

## **Data Practices (Privacy)**

**Course: 133**

**Axis Alternatives 245D BSS**

**Axis Minnesota 245D ISS**

Purpose:

In order to provide high quality, comprehensive services to people served by AXIS, much information is needed. This information takes many forms, such as medical data, social and family histories, professional evaluations, behavioral data, functional skills assessments, performance data for skill training programs, etc. When used appropriately, this information helps team members make well-considered decisions concerning the person's care and treatment.

Much of the information collected and maintained is very detailed and extremely personal in nature. Privacy issues are complicated by the fact that there are many people and many agencies involved in delivery of services for people in licensed programs. Assuring access to people and agencies who have a legitimate need for information while at the same time protecting the individual's right to privacy and control over personal information is our responsibility.

The Minnesota Government Data Practices Act

In Minnesota, the Minnesota Government Data Practices Act, passed in 1979 and formerly called the Data Privacy Law, regulates information handling of all government agencies and private agencies which are licensed by the state. The Act has two main purposes:

- To insure that individuals are given certain rights when an agency collects, stores, and uses information about them, and;
- To facilitate access to the information which should lawfully be disclosed.

Data Privacy and Confidentiality

- Persons receiving services have the right to expect that all personal information regarding them be kept confidential. Safeguarding this right is the foundation for mutual respect between person receiving services and staff.
- AXIS will only collect data that are genuinely needed. This includes data that are mandated by law or applicable rules and regulations and data that are needed to provide appropriate services.
- It is each staff person's responsibility to make sure that the individual information they collect and record is complete, accurate, current, and necessary.
- Data privacy refers to all information on persons receiving services gathered for program purposes, including their presence or status in the program.
- Preserving confidentiality and protecting data privacy refer to both written and verbal exchanges. Discussions and conversations about persons receiving services should occur only in the line of duty.

AXIS requires that all employees protect the confidentiality of persons served by AXIS.

This means that private information concerning an individual is to be given to and discussed by only those staff who have a need to know the information in order to provide the required services and supports to that individual.

Information concerning the individual's history, medical or behavioral status, family situation, etc. is private.

Information concerning an individual in a specific house is not to be disclosed to or discussed by staff in other houses.

This includes informal conversations between staff working in different houses, communications in writing, fax communications and e-mail communications.

If a staff person floats from one house to another, it is their responsibility to inquire about and obtain specific information they will need to serve and assist individuals who live in that house.

Information concerning a specific individual must not be given to persons or agencies outside of AXIS (including family and friends of other individuals) without proper authorization and signed releases.

Disclosure of private information to anyone not actively involved in providing services to that individual, without proper authorization and releases, is grounds for immediate termination of employment.

#### Privacy Rights Notice (Tennessee Warning)

Whenever a person receiving services (or their legal representative) is asked to provide private or confidential information about themselves, they must have information about how that data will be used. The privacy rights notice gives some basic information about routine use of data and data sharing within the program and service delivery system. This notice does not take the place of informed consent and signed authorizations to release specific information.

A privacy rights notice must contain the following components:

- The purpose and intended use of the requested data within the agency or statewide system;
- Whether the individual may refuse or is legally required to supply the requested data;
- Any known consequences for supplying or refusing to supply the data, and;
- The identity of other persons or entities authorized by state or federal law to receive the data.

#### Authorization for Release of Information

In addition to the fairly general privacy rights notice discussed earlier, further safeguards need to be taken whenever specific information is requested.

##### A. Conditions for Release of Information

Before information regarding a person receiving services can be given out, the following must be assured:

- Consent must be given by the person or their legal representative;

- The consent must be informed. Explanations of rights must be given in a manner to assure that the person understands to what they are being asked to consent;
- The consent must be voluntary. There must be no use of coercion or threats in order to get a person receiving services or their legal representative to sign a release of information authorization;
- Person receiving services or their legal representatives can choose to release only part of the requested information, and;
- The "authorization to release information" form can be signed only by the person receiving services or their legal representative.

#### B. The Consent Form

The consent form should:

- Designate who will get the information;
- Specify what information can be released;
- Indicate who will release the information;
- Specify the purpose(s) for use of the information both immediately and in the future;
- Contain a reasonable expiration date, not to exceed one year;
- Contain a statement clearly specifying the person receiving services' right to revoke their permission to release this information;
- If permission is later revoked, the written revocation should be attached to the original consent form or an oral decision to revoke the consent should be clearly noted, dated, and signed on the original consent form;
- Contain a statement that this information is private and protected by the Minnesota Government Data Practices Act;
- Be written in plain English, and;
- Be dated.

#### Informed Consent

Informed consent refers to the person's ability to voluntarily participate in a rational decision-making process regarding treatment or services and the ability to weigh the risks and benefits of the proposed treatment/services after being provided the information. If the person is under guardianship or conservatorship, the legal representative is responsible for giving informed consent.

#### A. Requirements for Informed Consent

Informed consent is generally required for:

- The person's participation in research projects;
- Release of photos, videotaping, and multimedia projects;
- Reviewing Vulnerable Adults/Children incidents with Human Rights Committee;
- Release of personal record information;
- Aversive or deprivation procedures, and;
- Psychotropic medication authorization.

Before it is implemented, the proposed procedure, program, treatment, or use of the information must be explained to the person receiving services or their legal representative in terms they can fully understand.

#### B. Conditions for Informed Consent

The following conditions must be met:

- Consent is freely provided, not under duress;
- The person receiving services' condition is clearly understood by the person or his/her legal representative;
- The reason for the authorization is completely understood by the person giving consent;
- Alternatives to the procedure, program, treatment/service, or use of information (if any) are explained and fully understood;
- Risks and benefits of the procedure, program, treatment, or use of information are explained and fully understood;
- Chances of success of procedures, programs, or treatments are explained and fully understood, and;
- The consent is time-limited and in writing.

#### Emergency Situations

The statute allows for release of information without informed consent when the health or safety of the person is clearly in jeopardy. Documentation required for releasing information under these circumstances includes:

- The date and time;
- The person or agency to whom the information was released;
- The reason for the release of this information;
- Why consent could not be obtained;

- The specific information released, and;
- The name of the person who made the emergency release.

The person should be informed about the emergency release of information as soon as possible. Documentation of this should be made in the person receiving services' record.

#### Access to Records

The law requires that persons receiving services or their legal representatives be allowed access to their records. Persons receiving services are informed on their admission to AXIS of their right to review their records as well as any policies and procedures the program has for this. If a person receiving services is denied access to his/her record, the reason for denial must be documented prior to the person's written request for access. Persons receiving services or their legal representatives can challenge the accuracy or completeness of the information contained in the record.