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HUMAN RIGHTS AUTHORITY- CHICAGO REGION

REPORT 17-030-9006
SAINTS MARY AND ELIZABETH MEDICAL CENTER

Case summary: The HRA substantiates the complaint that the guardian was denied her right to take part in the care and decision making for her ward.

INTRODUCTION

The Human Rights Authority of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at Saints Mary and Elizabeth Medical Center (St. Mary's). It was alleged that the facility prevented the guardian from exercising her right to take part in the care and decision making of her ward and that the physician refused to speak with the guardian and address concerns regarding her ward's care. If substantiated, this would violate the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-107) and the Illinois Probate Act (755 ILCS 5/11a-17a).

Saints Mary and Elizabeth Medical Center is the former St. Mary of Nazareth and St. Elizabeth Hospitals that were operationally joined in 2003 under the Resurrection Healthcare System. The St. Mary of Nazareth Hospital incorporates three floors of adult behavioral health treatment with a total of 120 beds.

To review these complaints, the HRA conducted a site visit and interviewed the Director of Behavioral Health, the Nurse Manager, and the Social Worker. Hospital policies were reviewed, and the adult recipient's clinical records were reviewed with written consent.

COMPLAINT SUMMARY

The complaint indicates that the recipient was admitted to St. Mary's Hospital on 6/30/16 for a psychiatric evaluation. On 7/01/16 a guardian ad litem was appointed for the recipient and then on 7/06/16 the recipient's mother was appointed guardian and the hospital social worker notified the guardian that on that day she had received the Letter of Office. Allegedly, the recipient's guardian requested to speak with the recipient's physician but was informed by the social worker that there is no access to physicians beyond messages that are left on sticky notes on the recipient's file. The guardian was reportedly told that the physician is self-employed and in private practice with no office.

Although the social worker had notified the physician that the guardian requested to speak with him, he did not contact the guardian until after the recipient was discharged. Allegedly, the guardian was never given the right to have input into her ward's care and never signed consents for her treatment, medication, treatment plan or discharge.

FINDINGS

The hospital record indicates that the recipient was admitted to the emergency department (ED) on 6/29/16. The chief complaint is stated as, "24 year old female presents to the ed after found walking around a coffee shop. Patient was reported missing a few days ago, is from a nursing home. Apparently she escaped the home and today called mom from an unknown number. Mom reported to the [fire department] and brought to ED. Patient states she left, was moving around, 'with her people and her locations'. Very tangential and cannot obtain appropriate history. Denies any pain, denies any voices." ED notes entered at 11:41 a.m. indicate that the recipient's mother was notified and her phone number is listed in the notes. On 6/29/16 at 1:48 p.m. the recipient was medically cleared for admission to the behavioral health unit with a diagnosis of Chronic Schizophrenia, and she then signed an application for voluntary admission.

The recipient's Behavioral Health Psychosocial Assessment, dated 6/30/16, is included in the record. It states, "Patient Approached in room. Is open to approach and cooperative with interview. Patient presents as mildly delusional, however is fairly high functioning. Appearance is disheveled with good hygiene. Patient's mood is euthymic, affect is flat. Patient is a fair historian with poor insight. Patient's mother called in tears and was wondering how to seek temporary guardianship. Patient refused release of information to speak with mother. Patient does not seem to be responding to audiovisual hallucinations at time of interview. Patient appears stated age. Patient is a 24 year old Caucasian female admitted voluntarily to [St. Mary's] on 6/29/16 with an admitting diagnosis of acute psychosis under the care of Dr… . Per ED notes, Patient was found wandering around a [neighborhood] coffee shop after she had eloped from [a nursing home] and had been gone a few days. At interview, Patient reports that she was placed 'psychiatrically-ly' and they told her she could leave whenever she wanted and 'people kept telling other people to tell me to leave', so she left. Patient denies suicidal ideation/homicidal ideation/audiovisual ideation stating 'negatory.' Patient denies substance use/abuse again stating 'negatory.' Tox screen positive for cocaine." The Assessment also indicates that the recipient received an injection of Invega Sustenna every 28th of the month, however because she had eloped, she had missed her current dose of this medication. The record shows that the recipient's medications from her nursing home were continued at St. Mary's.

The record contains the recipient's Psychiatric Evaluation, completed 7/01/16. It states that the recipient is "floridly psychotic" and unmanageable in a less restrictive environment. The provisional diagnosis is Paranoid Schizophrenia. The following day the recipient was again seen by her physician for psychotherapy and although she was compliant with her medication she remained actively hallucinating. Nursing Progress Notes from 7/04/16 indicate that the guardian ad litem had visited the recipient to "explain guardianship and her rights" to her. Notes also state, "Patient's mother, … has applied petition for guardianship. Copies filed in chart. Social

Worker notified through voicemail. Attorney would like Social Worker to contact as she will be faxing legal paperworks."

The clinical record contains the Letter of Office indicating that on 7/06/16 the recipient's mother had been appointed temporary plenary guardianship of her daughter for a period of 60 days. Physician Notes from 7/07/16 again indicate that the recipient was seen for psychotherapy and he states, "…The patient appeared to be responding to Zyprexa. She is a bit calmer. The patient is tolerating her Invega Sustenna shot. She now agrees to return to her [nursing home]. Unfortunately, the patient remains very delusional. She now claims that the Zyprexa makes her fall out of bed and is refusing to take it. We discussed medication options. The patient agreed to Seroquel augmentation." Notes from 7/06/16 also state, "Social Worker received more papers from [guardian ad litem]. Pt's mother is now pt's temporary legal guardian until 9/06/16. SW to contact mother regarding pt's care and discharge." Also on 7/07/16 Nursing Notes indicate that RN spoke with the patient's mother regarding medication changes. She notes, "… Okay to give and relayed that she wanted to speak with the doctor regarding Sustenna Invega." Social Work Notes from 7/07/16 state, "SW spoke to pt's mother. [She] reports that she wants [her ward] to be discharged back to [her former nursing home]. SW called [staff] at [nursing home] to confirm that pt can return and to see if [staff] needed additional documentation from SW…."

A Physician Note from 7/08/16 states, "…Zyprexa was discontinued at pt.'s request due to complaint of falling out of bed, and she was started on Seroquel at night yesterday. She has tolerated this medication change well without any noted side effects. Pt. has been well behaved while on the unit over the past week and not required PRN [as needed] meds for the past three days. She requests additional medication to help with feeling of mild anxiety during the day, for which temporary Xanax use was discussed. The pt. agreed to trial low dose Xanax during the day, after explaining risks and potential side effects. As per Social Work note her mother has been made her temporary legal guardian, and requests to speak with her psychiatrist. This writer called mother's number twice, but she did not answer. A generic message was left stating that another attempt to reach her would be made again tomorrow."

On 7/08/16 the Licensed Social Worker met with the recipient's mother and they discussed treatment issues: "SW discussed mother's concerns regarding not speaking to MD. SW explained the legality of guardianship, explaining that since temporary guardianship paperwork was received she should be informed of all medication changes prior to administering to the patient. Pt.'s mother stated that the patient had been given Invega Sustena in 10/2015 and it was an ineffective treatment. Pt.'s mother asked why no medical records follow the patient from hospital to hospital. SW explained limitations of electronic charting and HIPAA. Pt's mother stated understanding of systemic limitations, but continued to express concerns about treatment. Patient's mother continues to request a call from MD about course of treatment for patient."

A Nursing Note written on 7/09/16 states, "Mother came during visitation hours and gave a letter for Dr… [Attending Physician]. Letter in chart. Please relay to MD." The physician then noted on 7/10/16 "…I again tried to contact the patient's mother without success… ." A Discharge Note entered by the Resident Physician on 7/11/16, the day of discharge, states, "… Mother is temporary legal guardian, multiple attempts to call her at number

provided by Social Worker were unsuccessful." A Physician Note written by the recipient's psychiatrist on 7/09/16 states, "The patient actually has remained compliant with medications. She is guarded and withdrawn, but her behavior is actually more appropriate. She is more directable. The patient's mood was euthymic. She is pleasant. I again tried to contact the patient's mother without success. She denies suicidal or homicidal thoughts and agrees to return to [her former nursing home]."

The record contains the Medication Administration Record which lists the psychotropic medications which were administered to the recipient during her hospitalization:

Invega Sustenna 234 mg administered intramuscularly 7/01/16 and administered every thirty days.

Haldol 5mg administered twice PO (orally) on 7/05/16 and also on 7/04/16 prn for anxiety

Ativan 2mg administered PO 7/10/16, twice on 7/05/16 and on 7/04/16 prn for anxiety

Zyprexa 10mg administered PO on 7/06/16 and 7/05/16 for anxiety

Seroquel 50 mg administered PO 7/07/16 for anxiety

Seroquel 100 mg administered PO on 7/10/16, 7/09/16, and 7/08/16, for anxiety

Xanax 0.25 mg administered PO 7/11/16, administered twice on 7/10/16, administered twice on 7/09/16, and on 7/08/16 for anxiety

The record contains the recipient's Medication Consent document signed by the recipient on 7/05/16. This form shows that the physician determined that the recipient had decisional capacity and she consented to the following psychotropic medications: Ativan, Haldol, and Zyprexa. There is no informed consent given for Invega, Seroquel, or Xanax.

HOSPITAL REPRESENTATIVES' RESPONSE

Hospital representatives were interviewed regarding the complaint. They indicated that generally when guardians request to speak with a physician, the physician will be paged or a note will be placed on the patient's chart indicating that he/she should contact the guardian. In this case, the Social Worker left messages for the physician as well as his resident, to call the guardian. The record shows that the physician, the resident, and the Social Worker, all attempted to contact the guardian however she was not able to be reached. It was noted that the recipient did not wish for information to be shared with her parent when she was initially admitted to the hospital and that the guardianship did not become effective until 7/06/16. The recipient was discharged on 7/11/16, so there was a period of four days in which staff attempted to contact the guardian. Staff also indicated that the record shows that the guardian did have input into the recipient's care by her discussion of the medication that was administered to her daughter and her approval of discharge plans.

Hospital representatives were interviewed regarding the recipient's medications and the lack of consent from either the recipient or her guardian. They indicated that the recipient's medications were continued from her nursing home placement, although the regimen had been revised while she was a patient at St. Mary's. The recipient had been accepted as a voluntary admittee and she consented to the medications she was administered. Additionally, the recipient

requested medication for anxiety and was then administered medication on an as needed basis. Staff noted that the progress notes from the recipient's Social Worker show that the guardian had input regarding medications, particularly the Invega Sustenna, but that a formal written consent form is not part of the record. Staff were asked if there is any documentation such as consents for treatment, medication, treatment team meetings or discharge staffings that show the inclusion of the guardian and they indicated no.

STATUTORY BASIS

The Mental Health Code guarantees all recipients adequate and humane care in the least restrictive environment. As a means to this end, it outlines how recipients are to be informed of their proposed treatments and provides for their participation in this process to the extent possible with the inclusion of the guardian in all aspects of care:

"(a) A recipient of services shall be provided with adequate and humane care and service in the least restrictive environment, pursuant to an individual services plan. The Plan shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient. The facility shall advise the recipient of his or her right to designate a family member or other individual to participate in the formulation and review of the treatment plan. In determining whether care and services are being provided in the least restrictive environment, the facility shall consider the views of the recipient, if any, concerning the treatment being provided. The recipient's preferences regarding emergency interventions under subsection (d) of Section 2-200 shall be noted in the recipient's treatment plan. [Section 2-200 d states that recipients shall be asked for their emergency intervention preferences, which shall be noted in their treatment plans and considered for use should the need arise].

(a-5) If the services include the administration of…psychotropic medication, the physician or the physician's designee shall advise the recipient, in writing, of the side effects, risks, and benefits of the treatment, as well as alternatives to the **proposed** treatment, to the extent such advice is consistent with the recipient's ability to understand the information communicated. The physician shall determine and state in writing whether the recipient has the capacity to make a reasoned decision about the treatment. The physician or physician's designee shall provide to the recipient's substitute decision maker, if any, the same written information that is required to be presented to the recipient in writing. If the recipient lacks the capacity to make a reasoned decision about the treatment, the treatment may be administered only (i) pursuant to the provisions of Section 2- 107 [to prevent harm] or 2-107.1 or (ii) pursuant to a power of attorney for healthcare under the Power of Attorney for Health Treatment Preference Declaration Act. A surrogate decision maker, other than a court appointed guardian, under the Health Care Surrogate Act, may not consent to the administration of authorized involuntary treatment. A surrogate may, however, petition for administration of authorized involuntary treatment pursuant to this Act. If the recipient is under guardianship and the guardian is authorized to consent to the administration of authorized involuntary treatment pursuant to subsection (c) of Section 2-107.1 of this Code, the physician shall advise the guardian in writing of the side effects and risks of the treatment, alternatives to the proposed treatment, and the risks and benefits of the treatment…." (405 ILCS 5/2-102).

"An adult recipient of services, the recipient's guardian, if the recipient is under guardianship, and the recipient's substitute decision maker, if any, must be informed of the recipient's right to refuse medication. The recipient and the recipient's guardian or substitute

decision maker shall be given the opportunity to refuse generally accepted mental health or developmental disability services, including but not limited to medication. If such services are refused, they shall not be given unless such services are necessary to prevent the recipient from causing serious and imminent physical harm to the recipient or others and no less restrictive alternative is available." (405 ILCS 5/2-107 a). Additionally, the Code states that upon commencement of services or as soon thereafter as the recipient's condition permits, the guardian shall be informed orally and in writing of the rights that are guaranteed by the Code which are relevant to the recipient's services plan, and the recipient's preferences for emergency treatment are to be communicated to the guardian (5/2-200). And, whenever a guaranteed right of the recipient is restricted, the recipient and his/her guardian must be given prompt notice of the restriction and the reason therefore. (5/2-201 a).

The Illinois Probate Act of 1975 defines the duties of the guardian:

"To the extent ordered by the court and under the direction of the court, the guardian of the person shall have custody of the ward and the ward's minor and adult dependent children; shall procure for them and shall make provision for their support, care, comfort, health, education and maintenance, and professional services as are appropriate….The guardian shall assist the ward in the development of maximum self-reliance and independence." (755 ILCS 5/11a-17a).

Also, the Probate Act gives direction to providers to rely on guardian decision making:

"Every health care provider…has the right to rely on any decision or direction made by the guardian….to the same extent and with the same effect as though the decision or direction had been made or given by the ward." (755 ILCS 5/11a-23).

HOSPITAL POLICY

St. Mary's Hospital Medications and Psychotropic Medications policy (#1408.75) states, "If psychotropic medication is ordered, the physician shall advise the patient in writing or verbally of side effects to the extent that he or she can understand. Patients must likewise be advised of his/her rights to refuse such services. A new informed consent for psychotropics will be initiated for each new psychotropic medication order. The patient's signature is optional. The attending physician must complete the informed consent for psychotropics form." The policy does not mention whether guardians or substitutes are provided the same written drug materials.

CONCLUSION

The Progress Notes included in the clinical record for this case indicate that several attempts were made by the recipient’s physician and his resident to contact the recipient’s guardian after being asked to do so by the social worker. It should be noted that a sticky note left on a patient’s chart is an unreliable plan for putting physicians in touch with guardians and a more effective procedure could be developed with some follow-up attached to it. In this case it appears that the physician attempted to contact the guardian, so the HRA cannot substantiate the allegation that the facility prevented the guardian from speaking with the physician or that the

physician refused to speak with the guardian. However, the record is missing several key components of guardian involvement and patient care which show that although the facility staff and physician did not purposefully refuse to speak with the guardian, the guardian was denied her rightful input into her ward's care.

The record for this case indicates that when the recipient was admitted into St. Mary's on 6/29/16 she did not have a guardian and at that time she denied her mother access to her health information. A medication reconciliation was completed and a decision was made to continue the recipient on her already established medication regimen of Invega Sustenna, whose administration was delayed due to the recipient's elopement from her nursing home. In the meantime the recipient's mother was granted temporary plenary guardianship on 7/06/16, at which time she was given the right under the Mental Health Code, to be included in the formulation of the recipient's plan of care and to be informed of her right to refuse medications along with the recipient. Physician Notes as well as the Medication Administration Record show that decisions regarding the revision of the medication regimen did not include the guardian. For instance on 7/07/16 the decision was made to augment the patient's administration of Zyprexa with an additional medication, Seroquel. On 7/08/16 the medication Xanax was added to the regimen, again without the consent of the guardian. Other medications, such as Haldol, Ativan and Zyprexa, were also administered upon the request of the recipient, without guardian consent. It seems reasonable that even if the physician could not reach the guardian by phone, that someone would be able, by phone or email or text (or directly to the guardian in person during one of her hospital visits), so as to alert the guardian and then obtain her consent. Also noted and equally alarming is the fact that the medication consent form is included in the record and does not include the recipient's consent for three of her administered medications, Invega, Seroquel, and Xanax. Finally, the record does not present a Treatment Plan, a Discharge Plan, or any other document which indicates the inclusion of the guardian in the recipient's care. The HRA substantiates the complaint that the guardian was denied her right to take part in the care and decision making for her ward.

RECOMMENDATIONS

1. Train staff and physicians to honor the role of the guardian. Make every effort to contact the guardian immediately after staff are made aware that the recipient has an appointed guardian and obtain consent from the guardian for all treatment, including medication. Include the guardian in all facets of the recipient's care and ensure that they are given the information necessary to make informed decisions. Ensure that the decisions and directions of the guardian are relied upon to the same extent as those of the ward. Develop policy and procedure for these components of the law.

2. Ensure that if psychotropic medication is a proposed treatment, that consent is obtained from both the recipient and their guardian after both have been informed of the side effects, risks and benefits of the treatment as well as alternatives. Ensure that a written physician statement of decisional capacity is included in the record. Incorporate these requirements into the hospital policy.

SUGGESTIONS

1. Develop a reliable procedure for alerting physicians of guardian concerns and requests to be contacted. Include in this procedure some type of follow-up to ensure that physicians speak with guardians or in other ways address their concerns.

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.

Presence
Saints Mary and Elizabeth Medical Center

HUMAN RIGHTS AUTHORITY
CHICAGO REGION

REPORT #: 17-030-9006

ISSUE #1

Immediate Action: Train staff and physicians to honor the role of the guardian.

Plan of Prevention: Educate Social Workers on the best way to communicate with the physician regarding the involvement of a guardian. Address the involvement of the guardian during multi-disciplinary treatment team meetings to ensure the communication among all disciplines.

Monitoring: Social Workers must obtain, document, and monitor guardianship paperwork. It is the role of the Social Worker to inform the treatment team that a patient has a guardian and support this through proper documentation.

ISSUE #2

Immediate Action: Ensure that if psychotropic medication is a proposed treatment, that consent is obtained from both the recipient and their guardian after both have been informed of the side effects, risks, and benefits of treatment, as well as alternatives.

Plan of Prevention: Educate nurses on the importance of communicating with the guardian and patient regarding recommendations for psychotropic medications. Inform nurses that the guardian is equally involved in the proposed treatment plan and recommendations for medication.

Monitoring: Nurses must monitor and document that the patient and guardian have been (1) informed of the proposed treatment plan and recommendations for psychotropic medication (2) given consent to administer psychotropic medications.

ISSUE #3

Immediate Action: Develop a reliable procedure for alerting physicians of guardian concerns and requests to be contacted. Include in this procedure some type of follow-up to ensure that physicians speak with guardians, or in other ways, address their concerns.

Plan of Prevention: Alert physicians of guardian concerns and requests, both upon admission and during multi-disciplinary treatment team meetings, in written and verbal formats.

Monitoring: Nurses and Social Workers must be responsible for notifying physicians of guardian concerns and requests in written and verbal formats.

Completion Time: 2 weeks