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HUMAN RIGHTS AUTHORITY-NORTHWEST REGION

REPORT 10-080-9007 Freeport Terrace
10-080-9008 Olson Terrace
10-080-9009 Canterbury Place

Case Summary: the HRA substantiated rights violations in all complaints. The facilities elected not to include responses in the public record.

INTRODUCTION

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving complaints of possible rights violations at three Frances House locations. Complaints at Freeport Terrace allege that the facility failed to provide nursing attention, proper documentation and guardian notification for a resident's injury. Complaints at Olson Terrace allege that the facility failed to include a resident's guardian in making medical decisions and the complaint at Canterbury Place alleges that the facility administered psychotropic medication to a resident without his guardian's informed consent. Substantiated findings would violate protections under the Probate Act of 1975 (755 ILCS 5), the Centers for Medicare/Medicaid Conditions of Participation (42 C.F.R. 483), the Nursing Home Care Act (210 ILCS 45) and the Administrative Code for Intermediate Care Facilities for the Developmentally Disabled (ICF/DD) (77 Ill. Admin. Code 350).

The homes serve adult men and women with developmental disabilities. Freeport Terrace and Olson Terrace have sixteen beds each while Canterbury Place is smaller with four. They are managed by Frances House, a DD Homes Network affiliate in northwestern Illinois, and licensed by the Illinois Department of Public Health.

The HRA visited the Freeport and Olson Terrace locations to discuss the issues with program representatives. Relevant policies were reviewed as were sections of the recipients' records with proper authorization.

FINDINGS

10-080-9007 Freeport Terrace

The complaint here states that on October 20th, 2009 a resident showed her guardian a red, scabbed-over sore on her hand and reported that it happened days earlier when a peer attacked her at the day training center; she said the police were called because the peer was so

violent. She told her guardian that the staff at home took care of the injury and that she was not seen by a physician or nurse. The complaint concludes by stating that the home provided no explanation or notification of the injury to the guardian.

A representative from the resident's day training center joined our visit to Freeport Terrace. She explained that no one saw the incident as described and that the police were never at their facility. Rather, the resident approached a staff member on October 12th and showed her hand saying a peer scratched her on Friday, the 9th. Those involved with the resident were questioned, but none of them knew what happened. On the 22nd she got a call from the guardian who was asking about the incident and for documentation. At that point she interviewed all staff members and had an incident report completed from the 12th when the resident first approached them. They never determined what happened, and the incident report was sent to the guardian.

According to that report, a registered nurse wrote that the resident presented a scratch on the 12th; the resident said she told staff at home after it happened on the 9th, there were no witnesses, and the facility would monitor daily. The nurse concluded her report by saying that the scratch was healing well without signs of infection.

As far as the home's role in the matter, they said that a staff member saw the scratch when the resident came home on the 9th and applied some ointment. It was monitored daily with follow up from the home's nurse. A minor scratch does not require an incident report or notice to any guardian, only something more significant. Neosporin is an as needed medication that can be applied without alerting the nurse.

Progress notes from the resident's chart at home state that on October 9th she came home with a quarter-sized bump on her hand. Per the medication records, Neosporin was applied daily from the 9th through the 14th, and again on the 21st and 23rd. The nurse visited on the 24th to give flu shots when the resident showed her the sore. The nurse noted a one centimeter abrasion that was scabbed-over with no exudate, edema or redness present.

An email from the guardian asking for information from the home's director was referenced. In the correspondence, the guardian reiterated all she knew: that the resident said she was attacked, the police were called, the staff at home took care of the injury, and it appeared to be healing. The guardian wrote, "[I] was never made aware of this incident. So again I find myself out of the loop and in need of ideas to help strengthen communication. Please let me know how I can be a more informed part of the team." We asked the director how he responded and what findings along with ideas to strengthen communication were ultimately provided. He said this was four months ago and that he talked to her but did not specifically remember. He said that if a guardian wants to be part of anything they can always come by and that their policy does not change; they do not notify about one centimeter scratches.

We checked in with the guardian who reports that she never got a response on what might have occurred with her ward or to her request to be a more informed part of the team.

This complaint states that a resident's guardian learned at an October 20th, 2009 staffing that a medical test she agreed to in May was never done. Reportedly, the home decided it was no longer necessary to pursue and failed to consult with the guardian before making that decision.

Olson Terrace told us that the resident has long had a spinal condition. His new physician was clearing him for Special Olympics and wanted to have a Magnetic Resonance Imaging, or MRI, done to rule out any more problems. They made a first attempt with the test on April 7th but the resident was reluctant and uncooperative. They rescheduled, got the guardian's consent to administer Valium to help him relax, and tried again on May 14th without any luck. Technicians at the clinic tried to encourage the resident to go through with the MRI; they let him wear his clothes but he did not want to take his Olympic medals off or go through the machine. They said that physician notes would reflect no medical need to carry on with the test.

On consulting with the guardian, the home said they attempted to reach the guardian at least twice after the failed tests and got no response. The home's administrator said they have no documentation of these attempts but that she was satisfied they were made.

An individual service plan from the resident's chart lists a spinal deviation diagnosis and prohibits contact sports and other activities that could cause impact to his spine. A physician's consult on March 11th cleared the resident for all activities as long as his spine x-rays were ok. Results from those showed a widening of the predens space and concern for C1-C2 subluxation, or partial dislocation, which could be further assessed with flexion/extension lateral views of the cervical spine; he was referred to a neurologist for that. The neurologist's consult report stated that the resident's condition was common to people with Down syndrome and that he becomes quite anxious when faced with an MRI-associated procedure. The resident was noted to be asymptomatic with no evidence of cord or brainstem involvement. The physician recommended no further studies because of the anxiety they cause and that he should be followed on a periodic, as needed basis.

The record included a consent form for Valium that was signed by the guardian's office on May 13th. It was for a one-time dose to have the medical test completed, which was given on the 14th. There are no physician reports or test results for the MRI attempt on the 14th; the home said that the resident refused to go through with the test and that there were no further assessments. All subsequent nursing and case management entries for the months that followed mention the resident's stability and no medical concerns.

10-080-9009 Canterbury Place

Complaints with Canterbury Place state that the guardian learned at a staffing in early November that a resident was having increased behavior problems at his new day training center and that the psychotropic medication, Risperdal, was started about a month earlier without her informed consent. Staff from the home reportedly handed the guardian a blank consent form at that time and asked her to sign it, which the guardian refused to do until information about the medication and its need was provided.

The home's administrator and a program nurse explained that in an appropriate scenario, new orders for psychotropic medications are cleared with guardians and the facility's behavior management committee before they are started. A nurse reviews the orders, enters them in the record and covers particulars with the staff. In this case they said, Risperdal was ordered on September 30th. A house manager from another site took the resident to his appointment where the order was given and a key player, the guardian, was forgotten. Likewise, the former nurse, who is no longer employed at the home, checked the new medication in but failed to follow through in alerting the right people, and, the former case manager who was said to hand the guardian a blank consent form, is no longer employed there either. The administrator said that she went over the issue with managers, and this was a one-time mishap that should not happen again. A completed consent form was provided to the guardian who signed it on November 4th.

A physician's September 30th consultation report from the resident's chart stated that the resident was seen for a three-month revisit. The physician noted increased aggressions and added one half milligram of Risperdal twice daily to the resident's medication regimen. A subsequent physician's report on October 13th stated that there was no improvement over the last two weeks, and the Risperdal dose was increased to one milligram, twice daily. Medication administration records showed that the drug was started at home on October 2nd, and according to the corresponding consent form, informed consent was received on November 4th. Monthly summaries from September through November make no mention of the resident's behavior struggles or contact with his guardian about his struggles and the need for more medication.

CONCLUSIONS

Frances House policies on medical (7.07) and nursing services (7.02) state that each individual shall be seen by his physician as often as necessary, that a nurse is always accessible to the facility and that responsible staff shall identify and report symptoms of illness, injuries and emergencies. Procedures for reporting minor illnesses or injuries to the nurse include the following: a. the direct support person observes or is approached with a minor illness or injury, b. relays the symptoms to the nurse via telephone, if immediate need or in writing, and documents on a progress note when appropriate, c. the nurse makes a decision based on the information given, and the staff documents it, d. if the individual requests as needed medication from standing orders, the staff shall document use and results in the record, and e. the nurse shall follow up within 48 hours, or immediately when necessary. Regarding medical condition and treatment, the program's medical services policy (7.07) states that each individual shall be fully informed by a physician of his health and medical condition and that each individual shall be given the opportunity to participate in planning his total care and medical treatment. The Policy for using behavior modifying medications (7.11) calls for signed guardian consent.

Under the Probate Act of 1975, personal guardians are to procure for their wards' support, care, and health (755 ILCS 5/11a-17). Providers hold the right to rely on any decision or direction made by the guardian that is not contrary to the law, to the same extent as though the decision or direction had been given by the ward (755 ILCS 5/11a-23). Federal rules require facilities to inform each client, parent or legal guardian of the client's medical condition, development and behavioral status and to promote their participation in the active treatment process (42 C.F.R. 483.420). For ICF/DDs in Illinois specifically, facilities must immediately

notify the resident's guardian whenever unusual circumstances arise. Nursing services include the training of direct care personnel on detecting signs of illness, basic skills to meet the health needs of residents, and first aid in the presence of an accident or illness (77 Ill. Admin. Code 350.3210; 350.1230). Every resident shall be permitted to participate in planning his total care and medical treatment to the extent his condition permits. Psychotropic medication shall not be prescribed without the informed consent of the resident and the resident's guardian (210 ILCS 45/2-104; 45/2-106.1).

In #9007 the issue is whether Freeport Terrace should have notified the guardian and made appropriate documentation of nursing care for a resident's injury. The home's perspective as reported to us is that the injury was merely a one centimeter scratch and not significant enough to alert anyone. We understand that facilities cannot call guardians and families on every slight incidental. But, according to the record, this was not a mere one centimeter scratch when it was first observed--it was described as a quarter-sized bump. That seems more significant, at least minor, and perhaps the nurse should have been the one to assess and decide what was needed per policy. The guardian saw it eleven days after it was said to happen and when it was still noticeable enough to raise questions, was told it was caused from an attack by a male peer and that the incident was so violent the police were called. She learned that the home's nurse had not been involved and asked the program's director for information and how to be a more informed part of the team. A nurse assessed the scratch four days after that, and the home has yet to provide any response to the guardian's questions. You begin to see the guardian's concern for her 80-year-old ward. The complaint is a substantiated violation of the cited policy and rules for nursing and guardian involvement.

In #9008 the issue is whether Olson Terrace should have included the guardian in deciding how to proceed with a medical concern after testing attempts failed. In short, the home stated that the tests were not essential according to a physician, and they tried reaching the guardian twice without success although they cannot demonstrate when. Protections that are outlined above say that the resident is permitted participation in the planning of his total medical care to the extent he can. Since this resident has a legal guardian, she is the one to participate for him and is to be fully informed by the facility of his medical condition and development; in turn, the facility is to rely on her directives provided they are not unlawful. Without evidence to show that the guardian was fully informed about results of a test she wanted done, the complaint is a substantiated violation of the cited laws for guardian notification and inclusion in medical care planning.

In #9009 the issue is whether Canterbury Place administered psychotropic medication to a resident without his guardian's informed consent. By the facility's own admission and as demonstrated in the record, this resident was given Risperdal twice daily for thirty-two days before his guardian was asked for her consent, which is in violation of the program's policies and regulations for ICF/DDs. The complaint is substantiated.

RECOMMENDATIONS

1. Consider any injury that is displayed with the story of being attacked and having police

- intervention as an unusual incident or circumstance and report to guardians and families on how the home is dealing with the situation.
2. Have nurses determine and document when minor injuries need attention.
 3. Consult guardians whenever a desired medical procedure changes course.
 4. Instruct all appropriate staff to document failed attempts at reaching guardians.
 5. Alert guardians to behavior problems and obtain consent before medications are started.
 6. Cover with all appropriate staff that guardian informed consent is required before any psychotropic medication is started.

SUGGESTIONS

1. Respond to the guardian and come up with ways to help her be a more informed part of the team.
2. Concerning medical issues, try more than twice to reach guardians.
3. Be sure to reference behavioral struggles that warrant medications in monthly summaries.
4. The staff at Canterbury Place seemed to shrug off the Risperdal situation as a one-time error. We view it with more urgency and express how serious a problem not having informed consent is, particularly when in this case there were sixty-four error doses given, not one.
5. The program's residents' rights statement includes the right to refuse experimental research but fails to include the right to refuse treatment as required by the federal participation requirements (42 C. F. R. 483.420). The form should be revised so that all residents and their guardians/families are accurately informed of their rights.