

Core Values of Home and Community-Based Long Term Care Service Delivery Systems

Principles and Guidelines for Service
Delivery Concepts of

Informed Choice and Informed Consent

White Paper

Ethic of Care

OKDHS ADvantage Administration

Ethic of Care

Informed Choice and Informed Consent¹ **Expected Outcome:** Using the principles of Autonomy, Responsibility, and Accountability as a basis, these practice guidelines for service delivery Ethic of Care clarify fundamental values and promote improved practice of all health care Providers..

¹ “Principles and Guidelines for Informed Choice and Consent: For all Health Care Providers and Planners” New Zealand Department of Health, May 1991.

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DEFINITIONS

Ethic of Care²

- ▶ Ethic of Care based Service Delivery is:
 - The “right service” (appropriate, least intrusive intervention);
 - In the “right amount” (to meet the Consumer’s need);
 - Delivered by the “right Provider” (qualified and competent);
 - To the “right person” (a Consumer that needs service);
 - In the “right setting” (least restrictive, most integrated setting as appropriate to the person’s needs);
 - At the “right time” (a balance between Consumer preference and Provider ability);
 - For “the right price” (a balance between Provider prosperity and payer affordability);
 - To achieve a “right outcome” (Consumer directed/Provider supported).

Informed Choice

- ▶ Informed Choice involves the exchange and understanding of relevant information so that a knowledgeable, reasoned and un-pressured decision can be made by the health care Consumer, or the Consumer’s delegated representative, who has the competence and legal capacity to make such choices:
 - Informed Choice is a pre-condition of Informed Consent
- ▶ Informed Choice emphasizes the autonomy of the individual, and involves respect for the rights of individuals to make decisions about actions that affect them.
- ▶ Consumer Informed Choice is a pre-condition for establishing what care is “reasonable” and “right” to deliver to the Consumer.

Informed Consent

- ▶ Informed Consent is a voluntary and un-pressured agreement by a Consumer to accept a service, treatment, or intervention about which the Consumer is knowledgeable with regard to purpose, expected outcome, mode of delivery, health and safety risk and alternative options.

² Ethic of Care Concepts of Reasonable Care and Legal Risk, OK DHS ADvantage Administration, March 2002.

- ▶ Informed Consent documents the Consumer's Choice to accept, or not accept as the case may be, a treatment, service or intervention and documents that the Consumer's autonomy including the right to make this decision has been honored.
- ▶ Consumer Informed Consent is a pre-condition for establishing that care is "reasonable" and "right" to deliver to the Consumer.

OVERVIEW

Purpose of Informed Choice/Consent Guidelines

- ▶ Help Providers achieve high-quality and appropriate "Consumer centered" health care, of which informed choice and informed consent are essential aspects;
- ▶ Provide guidance for the development, practice, and assessment of informed choice and informed consent policy and practice within all health care services;
- ▶ Identify the ethical requirements involved in informed choice and informed consent and who is responsible for carrying them out.

Informed Choice and Consent Service Delivery Expectations

- ▶ Health care Providers have the desire to assure Consumer Informed Choice and Consent and have the relevant knowledge, skills, and competence to adequately explain options and implications of each to their health service customers;
- ▶ Health care Providers and funders respect the rights of Consumers;
 - Providers and funders proactively educate Consumer/family on consumer's rights and responsibility to be an informed and active participant in care decisions;
- ▶ Consumers, or their representatives, have the desire to actively and responsibly participate in decisions affecting their health care services;
- ▶ Delivery system Funders and their administrative agents commit adequate resources to reimburse Providers and to provide oversight to support Consumer Informed Choice and Informed Consent service delivery;
- ▶ If any of the above, A through D, Informed Choice and Consent Service Delivery expectations is not met, all parties commit resources to correct.

Benefits of Understanding and Application of Consumer Informed Choice/Consent

- ▶ Increases the individual's control over their own life, and increases their autonomy and integrity;
- ▶ Promotes trust and partnership between the health care Consumer and the health care Provider;
- ▶ Encourages individuals to accept responsibility for their health.
- ▶ Minimizes inappropriate care and adverse risk to all parties;

- ▶ Promotes respectful appreciation of each partner’s role and responsibility to achieve appropriate, quality care..

Informed Choice and Consent Infrastructure:

- ▶ Curriculum and training that incorporates concepts and principles of Consumer Autonomy, Responsibility, and Accountability into all long term care service delivery levels: Funder, Provider, and Consumer/family;
 - Provider requirement to educate staff to respect Consumer Autonomy, Responsibility, and Accountability and to follow procedures to appropriately present each Consumer with choices and obtain Consumer Informed Consent for each service;
- ▶ Quality Assurance/Quality Improvement (QA/QI) systems at Funder and Provider levels based on Ethic of Care principle of “informed choice of service” as defined by individual care plans appropriately developed and implemented using “reasonable care” procedures to achieve Consumer directed/Provider supported outcomes;
 - Informed Choice and Informed Consent are parts of a process that is integral to quality health care service delivery;
 - Informed Choice and Informed Consent are NOT to be compartmentalized as isolated events, separate and apart from health service delivery.
- ▶ Ethics committees intrinsic to Funder and Provider QA/QI systems that are charged with the responsibility and empowerment with the authority to:
 - Systematically review situations in which disagreement exists on Ethic of Care principles being followed and to evaluate failures to provide the “informed choice/informed consent” service delivery;
 - Discover reasons for failure; and
 - Make recommendation for policy, procedure and/or personnel changes to prevent future failures.

Criteria for Development of Guidelines

- ▶ Are defined, relevant and attainable;
- ▶ Are subject to continuing evaluation and revision;
- ▶ Respect the individual, including their race, culture, religion, gender, sexual orientation, level of ability and age, regardless of ability to pay or pay source for health care;
- ▶ Facilitate partnership between health service Providers/planners and health service Consumers;
- ▶ Comply with the Federal and State laws and regulations.

PRINCIPLE ONE

autonomy

Autonomy means self-determination. In any individual case, autonomy may be influenced by the cultural values and beliefs of the individual.

The principle of autonomy requires that the right of each person to individual beliefs, desires, values, and goals be respected and safeguarded.

Health care involves an agreed transaction between Providers and Consumers of services. Since the relationship behind the transaction is often an unequal one, special care is required to ensure respect for the autonomy of Consumers.

Respect for autonomy involves seven key points:

1. effective communication
2. adequate information
3. comprehension
4. competence
5. absence of coercion
6. the right to refuse proposed assistance, equipment, or treatments and/or procedures
7. advocacy.

The following guidelines for autonomy are given in the context of each of these key points.

Guidelines for Respecting Autonomy in the Informed Choice and Informed Consent Process

Communication

- ▶ Effective communication is the key to enhancing autonomy. In general, communication is necessary before any proposed assistance, equipment, or treatment, procedure, examination, teaching, or research commences. In ADvantage and State Plan Personal Care Programs, the Uniform Comprehensive Assessment Tool (UCAT) and the Nurse Evaluation provide Consumer health and safety assessment information.
 - The provider gives the consumer communication supports and information needed to facilitate communication and enable the consumer to make informed decisions.
- ▶ In exceptional circumstances, the condition of the Consumer may make communication impossible and there may be no-one authorized or available to consent on the Consumer's behalf. In emergencies, for instance, the primary need is to treat the Consumer. Where the ability to consent is absent or impaired, treatment should be no more than that needed to treat the immediate problems or crisis. Once the emergency is over, the Consumer must be given information about the treatment they received.
- ▶ Providers and/or administrative representatives communicate directly with the consumer unless a legal document or agreement delegates authority to another person to speak and decide on behalf of the consumer:

- Legal documents or agreements that delegate this authority are “durable power of attorney” or “power of attorney”, or a court may delegate this authority to a “curator” or “guardian”.

Information

- ▶ Information must be accurate, objective, relevant, and culturally appropriate.
 - When an intimate examination is believed to be necessary, the health Provider needs to talk this over with the Consumer beforehand, in a way that is culturally sensitive.
- ▶ The information is specific to the individual situation. Any information that may affect the Consumer's decision needs to be provided.
- ▶ The *minimum* information about provision of assistance, equipment, or treatment and/or procedure consists of:
 - The Provider's professional assessment of the condition that the assistance, equipment, or treatment is proposed for;
 - The Provider's professional assessment of the nature, likely effects, risks and benefits of the proposed assistance, equipment, or treatment;
 - The Provider's professional assessment of the expected outcome;
 - The options - including alternative treatments or services, the risks and benefits of each and that the Consumer has the right to seek additional opinions about these and other possible options;
 - Information that will answer the specific questions of Consumers;
 - That the Consumer has the right to refuse the assistance, equipment, services, treatment or procedures.
- ▶ In addition, Providers should supply any information that they think may be relevant to the particular Consumer, since Consumers often do not know what questions to ask.
- ▶ The health care Provider gives the name of the person who will carry out the assistance or procedure and information about this person's credentials, qualifications and experience, and whether they are under supervision.
 - If under supervision, the Provider gives the Consumer the name and credentials of the supervisor and information on how to contact the supervisor.
- ▶ The health care Provider responsible for undertaking the assistance, equipment, procedure or treatment has the primary responsibility for ensuring that adequate information has been provided and that all attempts have been made to ensure that the Consumer understands the information. (The actual process of providing this information may be delegated.)

- ▶ Consumers have the right to decline information if that is their choice, but this decision should not provide justification for a permanent withholding of information from them.

Comprehension

- ▶ The Provider supplies information in a way that makes it accessible for those who need it to make their informed choice.
 - For example in Braille, large print, appropriate foreign language etc.
- ▶ Providers show consideration for the dignity of individual Consumers when discussing assistance, equipment, treatment or procedures.
 - If Consumers feel deprived of their dignity - for instance, being in a state of undress - they will feel at a disadvantage and may not be able to concentrate on the information.
- ▶ Providers make sure that Consumers have adequate privacy during discussion.
 - Lack of privacy can create feelings of disadvantage, and reduce the Consumer's ability to concentrate on and understand the information.
- ▶ Providers allow Consumers time to think about the information and to discuss it with others.
 - Except in emergency situations, the Provider encourages the Consumer to take time to consider and discuss options with others and reflect before reaching a decision.

Competence

- ▶ Except where there is clear evidence to the contrary, the Provider presumes the Consumer is competent to make decisions about assistance, equipment, or treatment and procedures.
 - Treating a person as incompetent or as not having capacity removes their autonomy; consequently, Providers make every effort to support and enhance the decision-making capacities of Consumers.
 - If the Consumer wishes it, consultation with, and inclusion of, the family/friends (or others who can give support to the Consumer) may be a helpful part of this process.
 - A Court adjudicated document confirming Consumer status of “not competent” or that the Consumer “lacks mental capacity” shall be required in each situation in which the Consumer does not participate in an Informed Choice/Informed Consent decision about their health care service and the Provider must make this document part of the Consumer's permanent file.

Absence of Coercion

- ▶ To coerce is to compel by force an action or choice or to constrain by force an action or choice.

- ▶ Providers shall not coerce Consumers.
- ▶ Providers should be alert to actual coercion by others, and to inadvertent coercion that can occur because of the Consumer's circumstances or background.

The Consumer's Right to Refuse Proposed Assistance, equipment, or treatment

- ▶ Implementing informed choice and valid consent means respecting the Consumer's right to refuse assistance, equipment, treatment or participation in teaching activities, and their right to have a change of mind without fear of recrimination, penalty, or the withdrawal of physical and emotional support or other adverse action.
 - In some cases, a referral (in consultation with the Consumer) to another provider may be an appropriate option;
- ▶ The Consumer has the right to refuse treatment or care even when the consequences of such refusal are likely to be injurious or harmful to the Consumer;
 - The Provider is responsible for informing the Consumer of care and treatment options and likely consequences of care and treatment options including the consequences for not pursuing care and treatment options;
 - The Provider documents the information provided to the Consumer and the Consumer's Informed Choice.
- ▶ The Consumer's choice is constrained by the legally permitted options available. The choice is a qualified selection – a choice that is legally permitted by local, state and federal law.

Advocacy

- ▶ Providers inform Consumers of their right to have other people of their choosing present during discussions, and their wishes on this shall be respected. These "other people" may include family/tribal members, a friend, a patient advocate, or someone else who can give support to the Consumer.
- ▶ To protect the interests of the Consumer, there may be some situations in which the health care Provider may advise that some form of advocacy be used.
- ▶ These guidelines recognize that parents and guardians are the natural advocates of their children and have considerable powers of consent on their behalf.
- ▶ Providers shall seek and take in to account children's wishes about assistance, equipment, or treatment options and/or procedures.
- ▶ In situations where communication between Provider and Consumer is limited or impossible, an appropriate interpreter, facilitator or resource person shall be used.

PRINCIPLE TWO

responsibility

The principle of responsibility refers to who is answerable for ensuring that the informed choice process is carried out effectively.

Responsibility for informed choice involves two key points:

1. Individual responsibility
2. Shared responsibility.

Guidelines for Principle 2

Individual responsibility

- ▶ Because of the inequality of the relationship between Providers and Consumers, the Provider has primary responsibility for providing the information that will help a Consumer to make an informed choice.

Shared responsibility

- ▶ Consumers have a responsibility to provide information about their condition and circumstances. This will help to develop and sustain a collaborative relationship between Consumer and Provider, which in turn will produce information that is more relevant for both parties.

PRINCIPLE THREE

accountability

The principle of accountability refers to *how* a person responsible for the informed choice process is answerable.

Accountability for informed choice involves five key points:

1. implied consent
2. general consent
3. spoken consent
4. written consent
5. documentation of the informed choice and consent process.

Guidelines for Principle 3

Implied Consent

- ▶ It should not be assumed that implied consent is informed choice and consent. Examination and/or provision of assistance, equipment, treatment/procedures should be undertaken only with reference to the principles and guidelines within this document.

General Consent

- ▶ A Consumer's general consent for further assistance or treatment/procedures that have not been discussed explicitly with that Consumer is not necessarily informed consent. General consent should not be used as part of the process of informed choice and consent for a specific treatment/procedure.

Spoken Consent

- ▶ Informed spoken consent is acceptable for assistance/procedures/treatments where there is a known level of risk and where a person is conscious and able to call a halt to the assistance/procedure/treatment.

Written Consent

- ▶ Written consent offers some protection to both Consumers and Providers. Its use promotes the Consumers awareness of the issues involved in seeking and making an informed choice. It also alerts the Consumer to the fact that provision of some assistance, equipment or procedures are more significant than others.
- ▶ Written consent must be obtained where either party requests it or regulation, policy or procedure requires it. A copy of the signed and dated consent form/plan is to be made available to the Consumer.
- ▶ Written consent constitutes no more than a "prompt" to both service Providers and Consumers. It is not a full documentation of the process of informed choice.

Documentation of the Informed Choice and Consent Process

- ▶ Documentation is important as a record of the process involved in making informed choices.
 - It involves more than just a written consent or a signed plan of care;
 - The documentation records not only the Consumer's informed choice; but also, confirms that the Consumer comprehended the options and their selection:
 - Documentation records what options were presented to the Consumer and how they were presented; and
 - Records how the Provider reviewed the Consumer's selection; and
 - Records the Consumer's confirmation of selection:
 - Consumer's verbal or nonverbal response indicating understanding of the options prior to committing to one by signature.
- ▶ Documented confirmation of Consumer status of "not competent" shall be required in each situation in which the Consumer is not privy to an Informed Choice/Informed Consent decision about their health care service;
 - Provider/Administrative Agent shall document how (assessment tool, records and processes) the Consumer status of "not competent" was confirmed.
- ▶ If in general terms, documentation should consist of brief notes outlining what information was given to a Consumer, and when this was done. Notes could also specify questions made by the Consumer.
- ▶ The Provider documents Consumer decisions with particular note made of the person's wishes - for instance, if there is a change of mind about options or the continuation of assistance, equipment, or treatment and/or involvement.
- ▶ The Provider makes documentation available for the Consumer to inspect, and copy if they so wish.
 - If another person speaks for or decides on behalf of a Consumer, a legal document that supports this delegation of authority must exist in the Consumer's permanent file.

Glossary of Legal Terms

- durable power of attorney** A [power of attorney](#) that remains in effect if the [principal](#) becomes [incapacitated](#). If a power of attorney is not specifically made durable, it automatically expires if the principal becomes incapacitated. See [durable power of attorney for finances](#); [durable power of attorney for healthcare](#).
See Topic: [Wills & Estate Planning](#) [Retirement & Elder Care](#)
- durable power of attorney for finances** A legal document that gives someone authority to manage your financial affairs if you become [incapacitated](#). The person you name to represent you may be called an [attorney-in-fact](#), [healthcare proxy](#), [agent](#) or patient advocate, depending on where you live
See Topic: [Wills & Estate Planning](#) [Retirement & Elder Care](#)
- durable power of attorney for healthcare** A legal document that you can use to give someone permission to make medical decisions for you if you are unable to make those decisions yourself. The person you name to represent you is called an [attorney-in-fact](#).
See Topic: [Wills & Estate Planning](#) [Retirement & Elder Care](#)
- power of attorney** A document that gives another person legal authority to act on your behalf. If you create such a document, you are called the [principal](#) and the person to whom you give this authority is called your [attorney-in-fact](#). A power of attorney may be "general," which gives your attorney-in-fact extensive powers over your affairs. Or it may be "limited" or "special," giving your attorney-in-fact permission to handle a specifically defined task. If you make a [durable power of attorney](#), the document will continue in effect even if you become [incapacitated](#). For examples, see [durable power of attorney for finances](#); [durable power of attorney for healthcare](#).
See Topic: [Consumer & Travel](#) [Lawsuits & Mediation](#) [Debt & Bankruptcy](#) [Small Business](#) [Wills & Estate Planning](#) [Retirement & Elder Care](#)
- attorney-in-fact** A person named in a written [power of attorney](#) document to act on behalf of the person who signs the document, called the [principal](#). The attorney-in-fact's power and responsibilities depend on the specific powers granted in the power of attorney document. An attorney-in-fact is an [agent](#) of the principal.
See Topic: [Wills & Estate Planning](#) [Retirement & Elder Care](#)

- guardianship** A legal relationship created by a court between a [guardian](#) and his ward--either a minor child or an [incapacitated](#) adult. The guardian has a legal right and duty to care for the ward. This may involve making personal decisions on his or her behalf, managing property or both. Guardianships of incapacitated adults are more typically called [conservatorships](#) .
See Topic: [Caring for Children](#) [Wills & Estate Planning](#) [Divorce & Child Custody](#) [Retirement & Elder Care](#)
- guardian** An adult who has been given the legal right by a court to control and care for a [minor](#) or her property. Someone who looks after a child's property is called a "guardian of the estate." An adult who has legal authority to make personal decisions for the child, including responsibility for his physical, medical and educational needs, is called a "guardian of the person." Sometimes just one person will be named to take care of all these tasks. An individual appointed by a court to look after an [incapacitated](#) adult may also be known as a guardian, but is more frequently called a [conservator](#).
See Topic: [Caring for Children](#) [Wills & Estate Planning](#) [Retirement & Elder Care](#)
- conservator** Someone appointed by a judge to oversee the affairs of an [incapacitated](#) person. A conservator who manages financial affairs is often called a "conservator of the estate." One who takes care of personal matters, such as health-care and living arrangements, is known as a "conservator of the person." Sometimes, one conservator is appointed to handle all these tasks. Depending on where you live, a conservator may also be called a [guardian](#), committee or curator.
See Topic: [Lawsuits & Mediation](#) [Wills & Estate Planning](#) [Retirement & Elder Care](#)