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**Peoria Regional Human Rights Authority  
Report of Findings  
PARC  
Case #09-090-9004**

The Peoria Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegations regarding PARC's Community Integrated Living Arrangement (CILA) program:

1. The agency did not adequately evaluate and address triggers for a resident's behaviors that then led to more extreme behaviors.
2. The agency did not have a behavior plan in place to address the resident's behaviors.
3. The agency pursued the use of excessive force for behaviors rather than using less restrictive approaches.
4. The agency inappropriately pursued the discharge of a resident, leaving him unattended at the hospital and refusing his return to the group home, and failed to follow discharge requirements, including a discharge notice.
5. The agency does not adequately keep the guardian informed of incidents in that lines of communication are poor, incident reports are sent a week later with no more immediate notification and, in a recent incident, the report was not provided until the guardian requested it and then the report lacked sufficient information.
6. Subsequent to an incident and after the involvement of the Illinois Department of Human Services (DHS), another placement was secured within the agency, but the placement may not be appropriate to the resident's needs.
7. The agency does not ensure that staff authorized to dispense medications are present and as a result the resident is either not given necessary medications which help control his behavior or medications are dispensed at irregular intervals.
8. The treatment plan for the resident required one-on-one social interaction due to the inability of current housemates to interact with the resident. The agency discontinued the one-on-one alleging that they did not want the resident to become dependent on the staff person, but the agency did not consult or advise the guardian of the proposed change.

If found substantiated, the allegations represent violations of the Mental Health and Developmental Disabilities Code (Mental Health Code) (405 ILCS 5/1 et seq.) and regulations that govern CILAs ( Ill. Admin. Code 115).

PARC is an acronym for People Advocating for Respect and Consideration of individuals with developmental disabilities. PARC, located in Peoria, provides a range of residential and vocational services to individuals with developmental disabilities. PARC's residential program serves 161 individuals at 22 different sites; 18 residential sites are licensed as CILAs.

To investigate the allegations, an HRA team interviewed the resident's guardian, interviewed agency staff, examined a resident's file, with the guardian's consent, and reviewed pertinent agency policies.

### COMPLAINT STATEMENT

The complaint states that the guardian was notified on 08-09-08 of an incident at a CILA home involving the resident and staff. The guardian was advised that the resident became very agitated and aggressive; police were called. According to the complaint, staff informed the guardian that staff were out of behavioral options and the current placement may not be the best for the resident. The guardian reportedly asked that the police not intervene until he could arrive. When the guardian arrived, the resident was reportedly upset and afraid. The guardian allegedly begged police not to taser the resident as he had been tasered in a prior incident. The resident was handcuffed, placed on a stretcher, and transported by ambulance to the hospital.

Agency administration reportedly asked the guardian if he was going to the hospital and provided the guardian paperwork to take with him. The complaint states that no PARC staff accompanied the resident to the hospital. Upon arrival, the resident was given medication and a medical test, but the hospital would not admit as there were no available beds and the resident had calmed. The hospital reportedly stated that the providers usually accompany residents to the hospital to provide more thorough behavioral information. The guardian then contacted PARC officials to let them know that the hospital was refusing to admit. PARC staff allegedly told the guardian that the resident could not return to the CILA site and that he could possibly go to a homeless shelter until PARC could hold a meeting regarding the resident's readmission sometime in the next week. PARC staff reportedly informed the guardian he would inquire about alternative placement in the interim, however, at about 3 a.m., the guardian took the resident to his own home where he stayed for a period of time. Upon leaving the hospital, the guardian attempted to secure medication for the resident; the PARC stated that it could not provide the medications and the hospital also stated it could not provide medications since it would not be admitting the resident.

The complaint states that subsequent to this incident, PARC has readmitted the resident after the Illinois Department of Human Services (DHS) became involved but assigned him to a different home which is not appropriate for him as most of the residents have physical impairments. The resident is physically able and has autism. In addition, the complaint indicates that there are continued problems with communicating with the guardian, dispensing medications (an incident occurred 11-01-08), the discontinuation of the 1:1 staff support, and an incorrect

lease for the resident. In December 2008, the resident had another behavioral incident that again resulted in police intervention; in this incident the resident was tasered multiple times.

## FINDINGS

### Interviews

An HRA team met with PARC administrative and program staff to learn about the agency's service delivery system as well as about the incidents in question. With regard to staffing levels, PARC stated that staffing levels vary. At the site where the first incident occurred, there are 3 staff for 8 residents until second shift when there are 2 staff for 8 residents. At the current site, the staffing level is about 2.5 staff for 7 residents. Both sites have residents with diverse needs. An on-call nurse is available for each site; each nurse supervises 45 to 50 residents. PARC has a contracted physician or residents can use their own physicians. A psychiatrist is also available primarily for psychotropic medication monitoring. And, the agency works with a psychologist for counseling services. A Qualified Mental Retardation Professional (QMRP) is assigned to each person; QMRP caseloads average approximately 20 to 30 residents per QMRP.

The PARC staff explained that the resident moved into a PARC home approximately seven years ago. He has a past history of placement in a state-operated facility as well as participation in an autism special education program. The resident sees a psychiatrist through a specialized clinic for persons with developmental disabilities. Staff indicated that the resident experiences anxiety and has infrequent behaviors. There is usually an antecedent to the behaviors and because of the infrequent behaviors, he was not on a behavior plan until recently. Staff indicated that the resident also has behaviors when patterns change. The plan is more a set of guidelines for staff at the PARC day program which the resident attends during the day, but staff at the CILA site have also received an overview. Staff reported that there was an incident on the contracted city bus a couple of years ago and the city bus driver called the police who tasered the resident. PARC indicated that it has procedures for bus/car trips and contingency plans for various scenarios; a bus monitor has since been assigned. Most behaviors exhibited by the resident tend to focus on staff by trying to control staff's hands, pushing/pulling staff, or directing staff. PARC indicated that it sometimes sees warnings for the resident's behaviors.

With regard to the August incident, staff indicated that the QMRP received a call from staff at around 5:30 to 6 p.m.. There were 4 to 5 police officers outside of the home and 2 more officers inside. The resident was waiving his hands back and forth. The QMRP tried to talk with the resident about what he needed (e.g. something to eat, a particular activity or the need to take a shower which is typically calming for the resident). On-call PARC staff arrived. The resident pushed staff against the wall, removed a staff person's cell phone and threw it outside, and became increasingly agitated upon seeing police outside. The QMRP did a body lock restraint on the resident, taking him down with staff assistance. They then tried to calm him asking him to take deep breaths and drink some water; the resident was then released and he went to his room. Police then entered the resident's room; police handcuffed him and staff talked the

resident onto the gurney. Staff advocated to police not to use any type of force. PARC indicated it is still reviewing information as to what happened that may have precipitated the behaviors and believe that the behaviors may have been related to snacks or the medication pass. One staff person was dragged down the hall of the home by her hair; 3-4 staff persons were injured. One staff person called the police concerned about the safety risk of the other residents. The guardian arrived shortly after police. An attempt was made to call a local crisis team before calling the police but staff were reportedly told that there was no one on duty from the crisis team at the time the call was made.

PARC wanted the resident admitted for a psychiatric evaluation but the hospital refused. Contacts were made with other hospitals and the local pre-admission screening agency. The hospital provided Aptiva and the resident calmed. Blood work was completed indicating an infection and a CT scan was done indicating an abnormality or possible sinus blockage. PARC stated that staff warned the guardian not to allow the hospital to discharge the resident. PARC also asserted that the resident was never discharged from its residential program.

Subsequent to the incident, a meeting was held with the DHS. PARC indicated that it had alternative living arrangements available almost immediately but the guardian refused. PARC staff reported that it was attempting to arrange for 1:1 support in the current placement which was refused by the guardian. Contact was also made with the resident's psychiatrist and the pre-admission screening agent. The resident stayed with the guardian for about 3 weeks by the guardian's choice. The guardian identified a preferred placement; however, there was not current vacancy at that placement and the staffing levels at the placement were lower than needed by the resident. Eventually, the resident was placed at his current CILA placement although staff continue to review options. At the current placement, the atmosphere is more like a home, quieter and several staff already know the resident. The 1:1 funding was phased out as there was no continued need. A Clinical Administrative Review Team (CART) review was held and the team questioned the need for a medication change; this recommendation was refused by both the guardian and the psychiatrist.

Staff indicated that the resident has some underlying medical issues, including growths on his face that have been removed in the past. The resident has voiced complaints of headaches for which Tylenol has been prescribed on an as needed basis. Blood tests done at the hospital indicated an infection for which an antibiotic was prescribed and the resident has a congenital malformation that may be a contributing factor. PARC is still reviewing the sinus concern as identified in the hospital CT scan through contact with an Ear, Nose and Throat physician. And, contact with a neurologist is being pursued.

Since the incident, PARC has pursued some changes. In the future, staff will accompany the resident to the hospital even if the guardian is involved. An apartment has been secured for emergencies; the resident stayed at the apartment as a transition to the current placement. The QMRP will be attending training offered by the Crisis Prevention Institute specific to approaches to be used for persons with autism.

With regard to a medication error as identified in the complaint, administration reported that medication administration times can be adjusted with nursing approval. There is typically an hour's leeway in administering a medication.

PARC staff acknowledged an error on a lease agreement that has since been corrected.

Finally, PARC staff asserted that agency staff maintain ongoing communications with the resident's guardian.

## **Records**

The HRA team began its record review by examining documentation related to the incident that occurred on 08-09-08 at the prior group home. An incident report states that the resident became aggressive at about 5:30 p.m. injuring 5 of 6 staff persons by grabbing staff around the neck, pulling staff by the arms, and pushing staff. The resident reportedly broke a cell phone and could not be calmed. An emergency medical service and the police were called. The resident was sent to the hospital where he had a CT scan of the head and lab work. Follow-up appointments with the psychiatrist and attending physician were made. An unsigned/undated summary of the incident is consistent with the verbal report made to the HRA by the QMRP; the summary notes indicate contact with the DHS for technical assistance. The QMRP made notes of his interviews with staff involved in the incident. The HRA was provided with notes of all staff interviewed with the exception of the staff who was initially involved with the resident's aggression as the agency could not locate those notes. The notes reviewed indicated that resident had taken an afternoon nap, had eaten supper (although one staff person noted he ate about 50% of his meal), left the dining area, and then returned to the dining area repeatedly stating the words "eat" and "shower." He eventually became aggressive toward three female staff persons pushing all three outside of the home. Another staff person appeared to remain inside the home after locking the doors of the other residents. It is difficult to determine when back-up staff were called and when the police were called. Eventually the QMRP arrived, the resident calmed and the police left. The QMRP went to check on the other residents and during this time the resident approached staff; at this time another staff person arrived and the resident pushed this staff person. Again, the resident repeated the words, "eat" and "shower." The QMRP then performed a body lock and restraint after which he seemed to calm down and was released. Upon being released the resident entered his room and staff heard banging noises; an administrator arrived and decided to call police back to the home. The police restrained the resident, placing him on a gurney; the resident was transported to the hospital. Although the QMRP inquired about potential causes of the incident, staff indicated that they were not sure of the cause.

When the resident arrived at the hospital after the incident, he was examined and given injections of Olanzapine and Lorezepam. The hospital completed a CT of the head after learning from the guardian that the resident was having headaches; lab work was also completed.

With regard to the incident that occurred on 12-03-08 at the newly assigned group home, an incident report states that the resident came home from work and appeared upset; he was offered something to eat and calmed down. However, at around 7 p.m. during medication passes, the resident became upset again. One staff person's notes dated 12-04-08 (versus 12-03-

08 as per the incident report) states that the resident was agitated and tried to take the medication of other residents and then began pushing staff; the QMRP was called but could not be reached. The resident then approached staff, grabbing at hands, bending fingers back, and pushing and punching them. He locked at least one staff person out of the house and he pulled a resident across the floor causing a rug burn. Eventually, the staff contacted the house manager and the resident's guardian. When the house manager arrived, he was aggressive to her as well and the police were called. Upon arrival, the police tasered the resident several times and placed him in handcuffs. He was taken by ambulance to the hospital. Agency staff and the guardian accompanied the resident to the hospital where he was given injections to calm; he was found to have a urinary tract infection for which medication was prescribed. The resident was taken to an apartment with 1:1 staffing by PARC. Police reports document that when the police arrived they had to find an entry point to the group home as the resident had locked the doors. Eventually a staff person unlocked a door from the inside. Police entered and ordered the resident to the floor; the resident ran to a back room and police deployed a taser that did not impact the resident; a taser was deployed by another officer with no effect. At the same time police were ordering the resident to put his hands behind his back. A third officer entered the room and tasered the resident 12 times per the officer's report. He was eventually incapacitated, handcuffed and transported to the hospital.

The HRA examined program information on the resident. An annual service plan effective November 2007 through 2008 documents the resident's "non-negotiables" which includes, routines, family visits, people who speak to the resident calmly and softly, medication for anxiety, physical activity, a large breakfast, a snack and alone time after work and the same seat at work and at the dining table. Under a section entitled, "what doesn't work," the plan documents that the resident needs to avoid being surprised, loud people, unstructured environment, noise, and situations where staff/peers are distressed. Additional stressors are listed as people who use a loud voice, people forcing the resident to do things that the resident doesn't want to do, being interrupted and being rushed. The plan documents the resident's diagnoses as Cognitive Impairment, Autism, Anxiety, viral warts, Spina Bifida, and hay fever/seasonal allergies. He has had surgery to remove Keloids on his face. The plan section that discusses behaviors indicates a couple of incidents in the past year in which antecedents were identified. A procedure was instituted to assist staff in addressing the resident's anxiety in different scenarios such as traveling back and forth to work, when the resident is getting up in the morning, after work and in the evening. At dinner time, staff are to give him larger servings and seconds if requested. After dinner, the resident usually takes a shower and then watches television. At 8 p.m., the resident usually takes his medication and then goes to bed. Goals listed in the 2007 service plan include, increasing activities of daily living (laundry), leisure activities, money management, medication/behavioral monitoring, and self-medication skills. The HRA also reviewed an MRI completed on the resident in April 2007 which documents the resident's history of Chiari malformation but indicates that the MRI is otherwise unremarkable.

The HRA team also reviewed documentation surrounding the November and December incidents. Residential progress notes beginning 08-01-08 through 08-09-08 reveal the following:

- 08-01-08 - the resident complained of headaches, did not eat all of his breakfast and took Tylenol and Sudafed.
- 08-02-08 - complained of headaches at 2 a.m.

08-03-09 - walked around holding his head in the early a.m.; stayed in bed until noon.

08-04-08 - walked around all night.

08-06-08 took Tylenol and Sudafed for headache.

08-07-08 - took Tylenol and Sudafed for headache.

08-09-08 - agitated in a.m. "desperate to take pills, and trying to get his meds. He has a swollen eye."

The medication sheets document that the resident was administered Tylenol and Sudafed every day from 08-01-09 through 08-09-09 for headaches. The physician's order sheets indicate that antibiotics were ordered beginning 08-13-08 after seeing his attending physician although office visits notes do not clearly document the reason for the antibiotic; the diagnoses listed on the office visit form include Autism, Retardation, headaches and sinusitis.

Record information between the 11-08-08 and 12-03-08 incidents documents additional information. Of note, day program notes from October 2008 indicate an aggressive behavior requiring a team response on 10-29-08 and an incident of the resident grabbing and shoving staff for 30 minutes on 11-03-08. A leisure assessment completed on 11-04-08 documented that the resident does not respond well to strangers. The QMRP's program service summary indicates in November 2008 that the resident had 19 episodes of anxiety but no aggression or property destruction; the report states that the resident seems "on edge" on a daily basis. In December 2008, the QMRP's summary documented 3 days of anxiety prior to the December 3<sup>rd</sup> incident, medication changes after seeing the psychiatrist on 12-12-08, antibiotic treatment for a urinary tract infection identified by the hospital on 12-03-08, temporary emergency placement at an apartment with staff support and eventual placement at another CILA home where the resident is reported to be doing well. Day program documentation for December 2008, indicates that the resident became upset at the day program on 12-03-08 possibly the result of another resident grabbing his food tray; day program documentation also notes the resident's anxiety at work and lethargy on 12-11 and 12-12 after medication changes. In the 12-04-08 psychiatric review completed after the December incident, the psychiatrist changed the resident's medication and also recommended that the agency consider a light box for "possible seasonal affective disorder." The HRA noted that additional medication adjustments were made in January 2009 as per physician order sheets.

Behavior programs were also examined by the HRA team. A behavior plan developed for the resident's prior residential site as well as the day program is dated 08-25-08. Potential underlying causes are listed as being autistic tendencies, anxiety, seasonal allergies, possible medical concerns and possible adverse reactions to medications and then lists means of addressing these possible contributing factors. Some examples include maintaining a set schedule for the resident; preparing the resident when the schedule must be changed; and, recognizing that the resident had multiple restraints at the prior state-operated placement and may have an aversion to staff intervention. It is noted that the resident also seems to have behavioral issues when peers are having behavioral needs. Also, it is documented that the resident needs environmental controls such as an organized living area and reduced noise. Medical issues are taken into account as well, including allergy issues and Chiari Malformation (which is listed as a possible cause for headaches). The long term behavioral goal is for the resident to follow his routine without physical aggression for two consecutive months by 03-31-

09; a short-term goal is no incidents of physical aggression for 80% of the days in 3 consecutive months by 12-31-08. The plan incorporates the previously developed routine with additions that address environmental supports at the day program as well as interventions at both the CILA home and day program when the resident shows signs of anxiety or is physically aggressive. When showing signs of anxiety staff are to approach the resident, give him space and ask him to calm. Staff are also to ask if anything is wrong or if anything hurts and then proceed with nursing intervention if needed. If he continues to be anxious, staff will ask him if he wants to go outside or to his room. If he wants to take a shower, he can take a shower. Staff are to praise the resident for calming. If he becomes aggressive, staff are to remove peers, call for back-up, provide space, provide reassurance, and offer activities or a shower. The HRA did not find that the plan was signed.

After the December incident, a support plan was developed to transition the resident to the new placement. The support plan included 1:1 staff for second shift, medication passes in the bedroom at a consistent time, refresher training in aggression management for staff (completed 12-29-08), a scheduled routine after day program, a cordless telephone at the new site pre-programmed with emergency contacts, monthly reviews of emergency situations at staff meetings, a 1:1 bus monitor and temporary placement at an apartment after an aggressive episode.

A subsequent plan, developed for the current placement is similar to the prior plan with some additions. There are updates regarding medication changes and the possible impact of medication changes on behaviors. It is noted that the most recent behaviors occurred around the time of medication passes, and, as a result, it is recommended that medications be administered in the resident's room to help reduce stimuli. To address anxiety, staff are to contact the home manager, reassuring the resident, prompting the resident to go to his room or outside, asking the resident if something is wrong, contacting the nurse if he indicates he is not feeling well, allowing him to take a shower if he requests and praising him for calming behaviors. If he becomes physically aggressive, staff are to call the house manager, ensure the safety of peers, provide him with as much space as possible, use approved aggression management techniques if needed, maintain staff presence until the resident calm, restrain if necessary, and prompt him to calm and take deep breaths while in restraints. A list of emergency contacts is included with office and cell phone numbers along with specific directions for the bus driver should the resident become anxious during the trip to and from the day program. The plan was approved by the guardian, QMRP, administrative staff and the internal human rights committee.

Additional documents reviewed included an occupational therapy sensory inventory which documents the resident's difficulties with transitions and identifies strategies to assist with transition such as plenty of time, advanced notice, and a structured approach to transition. The evaluation indicated that the resident may benefit from activities that involve large muscles and heavy work, and he may benefit from tactile input.

The HRA examined the medication administration sheet for 11-01-08 and noted that Buspar is ordered to be given at 12 p.m.; the sheet documents that the medication was given and no time differentiations are noted.



The HRA also reviewed lease information. One lease documents information on another resident. A revised lease only documents information on the resident.

### **Policies**

The HRA concluded its agency review by examining pertinent policies. PARC's admission and discharge policy states in its list of admission criteria that applicants must "...Not demonstrate a primary need for treatment of serious...behavior disorder." The policy also states that transfer or discharge can occur, upon interdisciplinary team approval, if a resident "...exhibits behavior placing him/her or others in serious danger."

PARC's policy on behavior management requires that programs include specific information including, goals, target dates, underlying causes, baseline information, procedures, and signatures. All programs are to be developed with the involvement of the resident, the guardian and the interdisciplinary team. The policy stresses positive, gradual and least restrictive approaches. Various levels of programs are described; level three programs involve the use of psychotropic medication, physical restraints or rights restriction. Level three programs require a review by the human rights and professional review committees. An addendum to the policy outlines guiding principles for staff in the use of aggression management including, exhausting alternatives before using force, using the least amount of force needed, avoiding being angry or vindictive, and being calm and professional. Staff are also expected to be careful observers, noting and documenting possible behavioral causes as well as being attuned to individualized programs. Crisis avoidance techniques are included as well as procedures for containment. After an incident, one staff person is to complete an incident report and certain administrative staff as well as the professional review committee are to review the reports. Addendum C to the behavior management policy addresses psychotropic medication and requires guardian consent before medication begins, a medication reduction plan unless clinically contraindicated and procedures for using emergency medication. Another addendum to the behavior management policy outlines reviews to be completed by the professional and human rights review committees, including behavior programs and psychotropic medication information.

PARC's policy on rights identifies rights associated with the Mental Health and Developmental Disabilities Code, the Mental Health and Developmental Disabilities Confidentiality Act, and the CILA rules. The policy documents the right of service recipients to contact external advocacy resources as well as the internal human rights committee and PARC President. The policy also states that staff will receive initial and ongoing rights training. The rights statement signed by residents or their guardians was also reviewed. The statement is comprehensive and includes the right to adequate and humane services, the right to be free from restraint except to protect the resident or others, the right to present grievances, and termination criteria.

A CILA services consent form was examined. The form indicates that the individual or guardian agrees to participate in the CILA program, agrees to participate in service planning and understands termination criteria. The level of CILA support is listed. The resident/guardian signs along with the agency QMRP. The consent is renewed annually.

The agency on-call procedure was also reviewed. The procedure lists on-call hours, numbers, and reasons for contacting on-call. Severe behaviors, and the use of aggression

management are reasons for notifying on-call although life threatening emergencies require notification of 911 before contacting nursing. Nursing on-call is also to be notified of all medication errors.

Finally, staff training agendas related to aggression management were examined. The aggression management training series consist of 5 different modules covering such topics as guiding principles, causes of aggression (e.g. physical needs, psychological issues or situational concerns), risk assessment, the crisis situation, intervention techniques, non-confrontational techniques, and responses to aggression.

## MANDATES

The Mental Health and Developmental Disabilities Code (405 ILCS 5/1 et seq.) requires in Section 2-102 the following:

*A recipient of services shall be provided with adequate and human 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....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.*

CILA regulations (59 Ill. Admin. Code 115) provide guidance on the provision of services. Services are to be provided through a Community Support Team comprised of the resident, the guardian, the QMRP, and other service provider representatives (59 Ill. Admin. Code 115.220). The team is responsible for assessment, planning service coordination, service delivery consistent with service plans based on resident assessments, and advocating on behalf of the individual (59 Ill. Admin. Code 115.220 b, c). The identified QMRP is specifically responsible to assure that services are consistent with the service plan, that gaps are identified and addressed, that issues are brought to the attention of the individual or guardian and that the QMRP advocates on behalf of the individual (59 Ill. Admin. Code 115.220 e). Section 115.230 of the CILA regulations require monthly QMRP reviews of service plans to ensure that services are being implemented and that the plan continues to meet the individual's needs or that the plan be revised. This section stresses that the CILA agency must ensure that direct care staff are knowledgeable of resident service plans.

Section 115.320 of CILA regulations addresses CILA agency administrative requirements including the provision of services in the most appropriate setting to meet the needs and preferences of an individual. CILA agencies are required to have a process to review behavior management and human rights issues. Staff involved in providing direct care to residents are required to have training related to safety, behavior management, rights, documentation, etc. This section also addresses unusual incidents and requires agencies to have policies/procedures to handle, investigate, report, track and analyze incidents including, abuse, neglect, physical injury, assault, etc. And, the CILA is to maintain resident records which are to be kept confidential.

CILA termination criteria are addressed in Section 115.215 and state that the community support team can consider termination if the CILA program cannot meet a resident's medical needs, the resident's behavior places the resident or others at risk, there is an agreed-upon transfer or the resident no longer benefits from CILA services. Termination must be approved by the Department of Human Services.

Regulations are also in place to address medication administration (59 Ill. Admin. Code 116). These regulations require agencies to keep medication records that include the drug information, the resident's name, prescribing physician, the dose, the route of administration, the date and time given, etc. Medication errors are to be documented and reported to medical professionals.

Finally, the HRA examined the Illinois Police Training Act (50 ILCS 705/7) which identifies specific training required for probationary police officers, including curriculum "...aimed at identifying and interacting with persons with autism and other developmental disabilities..." A sample training agenda for area police was secured; the agenda addressed autism and how police should interact with individuals who have an autism diagnosis and listed the following approaches: "reduce external stimuli, avoid touching, use direct, simple short phrases, repeat commands allowing for time to respond...allowing them to pace, rock, etc."

## CONCLUSIONS

### **Complaint #1: The agency did not adequately evaluate and address triggers for a resident's behaviors that then led to more extreme behaviors.**

Staff reported that guidelines identifying potential triggers for the resident had been in place for the resident prior to the incidents. Staff also reported the potential for underlying medical concerns that could contribute to the resident's behaviors.

The record indicated ongoing complaints of headaches for which over-the-counter medications were given prior to the August 2008 incident and 19 incidents of anxiety in November 2008 prior to the December 3, 2008 incident. Also noted was a behavioral incident at the day program on the same day as the December 3<sup>rd</sup> incident. The incident report for the August incident lacked documentation related to possible antecedents and the QMRP, versus the involved staff, completed narrative reports on the incidents although the report for the staff initially involved was not provided. The December incident had a better accounting of what transpired with the involved staff persons submitting their own accounts. The behavior plan developed and then revised after the incidents identified potential triggers. The psychiatrist mentioned the possibility of Seasonal Affective Disorder; however, the HRA did not find follow-up on this. The emergency room visits that occurred after the incidents each resulted in orders for antibiotics.

The agency maintains a thorough policy on behavior management that encourages staff to be "careful observers" related to behaviors; staff training reflects the importance of observation skills to help identify resident needs and issues.

The Mental Health Code requires the provision of adequate care and CILA regulations require the provision of ongoing assessments.

**The HRA is very concerned that the ongoing headaches documented prior to the August incident and the frequent incidents of anxiety noted prior to the December incident did not result in further review, assessment or referrals to medical professionals. As a result, the HRA substantiates this allegation. At the same time, the Authority acknowledges the work that has occurred since by incorporating additional triggers into the behavioral planning process. The Authority recommends the following:**

- 1. To ensure the provision of adequate care and CILA service delivery based on resident assessments and needs, review repeated patterns of medical complaints, incidents of anxiety or behaviors to determine the need for further assessment.**
- 2. For the resident in this case, continue to monitor the impact of underlying medical issues and anxiety that may contribute to his behaviors. Follow-up on the psychiatric recommendation related to Seasonal Affective Disorder.**

The HRA also offers the following suggestion:

The HRA suggests that the agency ensures that behavioral incidents that occur at work are reported to staff at the residential site.

**Complaint #2: The agency did not have a behavior plan in place to address the resident's behaviors.**

Staff reported that a behavior plan was not in place prior to the incidents because the resident had infrequent behaviors; documentation seems to support this staff statement. However, a set of guidelines were developed to prompt staff on matters that might impact the resident's behaviors. A behavior plan was developed after the first incident and then revised after the second incident. The HRA noted that the copy of the first plan as provided to the HRA was not signed by the staff, guardian or review committees although the HRA may have received a draft copy. The second plan was signed by all parties. The HRA also found that the agency maintains a thorough behavior management policy directing staff to develop a behavioral plan when appropriate. The Mental Health Code and CILA regulations require the provision of services based on a service plan. Due to the infrequency of behavioral incidents prior to the August incident and the subsequent development of a behavioral plan, the HRA does not substantiate this allegation. The HRA does offer the following suggestions:

1. Although the guidelines provide excellent information regarding a resident's needs and issues, there is a question as to the extent that such guidelines might be followed if not part of a formal behavior plan or service plan that would require tracking and monitoring. Although these guidelines are now incorporated into a behavior plan for the resident in this case, the HRA suggests that, in the future, guidelines such as these be incorporated into a resident's service plan.

2. The Authority also suggests that the agency ensure that all plans are signed by members of the interdisciplinary team.

**Complaint #3: The agency pursued the use of excessive force for behaviors rather than using less restrictive approaches.**

Staff reported that police were called for two behavioral incidents after the resident's physical aggression could not be contained by staff. Documentation seems to indicate that police were called after the aggression began and when staff were attempting to protect other residents; in the first incident, staff unsuccessfully attempted to secure assistance from a crisis team before calling police. Once the police were called the extent of force used was out of the hands of the agency although there is some evidence to indicate that staff advocated for the police not to use force. In the first incident, the police handcuffed the resident and had him put on a gurney for transport to the hospital. In the second incident, police reports indicate that the resident was tasered at least 12 times. The behavior plan developed in August 2008 identifies a progressive intervention approach beginning with least restrictive interventions but includes more restrictive approaches if the least restrictive interventions are unsuccessful; it appears from staff documentation of the December 2008 incident that staff attempted using less restrictive approaches until the resident began taking the medications of peers during medication pass. The February 2009 plan appropriately includes the approval of review committees since it utilizes restrictive interventions after other efforts fail. The guidelines developed prior to the behavior plan identified preventative approaches.

The agency's behavior management policy, addendums and staff training assert the use of least restrictive interventions before using more restrictive measures. And, consistent with mandates, agency policies require that any behavior plans using restrictive interventions be approved by the behavioral management and human rights committees.

The Mental Health Code requires the provision of services in the least restrictive setting. Based on the available evidence, it appears that the agency contacted police after the aggression began; the resident's behavior plan, guidelines and agency policy seem to support the principle of least restriction; therefore, the complaint is not substantiated. However, the HRA takes this opportunity to make the following suggestions.

With regard to the first incident, there was no direct staff documentation about the incident and no identified precipitating factors; the HRA was not provided with the QMRP summary of the staff person who interacted with the resident at the time the incident began. Incident forms were not thoroughly completed. The HRA strongly suggests the following:

1. Staff directly involved in a behavioral incident document their own accounts being "careful observers" as to precipitating factors and documenting least restrictive interventions attempted.
2. Incident forms should be thoroughly completed.

3. Recently developed mandates require police training on interacting with persons with developmental disabilities, including individuals with autism. The techniques used by police appear to be inconsistent with recommended approaches as documented in a training outline secured by the HRA. And, evidence indicates that staff were concerned about the use of police force with regard to the resident in this case. The HRA strongly suggests that the agency reach out to law enforcement to offer the provision of training specific to persons with developmental disabilities, particularly with regard to individuals who may have more frequent contact with the police.

**Complaint #4: The agency inappropriately pursued the discharge of a resident, leaving him unattended at the hospital and refusing his return to the group home, and failed to follow discharge requirements, including a discharge notice.**

Staff reported that the resident was not discharged from the agency in August 2008 when he was transported to the hospital. They contend that the refusal to take him back was based on the agency's assertion that the resident needed hospitalization. In the December incident, staff accompanied the resident to the hospital; when he was not admitted, an apartment was secured until he could be transitioned back to a CILA home.

With regard to the first incident, hospital documentation indicated that the resident and guardian were at the hospital without staff and when the hospital refused to admit, the agency refused to take the resident back and no alternative placements were offered. The resident's record does not contain documentation of discharge notices, plans or meetings. The guardian took the resident home although the agency subsequently made arrangements for his return soon after the hospital visit.

Although there were no documented, formal attempts to discharge the resident, the resident was left without any supports when he was taken to the hospital in August 2008. CILA regulations place the responsibility of assuring service provision upon the agency, the community support team and the QMRP. While the HRA cannot say that the agency inappropriately discharged because there was no documented evidence of a formal discharge, the **HRA does find a rights violation associated with the lack of adequate care and CILA supports when the agency did not make provision for the resident's care upon discharge from the hospital emergency room in August 2008. The HRA notes the agency's provision of a transition placement after the December 2008 hospital visit. The HRA recommends the following:**

- 1. When residents are discharged from hospital settings, including hospital emergency rooms, arrange for adequate care and/or CILA supports consistent with Mental Health Code rights and CILA requirements**

The HRA also suggests the following:

1. In order to effectively advocate for a resident and to ensure adequate assessment of resident needs as required by CILA standards, the HRA recommends that staff accompany CILA residents in need of hospitalization, when possible.

**Complaint #5: The agency does not adequately keep the guardian informed of incidents in that lines of communication are poor, incident reports are sent a week later with no more immediate notification and, in a recent incident, the report was not provided until the guardian requested it and then the report lacked sufficient information.**

Staff contend that they are in constant communication with the guardian of the resident in this case. The record indicates that staff contacted the guardian during each of the two behavioral incidents. Also, the resident's service plan meeting documents guardian attendance. Otherwise, documentation of guardian notification appears to be limited and the incident reporting form does not include a section to document guardian notification. The HRA does note that there was documented evidence in the record of the guardian's frequent contact with the resident; as a result, the guardian and agency staff may have had regular interactions. Although the guardian was notified of the two incidents while they were occurring, it is unclear when he received copies of the incident reports. While the HRA contends that some delay to allow time for completion would be expected, the HRA does concur that the incident reports for the two incidents in this case were not thoroughly completed and accounts of the first incident lacked sufficient information regarding antecedents and interventions. The issue of staff documentation in incident reports is addressed above in complaint #3. The agency does not maintain a policy on guardian notification. The Mental Health Code and CILA regulations require the involvement of a resident's guardian. Because there was evidence that the guardian was notified during the incidents and there is documented evidence of guardian involvement in service planning, the HRA does not substantiate the complaint. The HRA does suggest the following:

1. Revise the incident reporting form to include a section regarding guardian notification.
2. Consider the development of a policy/procedure on guardian notification.

**Complaint #6: Subsequent to an incident and after the involvement of the Illinois Department of Human Services (DHS), another placement was secured within the agency, but the placement may not be appropriate to the resident's needs.**

Staff reported that the placement situation continues to be reviewed. Placement has changed and a transition placement was provided temporarily after a behavioral incident. Staff stated that the guardian's preferred placement does not have an available vacancy. And, some alternative options were refused by the guardian. Staff stated that the current placement is homelike and quiet.

The HRA acknowledges the placement limitations due to guardian preference and available vacancies. These limitations together with the HRA's belief that the most appropriate placement is better addressed by the guardian, the community support team and the Illinois

Department of Human Services leave the HRA determining that this complaint is beyond the HRA's scope and ability to address.

**Complaint #7: The agency does not ensure that staff authorized to dispense medications are present and as a result the resident is either not given necessary medications which help control his behavior or medications are dispensed at irregular intervals.**

Staff reported that medication times can be adjusted with nursing approval and that an hour's leeway in administering a medication is acceptable. The complaint identified a specific date on which medication was delayed; however, the record indicates that the medication was given at the correct time. The resident's behavior management plan was changed so that the resident now receives medication in his room because one incident occurred during the time of a medication pass. A support plan developed to help a resident transition back to a CILA home documents that medication times should be consistent; however, this recommendation did not carry over into the resident's behavior plan. The agency's behavior management policy addresses medication but it is not specific to medication times. CILA regulations require that staff document the time a medication given.

The HRA does not discount the complaint that medication administration was delayed when appropriate staff were not present on a given day to administer the medication, however, the documentation for that day does not indicate that the medication was delayed nor was there documentation of nursing approval to adjust the medication time. Therefore, the HRA cannot substantiate the allegation. The HRA strongly suggests the following:

1. Ensure that staff correctly document the time that medication is given.
2. Ensure that staff seek and document nursing approvals for any changes related to medication administration.
3. Consider revising the resident's behavior plan in this case to add a statement about administering medication at consistent times as stated in the transition support plan.

**Complaint #8: The treatment plan for the resident required one-on-one social interaction due to the inability of current housemates to interact with the resident. The agency discontinued the one-on-one alleging that they did not want the resident to become dependent on the staff person, but the agency did not consult or advise the guardian of the proposed change.**

Staff stated that 1:1 staffing for the resident was discontinued because there was no longer a need. The complaint states that the 1:1 staffing facilitates the resident's social interactions at the current CILA home. The record documents the provision of 1:1 staff in the transition support plan but not in the resident's behavioral plan or service plan. The agency does not have a policy specific to 1:1 staff support and Mental Health Code and CILA regulatory



provisions require the provision of services tailored to the individual's needs and pursuant to a service plan with guardian input.

Because the 1:1 support is not specified as a need in the resident's behavior or service plan, the HRA does not substantiate this allegation. However, the Authority does suggest that the resident's community support team review the resident's ability to have social interactions at his current CILA home and make any service plan revisions to address any identified social needs. The HRA also suggests that the agency ensure that staff who work with individuals who have autism are adequately trained on autism, including training on communicating with persons who have autism.

**The HRA acknowledges the full cooperation of the agency and its staff during the course of its investigation.**