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HUMAN RIGHTS AUTHORITY- CHICAGO REGION

REPORT 09-030-9015

ADA S. MCKINLEY COMMUNITY SERVICES, Inc.

Case summary: The HRA did not substantiate that that the agency did not include the guardian in the recipient's care and decision making.

INTRODUCTION

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving a complaint of possible rights violations at Ada S. McKinley Community Services Inc. (Ada S. McKinley). It was alleged that the agency did not follow Code procedures when it did not include the guardian in the recipient's care and decision making. If substantiated, this allegation would be a violation of the Mental Health and Developmental Disabilities Code (405 ILCS 5/100 et seq.) and the Illinois Administrative Code for Community Integrated Living Arrangements (59 Ill. Admin. Code 115.220).

Ada S. McKinley provides residential services for more than 35 persons with disabilities in seven Chicago area Community Integrated Living Arrangements (CILAs).

To review these complaints, the HRA conducted a site visit and interviewed the CILA Director and the recipient's Team Leader and Quality Mental Rehabilitation Professional (QMRP). The recipient's clinical records were reviewed with written guardian consent.

COMPLAINT SUMMARY

The complaint alleges that the provider did not communicate with the guardian regarding the recipient's care and did not inform the guardian that he had been hospitalized. The complaint alleges that the recipient had been gaining weight and the guardian had expressed concern about this fact at a staff meeting, but nothing was done about it. On 1/22/09 the recipient was taken to a hospital with a dangerously high blood level and the guardian believed he was diabetic and would be forced to go to a nursing home as a result. The complaint alleges that the guardian was not contacted by the facility, although she spoke with the doctor involved in the case as well as the case manager. The complaint also alleges that at one time the guardian was called by a dentist who stated he was in the operating room about to perform oral surgery on the recipient

and he needed to know if the recipient had ever had surgery. The attendant who was with the recipient did not know this information.

FINDINGS

The record shows that the recipient was admitted to the Ada S. McKinley CILA on 9/03/07. All admission forms, including but not limited to the CILA agreement, Clients Rights form, Department of Human Services Rights of Individuals document, Informed Consent for Psychotropic Medication form, and a CILA Contract, were signed by the recipient's guardian. The recipient's Individual Habilitation Plan (IHP) (to include the Service Plan and Behavior Plan) was signed by the recipient's guardian and the family contact names and contact information are recorded in the file. The annual update on the IHP is also included in the record and contains the guardian's signature. Facility representatives stated that the guardian was present in the home three times during the recipient's stay there- at the time of his original IHP development in October of 2007, at the time of the second IHP planning update in October of 2008 and June of 2008. Staff did not recall that the guardian had mentioned a concern about the recipient's weight and it is not recorded in the clinical record of the staffing. The Nursing Notes as well as the Medical History indicate that the recipient entered the CILA weighing 264 pounds and weighed 263 pounds at the time of his medical update in August, 2008. Staff indicated that the recipient wore the same size clothes throughout his stay at McKinley and did not appear to have gained a noticeable amount of weight, however it was noted in the IHP in 2007 and 2008 that the recipient was above his ideal weight of 171-209 pounds. No plan was initiated to address the recipient's weight.

Facility staff were interviewed about the inclusion of the guardian in the recipient's care and decision making. They stated that guardians are encouraged to have input into their ward's care at all times and are invited by mail one month in advance of staffing updates. If guardians are unable to attend staffings, then the IHP and all related forms are sent by certified mail to the guardian. Staff also noted that the guardian consent is necessary for all procedures that are completed for the recipient including routine medical, dental and hygiene care (routine dental, foot, nail, and vision care as well as hearing, speech, and language assessment), and for all medication, activities and outings. Staff also noted that routine medical procedures are generated from the IHP planning sessions, when the recipient is assessed by a doctor and then a plan is put in place to have each issue addressed. In this case the initial IHP in October of 2007 identified the need for dental examinations and the second IHP, completed in October 2008, indicated that the examinations and extractions had been completed.

Facility staff reported that when the recipient in this case was admitted to the facility his guardian had expressed a concern about his teeth because she believed he was having tooth pain (the recipient is non-verbal). The guardian requested that the facility find a dentist for the recipient, however, when he went to the dentist staff were told that he needed several extractions and would have to go to another dentist for this work. The guardian was contacted and told that the recipient would be seeing another dentist at a nearby hospital. The morning of the scheduled extractions the dentist informed the staff that the guardian would have to sign new consent forms and the guardian then came to the office to sign the necessary papers. Unfortunately, that day the recipient was tested and given blood work and he was rescheduled for his tooth extractions

for a later date. Staff stated that the guardian had requested to be present for the extractions, so the day that this was rescheduled (3/31/08) the Ada S. McKinley staff took the recipient, then picked up the guardian, and had the procedure completed. The procedure was routine and there were no complications afterwards. This was the only incidence of dental surgery for the recipient.

On 1/22/09 there is an entry in the Medical/Nursing Progress Notes that the recipient had been admitted to a hospital for "observation & dehydration, vomiting." Another entry on the same day states, "Talked to [recipient's] guardian....and told her what he was being admitted for @ 1:10 p.m. and his sister ... " On 1/23/09 there is an entry which states, "QMRP....travel to Trinity Hospital to observe client. Client was moved to rm 204 b1 due to high blood sugar. Client was given another IV due to self-removal of previous one. QMRP....contacted [guardian] via phone with current information @3:45 p.m. QMRP....spoke to assigned nurse....who stated he has been ordered insulin and will receive shots daily. His blood sugar was 572. Client's brotherand sister....came to visit upon QMRP ...leaving." The record shows that the staff from McKinley continued to contact the hospital for daily updates on the recipient.

On 2/2/09 at 1:09 p.m. there is an entry in the Medical/Nursing Progress Notes that state, "QMRPreceived a phone call from ...hospital social worker,....., and in conjunction with [guardian], they were looking for a nursing home to accommodate his diabetic status. QMRPasked if he would be released on insulin shots. At this time his sugar is unstable. He will be released to a nursing home. QMRP....gave the social worker the CSO [Community Service Options] name and phone number for the client to be pre-screened. Social worker will notify ASM [Ada S. McKinley] of any discharge planning."

On 2/2/09 there is another entry in the Medical/Nursing Progress Notes entered by the QMRP. It states, "QMRP....contactedhospital to discuss the progress of [recipient]. According to the nurse assigned [recipient] is no longer on insulin shots his sugar was 143 and he was doing fine. He is expected to be discharged from the hospital on today or tomorrow. However they could not give me a name of his discharge planner. QMRP....explained that he could not return to the CILA on insulin shots therefore this information is needed ASAP. Assigned nurse took down QMRP.... phone number and stated that the discharge planner would be contacted (sic) the group home." The guardian reported that she had discussed the above issue with the case manager but had not had any discussion with the CILA Director, who she had expected would contact her.

Facility representatives explained that it is their policy that residents cannot be on a regimen of injections while in the facility. They stated that they did not plan to discharge the recipient and were not aware that he would need injections indefinitely. They stated that when residents necessitate insulin injections they are usually sent to a nursing home to stabilize and then return to the group home when they are able to be continued on insulin pills. In this case, they stated that the recipient was removed from the hospital by his guardian before the Ada S. McKinley staff could make this determination. The record included a letter written to the facility staff from the guardian on 2/10/09 stating, "This letter is to inform you that [recipient] will not be returning to CILA #9 or any other Ada S. McKinley CILA. Once [recipient] is discharged from He will be going to another agency's CILA."

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).

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 developmental 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).

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 services plan, whether provided by an employee of the licensed agency, consultants, or sub-contractors." (59 Ill. Admin. Code 115.220).

AGENCY POLICY

Ada S. McKinley policy states, "It is the policy of the Ada S. McKinley Community Services, Inc. to assure that no client shall be deprived of any rights, benefits, or privileges guaranteed by law based on their status as a client. In addition to having all the rights enumerated in Chapter 2 of the Mental Health Code of Illinois, the Confidentiality Act, 59 Ill Adm. Code part 115, and the Americans with Disabilities Act; CILA residents shall also have the right to:

- A. Be free from the use of seclusion,
- B. Be free from abuse and neglect in any form,
- C. Be free to contact the Guardianship and Advocacy Commission, Protection and Advocacy Inc., the Ada S. McKinley Community Services Inc. Residential Services Division Human Rights Committees, the Executive Director of Ada S. McKinley, or the Department of Human Services and receive assistance from staff in contacting any of the above.
- D. To receive services deemed necessary by the client, client's guardian, or client's CST until the resident withdraws voluntarily or is discharged per Ada S. McKinley Community services, Inc. policy..."

Agency policy also guarantees recipients the right to refuse treatment: "You or your guardian (on your behalf) have the right to refuse services, including medication". Additionally, "Except in an emergency, no medical or dental services will be provided to you without the informed consent of you or your guardian. You have the right to purchase and use the services of private physicians and other professionals of your choice."

Ada S. McKinley policy regarding the IHP development states that the IHP "will be prepared jointly by the residential staff and the staff providing day treatment services to the resident to assure that a single comprehensive habilitation plan is developed. The Individual Habilitation Team is mandated to consist, at a minimum, of "the QMRP, direct care staff from the day and residential program, and the case coordinator/ISC. Consultants will participate on an as needed basis, and every effort will be made to involve the client/guardian."

CONCLUSION

The complaint in this case alleged that the facility did not include the guardian in the recipient's care and decision making, specifically, the facility did not notify the guardian of the recipient's hospitalization and did not provide the recipient with adequate care when he underwent dental surgery. The record includes the recipient's original IHP and subsequent update, and both are signed by the guardian. Additionally, there is documentation in the file to indicate that the guardian was present for the oral surgery of her ward, and was notified of the ward's hospitalization. The guardian stated that she had been concerned about her ward's weight gain and its results, however this is not noted in the clinical record, and the nursing notes indicate a relatively minor weight gain for the recipient during the time he was a resident at Ada S. McKinley. Throughout the recipient's stay at the facility the QMRP assumed the required duty to supervise all services in the services plan, and this included the contact with the guardian

regarding the ward's hospitalization, as recorded in the clinical file. The HRA does not substantiate the complaint that the agency did not follow Code procedures when it did not include the guardian in the recipient's care and decision making.