



FOR IMMEDIATE RELEASE

**East Central Regional Human Rights Authority
Fox Developmental Center
Report of Findings
Case # 20-060-9008**

The East Central Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission voted to pursue an investigation of Fox Developmental Center after receiving the following complaints of possible rights violations:

Complaints:

- 1. Inadequate treatment planning**
- 2. Inadequate guardian inclusion**

If the allegations are substantiated, they would violate protections under The Mental Health and Developmental Disabilities Code (405 ILCS 5/3-209, 5/2-102, 5/2-107), The Illinois Probate Act (755 Ill. Comp. Stat. Ann. 5/11a-17 and 23) and The Code of Federal Regulations (42 CFR 483.429).

Complaint Summary: The complaint states the provider is knowingly performing swallow studies when the consumer is already lethargic (very high ammonia levels). If the swallow studies are accurate, the provider is reportedly not working with the consumer on therapies to increase the consumer's ability to swallow and rehabilitate that function. Lastly, the guardian is allegedly being treated poorly when visiting the consumer just because the guardian disagrees with how the Center is handling the care. Since the guardian advocated for new swallow studies, the provider now requires the guardian to have all the food that the guardian brings into the facility checked by the staff (the guardian has been bringing in lunch for the consumer and eating with the consumer for many years without this requirement) so the guardian reportedly feels like the provider is treating the guardian as if the guardian will hurt the consumer.

Investigation

The HRA proceeded with the investigation after having received proper consent. To pursue the matter, the HRA visited the facility and the program representatives were interviewed. Relevant practices, policies and sections of the consumer's record were reviewed.

Interviews:

On June 3, 2020 at 9:30am, the HRA met with Fox Developmental Center staff members via WebEx video call. The meeting began with introductions, a review of HRA procedures, and a review of the allegations being addressed in this investigation.

The staff provided some general information about Fox. Fox is a State Operated Developmental Center serving approximately 80 individuals with a variety of medical and mental health needs. All staff are trained in Human Rights and Abuse and Neglect at their orientation and through an annual refresher. Individuals living at Fox (and their guardians when applicable) are given information on their rights and grievance procedures at placement. The rights and grievance procedures are also reviewed annually. Fox was aware that the guardian had concerns about the individual's circumstances, but no formal grievances have been filed in relation to this complaint.

The individual has resided at Fox for many years and has a current treatment plan. Staff reported that in 2019, the individual's plan included total feeding assistance. Staff stated that there were rare occasions when the individual was able to feed herself, however, almost all meals were fed to her by Fox staff or the individual's guardians. The guardians regularly visited with the individual and provided a meal. Fox stated that the guardians were not required/asked to bring food to the dietary department for inspection at that time.

On July 8, 2019, the individual was lethargic, barely responsive and was taken to the hospital. While at the hospital, the medical team downgraded the individual's food consistency to a Dysphagia 1 diet (puree food with honey consistency liquids). Fox reported that the downgrade was based on a clinical bedside evaluation of the individual's eating. Video swallow studies were discussed but no video swallow studies were conducted due to the individual's lethargic state. The individual was hospitalized from 7/6/19 to 7/14/19 and was discharged to Fox with instructions to continue a pureed diet. After returning from the hospital, the guardian expressed dissatisfaction with Fox's decision not to increase the individual's diet consistency but agreed to follow the medical recommendations at that time. Staff stated that the guardian's ability to provide meals did not stop, however Fox began to enforce its policy that food brought in must be checked by dietary to assure that the medical orders were followed. Fox stated that this change in requirements was not related to an incident or concern with the individual or guardian. The decision was based on Fox's discovery that they had not been following its own policy to have all outside food consistency checked by dietary for appropriate modifications. Fox staff added that this change in enforcement was applied to all outside food brought in from visitors and not specifically just applied to these guardians.

Fox noted that because the patient had a history of silent aspiration, a video swallow study was requested before Fox would increase the diet. The video swallow study was completed on 10/3/19 and the results recommended that the individual continue a Dysphagia 1 diet. The guardian requested a second opinion. The second video swallow study was completed on 11/7/19 and the results showed some improvement. Fox agreed to start slowly transitioning back to a Dysphagia 2 diet starting with a three-day trial. Fox staff reported that the diet transition requires the individual's service plan to be changed, all staff to be notified and trained on the change, and then implementation. Due to the holidays, the implementation did not begin until January 2020.

Since January, the individual has slowly built up her diet and is currently back to the Dysphagia 2 diet that she was on prior to the hospitalization.

Fox staff reported that the guardians have always been very involved in the individual's treatment. The staff stated that they understand that the individual and her guardians share a meal each week and having that ritual and bonding time is important to them. The intention was never to upset the guardians or change the plans, but Fox staff stated they are required to follow medical recommendations for the safety of the individuals that reside at the facility.

Records Reviews:

Fox Developmental Center provided the HRA with the following records:

The Individual Support Plan (ISP) dated 3/26/19 states that the individual "has a good appetite. She really enjoys hot dogs, polish sausage, mashed potatoes, and foods cooked to her preference. She does not like citrus fruits, spiced apples, applesauce, lima beans, French and 1000 Island dressing. She is provided with specific finger foods; however, sometimes will not pick them up. Staff provides her with hand shaping and at times this is unsuccessful." The ISP also notes that the individual will sometimes bite through foods but does not chew her food thoroughly, so she receives ground meat and some of the dental soft foods are cut up into ¼ inch pieces and presented with a teaspoon. Foods that she can tolerate in larger pieces are offered as finger foods. She receives thin consistency liquids delivered with a teaspoon, per Videofluoroscopic (VSS) results. If she were to receive liquids via a tablespoon it would need to be nectar consistency.

A Fox Nutritional Assessment dated 7/15/19 states the patient was in the hospital for evaluation and treatment of dysphagia and altered mental status. The assessment reiterates that the individual was on a Dysphagia 2 diet as of 3/28/19, during the hospital stay the diet was downgraded to honey-thick liquids, and upon return to Fox the individual was set to remain on a downgraded/pureed diet.

The Special Team Meeting documentation for 7/16/19 states that the guardian "wanted it documented that he does not agree with the new consistency, that food is very important to the individual and the family, and that the guardians feel that the individual was not eating well because she was not feeling well." Fox staff agreed to monitor the individual closely at meals and they hoped that at some point the diet consistency could be upgraded, however, the staff were concerned for the individual's safety. The guardian made his feelings known but agreed to abide by the decisions of the medical community at this time.

A Nutritional Assessment addendum dated 7/16/19 states that "the guardians are upset and wanted it documented that they did not agree with the new diet." The Guardians were informed that all food brought in needs to be processed by dietary and therefore needs to be in the kitchen by 10am for a lunch meal or 3 pm for a supper meal.

A Speech and Language note dated 8/19/19 states that "no further aspiration was noted, and the Speech therapist would discuss with the physician about VSS readiness." The 8/21/19 note states

that they “are working on a discussion with the physician about getting permission for VSS advancement.”

The Videofluoroscopic Swallow Evaluation dated 10/3/19 states that the individual “is currently on a puree texture and honey thick liquids diet and the guardian would like to upgrade the diet.” It notes that the patient was downgraded from minced and moist diet and regular liquids on 7/9/19 and to puree diet and thick liquids on 7/12/19 due to overt coughing. The Patient was eating 3 meals a day. The recommendation of the VSS was honey thick liquids only by spoon for general aspiration precautions.

The Fox Interdisciplinary Team Special Team Meeting Documentation dated 10/10/19 states that “the guardian did not agree with the 10/3/19 VSS results and requested a second opinion.” It was agreed that, until the evaluation was completed, the individual would continue on the current diet and all food brought in for the individual by the guardian would be sent to the kitchen to ensure proper consistency. It states that the guardian agreed.

The Videofluoroscopic Swallow Evaluation completed on 11/6/19 showed improvement and recommended that the individual continue to receive a baseline diet and recommended that the provider trial the patient with soft solid and thin consistencies for a potential upgrade to her diet.

The Fox Interdisciplinary Team Special Team Meeting Documentation dated 11/7/19 reiterated the previous swallow study concerns, reviewed the 2nd opinion recommendations, and noted that they were better than previous swallow studies. Fox staff recommended that the individual would continue to get a baseline diet but added that the speech and language staff at Fox will trial the individual with soft solid and thin liquid consistencies to determine tolerance and ability for a potential upgrade over the next month. The guardians disagreed because they wanted the change sooner.

The HRA reviewed the Speech and Language pathologist notes for the assessments done on the individual from 11/13/19 to 12/2/19. On 11/19/19 the Speech and Language pathologist recommended allowing oatmeal on the current purred diet. On 1/26/19 the individual had oatmeal without issues. The note dated 12/2/19 states “observed the individual at lunch with dysphagia 1/pureed solids and nectar consistency liquids by teaspoon, oral stasis noted intermittently throughout meal. Coughing episodes x2 with puree fruits at end of meal will await 12/2/19 meeting with guardian and administration to discuss further diet advancement.”

The Fox Habilitation Plan Updates dated 1/13/2020 states that (following a phone conversation between the physician and the guardian) everyone was comfortable moving forward with a 3-day trial of the dysphagia 2 diet and then the team would meet to review and make changes as clinically indicated. There is also a note by the physician that the individual coughing is not always a negative response as long as the cough is strong and clear to lessen aspiration. However, if the individual has a weak cough or is lethargic, it would be a strong indicator that she is at risk of aspiration. Liquids were to remain of nectar consistency and if she did well the team would meet again to move forward with thinner liquids at some point in the future.

A Nutritional Assessment dated 2/7/20 states that the individual completed a diet change trial for three days in January 2020.

An Oral Motor/Swallowing/Hearing/Speech and Language Assessment Summary dated 3/10/20 states that the individual receives a Dysphagia 2 diet.

The Individual Service Plan (ISP) dated 3/10/20 states the individual “has a good appetite. She really enjoys hot dogs, polish sausage, mashed potatoes, and foods cooled to her preference. She does not like citrus fruit and juice, spiced apples, applesauce, lima beans, French, and 1000 Island Dressing. She is provided with specific finger foods; however, sometimes will not pick them up. Staff provides her with hand shaping and at times this is unsuccessful.” Page 24 states “The family understands that, due to Fox Center Guidelines, all food needs to be taken to the kitchen to ensure proper food consistency is maintained”.

Policy Review:

The Operational Policy Guide 1332 for Individual Support Plan Review Process indicates that the individual’s ISP (Individual Service Plan) is monitored and reviewed monthly. Each month a form titled “Skill/Behavior Objective Monthly Review” is completed with a statement that compares the individual’s progress from the last month and compares the monthly data from the previous month to assess progress. If no progress has been noted, Fox must document an analysis of the potential reason, as well as recommend changes in methods, activities, strategies, or environments if warranted by analysis. The Interdisciplinary Team (IDT) may be reconvened at any time due to lack of progress, however, if no progress is noted for six consecutive months a STM (define) must be held. Additionally, it states that if some training has not been implemented, the reason must be determined and documented. If remediation is initiated, this should be documented as well.

The Operational Policy Guide 1301 for Scheduling of Individual Support Planning Annual Meetings and Special Team Meetings states “The scheduling of the meetings must also facilitate the participation of all Interdisciplinary Team (IDT) Members including professional staff, direct support staff, and other persons involved in the provision of services and supports to individuals who reside at Fox Center, as well as the individual and their guardian.”

The Operational Policy Guide 6136 states “for all individuals with altered consistency diets (food and/or liquids) must have all outside food/liquid sent to dietary in order to achieve a proper diet consistency”.

Conclusions

Complaint 1. Inadequate treatment planning

The Mental Health and Developmental Disabilities Code (405 ILCS 5/3-209) states that a treatment plan “shall include an assessment of the recipient's treatment needs, a description of the services recommended for treatment, the goals of each type of element of service, an anticipated timetable for the accomplishment of the goals, and a designation of the qualified

professional responsible for the implementation of the plan. The plan shall include a written assessment of whether or not the recipient is in need of psychotropic medications. The plan shall be reviewed and updated as the clinical condition warrants, but not less than every 30 days.” The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102) 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.”

The individual’s treatment plan created on 3/26/19 stated that she was on a Dysphagia 2 diet. In July 2019, the individual was hospitalized because she was lethargic and non-responsive. The hospital downgraded the individual’s diet to honey-thick liquids based on observation and lethargy. On 7/15/19 the individual returned to Fox, the treatment team met and adjusted the patient’s treatment plan to include that the individual was on a downgraded/pureed diet. Fox staff agreed to monitor the individual closely at meals to assess if the diet consistency could be upgraded. A Speech and Language note dated 8/19/19 states that no further aspiration was noted. Fox required a swallow study be completed before a dietary increase due to a history of silent aspiration. Swallow studies were completed on 10/3/19 which agreed with the downgraded/pureed diet. The guardian was not happy with the results and requested another swallow studio be conducted by a facility of his choosing. The second swallow study was conducted 11/6/19. The second study showed improvement and recommended that the individual continue to receive a baseline diet and recommended that the provider trial the patient with soft solid and thin consistencies for a potential upgrade to her diet

On 11/7/19 Fox agreed to trial the individual with soft solid and thin liquid consistencies to determine tolerance and ability for a potential upgrade over the next month. The HRA reviewed the Speech and Language pathologist notes for assessments done on the individual from 11/13/19 to 12/2/19. On 11/19/19 the Speech and Language pathologist recommended allowing oatmeal on the current purred diet. On 11/26/19 the individual had oatmeal without issues. The note dated 12/2/19 states “observed the individual at lunch with dysphagia 1/pureed solids and nectar consistency liquids by teaspoon, oral stasis noted intermittently throughout meal. Coughing episodes x2 with puree fruits at end of meal will await 12/2/19 meeting with guardian and administration to discuss further diet advancement.”

The Fox Habilitation Plan Updates dated 1/13/2020 states that (following a phone conversation between the physician and the guardian) everyone was comfortable moving forward with a 3-day trial of the dysphagia 2 diet and then the team would meet to review and make changes as clinically indicated. There is also a note by the physician that the individual coughing is not always a negative response as long as the cough is strong and clear to lessen aspiration. However, if the individual has a weak cough or is lethargic, it would be a strong indicator that she is at risk of aspiration. Liquids were to remain of nectar consistency and if she did well the

team would meet again to move forward with thinner liquids at some point in the future. A Nutritional Assessment dated 2/7/20 states that the individual completed a diet change trial for three days in January 2020. An Oral Motor/Swallowing/Hearing/Speech and Language Assessment Summary dated 3/10/20 states that the individual receives a Dysphagia 2 diet.

Based on the findings above as documented in the individual's record the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint of inadequate treatment planning is **unsubstantiated**.

However, the HRA was not provided documentation from any Interdisciplinary Team Special Team meeting that may have occurred in December 2019. Furthermore, the HRA was not provided any further notes from the speech and language pathologist or any other staff at Fox after 12/2/19. This does not follow Operational Policy Guide 1332 for Individual Support Plan Review Process that requires that progress is recorded and compared monthly. The HRA **strongly suggests** that Fox follow their own policy on reviewing and recording progress monthly.

Complaint 2. Inadequate guardian inclusion.

The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-107) states "An adult recipient of services or the recipient's guardian, if the recipient is under guardianship, and the recipient's substitute decision maker, if any, must be informed of the recipient's right to refuse medication or electroconvulsive therapy. 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 Probate Act (755 Ill. Comp. Stat. Ann. 5/11a-17) states "(d) A guardian acting as a surrogate decision maker under the Health Care Surrogate Act² shall have all the rights of a surrogate under that Act without court order including the right to make medical treatment decisions" The Probate Act (755 ILCS 5/11a-23) states "Reliance on authority of guardian, standby guardian, short-term guardian. (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. A reliant shall not be protected if the reliant has actual knowledge that the guardian, standby guardian, or short-term guardian is not entitled to act or that any particular action or inaction is contrary to the provisions of the law."

The Code of Federal Regulations (42 CFR 483.429) states "Standard: Protection of clients' rights. The facility must ensure the rights of all clients. Therefore, the facility must—(1) Inform each client, parent (if the client is a minor), or legal guardian, of the client's rights and the rules of the facility; (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;”

The guardian was present and included in all meetings regarding the individual. The guardian advocated for an increased diet consistency and expressed the desire to refuse this service. In July 2019, Fox informed the guardian of the risks associated with the refusal of that service and the guardian agreed to abide by the decisions of the medical community at that time. On 11/7/19 the Fox staff recommended that the individual would continue to get the baseline diet but added that the speech and language staff at Fox will trial the individual with soft solid and thin liquid consistencies to determine tolerance and ability for a potential upgrade over the next month. The guardians disagreed because they wanted the change sooner. The HRA agrees that The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-107) was followed in July 2019 when the guardian agreed to follow the medical advice, however, in November 2019 the guardian disagreed with the plan to slowly trial the individual over the next month. Therefore, the guardian was not allowed the right to refuse treatment per the Code (405 ILCS 5/2-107 and 42 CFR 483.429).

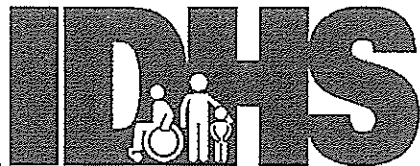
Based on the findings above the East Central Human Rights Authority concludes that the consumer’s rights were violated and, therefore, the complaint is **substantiated**. The HRA makes the following **recommendations**:

1. Fox ensure that their practices align with The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-107), The Probate Act (755 Ill. Comp. Stat. Ann. 5/11a-17 and 23) and The Code of Federal Regulations (42 CFR 483.429). If there are concerns about a guardian’s decisions, Fox should address through the treatment planning process or consider contact with the courts.

Prior to July 2019, Fox allowed the guardians to bring food into the facility and feed the individual without inspection by a dietary department staff. After the meeting, the guardians were made to have their food inspected by the dietary department to ensure that the discharge instructions were being followed. Fox staff reports that this change was an enforcement of an already existing policy. While the HRA understands that Fox was making efforts to enforce an already existing policy and Fox believed that this enforcement was to keep the individual safe, changing the treatment plan to enforce a restriction that was not previously needed based solely on the fact that the guardian expressed disagreement with the treatment plan could be considered retaliatory. The HRA **strongly suggests** that Fox cease the practice of only enforcing policies on a selective basis to avoid further appearances of retaliation.

RESPONSE

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



JB Pritzker, Governor

Illinois Department of Human Services

Grace B. Hou, Secretary

William W. Fox Developmental Center
134 West Main Street • Dwight, Illinois 60420

April 19, 2021

Lara Davis, Disability Rights Manager
IGAC
2125 South First Street
Champaign, IL 61820

Re: HRA Case #20-060-9008

Dear Ms. Davis,

Regarding the complaints of the above-mentioned investigation, Fox Center was to respond to the findings and recommendations within 30 days of receiving the final report.

Complaint #1: Inadequate treatment planning.

The complaint was unsubstantiated. However, it was noted that HRA was not provided documentation from any Interdisciplinary Team (IDT) Special Team Meeting (STM) which may have occurred in 12/2019 or any notes from the speech language pathologist (SLP) or any other Fox staff. It was recommended that the Fox Center follow its own policy requiring progress to be recorded and compared monthly, as cited in *Operational Guide 1332*, Individual Support Plan Review Process.

Fox Center's Response to Complaint #1.

The records requested by HRC were for the period of 7/1/2019-11/15/2019. Please see the attached letter as corroboration to the time period requested. Fox Center has documentation in the form of case notes and a special team meeting (STM) that we could have provided but were beyond 11/15/2019. At this time, we cannot include notes because due to COVID19, the consent the guardian signed is no longer valid. If desired, the records may be sent if the guardians are willing to authorize the release of records.

Complaint #2: Inadequate guardian inclusion.

The complaint was substantiated. HRA found that the consumer's rights were violated, citing that the guardians disagreed with the plan to upgrade the diet at a slower rate. It was recommended that Fox Center ensures that their practices align with the Mental Health & Developmental Disabilities Code, The Probate Act, and the Code of Federal Regulations. Additionally, the HRA



Illinois Department of Human Services

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strongly suggested that Fox cease the practice of only enforcing policies on a selective bases, to avoid the appearance of retaliation.

Fox Center's Response to Complaint #2.

In 10/2019, a video fluoroscopic swallow study (VFSS) showed silent aspiration. One month later, a repeat study was performed that did not show silent aspiration. Fox's speech-language pathologist (SLP) maintains that having a 1 or 2 minute VFSS that does not show silent aspiration and is not absolute in and of itself, does not detract from the significant risk of aspiration, choking, and/or death from advancing a diet with respect to the recipient's specific medical history. In conjunction with a facility physician; an independent SLP; and a radiologist selected by the guardians, using a methodical approach was deemed medically necessary to prevent irreversible serious and imminent physical harm to the recipient. In the SLP notes (that can be requested), it corroborates that every effort was made to prevent harm to the recipient by a utilizing a conservative process of diet advancement. However, the notes from 1/9-2/18/2020, detail that the delays were at the behest of the co-guardian's timeline.

Regarding the recommendation to not selectively enforce policies, Fox Center has attached a copy of its revised Operational Guide #6136, Dining Out/Special Events Guidelines. In it, Fox Center has added, "Staff must offer but not demand to take food brought in by a guardian to the dietary department, to achieve a proper diet consistency." However, Fox Center maintains that this Operational Guide came to our attention because of an incident that occurred at the Center where Fox staff assisted an individual with takeout food. It was that incident that had us reviewing eating out guidelines and resulted in us realizing that we needed to follow our own policy. Fox not only spoke to the guardians associated with this compliant. But other guardians that brought food to their loved ones having a modified diet consistency; whereby the food was mechanically altered (i.e., purred or made dental soft by a blender) for safe eating.

Please let us know if you have additional questions or concerns.

Kind regards,

A handwritten signature in black ink, appearing to read 'Sybil Nash'.

Sybil Nash, SPSA/Center Director