



FOR IMMEDIATE RELEASE

SPRINGFIELD REGIONAL HUMAN RIGHTS AUTHORITY

REPORT OF FINDINGS

HRA CASE # 13-050-9022

UNITED CEREBRAL PALSY LAND OF LINCOLN

INTRODUCTION

The Springfield Regional Human Rights Authority (HRA) has completed its investigation of allegations of rights violations at United Cerebral Palsy Land of Lincoln (UCPCLL), an agency in Springfield that provides services to consumers with developmental disabilities, including but not limited to Community Integrated Living Arrangements (CILAs). The allegation being investigated is that the agency may have violated consumers' rights when it changed its system of charging for services, and utilizing food stamps, medical and dental services.

If substantiated, the allegation would be a violation of the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-102) and the Illinois Administrative Code (59 Ill. Adm. Code 115.710).

Specifically, the allegation states that the agency changed its procedure regarding charges and benefits offered and that those changes may not be equitable. The expenses and charges for residents relating to meals, cable television, medical and dental expense co-payments are different according to income and other factors.

METHODOLOGY

To investigate the complaint an HRA team visited the UCPLL administrative offices and interviewed the agency's Chief Financial Officer (Officer) and her Assistants. The Adult Services Manager (Manager) provided written correspondence and documentation to the HRA. The HRA Coordinator shared correspondence with the guardian and with consent, the HRA reviewed portions of consumers' records.

FINDINGS

The guardian stated that UCPLL changed its rules without consulting consumers or their families and guardians. The guardian explained that UCPLL's changes may be unfair because charges for individuals' services related to rent, utilities, and food are inequitable. For example, prior to the changes, a resident who had adequate income and assets was able to purchase an expanded cable television package (which he enjoys and prefers) and since the billing change, he has had to revert to basic cable programming. The guardian said that in the past consumers' medical and dental expenses were paid by UCPLL. Now those expenses are passed on to consumers to pay out-of-pocket for those services. The guardian said all consumers are now required to apply for a Link Card (food stamps) and that funding amount is based on individual income. The UCPLL requires housemates to combine their food stamps and share the food equally. According to the guardian, the UCPLL staff were unsure how individuals' cost of care is computed and the agency has not provided clear verification or a description of the program changes.

The Officer explained that the Department of Human Services reduced the individual CILA payments and that resulted in UCPLL losing money while providing services. The Officer noted that while it was a non-for-profit agency, a reduction of deficit spending was a benefit to all consumers and staff. At that time UCPLL made the decision to remodel its fiscal management and that included changes regarding the use of individuals' funds. The Officer said that this was a complex and difficult decision and UCPLL knew it would be a difficult adjustment for persons who had received services under the previous system. The Officer explained that each home's QMRP was responsible for sharing these changes with consumers and their guardians.

The Officer stated that the revised policy changed how UCPLL assessed consumers' cost of care and provided supplemental services such as dental and medical services. The Officer explained that the cost of care varies for each consumer; however, the agency attempts to group consumers together who have similar needs and costs for care. According to the Officer, UCPLL was losing money while providing CILA services and, during a 2012 audit conducted by the Illinois Department of Human Services, the auditor suggested allowable changes that would reduce the agency's losses. The Officer stated that UCPLL delayed implementing this new system until it could no longer sustain the fiscal deficit effecting the CILA residential and day training programs under the previous system.

The determination of payments for individuals by the Department of Human Services has changed. The Officer said that prior to changes implemented January 1, 2013, UCPLL allowed consumers to keep all unearned income, including Supplementary Security Income (SSI), Social Security Disability Income (SSDI), Veteran Administration (VA) benefits and work income. These funds were deposited into individual accounts managed by a residential accountant who considered and approved payment for rent, utilities, and personal expenses. According to the Officer, UCPLL did not pay for individuals' medical, dental or personal expenses, however, under the old program it maintained a fund that was used to loan money to consumers for unexpected expenses or when income deficits occurred.

The Officer explained that the money held in individual accounts at the end of 2012 remained the property of each individual and that those consumers are allowed to

spend as they wish with no attachment from UCPLL.

According to the Officer, the cost of CILA care rates and projections are based on several factors, including individual needs, desires and income. The Officer explained that these factors dictate and project the costs for individual services. The Officer said that the formulas are complicated and take into consideration how many other persons are living in the same CILA location, nursing hours required, staffing hours required and location of the residence.

The Office explained that prior to implementation of the new calculation process; each consumer was allowed to retain \$50.00 for personal spending for each month. Under the system adopted January 2013, UCPLL allows each person \$75 for personal spending per month. Out of his/her income, a consumer will be responsible for rent, utilities, and his/her portion of household food and supplies. In addition, each consumer can keep the first \$55 per month of any work income, plus $\frac{1}{2}$ of any work income over \$55. According to the Officer, consumers have access to these funds through the use of a gift card under the supervision of an agency Qualified Support Person (QSP). Funds not on the card remain in a checking account and can accumulate for larger purchases at a later date.

UCPLL now pays costs related to living expenses per the policies of UCPLL and the Department of Human Services. Because most residents live in apartments throughout the area, the rent is paid directly from the individuals banking accounts. Any other household supplies, medical costs and dental expenses are paid through the agency.

Regarding shared food stamps the Officer stated that consumers share their food stamps to purchase weekly groceries. The Officer noted that a consumer with less income receives more food stamps; however, a consumer who has more income pays more for his/her cost of care. The Officer noted that all consumers' income, less \$75.00 per month for personal needs, is paid towards their cost of care (room and board). Therefore, persons with more income pay more towards room and board expenses and those with less income and additional food stamps contribute more funds for food for everyone in the home. The Officer explained that the pooled food stamps are divided by weeks and spent each week by household members based on the dietician's planned meals and other choices by individual consumers. The Officer said that each consumer has enough resources between the extra food stamps and personal funds to have any foods they desire within reasonable limits.

The Officer stated that almost all medical costs are paid for by Medicaid or Medicare and that the new formula pays for an annual dental checkup. At this point in time, dental emergencies are addressed in emergency departments at local hospitals and in some cases when it is determined a medical need, dental work is paid for by Medicaid.

The Officer said that the current policy does not contain language regarding cable television and that basic cable and televisions are provided in the common areas of all homes. Any consumer wishing additional channels may request such services through their case manager and, if they have the funds, may purchase extra services from the local cable company.

According to the Officer, it was and is the responsibility for each home's QMRP to discuss CILA billing and services with individual guardians and/or family members.

DOCUMENTATION

In a written statement, the Adult Services Manager stated:

On November 26, 2012 a letter was sent out to all guardians explaining the changes to the individual's funds. On this same day, the QIDP's (Qualified Intellectual Disability Professional) met with all individuals explaining the changes and answering any questions anyone had.

A consumer's Chronological notes entry dated November 26, 2012 states:

Guardian contact: Via fax: QIDP updated guardian of new finance procedures that will be effective as of 01/01/13.

The agency provided an unsigned Memorandum style letter dated November 26, 2012 states:

To Whom It May Concern:

As a result of an audit and recommendation from the Department of Human Services, United Cerebral Palsy will be changing how customer's funds are allocated. Effective January 1, 2013 UCP will begin billing for CILA services rendered to each customer. The finance department will issue an invoice detailing the cost of services on a monthly basis. The attached document details the process for calculating the CILA service fee. [See the policy below]

We encourage you to schedule time with your Qualified Intellectual Disability Professional to discuss the new billing process in detail. Please feel free to contact us at....with questions or to schedule a meeting.

Procedures for using "Household/Participants Request-Residential Finance" Form:

This two-part form should be used for 1) request for additional spending above and beyond the monthly amounts loaded to household cards, 2) request for additional spending above and beyond the approved monthly amounts loaded to clients cards (would only apply if the client has been accumulating money in their checking account), and 3) for bills to be paid by UCP for the benefit of a participant. All blanks should be completed by the originator of the form.

Situation 1)-The first block of form is to request additional spending for the house beyond what is normally loaded on the card. The originator should give appropriate details of what the expenditure will be for, and whether a check or card load is requested.

Situation 2)-If a participant has been saving part of their monthly personal money, the QSP can use this form to request an additional amount be added to their card, or paid out by check. The next three blocks of the

form can be used for this purpose. Again, appropriate details should be given for the purpose of the expenditure. One form may be used to request funds for multiple participants.

Situation 3)-As part of the implementation of the CILA fee being charged to the participants effective January, 2013, UCP will assume responsibility for expenses of participants related to care and well-being, excluding those of a personal nature. This will, in the majority of cases, include only medical bills, dental bills, and medical supplies. Bills that are received in Residential Finance will be forwarded to the appropriate QSP so that they can provide the form and approvals. The three blocks used in situation 2) above can also be used for these types of bills. Attach the bill, and give appropriate details on the form about the expenditure. Please note that in these cases, you will only be requesting a check.

All forms originated at the group homes should go to the appropriate QSP for their approval. In addition, the Qs should obtain appropriate approvals as listed on the bottom of the form prior to sending the form to Residential Finance. (Expenditures under \$100 require approval by the Adult Services Manager or the Adult Services Director; if over \$100, it must also be approved by either Chief Operating Officer or the President). The white copy goes to Residential Finance, while the blue copy should be retained by the originator. The Qs are responsible for obtaining receipts for the expenditures, if applicable. They should be attached to the blue copy and sent to Residential Finance for filing. A file should be kept by each Q of those forms awaiting receipts and they should follow up to be sure they are obtained in a timely manner. (NOTE:Any forms sent to Residential Finance without appropriate levels of approval will be returned.)

UCPLL POLICY

Each client will have a checking account, into which monthly income from all sources (supplemental security income, disability income, VA income, social security income, retirement pension payments, work income, tax refunds, etc.) will be deposited. Out of this income, the client will be responsible for rent, utilities, and their portion of household food and supplies (see attached listing for items included in household supplies). In addition, the client will be allowed to keep \$75 per month of the income for personal spending (see attached listing for items that are consider personal), and can keep the first \$55 per month of any work income, plus ½ of any work income over \$55. The client will have access to these funds through use of a gift card, which will be loaded monthly to a level approved by the appropriate QSP. Any funds not on the card will remain in the checking account and can accumulate for larger purchases at a later date.

Once a month, after receiving the client's checking account statement, each client will be charged a CILA service fee, calculated as follows:

Total income for all sources less:

Rent/Utilities
Household Food/Supplies
\$75 for Personal Spending
Retained Work Income, if any

This fee will be paid by check from each client account. As a result of this fee, UCPLL will be responsible for all other client expenses for their care and well being, except for those that are personal in nature.

MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES CODE

Pursuant to the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-105):

A recipient of services may use his money as he chooses, unless he is a minor or prohibited from doing so under a court guardianship order. A recipient may deposit or cause to be deposited money in his name with a service provider or financial institution with the approval of the provider or financial institution. Money deposited with a service provider shall not be retained by the service provider. Any earnings attributable to a recipient's money shall accrue to him. Except where a recipient has given informed consent, neither service provider nor any of its employees shall be made representative payee for his social security, pension, annuity, trust fund, or any other form of direct payment or assistance. When a recipient is discharged from a service provider, all of his money, including earnings, shall be returned to him.

ADMINISTRATIVE RULE

The Illinois Administrative Code (59 Ill. Admin. Code 115.20) states:

Agencies licensed to certify CILAs shall provide for services through a community support team (CST).

a) The CST shall consist of the QMRP or QMHP, as indicated by the individual's primary disability, the individual, the individual's guardian or parent (unless the individual is his or her own guardian and chooses not to have his or her parent involved, or if the individual has a guardian and the guardian chooses not to involve the individual's parent), providers of services to the individual from outside the licensed CILA provider agency, and persons providing direct services in the community;

b) The CST shall be the central structure through which CILA services are provided to one or more individuals. The CST shall:

1) Be responsible for all service functions including assessment, planning, coordination and delivery...

- 1) Modifying the services plan based on on-going assessment and recommendations;
- 2) Linking individuals to resources and services;
- 3) Advocating on behalf of individuals...

...9) Providing assistance to the individual in obtaining health and dental services, mental health treatment and rehabilitation services (including physical therapy and occupational therapy), and substance abuse services...

...14) Providing assistance in money management, including representative payeeship, and applying for financial entitlements including assisting individuals to access the Department's Home Services Program (89 Ill. Adm. Code: Chapter IV, Subchapter d)...

...e) A CST member who is a QMRP or a QMHP shall be designated for each individual and shall:

1) Convene the CST as required by Section 115.230 to revise the services plan as part of the interdisciplinary process;

2) Assure that the services specified in the services plan are being provided;

3) Assure the participation of team members and necessary non-team member professionals;

4) Assure and document in the individual's record, at least quarterly, that the individual's residence meets environmental standards as specified in Subpart C of this Part;

5) Identify and address gaps in the service provision;

6) Monitor the individual's status in relation to the services plan;

7) Advocate for the individual's rights and services;

Section 115.230 states:

....e) The agency shall assure that each individual receives an initial assessment and reassessments that shall be documented in the individual's record and the results explained to the individual and guardian....

...n) The CST shall review the services plan as a part of the interdisciplinary process at least annually for individuals with developmental disabilities and semi-annually for individuals with mental illness and shall note progress or regression which might require plan amendment or modification...

...A) A physical and dental examination, both within the past 12 months, which shall include a medical history;

The Illinois Administrative Code (59 Ill. Admin. Code 115.710) states that:

The components of Department reimbursement for CILA services for persons with developmental disabilities may include, but shall not be limited to, the following, using costs as reported on the Interagency Statistical and Financial Report, or its successor, and other sources as deemed appropriate by the Department:

a) Base support costs including allowances for "room and board", "program", "transportation", and "administration". Base support costs are considered to be those that are incurred in the delivery of CILA supports to individuals with developmental disabilities for the purchase of services that are common to all CILA recipients with similar living arrangements and direct service staffing and transportation needs.

1) Room and board cost centers

The "room and board" allowance includes costs incurred in keeping a home in normal operation. Cost centers under the room and board major allowance category may include:

- A) Housing;
- B) Utilities;
- C) Telephone;
- D) Building and Property Insurance;
- E) Maintenance and Housekeeping;
- F) Food Supplies;

- G) Nonfood Supplies; and
- H) Other, not elsewhere classified.....

CONCLUSION

The program's new procedures were referred to the Department of Human Services for analysis. Regarding our review, the Administrative Code states that through the interdisciplinary process, the CST shall be responsible for implementing a services plan and assure that each individual receives documented assessments documented in the individual's record and the results explained to the individual and guardian. The Code calls for providing assistance in money management and applying for financial entitlements and routine dental exams.

The allegations that the agency violated consumers' rights when it changed its method of assessment and utilization of funds charges for services is substantiated because there is no documentation that the changes were discussed during Individual Service Plan meetings.

RECOMMENDATIONS

The HRA recommends that the UCPLL review its policy regarding the January 1, 2013 changes and ensure that guardians and families have access to assessments and how individual charges and expenditures are determined. These plans should be discussed and written during service plan meetings.