FOR IMMEDIATE RELEASE

REPORT OF FINDINGS
INDIVIDUAL ADVOCACY GROUP INCORPORATED — 13-040-9001
HUMAN RIGHTS AUTHORITY— South Suburban Region

[Case Summary— Although the second complaint as presented below was not substantiated, the Authority made corrective recommendations regarding the two complaint issues mentioned in the report. The public record on this case is recorded below; the provider's response immediately follows the report.]

INTRODUCTION

The South Suburban Regional Human Rights Authority (HRA) has completed its investigation into allegations concerning Individual Advocacy Group Inc. The complaint stated that the agency failed to provide the resident's guardian with incident reports and especially those involving serious injuries. Additionally, the complaint alleged that the guardian's concerns about money being deducted from the resident's check to cover damages to the home were not adequately addressed. If substantiated, these allegations would be violations of the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/4), the Illinois Administrative Code (CILA Rules, 59 Ill. Admin. Code 115.100 et seq.) and the Illinois Probate Act (755 ILCS 5/11a-17 and 5/11a-23).

Located in Romeoville, Individual Advocacy Group provides residential, day training, counseling, and other supportive services to children and adults with developmental disabilities, behavioral health needs and brain injuries in 21 counties throughout Illinois. This agency manages more than 20 Community Integrated Living Arrangements (CILAs) and has about 165 residents in its CILA program.

METHODOLOGY

To investigate the complaint, the agency's CILA Director, the Regional Director, the Director of Program Services, three Directors of Clinical Services and a Behavioral Analyst were interviewed. The complaint was discussed with the resident's guardian and his mother. Sections of the adult resident's record and a copy of his Guardianship Order, dated September 17th, 2002, were reviewed with written consent. This order appoints guardianship over the resident's personal care and finances. Relevant agency policies were also reviewed.

COMPLAINT STATEMENT

The complaint stated that the resident's guardian was not provided with incident reports and especially those involving serious injuries. It was reported that the guardian learned that the

resident's eyes were blackened when his mother picked him up for a home visit in 2012. The resident told his mother that someone had pushed him down to the floor, but the staff allegedly said that his injuries were caused by an accidental fall. According to the complaint, his mother filed a police report because she did not want to be blamed for his injuries. The complaint alleged that the guardian was informed that the resident had "trashed" the living room in the home and that money would be deducted monthly from his funds for damages, totaling $8,000. It was reported that the staff refused to tell the guardian exactly what items were damaged and to provide incident reports concerning this issue. According to the complaint, a staff person told the guardian that there were about 300 incident reports involving the resident and that she would have to pay a fee to get copies of them.

FINDINGS

Information from the record, interviews and program policy

According to the record, the resident is diagnosed with Schizoaffective Disorder, Impulse Control Disorder, Mild Mental Retardation and has symptoms of Paraphilia Disorder. The latter disorder is characterized by recurrent, intense, sexually arousing fantasies or urges involving a specific act, depending on the paraphilia. He is prescribed psychotropic medications and has been a client of the agency for many years. His method of communication includes spoken and written words, sign language and gestures. He understands what is articulated by others. His legal guardian (aunt) helps him with making medical and financial decisions. His mother is also very involved in his life and he goes on home visits about every other weekend. He has been moved to three different homes managed by the agency because of his inappropriate behaviors.

The resident's file contained an incident log, dated January 10th, 2010 to October 6th, 2012, totaling 159 occurrences. His behaviors included self-inflicted injuries, physical and verbal aggression towards others, property destruction, inappropriate boundaries and sexual behaviors, elopement, etc. The agency provided the HRA with seven corresponding incident reports for the above three-year period after the site visit. We noticed that the names of the staff members who completed the incident reports, employees who were notified, and the agency's Regional Director who signed them were redacted on forms. We also noticed that the record lacked documentation that the guardian was provided with copies of actual incidents reports or that she had requested them. The HRA notes that only a few of the many documented incidents will be mentioned in the report.

For 2010, there were sixty-four incidents recorded on the behavioral log, and we begin with the incident alleging that the resident was physically aggressive towards his housemate after talking to his mother by phone on March 22nd. It was also recorded that the resident punched himself in his eye. However, there was no indication whether or not bruising was observed. A corresponding incident report explained that the resident became very agitated because [name deleted] had mentioned an incident involving a closet door that had occurred on the 21st. The resident swung at his housemate and was belligerent. He threw his notebook twice and almost hit the staff person with the book. The agency's Regional Director and the police were called to the home for assistance. We noticed that the incident report does not mention self-injurious behavior involving his eye and that there was no mention about a closet door on the behavioral log on that previous day.

On April 1st, 2010, the resident was described as being very upset because he did not have cigarettes. He reportedly threatened to kill a staff person; he slammed doors in the home and broke the handle on the garage door. The police were called to the home, and he was transported to a hospital's emergency department for an evaluation. A corresponding incident report indicated that the agency's residential director was also called for assistance and that the resident was hospitalized. On the 16th, the resident started slamming the dresser drawers after a phone call from his mother. He reportedly requested a pair of panties and a bra and, he made sexual gestures and asked the staff person to have sex with him.

For 2011, the HRA reviewed forty-nine behavioral incidents involving the resident, and a list of items that he had allegedly damaged such as the garage door, walls, etc. For example, on February 3rd, it was recorded that the police were called to the home because the resident punched his roommate. He also threw a chair and a book, and tried to cut his wrist after he broke a kitchen dish. A corresponding incident report stated that the resident became upset because his housemate had accused him of drinking all of the milk in the refrigerator. Per the report, the resident punched his roommate on his arm, and he responded by hitting the resident in his face. The resident was transported to the emergency department for an evaluation but was not hospitalized. On April 21st, the resident reportedly was physically aggressive towards a staff person, and he punched a hole in several walls in the home. On May 10th, the resident was described as being very violent because he could not go on a home visit. It was recorded that the resident damaged vehicles, walls and the garage door by kicking them multiple times. He threw litter on the lawn, and broke chairs and a table.

For 2012, documentation indicated that the resident had engaged in forty-six behavioral incidents. For example, on March 11th, the resident reportedly was upset because there were no cigarettes in the home. He punched the couch; he turned over a table and broke one of the legs on the table. He tried to bite a staff person and threw a clipboard at him. A corresponding incident report stated that the resident started biting his hand after he had calmed down. However, there was no indication whether or not bruising was observed. On the 12th, an incident report indicated that the resident's eye, nose and forehead were bruised when he was wakened for morning medication. It was recorded that the overnight staff person believed that the evening staff person had reported the earlier incident leading up to his bruises until [name deleted] asked him what had happened. A second incident report, completed on that same day, reflected that the resident said that he had bumped his head because a certain housemate pushed him down on the floor. The staff person noted an abrasion with minimal swelling. An ice pack was applied to the area before he was transported to the day training center. The same treatment was applied many times at the day program but swelling was still noted. The agency's nurse instructed that the resident should be monitored for additional swelling every two hours. On the 18th, the resident's mother reportedly asked who was working on the evening that the resident was injured. She was instructed to call the agency's Regional Director concerning this issue. It was recorded that she reported the resident's injuries by phone or in-person to three police departments.

On April 11th, 2012, the resident's treatment and behavioral support plans were updated. His behavioral plan targeted those previously mentioned and interventions concerning smoking such as trying to light cigarettes on the stove. A financial goal to pay the agency $10.00 each

month for property damage from his personal allowance of $50.00 was added to his plan. A "communication tree" was also added as requested by his family. It was documented that the resident's family had agreed to call the agency's Behavioral Analyst about medical and clinical concerns and the Regional Director regarding all other issues.

On April 20th, 2012, the resident was hospitalized because of physical aggression toward the staff and destruction of property. He reportedly broke three chairs, one table, and the china cabinet glass. He also damaged a staff person's car. On the 29th, the resident became aggressive because there was no answer when he called his mother. He reportedly refused to talk to his mother when she returned his call. He started hitting the kitchen faucet and the counter top with his hand when he was reminded about the smoking schedule. He broke the faucet and threw garbage at the staff person. He reportedly "excessively" scratched his neck and chest. On May 5th, it was recorded that the resident's mother came to the home unannounced and demanded an incident report regarding the scratches on the resident's chest. The staff person wrote that the resident's mother was aware that she could not have copies of incident reports. His mother reportedly blamed another peer for his injuries although there had not been any contact between them for more than a month. On the 12th, the resident engaged in three behavioral incidents that included verbal and physical aggression toward others, punching walls and doors, and other objects in the home. On the 15th, an addendum to the resident's treatment plan documented that money was not deducted from his funds and that his financial goal to pay for damages was discontinued because the guardian refused to give consent. On the 30th, the agency's Regional Director was called to the home because the resident broke several items in the home and injured his finger.

For June 19th, 2012, there were two documented incidents that included verbal and physical aggression and property destruction. The resident reportedly hit a staff person in his face, and threw a clip board and the television remote at him He broke a light blub and the light fixture in his bedroom. It was recorded that leading up to the incidents that the resident was upset because his mother would not agree to a home visit. On July 20th, the resident punched the walls as the staff were preparing to move him to a different home. Then, he went outside and damaged a staff person's car. On August 14th, the resident reportedly was very inappropriate while waiting to be seen by his physician in the community. It was recorded that the resident made sexual gestures such as pointing to female patient's breasts. He removed all of his clothing and began to masturbate when he was asked to move to a private room. He was asked to leave his physician's office and to return on another day.

On August15th, 2012, a special staffing reportedly was held, and the resident's family and the community prescreening worker were provided with a copy of his behavioral log. His family reportedly was informed about the incident that had occurred at his physician's office on that previous day. The guardian inquired about the onset of behaviors such as the resident wanting a bra and nail polish, and masturbating in public. She was informed that the resident had displayed the same behaviors at his previous placements. We also noticed that a report documented that he had asked for female apparels several times, but the guardian would not allow this. On the staffing day, the guardian was informed that the resident's inappropriate behaviors have cost the agency money and that they would continue unless he gets a bra. The guardian reportedly

agreed that the resident could wear a bra and that the agency could deduct $5.00 for damages from his funds every month.

For 2012, the resident's record contained a list of items that he had allegedly damaged, totaling $11,838.65. Included in the total was $4250.00 for floor carpeting, $1500.00 for garage door, $1865.00 for various doors and labor, $1100.00 for holes in the walls, $600.00 for ten chairs, $482.22 for kitchen window (broken twice), $580.00 for window blinds, $150.00 for box spring mattress, $183.43 for glasses that belonged to a staff person, $100.00 for painting the closet, $583.00 for repairing a staff person's car, $50.00 for medicine box, $180.00 for stair railings (broken six times), $100.00 for family room table, $65.00 for ceiling fan, and $75.00 for miscellaneous such as pictures, clipboard, etc.

When the complaint was discussed with the staff, the HRA was informed that the resident has been a client of the agency for about six years. He is compliant with medication overall. He was moved to another home managed by the agency in October 2012 for biting his roommate on the chest. He has engaged in five behavioral episodes of physical aggression since he was moved. We were told that male staff members are required during the day to manage his behaviors. Three staff members are assigned to the home during the night shift because of them. His behaviors are very extreme and he cannot be managed in the home or at the agency's day training center. According to the staff, the agency sought help from the Illinois Crisis Prevention Network (Support Service Team). This is a network of highly trained professionals, who have partnered with the Department, to work with individuals with severe behaviors and are struggling to maintain in their current home or placement. The Support Service Team reportedly had agreed that the resident cannot be managed in the home and that the agency was seeking an alternative placement.

The HRA was informed that guardians are notified about incidents and that they are provided with a written summary of them. They said that the resident's mother had requested copies of incident reports, but the guardian did not request them until the summer of 2012. The guardian reportedly was provided with a written summary of behavioral incidents from 2010 to the staffing date in August 2012. We found no documentation of her record request in the chart. The HRA was informed that the agency does not provide copies of incident reports to guardians because sometimes they contain confidential information such as other clients' names. They also said that the reports also contain names of staff members. We noticed that the names of the staff members were redacted on the incidents reports reviewed. According to the staff, the agency's policy does not direct that a summary of the incident should be provided to the guardian, but this is the agency stated practice. The HRA was told that incident reports are not kept in the resident's record. The staff were informed that anything except for therapy notes are part of the record and that those who are entitled have access to them under the Confidentiality Act.

According to the staff interviewed, the guardian had signed a contract regarding damages when the resident was first admitted to his CILA program. However, she reportedly had refused to renew the agreement by signature over the past several years. The staff reported that the agency did not deduct any money for damages from the resident's funds as planned. The HRA found no written indication that money was taken from his funds. The guardian told the HRA that she had requested incident reports many times. She said that she was not willing to give

consent for money to be deducted from the resident's funds because the agency did not provide incident reports or explain why they were unwilling to provide them. According to the guardian, the resident is no longer a client of the agency, and he has not exhibited any behavioral episodes at his new placement.

Subsequent to the site visit, the staff reported that the resident still lives in a home managed by the agency, and they insisted that the guardian was included in all aspects of the resident's well-being. The agency provided additional documentation such as staffing attendance sheets, emails, and notes concerning the resident. According to emails dated May 1st, 2012, the community prescreening worker told the agency's Behavioral Analyst that the guardian had called her concerning reports of incidents and damages discussed at the resident's annual staffing. The community worker wrote that she believed that the Behavioral Analyst had said at the staffing that she would check with her supervisor to see if the reports could be released. She told the Behavioral Analyst that she might receive a fax from the guardian for copies of the reports. The Behavioral Analyst told the community worker that she had only received consent for medication changes. We notice that the resident's guardian did not participate in his annual treatment staffing on April 11th, 2012 and that his mother participated by phone. His mother also participated by phone in his annual treatment staffing for 2012, and she was called after his plan was reviewed in 2013. According to the staff, the guardian gave verbal consent for the resident's mother to be included in his care at the agency, and his aunt and his mother are now co-guardians of the resident. An order indicated that the resident's mother became co-guardian on January 16th, 2013.

The HRA reviewed case notes written between 2010 and 2012 documenting that the resident's mother was informed about eleven of his many behavioral episodes mentioned in the report and that the guardian was notified by phone about three of them. We were informed that the agency was unable to get records concerning guardian notification from the phone company. We reviewed a note written by the community worker documenting that the agency's Behavioral Analyst provided the resident's guardian and his mother with an outline of incidents and a list of the items that he had allegedly damaged. This information was reportedly provided at the staffing meeting on August 15th, 2012. However, the guardian disagrees with this.

According to IAG's "Interdisciplinary Team" policy, whenever Person Center Planning activities occur for an individual, every possible attempt will be made to involve the family member, guardians or caregivers in the planning process. The policy directs the staff to make every attempt possible to keep relevant participants informed of all aspects of the individual's life.

The agency's "Person Centered Planning" policy directs the staff to strive for family and professional collaboration in all settings, especially in the areas of care giving, program development, etc.

The agency's "Individual Rights" policy includes the following, unless specifically modified by the person's guardian or court order: 1) to examine and review the resident's record, 2) to present a grievance, and, 3) to contact the Guardianship and Advocacy Commission, the agency's Human Rights Committee or the Illinois Department of Human Services.

The agency's "Incident Reporting" policy states that an incident report form will be completed and forwarded to the Director within 24 hours of the incident. A completed report should include, at the minimal, the following information: 1) the date, time and a detailed description of the event, 2) the names of involved parties, 3) the names of injured parties, 4) the nature of the injuries, 5) the names and location of witnesses, 6) action taken and persons notified, and, 7) the need for follow up. The Director or designee is required to notify the client's emergency contact person, guardian, representative, or public agency financially responsible for the individual's care. If the incident can be investigated by the agency, the House Manager will make provisions for follow up and the client's family or guardian will be notified "about necessary information."

IAG's "Grievance Procedure" policy states that clients and guardians have the right to present grievances and to appeal decisions, deny, modify, reduce or terminate services. The policy includes procedures as follows: 1) The grievance must be submitted in writing to the Regional Director. The staff person will review all relevant records and respond in writing within ten days after receipt of the grievance. 2) Unresolved grievances can be submitted to the agency's Chief Executive Officer or Chief Operating Officer who will also respond in writing within ten days of receipt. The decision of the Executive Director or the Chief Operating Officer shall be considered the agency's resolution to the grievance. A copy of the notification to the client regarding the resolution will be maintained in the client's permanent file.

CONCLUSION

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

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

Section 110/4 states that,

> The parent or guardian shall be entitled, upon request, to inspect and copy a recipient's record. Whenever access or modification is requested, the request and any other action taken thereon shall be noted in the recipient's record.

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

> A recipient of services shall be provided with adequate and humane care and services in the least restrictive environment, pursuant to an individual services plan. The plan shall be formulated and periodically reviewed with the participation of the

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

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

Section 5/11a-23 states that,

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

According to the CILA Rules, Section 115.220 (e) (13) of the Illinois Administrative Code,

> The community support team shall be directly responsible for working with the individual and parent(s) and/or guardian to convene special meetings of the team when there are issues that need to be addressed as brought to the attention of the team by the individual, parent(s) and/or guardian.

Section 115.250 (c) of the Illinois Administrative Code states that,

> Individuals or guardians shall be permitted to present grievances and to appeal adverse decisions of the agency and other service providers up to and including the authorized agency representative. The agency representative's decision on the grievance shall be subject to review in accordance with the Administrative Review Law [735 ILCS 5/Art.III].

The Authority substantiates the complaint stating that the agency failed to provide the resident's guardian with incidents reports and especially those involving serious injuries. The resident's record contained 159 documented behavioral episodes from January 10th, 2010 to October 6th, 2012. The staff interviewed said that the guardian did not request incident reports until the summer of 2012. However, emails dated May 1st, 2012 indicated that the agency's Behavioral Analyst was informed by the community worker that the guardian wanted incident reports and property damage reports. The community worker believed that the Behavioral Analyst had said that she needed to ask her supervisor if the reports above could released when they were discussed at the resident's annual staffing on April 11th, 2012. Once informed, the guardian's record request should have been documented in the resident's chart and the program's "Incident Reporting" policy states that guardians are to be notified nonetheless. According to special staffing report, dated August 15th, 2012, the resident's family and the community prescreening worker were provided with a copy of the behavioral incident log for the above three-year period. The staff interviewed reported that the agency stated practice is to provide a summary of the incident versus a copy of the actual incident report to guardians. They said that

sometimes reports contain protected identifiable health information such as the names of other clients involved in the incident. They said that incidents reports also include staff members' names, which the HRA notes is not protected under privacy rules concerning health information. We were informed that incident reports are not kept in the resident's record, but they are maintained is a separate file.

The Confidentiality Act, Section 110/2 clearly defines records and incidents reports as being part of the resident's record, and Section 110/4 of the Act and the agency's rights policy guarantees guardians access to records. The Act does not require a written request for records or approval from one's supervisor as suggested by the Behavioral Analyst's response to community worker above and the agency responses to the investigation findings. The Illinois Probate Act Section 5/11a-17 and 5/11a-23 and program "Interdisciplinary Team" policy further directs the provider to include the guardian in all aspects of the resident's well-being. The agency violates the above Sections of the Confidentiality Act, the Probate Act and program policy.

Additionally, the complaint alleged that the guardian's concerns about money being deducted from the resident's check to cover damages to the home were not adequately addressed. It was reported that the staff refused to tell the guardian exactly what items were damaged and to provide incident reports concerning this issue. We found evidence that the guardian had requested information on May 1st, 2012 concerning items that the resident had allegedly damaged. This information was reportedly provided in August 2012, although many of the incidents had occurred in 2010 and 2011. There was no written indication that the guardian had filed a grievance with the agency concerning this issue. The special staffing report indicated that the guardian had agreed to pay the agency for property damages, but the staff said that money was never deducted from the resident's funds. The Authority substantiates the complaint with regard to the lack of guardian access to incident reports and due to the staff reported practice that does not comply with Confidentiality Act.

RECOMMENDATIONS

1. Follow the Health and Developmental Disabilities Confidentiality Act Section 110/4 and the agency's clients' rights policy concerning access to records.

2. Document all requests for access to records in residents' charts.

3. The agency shall follow its "Interdisciplinary Team" policy, Mental Health Code provisions regarding guardian participation in treatment, and the Illinois Probate Act sections on a provider's reliance on guardian decisions/direction and update guardians about all aspects of the resident's life.

4. The agency shall follow its "Incident Reporting" policy and provide guardian notification.

SUGGESTIONS

1. Follow the Confidentiality Act and secure written authorization from the guardian in order to disclose information to another individual.

2. Ensure that guardians are offered the formal grievance process when disputes arise or issues are unresolved.

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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Founders:
Dr. Charlene A. Bennett
Dr. David H. Brooks

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INDIVIDUAL ADVOCACY GROUP

A Group That Advocates for Individuals with Special Needs

January 17, 2014

Ms. Judith Rauls, Chairperson
Guardianship & Advocacy Commission
Regional Human Rights Authority
West Suburban Regional Office
P.O. Box 7009
Hines, Illinois 60141-7009

RE: HRA No. 13-040-9001

Dear Ms. Rauls:

Individual Advocacy Group (IAG) is responding to the final report issued by the Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission dated December 16, 2013, as it is required to do if the report contains recommendations. IAG is filing its response within 30 days of receiving the HRA's report as required by the Authority's rules. IAG is also commenting on HRA's investigatory process.

General Comments About the HRA Process

IAG wants to express its concerns about the investigative methods and procedures the HRA and its staff used in conducting its investigation into the two complaints. There was -- 1) a major factual error that would have had significant implications for IAG if the fact had been true; 2) simple factual error about whether IAG was supplying the individual with supports and services at the time the complaints were lodged; and 3) the deliberate misuse of facts to draw an incorrect conclusion.

Significant Factual Error. In the initial report issued August 15, 2013, the HRA wrote a Comment that the –

> "resident's mother had told a (IAG) staff person that the resident said that a person had choked him. A corresponding incident report stated that the resident also told his mother that a (IAG) staff had choked him. Per the report, his mother was not able to provide the date of the alleged incident and she was informed that the House Manager would

be notified. There was no documentation that the agency reported the allegation as required by law, which violates the above Sections. The Authority strongly suggests that the agency review abuse and neglect reporting laws with appropriate staff members."

In fact, IAG had complied with the requirement regarding the incident by reporting it to the Office of the Inspector General (OIG). If the agency had not reported the alleged incident about IAG staff choking the individual to the OIG in accordance with the rules laid out in the Abuse and Neglect regulations, IAG would have been subject to severe sanctions by the OIG. The HRA and its staff never checked with IAG about this situation to determine whether IAG had followed the procedures for reporting Abuse and Neglect incidents to the OIG. The HRA just wrote it into its report as though not reporting the incident were true. The first time IAG knew anything about this allegation was when it received the initial written report from HRA in August 2013.

The HRA was genuinely chagrined when IAG produced its file on the alleged incident and the letter exonerating IAG regarding the alleged incident. But if the HRA had been truly investigating the complaints and other allegations involving this individual instead of merely going through the motions and printing whatever the complainant told to the HRA members and staff, it would have requested the file from IAG about this alleged incident while it was conducting its investigation between December 2012 (when it conducted its onsite investigation at IAG's offices) and August 15, 2013, when it issued its initial report. A request was never made. The only redeeming feature of this improperly conducted investigative procedure was that the Comment was removed from the HRA's final report.

Simple Factual Error. In its initial report issued August 15, 2013, the HRA wrote –

"According to the guardian, the resident is no longer a client of the agency, and he has not exhibited any behavioral episodes at his new placement."

This statement is false. The individual has been and remains in IAG's program. Again the HRA and its staff never checked with IAG to determine if basic facts were true but merely wrote it into the report

making it appear as though the individual had moved from IAG to another social service agency. Again the HRA and its staff were chagrined to learn from IAG's Chief Executive Office at the hearing in September 2013, that the individual had never left the care of the agency since his arrival several years ago. The guardian's statement that the individual had left IAG for another placement was false.

In fact, IAG attempted to Discharge the individual and requested authorization from the guardian to prepare intake packets for distribution by the local ISSA agency. The guardian blocked the distribution of the intake packets, thus forcing the individual to remain with IAG. The guardian surely knew that the individual continued to receive supports and services from IAG throughout the period. Making a false statement to the HRA about where the individual lives should bring into question whether the remainder of the guardian's statements in this matter should be discredited.

Instead of completely removing this factual error from its final report, the HRA and is staff made a clumsy attempt to "explain away" the error. Not even in the same paragraph in which the factual error was written but in the next paragraph the HRA wrote –

> "Subsequent to the site visit, the staff reported that the resident still lives in a home managed by the agency, and they insisted that the guardian was included in all aspects of the resident's well-being."

The clumsy way the sentence is worded makes it almost appear as though it was HRA staff that reported the individual was still with IAG when, in fact, it was IAG's CEO who made the statement during the HRA's September 2013 meeting. And what does the second part of that sentence have to do with the first part of the sentence "correcting" the factual error that the individual had relocated to another social service agency? It would appear to be an attempt to gloss over the fact that the Authority and its staff conducted a sloppy investigation when it could not even determine that the individual had never left IAG's Community Integration Living Arrangement (CILA) program.

Deliberate Misuse of Facts to Draw an Incorrect Conclusion. The HRA and its staff twisted information provided by IAG in its attempt to substantiate the complaint that IAG had not responded to requests by the

guardian for incident reports. On page 6 of its final report the HRA states–

> "According to emails dated May 1st, 2012, the community prescreening worker told the agency's Behavior Analyst that the guardian had called her concerning reports of incidents and damages discussed at the resident's annual staffing. The community worker wrote that she believed that the Behavioral Analyst had said at the staffing that she would check with her supervisor to see if the reports could be released. She told the Behavior Analyst that she might receive a fax from the guardian for copies of the reports. The Behavior Analyst told the community worker that she had only received consent for medication changes." (See Attachment 1 for the actual email correspondence between the IAG Behavior Analyst and the ISSA Individual Service Coordinator.)

On page 9 of HRA's final report, it attempts to use this email correspondence between IAG's Behavior Analyst and the ISSA Individual Service Coordinator to prove that IAG should have noted in the individual's record that the guardian – through the community worker - had made a request for incident reports and that this request should have been documented in the individual's chart. The guardian never made the request. She may have intended to make a request but she never sent a fax making the request. So how did the HRA and its staff draw the conclusion that IAG should have noted the "request" in the individual's chart? It would appear that the HRA and its staff were trying to bolster its very weak conclusion that IAG had disregarded the guardian's requests for incident reports.

Response to Complaints and HRA "Findings"

Complaint #1. The resident's guardian was not provided with incident reports and especially those involving serious injuries.

Again HRA misconstrues data in an attempt to dramatize its point. On page 2 the report states "The resident's file contained an incident log, dated January 10th, 2010 to October 6th, 2012, totaling 159 occurrences." (See Attachment 2 for the "log."[1]) By making this statement, the report

[1] The "log" is a summary of occurrences produced by IAG for the guardian in the summer of 2012 and subsequently updated through April 2013. August 2012 is the

makes it appear to the reader that IAG had not contacted the guardian 159 times regarding "occurrences" during this twenty-one month period. However, there is a significant difference between an "occurrence" that IAG staff may note on a behavioral log[2] and a "reportable incident" which IAG staff must report to a guardian.

An incident is reportable to a guardian (and others depending upon the issue) occurs when an individual requires third party (non-IAG) supports and services, such as hospitalization or calls to emergency service personnel (e.g., police). Only 20 instances out of the 159 "occurrences" were incidents that would have required IAG to contact the guardian. (See Attachment 3 for a list of reportable incidents.)

IAG acknowledges that it should have done a better job of documenting its reporting of incidents to the guardian. There were many times IAG staff left voicemail messages with the guardian according to a protocol that had been established between IAG and the guardian. However, in several instances, IAG staff did not make a note of the contact in the individual's record at the time the voicemails were left. Going forward, IAG will follow its amended policy regarding contacting the guardian every time there is a reportable incident. Additionally, staff will "time stamp" the contact in the individual's record. A procedure already in place is that when the guardian requests access to the individual's record, IAG will provide the guardian access to inspect and copy the individual's record. These requests will also be "time stamped."

Complaint #2. The guardian's concerns about money being deducted from the resident's check to cover damages to the home were not adequately addressed.

This complaint was not substantiated by the HRA.

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first time the guardian ever requested that IAG produce incident reports. Instead of preparing a report that listed only "reportable incidents" IAG staff prepared a report that listed all behavioral incidents, including those that were reportable.)

[2] HRA itself uses this term three times in the report. On page 2 it states, "For 2010, there were sixty-four incidents recorded on the behavioral log...." For 2011, the HRA reviewed forty-nine behavioral incidents..." For 2012, documentation indicated that the resident had engaged in forty-six behavioral incidents." This would indicate that the HRA and its staff knew the difference between a "behavior" and a "reportable incident" and simply chose to ignore it in order to make it appear as though IAG had not contacted the guardian 159 times over 21 months.

Actions Taken Regarding Human Rights Authority's Recommendations

Recommendation #1.

Follow the:

a. Health and Developmental Disabilities Confidentiality Act Section 110/4
   i. "The parent or guardian shall be entitled, upon request, to inspect and copy a recipient's record. Whenever access or modification is requested, the request and any other action taken thereon shall be noted in the recipient's record."
b. Agency's clients' rights policy concerning access to records.
   i. "Individual Rights" policy includes the following, unless specifically modified by the person's guardian or court order: 1) to examine and review the resident's record, 2) present a grievance, and 3) to contact the Guardianship and Advocacy Commission, the agency's Human Rights Committee or the Illinois Department of Human Services.

IAG Response. Individual Advocacy Group has instructed its staff that guardians shall be entitled upon request (whether written or oral) to inspect an individual's record and that staff will make a copy of a recipient's record after confidential information regarding other recipients has been redacted from the record. Also, IAG has directed its staff to "time stamp" the guardian's requests for information and make it an entry in the individual's file.

Recommendation #2.

Document all requests for access to records in the residents' charts.

IAG Response. Individual Advocacy Group has instructed its staff that it must note it in the individual's record all requests by a guardian for access to an individual's record.

Recommendation #3.

The agency shall follow its "Interdisciplinary Team" policy, Mental Health Code provisions regarding guardian participation in treatment, and the Illinois Probate Act section on a provider's reliance on guardian

decisions/direction and update guardians about all aspects of the resident's life.

c. "Interdisciplinary Team" policy, whenever Person Center Planning activities occur for an individual, every possible attempt will be made to involve the family member, guardians, or caregivers in the planning process. The policy directs the staff to make every attempt possible to keep relevant participants informed of all aspects of the individual's life.
d. Section 5/2-102 of the Mental Health Code – A recipient of services shall be provided with adequate and humane care and services in the least restrictive environment, pursuant to an individual services plan. The plan shall be formulated and periodically reviewed with the participation of the resident to the extent feasible and the resident's guardian, if appropriate.
e. Section 5/11a-23 of the Illinois Probate Act – Every health care provider and other person (reliant) has the right to rely on any decision or direction made by the guardian…to the same extent and with the same effect as through the decision or direction had been made or given by the ward.

Individual Advocacy Group has always followed its own Interdisciplinary Team policy, the Mental Health Code and the Probate Act. Guardians (and other relevant participants) are always invited to participate in the annual planning process, special staffing, behavior plans, etc. Through these scheduled meetings Individual Advocacy Group's staff keeps the recipient's guardian (and other relevant participants) informed of all of aspects of the individual's life.

IAG Response. As the Human Rights Authority stated in its report (pp 4-5), Individual Advocacy Group involved the guardian in the decision-making process regarding the individual's payment of a monthly amount to reimburse the agency for damage caused by the individual. Not until the guardian had given her consent was Individual Advocacy Group prepared to implement the reimbursement plan. So, Individual Advocacy Group relied upon the decision made by the guardian to the same extent as though the individual had made the decision or direction, exactly as the Human Rights Authority eventually determined in its decision.

Recommendation #4.

The agency shall follow its "Incident Reporting" policy and provide guardian notification.

> The agency's "Incident Reporting" policy states that an incident report form will be completed and forwarded to the Director with 24 hours of the incident. A completed report should include, at the minimum, the following information: 1) the date, time and a detailed description of the event, 2) the names of involved parties, 3) the names of injured parties, 4) the nature of the injuries, 5) the names and location of witnesses, 6) action taken and persons notified, and 7) the need for follow-up. The Director or designee is required to notify the client's emergency contact person, guardian, representative, or public agency financially responsible for the individual's care. If the incident can be investigated by the agency, the House Manager will make provision for follow up and the client's family or guardian will be notified about necessary information.

IAG Response. Individual Advocacy Group will amend its Incident Reporting policy to include the following language:

> "The Director or designee is required to notify the client's emergency contact person, guardian, representative, or public agency financially responsible for the individual's care if the client is hospitalized, emergency service personnel are called to the scene, or otherwise agreed upon in the Individualized and Personalized Plan. If there are other reporting requirements, those requirements would be set forth in the Individualized and Personalized Plan. The Director of designee will record each attempt to contact the relevant third party, and if the relevant third party cannot be contacted by telephone after five attempts, IAG will send a certified letter to that third party detailing the reportable incident."

Posting the Report on the Commission's Website

IAG strongly recommends that the Illinois Guardianship and Advocacy Commission (Commission) not post this report on its website because of the possible adverse effect it might create in the communities where other individuals with mental illnesses and intellectual disabilities reside. Or, if

the Commission decides to post the report on its website, it redact the specific incidents in it which are not germane to the findings and recommendations of the report – the actions were not reportable incidents as defined. The general public might perceive incorrectly that other individuals suffering from similar disabilities who live in their communities are likely to engage in some of the extreme behaviors (e.g., the doctor's office event) that seemingly routinely occur with the individual who is the subject of this report.

Sincerely,

Dr. Charlene A. Bennett
Executive Director/CEO

Attachments

cc: Dr. Mary A. Milano