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**Egyptian Regional Human Rights Authority
Report of Findings
Coleman Tri-County Services
Case #12-110-9010**

The Egyptian Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegation concerning the agency's Developmental Training program:

Office of State Guardian representatives, family guardians, family members and case management/pre-screening representatives are not allowed to interact with agency clients in the program areas of the developmental training center.

If found substantiated, the allegation represents possible violations of the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102), regulations that govern developmental training programs (59 Ill. Admin. Code 119), Probate Act provisions and regulations/mandates specific to case coordination units.

Coleman Tri-County Services offers an array of early intervention, employment and residential services to persons with developmental disabilities residing in Gallatin, Saline and White Counties. The complaint in this case specifically pertains to the developmental training program located in Harrisburg.

To investigate the allegation, an HRA team interviewed an agency administrator and receptionist, toured the training program, examined the client handbook, agency policies, the client rights statement and human rights committee minutes, interviewed representatives of the case management agency and interviewed a guardian.

COMPLAINT STATEMENT

According to the complaint, a guardian who clearly identified himself using a business card was informed by the receptionist that he would not be allowed to interact with his wards or observe the program room; instead, the guardian was told he could meet with individuals in the facility conference room. The complaint states that this is a new policy and no one is allowed in the program areas. The complaint contends that access to the program area is warranted in order to fulfill mandated responsibilities.

FINDINGS

Agency Interviews

An HRA team met with and interviewed a facility administrator at the agency's administrative offices and a receptionist at the day training site. The Administrator reported that the agency provides a range of services for 300 persons with developmental disabilities; approximately 90 individuals receive developmental training services in four different settings, including the Harrisburg facility. The administrator stated that the issue was one of miscommunication and began when a representative of a case coordination agency was attempting to complete a questionnaire on a consumer. The administrator reported that the questionnaire was being administered in the program area and required 45 minutes which took time away from agency staff who were working with consumers and was a distraction to other consumers. As a result, the agency decided to direct future visits from the case coordination agency to the facility conference room when completing the questionnaire to decrease program distractions and to help ensure the confidentiality of program participants. According to the administrator, when a guardianship representative from the Office of State Guardian (OSG) arrived for a visit, the receptionist thought that he was a representative of the case coordination agency and directed him to the conference room. When he questioned this, the administrator clarified with staff and the guardian who was allowed access to the program area on the same but the guardian reportedly refused. The administrator stated that they have no policy regarding visitation; the only current practice in place is to direct the case coordination staff to the conference room for the questionnaire. The administrator stated that she followed up with the Office of State Guardian administrator. She also stated that an ongoing concern is the confidentiality of all program participants although the Office of State Guardian administrator confirmed that, with regard to confidentiality of OSG wards, he is fine with external visitors observing the program. The administrator indicated that contact was also made with an Illinois Department of Human Services (DHS) representative who suggested the possible need for some type of future training. The administrator stated that the issue was presented to the agency's internal human rights committee which determined that a related policy was not warranted. The human rights committee meets monthly and is comprised of a psychologist, pharmacist, representatives of various providers, a client, a family member and a licensed social worker. The administrator stated that family tours of the facility are routinely given and visitors are escorted within the facility for safety reasons.

The HRA team then spoke to the receptionist located at the day training program site. She reported that the guardian arrived at the program and she notified the administrative offices. The contact at the administrative office mistakenly thought he was from the case coordination office and initially directed him to the conference room but later offered him access the program area after receiving clarification, but he reportedly refused the later offer to view the program area.

Day Training Program Tour

The HRA Team toured the day training program; however, consumers had already left for the day. A security code is needed to enter the day training building. The receptionist lets visitors into the building after checking identification. There is no sign-in sheet for visitors. The program area is down a hall from the reception area and is comprised of several rooms. The HRA team noted that there was no identifying client information posted in any of the observed program areas.

Policy Review

The HRA team examined the agency's policy manual. The grievance policy allows consumers, guardians and families to file complaints concerning the agency and complaints are resolved using the agency chain of command up to the agency's Board of Directors. The agency rights statement includes the right to "uncensored visitation." The agency maintains no specific policies that guide visitation parameters.

Human Rights Committee Meeting Minutes

The HRA team reviewed the 11-09-11 minutes of the agency's internal human rights committee that addressed the program visitation issue. The minutes state that staff did not realize the individual who visited was a guardian and instead thought he was a representative of the case coordination unit with a lengthy questionnaire to complete; he requested to speak to an administrator who clarified that he was a guardian and could access the program area, but he refused. The minutes indicate that telephone contact was made with the guardian who indicated that he would file a complaint with the HRA; contact was also made with the Office of State Guardian (OSG) Administrator who indicated he was not concerned with confidentiality issues of OSG wards at the day program site. According to the minutes, contact was made with a DHS representative and training was discussed; in addition, the administrator provided the committee with information about job duties and regulations related to the case coordination unit and guardians. The minutes further state that "CTS [Coleman Tri-County Services] ask that [the case coordination unit] make short visits to the areas for 'natural environment' views but for the lengthy questionnaire that they go to a private area. CTS further asks that if the [unit] has questions for staff that they be directed to the designated building supervisor to assure that all questions are answered and that the least amount of disruption to the work environment or activity occurs. The committee feels that the regulations are being met and the individual's rights are protected and if [the administrator, OSG Director and case coordination unit] are okay with the process then the issue is resolved."

Interview with Case Coordination Unit

The HRA contacted the case coordination unit after its visit with the agency. The agency director reported that there had been a problem with unit representatives accessing the program area but he put the HRA in touch with one individual who has visited the program; this individual reported that she had been denied access in the past, could not say that the issue had been resolved and wished that the agency saw the unit as a partner serving mutual consumers. The individual stressed that a questionnaire the unit is required to complete includes a section on direct observations of the program areas. At the request of Coleman DT, another unit representative was interviewed at a later date. This unit representative was also referenced by a guardian as being an individual who has regular and recent contact with the agency. The representative reported that there had been confusion and misunderstanding about her ability to access to the program area but after clarifying her role and responsibility, she gained access and the matter is resolved. The representative stated she was most recently at the facility in the past week. She was unable to indicate whether or not family guardians or other individuals involved in a client's treatment planning can access the program areas.

Follow-Up Contact with a Guardian

At a later date, the OSG guardianship representative was contacted and reported that he has not been denied access to the program area to meet with and observe wards since the initial refusal. However, he stated that he is strongly encouraged to visit with wards privately in a room away from where programming occurs at each Coleman facility.

Client Handbook

The Client Handbook was reviewed by the HRA team. The handbook stresses the use of person centered program plans that focuses on client choice and input. The handbook addresses opportunities to share feedback such as through monthly client management meetings at which clients can express concerns, offer suggestions and review issues. Another opportunity to share feedback is through a survey distributed twice a year as per the handbook. A rights statement is also included in the handbook; the rights statement addresses the "right to talk alone with your guests at the work site...[and the] right that your name or your forms in your file are not discussed with anybody else unless you say it is ok." Contact information for filing rights complaints is provided, including contact information for the internal human rights committee and the Guardianship and Advocacy Commission. The handbook includes a section on the agency grievance process and a grievance form. A handbook section entitled, Working Agreements, lists the types of agencies that have working agreements with Coleman Tri-County Services, including ambulance services, various consultants, the pharmacy, etc. Neither the case coordination unit nor the Office of State Guardian is listed as having a working agreement with the agency. However, in the glossary section of the handbook, a case coordination unit is defined as a unit that "...is responsible for insuring that all needed services are being provided to individuals who are developmentally disabled. The Case Coordinator provides advocacy for all developmentally disabled adults and children during interdisciplinary team meetings and staffings such as those held in schools and rehabilitation facilities." A legal guardian is also defined as "a court appointed individual responsible for the client's legal personal affairs (include agency consent forms)." Confidentiality is defined as "the suppression and protection of all personal and case record information regarding an individual served, unless permission is given for release."

MANDATES

The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102) states:

A recipient of services shall be provided with adequate and humane care and services in the least restrictive environments, pursuant to an individual services plan. The Plan shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient. The facility shall advise the recipient of his or her right to designate a family member or other individual to participate in the formulation and review of the treatment plan.

The Illinois Probate Act (755 ILCS 5/11a-17) states that a guardian "...shall have custody of the ward ...and shall procure for them and shall make provision for their support, care, comfort, health, education and maintenance, and professional services as are appropriate...." This section of the Probate Act further states that:

Decisions made by a guardian on behalf of a ward shall be made in accordance with the following standards for decision making. Decisions made by a guardian on behalf of a ward may be made by conforming as closely as possible to what the ward, if competent, would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the ward's personal, philosophical, religion and moral beliefs, and ethical values relative to the decision to be made by the guardian....If the ward's wishes are unknown and remain unknown after reasonable efforts to discern them, the decision shall be made on the basis of the ward's best interests as determined by the guardian. In determining the ward's best interests, the guardian shall weigh the reason for and nature of the proposed action, the benefit or necessity of the action, the possible risks and other consequences of the proposed action...and shall take into account any other information...that the guardian believes the ward would have considered if able to act for herself or himself.

Regulations that govern developmental training (59 Ill. Admin Code 119) state in section 119.220 that an interdisciplinary team is responsible for implementing a treatment plan; the team is to provide for the active involvement of the guardian, persons who work with the individual and professionals who assess the individual's strengths and needs. Section 119.235 addresses rights and confidentiality and state that rights are protected in accordance with the Mental Health and Developmental Disability Code and confidentiality is to be protected in accordance with the Mental Health and Developmental Disabilities Confidentiality Act. This section also requires that training programs have a grievance process for consumers and guardians. Section 119.260 addresses administrative requirements and states that the training program shall have policy to "...ensure that Department -authorized consumer-interest groups shall be permitted, with the consent of the individuals, to visit a program...."

Under the Developmental Disability and Mental Disability Services Act (405 ILCS 80/4-1), the Illinois Department of Human Services can designate screening and assessment units to provide assessments, develop service plans, link individuals to "...community providers for implementation of the plan; and monitor the plan's implementation for the time necessary to insure that the plan is appropriate and acceptable to the persons with mental disabilities and their families." Specific case coordination and monitoring follow-up is also to be provided by case coordination units on behalf of individuals discharged from state-operated facilities (59 Ill. Admin. Code 59.125)

The Illinois Department of Human Services (DHS) maintains an on-line program manual for Division of Developmental Disabilities' programs to serve as "...a guide to information about Illinois' developmental disabilities service system." In addition, the manual addresses supplementary requirements for disability service providers under contract with DHS. In a section providing an overview of services, descriptions of pre-admission screening (PAS), individual service and support advocacy (ISSA) and independent service coordination (ISC) are

included. The PAS is described as the 'front door' into services for persons with developmental disabilities as well as a monitoring entity to "...ensure compliance with applicable Federal and State laws, arrange for and conduct assessments, make necessary determinations regarding eligibility for services, education individuals and families, and make referrals and provide linkage to appropriate and needed services." The ISSA is described as an entity that "...represents the Departments interests in determining whether program services are being provided in the interest of and to the satisfaction of individuals receiving services, alerts the Division when monitoring and technical assistance are necessary; and provides support to individuals, guardians and providers in working through a variety of service issues, including those requiring conflict resolution, increased communication, and possible changes in support levels." The ISC "...promotes service accessibility and continuity of care, and seeks to maximize an individual's potential for independence, productivity and community integration." The ISC ensures assessments and service plan implementation as well as service monitoring and advocacy. More specific manual information details the ISSA duties which include participation in the treatment plan, visits to a service recipient's residence and day program to "...assess whether program services are being provided in the interest of and to the satisfaction of individuals receiving the services...", collaboration with providers, referrals, redeterminations, etc. A manual attachment describes the program requirements for PAS/ISC/ISSA which include direct involvement of a service recipient/guardian in contracted activities.

The Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/5) guarantees that consumer information not be disclosed to others without written consent.

CONCLUSION

The complaint states that Office of State Guardian representatives, family guardians, family members and case management/pre-screening representatives are not allowed to interact with agency clients in the program areas of the developmental training center.

The administrator and a receptionist reported that a guardian was mistakenly denied program area access but was granted access later in the same day; however, the guardian reportedly refused. The administrator reported that representatives from the area case coordination unit can visit the program area except when completing a lengthy questionnaire and family members can visit the program area with an escort. Facility administration voiced concerns regarding confidentiality protections and although there was no identifying information observed in the program area.

The HRA acknowledges that any disclosure of specifics about an individual consumer's services or the consumer's full identity in the presence of others places confidentiality protections as under the Mental Health and Developmental Disabilities Confidentiality Act, at risk. At the same time, the Mental Health and Developmental Disabilities Code guarantees the right of a guardian and an individual designated by the consumer to participate in treatment planning. To adequately participate in treatment planning, observations of program areas to evaluate current plan provisions and/or the need to change the plan could very well be warranted. Probate laws mandate that court-appointed guardians procure needed services and make decisions based on what the individual would want or using best interest standards. Again, to make informed

decisions regarding services, a guardian's direct observation of programming could be essential. Regulations that govern developmental training programs guarantee treatment planning participation of persons involved in an individual's care which could include guardians, designated individuals and ISSA representatives. The Community Services Act together with program manuals issued by the DHS require PAS/ISC/ISSA agencies to assess consumers, participate in treatment planning and monitor service implementation and provision; again, all activities that warrant direct observation of programming. An ISSA representative interviewed stated that ISSA staff had been directed to a conference room to complete a questionnaire even when the questionnaire requires them to document observation of the program areas. Another ISSA representative indicated confusion over the ISSA's ability to access the program area but indicated that the confusion has been resolved and she reports currently having access; she is not sure if designated individuals or private guardians have such access. The agency's rights statement guarantees the right to uncensored visitation.

In order to fulfill monitoring and treatment planning participation, the HRA contends that direct observation of programming is warranted for court-appointed guardians, ISSA representatives and individuals designated by consumers to participate in treatment planning. **Both the guardian and the ISSA representatives reported that program access had been denied which represents a violation of mandates that govern ISSA and guardian/designee treatment planning participation and monitoring. However, the HRA acknowledges that matter was resolved shortly thereafter and the guardian and ISSA representative gained and have maintained program access.** The HRA also recognizes the agency's responsibility to ensure that confidential information is not disclosed without written consent and encourages all parties involved to be cognizant of confidentiality when addressing or questioning consumers or staff in the presence of others. For the purposes of this case, Coleman TriCounty Services staff must refrain from disclosing confidential information in the presence of others. The HRA also noted that developmental training regulations requires that the program have a policy in place that consumer interest groups be permitted to visit the program with consumer consent; such a policy was developed subsequent to the HRA's investigation and provided to the HRA. Because program area access is being allowed for individuals with monitoring/treatment planning and because the agency has developed a visitation policy as required, the HRA offers no further recommendations.

The HRA does offer the following suggestions:

1. Ensure continued program area access and observation to individuals that have mandated monitoring responsibility or who participate in a consumer's treatment planning.
2. Ensure that all staff are trained on and follow the agency's visitation policy.
3. Remind staff that disclosing confidential information about consumers in the presence of others without written consent is a violation of confidentiality protections and thus, staff should direct such specific consumer discussion to a private area of the facility.
4. Consider the development of a visitation policy that would ensure access to program areas when appropriate and to define parameters to protect confidentiality, safety and to

protect against visits to which consumers have not consented. Consider the use of a sign-in/sign-out sheet as an additional safety measure.

5. Include visitation information in the client handbook.
6. As referenced in the handbook, consider developing working agreements with the Office of State Guardian and the ISSA to facilitate collaboration on behalf of consumers.

The HRA acknowledges the cooperation of the agency and its staff.