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**FOR IMMEDIATE RELEASE**

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North Suburban Human Rights Authority  
Report of Findings  
Ray Graham Association for People with Disabilities  
HRA #09-100-9039

Case Summary: allegations #3 and #5 were substantiated; the remaining allegations were unsubstantiated. The HRA's public record on this case is recorded below; the provider's response immediately follows the report.

The North Suburban Regional Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission has completed its investigation of alleged rights violations at the Ray Graham Association for People with Disabilities (RGA).

In June 2009, the HRA notified RGA of its intent to conduct an investigation, pursuant to the Guardianship and Advocacy Act (20 ILCS 3955). The following complaints were accepted for investigation:

1. A resident's personal hygiene is being neglected by staff members
2. A guardian has not been able to adequately communicate with a resident because the in-coming telephone line is also linked to the fax machine
3. A resident cannot use his LINK card on personal outings
4. A resident's medicated shampoo has not been re-ordered in a timely manner and there is no documentation showing that the medication is being used as prescribed
5. Many meals lack nutritional value
6. Guardians are not notified of resident illnesses
7. ISPs are not being implemented properly in either the day or residential programs

If found substantiated the allegations would violate the Mental Health and Developmental Disabilities Code (405 ILCS 5) and the Administrative Codes for Community Integrated Living Arrangements and Medication Administration in Community Settings (59 Ill. Admin. Code 115 and 116).

## **Background**

Founded in 1950, Ray Graham Association for People with Disabilities, located in Downers Grove, is a nonprofit organization that provides a broad array of services and supports to more than 2,500 children and adults with disabilities that include mental retardation, cerebral palsy, and autism. Services include vocational, respite, educational, recreational, and residential programs. The focus of this investigation was the Bensenville Community Integrated Living Arrangement (CILA), which is a 6-bed home with 4 bedrooms that serves low to higher functioning individuals.

## **Method of Investigation**

To pursue this investigation the HRA reviewed, with written authority, a portion of the clinical record (the past year) of the consumer whose rights were alleged to have been violated. A site visit was conducted at the administrative offices, at which time the allegations were discussed with the program Administrator, an Employee Services/Human Resources/Risk Manager, the site supervisor, a DSP (Direct Support Professional), an RN/Director of Nursing, and the Qualified Human Services Coordinator. An unannounced visit was conducted at the CILA; the HRA interviewed two residents residing in the home and home staff. This unannounced visit was conducted on a Wednesday afternoon; the resident identified in this investigation was on a home visit and had been on this visit for the past five days. Home staff did not know when he was expected to return. An unannounced visit was conducted at the resident's day program on a Thursday morning; the resident was not in attendance. During this visit the HRA spoke to one of his teachers.

**Allegation #1: A resident's personal hygiene is being neglected by staff members.**

**Allegation #4: a resident's medicated shampoo has not been re-ordered in a timely manner and there is no documentation showing that the medication is being used as prescribed.**

### **Findings**

The resident is a 28-year-old male with severe mental retardation with autistic features. He has legal guardians. He was admitted to the CILA program in 2005. According to the Individual Support Plan (ISP), the resident is to use a quarter-sized amount of shampoo to his hair independently for 2 out of 7 days per week for 12 consecutive weeks by 8/09; it was documented that the resident has not met the goal due to frequent home visits. The physician's order stated that the shampoo (used for Seborrheic Dermatititis) is to be used at bedtime four times a week - Monday, Wednesday, Friday and Saturday. Treatment Administration Records and treatment plan data showed that when the resident is at the CILA site, the shampoo was used as ordered and as instructed per the ISP. Physician orders document that the pharmacy is to dispense a one month supply of the shampoo with 11 additional refills.

At the site visit, it was stated that the resident gets assistance with everything involving daily living skills. He showers and shaves daily when at the CILA; this includes staff assisting him in putting a small amount of the medicated shampoo in his hand and applying it to his head. The home manager reorders the medicated shampoo and picks up the reorder at a different facility location. It was stated that the only time that the home does not have the shampoo on-hand is when the shampoo is not returned after a home visit. The agency acknowledged that the guardians have expressed concern that shampoo seemed to be depleted sooner than necessary. It was stated that home staff have been instructed to monitor the resident to ensure that he follows his treatment goal, by using only a quarter-sized amount of shampoo. Regarding other areas of his personal appearance, it was stated that sometimes they have to help him with his shirts to see that he has it turned in the right direction. It was stated that the resident is cooperative with hygiene tasks. The day program staff member stated that this resident always has on clean clothes/new shoes and that he is without odor; she stated that his hygiene has never been a problem or cause for concern. The HRA attempted to observe this resident's hygiene at both the CILA and the day program without success.

The QMRP keeps a running log of this family's concerns. The HRA was given a copy of this log (6/08-6/09). In August 2008 it was noted that the family felt that the shampoo bottle was empty quicker than it should have been; the log noted that staff were to remind the resident to use appropriate amounts of shampoo. In April 2009 it was noted that the family voiced concerns that

the resident's hair appeared oily and that the showerhead he uses seems to be too low for him. The follow-up documentation stated that: "Will support [resident] to use a different bathroom to shower per family wish." There was a work order in the information reviewed by the HRA which showed that a new arm fixture for the new shower head was installed.

While at the CILA, the HRA was shown that the medicated shampoo is stored in a locked closet, in a bin marked with the resident's name; the shampoo was not there at the time of the visit as the guardians had taken it home. Home staff stated that when it is time for the resident to use the shampoo, he is given the bottle and completes the task; the bottle is then returned to the locked closet. When on a tour of the home, the bathrooms were checked to see if the shampoo was in the shower stall(s); no medicated shampoo was observed. The HRA noted that the other residents in the home were well groomed. When asked, it was stated that the two residents observed are independent in their hygiene tasks, but may at times need reminders to complete the tasks.

### **Conclusion**

Pursuant to the Illinois Administrative Code, Standards and Licensure Requirements for Community-Integrated Living Arrangements Section 115.240, "When medical services and/or medications are provided, or their administration is supervised, by employees of the licensed agency, the licensed agency shall certify that they are provided or their administration is supervised in accordance with the Medical Practice Act of 1987 and the Illinois Nursing and Advanced Practice Nursing Act." Section 116.50 of this same Code states that "Authorized direct care staff shall not administer PRN medications unless there is a written protocol approved by a nurse-trainer and prescribing practitioner for each individual and for each medication. A written protocol shall include the following information: 1) the name of the individual; 2) the name, route, and dosage form of the medication; 3) dosage or quantity to be taken; 4) frequency or times of administration; 5) conditions for which the medication may be given; 6) contraindications for the medications; 7) a maximum or stop dosage; 8) any necessary special directions and precautions for the medication's preparation and administration; 9) common severe side or adverse effects or interactions and the action required if they occur; and 10) proper storage." Section 116.70 of the Code states that "1) An individual medication administration record shall be kept for each individual for medications administered and shall contain at least the following: A) the individual's name; B) the name and dosage form of the drug; C) the name of the prescribing physician, physician assistant, dentist, podiatrist, or certified optometrist; D) dose; E) frequency or times of administration; F) route of administration; G) date and time given; H) most recent date of the order; I) allergies to medication; and J) special considerations".

The HRA cannot discount the guardian's claim that the resident's hygiene is being neglected. The HRA recognizes that a residential program might not provide the care that one might receive at home. However, nothing was found to support the allegation. According to the information obtained the medicated shampoo is being used as prescribed and pursuant to the ISP. There was no documentation indicating that the home has been without the shampoo and home staff stated that the shampoo is being re-ordered in a timely manner; the allegations are unsubstantiated.

### **Allegation #3: A resident cannot use his LINK card on personal outings.**

#### **Findings**

The guardians explained they wanted the resident to be able to use the LINK card to shop when the resident is on a home visit.

According to the Illinois Department of Human Services web-site, the Illinois LINK card allows food stamp recipients to receive this benefit electronically, via the use of a card that looks like a credit card. Every month a pre-set amount of funds are available to the eligible individual or family via the Illinois LINK card.

At the site visit, it was explained that Ray Graham is the proxy for the Link card and they are responsible for its use and must have a staff present when a resident uses the card. While at the CILA, the resident could purchase the items the guardians want purchased, but the family prefers to purchase the items. Previously, the resident had the use of his Link card as a formal goal in his ISP but this was discontinued. He still goes shopping and uses his LINK card, but it is not a formal goal.

### **Conclusion**

Pursuant to the Community-Integrated Living Arrangement Individual Rate Determination Model user guide, the "Third Party Payment" is that portion of the individual CILA rate that is reimbursed by finding sources other than the Department of Human Services. The Third Party Payment is assumed to be used first to offset the costs associated with providing Room and Board to the persons living in CILA homes. The Third Party Payment is comprised of "Earned Income," "Unearned Income," "HUD Assistance," and the "Food Stamp Credit." The user guide states that in regards to food stamps, an offset equal to \$360 per person, per year, is added to the Third Party Payment. The \$360 per person, per year, Food Stamp offset is fixed and is applied to all individual CILA rates determined by the Model. The Model disregards Food Stamps received by individuals in excess of \$360 per person, per year.

The allegation that a resident cannot use his LINK card on personal outings is substantiated. It is recommended that the agency allow the resident to use entitled portions on the Link card when he is on a home visit and when used submit relevant receipts to agency staff and/or engage his family to determine how a planned program will ensure the resident an opportunity to experience use of his Link card in the community.

### **Allegation #5: meals lack nutritional value.**

#### **Findings**

At the site visit, it was stated that the guardians provide the food items for the resident's daily lunch; they provide a specific lunch meat; bread and yogurt. The house provides cheese and bananas. The program supervisor buys groceries for all the diets/meals. When asked if they have a nutritionist who approves the diets, it was stated that the menus come from the office. The HRA received and reviewed four different menus for the home. The menus included meals such as: breakfast - pancakes/sausage, milk, applesauce, orange juice, coffee; lunch - tuna sandwich, fresh fruit, snack crackers, juice, water or pop; dinner - spaghetti/sauce, garlic bread, salad and water. Modifications or substitutions for specialized diets were noted on the menus. It was stated that the program does not have a nutritionist on staff, but that once a year a nutritionist meets with the supervisors to help them develop menus. The HRA had two separate reviews by nutritionists of the same menus submitted. One nutritionist stated that:

*not knowing the medical status of the clients receiving these meals creates a challenge in their assessment. These comments are not to be taken as more than an educated overview based on the written knowledge provided in your fax. The positive aspects I saw were there does seem to be adequate protein being served as well as starches over the period of a day. I was concerned about some of the modified meals. Rice noodles and a sauce do not meet 14 grams of protein for that meal or a 2 oz equivalent unless the noodles are special high protein noodles. Tues. p 10 at noon on another modified meal was a large salad without cheese. There was no protein mentioned in that meal also. The fruit/vegetable intakes offered on a daily basis I feel are low. Without consuming 100% juice the menus do not always provide adequate Vitamin C or A, not to mention the phytonutrients we know whole fruits and vegetables are known to provide as well as fiber. I do not feel offering pop as a beverage is good nutritional practice when important nutrients are lacking in the menu offerings. Dairy intake based on the menu offerings is also inadequate. If these clients are unable to tolerate dairy I hope*

*they are being supplemented with calcium, Vitamin D, and riboflavin just to mention a few nutritional inadequacies. It is well documented absorption is better from food than supplements whenever possible. In conclusion while the menus meet some of the daily needs for an average adult there are certainly nutrient limitations as discussed above. If any of these clients are on medications for depression or seizure disorders supplementation with Vitamin D, Calcium, folate, fish oil, and Vitamin B12 should also be considered pending a review of their medical status on an individual basis. Medical monitoring for nutrient deficiencies is also recommended. These involve simple blood tests for some of the nutrients I discussed.*

The second nutritionist also started out by saying that without knowing the medical status of each resident, a sound assessment was difficult. This nutritionist summarized the nutritional value of the meals by stating that she was concerned that the recommended daily calorie intake seemed low, and that the daily intake of dairy was a concern.

A review of the Summary of Family Concerns log showed that the family reported that the resident's voice was "raspy" possibly due to not having a banana in his lunch; the follow-up documented indicated that a banana was not available because the resident had been on a home visit and the family had not notified the staff of his return date. Other concerns and follow-up (f/u) measures regarding food included:

- no cheese in the home - f/u-cheese was purchased
- pre-package salami [guardians only want the resident to have fresh sliced salami from a specific store] found in refrigerator - f/u-only fresh cut salami will be purchased
- the resident had one slice of white bread at dinner instead of wheat bread -f/u staff were to ensure that the resident is offered only wheat bread
- too many slices of salami on lunch sandwich - f/u- staff to ensure only four slices go on sandwich.

During the unannounced visit, the HRA observed the evening meal to be: baked chicken boxed mashed potatoes, canned vegetable, and beverages. Home staff showed the HRA around the kitchen and the refrigerator and cupboards were full of food items; it was pointed out areas where specific food for two individuals on a special gluten free diet was stored. The HRA was also shown a loaf of wheat bread (specific brand that guardian prefers) that was in the home; it was stated that this is the only brand purchased for meals. In discussing the meals with the residents, one resident was focused on his gluten free diet and asked why he could not have certain things; he did say the food was ok. The second resident stated that the meals were good and that he received enough to eat.

### **Conclusion**

The USDA *Dietary Guidelines for Americans* provide science-based advice to promote health and to reduce risk for major chronic diseases through diet and physical activity. By law (Public Law 101-445, Section 301), the Secretaries of the Department of Health and Human Services (HHS) and the Department of Agriculture (USDA) issue a report at least every 5 years that "shall contain nutritional and dietary information and guidelines for the general public." Every 5 years, an expert Dietary Guidelines Advisory Committee is appointed to make recommendations to the Secretaries concerning a revision of *Dietary Guidelines for Americans*. The recommendations are to be targeted to the general public age 2 years and older and based on the preponderance of scientific and medical

knowledge that is current at the time of publication of the Committee's report. Key recommendations include: Consume a sufficient amount of fruits and vegetables while staying within energy needs. Two cups of fruit and 2 1/2 cups of vegetables per day are recommended for a reference 2,000-calorie intake, with higher or lower amounts depending on the calorie level. • Choose a variety of fruits and vegetables each day. In particular, select from all five vegetable subgroups (dark green, orange, legumes, starchy vegetables, and other vegetables) several times a week. • Consume 3 or more ounce-equivalents of whole-grain products per day, with the rest of the recommended grains coming from enriched or whole-grain products. In general, at least half the grains should come from whole grains. • Consume 3 cups per day of fat-free or low-fat milk or equivalent milk products.

Pursuant to Section 5/2-102 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." Based on the information from two nutritionists, there are aspects of the program's menu and modified meals that lack in daily calorie intake, protein, vitamins and dairy. The complaint is substantiated. The HRA recommends that the agency revisit the menus to ensure that the Nutritionists' concerns are addressed or provide documentation to show they have been addressed.

#### **Allegation #6: guardians are not notified of resident illnesses.**

##### **Findings**

The guardians advised the HRA that they learned that the resident's temperature was high and they were not notified. The guardian stated that while on a home visit they noted that the resident had a temperature of 101 and took him to a physician. They learned that the resident had a viral flu; he then was home for the following week. The guardian did state that he was not sure the agency was aware that the resident had a fever, but if they were not aware of the elevated temperature - they should have been. Documentation indicated that the resident left the home on 3/27/09 for a home visit. It was written that he was taken to a physician on 3/28/09 due to a fever. The Physician's Note of 3/28/09 references a viral upper respiratory infection and calling for conservative care, fluids and over-the-counter decongestant; no temperature was listed. A follow-up visit was noted 4/6/09 which indicated URI/viral syndrome resolved. The resident returned to the CILA on April 6, 2009.

At the site visit, agency personnel were somewhat surprised at this allegation, since it was said they are in contact with the family on a weekly basis. It was explained that the family takes the resident to all medical appointments; the RN stated that she has limited contact with the guardians and that she was not aware that he had had a fever. The agency does not have a policy for guardian notification.

##### **Conclusion**

Pursuant to the Probate Act of 1975 Section 11a-3, "Guardianship shall be utilized only as is necessary to promote the well-being of the disabled person, to protect him from neglect, exploitation, or abuse, and to encourage development of his maximum self-reliance and independence. Guardianship shall be ordered only to the extent necessitated by the individual's actual mental, physical and adaptive limitations."

The HRA cannot discount the assertion that the resident had a temperature; however both the guardian and home staff said that the agency knew nothing of an elevated temperature. Since the agency did not know the resident had an elevated temperature, notification is not feasible. The allegation is unsubstantiated.

Although CILA rules and regulations do not mandate guardian notification, best practice dictates that a policy for guardian notification be developed.

**Allegation #2: a guardian has not been able to adequately communicate with a resident because the in-coming telephone line is also linked to the fax machine.**

**Findings**

It was stated they are very mindful that the phone line can and does get tied up when the fax machine is in use. They continue to work closely with site staff to assure that phone lines are not occupied unnecessarily.

During the visit to the site, the HRA observed that the home staff member was on and off the phone, thus the fax machine was not connected. When asked how she would turn the fax machine on or off, she replied that she would either unplug the fax machine at the wall or turn it off on the machine. The staff member commented she was aware of the need to keep the fax turned off so phone calls could be received.

**Conclusion**

Pursuant to the Illinois Administrative Code, Standards and Licensure Requirements for Community-Integrated Living Arrangements Section 115.300 "The agency shall develop, implement and maintain a disaster preparedness plan which shall be reviewed annually, revised as necessary, and ensure that: F) A telephone is available with a list stating the telephone numbers of the nearest poison control center, the police, the fire department and emergency medical personnel or an indication that 911 is the appropriate number to call."

By the agency's own admission, there may be times that incoming calls cannot go through due to the fax machine. The CILA mandates address the need to ensure that the home has a telephone for out-coming calls in case of an emergency; the CILA has met this mandate; the allegation is unsubstantiated.

**Allegation #7: ISPs are not being implemented properly in either the day or residential programs.**

**Findings**

At the site visit, it was stressed that this resident is with his family for an exceedingly high number of days and that this greatly affects their ability to offer quality programming to the resident. (During a ten-month period, the resident had been gone from the program 158 days). The resident has an ISP that lists measurable objectives with timeframe and prompt/support levels; where and how the skill building goal is to run, and the data collection tool/frequency. The QMRP writes a monthly report as to how the resident is working towards his goals. Objectives included: demonstrate 3 skills related to using his medicated shampoo independently for 2 out of 7 days per week for 12 consecutive weeks by 8/09 (CILA); practice his speech skills by using his vocabulary cards with staff support for at least 20 minutes per day for 3 out of 7 days per week for 12 consecutive weeks by 8/09 (Community Learning Center - CLC); demonstrate 4 skills related to economic self-sufficiency with 2 or fewer verbal prompts for 3 out of 7 days per week for 12 consecutive weeks by 8/09 (CILA & CLC); complete three skills related to checking out books from the library two times per month with staff support for 6 consecutive months by 8/09 (CILA & CLC); complete 4 skills related to cleaning his eyeglasses with verbal prompts three times per day for 4 out of 7 days per week for 12 consecutive weeks by 8/09 (CILA & CLC). The summary lists the data, as directed by the ISP for the day and residential programs that was collected for each week (how many times the goal was completed) and gives a status summary (goal met or not met).

The resident had just had his annual ISP and the guardians approved all the goals. The guardians also receive a copy of the monthly report that the QMRP writes which includes how the resident is doing with each goal. It was stated that during this meeting, the guardians questioned the

data (about how the prompts were used/recorded) and once this was explained, the guardians understood and were satisfied with the information reviewed.

**Conclusion**

Pursuant to the Illinois Administrative Code, Standards and Licensure Requirements for Community-Integrated Living Arrangements Section 115.220, "The agency shall provide or arrange for those services not indicated in subsection (c) of this Section, but identified in the individual integrated services plan as needed by the individual. If arranged, such services shall be documented in a written agreement between the licensed agency and the other service providers and shall minimally address training, services to be provided, quality assurance requirements and protection of the individual's rights. The agency shall remain responsible for insuring the quality of services and the protection of the individual's rights."

The HRA found nothing to support the claim that the ISPs for the residential and day program are not being implemented properly; the allegation is unsubstantiated.

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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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# Ray Graham Association

Empowering people with disabilities

Administrative Offices  
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December 1, 2009

Mr. Dan Haligas, Chair  
North Suburban Regional human Rights Authority  
9511 Harrison Street, W-300  
Des Plaines, Illinois 60016

Dear Mr. Haligas:

RE: HRA#09-100-9039

Below is the agency response to the above-referenced complaint. Please feel free to contact me if you need any additional information.

Allegation #3

The attached correspondence will be sent to the guardian offering to meet to develop a plan that addresses the complaint raised by the guardian, while assuring that some funds remain available for household food purchases.

Allegation #5

A Registered Dietitian will review menus used in the CILA for the past 3 months and provide recommendations for any changes that would improve the nutritional value of meal options. Modifications to future menus will be made accordingly.

Thank you for your diligent investigation and the opportunity to respond to this matter.

Respectfully,

Kathleen Carmody, MSW  
Chief of Staff