



FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY - NORTHWEST REGION

REPORT 09-080-9010
ILLINOIS DEPARTMENT OF HUMAN SERVICES
DIVISION OF REHABILITATION SERVICES

Case Summary: the HRA did not substantiate these complaints. The public record on this case follows, and a response was not required.

INTRODUCTION

The Human Rights Authority of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving complaints of possible rights violations at the Illinois Department of Human Services, Division of Rehabilitation Services (DRS) in Rockford. It was alleged that the DRS has not provided a recipient with adequate care and services in the following ways:

1. Service planning assessments are rushed and are not thoroughly achieved.
2. The recipient is asked to sign assessments and other documents without explanation of their purposes.
3. The recipient's mother is not asked for her input.
4. The recipient is routinely threatened with reduction or loss of services.

Substantiated findings would violate requirements under the Administrative Code for Home Services Programs (89 Ill. Admin. Code 676 et seq.).

This review centers on home services provided to an adult recipient who has a traumatic brain injury. Although he maintains his legal rights, his mother acts as a personal assistant and helps him with daily living needs; her role in that capacity is funded by the DRS. Approximately 2,600 people in the area receive some form of home services from the program. Intentions are to promote maximum independence and prevent institutionalization. Services in addition to personal assistance can include adult day care, homemaker, health maintenance and respite care, meal delivery, habilitation, behavioral therapies and supported employment.

We visited the Rockford office and discussed the issues with the regional manager and the recipient's service counselor. Determination of need procedures were reviewed as were related sections of the recipient's file with authorization.

COMPLAINT SUMMARY

The complaint states that the service counselor visited the recipient's home twice to complete assessments. It was said that she was much too quick, taking about fifteen minutes or less to complete them, and that she asked irrelevant questions instead of appropriate ones about the recipient's condition and struggles. She allegedly ignored the recipient's mother although the mother is the caregiver, and had the recipient sign various forms without explanation. It was further reported that the counselor threatened to cut off services because the recipient was at twenty-nine points and that such threats are unnecessary and cause undue anxiety.

FINDINGS

Interviews:

DRS representatives explained that a determination of need is completed every six months for individuals in the home services program who have traumatic brain injuries; they are completed only once per year otherwise. More frequent assessments are necessary for those with brain injuries because there can be significant changes, and counselors will look for improvements or deteriorations. The counselor in this case told us that she covers a variety of information with recipients in addition to the needs assessments, including service plans, recipient rights, privacy issues and the appeal process and asks if there are any questions. She makes sure to have an informant present in doing so, which for this recipient is his mother. It is essential to have another person present while assessing, again because of the nature of the disability. Or, if someone does not pass the "mini mental" section, a short evaluation of the recipient's current mental state, then it would be necessary to have a knowledgeable informant available as well. She said that she goes through an extensive, detailed assessment and asks relevant questions about what the recipient can and cannot do. Her initial visits take anywhere from one and a half to three hours while subsequent visits last at least forty-five minutes. Nothing is signed or initialed without explanation.

The counselor offered that she has never been approached by the recipient or his mother regarding these complaints or to appeal any previous determination. She spends a lot of time with him and never asks the mother to step out. The mother is free to provide her thoughts but tends to focus on her own disabilities and needs some redirection. Both representatives said they suspect that these concerns arise from changes made when the DRS took over the assessment role from a community agency. The previous assessors likely spent more time with the pair as they had far lighter caseloads. They are still involved but are only doing monthly checkups at present. The DRS counselor takes on three counties and up to three-hundred recipients who are to be seen twice per year. She expects her region to increase by five more counties.

On the issue of reducing or losing services, we were told that this could be a real concern for the recipient and his mother. There was a drop in personal assistance hours last summer based on a determination of need at that time. In the fall there was an increase because the recipient had leg surgery, and in December the hours dropped back down although not as low as before. Home services are guided by an established point system where the bottom rung for needs sits at twenty-nine; any score below that disqualifies a recipient from the program. One of this recipient's latest determinations scored a twenty-nine, and the counselor has talked with the recipient about preparing for the possibility of getting therapies at a local mental health center

should he lose services. She said that she warns recipients when they are close to the cut off but never in a threatening manner; the idea is to counsel them.

Record review:

The recipient's service plan completed in July 2008 assigned sixty-six hours per month of personal assistance for eating, bathing, grooming, dressing, and doing laundry among other activities of daily living. Ten additional hours per month were set up for counseling as a behavioral service. The mini mental section within the corresponding determination of need showed that the recipient was oriented and comprehended what was asked of him at the time of the assessment. The determination noted deficits in cutting food, steadiness in the shower and with washing his back although he does not want to be helped with that, needing reminders and prompts to groom and dress appropriately, sometimes needing a hand getting out of bed, having frequent night terrors, needing some help, prompts and reminders with preparing food and doing laundry, housework and taking medications, having poor memory, and being easily frustrated, all of which were called moderate to minimal impairments. It also noted that the recipient drives independently except when he is in too much pain. The determination of need was scored at twenty-nine. Attached narratives listed the recipient, his mother and the counselor as assessment participants. There were references about the recipient's presenting condition as well as the home's condition at the time of the assessment. A statement acknowledging that the recipient agreed with services as planned was signed by the recipient and his mother. An eligibility agreement form that listed a variety of recipient rights as they relate to the program, including being part of service planning and being educated on privacy matters, was initialed and signed by the recipient and signed by his mother and the counselor. The recipient completed and signed an evaluation of his personal assistant, wherein he noted that he wanted her to have more hours because she worked "24/7 every day". That form was signed by the mother as well.

Case notes from the community agency that were entered a few weeks prior to the July service plan development stated that the recipient and his mother were reminded about a change in reassessments, referencing that the DRS would be doing them, and that the mother expressed worry over this. Another community note entered a few days after the plan's development stated that the mother worried because the recipient had not been totally honest with the DRS service counselor, probably because she was new. The writer noted that he encouraged the mother to contact the counselor on the matter. There are no subsequent notes to suggest that the mother followed through on the issue specifically.

The service plan was revised in November raising personal assistance hours to ninety-seven because the recipient had a full length cast on his leg. A reassessment was completed in January, at which time the hours were dropped to eighty-four. Determinations were similar to the ones arrived at six months earlier, only there were increased needs in getting outside the home and in routine health maintenance due to the recipient's leg. The determination of need was scored at thirty-three. The same forms attached to the previous plan were included on this one, and each was initialed and signed by the recipient and signed by his mother and the counselor.

CONCLUSION

According to the determination of need instructions manual, determinations define the

need for services as they relate to the recipient's ability to perform basic activities of daily living essential to remaining at home. A recipient's orientation and mental functioning are to be evaluated by the "mini mental state examination". If the score is ten, the recipient requires an informant; if the score is zero, an informant is not required. Persons in the brain injury waiver program should always have an informant present during interviews. The determination of need is to be completed with the recipient in his home. Scoring is based on the assessor's judgment in regard to each recipient's abilities and resources and on the recipient's responses, the assessor's observations, any recent medical or psychological evaluations available, and the reports of others in regard to the recipient. The interview sequence and approach is left to the assessor's discretion, allowing flexibility for the recipient to participate with ease. A designated informant may speak for the recipient only when the assessor determines via the mini mental that the recipient is unable to respond. A designated informant can be any person selected by the recipient to assist in the process.

Regulations for home service programs require all communications given to a recipient to be in a language and at a level which the recipient can understand (89 Ill. Admin. Code 676.20). In order to receive and continue services, the recipient must sign all forms and supply any information required to complete them (89 Ill. Admin. Code 676.130). The recipient must receive a total determination of need score of at least twenty-nine points (89 Ill. Admin. Code 682.100). All services provided must be necessary to meet an unmet care need and be listed on a service plan that is developed for the recipient and agreed to and signed by the recipient and the counselor. Services must be safe and adequate (89 Ill. Admin. Code 684.10). The counselor has the responsibility to identify the appropriate level of service provided based on the recipient's approval of the plan. A recipient has complete discretion in which personal assistant he wishes to hire, provided that the assistant meets criteria (89 Ill. Admin. Code 684.20).

Complaints in this case state that service planning assessments are rushed and are not thoroughly achieved, the recipient is asked to sign assessments and other documents without explanation of their purposes, the recipient's mother is not asked for her input, and the recipient is routinely threatened with reduction or loss of services. All indications from interviews and the file we reviewed suggest that the abundance of materials in the assessment packet complete with signatures from the recipient, his mother and the counselor are done thoroughly and with understanding. Procedural manuals and home service regulations identify the recipient as the key supplier of information, although he can select an informant to assist in the process. We cannot say for certain whether the counselor ignores the mother's input, but given the mother's signatures on various assessment packet forms, there is evidence to show that she is a participant at some level. A recent determination of need scored the recipient at twenty-nine, which is indeed the cut off for services per regulations. We find no rights violation in advising the recipient of his status.

SUGGESTIONS

1. To allay anyone's concerns, consider documenting time spent with recipients and/or personal assistants when making case management/progress note entries.
2. Discuss with this recipient whether he intends for his mother to be more involved in the assessment process.