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**FOR IMMEDIATE RELEASE**

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HUMAN RIGHTS AUTHORITY - NORTHWEST REGION

REPORT 09-080-9007

LUTHERAN SOCIAL SERVICES OF ILLINOIS

Case Summary: Substantiated violations were found regarding communication rights and restriction processes. The facility responded with staff training and policy revisions. The HRA's findings and the facility's response are recorded below.

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving complaints of potential rights violations within Lutheran Social Services of Illinois' residential program. The following allegations were made concerning the program's Community Integrated Living Arrangement, or CILA, located in Dixon:

1. Resident telephone calls are not unimpeded, private and uncensored.
2. Staff members restrict or threaten to restrict community outings, family visits, use of the telephone and personal properties, and remove food items from the menu as consequences for misbehaving or being uncooperative.
3. Recipient rights information is not available to residents, they are not allowed to contact advocacy agencies and they are not asked to designate a person or agency of choice to be notified of rights restrictions.

Substantiated findings would violate rights protected by the Mental Health and Developmental Disabilities Code (405 ILCS 5) and the CILA Rules (59 Ill. Admin. Code 115).

The Dixon CILA is a unique home in that it only serves adults who have Prader-Willi Syndrome, a chromosomal disorder that impairs physical and mental development and causes compulsive eating. There are four males and four females who live there, each relatively high functioning and independent with daily living skills but needing supervision given the disability.

We met at the home with its manager where we discussed these issues and interviewed several of the residents privately. We also looked at relevant program policies as well as documents from resident files with identifiable information redacted.

FINDINGS

The first complaint states that in order to make telephone calls residents have to tell staff whom they are calling and that all calls are limited to ten minutes without exception. It was also

reported that one resident's conversations with his girlfriend can be overheard by staff on the office speaker phone.

To follow up on the complaint an HRA representative spoke with one of the residents at the home. Within ten minutes of their conversation a female's voice was heard in the background politely insisting that the resident get off the phone. Asked if that was a staff person, the resident said yes and ended the call.

In response, the home's manager stated that although it is not a written policy she limits telephone calls to ten minutes so that the seven residents who use the phone can get equal time; it's more of an expectation than a rule. The staff are instructed to ask about outgoing calls and to tell residents when their times are up. The practice has been in place for a while but is not as strict as it used to be. She used to keep a log of the names and places that residents called, but realizes that may have been censoring. She explained that they still ask where calls are being made because the residents might order restaurant food, which is a dangerous and uncontrollable affect of Prader-Willi Syndrome. She does not complete rights restriction notices for the limited telephone use and does not maintain a rights restrictions file.

The complaint that one resident's conversations with his girlfriend were overheard by staff on the office speaker phone came to us just after our visit when the manager retired. We notified Lutheran's administration and were told that they would look into the allegation. The manager's replacement said later that the home has new telephone equipment with two lines that may not be working properly and that it was possible to briefly hear the other line in use; the problem is not intentional. She also felt confident that the staff were not trying to listen in on conversations. She is spending a lot of time in the home at different hours to observe, and the staff have been instructed to end the ten-minute rule. The HRA followed up with the resident who said the situation seems to be better but that he would like the problem fixed permanently. Other residents reported that they are pleased with being able to stay on the phone longer.

We reviewed eight masked individual services and behavioral plans. Although there were a couple references to the occasional unwarranted 911 calls, which had not occurred in the past five years, none of them cited individually determined needs to monitor or restrict telephone use. There were no indications that the telephone practice as it relates to each individual was approved by the home's human rights committee, and there were no restriction notices in the records provided to us.

## CONCLUSION

The home provided copies of Lutheran's residential policies covering the gamut of service areas but there was nothing specific to telephone use or procedures for restricting a guaranteed right. A policy on individual rights and rights education materials that are shared with residents and families do acknowledge however the right to unimpeded, private and uncensored communications. There is also a staff training policy that calls for resident rights to be included within the forty hours of orientation for new hires.

Pursuant to the CILA Rules, "Employee advisement of the individual's rights and justification for any restriction of individual rights shall be documented in the individual's record." (59 Ill. Admin. Code 115. 250). "Each agency is required to establish or ensure a process for the periodic review of...human rights issues involved in the individual's treatment or habilitation." (59 Ill. Admin. Code 115.320). "The rights of individuals shall be protected by Chapter II of the [Mental Health and Developmental Disabilities] Code...." (59 Ill. Admin.

Code 115.250). Under Chapter II of the 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. (405 ILCS 5/2-102).*

*...a recipient who resides in a...developmental disabilities facility shall be permitted unimpeded, private, and uncensored communication with the persons of his choice by mail, telephone and visitation.*

*Reasonable times and places for the use of telephones...may be established in writing by the facility director.*

*Unimpeded, private and uncensored communication by mail, telephone, and visitation may be reasonably restricted...only in order to protect the recipient or others from harm, harassment or intimidation.... (405 ILCS 5/2-103).*

*Whenever any rights of a recipient that are specified in this Chapter are restricted, the professional responsible for overseeing...the recipient's services plan shall be responsible for promptly giving notice of the restriction...to: the recipient...his parent or guardian; [and any person or agency designated by the recipient]. .... The facility director shall maintain a file of all notices of restrictions of rights...for the past 3 years. The facility director shall allow the Guardianship and Advocacy Commission...to examine and copy such records upon request. (405 ILCS 5/2-201).*

The HRA appreciates the home's regard for resident safety but believes that efforts in this instance were too strict. The telephone expectations were not based on individual determinations of need, pursuant to individual service plans. The ten-minute limit was unreasonable and impeding, particularly in the least restrictive environment of a home; we're pleased that the new manager has appropriately ended the practice. Having to seek approval to call someone is censoring and does not allow communication with persons of a resident's choice, and, overhearing conversations on the faulty equipment does not ensure privacy. It is not clear whether that practice and the problem have ended. In addition, the telephone restrictions were not supported with notices to each resident, placed in their records or in a facility file and delivered to whomever they might have designated, and, the home's human rights committee was not involved in reviewing the matter. The first complaint is a substantiated rights violation.

## RECOMMENDATIONS

1. Periodically cover individual rights and service planning with all staff and ensure that those responsible for implementing service plans make individual service determinations based on need (59 Ill. Admin. Code 115.320 and 405 ILCS 5/2-102).
2. Stop the practice of making residents get approval for telephone calls unless it is necessary on an individual basis to prevent harm, harassment or intimidation (405 ILCS 5/2-103).

3. Resolve the faulty telephone situation and ensure that all residents' telephone conversations are private unless it is necessary on an individual basis to prevent harm, harassment or intimidation (405 ILCS 5/2-103).
4. Cover with all staff that unimpeded, private and uncensored communications by mail, telephone and visitation is a guaranteed right and that any restriction must be supported with a notice and documented in records pursuant to the Administrative and Mental Health Codes (59 Ill. Admin. Code 115.250 and 405 ILCS 5/2-201).
5. Develop policy that outlines procedures for restricting rights (405 ILCS 5/2-201).
6. Require facility directors to maintain 3-year files of all rights restrictions (405 ILCS 5/2-201).
7. Engage the home's human rights committee whenever services potentially risk any right (59 Ill. Admin. Code 115.320).

The second complaint states that staff members restrict or threaten to restrict community outings, family visits, use of the telephone and personal properties, and remove food items from the menu as consequences for misbehaving or being uncooperative.

Of the five residents we met with privately, two said that the manager threatens the loss of an outing or a family visit for doing something wrong; four reported that the manager says they will lose telephone privileges for not getting off when asked, one adding the loss of personal computer time for "losing my cool"; and two said that the manager and staff sometimes take coffee away, one of them saying other food items on the menu as well, when they misbehave, get up late or refuse to exercise.

The manager provided a response letter at the onset of our review. She wrote that community outings are contingent on a resident's behavior prior to an outing and that family visits are never withheld unless prearranged by a family or part of a behavior plan, although to her knowledge has not been used. According to the letter, they have indicated to residents that their families will be notified about unacceptable behaviors and that their families may question the length of the next visit. Elaborating during our interview, the manager said that some residents have been known to get quite angry at times. She or the staff may say to them that they could lose a privilege, like use of the telephone or an outing, but never family visits or use of computers or other personal properties. She said there must be some incentive to promote appropriate behavior and that for example, residents may also earn two pieces of sugar free candy. There are times when coffee is withheld in the morning for bad manners; she told us about the time a fellow put an entire egg in his mouth so he was only allowed half a cup. She asserted that coffee is not on the menu and that menu items are never removed as a consequence for bad behavior.

We reviewed masked activity summaries and behavior plans for all residents in the home. The summaries covered two to three months and demonstrated that each resident went on numerous community outings and family visits during that time. Regarding the behavior plans, most of them listed outbursts, potential physical harm and destruction of property as targeted problems. One individual's included sexual inappropriateness that has caused public humiliation and harassment charges; another individual's included false accusations. One plan stated that for reinforcement the resident's family agrees to forego the next visit following a physically aggressive incident. None of them withhold food or drink as behavioral consequences.

We also reviewed a diet protocol and menus. The protocol was set up to help residents reach and maintain appropriate weight goals. Increased snack and meal portions are built in as

rewards for achieving success and can be reduced again for weight gain. These are additions to the established menu and do not take away from the menus' required portions. Coffee was not included in the protocol nor was it ever listed on the menus that covered a seven week period.

## CONCLUSION

The program has several policies in place to address the array of service provisions, the development of client-centered service plans that include dietary requirements, the development of behavior plans, the encouragement of the individual's input and choice, and the promotion of community integration along with supervision based on individual needs, all of which fall in line with basic tenets of the CILA Rules (59 Ill. Admin. Code 115.100 et seq.).

The superceding Mental Health and Developmental Disabilities Code states that all recipients are to be provided with "...adequate and humane care and services in the least restrictive environment, pursuant to an individual services plan." Services plans are to be formulated with the participation of the recipient to the extent feasible, and any guardian (405 ILCS 5/2-102). It defines adequate and humane care and services as those "...reasonably calculated to prevent further decline in the clinical condition of a recipient...so that he or she does not present an imminent danger to self or others." (405 ILCS 5/1-101.2). The Mental Health and Developmental Disabilities Administrative Act adds that in formulating individualized behavioral support plans, "Interventions must not:...withhold essential food and drink;...cause physical or psychological pain;...or produce humiliation or discomfort." (20 ILCS 1705/15f). As noted in the first complaint, the Mental Health Code states that all recipients enjoy the right to communications, including telephone use, with the persons of their choice unless it is necessary to prevent harm, harassment or intimidation (405 ILCS 5/2-103) and that every recipient "...shall be permitted to receive, possess and use personal property...unless necessary to protect the recipient or others from harm." (405 ILCS 5/2-104).

The first issue in complaint #2 is whether the program restricts or threatens to restrict community outings and family visits for misbehavior. Since the primary function of a CILA is to promote community integration it makes sense to say that outings and family visits are absolutely necessary, and in this case records showed that all of the residents participate in them frequently. It is also understandable that from time to time an individual's behavior on a certain day may not be the best for an outing or visit, particularly when some are challenged with outbursts, potential physical harm and sexual inappropriateness. Holding someone back to prevent those, if truly needed, would seem to be an adequate and humane option. This part of the complaint is not a rights violation.

The next part of the complaint is whether staff restrict or threaten to restrict use of the telephone and personal properties for misbehaving or being uncooperative. According to the manager, she and the staff do tell residents that they could lose telephone privileges but never use of their computers. Telephone use is not a privilege but a guaranteed right under Chapter II of the Code, and in this case the stated practice is a substantiated violation. The use of personal properties such as computers is a guaranteed right as well unless the use becomes potentially harmful. Although one resident's claim of losing computer time as a behavioral consequence is not discredited, there is no specific evidence to prove that the right is being unjustly restricted; that part is not substantiated.

The last issue in complaint #2 is whether staff remove food items from the menu for misbehaving or being uncooperative. Two residents said that coffee is removed whenever they get up late or refuse to exercise, and one of the two said that other menu items were sometimes removed too. Coffee seems to be a special breakfast addition in the home and is not a menu item based on the menus we observed. The behavior plans do not withhold essential food or drink, and there is no indication that this is ever done in the home. The last part of the complaint is not substantiated.

### RECOMMENDATIONS

1. Stop the practice of restricting the telephone as a behavioral consequence and instruct all staff that privileges, not rights, may be earned (405 ILCS 5/2-100 et seq.).

### SUGGESTIONS

1. Be sure that other residents' privileges are not penalized because of one person's behavior.
2. Be sure that families are deciding when an individual cannot visit as in the one resident's behavior plan; otherwise it would be a restriction of the right to visit with persons of choice.
3. A behavior plan should address any resident's loss of community outings.
4. Staff should talk with residents to clarify what the diet protocol is for. It may provide some confusion because snack and meal portions fluctuate as a resident's weight does.

The third complaint states that recipient rights information is not available to residents, they are not allowed to contact advocacy agencies and they are not asked to designate a person or agency of choice to be notified of rights restrictions.

In her written response letter, the manager stated that each resident signs a rights document that has been read to them and that they are asked if they understand the information. At least once every four to six weeks they play a residents' rights bingo game. Rights are posted in the home's common area and there are posters on how to file a grievance and contact the Office of the Inspector General.

The HRA reviewed rights documents from each resident's file with identifiable signatures masked. Entitled, Client's Bill of Rights and Responsibilities, they are reviewed with the residents and their guardians or families on an annual basis. They seemed to be program-generated as opposed to the state-generated ones most often used and required in facilities. They included information on confidentiality, accessing records, filing grievances, contacting advocacy agencies and most of the rights under Chapter II of the Mental Health Code. Not included in the information were the right to receive, possess and use personal properties and the right to use money as a resident chooses. We also observed various postings in the home during the site visit, but the rights information was very limited and did not include specific rights under the Mental Health Code as relevant to services.

On the matter of residents not being allowed to contact advocacy agencies, an HRA representative provided his business card to a particular resident who later informed him that a staff person at the home took it away and ripped it up. During our interviews at the home, the

resident said that the staff person threw the card away. Another resident said that they would get into trouble if they called the Guardianship and Advocacy Commission but did not say that had ever happened. The manager told us that she looked into the business card issue and that according to the accused staff person, the resident dropped the card twice and both times the staff person picked it up and gave it back to her. The manager said that the resident's accounts are not always reliable, and she did not know why one or more of the residents feel unable to contact advocates; she would talk to them and provide reassurance.

Regarding the right to designate anyone to be notified whenever rights are restricted, the manager said that all residents take part in their services planning and that their choices and preferences are incorporated. It was never made clear that each resident is asked about designating a person or agency to be notified whenever a right is restricted specifically. An administrator at Lutheran's headquarters clarified later that they do this informally but can take steps to make it more formal. All of the residents we interviewed said they have not been asked if they wanted to designate someone and none of the records given to us provided evidence of being asked; the bill of rights form did not reference the right.

## CONCLUSION

Lutheran's individual rights policies cover all of the Mental Health Code's established rights unlike the document used at the Dixon home. Accompanying the policy is an old copy of the Medicaid Waiver rights form that lists all of the Code's rights including designating someone to be notified of restrictions, which does not appear to be used at the home.

Per the CILA Rules,

*...agencies licensed to certify CILAs shall assure that a written statement...is given to each individual and guardian specifying the individual's rights. All individuals enrolled in the Medicaid DD Waiver shall be given a written copy of DHS Medicaid Home and Community-Based Services DD Waiver, Rights of Individuals.*

*Employees shall inform individuals entering a CILA program of the following:...Their right to contact the Guardianship and Advocacy Commission, Equip for Equality, Inc., the Department's Office of Inspector General, the agency's human rights committee and the Department. Employees shall offer assistance to individuals in contacting these groups giving each individual the address and telephone number.... (59 Ill. Admin. Code 115.250).*

According to the Mental Health Code,

*Upon commencement of services...every adult recipient, as well as the recipient's guardian or substitute decision maker...shall be informed orally and in writing of the rights guaranteed by this Chapter which are relevant to the nature of the recipient's services program. Every facility shall also post conspicuously in public areas a summary of the rights which are relevant to the services delivered by that facility. (405 ILCS 5/2-200 a).*

*A recipient who is 12 years of age or older...at any time may designate, and upon commencement of services shall be informed of the right to designate, a person or agency to receive notice under Section 2-201 or to direct that no information about the recipient be disclosed to any person or agency. (405 ILCS 5/2-200 b).*

*Whenever any rights of a recipient that are specified in this Chapter are restricted, the professional responsible for overseeing...the recipient's services plan shall be responsible for promptly giving notice of the restriction...to: the recipient...his parent or guardian; [and any person or agency designated by the recipient]. (405 ILCS 5/2-201).*

Based on the documentation from records and observed postings in the home, required rights information provided to the Dixon residents has been incomplete. Without a required Medicaid DD Waiver rights form under the Administrative Code or a Rights of Individuals Receiving Mental Health and Developmental Disabilities Services that satisfies rights education under the Mental Health Code, the complaints that recipient rights information is not available, at least in full, or that residents are not asked to designate a person or agency to be notified of rights restrictions is a substantiated violation. All of the program's policies and rights documents advise residents, guardians and families on how to contacting various agencies, including the Guardianship and Advocacy Commission. With that, there is no evidence to suggest that residents are not allowed to reach the Commission or other advocates; that part of the complaint is not substantiated. However, we think the allegation still deserves attention for every resident who may have the perception.

## RECOMMENDATIONS

1. Discontinue using the bill of rights document, or, revise it to include the missing requirements (59 Ill. Admin. Code 115.250 and 405 ILCS 5/2-200).
2. Instruct the new manager to immediately cover the Medicaid DD Waiver rights form with all Dixon residents and their families and guardians, which can be downloaded from the DHS website (59 Ill. Admin. Code 115.250).
3. Review the need to use the Rights of Individuals Receiving Mental Health and Developmental Disabilities Services form, which also can be downloaded from the DHS website (405 ILCS 5/2-200).
4. Post conspicuously in public areas the full array of rights as they relate to the services being provided in the home (405 ILCS 5/2-200).

## SUGGESTIONS

1. The program's individual rights policy states on page 2 (I., E) that individuals have the right to participate in plan development and that families and legal representatives may too. The bill of rights document states something similar in #4. The Code does not limit participation to just family or guardians but includes *anyone* so designated in writing by the resident and states that the facility must advise each resident of this right (405 ILCS 5/2-102 a). The policy should be revised and staff in all facilities who are responsible for plan development and implementation should be familiar with this requirement and carry



- it out.
2. The new manager should meet with all residents in the Dixon home to reassure that there is no retaliation for contacting advocacy agencies.
  3. Train all staff to offer assistance to any resident who wishes to contact the Guardianship and Advocacy Commission or other advocacy agency.

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## **RESPONSE**

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

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Behavioral Health Services  
Administrative Office  
1001 E. Touhy Avenue, Suite 170  
Des Plaines, Illinois 60018  
847.635.4600



## Lutheran Social Services of Illinois

March 16, 2009

Erin Wade, PH.D., Acting Chairman  
Human Rights Authority  
Illinois Guardianship and Advocacy Commission  
4302 N. Main Street - Suite #108  
Rockford, Illinois 61103-5202

Reference: HRA Case #09-080-9007

Dear Erin Wade,

In reply to investigation that the Human Rights Authority completed Lutheran Social Services of Illinois wishes to submit the following response.

In regards to the recommendations of the first complaint:

1. Individual Service Plans are completed on an annual basis and are based on the goals, and needs of each individual. The Community Support Team includes members of the residential staff, day training staff, guardian (if applicable), and others that the individual being served wishes to invite. The rights of the individual are reviewed at this time. For those staff members not in attendance the plan is reviewed with them.
2. The residents of the home have been informed that they do not have to ask staff permission to use the telephone. Further, it is Lutheran Social Services of Illinois intention to provide a telephone in an area of the house that is conducive for privacy. This new telephone should be installed by April 30, 2009.
3. It is Lutheran Social Services of Illinois intention to provide a telephone in an area of the house that is conducive for privacy. This new telephone should be installed by April 30, 2009.
4. Training for all residential staff to review all rights in accordance with the Administrative and Mental Health Codes has been scheduled for March 26, 2009.
5. A policy for dealing with any restriction of a resident's right has been developed and is being implemented.
6. The program director has been informed of the need to maintain a file of any and all restriction of rights and to keep that file for a timeframe of three years after the incident has occurred.
7. The Human Rights committee will convene before the rights of an individual are restricted and will review any and all rights restrictions at least quarterly.

In regards to the recommendations of the second complaint:

1. A training for all residential staff to review all rights in accordance with the Administrative and Mental Health Codes has been scheduled for March 26, 2009

In regards to the final recommendations:

1. The facility is currently using the revised bill of rights document.
2. The program director has met with all of the residents and reviewed their rights as noted in the Medicaid DD Waiver.

3. The program is currently using the Rights of Individuals Receiving Mental Health and Developmental Disabilities Services forms.
4. The rights of individuals receiving services are posted in the house.

Lutheran Social Services of Illinois is requesting that these responses be made apart of the public record.

Sincerely,



Kevin Bercaw, LCSW  
Associate Executive Director