

Respect Enrollee Choice about Sharing Psychiatric Information

One of the primary barriers to integrating behavioral and physical health care is the persistent stigma that society, including many health care professionals, place upon individuals receiving behavioral health service. This stigma has been persistent over many decades and health care professionals are not above reproach. In one study, for example, nurses were found to act as “stigmatizers,” carrying negative attitudes founded on the belief that individuals with mental health issues are dangerous, weak and to blame for symptoms.¹ While theoretically, better health care decisions would be the result of complete information about the person receiving services, this is not always the case in practice.²

Unfortunately federal and state law do not protect the sharing of psychiatric information other than progress notes among persons treating an individual. Diagnoses, medications, and treatment plans are shared without the consent of the person being served. Lack of control of psychiatric information may lead to:

- Avoidance of needed behavioral health care;³
- Lack of forthrightness that can undermine care and research into best practices;⁴
- Inadequate physical health care;⁵
- The spread of misinformation, damaging in health care settings, as well as in other settings (e.g., employment).⁶

Therefore, the Implementation Council should recommend that MassHealth should require ICOs to:

1. Establish electronic health records that segregate psychiatric information, not just progress notes.
2. **Require consent by the enrollee before psychiatric information is shared with any provider⁷** and documentation of a conversation of the benefits and risks of sharing information in the medical record.
3. Allow the individual the ability to revoke the sharing of information at any time.

While electronic records may help spread valuable information to providers, they also can spread erroneous information quickly. Therefore, MassHealth should:

1. Adopt criteria as set out in DMH Policy 95-5r to be used by the ICOs that specify when and how an enrollee’s own behavioral health records may be withheld from the enrollee, including documentation of the rationale for the failure to provide an enrollee access to their own records, ensuring that the least amount of information possible will be withheld, if any. Denial of records should be appealable to the MassHealth Board of Hearings.
2. Require ICOs to provide a meaningful way to allow enrollees to correct electronic and other health records.

MassHealth also should ensure that people with lived experience are active participants in the development of any privacy policies.

¹ C Ross and E. Goldner. “Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: a review of the literature.” 16. *J Psychiatric and Mental Health Nursing*. 558-568 (2009).

² See e.g., G. Thornicroft, *Discrimination in health care against people with mental illness*, 19 *International Review of Psychiatry* 113 (2007) (“There is strong evidence that people with a diagnosis of mental illness, for example, have less access to primary health care and also receive inferior care for diabetes and heart attacks. . .” (citations omitted)); M. Graber, et al., *Effect of a Patient’s Psychiatric History on Physicians’ Estimation of Probability of Disease*, 15 *J. Gen. Internal Med.* 204 (2000) (One survey of 300 family physicians determined that “past psychiatric history influences physicians’ estimation of disease presence and willingness to order tests.”); S. Parle, *How does discrimination affect people with mental illness?* 108 *Nursing Times* 28:12-14 (2012) (physical symptoms ignored); R. Hall, *Physical Illness Manifesting as Psychiatric Disease*, 37 *Arch. Gen. Psychiatry* 989-95 (Sept. 1980) (One hundred patients were intensively evaluated for the presence of unrecognized medical illnesses that might have affected their hospitalization. Forty-six percent of these patients suffered from physical, medical illnesses previously undiagnosed by their physician and which physical, medical illnesses either directly caused or greatly exacerbated their psychiatric symptoms. An additional 34% of patients were found to be suffering from at least one other undiagnosed physical, medical illness requiring treatment though unrelated to their psychiatric symptoms.).

³ The reaction to stigma results in a desire for more privacy. See O. Wahl, *Mental Health Consumers’ Experience of Stigma*, 25 *Schizophrenia Bulletin* 467 (1999) (In a survey of 1,301 mental health consumers, the majority tried to conceal their illnesses due to associated stigma and “worried a great deal that others would find out about their psychiatric status and treat them unfavorably.”)

⁴ Consumer Action, Ensure “meaningful use” by giving consumers control (June 2009), http://www.privacy-information.org/articles/ensure_meaningful_use_by_giving_consumers_control_over_their_health_information (last accessed December 13, 2012)

⁵ Persons with psychiatric histories are all too familiar with the repercussions of being told that physical ailments are “all in the head,” from delayed diagnoses of mononucleosis, lupus, and a viral infection causing balance problems to near-fatal misdiagnoses of congestive heart failure and anaphylaxis.

⁶ See, e.g., J. Tse, *How accurate is the electronic health record? – a pilot study evaluating information accuracy in a primary care setting*, 168 *Stud Health Technol Inform.* 158-64 (2011) (Inaccuracies in medication lists were reported in 51% of records reviewed with 32.1% of all medications being inaccurately recorded.).

⁷ Obviously, an exception to this rule would be applied if the person is unconscious or otherwise unable to give consent.