



FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY – CHICAGO REGION

REPORT 19-030-9007
UCP Seguin of Greater Chicago

CASE SUMMARY

The HRA found allegations of a consumer not being allowed to smoke outside his home unsubstantiated. During the investigation the HRA was made aware of the fact that the facility and guardian were in contact with each other at various points prior to the investigation. HRA's public record on this case is recorded below; the provider's response immediately follows the report.

INTRODUCTION

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation due to complaints of rights violations in the treatment of a consumer of Community Integrated Living Arrangement (CILA) services at UCP Seguin of Greater Chicago (UCP Seguin), a state funded provider of services for individuals with disabilities.

The organization is headquartered in Cicero, IL but provides services to the Greater Chicagoland area. Currently, UCP Seguin provides day program services to over 24,000 consumers. UCP Seguin also has 41 adult group homes and 34 adult foster homes, with roughly 500 consumers residing in those homes. UCP Seguin also operates 160 children's foster homes with roughly 175 children residents.

Substantiated findings would violate protections under the Mental Health Code (405 ILCS 5) and the Standards and Licensure Requirements for Community Integrated Living Arrangements (59 IL Admin Code 115).

COMPLAINT SUMMARY

It was reported that an adult consumer with a disability, living in an adult foster home, was not allowed the basic human right to choose to smoke cigarettes outside his home. The complaint is that services were not provided in the least restrictive environment, considering the consumer's input and choices.

FINDINGS

Guardian's Interview

The guardian reported that the consumer was not allowed to smoke outside of his home. The guardian reported that the consumer had been threatened to be punished if he asked to smoke. The guardian reported reaching out to the facility, but concerns were not appropriately handled. The guardian stated that she initially asked the facility to allow the consumer to smoke per his wishes and the facility refused citing a previous guardian's decision. The guardian maintained that even though a prior guardian restricted the consumers smoking, there needed to be a reassessment done.

The guardian reported that a reassessment was done in October of 2018. Since that time the consumer has been restricted to smoking only one cigarette daily. The guardian reports that this restriction is in place due to the limited amount of funds the consumer has. The guardian agrees with this restriction, as it helps maintain the consumer's personal allowance.

Site Visit and Interviews

The HRA conducted a site visit to UCP Seguin on March 28, 2019. The HRA interviewed the director of case management, director of quality assurance, director of clinical services, case management coordinator, quality assurance investigator, adult foster care administrator, adult foster care parent and quality assurance analyst. During the interview the HRA asked the staff to explain the process of restricting a consumer's rights.

The director of case management informed the HRA that the facility reviews the consumer's behavior plan. After reviewing the plan, the agency develops a new plan along with an Individual Service and Support Advocate (ISSA) agent, the consumer and guardian (if any) to curb or improve certain maladaptive behaviors. This director furthered that if there is a hint that a right of an individual with disabilities is being violated, the restriction is forwarded to UCP Seguin's Human Rights Committee. There the restriction is discussed and analyzed to maintain uniformity with all state and federal laws. UCP Seguin's Human Rights Committee also reviews every restriction every three months.

The director of clinical services informed the HRA that the consumer had not smoked cigarettes in over two years. The HRA questioned the need to restrict the consumer's choice to smoke and how he spends his money, considering the consumer had not smoked. The case management coordinator stated that the consumer lived with nonsmokers and attended a day program that

had no active smokers present. The belief was that because there were no active smokers; the consumer stopped on his own.

The director of case management furthered that the previous day program was closed, so the consumer was moved into a larger day program. The larger day program has many more participants, and some of those participants exercise the choice to smoke. The consensus amongst all the staff present was that the consumer changed his mind about smoking.

The adult foster parent informed the HRA that the consumer did not ask to smoke until recently. The foster parent stated that the consumer had resided in the home for over five years. The foster parent then stated that if the consumer wanted to smoke he could outside the home. The foster parent also stated that the consumer never asked her to purchase cigarettes. The foster parent finally stated that the consumer was never threatened at any time with punishment should he have asked to smoke.

The case management coordinator informed the HRA that the consumer manages his own funds. The team stated that the consumer only had sixty dollars (\$60) a month to manage, as he currently has no outside source of income. The HRA inquired about whether the guardian consented for the consumer to self-manage funds. Staff informed the HRA that they maintained consents from the guardian that are renewed yearly. The HRA was also informed that the only current limitation on whether the consumer smokes is the availability of funds.

The HRA finally asked about the service plan. The staff informed the HRA that the agency does not create individualized service plans, they only implement the plan that the ISSA agency creates with the consumer. The director of case management stated that the ISSA agency uses a discovery tool and meets with the consumer, discusses goals he or she would like to complete and then develops a plan.

ISSA Agency Interview

The HRA interviewed the ISSA Agency for the consumer via phone on April 9, 2019. The assigned agent was recently assigned to the consumer and had no knowledge about him. The assigned agent referred the HRA to the team lead. The team lead indicated that the consumer had been an active smoker when she met him in November of 2018. The team lead further stated that she had not known the consumer prior to the discovery tool meeting. She stated she would not have known about prior smoking request.

Consumer Interview

The HRA interviewed the consumer in private at his home. The consumer informed the HRA that he previously resided in another facility. He mentioned that he smoked and chewed tobacco at the previous facility. The consumer then stated he was not comfortable and requested the presence of his "mom" (adult foster parent). The HRA continued the interview with the "mom" present.

The consumer was asked why he choose to stop smoking; he gave no definitive answer. He did mention that he is smoking now and stated he smokes “every morning.” The consumer asked his “mom” if he could start back chewing tobacco. The consumer’s mom began informing him about the financial risks associated with purchasing chew and cigarettes. She also informed him that he would not be allowed to take the chew to the workshop, as a safety precaution.

The HRA asked the consumer if he was responsible for managing his own money, he was unable to give a clear answer to this question. The consumer’s mom indicated that he managed his own funds but need to purchase his hygiene products first. She also explained to the consumer, that if he spent all his money on tobacco he would not have money for outings. The consumer’s mother then informed the HRA that the consumer is allowed one cigarette per day.

The consumer then gave the HRA a tour of his room. The HRA completed the tour alone with the consumer. During the tour he was asked how often he receives his allowance. The consumer was unable to answer this question. The consumer informed the HRA that he does indeed like smoking and will continue. The consumer also informed the HRA that he does not work and has no concerns about his placement or care.

Individual Service Plan Review

The HRA completed a review of the Individual Service Plan from UCP Seguin implemented on November 15, 2017. Under the supervision section it states, “if [consumer] purchases cigarettes with his own money, a smoking schedule is in place and should be followed.” The plan also states under the special provisions needed for safety and security section, “[consumer] has history of smoking cigarettes ... doctor has recommended ... stop smoking due to health risks. [Consumer] has not smoked since 2016.”

The plan has a residential section which states the consumer, “does not currently smoke, but should he decide to begin smoking again his lighter and cigarettes have restricted access that has been approved by the [UCP Seguin] Human Rights Committee.” The plan furthers that by law the consumer must smoke at least fifteen feet from the door.

Finally, on page eight of the plan, under the client comments section, the consumer stated, “he was pleased with the outcome of the staffing and it was ‘a good staffing’. [He] expressed the desire to have more cigarettes and ‘chew’.” This section states that the consumer was informed of how much money was being saved by not smoking.

The HRA compared the November 15, 2017 plan with the Individual Service Plan – Implementation Strategies from UCP Seguin implemented on December 11, 2018. In it most of the language, risk and descriptors remain unchanged from the previous year. There is a change in the residential section which reflects that the consumer “has resumed smoking at the demand of his [guardian].”

There is also a change in the client comments where the consumer informs the facility that he does not want to discontinue smoking. The HRA could not verify in writing, a documented agreed upon restriction of one cigarette per day for financial reasons.

Policy Review

The HRA reviewed UCP Seguin's consumer handbook and found no causes for concern. The handbook details the services that UCP Seguin provides and the type of housing models it offers. On the final pages of the consumer's handbook, it outlines verbatim many of the rights that are protected by the Mental Health and Developmental Disabilities Code.

For example, the handbook states on page 21 that a consumer has a, "right to participate in planning [their] total care and medical treatment." Thus, giving each consumer the opportunity to contribute in all decision regarding their care. This idea is furthered on page 22 where it states verbatim, "you have a right to make decisions and choices for yourself and decide what you want your life to be." The handbook also addresses Code section 5/2-105 by informing residents that they "have a right to manage your own personal finances."

CONCLUSION

Consumer not being allowed to smoke outside his home.

Under the Mental Health and Developmental Disabilities Code (Code), "a recipient of services shall be provided with adequate and human care and services in the least restrictive environment, pursuant to an individual services plan." The Code furthers that "the plan shall be formulated and periodically reviewed with the participation of the recipient ... and the recipient's guardian...." The consumer indicated his personal goals and preferences in his service plan that was instituted on November 15, 2017.

On this date he informed all in attendance that he would like to smoke and have chewing tobacco. He was informed of the financial consequences of smoking and deterred from carrying out his wish. The current staff and guardian are uncertain as to why or when the consumer stopped, but it is typed clearly in the client comments section that he wanted to smoke.

Furthermore, the CILA Rules (59 ILL. Admin. Code 115.200) stipulate that, "the individual or guardian shall agree to participate in the development and implementation of the individual integrated services plan, which shall be indicated by the individual's or guardian's signature on the plan or a note describing why there is no such signature." Consumers are "...recognized 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 should they be considered 'individuals who have a mental disability.'" The facility and guardian were aware of the consumer's wants over a year prior to the HRA opening this case. The facility, guardian and consumer also signed the plan.

The guardian admitted in the interview that there is a restriction in place due to limited funds. The facility also agreed that there is a restriction in place due to limited funds. There is a consensus that the consumer can purchase whatever is desired, provided there are funds to support the purchase.

Although it seems that in the recent past the consumer's views and choice for smoking were not appropriately considered and restricted, the HRA notes that at present the facility, guardian and consumer have worked together to develop a system to which the consumer can exercise his personal choice to smoke. The facility, medical personnel and guardian have also informed the consumer of all the risks associated with smoking. Therefore, a rights violation of the Code 405 ILCS 5/2-102, 5/2-105 and 59 ILL. Adm. Code 115.200 is unsubstantiated based on the information reviewed.

SUGGESTIONS

The agreement by all parties to limit tobacco purchases to available funds and the "one per day" current cigarette allowance should be clearly documented in the service/implementation plan, and Seguin should consider completing restriction notices on spending if the consumers insists on exceeding the limits and the facility restricts access to personal funds.

The HRA would suggest the following as this investigation was only focused on whether care and services were provided in the least restrictive environment. The HRA noticed that UCP Seguin's entire policy on behavior management procedures would need to be revamped to ensure that it is completed in line with the code.

For instance, the following is written in the policy:

Restriction of mail, visitors, telephone calls: A procedure in which mail, visitors or telephone calls are limited contingent on a target behavior or due to a history of past target behaviors. In addition to the written approval of the individual who is legally competent or to an individual's guardian, the individual's interdisciplinary team, the Behavior Management Committee and the Human Rights Committee, must approve in writing every program intervention procedure involving the restriction of mail, visitors, and/or telephone calls.

The HRA would caution the facility that in pursuing behavior modification, respect the Code's intention that consumers, regardless of legal status, do not have to earn their communication rights and they may only be restricted to prevent harm, harassment or intimidation, not to get them to comply with service plans, house rules, etc. As 405 ILCS 5/2-202 would state any "policies and procedures may amplify or expand, but shall not restrict or limit, the rights guaranteed to recipients."

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.

July 2nd, 2019

Chicago Region Human Rights Authority
Illinois Guardianship and Advocacy Commission
PO Box 7009
Hines, IL 60141

Re: HRA Case Number 19-030-9007
Request for Reconsideration

Below is a response to the HRA report of findings of the investigation dated May 28th and received by UCP Seguin of Greater Chicago on June 3rd, 2019. Please consider this letter as UCP Seguin's (The Agency) request for reconsideration of the content of the report. Our request for reconsideration is based on identified inaccuracies and respectfully requests that the HRA review and reconsider the content of the report. The Agency's response to the inaccuracies are noted below.

Report states: "The guardian reported that the consumer had been threatened to be punished if he asked to smoke."

Response: Per the attached document (page 50), the email with the complaint states "He stated to me last week that his foster parent does not allow him to smoke and threatens him with punishment". These are two separate allegations. OIG investigated the punishment portion of the allegation, which was unfounded on 1/28/19 (Case Number 1619-0149).

Report states: "The guardian reported reaching out to the facility, but concerns were not appropriately handled".

Response: The only correspondence that we have regarding the guardian's concerns are via email, which is attached on page 49-50. The Case Manager, who has known [REDACTED] for years, responded in less than two hours to the guardian's concerns to provide an explanation as to the rationale to the original reduction in cigarettes. The guardian stated, "I will need a new evaluation for this as [REDACTED] is retired and no longer his guardian. Our administrator and I will review". UCP Seguin staff never heard back from the guardian requesting any other course of action.

Report states: "The guardian stated that she initially asked the facility to allow the consumer to smoke per his wishes and the facility refused citing a previous guardian's decision."

Response: At the time of the complaint, [REDACTED] had a restriction in his Behavior Plan for him to have one cigarette per day. It is important to note that at no point in time was he restricted from all cigarettes. As explained during the HRA interview, all [REDACTED] would need to do to smoke one cigarette per day was to ask a UCP Seguin staff or his Adult Foster Parent to smoke and to have sufficient funds to purchase cigarettes. Scott occasionally talked about wanting to smoke or would talk about when he used to smoke, but never asked to go purchase cigarettes or set aside money to purchase them. He had been smoke free for 2 years. Additionally, this restriction of one cigarette per day was approved by not only the Human Rights Committee, but his current guardian [REDACTED]. See page 13 of the attached packet for her signature of consent.

Report states: "The guardian reported that a reassessment was done in October of 2018."

Response: The report fails to detail the doctor's report (reassessment), which indicates:

- Hasn't smoked in nearly 2 years.
- Breathing is better. Is not requiring albuterol rescue inhaler use
- Normal lung exam today
- Do not recommend resuming smoking
- Smoking increases risk of 1) worsening breathing/lung disease (ie COPD); 2) heart disease/heart attack (in patient already with significant cardiac risk factors: diabetes, hypertension); 3) cancer (ie lung cancer, GI cancer, kidney cancer).
- There are no health benefits of smoking cigarettes.

Report states: "Since that time the consumer has been restricted to smoking only one cigarette per day."

Response: The restriction of only one cigarette per day was put in place on 11/17/16, and remains unchanged to date.

Report states: "The director of case management furthered that the previous day program was closed, so the consumer was moved into a larger day program. The larger day program has many more participants, and some of those participants exercise the choice to smoke. The consensus amongst all the staff present was that the consumer changed his mind about smoking."

Response: The reason that [REDACTED] changed day programs was because he moved homes (with his AFP and housemates) and is now attending a day program that is closer to his current home. [REDACTED] used to attend this day program several years ago, when he was a smoker. It is possible that [REDACTED] moving back to the previous environment where he used to smoke triggered his desire for smoking.

Report states: "The HRA could not verify in writing, a documented agreed upon restriction of one cigarette per day for financial reasons."

Response: The rationale for the restriction is for medical reasons. This is documented multiple times in the Behavior Plan (signature on page 13), the Implementation Strategy (page 25) and the HRC Sheet (Page 12). Additionally, it is documented in his Implementation Strategy that [REDACTED] is not presently employed and therefore has no income other than his \$60 allowance. Because [REDACTED] has the ability to manage his own funds, it is not considered a financial restriction if he chooses to spend his money on other items or activities other than smoking.

Report states: "On this date he informed all in attendance that he would like to smoke and having chewing tobacco. He was informed of the financial consequences of smoking and deterred from carrying out his wish."

Response: During [REDACTED] staffing, UCP Seguin staff reminded [REDACTED] about the risks and disadvantages of smoking, per his doctor. If [REDACTED] had further requested to purchase cigarettes, his wishes would have been honored as long as he had the money to purchase the cigarettes. If [REDACTED] disagreed with this recommendation to continue to be smoke-free, it would have been documented. Due to the addictive nature of nicotine, it is fairly common for former-smokers to express a desire to return to smoking but continue to choose to not smoke when they consider the risks associated with smoking.

Report states: "The facility also agreed that there is a restriction in place due to limited funds."

Response: As noted throughout the response the rationale for the restriction of one cigarette per day is due to medical issues. [REDACTED] has the responsibility of ensuring he has the funds to purchase cigarettes if he so chooses. It is not a restriction to allow him to manage his personal funds as he chooses, as long as he does not exceed one cigarette per day.

Report states: "Although it seems that in the recent past the consumer's views and choices for smoking were not appropriately considered and restricted, the HRA notes that at present the facility, guardian and consumer have worked together to develop a system to which the consumer can exercise his personal choice to smoke".

Response: The agency disagrees that UCP Seguin was not appropriately considering and restricting [REDACTED] views and choices for smoking. [REDACTED] restriction of having one cigarette per day has remained unchanged since 2016. [REDACTED] recently began smoking again because he chose to purchase cigarettes, but he has always had the ability to do so.

Report states: "The agreement by all parties to limit tobacco purchase to available funds and the "one per day" current cigarette allowance should be clearly documented in the service/implementation plan and Seguin should consider completing restriction notices on spending if the consumers insists on exceeding the limits and the facility restricts access to personal funds."

Response: The Implementation Strategies states "Restriction of cigarettes and lighter (rationale: Came to UCP Seguin with a smoking schedule/medical issues)." The purpose of the Implementation Strategies is to give an overview of the services [REDACTED] receives. The detailed instructions on how this restriction is implemented is found in [REDACTED] Behavior Plan. Again, this restriction is in place due to medical recommendations and [REDACTED] funds are not restricted.

Report state: The last three paragraphs of the report.

Response: The quote from the Behavior Management Procedure is only a portion of the larger procedure and does not accurately represent the Behavior Management Procedure. The full text is:

"Level II procedures involve some restriction of rights, but do not involve controversial and/or noxious or painful stimulation. Behavior intervention programs, which include Level II procedures, require review and approval by Behavior Management Co-chair, Behavior Management Committee and Human Rights Committee prior to implementation with subsequent re-review and approval at least quarterly or more as needed for continued program implementation.

Restriction of mail, visitors, telephone calls: A procedure in which mail, visitors or telephone calls are limited contingent on a target behavior or due to a history of past target behaviors. In addition to the written approval of the individual who is legally competent or to an individual's guardian, the individual's interdisciplinary team, the Behavior Management Committee and the Human Rights Committee, must approve in writing every program intervention procedure involving the restriction of mail, visitors, and/or telephone calls.

For example: Only being allowed to call a sibling on Saturdays due to a history of threatening phone calls during business hours almost causing the sibling to lose a job, or ending a visit if the person begins engaging in verbal aggression."

At no point in time does the policy state that individuals have to earn their communication. Communication restrictions are highly individualized and only used as a last resort, which is why they must be approved by the guardian, HRC, and BMC before they are implemented. In the event that either party does not agree to the restriction, the restriction is not implemented. These restrictions are only in place to prevent harm, harassment or intimidation and is therefore in compliance with the Code.

Additionally, the following omissions were made in the report:

- [REDACTED] had signed and approved the restriction of one cigarette per day.

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- The Behavior Management Plan specifically states "It is his right to be able to smoke/chew. He is just on a schedule because he came to UCP Seguin and we need to keep it in place for consistency and due to his health."
- The report does not mention the multiple documents that were provided regarding the physician's view on Scott's smoking.

We appreciate HRA's reconsideration of information contained in the Report. UCP Seguin is requesting that the closure of this case be delayed until further review and discussion of the above concerns.

Sincerely,

