

§483.420 Condition of participation: Client protections

§483.420(a) Standard: Protection of Clients' Rights

The facility must ensure the rights of all clients. Therefore, the facility must

Guidelines §483.420(a)

“Ensure” means that the facility actively asserts the individual’s rights and does not wait for him or her to claim a right. This obligation exists even when the individual is less than fully competent and requires that the facility is actively engaged in activities which result in the proactive assertion of the individual’s rights, e.g., guardianship, advocacy, training programs, use of specially constituted committee, etc.

W122

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

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Guidance §483.420(a)

The facility must ensure the client's rights and does not wait for him or her to claim a right. This obligation exists even when the client is less than fully competent and requires that the facility is actively engaged in activities which result in the protection of the client's rights, advocacy for individual clients who have no family or an inactive family, and training programs for clients and staff on the understanding and protection of client rights.

W123

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(1) Inform each client, parent (if the client is a minor), or legal guardian, of the client's rights and the rules of the facility;

Guidance §483.420(a)(1)

The obligation to inform requires that the facility presents information on rights to the client, his or her family or his or her legal guardian in a manner and form which they can understand. In most instances, family means parent. However, in those instances where parents are deceased or choose not to be active in the client's life and there is another family member who does wish to be active, but is not the legal guardian, this family member should be informed of the client's rights. Printed materials should be provided in understandable terms and provided in the language necessary to ensure understanding. Specialized methods, as indicated, should be provided for communication with clients, families or legal guardians with hearing or vision impairment.

Pro-active assertion of client rights includes, but is not limited to:

- Signed evidence that the client, his or her family and/or his or her legal guardian have been informed of the client's rights, and
- Evidence that the communication of these rights were provided at the client's level of comprehension, and in the language understandable to the client.

The obligation to inform also requires that the facility make some determination of whether the client and his or her family, or legal guardian understood the rights presented and made additional efforts to communicate the rights if the rights were not understood.

If the facility has written "rules of the facility", these rules must be communicated to the client, their family and or legal guardians at the time of admission and must not be in conflict with any of the rights listed in 42 CFR 483.420 (a) (1-13).

W124

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(2) Inform each client, parent (if the client is a minor), or legal guardian, of the client's medical condition, developmental and behavioral status, attendant risks of treatment, and of the right to refuse treatment;

Guidance §483.420(a)(2)

Clients, their families or legal guardians are promptly informed of any change in the client's medical or behavioral needs that requires immediate alteration to programmatic or medical intervention. Promptly is defined by the level of severity of the alteration. In each case, they must also be informed of the attendant risks of any recommended treatments or interventions and of their right to refuse treatment, training or services.

If parents or legal guardians wish for other members of the client's family to be informed of such changes, they must put this permission in writing.

The communication of this information must be provided in the manner and language understood by the client or their family or legal guardian (language boards, sign language, etc.).

The term "attendant risks of treatment" describes the risk vs. risk and risk vs. benefit associated with the treatment. These risks include possible side effects, other complications from treatments including medical and drug therapy, unintended consequences of treatment, other behavioral or psychological ramifications arising from treatment, etc.

The facility actively attempts to engage clients who refuse to participate in active treatment. While the regulation recognizes the client's right to refuse treatment, persistent refusal that impacts the health and safety of the client and/or others, or the ability to provide overall active treatment, may result in facility's consideration of alternative placements for the client. It is expected, however, that the facility has assessed the reason for refusal, and developed and implemented all possible interventions to engage the client in active treatment programs prior to referring the client to another therapeutic setting.

A client, his or her family member, or legal guardian who refuses a particular treatment (e.g., a behavior control, seizure control medication or a particular intervention strategy) must be offered information about acceptable alternatives to the treatment, if acceptable alternatives are available. The client's preference about alternatives should be elicited and considered in deciding on the course of treatment. If the client, family member, or legal guardian also refuses the alternative treatment, or if no alternative exists to the treatment refused, the facility must consider the effect this refusal may have on other clients, the client himself or herself, and if they can continue to provide services to the client consistent with these regulations.

If the facility is unable to provide services to a client due to consistent refusal to participate, they must weigh all options including an involuntary discharge. Involuntary discharge must be for good cause (see 483.440(b)(4)(i)).

When a client is considered for participation in experimental research the client, his/her family and/or legal guardian must be fully informed of the nature of the experiment (e.g., what medications or physical interventions will be utilized, the length of the research, any possible side effects and how the information from the research will be utilized). Information regarding the possible consequences of participating or not participating must be provided to the client, family member or legal guardian. The written consent of the client, his/her family or legal guardian must be received prior to participation. For a client who is a minor or who has been adjudicated as incompetent, the written informed consent of the parents of the minor or the legal guardian is required. The signed, informed consent documentation must be in compliance with HHS Guidelines for Research Involving Human Subjects. The signed consent must also include a clear discussion of what treatments will be included in the research, the time limits for the research and should clearly inform the client, family member or legal guardian that the client may end participation at any time without fear of recrimination. If the research protocol indicates that clients receive compensation, then clients are compensated per the protocol.

Any research must be reviewed and approved by the Specially Constituted Committee. See W263.

W125

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(3) Allow and encourage individual clients to exercise their rights as clients of the facility, and as citizens of the United States, including the right to file complaints, and the right to due process;

Guidance §483.420(a)(3)

To the extent that a client is able, choices are made on his/her own. Each client has autonomy of decision making and choice.

They are free to move about without limitations imposed due to staff preferences or staff convenience.

Clients are not restricted without due cause or due process.

To the extent that the client is able to make decisions for him or herself, it is inappropriate to delegate the person's right to others (e.g. parents, family members, etc.).

The facility has an obligation to assure client health and safety and must balance that obligation with the rights of clients.

If the facility has implemented a restriction, the following should be in place:

- An assessment supporting the need for the restriction;
- An individualized behavior plan to reduce the need for the restriction has been developed and implemented;
- A written informed consent for the behavior plan which includes the restriction;

- Approval of the Specially Constituted Committee; and
- Monitoring by the Committee of the progress of the training program, designed to reduce and eventually eliminate the restriction.

Clients, families, and legal guardians have the right to register a complaint with the facility and the State Survey Agency. If so, the facility must respond promptly and appropriately. The facility must ensure protection of the client from any form of reprisal or intimidation as a result of a complaint or grievance reported by the client, family, or legal guardian.

Issues involving the exercise of constitutional rights such as voting should be addressed as a component of the IPP when the Interdisciplinary Team (IDT) determines a need for training. Clients who have been adjudged to need guardianship or have been assessed as needing assistance to advocate for themselves should receive assistance or support so they may exercise their rights as citizens of the United States.

W126

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(4) Allow individual clients to manage their financial affairs and teach them to do so to the extent of their capabilities;

Guidance §483.420(a)(4)

The regulation is clear that in those cases where a client already possesses the skills necessary to independently manage their own financial affairs, the facility will allow the client to continue to do so. Formal training in financial management must be provided for all other clients in the facility to the extent of their capabilities. The regulation places the responsibility for determining the extent of the client's capabilities in this matter upon an assessment and interdisciplinary process within the facility.

To reach a determination as to whether a money management program is appropriate, the facility IDT uses the comprehensive functional assessment (CFA) to evaluate the ability of each client to participate in such a program. Under 42 C.F.R. 483.440(c)(3), the team evaluation must establish, through documentation, that the IDT considers all of the objective data within the assessment in reaching their determination, especially the identification of client skills which can be used across training programs. Examples of assessment findings that may be considered by the IDT include skills that can be cross-utilized in training programs such as:

1. Fine motor coordination;
2. The ability to make choices;
3. The ability to identify preferences; and
4. Cognitive abilities including tracking, attention span, communication, and the client's ability to understand the cause and effect. (The client understands of cause and effect is significant in the determination.)

Money management includes a broad spectrum of programs with varying levels of participation by the client ranging from the use of choice in money expenditures, to an understanding of the concept of money, and ultimately to actual money handling and budgeting. The IDT must not conclude that a money management program is inappropriate based solely upon the level of intellectual or physical disability of the client.

The CFA must be reviewed at least annually per 42 C.F.R.483.440(f)(2). As a part of this annual review, a client's ability to participate in money management will also be reviewed. The annual review should always include an update to the CFA and take into consideration any changes in the client's circumstances since the last IPP. The need for a formal money management program must be addressed in every client's IPP by the IDT on an annual basis.

The determination of the appropriateness of a formal money management program is made by the IDT and must be based upon a CFA. The IDT discussions resulting in that determination must be established through documentation in the client's IPP.

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(5) Ensure that clients are not subjected to physical, verbal, sexual or psychological abuse or punishment;

Guidance §483.420(a)(5)

Identification of patterns or isolated instances of physical, verbal, sexual or psychological abuse or punishment without prompt identification and corrective action by the facility would result in a non-compliance determination for this Standard and Condition level non-compliance.

The facility must develop and implement systems that protect clients from all forms of abuse, neglect, or mistreatment, including client to client abuse, neglect, or mistreatment.

- a. The facility is expected to ensure that staff possess and demonstrate needed competencies to effectively and appropriately interact with clients.
- b. The facility must monitor to assure that systems are effectively implemented and the facility takes immediate actions to address circumstances where abuse, neglect, or mistreatment have occurred and prevent reoccurrence.
- c. The facility must be organized in such a manner as to proactively assure clients are free from any threat to their physical and psychological health and safety.
- d. The facility must act to prevent physical, verbal, sexual or psychological abuse.

If the facility fails to implement appropriate corrective action, the potential of additional threats to the clients remain at the facility.

"Threat", for the purposes of this guideline, is considered any condition/situation which could cause or result in severe, temporary or permanent injury or harm to the mental or physical condition of clients, or in their death.

"Abuse", for the purposes of this guideline, is the willful infliction of injury, unreasonable confinement, intimidation or punishment with the resulting physical harm, pain or personal anguish.

Physical abuse refers to any action intended to cause physical harm or pain, trauma or bodily harm (e.g., hitting, slapping, punching, kicking, pinching, etc.). It includes the use of corporal punishment as well as the use of any restrictive, intrusive procedure to control inappropriate behavior for purposes of punishment.

Verbal abuse refers to any use of insulting, demeaning, disrespectful, oral, written or gestured language directed towards and in the presence of the client. Psychological abuse includes, but is not limited to, humiliation, harassment, and threats of punishment or deprivation, sexual coercion and intimidation (e.g. living in fear in one's own home). Since many clients residing in ICF/IIDs are unable to communicate feelings of fear, humiliation, etc. associated with abusive episodes, the assumption is made that any actions that would usually be viewed as psychologically or verbally abusive by a member of the general public, would also be viewed as abusive by the client residing in the ICF/IID, regardless of that client's perceived ability to comprehend the nature of the incident.

Sexual abuse includes any incident where a client is coerced or manipulated to participate in any form of sexual activity for which the client did not give affirmative permission (or gave affirmative permission without the attendant understanding required to give permission) or sexual assault against a client who is unable to defend him/herself.

The facility must implement, through policies, oversight and training, safeguards to ensure that clients are not subjected to abuse by anyone including, but not limited to, facility staff, consultants or volunteers, staff of other agencies serving the client, family members or legal guardians, friends, other clients, or the general public.

The facility must take whatever action is necessary to protect the clients residing there. For example, if a facility is forced by court order or arbitration rulings to retain or

reinstate an employee found to be abusive, the facility must take measures to protect the clients of the facility (such as assigning the employee to an area where there is no contact with clients).

W128

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(6) Ensure that clients are free from unnecessary drugs and physical restraints and are provided active treatment to reduce dependency on drugs and physical restraints;

Guidance §483.420(a)(6)

The facility must implement an aggressive active treatment program, which includes appropriate replacement behaviors, to address the reduction/elimination of physical restraints and drugs to manage behaviors.

For purposes of this Guideline drugs to manage behavior are “unnecessary” if there is evidence the drugs are being used:

- In excessive dose (duplicate therapy);
- For excessive duration;
- Not monitored adequately;
- Without adequate indications for its use;
- With adverse consequences which indicate the dose should be reduced or discontinued; or
- Any combination of the reasons listed above.

The long term use of a drug/physical restraint to manage behavior combined with one or more of the following may indicate unnecessary use:

- The client's developmental and/or behavioral needs are not being met and the appropriateness of less restrictive approaches to manage inappropriate behaviors should be questioned;
- Staff behavior may be prompting behaviors in clients which result in the chronic use of physical restraints and drugs to control behavior;
- Staff may have inadequate training and/or experience to provide active treatment and employ preventive measures;

Restraints applied for behaviors when less restrictive measures have not been tried or have been tried and found to be just as effective.

W129

(Rev. 144, Issued: 08-14-15, Effective: 08-14-15, Implementation: 08-14-15)

§483.420(a)(7) Provide each client with the opportunity for personal privacy and

Guidance §483.420(a)(7)

The facility must provide areas within the living area in which the client can have time to be alone, when appropriate, and to have privacy (their conversations cannot be overheard) for personal interactions/activities. There should be a location where the client can meet privately with family and/or friends and a telephone available where he/she can hold private telephone conversations.

Personal privacy for clients also includes the right to have certain personal information about them kept confidential. Staff should not discuss one client in front of others (clients, parents, legal guardians, visitors, etc.) and should not post personal information about clients in areas where other clients, families and the public can read the information.

Video/audio taping or live feed must not be used in place of or for the convenience of staff. The facility may install video/audio equipment for purposes of observing client/staff interactions. Video/audio equipment may only be installed in common areas (in no case may videotaping or live feed be done in bathrooms or areas where

private visits are conducted). The clients, families and/or legal guardians of the clients residing in the areas where videotaping or live feed will occur must give informed consent for the installation and must be assured that no personal privacy will be jeopardized. The use of the equipment must be presented at and approved by the specially constituted committee for the facility prior to the installation of video or audio devices.

Motion sensors should not be considered cameras.

W130

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(7) ensure privacy during treatment and care of personal needs;

Guidance §483.420(a)(7)

Clients must be provided privacy during personal hygiene activities (e.g., toileting, bathing, dressing) and during medical/nursing treatments that require exposure of one's body.

People not involved in the care of the client should not be present without their consent while they are being examined or treated.

Whenever possible, the facility should be sensitive to clients' preferences for same sex care in private situations.

W131

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(8) Ensure that clients are not compelled to perform services for the facility and

Guidance §483.420(a)(8)

Clients are not required or expected to be a source of labor for a facility. The client must not be required or expected to do productive work for the facility, other than appropriate care of one's own personal space or shared responsibilities for common areas.

W132

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(8) ensure that clients who do work for the facility are compensated for their efforts at prevailing wages and commensurate with their abilities;

Guidance §483.420(a)(8)

"Work", as used in the regulation, means any directed activity, or series of related activities which results in a benefit to the economy of the facility or in a contribution to its maintenance, or in the production of a salable product. In deciding whether a particular activity constitutes "work" as defined above, the key determinant is whether the facility would be required to hire additional full or part-time staff (or pay overtime to existing staff) to perform the service the client is asked to perform.

Clients volunteering to do real work that benefits the facility should give informed consent for such practices and understand that by providing employable services they are able to be compensated. This does not preclude a client from helping out a friend or being kind to others. Self-care activities related to the care of one's own person or property are not considered "work" for purposes of compensation.

In general, participation in any household task which promotes greater independent functioning and assists the client to prepare for less restrictive setting (and which the client has not yet learned) is permitted as long as tasks are included in the IPP in written behavioral and measurable terms. This participation must be supervised, and indices of performance should be available. No task may be performed for the convenience of staff (e.g., supervising clients, running personal errands).

"Compensated" means the client is provided with money or other forms of negotiable compensation for work (including work performed in an occupational training program) and such compensation is to be used at the client's discretion.

Prevailing wage refers to the wage paid to non-disabled workers in nearby industry or the surrounding community for essentially the same type, quality and quantity of work or work requiring comparable skills. A client who works in the facility must be paid at least the prevailing minimum wage, unless an appropriate certificate has been obtained by the facility in accordance with current regulations and guidelines issued under the Fair Labor Standards Act, as amended.

Any client performing "work", as defined above, must be compensated in direct proportion to his or her output. The facility should utilize Department of Labor and/or Department of Vocational Rehabilitation formulas and techniques for determining rate of pay. A client's pay is not dependent on the production of other clients when he or she works in a group.

When the client's active treatment program includes assignment to occupational or vocational training or work, specific work objectives of anticipated progress should be included in the IPP along with reasons for the assignments. If the training of clients on particular occupational activities or functions involves "real work" to be accomplished for the facility, the clients must be compensated based on ability. For example, if in the process of work training activities which involve learning to clean a floor, the floor for a particular building is cleaned and does not require further janitorial cleanup, then the client must be compensated for this activity at the prevailing wage.

W133

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(9) Ensure clients the opportunity to communicate, associate and meet privately with individuals of their choice,

Guidance §483.420(a)(9)

Privacy must be provided for both face-to-face interactions and electronic interactions.

The facility must provide opportunities for the client to communicate, through regular mail, telephone and/or electronic mail and meet in private with persons of their choice (e.g., friends from the community, family members, and advocates). There may be instances where legal guardians override the wishes of the client. In these instances, the facility should be actively working with the legal guardian and the client to reach the maximum agreeable level of interaction for the client.

Space must be provided for clients to receive visitors in reasonable comfort and privacy.

W134

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(9) and to send and receive unopened mail;

Guidance §483.420(a)(9)

Clients must be provided the opportunity to send/receive all types of mail unopened and read the contents themselves if able. If the staff has to open and read mail to the client, this should be done in a private place allowing the client as much participation as possible.

Clients who have their own electronic equipment must be provided the opportunity to send, receive, and read electronic mail with privacy.

W135

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(10) Ensure that clients have access to telephones with privacy for incoming and outgoing local and long distance calls except as contraindicated by factors identified within their individual program plans;

Guidance §483.420(a)(10)

Any restriction of telephone access must be explained in the IPP with a plan to advance the client's access. For persons with hearing loss who could benefit, Text Telephone (TTY) services or other accommodations should be provided.

As with any other rights restriction, the restriction must be addressed in the IPP, written informed consent obtained, and the plan must be reviewed and approved by the specially constituted committee.

W136

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(11) Ensure clients the opportunity to participate in social, religious, and community group activities;

Guidance §483.420(a)(11)

Clients should be offered the opportunity to participate in various types of activities in the community (e.g., going to grocery stores, hair salons, restaurants, places of worship, pharmacies, community meetings and events) based on their interests and choices. The facility must make accommodations for physical issues such as hearing impairment and mobility limitations. In addition, clients should be taught the applicable skills to participate in their choice of activities to the fullest extent of their abilities.

It is not acceptable for all client activities to be provided in the facility.

When a client is identified to be on restriction from community integration opportunities, interview clients, families, legal guardians and staff to determine if due process was afforded for this restriction and whether the restriction is included in the IPP.

In the event of a court placement that restricts community access, due process does not apply.

There should be evidence that the facility assists and encourages all clients, regardless of functioning levels, to have input into the decisions on community integration activities. It is not acceptable to require clients to attend unwanted activities due to staffing considerations.

W137

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(12) Ensure that clients have the right to retain and use appropriate personal possessions and clothing, and

Guidance §483.420(a)(12)

Clients should have personal possessions and clothing which meet their needs, interests and choices.

Clients should have free access to their own possessions and clothing. When considering whether a client has free access to their personal possessions and clothing, ensure that physical limitations have been addressed.

Clients who are unable to access and use personal possessions and clothing appropriately are involved in programs to learn the necessary skills to do so.

In situations where the behavior of one or more clients in a living area prevents free access to personal possessions for each client, the facility must develop IPPs for the client with disruptive behavior. The facility must also ensure that during the implementation of this program plan that none of the other clients have their rights infringed upon. Clients should not be without personal possessions because of the behavior of others with whom they live.

All client possessions, regardless of their apparent value to others are treated with respect for what they may represent to the client. Where those choices include socially stigmatizing materials, the facility should provide learning opportunities to make more socially appropriate choices. The facility should encourage clients to use or display possessions of his or her choice in a culturally normative manner.

If a method for identifying personal effects is used, it should be inconspicuous and in a manner that will assist the client to identify them.

"Appropriate" clothing means a supply of clothing that is sufficient, in good repair, accounts for a variety of occasions and seasons, and appropriate to age, size, gender, and level of activity. Modification or adaptation of clothing fasteners should be considered based on the needs of a client with a physical disability to become more independent.

As appropriate, each client's active treatment program maximizes opportunities for choice and self-direction with regard to choosing and shopping for clothing which enhances his or her appearance, and selecting daily clothing in accordance with age, sex and cultural norms.

Clients are permitted to keep personal clothing and possessions for their use while in the facility. Determine how the facility both ensures the safety of personal possessions while at the same time providing client access to them when the client chooses.

Clients are provided the opportunity, encouraged, and trained to use age-appropriate materials. The term "age-appropriate" refers to anything that reinforces recognition of the client as a person of a certain chronological age. Clients who choose to keep items traditionally used by children such as dolls or model cars are not an automatic citation. There must be evidence the facility is encouraging the client to use these possessions in a socially appropriate, nonstigmatizing manner. The facility's environment must be furnished with materials and activities that will enhance opportunities for growth.

W138

(Rev. 135, Issued: 02-27-15, Effective: 04-27-15, Implementation: 04-27-15)

§483.420(a)(12) ensure that each client is dressed in his or her own clothing each day; and

Guidance §483.420(a)(12)

Clothing such as pajamas, underwear, socks, hats, mittens/gloves, and coats should be the personal property of the client and not considered "stock" items. There should be no communal clothes. If clients are unable to do their own personal laundry the facility must ensure that clothing is properly laundered and returned to the appropriate client.

The staff of the facility should ensure that clients dress appropriately for the season and the occasion by implementing training programs or guidance for the client as indicated.