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HUMAN RIGHTS AUTHORITY-SPRINGFIELD REGION

REPORT 19-050-9002
HELP AT HOME, LLC

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation into complaints regarding services provided to a resident in a Help at Home Community Integrated Living Arrangement (CILA) in Springfield. Allegations were that the resident's guardian was not informed of medical appointments, the subsequent use of psychotropic medication, and there was a lack of activity for the resident outside of the home.

Substantiated findings would violate recipient rights under the Mental Health and Developmental Disabilities Code (405 ILCS 5) and the CILA Rules (59 Ill. Admin. Code 115).

Help at Home is a growing program in the region that serves adults with developmental disabilities, about twenty-eight through its CILA program at the time of our visits. The HRA met with various administration, habilitation and nursing representatives who were familiar with this resident, spoke privately with the resident and her roommates in their home, and reviewed relevant program policies as well as the resident's record with authorization. The resident has since moved out of the Help at Home program.

The complaint states that the resident had psychiatry appointments in May 2018 and two prompt care visits in July 2018 and the guardian was not informed of them until the resident told her afterwards. The provider allegedly refused the guardian's requests for routine medical updates because the staff were too busy or because of privacy laws. Trazodone was reportedly ordered at the first appointment in May when the guardian was told not to attend since no one was allowed in the room with patients. She went to the second appointment anyway and told the doctor to stop the medication. The doctor asked at that time why the resident was so depressed, and the guardian said she never goes out except to the grocery store.

FINDINGS

Medical appointments:

According to the record, a psychiatry appointment in question was held on May 17, 2018 with an advanced practice nurse. A summary of the visit stated that the resident's primary complaint was insomnia and that Trazodone was ordered for sleep "after consent from guardian." The resident was to return in one month for a follow up. A nursing progress note from the home showed that the guardian was called right after the appointment and was informed of the medication. The guardian expressed her concerns about the medication but agreed to try it until the next appointment that she planned to attend. The nurse told her it was her choice to attend if she wanted. Another nursing entry from a few days later referenced a call from the guardian who wanted permission to go on the next appointment because she was worried about them discussing her. She was encouraged to call the practitioner's office and relay that herself. A summary of the follow up visit on June 15, 2018 stated that the guardian was present and that Trazodone had been discontinued at her request. Future appointments were to be scheduled as needed.

The first of two express care visits in question occurred on July 11, 2018, when the resident was seen for ear pain. A cyst was noted on an earlobe, and a daily warm compress was prescribed with a return visit if no improvement. There was no documentation to show whether the guardian was alerted. The second was to the same place on July 20, again for the ear pain. TMJ (jaw joint pain) was diagnosed this time and the resident was given a muscle relaxant and a steroid; the home was to call the express care nurse three days later with updates on the results. There were no calls made to the guardian.

The resident had other express care visits: on July 26 for knee pain when an osteoarthritis flareup was treated, then on July 31 when at a trip to the emergency room for stomach pain and vomiting; a urinary tract infection was treated. The guardian was notified of the details by email in each case, and this system of communication seemed to carry on for the rest of the year.

Regarding the psychiatry appointments, the staff we interviewed said that no one at Help told the guardian she could not attend them. The fact was that the nurse practitioner wanted to speak to the resident alone sometimes, and they had only tried to explain that to her. At the time of these appointments it was never made clear to them exactly when the guardian wanted to be contacted. She originally wanted to be alerted about scheduled appointments but then took issue with the express care visits, after which they held a meeting with her and the independent service coordinator to come to some arrangement for communication. Help was also concerned about the guardian's approach to direct services staff with directives or for information, and they wanted to designate particular staff persons to reach instead to ensure timely and accurate communication. They never said that staff were too busy to call her about general information or appointments and the Health Insurance Portability and Accountability Act (HIPAA) confidentiality reference was made only in regard to other residents' personal information. They also decided that the nurse would email the guardian with details after each appointment, and they believe it was going well.

The independent service coordinator who attended this meeting was interviewed as well for her recollection of the issues. She verified what we were told and said that the whole point of the meeting was to improve communication and to be sure the right people were involved.

On the Trazodone and other psychotropics being prescribed in general, the staff said that the nurse talks with residents about the medications and goes over the consult sheet; guardians often attend the appointments and get all education there, otherwise they are contacted by phone or email about the details and to get their consent. It was not clear whether this guardian was provided written information about Trazodone, but she was in agreement with its use until she decided to stop it after one month.

Activities:

The resident's implementation strategy plan, formerly the service plan, covering the same time period stated that she was content in her home but that "finding motivators to engage her in activities at home and in her community is challenging", particularly because she was retired and wanted to spend her days relaxing and being more flexible. She did not want to work or attend day training. Going out to eat, shopping and going to movies with family were identified as her preferences with the caveat that she did not like a lot of walking or being out in extreme temperatures. The plan also noted her mobility issues for which she sometimes used a walker.

The HRA reviewed monthly summaries that included the resident's activities between May and July 2018 and then more recently between December 2018 and February 2019. An objective in each was to choose an activity outside her home at least twice per month. During the first sample period she met her goal of two activities, either going grocery or personal shopping, bowling or out to eat with her guardian, however she refused a dance and any other activity offered except for dining out with her guardian. Exactly what other activity was offered, is not clear. There was little change during the second period: going to the grocery store and eating out with her guardian; she refused to go bowling or to the monthly dance. Summaries covering the second period were also reviewed for the resident's two housemates, both of whom are also retired and have some physical limitations. Likewise, the women went out to eat and grocery or personal shopping and declined the dance and bowling mostly due to the extremely cold weather. One woman attended church.

The staff explained that the resident often refuses outings and prefers dining with her guardian more than anything. She inconsistently uses a walker for leg pain, which is not a real barrier, and she tends to be easily influenced by others, agreeing with or complaining about the same things they do. She has a mild intellectual disability however and is quite capable of letting her preferences known. They also expressed concern about the guardian who often rejects suggested outings on the resident's behalf. The staff were satisfied with the amount of activity and choice she and the other residents were getting and stressed that this particular resident's inactivity was not a reflection of their inability to provide activity. There are two direct care staff in the home between noon and 6p.m. and they use their own vehicles to transport the residents, although a company van can be available.

An HRA team visited the resident and her two roommates in their home. All three were retired and said they liked living there, although this resident said she was not happy that her guardian was making her move. She focused on that issue during our conversation but did say that she liked going out to dinner and that sometimes it was difficult or not possible to go anywhere

when someone has to use a walker or needs help or when there is only one staff car available. The other residents made similar statements.

CONCLUSION

Help at Home policy on the Coordination of Health Care Needs calls for all consumers to be informed of their medical status and to respect their rights to refuse medical care.

Under the Code, all recipients shall be provided adequate and humane care pursuant to an individual services plan, with the recipient's and guardian's participation (405 ILCS 5/2-102a). All guardians are to be provided written information about all proposed psychotropic medications (405 ILCS 5/2-102a-5). The CILA Rules add that the array of services includes medical care, and the guardian is a key member of the planning team (59 Ill. Admin. Code 115.220).

There was indication that someone, likely at the practitioner's office, preferred the guardian to stay away so the resident and provider could have privacy. Ultimately, Help at Home never prevented her from attending according to the documentation, in fact she was told it was her choice to go, and the guardian went to the second appointment and made her treatment preferences known. It seems obvious that any guardian should be alerted to cysts and TMJ being treated, which are not so minor. Since the Code intends for the guardian to be involved in all areas of treatment and treatment planning, a violation is substantiated. Help addressed the discrepancy immediately however and met with the guardian to agree on a way to better communicate. The HRA has no other recommendation since the matter was resolved and the resident no longer resides within the program. Regardless of why the guardian was not at the first psychiatry appointment, the documentation showed that she was immediately apprised of the Trazodone order and the purpose and then gave her verbal consent. A violation is not substantiated.

The program's Bill of Rights states that its residents shall enjoy the same rights as any other person, including the right to have private access to friends and the community.

The Code intends for all services to be least restrictive and recipients enjoy the right to communicate with anyone they choose, meaning by visits in and out of their homes or through activities in the community (405 ILCS 5/2-102a; 2-103). The CILA Rules state that services are to be oriented to the individual who is considered a citizen of the community (59 Ill. Admin. Code 115.200).

The complaint asserts a lack of activities outside this resident's home, that she only goes out to the grocery store. Although the lack of variety seems to be a glaring problem, the resident is retired and prefers to relax or be flexible as stated in her service plan and to us. She seemed to exercise her choices and her rights were not being violated. The complaint is unsubstantiated.

SUGGESTIONS:

Complete consent forms and be sure to forward written drug information to guardians if they were not present or the information was not shared at the appointment. Procedures should be set in policy.

Add guardian involvement/contact procedures to the Coordination of Health Care Needs policy.

Have the program's human rights committee review the variety of activities offered on a periodic basis. Naturally, if a person does not like walking, she may not like dancing or bowling, and grocery/personal shopping is a necessity of living that the home is obligated to assist with, not count as a community activity. As stated in the Bill of Rights, perhaps residents can be encouraged more to make friends or connections in the community.