



FOR IMMEDIATE RELEASE

**Peoria Regional Human Rights Authority
Report of Findings
Case #09-090-9021
DD Homes Network**

The Peoria Regional Human Rights Authority (HRA), a division of the Illinois Guardianship and Advocacy Commission, accepted for investigation the following allegation concerning Community Integrated Living Arrangements (CILAs) operated by DD Homes Network:

The agency violates the right to individualized treatment pursuant to an individualized treatment plan with input from the individual and/or the guardian.

If found substantiated, the allegations violate the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102) and regulations that govern Community Integrated Living Arrangements (89 Ill. Admin. Code 115).

To investigate the allegations, an Authority team met with and interviewed representatives of DD Homes Network, toured a CILA site, examined relevant policies, interviewed a service recipient, interviewed a vocational provider representative and, with consent, examined the record of a recipient.

While the complaint concerns the Catherine Court CILA located in Pekin, Il., it was reported that the complaint pertains to the approximately 23 CILAs operated by DD Homes Network throughout the State. Catherine Court provides residential services for 5 individuals who have developmental disabilities.

COMPLAINT DESCRIPTION

According to the complaint, certain foods were recently banned from the facility in a blanket fashion without regard for individual resident needs or preferences. Residents were not allowed to consume or purchase these items even if they had no prior problems with these items. Examples of the items included hot dogs and peanut butter. The complaint further states that residents of the CILA homes have not been allowed the right to exercise choice with regard to vocational programming. Specifically, residents have not been allowed to participate in certain types of activities sponsored by a vocational program that are deemed social or recreational by the residential facility. The complaint indicates that if the vocational program is having a social event or an outing, residents from CILAs operated by DD Homes Network are not allowed by the residential site to participate, citing that residents attend the vocational program to work and such activities are not considered to be work as per the residential provider.

FINDINGS

Interviews with Agency Personnel

According to staff at Catherine Court, a corporate menu is developed for use in the CILAs. This menu, developed by a dietician, was revised in 2009 and with the revision, some food items were discontinued. However, staff contend that individual residents can still purchase the food items. A list of preferences are kept for each resident and substitutes are made available should a resident dislike a particular food item. Residents also participate in the selection of some menu items. For example, the home hosts a monthly ethnic night and residents select the cuisine for the evening. Residents are allowed some choice for their birthday meal, including a birthday cake. And, some planned activities, such as watching a football game, allow residents to choose preferred snacks. Residents can also participate in a monthly dining experience which allows them to choose their own food from a menu.

Staff confirmed that hot dogs and peanut butter were removed from the menu but residents were never restricted from purchasing these items. According to staff reports, no residents at Catherine Court are on a special diet but one resident has some problems with cramming food. Staff acknowledged that there were resident complaints when the menu change occurred and, to address the complaints, residents were redirected to the option of purchasing the items on their own. Staff further explained that there are two resident councils that meet on a regular basis. The general resident council addresses any residential issues as well as upcoming events and activities. A separate dietary council allows for discussion of the menu.

With regard to shopping, staff reported that residents shop at least one time per month. A shopping sheet is used as a planning tool and identifies a range of resident account funds available for the resident to spend as well as the items that the resident is interested in purchasing. The resident initially completes the form or completes the form with staff assistance and then staff will counsel residents on items that cost more than the resident has in his/her account. The sheet provides guidance for the residents and the staff who accompany the shopping outing. Resident checkbooks are managed by the home managers. For the resident whose record was reviewed, she has an outstanding fine on which she is making payments; she also participates in activities that have fees. Thus, her available funds may be different from other residents. The resident is also on a money management goal for writing checks.

Staff then discussed vocational programming and reported that there was confusion and miscommunication over past policies but communications have been rectified. When the vocational program sponsors an outing, the residential program requests additional information including: the staff ratio; outing details; and the vocational merit. Staff stated that they have not declined any outings and if a resident truly wants to go on a vocational outing, he/she would be allowed to do so.

The HRA concluded by asking staff about a grievance process. Staff responded by stating that there is no formal grievance process but the Preadmission Screening Agent represents one available source for resident complaints. The number of a facility representative is posted and staff reported that the cell phone number for the Qualified Support Professional (QSP) is available.

Interview with DD Network Corporate Staff

On a different date, during a visit to an intermediate care facility (ICFDD) also operated by DD Homes Network, the HRA interviewed a corporate representative of DD Homes Network. The representative reported that the network provides residential services to approximately 1200 to 1300 residents in either intermediate care group homes or CILAs located across the state. Most residents have developmental disabilities and related conditions.

With regard to menus, the representative reported that corporate dieticians prepare menus every six months. Resident preferences and dislikes are reviewed individually and substitutions are identified. An acceptance of diet form is used when the menu is changed to gauge preferences. Resident preferences are also reviewed at admission. A monthly dietary consultation is held at each residential site involving the residents, the cook and the QSP to discuss menus, plan events involving food and the monthly dining out activity. The cooks meet quarterly and provide feedback to the dieticians. With the revised menu, some items were removed and other items were added. The representative stated that hot dogs and peanut butter were not specifically removed but removed as part of the menu cycle but these items could return. The representative stated that at a baseball event, hamburgers were served in the box seat but this was not the agency's decision. Also, residents can request items such as peanut butter for sack lunch. At the ICFDD facility where the HRA met with the representative, there were no available hot dogs or peanut butter.

The HRA also inquired about vocational programming. The representative stated that there is a contract between the ICF and the vocational program that involves 5 hours of active treatment at the vocational program. The agency has asked vocational training staff to review outings with the residential program to ensure the provision of 5 hours of active treatment. The representative stated that activities and outings must have vocational merit and adequate staffing.

Interview of Service Recipient

The HRA interviewed the service recipient at her vocational site. She reported that she was interested in participating in a vocational outing that involved attending a festival but the house manager said that she could not attend. She also stated that staff tell her how to spend her money; she says that she receives \$10 per week in spending money while other residents receive anywhere from \$20 to \$100 per week for spending. With regard to the banning of certain foods, the recipient stated that the home banned hot dogs and peanut butter even though no resident at the house where she resides has had any choking problems or problems with these food items. She indicated that all residents seemed to like these items. She also stated that staff will not allow her to buy any food; she reported that she purchased some ramen noodles on once occasion and staff discouraged her from buying them in the future.

Interview of Vocational Representative

The HRA also interviewed a representative of a vocational program that serves residents of DD Homes Network. The representative confirmed that the program has quarterly discussions with staff of DD Homes Network. With regard to vocational outings, the representative stated that the outings fill gaps when there is no work and allow residents to work on skills in a different way. Initially, residents of DD Homes Network were not allowed to participate in any outings. Now, an outing can be presented for prior approval and the residential case manager

evaluates in terms of an outing's relevance to work. This arrangement is not part of any written agreement. Examples of outings include visits to the animal control center which is located on the grounds of the vocational center and shopping for items to be served in a concession stand, shopping for a Christmas tree and attending a festival. Although all of these activities were initially denied by the DD Homes Network group home, the animal control visits and shopping for the concession stand were later allowed by the group home. Shopping for a Christmas tree or festival participation have not been allowed by the group home.

Tour of CILA Home

During a tour of the CILA home, the HRA found a posted menu in the kitchen that listed substitutions. Fresh fruits were found in the pantry. The kitchen also had a locked cabinet for client purchases; items in the cabinet were labeled with resident names. The HRA found a resident's peanut butter in the general pantry. The HRA observed a sample resident dislike list posted on the refrigerator.

The HRA found resident rights information posted along with the number of a facility representative but the phone number of the Office of the Inspector General was not posted; the HRA pointed this out to facility staff.

Record Review

According to the record reviewed by the HRA with the resident's consent, the resident was admitted to the CILA Home on 10-06-03. She maintains her legal rights. Her diagnoses include a mild cognitive impairment and a Bipolar Disorder. A dietary history form completed at admission indicated that the resident can eat peanut butter; the form also documented the resident's preferences, dislikes, meat cutting skills, and swallowing abilities.

The resident's most recent treatment plan, dated 10-06-09, includes goals for medication, writing checks, showering, community access and decreasing aggressiveness. The dietary section of the plan states that the resident is to have limited concentrated sweets and she has problems staying on her diet. The resident was present for the treatment planning meeting.

The record includes an annual nutritional assessment as well as a resident signed rights statement. The resident's vocational assessment states that the resident could work a machine although her behaviors could present some safety concerns.

The record indicates that the resident has occasional behavioral issues, including taking items and money from others. There was also an incident over keeping snacks in her room.

The HRA reviewed an example of activities in which the resident participated. During November of 2009, the resident went to a restaurant, bowling, a movie, the bank and a movie store. The HRA also examined a shopping sheet for the resident which included items that the resident was interested in purchasing as well as an available range of available funds. The resident receives \$50 per month of spending money; her balance at the time of the HRA visit was \$20. Staff had crossed off two items on the shopping list: a stuffed animal and a magazine. A soda purchase remained on the list. A staff member signed off on the list but there was no place for a resident signature. The HRA also reviewed evidence of the resident's \$175 fine. The HRA

also examined the masked shopping list of another resident at the facility dated 12-03-09 which included peanut butter.

The HRA asked to see the resident's 6 month review and was given a summary by the Qualified Support Professional (QSP). The resident had signed a resident rights statement.

Policies and other Documents

The HRA asked to see resident council meeting minutes. Minutes from 11-17-09 were shared; the minutes indicated discussion of activity planning as well as menu planning for ethnic night and dinner out. Another set of minutes for November were reviewed although the specific date was not listed; at this meeting, Christmas Party plans were discussed. The HRA asked to see the council minutes for the meeting at which complaints were voiced. Staff stated that they were "not sure" they had the minutes but they would look for them and send them if they were found. The HRA never received the minutes for the time frame in question.

The agency's policy on Individual Service Plan Development requires the development of a plan based on the individual's goals and identified needs with monitoring by the QSP. The Community Support Team is to identify choices and needs by examining the individual's current situation, the individual's desired outcomes and the means to achieve those outcomes. The QSP of the vocational program is to be a part of the Community Support Team for the resident. Within 60 days prior to the annual planning meeting, numerous assessments are to be completed including a vocational update and a nutritional evaluation. The planning process is to include a review of many factors including vocational activity, leisure skills and interests, individual characteristics, etc. The QSP is to provide a summary that addresses program progress, behavior, medical issues, vocational issues, dietary concerns, etc. For the dietary summary, the QSP is to share information about the resident's diet, weight changes, or any other dietary concerns. The summary for vocational programming is to describe programming that occurs, resident progress and any concerns or changes. The agency utilizes a receipt form to secure a signature from the resident indicating receipt of and agreement with his/her service plan.

The HRA examined two separate policies on resident rights (5.34 and W5.34). Overall, both policies are similar with a few exceptions. Both policies stress resident participation in treatment planning. Both policies indicate that residents will be encouraged and assisted in exercising rights. In addition, residents are to be encouraged to share complaints "...or recommendations concerning the policies and services of the facility to staff or to outside representatives...." Residents are to be encouraged to manage their own financial matters. A section on "Association and Correspondence" states that residents are to be encouraged "...to communicate, associate and meet privately with individuals of his/her choice, unless this infringes on the rights of another Individual." According to the section on activities, the policy states that "Each Individual shall be encouraged to participate in social, religious and community group activities...[and an] Individual's contraindication shall be documented in their record by the [QSP]." With regard to personal possessions, residents are to be encouraged to retain and use personal possessions and clothing as space allows. In the W5.34 policy, a grievance process, using the chain of command and ending with the Executive Director, is described. The agency uses the Rights Statement prepared by the Illinois Department of Human Services to distribute to residents; the form requires a resident/guardian signature and includes the right to refuse

treatment, the right to participate in treatment plan, the right to exercise rights and the right to report complaints to external agencies which are subsequently listed.

Dietary information was also reviewed. The agency's diet history form allows for the documentation of an individual's diet, allergies, food dislikes, foods that the individual cannot eat, swallowing/chewing difficulties, serving sizes, etc. A nutritional assessment allows for the documentation of an individual's height, weight, ideal body weight, activity level, chewing ability, lab levels, medications, prescribed diet, allergies, likes/dislikes, appetite, eating skills, eating problems (e.g. needs prompt, chewing, swallowing, choking), eating equipment, snacks, and summary/plan of care. The HRA examined a recent list of menu items that were removed as well as a list of items that were added; a variety of items were on the lists although peanut butter and hot dogs were not.

MANDATES

According to the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102), "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 recipientIn 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." Section 5/2-104 states that "Every recipient...shall be permitted to receive possess and use personal property..." and Section 5/2-105 states that "A recipient of services may use his money as he chooses...." Section 5/2-107 guarantees the recipient's right to refuse treatment by stating that "The recipient...shall be given the opportunity to refuse generally accepted mental health or developmental disability services, included but not limited to medication. If such services are refused, they shall not be given unless such services are necessary to prevent the recipient from causing serious and imminent physical harm to the recipient or others and no less restrictive alternative is available."

Regulations that govern CILAs (59 IL Admin. Code 115) defines the purpose of CILAs in Section 115.100:

The purpose of the Community-Integrated Living Arrangements Licensure and Certification Act [210 ILCS 135] is to license agencies to certify living arrangements integrated in the community in which individuals with a mental disability are supervised and provided with an array of needed services.

The objective of a community-integrated living arrangement is to promote optimal independence in daily living and economic self-sufficiency of individuals with a mental disability.

Section 115.200 of the CILA regulations provide further explanation of the focus of service provision:

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.

Individualized treatment planning for CILA residents is discussed in Section 115.230 which states the following:

Within 30 days after an individual's entry into the CILA program, a services plan shall be developed that:

- 1) Is based on the assessment results;*
- 2) Reflects the individual's or guardian's preference as indicated by a signature on the plan or staff notes indicating why there is no signature and why the individual's or guardian's preference is not reflected;*
- 3) Identifies services and supports to be provided and by whom; and*
- 4) States goals and objectives. Objectives shall:*
 - A) Be measurable;*
 - B) Have timeframes for completion; and*
 - C) Have an employee assigned responsibility.*

Minimum requirements for day training programs (59 Ill. Admin. Code 119) state in Section 119.200 that such programs are to promote community integration and provide at least 5 hours of programs per day excluding meals and transportation and unless a physician or interdisciplinary teams agrees to less than 5 hours. Individuals participating in work activities must have assessments or documentation that the activities are related to individual goals/objectives, the activities teach new skills, that the individual cannot work at competitive wage levels, and that other goals/objectives are being addressed (59 Ill. Admin. Code 119.232).

CONCLUSION

The complaint states that the residential provider violates the recipients' right to individualized treatment pursuant to an individualized treatment plan with recipient/guardian input. According to the complaint, the agency has applied blanket practices with regard to the banning of certain foods rather than evaluating individual resident needs and preferences. Furthermore, the complaint contends that the agency did not allow residents to use their money to purchase food items that the agency banned. Finally, the complaint contends that the agency controls a resident's ability to participate in outings and activities offered by the vocational program.

CILA and administrative staff reported that certain food items were removed from the menus by the corporate dietician but residents can still purchase these items if they choose. Staff reported that individual nutritional assessments are completed for each resident and resident preferences and dislikes are part of the assessment process. The HRA found evidence of this in a resident file and with the posting of a resident's list of dislikes. However, in an interview, a resident reported that the foods were banned, that she is discouraged from buying food items and that she is told how to spend funds. At the same time, her record also identified spending limitations due to other financial commitments. During the tour, the HRA found that at least one resident had purchased peanut butter, and a masked shopping list indicated a resident's plan to

purchase peanut butter. The HRA noted that residents have access to a dietary council to voice food concerns and to provide input on the selection of some menu items.

With regard to activity participation at the vocational program, the resident and vocational staff both confirmed that activities were denied and some, but not all, were reinstated. Residential and administrative staff argued that residential staff must assess the activities for adequate staffing ratios and vocational merit. Currently, any outing must be pre-approved by the residential case manager.

The agency maintains a service planning policy that focuses on resident assessments, resident choice and resident interests. The resident rights policy stresses resident participation in treatment and includes a resident's right to exercise his/her rights as well as the right to refuse treatment. Dietary assessment forms allow for the documentation of individual resident dietary needs and preferences.

The Mental Health Code guarantees recipient participation in treatment planning, the recipient's right to use his/her own funds, the recipient's right to use his/her own personal belongings, and the recipient's right to refuse treatment. CILA regulations state that CILAs are to help the recipient reach his/her optimal independence through the provision of services that meet resident needs and are based on resident/guardian preferences. Vocational regulations require the provision of 5 hours of vocational programming that promote community integration, are individualized and are related to resident goals.

With regard to the reported food ban, the HRA accepts the agency's report that menu changes occurred. Although the HRA could not confirm or deny that the removal of certain menu items also led to restricted purchases, it does appear now that residents can buy the items that were removed from the menu. The HRA notes that one resident indicated that she was not allowed to buy food items but this same resident had other outstanding purchases and bills that impacted her purchasing. The HRA does not substantiate the complaint with regard to the food. However, the HRA does take issue with the current stance that the residential group home manager ultimately and solely approves or disapproves a resident's participation in a vocational outing. While the HRA acknowledges the residential provider's interest in assuring a safe staffing ratio, once the staffing ratio has been confirmed, the process in place fails to allow residents their right to participate in their own treatment planning. And while the HRA also acknowledges the residential provider's interest in activities that have vocational merit, it also questions why vocational merit cannot be found in most activities particularly if the activities allow a resident to interact with his/her own community, noting that community integration is a key component of vocational mandates. Furthermore, even if vocational merit could not be found with a given activity, residents maintain the right to refuse treatment unless that refusal represents an imminent threat of harm. Finally, the case manager's refusal of resident participation in vocational activities fails to engage other members of a resident's treatment team.

Based on its findings specific to the vocational outings, the HRA substantiates the complaint that the agency violates the right to individualized treatment pursuant to an individualized treatment plan with input from the individual and/or the guardian. The HRA recommends the following:

Ensure individualized treatment planning with recipient/guardian input by engaging the resident and treatment team when vocational questions or issues arise. Discontinue the practice of the residential case manager having the only say with regard to a resident's vocational participation.

The HRA also offers the following suggestions:

1. The HRA did not find the OIG number posted in the CILA Home toured. Ensure that the OIG number is posted along with an explanation of the OIG role.
2. To confirm resident agreement with the shopping expense form, include a resident signature line.
3. Ensure that each resident has a documented six month treatment plan review that goes beyond a QSP summary.
4. Ensure that minutes are maintained for each resident council meeting.