



FOR IMMEDIATE RELEASE

SPRINGFIELD REGIONAL HUMAN RIGHTS AUTHORITY

REPORT OF FINDINGS

HRA CASE # 14-050-9011

SPRINGFIELD ARC, INC.

INTRODUCTION

The Springfield Regional Human Rights Authority (HRA) has completed its investigation of a complaint with Springfield ARC, Inc. (SPARC) a community provider of services for persons with developmental disabilities in Springfield, including Community Integrated Living Arrangement (CILA) services for about 100 persons. The allegation states that the agency is not adhering to the Code when it initiates discharge of a consumer because of medical issues.

If substantiated, the allegations would be a violation of the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102 a.), the Illinois Administrative Code (59 Ill. Admin. Code 115) and SPARC policies.

Specifically, the complaint states that SPARC is pursuing discharge of consumer from CILA services during a period in which the consumer is experiencing health issues that require surgery.

METHODOLOGY

To investigate this complaint, an HRA team visited the SPARC's administrative headquarters and interviewed the agency's Executive Director and the Resident Director (Associate). With consent, the team also reviewed the records of a consumer. The HRA Coordinator shared correspondence with the consumer's guardian.

FINDINGS

The guardian stated that the consumer needs and qualifies for SPARC CILA services and that the agency's attempt to discharge the consumer from such services may cause a life threatening situation. According to the guardian, the agency has made it clear that it does not want to serve the consumer and this action to discharge is taking place while

the consumer is dealing with serious health issues. The guardian concluded that the consumer was living in the least restrictive setting and that SPARC's attempt to stop services is against CILA rules. The consumer and guardian are grieving the discharge notice.

The Executive Director explained that the consumer resides in a private apartment and has received intermittent CILA services from the agency for the past six years. The Executive Director indicated that the consumer is scheduled to receive five hours of support per week; however, the support that the agency is contracted to provide and the support the consumer and his family demand are not the same. According to the Executive Director, the consumer demands that SPARC only arrive on Wednesday afternoons to provide transportation to shopping. The Director also stated that the consumer's assessed ability to self medicate does not meet the criteria set forth in the Department of Human Service's guidelines; however, he and the guardian continue to insist that the consumer self-medicate. The consumer refuses to allow SPARC staff to assist with medication education and administration and other contracted services.

According to the Executive Director, the consumer has congestive heart failure, is on oxygen and smokes cigarettes. SPARC is concerned for the consumer's health and safety; and, as part of the contractual services, feels it is the agency's responsibility to provide meaningful services, but the consumer utilizes CILA services only as a taxi service.

The Executive Director explained that the agency is actively attempting to discharge the consumer from services because of moral and legal obligations it must observe while servicing program participants. In this case, the agency feels the consumer is misusing the program and that he is in serious danger of self harm because of fragile health and lifestyle choices.

The Executive Director stated that the guardian appealed the discharge and the Department of Human Services upheld that appeal.

The Director stated that the consumer continues to be supported by SPARC although a second discharge letter was sent on January 8, 2014. SPARC has not received notification from the Department as to their finding regarding that discharge. The guardian appealed the second discharge, as he did the first. The Director said that the agency continues to believe that the consumer's health and safety are in imminent danger, in part because he is currently not be adhering to his medication course and the required blood work and other follow-up medical treatment that is needed. According to the Director, the consumer's guardian supports the consumer's non-compliance regarding the medications and he continues to prohibit the agency from operating within the Medicaid Waiver and Rule 116.

DOCUMENTATION

Self Administration of Medication Assessment dated October 9, 2013 states:

...Person removes the correct medication from the medication supply for that particular administration time: U [unable]...

...Person removes the correct amount of the correct medication from the medication supply for that particular administration time: U [unable]...

...Person takes medication in the prescribed way: U [unable]...

...person returns medication to the container [supply] storage unit: U [unable]...

If all items are answered 'Yes' proceed...If 'No; to one or more. When a client is 'not independent' qualified persons must administer medications and supervise any self-medication training programs.

The Semi-Annual Program Review dated August 8, 2013 states;

...Concerns/Open Discussion: there were many concerns brought forth by the SPARC team in regards to [the consumer]'s return home to his apartment given his rather fragile medial state and use of oxygen. One very good thing [the consumer] had done while in rehab was quit smoking cigarettes. This of course greatly reduces the chance of a fire or explosion with his oxygen concentrator. SPARC communicated to the team that ideally SPARC would like to see [the consumer] supported in a 24-hour CILA environment due to his increased medical needs [this idea was supported and even preferred by [the consumer]'s father and guardian from May 2013 - July 2013. [The consumer] adamantly refused this idea, having told his father that he would 'run away' if placed in such a situation."

The report discusses that the consumer has cell phone, home phone and "life alert" system.

STATUTES AND RULES

The following rights are guaranteed under the Mental Health and Developmental Disabilities Code:

A recipient of services shall be provided with adequate and humane care and services 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, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient. (405 ILCS 5/2-102 a).

ADMINISTRATIVE CODE

Section 115.220 states:

a) The CST [community support team] shall consist of the QMRP or QMHP, as indicated by the individual's primary disability, the individual, the individual's guardian or parent (unless the individual is his or her own guardian and chooses not to have his or her parent involved, or if the individual has a guardian and the guardian chooses not to involve the individual's parent), providers of services to the individual from outside the licensed CILA provider agency, and persons providing direct services in the community.... The CST shall:

5) Be available to respond to an individual's needs on a 24-hour basis.

c) The CST shall be directly responsible for....

3) Advocating on behalf of individuals;

4) Providing informational, educational and advocacy services to family members....

Section 115.230 states:

Agencies licensed to certify CILAs shall comprehensively address the needs of individuals through an interdisciplinary process.

(a) Through the interdisciplinary process, the CST shall be responsible for preparing, revising, documenting and implementing a single individual integrated services plan for each individual....

CILA

State of Illinois: Medicaid Home and Community-Based Services Waivers for Individuals with Developmental Disabilities Provider Manual states....

...The difference between traditional care and shared living models is shift employees routinely share supervision, care and training responsibilities with the host family caregivers in the shared living model.

d. Intermittent CILA serves individuals whose service plan documents that they do not require 24-hour on-site staff presence

and documents the situations in which individuals may safely be away from direct staff supervision. Intermittent Residential services in apartments or family homes have staff available on-call 24-hours per day. On-site shift staff are available to provide both scheduled and unscheduled supports and services as needed by the participants served and as specified in each participant's service plan....

Community-Integrated Living Arrangement (CILA) Individual Rate Determination Model addresses terminations without the individual's consent.

1. A community agency wishes to terminate CILA services to an individual without the individual's (or the guardian's) consent.

2. The community agency forwards a termination notice to the individual (or their guardian) with a projected date of termination and the reason for the termination, as well as instructions as to the individual's right to appeal to the termination of CILA services, including the process and time frames for an appeal. The notice must provide at least 30 days in advance of the projected date of termination.

3. If the individual does not exercise their right to appeal the termination:

The provider agency confirms the discharge date with the individual or their guardian.

The community agency completes the paper OBRA 8A and forwards to the PAS/ISC agency.

PAS/ISC agency signs the paper OBRA 8A and forwards it to the Network Facilitator.

The Network Facilitator confirms the appropriateness of the termination and, upon doing so, forwards the paper OBRA 8A and the attached documentation to the CILA Rates Unit.

The CILA Rates Unit prepares a "Recognition of Termination" memo and mails it to the community agency, PAS/ISC, and the Network Facilitator, OCAPS, and places a copy in the individual's file.

The CILA Rates Unit notes the termination on the CILA Vacancy Report, or moves the CILA capacity based on the direction of the Network Facilitator.

4. If the individual does exercise their right to appeal termination of CILA services, there are three levels of termination appeal:

Community Agency Internal Appeal Process (Executive Director);

Department of Human Services (Informal Review);

Department of Public Aid (Bureau of Administrative Appeals);

- An individual may not be terminated from CILA services until all appeals are exhausted, or the individual does not exercise their appeal right, or the individual becomes willing to terminate CILA services.
5. Given a final decision, the CILA Rates Unit and the Office of Clinical, Administrative, and Program Support (OCAPS) confirm that the individual has either chosen not to exercise their appeal rights, or that all appeal rights have been exhausted.
 6. Given confirmation, OCAPS terminates the individual from the CILA payment system. OCAPS calculates the payment adjustment due to, or owed by, the community agency from the termination date

CONCLUSION

The Mental Health and Developmental Disabilities Code states that a recipient of services shall be provided with adequate and humane care and services in the least restrictive environment, pursuant to an individual services plan.

According to the documentation, the consumer may not meet the requirements to continue intermittent services and there is evidence that the consumer would not accept CILA residential services. The HRA notes that SPARC has adhered to rules regarding discharge and allowing the appeal process. Recently, the Department upheld the consumer's and guardian's desire for independent living.

The allegation that the agency violated a consumer's rights when pursuing discharge is not substantiated.