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HUMAN RIGHTS AUTHORITY-PEORIA REGION

REPORT 19-090-9016
Horizon House of Illinois Valley, Inc

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving complaints of possible rights violations at Horizon House of Illinois Valley in Peru, Illinois. The complaints alleged the following:

1- Inadequate Guardian Notification
2- Inadequate Guardian Participation in Treatment.

Substantiated findings would violate protections under the Mental Health and Developmental Disabilities Code (405 ILCS 5) and other state regulations for community integrated living arrangements (CILA) (59 Il Admin Code 115). Horizon House of Illinois Valley (HH or HHIV), Inc. serves the LaSalle, Peru, Marshall and Putnam counties. This agency has eleven CILA homes, operates two occupational day programs and has clients working independently in the community. The agency serves thirty families at the day program. They currently have 68 residents living in their CILA program with 11 CILA houses with 4-8 residents residing in each of the homes. The agency employs 148 staff and is in need of hiring 10 more Direct Support Staff (DSP) for their CILA homes. They currently employ five Qualified Intellectual Disability Professionals (QIDP) which the agency calls Team Leaders (TL). There are two nurses. An average caseload size for the Team Leader is 22 and is a mixed caseload of day program clients and CILA residents.

COMPLAINT SUMMARY

The complaint states that in early March 2019, an adult with a disability, who has a legal guardian, was discontinued from prescribed psychotropic medications which resulted in behaviors at the group home and day program he attended. Subsequently, an involuntary admission to a Chicago area hospital resulted for the individual. The complaint alleges that the agency did not notify the legal guardian of the medication being discontinued and the individual should have been weaned from the medication via a gradual reduction. On

or around 3/21/19, this individual was sent to a local area hospital for a psychiatric evaluation due to behaviors at the agency day program and the guardian was never notified or communicated with that the individual was being sent to the hospital. The complaint also alleges that the legal guardian tried to contact the agency caseworker during the evening hours after learning of the individual's involuntary admission. The guardian was never allowed to speak with a caseworker and was hung-up on by the on-call worker.

Interview with Staff (7.22.19)

An interview was held at Horizon House in Peru, Illinois with HRA members and Horizon House administration and staff. The agency is structured in a way that the Team Leader coordinates most
of the case management responsibilities for a client. There is a House Manager and Direct Support Staff also in this chain-of-command. A Team Leader organizes medical appointments, schedules yearly Personal Care Plan meetings, helps with client transportation, training DSP staff on behavior plans, coordinates psychiatric appointments, communicates client needs within the agency chain of command and many other situations that fall under the scope of this position.

The agency has two psychiatrists who examine clients at the day program. One psychiatrist comes to the agency day program one time per month and the other psychiatrist examines Horizon House clients on a quarterly basis. Generally, if there is a change in medications, it is the Team Leader who will notify the legal guardian of the medication changes and receive verbal consent, especially for psychotropic medication. The length of time for the TL to confirm consent from the legal guardian depends on how easily it is to contact the legal guardian. The Team Leader can call a home or cellular phone number, leave a voice message, mail or email legal guardians, but will not send a text message. If a client is having an adverse reaction to a medication then it would be considered an emergency and they would stop the medications if doctor-ordered. The agency uses a medication consent form that the nurse is responsible for completing that has the actual dosage and brand name for a medication. The nurse would facilitate the agency written consent form and usually mails the consent form to the legal guardian for signature and the guardian mails the form back to Horizon House.

The agency also has a 24/7 rotating on-call system with the house managers and a Residential Services Coordinator. The staff is on-call for seven days from Wednesday-Wednesday.

The HRA has a signed consent by the legal guardian for the individual who is involved with this complaint. The client's Plenary Letters of Office for legal guardianship of person and estate list his mother and father as guardians with his mother being his representative payee. This individual has been a client of the day program for many years and recently moved into a Horizon House CILA in August 2018. This individual had been struggling with the residential change as he had been living with family before the transition. This person is prescribed psychotropic medications: Concerta, Depakote and Klonopin and had been escalating in verbal and physical

aggression since he was placed in a CILA setting. This individual had been taken to a local area hospital for aggressive behaviors in late February 2019. The guardian was present at the hospital during the ED assessment and involuntary admission/transfer to a Chicago hospital. The individual was involuntarily admitted to a Chicago area hospital for a psychiatric evaluation. During this admission he was started on Neurontin. After this admission he returned to his agency CILA.

In early March 2019 he became dizzy, unsteady and had several falls and it was determined this was an adverse reaction to the Neurontin medication that he had recently started. He was sent to a local area hospital emergency department (ED) and this emergency room physician discontinued the Neurontin and he returned to the CILA. This situation was identified as a medical need due to the falls and the DSP staff facilitated the ED visit, notified on-call, and notified nursing; the TL found out when she returned to work on Monday. The TL notified the patient's mother of his weekend visit to the ED. The mother had also observed her son being off balance and had concerns before the Neurontin medication was discontinued. The guardians were not notified that their son went by ambulance to a local Emergency Department due to safety concerns from his behavior at day program. His primary care physician was notified of the medication changes; the individual was to come in for an appointment if he continued to have falls after the medication was stopped and he had a psychiatrist appointment scheduled for 3/21/19.

Later this same month, on 3/21/19 this individual's behaviors continued to escalate. This situation started early in the morning around 9am when he arrived at day program for work. He was physically aggressive towards a day program staff. He was hitting, threatening to kill staff and targeting her verbally. Horizon House staff report that this individual is usually redirectable but on this day he was not responding. The TL reports that she had tried to contact the legal guardian four times throughout the day but did not leave a message as the guardian usually calls back when she sees a missed call from the agency and the TL wanted to speak with the guardian directly. The TL went to the CILA to gather this individual's documentation packet, which includes the face sheet that has the legal guardian information, and some personal belongings. The TL went to the ED to relieve the DSP that was there and give the documents to the ED staff. The TL also reports that she told DSP staff to let the legal guardians know the situation if they called the house. The TL states she informed the hospital that this individual has a guardian and asked them to keep calling them because she had not spoken to them. The TL left the hospital around 8pm that evening. The TL then phoned the CILA, later that evening and let them know he was being involuntarily admitted to an out of area hospital. The TL admits that she did not speak with the legal guardians on this day.

At some point during the evening the legal guardian called the CILA and house staff provided the direct on-call number to the father who is also legal guardian. Staff explained during the site visit that the father was obsessively calling the on-call staff. On-call staff did hang-up the phone at some point due to the nature of the conversation by the father. The TL was contacted by on-call staff who notified her of this person demanding to speak with her. The TL did not want to return a phone call to the father

afterhours because she only had her personal cellular phone to use and was concerned with him having her personal phone number. The TL contacted her supervisor to discuss the legal guardian demanding to speak to her and asked if the supervisor would call him back. The supervisor did not call the legal guardian back that evening.

As of 5/7/19 this individual is no longer receiving services from Horizon House of Illinois Valley, Inc. Per the staff involved in the site visit, he was discharged from the agency in agreement between the agency and the legal guardians.

FINDINGS (Including record review, mandates, and conclusion)

Complaint #1- Inadequate Guardian Notification.

The HRA reviewed the Horizon House of Illinois Valley, INC. Intervention Report from 3/21/19 documenting a behavioral incident that began at 8:20am. This behavioral issue is documented in detail and was reviewed by the Team Leader on 3/22/19. The section of this report titled Follow-Up Notes states "3/22/19 [resident] was at [hospital] until transported to [Chicago hospital]. He settled down at the hospital with no issues. He did not want any lunch offered to him while there." On this document there is nothing in writing by the Team Leader that indicates she had a conversation with the Legal Guardian or attempted to contact the legal guardians about the individual being sent to the hospital.

The HRA reviewed HHIV Monthly Monitoring Report completed by the Team Leader for March 2019 and were signed and dated 4/11/19. This document is used to track progress on Individual Service Plan Outcomes, Implementation Strategies, Medical/Health needs, Day Service/vocational goals that were developed by the HHIV team on 11/13/18. This document has an Additional Information/Comments section that reads "Is there any Guardian/Family/Significant other concerns?" The answer to this question is marked "yes". The response to this question was written by the Team Leader and states, "[Resident's] family was unable to be reached when he was taken to [local hospital] for significant incident. [Local hospital] was informed of this as well as [Chicago hospital]. They were also given guardian contact information. Later that evening Horizon on-call was called by [Resident's] father stating he just found out [resident] was already up in the hospital. [Team Leader] spoke the following day with [Mother] and she did see where the [Team Leader] tried to call. [Team Leader] explained she was with [Resident] in the hospital all day and asked the hospital to be in contact with them. [Team Leader] attempted to call when in the building before going to the hospital, when TL came back for the guardianship paperwork, before and after an afternoon meeting. When [Team Leader] was told that [Resident] was being transferred TL assumed they had contacted guardian but obviously that was not the case. They were extremely upset over the entire situation, but we were able to talk through it and figure things out."

The HRA reviewed the Horizon House Residential On-Call system Log of Calls notes with two dates of entries that state the following: "3/2 4:33pm- [Staff] from

[Resident's Home] called to report (unintelligible handwriting) [Resident] is unsteady and dizzy. Called nurse on call. 3/2 5:04pm- [Staff] returned call and reported [Resident] is going to ER for evaluation on possible med side effect TL- [Staff] was notified."

Residential On-Call Log notes dated 3/21/19 and beginning at 6:26pm states, "See separate typed page for all calls related to [Resident's Home] and [Resident's] dad." This page states "3/21/19 at 6:26pm- On-call staff was in the shower and missed a call from [CILA] and [Resident] dad. The message stated that he had questions about his son and he needed me to call him back now. The message from [CILA] staff said that they gave [resident] dad the on call number. I first called [CILA] and spoke to [Staff]. I asked her what was going on. She said that legal guardian had called there demanding a phone number, so they gave him the on call number. I firmly explained to her that the on call phone is for the Horizon house HH staff and should not be given to any guardians. HH staff stated that she tried to call me, and I didn't answer. I asked her if she followed the on call procedure by calling and waiting 10 minutes. Call back wait another 10 minutes etc. She said nope I just called once. I told her several times that she needs to get with HH staff for a copy of the on call procedure. We were again talking about them giving the on call number to a guardian. HH staff stated that they can't give him Team Leaders number and he was demanding a number. I told her that per the procedure the staff should have been the ones to call the on call phone and explaining what was going on. Then the on call person could have contacted whoever they needed to address the situation. 6:35pm Legal guardian left another message. 6:44pm On call staff called Team Leader. Informed her of the situation. She did not want to call him back from her personal phone. They do not want this guardian to have their personal numbers. Team Leader and On Call staff spoke for a bit. It was decided that if the legal guardian continued to call on call staff the Team Leader would call him back otherwise she would stick to the plan of calling legal guardian in the morning. As I was on the phone with team leader the phone rang twice, and it was the resident's legal guardian. 6:50pm- legal guardian left a message. 6:56pm Legal guardian called and left a message. He stated that he was going to call back every 10 minutes until someone called him back. 7:13pm Legal guardian called and left a message. 7:13pm On call staff called Team Leader back to let her know that the Legal Guardian was calling back every 10 minutes until someone called him back. Team Leader was going to call [staff] supervisor and call on call back. 7:30pm Team Leader called back. [Staff] supervisor beeped in while on the line with Team Leader. Team Leader said that the supervisor was going to call the legal guardian. On Call staff called supervisor when off the phone with the TL. After talking with [staff] supervisor it was decided that on call staff would call the legal guardian back and just tell him that the TL will be in touch with him in the morning. 7:36 pm On Call staff called legal guardian. On-call staff explained that I was the on-call person and I didn't have any information about his son, but the TL would be in touch with him in the morning. Legal Guardian was very upset. He said that TL needed to call him back now!! He has always thought highly of HH until this incident and now he has no respect for this place. He will not recommend HH to anyone any more. On-call staff told him I was sorry he felt that way, but TL would be in touch with him in the morning. He said that he wants to know why his son has been In the hospital since 9 this morning and no one has

called him. On-call staff told him that he is in [Chicago hospital] and I could give him the phone number. [Legal Guardian] needs someone to call him back that knows what is going on. Legal Guardian asked On-call Staff where my emergency numbers are. On-call Staff just kept repeating that the TL would call him in the morning. Legal Guardian told me to stop repeating myself he's not stupid he heard me the first time and that's not good enough. On-call staff let him vent. He then asked if on-call staff was still there. On-call staff said yes, and that TL would call him in the morning. Legal Guardian started angrily saying things again so On-call Staff simply said TL would be in touch with him in the morning. I hope you have a good night. Good bye and On-call Staff hung up. On-call Staff then called [Staff] supervisor to let her know."

The HRA reviewed a document titled Horizon house of Illinois Valley, Inc. Agreement to Participate in Community Day Services/Consent for Emergency Services. This document states "The Community Day Services (CDS) program provides for supervision and array of services based on the participant's needs and personal outcomes. The purpose of CDS is to promote learning, independence and exposure to vocational, recreational, personal/social and educational experiences both on-site and in the community. Employment in the community will always be considered as your first option. I will be contacted to provide consent for service changes. I consent to the provision of emergency medical services as required." This form is signed by one of this individual's legal guardian, his father. It is witnessed by the Team Leader and dated 11/13/18.

The HRA reviewed a Horizon House of Illinois Valley, Inc. Agreement to Participate in CILA/Consent for Emergency Services form. This form states "The CILA program provides for supervision and an array of services based on the participant's needs and outcomes. The objective of a CILA is to promote optimal independence in daily living, community integration, and economic self-sufficiency. Participation in the development and implementation of the individual integrated services plan is required. When medical services and/or medications are provided, or their administration is supervised, by employees of the licensed agency, the licensed agency shall certify that they are provided, or their administration is supervised In accordance with the Medical Practice Act of 1987 and the Illinois Nursing and Advanced Practice Nursing Act. I will be contacted to provide consent for service changes and/or non-emergency medication changes or treatment plans. I consent to the provision of emergency medical services as required." This form is signed by the father, who is one of the legal guardians and witnessed by the Team Leader on 11/13/18.

The HRA reviewed Horizon House of Illinois Valley, Inc Emergency Medical Intervention Procedure. This policy was created and approved 3/14/1989, last reviewed 5/30/2012 and last reviewed by a Registered Nurse and Health Services Committee Chairperson 1/2/17. Procedure line six states "The designated emergency on call contact (residential on call or Team Leader) will be notified immediately of any medical emergency requiring treatment at a medical facility. Other agency staff (House Manager, Day Program Staff, RN, back up Team Leader, etc.) will be notified by designated emergency on call contact as deemed appropriate." Procedure line seven states "The

Team Leader will immediately inform the guardian or designated emergency contact person of any medical emergency requiring treatment at a medical facility. If the Team Leader cannot be contacted, guardian notification will be made by the following staff persons in this order of preference. A. Team Leader Back-up Designee, B. On call Person, C. Hab supervisor (for individuals who only attend Day Services) and D. Employment/Community Support Services Coordinator (for individuals only in Supported Employment)."

The HRA also reviewed HHIV Instruction Summary for Emergency On-Call System. This policy defines when the on-call system should be used and what types of emergencies constitute use of the on-call process. This policy is dated 11/20/12. The policy states when and how to use the on-call system, "The emergency on-call system is for use only when a supervisor is unavailable/off duty, or no other supervisor is in the home. Use the system for emergencies or certain non-emergencies as defined below... Emergencies are intense behavioral challenges that cannot be resolved by the staff on duty or that present a threat of harm to someone, property destruction, serious medical problems, medication problems, missing residents, evacuations, staff leaving due to personal emergency, Fires/smoke problems, gas odors, water leakage, broken windows or other major mechanical problems such as furnace, laundry, kitchen, or electrical equipment problems 1.) Ensure the safety of all residents and staff 2.) Contact emergency personnel (911) if necessary 3.) Call the on-call cell phone when it is safe to do so. If you call the cell phone and get no answer, you need to leave a message including name and phone number where you can be reached. The on-call supervisor will return your call. Stay off the phone line and wait for a response. If no call in 10 minutes call again, if no call in 10 minutes call a third time, if no call in 5 minutes then call the 'on-call' person at home. If unable to contact them call either the House Supervisor, the Director of Residential Services, or the Director of Programs and Services. You must talk to someone. You cannot just leave a message and stop there."

This policy also explains how to use the on-call system for behavioral concerns and states "Be prepared to: Describe what preceded the behavior, how long it lasted, how intense it was, and what the staff response was. Explain what, if any, behavior program is in place to address this particular behavior and how that program is being implemented. If the program is not being implemented, you will need to explain why not. The on-call supervisor will determine the need to contact the Team Leader." The agency also provided an update to this policy that was reviewed by the Director of Residential Services and the CEO on 7/26/19.

CILA regulations 59 Ill. Adm. Code 115.220. Community support team state: "Agencies licensed to certify CILAs shall provide for services through a community support team (CST). a) The CST shall consist of the QMRP or QMHP, as indicated by the individual's primary disability, the individual, the individual's guardian or parent (unless the individual is his or her own guardian and chooses not to have his or her parent involved, or if the individual has a guardian and the guardian chooses not to involve the individual's parent), providers of services to the individual from outside the licensed CILA provider agency, and persons providing direct services in the community; b) The

CST shall be the central structure through which CILA services are provided to one or more individuals. The CST shall: 12) Assisting the individual in accessing medication information including observing and reporting effects and side effects of prescribed medications; ... The agency shall remain responsible for insuring the quality of services and the protection of the individual's rights. e) A CST member who is a QMRP or a QMHP shall be designated for each individual and shall: 1) Convene the CST as required by Section 115.230 to revise the services plan as part of the interdisciplinary process; 2) Assure that the services specified in the services plan are being provided; 3) Assure the participation of team members and necessary non-team member professionals; ... Identify and address gaps in the service provision; 6) Monitor the individual's status in relation to the services plan; 7) Advocate for the individual's rights and services; 8) Facilitate individual linkage and transfer; 9) Provide for a written record of team meetings within 30 days after each team meeting; 10) Assure that information specified by the services plan is included in the individual's record; 11) Initiate and coordinate the interdisciplinary process as often as specified in the services plan or when required by problems or changes; 12) Assure availability of a written services plan to all team members; and 13) Work with the individual and parent(s) and/or guardian to convene special meetings of the CST when there are issues that need to be addressed as brought to the attention of the team by the individual, parent(s) and/or guardian."

The Probate Act of 1975 755 ILCS 5/11a-17. Duties of personal guardian require that: "(a) To the extent ordered by the court and under the direction of the court, the guardian of the person shall have custody of the ward and the ward's minor and adult dependent children and shall procure for them and shall make provision for their support, care, comfort, health, education and maintenance, and professional services as are appropriate ... A guardian of the person may not admit a ward to a mental health facility except at the ward's request as provided in Article IV of the Mental Health and Developmental Disabilities Code and unless the ward has the capacity to consent to such admission as provided in Article IV of the Mental Health and Developmental Disabilities Code."

The Mental Health and Disabilities Code (405 ILCs 5/2-102) states: "(a) 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. If the services include the administration of electroconvulsive therapy or psychotropic medication, the physician or the physician's designee shall advise the recipient, in writing, of the side effects, risks, and benefits of the treatment."

Conclusion - Complaint #1

The HRA concludes the allegation of inadequate guardian notification as **SUBSTANTIATED.** Although the legal guardians were eventually notified via the on-call staff later in the evening of 3/21/19 that their son had been sent to a local hospital and

was being admitted to another out of area facility, the transfer to the other facility had already happened by the time the legal guardians became aware of the situation. In accordance with the Code (405 ILCs 5/2-102) and the Probate Act (755 ILCS 5/11a-23) the facility is to rely on the guardian for decisions and the guardian is to be included as a part of treatment. HHIV staff also reported via the site visit and the HRA confirmed from reviewing the provided documentation, that the Team Leader is the primary Community Support Team individual responsible for notifying the necessary parties of any emergency situations. The Team Leader documented on a Monthly Progress Note that efforts were made to contact them via telephone (and is not specific about which contact number was used) but she never spoke directly to the mother or the father, until the next day, about their son being involuntarily admitted to a Chicago Hospital in March. According to Rule 115, the Team Leader (QMRP or QHDP) is the staff that are to "Assure the participation of team members" (59 Il Admin Code 115.220) and this did not occur.

Additionally, the On-Call notes provided by HHIV also note that after a lengthy afterhours conversation with the legal guardian the on-call worker ended the conversation with the legal guardian by saying good-bye and hanging up the phone on the resident's father due to the legal guardian's demands not being met.

The HRA makes the following **RECOMMENDATIONS**:

- All Horizon House of Illinois Valley staff need to be retrained on the Emergency Medical Intervention Procedure regarding guardian notification. Provide evidence of Horizon House staff having been trained on the revised on-call procedure.

The HRA makes the following suggestions:

- Individual's who receive services from Horizon House of Illinois Valley, and have a legal guardian, or such as this instance, more than one legal guardian should have a listed priority order for emergency contact information. Who to contact first and what number to use first.
- The case file should also reflect the legal guardian's communication preference, ex. phone calls at home, phone calls on their cellular phones, via email, etc.
- If the emergency on-call staff is unable to address the need of a legal guardian, then those up the chain of command within the agency should be prepared to make a phone call and help diffuse a crisis situation, such as the one evident in this case.
- The Horizon House Instructional Summary For Residential Emergency On Call System should define the operating hours for the use of on-call. During the site visit the CEO stated that the on-call system is used 24/7 and this should be written into the on-call policy.
- The 7/26/19 on-call policy is confusing on page 2 where it reads "If no one answers when you call the On-call cell phone, you need to follow step #4 on the previous page of this document." There is no clearly defined step #4 on page 1 of this document. This policy should be numbered correctly.

- The agency should notify all legal guardians and/or family contacts how grievances should be filed if someone is unhappy with services being provided by Horizon House of Illinois Valley.

Complaint #2 - Inadequate Guardian Participation in Treatment

The HRA reviewed the Individual Service Plan (ISP) dated 11/13/18. The meeting to review the ISP took place on this same date. The medication list on this ISP are: Divalproex, Clonazepam, Lexapro, Methylphenidate, and Topamax. There is also an area marked with a checkmark to indicate that information on medication risks, benefits, side effects was provided and discussed. Another box is marked with a checkmark to indicate the individual has a reduction plan for one of his psychotropic medications, Clonazepam. This same document also has a section titled RN Comments and Recommendations and it is documented that the individual's family reported that "without Clonazepam the individual would threaten others, have physical aggression and would not sleep. These behaviors would occur several times per hour". There is no signature on the line for a Registered Nurse. This document has a section titled Approval of Written Plan Contents and it is signed by the legal guardians.

On 2/11/19, this individual had a behavioral health inpatient admission to a Chicago area hospital. He discharged from the hospital on 2/25/19 and returned to HHIV. His discharge medications were: Depakote, Gabapentin (Neurontin), Concerta, Lexapro, and Klonopin. His Topamax was discontinued during this hospital admission and he was started on the Neurontin. Topamax and Neurontin are both antiseizure medications that are being prescribed to treat a mood disorder for this case.

On 3/2/19 the HRA reviewed a prescription from a local area hospital where this individual received treatment in the Emergency Department and the Neurontin was discontinued. This was due to the adverse reaction he was having from this medication, which is described in the Intervention Report that documents an incident that occurred at the group home on 3/2/19 at 4:00pm. This Intervention Report notes the resident went out to lunch with his mom. When they returned she asked if staff had noticed "[resident] was unsteady when walking". Staffs response on the form states "we had just come to work before she arrived, so we had not seen him walking." The section titled During (Describe what happened, how you responded, how long it lasted; for illness/injury, the nature and extent and what treatment or response was required e.g. ambulance, trip to emergency room, urgent care, contact with on-call supervisor) states "[resident] came upstairs at approximately 4pm to take his meds. His knees buckled, and staff caught him and helped him to a chair. He could not walk without assistance. On call was notified. The nurse called back and told us to take him to the ER. They tried medication for vertigo, irrigated his right ear, gave him an IV for fluids. Nothing helped him walk without wobbling, room spinning. They released him after 4 hours. There was no change to his condition. Staff helped him into the house. He went into the bathroom and fell down, hitting his shoulder on the Sterlite cabinet. On call and nurse notified again. The section titled After (What steps or suggestions did the person and staff develop that

will help to reduce the likelihood of recurrence of the Incident.) Dr prescribed PRN med for dizziness. They discontinued his Neurontin and he is to see his primary physician on Mon." This note was reviewed by the Team Leader on 3/6/19 and her signature is observed on the form. There is a section on this document titled Follow-Up Notes and there is nothing entered. The HRA did not observe a Nursing Note in the file documentation that confirmed the guardian was notified of the medication change, but it is important to note that this Emergency Department visit was triggered by concerns from the legal guardian and the resident's medical issues that followed their visit.

The HRA reviewed one nursing note from this visit to the local hospital emergency department dated 3/2/19. This note states "On-Call: experiencing dizziness, unsteadiness, and rapid respirations; sent to ER; returned from ER with orders to stop Neurontin and start Meclizine for dizziness and Odansetron for nausea; orders processed and sent to house; instructions include close monitoring especially during ambulation and push fluids to flush Neurontin from system; return to ER if symptoms worsen."

The HRA reviewed HHIV Monthly Monitoring Report completed by the Team Leader for March 2019 signed and dated 4/11/19. This document is used to track progress on his Individual Service Plan Outcomes, Implementation Strategies, Medical/Health needs, Day Service/Vocational Goals that were developed by the HHIV team on 11/13/18. This document notes all current medications for the month of March for this resident. The medications listed on this form are: Divalproex, Neurontin, Clonazepam (Klonopin), Lexapro and Methylphenidate (Concerta). This same note reports a trip to the ED where the Neurontin medication was discontinued at a local hospital. There is no mention on this Monthly Monitoring Report of the TL contacting the guardian to discuss medication changes made that month.

The HRA reviewed a Quarterly Psychiatric Form dated 5/3/19; the individual's mother who is a legal guardian attended a psychiatrist appointment with her son.

The HRA reviewed a HHIV form titled Medical Services Guardian Consent Form dated 12/7/18. The purpose of this medication consent was for an increase in Depakote to 1000mg twice daily. This form documents verbal consent was received by the TL on 12/10/18 at 11:00am. The guardian's signature is noted on this form but has no date. The nurse's signature is dated 12/7/18. There are also other medications handwritten on this form by an unknown person, "Lexapro 20, Con, 8, Clonzapam 0:5, Depacot 1000, Top 60 -x 2". It is unclear to the HRA who wrote the additional medications listed and there are no HHIV Medical Services Guardian Consent forms available for the month of December for these additional consents.

The HRA reviewed HHIV form titled Medical Services Guardian Consent Form dated 4/2/19. This form was completed by a HHIV registered nurse for a new medication ordered for this individual. The new medication is Neurontin 100mg 3 times daily. This consent form's purpose states "discharge orders from hospital to help with aggression." The Registered Nurse's signature is noted and dated 4/2/19. This form states under

section III, Follow-Up Written Consent: I have been informed of the potential risks, benefits and side effects of this medication. The HRA observes written consent by the mother, who is legal guardian, and dated 4/8/19.

The HRA reviewed HHIV Medical Services Guardian Consent Form for a medication increase dated 4/5/19. The prescribing physician and medication ordered is: "increase Gabapentin to 100mg twice daily and 200mg at night. For the purpose of: treat anxiety and decrease maladaptive behaviors". Section II is titled Immediate Verbal Consent and there is a date of 4/12/19 and a time of 2:00pm and the outcome states TL notified nursing of verbal consent. Section III for Follow-Up Written Consent: I have been informed of the potential risks, benefits and side effects of this medication. The HRA observes written consent by the mother, who is legal guardian, and dated 4/17/19.

The HRA reviewed HHIV Medical Services Guardian Consent Form for a medication increase dated 4/24/19. The prescribing physician ordered "Increase Depakote to 750mg twice daily". This form documents that verbal consent from guardian was received at 3:00pm by the Team Leader. There is no formal guardian's signature on this form.

The HRA had follow-up with the HHIV CEO to verify there are no other Medical Services Guardian Consent Forms for review by the HRA specific to this individual's admission to the agency CILA in November 2018 or upon discharge from the hospital back to the facility in February and March 2019.

The agency provided their policy titled Horizon House of Illinois Valley, Inc. Medication Orders Procedure. This procedure was approved October 2, 1990 and was revised and reviewed on 11/1/17 by the Health Services Committee Chairperson who is a Registered Nurse. The policy states "All medications, including patent or proprietary medication (e.g., cathartics, headache remedies or vitamins, but not limited to those) shall be given only upon the written order of a physician, advanced practice nurse, or physician assistant. Step 2. The Team Leader will contact the guardian for verbal permission for any new or changes with an individual's psychotropic medication. In the absence of the Team Leader the back-up Team Leader will contact the guardian for consent. No psychotropic medication will be started without guardian consent. Verbal authorization must be verified and documented by two staff."

The Mental Health and Developmental Disabilities Code 405 ILCS 5/2-102. Care and services; psychotropic medication; religion states (a) 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 recipient's preferences regarding emergency interventions under subsection (d) of Section 2-200 shall be noted in the recipient's treatment plan."

The Probate Act of 1975 755 ILCS 5/11a-17. Duties of personal guardian requires that "(a) To the extent ordered by the court and under the direction of the court, the guardian of the person shall have custody of the ward and the ward's minor and adult dependent children and shall procure for them and shall make provision for their support, care, comfort, health, education and maintenance, and professional services as are appropriate ... A guardian of the person may not admit a ward to a mental health facility except at the ward's request as provided in Article IV of the Mental Health and Developmental Disabilities Code and unless the ward has the capacity to consent to such admission as provided in Article IV of the Mental Health and Developmental Disabilities Code."

Conclusion - Complaint #2

The HRA concludes the that allegation of inadequate guardian participation in Treatment is **SUBSTANTIATED.** The agency has an emergency consent signed by one of the two legal guardians, who is the father, and this permits the agency to meet the medical needs of this individual. Part of this second allegation is specific to the individual's Neurontin medication being stopped without a gradual reduction which resulted in increased behaviors. It appears, based on the documentation provided, that the legal guardians were aware of the new medication Neurontin being started during a hospital admission in February 2019. This medication was suddenly stopped on March 2, 2019 due to an adverse medical reaction that prompted the individual being sent to the Emergency Department for treatment. It is unclear to the HRA if the Chicago Hospital that discontinued the individual's Topamax during a February 2019 inpatient admission communicated this change to the legal guardians. The Neurontin medication was discontinued due to adverse side effects the resident was feeling which resulted in vertigo and instances of him falling. From 3/2/19 on, behaviors increased and resulted in the individual being sent to a local ED. The Topamax did not require a medication consent when the individual returned to the HHIV CILA since he was no longer prescribed that medication, but the agency should have a Medical Services Consent Form documenting the guardian's consent for this medication from when he admitted to the CILA. Unfortunately, the HRA was unable to review any Medical Services Guardian Consent Forms, other than the April 2019 forms, to verify that the necessary HHIV staff had communicated medication changes on a regular basis with the legal guardians. Nor was the HRA able to review any signed Medical Services Guardian Consent Form for the regularly prescribed medications upon the individual's admission to the Horizon House of Illinois Valley CILA Program for the months of November and December 2018 or January, February and March of 2019.

The Mental Health and Developmental Disabilities Code provides for the inclusion of the guardian in all aspects of treatment from the time that services begin: "A recipient of services shall be provided with adequate and humane care 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...."(405 ILCS 5/2-102). The Probate Act of 1975 reads "To the extent ordered by the court...the guardian of the person shall have custody of the ward and...shall procure for them and shall make provision for their support, care, comfort, health...and maintenance...." (755 ILCS 5/11a-17). Also, "Every health care provider...has the right to rely on any decision or direction made by the 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" (755 ILCS 5/11a-23).

The HRA makes the following **RECOMMENDATION:**

- Comply with the Mental Health Code by ensuring that individuals and their legal guardians, if applicable are actively involved in decisions and care planning needs for all Horizon House service recipients that are involved with this agency. Provide evidence to the HRA that this information is communicated to all HHIV staff.

The HRA suggests:

- The agency should review all face sheet information for CILA and Day Program clients and ensure that legal guardians are clearly identified and that there is a priority list on who to call first and which number to use, in case of emergency.
- The agency should review its internal process for verbal and written consent and how verbal consent is documented by the Team Leader and the nurse.
- Per **the Mental Health and Developmental Disabilities Code 405 ILCS 5/2-102** Ensure all Medical Services Guardian Consent Forms for psychotropic medications are signed by a legal guardian upon admission to the agency and when medications are made. Ensure that signed forms are readily available in an individual's case record.

RESPONSE

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

REGIONAL HUMAN RIGHTS AUTHORITY

HRA CASE NO. 19-090-9016

SERVICE PROVIDER: – Horizon House of Illinois Valley

Pursuant to Section 23 of the Guardianship and Advocacy Act (20 ILCS 3955/1 *et seq.*), we have received the Human Rights Authority report of findings.

IMPORTANT NOTE

Human Rights Authority reports may be made a part of the public record. Reports voted public, along with any response you have provided and indicated you wish to be included in a public document will be posted on the Illinois Guardianship and Advocacy Commission Web Site. (Due to technical requirements, your response may be in a verbatim retyped format.) Reports are also provided to complainants and may be forwarded to regulatory agencies for their review.

We ask that the following action be taken:

__X__ We request that our response to any recommendation/s, plus any comments and/or objections be included as part of the public record.

_____ We do not wish to include our response in the public record.

_____ No response is included.

Dan Fitzgerald
NAME

CEO
TITLE

2/24/2020
DATE

HORIZON HOUSE

Together Building Futures. Living. Working. Playing.

Erin K. Nowlan
Illinois Guardianship and Advocacy Commission
401 Main Street, Suite 620
Peoria, IL 61602

RE: HRA Case # 19-090-9016

August 10, 2020

Dear Ms. Nowlan;

Enclosed is documentation regarding completion of training for the recommendations made by the Human Rights Authority in the above referenced case.

Some of this training was initiated by Horizon House of our own volition prior to HRA request. The documentation for training for all staff was initiated in early March. Shortly after that the priority for the agency became protection of persons served from the Coronavirus. Unfortunately, some of the documentation was misplaced during that time. For those sites we repeated the training process. You will note differing dates of signatures verifying staff training ranging from late February to early August.

All re-training recommended has been completed.

I believe this constitutes a complete response, however, if there is further information you require please contact me by phone at 815-223-4488 ext. 29 or e-mail at dfitzgerald@hhperu.org .

Sincerely,

Dan Fitzgerald
Chief Executive Officer

cc: Horizon House Human Rights Committee

Enc.

HORIZON HOUSE OF ILLINOIS VALLEY, INC.
RESPONSE TO HRA RECOMMENDATIONS
CASE #19-090-9016
February 21, 2020

Complaint #1

Recommendation:

> "All Horizon House of Illinois Valley staff need to be retrained on the Emergency Medical Intervention Procedure regarding guardian notification. Provide evidence of Horizon House staff having been trained on the revised on-call procedure."

Response:

A memorandum attached to the Emergency Medical Intervention Procedure (MED-01-03-01) will be posted in all agency communication books. The memo will highlight the importance of assuring that guardians of persons served are contacted when medical procedures requiring consent for treatment occur as well as ensuring the process for notification of critical incidents involving their ward. The memo will be accompanied by a site specific listing of the Team Leader and the back-up Team Leader. A signature sheet for each staff person to acknowledge that they have read and understand the memo content will be maintained as documentation.

See attached documentation:

Memo to be distributed to agency staff;
Team Leader assignments by residential site;
Team Leader Back-up memo (to be re-issued to On-Call Supervisors only).

Comment:

Agency staff are, and will continue to be, trained in the use of the emergency on-call system. The incident of 03/21/2019 involved the On-Call Supervisor, the Team Leader and the Team Leader Supervisor. No agency DSP, no agency medical staff or any other agency job classification were involved. Horizon House has 148 staff members. The circumstances of this complaint are more objectively viewed through the experience that the three (3) specific staff members involved have had with this specific guardian.

In the incident of 03/21/2019 the Horizon House Team Leader tried repeatedly to contact the designated guardian during the course of the day the individual was hospitalized. She was unsuccessful, but they (guardian) acknowledge that they noted the missed calls on their phone.

One (1) agency DSP misunderstood the Instructional Summary for Emergency On-Call System and gave out the on-call number to the guardian. The On-Call Supervisor then appropriately followed the Instructional Summary for the Emergency On-Call System by contacting the individual's assigned Team Leader.

In this incident a hospital made arrangements for transfer and acted on that transfer when they could. The Team Leader was not aware the individual had been transferred until notified by the On-Call Supervisor.

Due to a history of inappropriate and inflammatory comments from this guardian that Team Leader did not want this guardian to have her personal cell phone number. But that Team Leader appropriately followed the Emergency Medical Intervention Procedure (MED-01-03-01), activating the Team Leader back-up system, by calling the Team Leader supervisor.

The Team Leader supervisor should have called this guardian. That staff member will, of course, be included in the training.

The on-call person could provide this individual with no additional information that the guardian did not already have. She remained calm and relayed to the guardian what information she was instructed to relay. She was unsuccessful in her attempt to de-escalate this situation. As this guardian became more volatile she appropriately discontinued the conversation in as respectful a manner as she could have under the circumstances.

HORIZON HOUSE OF ILLINOIS VALLEY, INC.
RESPONSE TO HRA RECOMMENDATIONS
CASE #19-090-9016
February 21, 2020

Complaint #2

Recommendation:

> "Comply with the Mental Health Code by ensuring that individuals and their legal guardians, if applicable are actively involved in decisions and care planning needs for all Horizon House service recipients that are involved with this agency. Provide evidence to the HRA that this information is communicated to all HHIV staff."

Response:

Horizon House has complied, and will continue to comply, with provisions of the Mental Health Code. The active involvement of individuals and their legal guardians is reflected in agency policy, procedure, staff training, daily practices and documentation systems.

See attached sample documentation:

AD-01-01-01 Entrance/Exit Criteria Procedure
HAB-01-01 Individual Habilitation Plan Policy
HAB-01-01-01 Individual Service Plan Development Procedure
PER-05-01-01 Conflict Resolution Procedure for Persons Receiving Services
DSP Training OJT/CBTA #13 Introduction to the Service Plan
Community Support Team Meeting Invitation Checklist
Community Support Team Meeting RSVP
DSP Training Module 6 Workbook "Visits to the Doctor or Dentist" p. 77-78
BEH-01-01-04 Behavior Management Program Format

Comment:

This guardian/family's active and extensive involvement in decisions and care planning needs for their son/ward was well documented. This was an isolated incident that does not reflect the values and practices of the agency nor of any of the three (3) staff involved.