACIAL AND ETHNIC HEALTH CARE DISPARITIES (2005) *available at* http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion9121.page; AMA CODE OF MEDICAL ETHICS

OPINION 9.122 GENDER DISPARITIES IN HEALTH CARE (1994) *available at* http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion9122.page.

[13] Sara Rosenbaum, *The Americans with Disabilities Act in a Health Care Context*, *in* THE FUTURE OF DISABILITY IN AMERICA app. D. (Institute of Medicine (US) Committee on Disability in America; Field MJ, Jette AM, eds., 2007) *available at* http://www.ncbi.nlm.nih.gov/books/NBK11429/ ("The fact that physical and hearing access should dominate the U.S. Department of Justice complaint process is not surprising and should not be taken as a sign that perhaps more subtle forms of discrimination aimed at avoiding certain patients does not exist. Overt physical and communication barriers are the most visible forms of discrimination, as are architectural barriers and the failure to promote the accessibility of services through the use of specialized equipment. However, health care entities can engage in other, more subtle forms of discrimination, such as the refusal to serve "disruptive" patients or members of Medicaid managed care plans." (citing Sara Rosenbaum, Peter Shin, Marcie Zakheim, et al., *Negotiating the New Health System: A Nationwide Study of Medicaid Managed Behavioral Health Care Contracts*, Vols. 1-2 (Washington, DC: Center for Health Policy Research, The George Washington University Medical Center (1997)) "**Neither the U.S. Department of Justice nor the Office for Civil Rights at the U.S. Department of Health and Human Services maintains written interpretive guidelines related to services to qualified persons with mental disabilities by public facilities or places of public accommodation.**") (emphasis added).

[14] Kamini Vasudev, MD DNB MRCPsych and Brian V Martindale, FRCP FRCPsych, Physical healthcare of people with severe mental illness: everybody's business! Ment. Health Fam. Med. 2010 June; 7(2): 115-122 *available at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2939459/.

[15] *Id.*

[16] Patient Protection and Affordable Care Act § 3502 (c) (4), 42 U.S.C. § 256a-1 (2011).

[17] The PCMH model described herein requires primary care providers operating under this section of the ACA to provide the care team with access to participant health records and meet regularly with the care team to ensure integration of care. *See* Patient Protection and Affordable Care Act § 3502 (d), 42 U.S.C. § 256a-1 (2011).

[18] AMERICAN MEDICAL ASSOCIATION, POLICY H-90.975 ENHANCING PHYSICIANS' INTEREST IN MEDICAL CARE FOR PEOPLE WITH PROFOUND DEVELOPMENTAL DISABILITIES *available at* http://134.147.247.42/han/JAMA/https/ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=%2fresources%2fdoc%2fPolicyFinder%2fpolicyfiles%2fHnE%2fH-90.975.HTM (last visited Nov. 15, 2013).

[19] AMERICAN MEDICAL ASSOCIATION, POLICY H-90.976 MEDICAL AND DENTAL CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES *available at* http://134.147.247.42/han/JAMA/https/ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=%2fresources%2fdoc%2fPolicyFinder%2fpolicyfiles%2fHnE%2fH-90.976.HTM (last visited Nov. 15, 2013).

[20] AMERICAN MEDICAL ASSOCIATION, POLICY H-285.921 MANAGED BEHAVIORAL HEALTH ORGANIZATIONS (MBHOS) *available at* http://134.147.247.42/han/JAMA/https/ssl3.ama-assn.org/apps/ecomm/PolicyFinderForm.pl?site=www.ama-assn.org&uri=%2fresources%2fdoc%2fPolicyFinder%2fpolicyfiles%2fHnE%2fH-285.921.HTM (last visited Nov. 15, 2013).

[21] American Diabetes Association, American Psychiatric Association, American Association of Clinical Endocrinologists, North American Association for the Study of Obesity, *supra* note 1.
[22] 42 U.S.C. § 12182 (2011).
[23] 29 U.S.C. § 794(a) (2011). Jurisdiction is conferred if your members receive federal funding, e.g., Medicare or Medicaid.