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HUMAN RIGHTS AUTHORITY - PEORIA REGION
REPORT OF FINDINGS

Case #15-090-9015
Carle Hospital

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation regarding possible rights violations with services at Carle Hospital. The complaints alleged the following:

1. The hospital detained a patient seeking discharge without due process

If found substantiated, the allegations would violate the Medical Patient Rights Act (410 ILCS 50), the Healthcare Surrogate Act (755 ILCS 40), the Centers for Medicare and Medicaid Service regulations (42 CFR 482), and the Mental Health and Developmental Disabilities Code (MHDD Code) (405 ILCS 5/2). The Adult Protective Services Act (3210 ILCS 20) was also reviewed as part of this case.

The hospital serves the east central region of Illinois and has 394 beds. The hospital is a level 1 trauma center and a level 3 perinatal center; the staff consists of 6,500 individuals throughout the Carle Enterprise. The hospital is located in Urbana, Illinois but the case was accepted and investigated by the Peoria Regional HRA due to conflict of interest with East Central HRA members.

To investigate the allegations, HRA team members met and interviewed members of the Carle Hospital staff and reviewed documents pertinent to the case, including patient records, with consent.

COMPLAINT STATEMENT

The complaint alleges that a patient was not allowed to leave the hospital and did not receive due process through the courts. The patient attempted to leave against medical advice (AMA), but hospital security prevented her from leaving. Eventually, the hospital involved the court.

INTERVIEW WITH STAFF

Interview with Carle Hospital staff (3.12.2015)

Staff began the interview by stating that in May 2013 a social worker met with the patient. The patient was confused but was not determined to lack decisional capacity at that time. The patient was diagnosed with Human Immunodeficiency Virus (HIV) but the patient's father does not believe in HIV as a diagnosis. The hospital staff stressed the importance of the patient taking her medication. From July 2013 through March 2014 the staff continued to follow the patient's case and in September 2013, they contacted the adult protective services because of medical noncompliance by the patient's father after several reminders to comply with treatment and medication. After meeting with the adult protective services, the patient's father brought the patient to an appointment, and at that appointment it was obvious that they were noncompliant with medications. The patient denied that her father was abusing her or withholding medications. In October 2013 the staff had multiple conversations with the patient's father about Medicaid coverage because of an error that caused the patient to lose coverage, and the issue was resolved. Then the patient missed 8 appointments and had no lab work completed. The patient was discovered wandering 5 miles from her home and was taken to a different medical center because her symptoms seemed to indicate a mental health diagnosis, but was then transferred to Carle after discovery of her medical history at the hospital. The patient had not received medications for several months and told staff her father was physically abusing her. She no longer wanted contact with him or for him to receive medical information. The staff made a second report to the adult protective services regarding the abuse. On March 14, 2014 it was determined that the patient lacked decisional capacity. The staff looked for a decision maker but all the patient's family lived overseas, except for her father which they did not feel comfortable with because of the abuse allegations. They involved the patient's significant other as the surrogate decision maker. The staff also began looking for a nursing home for the patient. It was determined that the patient needed 24 hour care because of her mental status but the surrogate could not provide that. The patient was admitted March 6, 2014 and discharged November 19, 2014.

In April 2014, the patient's father somehow made contact with the patient and the patient retracted her statement about her father visiting. When the patient's father began to visit, the patient started to say she wanted to return home. Staff allegedly heard the patient's father convincing the patient to leave with him. The patient eventually said that if she could not be discharged to the patient's surrogate, then she was agreeable to staying in the hospital. Once the patient's father was back in the picture, the surrogate stopped responding to the hospital and eventually declined acting as surrogate and asked if the patient could be discharged to her father. With no surrogate decision maker, the hospital began the guardianship process. The guardianship was also prompted by the pending abuse investigation. In May 2014, placement was found but later the facility decided that they would not admit the patient. The adult protective services investigation substantiated physical abuse and neglect charges against the patient's father. The court proceedings determined that the Office of State Guardianship (OSG) would be the patient's guardian and not the patient's father. The hospital still tried to find placement for the patient after the guardianship appointment and no facility would admit the patient.

Eventually it was determined that the patient would return home with the patient's father and the OSG still acting as the patient's guardian. There was a plan developed to provide care

for the patient. In February 2015 there was a visit where staff tried to convince the patient's father that HIV is a diagnosis but the patient's father was not in agreement to follow up on abnormal test results. The patient's guardian agreed to attend an upcoming infectious disease appointment. The patient was also provided an automated pill dispenser that is set on an alarm that reminds the patient to take her medicine.

The staff explained that physicians determine whether a patient has decisional capacity. The physicians use an assessment in which they question whether a patient understands his/her diagnosis and the ramifications. In this case, the patient had very little insight. When it was determined that the patient did not have decisional capacity, the hospital used the list provided in the Healthcare Surrogate Act and eventually asked the patient's significant other to act as surrogate. When the significant other agreed, he signed an affidavit stating his agreement to be the surrogate. Staff explained the patient never wanted to leave until her father began visiting at the hospital. In the beginning of her stay, she wanted to go home with the surrogate decision maker, but he had two jobs and could not care for her, so she agreed to stay. When her father would visit, he would shut the doors of the room even though the hospital stipulated they would be kept open. Allegedly they were in the bathroom together and then the patient was found with her shirt off and her father rubbing her back. After her father would leave, she would be a different person and be agitated and noncompliant. There were a couple of times when the patient would ask her father to leave. Her father's visitations were restricted and this strict schedule helped the patient with her dementia-like symptoms. The staff explained that the patient never made a documented request for discharge.

Staff explained that there was a time when the patient's father was trying to sign her out of the facility AMA. Staff said that the patient's decision maker can sign the patient out AMA but her father was not the decision maker. Security was called then and on three other occasions; twice to protect staff and another time with the surrogate decision maker, which turned out to be more of a misunderstanding because he was upset with the nurse. Staff said that the patient never called a hospital advocate but the patient's father called the patient relations department requesting discharge. The abuse allegations prevented the department from acting on the request. Her father wanted an independent medical consult for the patient, which she received, and the physician agreed with Carle Hospital's diagnosis. The hospital had an ethics consult but other than that, did not investigate other than reporting to external agencies.

Staff explained if a patient requests discharge AMA, there is a form that he/she completes that describes the risks and provides instructions. If patients are deemed to not have decision making capabilities, then they are not allowed to make a decision about discharge AMA. To determine the need for a healthcare surrogate, the staff beginning by determining if there is a living will, if there is a healthcare Power of Attorney, or if the patient has decisional capacity. If these do not exist, staff begin at the top of Healthcare Surrogate Act priority list and attempt to find someone that is appropriate in accordance with the law. If a close friend is chosen they are required to sign an affidavit, and enter the surrogates name into the medical history along with contact information.

Staff explained that the discharge planning process starts at admission. The social worker and case manager work together and discuss needs. The patient is given a folder during

admission explaining the discharge planning process and his/her rights. If the patient wants to leave AMA, it is explained to him/her that there could be repercussions to the decision. If the surrogate decision maker had said that he wanted the patient discharged, and had 24 hour care, the hospital would have helped them and discharged the patient AMA. The surrogate had asked if the patient could leave with her father, but there was no 24 hour healthcare available and there were pending allegations against the father. The father would visit the patient, and then the patient would become riled up and ask the surrogate to leave, so the surrogate would inquire with a hospital employee. They said that if the surrogate would have expressed that he did not care about the 24 hour care and he just wanted her to leave the facility, then they probably would have allowed her to leave because he was the decision maker.

FINDINGS (Including record review, mandates, and conclusion)

From reviewing the patient records, the HRA determined the following timeline:

- The Hospital Information Management (HIM) Correspondence report indicates that the patient was admitted to the facility's emergency department on 3/6/2014. A consultation note, dated 3/7/2014, reads "… this is a 31-year-old lady originally from [Continent], well known to me from her previous hospital admission for HIV/AIDS and multiple other complications. Last seen by me in September 2013 for follow-up. Since then, she was supposed to follow up with me and that did not pan out. She was brought in today. Per one of the notes she was found five miles away from her house by the cops, was taken to [facility] and from there, she was transferred here. When I see her, she is very anxious and nervous. She repeatedly says she does not want to talk much, but she keeps on talking. She mentions that her father has been hitting her every day; even hit her head against the wall. She says she has not been taking her medications for over two weeks. When I saw her back in September, at that time too my concern was she is noncompliant with medications. She said she went out of her house because her father was hurting her and hitting her. Later in the consultation it states that "On the inner side of her left thigh I notice some bluish discoloration. When asked, she said 'my dad hit me.'" The HRA reviewed a progress note, dated 4/13/2014, after the admission. The progress note was a follow-up consultation for the patient and reads "[Patient] was seen by [Physician] on March 10, 2014. At that time, he diagnosed her with delirium and cognitive disorder secondary to HIV. She was noted to have a history of HIV/AIDS, poor compliance with her AIDS treatment and now she is diagnosed with CNS toxoplasmosis and Cryptococcus meningoencephalitis. Throughout her hospitalization, her mental status has waxed and waned according to the nursing staff. At times, they seem to be able to carry on a reasonably coherent conversation with her. At other times, her speech will be pressured and what she will be talking about is largely nonsensical. In talking with [Physician], she was less convinced of [Patient's] ability to really have a real coherent discussion where she truly understands the nature of her illness." Another hospitalist progress note, dated 3/13/2014, states that "Based on above answers to screening tool it is the internal medicine attendings opinion that the patient lacks medical decision capacity." A hospitalist admit note, dated 3/6/3014, states the patient had been missing from home since midnight when her father came home and she was not there. The patient was last seen by her father at 4:30pm and called the police when she was not there. The note

proceeds to state "Pt does not provide hx. She wants her father to leave her room and the hospital. She states, her father hurts her at home. Her father denies any physical abuse. He is concerned that she may have been hurt while she was MIA."

- The hospitalist progress notes, dated 3/10/2014, state that there was an attempt to contact the patient's fiancé and that the patient admitted to physical abuse by her father and does not want to return to him. On 3/11/2014 he was called again with no response and staff documented if there is no fiancé they may have to have a guardian appointed. On 3/14/2014, notes documented that the process for guardianship was initiated.
- A hospitalist progress note on 3/25/2014 indicates that the patient's fiancé is actually her boyfriend and he agreed to be the patient's surrogate decision maker. The HRA was provided an affidavit, dated 3/25/2014, that the individual signed to act as a healthcare surrogate.
- A staff progress note dated 4/2/2014 reads that staff "… called and discussed ECF [Extended Care Facility] placement with [Surrogate], Guardian of patient. [Surrogate] is wanting her placed in the Champaign/Urbana area. [Staff] has sent referrals to [Three facilities]. Awaiting on response. The problem with placement is that patient is on Medicaid and very few NH [Nursing homes] accept Medicaid and the presence of sitter ECF prefer pt to be without sitter for 24 hours before admitting to ECF. Notified [Surrogate] about the barriers we are encountering."
- A social work note on 4/7/2014 reads that the patient's surrogate contacted the social worker and said that the patient wants to return home and have her father care for her. The note proceeds to state "SW [Social Worker] expressed concerns that it would not be appropriate for pt to return home to dad. SW reminded [Surrogate] that dad was not attentive to pt's medical needs previously. In addition, pt had reported that dad is physically abusive." On 4/8/2014 social work met with the patient and she did not want to live with her father but rather the surrogate. Another note on 4/15/2014 states that the surrogate contacted the hospital again and said that the patient is still "stating that she wanted to return home with father caring for her. [Surrogate] asked pt why she didn't voice this during SW visit last week. Pt reports that she wants to talk to SW [Social work] with [Surrogate present]."
- A hospitalist note dated 4/17/2014 reads "According to [healthcare surrogate] he knows the pt for the last 6 yrs. Pt was in her usual state few days before coming to the hospital and they went out for dinner. Pt was depressed at that time. Pt's father has never been open to [healthcare surrogate] regarding her medical treatment. Pt has not been taking her HIV medications for a long time. She also has c/o physical abuse by her father. [Physician] explained the plan of care regarding Antibiotic management … [Healthcare surrogate] would like to take some time to think and he will let us know regarding his decision regarding further plan of care regarding hospice. He is agreeable for ECF placement, provided we can have pt off sitter for 24 hrs. CPR has been discussed, and the further outcome from resuscitation has been explained and therefore he decided for DNR and form has been signed. It was also decided that due to concern for physical abuse father will only visit pt when [Surrogate] is present." Another staff progress note for 4/17/2014 reads "Early evening after care conference with [Surrogate]. Pt, [Surrogate] along with father thinks it is best to take her home now. RN explained the importance of staying in hospital, receiving meds, taking meds and case manager will meet with her and family tomorrow. [Surrogate] agrees thinks that would be best.

However, father and pt are pushing to be DCed now. Pt very agitated, refusing to be touched, refusing all meds. Father attempting to dress pt to take her home. [Physician] notified. Explained to [Surrogate] and pt that if they decide to leave now, they would be leaving AMA. [Surrogate] agreed to keep her here for another night. Father shaking his head and not ok with this."

- On 4/19/2014 a nursing shift summary reads "Pt verbalizing 'I wish my father could freely visit me in the hospital.'" Another note from the same day reads "Pt's father sent up to pt a bag with clean clothes, a pair of flip flops, a hair brush, pizza and some Russian food. Pt appeared delighted and happy upon hearing that it was her father who gave such things. Later in the night, pt received phone call from her father to which pt happily answered the call and spoke to her father at length. Pt invited her father to visit her in the hospital but staff reminded pt about visitation restrictions imposed on her father due to abuse allegations. Pt verbalized to RN and sitter at bedside: 'I wish my father could freely visit me in the hospital.'"
- In a hospital psychiatry follow-up note, dated 4/22/2014, it reads "Patient continues to have disorganized thought process, constantly insisting on going home with her father. When specific inquiry today, she denies abuse by father but cannot give a coherent story of why she had accused him on admission. As noted, patient has been poorly complaint with meds (including psych meds) while in the hospital." An ethics consult dated 4/24/2014 reads "Father is reportedly under investigation by Adult Protective Services – full details not know here. We need info, but if this is an open investigation, we probably cannot recommend that she go to father's house." The consult also reads "If father is cleared of abuse charges, there is still a serious question about his acknowledgement of HIV status, and ability to act in patient's best interest – complying with medical regimen. Reportedly, he has not facilitated attendance at medical appointments, and has not facilitated her taking her HIV medications." In the legal issues section of that same consult, it reads that there is concern about the surrogate decision maker participating in discussions and another surrogate may be needed but the patient only has family in another country, so that means the Office of State Guardianship (OSG) may be involved. The recommendations state that if the surrogate is not in a position to serve as a decision maker, the OSG should be contacted if another surrogate cannot be located in a reasonable time frame.
- A staff note on 4/23/2014 reads "SW received call from [Surrogate] on this date. [Surrogate] states that he visited pt the other night along with dad. [Surrogate] states that pt really wants to go home and does not want ECF placement. [Surrogate] also states that pt reports that she is agreeable to dad caring for her at home. SW reminded [Surrogate] that pt needs 24hr care at discharge and, unfortunately, pt does not have anyone to provide that care for her. There is currently an open investigation with adult protective services regarding the alleged abuse from dad. SW also reminded [Surrogate] that dad previously did not provide the medical attention that pt needed in the past despite many promises to do so. SW acknowledged that it is very difficult for pt to be in the hospital this long but at the same time we have to act in pt's best interest. [The Surrogate] voiced understanding and is still in agreement to ECF placement at this time.
- A nursing shift note on 4/29/2014 reads "At 1745 I was in patient's room with the door closed attempting to change PICC line dressing on pt. The door burst open and the pt's POA [Surrogate] was there. I asked who he was and then stated, 'oh good maybe you

can help me as I am trying to get her to the bed.' [Surrogate] stated he was taking the patient home. I told him the patient had not been discharged yet. He asked for me to 'give him the paper to sign.' I turned around and found the patient's father walking down the hall. [Surrogate] was informed that [Patient's] treatment was not completed and she could not leave at this time. Pt's father asked to leave several times by myself. He went to waiting room. [Surrogate] became angry patient could not leave, security called to bedside. [Surrogate] and the patient were packing her things while waiting for security. [Physician] paged and informed of the above. [Surrogate] pointing his finger at me, asking for my first and last name, and threatening me. Security escorted [Surrogate] and patient's father to the parking lot. According to security, [Surrogate] is to call the unit before returning. If he returns to the unit, security is to be notified. Pt is calming down in her room at this time." Another nursing note dated 4/30/2014 reads "Multiple discussions today with patient's discharge planning. Pt calm and cooperative with care today. Received information from social worker that pt cannot be signed out AMA by [Surrogate]. Case management trying to find transportation for patient. Will endorse to noc [night] shift. Continue to monitor." A social work progress note from 5/1/2014 reads "SW received call from RN regarding events that occurred last night. RN explains that [Surrogate] and pt's father, [Name], arrived last night. Per RN, [Surrogate] threatened to sign pt out AMA. [Surrogate] and [Father] were escorted off the property by security. See RN note from 4/29 for details. Per multiple discussions, [Surrogate] cannot sign pt out AMA unless he is able to prove adequate 24 hr care for pt at home. Due to open investigation with adult protective services, it would not be safe discharge plan for pt to return to dad's care. Staff should call security if [Surrogate] tries to sign pt out AMA without being able to provide adequate 24 hour care."

- Hospitalist notes dated 4/30/2014 – 5/2/2014 state that the patient was going to be discharged to an ECF facility but then was refused right before discharge from the hospital. A hospitalist note on 5/5/2014 reads "Pt is upset today. Says she does not want [Surrogate] to be her husband anymore. She wants '[Surrogate] to be off the List'. She says her father is the only person that can see her now. She wants to go home with her father. Father is going to call Social Security. Pt today denies her father ever hurting her in the past.
- Another hospitalist note, dated 5/6/2014 reads "Looking for ECF placement again. Was refused from [facility] just before d/c 2d ago. Pt allegations of abuse by father is under investigation. Pt cannot go home with father until investigation is complete and father acquitted."
- A nursing note, dated 5/9/2014, reads "Pt slept most of day. She was taken for a walk outside. Pt's father arrived with power of attorney papers signed. Security and case manager aware of the situation. Paperwork denied. Father escorted off unit."
- A staff progress note, written by a social worker on 5/14/2014, states that the patient's father arrived at the facility with completed healthcare power of attorney paper (HCPOA) completed that makes him the HCPOA agent. This paperwork was signed by the surrogate as well. The notes stated that the patient "has been deemed non-decisional by MD, therefore is not able to sign HCPOA paperwork" and also that there is still a pending abuse investigation so the current surrogate remains intact. That same day staff received a call from Adult Protective Services stating that the report regarding medical abuse had been substantiated. They also received a call from the surrogate stating they

did not want to be the health care surrogate any longer. There is also a note that staff received a call from the father's attorney with questions about the HCPOA and they were sent to a department that was qualified to answer those questions.

- A medical progress note on 5/15/2014 reads that the hospital is going to pursue guardianship for the patient.
- A social work note dated 5/22/2014 reads "Risk Management confirmed findings with [Name], the investigator from Adult Protective Services, that both physical abuse and passive neglect allegations were substantiated. Previously, it was our understanding that only the passive neglect was substantiated."
- According to the social work notes, the OSG contacted the facility stating they received the request for temporary guardianship and hoped to file the petition by the end of the week.
- The social work notes state that the patient attended a court hearing for temporary guardianship and according to the notes, the guardianship was appointed on with a court hearing for permanent guardianship scheduled. The HRA was not provided the court order for temporary guardianship.
- According to the notes, there was a plenary guardianship hearing and there was a motion for an independent medical exam. The hearing was rescheduled to allow time for the examination.
- The staff progress note, dated 7/11/2014, documented an incident where the patient exited the room and ran down the hallway despite staff instruction. The patient then began to get physical with staff and was administered intermuscular Haldol injection.
- In the notes on 7/28/2014 there was an updated list of facilities contacted to transfer the patient. There were over 26 places contacted (one list item stated a company that has several homes) and all the places said they could not meet the patient's needs.
- A note by social work staff, reads that staff "attended plenary guardianship hearing today, Office of State Guardian and [Father's Attorney] (on behalf of [Father]) have been able to come up with a resolution which was presented and approved by the court on this date. The results of the hearing include: - Office of State Guardian has been appointed as plenary guardian of person and estate – Pt will continue to stay at Carle Foundation Hospital until status hearing … and OSG will try to arrange for 24 hour supervision so that pt can return home …SW will continue to work with OSG regarding help at home." The HRA reviewed the order appointing plenary guardian.
- On 11/20/2014 the patient was discharged to home.

The HRA reviewed the facility registration, admitting and discharge information booklet which reads that the patient has the right to "Receive as much information as you may need in order to give or refuse consent for any planned procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment." The booklet also reads that the patients have the right to "Refuse treatment and be told what effect this may have on your health. This included leaving the hospital against your doctor's advice."

The HRA reviewed the facility policy regarding discharge against medical advice. The statement of policy reads "Adult patients have the right to accept or refuse any and all medical care, provided that the decision to accept or refuse these treatments is made on an informed basis and provided that the adults have the mental capacity to make and understand the implications of

such a decision." The policy explains the risks and benefits of treatment and the consequences of not undergoing treatment and if the patient wants discharged, there is appropriate documentation that must be completed and the patient must meet "the standard of Meaningful Understanding." The procedures state after explanation of risks, discharge instructions should be provided to the patient if possible. The patient's attending physician must be notified and AMA consent must be signed (if the patient refused the practitioner will sign the form and state that they refused). The practitioner involved must also document the incident in the medical record.

The HRA reviewed the facility policy on assessing decisional capacity. The purpose of the policy reads "To ensure that patients' decisional capacity for informed decision making is properly assessed and documented in accordance with applicable medical, ethical and legal standards of practice." Also the purpose is "To promote the right of patients possessing decisional capacity to make their own healthcare decisions, and to protect patients lacking decisional capacity either in themselves or in their authorized agents." The facility defines decisional capacity as "A patient is considered to be of decisional capacity with respect to a particular medical decision if he or she has the ability to understand and appreciate the nature and consequences of the decision regarding medical treatment including the ability to discuss alternative therapies and outcomes and the ability to reach and communicate an informed decision in the matter as determined by the attending physician. Unlike the standard of legal competency utilized by the courts in the context of guardianship proceedings (see paragraph C below), decisional capacity is presumed by this policy to be task – or decision-specific rather than global or context-independent." The statement of policy reads that it is the facility policy to "respect a patient's autonomy to make his/her own medical decisions" and if the decisional capacity is questioned, steps are taken to evaluate the capacity. The policy illustrates the applicability of the policy, discusses presumption of decisional capacity, and lists evidence of possible impaired decisional capacity. The policy also illustrates evaluations used to determine capacity, specific methods of evaluation and a discussion of minors. In the section titled "Lack of Decisional Capacity" it reads that "If, after appropriate clinical investigation, a patient is determined to lack decisional capacity, this determination will be documented in the patient's medical record. Decisions made on behalf of a patient lacking decisional capacity will then be made by the patient's guardian, health care power of attorney agent, health care surrogate, or in accordance with the patient's living will (or other advance directive), whichever applies, consistent with Withholding/Withdrawing Life Sustaining Treatment – RI213 and Surrogate Decision Making –RI212." The policy also reads "For patients who refuse a recommended course of treatment or who elect to leave against medical advice with potentially serious consequences, assessment (to the extent possible) and documentation of the patient's decisional capacity should be noted in a chart note in the patient's medical record. [For such patients, further action and documentation may be necessary. Refer to CFH's Policy on 'Refusals of Treatment' (pending).] Refer to Release Against Medical Advice ("AMA") – RI106." The HRA requested the policy regarding refusal of treatment but it could not be located.

The HRA reviewed the facility Surrogate Decision Making policy which reads "The Carle Foundation and its subsidiaries and strategic business units recognize the fundamental ethical and legal rights of its patients to make decisions relating to their own medical treatment, including the right to forgo life sustaining treatment. However, when a patient: 1) lacks the capacity to understand and appreciate the nature and consequences of a decision regarding

medical treatment and/or forgoing life-sustaining treatment; and 2) lacks the ability to reach and communicate an informed decision in the matter as determined by the attending physician, then she or he lacks 'decisional capacity.' Treatment decisions for patients who lack decisional capacity shall be made in accordance with any valid advance directives completed by the patient including a Living Will or Health Care Power of Attorney. Should a patient lack decisional capacity but have no valid advance directive or available health care power of attorney, valid decisions relating to medical treatment, including decisions relating to life-sustaining treatment, may be made by a surrogate decision maker in accordance with the Illinois Health Care Surrogate Act, 755 ILCS 40." The procedural section starts by stating the attending physician will determine if the individual has decisional capacity. Next, the physician will determine if the patient has a qualifying condition per the Health Care Surrogate Act. Then the physician will determine whether the patient has a living will or power of attorney for health care, and if so, decisions will be made based of those documents. If those do not exist, decisions can be made by a surrogate decision maker and the policy lists the order of priority. If the surrogate is considered a "close friend" on the priority list, an affidavit must be signed and presented to the physician and if there are multiple surrogates, they must reach a consensus on decisions. If no surrogate decision maker is available, then the physician is to contact Risk Management to initiate a legal proceeding for a guardian.

The Health Care Surrogate Act reads "Surrogate decision making. (a) When a patient lacks decisional capacity**,** the health care provider must make a reasonable inquiry as to the availability and authority of a health care agent under the Powers of Attorney for Health Care Law. When no health care agent is authorized and available, the health care provider must make a reasonable inquiry as to the availability of possible surrogates listed in items (1) through (4) of this subsection. For purposes of this Section, a reasonable inquiry includes, but is not limited to, identifying a member of the patient's family or other health care agent by examining the patient's personal effects or medical records. If a family member or other health care agent is identified, an attempt to contact that person by telephone must be made within 24 hours after a determination by the provider that the patient lacks decisional capacity **…** The surrogate decision makers, as identified by the attending physician, are then authorized to make decisions as follows: (i) for patients who lack decisional capacity and do not have a qualifying condition, medical treatment decisions may be made in accordance with subsection (b-5) of Section 20; and (ii) for patients who lack decisional capacity and have a qualifying condition, medical treatment decisions including whether to forgo life-sustaining treatment on behalf of the patient may be made without court order or judicial involvement in the following order of priority: … (7) a close friend of the patient; … The health care provider shall have the right to rely on any of the above surrogates if the provider believes after reasonable inquiry that neither a health care agent under the Powers of Attorney for Health Care Law nor a surrogate of higher priority is available" (755 ILCS 40/25). The Act also reads "Reliance on authority of surrogate decision maker. (a) Every health care provider and other person (a "reliant") shall have the right to rely on any decision or direction by the surrogate decision maker (the "surrogate") that is not clearly contrary to this Act, to the same extent and with the same effect as though the decision or direction had been made or given by a patient with decisional capacity. Any person dealing with the surrogate may presume in the absence of actual knowledge to the contrary that the acts of the surrogate conform to the provisions of this Act" (755 ILCS 40/30). Both the Medical Patient Rights Act (410 ILCS

50/3(a)) and Centers for Medicare and Medicaid Service regulations (42 CFR 482.12(b)(2)) state that the patient has the right to refuse treatment.

The Mental Health and Developmental Disabilities Code (MHDD Code) reads "(a-5) If the services include the administration of electroconvulsive therapy or 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 the 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 or 2-107.1 or (ii) pursuant to a power of attorney for health care under the Powers of Attorney for Health Care Law[1] or a declaration for mental health treatment under the Mental Health Treatment Preference Declaration Act.[2] A surrogate decision maker, other than a court appointed guardian, under the Health Care Surrogate Act[3] may not consent to the administration of electroconvulsive therapy or psychotropic medication" (405 ILCS 5/2-102). The Code also reads "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. The facility director shall inform a recipient, guardian, or substitute decision maker, if any, who refuses such services of alternate services available and the risks of such alternate services, as well as the possible consequences to the recipient of refusal of such services" (405 ILCS 5/2-107) and "(a) Whenever any rights of a recipient of services that are specified in this Chapter are restricted, the professional responsible for overseeing the implementation of the recipient's services plan shall be responsible for promptly giving notice of the restriction or use of restraint or seclusion and the reason therefor to: (1) the recipient and, if such recipient is a minor or under guardianship, his parent or guardian; (2) a person designated under subsection (b) of Section 2-200 upon commencement of services or at any later time to receive such notice; (3) the facility director; (4) the Guardianship and Advocacy Commission, or the agency designated under "An Act in relation to the protection and advocacy of the rights of persons with developmental disabilities, and amending Acts therein named', approved September 20, 1985, if either is so designated; and (5) the recipient's substitute decision maker, if any" (405 ILCS 5/2-201).

The Adult Protective Services Act (320 ILCS 20/9) addresses protections for an eligible adult ("an adult with disabilities aged 18 through 59 or a person aged 60 or older who resides in a domestic living situation and is, or is alleged to be, abused, neglected, or financially exploited by another individual or who neglects himself or herself" 320 ILCS 20/2 (e)) who lacks decisional capacity as follows: "If it reasonably appears to the Department or other agency designated under this Act that a person is an eligible adult and lacks the capacity to consent to an assessment of a reported incident of suspected abuse, neglect, financial exploitation, or self-neglect or to necessary services, the Department or other agency shall take appropriate action necessary to ameliorate risk to the eligible adult if there is a threat of ongoing harm or another emergency exists. The Department or other agency shall be authorized to seek the appointment of a temporary guardian as provided in Article XIa of the Probate Act of 1975 for the purpose of

consenting to an assessment of the reported incident and such services, together with an order for an evaluation of the eligible adult's physical, psychological, and medical condition and decisional capacity."

Complaint #1 - Conclusion

In reviewing all the documentation surrounding this complaint, the HRA saw no evidence that the facility detained a patient without allowing due process. The patient was found to lack decisional capacity and a surrogate was sought and determined, which follows the Health Care Surrogate Act (755 ILCS 40/25). After the surrogate decided that he no longer wanted to act as a decision maker, the facility then prompted court proceedings. Because of this, the HRA finds this complaint **unsubstantiated.** The HRA acknowledges the facility ensuring the safety of the patient by not allowing discharge to the home of the patient's father during an active abuse investigation involving the father, and would not advocate that a facility disregard patient safety or existing protections for patients who may subject to abuse. As per the documented hospital's ethics review, the abuse allegations and the active abuse investigation of a patient with a disability who lacked decisional capacity, as documented, impacted the hospital's actions to protect the patient from risks consistent with the Adult Protective Services Act. At the same time, the HRA is concerned that in similar situations, when safety or abuse is not an issue, that the facility is compliant with the Health Care Surrogate Act (755 ILCS 40/32) and **suggests** the facility review this situation and others to assure that the Act is followed. Additionally, the HRA reviewed documentation that a patient was given Haldol in a situation where she was physical with the staff. The HRA questions the patient's ability to consent to psychotropic medication per the MHDD Code (405 ILCS 5/2-102) and did not review a rights restriction for the medication being given to the patient per the MHDD Code (405 ILCS 5/2-201). The HRA **suggests** that the facility review their practices to assure that they are in compliance with the MHDD Code regarding consent, patient capacity, and forced medication. Also, it is mentioned in the decisional capacity policy that a refusal of treatment policy was pending, but when requested staff could not be located. The HRA **suggests** reviewing the decisional capacity to assure the information in the policy is accurate.