



Illinois Alcoholism and Drug Dependence Association  
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*Testimony submitted to the Data Security and Privacy Committee of the ILHIE Authority Board from Eric Foster, Chief Operating Officer, Illinois Alcoholism & Drug Dependence Association, March 29, 2012, on behalf of Bruce Suardini, CEO, Prairie Center Health Systems Inc.*

On March 21, 2012, Prairie Center Health Systems, Inc. CEO, Bruce Suardini, and Assistant Director, Gail Raney, met with groups of clients to get their feedback regarding confidentiality of substance abuse treatment records in a health information exchange. A total of 25 clients participated, 9 outpatient services consumers and 16 residential services consumers. Of these, 16 were males and 9 were females. At the beginning of each group, Mr. Suardini and Ms. Raney explained the concept of health information exchanges (HIE) and briefly reviewed current confidentiality laws related to substance abuse treatment records. Below is a summary of the feedback from consumers who participated in these focus group discussions.

Overall, consumers relayed that they would be hesitant to participate in an HIE if substance abuse treatment records were included. They voiced concerns about not having a say in who, specifically, would have access to their substance abuse treatment records if these records were part of a larger medical record. Consumers were also apprehensive about re-release of substance abuse treatment records if they became part of a larger medical record. Questions such as, "Could an employer find out about my substance abuse treatment history?" and "Could an attorney more easily access my substance abuse treatment record?" were asked during these discussions.

When asked whether they would choose to participate in a health information exchange, opinions varied. One client replied, "Because I am comfortable in my Recovery, I have already told my doctor about my substance use history on my own. I don't think he needs access to my whole substance abuse treatment record." The issues related to stigma surrounding substance use disorders were a major reason for clients to state they would not feel comfortable with their substance abuse treatment record being part of an HIE record. "Would I get the same quality of medical care if a doctor knew about my substance use history?" one consumer asked.

Some liked the idea of limiting access to substance abuse treatment records to only life threatening situations where the consumer/patient was unable to give medical provider information about their substance use disorder/history. Most relevant to them was that they not be given addictive medications during medical treatment.



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Others recommended that only certain parts of the substance abuse treatment record be included in the HIE record, as substance abuse treatment records contain more than just medical/physical health related topics. Some of these include criminal history, family history, history of emotional trauma, etc. In addition, consumers worried about how information in substance abuse treatment case notes would be used in a medical setting. Many felt that having substance abuse treatment records as part of the larger medical record would inhibit some substance abuse treatment clients from telling the full truth in therapy, with some even indicating it would have kept them from seeking substance abuse treatment in the first place.

Finally, when the discussion turned to whether the model would be an opt-in versus an opt-out model, clients felt an opt-out model would create a problem in that it would “red flag” people who chose not to participate in an HIE.