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HUMAN RIGHTS AUTHORITY - NORTHWEST REGION

REPORT 11-080-9001 AND 11-080-9002
BETHESDA LUTHERAN COMMUNITIES

Case Summary: only violations were found in the lack of information provided within service plans. The program has redeveloped the plans to be all inclusive.

INTRODUCTION

The Human Rights Authority opened an investigation into complaints regarding services within Community Integrated Living Arrangements (CILAs) at Bethesda Lutheran Communities, a program that offers employment assistance, case management and residential supports to people with developmental disabilities across the nation. They run nine CILAs in Springfield and nine in northern Illinois. This review centers on two of them in a duplex setting in Freeport.

Allegations in 11-080-9001 are that service plans in general do not list problem areas, a means to track improvements, and medical information such as diagnoses, medications, assessments and progress, and, that a resident's weight issues are not being addressed. Allegations in 11-080-9002 are that a resident's knife-throwing behaviors are not being addressed.

If substantiated, the findings would violate rights to adequate care and services as protected under the Mental Health and Developmental Disabilities Code (405 ILCS 5) and the CILA Rules (59 Ill. Admin. Code 115).

We toured the facilities and interviewed representatives who are responsible for resident care and programming. Relevant policies were reviewed as were resident records with guardian consent.

To summarize the complaints, concerns were raised that individual service plans within the program are not uniform and differ from person to person. The plans are reportedly vague in that they provide little to no information about diagnoses, medication regimens, strengths, weaknesses and needs and fail to demonstrate goals in a measurable way. It was also said that one resident's guardian wants the home to lock unhealthy snack items in a designated cabinet to help the resident control her weight. It was suggested that staff carry a key so other residents

could have access. The third allegation involves another resident whose guardian wants knives locked away for everyone's safety. He reportedly has a history of throwing knives, and Bethesda's human rights committee refuses to discuss the matter or approve the request.

FINDINGS

On the first item regarding individual service plans, staff explained that one or two of them are newer to the program and have been writing out plans using previous ones as examples. Typically all annual plans are based on various assessments as appropriate and on personal outcome measures. A functional assessment, such as the Specific Level of Functioning or SLOF, is one of those tools and there are also twenty-two outcomes from assessing "wants and desires". The support team, including the individual and any guardian, provides input as well when the plan is being developed. Collectively they come up with goals and other services depending on targeted needs. The staff agreed that their plans were not the most informative and could better reflect how the residents are followed by physicians and therapists, have various medical or social issues and are engaged in vocational and community activities, more of a snapshot of the individual in other words. They said there is an upcoming meeting with Bethesda home leaders state-wide to draft a formal and comprehensive plan template, and they will share it with us as soon as it is finalized.

We looked at two service plans in place at the time this complaint was received. The first resident's plan lists her date of birth, meeting participants, a brief description of her day-training involvement and part-time job, a brief description of whom she sees for her health needs, a statement from the resident about her weight and living situation, itemized goals and their first short-term objectives, the names and signatures of staff trained to implement the goals, and nothing else. There are no diagnoses or indication whether the resident has any medical problems or takes medications, no references to her disabilities and assessment results or recommendations, and no acknowledgment of guardian input if there is any. All of these exist in other areas of the record; they just are not included in the service plan. The second resident's plan contains far less. It lists his name, goals and first short-term objectives, and the names and signatures of the staff trained to implement them. There are no descriptions about his disabilities, what his medical/psychological issues are or who follows him, any medications he may be taking, his social, vocational and living situations nor any reference to his or his guardian's input. Again, all of this important information can be found in other areas of the record but is absent from the overall service plan.

A draft of Bethesda's new service plan template was provided to us a few weeks later, which the program will be using for all residents. The template is thorough and informative, giving a summary of all facets of the individual's life as a service recipient. The heading lists the individual's name and birth date and all support team members whether they participate or not. There is a section noting the individual's input regarding likes, dislikes and about his communication skills. Other sections summarize family and social relationships, health and various health assessment results, diagnoses, histories, medications and recommendations. There is a section on safety and security, rights, any restrictions that may apply and reference to the facility's human rights committee reviews. Another section designates guardianship status,

supervision levels, use of psychotropic medications and finance management. The template rounds out by addressing his home life, diet, community life, spirituality, support services, personal goals and progress and a summary of the planning meeting.

On the issue of locking unhealthy snacks in the home, we were told that the first resident indeed has a weight problem and that she acknowledges it herself. She is a short woman at about 5'3" and weighs typically around 200+ pounds. Her challenge is getting up in the middle of the night to find snacks, but the home feels she and they are adequately addressing the situation. She works out on her bike each day and has no problems with exercising. She also talks to her therapist regularly about dealing with her weight, and she is monitored by the facility's nurse. The home uses a baby monitor to help staff listen for her stirring around for food during the night, and they are able to discourage her, which has proven successful; there was only one incident in the last month. Her guardian always wants the food locked up although the resident and the home feel it unnecessary when her exercising and therapy are working. They approached their human rights committee and decided that since the request would affect other residents, it would be better to stay on course and track her progress instead.

The resident's service plan lists a goal to have ten or less incidents of eating during sleep hours per month given one verbal prompt. The method to carry out the objective is for staff to monitor the resident and discourage her from eating. If she is seen eating, they are to discuss her need for weight loss. Each verbal prompt is to be recorded. Monthly progress notes from the same timeframe document her progress. She had five incidents of trying to eat snacks one month, eight the next, with a caveat that she is still doing well, walking more and attending the YMCA, and only three the next. This goal is part of her behavior plan, which was more recently revised to include Bethesda's rights committee directive to keep all "junk foods" in one location with an alarm to let staff know when someone tries to access. We observed the cabinet and alarm during our visit. According to rights committee minutes, the resident's nighttime eating was addressed at one of their meetings. The guardian's request to lock junk foods was reviewed, and the committee did not agree given the resident's progress and because it affects the rights of the other residents. They recommended an alarm be placed on the cabinet instead and to revisit the issue later. A second goal is to lose weight and be healthy by exercising at the Y for a minimum of thirty minutes each session. This goal is not part of her behavior plan. Success is measured at a seventy-five percent completion rate for three consecutive months. Staff help the resident choose three days per week to exercise, and give any encouragement to complete the task as needed; verbal prompts recorded. She met her goal exercising at the Y eighty-nine percent one month, one hundred percent the next, and then eighty-seven percent the following month. Both goals are to be carried over at her bi-annual staffing.

Regarding the second resident's alleged knife-throwing behavior we were told that the home is unaware of that ever happening; however, the resident has pulled a knife on staff once or twice, the most recent incident about a year ago. They said he has never gone after anyone and he is not tracked for physical aggressions in his behavior plan. His guardian requested to have all knives and sharps locked up. They approached their rights committee chair who initially said it was a violation of everyone's rights and would not be reviewed. The subject however, was ultimately addressed at the same committee meeting according to their minutes. The guardian's request was approved, and the resident's behavior plan is to be updated to include the locking of

blunt and sharp items and anything that can be used as a weapon as requested by the guardian, and, there should be a review to restore his right. A revised behavior plan was shared with us a while later. It added a potential physical threats and aggression component, namely the knives and biting his wrists when caught stealing. Cutlery in the CILA is to be locked for the safety of everyone. The restriction will be revisited every six months, and will be considered appropriate for removal if the resident displays one or less incidents in the six month period. Progress notes from the same timeframe do not track knife incidents as the revised behavior program was not yet implemented. We observed the knives and other sharps locked in a staff area when we toured the facility.

CONCLUSION

Bethesda's plan development policy states that each person's needs will be addressed through the interdisciplinary process. The plan will be based on a variety of assessments, including personal outcome measures, medical and dental exams, self-administration of medications, and psychosocial, functioning, behavioral, educational, and vocational and communication areas. The plan must reflect the individual's and any guardian's preferences, identify services and supports to be provided and by whom, state goals and objectives that are measurable, identify levels of supervision and include the individual's and the guardian's signatures.

The MHDD Code states that all recipients will receive adequate services in the least restrictive environment pursuant to their individual service plans (405 ILCS 5/2-102a). Under the CILA Rules, on which the program's policy seems to be based, a plan must be developed on assessment results, reflect the individual's and the guardian's preferences, include their signatures unless it is noted why their input or signatures are absent, identify services and supports, state measurable goals and the level of supervision needed (59 Ill. Admin. Code 115.230).

Bethesda has policies and procedures in place to develop thorough and appropriate service plan contents as required. For whatever reason, they were not being followed at the time this complaint was presented. The plans we observed barely reflected the individuals' array of services, and that part of complaint #9001 is substantiated. But we appreciate the attention given to the matter when an excellent plan format was created immediately to ensure that all homes will be in compliance. So, Bethesda has resolved the problem.

SUGGESTIONS

1. Be sure that the template refers to whether the individual has a current behavior support plan.
2. Include a section to note guardian input as well as individual and guardian signatures.
3. Revise goals whenever objectives are met, or, refer to them as maintenance goals.
4. Refer to the Department's DD Waiver Manual for providers. There is a section on individual service plan requirements, and a checklist is currently being developed.

The program's rights protection and promotion policy states that any standing practice that restricts an individual's rights is prohibited. Situations exist where total freedom to act, do or decide is not possible and in these cases limitations may occur. The need for a restriction must be weighed against safety risks, dignity and other interests, and the individual's opinion should be heard. Restrictions are seen as temporary measures and will be reviewed by the human rights committee. Committee policy states that their focus is to protect and promote rights, and they will meet no less than once per year to review, approve and monitor all rights limitations.

According to the MHDD Code, all care and services are to be adequate, humane and provided in the least restrictive environment pursuant to individual service plans that are formulated and periodically reviewed with the individual's, to the extent feasible, and the guardian's participation (405 ILCS 5/2-102a). Adequate and humane care and services are those reasonably calculated to prevent further decline in an individual's clinical condition so that he or she does not present an imminent danger (405 ILCS 5/1-101.2). Restrictions are permitted with appropriate reasons and notification (405 ILCS 5/2-201). The CILA Rules require services to be provided in the setting most appropriate to an individual's needs. Agencies must establish a process for the periodic review of behavior intervention and human rights issues (59 Ill. Admin. Code 115.320).

Concerning the first resident's weight issues not being addressed, the record provides evidence to the contrary. She has been working on goals to exercise, be healthy and attend the local YMCA with documented success, and when her guardian asked that all snack foods be locked away, the facility consulted their rights committee and came up with an alternative to meet the resident's need but avoid restricting the rights of everyone else in the home. We view this as a protection of rights, not a violation. That part of complaint #9001 is not substantiated.

The second resident's issue with knives is also being addressed. First, there is no indication in his record or from staff recollection that he even has a problem throwing knives. Since there was a recent incident where he brandished a knife on staff, the facility approached their rights committee who reviewed and approved the guardian's request to have all sharp objects locked and out of reach for safety. The complaint in #9002 is not substantiated.

SUGGESTIONS

1. Use rights restriction notices, which can be downloaded from the Department's forms library website.
2. Ask all residents and their guardians at the commencement of services whether they want any person or agency to be notified whenever a guaranteed right under Chapter II of the MHDD Code is restricted (405 ILCS 5/2-200 and 5/2-201). Each can give different responses and must be followed. We suggest repeating the questions when rights information is shared at annual staffings.

3. Check with the Department's forms library after August 1st. The rights form is being updated to include freedom from financial exploitation.
4. Consider a campaign to involve all residents in choosing and purchasing healthy snacks as opposed to "junk food".