



FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY-SPRINGFIELD REGION

REPORT 18-050-9004
PATTERSON HOUSE, INC.

The Human Rights Authority (HRA) opened an investigation into potential rights violations at Patterson House, a residential service provider to adults with developmental disabilities in the western area of central Illinois. The complaint is that the program's statement of house rules does not allow services in the least restrictive environment, substantiated findings of which would violate protections under the Mental Health and Developmental Disabilities Code (405 ILCS 5), Home and Community-Based Services Requirements (42 CFR 441.710) and the ID/DD Community Care Act (210 ILCS 47).

Patterson has two Community Integrated Living Arrangements (CILAs) and four Intermediate Care Facilities for the Developmentally Disabled (ICFs) under its management. Ten people live in the CILAs and sixteen live in each of the ICFs whose ages range from eighteen to seventy-four, their functioning levels low to high. About one quarter of the residents maintain their legal rights while the rest have court-appointed guardians. The HRA toured an ICF in Carlinville where the Administrator and various managers representing each home were interviewed.

FINDINGS

According to the Administrator, she recently took over her current capacity after working in the program for sixteen years and intended to transform general practices into something formally written, the result of which is the statement of rules in question. They were meant to promote a consistent environment, particularly where sixteen adults live together, and not to be over restrictive. She and several of the managers insisted that in fact, most of the rules are not strictly applied anyway and they are very relaxed with the visiting and telephone hours. No one has complained to them about these rules to date. They were covered with every individual, provided to guardians, including a state guardian, and were Human Rights Committee-approved, and, although they were asked to sign the statement of rules, there are no consequences for not following them, rather, any pattern of trouble would be addressed individually.

Patterson shared an August 2017 letter sent to interested parties about the written rules. It explains how these rules have always been part of the program's culture but never put in writing. They were meant to be in the best interest of everyone as guidelines and that any deviation could be outlined in each person's plan if needed or requested. The letter invites anyone to challenge a rule if too restrictive and leaves the Administrator open to suggestion.

The HRA acknowledges the commitment to individuality as expressed in the interviews and letter and adds parallel statutes and administrative codes to further highlight the idea but reveal some departures within the house rules. Each section of the house rules as written are categorized in the following mandated concepts for CILAs and for ICFs:

Humane and individual care and services (including age appropriateness and independence); least restrictive environment

Mandates:

No recipient of services shall be deprived of any rights, benefits or privileges guaranteed by law...solely on account of receipt of such services. (405 ILCS 4/2-100).

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...with the participation of the recipient to the extent feasible.... In determining whether care and services are being provided in the least restrictive environment, the facility shall consider the views of the recipient, if any.... (405 ILCS 5/2-102a).

...the facility director of each service provider shall adopt in writing such policies and procedures as are necessary to implement this Chapter [Chapter II, Rights]. Such policies may amplify or expand, but shall not restrict or limit, the rights guaranteed to recipients by this Chapter. (405 ILCS 5/2-202).

A facility, with the participation of the resident...must develop and implement a comprehensive care plan...that allows the resident to attain or maintain the highest practicable level of independent functioning.... (210 ILCS 47/3-202.2a).

A facility shall establish written policies and procedures to implement the responsibilities and rights provided in this Article. (210 47/2-210).

Services shall be oriented to the individual and shall be designed to meet the needs of the individual.... 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. (59 Ill. Admin. Code 115.200c).

Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time. (42 CFR 441.710 C).

House rules:

-All individuals, upon admission, will be subject to 24-hour supervision within the home and out in the community. Each person will be evaluated within the first 30 days and then annually for decrease in supervision.

-Men and women do not go into each other's "ends" or bedrooms for a co-ed CILA unless stated in their plan. This ensures all to the utmost privacy in a multi-person home. (The rule applies to ICFs as well).

-Mealtimes are as scheduled per home. Everyone must arrive to meals at a timely manner, or will be offered the cold substitute meal. Because this is a home, not a restaurant, schedules must be adhered to at all times. (and then meal times are listed).

-Substitutions for menus will only be made if the item being served is on that individual's dislikes list. Substitutions will be from the same types of food...vegetable for vegetable, etc. There will be 2 other options available as a substitute, if the individual chooses to not eat the substitution, nothing will be given in its place.

-“Lights out” is 10 p.m. on weekdays, 11 p.m. on weekends. This means that all must be in their rooms and quiet to not disturb others in the home. (It goes on to say that if a person chooses not to sleep he must be considerate to his roommate and that headphones are encouraged in such cases).

-All activities/movies/TV in common areas must be rated PG-13 for the safety/comfort of all.

-To ensure everyone's safety, and to help with infection control, all individuals must wear shoes/slippers/no-slip socks outside their bedroom.

-Individuals requiring “private time” to take care of sexual needs will be encouraged to use the restroom. (The rule goes on to say that those desiring a sexual relationship will be appropriately educated in related health and safety matters and that special arrangements will be made in individual plans).

It is puzzling why house rules are necessary when not strictly applied as described by the Patterson staff, and although they were meant to be in the best interest of everyone and create a consistent environment, they actually present blanket conditions that pull away from individuality and independence as purposed in the mandates. Intended or not, the rules seem to set up boundaries and restrictions to the least restrictive environment before any problem or reason to need them arises, void of personal considerations. Violations in the rules as written are substantiated.

RECOMMENDATIONS

1. Do away with the rules all together and refer to the established recipient/resident rights under the Mental Health Code (405 ILCS 5/2-100 et seq.) and the Community Care Act (210 ILCS 47/2-101 et seq.) as house rules or rewrite them in compliance. (405 ILCS 5/2-202).
2. Any required 30-day evaluation can still be individualized for the need to provide 24-hour supervision upon admission through the interdisciplinary process where the recipient/resident and any guardian must be given the opportunity to formulate the service/care plans and speak into the least restrictive environment. Perhaps a new individual who already has an established history of independent community access needs less supervised time at the onset or none at all. They are not to be “deprived of any rights...solely on account of receipt of services.”
3. Allow residents to move about their homes freely, encouraging them to knock or ask for permission before entering another person’s room instead of prohibiting them from going into certain “ends”. Restrict access for any individual who then presents a problem with privacy invasion.
4. Because the facility is a home and not a restaurant is precisely why individual considerations and accommodations must be made for anyone who misses a meal or has unreasonable likes or dislikes. Chronic tardiness in anyone can be addressed individually instead of a punitive cold meal.
5. Because the facility is a home and not a dormitory or correctional center and because its residents are adults, remove any “lights out” policy and instead work with those who tend to stay awake later so that roommates are not disturbed. Allow people to stay up and watch late night programs in their living rooms as they choose and address anything viewed as unsafe or uncomfortable as it arises. An R-rated show may not offend all *adults* in the home.
6. Sexuality is a human right and it seems to be protected at Patterson. However, since relieving oneself in a bathroom that is used by everyone in the home is perhaps not the most appropriate or sanitary option, the program must focus again on individual accommodations in private rooms; the “alone time in their room” as stated within the rules is best. There is also no condition to be in a sexual relationship of having to first go through sex education with the QIDP, who may or may not be qualified to do that. Rather, the home must respond to a resident’s choice in having a relationship by providing the necessary arrangements and education.

SUGGESTIONS

1. The HRA understands Patterson’s obligation to satisfy public health surveyors who focus on life safety issues, like having residents wear shoes or non-slip socks around the home. We believe safety and compliance can both be achieved if residents are encouraged and reminded to keep safe and to wear shoes or socks instead of demanding.
2. Cover the Mental Health Code and the Community Care Act with the program’s human rights committee on a routine basis.
3. Be sure than anyone who teaches sex education and hygiene is qualified. The program’s nurse may be a better option. Consider linking residents to available community based sexual education programs and services if needed.

Communications, reasonable restrictions and least restrictive

Mandates:

*...a recipient who resides in a...facility shall be permitted unimpeded, private and uncensored communication with persons of his choice by mail, telephone and visitation. Reasonable times and places for the use of telephones and for visits may be established in writing....
...communication may only be reasonably restricted to prevent harm, harassment or intimidation.... (405 ILCS 5/2-103).*

Whenever any rights of a recipient...are restricted [the facility] shall be responsible for promptly giving notice of the restriction...and the reason therefor to: the recipient [his guardians and anyone else so designated]. (405 ILCS 5/2-201).

The Community Care Act states the same, almost verbatim, but requires a physician's order to restrict. (210 ILCS 47/2-108).

Individuals are able to have visitors of their choosing at any time. (42 CFR 441.710 D).

House rules:

-Visiting hours are scheduled from 10 a.m. to 8 p.m. daily. Any variance must receive prior approval.

-The house phone is considered a business phone M-F from 8 a.m. to 5:30 p.m. Individuals living in the home will only be able to use the phone during these times for emergency/extreme circumstances. During non-business hours, calls on the house phone must be limited to 20 minutes to ensure all have access to the phone as needed. All phone calls stop at 10 p.m. on weekdays and 11 p.m. on weekends, which is part of the "lights out" rule.

-Internet access is not a right, but a privilege given as warranted. If a person becomes a danger to themselves or others by using this privilege inappropriately, access will be limited or denied.

The visiting hours seem to be reasonable and the staff said they are very relaxed about them anyway, although new HCBS regulations for CILAs place no limits on visitation. Trouble comes in the phone being considered a business phone on weekdays 8-5:30, during which any resident at home that day has no telephone access unless there is an extreme circumstance. Also, twenty minutes is not a reasonable time for phone calls within one's own home, particularly if no one is waiting behind you. The business hour ban and 20-minute limit impedes a person's right to communication and are unreasonable restrictions. Violations are substantiated.

RECOMMENDATIONS

1. Stop the 20-minute limit and allow residents to use their phone as they like, politely stepping in to accommodate others when needed.
2. Set reasonable calling times that include weekday, business hours.
3. Restriction notices and/or physicians' orders must be completed whenever a resident's phone call or visit is denied, restricted or limited.
4. Disband visitation limits in CILAs per the new HCBS standards.

SUGGESTIONS

1. Consider installing extra phone lines and using wireless phones if one line is not permitting reasonable phone use for the residents and staff.
2. Patterson is cautioned when considering internet use a privilege not a right. They explained that very few residents have computers and that the program pays for internet access. This is a difficult balance when the computer is owned by the resident. He may be using his property to communicate via the computer, both his right, and the home should be sure to restrict not because they pay for internet, but because there is a need to prevent harm, harassment or intimidation.

Food and property, use of own money, least restrictive and individual

Mandate:

A recipient of services may use his money as he chooses, unless prohibited from doing so under a court guardianship order. (405 ILCS 5/2-105).

A resident shall be permitted to manage his or her own financial affairs unless he or she or his or her guardian...authorizes the facility in writing to manage such resident's financial affairs... (210 ILCS 47/2-102).

Every recipient who resides in a...facility shall be permitted to receive, possess and use personal property and shall be provided with a reasonable amount of storage...except, possession and use of certain classes of property may be restricted...to protect the recipient or others from harm. (405 ILCS 5/2-104).

A resident shall be permitted to retain and use or wear his or her personal property in his or her immediate living quarters, unless deemed medically inappropriate by a physician and so documented in the resident's clinical record. The facility shall provide adequate storage space for the personal property of the resident. (210 ILCS 47/2-103).

House rules:

-No food allowed outside of the dining room/kitchen or other designated eating areas. No food or snacks are to be kept or eaten in bedrooms ever. Due to limited storage space, items on hand must be limited as well. Each individual can buy one box of snacks and one package of drinks per designated shopping trip. Outside snack/soda purchases from family and guardians is not allowed except special occasions and holidays.

-The rules state that individuals are to care for their home, including keeping their personal areas clean. If you are unwilling to care for your own personal items, you will be limited on how many personal items you will be able to keep in your room. It goes on to state that storage is limited.

-Any non-accidental destruction of property will be the sole responsibility of the individual that destroyed the property. This includes company property, other individuals' property and staff property.

The HRA recognizes the challenges facing homes with sixteen residents and the limited space therein, and it seems that Patterson makes the effort to provide storage space. But since residents are permitted to spend their money as they choose, unless prohibited under court order, the program needs to take an individual approach when determining how many items a resident can purchase on shopping trips or when prohibiting foods purchased by families or guardians. Residents may also use their property unless it is harmful or medically inappropriate, not unless they fail to keep their rooms clean. Once again, any harms or hazards presented by an unclean room should be addressed when an individual need arises and within individual care planning. A violation is substantiated.

RECOMMENDATIONS

1. Make individual determinations on when it is necessary to limit or restrict a resident from purchasing what he wants. Guide the resident on making wise choices, and when purchases are unreasonable or harmful and the resident insists, then proper restriction notices must be completed.
2. Make individual determinations on when it is necessary to limit or restrict a resident from using personal property due to potential harm and complete restriction notices.

SUGGESTION

1. Because the facility is a home, Patterson should allow residents to have snacks in their rooms. Make individual determinations when safety or sanitation becomes an issue for a particular resident.
2. Some residents may have disability-related challenges that may be at the root of destructive behaviors. Instead of a blanket policy of holding everyone solely responsible for destroyed property, be sure the problem is not first identified and addressed in a behavior plan.

The right to refuse

Mandates:

An adult recipient of services or the recipient's guardian...must be informed of the recipient's right to refuse medication.... The recipient or the recipient's guardian...shall be given the opportunity to refuse generally accepted mental health or developmental disability services, including but not limited to medication.... (405 ILCS 5/2-107).

Every resident shall be permitted to refuse medical treatment and to know the consequences of such action, unless such refusal would be harmful to the health and safety of others and such harm is documented by a physician in the resident's clinical record. (210 ILCS 47/2-104).

House rules:

-All residents must follow all recommendations made by medical professionals and consultants. This includes, but is not limited to lab work, medications, medical appointments, diet orders, exercise and other medical testing(s), etc. If the person is unwilling or unable to follow recommendations, further intervention programming will be put in place to help ensure compliance.

This house rule ignores the fundamental right of any adult resident and his or her guardian's to refuse services, which under the Mental Health Code includes treatment and habilitation, care, examination, evaluation and diagnosing and under the Community Care Act all medical treatment. As a blanket policy, this rule fails to allow residents to exercise this right and to know the consequences of exercising this right, and a violation is substantiated.

RECOMMENDATION

1. Do away with this house rule and review existing program policies to ensure that the right to refuse is permitted and properly addressed on an individual basis according to individual needs.
2. Staff must be trained on the right to refuse treatment.

COMMENTS

A review of existing program policies apart from these rules showed that many of them are not overly restrictive and are in fact compliant with statutes and regulations. Patterson should review and rely on those instead and be sure that staff are trained to carry them out accordingly.

The overall issue within these house rules seems to be that Patterson operates by setting limitations and restrictions first and then letting residents exercise their rights within them. It should be reverse: they exercise their rights and then restrictions are applied as needed.

Patterson should consider these rules in light of new HCBS regulations under which most of these will be in direct conflict.

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, some provider responses appear verbatim in retyped format.

**Patterson House, Inc.
636 W. Imboden
Decatur, Illinois 62521
217-422-6510**

December 4, 2017

Ms. Tara Dunning, Chair
Human Rights Authority
Illinois Guardianship and Advocacy Commission
#521 Stratton Building
401 S. Spring Street
Springfield, Illinois 62706

RE: #18-050-9004

Dear Ms. Dunning:

I am writing in response to the letter we received date 11/29/17. We are pleased to hear that there are no further findings into this investigation than what was discussed at our initial meeting. Directly after the meeting, as discussed, we eliminated the "house rules" and instructed all Management and QIDPs to individualize any type of restrictions as needed into their care plans instead. This was put into place effective immediately. We also trained our staff on right to refuse treatment and the correct form to use if a right is continued to be restricted without their consent. Our employees are also currently trained at least yearly on Resident Rights as found on the DHS website. We also continue to get BM/HR approval for all type of rights restrictions prior to the restriction being put into place.

It was a pleasure working with your office and we are pleased to hear that our general "philosophy" of care is cohesive with both state and federal standards. We are always looking to improve our care for the individuals we serve and appreciate all input you provided in this manner.

Sincerely,

A handwritten signature in black ink that reads "Nicki Palmer". The signature is written in a cursive style with a long horizontal line extending to the right.

Nicki Palmer
Administrator
Patterson House, Inc.