

Rights for Consumers of Disability Related Services

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Introduction

Individuals who receive services for mental illness, substance abuse, or developmental disability in Wisconsin have rights specifically created by state law for their protection. These rights are intended to assure that treatment will be provided in the least restrictive setting appropriate for an individual's needs. Furthermore, services are to be provided in a humane, caring environment where respect for each individual will be recognized. In part the law which provides for these rights was enacted to establish standards by which service providers would operate their programs. The law also establishes ways for individuals to enforce their rights when they believe a service provider's actions do not meet legal requirements. The rights are contained in Section 51.61 of the Statutes and an accompanying Administrative Code, HFS 94.

Recently enacted federal law and regulations also provide rights in the areas of freedom from abuse, use of seclusion and restraints, participation in treatment planning and privacy. These measures only apply to certain facilities, such as hospitals and residential facilities for children.

Persons Covered

State law
Sec. 51.61(1), Wis. Stats.

Wisconsin law contains an extensive set of rights for persons receiving services for mental illness, developmental disability, or substance abuse, including persons receiving care and treatment through the state Department of Health and Family Services (**DHFS**), a county Department of Human Services (also called the Department of Community Programs or Unified Services Board), or public or private "treatment facilities". It covers persons who are voluntary clients, civilly committed, under protective placement, or under a variety of forensic commitments.

Sec. 51.01(1g), Wis. Stats.

"Treatment facilities" are defined as any publicly or privately operated facility or unit providing treatment for alcoholic, drug dependent, mentally ill or developmentally disabled persons, including but not limited to inpatient and outpatient treatment programs, community support programs and rehabilitation programs.

Federal Law
42 USC § 290 aa
42 CFR § 482.13

Federal law contains a few rights that apply to everyone in a hospital or community based residential facility for children that receives some sort of federal funding. There are also additional rights pertaining to persons in hospitals that are certified under the Medicare and Medicaid programs.

Other laws protecting rights

Some individuals who are protected by the rights described here are protected by other laws as well. For instance, people who are living in a nursing home or community based residential facility are entitled to rights established by state law for people living in these treatment settings. Licensing and certification standards for a wide variety of community programs and residential facilities contain provisions relating to an individual's rights. These may include specifications for treatment and discharge plans, the right to be free from abuse and neglect, information to be provided upon admission, etc. Also, the federal laws governing Medicaid and Medicare provide additional rights for persons in nursing homes and intermediate care facilities for people with mental retardation (ICF-MRs). *(See Rights in Residential Settings chapter, pg. 244.)*



When someone's rights are being violated under both state and federal law, it is worth considering three factors before deciding which avenue to pursue: (1) how long each governmental office can delay before deciding on a complaint/grievance; (2) what sort of "batting average" other consumers have had in achieving a positive outcome using each alternative strategy; and (3) how difficult the preparation of the complaint/grievance will be under each option.

Specific Rights**Clients have the right to:**

- Information
- Appropriate treatment and services
- Freedom from seclusion and restraints
- Give informed consent prior to receiving treatment
- Refuse work benefitting the facility
- Confidentiality of records
- Manage funds and property
- Communicate with non-residents
- Privacy
- Present complaints
- Protection during discharge and transfer

Right to Information

Sec. 51.61(1)(a), Wis. Stats.
(See also HFS 94, Wis. Admin. Code)
42 CFR § 482.13(a)(1) and (2)

Both state law and federal regulations require that at the time of entering treatment or services, persons must be informed of their rights and the availability of a grievance procedure if they feel their rights have been violated. State law requires the information must be provided in the person's primary language, and in a manner that is meaningful and understandable. The State of Wisconsin has brochures and other information that may be useful in informing persons of their rights.

Sec. 51.61(1)(w), Wis. Stats. Also, when persons enter treatment they must be informed of any responsibility for the cost of this care that they or other family members may have. If they request information about costs, the facility must provide written information about the charges for the services to be provided.

Right to Appropriate Treatment and Services in the Least Restrictive Environment

Sec. 51.61(1)(e),(f) and (fm), Wis. Stats. Under Wisconsin law persons covered by Sec. 51.61 have a “right to receive prompt and adequate treatment, rehabilitation, and educational services” which are appropriate for the individual’s condition. This treatment must be provided under the “least restrictive conditions necessary to achieve the purposes of the admission, commitment or placement.” The person must also be informed about one’s care and treatment and one’s right to participate in treatment planning. If an individual disagrees with his/her treatment plan, s/he has a right to obtain a second opinion.

Second opinion

Lack of funds provision In 1995 the legislature modified the right to treatment and said that it is limited to programs, services, and resources that the county board of supervisors is reasonably able to provide within the limits of state and federal funds and required county matching funds. It is unclear how this so-called “county shield law” will be interpreted in future cases when a person is receiving inappropriate or inadequate services and the county cites a lack of funds as the reason.

In recent years, the Americans with Disabilities Act (**ADA**) has been interpreted as including protections in the area of “least restrictive environment”. This aspect of the ADA may apply in some circumstances to individuals receiving services under Chapter 51 of Wisconsin Statutes, in spite of the limits on county responsibility included in the county shield law. *(For further information on this aspect of the ADA, see ADA: Title II-Government Program and Services chapter, pg. 323.)*

Right to Freedom from Seclusion and Restraints and Unnecessary or Excessive Medication

Seclusion and restraints
Sec. 51.61(1)(i), Wis. Stats.

Clients have a right to be free from physical restraint and seclusion except in emergency situations when the person poses a threat of physical harm to self or others. Use of seclusion or restraint must be authorized in writing by designated, trained staff, should be used for the shortest time possible and only when less restrictive measures are ineffective or not feasible, and must be closely monitored.

42 § USC 290 aa Federal law governing hospitals (for all ages) and community based residential facilities for children, which receive any federal funding, requires that seclusion and restraints be used only to ensure the physical safety of the individual or others. For hospitals, restraints are defined to include a drug or medication used to control behavior or restrict movement, which is not a standard treatment for the

individual's condition. Such use of medication is prohibited in children's community based facilities. Additional requirements regarding who can order seclusion or restraints, monitoring, staffing levels and training are also contained in the law.

42 CFR § 482.13(f)

The federal Medicaid and Medicare regulations for hospitals contain additional standards for use of seclusion and restraints. These include a requirement that less restrictive interventions have been determined to be ineffective, that a physician (or other licensed independent practitioner) see the patient within one hour of initiation of seclusion or restraint to determine appropriateness, that the measures be used for very limited time periods and ended at the earliest possible time, and that staff be adequately trained.

Medications

Sec. 51.61(1)(h), Wis. Stats.

Under state law clients have a right to be free from unnecessary or excessive medication at any time. Medication may not be used as punishment, for the convenience of staff, as a substitute for a treatment program, or in quantities which interfere with the treatment program.

Right to Give Informed Consent

Sec. 51.61(6), Wis. Stats.

Unless a person is under a court order which expressly authorizes involuntary treatment, the client has a right to give informed consent to all treatment and services, including medications.

Definition of informed consent

HFS 94.03, Wis. Admin. Code

The Wisconsin Administrative Code provides a definition of informed consent which requires that the person be given information about the benefits of the treatment, risks and side effects, alternatives and probable consequences of not receiving treatment, that the person be competent, and that the person not be coerced. The person must sign the consent form and be given a copy, upon request.

Minors and persons under guardianship

Sec. 51.61(6) and (8), Wis. Stats.

If the person has been found to be incompetent, the court appointed guardian is generally authorized to consent to treatment. If the client is a minor under age 14 the parent or guardian consents; if age 14 or older, the child and the parent or guardian must consent.

Electroshock and other drastic treatments

Sec. 51.61(1)(i) and (k), Wis. Stats.

Electroshock therapy, psychosurgery and other drastic treatments, and experimental treatment can be used only with the informed written consent of the individual. However, a recent court of appeals opinion held that when an individual has a guardian and is incapable of giving consent to electroshock therapy, a court order can authorize such treatment if the person's mental status presents a life threatening condition, the treatment would be a life saving remedy, all other reasonable alternatives have been exhausted, two physicians recommend it, and the court finds it would be in the individual's best interest.¹

42 CFR § 482.13(b) Federal Medicaid and Medicare regulations governing hospitals also give a patient the right to participate in treatment planning, to consent to or refuse treatment, and to formulate advance directives.

Rights Related to Work and Finances

Payment for work
Sec. 51.61(1)(b), Wis. Stats.

Clients have a right to refuse to do work which would benefit the facility or to perform services for the facility which are not included in a treatment plan for the individual. Under certain limited conditions clients may volunteer to do work which benefits the facility if it is of therapeutic value to the resident. Otherwise clients must be paid for work which they agree to do.

Managing money
Sec. 51.61(1)(v), Wis. Stats.

Clients have a right to manage their own money unless they have a guardian or payee. Service providers may not be payees unless the client consents or no one else who is suitable can be found.

Rights Related to Records

Confidentiality and consent to release

Sec. 51.30(4)(a), Wis. Stats.

Sec. 51.30(5), Wis. Stats.

Sec. 51.30(4)(b), Wis. Stats.

The records of a person receiving services for mental illness, developmental disability or substance abuse are covered by Sec. 51.30 of the statutes and HFS 92 of the Administrative Code. Substance abuse records are covered by a set of federal regulations as well. Under these laws the general rule is that records are confidential and may be released only with the client's informed consent. If the client is incompetent, his/her guardian has the power to consent or refuse to do so. In the case of minors receiving mental health services, the parent, guardian, or person acting in place of a parent may consent. A minor age 14 or older may also consent. However, there are a large number of exceptions to the rule of confidentiality that allow releases without consent, for example, audits, research, emergencies, etc. These are complex and beyond the scope of this brief review.

Access to records
Sec. 51.30(4)(d), Wis. Stats.

Clients also have a right to have access to their own treatment records. The right is absolute after discharge from treatment. It may be limited while the person is still in treatment. If the person finds inaccuracies in his/her records, s/he has a right to request that the record be corrected.

Right to be Treated with Dignity and Respect in a Humane Environment

Sec. 51.61(1)(x), Wis. Stats.

Sec. 51.61(1)(m), Wis. Stats.

All clients have a right to be treated with respect and dignity. Clients residing in an inpatient or residential setting have the right to a humane physical and psychological environment. This includes freedom from arbitrary decision-making, from unreasonable searches and the right to certain forms of expression and socialization.

42 USC § 290 aa

Federal law requires that individuals in hospitals (all ages) and community based facilities for children be free from physical or mental abuse, corporal punishment, and restraint or seclusion used for discipline or convenience.

Right to Have and Manage Personal Property

Sec. 51.61(1)(q), Wis. Stats.
Sec. 51.61(1)(r), Wis. Stats.

Residents have the right to retain and use personal clothing and effects.* Secure storage space for private use must be provided.*

Right to Meet and Communicate With Others

Visitors and phone calls

Sec. 51.61(1)(t), Wis. Stats.
Sec. 51.61(1)(p), Wis. Stats.

Clients have a right to meet with visitors daily.*

Clients have a right to make and receive a reasonable number of telephone calls.*

Mail

Sec. 51.61(1)(c), Wis. Stats.

Clients have a right to send and receive sealed mail, except mail can be inspected, but not read, in the client's presence if contraband or a threat to security is thought to be contained in the mail, as documented in the record. Communication with attorneys and public officials may not be restricted.

Religious worship

Sec. 51.61(1)(l), Wis. Stats.

Clients have the right to religious worship of their choice.

Right to Privacy

Sec. 51.61(1)(s), Wis. Stats.

Clients are to have reasonable protection of privacy in matters such as toileting and bathing.*

Sec. 51.61(1)(o), Wis. Stats.

Clients have a right not to be filmed or taped unless they give written, informed and voluntary consent.

Right to Present Complaints and Grievances

Grievance procedures

Sec. 51.61(5), Wis. Stats.

HFS 94.40-94.55, Wis. Admin. Code

Individuals may enforce their rights through a grievance procedure. The Department of Health and Family Services operates a procedure for residents of state facilities. Each county Department of Human Services (also called Department of Community Programs or Unified Services Board) and each facility providing treatment is required to have its own procedure for its clients. These grievance procedures must be in writing and available to all clients. DHFS Services has developed administrative rules to govern these grievance procedures which include appeal stages at DHFS. These rules include time limits, notification of clients about how the grievance procedure operates, protections against retaliation for using the grievance procedure, and numerous procedural requirements.

Complaints

Persons may also file complaints regarding violations of federal Medicaid and Medicare regulations and violations of state law with the Wisconsin Department of Health and Family Services, Bureau of Quality Assurance (**BQA**). BQA licenses and certifies a wide variety of institutional and community programs; consumer rights are included

*These rights may be restricted for medical or therapeutic reasons after the need is documented by responsible treating personnel in the individual's record. Individuals receiving services under Chapter 51 may challenge the decision and may submit a grievance, as well. (See Sec. 51.61(2), Wis. Stats.)

in the licensing and certification codes. BQA will investigate consumer rights violations to see if a code violation has occurred. It has the power to sanction the program if violations are found. BQA can be contacted at:

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

Court actions

Sec. 51.61(7), Wis. Stats.

In addition, the law enables one to bring a court action to enforce his/her rights under Section 51.61. One can obtain an injunction to cause the person or organization to stop violating his/her rights and can obtain actual monetary damages and exemplary damages of \$500-\$1,000 for each violation if the action was willful and knowing. The individual can also obtain reimbursement for litigation costs and attorney fees.

Criminal sanctions

Secs. 940.295(1)(j)2., 51.30(10), and 51.61(5)(d) & (7m), Wis. Stats.

Finally, there are criminal sanctions for violations of certain patient rights under certain circumstances. These include the right to be free from abuse and neglect, the right to give informed consent to treatment, the right to confidentiality and to have access to one's own records, the right to be free from retaliation or discrimination for using the grievance procedure or communicating with government officials, the Wisconsin Coalition for Advocacy (WCA), or one's lawyer.

Advocacy assistance

The Wisconsin Coalition for Advocacy can provide information and/or advocacy assistance in cases involving consumer rights violations. A wide range of materials have been developed by WCA, including videos, pamphlets, and handbooks on consumer rights. *(See cover page of this guide for contact information.)*

Transfer and Discharge from Inpatient Units

Sec. 51.35(4m)&(5), Wis. Stats.

A person being transferred or discharged from an inpatient psychiatric hospital has the right to necessary transitional services and a proper residential living arrangement. Transfers or discharges may not be made to a homeless shelter unless it is on an emergency basis not to exceed 10 days. A person with a chronic mental illness must be referred to the county department of human services or community programs for an assessment of their need for community-based services. They must also be given assistance in applying for any public benefits for which they are eligible.

Rights Preserved

Sec. 51.59, Wis. Stats. State law provides that unless specifically limited by a court, individuals receiving mental health, developmental disability, alcoholism or drug dependency treatment keep all civil rights enjoyed by other citizens.

Consumer Death Reports

Sec. 51.64, 50.035(5)(b), 50.04(2†)(b), 48.60(5), Wis. Stats. State law requires that if a death of a person participating in any of a wide variety of community or institutional programs is believed to be a suicide or related to the use of seclusion, restraint or psychotropic medication, it must be reported to the Wisconsin Department of Health and Family Services (**DHFS**) within 24 hours. DHFS then conducts an investigation to determine if there were code violations or if action(s) could be taken to prevent similar occurrences in the future.

42 CFR § 482.13(f)(7) Federal Medicaid and Medicare regulations require that all deaths that occur while a hospitalized patient is in seclusion or restraints or where it is reasonable to assume the death is a result of restraint or seclusion must be reported to the Health Care Financing Administration (**HCFA**).

42 USC 290 aa Similar deaths of patients/residents of other facilities must be reported to state regulatory agencies.

1. Professional Guardianship v. Ruth E.J., 196 Wis. 2d 794 (Ct. App. 1995)