

THE REALITIES OF HOUSE RULES

Posted 7/30/19 via Capstone e-Newsletter

By Katherine Dunbar | CQL Vice President of Accreditation

kdunbar@thecouncil.org

Do you have rules at your house? Typically, families have at least a few unwritten rules around common courtesies such as letting someone know you are leaving, knocking on closed doors, not entering others' bedrooms without permission - just to name a few. Unrelated adults who live together may have the same kind of rules or roommate expectations. What is not commonplace however, are restrictions like locked chemicals, locked thermostats, expecting someone to obtain "permission" to leave the home, door alarms alerting others and causing action, and cameras in common areas.

Even though these practices are not typical for those without disabilities, they are regularly used in services and supports for people with intellectual and developmental disabilities (IDD), through the creation and enforcement of 'house rules.' Restrictions such as the ones listed above can come at the expense of independence, self-determination, privacy, due process, and other quality of life areas. Although formalized, written 'house rules' are not commonly adopted outside of the human services system, the closest equivalent that would apply involves the use of leases.



LOOKING AT LEASES



The HCBS Settings Final Rule, first released by the Centers for Medicare & Medicaid Services (CMS) in January 2014, provides guidance and requirements for people receiving (and providers supporting people receiving Medicaid Home and Community Based Services (HCBS). The rule states that people receiving HCBS supports are entitled to access to the benefits of community living, to exercise their rights (such as privacy, visitors at any time, access to food at any time), to make choices (including their daily schedule, who they live with and how they decorate their home), to select the services they use, and to select who provides those services.

Among these requirements, it mandates that people have a lease or other legally enforceable agreement and are offered the same protections that a lease offers to people without disabilities. The Final Rule specifically states "For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant..."

Organizations most often solicited and honored people's opinions about community staff (54.2%), and least often about employment staff (40.9%). However, the numbers were relatively low regardless of staff type. This is problematic not only because people are not being involved in decisions that directly affect them, but also because when they are included in decisions about staff, people have higher quality of life (see figure below). When organizations actively solicit the person's preferences, provide options to the person, and honor their choices for all five staff types, the person has more personal outcomes present (14.5 out of 21 outcomes present; 68.8%) – better quality of life – than when they do not do this (8.6 out of 21 outcomes present; 41.0%).

In a summary of key provisions, CMS also lists the following requirements for provider-owned or controlled home and community-based residential settings:

- The individual has a lease or other legally enforceable agreement providing similar
- protections;
- The individual has privacy in their unit including lockable doors, choice of roommates and
- freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.

Sometimes, a provider of services may act as the landlord. During CQL Accreditation on-site visits, CQL reviewers have seen some providers go beyond the typical rules and protections of a lease. For instance, it would be common to have clauses in the lease that prohibit certain pets, restrict altering the premises or painting the walls without permission. It would not be typical to find restrictions around locking food (which the Final Rule specifically allows access to food at any time), restricting keys to the home, requiring visitors to sign a log, or imposing curfews. Aside from binding leases or formalized house rules, there are also instances where there are unwritten house rules that impact the lives of those receiving services.

UNWRITTEN HOUSE RULES

Like stated above, unwritten house rules can be more common inside of the human service system. Considering these unwritten 'house rules' can often go unnoticed since they are not formally adopted or recognized by an organization, agencies should be especially attentive to these types of guidelines.

Examples of unwritten house rules:

- You can only eat in the kitchen
- Overnight visitors are not allowed
- Bedroom doors must remain open while your significant other is visiting
- Use of common areas is limited in the evenings
- No one can access knives, cleaning supplies, etc.
- Decorations, furnishings, and paint colors in common areas must be approved by staff



Sometimes, staff members may knowingly or unknowingly establish a rule that people receiving services feel they have no choice but to follow. Teaching people about their rights and listening to concerns may reveal some of these “unwritten” house rules. Often times, these “unwritten” rules develop as a result of the perceived conveniences that they provide staff, and tend to remain in place due to a lack of understanding about what a restriction really means. Rules can also take the form of hierarchical dynamics, where staff expect that people receiving services ask for permission to have a snack, use a phone or computer, etc. In addition to this, although it is the home of those who live there, staff at times are the ones who answer the front door, pick up the phone, open the mail, etc.

Organizational leadership also may not realize that house rules involving restrictions have become commonplace and expected in a home. Staff training and educating people receiving services, as well as having open conversations about “the rules” can help avoid issues. Be present, observe, ask questions, talk with people – that will help ensure that people are being treated with dignity and respect at all times. CQL uses various tools and approaches in observation and information-gathering to understand and assess the use of unwritten, written, formal, and informal ‘house rules.’

CQL RULES AND HOUSE RULES

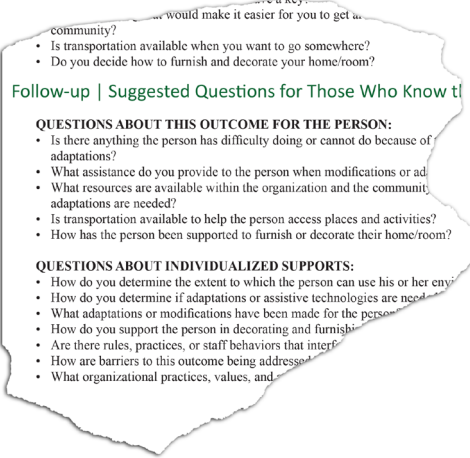
In the Basic Assurances® we stress that people have the right to move freely, visit and be visited by whomever they choose, have access to all personal possessions, and have autonomy in life choices. The Basic Assurances® is organized by 10 different factors with indicators to set expectations for each factor, then uses probes for determining the presence of an indicator. Here are some examples of the probes that might be used in connection to a person’s home, the existence of house rules, or the lease-related issues raised above.

- Does the assessment address people’s civil and legal rights and personal freedoms? Examples include people having the ability to visit and be visited by whomever they choose, and having access to personal possessions.
- Do people have autonomy and independence in making life choices including control over their own schedules and routine?
- Are people supported to decorate their homes as they choose and to maintain homes that are safe and sanitary?
- Do the organization’s policies and practices promote frequent and informal visits at people’s homes?
- Can families and friends visit people at reasonable times without prior notice, unless the person explicitly requests they not do so?
- Do people have private space to visit with family and friends?

In the Personal Outcome Measures® (POM) we also focus on rights, being treated fairly, access to environments, and choosing services. We use information-gathering questions to explore quality of life indicators, the presence of outcomes, and supports that help people achieve those outcomes. To collect information regarding a person’s home, how and if house rules are used, and the potential impact on a person’s life, the POM uses questions like these below.

Conversations with the Person:

- What kinds of safety risks are you concerned about in your home?
- Are your living and working environments clean and free of health risks?
- How do you protect your personal property and other resources?
- Are there things you have to do without? If so, what are they and why can't you have them?
- Is there anything you can't do or use because you don't have the proper equipment or modifications (use the kitchen, bathroom, or telephone; perform job duties; take care of personal needs)?
- Do you know how to use appliances and equipment (microwave, stove, telephone, washer, dryer)?
- Are there things that you are prevented from doing due to rules, practices, regulations, or staff behavior?
- What do you like about your living situation?
- What would you like to be different?



Suggested Questions for Those Who Know the Person Best:

- Is the person involved in all decisions affecting his or her life?
- How has the person been supported to furnish or decorate their home/room?
- How do you determine the extent to which the person can use his or her environments?
- How do you support the person in decorating and furnishing their home/room?
- Are there rules, practices, or staff behaviors that interfere with the person using his or her environments?

THE RULES OF RESPECT

There is an understandable level of common courtesy shared among roommates and housemates, that can be arranged between them. This could include informal expectations like knocking on doors before entering, cleaning up after yourself, being considerate of others' belongings, etc. But the topic of house rules really comes down to respect.

You can apply the principles of your expectations to those who are receiving services. Ask yourself if the rules being imposed on people would be acceptable to you, in your own life? Would these be fair for you to apply to others? Are you treating adults as children? As support providers, we need to look differently at how people are being treated in their own homes.