



FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY - PEORIA REGION
REPORT OF FINDINGS

Case # 12-090-9015
St. Mary's Square

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving a complaint of possible rights violations at St. Mary's Square in Galesburg. The possible violations were as follows:

- 1. Residents are not placed in the least restrictive environment when the entire facility made a policy change that residents could only have food and water during certain times, under supervision, and regardless of the supervision level on the resident's treatment plan.**
- 2. The residents are subsequently not allowed money from their accounts to use for snacks in violation of financial rights.**
- 3. There is a lack of individualized treatment plan and supervision plan when all patients were restricted from eating or drinking without supervision.**

If found substantiated, the allegations would violate the Intermediate Care Facilities for the Developmentally Disabled Code (77 II Admin Code 300 & 350) and the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102).

St. Mary's Square is an Intermediate Care Facility for the Developmentally Disabled (ICFDD) that services the entire state of Illinois. They have 205 individuals who use the services at the facility and 250 employees ranging from RNs and Direct Service personnel to Food Service and Laundry. The facility staff explained that they are currently opening 25 new Community Integrated Living Arrangements (CILA) in Knox County which will be open in the next 1 or 2 years.

COMPLAINT STATEMENT

The facility has recently implemented a policy that residents cannot have access to food or drink in the living areas; they can only eat or drink in the dining room at meal times or at an 8:30 pm snack time. If a resident wants water outside of those times, they must make the request from a nurse while she is making medication passes. The complaint also alleges that residents who receive designated amounts of money every day to buy a snack from the vending machine no longer receive that money and the vending machines have been locked. Also consumers who

would often get their own glasses of water can no longer do that. The facility has stated the new policy has been adopted because residents with g-tubes have been digging out discarded food or drinks from trash cans and that it presents a choking risk.

FINDINGS

Interview with staff (4/30/2012)

The HRA interviewed St. Mary's Square staff members regarding the allegations cited in this complaint. The staff explained that the Illinois Department of Public Health (IDPH) was reviewing the facility for licensure and discovered an individual with a G-tube who had five or six incidents where he/she was found with corn kernels, soda, and popcorn. Staff stated that there are 34 individuals in the facility with G-tubes. The staff stated that often times, G-tube patients do not understand that they cannot have food by mouth. Documents showed that a nurse checked the patient and found no food in his lungs. The IDPH filed immediate jeopardy citations because of their findings and the facility had 10 days to present an abatement program.

The facility staff stated that they have a food policy that has been updated. The staff explained that the policy states that staff cannot have food because of the possibility of leaving food out that residents will take. This restriction applies to staff above the first floor. Staff explained that the statement in the policy is that residents may not have food or beverages within the facility unless supervised, but the policy never said they could not have water or food. The facility said that they received an A violation and was fined by the IDPH; the facility is currently appealing the fine. The staff said that at a resident staffing, an employee said St. Mary's Square was keeping food and water away from people and this was an untrue statement. There was a communication problem that generated the statement, and the facility has since changed the policy. The facility added a section to the policy that residents who can handle food and water are allowed both throughout the facility without supervision. Residents who are deemed unable to have food and water without supervision, can receive training to develop this skill. The facility staff stated that they still have parties on the residents' floors and hydration therapy, which is when staff bring liquids to the resident floors as a supplement during the day for hydration. Hydration therapy is twice a day on the weekends and consists of a cart being taken around the floors with water, Koolaid, tea, etc. and residents choose their beverage. During the week, hydration occurs when residents come home from the day/vocational program. The staff explained that the issue deals more with residents and staff not disposing food and water correctly. The facility is trying to control the disposal of food and water.

The staff explained that they only had a 10-day window to respond to the citations given by the IDPH. They stated that they had not met with the residents' family members until March 31st but the staff explained that they have been having regular meetings with families in general.

The staff explained that the situation also was a result of a choking death that occurred at the day training facility with which St. Mary's Square contracts. The IDPH visited the facilities to investigate the incident and then later in the year, when reviewing for licensure, they discovered documentation in the resident's file regarding choking, and gave St. Mary's Square the violation. The staff explained that they had no intent on trying to take individual rights away when creating the policy. The staff stated that they acted quickly and did not act as thoroughly

as they should have. With that being said, they did explain that they have given thought about what they were going to do to remedy the situation. Staff explained that some individuals were upset but they had no problems with behaviors. They said that St. Mary's staff complained the most.

The staff explained that if there is information for a change of condition regarding a resident, the facility has a staffing and a representative for the day program attends the meeting at St. Mary's Square. The change in condition is made to the resident's plan. The St. Mary's Square staff explained that they have daily contact with the day program. They also explained that any choking protections made had to be made at both St. Mary's Square and the day program.

The staff explained that they were in the process of adding the policy into the resident's plans. The day program is a subcontractor so St. Mary's Square is responsible for issues that occur there. St. Mary's Square staff explained that it is their responsibility to make sure that rules between facilities are similar. They said the day program has a copy of the policy. When there are policy changes, St. Mary's Square has a conversation with the day program's director. The day program is also included in every individual service plan. In this instance, St. Mary's Square spoke directly to the day program director.

The staff said the policy never restricted money for snacks. Residents receive banking money at the day program to buy snacks. The staff stated that they encourage residents' families to not violate the residents' diets by giving them food. Overall they have good families that follow the rules. They explained that many of the residents have been with the facility for 20 years or longer. The staff said that supplements are given three times a day and that these supplements could consist of snacks and beverages. The staff explained that the facility mostly consists of elderly and medically fragile individuals. They said many of the residents receive water from the nurses and also receive water at medication passes. At meals, residents receive milk, water, tea or juice, etc.

The staff explained that they have lessened the restrictions in the policy. They explained that no drinks were taken away from residents. The staff was unsure as to how long the first version of the food and water policy lasted; they speculated that it was two or three weeks. The staff said there is a facility Human Rights Committee and the policy was discussed with the Committee. The facility staff stated that they considered every risk of the policy while creating it. The staff said the policy also satisfied the abatement and the policy was approved by the IDPH. The facility had to write a plan of correction for federal and state agencies.

The staff explained that if a resident's situation is severe, they may have a Interdisciplinary Team (IDT) staffing to discuss it. Even mild situations are shared at an IDT meeting. The facility also performs assessments in an ongoing fashion. If a resident is admitted to the hospital, information is sent to the day program, and anything that is observed by the day program is reported to St. Mary's Square. Staff explained that the choking death was a behavior issue and not a physical issue. St. Mary's Square staff explained that IDPH mandates require that if a residential facility contracts for day program services then the residential service is responsible for what occurs at the day program.

The staff stated that the food and water policy was adopted in January 2012. After the interview, the HRA called the staff regarding the policy for clarification and they had stated that not every resident had gotten a specific addition to the ISP, but those capable of having food and water without supervision had been identified and those that were not able had been put into a program where they could possibly achieve this. Staff explained that the goal of the facility is normalization for the residents. Each floor has an activity director and they have quarterly highlights and quarterly dinners. Some of the activities they participate in are movies, ball games, and trips to Peoria. Residents are sometimes involved in Special Olympics, a bowl-a-thon and the Best Buddies program from Knox College. There is also a Halloween Party and Christmas Party for the entire community. The residents attend church and an in-house church service. The residents have also gone on major vacations to Orlando, the Wisconsin Dells and to Chicago or St. Louis for sporting events. Staff stated that those types of trips are becoming more difficult with more individuals using wheelchairs.

Staff explained that they primarily serve individuals receiving public benefits; everyone is now on Supplemental Security Income (SSI). Residents are allotted \$30 a month unless they have jobs through a workshop. Their money goes into a residential fund. Residents have banking twice a day; once at the workshop and once at the facility. Residents have two accounts and can have up to two thousand dollars in total assets. It is determined at the IDT staffing how the resident's money is spent. Some only want several dollars per week and some want ten dollars a week. The finances are individualized. Some residents have their own checking accounts. The residents will sometimes request vouchers to go to yard sales, etc. On a later call to the St. Mary's Square staff, it was stated that each individual has an interest bearing savings account through a bank. Anything over \$100 goes into that account and anything below the \$100 is kept at the facility for the residents.

Staff stated that they did not restrict the residents from receiving their own money. Some residents were not allowed to buy snacks with the money because of physical issues, so they spent the money elsewhere, but those individuals would not have been allowed to buy snacks prior to the policy. When the policy was created, residents that could buy snacks still would, they just had to be supervised. Staff said that the policy is still a work in progress. Staff also explained that they did not hear that the policy was an issue with the residents. The staff also stated that there is a grievance process if the residents do have complaints.

The staff said that, in the facility, there is a mix of independence levels, but many of the residents are dependent on assistance from staff. Staff said that the majority of the residents are considered to be at either the severe or profound level of cognitive functioning. The facility staff explained that there also is a group of younger residents that are active. The staff explained that there are 134 individuals using wheelchairs. The facility has eating skills programs that the staff described as "pretty in-depth." The staff stated that they feel like they have done everything they were supposed to have done in the situation. Staff explained that supervision standards are in the individual treatment plans and staff consider residents independent unless it is written differently in their plans.

FINDINGS (Including record review, mandates, and conclusion)

Because of the similarities in the complaints, the HRA has combined complaint #1 and complaint #3.

Complaint #1 Residents are not placed in the least restrictive environment when the entire facility made a policy change that residents could only have food and water during certain times, under supervision, and regardless of the supervision level on the resident's treatment plan & Complaint #3 There is a lack of individualized treatment plan and supervision plan when all patients 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 releases for 5 individuals and requested 3 additional masked records for recipients who require supervision regarding food and water.

The HRA began by reviewing the original policy regarding food and water provided by St. Mary's Square and a revised version of the same policy. The policy has an adopted date of 1/28/12 and then the updated policy had a date of 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 is "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, that has a revision date of 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."

The HRA reviewed the individual service plans regarding the food and water policy. All records reviewed had an addendum stating whether the individual was able to consume food/drink and dispose of trash. All addendums reviewed were dated 3/28/12 or 3/29/12 which is 17 or 18 days after the updated policy had been adopted. The HRA reviewed formal programs in the ISPs, dated after the addendum, that dealt with the residents disposing trash. The HRA also reviewed short term and long term objective sheets, dated after the addendum, dealing with the residents eating and throwing away trash. The HRA did not see any evidence that the actual ISPs were changed or updated because of the new policy prior to the addendum dates. There was one plan reviewed that fell in between the adoption date of the policy and the updated policy and this plan was dated 2/15/12 but made no mention of the policy outside of the attached addendum.

The HRA also reviewed St. Mary's Square policies that were pertinent to the complaint. In a policy on the subject of facility goals for residents, it reads "The facility shall provide program and facility goals determined by each person's developmental abilities, providing the least restrictions to promote independence and designed to meet goals of normalization." The same policy reads "The facility is an intermediate care community facility concerned with and about training and care for adults with developmental disabilities. To support this concept, the facility strictly adheres to the absolute rights of all individuals residing within the facility. To us, this means each resident must be actively involved in determining his own destiny, determining his life goals and determining his own habilitation." The policy also states "Normalization requires the right of individuals to make or participate in meaningful decisions and to express their individuality in lifestyles ... The facility recognizes that in order for the adults with developmental disabilities to make meaningful decisions, training programs must develop the capacity of the residents to make responsible decisions affecting their own lives." The policy finally states "In regard to the expression of their own individuality, residents are encouraged to perform their own tasks of daily living; ... make their own choices and decisions."

The HRA researched state and federal mandates in accordance with the complaints raised within this report. The ICFDD regulations state that "The facility shall provide, either directly or through arrangements with an outside resource, as needed by the individual resident, all resident living services, training and guidance necessary in the activities of daily living and in the development of self-help skills for maximum independence" (77 II Admin Code 350.1010). The regulations also read " a) *No resident shall be deprived of any rights, benefits, or privileges guaranteed by law based on their status as a resident of a facility.*(Section 2-101 of the Act) (A, B)" (77 II Admin Code 350.3210). The Mental Health and Developmental Disabilities Code (MHDDC) (405 ILCS 5/2-102) requires 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. 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 Mental Health Code also states that "No recipient of services shall be deprived of any rights, benefits, or privileges guaranteed by law, the Constitution of the State of Illinois, or the Constitution of the United States solely on account of the receipt of such services" (405 ILCS 5/2-100 a).

Conclusion - Complaint #1 and Complaint #3

Between the dates of 1/28/2012 and 3/11/12 the facility policy stated that no resident was able to eat or drink food without being under supervision. Because the facility was not following the rules dictated in the ICFDD regulations regarding the provision of training and guidance necessary to develop self-help skills for maximum independence (77 II Admin Code 350.1010) nor providing adequate and human care and services in the least restrictive environment for all pursuant to their ISPs (405 ILCS 5/2-102), as well as not following its own policy regarding resident goals for independence, the HRA finds this complaint to be **substantiated**. Because the HRA saw evidence that the policy has been revised to allow a less restrictive environment and because the HRA saw evidence in the ISPs reviewed that there has been an amendment added to the plans, the HRA has no **recommendations** at this time and believes the facility has made the

required changes needed to rectify the situation. The HRA would like to make the statement that, in cases such as this, the HRA is concerned about the facility making institutionalized policy rather than decisions based on the individual. In future occurrences such as this, the HRA asks the facility to recognize each resident as an individual who is afforded the right to individual treatment in the least restrictive environment possible.

The HRA would like to make the following **suggestions**:

- Because the facility stated that they had not made specific additions to the individual's ISPs regarding the supervision, the staff needs to assure that the amendments are added to the individuals' ISPs per the Mental Health and Developmental Disabilities Code.
- The resident rights policy has a revised date of 1/2003, making it nine years since the policy has been reviewed for updates. The Resident's Rights document that is to be signed by the resident or the guardian has a revision date of 9/1986, making it 26 years since the last review and update. The HRA **strongly suggests** that the facility review the policy for all updates and changes in regulations and then add these updates to the resident's rights policy and form.
- In reviewing the residents' ISPs and the ISPs provided by the day training facility, the HRA noticed some differences between the two documents in the group that were reviewed. The HRA **strongly suggests** that St. Mary's Square assure that the residents have updated ISPs sent to the day training facility to ensure that all staff are on the same page regarding resident treatment plans.
- Staff stated that they had meetings with the resident's families on March 2012 but the policy was adopted in January 2012. The facility staff did state that they had regular meetings with the families through those months. The HRA is concerned because, if the regular meetings were not with every client that had a guardian or active family member, then the guardian/family would not have known about the policy until a couple of months after it was adopted. The HRA suggests that in the future, have any family meetings regarding new policies as soon as possible after the policy is adopted.

Complaint #2 The residents are subsequently not allowed money from their accounts to use for snacks in violation of financial rights.

The HRA reviewed the financial records for the 5 individuals for whom they received consent and the 3 masked records for individuals that were provided. The financial records ranged from 11/11 to 4/12 (three sets of resident records also have financial records for October) and, of the resident records provided, 6 of the 8 records had documentation of withdrawing snack money for the day program. Of the two individuals who did not have records of withdrawing the snack money, one individual did not work/attend the day program and the other had a G-tube and did not eat at the day program (this information was provided by the individual's records acquired from the day program). Also, 6 of the 8 records had a "banking" withdrawal occurring each month and in April, the banking withdrawal occurred on 4/23. Of the two records missing banking withdrawals, one is missing the 4/23 date and the other has no banking withdrawals at all during the 11/11 through 4/12 dates. For one of the sets of resident's records, there is no explanation for the banking being missing for the month, but for the other, the staff member who provided the information wrote a statement that reads "In reviewing the financial records of

[resident], one of the individuals for which we had received a release, I noticed that she was not receiving banking. [Resident] was unable to consume water or food by mouth, receiving all nourishment via a g-tube. [Resident] was also hospitalized for 23 days of this period of time. [Resident] died on April 24. Because she was not purchasing daily snacks she had been taken off of banking. This was a misunderstanding by the facility QMRP. The facility policy (enclosed) is that all residents receive access to their money through our banking program. Believing that this may not have been an isolated situation I inserviced the QMRPs of the facility (enclosed) that ALL residents are to receive banking even if they are not purchasing daily snacks." The statement also reads "In policy 3.25 I also addressed practices that have been occurring, such as residents accessing their money for activities or other purchases, by making a request to their QMRP. You will see these actions on some of the financial reports enclosed as they are common practice in the facility."

St. Mary's Square provided the HRA with two versions of the banking policy, the first has a revision date of 3/25/2008 and the second has a revision date of 5/15/2012. The original policy, dated 3/25/2008 is the one that would be involved with this situation due to the date of the incidents, which occurred prior to March 2012. The revision date occurred after the HRA conducted a site visit with the facility. The first policy states that "St. Mary's Square Living Center (SMSLC) shall provide residents access to their monies" and that "St. Mary's Square will provide a procedure for routine access to resident's monies through its daily banking procedures." The update to the policy states that the residents can access their monies through resident banking or through requests to the QMRP and also that "Residents may also access their funds at any time for activities or purchases not specified in banking through a request to the QMRP." The policy proceeds to read that "The Interdisciplinary Team coordinated by the QMRP shall determine the amount and frequency each individual resident is to receive for banking. Changes in banking amount and/or frequency will be reviewed at resident's staffing." This statement appears in both policies. The original policy states that each night, staff will pass out banking money to the resident following the amount and frequency specified by the QMRP. The policy states that the amount given will be tracked daily and the bags containing the individual's money will be returned to the Team Leader and Administrative Assistant for reconciliation and an end-of-month report will be prepared. From reviewing the individual resident banking, the money is taken out in a lump sum and then divided nightly. The snack money for the day program is also taken out monthly. Updates to the original policy reads "All residents must have access to their monies and therefore must receive banking in the amount and frequency that is agreed upon by each resident and their Interdisciplinary Team and stated in their ISP and coordinated by their QMRP." Another update reads "All requests to the QMRP for additional money for activities and purchases will be considered based on money available. The QMRP is encouraged to discuss purchases, particularly of large sums, with parents or guardians, if applicable." In reviewing the resident's ISPs, all have banking amounts added to them as stated in the policy with the exception of the individuals previously mentioned in this report.

St. Mary's Square provided a copy of the banking in-service that was discussed earlier in the staff member's statement. The in-service is dated 5/24/12 and states "The policy of the facility is to provide access to each person's monies through a process we call banking. Banking is a routine or procedure where funds are made available and dispensed on a schedule determined at the ISP staffing. The scheduled access may be daily, weekly, monthly, or even

longer if this is the choice of the resident. It is still banking if the person has chosen to not receive daily banking but has instead agreed to have a shopping trip scheduled once a month, or has agreed to have certain items purchased for them that they are saving for. Arrangements and documentation for outings or item purchases are the responsibility of the QMRP. Banking is not just money to purchase daily snacks. The schedule and purpose of the banking is each resident's choice. It is their access to their money. If it is their choice to forgo daily snacks to purchase a DVD each month then that is there [sic] banking and it should be explained and agreed upon in their ISP. ALL residents must have access to their monies, therefore all residents must have banking and it MUST be described in the ISP."

The HRA reviewed savings statements of four of the individual's records and saw evidence that they had money in interest bearing accounts in a bank outside of the facility.

On the resident's rights form, it reads "Each resident has the right to manage his or her personal financial affairs, or is to be given at least a quarterly accounting of financial transactions made on his or her behalf, should the facility accept the resident's written delegation of this responsibility to the facility, or upon written request, be given monthly accounting of such transactions. Any resident funds held or controlled by the facility, and any earnings from them, shall be credited to the resident and may not be commingled with other funds or property except that of other residents." The facility policy regarding financial affairs reads "Each individual shall be allowed to manage his/her personal financial affairs." The policy also reads "If Individual requests assistance from the facility, it shall be in writing and the Individual shall sign and request 'Personal Allowance Funds Management Authorization'" and "The facility shall comply with the record keeping requirements."

The ICFDD regulations read "a) *A resident shall be permitted to manage his own financial affairs unless he or his guardian or if the resident is a minor, his parent, authorizes the administrator of the facility in writing to manage such resident's financial affairs under subsections (b) through (o) of this Section. (Section 2-102 of the Act)*" (77 Il Admin Code 300.3260). The MHDDC reads "§ 2-105. A recipient of services may use his money as he chooses, unless he is a minor or prohibited from doing so under a court guardianship order" (405 ILCS 5/2-105).

Conclusion - Complaint #3

The facility admitted to a resident not being signed up for banking and then, in reviewing another ISP, the HRA discovered that there was another resident missing banking for a month. Because of this, the HRA finds the complaint **substantiated** but because the facility appears to have resolved the situation through a staff in-service, the HRA offers no recommendations.

The HRA would like to make the following **suggestions**:

- The HRA acknowledges that many of the residents may need assistance with their banking, and can understand that there may need to be a specific amount decided upon by the IDT team for the resident's banking, but the HRA would like to suggest that the facility take great care that they are not presenting another blanket policy for residents

and are not restricting some individuals who could require little or no assistance with their banking. The HRA suggests that the facility assess the residents to assure that this policy is applied in the least restrictive and individualized manner as possible. The HRA recognizes that the QMRP has a lot of responsibility regarding the individual's money with statements in the policy such as "All residents must have access to their monies and therefore must receive banking in the amount and frequency that is agreed upon by each resident and their Interdisciplinary Team and stated in their ISP and coordinated by their QMRP" and "All requests to the QMRP for additional money for activities and purchases will be considered based on money available." The HRA would like to suggest that the facility emphasize that the QMRP is not the primary decision maker regarding the resident's finances (unless stated so by the resident) and that the residents and guardians should ultimately have the final decision regarding their finances.

- The resident's rights form states that each resident's funds cannot be commingled with other funds or property except that of other residents. While the HRA saw no evidence of resident's funds being mixed or residents not receiving funds due to them, they believe that the policy currently needs further clarification due to the confusing nature of the wording.