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## Testimony in Opposition to House Bill Number 5499

### GAE Committee

March 7, 2016

Good afternoon Senator Cassano, Representative Jutila, Senator McLachlin, Representative Smith and members of the committee. Thank you for the opportunity to testify in opposition to HB 5499, "An Act Concerning The Preservation Of Historical Records And Access To Restricted Records In The State Archives."

As a democratic society, we are legally, morally, and ethically obligated to protect all vulnerable populations within our society. The Federal Government set precedent with protection of vulnerable populations by utilizing the Belmont Report to construct stringent guidelines for research that became "The Common Law." This law is designed to protect vulnerable populations **with special attention to those who have been institutionalized** due to the duress of their illness and environment.

In this spirit of protection and advocacy, as a Representative of the vulnerable populations of the State of Connecticut and as a healthcare professional, **I oppose HB 5499**. This bill sets precedent with far reaching implications for some of our most vulnerable citizens. Although the premise of historical research into State archival (medical) records appears innocuous on its surface, the deeper implications of this bill must be brought to light.

To begin, the stigma associated with mental illness is a matter of common knowledge within our society. This stigma is often an insurmountable barrier to those who need help. The stigma is real and the implications from carrying a psychiatric diagnosis are real. Mental illness is never a disease unto the affected individual. It is a disease that affects the entire family unit, even the family lineage. The fact is, that there have been genetic links tied to bipolar disorder, schizophrenia, and other mental illnesses. Exposing the diagnosis of mental illness of an

individual, in fact, exposes the entire family and its descendants. Maintaining confidentiality of mental illness exceeds the lifetime of the affected individual. The desire for continued confidentiality extends to the living family and descendants in the case of mental illness.

Confidentiality is critical to the relationship of trust between the physician and the patient. If that trust is shattered, if the guarantee of confidentiality is removed, even after being deceased, then the patient may not be forthcoming and outcomes will be affected. The need for trust is even greater with disadvantaged populations. There is infinitely more risk associated with being forthcoming. *Studies have documented the fact that mental health patients will avoid care if they are not certain of their provider's privacy policies. Another study reported that mental health patients revealed even less information to their providers when the limits of confidentiality were explained in a way that they understood.* Confidentiality, to this patient population is so important that they will compromise the quality of their treatment and outcomes rather than risk exposure.

The Provision of Connecticut General Statutes/Medical records states that ... "all parts of a medical record shall be retained for a period of seven (7) years from the last date of treatment, or, upon the death of the patient, for three (3) years." This then begs the question as to why any patient, who has happened to receive care from the State of Connecticut, would have their records retained beyond the mandate of the statute. Why would their records be archived? If this were to be attempted in the private sector, the courts would not be able to contain the litigious fall-out.

Lastly, and possibly, most importantly, the new modifications of the HIPPA Rule passed in January of 2013 are being misconstrued for use in this legislation. There is no mandate for the retention of records for 50 years. The mandate for record retention is set by the individual States. **The rule mandates PROTECTION FOR 50 YEARS NOT AUTOMATIC DISCLOSURE THEREAFTER!**

Further, the law clearly states that "disclosure of health information is permitted to family members who were involved in the individual's care or payment for care, UNLESS THE INDIVIDUAL HAD EARLIER EXPRESSED A PREFERENCE OTHERWISE." First, this rules out historians completely. Secondly, it suggests that the person has the capacity to determine how they want their medical information handled after their passing. The fact is that a percentage of the mental health population are not capable of understanding or giving or denying permission in regard to this critical issue. Many mental health patients who have been institutionalized have conservators because they cannot make these choices. This underlines the level of their vulnerability and the degree to which their protection is paramount.

In summation, this bill furthers inequity between the private sector and the most vulnerable sector of our society who are served by the state. It sets precedent for two different sets of rules for those who have and those who have nothing. The bill is a perversion of a Federal guideline suggesting a statute that does not exist and was not intended. At no point is removing or compromising patient confidentiality acceptable. That is why the HIPPA laws were created and are enforced. Every citizen has a right to have their medical record remain private for as long as

they choose, even into the hereafter, if that is their wish. There are extremely few legally justifiable reasons for breaching their wishes and their trust. HB 5499 does not constitute one of them.