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East Central Regional Human Rights Authority
Report of Findings
Shelby County Community Services, Inc.
Case #14-060-9001

The East Central Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegation concerning Shelby County Community Services, Inc.:

> Agency directives place conditions and limitations on a guardian's access to an individual's record that are inconsistent with rights guaranteed by the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/1 et seq.).

If found substantiated, the allegation represents a violation of the Mental Health and Developmental Disabilities Act, the Illinois Probate Act, provider regulations and federal privacy regulations.

Shelby County Community Services, Inc. provides a range of services to persons with both developmental disabilities and mental health needs, including residential, vocational and counseling services. The complaint concerns a residential site that provides supervised apartments for 12 individuals.

To investigate the allegations, a Human Rights Authority (HRA) team, interviewed agency representatives, examined pertinent documents and toured the vocational and residential programs.

FINDINGS

Interviews

In a meeting with agency representatives, the HRA team learned about the agency's services. The agency sponsors a developmental training program for individuals with both developmental disability and mental health diagnoses. Approximately 55 individuals participate in developmental training and an additional 27 individuals do contract work. There are 2 individuals whose primary diagnosis is a mental health diagnosis for which there is no funding. The agency sponsors a mental health clinic for children and adults along with an activity/drop-in center for persons with mental health needs. The agency also provides substance abuse programs. The agency sponsors 2 group homes and a supported apartment program. The apartment program serves 12 individuals. There is an agency staff person always available to the

apartment residents if not in person, by phone. In addition, an on-call nurse is available 24-hours per day. Apartment residents receive case management, medication management, counseling, and transportation services.

With regard to apartment records, records are kept in the staff office and individuals must complete a record access form which is then referred to the appropriate caseworker. If a service recipient has a guardian, the guardian is notified of a recipient's request to access records. When reviewing a record, the individual would be in view of staff but not necessarily at the table during the review. Information regarding record access is being added to the Client Handbook; service recipients as well as guardians receive copies of handbooks. The agency representatives stated that it never charges for copies and that the only items that are not copied are items which cannot be redisclosed as per confidentiality protections or as stated on the documents. Staff are trained on record access policies and can approach supervisors with questions.

The HRA team was informed that the staff directive was the result of a recent incident in which a guardian arranged a meeting to review a record and directed staff to leave the room after which the guardian began writing in the records. When staff intervened, the guardian requested copies of the records and staff needed time to complete this task and allow the agency director to approve. Once the copies were made, staff delivered the copies to the guardian's home. Staff explained the guardian's concern over the service recipient's diagnosis which has limited his access to funding; although the individual has some developmental needs, his mental health needs are considered primary thus limiting access to funding for the services he currently receives. The guardian is concerned that the documentation of his diagnosis will have future repercussions on service access; according to agency staff, the agency currently does not get paid for the services the individual receives. The agency believes that the guardian may be attempting to alter the primary diagnosis for funding purposes. The agency reported that a staff person offered the guardian the opportunity to dispute anything in writing.

Approximately 25 adult clients have a guardian. Staff reported that the agency distributes surveys to guardians to seek feedback. The agency also has a formal grievance process and the Department of Human Services rights statement is provided to recipients and guardians.

Documentation

The HRA examined a masked statement related to the incident referenced by staff. According to the statement, a guardian called requesting access to a record on 10-09-12 after 3 pm and the staff responded that she could access the record, as the individual's guardian, but she would need to come over before 4:30 pm or return on October 11th when the staff person was available. At 4 pm on October 9th, the guardian called and reported that she was at the apartment and staff would not allow record access. The apartment staff person came on the line and reported that she would not allow record access without the appropriate approval. The agency executive director was involved and stated that that the individual could "…look at the information with a staff person but that there is a procedure for looking at files, and getting copies of the information from the files. Once the form for this is filled out, it has to be approved by the Ex. Director. I was told to tell the resident. Staff person to stay with [the guardian] and not let her take anything out of the file until the form was completed and approved…..Later that evening I called residential staff and was told [the guardian] went through her son's file and took many

documents out and wrote on them." A letter from an attorney to the facility stated that the guardian reports that facility staff "…have been reluctant and/or refused to give the Guardian information and access to [the recipients] case files and status as to his needs and progress. It is her understanding that these individuals have stated that their denial is because they do not believe she is entitled to this information. As I am sure you are aware, the Court appointed plenary guardian for a disabled person is for all legal purposes the same as if she were him with no disability and no one else is in any better position than she to this type of information. It is my hope, and that of the Guardian, that this letter will [sic] taken seriously and the appropriate parties informed as to their need and duty to cooperation [sic] and communicate with [the guardian] regarding all aspects of care being provided by your facility…." Masked e-mail communication from the agency executive director and dated 11-15-12 informed staff of the letter and requested information about any incidents. The staff person responded in an e-mail as follows: "I don't understand. Info that she requested was copied and hand delivered…." Another staff person documented in an e-mail that the guardian arrived at the apartment and directed staff to sit in another room while she copied documents; when staff refused, she started writing in the files and staff informed her that there was a process that needed to be followed. Administrative staff were notified and staff explained agency policies. The e-mail stated that the requested documents were delivered to the guardian 2 days after the request. The e-mail also referenced another request for a medication list; staff notified the nurse and the medication administration report was copied and given to the guardian within 15 minutes.

The HRA team reviewed the undated "Direction for SCCS Staff For Viewing of Consumer Records by a Legal Guardian." According to the directive, "Legal guardians may view certain contents within the consumer records of the individual under his/her guardianship with advance notice to and the approval of an appropriate Coordinator of Shelby County Community Services, Inc. (SCCS). No document may be viewed that would violate the confidentiality of another consumer." The directive's procedure states the following:

> "A legal guardian who wants to view the contents of the consumer file…should contact an appropriate coordinator to make prior arrangements for scheduling a viewing. The advance notice will be for an amount of time that is reasonable for the SCCS staff as well as for the convenience of the legal guardian. Identification and proof of guardianship must be presented by the legal guardian prior to viewing a consumer file. The legal guardian will be made aware of and understand that the consumer file is the property of SCCS. An appointment time will be set for the viewing of the consumer file that will coincide with the staff schedule so as not to disrupt client care. Consumer records must be viewed only in the presence of a SCCS staff person. The SCCS staff person will monitor the viewing to insure that no document is removed from the consumer file and/or from the office by the legal guardian. The guardian may not mark on or in other way alter or deface a consumer record. Should the legal guardian attempt through any means to alter or deface the consumer record, the viewing session will immediately be ended. The legal guardian will behave respectively with the SCCS staff member. If the SCCS staff member feels disrespected, the staff member has the authority to immediately end the viewing session. The Executive Director will be immediately notified of such an occurrence. A photocopy of some portion of the consumer record may be requested by the legal guardian. Only upon the written approval of the Executive Director of SCCS,

the copies portion of the file may be mailed to the legal guardian. A copying and mailing fee may be charged to the legal guardian and when charged is payable in advance."

The agency's "Client right to review file" policy last revised in 10/2012 states that "It is the policy of SCCS, Inc. to comply with the Administrative Code Part 119, (specifically Section 119.260, i-1) in respecting the Rights of Clients and or their guardians that wish to inspect their own/ward's files." The procedures require that the client or guardian notify a program coordinator who will then notify a case manager. Within 2 days, the case manager will contact the client/guardian and assist him/her in completed the required form, including "…his/her purpose for wanting to inspect the file and the nature of the information to be disclosed." The procedure further states that "If there is information in the file that cannot be released to the client/guardian because the originating individual has not given authorization, the information will be removed prior to examination of the file by the client. The information will be returned to the file after the examination." The case manager will assist in the record review "…as necessary." And, "the disclosure is authorized for two weeks from the date signed." This policy is included, verbatim, in the most recent client handbook dated July 2013. The HRA notes that the policy's reference to Rule 119 is misplaced in a policy that governs residential care as Rule 119 specifically governs developmental training programs.

The "Client/Guardian Request to Inspect File" form states that "I, (blank), hereby request Shelby County Community Services, Inc. to disclose to me the following specified information from my/my ward's Case File." The form includes space to document the "purpose for which the disclosure is to be made" as well as the name of the staff person assisting in the case record interpretation, the sate of the request and the date of the review. The form concludes with a statement that the disclosure is good for 2 weeks from the date signed and has signature lines for the client/guardian and the case manager.

The agency's client rights statement as documented in the client handbook includes the right for a client to examine his/her record, information about the agency grievance process and contact information for external advocacy sources, including the Guardianship and Advocacy Commission.

Tour

The HRA team toured the facility and visited the apartments. The HRA team noted that the undated staff directive regarding guardian access to records was posted on the door of the staff office. The HRA asked the apartment staff person how she would respond to a guardian's request to review a record; the staff person stated she would not provide it. When asked what she would do, she stated she would contact her supervisor. The administrator reported that the directive was more of an internal document for staff and he would see that it was removed from the door.

MANDATES

The Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/2) defines "Guardian" as "a legally appointed guardian or conservator of the person." "Recipient" is defined as "a person who is receiving or has received mental health or developmental disabilities

services." And, "Record" is defined as "any record kept by a therapist or by an agency in the course of providing mental health or developmental disabilities service to a recipient concerning the recipient and the services provided." The Act states in Section 110/4 that "The following persons shall be entitled, **upon request**, to inspect and copy a recipient's record or any part thereof: (1) the parent or guardian of a recipient who is under 12 years of age; (2) the recipient if he is 12 years of age or older; (3) the parent or guardian of a recipient who is at least 12 but under 18 years, if the recipient is informed and does not object or if the therapist does not find that there are compelling reasons for denying the access….; (4) the guardian of a recipient who is 18 years or older;…." This section also specifies that "Assistance in interpreting the record may be provided without charge and shall be provided if the person inspecting the record is under 18 years of age. However, **access may in no way be denied or limited if the person inspecting the record refuses the assistance**. **A reasonable fee may be charged for duplication of a record. However, when requested to do so in writing by an indigent recipient, the custodian of the records shall provide at no charge to the recipient**….**Any person entitled to access a record under this Section may submit a written statement concerning any disputed or new information, which statement shall be entered into the record.** Whenever any disputed part of the record is disclose, any submitted statement relating thereto shall accompany the disclosed part. Additionally, any person entitled to access may request modification of any part of the record which he believes is incorrect or misleading. If the request is refused, the person may seek a court order to compel modification…..Whenever access or modification is requested, the request and any action taken thereon shall be noted in the recipient's record."

The Illinois Probate Act (755 ILCS 5/11a-17) describes the authority and duties of personal guardians and states that guardians are to "…shall make provision for their [wards] support, care, comfort, health, education and maintenance, and professional services as are appropriate….The guardian shall assist the ward in the development of maximum self-reliance and independence." The Act states that the guardian is to file reports with the Probate Court explaining specifics about the ward's condition, including mental, physical and social conditions as well as services provided, residential care, etc. Section 11a-23 of the Probate Act states that "Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian…that is not clearly contrary to the law, to the same extent and with the same effect as tough the decision or direction had been made or given by the ward."

According to the Code of Federal Regulations (45 C.F.R. 164.524) that govern privacy in public welfare, "…an individual has a right of access to inspect and obtain a copy of protected health information about the individual in a designated record set for as long as the protected health information is maintained in the designated record set…." There are exceptions, including psychotherapy notes, information compiled for criminal/civil legal action, certain records in a correctional institution, certain research situations etc. And, when access is denied there are parameters within the regulations in which a review of the denial can be requested. The U.S. Department of Heath and Human Services (HHS) website on the Health Insurance Portability and Accountability Act's (HIPAA) frequently asked questions section states that the "HIPAA Privacy Rule permits a covered health care provider to use or disclose protected health information for treatment purposes." However, a patient can restrict a restriction on disclosure for treatment purposes although the health care provider does not necessarily have to agree with the restriction. The website states that "The Privacy Rule standards address the use and

disclosure of individuals' health information—called 'protected health information' by organizations subject to the Privacy Rule — called 'covered entities,' as well as standards for individuals' privacy rights to understand and control how their health information is used. Within HHS, the Office for Civil Rights ('OCR') has responsibility for implementing and enforcing the Privacy Rule with respect to voluntary compliance activities and civil money penalties. A major goal of the Privacy Rule is to assure that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being."

The Illinois Administrative Code that governs Developmental Training Programs (59 Ill. Admin. Code 119.260) states in section 119.260 I (1) that "The program shall ensure the confidentiality of an individual's record in accordance with the Act and shall ensure safekeeping of all records against loss or destruction. Individuals or their guardians shall have access to the individual's record **upon request**." Again, the HRA notes that Rule 119 governs developmental training programs versus residential services.

Inquiry to HHS

The HRA sent an e-mail inquiry to the HHS regarding the disclosure of information in a resident's records that originated elsewhere when a resident seeks access to his/her record as follows:

> A resident with a disability lives in a group home and has access to his record; however, the record may also contain information from another source but still pertaining to the resident such as lab reports, physician's exams, hospital reports. The group home provider contends that the information regarding the resident but from another source even if the information concerns his care and treatment cannot be shared with the resident when he asks to access the record on the grounds of HIPAA. In other words, the group home says they have to censor the record to take out items that did not originate with the group home even though they pertain to the resident's care and treatment. Is this accurate?

Citing Section 164.524 as previously documented in this report, the HHS responded to the above HRA inquiry as follows:

> No, that is not accurate. Please review: With limited exceptions, a covered entity is required to provide an individual access to his or her protected health information in a designated record set. This includes information in a designated record set of a business associate, unless the information held by the business associate merely duplicates the information maintained by the covered entity. Therefore, the Rule requires covered entities to specify in the business associate contract that the business associate must make such protected health information available if and when needed by the covered entity to provide an individual with access to the information. However, the Privacy Rule does not prevent the parties from agreeing through the business associate contract that the business associate will provide access to individuals, as may be appropriate where the business associate is the only holder of the designated record set, or part thereof.

CONCLUSION

The complaint alleges that Agency directives place conditions and limitations on a guardian's access to an individual's record that are inconsistent with rights guaranteed by the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/1 et seq.)

Facility staff acknowledged that a directive was put in place after an incident involving a guardian who reportedly accessed a record and attempted to strike out and remove portions of her ward's record most probably due to concerns related to his primary diagnosis and the subsequent impact on his funding. Staff stated that the directive was not an attempt to deny access altogether but to protect the file contents. And, the ward's services at the agency remain intact regardless of the funding situation as per staff. Also, staff voiced concerns about HIPAA protections if redisclosing information derived from another source, hence, the review and potential removal of items from the file by the executive director. Staff acknowledged that guardians are entitled to record access to fulfill responsibilities under the Illinois Probate Act.

In reviewing the staff directive, policies and consumer handbook, the HRA finds that some statements appear inconsistent with the Mental Health and Developmental Disability Confidentiality Act and other mandates, some statements appear to give staff significant discretion over the conditions surrounding record access and still other statements could be misconstrued by guardians and staff alike. For example:

- Both the directive and policy state that there is an appointment scheduling process for gaining record access that includes a 2-day turn around to complete a form which requires the resident/guardian to identify a purpose for accessing the record and then a two-week time frame for actually providing record access. Both the Confidentiality Act and Rule 119 state that record access is to occur "upon request." While the HRA recognizes that arrangements may need to be made if the office in which the records are kept is locked and unstaffed, but the HRA also contends that a more than 2-week turnaround for record access goes well beyond mandated requirements. In addition, there is no requirement within the Act or Rule 119 for the completion of a form or the identification of a purpose in order for a guardian/resident to review his/her record. The HRA recognizes that while the documentation of a record access request by a resident/guardian is warranted, a form is not and the identification of a purpose is required only if the resident/guardian is consenting to the release of information from the provider to another entity. HIPAA requirements mostly apply to health care entities to protect the recipient's information from being inappropriately disclosed to another entity without consent versus limiting a recipient's access to his/her own records. Still, health care providers can exchange information for treatment purposes. The HRA contends that most of the information contained in the agency's records of a service recipient is treatment related and as per HIPAA requirement there are only limited circumstances in which a recipient's access to his/her own record can be denied. Also, the HRA reiterates that Rule 119 applies to developmental training programs versus residential services.

- The directive states that staff have discretion to end a record viewing if they feel "disrespected." The HRA contends that such a statement is highly subjective, restrictive and in conflict with Act and Code provisions.

- The directive states that records can only be viewed in the presence and with the monitoring of staff. The HRA acknowledges that it is reasonable for staff to be present to protect the record and monitor the review. However, neither the directive nor the policy explain the Act provisions that assistance in interpreting the record may be provided but access to the record is not to be denied if assistance is refused.

- Neither the directive nor the policy include provisions for disputing record contents.

- Neither the directive nor the policy include provisions for obtaining copies at no cost if the recipient/guardian is indigent.

While the HRA takes issue with the directive and policy, it would like to note that in its review of masked documentation of an incident involving a guardian's request for record access, the access was granted on the same day of the request even though several calls were made to facilitate the access, the guardian appeared to have access without significant staff intervention and copies appeared to have been provided at no cost to the resident or guardian within 2 days. In addition, the HRA examined masked documentation of a subsequent request for medication information that indicates the information was provided within 15 minutes. It also appears that in each situation access was granted without the completion of any form.

Based on a review of the available evidence, the HRA finds that the directive and policy appear to be inconsistent with mandated requirements although masked documentation of a record access incident seems to indicate that Act and Code provisions were mostly followed in spite of the directive and policy. The HRA recommends the following:

1. **Revise the directive and policy to be consistent with Confidentiality Act provisions, using the exact verbiage as much as possible. Include provisions for disputing records and obtaining copies if indigent. Ensure that 119 references are for Developmental Training Programs while Confidentiality Act provisions cover all agency programs.**

2. **Train staff on the revisions.**

The HRA also offers the following suggestions:

1. Consider a legal review of HIPAA requirements related to the guardian's/recipient's access record contents from another source when the contents from the other source pertain to the recipient's treatment.

2. Consider contact with Illinois Department of Human Services representatives regarding the guardian's concern in this case over her ward's diagnosis and funding.