



FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY- CHICAGO REGION

**REPORT 13-030-9004
Anixter Center**

Case Summary: The HRA did not substantiate the complaints that the facility administered psychotropic medication without the consent of the recipient's physician or guardian or that the recipient was not eating healthy foods and others were eating his food. Additionally, it was not substantiated that the recipient's funds had not been used to purchase appropriate clothing for the recipient. The HRA did substantiate that the facility did not send the recipient's monthly budget statement to the guardian and that the facility did not address the guardian's concerns regarding the recipient's care. The provider response is attached.

INTRODUCTION

The Human Rights Authority of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at Anixter Center. It was alleged that the facility administered psychotropic medication without the consent of the recipient's physician or guardian, that the facility would not send the ward's monthly budget statement to the guardian, that the ward has not been eating healthy food and other residents have been eating his food, that the ward's money has not been used to purchase appropriate clothing for the ward, and that the facility has not addressed the guardian's concerns about the care of the ward. If substantiated, these allegations would be violations of the Mental Health and Developmental Disabilities Code (405 ILCS 5/100 et seq.), the Illinois Administrative Code, Medicaid Community Mental Health Services Program regulations (59 IL Admin Code Part 132.85), and the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23).

Anixter Center is a non-profit organization providing disability services and support to low income persons and persons with disabilities including employment and residential services, comprehensive behavioral health services, literacy training, and services for the deaf and hearing impaired. The Center operates Jarvis House, a 39- unit CILA in Chicago.

To review this complaint, the HRA conducted a site visit and interviewed the Mental Health Coordinator for Jarvis House and the Director of Residential Services. Corporate policies were reviewed, and the recipient's clinical records were reviewed with written guardian consent. The guardian's Court Order for Guardian of the Person has been entered into the record.

FINDINGS

The record contains the Court Order appointing the recipient's father as limited guardian of the person of his son. It states, "[The guardian] shall have the authority to: 1) Access [the recipient's] medical records, 2) Communicate with [the recipient's] medical care providers about his son's medical condition, 3) Direct [the recipient's] medical and care treatment, and 4) Authorize residential placements for [the recipient]. Handwritten on the form it states, "Authority does not extend to psychotropic drugs or placement under the Mental Health Code." The recipient's Mental Health Assessment, completed 4/01/12 indicates that the recipient's father has full guardianship of the recipient and his contact information (phone number) is included in this document. This investigation covers the period of March, 2012, when the recipient was admitted to Jarvis House, until September, 2012 when the complaint was filed.

The record shows that the recipient was admitted to Jarvis House on 3/01/12 with a diagnosis of Bipolar Disorder. Issues related to the recipient's care are first noted in a file note written by the mental health counselor, dated 5/16/12. The note, unsigned, states, "Mr... [guardian] has contacted me via text messages. He stated his concern regarding [recipient's] eating junk food and not packing a lunch for day program. [Guardian] called me and asked me why [recipient] was eating junk food. He asked me if [recipient] was taking lunch to the day program. I told [guardian], per my knowledge, that [the recipient] was eating healthy food, but also had the right to eat foods that he wanted to. I told [the guardian], per my knowledge that [the recipient] was bringing food to the work shop. I communicated to him that [the recipient] has a link card and spending money, so if he chose not to bring a lunch he always had the option to purchase a lunch at the work shop. [The guardian] insisted that we (Jarvis staff) control what type of foods [the recipient] purchases. I communicated to [the guardian] that controlling the foods [the recipient] purchased would violate his rights. I reassured [the guardian] that [the recipient] was being trained in meal planning and preparation which includes healthy eating choices. I reassured him that I would conduct an investigation to address his concerns." The record contains the follow-up response to the investigation written 5/24/12. It states, "[The guardian] contacted me today via phone. I explained to him that I just completed the response letter addressing his concerns regarding [the recipient's] eating habits and meal planning/preparation training. He asked me to read the letter over the phone. I read him the letter and he was satisfied with our investigation. He was content and approved of the feedback that was given to him. I asked [the guardian] if he would like to set up a team meeting with myself and the Jarvis staff. I communicated to him that his feedback regarding [the recipient's] diet and meal planning was always welcome. I asked him if he would like the letter I just read to him over the phone regarding our investigation. [The guardian] stated that he would contact me soon to arrange a meeting and that I could give him the letter at that time. I communicated to him that I needed to send my letter to my supervisors so they would verify I completed my investigation. [The guardian] was satisfied with that request." The record also includes a letter written on 5/24/12 by the Mental Health Coordinator which indicates that he had spoken to the

guardian about his concerns and that the recipient was receiving training on meal planning and preparation and that he was being assisted with developing budgeting skills. The guardian is then invited to view any data and review any financial transactions to address his concerns.

The first formal correspondence from the guardian expressing his concerns is addressed to the agency President and is dated 6/08/12. It indicates that the recipient has expressed to his father that on some days he only eats one meal and that on others, he doesn't eat a nutritional meal at all. Additionally, the guardian is concerned that his son's roommate has been eating his food without his son's consent and that he feels staff are not addressing the problem. He indicates that he has spoken with staff to no avail and has still not received the letter with the staff response in it. He notes that staff are not responding to his requests in a timely manner. Additionally, he indicates that he has requested documentation that lists the services offered by Jarvis House and requests an investigation. His home phone number, cell phone number, and email and home address are included in the letter. On 6/14/12 the record shows that the guardian wrote another letter adding a medication concern to his list of issues with the facility: "I am writing to inform you that my son has reported to me that since he has been a resident of Jarvis House he has been given unprescribed medication from members of the Jarvis staff; I am deeply concerned by this. The two medications in question are Ativan and Haldol. I contacted my son's psychiatrist two days ago; she reported that she has not prescribed these medications to [the recipient] and immediately contacted [the Mental Health Coordinator], at Jarvis House, who denied giving [the recipient] these medications. Please know that I am in receipt of a Mental Health Assessment from Anixter Center mentioning these two medications as being part of his current psychotropic medications." The letter ends by the guardian informing staff that due to the seriousness of these findings, he is making a formal complaint to the Illinois Department of Human Services.

Another correspondence is included in the record from the guardian dated 7/18/12 to the Director of Residential Services. It states, "Please let this letter serve as a formal complaint with..., the Manager of Jarvis House. Over the past several months, I shared a number of concerns that I had with [the Manager] in reference to the poor level of service that my son has received since being a resident of Jarvis House.

- One of my main concerns was that [the recipient] was not eating healthy meals and his roommate was eating his food while [the recipient] was away from the residence.
- I also had a concern that members of the Jarvis staff were not educating my son of the healthy food choices available to him while shopping. [The recipient] would go a full day without eating a meal. This is definitely a concern because it is strongly recommended that [the recipient] eats while taking his medication.
- My son is currently wearing combat boots in 90-100 degree weather; I had to give [the recipient] my pair of gym shoes, when he has an income that should support him in purchasing shoes if he needs them.
- I am concerned that [the Mental Health Coordinator] would allow my son to take Haldol without consent from my son's psychiatrist. When he was confronted by the psychiatrist, he lied stating that my son has not been prescribed the medication. I have pictures and video footage stating otherwise. When my son became a resident of this facility, I gave [the Mental Health Coordinator] a current Neuropsychological Evaluation, referred by his

psychiatrist, dated 11/17/11 and Haldol was not one of the prescribed medications in this report.

- I would like a copy of [the recipient's] budget on a monthly basis mailed to me; I am in receipt of a letter from [the Mental Health Coordinator] stating that I can view the budget in his office."

I am requesting that you discuss these issues with [the Mental Health Coordinator]. I would like a monthly copy of [the recipient's] budget, a report from his doctors after every visit, if this problem continues, I will become his payee, shop for him and change his medical doctor and psychiatrist; that way, I will have more control as to what is going on in my son's life. [Director of Residential Services], thank you for offering to meet with me on July 27, 2012, at this point I see no need to do so as these were the issues that I wanted to discuss with you. If you have any questions, please do not hesitate to call me at..." Another copy of this letter was sent on 7/19/12. On 8/14/12 the guardian sent a letter to the President of Anixter Center, again enumerating his concerns exactly as stated previously and alerting the president that he had not received a response to the letters sent in June and July.

The record contains the facility response to the guardian complaints, addressed 9/17/11 from the President. It states,

"This letter is in response to your letter to me of August 14, your letters to our staff dated June 8, 2012, June 14, 2012, and July 18, 2012 and your call with ...on September 4, 2012.

Please note that our staff has notified the local police department concerning your threats you made to ... during your phone call. We take the safety and well-being of our staff, residents and others receiving services very seriously and your verbal abuse of, and threats directed to, ... present a direct threat to those individuals. Your further abuse of our staff will not be tolerated, and we will continue to report any threatening activity to the local authorities.

We do appreciate that, like us, you want the best for your son and that you may be frustrated with not having instant access to information and control with respect to your son's care. We have taken all of your concerns very seriously and are in the process of reviewing each one of them. We are also preparing a more formal response regarding your inquiry of the legal responsibilities that you, the Jarvis House, and the Anixter Center each have to your son with respect to his care. Unfortunately, this analysis is still ongoing. We will provide you with an update as soon as possible., In the meantime, you are always welcome to contact our staff if you have any comments or questions regarding your son or his care. To the extent we are legally permitted, we will be responsive to those comments and questions. However, we ask that you do this in a respectful and non-threatening manner."

The clinical record contains documentation of the recipient's medical care, dental care and medications. There is no indication of the guardian's informed consent for any of this care. The record (Mental Health Assessment) does show that the recipient had problems with psychotropic medication: "[Recipient] has difficulty with anger and depression. These symptoms prevent him from achieving his goals of living independently and going back to school. [Recipient] has difficulty with side effects from psychotropic medication. He becomes

weak and dizzy. His eyes roll up into his head and can't see...." This assessment indicates that the recipient was seen by his personal psychiatrist who prescribed the following psychotropic medication before admission to Jarvis House: Cogentin 4 mg, Depakote 1000 mg, Ativan 2 mg PRN (as needed), Haldol 2 mg PRN, and Risperdal 4 mg. Admission medication orders dated 3/01/12 indicate that the recipient's psychiatrist at Jarvis House had continued all of his previously prescribed medication including Haldol and Ativan for periods of anxiety. The Medication Administration Record indicates that the recipient was administered PRN Ativan on 4/08/12 and 4/23/12 for anxiety, and Haldol on 5/23/12 for "anger/anxiety." The record contains two Notification of Medication Change forms which are signed by the recipient's treatment team, however they are not signed by the guardian. The record also indicates that the recipient was examined by a dentist for tooth pain 7/11/12, and by a physician for back pain 7/17/12 and was seen approximately monthly by his physician for general exams. There is no indication in the record that the guardian was made aware of these visits or their results.

The recipient's Individual Service Plan (ISP) is included in the record (dated 5/08/12). It indicates the following goals/objectives for the recipient: "[Recipient] will maintain and implement healthy choices, research healthy menu options and prepare. [Recipient] will learn more about reading food labels and try to be more conscientious about eating less processed foods." For budgeting issues it states, "[Recipient] will maintain and adhere to self appointed budget, continue to pay bills on time and resolve outstanding debts, will be able to identify personal needs, prioritize purchases, and be able to maintain a self determined budget." The ISP also adds a daily goal of "[Recipient] will be able to initiate and address hygiene practices daily with a minimum of prompting from staff." All goals/objectives indicate staff support for their completion. The document is signed by the recipient and his guardian.

There is no indication in the record that the guardian received the recipient's monthly budget statement either before his request for it or afterward.

The record contains daily progress notes and many of them address the recipient's nutrition. A sampling of them include:

- 5/17/12 "Staff asked [recipient] what he was having for breakfast. [recipient] told staff he did not have time to eat breakfast. Staff let [recipient] know that he had plenty of time to eat a small breakfast and make a lunch. Staff then asked [the recipient] again what he would have. [recipient] told staff that he would have noodles for breakfast and a mango for lunch. Staff redirected [the recipient] to have the mango for breakfast and make a sandwich for lunch."
"Staff and [recipient] talked about different items he could add to his grocery list for lunch and breakfast. Staff explained to [recipient] the importance of a good breakfast and a lunch to keep him going throughout the day. [recipient] agreed that he needed to eat a more balanced diet, but he did admit that he uses his link card to buy junk food..."
- 5/22/12 "[Recipient], with this writer's assistance, went shopping for groceries. The last time he went he picked out more than he had money to pay for. This time he was coached on keeping a running tally on what he is spending..."
- 5/24/12 "[Guardian] sent a letter to resident manager to address issues related to [the recipient's] daily diet. [Guardian] is dissatisfied with the support [the recipient] is

getting from staff and day program. [The guardian] stated he will be faxing a list of foods he wants his son to eat. Staff's role is to encourage, suggest, and support with goal without violating basic human rights. Staff will continue to respect [recipient's] ability to choose what he wants to eat, while at the same time educate and train him on healthy eating, cooking, shopping. [Recipient] will go shopping without staff the day his Link card is charged and spend all of money (sic) that day. [Recipient] will give his money away or spend it impulsively. [Recipient] splits staff or deflects from his own responsibility in any bad choices he has made and downplays his capabilities when he is held accountable for his decisions. This is a pattern of behavior that has been observed by both residential and day program staff. Continuous documentation and possible meeting with [recipient] and his father will be scheduled to address these concerns."

- 6/08/12 "Staff asked [the recipient] what he was having for breakfast and what he was taking for lunch. [The recipient] told staff he did not have any food for lunch and he had hotdogs for breakfast. Staff asked [the recipient] if he had some oatmeal and he said "yes". Staff then asked [the recipient] why he could not have oatmeal for breakfast and hotdogs for lunch. [The recipient] told staff that he did not know. Staff and [the recipient] went to his room and fridge to see what food he had. He had numerous options for breakfast and then decided to eat his oatmeal and take a sandwich for lunch. He did not need help for meal planning. He stated he will eat hot dogs for dinner tonight."
- 6/09/12 "...Staff asked [the recipient] what he had for lunch and he said a sandwich. Staff inspected his cabinets and refrigerator for food. He did a good job of buying a balanced diet of food. Staff asked [the recipient] what he would have for dinner and he said he would take his link card and eat out. Staff asked [the recipient] if there was anything he would like to learn to cook and he said no. He stated he knows how to cook all of his foods."
- 6/17/12 "[Recipient] had a written grocery list because he would be going grocery shopping later that day. Although he had done a pretty good job listing all the foods he wanted, I helped him add a few more items to the list that he might need to complete breakfast lunch and dinner. I also assisted him with estimating the cost of each item, so he would be able to know how much money he would need. I communicated to him that he would have to ensure that he would need to make his money last until the end of the month, due to his budget. I reminded him to also use his link card to help him toward that goal. He agreed that he would need to stay on his budget in order to become independent. Staff also promoted healthier food choices...."
- 6/23/12 "[Recipient] admits he knew that the quantity of groceries we bought 6/17 would be his supply of food to last at least 3 to 4 weeks. [recipient] requested more money, even though he is on a budget. [Recipient] could not account for rapidly depleting supply of food. Instead, he suggested that it was my fault or I 'set him up' by somehow allowing him to purchase food in large quantity. I redirected conversation to personal responsibility and budgeting skills. I recommended that [the recipient] use his link card if he ran out of food. [Recipient] did not anticipate my response or offered solutions, this was not the answer he was looking for. I then asked him if we could look in his refrigerator. He had enough food for a week and he still had money on his link card. I

asked him if he let his roommate eat his food and he replied, “no”. Staff and [the recipient] concluded that he will have enough food until next pay period.”

The record shows that the residential staff was almost daily involved in the recipient’s food selection, buying, preparation, and budgeting.

The progress notes contain numerous references to the recipient’s clothing and related budgeting. Some examples which demonstrate the issues are:

- 6/18/12 “[The recipient] came home wearing a long sleeved shirt. I asked him if he was hot considering it was 100 degrees outside. He stated that he was not hot because he had taken off his hooded sweater that he had on before. We discussed how dangerous it was wearing winter clothing in the summer and he was prompted to go upstairs and shower, and change into appropriate clothing.”
- 6/29/12 “[Recipient] came down for workshop with jeans and boots. Staff told [the recipient] that it would be ninety eight degrees today and he was overdressed. [The recipient] explained to staff that he did not wear shorts. Staff asked [the recipient] if he had sandals or tennis shoes because his boots would be very hot. [The recipient] told staff that he was fine. Staff gave [the recipient] four prompts to change. [The recipient] refused and left for workshop.”
- 7/30/12 “Staff asked [the recipient] if he had changed clothes due to an odor that was following him. Staff asked him why he was wearing a sweat top, with a shirt underneath with sweat pants in 86 degree temperatures. [The recipient] stated that he was fine. Staff reminded him of the risk of overheating. Staff prompted him to change and take a shower. Staff communicated to [the recipient] that his father had brought this issue of dressing poorly for the warm weather. [The recipient] stated that his father has never brought this to his attention even when he sees him. I asked [the recipient] if myself and other staff had done a good job of prompting him to wear appropriate attire and he replied 'yes'. He stated that we had this conversation at least 3 times, however he feels his attire is 'fine for him.’”
- 8/19/12 “ I set aside money for [the recipient’s] phone bill as I would be on vacation day it was due. Coworker assisted [the recipient] with facilitating payment by ensuring he went up to local store to pay in full. [The recipient] walked up to store with [staff] and paid bill in full. When I returned from vacation, I thanked [the recipient] for taking care of his phone bill on his own and for putting the receipt in my mailbox. We talked about budgeting. [The recipient] decided he no longer needs or wants to purchase a new pair of shoes. He said there was no point to getting a new pair because they always have problems with wear, tear, or odor. I told [the recipient] that we would find a good pair of shoes for him that would be worth the investment. [The recipient] wasn’t interested in buying shoes anymore. I told him I would document conversation just to be clear but if he changes his mind, let us know and we would be available to help him shop comparatively for new pair of shoes or anything else he needs.”

FACILITY REPRESENTATIVES' RESPONSE

Staff were interviewed about the complaints. The staff indicated that only about 5-10 percent of their clients have guardians and therefore they were unfamiliar with guardian rights

and responsibilities. They indicated that although they realized the father of the recipient was his legal guardian, they were confused about the parameters of his authority. This was clarified in June of 2013 when the recipient was appointed a guardian ad litem, who presented the issue before a probate judge, and he defined the role of guardian of the person. The staff then met with the guardian and the guardian ad litem, and developed standards set by the judge and by which everyone in the treatment team would communicate the recipient's progress and needs going forward.

Staff were asked about the staff involvement with the guardian during the period of this case. They indicated that the recipient was admitted into Jarvis House in March of 2012 and for the first 8-9 months the staff only spoke on the phone with the guardian or communicated through text message and had no email or regular address for the guardian until July of 2013. They indicated that the guardian refused to speak to the Mental Health Counselor and that all calls (after the first letter from the guardian) were then made by the Director of Residential Services, who contacted the guardian weekly for updates regarding his son's care. The Director stated that she had set up a meeting with the guardian in May, 2013 and that he did not show up. Shortly thereafter, the meeting was arranged with the guardian and a guardian ad litem to review the conditions of the guardianship with a mental health judge, and in June, 2013 the guardian gave his address and fax number to facility staff.

Staff were asked about the lack of the guardian's consent for medication. They stated that the recipient was admitted to Jarvis House from another facility where his physician ordered all of his medication and these orders were transferred with him to Jarvis, including an order for Haldol and Ativan, and that the guardian was aware of this at Intake. Later, in April and May, the recipient was administered Haldol and Ativan when he was experiencing periods of anxiety, and when the guardian was made aware of this, he objected to the use of these medications and they were then discontinued by the psychiatrist. Staff indicated that the guardian was present for every treatment plan meeting and was faxed the results of every doctor or dental visit.

Staff were asked about the guardian's request for monthly budget statements. They indicated that the guardian had not signed all the Intake documents when his ward was admitted, so initially there was no address to send the statements to. In May, 2012 the guardian requested that the staff buy the recipient all of his food, however staff were unable to do this because the recipient has the right to buy his food, etc. Staff then began budgeting the recipient's funds because the recipient was not his own payee from March until July of 2012. When he became his own payee in July, 2012, the facility relinquished their authority over the recipient's budget and they forwarded two months of budget statements to the guardian. Since July of 2012 the facility has had no authority over the recipient's budget. Staff indicated that the guardian was always welcome to come to the facility and request to see or copy anything from his ward's file.

Staff were asked about the recipient's food and the concern that other residents were eating his food. They indicated that they continuously educate the resident about diet and nutrition, and that it is addressed in his Treatment Plan, however they cannot force the recipient to eat specific food because he has the right to choose his diet. They indicated that the residents in this house pool their food and that the food is stored, prepared, and eaten as a community, so

there is always the possibility that some items may be eaten by other residents, however not to the extent that the recipient would suffer from being deprived of his food.

Staff were asked about the recipient's use of his funds to buy appropriate clothing. They indicated that there are some residents who at times prefer to wear clothing which seems inappropriately warm for the temperature outdoors. This is not uncommon and staff urge the residents to wear appropriate clothing, however they cannot force them to buy or wear the clothing that is recommended. This behavior requires daily redirection, which the staff feels is given to the recipient. With regard to the recipient's funding for clothing, the recipient was made his own payee in July of 2012 so he and his guardian have been responsible for his clothing budget since that time.

Staff were asked about their efforts to address the guardian's concerns as expressed in the letters he sent to the facility. They stated that they had regular (weekly) communication by phone and text message with the guardian and addressed each concern as it was brought to their attention. They indicated that they had problems sending documents to the guardian, who did not give them his address, until after the recipient had been at the facility for over six months.

STATUTES

The Mental Health and Developmental Disabilities Code provides for the inclusion of the guardian in all aspects of treatment:

"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).

If treatment includes the administration of psychotropic medication, then the guardian must be advised in writing of the side effects, risks and benefits of the treatment:

"If the services include the administration of...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, as well as alternatives to the proposed treatment, to the extent such advice is consistent with the recipient's ability to understand the information that is communicated. The physician shall determine and state in writing whether the recipient has the capacity to make a reasoned decision about the treatment. The physician or the physician's designee shall provide to the recipient's substitute decision maker, if any, the same written information that is required to be presented to the recipient in writing." (405 ILCS 5/2-102 a-5).

The Mental Health Code also allows the guardian to refuse treatment for the recipient:

"An adult recipient of services, 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. The recipient and the recipient's guardian or substitute decision maker shall be given the opportunity to refuse generally accepted mental health or

development disability services, including but not limited to medication. 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." (405 ILCS 5/2-107 a).

And, whenever a guaranteed right of the recipient is restricted, the recipient and the guardian must be given prompt notice of the restriction and the reason therefore. (405 ILCS 5/2-201 a).

Also, the Mental Health and Developmental Disabilities Confidentiality Act states that the guardian of a person who is 18 years or older shall be entitled, upon request, to inspect or copy a recipient's record or any part thereof (740 ILCS 110/4a). Additionally, whenever this access is requested, the request and any action taken thereon must be noted in the recipient's record (d).

The Illinois Administrative Code (59 IL Admin. Code Part 132.85) Medicaid Community Mental Health Services Program outlines the requirements for recordkeeping:

"The provider shall maintain records, including but not limited to the following:

- 1) All payments received, including cash;
- 2) All payments made, including cash;
- 3) Corporate papers including stock record books and minute books;
- 4) All arrangements and payments related in any way to the leasing of real estate or personal property, including any equipment;
- 5) All accounts receivable and payable;
- 6) Service billing files;
- 7) Clinical records as defined in Section 132.100; and
- 8) Individual client information, including: guardianship, representative payee, trust beneficiary and resource availability.

...Required records shall be readily available for inspection, audit, and copying during normal business hours by personnel representing the Certifying State Agency, the public payer, HFS, or the Centers for Medicare and Medicaid Services (CMMS), U.S. Department of Health and Human Services. Reviewing personnel shall make all attempts to examine such records without interfering with the professional activities of the provider.

...The compilation and storage of and accessibility to client information and clinical records shall be governed by written policies and procedures, in accordance with the Confidentiality Act and HIPPA."

The Illinois Probate Act of 1975 defines the duties of the guardian:

"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; shall procure for them and shall make provision for their support, care, comfort, health, education and maintenance, and professional services as are appropriate....The guardian shall

assist the ward in the development of maximum self-reliance and independence." (755 ILCS 5/11a-17a).

Also, the Probate Act gives direction to providers to rely on guardian decision making:

"Every health care provider...has the right to rely on any decision or direction made by the guardian....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).

PROGRAM POLICY

The Anixter Center provides policy regarding the Service Planning Process (Policy No. 107) which includes the guardian, stating, "Individuals served, and/or their parent or guardian when appropriate, have the responsibility and right in formulating their service plan..." There is no more policy describing the rights of guardians.

CONCLUSION

The record in this case presents an unusual court order for limited guardianship of the person that contains the directive, "Authority does not extend to psychotropic drugs or placement under the Mental Health Code." It is not clear if this does not allow for guardian consent to medication and involuntary commitment, or if it prohibits guardian consent over the refusal of the recipient, which is the standard for guardianship of the person. In either case, the court gave the guardian the authority to access the recipient's medical records, communicate with the recipient's medical care providers, direct the recipient's medical care and treatment, and authorize his residential placement. It is unclear how the guardian could direct the recipient's medical care and treatment without the authority to consent to medication, however the HRA will have to honor the court's decision, whose apparent intent was to limit the rights of the guardian regarding medication. The HRA does not substantiate the complaint that the facility administered psychotropic medication without the consent of the guardian. Fortunately for all those involved, a hearing on this matter was held before a judge who then clarified the role of the guardian and all parties have agreed to the stated terms. However, the HRA reminds Anixter Center staff that guardians, even those with limited guardianship, have the right to receive information on the risks, benefits and side effects of psychotropic medications in order to assist in the care and decision making for their wards.

The record shows that the recipient, for the period of this investigation, was his own payee as requested by his guardian, and thus the facility was not responsible for his budget. However, the facility was still responsible for sending the monthly financial statement as requested by the guardian and they did not begin this practice until after the meeting in June, 2013. The HRA substantiates the complaint that the facility would not send the ward's monthly budget statement to the guardian.

The record shows extensive interaction between the recipient and the House staff in an effort to educate the recipient on healthy and economic food choices. The staff is to be commended for their almost daily focus on the purchasing, selection and preparation of the

recipient's food and the constant education and redirection that was needed for all the residents. The HRA does not substantiate the complaint that the ward was not eating healthy food and that other residents had been eating his food.

The record shows that staff redirected the recipient, almost daily, on his choice of suitable clothing for the very hot weather that was occurring at the time. It is evident from the record that the recipient had appropriate clothing to wear but even if staff had forced the recipient to buy other clothing he would have chosen to wear the clothes in which he was most comfortable. The HRA does not substantiate the complaint that the ward's money had not been used to purchase appropriate clothing.

The personal file notes from the mental health counselor indicate that he spoke with and texted the guardian regularly and that although he often addressed his concerns, it is not clear that the guardian was made aware of this. This is demonstrated in the progress notes which show the effect of these communications, namely, that the recipient's medication was discontinued, his shopping supervised, etc. The phone conversations between the Director of Residential Services and the guardian were not documented; the only record we have of them is the written correspondence from the guardian, and these letters show that the guardian remained very concerned about his son's care in letters written on June 18 and June 19, 2012. On June 8, June 14, and again on August 14, 2012 the guardian turned to the agency president with his written concerns, and the response to this letter was sent on September 17, 2012. Although the letter states that the agency is preparing a formal response, it asks the guardian to address any comments or questions to the same staff with whom the guardian has been dissatisfied. We do not know how or when the guardian was given the results of the President's review of the situation, however we note that the June 8th letter contains the guardian's home and cell phone numbers as well as his home and email addresses, so contact information was available. It is not clear why the President's review of the matter could not have resulted in the staff receiving this information in June of 2012. Additionally, a three month wait for a formal response to a concerned guardian is not acceptable and it is not clear that this response was ever received by the guardian. The HRA substantiates the complaint that the facility did not address the guardian's concerns about the care of the ward.

RECOMMENDATIONS

1. Develop policy for and train staff in the rights and role of guardians, including the right to be given information on financial records and on medication risks, benefits and side effects. Ensure that requests and actions taken upon them are documented in the clinical record. Ensure that guardians are given the necessary information to make informed decisions for the well-being of their wards, "to the same extent and with the same effect as though the decision or direction had been made or given by the ward." Ensure that guardianship status is clarified at Intake.

2. Develop policy regarding the management of consumer finances and train staff in this federally mandated policy.

SUGGESTIONS

1. Seek and document informed consent for all recipients who maintain their legal rights.
2. Ensure that contact information for the guardian is obtained at Intake or as soon thereafter as possible.

RESPONSE

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

October 2, 2013

Nicole Erickson
Illinois Guardianship & Advocacy Commission
Nicole Erickson, HRA Chairperson
1200 S. 1st Avenue. Box 7009
Hines, Illinois 60141

Re: #13-030-9004

Dear Ms. Erickson,
Below is the response from Anixter Center regarding the investigation. Thank you for your time and effort in reviewing this case.

Guardianship & Advocacy Commission Recommendations

- 1) Develop policy for and train staff on the rights and roles of guardians, including the right to be given information on financial records and on medication risks, benefits and side effects. Ensure that requests and actions taken upon them are documented in the clinical record. Ensure that guardians are given the necessary information to make informed decisions for the well-being of their wards, “to the same extent and with the same effect as though the decision or direction had been made or given by the ward.”
- 2) Develop policy regarding the management of consumer finances and train staff in this federally mandated policy.

Anixter Center Response

All DSPs (direct support workers) receive DHS approved training on the rights and roles of guardians within 120 days of hire.

However, a refresher training will be delivered by November 20, 2013 to all residential managers. This training will review the rights and roles of guardians including finances, medications and documenting guardian requests (and our response) in the record. The training will also cover the policy regarding consumer finances. Next, the managers will review the information with staff in team meetings.

Additionally, the policy on guardianship rights and the financial policy per Rule 132 will be sent via email to program staff.

Prior to starting services, a meeting will be held with the guardian and client to review and sign paperwork including the rights statement, and to discuss communication strategies. Anixter Center will obtain contact information for the guardian at intake.

Please note that page 1 of the report states that Jarvis is a 39 unit CILA and this is incorrect. Jarvis has a capacity of 12 individuals and is under the DMH category Supervised Residential.

Anixter Center will allow the posting of this response in conjunction with the report. Thank you.