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**FOR IMMEDIATE RELEASE**

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**HUMAN RIGHTS AUTHORITY – METRO EAST REGION  
REPORT OF FINDINGS  
CASE #17-070-9013  
CARITAS FAMILY SOLUTIONS**

The Human Right Authority (HRA) has completed its investigation of possible rights violations at Caritas Family Solutions (Caritas). Caritas has four Community Integrated Living Arrangements (CILAs) that serve 14 individuals in the St. Clair County area of Illinois. Two CILAs are located in Caseyville, a third is in Fairview Heights and the fourth is located in Swansea.

The allegations being investigated are:

1. The facility failed to protect individuals' right to privacy when it sent identifying information to agencies and persons who were not involved in the resident's care
2. The facility violated consumers' rights when it failed to make reasonable attempts to obtain informed consent from an appointed guardian(s) before making medication changes.

If found substantiated, the allegation would violate the Mental Health and Developmental Disabilities Code Confidentiality Act (740 ILCS 110/3a & 405 ILCS 102), the Illinois Probate Act (755 ILCS 5/11a-23), the Mental Health and Disabilities Code, the Code of Federal Regulations (45 C.F.R 164.508 (a)(1)), and company confidential policies,

**METHODOLOGY**

To pursue the investigation, an HRA team visited Caritas and interviewed staff, and obtained and reviewed records, the agency Handbook, policies and procedures as well as the email detailed in the complaint.

**FINDINGS**

The first complaint states that the agency sent an email to multiple providers and individuals (including state and private guardians as well as outside providers) that included identifying information of residents. As a result, the facility failed to protect individuals' right to privacy by sending identifying information to individuals not involved in the resident's care.

A total of twenty-nine individuals received the email which listed full names of all individuals residing in Caritas CILAs including emails with domains from yahoo, gmail, outlook, commlink, ddsme, whisperhome, cuinc, commlink, etc. indicating nonessential members being given the full names of the individuals receiving care. This email was reviewed by the HRA and appears to have been a notification informing guardians and outside agencies which QIDP would be assigned to each resident as an additional QIDP has been added to the agency.

During the onsite interview, staff verified the email error and stated that the agency privacy policy is to follow Health Insurance Portability and Accountability Act (HIPAA) guidelines. As

a result, the staff typically use initials in emails to protect the identity of the individuals. The company provides confidentiality training and relevant confidentiality procedures are listed in the handbook. Direct support persons (DSPs) are trained by a lead Qualified Intellectual Disabilities Professional (QIDP) and they also receive coordinated on-the-job trainings.

The guardian notified staff of the confidentiality breach. The staff immediately brought it to the attention of the supervisor, admitting an unintentional error had occurred. The incident was addressed with the supervisor, staff, and guardian. Additionally, an email with an acknowledgement letter was sent notifying everyone of the event and the breach of confidentiality.

The Mental Health and Developmental Disabilities Confidentiality Act states, “All records and communications shall be confidential and shall not be disclosed except as provided in this Act. Unless otherwise expressly provided for in this Act, records and communications made or created in the course of providing mental health or developmental disabilities services shall be protected from disclosure regardless of whether the records and communications are made or created during a therapeutic relationship” (740 ILCS 110/3a).

Also, the Code of Federal Regulations, specific to HIPAA protections, details the use and disclosures for which authorization is required. Part a section 1 states, “(a) Standard: Authorizations for uses and disclosures (1) Authorization required: General rule. Except as otherwise permitted or required by this subchapter, a covered entity may not use or disclose protected health information without an authorization that is valid under this section. When a covered entity obtains or receives a valid authorization for its use or disclosure of protected health information, such use or disclosure must be consistent with such authorization” (45 C.F.R 164.508).

The Caritas confidentiality policy states that “Caritas Family Solution and its employees assume the obligation to protect, maintain, and preserve the confidentiality of all information related to individuals served. Anyone providing services in an official capacity (employee, board member, volunteer, and intern) for Caritas shares the responsibility for strictly preserving confidentiality. Information regarding individuals served shall only be disclosed in accordance with the Mental Health and Developmental Disabilities Confidentiality Act and according to Caritas policy and procedures. Anyone providing services in an official capacity shall receive training in protecting confidentiality.”

The second complaint states that a resident’s medication was changed without receiving consent from the individual's guardian. As a result, the facility violated consumers’ rights to informed consent.

During the onsite interview, staff gave an overview of the agency’s medication consent procedure. When the staff take a client to the doctor, and the physician makes medication changes, staff stated that the policy is to first notify the resident’s guardian and obtain approval for the medication change. Once approval is received, the Registered Nurse (RN) is notified and completes a new Medication Administration Record (MAR). Next, the physician order sheet is completed for the individual’s primary doctor to sign and the pharmacy fills the script.

Staff explained that the guardian assisted the individual to the physician’s visit with no staff present. The physician changed the prescription under the assumption the medication change was the guardian’s request. As a result, the script was sent electronically to the pharmacy and was filled. The physician made the medication changes on the physician order sheets bypassing normal procedure and knowledge of any staff, including the RN due to the electronic fillable

scripts. The prescription for Oxybutynin was changed from BID, meaning the medication is taken twice a day, to a once daily (QD) extended release tablet. This medication is used to treat symptoms of overactive bladder, such as frequent or urgent urination, incontinence, and increased night-time urination. Staff explained the medication was sent to the home and administered to the individual. No adverse effects were noted from the medication change.

Caritas states its use of the medication change form is utilized for more major medication changes and does not typically have guardians sign consents for minor medication changes, thus indicating the prescribing physician is accountable for notification of the guardian and that requiring guardian signatures on consents can cause major delays on the medications that clients may need.

The agency claimed to assume the guardian was aware of the medication change due to her being the only advocate present at the time of the doctor's visit. As a result, no error form was filled out due to no admission of error on the part of the company or the staff. In the interview, the company's only admission was in a communication weakness. There was no documentation of the guardian's consent for the medication change.

There was no guardian consent policy available for review. After requesting such documentation and policies, there is a Residential CILA consent for medication treatment that is to be completed for all medication changes including a new medication, increase, decrease, discontinuation, and hold. The sheet requires the drug, dose, route, frequency, reason, prescriber, and guardian written or verbal consent to be documented. There was no documentation of a guardian's consent to the medication change from Oxybutynin BID, meaning the medication is administered two times a day, to Oxybutynin once daily, extended release tablet, indicating the medication is taken once daily and releases over time eliminating the need for two pills a day.

The Mental Health and Developmental Disabilities Code states 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" furthering support that the guardian should be a part of the treatment team (405 ILCS 5/2-102). Additionally, section 5/2-107 of the Mental Health and Developmental Disabilities Code allows, "An adult recipient of services or the recipient's guardian, if the recipient is under guardianship, and the recipient's substitute decision maker, if any, must be informed of the recipient's right to refuse medication or electroconvulsive therapy. The recipient and the recipient's guardian or substitute decision maker shall be given the opportunity to refuse generally accepted mental health or developmental disability services, including but not limited to medication..." (405 ILCS 5/2-107).

The Illinois Probate Act reads, "Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian, standby guardian, or short-term guardian that is not clearly contrary to the law, to the same extent and with the same effect as though the decision or direction had been made or given by the ward" (755 Ill. Comp. Stat. Ann. 5/11a-23).

After receiving the complaint, Caritas implemented a new policy that details how they will require consent from guardians for future medication changes. This new medication consent procedure requires the facility to obtain verbal consent before a medication is changed (including medication increase, decrease, or discontinuation by the client's physician). Only when verbal consent is given, will the medication be given to the resident. The facility will also send a paper

medication consent form within seven business days, but will use verbal consent for quicker access to the guardian. If the guardian does not give verbal consent, Caritas will not implement the medication change and will have the physician, RN, and guardian deliberate on the most appropriate course of action.

### **CONCLUSION**

The complaint that states the facility failed to protect the individuals' right to privacy by sending identifying information to agencies and persons not involved with the residents' care is **SUBSTANTIATED**. In line with the Confidentiality Act, the full names of the residents receiving care should be protected to ensure patient privacy from individuals not providing the care. Since the residents' names were sent to staff outside of direct care using external domain names, consent is needed. Following the Code of Federal Regulations, an individual's name is considered identifiable information which is to be protected on documents or correspondence unless proper authorization is provided. This also violated company confidential policy to strictly preserve confidentiality to only individuals providing services in an official capacity.

The complaint regarding the agency's failure to make reasonable attempts to obtain informed consent from appointed guardians before making medication changes is also **SUBSTANTIATED**. Not allowing the guardian to provide consent for the medication changes is a violation of the rights of the individual to include the guardian in the treatment plan including the changes in medication. This also does not allow the recipient, and in this case the guardian, the right to refuse the medication as guaranteed by the Mental Health and Disabilities Code. Staff admitted to the lack of guardian consent when following the physician's orders.

### **RECOMMENDATIONS**

Consistent with the Confidentiality Act (740 ILCS 110/3a), the Illinois Administrative Code (59 Ill. Adm. Code 115.320 (h)), and the Code of Federal Regulations (45 C.F.R 164.508 (a)(1)), the HRA recommends that Caritas staff ensure the confidentiality of all individuals receiving care. The HRA recognizes that the agency immediately addressed the issue when the mistake was discovered. The HRA **recommends** revisiting confidentiality mandates with all staff on a periodic basis.

Although it was assumed that the guardian was aware of the medication change because he/she accompanied the resident to the physician, there is no documentation to that effect. All medication changes should receive verbal and then written consent as verification that the agency obtained informed consent. Caritas has since revised their policy and has taken the necessary steps to become compliant with the regulations of informed consent, as reflected in their new medication consent procedure. While there is a finding that the complaint is substantiated, the HRA recognizes that the facility has resolved this issue.

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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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**REGIONAL HUMAN RIGHTS AUTHORITY**

**HRA CASE Numbers 17-070-9013**

**SERVICE PROVIDER: Caritas**

Pursuant to Section 23 of the Guardianship and Advocacy Act (20 ILCS 3955/1 *et seq.*), we have received the Human Rights Authority report of findings.

**IMPORTANT NOTE**

Human Rights Authority reports may be made a part of the public record. Reports voted public, along with any response you have provided and indicated you wish to be included in a public document will be posted on the Illinois Guardianship and Advocacy Commission Web Site. (Due to technical requirements, your response may be in a verbatim retyped format.) Reports are also provided to complainants and may be forwarded to regulatory agencies for their review.

We ask that the following action be taken:

We request that our response to any recommendation/s, plus any comments and/or objections be included as part of the public record.

We do not wish to include our response in the public record.

No response is included.

*Juan M. Harris*  
NAME

*REGIONAL DIRECTOR*  
TITLE

*7-30-18*  
DATE





August 7, 2018

Caritas Family Solutions  
645 Berkshire Boulevard  
East Alton, Illinois 62024

Human Rights Authority  
Illinois Guardianship and Advocacy Commission  
Metro East Regional Office  
4500 College Avenue, Suite 100  
Alton, Illinois 62002

To whom it may concern:

The Caritas Family Solutions CILA Program has enclosed its original response items to complaint #17-070-9003. This response is dual in nature, to address the deficiencies in medication change procedures and participant confidentiality. To address the deficiencies in medication change procedures, the program updated its protocols to include notification of the guardians and either verbal or written consent to implement medication changes. The program has begun to implement these changes to ensure that no medication changes occur without guardian consent. See enclosed protocols and consent.

To address the breach in confidentiality, the program has implemented more in-depth training on the confidentiality policy in place in the agency. Email scenarios are now included in this training and staff are informed that participants' full names, medical conditions, or any other personal information should never be used in correspondence. See enclosed agency confidentiality policy.

Sincerely

Lisa Winter  
Director of Community Residential Services  
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## Medication Consent Procedures

- I. **Purpose:** To outline the process by which notification will be given to and consent will be gained from guardians for the addition, omission, or changing of medication. These procedures adhere to Title 59, Chapter 1, Part 112.90 (Administration of Psychotropic Medication), in regards to psychotropic medication, as well as imposing medication change protocols on non-psychotropics.
- II. **Accountable Staff:** All RN's, as well as management staff, employed through the Caritas Family Solutions CILA Program are accountable for the training and monitoring of staff in accordance with these procedures. All RN's employed through the program are expected to follow these procedures.
- III. **Definitions**
  - a. Code – Mental Health and Developmental Disabilities Code [405 ILCS 5]
  - b. Guardianship – the legal relationship between an adult recipient or ward and a court appointed guardian, including a public guardian such as the Office of State Guardian. Illinois guardians may make legally binding decisions on behalf of wards in personal or financial affairs, or both. For the purposes of this Part, the guardian must have court authority to make personal decisions for the ward. Guardians with personal decision-making authority will typically act under a plenary guardianship. A plenary guardian is one who has full decision-making authority over the person without restrictions. However, a guardian may also legitimately act under a temporary or a limited guardianship in which the guardian has clearly defined medical decision-making authority. A parent of an adult recipient without guardianship is not legally authorized to make binding decisions on behalf of a recipient. When doubt exists as to the decision-making authority of a guardian, the guardian shall supply either letters of office or a copy of a court order documenting legal authority to act on behalf of the ward.
  - c. Informed Consent – the voluntary and knowing choice by a recipient or his/her legal guardian
  - d. Psychotropic medication – medication used for antipsychotic, antidepressant, antimanic, antianxiety, behavioral modification or behavioral management purposes
- IV. **Procedures:**
  - a. When a new medication is prescribed or a current medication is increased, decreased, or discontinued by the client's physician (as dictated by CILA standards), the CILA RN will call the guardian for verbal consent before the change is implemented.
  - b. Once verbal consent is given, the medication will be changed accordingly and the RN will send the Medication Consent to the guardian via email, fax, or mail, as well as

information about the medication's side effects, risks, benefits, etc. within seven business days.

- c. If the guardian does not release verbal consent for the medication change, the following steps will be taken:
  - i. The change will not be implemented.
  - ii. RN will inform the prescribing doctor of the guardian's response.
  - iii. The physician, RN, and guardian will deliberate on the most appropriate course of action.
  - iv. CILA administrative staff, RN, and the QIDP will then file the refusal/consent in the client's personal medical information.
  - v. If the client is his or her own legally appointed guardian, the refusal or consent will be obtained from the client.



## Residential CILA Consent for Medication Treatment

Client Name: \_\_\_\_\_

New Medication  Increase  Decrease  Discontinuation  Hold

<b>Drug</b>	
<b>Dose</b>	
<b>Route</b>	
<b>Frequency</b>	
<b>Reason</b>	
<b>Prescriber</b>	

I have received written information on the medication listed above. This information includes any potential benefits, risks, & side effects. I give approval for the medication listed above to be discontinued/received as prescribed. I also give approval for a generic medication/therapeutic exchange if needed.

\_\_\_\_\_  
Signature of Client/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Co- Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Staff Providing Medication Information

\_\_\_\_\_  
Date

(if Client has Guardian)

Verbal Consent Received On: \_\_\_\_\_ at \_\_\_\_\_ by \_\_\_\_\_  
(Date)
(Time)
(Staff Name)

**CARITAS FAMILY SOLUTIONS  
AGENCY POLICY AND PROCEDURES MANUAL**

Policy Title: **Confidentiality Policy**

Type: Agency

Policy Number: 620.01

Effective Date:

Approval:

\_\_\_\_\_  
Chief Executive Officer

\_\_\_\_\_  
Date

\_\_\_\_\_  
Secretary, Board of Directors

\_\_\_\_\_  
Date

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I. Policy Statement: Caritas Family Solutions and its employees assume the obligation to protect, maintain, and preserve the confidentiality of all information related to individuals served. Anyone providing services in an official capacity (employee, board member, volunteer, intern, etc.) for CARITAS shares the responsibility for strictly preserving confidentiality. Information regarding individuals served shall only be disclosed in accordance with the Mental Health and Developmental Disabilities Confidentiality Act and according to CARITAS policy and procedures. Anyone providing services in an official capacity shall receive training in protecting confidentiality.

II. Agency Values:

*Sacredness of Human Life* - We value the sacredness of human life, created in the image of God, which impels us to respect life as a gift from God in all stages of development and wholeness.

*Dignity & Diversity* - We value the unconditional love of God for each of us which calls us to reverence the dignity of every person and to appreciate the differences among us.

