



FOR IMMEDIATE RELEASE

**East Central Human Rights Authority
Report of Findings
William W. Fox Developmental Center
Case 14-060-9003**

The East Central Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegations concerning the Fox Developmental Center:

- 1. A recipient of services is not provided with adequate and humane care and services in the least restrictive environment pursuant to an individual service plan.**
- 2. The facility impedes visitation for an individual receiving services.**
- 3. The facility attempts to override the guardian's decisions.**

If found substantiated, the allegations represent violations of the Mental Health and Developmental Disabilities Code, 42 Code of Federal Regulations (CFR), part 483, Subpart I, Requirements for Intermediate Care Facilities for persons with Intellectual Disabilities and the Illinois Probate Act of 1975 (755 ILCS 5/11a-23).

Per the Department of Human Services website Fox Developmental Center profile: "Fox Center currently serves 117 individuals with a variety of needs. They serve people with moderate to very high medical needs as well as moderate behavioral needs. Fox Center has 5 living areas with 20-25 individuals on each living area. Fox Center's building is 3 stories with 1 or 2 living areas on each floor. Individuals at Fox Center attend one of two off-campus day training sites, or one of five in-house Adult Training Rooms."

COMPLAINT STATEMENTS

Per the complaint:

- 1. Staff are not adhering to a guardian's directives.
- 2. The guardian is not always consulted regarding care.
- 3. Visitation has been impeded for an individual who has profound intellectual disabilities associated with Rett Syndrome, as after the complaints were accepted by the HRA, Fox staff allegedly searched through the guardian's belongings.
- 4. This non-ambulatory individual is reportedly not being provided physical therapy for weight loss, prescribed by her physician.

- 5. She has been provided a very low caloric diet.
- 6. The individual was allegedly being denied the opportunity to have an independent video-fluoroscopic swallow study to determine what type of diet consistency she should have. There is concern about the individual being set up to appear to need an enteral feeding when it is believed that she could still feed herself. Per the website of WEB MD, "If a person is having ongoing and serious trouble swallowing and can't get enough food or liquids by mouth, a feeding tube may be put directly into the stomach through the abdominal skin. This procedure is called a percutaneous endoscopic gastrostomy (PEG). The tube allows enteral feeding (feeding directly through the gastrointestinal tract) to occur by bypassing the mouth and esophagus (the "food tube" leading to the stomach)."

INVESTIGATIVE INFORMATION

The HRA proceeded with the investigation. Written authorization to review the patient's record was received, and the HRA team reviewed the medical record prior to a site visit conducted on December 12, 2013. To investigate the allegations, the HRA team interviewed agency staff, discussed the examination of the resident's records, reviewed pertinent agency policies and documents and toured the facility.

Interviews

Staff Services: The HRA asked staff at Fox to describe the types of services Fox provides. Staff explained that Fox is a state residential facility for adults with developmental disabilities. They serve people with serious and profound medical issues. There are 113 individuals served, and they could take 20 more individuals if necessary. There are about 20 individuals who receive day training services off campus. There is an annual meeting to develop individual service plans (ISP) addressing the full array of services provided to each resident, including dental services, physical therapy, speech therapy, psychology services and adult training for individuals. The direct care staff are considered mental health technicians, and all professional team members provide training on their specialties to the direct care staff. A total of 27 staff members, including nurses, are assigned to each area. There are at least 6 staff on dayshift, 6 staff on pm shift and 2 staff on nightshift. There are qualified intellectual disabilities professionals (QIDP) responsible for each area. There is also a facility residential supervisor available at all times.

Staff Training: The HRA asked what training is in place to assist staff in providing adequate and humane care. Staff explained that initial training includes the rights of individuals, positive interactions, discipline specific training, and an overview on how to provide services by the psychologist. There is training on "People first language". A speech/hearing trainer provides training on feeding which includes having workers feed each other as part of the training. There is abuse and neglect prevention training. There is also training for personally protected information and for handling behaviors. In-service trainings are also provided to staff.

The HRA team asked about training that staff receive regarding abuse/neglect and resident rights and when they receive that training. It was explained that it is provided upon hiring new staff. Management tries to embed, throughout the year, rights and abuse protections

through in-service training. Human rights are touched on annually in the abuse and neglect prevention training. The HRA was provided 3 calendars of the scheduled in-service training.

When asked how available the Office of Inspector General (OIG) contact information is for residents and staff, staff explained that it is posted on every living area and in each department.

The HRA asked how staff members are trained in recognizing and reporting incidences of abuse and neglect. They are trained on hire and must complete the state approved Rule 50 training provided by the Illinois Department of Human Services (DHS).

Regarding confidential reporting, staff explained that the policy requires staff to call the OIG number or report abuse/neglect incidents to a supervisor. If a report impacts the safety of an individual they would be required to tell a supervisor to keep the resident safe. There is an internal investigator at the facility.

Complaint Specific Dialog Re: Complaint Statements # 1 and # 2: The HRA asked about the policy for notifying the guardian if there is an incident. The response was it depends on the individuals and the guardian. Some guardians only want to be notified if there is something serious. Others want to be notified about everything and want to keep in daily contact with staff about their wards. All residents at Fox are under guardianship or have substitute decision makers. The staff are aware that this resident's guardians want close communication and to be involved in all decision making.

The HRA asked if either guardian made a complaint to staff or formulated a grievance regarding the issues of the complaints. Per staff, neither had made a complaint.

Regarding Guardian Communication and Resident's Rights, the HRA asked staff about the process for developing an individual service plan and services, including various professional services such as speech pathology, dietary, occupational therapy, physical therapy. The QIDP writes the plan and the shell of the plan is given to the team. It is discussed with the team at the annual meeting with the individual and the guardian present. The individual service plans at Fox tend to have more medical objectives. Social workers provide an assessment and review the rights.

The HRA asked if the issues of this case had been discussed with the human rights committee, especially regarding the issue in which the guardian and facility reached an impasse concerning a treatment plan. It was explained that either the guardian and/or the individual would have to present the matter to the Human Rights committee. The committee consists of two members who are retirees, two family members, a person with experience on the residential committee, a clergy, and a social worker; the training person for Fox is the chairperson. This case has not been discussed. The committee meets once a month or more if necessary. They may also have a telephone committee meeting.

The HRA team asked if Fox had a medical ethics committee. Staff responded that they do have a medical consortium committee which meets on an as needed basis. This committee

has not felt a need to discuss the issues of this case. They do have an executive staff committee in which Fox employees have discussed this case. The HRA asked if only Fox employees serve on this committee, and the response was, yes.

Re. Complaint Statement# 3: The HRA asked if visits with families have ever been restricted for any facility residents. Staff reported a case when visitation was restricted due to food being brought into the facility, but not in this case.

It was discussed that the guardians do bring food for the resident. It is given to staff to have it pureed. When asked what would happen if the guardian refused to comply with pureeing, the staff responded that they would have to supervise the visits. Staff explained that no decisions have been made to give the guardians supervised visits. Regarding food, staff members are to ask if they have food for the individual and offer to take it to dietary. Supervisory staff stated no staff had been advised to go through the guardians' belongings to search for food. The HRA was asked to provide a date, time or name of the staff who searched the guardians' belongings so it could be followed up by management at Fox.

The HRA followed up after the interview with the Fox Director. Per the Director, the supervisor spoke to the employee who may have been involved in searching the guardians' belongings. The employee stated that she has never gone through the guardians' belongings; she goes to the room and asks if they need anything. She also asked if they needed her to take any of the food to dietary to be pureed. She reported that the guardians show her the food they have provided to ensure accurate consistency. If they need no assistance, she carries on with her duties. The employee was reminded by the supervisor that at no time should she go through the guardians' possessions. The employee stated that she understood and that she has not done that.

Re. Complaint Statement # 4, The HRA asked about the physician's recommendation to provide physical therapy (PT) for weight loss. Per staff and the physical therapist at Fox, this was brought up by a physician, for caloric burn. The physical therapist presented, at that time, information from other respected medical communities such as Live Strong.com, and Mayo Clinic that in order for the individual to have calorie burn she would need active exercise. Since the individual's activity level is very limited, this type of therapy could not be provided. Her attending physician wrote an order for physical therapy, if practical. At this time passive range of motion (PROM) is being provided by the therapist. Active range of motion (AROM) would have to be provided for weight loss. The technicians are providing PROM daily. The individual maintains 90% flexation. When asked how they determined that she should not receive therapy for weight loss, the staff responded that it went through a team meeting, which included the individual's physical therapist, instead of PT doing an assessment. When asked about the usual protocol regarding PT for calorie burn, the response was the physician's request was unusual, in view of the resident's inability to engage in active range of motion. The HRA asked if a second opinion, external to Fox, could be provided to determine if PT was not necessary or therapeutic. The response was the guardian did not request it. The resident is being dressed and bathed. She is moved in and out of her bed with a mechanical lift to her wheelchair. Year after year her range of motion has remained the same as per staff.

Re. Complaint Statement # 5, another verbalized concern was the resident's 800 calorie diet. Staff explained it was an 800 plus caloric diet. The dietician uses a thickening agent at 20 calories per tablespoon for her food and drinks. She usually receives more than just the 800 calories. The cooking staff use the broth and juices of the food prepared to make the puree which improves the taste of the food. The facility has had a goal of weight loss for this patient.

Re. Complaint # 6, alleging the refusal of an independent video-fluoroscopic swallow study at a hospital chosen by the guardians, staff explained that they do not have a contract or procurement code arrangements to cover the cost of the test at the facility the guardian would like to use. The guardians would like the resident to have a soft dental diet. They believe she can eat soft foods without choking. Through the years, she had several swallowing studies with most recommending a soft mechanical diet. The last study recommended a pureed diet already provided by the facility. The resident was hospitalized at the time of the last study, and was lethargic at the time of the examination. The guardians were disappointed at the results of the study, citing the resident's condition at the time of the test. After the most recent swallowing study, the physician wrote a new order for a study after consulting with the guardian; then, the physician retracted the order and the guardians received a letter indicating they would have to pursue another swallowing study at their own expense, and with a private physician's order. The HRA team questioned if the individual is a Medicaid patient, and if so, should she be able to receive services from any Medicaid provider. Staff did offer to provide transportation to a physician to get a prescription for a video swallow and to transport her to a facility where the test would be provided. The facility has to justify the payments that are incurred. The facility determined the resident was to continue with her pureed diet per physician's orders.

The HRA team suggested that since the individual was ill and in the hospital when the last test was completed, the resident's changed physical condition could provide justification with the payer sources.

Staff responded that the individual frequently has time periods of lethargy and even during her lethargic periods she can eat a pureed diet. The concern is they would be liable if something happened to the individual if she ate the dental soft food.

Per the speech pathologist, there have been undigested pieces of food in the individual's briefs. The individual chews food and bites through it twice, regardless of size, and there is no grinding motion when she eats. The staff are concerned that the resident would not digest food from a diet other than pureed, fearing nutritional deficits. Nursing has expressed that the individual no longer has a gag reflex. She does not have a gag reflex when her teeth are being brushed according to the speech pathologist.

A 5/22/13 swallowing test stated that the resident could be offered dental soft foods that are mashed or receive a pureed diet. HRA asked about the recommendations of being able to have small bites of food and alternating liquid. The facility ignored the results of that study and

did not advance her diet order to soft foods; instead, she was kept on the pureed diet per guidance from the speech therapist.

Per the speech therapist, the dietician and speech pathologist had many discussions about this resident. Earlier (see Documentation notes), the resident had been provided a month's worth of soft solids added at meals. The speech therapist observed that the resident was able to consume, but not chew it. She never saw the grinding motion break down the food material. Thus when the diet order could have been advanced per the swallowing study, the facility deemed she needed to be continued on the pureed diet in order to safeguard her welfare. The record does not indicate this decision was discussed with the guardian at the time of the decision. When this resident had episodes, viewed as choking episodes, she would turn red to blue from choking. Many times this occurs after she eats. She also has a diagnosis of *gastro esophageal reflux* disease (GERD). The therapist has suspected possible reflux.

The HRA asked how many residents are on an enteral feeding program. Staff responded approximately 40% of residents receive enteral feeding. When asked about the process that would be followed before putting a client on an enteral feeding program, the response was the speech pathologist would complete an observation of that person's meals. If at that time, they are showing signs of aspirating, the resident's physician would order an evaluation, as well as a gastroenterologist consult or a surgical consult. There is a provider locally in Kankakee who is willing to do the test. Residents at Fox Developmental Center may be taken there for evaluation. This resident was never considered for an enteral tube feeding, according to staff.

General Query: The HRA asked what procedures are in place to insure resident safety and protection. Per the record it appears that the resident had two leg fractures that occurred while she was at Fox. Staff responded that the individual has severe osteoporosis. Her T-score is minus 5, which is very low. (Per the National Institute of Health (NIH) website "... The more standard deviations below 0, indicated as negative numbers, the lower your bone mineral density (BMD) and the higher your risk of fracture....A T-score between +1 and -1 is considered normal or healthy. A T-score between -1 and -2.5 indicates that you have low bone mass, although not low enough to be diagnosed with osteoporosis. A T-score of -2.5 or lower indicates that you have osteoporosis. The greater the negative number, the more severe the osteoporosis.")

Per staff, a seizure could have caused her injury. If any injury is observed, a technician files a report and notifies a nurse and supervisor. The supervisor comes to the area and assesses the environment. The nurse will do an assessment and the physician is notified. Staff document every injury even if a quarter inch bruise. Then it is reviewed by a manager. If an individual has an injury, it is reported to the Department of Public Health. The manager also completes a monthly injury report. Every injury is reviewed by the Human Rights Committee.

The HRA was provided a tour of the facility where the resident lives. Even though the Fox Center had some modern updates to accommodate the needs of the individuals served, it still maintained the beauty of marble and wood that was used when it was originally built. It was very clean and neat. In the common areas, Christmas decorations made by the residents were displayed. Each room was decorated according to each resident's personal taste. The facility smelled clean and free of odors. Staff interaction with the residents appeared to be very positive.

Several residents were participating in various art activities. Some of the residents were excited because the therapy dogs were coming to visit the center and interact with the residents that afternoon. Information regarding how to contact OIG was posted all over the facility. Rights information was posted, but it was outdated and placed in areas that would be hard for a resident or a guardian with limited mobility to access and read. The rights information was not as readily available and sparsely placed.

The HRA learned about the foster grandparents program offered at Fox. Retirees volunteer at the Fox Center and visit with individuals at the center an average of 45 minutes per week with residents who participate in the program.

Records Review

On 7/2/13 the annual individual support plan was reviewed. On page 4 it documents that: "...The resident enjoys her weekly visits with her parents, especially the home cooked meal they bring her each week that they help her to eat. They also assist the resident on selecting her menu for the week. The resident requires full staff assistance with her meals. She uses a coated spoon to receive her meals, beverages, and medications. The resident doesn't chew her food, so it is pureed for her. Her beverage is nectar consistency; she had a mild delay in her swallow initiation with no aspiration of liquid material or residue remaining after swallow during a VFSS. The resident can't complete skills by herself and likes help for family style dining such as placing pepper on her food, pouring her beverage, and placing her clothing protector in a hamper. She has focused on these activities more this past year as she previously would turn her head away from the task or look at anything but what the task was...."

Under the section marked rights and the area of Informed Refusal of Services: "The resident and her guardians have the right to refuse any treatment or procedure. They will be informed of any consequences that may occur as the result of any refusal."

In the area marked Due Process: "The resident's rights and responsibilities were explained to her prior to the ISP meeting and a copy of these rights was provided to her and her guardian."

In the area marked Freedom from Abuse, Neglect, Mistreatment, and Financial Exploitation: "The resident, her guardian, staff, volunteers, and contractors are provided information/training in the detection and prevention of abuse and neglect and financial exploitation on an annual basis. This information/training includes provision of the hotline phone number for reporting abuse and neglect to the Office of Inspector General (OIG).

Clinically, the individual's rights are restricted by her need for a plenary guardian of person due to her inability to provide informed consent. The individual's parents are her co-guardians and are very responsive to all communications. They call every night and visit once a week at least. They like to be notified of all health issues that occur (illness, Nebulizer treatments, changes in her medication, seizures, etc.) as well as any change in her schedule such as respite changes. They will often accompany the resident on medical appointments. When hospitalized in June, her parents were present when she arrived at the emergency room (ER) and subsequent admittances to the hospital."

The Nursing Physical Development and Health Assessment documented that in the prevention of skin breakdown that there were no pressure sores. During the individual's hospitalization from 6/11/13 - 6/16/13 a sitter was provided at the hospital.

Under presentation of pain, the treatment plan documented **Gastroesophageal Reflux Disease (GERD)** and gastric ulcer.

On page 6 of the ISP in the second paragraph from the nutritional assessment summary it states: "Due to coughing noted during and after meals, a video-fluoroscopic swallow study was completed on 5/20/13. The recommendation to continue pureed diet with nectar thick liquids has been followed."

The following is a timeline based on documentation the HRA reviewed in the record of care received by the patient that would apply to the allegations:

9/5/92 Letters of guardianship for the resident which state: "The resident's parents had been appointed as Guardians of the person, a disabled person, and are authorized to have under the direction of the court, the custody of the ward, and to do all acts required of them by law." There were no limitations on the duties and powers of the guardians in the order.

9/5/07 Video-fluoroscopic swallow study #1: the recommendations from this test recommend "to continue the general consistency diet at this time. Cut all food in small bite size pieces. If difficulties arise, it may be necessary to change the diet consistency to mechanical soft."

10/27/08 Notes by the speech-language therapist document the following: "The resident's oral, motor and swallowing abilities were re-evaluated during her lunch today. She did not chew her food, but swirled the food around her oral cavity. She had small diced apples, squash, tuna and noodles. A dish of applesauce was ordered also. A piece of apple was added to her squash to see if she would chew the squash to break down the skins. No chewing took place. It is recommended to downgrade the resident's diet to pureed at this time. She will be re-evaluated to dental soft diet at a later date."

11/03/08 Notes by the speech-language therapist document that she was assessed for dental soft food. For the resident's safety it was recommended that she remain on pureed consistency food.

4/15/09 Notes by the speech-language therapist document that the resident was assessed for dental soft food. For the resident's safety it was recommended that she remain on pureed consistency food.

4/23/09 Notes by the speech-language therapist document the resident received chewing therapy.

7/15/09 Notes by the speech-language therapist document the resident was assessed eating chunky fruit and had chewing exercises. "The resident bit through the fruit, but had no actual chewing to break the fruit down well enough for her body to use the food effectively. She will remain on pureed food."

7/16/09 Notes by the speech-language therapist document "The resident was checked for a gag reflex. She allowed having a spoon touch the gag reflex area, three times with no wrenching or sounds related to a gag. Also if ever the resident choked on food, the chances of breaking bones by doing a Heimlich maneuver are great. It is recommended that the resident remain on the pureed consistency until her parents are able to obtain a second video-fluoroscopic swallow study."

9/21/09, 5/21/10, and 5/26/11 Notes by the speech-language therapist recommend to continue a pureed diet.

11/28/11 Notes by the speech-language therapist document "...the resident coughed once on thin beverages given by tablespoon and had a red face, which cleared quickly."

11/29/11 Notes by the speech-language therapist state: "The resident's ability to take in thin liquids during lunch was assessed. Thin liquids just fell from the corner of her mouth...."

12/14/11 Notes by the speech-language therapist document that "Staff have been assisting the resident with other meals and have voiced concerns about her coughing during meals. I will observe/evaluate her during lunch tomorrow, but I am recommending that she be evaluated VFSS as soon as it can be arranged to rule out a swallowing problem."

12/20/11 Video-fluoroscopic swallow study #2 stated:"...Prior to 2009 the resident was eating a mechanically soft diet. However, chunks of food were noted in the patient's solid waste and her diet was downgraded to a pureed consistency, at this time, her father is wishing to have her oral and pharyngeal swallowing stages evaluated to see if she can safely resume eating soft solid foods....Staff has recently noted coughing during meals...."

"Consistencies tested: The patient was fed by evaluator from a plastic coated spoon supplied by the Fox Center. She was fed at a slow rate, small bolus sizes of no more than 1 tablespoon at a time. She was given multiple trials of nectar thick liquid; two trials of thin liquid (one from a spoon and one from a 5cc cup) pudding; raspberries in yogurt, slightly mashed; and small pieces of cookie and banana. Pieces of cookie were placed in the patient's hand and she fed herself with minimal assistance...."

Recommendations:

1. Speech therapy (ST) for therapeutic feedings and diet texture analysis.
2. Continue pureed diet and nectar thick liquids.
3. Add a repertoire of mechanical soft solid food per ST recommendations and per ST swallowing guidelines."

12/20/11 Notes by the speech-language therapist state that "The resident participated in a VFSS today at the hospital, speech, language and pathology providing the foods and liquids. It is possible that the resident is aspirating on thin liquids. The resident was able to munch raspberries coated in yogurt and used a munching pattern to break down a soft cookie. Recommendation is to mash or puree diet and Fox speech language and pathology giving

therapeutic feedings and diet texture analysis. Continue nectar consistency liquid delivered by a spoon. She experienced no aspiration on pureed, soft solid or nectar liquids."

2/3/12 Dietary notes document that the guardian requests that chocolate milk at breakfast be provided along with finger foods for therapeutic feeding by speech-language therapist mid-morning Monday, Wednesday and Friday.

12/22/11, 2/6/12, 2/8/12, 2/15/12, 2/22/12, and 2/24/12 Notes from the speech-language therapist document observations of attempts to feed the individual small bites of melon and small bites of a graham cracker. In some instances the resident would chew a couple of times, but was not breaking down the food before she swallowed. In other instances food would be pocketed to the side of the resident's mouth.

2/29/12 Notes from the speech-language therapist document that no improvement was seen and will discontinue exercise due to no progress.

5/20/12 Dietary notes document that the guardians want the Beneprotein discontinued and to increase their daughter to a 1200 + calorie plan.

12/6/12 Dietary notes document that the dietician discussed with guardians about decreasing diet to 1000+ calorie diet due to increasing weight.

4/29/13 The physician's note documents the resident was not swallowing normally at lunch and dinner and that she had been coughing.

5/5/13 The physician's note states that he discussed with the guardian that the resident had finished her lunch, her face turned red and she coughed and expelled a rope of saliva. He recommended another VFSS and the guardian agreed.

5/7/13 Notes by the speech-language pathologist document "...the resident's face changed color, according to verbal reports given....To rule out any swallowing deficiency, a VFSS is being requested. Both physician and nurse have been notified."

5/10/13 A referral and report from the physician states: "Please evaluate oral motor and swallowing abilities. The resident has had numerous instances of lips and area around her mouth turning blue, has excessive saliva expelled from her oral cavity after these change of color instances and possible fatigue during meal times. She is currently on pureed diet with nectar consistency liquids, which are given by coated tablespoon, one small bolus at a time. Please evaluate the safest liquid consistency also."

5/15/13 Notes by the speech-language therapist document "...The individual had finished all of her food and staff had begun thickening her tea. Before she had any of her tea, she began to cough. Her face turned red and she expelled some thick saliva. When she calmed, and her face was her normal color, she took in 1 ½ cups of her thickened tea, with no more difficulties."

5/18/13 The outcome of special team meeting written by the QIDP, under the section of "what are we concerned about" states: "Staff are concerned with response to her **gagging**. The individual has severe osteoporosis and weighs over 200 pounds. She uses a mechanical lift. In case of an emergency, should she receive a transfer to the floor in order for CPR or the Heimlich to be performed, staff are very concerned about broken bones and injuries. The resident has been seizure free since 11/1/12. She is very sensitive to anticonvulsant changes. The team also discussed the use of Robinal to aid in drying her secretions however side effects include decrease in urine output and an increase in constipation.

What's next: The resident's Primadone will be slightly decreased from 250mg to 225 mg at 5:00 am tomorrow. She will have a Primadone level tomorrow. The team felt it was the resident's best interest to have a video swallow test to determine if she is experiencing issues with her ability to swallow. Her guardian prefers the Phenobarbe be decreased and the VFSS be postponed for now. He feels she has been sleepy and responding as though she is over medicated. The team however feels it is important for the resident to have a VFSS to determine any changes in her ability to swallow and/or manage her saliva. The team agrees to return to her previous alternate position schedule with a respite prior to her lunch and early in the afternoon. The team felt that it's possible the resident could be drowsy due to the warm weather we are experiencing and the warmth in the building. Her physician was also approached yesterday with concerns for the resident. He is looking into a possible metabolic syndrome given the resident's continued weight gain despite her 855 calorie diet.

This meeting was unplanned; therefore, her parents were not contacted during the meeting, but called afterward. They are very involved in the resident's care and were unhappy that they were not made a part of this meeting. Her guardian would like the resident to continue to attend her day training and be around people rather than on respites. Her schedule will be modified to accommodate both. Her parents were unsatisfied with her diet, lack of foods to encourage her chew, and inconsistencies in nursing care (medication administration - however staff have been in-service in the resident's protocol for medication administration.)"

5/22/13 A video-fluoroscopic swallow study #3 was conducted and it documents the reason for the referral was choking episodes. Notes document that it was reported by her father she was not herself today, that she was lethargic. Diet texture recommendations: "Nectar consistency liquids with a dysphagia 2 diet meaning she can have dental solid foods that are mashed or receive a pureed diet."

Under other recommended referrals, it states that coughing at meals may be due to reflux and that the Physician may consider treating for reflux.

5/30/13 Occupational therapy assessments state: "The resident's passive range of motion (PROM) or movement is within normal or functional limits in her arms and legs with exception of her left knee and both ankles. Both feet are contracted in the supinated (turned up and in) position. The resident does actively move her arms and demonstrates limited grasping skills in both hands. She uses a wheel chair to provide support throughout the day, and she requires assistance from others to move the wheelchair from one place to another...."

6/11/13 Notes document the resident had been vomiting a brown substance. With permission of the guardian, the resident was being sent to the hospital.

6/18/13 The summary of the occupational therapy assessment that was completed documents that the resident "demonstrates a basic palmer/take grasp. The resident will feed herself finger foods with a little assistance, if the opposite arm is redirected to avoid the clasping of her hands. The resident is dependent on staff for a majority of her activities of daily living. Bathing is performed on the shallow tub for safety."

6/19/13 Notes by the speech-language pathologist state: "Re-evaluated the resident's oral motor/swallow abilities. No coughing during or after lunch. Continue pureed diet and nectar consistency liquids."

6/24/13 The Psychological Examination states that the individual's level of performance falls within the profound range of mental impairment. Under the strengths section it states: "...Music, food, and physical touching seem to motivate her. The resident learns primarily through repetition. She has the use of her upper extremities and some visual tracking ability."

6/30/13 Notes by staff document that the resident had a coughing episode. She was assessed by the physician and her lungs were clear.

7/21/13 Video-fluoroscopic swallow study #4 was conducted. Per the record the resident was admitted to the hospital on 7/17/13 with an admitting diagnosis of hypothermia. While at the hospital she was given another swallow study. The documentation stated: "...Upon arrival the patient appeared lethargic/sleepy. She was able to be awakened. She was positioned upright at an approximate 90° angle and a lateral view was obtained....She was given the following consistencies: thin liquid, nectar six liquid and pureed consistencies. Each of the consistencies was swallowed without difficulty. There was no throat clearing, coughing, or choking with any consistency. There was also no aspiration or penetration into the laryngeal vestibule...."

Recommendations:

1. Continue pureed consistency diet with nectar-thick liquids.
2. Present liquids via a spoon. Do not use cups, glasses, or straws.
3. Position upright when eating and drinking.
4. Alternate giving the patient small bites of food and drinking small amounts of liquid.
5. Maintaining patient upright position after eating/drinking for 30 minutes."

7/23/13 The nutritional assessment documents that the resident was hospitalized from 7/17/13-7/22/13 and her differential diagnosis included infection verses central hypothermia versus medication.

7/25/13 On the addendum of the nutritional assessment the guardian voiced the following concerns:

"a) Pedal edema - 2 mg sodium diet remains appropriate. The food is bland Ms Dash to be included.

b) That pureed food was too thin. The direct care staff are to call kitchen if food is too thin.

c) Request thin liquids. Recommend nectar thick liquids given history of coughing/turning red in face after drinking thin liquids. Direct care staff report they place her head in midline and give verbal cues to chew and swallow..."

8/1/13 An addendum states: "Received Speech pathologist findings and recommendations from VFSS continue pureed diet and nectar liquids, her current diet consistency. Updated meal protocol when parents visit and provide home-cooked meals, they are to be sent to kitchen to be pureed. Guardian requested another VFSS..."

8/12/13 At a follow-up appointment from a recent hospitalization on 7/21/13 it was documented in the record that based on the most recent swallowing test there was no indication for a PEG tube. In the plan it stated: "Diet as tolerated. Would have another bedside swallow evaluation regarding dietary consistency if aspiration concern remains."

8/28/13 The physician ordered a VFSS to be at a specific hospital per the request of the guardians.

8/29/13 The order for the VFSS was canceled.

9/13/13 The physician treatment plan for morbid obesity states: "39 year old female with weight gain. Weight gain is multi-factorial. Dietary consultation recommended with low calorie diet. Given her lack of mobility and decreased muscle tone, her caloric use is limited as there must be a balance between nutrition needs and caloric intake to prevent continued weight gain. I have recommended physical therapy daily to promote calorie burn." In the history of present illness it states: "... Per her parents, her total calorie intake was about 1000 calories per day. Over the five years she has gained 50 pounds. She is non-mobile with a history of two broken legs due to severe osteoporosis. She has a new diet due to weight gain and was put on an 800 calorie diet in January of 2013. She has not lost weight to date...."

"The patient is dependent on caregivers for all activities of daily life at this time. She does not participate in physical therapy and has limited movement of limbs."

The patient's history documents that she had a history of 2 broken legs due to severe osteoporosis.

9/22/13 The guardian reports that the individual is coughing from congestion (no fever) which was reported to physician. *Robitussin-DM* was prescribed.

9/30/13 The resident started coughing and turned beet red and her lips turned blue; the technician loosened her belt. She swallowed, started to breath and her regular color returned.

10/21/13 A letter from the Fox Center Director to the guardian states: "Please be advised that the Center will not be providing you with the fourth video swallow study. The Center is in possession of three such tests results that draw essentially the same conclusion that no-solid food

should be provided to the resident; rather, it should be pureed. As a result of these findings; the medical staff feels it would be clinically inappropriate to order a fourth set of tests.

You have advised the Center that you think the results from these three studies are mistaken and you feel strongly that a fourth test should be undertaken, at a hospital of your own choosing. While you will need to obtain a doctor's order without the Center's assistance, we are willing to transport the resident for this purpose to a hospital of your own choosing within a reasonable range from the Fox center. Be further advised that you will be fully financially responsible for paying for this fourth test.

While we know this is not the news you are seeking, please know that we remain available to discuss (this matter) further and, if you like to move forward, to discuss the details of transporting the resident."

There were no notes from the Human Rights Committee discussing the issues in this case.

Policy Reviews

In the *Interdisciplinary Team Process* (IDT) (11/4/2011) under the section of goals it states: "Personal Goals reflect what a person wants for the future. Each person has a unique way of expressing dreams, directions, hopes and desires. Personal Goals are statements about what the person wants to do or accomplish in the years ahead. Each person directs his or her own process of considering and selecting goals. It is Fox Center's responsibility to provide people with the support they need to experience a variety of options so they can make choices about the future. The person's desires and goals are the focus of the Individual Support plan. The person's Personal Goals are addressed by the IDT Team after reviewing the Personal Preference Assessment...."

Under the Procedures: A. IDT Membership it states: "The IDT is individualized and includes the person served, family/guardian, QSP (QM RP), nurse, direct support staff and other as determined through needs, assessments and desires of the individual. Interdisciplinary Teams are characterized by a high degree of interaction among members as the IDT develops a plan based on the personal preference and goals of the person receiving services. The service planning process considers the person's needs and preferences as whole rather than addressing particular needs and preferences in isolation.

IDT Members are treated in a courteous and respectful manner. All members have equal rights and responsibilities during the meeting...."

Continued in the Procedures, the B. IDT Meetings section states: "...The meetings are scheduled at a time to maximize the participation of members, especially the person served and the guardian/family/friends. Conference calls are used to allow participation of guardians, family members and others who may not be able to attend in person. If a guardian is unable to attend he/she is asked if they want an Advocate to participate. Assistance is provided in identifying an Advocate as needed...."

The Procedures, C Assessment section states: "Each person served has an up-to-date, comprehensive functional assessment (CFA). An initial CFA is completed within 14 days of admission and updated at least annually. The CFA covers all required areas; physical development/health, nutrition, sensorimotor, affective development, adaptive behavior and vocational/educational, as applicable, as well as social and medical history and any other areas required by state/local policies...."

"...Thus people performing assessments need to be personally aware of how the person sees him/herself, or things important to him/her, and his/her dreams, and need to use this information as a focal point when conducting evaluations...."

Section D. on ISP development states: "The IDT reviews and discusses the person's preferences, desires and personal goals. The IDT promotes exercising rights, responsibility and self-determination/choice by the person served. Rights restrictions are identified, risk versus benefit reviewed...."

The HRA reviewed the *Rights of Individuals* (4/2/2013). In section A. 2. it states: "Each person will have the right to receive unopened mail, uncensored telephone calls, and regular visitors as set forth in Section 2-103 of the Mental Health And Developmental Disabilities Code;...."

According to the *Explaining Legal Rights* (1/9/12) policy: "...The information (rights) must be administered in written and oral form and be appropriate to the type of admission. The person and his/her guardian/parent will receive copies of the rights information. Further, summaries of rights are posted in public areas throughout Fox Developmental Center...."

The *Visitors Policy* (8/28/2013) section 2) states: "Family and friends of individuals who reside at Fox Center are urged to visit, with no restrictions placed on the day or times during which they visit...."

The *Communication Rights for Individuals Who reside at Fox Center* (1/9/2012) section 4. states: "Reasonable restrictions may be made upon the privacy of communication by mail, telephone, and visitation in order to protect the individual or others from harm, harassment or intimidation. No such restriction shall be made unless notice of the restriction is given to the individual...."

"...If a restriction is placed on an individual's rights, the interdisciplinary team responsible for implementing the individual's support plan shall provide immediate notice of such restriction to:

- a. The individual and, if such individual is a minor or under guardianship, his parent/guardian;
- b. A person designated by the individual upon commencement of services or at any later time to receive such notice; or if no such person is designated, the nearest relative of the individual; and

- c. The Guardianship and Advocacy Commission, if the individual so designates.
5. Each restriction will be reviewed by the Facility Human Rights Committee."

MANDATES

The Mental Health and Developmental Disabilities Code (405 ILCS 5) in section **2-102 (a) regarding care and services** states: "a recipient of services shall be provided with adequate and humane care and services 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...."

Furthermore, under section 5/2-107 regarding the refusal of services, the Code states: "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 or electroconvulsive therapy. 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."

According to the Medicaid Conditions of Participation (42 CFR 483.420), Client Protections, section (a) Standard: Protection of Clients' Rights, "The facility must ensure the rights of all clients. Therefore, the facility must: (2) Inform each client, parent (if the client is a minor), or legal guardian, of the client's medical condition, developmental and behavioral status, attendant risks of treatment, and of the right to refuse treatment; (3) Allow and encourage individual clients to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process;..."

It continues in section (c) Standard: Communication with Clients, Parents, and Guardians stating that "The facility must: (1) Promote participation of parents (if the client is a minor) and legal guardians in the process of providing active treatment to a client unless their participation is unobtainable or inappropriate; (2) Answer communications from clients' families and friends promptly and appropriately; (3) Promote visits by individuals with a relationship to the client (such as family, close friends, legal guardians and advocates) at any reasonable hour, without prior notice, consistent with the right of that client's and other clients' privacy, unless the interdisciplinary team determines that the visit would not be appropriate;...."

Section 483.480 regarding dietetic services, part (a) Standard: Food and Nutrition Services states: "(1) Each client must receive a nourishing, well-balanced diet including modified and specially-prescribed diets..." Section (4) states that the facility is required to: "Supervise and staff dining rooms adequately to direct self-help dining procedure, to assure that each client receives enough food and to assure that each client eats in a manner consistent with his or her developmental level...."

The Probate Act of 1975 (755 ILCS 5/11a-23) states, " (a) For the purpose of this Section, 'guardian,' standby guardian,' and 'short-term guardian' includes temporary, plenary, or limited guardians of all wards. (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."

Per the Mental Health Code, regarding the rights of recipients, Section **5/2-103 states:** "Except as provided in this Section, a recipient who resides in a mental health or developmental disabilities facility shall be permitted unimpeded, private, and uncensored communication with persons of his choice by mail, telephone and visitation...."

(c) Unimpeded, private and uncensored communication by mail, telephone, and visitation may be reasonably restricted by the facility director only in order to protect the recipient or others from harm, harassment or intimidation, provided that notice of such restriction shall be given to all recipients upon admission...."

CONCLUSION

Regarding Complaint 1. A recipient of services is not provided with adequate and humane care and services in the least restrictive environment pursuant to an individual service plan and Complaint 3. The facility attempts to override the guardian's decisions; the resident via her guardians has the right to participate in the development and implementation of his or her plan of care. In the *Interdisciplinary Team Process (IDT)* (11/4/2011) policy, a person's desires and goals are the focus of the Individual Support plan. The people performing assessments need to be personally aware of how the person sees him/herself, or things important to him/her, and his/her dreams, and need to use this information as a focal point when conducting evaluations. The interdisciplinary team should promote exercising rights, responsibility and self-determination and choice by the person served. Rights restrictions are identified and the risks versus the benefits are to be reviewed. The resident via her guardians has the right to make informed decisions regarding her care. The resident 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.

The guardians have expressed their wishes for the resident to enjoy dental soft foods, with her meals, but have been overridden by what the facility staff deem as unsafe or not nutritious. It is also documented by the physical therapist and by her physician that one of the few activities the resident is capable of completing on her own is to pick up a piece of dental soft

food, put it in her mouth and be able to chew. Two out of three video-fluoroscopic swallow studies suggested a mechanical soft dysphagia diet, and a third suggested a pureed diet with advancement of dental soft foods at the speech therapist's direction. These three studies thus supported the guardian's wishes, either in whole or in part. The facility chose to continue to implement a pureed diet for the client, even after new dietary guidelines were suggested, in favor of their perception that the client's welfare would be best served by this decision. Finally, during a hospitalization in July, 2013, another swallowing study was conducted when the patient was very ill and lethargic, indicating the need for a pureed diet. The record does not document a comprehensive team meeting with the guardians following the July, 2013 evaluation. It does indicate the guardian had a discussion with the physician, who wrote another order for a swallowing study, because of the guardian's concerns about the resident's physical status at the time of the exam. However the order was retracted, because the medical staff felt it would be clinically inappropriate to order the tests.

The record does not show that this decision was addressed with the guardians in person. Instead a letter was sent to the guardians indicating another swallowing study could not be conducted, unless it was done privately and paid for by the guardians. The letter cited incorrect data that all of the swallowing studies indicated the need for a pureed diet. Considering the profound disabilities of their child, it would be extremely difficult for the guardians to obtain a new swallowing study, without it being facilitated by the facility. While the facility assesses that a large part of this client's dietary issue is the inability to chew, rather than to swallow, the guardian appears not to have an understanding of the interdisciplinary treatment team's conclusion. The facility had knowledge that the guardians were unhappy with the decision to remain on a pureed diet. The guardians enjoy bringing special foods and feeding it to the resident. The resident's diet has been an issue of concern and conflict with staff and the guardians for over 7 years, but there is no evidence it was ever discussed by the Human Rights Committee, nor did the facility share any pathway for resolution of the impasse for the guardian. The HRC committee could provide a more impartial opinion than the committees that are only comprised of Fox staff. The HRC committee could have considered if this individual's dietary regime was conducted in a manner "...consistent with her developmental level...."

It is unknown if the guardian was ever advised of the right to refuse treatment. Such a conversation would have met the spirit of the Mental Health and Disabilities Code *under section 5/2-107 regarding the refusal of services, the Code states: "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 or electroconvulsive therapy. 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."*

The right to refuse treatment was documented in the individual's ISP, but a conversation was not documented regarding the guardian's known wishes for the individual's eating program due to staff concerns about eating and choking. It is the facility's duty to explain resident's rights to the individual and her guardian. Guardians should not be just given a copy of the rights.

When issues arise, there should be careful dialog around any possibility of a violation of an individual's rights.

The record substantiates the guardian's complaint that they were not always consulted regarding care. On 5/18/13 a special team meeting was held and documented by the QIDP, as staff members were concerned about the resident gagging. Even though the guardians see this resident weekly, traveling quite a distance, and although they call to check on her daily and make themselves available to see the resident at the hospital, they were not contacted to participate in the 5/18/13 meeting via the phone. They were informed of planning **after** the meeting. This is in violation of *Procedures, B. IDT Meetings section* which states: "...The meetings are scheduled at a time to maximize the participation of members, especially the person served and the guardian/family/friends. Conference calls are used to allow participation of guardians, family members and others who may not be able to attend in person. If a guardian is unable to attend he/she is asked if they want an Advocate to participate. Assistance is provided in identifying an Advocate as needed...." This also violates Mental Health Code provisions that guardians are participants in treatment planning.

The HRA appreciates that the facility could not provide physical therapy that the physician recommended because of the resident's inability to participate in active range of motion exercises. The facility has kept this resident free from additional contractures utilizing passive range of motion. It is clear the facility has conducted regular PT reviews and treatment. Nursing efforts and physical positioning have kept this client free from decubitus ulcers. The patient's caloric intake is monitored to prevent weight gain. Her diet is 800 calories +. Assessing and determining the best medical care for a resident is beyond the scope of the HRA's authority and expertise. However, the HRA contends that by excluding the guardian from discussion of individual preferences and by overriding the guardian's known wishes, without utilizing a careful pathway for communicating the guardian's rights as surrogate decision maker, the facility is not providing adequate and humane care and services in the least restrictive environment pursuant to an individual services plan. While the HRA commends the facility on keeping the guardians advised of the resident's overall health and welfare, it does find the **Complaints 1. & 3. substantiated on the basis of the failure to invite the guardian to the 5/18/13 meeting and to involve the guardian in decision making.**

Regarding Complaint 2., the facility impedes visitation for an individual receiving services: After the HRA provided a date, time and a possible first name of the staff that allegedly searched the guardians' belongings, a supervisor spoke to the staff member who might have been the person who completed the search about the allegation. Per the supervisor, the staff stated that she had never gone through the guardians' belongings. The supervisor reminded the staff that at no time should she go through the guardians' possessions. The employee stated that she understood and that she has not done that. **The HRA cannot substantiate complaint #2 that the facility impeded visitation for an individual receiving services based on one person's word against another.** Fox policies and procedures follow the Mental Health Code regarding an individual's right to unimpeded, private, and uncensored communication with persons of his/her choice by mail, telephone and visitation. If rights are to be restricted it is the facility's policy to complete rights restriction notices and issue them to anyone designated (405 ILCS 5/2-201). **The HRA strongly suggests that all staff who have any contact with an individual and**

their guardians be advised that searching a guardian's belongings would be a rights violation unless there was an appropriate rights restriction for a specific individual.

The HRA recommends the following:

- 1. Ensure guardian participation in treatment planning consistent with the Illinois Probate Act, the Mental Health Code and facility policy.**
- 2. When there are differences over an individual's treatment, particularly when the differences involve a recipient right such as the right to refuse, address through the treatment planning process, with guardian/recipient participation, and document accordingly. Include in the treatment plan review the need to consider additional resources to review the situation, including internal committees or external experts.**
- 3. The resident's rights and responsibilities should be explained to the guardians as well as the individual so they can effectively advocate for the individual.**
- 4. When there are human rights issues, inform individuals and the guardians of their right to bring these issues to the Human Rights Committee. The facility has insured that a divergent Human Rights Committee exists, with a broader make-up than just utilizing Fox staff members. If only Fox staff members comprise such committees, the deck is stacked in favor of what Fox staff decide is best for an individual. It is noted that the HRA was told that injuries would be discussed by the HRC, but there were no notes provided to the HRA that the injuries that occurred from the resident's osteoporosis were discussed by Fox's HRC.**

The HRA also takes this opportunity to make the following suggestions:

1. The HRA recognizes there may be a need for an impromptu meeting, however staff should make a reasonable attempts to contact the guardians by phone and document the facility's efforts to include guardians in the decision-making process per the policy at Fox.
2. Post updated rights information in areas that are accessible for the individuals served and their guardians as required by 405 ILCS 5/2-200.
3. Initiate a conversation with the guardian to attempt to resolve the dietary concerns to determine if there is common ground where everyone (facility and guardians) can achieve resolution.
4. Regarding the medical consortium committee, the HRA encourages Fox to once again have a divergent committee with a broader make-up than just utilizing Fox staff members.

As part of the investigation the Fox Developmental Center was urged by the HRA team to consult with their legal team to assist them in defining possible solutions to the current impasse between the facility and the guardian regarding dietary issues. The

Fox Director was advised against any kind of waiver or release from liability concerning resident's parents feeding her another consistency diet. The HRA was advised that the resident is scheduled for another video swallow test and to be assessed by a new speech therapist. The HRA hopes that this might provide a fresh impartial assessment.

The HRA commends the leadership at Fox for providing a very positive therapeutic milieu for this resident. This client receives careful, compassionate care, and the guardian is appreciative of the care given the resident. It is evident that extra measures for the welfare of the client have been provided, such as providing a sitter for the individual while she was in the hospital and offering transport for a private physician evaluation. It is also positive that Fox Developmental Center embraces the inclusion of therapy dogs for treatment and the foster grandparent program. The HRA acknowledges the cooperation of Fox Developmental Center and its staff during the course of its investigation.

RESPONSE

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



Pat Quinn, *Governor*

Michelle R.B. Saddler, *Secretary*

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June 9, 2014

Human Rights Authority
Annette Becherer, Chairperson
2125 South First Street
Champaign, IL 61820

Dear Chairperson Becherer:

Enclosed is Fox Center's response to the Recommendations made in the Human Rights Authority's investigation of Case #14-060-9003.

Recommendation #1

Ensure guardian participation in treatment planning consistent with the Illinois Probate Act, the Mental Health Code and facility policy.

Fox Center Response:

All QIDP's (Qualified Intellectual Disabilities Professional) received training 5/20/14 (new Q's will receive this training also) ensuring guardian participation including:

- Guardians are to be informed of all Special Team Meetings and Annual Reviews prior to the meeting and arrangements made to include them;
- QIDP's should deflect a "spur of the moment" meeting suggestion by team members and inform them that the guardian must be informed prior to a meeting; therefore, the meeting will need to be scheduled, unless there are extraordinary circumstances;
- QIDP's should document all attempts to notify the guardian of a meeting. Should a guardian be notified at least 24 hours prior and not respond, they will be called again on the day of the scheduled meeting to attempt again to inform them of the meeting.

Recommendation #2

When there are differences over an individual's treatment, particularly when the differences involve a recipient right such as the right to refuse, address through the treatment planning process, with guardian/recipient participation, and document accordingly. Include in the treatment plan review the need to consider additional resources to review the situation, including internal committees or external experts.

Fox Center Response:

All QIDP's received training 5/20/14 on ensuring guardian participation (new employees will also receive this training) including:

- If a guardian does not agree with a treatment plan and the rest of the team feels that it is in the best interest of the individual to proceed as the team requests, the issue will be forwarded to the Center's Human Rights Committee (HRC) for review. The Residential Services Director will be notified of any such instances.

Additionally, we will revise our Operational Guide "Interdisciplinary Team Process" by July 1, 2014, to include language regarding the process to be followed when a guardian disagrees with the treatment plan.

Consistent with 755 ILCS 5/11a-20 of the Probate Act, The Center nevertheless reserves the right to seek the removal of a guardian in the appropriate set of circumstances, such as conduct that clearly places the ward's health in jeopardy.

Recommendation #3

The resident's rights and responsibilities should be explained to the guardians as well as the individual so they can effectively advocate for the individual.

Fox Center Response:

The individual's rights and responsibilities are distributed and explained to the individual and guardian at the time of admission. The Center Social Worker has been instructed to distribute and explain individual rights and guardian rights at every Annual Review as well.

Recommendation #4:

When there are human rights issues, inform individuals and the guardians of their right to bring these issues to the HRC. The facility has insured that a diverse HRC exists, with a broader make-up than just utilizing Fox staff members. If only Fox staff members comprise such committees, the deck is stacked in favor of what Fox staff decide is best for an individual. It is noted that the HRA was told that injuries would be discussed by the HRC, but there were no notes provided to the HRA that the injuries that occurred from the resident's osteoporosis were discussed by Fox's HRC.

Fox Center Response:

All QIDP's received training 5/20/14 on ensuring guardian participation (new employees will also receive this training) including:

- If a guardian does not agree with a treatment plan and the rest of the team feels that it is in the best interest of the individual to proceed as the team requests, the issue will be forwarded to the Center's Human Rights Committee for review. The Residential Services Director will be notified of any such instances.

The current membership of Fox HRC currently consists of:

- 2 Fox employees (Occupational Therapist/Chairperson and Social Worker)
- Liaison from the Behavior Intervention Committee (Training Director at Fox Center)
- Pharmacist (not employed by Fox Center)
- PAS (Pre-Admission and Screening) Agent (not affiliated with Fox Center)
- 1 Local Clergy
- 1 Parent
- 2 Community Members

Additionally, we will revise our Operational Guide "Interdisciplinary Team Process" by July 1, 2014, to include language regarding the process to be followed when a guardian disagrees with the treatment plan.

The individual's rights and responsibilities are distributed and explained to the individual and guardian at the time of admission. The Center Social Worker has been instructed to distribute and explain individual rights and guardian rights at every Annual Review as well.

While it is true that the injuries (fractures from 3/23/04 and 4/10/09) incurred by the individual were not documented as being discussed at HRC, that process has now been revised (since the latter part of 2009). All injuries incurred by individuals at Fox Center are documented on an Injury Log. That document is then submitted to the HRC and reviewed at the meeting. Any issues noted are then brought to the Center Director's attention for appropriate follow-up.

While the Fox Center was advised that it was only required to respond to the Recommendations, the Center wanted to take this opportunity to also address the Suggestions.

Suggestion #1:

The HRA recognizes there may be a need for an impromptu meeting, however staff should make a reasonable attempt to contact the guardians by phone and document the facility's efforts to include guardians in the decision-making process per the policy at Fox

Fox Center Response:

As stated above, Fox Center QIDP's have received training 5/20/14 on ensuring guardian participation in Special Team Meetings and Annual Reviews.

Suggestion #2:

Post updated rights information in areas that are accessible for the individuals served and their guardians as required by 405 ILCS 5/2-200.

Fox Center Response:

Updated rights information has been posted in areas that are accessible for the individuals.

Suggestion #3:

Initiate a conversation with the guardian to attempt to resolve the dietary concerns to determine if there is common ground where everyone (facility and guardians) can achieve resolution.

Fox Center Response:

The dietary concerns have been resolved at the present time. A recent video swallow test has been completed where the individual's diet was upgraded to soft solids as tolerated with thin liquids. Fox's Speech/Pathologist continues to monitor for adequacy of the diet consistencies for all clients where dietary concerns are an issue.

Suggestions #4:

Regarding the medical consortium committee, the HRA encourages Fox to once again have a divergent committee with a broader make-up than just utilizing Fox staff members.

Fox Center Response:

In addition to the Medical Consortium Committee (consisting of Fox Center physicians and Fox Center Medical Director and Director of Nursing), Fox Center will confer with the DHS Medical Director in cases where there is disagreement in treatment plans concerning medical needs.

Fox Center would like to thank the HRA for the opportunity to work collaboratively in resolving these issues. We also thank the HRA for the many instances of positive feedback provided in its Report. We look at this experience as a chance to learn, grow, and improve our services for the individuals at Fox Center.

Respectfully submitted,

Cheryl Winnicki
Center Director
Fox Center