Springfield Regional Human Rights Authority
Report of Findings
Case #18-050-9014
Help at Home

The Springfield Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegation concerning Community Integrated Living Arrangement (CILA) services provided by Help at Home:

The provider violated protections under privacy and property regulations.

If found substantiated, the allegation represents violations of the Mental Health and Developmental Disabilities Code (405 ILCS 5/1-100 et seq.) and CILA regulations (59 Ill. Admin. Code 115, 116). To investigate the allegation, an HRA team met with and interviewed CILA administrative staff, reviewed a service recipient's record, with appropriate authorization, and examined pertinent provider policies. In addition, provider representatives, including a nurse directly involved with the service recipient, attended a meeting of the HRA and provided case related information.

Help at Home is based in Springfield where it provides CILA services to approximately 22 individuals in 8 different settings with plans to open additional CILA sites in other locations within the state. All Springfield CILA sites are leased. CILA service recipients are primarily individuals who have an intellectual and/or developmental disability.

According to the complaint, a program nurse arrived at the recipient's home unannounced and rummaged through his dresser drawers and nightstand without permission and explanation. The complaint further alleges that the nurse often appears without prior notice.

Findings

Five agency representatives attended the May 29, 2018 meeting of the Springfield HRA and reported that the consumer is physically and medically fragile. Any references to "rifling through" the recipient's belongings were done as part of quality assurance measures and to protect the recipient who puts his health and safety at risk.

In a follow-up site visit between the agency director and director of nursing, the HRA team inquired further about the actions on the day in question, the complaint and provider policies and practices.

According to the agency, the recipient's CILA in this case was its first CILA location in the Springfield area in April 2017 for individuals with developmental disabilities. The recipient has his own CILA site with no other service recipients served at the site; all other CILA locations in Springfield house 3 residents per site. The recipient's single CILA site provides 24 hours of CILA services per day, 7 days per week, via shifts of direct care workers and a nurse, when needed. The recipient who has a mild intellectual disability, uses a wheelchair and has multiple health issues. The agency provides nursing, personal care, meal preparation and housecleaning services. Staff stated that the recipient would frequently refuse treatment and medication, would not communicate health information to the agency and would not welcome the nurse into his home except when his

situation became dire. The agency stated that it attempted to conduct quality assurance measures but the recipient was not cooperative. The agency also attempted to obtain information regarding the recipient's urology care and needs without success even though the recipient lacked the ability to pass his own medications. Although the recipient was reluctant to cooperate, the nurse identified in the complaint had a better rapport than most staff per agency report. At the time of the incident, the nurse was attempting to review a Help at Home binder kept for every service recipient to clarify and update treatment. It was at this time that a bag of items that included medical paperwork and an injection were found sitting in the vicinity of the binder. The agency further stated that the recipient allowed the nurse to go through the items and paperwork in his presence and he agreed to allow the nurse to take the paperwork with her so that she could make copies and then return the originals. The agency stated that it conducted no searches of the resident's house and only removed the paperwork temporarily to secure copies and with the recipient's permission. The agency contends that the complaint made to the HRA coincides with the agency's recent efforts to pursue the recipient's involuntary discharge due to his unsafe and non-compliant behaviors such as drug use, prostitutes visiting his residence, medication non-compliance, not using his air conditioning, etc. The involuntary discharge notice was issued to the recipient in February 2018; he appealed but his appeal was denied. Prior to involuntary discharge proceedings, the agency stated that it had attempted several meetings to resolve related issues including meetings with the service coordination agency, the state department of human services, the support services team and the landlord. Staff reported that at the time of the HRA's site visit the recipient had been in the hospital for some time due to medical issues and was not doing well.

The agency reported that the nurse and all staff always knock and announce themselves prior to entering a CILA residence, including the residence of the recipient in this case. Staff are to seek permission before entering individual bedrooms. If a recipient is not home, staff would not enter a service recipient's room. The agency has a rights statement that residents sign at the time of their annual reviews. The agency maintains a Human Rights Committee that is comprised of community members, family members and service recipients. The agency stated that the recipient in this case did not have a behavior plan nor was he issued any rights restrictions; his service plan/discovery tool indicated goals to address medical needs, to keep his residence at a temperature of 78 degrees or lower and to turn in any bills so that they could be paid. The agency also maintains a grievance policy which was not pursued by the recipient in this case. The agency has no property restriction policy.

Record Review

The allegation was reported to the HRA on 03-16-18. The HRA found no documentation about an agency nurse reviewing/removing paperwork or conducting a quality assurance review in the nursing progress notes or in any other record information initially provided to the HRA prior to the site visit. The documentation sent to the HRA closest to the 03-16-18 date of reporting the allegation to the HRA was documentation of a medical visit summary dated 03-15-18 in which the recipient had a follow-up visit with a urologist. The urologist concluded the visit with a plan to address erectile dysfunction, per the recipient's request, and ordered the medication, Trimix, in injection form. A note was added to the visit summary and signed, but not dated, by the Help at Home nurse stating: "unable to have injection in home." There was no other documentation in the nursing or other notes regarding Trimix or the recipient's desire to have erectile dysfunction addressed. Instead, the recipient's diagnoses and medications were listed as mobility issues,

Edema, Gastrointestinal (GI) Issues, Hypertension, Lung Disease and skin irritations. The next nursing progress notes provided to the HRA prior to the site visit were dated 03-22-18 in which the nurse and director of nursing accompanied the recipient to a physician's appointment concerning GI bleeding; the physician recommended that the recipient go to the hospital for further evaluations to which the recipient refused. The recipient signed a statement of his refusing medical advice. A subsequent nursing progress note on the same page as the 03-22-18 note but dated 03-23-18 stated that the nurse contacted the recipient's power of attorney agent to update her on his wishes to refuse the hospital visit.

At the HRA's site visit, the agency provided the HRA team with an additional 1 ½ page of nursing progress notes dated 03-22-18 that were separate from the 03-22 to 03-23-18 notes provided in advance to the HRA. The HRA was informed that the agency attorney had reviewed the prior notes sent to the HRA and may not have included these additional 03-22-18. The additional 03-22-18 notes provided at the site visit documented that the nurse had received a call from direct care staff that morning with reports of blood in recipient's stool and urine. These notes further stated that when the nurse arrived, there were representatives from the service coordination agency present and they all were discussing the recipient's medical needs, including items "recently" removed from the CILA site such as nasal spray, icy hot topical spray, both of which were not on the MAR, along with a plastic syringe holder "mixed in" with the items. The nurse documented in these notes that the removal of these items was part of quality assurance measures. The nurse further documented that the quality assurance process was explained, that the recipient had been present and had approved of the removal of items from his home, that medical concerns continue and that the potential need for a nursing home was discussed. The nurse also documented the service coordination's discussion with the recipient about his "jumping to the negative" with regard to Help at Home." There was nothing in these separate 03-22-18 nursing progress notes that documented when the removal of items occurred nor any reference to the Trimix or the urology appointment.

A nursing assessment completed on 04-19-18 mentions a urology appointment for "ED" and that the last PSA (prostate levels) dated 03-20-18 were within normal limits. There was no mention of the Trimix in the nursing assessment. The assessment does document that the recipient refused a stool softener and a flu shot.

An Individual Service Plan (ISP) dated 06-15-17 indicated primary diagnoses of Major Depressive Disorder, a Mild Intellectual Disability and Cardio Obstructive Pulmonary Disease. The recipient was listed as a team member for the plan and signed that he reviewed and approved the plan. The plan documented his refusals of treatment and his telling "untruths" about staff. Other than service refusals, there is no documentation of other behaviors that put him at risk. The plan lists goals of increasing community integration by participating in community events, maintaining a home temperature of 78 degrees or lower, providing his representative payee with bills every week, and using his breathing machine daily. A history of frequent hospitalizations was listed and a medication assessment stated that the recipient is not independent in medications but is appropriate for medication training. The plan's risk assessment listed risks associated with medication administration, wheelchair use, toileting/transferring, transportation, financial exploitation and

employment loss. The plan concludes with statements that "Help At Home were not made aware of the extent of his medical concerns and his noncompliance upon his admission."

The HRA concluded its record review by examining the agency Disclosure Statement which states that Help at Home follows laws regarding the sharing of information, that the consumer can limit the information shared, that the consumer has a right to review/copy his own information at the agency and the consumer has a right to review a list of entities to which the agency shared consumer information. The consumer signed the disclosure on 04-19-17. Also on 04-19-17, the consumer signed confirmation statements that he received rights information, the grievance policy and information about how to access agency policies.

Agency Policies

According to the agency's "Policy on Coordination of Health Care Needs," all consumers are to be informed of their medical, developmental and behavioral status as stated in the ISP. The agency is to follow all professional orders but the policy also acknowledges the consumer's right to refuse treatment. Agency staff are to coordinate all care and recommendations, document all physician orders and medical appointments, and then, maintain/organize all health care related information in the consumer's file.

The Rights of Consumer policy lists the many rights contained in the agency's Bill of Rights which includes, but is not limited to, rights associated with respect, dignity, medical care, private access to friends and communications, the same rights as any other person, the right to due process and a human rights committee review when there is a right restriction, the right to control services to the degree possible, "within the authorized plan," and the right to file grievances. There are no rights statements about the right to refuse treatment or rights associated with personal belongings; and one statement includes the following as a "right:" "To be evaluated, treated or receive residential habilitation in the most restrictive environment." The HRA notes that the client signed the Department of Human Services Rights statement (IL462-1201) which also does not discuss the right to refuse or personal property rights.

The agency grievance process includes a timeline for responses, using a chain of command, that concludes at the agency's board of directors at which a hearing is held. An appeal process for service denial, reduction or termination begins with a notice and concludes with a hearing officer with timelines identified for each stage of the process.

A policy on the Human Rights Committee discusses the maintenance of committee records and company representation on the committee. There is also mention of collaborating with the state's regional human rights "committee."

Mandates

The Mental Health and Developmental Disabilities Code (405 ILCS 5) requires in Section 5/2-102, that service recipients be provided with adequate and humane care and services in the least restrictive environment consistent with an ISP with the participation of the service recipient whenever possible. Section 5/2-104 guarantees the right to possess and use personal property unless certain classes of property are restricted to prevent harm on condition that the restriction of that class of items be given to all recipient at admission. Otherwise, property can only be restricted

to protect the recipient or others from harm. If such restrictions occur, Section 5/2-201 dictates that the recipient be given notice of the restriction, the reason for the restriction, and information about the ability to notice others, including advocacy agencies; the restriction and rationale are to be documented in the recipient's record.

CILA regulations (59 Ill. Admin. Code 115) require that services be individualized to the person with input by the service recipient and recognizing recipients as "...persons with basic human needs, aspirations, desires and feelings and are citizens of a community with all rights, privileges, opportunities and responsibilities accorded other citizens. Only secondarily are they individuals who have a disability (59 Ill. Admin. Code 115.200)." Section 115.230 requires CILAs to address needs through an interdisciplinary process. Section 115.250 addresses rights protections, including protecting rights guaranteed under the Mental Health and Developmental Disabilities Code. This Section also stipulates that individuals are not to be denied/suspended or terminated from services for exercising their rights. Section 115.320 requires the establishment of a committee review process for human rights issues as well as a quality assurance plan to evaluate and resolve identified problems.

CILA regulations that govern medication administration (59 Ill. Admin. Code 116) stipulate in Section 116.60 that if a recipient is found not able to self-administer medication, then a plan to teach self-administration is to be established. Section 116.50 states that non-licensed staff are not to administer injections and Section 116.80 requires that all medication be kept in locked storage.

Conclusion

The complaint alleged that the agency violated privacy and personal property protections when a nurse entered a CILA recipient's site, without permission and rifled through the recipient's personal belongings. Staff reported that, during a quality assurance visit, a nurse removed and returned medical paperwork for copying purposes. Documentation provided at the time of the HRA site visit more specifically mentioned the removal of over-the-counter medication, done with recipient consent, and as part of quality assurance reviews. The HRA notes there was no documented restriction notice provided to the recipient when items were removed. CILA Rule 116 requires that all medication be kept in locked storage. Because there was no clear proof that the nurse entered the residence and examined/removed the items without permission and because CILA rules require that medication for a consumer who cannot self-administer medication be locked up, the HRA does not substantiate a rights violation. However, the HRA has several concerns and suggestions it would like to stress.

1. CILA rules require providers to educate individuals unable to self-administer medication; however, the HRA found no related goals for this recipient who was determined not to be able to self-administer medications. The HRA strongly suggests that such goals be added for similar service recipients.

2. There were no ISP goals or committee reviews related to medication/treatment non-compliance or any of the safety/behavioral concerns that the agency reported to the HRA as justification for pursuing involuntary discharge. The HRA strongly suggests that the agency pursue treatment goals for behaviors that can lead to service termination consistent

with Mental Health Code provisions (5/2-102) and the agency's Coordination of Care policy and review the recipient's situation with the human rights and behavior management committees.

3. It appears that the removal of items occurred sometime before the 03-22-18 nursing progress note in which the removal of items was discussed in the presence of the service coordination agency. However, there was no documentation, incident report or nurse progress notes specific related to the day this event occurred. The HRA strongly urges the agency to document such removals in a timely manner, including what was specifically removed and any related discussion on the day of the removal, perhaps on an incident form. And, if at any time, items removed from a service recipient include personal property, a human rights committee review must be conducted and a restriction notice must be issued to the recipient consistent with the Mental Health Code Section 5/2-201.

4. Expand the Bill of Rights to include the right to refuse (405 ILCS 5/2-107), the right to possess personal property except as allowed in the Mental Health Code and CILA regulations (405 ILCS 5/2-104 and 59 Ill Admin. Code 116.80), and the use of restriction notices when rights are restricted (405 ILCS 5/2-201). Review/revise the right "To be evaluated, treated or receive residential habilitation in the most restrictive environment," which is inconsistent with the Code's right to least restrictive treatment.

5. There was a great deal of reference to what the agency considered to be "quality assurance" checks but the HRA found no checklists, forms or policy related to quality assurance measures. Ensure that quality assurance checks are documented. Consider the use of a standardized form, to clarify for staff and recipients alike what is being and can be "checked," how often, etc. Standardizing quality assurance efforts, when possible, helps to assure that the quality assurance applies to service provision/staff and that such checks are not an attempt to single out recipients in any way. Educate recipients and staff about the quality assurance process and ensure that such checks are respectful of recipient privacy and rights. Seek and document recipient permissions to do checks if they involve recipient rooms or personal property. Include quality assurance checks regarding whether or not staff are knocking on recipient doors and gaining permission to enter.

6. When the HRA requests record documentation pertaining to an issue in advance of its site visit, ensure that all documentation is provided as authorized by the resident and/or guardian.

7. Finally, the HRA is concerned about what appears to be a chain of events that may have been the underlying rights concern. According to a medical visit summary of a visit that occurred a day before the HRA received the allegation, the recipient specifically talked to his urologist about and received medication for erectile dysfunction. The nurse documented on the medical visit form that injections were not allowed in the home. The nurse's statement that injections are not allowed in the home does not appear consistent with CILA regulations/allowances. And, other than a brief nursing assessment note about "ED" and the recipient's prostate labs, there was no other documentation about the recipient's erectile dysfunction or his desire to take specific medication for it. The HRA

reminds the agency that persons with disabilities maintain their constitutional rights, including sexual expression rights, regardless of being a recipient of CILA services. If there were concerns about this medication, injections or even the recipient's sexual expression, then an effort to address those concerns through the treatment planning process should have been attempted and documented by the agency while also recognizing the recipient's right to self-direct his treatment and interests.