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HUMAN RIGHTS AUTHORITY- CHICAGO REGION

REPORT 12-030-9015
Neumann Family Services

Case summary: The HRA did not substantiate the complaint that Neumann Family Services did not include the resident's guardian in the resident's treatment planning and care.

INTRODUCTION

The Human Rights Authority of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at Neumann Family Services (NFS). It was alleged that the facility 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), and the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23).

Neumann Family Services is a social services organization that provides education, housing, recreation, rehabilitation, mobility/transportation training and employment training to persons with disabilities and/or mental illness at 31 CILAs (Community Independent Living Arrangements) in the Chicago area.

To review this complaint, the HRA conducted a site visit and interviewed the Senior Director of Programs, the DD Residential Senior Manager, and the Residential Supervisor. Corporate policies were reviewed, and the recipient's clinical records were reviewed with written guardian consent. The guardian's Letter of Office for Guardian of the Person has been entered into the record

COMPLAINT SUMMARY

The complaint alleges that the facility does not include the guardian in her ward's care. Before entry into NFS, the recipient was evaluated by a specialist who recommended that the ward have a CT scan approximately quarterly. When the facility physician did not order this test and the guardian questioned him about it, the complaint alleges that he became angry and since

then it takes weeks or even months for the guardian to receive correspondence from the facility. The complaint also indicates that the guardian is not being informed when medications for her ward are changed and this causes her concern, since her ward suffered a slight stroke from medication in the past.

FINDINGS

The recipient was admitted into the Neumann Family Services agency, Adult Service Division, on 8/01/11- this investigation will cover the period of 8/11/11 through 3/12/12. The recipient's clinical record contains the psychiatric evaluation that was completed upon his admission to the agency. It states, "[Recipient] has been previously diagnosed with Bipolar Disorder Mixed with Psychotic Features, Personality Change due to Acquired Brain Injury, PTSD, Borderline Personality Disorder, Mild Mental Retardation, Victim of sexual abuse, and Perpetrator of sexual abuse... He was reportedly anoxic at birth and developed Mild Mental Retardation. He reported that he was sexually abused at age 5 by a ten year old boy. He reported many anger attacks, violence and unstable moods throughout childhood and he was placed in a residential facility. He was found to have abused two young children at his mother's day care center (per his report). He was in specialized treatment for sexual offenders, but removed by his mother. He was again placed in residential care. He has a history of severe aggression (once reportedly stabbed his mother), property destruction, self-injurious behaviors (superficial cuts to arms), and suicidal threats. Over 2010-2011, he aged out of his DCFS program and was referred for adult placement at Neumann Family Services. Upon admission, he showed agitated states, mood lability, and anxiety but denied suicidal ideation or intent. ..."

The record contains the recipient's Individual Program Plan (IPP) along with all subsequent IPPs (for which the guardian was present) and monthly staffing notes. The record contains all invitations to the guardian for the IPP meetings and indicates that the guardian was present and signed all IPPs which are mailed to the guardian after the staffing.

The record indicates that the guardian and her ward signed informed consents for all medications prescribed to the recipient and these consents are reviewed and signed again annually, unless changes are made to medications, at which time consent is obtained. The record also contains all physician's orders and each order indicates that the recipient has a guardian, and each order includes the guardian's name and contact information along with some indication that the guardian has been notified. Physician orders for 10/21/11 include an order for a CT scan of the recipient's head, requested by the guardian. On 11/03/11 another order indicates the discontinuation of tetracycline at the request of the guardian and an alternative cream is ordered. On 11/16/11 the recipient was discharged from a hospital recommended by the guardian for her son and the physician's orders indicate that the acne medication has been changed and that this change has been approved by the guardian. The physician's orders also indicate that the guardian requested melatonin for her son and this order was revised to reflect the amount requested by the guardian. Also, on 12/12/11 the physician's orders indicate that smoking cessation gum is ordered for the recipient, however it is later noted that the order is rescinded because the guardian did not approve.

The record contains two Incident Reports, on 10/11/11 and 11/08/11. The first incident involved verbal and physical aggression resulting from the interaction of the recipient with another house member and the second involved physical aggression resulting from an interaction with various members of the house. Both reports describe the incident, the intervention/action taken by staff, the treatment provided, and the persons, both internal and external, who were notified, and both reports show that the recipient's guardian was notified.

Facility Staff Response

Facility staff were interviewed about the complaint. They indicated that the recipient has done very well at NFS and has had very few problems adjusting to independent living. They indicated that this is the first adult residential placement for the recipient and this is a difficult adjustment for his guardian, who wants the same measure of control as when he lived at home. The recipient, however, is a young adult who is transitioning into adulthood, and he wants the independence and freedom of other young adults (he is age 21).

Facility staff were interviewed about the guardian's inclusion in the recipient's care. They noted that from the time the recipient entered their agency all staff were given the directive to contact the guardian for any decision making regarding her son and this directive has been strictly enforced. Additionally, the guardian has been given weekly calls from the Residential Supervisor (he states they are usually 30-90 minutes in length) and she has had weekly calls from her son's therapist, the Senior Director of Programs, and the Residential Senior Manager. The facility has provided the HRA with notes from the guardian's calls to the facility staff which are too numerous to include here, but which provide extensive evidence of the facility's attempts to honor the requests of the guardian. Additionally, the agency changed the staff nurse assigned to the recipient because the guardian did not approve of her, and the physician that was assigned to the recipient removed himself from the recipient's case because of the guardian and another physician was assigned to him thereafter. The guardian chose the hospital where the recipient was treated and the agency also changed the CILA at the guardian's request. Additionally, the guardian sets the dates for all IPP meetings and has requested that all the IPPs are forwarded to an external advocacy agency for review.

Staff reported that the guardian has requested her son receive quarterly CT scans for sinus polyps. The physicians who have attended the recipient at VNS have questioned the need for so many scans and have recommended these scans at 6 month intervals instead, and this issue has caused ongoing problems between the physicians and the guardian. The staff feel, however, that the physicians are more than responsive to the guardian's requests and are willing to discuss any problems that impact her son's care. VNS staff state that they cannot continue to adjust staff at the request of the guardian due to the fact that she cannot agree with anyone who is assigned to her son. The recipient, in the meantime, has continued to succeed at VNS and progresses steadily through the various independent living programs.

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 the 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 QIDP (Qualified Intellectual Disability Professional) 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 QIDP is also responsible for the supervision of "all services specified in the services plan, whether provided by an employee of the licensed agency, consultants, or sub-contractors." (59 Ill. Admin. Code 115.220).

PROGRAM POLICY

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

"NFS 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." Policy also indicates, "Once the IPP document has been finalized it is the responsibility of the QSP to send a copy of the completed/finalized IPP along with the Individual Service Plan Form to the PAS agent and if applicable to the guardian."

CONCLUSION

The clinical record in this case provides documentation to indicate an ongoing verbal and written interchange between the staff at NFS and the guardian of the recipient. Additionally, the record provides evidence that the agency staff revised their IPP's, physician's orders, and their agency practices to accommodate the requests of the guardian. The record also demonstrates that the guardian was involved in approving all prescribed medication changes and although she may prefer more frequent CT tests, an attending physician has recommended a more limited amount. The HRA does not substantiate the complaint that the facility did not include the guardian in the resident's treatment planning and care.