The case of Naomi Smith

Naomi Smith is in end stage renal failure. Without dialysis her life expectancy is 6 months or less She will decompensate slowly ,and while there will be some impact on her quality of life, there are a few measures he can offer to help her be comfortable. The story is true, but the names of all the parties are fictionalized. Let’s start with the facts.

Naomi

Naomi is 26 years-old. She is the youngest of 9 children. She was born prematurely with a rare genetic disorder. Her condition includes congenital profound hearing loss, renal insufficiency, cardiac disease, and intellectual disability. She has had a colostomy her entire life (her intestinal system failed to develop). She is a happy social individual. She can use some American Sign Language consistent with her developmental level, 2 years old. She attends a program Monday through Friday where she performs some manual tasks. While she can do the tasks, staff say she wanders often, socializing with others participants. The program is operated by Opportunity Knocks, Inc., a large provider of sheltered employment services.
Naomi lives in a group home selected by her mother. She has two roommates with similar developmental needs. She has been followed by a nephrologist her entire life.

Elizabeth Jones

Elizabeth is the oldest of Naomi’s siblings. She lives within the same community as Naomi. Since the death of their mother, Elizabeth has picked Naomi up every Sunday. Naomi attends church with her family and has dinner and then returns to the home. Elizabeth has taken on the role of primary support to Naomi. She attends meeting,calls staff frequently, and has made sure that Naomi has holidays with her family.

HH Services, Inc.

HH Services, Inc. operates the group home where Naomi lives. They operate 30 homes in the general community and have over 30 years experience supporting people with intellectual disabilities. Naomi has lived in the home for 4 years. She is happy to go off every week with her family and just as happy to come home. Staff say that she is happy to tell you what she wants but her words are few. She signs drive, her favorite word, to indicate she would like to take a ride in the van assigned to the home.

Opportunity Knocks, Inc. (OK, Inc.)

OK ,Inc has been providing sheltered employment services for over 40 years. They currently serve 200 people in two shops. Naomi has been attending for 4 years, pretty much the entire time since she finished public school and moved to HH Services, Inc. There is no real coordination between the workshop and the residence and up until now, Naomi has had minimal absences and no special needs.

Local Government Agency(LGA)

There is a local government agency who oversees Naomi’s care. They fund both the sheltered workshop and the group home.

Horizon Health System

Naomi has a primary doctor and a nephrologist through Horizon. The nephrologist, Dr. Hwang ,is a first year resident. Dr. Hwang has reviewed the records which reflect that all the appointments for the quarterly monitoring of Naomi’s condition has been kept. At this point, Dr. Hwang has indicated to HH Services staff that Naomi is in end stage renal failure. He has taken her case to the transplant program for review. Naomi is not a candidate for the program because of her additional health conditions.

Now the case

HH Services ,Inc. makes two phone calls. The first call is to Vision for Independence, Inc, an advocacy organization. Naomi is the first client with an end stage condition since the passage of ACT 69. While it would appear that Elizabeth is the right person to make the decision, HH Services just wanted to check.

The representative of Visions for Independence, Inc. agrees that Under ACT 69, the oldest sibling would be the person to make the decision

HH Services then calls Elizabeth. The staff member explains the nephrologist’s assessment. And Elizabeth then calls and speaks with the nephrologist. She knew this day was coming. HH Services staff have kept her up to speed on all her health conditions. She understands that dialysis is not a guaranteed treatment and that Naomi will need to hold still to participate. Elizabeth decides that referral to hospice is the right choice.

HH Services makes the referral and consults with a member of the Horizon Ethics Committee. The Ethics rep says that it is a personal choice which is made by some patients or their reps and that HH Services is following the ACT as they understand it

HH Services advises the staff at Opportunity Knocks. Staff at the workshop are upset and convinced that HH is withholding treatment from Naomi. The Exec of Opportunity Knocks is friendly with the Exec of Visions for Independence, Inc. He explains his concern. The Exec of Visions for Independence, Inc. calls the government agency who funds Naomi’s care, he states emphatically that the Government agency must stop the referral to hospice and get the dialysis underway. If they fail to follow that directive, he will contact his media rep at the local new station and make a public statement. In his statement he will make it clear that HH Services has the support of the LGA to take action in opposition to Naomi’s best interest and emphasize that they are withholding treatment because of her disability.

Local Government Agency (LGA)

LGA contacts HH Services Inc. and asks about the case. HH expreses some confusion. HH Staff had called Visions for Independence, Inc,. And in fact, HH services felt that they agreed that the sister is the right person to make the decision. LGA decides that it would be prudent to take the decision to a judge. They obtain a hearing within a few days.

Hearing

Judge Hiram Whitaker has been on the bench over 30 years. Unknown to most people, the Judge had a brother with an intellectual disability who died in his early childhood. He has faithfully agreed to help the LGA navigate these consent cases. This case is his first end stage case since the passage of ACT 69.

He hears the testimony of the nephrologist and the LGA psychologist. They present her health condition and her inability to make the decision for herself. Elizabeth and Naomi are present for the testimony. None of the information is new to Elizabeth. Naomi spends the hearing signing “sit” to anyone who stands up. Also in attendance is MaryLou McCann Esq. Mary Lou has served the court as an appointed guardian.

After the testimony the Judge confers with Mary Lou. Mary Lou then approaches Elizabeth. The Judge expects that the dialysis will be ordered, and if the family does not agree, the Judge will appoint Mary Lou as temporary guardian. Mary Lou will order the dialysis. Elizabeth agrees to the dialysis

And then what happens

Naomi has the necessary port implanted, and she heads for the first session. The dialysis center decides to try sedation, accidently gives her two doses(in stead of one). Even with the extra sedative, Naomi does not hold still to finish the first session. In the second session, again with the support of a sedative, Naomi wrestles to get out of the chair and damages the port.

A second port is installed., and Naomi restarts dialysis. The third session is a repeat of the second with one exception. The damage to the port is worse than the first time ,and Naomi is hospitalized. Elizabeth decides to take Naomi home. She asks for a discharge from all services. Naomi passes away within two months at home with Elizabeth.

In your analysis address the following factors. (20 points total )

Legal issues 6 points

* What is your assessment of Naomi’s competence to decide?
* Did the Judge follow Act 169 as written?

Ethical Issues 6 points

* Describe the ethical frame of Visions for Independence, Inc..and Opportunity Knocks, Inc.
* Describe the thinking behind the actions of the LGA

Negligence? 8 points

* If HH Services head successfully implemented Elizabeth’s decision, was there a probable case of negligence? Address the element of negligence in your argument .
* In the end, put yourself in Elizabeth’s shoes. Your mother appointed you to care for your sister. What are you saying to your other siblings?