



FOR IMMEDIATE RELEASE

**Springfield Regional Human Rights Authority
United Cerebral Palsy
Report of Findings
Case # 19-050-9004**

The Springfield Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission voted to pursue an investigation of United Cerebral Palsy in Springfield, IL after receiving the following complaints of possible rights violations:

Complaints:

1. The Provider has failed to provide adequate and humane care and services with guardian inclusion. Specifically, the resident's medications and meals are not provided according to prescription and the guardian has not been notified of emergency medical care.

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 Community Integrated Living Arrangement (CILA) regulations (59 Ill. Admin. Code 115.250).

Complaint Summary:

The consumer requires regular medication and has dietary requirements prescribed by a physician. The CILA home is not following the physician's orders and allows the consumer to go without medication and the required diet. In addition, the allegations state there is a lack of communication between the CILA and the guardian, specifically the consumer was taken for emergency care and the guardian was not contacted.

Investigation

The HRA proceeded with the investigation after having received written authorization from the consumer's guardian. 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.

Interviews:

On November 27, 2018 at 10:00am, the HRA met with United Cerebral Palsy (UCP) staff. The meeting occurred at 101 N 16th St in Springfield and began with introductions, a review of HRA procedures, and a review of the allegations being addressed in this investigation.

Staff provided some general information about UCP. Springfield UCP offers both adult residential homes and developmental training sites. Staff estimated that both programs currently serve approximately 94 consumers and employ 65-100 staff. All staff receive the DSP (Direct Support Professional) Training required by Illinois Department of Human Services. Abuse and neglect and human rights are part of the DSP training that is completed before staff can work within any UCP facility. The trainings are also renewed annually. The 50-70 DSP staff working in the residential homes are overseen by 2 supervisors that visit each home weekly and 1 QIDP (Qualified Intellectual Disabilities Professional). UCP stated that almost all the staff working in the residential homes are new (started July 1, 2018 or more recently) due to a total residential program overhaul completed by management at the end of the fiscal year.

Consumers can report grievances to the DSP or supervisor at any time. If the resolution is not received, the consumer can “go up the chain of command” to the director and board. Consumers are notified of the grievance procedure at admission in the Rights and Responsibility packet which is reviewed annually. UCP has an internal Human Rights Committee that meets quarterly, however, that committee has not reviewed the concerns in this case.

The CILA home has 3 beds and one UCP staff is scheduled to the home for each shift (3 shifts). All the consumers in the home have 24-hour supervision. At the time of the incident, staff were informed of the consumer’s Individual Service Plan, including the consumer’s supervision needs, verbally from the staff’s supervisor. In October 2018 UCP changed the communication method by creating binders containing the consumer’s person-centered plan and placing the binders in the consumers residence for reference.

UCP reports that in February 2018 the guardian expressed concern about communication between the CILA and the guardian. UCP then began emailing the guardian each week with updates about the consumer. These weekly contacts are to be documented in the consumer’s file. In the event of an emergency, the guardian is to be contacted by the nurse or case manager. There was one occasion when the consumer was taken for emergency medical care, but the staff could not recall the date of the incident or when the guardian was notified. The HRA requested copies of the notes indicating that the guardian was contacted weekly and the notes relating to the incident of emergency medical care but that documentation was not received.

UCP indicated that they were using an electronic note taking system until August 2018. The electronic system was causing issues with staff log-ins and documentation was confusing and challenging to access. In August, the staff started using a half electronic and half paper-based note taking system. This system is also used for tracking medication administration and, therefore, the medication administration logs for this consumer are partially printed out and partially hand written. The medication logs provided to the HRA showed gaps in medication administration but UCP believes that these gaps are likely due to the change in documentation system rather than not administering medications. UCP confirms that there are incidents this year when the consumer refused to take medication and those incidents are logged. UCP stated it is not normal practice to notify a guardian if a consumer refuses medication unless it is an ongoing issue. UCP also added that they have hired a new Registered Nurse who has improved communication with consumers and guardians.

UCP confirms that the consumer is on a restricted diet. A physician has documented that the consumer may only have 40 carbohydrates a day to maintain a healthy weight and prevent medical issues. The consumer's service plan indicates that all staff are required to be trained on how to monitor carbohydrates to assist the consumer. UCP stated that all staff were made aware of the consumer needs by their supervisor and there was a recipe book in the home that the staff were encouraged to use for cooking and teaching. UCP does not have any training documentation to demonstrate that the staff were specifically trained on the consumer's dietary needs because it was done on a one-on-one basis. A weekly menu is created by the DSP in the home and consumers are assisted with all grocery shopping. In July 2018, the staff were directed to stop purchasing processed foods. UCP staff stated the consumer's finances are controlled by the guardian but staff discovered that the consumer's roommate often purchased meals for the consumer so that they could eat in the community. Since those meals were unmonitored, the staff has asked the roommate to stop purchasing food for the consumer. Recently, the UCP Chief Executive Officer has taken over the menu creation for each of the homes and started utilizing local grocery delivery in order to assure that all physician dietary orders are being adhered to. The HRA requested a copy of the new meal plans for the consumer's home but that documentation was not received.

At the end of the interview, UCP staff informed the HRA that the provider has recently made changes in staff, supervision requirements, documentation and record keeping. They hope that the changes implemented in August 2018 will keep issues like these from occurring again.

Records Reviews:

The Consumer's Discovery Tool and Personal Plan dated 2/20/18 states on page 4 that the consumer's housemate "has been buying me meals out in the community (but there is a stop being put to that option today)." Page 4 also states "I (the consumer) need assistance with my medications" and indicates that the consumer's medication is locked and she will need supervision to access. Page 6 reviews the consumer's dietary needs/concerns. It states that the consumer is gaining weight and has been put on physician's orders of 40 carbohydrates a day then states that "The diet has not been followed well since I (the consumer) have moved to the CILA." Page 6 and 7 also state that "All staff in the house are expected to be trained on how to monitor carbohydrates and to assist me." Page 8 states that the consumer and provider are aware that the consumer's parents are her guardians and that the guardians have requested better communication from the provider, including weekly emails with updates/issues, appointments, and medication changes.

Physician's orders for the consumer dated July, Aug, and Sept 2018 lists medications (including time of day to be administered and dosages) as well as a diabetic diet of low carb 40 grams per day.

Medication logs dated July 2018, August 2018 and September 2018 have several dosages administered but it is not indicated who administered the medications. There are documented refusals on 8/29/18 for not feeling well. There is documentation on one medication being refused on 8 occasions. The initials used on the logs to indicate administration do not match up with the refusals.

“T-logs” are used for all documentation for July, Aug, and September 2018. These notes indicate medication refusal on 7/27/18 because the consumer was upset that staff did not wake her up in time and did not get glucose test done. On several occasions the t-logs indicate that the consumer “waited for the nurse to pass meds” in the mornings but no confirmation that meds were taken.

T-logs for July, Aug, and September 2018 frequently include notations about the consumer’s dietary intake. Multiple meals are logged throughout the months but not consistently, including the consumer eating out on multiple occasions. None of the T-logs show documentation of carb intake or meal/dietary planning with the consumer. On one occasion a T-log indicates that staff suggested the consumer take a smaller portion of spaghetti instead of all the leftovers. On another occasion there is documentation of an outing where the staff noted that the consumer watched what she ate while they were at Dairy Queen. Most meals documented are high carb meals (i.e. stuffing and pasta in the same meal, Subway and Wendy’s in same day, etc.).

T-logs for July, Aug, and September 2018 show some guardian communication. A T-log for 7/5/18 states the program director responded to guardian’s request for information during an email. A T-log on 8/23/18 states the program director documented a “weekly update to guardian.”

The HRA requested the following records from UCP that were not provided; Rights and responsibilities packet, proof that the consumer has received the rights and responsibilities packet, UCP documentation of any rights restrictions applying to the consumer, UCP documentation of weekly contact with the guardian, UCP records that staff were trained on the consumer’s dietary restrictions (per the service plan), and a copy of the new meal plans being created by the director.

Policies

The HRA requested the following policies from UCP but was unable to obtain it; Consumer Rights and Responsibilities (specifically looking for the section stating the consumer’s right to report), UCP policies on guardian contact, UCP policies on medication administration and documentation, and UPC policies on dietary needs of consumers/meal planning.

Conclusions

Complaint 1. The Provider has failed to provide adequate and humane care and services with guardian inclusion. Specifically, the resident’s medications and meals are not provided according to prescription and the guardian has not been notified of emergency medical care.

The Mental Health and Developmental Disabilities Code (405 Ill. Comp. Stat. Ann. 5/2-102) states “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. 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 Illinois Administrative Code (Ill. Admin Code tit. 59, § 115.230) requires that “a) Through the interdisciplinary process, the CST [community support team] shall be responsible for preparing, revising, documenting and implementing a single individual integrated services plan for each individual”. The Probate Act (755 ILCS 5/11a-23) states “Every health care provider...has the right to rely on any decision or direction made by the guardian...that is not clearly contrary to the law, to the same extent and with the same effect as though the decision or direction had been made or given by the ward”

The consumer’s service plan indicates that the consumer will have regular medication administration per physician’s orders. The documentation provided by UCP does not clearly document that the consumer is receiving medication as prescribed. The consumer’s service plan indicates that a physician has ordered that the consumer not consume more than 40 grams of carbohydrates per day and that the staff in the consumer’s home will be trained to assist the consumer. The limited documentation provided to the HRA indicates that the consumer’s dietary orders are not regularly followed. It is unclear if the staff in the home were trained properly on the consumer’s dietary needs because no records were kept. UCP states that the consumer’s guardians were concerned about lack of communication and, therefore, weekly email updates began. The HRA only received documentation that the guardians were updated on two occasions. Again, it is unclear whether this communication is not occurring or whether it is just not being properly documented.

Based on the findings above the Springfield Human Rights Authority concludes that the complaint is substantiated. The HRA makes the following recommendations:

1. UCP ensure that all consumer service plans are developed and implemented per the Mental Health and Developmental Disabilities Code (405 Ill. Comp. Stat. Ann. 5/2-100) and Rule (115 Ill. Admin Code tit. 59, § 115.230). The HRA acknowledges that a Policy on Implementation Strategy was developed to address prior HRA Case #18-050-9012 specific to the implementation of consumer services plans and recommends that the agency ensure that the Code, CILA rules and newly developed policy are followed.
2. UCP ensure that all staff are properly trained on Rule 115 (Ill. Admin Code tit. 59, § 115.230) to ensure that the service plans are followed by the staff in the homes where the consumer resides.

The HRA finds UCP’s lack of cooperation in providing documentation and policies to the HRA concerning. While the HRA understands that the provider is undergoing changes to its system, policies and staffing, the Mental Health and Disabilities Confidentiality Act (740 Ill. Comp. Stat. Ann. 110/8), the Guardianship and Advocacy Commission Act (20 ILCS 3955/18), and the Human Rights Authority Regulations (59 Ill. Adm. Code 310.60) give the Human Rights Authority the right to obtain records regarding the consumers in their care during an investigation. The Human Rights Authority suggests that UCP review the laws and make a greater effort to comply in the future.