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FOR IMMEDIATE RELEASE

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**East Central Regional Human Rights Authority  
Individual Advocacy Group, Englewood  
Report of Findings  
Case #18-060-9005**

*Case Summary: The HRA did substantiated the allegations that a Community Integrated Living Arrangement, or CILA, has no accessible transportation even though there are 2 residents in the CILA that use wheelchairs. As an aside, one of the two residents has an accessible vehicle that the CILA was using, without permission, for the other resident that does not have an accessible vehicle. In one of the resident's planning meetings, the CILA stated that it would be acquiring an accessible vehicle. However, that was in July and there has been no progress. Without an accessible vehicle, the one resident is unable to go shopping, go to church and get her hair done. The HRA did not substantiate the other two allegations. A provider response was required and the provider elected to make the response public, therefore, it is included at the end of the report.*

The East Central Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission voted to pursue an investigation of Individual Advocacy Group (IAG) after receiving the following complaints of possible rights violations:

**Complaints:**

- 1. A Community Integrated Living Arrangement, or CILA, has no accessible transportation even though there are 2 residents in the CILA that use wheelchairs. As an aside, one of the two residents has an accessible vehicle that the CILA was using, without permission, for the other resident that does not have an accessible vehicle. In one of the resident's planning meetings, the CILA stated that it would be acquiring an accessible vehicle. However, that was in July and there has been no progress. Without an accessible vehicle, the one resident is unable to go shopping, go to church and get her hair done.**
- 2. The CILA does not honor individualized preferences. One resident has specific/special dietary needs and the CILA's entire menu is based on that one resident's diet. Other residents are not able to get food preferences included on the menu and sometimes the offerings are pretty limited. Another example is a resident wants to go to a specific hair salon but is directed to another salon.**
- 3. CILA residents are told that they are not allowed to talk with anyone else about concerns or issues involving the CILA home – all information is to be kept internal to the home – even though most residents have a treatment team that consists of other service providers such as vocational programs, etc. and services are to be coordinated for continuity of care. Residents may even be discouraged**

**from calling external sources such as the OIG, advocacy resources, etc. A vocational program is not kept apprised of issues involving CILA residents that might impact service provision at the vocational program.**

If the allegations are substantiated, they would violate protections under the Mental Health and Disabilities Code (405 Ill. Comp. Stat. Ann. 5/2-100, 405 Ill. Comp. Stat. Ann. 5/2-103) and the Illinois Administrative Code (59 Ill. Admin. Code 115.200, 115.250, 115.220, 115.320 and 116.40).

### **Investigation**

Due to concerns about confidentiality in the small facility, the HRA proceeded with the investigation without written consent from any consumers residing there. To pursue the matter, the HRA interviewed IAG representatives, reviewed redacted documentation from the consumer files, and assessed agency policies and procedures.

### **Interviews:**

On February 22, 2018 at 10am, the HRA met with the IAG regional director. The meeting occurred at 701 Devonshire Dr. Champaign, IL. The meeting began with introductions, a review of HRA procedures, and a review of the allegations being addressed in this investigation.

The IAG website states that the IAG “provides a full array of quality, customized, outcome-focused services for people with developmental, intellectual, emotional, behavioral, neurological or mental disabilities”. IAG was started in 1995 and serves 21 counties in Illinois. Staff reported that the provider started opening facilities in the Champaign area 3 years ago and currently has 3 CILAs serving 10 consumers. All three homes are designed to serve consumers with developmental disabilities but consumers may have multiple diagnoses.

Staff reported that the CILA listed in this complaint has 4 consumers residing there. If fully staffed, this CILA would require no staff for first shift (all consumers are in community based programs during the day), 2 second shift staff, and 1 3<sup>rd</sup> shift staff. There is a daytime case manager that addresses the consumers’ needs at the community programs and is available to all 3 of the CILA homes in the event that there is a change in need during the day time hours. All staff are Direct Support Professional Certified (DSP) and are trained to distribute medication. In addition to the staff present at the CILA, there is a Registered Nurse and a LCSW Behavioral Specialist on call if needed. All staff receive Abuse and Neglect training yearly. It should be noted that the provider acknowledged that they are currently short staffed at this location. The executive director reported that she is often at this location covering shifts and must bring in certified staff to complete tasks such as medication distribution and Hoyer lifting.

The IAG has a grievance policy, active human rights committee, and numbers to make complaints to the Office of the Inspector General, Human Services, and **the** Human Rights Authority are posted within each CILA. Consumers residing at this facility all have the ability to

make phone calls, most of them have personal cell phones that can be taken to their bedrooms for privacy and the house phone is cordless.

Staff reported that the CILA does have a wheelchair accessible vehicle. There are 2 individuals that are residing at the facility that require wheelchair accessible transportation. IAG purchased the vehicle in July but did not have access to it until October due to the handicap modifications placed into it. Prior to October 2017, the CILA was using a “loaner vehicle” that a family provided to the CILA while they awaited the new van. Staff stated that the vehicle that was loaned to the CILA could transport one consumer using a wheelchair at a time. Staff do not believe that there was a contract with the van owner and the van owner never brought any concerns to them.

The IAG stated that the residents leave the CILA every day Monday through Friday to go to their community program (not everyone attends the same program and each of them are picked up by the community provider). In addition, regular outings are scheduled. A list of outings was provided to the HRA. The IAG van is used to transport the consumers that use wheelchairs for accessibility and other consumers are transported in staff vehicles.

Staff reported that there are not many unscheduled outings/community trips. Due to the staffing limitations, all appointments, shopping, and recreational activities must be scheduled in advance. In an emergency, staff would be called in to assist but otherwise there is limited flexibility. Even when fully staffed, IAG does not employ enough staff for each shift to accommodate unscheduled outings or to run “impromptu errands”. Should a consumer have a need to go somewhere outside of a scheduled event they would need to make their own transportation arrangements. IAG staff stated that she thinks that they keep logs of all the van usage and agreed to provide the logs to the HRA for review if available.

Consumers are able to choose their own providers. Each consumer has his/her own physicians, hair stylist, and shopping preferences. Family members often pick up consumers and take them to appointments or outings, however, the CILA can take them if needed. All consumers can leave the CILA and are only asked to sign a log to let staff know where they are going and when they will return (for safety purposes). Staff stated that the only incident that staff can recall of a consumer’s preference not being honored was in the fall. One consumer’s hair stylist left a salon and could not be located. The CILA attempted to locate the stylist in the community but was unsuccessful. When it came time for that consumer to get a haircut the consumer was upset at the thought of having to go to someone new.

The IAG stated that all consumers can express their individual preferences and have them honored. The meal planning is done regularly and consumers each add things to the list as the need arises. Staff plan only one meal for everyone, however, the diet is not restricted. There is one individual in the home who works closely with a dietician. This consumer’s guardian has outlined items that the consumer cannot eat as well as portion control but this does not impact the other consumers in the home. Due to the health concerns of this one consumer, there are some locked cabinets in the CILA but consumers that are not restricted can have the items at any time using the key. The director indicated that the consumers also have “fast food” meals brought in by the director when emergencies and staffing issues arise. Other preferences, such as

bed time, are honored as well. All staff are Hoyer trained and staff can be brought in from other homes if needed to assist at bedtime.

Staff report that consumers can have visitors at any time and drop-ins are welcome. There is a green sign-in book that visitors are asked to complete for safety purposes but there are no other restrictions. All consumers have their own bedrooms and can meet with visitors privately if needed. It should be noted that IAG acknowledged that there have been some visitor restrictions in the past because a guardian has stated that a consumer cannot have a specific visitor. There has also been an issue with previous staff coming to the home after they have been terminated to visit with the consumers. The previous staff were told that due to the termination they cannot visit the consumers at the CILA and suggested making arrangements with the guardian to visit elsewhere.

All consumer preferences are addressed in their Individual Service Plans. Planning meetings include the consumers, guardians (when applicable), and community providers. The consumer may also request that someone be present during the meeting and be made a part of the plan at any time. The IAG has not had any grievances filed in the last 6 months. Staff did state that some of the consumers attend community programs that are very large. The IAG feels that concerns/changes are reported to providers but often the communication in those facilities is challenging. The HRA asked if the staff have considered alternate community providers and staff stated that the issues have not been serious enough to warrant any changes.

### **Records Reviews:**

The IAG provided the HRA with the following redacted records:

Service plans indicate that two of the residents at the CILA on ~~Englewood~~ require a wheelchair accessible vehicle. A vehicle lease states that on 10/23/17 IAG leased a 2017 Dodge Grand Caravan. The IAG CILA Manual section 1.17, CILA Policies and Procedures “Transporting Individuals into the Community” and “Transportation” policies outline that the CILA is responsible for ensuring that groups are taken into the community for community based trips and employee requirements for transportation. The IAG CILA Manual section 1.17, CILA Policies and Procedures “Community Integration and Acceptance” states “Individuals in the CILA program are encouraged to participate in integrated activities and events”. No van/vehicle usage logs were provided (staff did indicate that they may not exist). The HRA reviewed documentation of outings, including photos of holiday functions, restaurant dinners, and recreational activities. Also a list was created for the HRA of current activity enrollments with community providers and sports functions including basketball and track and field teams. A staff statement provided states “The two individuals who attend (outside community program), appear to struggle with jealousy about missing out on what is happening when they are not present;” also noted was an incident that occurred when a consumer was in the community with family and was upset that they missed a CILA event.

Service plans indicate that one resident has strict dietary restrictions imposed by a physician and guardian. IAG menus for the CILA showed meals provided (along with portions) for random weeks over the last 4 months. Meals appear to cover a variety of food categories and do not

appear to be restrictive in terms of calorie or fat content. All service plans provided were created within the last year and signature pages confirm that IAG staff, guardians (when applicable), and community service providers were all present to create/review the plan.

The IAG CILA Manual section 1.17, CILA Policies and Procedures “Individual Rights” #17 states that consumers have the right to contact the Guardianship and Advocacy Commission, Human Rights Authority, or the Department of Human Services. The manual also has instructions and telephone numbers for these entities included if the rights are violated. It should be noted that the numbers in the manual are local numbers for consumers being served by the Rockford, IL offices. The IAG CILA Manual section 1.17, CILA Policies and Procedures “Visitation” outlines the requirements for leaving the CILA with visitors and having visitors at the CILA. Most limitations noted in this policy are in relation to guardian directives and safety concerns. There is no mention of staff (current or previously employed) being allowed visitation with consumers. No rights restriction notices were provided to the HRA to demonstrate that any consumer’s visitation rights are being withheld.

## **Conclusions**

**Complaint 1: The CILA has no accessible transportation even though there are 2 residents in the CILA that use wheelchairs. As an aside, one of the two residents has an accessible vehicle that the CILA was using, without permission, for the other resident that does not have an accessible vehicle. In one of the resident’s planning meetings, the CILA stated that it would be acquiring an accessible vehicle. However, that was in July and there has been no progress. Without an accessible vehicle, the one resident is unable to go shopping, go to church and get her hair done.**

CILA regulations (59 Ill. Admin. Code § 115.220) state “c) The CST shall be directly responsible for: 15) Assisting individuals to access transportation.”. The Mental Health Code (405 ILCS 5/2-100) states “(a) No recipient of services shall be deprived of any rights, benefits, or privileges guaranteed by law, the Constitution of the State of Illinois, or the Constitution of the United States solely on account of the receipt of such services.” The 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 environment, pursuant to an individual services plan. The Plan shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient. 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. 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.” IAG staff confirmed that it did not have a wheelchair accessible vehicle for the two consumers requiring wheelchair accessible transportation until October 2017 when the agency purchased a Dodge Grand Caravan. In the absence of transportation, the agency borrowed a van from a resident’s family member to assure that one

consumer had transportation available leaving one consumer who uses a wheelchair without means for transportation.

After completing the interviews, records reviews, and assessing applicable mandates, there is evidence to support the complaint. The agency did not have reliable transportation for all the consumers residing at the CILA prior to October 2017. Of the 4 consumers residing at the CILA, 2 are able to ride in the staff vehicles, one had access to his/her own wheelchair accessible vehicle, and one was left without adequate transportation.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were violated and, therefore, the complaint is substantiated. Since the agency obtained a vehicle in October 2017 that is capable of transporting both consumers who use wheelchairs, no recommendations or suggestions are being made in relation to this complaint.

**Complaint 2: The CILA does not honor individualized preferences. One resident has specific/special dietary needs and the CILA's entire menu is based on that one resident's diet. Other residents are not able to get food preferences included on the menu and sometimes the offerings are pretty limited. Another example is a resident want to go to a specific hair salon but is directed to another salon.**

The HRA reviewed the Mental Health Code (405 ILCS 5/2-100 and 5/2-102) as listed above and CILA regulations (59 Ill. Admin. Code § 115.200) which state that "c) Services shall be oriented to the individual and shall be designed to meet the needs of the individual with input and participation of his or her family as appropriate. Individuals are recognized as persons with basic human needs, aspirations, desires and feelings and are citizens of a community with all rights, privileges, opportunities and responsibilities accorded other citizens. Only secondarily are they individuals who have a mental disability. d) Based on their needs, individuals shall receive supervision and supportive services which may range from continuous to intermittent. CILAs shall be designed to promote optimal independence in daily living, economic self-sufficiency and integration into the community through the interdisciplinary process." Service plan reviews confirm that one of the four consumers residing at the CILA has a diagnosis that requires a more restrictive diet (1200 calories a day). This dietary restriction means that this consumer must eat premeasured food and have regular monitoring but does not require the individual to have separate meal plans. Staff state that the menu is made each week with input from all consumers and the menus provided to the HRA appear to include a variety of food preferences. IAG policies and service plans outline the unique needs and preferences of the consumers and how those are honored, including preferences of activities and community providers. Staff acknowledge that being understaffed affects the consumer's ability for impromptu errands or unscheduled events, however, they do not believe that this results in any consumer needs or preferences not being met.

While reviewing this complaint, the HRA was informed by IAG that the CILA is understaffed due to turnover. Entire shifts are often covered by management or outside staff who do not have DSP training. Staff stated that in those cases trained staff are called from other places to complete tasks such as putting the consumers in wheelchairs to bed with the Hoyer lift and medication distribution (these staff do not stay for the entire shift but rather to assist in things that the covering staff are unable to do). Without properly trained staff available in the home at

all times, there is concern that in the event of an emergency the safety of the consumers residing at the IAG CILA may be at risk. CILA regulations (59 Ill. Admin. Code § 115.320) state "1) Mental health and developmental disabilities employees shall be licensed or certified as required by Illinois laws" and "d) L) Other training which relates specifically to the type of disability or treatment and intervention techniques being used specific to individuals living in CILAs geared toward assisting employees to execute objectives obtained in the services plans;"

After completing the interviews, records reviews, and assessing applicable mandates, there is limited evidence to support that IAG staff has violated the consumer's right to individual preferences. While the consumers have very different needs and preferences, the client centered plans and services are created with the consumer and document preferences such as likes, dislikes, preferred providers, outings, and recreational activities. Other IAG documentation demonstrates that a variety of food preferences as well as activity preferences are being honored. However, staff reported that the agency is understaffed, experiences turnover and has other staff cover gaps, therefore, the HRA has concerns that these services may not always be provided by licensed staff per CILA regulations (59 Ill. Admin. Code § 115.320), and in the event of an emergency, consumers requiring medication and/or a Hoyer for evacuation could be at risk.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint is unsubstantiated and no recommendations are being made. The HRA would like to remind IAG staff that, should a consumer's rights be restricted for any reason, the consumer must be adequately informed of any restriction per Mental Health Code (405 ILCS 5/2-201).

While the HRA cannot confirm or deny that staffing levels have impacted resident needs, the HRA is concerned that there are not adequate, trained staff to meet individual resident needs and preferences, including safety risks such as appropriately using a Hoyer lift. Therefore, the HRA strongly suggests:

1. Ensure that any staff member working at IAG CILAs will, at a minimum, adhere to CILA regulations (59 Ill. Admin. Code § 116.40) Training and Authorization of Non-Licensed Staff by Nurse-Trainers.
2. Ensure that any staff member working at IAG CILAs (where a Hoyer lift is used for mobility of a consumer) will be trained to properly use a Hoyer lift per CILA regulations (59 Ill. Admin. Code tit. § 115.320 c) 7) b)).

The HRA also points out that program policies do not supersede Statute, namely the Code which guarantees each recipient the right to visitation with persons of his or her choice, not the program's choice, unless necessary to prevent harm, harassment or intimidation and that adequate space is to be made available for such visits, meaning in his home (405 ILCS 5/2-103). IAG's blanket policy prohibiting former employees from visiting at the CILA, if at a resident's request, is stricter than the Code unless necessary from preventing former employees from causing harm, harassment or intimidation, in which case rights restriction notices are required (405 ILCS 5/2-201). Policies and procedures may amplify or expand but shall not restrict or limit the rights guaranteed to recipients (405 ILCS 5/2-202).

**Complaint 3: CILA residents are told that they are not allowed to talk with anyone else about concerns or issues involving the CILA home – all information is to be kept internal to the home – even though most residents have a treatment team that consists of other service providers such as vocational programs, etc. and services are to be coordinated for continuity of care. Residents may even be discouraged from calling external sources such as OIG, advocacy resources, etc. A vocational program is not kept apprised of issues involving CILA residents that might impact service provision at the vocational program.**

The Mental Health Code (405 ILCS 5/2-103) states “Except as provided in this Section, a recipient who resides in a mental health or developmental disabilities facility shall be permitted unimpeded, private, and uncensored communication with persons of his choice by mail, telephone and visitation” and CILA regulations (59 Ill. Admin. Code § 115.250) state “To ensure that individuals' rights are protected and that all services provided to individuals comply with the law, agencies licensed to certify CILAs shall assure that a written statement, in a language the individual understands, is given to each individual and guardian specifying the individual's rights. All individuals enrolled in the Medicaid DD Waiver shall be given a written copy of DHS Medicaid Home and Community-Based Services DD Waiver, Rights of Individuals. a) Employees shall inform individuals entering a CILA program of the following: 1) The rights of individuals shall be protected in accordance with Chapter II of the Code except that the use of seclusion will not be permitted. 2) The right of individuals to confidentiality shall be governed by the Confidentiality Act. 3) Their rights to remain in a CILA unless the individuals voluntarily withdraw or meet the criteria set forth in Section 115.215. 4) Their right to contact the Guardianship and Advocacy Commission, Equip for Equality, Inc., the Department's Office of Inspector General, the agency's human rights committee and the Department. Employees shall offer assistance to individuals in contacting these groups giving each individual the address and telephone number of the Guardianship and Advocacy Commission, the Department's Office of Inspector General, the Department, and Equip for Equality, Inc. 5) Every individual receiving CILA services has the right to be free from abuse and neglect. 6) Individuals or guardians shall be permitted to purchase and use the services of private physicians and other mental health and developmental disabilities professionals of their choice, which shall be documented in the services plan. b) Employee advisement of the individual's rights and justification for any restriction of individual rights shall be documented in the individual's record. c) 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]. For all individuals enrolled in the Medicaid DD Waiver, their rights to present grievances and to appeal adverse decisions of the agency are detailed in 59 Ill. Adm. Code 120. d) Individuals shall not be denied, suspended or terminated from services or have services reduced for exercising any of their rights.”

IAG Policy and Procedures outline the consumer rights, including the right to report, and they outline the open lines of communication and visitation that should be occurring. The consumer's plans include the rights and responsibilities that are provided to the consumer (or their guardian when planning). Service plan meeting signatures confirm that IAG staff, guardians (when applicable) and community service providers were present at the service planning meeting for

each consumer. Staff report that IAG tried to provide updates to community providers if needed throughout the year.

After completing the interviews, records reviews, and assessing applicable mandates, there is no evidence to support that the consumer's rights were violated. The consumer's rights are provided to them (and their guardian if needed) annually. Information for reporting to external sources is provided through service planning and is in the IAG handbook. All consumers have an opportunity to make phone calls privately when at the home and spend the day at in a community program where reporting would be possible without IAG present.

Based on the findings above the East Central Human Rights Authority concludes that the consumer's rights were not violated and, therefore, the complaint is unsubstantiated. No recommendations or suggestions are being made in relation to this complaint.

The HRA would like to thank the Individual Advocacy Group staff for their cooperation with this investigation.

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## **RESPONSE**

**Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.**

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The East Central Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission recently made a complaint to Individual Advocacy Group (IAG) that one of its Community Integrated Living Arrangement (CILA) program sites did not have an accessible vehicle even though two individuals who resided in the CILA required wheelchairs.

Four person CILAs were new to the Champaign area and developed to provide a CILA setting that integrated with a single family home neighborhood. The project of developing four person settings was at its initial stages and supported strongly by the families and individuals who were interested in the plan. The CILA was the first of four to be built in a project developed by the Champaign County Community Mental Health Board CCCMHB. The CILAs are owned by CCCMHB and by agreement IAG leases the houses as CILA sites for adults with an intellectual and developmental disability (IDD).

When the CILA construction was completed and had passed licensing and Fire Marshal surveys, interested individuals and their family were interviewed for placement. The initial four people to be admitted to the CILA included two who used wheelchairs. We explained to the families that at that time we did not have a lift van which would delay admission or shift admission to the next CILA when it was completed and we had a lift van. One of the families had a lift van and volunteered to let IAG use it until we had purchased a lift van and it was delivered. As part of the agreement IAG would pay for the vehicle insurance, maintenance, fuel and minor damage (below deductible).

IAG policy and procedures requires that all employees have a current driver's license and auto insurance. Employees who use their own vehicle to transport individuals residing in the CILA who do not require a lift van to appointments and for community activities are paid mileage for transporting individuals.

All individuals residing at the CILA had access to transportation. A lift van was ordered in the latter part of the summer and was delivered in October.

