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REPORT OF FINDINGS
ELISABETH LUDEMAN DEVELOPMENTAL CENTER- 16-040-9014
HUMAN RIGHTS AUTHORITY- South Suburban Region

INTRODUCTION

The South Suburban Regional Human Rights Authority (HRA) has completed its investigation into allegations regarding Elisabeth Ludeman Developmental Center (ELDC), a state-operated facility located in Park Forest. The complaint stated that a resident's right to communication with persons of choice is being restricted. Additionally, the complaint stated that the facility will not provide the guardian with incidents and injuries reports as requested. If substantiated, these allegations would be violations of the Mental Health and Developmental Disabilities Code (the Code) (405 ILCS 5/100 et seq.), the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/4) and the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23).

METHODOLOGY

To pursue the complaint, a site visit was conducted at which time the facility's staff were interviewed. The complaint was discussed with the resident's guardian by phone several times. Sections of the resident's record were reviewed with written consent. Relevant policies were also reviewed.

COMPLAINT SUMMARY

The complaint stated that the resident was not allowed to talk to her guardian on March 8th, 2016 because she had refused to attend school due to illness on that previous day. Additionally, the complaint stated that the facility had failed to provide the guardian with copies of incidents and injuries reports upon her request.

FINDINGS

According to the record, the resident was readmitted to the ELDC from a behavioral health unit on November 5th, 2015. She had been discharged from the facility to a community living arrangement two months prior to returning to the facility. It was agreed that new assessments were not warranted because of her brief stay in the community and that they would be updated if needed. Also, the facility's interdisciplinary team had agreed to reinstate the resident's individualized support and behavioral intervention plans dated July 30th and June 12th, 2015, respectively. Her individualized support plan documented that she is verbal and able to express herself using grammatically correct sentences. She requires supervision in the community due to her inability to make appropriate social choices. Her mother is her legal guardian, and she wanted to be informed about all daily activities, appointments and any injuries.

The resident's behavioral intervention plan targeted symptoms of Bipolar Disorder, non-compliancy, verbal and physical aggression, property destruction, elopement, and inappropriate sexual behaviors. Her behavioral intervention plan stated that she has a history of calling her mother to intervene instead of accepting responsibility for her actions when she is upset and does

not get what she wants. It documented that her phone privileges would be delayed for one hour if she exhibited her targeted behaviors and would be resumed if she is able to demonstrate appropriate behaviors within that same hour. If she does not calm down within 60 minutes, her phone privileges would be delayed for another 30 minutes and thereafter until she exhibits appropriate behaviors. It stated that the resident's behaviors included meeting older men via the internet and arranging to meet them in the community and engaging in risky sexual activities. And, to prevent her inappropriate sexual behaviors that: 1) access to all electronic communication devices such as cell phones and iPods would be restricted at her home, and, 2) the facility prohibits all residents from using electronic communication devices such as cell phones. Her behavioral intervention plan documented that she was informed that all electronic communication devices would be taken away from her and given to her mother if she violates the facility's restriction on this issue.

The resident's behavioral intervention plan documented that she was placed in a privileges suspension program. She was reportedly informed that phone calls, the snack shop, and other privileges would be suspended for 48 hours at the minimal if she exhibited any of her maladaptive behaviors and especially physical aggression or extreme verbal aggression for longer than five minutes. Her privileges would be resumed if she is able to demonstrate appropriate behavior during the suspension time-frame above. If she displays significant maladaptive behaviors again, her privileges would be suspended for 24 hours and thereafter until she is able to demonstrate appropriate behavior. Her behavioral intervention plan was approved by ELDC's Behavioral Intervention Committee and its Human Rights Committee. It was reviewed on November 13th, 2015 and March 18th, 2016. It was documented that the guardian would be informed about how to appeal any rights restriction to the facility's Human Rights Committee or its Director according to the program policy.

The HRA reviewed many progress notes detailing the resident's inappropriate behaviors and her injuries. A therapist's note stated that the resident had exhibited self-injurious and physical aggressive behaviors on November 7th, 2015, which is seven days after she had been readmitted to the facility. She reportedly hit herself in the eye and put her hand in a staff person's face because she was on restriction and could not go outside for a walk. Her record lacked documentation of guardian notification. On December 6th, it was recorded that the resident was allowed to use the phone to call mother as requested. Then, she was allowed to call her sister and told the staff person that her sister's phone number was disconnected. Shortly afterwards, a male individual called the facility's home phone and asked to talk to the resident and said that she had called him twice. Two days later, the resident reportedly started kicking, hitting, scratching and trying to bite the staff because they prevented her from kicking her housemate. Then, she grabbed a bulb from the Christmas tree and tried to cut herself with the object. She was described as being "out of control" when additional staff arrived to the home for assistance. She reportedly threatened to stab the staff with a knife and was placed in a physical hold for 10 minutes. Also, mechanical restraint for 60 minutes was used due to her level of aggression. According to a nursing note, a small bruise with no swelling or bleeding was observed after the incident leading up to the use of restraint. Also, the nurse wrote that the guardian was notified that 6 point restraint was used because of aggressive and destructive behavior.

For 2016, the progress notes stated that a nurse at the resident's workshop had informed the facility's nurse that the individual had a 3" scratch on her right thigh on January 5th. It was recorded that the physician and the guardian were notified. On the 27th, it was recorded that the

guardian was informed that the resident had been very aggressive and tried to elope while attending her workshop. For February, Ativan was administered on the 9th because the resident pushed and scratched her housemate. Then, she started hitting and kicking at the staff because she was prevented from eloping. A nurse reportedly examined the resident and no injuries were observed and guardian notification was given. On that same month, an injury report documented that the resident fell while she was walking to the facility's van to attend her workshop on the 26th. A superficial abrasion with no bleeding on her right knee was noted. There was no documentation that her guardian was notified.

For March, the progress notes indicated that communication by phone was restricted because of behavioral issues. On March 7th, it was recorded that the resident had no complaints but had refused to get out of the bed and to go to work. Also, she refused medication and was non-compliant with performing other morning activities. Once notified, the assigned Qualified Intellectual Disabilities Professional (QIDP) instructed that the resident could not have any phone calls because of her refusal to go to work. On March 8th, a progress note documented that the resident was not allowed to talk to her mother as stated in the complaint. Her mother was informed that phone calls were temporarily being denied due to her recent behaviors. Her mother reportedly told the staff person that she was going to notify the Unit Manager about this issue. There was no documentation found during the record review that the guardian contacted the Unit Manager.

On March 8th, another staff person wrote that during a bed check that she heard a male voice and saw a light shining by the resident's head. On questioning, the resident told the staff person that the light was coming from a MP3 player. This is an electronic device that can play digital audio files. Then, she reportedly became verbally abusive and refused to show the staff person the device which was actually a cell phone. She put the cell phone in her panties and told the staff person that she was going to jail for rape if she removed the device. The night supervisor was called for assistance and the resident told the staff that she had gotten the cell phone from someone at her day training program. She told them that her mother said that she should not give the cell phone to anyone before she picked her up for a home visit on that Friday. She said that she has the right to have a cell phone and that her lawyer would be notified if the device was confiscated. Again, she became verbally abusive, and her mother was called about the on-going incident. She reportedly was allowed to talk to her mother after the night supervisor had finished talking to her. She was overheard telling her mother that the QIDP said that he would take her cell phone and that she would be on restriction and would not be able to go home for a visit. Her mother told her that she would pick up the cell phone on Friday and she took the battery out of the device and gave it to the night supervisor. Then, she told the staff that she was going to harm self and attempted to grab pins from a board and ran toward the kitchen. It was recorded that the resident was closely monitored and continued to be verbally aggressive and no injuries were observed. On the 22nd, the guardian was reportedly informed that the resident was transported to a hospital's emergency department for cutting her wrists at her workshop and was returned to the facility on that same day.

Regarding the complaint about communication, the facility's staff said that the resident's privileges suspension program includes phone calls as indicated in her behavioral intervention plan. The staff said that her phone calls were restricted for behavioral reasons on March 8th as documented in her record. The guardian told the HRA that the facility's staff were aware that the resident was experiencing stress because she had been sexually assaulted exactly one year ago when communication was denied on the incident day above. She said that she was informed

that the QIDP said that the resident could not receive phone calls because of behaviors on that previous day. She said that leading up to the communication restriction that the resident had refused to attend school because she was not feeling well. Also, the guardian explained that she did not know about the resident's two cell phones prior to the staff taking them from her. Later, she learned that the resident had purchased a cell phone from someone in the community when she had eloped from the facility and had borrowed another cell phone from someone at her workshop. She said that she had picked up the first cell phone after the resident's annual staffing in June 2015 and that the second cell phone was returned to its owner at her workshop. On questioning, the facility's staff said that the resident is allowed access to communication devices such as cell phones if she does not exhibit inappropriate behaviors. However, her behavioral intervention plan indicated that such devices are prohibited by the facility.

Regarding the complaint about record access, there was no documentation that the guardian had requested records found in the resident's chart. However, the guardian said that she did request copies of incidents and injuries reports on or around February of 2016. She said that the Facility Director told her that she would receive them. However, this did not occur. The guardian told the HRA during a subsequent discussion that the Facility's Health Information Administrator told her that the records would be provided in July or August of 2016. She said that she was still waiting for the records two months later. She explained that the facility's nurse had called her about three times in 2016 and said that the resident had an injury or that no injuries were observed. However, she wanted more information about the incidents and/or injuries and requested copies of records. At the site visit, the Facility's Health Information Administrator told the HRA that the guardian had requested records twice in 2016. She said that the guardian first requested copies of three injury reports on or around of March 2016 and that they were provided. She said that the guardian subsequently had requested copies of all documents since the resident was returned to the facility in November of 2015. She said that she was working on the guardian's second request for records and was unable to provide the date of her request. She acknowledged that she should have documented both of the guardian's requests in the resident's chart.

ELDC's "Rights of People Receiving Services" policy states that the facility is responsible for protecting and affirming the rights of its residents pursuant to the Mental Health and Developmental Disabilities Code. The policy states that the Unit Director of the home is responsible for ensuring that the resident and/or guardian receives and a copy of the Rights of Individual Receiving Mental Health and Developmental Services and the Application for Admission and an explanation of these rights at intake. It states that certain rights outlined in the Mental Health Code may be limited based on clinical recommendations. In some cases, this may be done through clinical and administrative procedures, and the responsibility to restrict rights rests with the facility. It states that rights shall not be limited without due process. Rights that may be limited include communication by telephone or cell phone, to send or receive mail in privacy, to receive visitors, and to have personal property. If a cell phone is used inappropriately, the ELDC's Interdisciplinary Team and its Human Rights Committee will address this issue. When rights are limited, this must be specifically explained to the resident, guardian or family or advocate if appropriate. This is usually done during an Interdisciplinary Team staffing at intake, annually or special team meeting. The affected person or individuals acting on the person's behalf are given an opportunity to object to the proposed restriction of rights.

The facility's "Management of Maladaptive Behavior" policy states that residents have the right to receive visitors, mail, and to make and receive calls unless the Interdisciplinary Team (IDT) makes a determination that a restriction is necessary pursuant to the Mental Health Code. According to the facility's rights statement, residents and guardians are informed whenever rights as identified in the Code are restricted. They are informed about how to appeal the facility's decisions.

According to ELDC "Clinical Records" policy, a resident's clinical record will be made available to the individual, parent, guardian or advocate upon their requests. It states that a qualified staff should be available to answer questions about the record.

The facility's "Injury Reports" policy states that clients will be provided with a safe environment in which the risk of injury is minimized. An injury report shall be completed for all injuries even if the injury does not occur on the facility's campus. The policy includes procedures for reporting injuries such as notifying the Residential Services Supervisor and the nurse within 10 to 15 minutes after observing them. It directs the staff to provide as much information as possible about the injury in the report's comment section. There was no mention of guardian notification.

CONCLUSION

According to Section 5/2-102 (a) of the Mental Health and Developmental Disabilities Code,

> 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 resident to the extent feasible and the resident's guardian, if appropriate.

Section 5/2-103 (c) of the Code states that,

> Unimpeded, private and uncensored communication by mail, telephone and visitation may be reasonably restricted by the facility director only in order to protect the recipient or others from harm, harassment or intimidation, provided that notice of such restriction shall be given to all recipients upon admission.

Section 5/2-201 of the Code states, whenever any rights of a recipient of services are restricted, the recipient and guardian shall be promptly given notice of the restriction.

According to Section 110/2 of the Mental Health and Developmental Disabilities Confidentiality Act,

> Record means all records and communications, except for the therapist's personal notes, kept by an agency in the course of providing mental health or developmental disabilities service to a recipient and the services provided.

Section 110/4 states that,

> The parent or guardian shall be entitled, upon request, to inspect and copy a recipient's record. Whenever access or modification is

> requested, the request and any other action taken thereon shall be noted in the recipient's record.

The Illinois Probate Act Section 5/11a-17 states that the personal guardian shall make provision for the ward's support, care, comfort, health, education and maintenance.

Section 5/11a-23 states that,

> Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian … to the same extent and with the same effect as though the decision or direction had been made or given by the ward.

The complaint stated that a resident's right to communication with persons of choice is being restricted. Based on the record and the facility's staff, the resident was not allowed to talk to her mother (the guardian) on March 8th, 2016 as stated in the complaint. Her behavioral intervention plan stated that she was placed on a privileges suspension program that included phone calls. It stated that she would not be allowed phone calls if she exhibited any of her targeted behaviors. Her record indicated that she was non-compliant with programming and had refused to attend school and to go to work, etc. on that previous day. The HRA noticed that the facility erroneously references phone calls as being privileges in her behavioral intervention plan. However, to make and receive phone calls is one of the resident's guaranteed rights under the Mental Health and Developmental Disabilities Code Section 5/2-103 (c), not a privilege to be earned. The Code allows communication to be reasonably restricted only in order to protect the recipient or others from harm, harassment or intimidation concerning that communication, provided that notice is given upon admission. The facility and its behavior plan violates Section 5/2-103 (c) of the Code and 2-201. Ludeman "Rights of People Receiving Services" policy states that certain rights found in the Mental Health and Developmental Disabilities Code may be limited based on clinical recommendations. Section 5/2-202 of the Code requires the facility to have policies concerning communication and restriction of rights, and states that such policies may amplify or expand but may not restrict or limit, the rights guaranteed to recipients in Chapter II.

Additionally, the complaint stated that the facility will not provide the guardian with incidents and injuries reports as requested. According to the guardian, she had requested records in early 2016 and that she was still waiting for them in October of 2016. The Facility's Health Information Administrator told the HRA that the guardian had requested records twice in 2016. She said that the guardian's first requested copies of three injury reports on or around of March of 2016 and that they were provided as requested. She told the HRA that she was still working on the guardian's second request for copies of records since she was readmitted to the facility in November of 2015. There was no documentation concerning the guardian requests for records found in her chart that would provide proof and the Facility's Health Information Administrator acknowledged that she should have documented them. The facility violates the Mental Health and Developmental Disabilities Confidentiality Act Section 110/4.

RECOMMENDATIONS

1. Follow the Mental Health and Developmental Disabilities Code Section 103 (c) and the facility's "Management of Maladaptive Behavior" policy in regard to communication. A restriction for phone communication should be the result of harm, harassment and intimidation from phone calls. Restricting a phone access for other behaviors such as non-compliancy with programming is not consistent with the Code.

2. Follow the Mental Health and Developmental Disabilities Confidentiality Act Section 110/4 and document all requests for access to records in residents' charts.
3. The facility shall follow its Rights of People Receiving Services and its Management of Maladaptive Behavior policy whenever any rights are restricted. Phone calls may not be restricted because of non-compliancy with programming.
4. Complete restriction of rights notices whenever guaranteed rights within the Code are restricted under Section 5/2-201 of the Code.

SUGGESTIONS

1. The facility should consider revising its policy on communication and potential restrictions to clearly conform to Section 5/2-103, 5/201 and 5/2-202 of the Mental Health Code.
2. Ensure guardian and resident involvement in treatment planning decisions, including behavioral intervention approaches.
3. If there are restrictions being reviewed and considered by the internal behavioral interventions and/or human rights committees, consider including residents/guardians for the discussions about their specific situations.
4. Document guardian notification preferences in individual treatment plans.

COMMENTS

Additionally, the guardian told the HRA that the resident had sustained a black eye, injuries to her mouth, and scratches on her arms and back area on October 1st, 2016. She said that the resident said that the staff had caused her injuries. However, a staff person told the guardian that her injuries were self-inflicted. She explained that she had called the resident twice on the incident night but phone communication was denied. She was told that she could not talk to the resident because she had bitten a staff person earlier on that same day. She said that she was not notified about the resident's injuries but saw them when she stopped by the home on that next day. She said that medical care was not provided on the incident night. She tried to call 911, when she saw the resident's bruises, but was not able to get telephone reception services. She said that she insisted that the resident should be seen by a physician. She requested a copy of the incident report involving her serious injuries sustained on October 1st. However, she was still waiting for a copy of the incident report. The Facility's Director told the HRA that she could not comment on the incident above because the Office of the Inspector General was still investigating the incident.

In February 2014, the Authority received a complaint (case #14-040-9011) involving the same resident and the right to communication and access to records. Regarding the complaint in case #14-040-9011, the Authority did not substantiate the complaint about communication as presented. However, the staff reported that the guardian was told that the resident could not talk on the phone when she had called one day. The Authority did substantiate the complaint stating that the guardian was not provided with incidents reports upon her request. The Facility Director told the HRA that guardians can receive copies of incidents reports upon their requests, but she would prefer that they do not request all of them. The guardian reported that she did receive copies of incidents reports after the HRA had met with the staff.