Rights in Residential Settings

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Introduction
Nursing homes are among the most regulated health care facilities in the nation. However, despite this, nursing home residents do not always receive the benefits of existing laws and regulations. The same can be said for Intermediate Care Facilities for the Mentally Retarded (ICF/MRs), Community Based Residential Facilities (CBRFs or group homes), and Adult Family Homes (AFHs). This chapter will summarize the rights of residents in all these facilities and provide guidance about how to enforce those rights.

Licensure, Investigation and Advocacy
In Wisconsin, nursing homes, ICF/MRs, CBRFs and some Adult Family Homes are licensed and inspected by the Bureau of Quality Assurance (BQA). This agency also investigates complaints against these facilities. BQA can be contacted at:

Bureau of Quality Assurance
Division of Supported Living
Department of Health and Family Services
1 W. Wilson St, P.O. Box 2969
Madison, WI 53701-2969
Tel: (608) 266-8481
Fax: (608) 267-0352

Advocacy agencies
The Board on Aging and Long Term Care (BOALTC) is a state agency which operates the Long Term Care Ombudsman Program. Ombudsmen investigate complaints and mediate disputes on behalf of residents of nursing homes, CBRFs, and AFHs. They may be contacted at their statewide toll-free number: 800-815-0015.

The Long Term Care Ombudsman Program generally focuses on complaints and disputes involving elderly persons. The Wisconsin Coalition for Advocacy (WCA) will provide information if the complaint involves a younger person with a disability, or a resident of any age in an ICF/MR. If the complaint meets WCA priorities, WCA can usually provide advocacy assistance. (See the cover page for contact information.)

1 Many Adult Family Homes are licensed and inspected by the county where they are located.
Although only BQA can issue citations or sanctions against a long term care facility, it is a neutral agency which does not advocate on behalf of residents. For advocacy services, contact either the Long Term Care Ombudsman program or WCA.

Persons and Facilities Covered
Wisconsin and federal law contain an extensive set of rights for persons residing in nursing homes. Similar (but not identical) rights apply to the residents of ICF/MRs, CBRFs, and Adult Family Homes. Certain rights are common to residents of all these facilities, while others depend on the type of residential facility involved. This section contains a definition for each type of facility, and references to the laws and regulations applicable to each one. The remainder of this chapter summarizes residents’ rights in a number of areas. This chapter is only a summary. For additional information, please refer to the laws and regulations mentioned below, or contact one of the advocacy agencies listed above.

Nursing homes defined
Sec. 50.01(3), Wis. Stats.

A nursing home is a place where five or more persons who are not related to the operator or administrator reside, receive care or treatment and, because of their mental or physical condition, require access to 24-hour nursing services, including limited nursing care, intermediate level nursing care and skilled nursing services.

Legal provisions about nursing homes can be found in Section 50 of the Wisconsin Statutes, and in Chapter HFS 132 of the Wisconsin Administrative Code. For nursing homes certified under the Medicaid program, additional provisions are found in Section 49 of the Wisconsin Statutes, in the United States Code and in the Code of Federal Regulations.

CBRFs defined
Sec. 50.01(1)(g), Wis. Stats.

A community-based residential facility (CBRF) is a place where five or more adults who are not related to the operator or administrator and who do not require care above intermediate level nursing care, reside and receive care, treatment or services above the level of room and board, but including no more than three hours of nursing care per week per resident. Legal provisions concerning CBRFs are found in Section 50 of the Wisconsin Statutes, and in Chapter HFS 83 of the Wisconsin Administrative Code.

ICF/MRs defined
42 USC § 1396d(d)

An intermediate care facility for people with mental retardation (ICF/MR) is an institution (or a distinct part of an institution) whose primary purpose is to provide health or rehabilitative services for individuals with mental retardation. The individuals with mental retardation in the ICF/MR must be receiving active treatment.

Active treatment
HFS 134.13(2) Wis. Admin. Code

Active treatment means an ongoing, organized effort to help each resident attain or maintain his/her developmental capacity through participation in a program of activities. An individualized plan must
be developed for the resident to attain or maintain the optimal physical, intellectual, social and vocational levels of functioning of which s/he is capable.

Legal provisions about ICF/MRs, also known as Facilities for the Developmentally Disabled (FDDs), are found in chapter HFS 134 of the Wisconsin Administrative Code. Lists of residents’ rights are found at HFS 134.31, and in Section 50.09 of the Wisconsin Statutes. For ICF/MRs certified under the Medicaid program, additional provisions are found in the United States Code and the Code of Federal Regulations.

An Adult Family Home is a place where three or four adults not related to the operator reside and receive care, treatment or services above the level of room and board and that may include up to seven hours per week of nursing care per resident.

Regulations for Adult Family Homes are found in sections 50.032 and 50.033, Wisconsin Statutes, and in two chapters of the Wisconsin Administrative Code, HFS 82 (for Certified Adult Family Homes) and HFS 88 (for Licensed Adult Family Homes). Two different lists of resident rights are found at HFS 82.10 and HFS 88.10. Some residents in both types of Adult Family Homes are also protected by Chapter 51 of the Wisconsin Statutes. (For more information on Chapter 51 protections, see the Rights for Consumers of Disability Related Services chapter, pg. 236.)

If you are not certain about your specific rights or the type of residential facility you are dealing with, contact one of the advocacy agencies listed earlier in this chapter.

Other Laws Protecting Rights

Many individuals will be protected not only by the law described here, but also by other laws protecting those who receive certain kinds of services in addition to nursing or personal care. (To learn about the rights available to persons receiving services for mental illness, developmental disability, or substance abuse, see Rights for Consumers of Disability Related Services chapter, pg. 236.) These rights apply not only to residents in the facilities covered in this chapter, but also to people who live in treatment settings such as the State Centers for people with developmental disabilities and the State Mental Health Institutes.

People living in nursing homes or ICF/MRs which are certified under the Medicaid program have additional protections under both state and federal law, some of which are discussed in this chapter.

2Although it is not stated in section 50.09, the residents’ rights listed there also apply to the residents of facilities for the developmentally disabled (or ICF/MRs). See HFS 134.31(1), Wis. Admin. Code.
Specific Rights

Residents generally have the right to:

- Information
- Appropriate services and respectful treatment
- Refuse treatment
- Freedom from abuse and restraints
- Nondiscrimination based on source of payment
- Refuse work benefitting the facility
- Have and manage personal property and finances
- Confidentiality of records
- Meet and communicate with others
- Privacy
- Present complaints and grievances
- Transfer and discharge protections

Note: Not all of these rights apply in all facilities.

Right to Information

Sec. 50.09(4), Wis. Stats.

A copy of each individual’s rights and responsibilities, as well as the facility’s rules, must be provided to each resident and each resident’s legal representative, before or on admission to a nursing home, CBRF, or ICF/MR. This information must also be posted in a prominent place in the facility.

Sec. 50.09(1), Wis. Stats.

Full information about the services included in the facility’s daily rate, and other available services and their cost, must be provided before or at the time of admission and whenever a change is made.

The residents of Adult Family Homes receive similar protections under sections HFS 82.10(5) and HFS 88.10(2), Wis. Admin. Code, and under Sec. 51.61(1), Wisconsin Statutes. (See pg. 246 for AFH regulations and other chapter reference.)

Wisconsin and federal law require a variety of information to be disclosed to nursing home residents, either orally or in an admission agreement, before or at the time of admission. This information forms the core of nursing home residents’ rights while they reside in the facility. Residents should ask for a written copy of the admission agreement and keep it for their future reference.

Nursing home residents’ right to information under federal law

42 CFR § 483.10

Federal law provides specific rights in nursing homes certified for Medicaid. For example, residents in these facilities have the right to:

- be fully informed of their total health status;

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• know the name, specialty, and contact information for the physician responsible for their care;

• be informed in advance of any care or treatment, or any changes in care or treatment that may affect the resident’s well-being;

• be informed of the method of applying for Medicare and Medicaid benefits;

• obtain the names, addresses, and phone numbers of all pertinent state advocacy groups and regulatory agencies. (This should include all three groups listed above.); and

• learn how to file a complaint with the BQA.

Right to Appropriate Services and Respectful Treatment

Adequate and appropriate care within the capacity of the facility must be provided in all nursing homes, CBRFs and ICF/MRs. Full information about treatment and care must be provided to each resident, and each resident must have the opportunity to participate in planning for his/her treatment and care. In addition, residents have the right to choose their own health care provider and pharmacist.

All persons covered by Section 51.61, Wisconsin Statutes, including AFH residents, have a right to “prompt and adequate treatment, rehabilitation, and educational services” appropriate for the individual’s condition. The treatment must be provided under the least restrictive conditions necessary to achieve the purposes of the admission, commitment or placement. Each person must also be informed about his/her care and treatment and the right to participate in treatment planning. In addition, an individual has a right to obtain a second opinion if s/he disagrees with the treatment plan.

Right to Refuse Treatment

Residents in all facilities have the right to refuse treatment. An ICF/MR resident may refuse medications, treatments and rehabilitative therapies. The resident may not be subjected to “drastic treatment, experimental research or behavior modification using aversive stimuli” without giving informed consent and having the opportunity to consult with others. Nursing home residents may refuse treatment and participation in experimental research. They also have the right to complete a living will or durable power of attorney for health care. A CBRF resident may refuse medication unless a court has found
him/her to be incompetent, and cannot be forcibly medicated without a court order. S/he may also refuse any other form of treatment unless it has been ordered by a court. Similarly, Adult Family Home residents cannot be forced to take medications, and may refuse any form of treatment, unless ordered by a court.

**Right to Freedom from Abuse and Restraints**

Nursing home, CBRF and ICF/MR residents have the right to be free from mental and physical abuse, and from chemical and physical restraints, except as authorized in writing by a physician for a specified, limited time period as documented in the resident’s record. Physical restraints may be used in an emergency to protect the resident or others from injury or to protect property.

Department of Health and Family Services (DHFS) rules interpret this provision to mean that nursing home residents may be placed in locked units only if the resident gives consent, a court orders the placement, or in an emergency to protect people or property. In this case, a physician’s order for the confinement must be obtained within 12 hours. Similar rules protect the residents of ICF/MRs. DHFS rules for CBRFs give residents the right to be free from all chemical restraints, and to be free from physical restraints (including confinement in a locked room) except with prior review and approval by DHFS, and written authorization from the resident’s primary physician. (See pg. 246 for AFH regulations and other chapter reference.)

**Right to Nondiscrimination Based on Source of Payment**

Both Wisconsin and federal law prohibit Medicare and Medicaid certified nursing homes from discriminating against residents based on the source of payment. This issue arises because nursing homes receive different payment amounts from different funding sources. Generally, the highest payments come from privately paying residents, the second highest from Medicare, and the lowest from Medicaid. Nonetheless, nursing homes must maintain identical policies regarding transfer, discharge and the provision of services for all individuals regardless of the source of payment.

State regulations guarantee the right to be “free from discrimination based on the source from which the facility’s charges for the resident’s care are paid.” Specifically, a nursing home:

- may not assign a resident to a specific area of the facility on the basis of payment source, unless the resident receives Medicare and only part of the facility is Medicare certified;
must offer the identical package of basic services to all residents, and if enhancements are offered, they must be made available to all residents at an identical cost;

may not require or offer an identification tag or other item that discloses a resident’s source of payment;

may not require a resident to continue to pay privately if s/he becomes eligible for Medicare or Medicaid; and

may not require residents to supplement the Medicaid rate.

Rights Related to Work

Residents have the right to refuse to do work for a nursing home, ICF/MR or CBRF which is not included for therapeutic purposes in that individual’s plan of care. Adult Family Home residents and others covered under Section 51.61 have similar protections. They may also volunteer to do paid work for the facility under certain conditions, if it is of therapeutic value to the resident. (See pg. 246 for AFH regulations and other chapter reference.)

Right to Have and Manage Personal Property and Finances

Nursing home, ICF/MR and CBRF residents have the right to keep and use their personal clothing and effects, and to keep other personal possessions as space permits. Adult Family Home residents and those receiving services for mental illness, developmental disabilities, alcoholism or drug dependency have similar rights, plus the right to secure storage space for their private use. (See pg. 246 for AFH regulations and other chapter reference.)

Residents have the right to manage their own financial affairs, including personal allowances under federal or state programs, unless the resident delegates this right to someone else, or a court restricts it. This right applies to residents of nursing homes, ICF/MRs and CBRFs.

Adult Family Home residents and others protected under Section 51.61 also have the right to manage their own money unless they have a guardian or payee. Service providers may not be payees unless the resident consents or no other suitable payee can be found.

Rights Related to Records

In nursing homes, ICF/MRs and CBRFs, residents’ health and personal records must be kept confidential. Residents have the right to approve or refuse the release of their records to anyone outside the facility, except as authorized by law. (See pg. 246 for AFH regulations and other chapter reference.)
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Right to Meet and Communicate with Others

Residents of nursing homes, ICF/MRs and CBRFs have the following rights:

1. The right to meet privately with visitors.
2. The right to make a reasonable number of phone calls.
3. The right to send and receive sealed mail.
4. The right to meet with and participate in activities of social, religious and community groups.

Note: These rights may be restricted for medical or therapeutic reasons after the need is documented by responsible treating personnel in the resident’s record. Communication with attorneys and public officials may not be restricted. Residents protected under Chapter 51 may challenge the decision and submit a grievance.

Residents of Adult Family Homes are protected under Chapter 51 and have rights that are similar in most respects. (See pg. 246 for AFH regulations and other chapter reference.)

Right to Privacy

Nursing home, ICF/MR and CBRF residents have the right to physical and emotional privacy in treatment, living arrangements and in caring for personal needs including:

- privacy for health care examinations, consultation and treatment. A resident must authorize the presence of any person not directly involved in his/her care; and
- privacy for visits by the individual’s spouse, including the right to live together in the same facility (unless documented as medically contraindicated).
Adult Family Home residents and others covered by Chapter 51 have reasonable protection of privacy in matters such as toileting and bathing. (See note on page 251.) They also have the right not to be filmed or taped unless they give written, informed and voluntary consent.

**Right to Present Complaints and Grievances**

Each nursing home, ICF/MR and CBRF must establish a system for receiving and reviewing complaints and rights violations. Residents have the right to present grievances for themselves or others, to the facility’s staff, administrator, public officials, or anyone else, without fear of retaliation. They may join with others within or outside the facility to work for improvements in resident care. The residents of nursing homes also have the right to start a case in court to protect their rights. Adult Family Home residents and others covered by Chapter 51 have different grievance procedures, but also have the right to bring an action in court. (See pg. 246 for AFH regulations and other chapter reference.)

**Right to Transfer and Discharge Protections**

Residents of nursing homes, ICF/MRs and CBRFs have the right to be transferred or discharged if they wish. If the resident is not seeking a transfer or discharge, the resident has the right to reasonable advance notice of any planned transfer or discharge, and to an explanation of the need for the transfer or discharge and any alternatives to it.

A nursing home, ICF/MR, or CBRF can force a resident to leave involuntarily only for certain reasons specified by law. These include the failure to pay, the need for care not provided by the facility, for medical reasons as ordered by a physician, or to protect the resident or other residents.

In any removal from a nursing home except an emergency:

- the resident and certain others must be given at least 30 days notice of the move;
- a planning conference must be held, including the resident, the guardian, if any, and anyone else the resident invites to review the need for relocation. The purpose of this conference is to assess the effect on the resident, to discuss alternative placements, and to develop a relocation plan;
- a resident cannot be forced to move unless an alternative placement is arranged, except in some cases of nonpayment of charges;
- the resident has the right to counseling about the move;
the resident must have the opportunity to make at least one visit to the potential alternative placement; and

- the resident has the right to receive help in moving.

ICF/MR residents have similar rights before a permanent involuntary removal from the facility.

A nursing home resident may appeal any involuntary transfer or discharge decision by writing a letter to the Bureau of Quality Assurance at the address listed earlier in this chapter. A CBRF resident or his/her representative may ask DHFS to review an involuntary transfer or discharge. The written request must be sent to the DHFS regional office licensing the CBRF within seven days after receiving the discharge notice. (See web site for regional office in your area.) In this case, the resident may not be discharged or transferred until after DHFS completes its review of the decision.

The resident of an Adult Family Home, his/her guardian, service coordinator, and certain others, have the right to written notice 30 days before the resident’s placement is terminated. This 30 day notice is not necessary in an emergency, when termination is necessary to prevent harm to the resident or others in the household.

Residents with developmental disabilities or mental illness who have been committed or protectively placed have discharge and transfer protections under sections 51.35 and 55.06, Wisconsin Statutes.

**Rights Exercised by Guardians**

All of the rights described above may be exercised by the court appointed guardian of incompetent individuals who would be able to exercise the rights themselves if they were not incompetent.

**Resident Death Reports**

If the death of a resident is believed to be a suicide, or related to the use of physical restraint (including a locked room) or psychotropic medication, it must be reported to the Wisconsin Department of Health and Family Services within 24 hours. DHFS then investigates to determine if there were code violations or if action could be taken to prevent any future incident.