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HUMAN RIGHTS AUTHORITY - PEORIA REGION
REPORT OF FINDINGS

Case # 12-090-9016

Knox County Council for Developmental Disabilities (KCCDD)

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving a complaint of possible rights violations at Knox County Council for Developmental Disabilities (KCCDD) in Galesburg. Complaints alleged the following:

- 1. Consumers were not placed in the least restrictive environment when the facility made a policy change that all consumers must be supervised while eating, drinking, or when they are around food or water.**
- 2. There is a lack of individualized treatment plans and supervision plans when all consumers were restricted from eating or drinking without supervision.**

If found substantiated, the allegations would violate the Illinois Department of Human Services (IDHS) regulations (59 II Admin Code 119) and the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102).

The KCCDD provides services such as developmental training and community employment to approximately 200 consumers.

The HRA interviewed KCCDD staff regarding these complaints and reviewed policy and records pertinent to the complaints in this case.

COMPLAINT STATEMENT

Previously, consumers were allowed to purchase sodas and eat food without supervision. Now, due to some consumers having possible choking risks, all consumers must be supervised whenever they eat, drink, or are even around food or liquids (e.g. handing out lunches, buying soda).

FINDINGS

Interview with staff (4/30/2012)

The HRA met with a KCCDD staff member to discuss the complaints introduced in this report. Staff explained that the changes made to policy were because of choking incidents. The

residential provider that is contracted with KCCDD had choking incidents at their facility and there were also some choking incidents at KCCDD. The residential provider is where the majority of the KCCD consumers live. The staff explained that the residential provider made policy changes that were influenced by the Illinois Department of Public Health (IDPH) and KCCDD had to comply with the modifications. The staff also explained that both the residential facility and KCCDD are easing the restrictiveness of the new policy. The changes dealt with consumers' prohibition to accessing food and water without supervision. The KCCDD staff and administration were unhappy with the changes. Now staff are finding new, creative ways to monitor the food issues.

Staff stated that every recipient has an individual plan. They explained that KCCDD seeks to serve consumers through the less restrictive means. They said that the pressure from the IDPH resulted from a situation in which an individual died from choking. KCCDD staff also explained that swallow studies are the residential provider's responsibility.

The staff said that the new policy for the facility consisted of staff closing and locking doors to keep consumers from areas where there is food and also staff had to prevent recipients from having food or water unsupervised. Staff had to escort consumers when getting food. The policy came from the residential facility to KCCDD. The KCCDD staff stated that choking incidents in the past from food and the incident was handled the way the facility thought it should have been handled. An ambulance was at the facility in seconds.

The individual who choked and passed away was at KCCDD when the incident occurred and not at the residential facility. The consumer did not have past choking problems. The incident occurred when the individual stuffed food in her mouth and then ran away from staff and choked. The ambulance response time was good but they were not able to open her airway to any real degree. The individual passed away at the hospital because of the choking. The individual was not thought to have a choking risk previously and the incident was very unexpected. Staff cover lunch but this particular individual stayed in her activity room to eat during the lunch hour. There is a core group that stay in their activity room during lunch and she was part of the group. The KCCDD has five nurses and two were on the scene when the incident occurred and attempted to remove the food.

The facility staff was upset over the new policy because the individuals were previously independent and then they were not. Staff explained that they have a copy of the new policy at KCCDD. Some of the consumers that were independent previously are now becoming independent again. The residential facility staff members are coming to KCCDD and watching consumers to analyze their independence level. The staff stated that they are trying to keep people at the same level of independence as they were before the policy was adopted. The area that was locked was the break area where the vending machines are located. The consumers can still go to the break area but they are now escorted. The staff explained that now some individuals are going to lunch alone. When the incident first occurred, everyone was monitored regardless of independence level.

Staff explained that the consumers did not understand the change and were verbal about it but nothing more than just "grumblings." They stated that it was mostly the staff complaining

about the policy change. The facility stated that they have community integration programs for the consumers. When consumers are out in the public working, the policy does not pertain to them. The staff explained that each individual has a treatment plan but the policy was a general statement and was not added to the individual's plans. The staff said that the consumers did not regress from the policy change. The staff also explained that the consumers in the facility would be considered to have more severe or profound cognitive functioning, with the exception of a few that would be considered to function in the moderate range.

The transition into less restriction for the food supervision has been written into the new policy. As far as the recipient's plans, the staff would verbally state the individual has less restrictions, which was noted in an incident progress note and then it would be written into the ISP at a later date. The staff stated that in the training/activity rooms, they have 1:6 or 1:7 staff to consumer ratio but at times the staff will increase. When consumers are eating, there will always be two staff in the training/activity room. For the consumers who eat in the lunch room, the trainers from their different rooms supervise.

The KCCDD staff stated that the residential provider would not necessarily let them know of a choking incident that occurred at the recipient's residence, but KCCDD staff always see the recipient's plan and partake in the staffings. If the KCCDD is given a directive that they disagree with, they can call the residential facility with the disagreement. The policy change was in effect for a couple of months before they lessened the restrictions. KCCDD staff explained that the residential provider contracts with the KCCDD for services, so under that contract they must follow the residential provider's rules.

Staff explained that although the consumers eat at KCCDD, the residential facility provides the consumers with their food and KCCDD does not cook for the consumers. KCCDD staff also explained that there are some consumers who use services that are not from the residential facility but rather from a private home that use their services and they were not affected by the policy. They said the consumers are part of the senior services center and they are the only other people serviced by KCCDD. People working outside of the facility and working in the manufacturing program were also not affected by the policy.

The staff stated that they are always looking to see what skills consumers have developed or that the facility has helped them to achieve. KCCDD has various classes and businesses where the clients make jewelry and cards, and working in these environments help promote a least restrictive environment (LRE). Staff said that under the policy, there may be situations where staff might be too busy to take a recipient for a drink but they would assist them as soon as possible. The staff member did not know the statistics on how many individuals reestablished their level of independence. The KCCDD staff member stated that the residential provider identifies which individuals are considered independent and if the residential facility is slow to update the individuals' supervision levels, then they stay under that policy.

The staff stated that there was concern about people who were no longer going to be independent. Staff said that if family members or guardians were concerned with the change, it would have been voiced with the residential facility. The staff member was aware of a couple of

calls but no big concerns. The staff also stated that they noticed no weight loss from this situation.

The staff member stated that the residential service staff comes to the facility to monitor the consumers. When the policy was adopted, the residential facility called the KCCDD and informed them about the policy. The KCCDD had a staff meeting about the policy. Staff explained that as soon as it was noted that the person was not going to have a problem getting water or food independently, they were allowed to do so. It was a team decision whether the restriction was lifted or not. KCCDD would speak with the residential facility about the decision so it was consistent. The staff member stated that for most residents the policy change did not change the possibility for reaching a goal on their ISPs. The facility does tend to push the limit as far as trying to move consumers forward.

FINDINGS (Including record review, mandates, and conclusion)

Due to the similarities between the complaints, the HRA combines complaint #1 and #2 for the purposes of this report.

Complaint #1 - Consumers were not placed in the least restrictive environment when the facility made a policy change that all consumers must be supervised while eating, drinking, or when they are around food or water & Complaint #2 - There is a lack of individualized treatment plans and supervision plans when all consumers were restricted from eating or drinking without supervision.

To investigate the case, the HRA reviewed policy and records pertinent to the complaint. The HRA provided the facility with releases for 5 individuals and requested 3 additional masked records for consumers who require supervision regarding food and water.

The HRA began by reviewing the original policy provided by the residential agency that contracts with KCCDD and a revised version of the same policy. These two policies were provided to the HRA by the residential agency. The date of the original policy was 1/28/12 and the date of the updated policy was 3/11/12. The original policy with the 1/28/12 date reads that "The facility shall manage the usage and disposal of food and beverages within the facility by all staff and residents." Also, the stated purpose of the policy was "To protect facility residents who should not have access to, nor consume food items." The procedure states that "A. Staff may not have food or beverages above the first floor with the exception of the second floor dining room. B. Residents may not have food or beverages within the facility unless supervised by the staff. C. Consumption of food and beverages on the first floor by staff is limited to the dining room, the staff break room, or in a room behind a locked door, such as an office. D. It is prohibited for staff to dispose of food items or trash in trash cans that are accessible to the residents, including remainders of items consumed by residents while being supervised." In the revised version, of the policy dated 3/11/12, there are two additional sections added to the procedure which read "C. Residents who have demonstrated that they can safely handle and dispose of food and beverage items responsibly, without exposing other residents to health risks, may do so without supervision throughout the facility." The second addition reads "D. Residents who have not demonstrated that they can safely handle and dispose of food and beverage items without exposing other residents to health risks may receive training to develop this skill." KCCDD had

the most updated version of the policy.

The HRA also reviewed an in-service education/meeting report dated 3/28/12 regarding the subject of "Supervision Requirement during Food and Drink Consumption." The list consisted of 27 names and indicated that certain residents were "... able to safely consume food and/or drink and safely dispose of related trash" while other residents were "... Unable to safely consume food and/or drink and safely dispose of related trash." There was another list of residents with G-Tubes who were not to receive anything by mouth. The HRA asked KCCDD staff for clarification as to why only 27 consumers were discussed in this meeting and they responded that the residential facility would have only sent information regarding certain caseloads, so that group of people were from a particular caseload.

The HRA reviewed patient individualized service plans and saw that, out of the 5 recipients that the HRA had consent to release records, three of the individuals had addendums added to their individual service plans stating that they could not safely eat or drink and dispose of the related trash. One individual had an addendum stating that he/she could safely eat and drink and dispose of trash and it was also stated, in a hand written note, that this individual worked at a different center so he was not a part of the restrictions. The individual that did not have an addendum had a G-tube and was not allowed to eat or drink at the KCCDD at all. Of the three individuals with masked records, two had addendums stating they could not safely eat, drink, and dispose of trash, and the third individual was already being provided supervision for dietary and eating concerns as well as for PICA (an eating disorder). It is noted that the in-service education that was reviewed by the HRA was dated 3/28/12 and that all addendums reviewed were dated 3/28/12 and 3/29/12. The HRA saw no other evidence of in-services or addendums regarding the policy prior to those dates although the policy was adopted in January of 2012 and updated in March of 2012.

The HRA reviewed the facility policy for implementation, development and updating of the individual program plan. In that policy, it reads the plan should contain information about "A prognosis regarding potential for a least restrictive living arrangement", which indicates that, according to policy, the least restrictive environment is taken into consideration.

The HRA also reviewed an individual's progress note which read that on 2/29/2012, "Also food safety was discussed and the reasons food is required to be locked up. Everyone appeared to understand the conversations and was cooperative during the drills."

In reviewing an individual's service plan, dated 9/12/11, it reads that the individual requires "Daily assistance in meal preparation and eating" and "She requires staff assistance in all areas of food preparation and clothing care and repair," but then later in the plan, under the At Day Training section, the Eating Skills passage reads "[Individual] can feed herself; throw away her trash, and clean her area with no staff assistance." These passages seem to indicate an inconsistency in the individual's plan. There is the 3/28/12 addendum attached that clarifies that the individual is unable to consume food and/or drink and safely dispose of trash but prior to that addendum, there is nothing clarifying the discrepancy.

The HRA did not review any Incident Progress Notes that were discussed in the

interview, only addendums stating whether the individual needed supervision or not.

The HRA contacted the IDPH who confirmed that, in accordance with IDPH Rule 350 (77 II Admin Code 350) which is titled the Intermediate Care for the Developmentally Disabled Facilities Code and the Centers for Medicare and Medicaid Services (CMS) regulations (42 CFR 483) the day program is to follow the residential program. The IDPH staff member quoted a particular regulation in the administrative code which reads "There shall be available sufficient, appropriately qualified training and habilitation personnel, and necessary supporting staff, to carry out the training and habilitation program. Supervision of delivery of training and habilitation services shall be the responsibility of a person who is a Qualified Mental Retardation Professional" (77 II Admin Code 350.1060).

The CMS regulations read "(1) If a service required under this subpart is not provided directly, the facility must have a written agreement with an outside program, resource, or service to furnish the necessary service, including emergency and other health care. (2) The agreement must-- (i) Contain the responsibilities, functions, objectives, and other terms agreed to by both parties; and (ii) Provide that the facility is responsible for assuring that the outside services meet the standards for quality of services contained in this subpart. (3) The facility must assure that outside services meet the needs of each client" (42 CFR 483.410(d)(3)). In reviewing the CMS "State Operations Manual - Guidance to Surveyors: Intermediate Care Facilities for Persons with Mental Retardation" the HRA reviewed the section regarding 42 CFR 483.410 which reads "Outside service providers meet the needs of each individual as identified by the interdisciplinary team." And "Programs and services are coordinated/integrated and consistent with those provided by the facility." The manual also reads "'Assure' means that the facility's staff actively participate with staff in outside programs in the assessment process and in development of objectives and intervention strategies. For example, if a public school is implementing a manual communication system with an individual, the direct care staff in the individual's living unit should have instructions to implement the program in the residential environment. Likewise, if the facility is implementing a behavior management program for the individual, it should be shared with and implemented as needed by the outside program. This communication is often difficult, but nevertheless essential to the provision of active treatment."

The Illinois Administrative Code requirements for developmental training programs reads "a) Developmental training programs shall prepare adults 18 years of age or older who are developmentally disabled to live and function in integrated social settings. b) Developmental training programs shall serve adults with developmental disabilities and major functional skill deficits to promote independence in daily living and economic self-sufficiency" (59 II Admin Code 119.100). The rule also reads that "To insure that the individual's rights are protected and that all services provided to the individual comply with the laws cited in subsections (a) and (b) of this Section, providers shall assure that: a) The individual's rights are protected in accordance with the Code, except that the use of seclusion shall not be permitted" (59 II Admin Code 119.235). The Code is defined as the Mental Health and Developmental Disabilities Code (59 II Admin Code 119.120) and reads "§ 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" (405 ILCS 5/2-102).

Rule 119 also reads that a facility must "4) Have a normal temperature and humidity comfort range in accordance with the American Society of Heating, Refrigerating, and Air Conditioning Engineers (ASHRAE), Handbook of Fundamentals (National Association of American Society of Heating, Refrigerating, and Air Conditioning, United Engineering Center, 345 East 47th Street, New York, New York 10017, 1977)" (59 Il Admin Code 119.255).

Conclusion for complaints #1 and #2

Because of the verification with the IDPH which confirms that the day training facility must provide treatment and services consistent with the residential facility, the HRA finds this complaint **unsubstantiated** but adds that there is a responsibility by the KCCDD to follow the regulations that state they must provide individuals with developmental disabilities the training needed to live and function in integrated social settings and promote independence in daily living (59 Il Admin Code 119.100). The HRA strongly **suggests** that in the future, if the facility is requested to provide services that contradicts the mission of the facility, they advocate on behalf of the individuals receiving service in order to protect the integrity of the facility's mission, allow individuals receiving services to have independence in daily living, and not stifled by institutionalized restrictions that may be unwarranted for some within the facility. Be certain that all residents are asked how they feel about these types of restrictions and that their rights to choice, particularly as members of the IDT, are respected.

The HRA also offers the following **suggestions**:

- During the HRA's tour of the facility, there was discussion that the boiler is not always functional, and on the day of the tour the lunch room temperature was not at a level that would be deemed comfortable. The HRA suggests the facility update or fix the boiler so that the consumers are able to be comfortable at the facility in accordance with 59 Il Admin Code 119.255.
- In reviewing the Human Rights Policy Procedure document, the HRA discovered that the address for the Springfield Guardianship and Advocacy office needs updated. The HRA suggests updating the address on the document to read 521 Stratton Building, 401 S. Spring Street, Springfield, IL 62706.
- Although the HRA acknowledges that this could have been the second time food being locked was discussed, there is still some concern with the fact that the policy was adopted on 1/28 but the HRA did not see evidence of it being discussed with the consumers until 2/29. The HRA suggests that, if this is not already occurring within the facility, that they discuss situations such as this with consumers immediately upon adoption of the policy.
- The HRA discovered discrepancies on whether an individual needed or did not need assistance with their food in an individual's ISP dated 9/12/11. The HRA strongly suggests that the facility review individuals' ISPs for errors such as this and correct any such inconsistencies.