FOR IMMEDIATE RELEASE

REPORT OF FINDINGS
INDIVIDUAL ADVOCAY GROUP INCORPORATED — 12-040-9002
HUMAN RIGHTS AUTHORITY— South Suburban Region

[Case Summary— The Authority made corrective recommendations regarding one of six allegations that were accepted by the service provider. 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 alleged that the agency failed: 1) to notify the guardian that the resident was moved to another day training site, 2) to provide financial records upon the guardian's request, 3 and 4) to adequately address the guardian's concerns about dental care and the acquisition of an assistive device to help the resident to communicate, 5) to include the guardian's input in developing treatment goals and objectives, and, 6) to secure the guardian's informed consent for a colonoscopy.

If substantiated, these allegations would be violations of the Mental Health and Developmental Disabilities Code, (the Code) (405 ILCS 5/100 et seq.), 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 132.148) 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 160 residents in its CILA program.

METHODOLOGY

To investigate the complaint, the agency's CILA Director, the Business Manager, the Director of Nursing, an Accountant and a Qualified Support Professional were interviewed. The complaint was discussed with the guardian. Sections of the adult resident's record and a copy of his Guardianship Order, dated August 21st, 1998, were reviewed with written consent. This

order appoints guardianship over the resident's personal care and finances. Relevant agency policies were also reviewed.

COMPLAINT SUMMARY

The complaint stated that the resident's guardian was not informed that the eligible person had been moved to a different day training site. It was reported that banking statements had been received several years ago, but the guardian was told that she would have to contact the agency's business office about financial records for 2010 and 2011, although she had previously requested them in writing. It was alleged that the guardian's concerns about the resident's dental gum disease was not adequately addressed. There was no follow-up concerning the guardian's written consent for the resident, who is verbally impaired, to participate in a community hospital's program to acquire a communication device. The guardian's input concerning treatment goals and objectives were not included in treatment planning. For example, she requested that goals to write definitions should be discontinued and those concerning matching pictures with words and writing his name in cursive should be included in his plan. Additionally, the complaint alleged that the resident had a colonoscopy without the guardian's written consent, but the agency's nurse claimed that she had discussed the medical procedure with the guardian.

Information from the record, interviews and program policies

According to the record, the resident is diagnosed with Intermittent Explosive Disorder and Mild Mental Retardation, and he has been a client of the agency since 2004. He is non-verbal but understands what is articulated by others. He communicates through sign language, gestures and writing. His legal guardian (sister) helps him with making medical and financial decisions. The record contained updated forms including but not limited to the Illinois Department of Human Services Rights of Individuals, informed consents for general medical treatment, an Emergency Treatment Release document, and a CILA Contract signed by the guardian. On March 17th, 2011, the guardian was informed by letter that an audit had showed that the agency did not have a copy of the resident's birth certificate, social security card and guardianship order. It was recorded that The Qualified Support Professional (QSP) had tried to reach the guardian by phone several times regarding the documents, but there was no written indication whether they were provided.

On April 28th, 2011, the QSP wrote that she attempted to notify the guardian that the resident had been moved to another day training center managed by the agency a few weeks earlier. The resident had made a good adjustment to the program change based on his continual access to the community and positive engagement, per the Interdisciplinary Team. Four days later, the staff person reportedly made another attempt to contact the guardian about the program change that offered smaller classes, but her phone was disconnected. According to the entry, the resident's desire to stay at his new training center would be discussed at his upcoming annual treatment staffing.

The record contained emails written by the assigned QSP and the Community Individual Service and Support Advocacy (ISSA) worker concerning a letter that the guardian had allegedly written to the present QSP explaining her concerns after the annual treatment staffing in July

2010, and a copy reportedly was provided to the community worker. On May 17th, 2011, the QSP was informed by the community worker that the guardian's concerns were never addressed and that she had not received any information regarding the resident's finances, per the guardian. The QSP was asked to provide the agency's corporate contact person information so that the guardian could request financial statements. She responded by saying that she did not attend the staffing in 2010, and that she had no knowledge of the letter. She had made many attempts to contact the guardian regarding medication and day training changes, etc., but she had not received any responses and was not able to leave any messages. The QSP wrote that she had only talked to the guardian one time since becoming the resident's assigned caseworker. This conversation reportedly occurred in September 2010, at which time; the guardian reportedly was informed that receipts can be obtained through the agency's corporate office. The QSP was given the guardian's email address on that same day. It is unclear whether a copy of the guardian's letter was faxed to the agency's staff person as reportedly offered by the community worker. But neither the letter nor the guardian specific written request for financial documents were found during the record review.

On May 19th, 2011, an email addressed to guardian stated that the resident receives $50.00 each month (personal allowance from Social Security Income) and that requests for receipts must be mailed to IAG's corporate office, per the agency's directives. The agency's address and accountant's name were listed with a notation that the record request also could be sent to the QSP. On that same day, the guardian reportedly was informed that the resident was attending a different day training site with smaller classrooms. And, "he absolutely loves it" and that he had access to the community daily. The guardian was asked to supply phone numbers where she could be reached, but there was no indication of this. Subsequent, documentation indicated that the guardian was invited to the resident's annual treatment staffing scheduled for July.

The resident's "Person Centered Plan," dated on July 13th, 2011, indicated that he weighed 201 pounds at the time. His plan and a medical note stated that his annual dental examination was completed on June 2011. X-rays were taken and tooth #5 was cracked or broken. A follow-up visit for deep cleaning of the gums (a therapeutic procedure to help prevent periodontal disease) was recommended. His record documented that he had no dental decay or infection in 2010 and 2011.

The resident's plan included residential goals to increase, improve or develop: 1) independent living skills, 2) knowledge of medication, 3) financial independence, 4) community integration and physical fitness, and, 5 and 6) communication and self advocacy skills. His day training program included a goal to increase his vocational skills by writing his telephone number and the QSP's number. A second goal stated that he would increase his domestic skills by matching three pictures at the minimal with the correct food group. A third goal stated that he would increase his educational skills by writing his name in cursive. His plan documented that the guardian can add, change or delete any of the goals at any time. The plan was signed by the guardian on September 29th.

A lengthy meeting note written by the QSP stated that the guardian was very "confrontational" and voiced concerns during the staffing on July 13th 2011. The guardian

reportedly replied "have you tried mailing anything" and requested that the agency should contact her by mail upon the staff person's request for updated contact information. On questioning, the guardian was informed that the hospital's funding had been cut for several individuals concerning a communication device, but the resident had been evaluated before the present QSP became his caseworker. According to the note, the guardian stated that "it probably won't be useful— he wouldn't understand anyway." She was informed that the resident's receptive language is good upon questioning his ability to understand what is articulated by others.

The meeting note further stated that the guardian questioned whether the home staff were running the goals. The QSP explained how data was collected monthly, but she continued to make statements about the accuracy of the information gathered and would not allow present and upcoming goals to be reviewed. The guardian reportedly voiced her dissatisfaction with the use of "reinforcements" and did not understand why the agency uses natural consequences like "increased independence" versus "something like stickers." It was explained that the agency administration believes that natural reinforcements like independence, knowledge are stronger than tangible items especially for an adult. But she repeatedly said that she also writes treatment goals and disagreed with the agency's system. Additionally, the guardian disagreed with the resident's day training program goals and specifically the use of a dictionary or encyclopedia. It was recorded that the resident enjoys tangible books and magazines, but she was only willing to allow a reading and writing goal if he could use the internet. She was informed that the internet was not always available due to the number of clients at the day training program.

The record contained many entries written by the nurse who allegedly said that the guardian verbally consented to a colonoscopy. On July 6th, 2011, the nurse told the treating physician that the medical procedure had not been scheduled because the QSP was having problems contacting the guardian. On that next day, the CILA Director and the QSP were informed that the colonoscopy had been scheduled for July 14th, but there was no indication of the guardian's written informed consent. On July 13th, the home staff was given instructions concerning preparing the resident for the medical procedure. On that same day, the nurse wrote that the colonoscopy was discussed with the guardian at the resident's day training center. She reportedly was informed that the colonoscopy had been recommended by the primary physician because the resident's weight loss during the past two years required follow up. It was documented that the guardian verbalized an understanding of the information shared; she verbally consented to the colonoscopy, and the treating physician's contact information was provided.

On July 14th, a colonoscopy and upper Endoscopy (EGD) examination were done at a local hospital. An EGD is an examination of the lining of the esophagus, stomach, and first part of the small intestines done with a flexible endoscopy. On that same day, the QSP was informed by the CILA Director that the guardian said that she was never contacted by the agency or consented to the colonoscopy. A corresponding note indicated that the QSP had been informed about the guardian's assertions on the previous day. She also wrote that the colonoscopy had been explained to the guardian; the resident's physician had ordered the medical procedure, and a "general release" was signed, per the agency's nurse.

On July 16th, the nurse wrote that the resident's medical procedures and results were explained to guardian, according to the treating physician. A follow up EGD visit was recommended, and the guardian's contact information was provided to the treating physician. On September 6th, the CILA Director asked the agency's nurse if the guardian was aware of the follow-up visit scheduled for September 8th. She wrote that "we really need to make sure this woman is on board and understands what is going on." A corresponding note stated that the nurse was planning on escorting the resident to his medical appointment, but she does not contact guardians and that the QSP was aware of this. She wrote that the resident's plan of care had been discussed with the guardian, according to the physician. And, she should be encouraged to call the physician if she had further concerns. On September 9th, the nurse was informed by a hospital employee that the guardian had refused to give consent for the follow-up procedure.

When the complaints were discussed with Individual Advocacy Group (IAG) staff members, the HRA was informed that the guardian had provided a copy of the guardianship order as requested in 2011. The agency has four day training sites, and the resident was moved to another day training center managed by the agency with his approval. His day training goals did not change and the move was only for a couple of months. The QSP further reported that a letter, dated on April 28th, 2011, was sent to the guardian regarding the program change. The investigation team did not find the letter during the record review, but the progress note above suggested that notification was attempted by phone on the same day. An email indicated that she was informed on May 19th, 2011.

According to the CILA Director and the QSP, the guardian had requested financial records for 2010 and was referred to the agency's business office. The agency's accountant said that she received an email from the CILA Director about the record request in November 2010 and that financial records were provided for that same year. The investigation team was informed that the guardian never followed up with the agency if she wanted more documents. On questioning, the QSP said that she would not have documented the record request because she had just started working at the agency in 2010. The Business Manager added that the record request does not have to be in writing. We were told that guardians have requested records from the agency and that they also can review them.

According to the staff interviewed, the resident does not have dental gum disease. They explained that the hospital's funding for the communication device had been cut and that the resident's uses a picture book to communicate with others. The staff said that contacting the guardian has been problematic and that she had recently requested notification only by mail. According to the staff, the guardian had sent a letter to the agency's Chief Executive Officer in 2011, but the HRA's request for a copy of letter was not met.

The nurse who allegedly said that the guardian was informed about the colonoscopy could not be interviewed because she is no longer at the agency. The Director of Nursing explained that the colonoscopy was ordered because the resident was experiencing weight loss, diarrhea and constipation. We were told that the nurse did not attend the resident's staffing on July 13th, but the guardian gave the nurse verbal consent for the colonoscopy after the meeting in the parking lot. The resident's colonoscopy was performed as planned, and follow-up was recommended. The treating physician reportedly spent about an hour on the phone with the

guardian explaining why an upper endoscope examination was necessary. The physician sent consent forms to the guardian as requested in September 2011, but they were not returned. Subsequent to the site visit, the HRA was informed that the agency was unsuccessful in arranging a meeting with the guardian as suggested by the investigation team. The resident reportedly had the follow-up procedure, and a hernia was found.

IAG's "Interdisciplinary Process" policy states that the purpose of the policy is to ensure that the team participates in a person centered planning process that reinforces the principles of normalization. The interdisciplinary process must include the Qualified Support Professional/Qualified Mental Health Professional, the Community Support Team, the individual and guardian if appropriate. It states that the individual and/or guardian need to be active participants in the process.

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 participate in setting goals and objectives, in planning program services and making changes when needed with the agreement of the Interdisciplinary Team, 2) to present a grievance, 3) to refuse medical treatment and medications, and, 4) to contact the Guardianship and Advocacy Commission, the agency's Human Rights Committee or the Illinois Department of Human Services.

IAG's "Individual Funds" policy states that to protect against malfeasance, CILA participants will be allowed to manage their money with minimal assistance from the staff unless the agency serves as the representative payee. Guardians will have access to financial records regarding individuals whom they are responsible for.

The agency's "Informed Consent" policy states that to ensure that individuals or legal guardians are given the opportunity to make informed choices regarding services offered by the agency, and to ensure confidentiality, signed informed consent is required for many situations such as medical testing or services, etc.

CONCLUSION

According to Section 5/2-102 (a) of the Mental Health and Developmental Disabilities 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 recipient to the extent feasible and the recipient's guardian, the recipients' substitute decision maker, if any, or any other individual designated in writing by the recipient…. In determining whether care and services are being provided in the least restrictive environment, the facility shall consider the views of the recipient, if any, concerning the treatment being provided.

According to Section 110/4 of the Mental Health and Developmental Disabilities Confidentiality Act,

> 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.

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.

The Illinois Administrative Code Section 132.148 (c) states that,

> Treatment plan development, review and modification is a process that results in a written Individualized Treatment Plan (ITP), developed with the participation of the client and the client's parent/guardian, as applicable, and is based on the mental health assessment report and any additional evaluations. Participation by the client or parent/guardian shall be documented by the client or parent/guardian's signature on the ITP. If there is no signature on

> the ITP, there must be a note in the record documenting participation. In the event that the client or parent/guardian refuses to sign the ITP, there must be a note in the record documenting that the plan was reviewed with them and the reason for refusal.

Complaint #1 that the guardian was not informed about changes in the resident's day training site is unsubstantiated. Although the resident's record and the staff indicated that he was moved to a different day training center for a few months, the HRA found no written evidence regarding the guardian's expectations about notification of programmatic changes in the record. There was evidence of the QSP's attempts to notify the guardian about the change, according to program policy, an email suggested that she was informed on May 19th, 2011.

Complaint #2 that financial records for 2010 and 2011 were not provided upon the guardian's request is unsubstantiated. Complaints #3 and 4 that the agency failed to adequately address the guardian's concerns about dental care and the acquisition of an assistive device to help the resident to communicate are unsubstantiated. The record indicated that the guardian was referred to the agency's business office upon her request for financial records in 2010. The agency's accountant told the HRA that financial documents were provided for 2010, and the staff interviewed said that the guardian did not request additional financial documents. There was no written documentation of the guardian's specific record request in the residential record. The resident's record clearly documented that he does not have dental gum disease as alleged in the complaint. There was no clear evidence that the guardian had requested an update concerning the assistive communication device before the treatment staffing on July 13th, 2011, best practice indicates that she should have been notified before the meeting. According to the staff interviewed, the guardian sent a letter to the agency's Chief Executive Officer in 2011, which suggests that she had concerns about service delivery as stated in the complaint.

Complaint #5 that the agency failed to include the guardian's input in developing treatment goals and objectives is unsubstantiated. Based on the resident's "Person Centered Plan," goals were changed as requested by the guardian. The plan was also signed by the guardian on September 29th documenting that she was included in its development.

In regard to the complaints above, the Authority finds no clear violations of Sections 5/2-102 of the Code, 110/4 of the Mental Health and Developmental Disabilities Confidentiality Act, 5/11a-17 and 5/11a-23 of the Probate Act, the Illinois Administrative Code Sections 115.220 (e) (13) and 132.148, or program policies.

Complaint #6 that the agency failed to secure the guardian's informed consent for a colonoscopy is substantiated. On July 14th, 2011, a nursing note indicated that a colonoscopy and an upper endoscopy examination were done, but the guardian's informed written consents for the medical procedures were not found in the record. The agency violates Sections 5/2-102 (a) of the Code, 5/11a-17 and 5/11a-23 of the Illinois Probate Act and program policy, which directs the staff to include the guardian in the resident's personal care and to obtain signed informed consent for medical testing and services. The agency's "Individual Rights" statement further guarantees residents or guardians the right to refuse treatment.

RECOMMENDATIONS

1. Review program policies and consent laws regarding substitute decision making with all appropriate staff. Under the Probate Act of 1975, if a court adjudges a person to be disabled, as in this resident's case, a guardian of his person is appointed because it was found by clear and convincing evidence that the resident lacked sufficient understanding or capacity to make or communicate responsible decisions concerning personal care (755 ILCS 5/11a-3).

2. The agency shall follow the Illinois Probate Act, Section 5/11a-23, program policy and client rights statement and rely on the guardian's directions by ensuring that written informed consent is obtained for non-routine and non-emergent medical procedures.

SUGGESTIONS

1. The agency shall revise its policy to include the level of communication desired by guardians concerning program changes. This issue shall be discussed during the annual treatment staffing and documented in residents' plans.

2. Include in resident's records all correspondences such as record requests and grievance letters.

3. We encourage IAG to ensure that record requests are documented in residents' charts pursuant to Section 110/4.

4. We strongly suggest that the agency should not rely on verbal consent for medical testing and services.

5. Address resident finances in annual treatment plans, including the provision of financial statements to residents/guardians.

COMMENT

The HRA noticed the agency's staff many attempts in the record to work with the guardian and to answer her questions and concerns. As before, we suggest that the staff should continue to engage her in all aspects of the resident's life pursuant to Section 115.220 (e) (13) of the Illinois Administrative Code.

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

August 8, 2012

Guardianship and Advocacy Commission
Human Rights Authority

RE: HRA No. 12-040-9002

Dear Ms. Rauls:

We have received a copy of the findings and recommendations for the above case and are including below the response from our agency. Please be advised that IAG, based on the issues brought up by this case, has been re-evaluating and amending our policies, as well as updating our executive staff on these changes as identified as part our QA/QI system all prior to the receipt of the findings of this case.

1) Program policies have been reviewed. IAG takes extremely serious that all our policies are properly and completely followed. Executive staff members responsible for assuring thorough execution of the policies have been retrained.

2) The nurse responsible for this case is no longer an employee of IAG.

3) IAG will continue to make sure that all guardian consents are specific to each medical procedure and our policy has been revised to reflect this language.

It is the practice of IAG to put the health and welfare of our individuals at the forefront of our services and supports. IAG makes every effort to communicate and work in conjunction with the individuals' guardians on a continuous basis and to ensure smooth working relationships with our guardians. There are occasions, however, that despite our best efforts people will try to find fault.

We were unfortunately unaware of the receipt of these findings prior to today and as a result we did not provide your offices with a timely response. We sincerely apologize for the delay, please know that it was not intentional or meant to be negligent. IAG has a solid history of exemplary supports for individuals; we appreciate your input on this matter. Be assured that we will do everything in our power to make certain that we have no further issues of this kind.

Sincerely,

Dr. Charlene A. Bennett
Executive Director/CEO

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