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August 28, 2012

Phyllis Hyman, Esq.
Patricia McCooey, Esq.
Department of Social Services
25 Sigourney Street
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Re: Concerns with DSS's Draft Consent Documents and Process for Secure Provider Portal

Dear Phyllis and Trish:

We have had a chance to review the draft documents you provided to the Care Management Committee of the Medical Assistance Program Oversight Council concerning the Department's proposal to allow primary care providers to access electronic medical records concerning their assigned patients' treatment by other providers in the Medicaid system, which you refer to as the Secure Provider Portal. We fully support this important effort and agree with Department representatives that the Portal will speed access to helpful information in treating and coordinating care for Medicaid enrollees. Nevertheless, we are concerned that these documents, and the process underlying them, if implemented as currently intended, will make it unlikely that Medicaid enrollees will see these documents, and, if they do, will result in the enrollees having great difficulty in exercising their rights. This is critically important in light of the Department's intention to automatically allow sharing of an individual's protected medical information **in the absence of affirmative opting-out** (except for certain sensitive information specially protected by statute).

We appreciate that you wish to allow for meaningful consent, notwithstanding that the default will be the ability to share records in the absence of any statement from the enrollee. But the proposed process, while having a veneer of effective consent, will assure neither actual privacy protection nor consumer engagement. We therefore urge changes to the underlying documents, and the proposed process they are based on, so that these concerns can be met, while allowing work toward the laudable goal of consensual electronic medical record sharing with treating primary care providers to proceed.

Suggested Changes to Process and Documents

We initially note that we do not agree with the Department's starting place that virtually all of an enrollee's medical records available electronically within the Department's system should be shared with their treating primary care provider without any affirmative consent by the individual. Even if not

legally required other than for the three particular categories of sensitive information, this is highly problematic. Allowing this to occur means that, defaults being what they are, the vast majority of enrollees will never actually make a decision to share their medical records but find that those records have been shared with their primary care provider anyway. In addition, for these and other reasons, all of our surrounding states now use opt-in consent for all patients in their electronic health record exchanges, **including for Medicaid**. We think that you should reconsider this basic decision.

Nevertheless, if you insist on an affirmative opt-out procedure, then, at a minimum, the slant of the documents and the inadequacy of the process for reaching out to enrollees to ensure they really know their rights and have a meaningful opportunity to withhold consent must be corrected. Some of the problems with the documents and the process include:

- There is no requirement for a signature or other acknowledgement by the patient that they saw these forms. Even HIPAA requires that, so we have some indication that the individual was actually informed of their rights. This is especially important if, as you propose here, the default is that consent will be assumed, and electronic medical records will be shared, in the absence of receiving any written consent from the enrollee. Each enrollee must have signed something acknowledging receipt of the written guidance about their rights (in their language) before their records may be shared.
- The forms are heavily one-sided.
 - They only mention the benefits of sharing information (and we agree there are many); there is no mention of the risks.
 - Breaches are not mentioned, nor are the penalties, how patients will be notified, and the means to report breaches if a patient believes their information has been inappropriately released.
 - There is no discussion of sensitive information that is **not** legally protected and can be shared, even without a completed opt-in form, such as information about abortions, contraceptive use and non-HIV Sexually Transmitted Disease diagnoses and treatment.
 - There is no acknowledgement that if a patient opts out, providers can and will still share their information the way they do now. They will not receive less service; they may just not be able to access comprehensive patient information **as quickly** without the new portal.
- There is no independent number to call for consumers with questions – no privacy officer. You have to call the program that is promoting the portal to get any answers, and it is not realistic to expect that this will result in balanced information being provided. An independent entity or individual should be listed, such as the Office of the Healthcare Advocate.
- The FAQs are written at grade level 10.3 – this is not a consumer-friendly communication.
- It must be extremely clear to consumers that opt-ing out will not impact their access to care in any way. And it must be made clear to providers that they cannot refuse to care for, or in any way pressure, patients who wish to opt-out.
- The FAQ says consumers **can't** opt-out for emergency purposes. But it does not say who will decide if it is an emergency. Will there be audits to identify patterns of violations, i.e. providers

who have a large number of “emergencies” and are just too rushed to take a proper history, providers who have a lot of “emergencies” on Friday afternoons? Are there provisions to ensure that if an audit report finds a problem, that there will be follow up with that provider to change their behavior? At a minimum, the FAQ should clarify that DSS will be auditing to ensure that this “break the glass” option is used only in true emergencies.

- The forms are complicated and ask for more information than they need. Every extra question on a form leads to fewer people filling it out.
 - For instance, the form asks for an email address. Consumers could think they have to have one to complete the form. Putting the word “optional” in the e-mail box, as well as in the telephone number box (for those who have no telephone), should help allay this concern.
 - It would be extremely helpful if the forms were pre-populated with the patient’s information, if this is possible. Who knows their HUSKY/Charter Oak ID #? In general, individuals are more likely to fill out a form if they don’t have to do research to complete it.
- The opt-out form says to mail it back to an address on the form. There should be a postage-paid, pre-addressed envelope mailed with it; even a 45 cent stamp is an impediment for very low income Medicaid enrollees.
- How will these be distributed? The FAQ implies that people will only get these by mail (notoriously unreliable) and on the website (less than notoriously unreliable), but this raises concerns:
 - Other states have found that websites, advertising, and other communications don’t work. Rather, the place people will most likely pay attention to consent is at a medical visit (as with HIPAA forms), so distribution through Medicaid providers needs to be implemented.
 - Will there be incentives to get providers to ensure every patient sees these documents, and has an opportunity to talk with a human being about the risks? Also, providers should accept the signed forms for submission to DSS, rather than requiring patients to take them home, get an envelope (and possibly a stamp) and mail it back.

To address some of the above concerns, we have attached a marked up FAQ document to show some changes we would like to see in it, using the word tracking changes feature. Other changes that we have suggested above go beyond the FAQ document.

In addition, we would urge that all four of the opt-out/consent forms for people to sign include this statement at the top:

“If you opt out of allowing your primary care provider to receive electronic health information through the Secure Provider Portal, your provider still will be able to access medical records from your other providers, just as he or she does now; and you should receive the same treatment either way. However, if you opt out, the receipt by your primary care provider of medical information from these other providers may be delayed.”

And the two forms concerning Consent to Disclose Sensitive Health Information should also say:

"This affirmative release is needed in order for your primary care provider to receive sensitive health information concerning mental health treatment, alcohol or drug treatment, and HIV-related information in electronic form. However, other sensitive medical information about you may nevertheless be shared with your primary care provider in electronic form unless you opt-out of the sharing of electronic health information entirely, using the Opt-Out Request form available at [website] or by calling [Toll-free tel. number]."

Even with all of the above changes, we have serious concerns that patient choice will be protected and respected. In addition, it appears that almost all of the above problems would be solved by simply requiring an opt-in rather than an opt-out process. Accordingly, we urge you to seriously reconsider the basic decision to go with an opt-out procedure with the default being the broad sharing of patient records with providers for whom such affirmative consent was never provided; providing for opting in to such sharing, as our neighboring states are doing, seems to be the far better policy choice.

We greatly appreciate your serious consideration of these concerns and suggestions. We also would be happy to meet with you to discuss our concerns in greater detail, so that we can work toward the common goal of broad sharing of Medicaid enrollees' medical records with treating primary care providers to facilitate treatment, while protecting their privacy rights and assuring meaningful consent.

Thank you.

Sincerely yours,



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