FOR IMMEDIATE RELEASE

East Central Human Rights Authority
Report of Finding
Case 13-060-9007
Saint Mary's Presence Hospital

The East Central Regional Human Rights Authority, a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegation concerning behavioral health services at Saint Mary's Presence Hospital in Kankakee.

Complaint:

The hospital discharged a patient with a developmental disability to a nursing home without consent from his guardian.

If found substantiated, the allegation represents a violation of hospital regulations (42 C.F.R. 482.13), and the Illinois Probate Act of 1975 (755 ILCS 5/11a-23).

COMPLAINT STATEMENT

Per the complaint an individual who was blind, nonverbal, and had a developmental disability was battling the final stages of cancer. He had been a chemotherapy patient for years. It was recommended by the patient's oncologist that he did not appear to be benefitting from chemotherapy anymore and needed palliative care. (*Palliative care* is medical care provided by physicians, nurses and social workers that specializes in the relief of the pain, symptoms and stress of serious illness.) A Do Not Resuscitate order (DNR) was initiated after the patient was hospitalized and intubated. He needed skilled care with specialized tracheotomy care upon discharge. The former home where the patient had lived refused readmission due to the staff's inability to provide for his medical condition. He was reportedly discharged by the hospital on Saturday and died the following Tuesday; he was completely unfamiliar with the nursing home, its staff and the other residents. It was the understanding of the guardian that if he was to be discharged it was to the hospice unit at the hospital. The guardian's wishes, which were reportedly not followed, were for the individual to be given the opportunity and dignity to die in a familiar environment and with familiar staff. There was also a concern that since this patient was nonverbal and could not communicate for himself, he would not have someone to communicate for him since his regular guardian would be unavailable on the weekend.

The HRA proceeded with the investigation having received written authorization to review the patient's record. To pursue the matter, the HRA visited the hospital where the

hospital and behavioral health representatives were interviewed. Relevant practices and sections of the patient's record were reviewed.

INVESTIGATIVE INFORMATION

Interviews

The HRA met with hospital representatives that included a representative from risk management, the chief financial officer (CFO), and the licensed clinical social worker (LCSW).

Hospital Staff explained that they staff 130 beds. The average stay is 3-5 days. They receive many patients with disabilities because of several large state facilities and group homes in the surrounding area. The geographic area that is served includes Kankakee, Iroquois, Livingston and Ford Counties. The hospital is a not-for-profit facility.

The HRA asked how this patient was discharged. Staff explained that the DNR was initiated at the hospital because of the patient's condition. Staff were aware that this patient had a guardian. On 9/28/12 the social worker made a call to the guardian after the patient had been in the facility for 10 days. The patient's previous home would not allow the patient to return because he would be on oxygen. The hospital and the guardian communicated on 10/2/12. The hospital would provide more information to the guardian to complete the DNR. The guardian would work on completing the DNR order and also stated that he wanted hospice and palliative care for the individual.

Hospital staff explained that on 10/5/12, there was an attempt to contact the guardian, but he was not available. The social worker spoke with the senior attorney at the guardian's state agency and he requested more information be obtained from the facility to complete the DNR order. On 10/5/12 through 10/9/12 the patient was taken off of ventilation and was still functioning. On 10/10/12 the social worker spoke with the guardian who stated that he wanted the patient to be sent to a specific nursing home, and receive hospice care from one of the hospices available in the area. On 10/13/12 the patient was discharged to the nursing home previously specified by the guardian.

The HRA pointed out that the patient was discharged on Saturday and died on Tuesday morning. Staff were asked if there was there a reason the transfer could not have waited until his regular guardian would be back on Monday to provide guidance. Hospital representatives stated that they would not have moved the individual if they could have foreseen him passing within the next couple of days.

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The HRA explained that there was some concern tied to this complaint that several nonverbal individuals with developmental disabilities had been discharged by the hospital on the weekends, holidays and evenings to long term care facilities without consultation with their guardians. The hospital staff reiterated that in this case they had consent from this individual's guardian.

The HRA was provided a tour of the facility and observed patient rights posted at the hospital. They also had the rights in printed handouts both in English and Spanish which were reviewed by the HRA.

Records Reviews

The guardian's documentation states that the patient was sent to the emergency room with an elevated temperature on 9/16/12 and was admitted to the hospital. He was admitted with bilateral pneumonia, dehydration, hypernatremia and sepsis. He had been intubated to prevent cardiac arrest. He had a gastric tube for feeding and had been put on a ventilator for acute respiratory failure. It was determined at his last oncology follow-up appointment that no additional chemotherapy was recommended, but palliative care was appropriate.

On 10/05/12 a DNR order was completed by the senior attorney of the state agency that oversees the individual's care based on the recommendation of the patient's physician. It was documented that, effective 10/13/12, the patient was discharged from his prior home retroactively. The guardian documented per a conversation with the social worker at the hospital, that staff are requesting consent to be given for the patient to be transferred to a skilled nursing facility. The patient was out of the intensive care unit and continued to need respiratory support. The previous facility would not accept him back because of medical care needs, especially continuous oxygen. The guardian agreed to the referral to nursing home and to hospice. On 10/15/12 documents were sent to the guardian for the patient to receive hospice care, which the guardian signed. On 10/17/12, the patient died. Per the death certificate, the cause of death was cardiopulmonary arrest and aspiration pneumonia. He died at the nursing home to which he had been transferred.

CONCLUSION

Per the record the guardian gave consent for the patient to be transferred to the nursing home and to receive hospice care. The Probate Act of 1975 (755 ILCS 5/11a-23) states, "(b) Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian, standby guardian, or short-term guardian that is not clearly contrary to the law, to the same extent and with the same effect as though the decision or direction had been made or given by the ward. Any person dealing with the guardian, standby guardian, or short-term guardian may presume in the absence of actual knowledge to the contrary that the acts of the guardian, standby guardian, or short-term guardian conform to the provisions of the law. "

According to the Medicare/Medicaid Conditions of Participation for Hospitals pursuant to 42 C.F.R. 482.13, "A hospital must protect and promote each patient's rights. The hospital must inform each patient, or when appropriate, the patient's representative (as allowed under State law), of the patient's rights, in advance of furnishing or discontinuing patient care whenever possible. The patient has the right to participate in the development and implementation of his or her plan of care. The patient or his representative has the right to make informed decisions regarding his or her care. The patient's rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment."

In this case the patient was unable to communicate for himself because of his disability and the progression of a terminal illness. He had a court appointed guardian who made decisions on his behalf. Per the guardian's own record, the guardian gave consent for the patient to be

transferred and receive care, including hospice care, at the nursing home. Per the record of the hospital, staff had obtained the guardian's consent. The hospital could have waited after the weekend to transfer the patient, but they could not have anticipated exactly when the patient would have died. Based on the evidence in the record, the complaint, **the hospital discharged a patient with a developmental disability to a nursing home without consent from his guardian is unsubstantiated.**

The HRA would like to thank Presence Saint Mary's Hospital staff for their cooperation with this investigation.