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East Central Regional Human Rights Authority
CCAR Industries
Report of Findings
Case 17-060-9020

Case summary: The HRA did not substantiate the allegations that the provider denied consumer access to psychotropic medication. The HRA did not substantiate the allegations that the provider required the consumer to use "bubble packs" for medication despite the consumer's statement that using this form of medication triggers PTSD. The HRA did not substantiate the allegations that the consumer moved closer to the provider and the provider is no longer making home visits. Consumer is being asked to come to the provider's office due to proximity. Since all allegations are unsubstantiated no provider response is required.

The East Central Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission voted to pursue an investigation of CCAR Industries in Charleston after receiving the following complaints of possible rights violations:

Complaints:

1. **Provider denied consumer access to psychotropic medication.**
2. **Provider requiring consumer to use "bubble packs" for medication despite the consumer's statement that using this form of medication triggers PTSD.**
3. **Consumer moved closer to the provider and the provider is no longer making home visits. Consumer is being asked to come to the provider's office due to proximity.**

If the allegations are substantiated, they would violate protections under the Mental Health and Disabilities Code (405 Ill. Comp. Stat. Ann. 5/2-102) and the Illinois Administrative Code (59 Ill. Admin. Code 115.240 and 115.220).

Investigation

The HRA proceeded with the investigation after having received written authorization from the consumer. To pursue the matter, the HRA visited the facility and the program representatives were interviewed. Relevant practices, policies and sections of the consumer's record were reviewed.

Per the CCAR website, "CCAR Industries is a not-for-profit 501(c)(3) organization that was founded by a local parents' group in 1969. Our mission is to provide community-based services and supports that enhance the quality of life of East Central Illinois citizens with developmental disabilities and/or other functional limitations throughout their lifespan."

CCAR Interviews:

On September 7, 2017 at 1:30pm, the HRA met with CCAR staff members, including: the CCAR Program Director, the CCAR Case Manager, and the CCAR Registered Nurse. The meeting occurred at 1530 Lincoln, Charleston, IL. in the CCAR offices. The meeting began with introductions, a review of HRA procedures, and a review of the allegations being addressed in this investigation.

The staff provided some general information about CCAR. CCAR provides services to individuals and families in multiple counties from birth to death. Services include, but are not limited to, residential and vocational services, a children's group home, several intermittent and family Community Integrated Living Arrangement (CILA) homes, respite programing, birth through 2 therapy and home based supports. CCAR states they serve approximately 375 consumers a year and have anywhere from 150 to 200 staff members (full and part time). Rule 50 (59 Ill. Admin. Code 50) training regarding abuse/neglect is provided to all staff upon hiring. After onboarding, all staff receive training on any updates that come out to Rule 50. All staff receive yearly Crisis Prevention Institute (CPI) and Cardio-pulmonary resuscitation (CPR) training. Qualified Intellectual Disability Professionals (Qs) have an additional 120 hours of training when hired and are required to successfully complete another 12 hours a year for their position. Human rights training is provided to both staff and consumers during the initial "handbook training" and additionally reviewed at each service planning meeting (generally twice a year). CCAR staff report that all staff and consumers are aware of the CCAR grievance procedures. Detailed grievance procedures are reviewed in the initial meetings and are located in the client handbook. Grievance information and state agency contact information are clearly posted on site.

The consumer named in this report is provided services through the Intermittent CILA program. He receives up to 15 hours per week of supportive services such as life skills, transportation, and medication management while residing in his own apartment. In addition, he has some crossover services with other community agencies for life skill assistance, money management, and employment assistance.

CCAR staff state that all consumers requiring medication management abide by the same monthly protocol. Prescription medication is delivered to CCAR from a mail order pharmaceutical company around the third week of every month. A CCAR staff Registered Nurse (RN) verifies the delivery purchase order, sorts the prescription medications, and validates that the consumers all have the correct pills and dosages. Each consumer receives exactly the number of doses required for the month (for example, if there are 28 days in the month the consumer gets 28 days of medications). Most consumers receive their medication in bubble packs with dates and times on them for tracking purposes; however, the consumer in this case has requested not to receive medication in bubble packs so his prescriptions come in bottles. If an error occurs in the mail order, the RN contacts the pharmaceutical company and corrections are made. In addition, the RN has the ability to place orders with a local pharmacy to assist as needed with new and emergency medications. The prescription medication is delivered to the consumer's residence differently depending on the program. For Intermittent CILA consumers, once prepared, the RN gives the medication to the staff to be delivered at the next home visit (usually within 24 hours).

The medication management program is completely voluntary and consumers can opt out of using this service at any time. CCAR reports that they changed pharmaceutical providers in June 2017. According to the staff interviewed, the change in companies did cause some problems but those problems were rectified and no prescription medication delays occurred for any of their consumers.

The change in pharmaceutical providers did result in the consumer receiving his monthly medication in bubble packs. CCAR is aware that the consumer does not want his medication in bubble packaging because it causes the consumer to experience PTSD symptoms. CCAR stated that returning the medication could have caused a delay in the start of his monthly dosage, therefore, the medication was delivered to the consumer in the bubble packaging that month. Upon receiving the medication, the consumer and the case manager opened the bubble packages and sorted the medication into the bottles together so that they were in the bottles. The consumer voiced that he was upset about receiving his June medications in bubble packaging and the correction was made so that subsequent medications are filled in bottles. Both CCAR and the consumer confirm that July and August medications came in the appropriate containers.

In addition to the medication coming in bubble packs, CCAR staff confirm that the consumer has had one other issue with medication in the last 6 months. One (non-psychotropic) medication was prescribed by a physician and filled by the consumer at a local pharmacy. This new medication was filled for 30 days and therefore could not be filled with the other medications on the first of the month (due to insurance billing issues). This added medication had to be filled separately by the consumer for a few months before it could be approved by insurance and added to the other monthly medications.

The consumer self-administers all of his own medications. He has a great deal of anxiety about running out of medication and contacts staff regularly about this concern. CCAR staff check the consumer's 'weekly pill reminder' box at many visits each month and there is no indication that the consumer has ever gone without any of his prescribed medications. The HRA suggested that a monthly pill reminder box may be more beneficial so that the consumer can see his medication is full through the end of the month. This would allow for the consumer to feel less anxious about not having enough medication to get him through to the end of the month and CCAR staff could easily view that the medication is filled/available through the end of the month without counting the pills out regularly.

CCAR does not have any concerns about the consumer's medication. Staff report the consumer has no medication related tasks in his service plan because he self-administers all of his own medication and there is no indication that the consumer does not take his medication or misuses any medication. In addition, CCAR reports that they have not had any medication complaints or grievances from the consumer. The consumer calls the CCAR staff several times per day and has expressed a great deal of anxiety about running out of medication but has never complained to CCAR about CCAR's medication program not working for him.

CCAR states that they do not require that consumers come into the CCAR office in order to receive services. If a consumer has an appointment in the office the CCAR staff provide transportation. Staff report that there may have been an incident with the previous caseworker

where the consumer called and requested assistance and was told to come into the office. However, the consumer has CCAR services in his home every other day (if not daily) and there is no reason to request for him to come to the office. The staff report that since the consumer lives close to CCAR it is convenient for staff to go over to his apartment and assist him more regularly.

CCAR Policy/Records Reviews:

CCAR provided the HRA with the following records: CCAR Industries' Client and Family Support Family CILA & Intermittent CILA Consumer Handbook (including the Complaint/Grievance Procedure on pg 18), the consumer's signed Summary of Individual Rights dated 8/13/15 and 9/7/16, Developmental Training Handbook 2015 (including the bus rules, special transportation arrangements, Summary of Individual Rights, Human Rights Policy, and CCAR Industries Grievance Procedure) with the consumer's signature dated 9/11/16, policy for 24 hour CILA medication, Procedure for Medication Storage, Transportation, and Disposal, and consumer case records dated March 2017 through September 2017.

CCAR's policies and procedures appear to support that consumer rights and responsibilities are outlined, including grievance procedures and contact information for violations if the internal grievance procedures are unsuccessful. The documentation provided demonstrates that the consumer is aware of his rights and responsibilities and has the ability to act on his own behalf if he feels that his rights are being violated.

CCAR provided the HRA with a Medication Administration Policy. This policy notes that it applies to all 24 hour residential homes and day programs. In the first paragraph of the policy CCAR highlighted that "assistance may also be provided to individuals in the Intermittent CILA settings in the areas of education, advocacy, and procurement of medications". Page 2 of the Medication Administration Policy states that "The Individual Service Plans (ISP) for CILA enrollees receiving medication administration services shall include any medication administration training required to ensure safety based upon a review of medication administration incidents, any contributing factors, and individual specific corrective action".

The consumer has been receiving services through CCAR since 8/13/15. He has a principal diagnosis of Mild Intellectual Disability. There is also record of Bipolar Disorder, NOS, Hypothyroidism, unspecified, and Psychotic Disorder, NOS.

There is no documentation relating to the consumer being denied psychotropic medication. The consumer has a Service Plan Goal titled "monitor medication". The 3/7/17 Service Plan review states that 'Support was provided. Criteria will be continued.' Case notes related to the consumer's medication monitoring record that the consumer was regularly taking medication and met the criteria for medication monitoring 35/35 times. Case note documentation states that staff do receive calls from the consumer with concerns about the medication 'running out', however, follow up home visits indicate that the medication bottles are full and there is no missing medication. A case note dated 5/3/17 confirms CCAR's report that the consumer and his physician had some questions about a (non-psychotropic) medication and that the consumer wanted to verify the medication with a pharmacy before taking it. It was confirmed to be correct

and the physician notified the consumer to continue taking the medication. A case note on 5/24/17 confirms that the consumer told the case worker that he was out of a medication. The case manager notes that she attempted to locate extra medication by contacting the RN but they were unable to provide him with the medication. On that date, the consumer confirmed that he did in fact have enough medication and the call was made in error.

There is no documentation that the consumer is being required to receive medication through bubble packs. There was no case documentation related to medication packaging found in the documents provided to the HRA.

There is no documentation to support that the consumer was told to come to the office in order to receive services.

Mandates Reviewed:

59 Ill. Admin. Code 115.240

j) Individuals who are able to independently self-administer medications will have access to their medications

405 ILCS 5/2-102

§ 2-102. (a) 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. The facility shall advise the recipient of his or her right to designate a family member or other individual to participate in the formulation and review of the treatment plan. In determining whether care and services are being provided in the least restrictive environment, the facility shall consider the views of the recipient, if any, concerning the treatment being provided. The recipient's preferences regarding emergency interventions under subsection (d) of Section 2-200 shall be noted in the recipient's treatment plan

59 Ill. Admin. Code 115.220

c) The CST shall be directly responsible for:
1) Modifying the services plan based on on-going assessment and recommendations;
2) Linking individuals to resources and services;
3) Advocating on behalf of individuals;
4) Providing informational, educational and advocacy services to family members;
5) Assisting individuals to select, obtain, and maintain CILAs which afford safety and basic comforts;
6) Participating with other providers of direct service during stays in other environments such as State-operated facilities, convalescent care facilities, community hospitals or rehabilitation facilities; continuing in-facility contact, participating in the services plan development, and the

on-going interdisciplinary process; providing on-going services to ensure the maintenance of the individual's living arrangement during these times such as paying the rent and utilities;
7) Assisting the individual in developing community supports and fostering relationships with non-paid persons in the community, e.g., neighbors, volunteers and landlords;
8) Providing personal support and assistance to the individual in gaining access to vocational training, educational services, legal services, employment opportunities, and leisure, recreation, religion and social activities;
9) Providing assistance to the individual in obtaining health and dental services, mental health treatment and rehabilitation services (including physical therapy and occupational therapy), and substance abuse services;
10) Providing supportive counseling and problem-solving assistance on an on-going basis and at times of crisis;
11) Assisting individuals with activities of daily living through skill training and acquisition of assistive devices;
12) Assisting the individual in accessing medication information including observing and reporting effects and side effects of prescribed medications;
13) Assisting the individual in accessing and providing training to obtain emergency medical services including State-operated facility services;
14) Providing assistance in money management, including representative payeeship, and applying for financial entitlements including assisting individuals to access the Department's Home Services Program (89 Ill. Adm. Code: Chapter IV, Subchapter d); and
15) Assisting individuals to access **transportation**

Conclusions

1. **Provider denied consumer access to psychotropic medication.**

The Illinois Administrative Code (59 Ill. Admin. Code 115.240) states "Individuals who are able to independently self-administer medications will have access to their medications". CCAR staff report that the consumer may have gone without a non-psychotropic medication after it was filled through a pharmacy rather than the CCAR mail order pharmacy but CCAR cannot monitor what is filled by the consumer because he resides independently. There is no documentation to support that the consumer has not had medication at any time in the last 6 months.

After completing the interviews, records reviews, and assessing applicable mandates, there is no evidence to support that the consumer was denied access to psychotropic medication. CCAR did state that there was miscommunication regarding a non-psychotropic medication being filled through a local pharmacy, however, no evidence suggests that the consumer was denied access to that medication by CCAR.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint is unsubstantiated. No recommendations or suggestions are being made in relation to this complaint.

2. **Provider requiring consumer to use "bubble packs" for medication despite the consumer's statement that using this form of medication triggers PTSD.**

The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102) 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". Additionally noted in this section of law, "the facility shall consider the views of the recipient, if any, concerning the treatment being provided". CCAR staff acknowledges that the change in mail order pharmaceutical companies resulted in the consumer receiving the medication in bubble packs despite the consumers stated preference. The consumer's service plan does not include a description of the preference for medication packaging. The service plan does not include any documentation of medication services other than "monitor medication" with no plan for how that will occur, including how monthly medication will be distributed to the consumer.

After completing the interviews, records reviews, and assessing applicable mandates, there is evidence to support that CCAR staff has violated the consumer's rights by providing medication to the consumer in bubble packs for one month. Both CCAR staff and the consumer confirm that the error was due to a change in pharmaceutical companies and the consumer has received the correct medication in the proper packaging for the last 2 months.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint is unsubstantiated. Since the medication has been delivered in the correct packaging for the last 2 months no recommendations are being made. However, the HRA would suggest that, since there is no clear policy for the Intermittent CILA medication delivery, CCAR include more thorough documentation of consumer medication delivery procedures and preferences in the consumer's service plan in order to set forth a clear plan on how to 'monitor medication' and preferences.

3. **Consumer moved closer to the provider and the provider is no longer making home visits. Consumer is being asked to come to the provider's office due to proximity**

The Illinois Administrative Code (59 Ill. Admin. Code 115.220) states that CILA programs are mandated to "Assisting individuals to access transportation". The Mental Health and Disabilities Code (405 ILCS 5/2-102) 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". CCAR staff state that it is not a requirement for consumers to come into the office to receive services. Staff reported that they go to the consumer's home regularly and documentation provided supports that the CCAR staff is in the consumer's home multiple times each week. There are documented times when the consumer has come to the CCAR offices for meetings or services but transportation was available. CCAR staff stated that this is possibly a miscommunication based on an isolated incident when the consumer may have been told that if he needed something immediately he could come to the office to get it. The consumer reports that CCAR staff are regularly in the home and provide all of his transportation needs.

After completing the interviews, records reviews, and assessing applicable mandates, there is no evidence to support that the consumer has to go to the CCAR office as a condition of receiving CCAR program services.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint is unsubstantiated. No recommendations or suggestions are being made in relation to this complaint.

The HRA would like to thank the CCAR staff for their cooperation with this investigation.