FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY- CHICAGO REGION

REPORT 08-030-9010
Victor C. Neumann Association- Wrightwood CILA

INTRODUCTION

The Human Rights Authority of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at Victor C. Neumann Association-Wrightwood CILA. It was alleged that the facility denied a resident the right to adequate and humane care when it did not include the resident's guardian in the resident's treatment planning and care. If substantiated, this allegation would be a violation of the Mental Health and Developmental Disabilities Code (405 ILCS 5/100 et seq.), the Illinois Administrative Code, Standards and Licensure Requirements for Community Integrated Living Arrangements (the CILA Rules) (59 Ill. Admin. Code 115.100 et seq.), and the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23).

Victor C. Neumann Association (VCN) provides education, housing, recreation, rehabilitation, training and employment opportunities to approximately 200 persons with disabilities in the Chicago area. Wrightwood CILA is one of the VCN's facilities and houses eight adult residents.

To review this complaint, the HRA conducted two site visits: one to the CILA where the site supervisor and Qualified Mental Retardation Professional (QMRP) was interviewed and another site visit to the corporate headquarters where the CEO, the Senior Director, a RN and the Director of Performance Improvement were interviewed. Corporate policies were reviewed, and the recipient's clinical records were reviewed with written guardian consent.

FINDINGS

According to the complaint, a recipient had eloped from her residence at the Wrightwood CILA, had been hospitalized, and had her psychotropic medications adjusted several times without notification to either of her guardians (parents) during the period of June, 2007 through January, 2008. Records were requested that documented the following four components of care: hospitalizations, psychotropic medication adjustments, elopements, and documentation of guardian notification for these events from 6/07 until 1/08. Records were requested first from the CILA residence and those that could not be obtained were then requested from the corporate office, where the resident's master file is secured. The recipient is a resident of the Wrightwood CILA and attends a day program at the VCN headquarters.

The record received by the HRA from the recipient's CILA contained one Individual Program Plan (IPP) that is dated 7/25/07. It addresses behaviors previous to the recipient's placement in the residential program in July of 2007, when she was a recipient at the VCN Crisis Center and indicates that it is reviewed twice yearly. This plan contains a Positive Behavioral Intervention Support Plan which addresses the recipient's potential for elopement and outlines positive behavioral intervention strategies and responses to her negative behaviors. The IPP indicates that the guardians were notified of this conference and attended via conference call. This IPP is also signed by the guardians.

The Senior Director of Programs was interviewed regarding the process for monitoring the day programs for their compliance with the goals and directives of the IPP. She stated that there is a tracking sheet for both the residence and the day programs that records compliance with behavior plans, goals and directives and this is based on the program outlined in the IPP.

The hospital records provided at the CILA indicate that the recipient was hospitalized six times during the reporting period: 1/04/07, 2/05/07, 4/10/07, 7/23/07, 8/02/07 and 12/22/07, generally for violent or threatening behavior. Her course of care generally involved medication stabilization and each time she was returned to the CILA upon discharge. There are no accompanying Progress Notes or Incident Reports explaining these hospitalizations, except one entry made on a Progress Notes sheet for 1/16/07 that states, "Informed Ms. …[guardian] of hospital's discharge orders. Received consent for…[illegible] and Prilosec from Ms…." There is no other indication from the record that the guardian was notified of the recipient's hospitalizations.

The supervisor of the CILA was interviewed regarding the guardian notification of hospitalizations. She stated that she (the supervisor), is "sometimes" notified of incidents but that the recipient had often acted out while in the day program at the VCN headquarters and thus she may not have been made aware of them. She stated that there is no policy for notification of guardians for hospitalizations, however she believed that since she was the QMRP for the CILA, it would be her responsibility to notify guardians. The administrative staff stated that hospitalization incidents are reported electronically and thus the staff at the respective homes should be aware of them. They then become part of the recipient's master file.

Documentation (physician's orders) received from the corporate headquarters indicated that within the reporting period of 6/07 through 1/08 there were 5 adjustments made to the recipient's psychotropic medication regimen: 7/12/07, 8/02/07, 10/04/07, 11/08/07, and 11/11/07. VCN Group Medication Consultation forms, obtained from the CILA, indicate three additional adjustments were recommended by the resident's physician on 3/08/07, 5/10/07, and 5/24/07. It is not clear from the documentation if these recommendations were then ordered. The record indicated that the facility had obtained consent from the guardian for all psychotropic medications when the recipient was admitted into the program, however there was no indication from the record that the guardians were informed of any changes or adjustments to the medications thereafter. Adjustments were made primarily to increase and decrease medication within therapeutic levels that were outlined in the original consents. The guardians, however, reported that they requested several times to have the supervisor/QMRP notify them of

psychotropic medication changes and they did not receive a response. The QMRP was interviewed about the reporting process and she stated that there is no procedure for notification of guardians regarding medication adjustment.

The VCN administrative staff were interviewed about the notification of psychotropic medication change or adjustment. Staff stated that unless a new medication is added, there is no notification of the guardian for adjustments to approved medications as long as the dosage is within the therapeutic range that is consented to by the guardian. The HRA asked about psychotropic medication changes that result from a hospitalization and are part of the discharge instructions. The administrative RN stated that consent should be obtained at the hospital for additional medications that may be ordered. The new changes would then be sent to the individual group home through a process of written notification, where each staff person from the group home would sign off on them.

It is unclear from the record how many times or on what dates the recipient eloped or attempted to elope from the CILA or her day program. The documentation from the Wrightwood CILA contained Comprehensive Monthly Progress Reviews for the period of July, 2007 through January, 2008. An entry made on the July report stated, "[Recipient] displayed aggressive behaviors 31 times this month and elopement or attempted elopement 5 times this month. Recipient was hospitalized on the 22nd and it continued through the end of the month." No dates for the elopements, Progress Notes or Incident Reports were provided to describe these events. Again on the September report it states, "[Recipient] had a difficult month at the beginning of the month. She eloped from the site one time in the month of September. Her behavior did improve towards the end of the month." The CILA did not provide Progress Notes or Incident Reports for these incidents and the supervisor stated that these records would be located at the corporate headquarters in the master file. Administrative staff from the corporate office provided two Incident Reports from the reporting period and one of them corresponded to the September elopement. The entire document was not present, however the section indicating that the guardian was notified was not checked. The other Incident Report described an attempted elopement from July 7, 2007 that was not documented in any of the records that we received. It does not indicate whether or not the guardians were notified of the elopement. The supervisor of the CILA was interviewed regarding the notification of the recipient's guardians of elopements and she stated that since these incidents may have occurred when the recipient was attending the day program, she may or may not have been apprised of them. She stated that there is no policy for notification of guardians regarding elopements. Administrative staff from the corporate headquarters stated that all incidents of elopement are documented electronically and then forwarded to the facilities for staff review. They are then entered into the resident's file.

There is nothing from the record that the HRA received to indicate that a behavioral plan was developed to address the recipient's elopement or attempted elopement other than what is present in the 7/25/07 IPP described above. It is not clear whether the Behavioral Support Plan was available to staff at the day program, and there is no policy which would require the day program staff to contact guardians for outstanding events.

STATUTORY RIGHTS

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 their guardian must be given prompt notice of the restriction and the reason therefore. (405 ILCS 5/2-201 a).

Additionally, 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).

The CILA Rules include the guardian in the recipient's community support team (CST) and indicates that the CST is to be the central structure through which CILA services are provided to the recipients. It also designates the QMRP as the CST member who works with the individual and parents 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) or guardian." The QMRP is also responsible for the supervision of "all services specified in the in the services plan, whether provided by an employee of the licensed agency, consultants, or sub-contractors." (59 Ill. Admin. Code 115.220).

The Rules also indicate that a physician or pharmacist shall be available to consult with the QMRP at least monthly to discuss staff's observations relating to the recipient's level, dosage, and types of any side effects from any prescribed medications (59 Ill Admin. Code 116).

Finally, the same administrative code for CILAs states that:

"The provider agency must ensure that current copies of individuals' service plans are kept at the individuals' residences. The provider agency must also ensure that direct care workers (including employees, contractual persons, and host family members) are knowledgeable about the individuals' service plans, are trained in their implementation, and maintain records regarding the individuals' progress toward the goals and objectives of the individual service plans." (59 Ill. Admin. Code 115.220 p).

PROGRAM POLICY

VCN provided the HRA with policy that directs the involvement of guardians in treatment planning:

"Neumann Association promotes the participation of consumers and guardians in the development, review, and evaluation of their Individual Program Plan/Individual Treatment Plan/Service Plans. When guardians cannot attend planning meetings, Neumann Association staff will discuss and review the plan with them and will provide them with a copy."

If a client is late in returning to their residence, VCN has developed a procedure for documentation and notification:

"1. If the client is late returning to the residence and is considered missing, as defined in the Unusual Incident Report Policy, the following individuals are notified:

a. Residential Supervisor/on-call QMRP
b. Residential Coordinator/Administrative Manager

c. Director/Senior Director
d. Human Rights Officer
e. Police, if directed by the Director or the Human Rights Officer
f. Family (if legal guardian).

2. The staff on duty completes the Unusual Incident Report"

In case of a medical emergency the VCN policy states that primary day program staff will contact family and guardians.

CONCLUSION

In this case the guardians alleged that they were not informed when their ward was hospitalized, when her psychotropic medications were changed, and when she eloped or attempted to elope from her VCN CILA. They alleged that this deprived them of input into their ward's care and treatment decision making. The CILA was asked to provide documentation that the guardians were given notice when the ward was hospitalized, when her psychotropic medications were adjusted, and when she eloped from the CILA for the period of June, 2007 until January, 2008. When informed that some of these documents were located at the corporate headquarters the HRA then scheduled another visit to the corporate headquarters to obtain this documentation. For the six hospitalizations that the recipient experienced, there was documentation of only one time that the guardians had been notified and this was concerning hospital discharge orders. For the five adjustments to the psychotropic medication, there is no documentation to indicate that the guardians were notified, and staff did not agree that guardians should be notified if the adjustments are made within the therapeutic range. For the six elopements or attempted elopements, there is no documentation that the guardians were notified, and it is difficult to tell from the record when these events occurred and which staff members were made aware of them.

The Mental Health Code includes the guardian in all treatment planning for the recipient and extends to the guardian the right to refuse treatment, including medication, for his or her ward. We recognize that a range of doses may have previously been consented to, but if medications are adjusted in any way and guardians are not apprised of this change, this deprives them their right to refuse medication on behalf of their ward, whether or not they decide to exercise this right. The Illinois Probate Act also relies upon the direction of the guardian and allows them to make provision for their ward's support, care, comfort, health, education, maintenance, and professional services. It goes as far as to rely equally upon the decision of the guardian as that of the ward. This care and decision making cannot be exercised if guardians are not made aware of outstanding events which impact the health and well being and course of treatment for the recipient. And finally, the Mental Health Code and the CILA Rules include the guardian in the community support team, which it identifies as the central structure through which CILA services are provided to the recipients, and facility policy requires guardian notification whenever a resident is considered missing. Without guardian notification of changes in treatment, resident behavior, and service delivery, the community support team is lacking a vital component in its determinations regarding resident care.

The CILA Rules state that the QMRP is responsible for the supervision of all services that are specified in the recipient's service plan, whether these services are provided by a VCN employee, a consultant, or a sub-contractor. They are to act as a liaison between the facility and the family and guardians of recipients. The QMRP is also directed to be available for a monthly consult with a physician or pharmacist to review the recipient's medication issues. In this case the QMRP was not only uninformed of the recipient's treatment issues and outstanding incidents, but also was not informed of company policy which maintains the facility's compliance with state and federal statute.

The HRA substantiates the complaint that Victor C. Neumann Association denied a resident the right to adequate and humane care when it did not include the resident's guardian in all of the resident's treatment planning and decision making.

RECOMMENDATIONS

1. Ensure that staff include the guardian **in all aspects of the residents' treatment**, including any medication changes or adjustments and outstanding events which impact the care of the resident. (405 ILCS 5/2-102, 5/2-102 a-5, 5/2-107 (a), 755 ILCS 5/11a-17 (a). Ensure that this notification is noted in the file.

2. The CILA Rules (Section 115.220 e) designate the QMRP as the CST member who works with the individual and parents and/or guardian when there are issues that need to be addressed. The QMRP is also responsible for the supervision of all services specified in the services plan (Section 115.230 o). Ensure that all QMRP's are knowledgeable of the services they provide to the residents and of incidents or issues as outlined in the Administrative Code Section 115.230. Ensure that the delivery of these services is documented in the record.

3. Instruct staff to follow policy and notify all designated persons, including guardians, whenever a resident is considered missing.

SUGGESTIONS

1. In many instances in this case staff may have notified the guardian regarding incidents involving the care of the resident, however there was no documentation to support this action. The HRA suggests that VCN provide training for staff to review the necessity for accurate and timely documentation of patient care.

2. It was very difficult for the HRA to obtain documents to investigate the allegations in this case due to the resident's files being located in two offices. Although the Administrative Code mandates that all current copies of the individuals' service plans are to be kept at the individuals' residence, it would be helpful if a complete file could be maintained at the individuals' residences so that decision making is informed by the complete record of resident care.

3. Develop a policy that addresses how and when guardians and other substitute decision makers are to be contacted regarding all facets of services.

RESPONSE

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

NEUMANN
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Re: Case #08-030-9010

Dear Ms. Dunford,

Enclosed please find Neumann Association's response to the Human Rights Authority's report of findings. If you have any questions or require additional information, please feel free to contact me.

Sincerely,

Tina Fogarty

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Senior Director of Programs
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