

Incorporating Values and Principles into Our Work

Hypo

On a monitoring visit to a large state facility serving people with intellectual disabilities a P&A advocate meets a woman lying in bed. She has a hard time talking, but with some back and forth the advocate comes to understand that the woman is in great pain and she wants you to see if the nurse can help her with the pain. You find the nurse and let him know of the resident's request for assistance. The nurse tells you there is nothing he can do for the resident right now as the next dose of pain medication is not due for a little while but he will be there right away when the window for the next dose opens.

Without any prompting, the nurse explains that the resident has a blood infection that is getting worse by the day and what they really need to do is amputate her infected leg to stop the systemic infection. He says that since the woman has no guardian or family decision makers to authorize the surgery, and she does not understand the gravity of the situation as evidenced by her intellectual disability and her continued refusal of the life-saving surgery, the lawyer for the facility was planning on securing an emergency court order this afternoon to get the procedure approved and performed by tomorrow at the latest in order to save the woman's life.

The advocate returns to the woman's room to give her the nurse's response. She lets the advocate know that she is aware of the proposed surgical intervention and can point to where they have told her they will make the amputation. She tells the advocate that the staff and doctors don't really talk about it too much, they just say she needs to do it. She was not, however, aware that they were going to try to force her to get it done.

She explains that she really does not want the procedure. She has already had two minor surgery's to cut away infected tissue on her leg, but the infection just came back. A year ago, she also has open heart surgery and she said the recovery process for that was tough. She says she does not want to go through another

major surgery that will be so hard to recover from, especially if it won't be successful like the recent minor surgeries.

Things to Consider:

- How should the P&A respond?
- What information should the decision maker have access to? Do they have access to it currently?
- What information is most relevant in your decision about the above question regarding who should make the medical decision?