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Applicability: DDSN Regional Centers, DSN Boards and Contract Service Providers

PURPOSE

The purpose of this directive is to implement the Adult Health Care Consent Act. **This directive establishes procedure for offering the opportunity for people to authorize to whom health care information can be disclosed** and ~~to~~ establishes procedures ~~and~~ to identify persons required to give legally valid consent for health care for people, including minors, receiving services from the South Carolina Department of Disabilities and Special Needs (DDSN) when it is determined that a person may be unable to give consent for a specific decision concerning his or her healthcare or participation in restrictive programs or more restrictive placements. This directive is applicable to persons voluntarily or judicially admitted to DDSN and residing in a Regional Center, community residence, or other setting operated by or under contract with DDSN.

PHILOSOPHY

People who have intellectual disabilities or related disabilities, autism, head and spinal cord injuries, or other similar disabilities are fully entitled to all the human and legal rights available to other citizens. They may elect to accept or refuse to participate in any requested activity. Blanket, “all or none” approaches to informed consent may result in denial of dignity and rights of individual persons and shall not occur. **All persons are to be presumed competent.** The

presence of a disability is not in and of itself, a reason to seek a surrogate. Because, however, a person's disability may adversely impact his/her decision process, close scrutiny must be given when consent from a person with a disability is required for a proposed activity or procedure that will:

1. create significant risks or harm,
2. have a potentially irreversible impact, or
3. intrude physically, psychologically or socially on the person

The level of scrutiny required to determine the need to obtain a surrogate must be balanced by the risk of the proposed health care against the person's ability to understand it, e.g. a person may understand the need to take insulin, but may not understand the need to have a particular type of surgery. In all cases where consent is required, the person with a disability must provide the consent, unless there is a legally recognizable exception or substitution, which, under the circumstances, is authorized or otherwise permissible.

DEFINITIONS

Adult Health Care Consent Act: This statute provides a legally recognized method of obtaining valid consent from an authorized person or other consent giver when the person is unable to consent on his/her own behalf. The Act is found at S.C. Code Ann. § 44-66-10 (Supp. 2010).

Authorization to Disclose: A health care provider or the provider's agents must provide to the patient, the opportunity to designate a family member or other individual they choose as a person with whom the provider may discuss the patient's medical condition and treatment plan.

Authorized Person: An "authorized person" is a person listed in the priority of consent givers for minor and adult consents pursuant to S.C. Code Ann. § 44-26-60 and § 44-66-30 (Supp. 2010).

Behavior Support and Restrictive Program: These are defined in DDSN Directive 600-05-DD: Behavior Support Plans.

Consent: As used in this directive, "consent" means the voluntary agreement to proposed health care by a person or authorized person with sufficient mental ability to make an intelligent choice. Consent is an active acquiescence as distinguished from "assent" which is a silent acquiescence. It is a process, not a form. Consent is the dialogue between the person or authorized person and the health care provider, both exchanging information, culminating in their agreeing to the proposed health care. It has three essential characteristics: capacity, information and voluntariness.

Department: "Department" means the S.C. Department of Disabilities and Special Needs, also referred to as "DDSN."

Emergency: In context of the Adult Health Care Consent Act, an “emergency” is a situation where a person is in immediate need of specific health care to prevent death, permanent disfigurement, loss or impairment of the functioning of a bodily member/organ, or other serious threat to the health of the person. The immediate need for such care would override any delay caused by attempting to locate an authorized person to give consent for the proposed health care and/or in locating two licensed physicians to certify the person as unable to consent.

Guardian: A “guardian” is a person appointed by a court to act and make decisions on behalf of another (ward). Sometimes this type of guardianship is referred to as a “guardian of the person.” A guardian generally can make health care decisions on behalf of the ward. The court order appointing the guardian should be read carefully to determine if any limitations have been placed on the guardian. However, a “conservator” is a person appointed solely to conserve and protect the ward’s estate and property. A conservator does not have authority to make health care decisions for the ward.

Health Care: As described in the Adult Health Care Consent Act, “health care” means a procedure to diagnose or treat a disease, ailment, defect, abnormality or complaint, whether of physical or mental origin. It includes the provision of intermediate or skilled nursing care; services for the rehabilitation of injured, disabled, or sick persons; and may include if indicated by this directive the placement in or removal from a facility that provides these forms of care. ~~This definition incorporates traditional medical procedures, both treatment and diagnostic; medications including psychotropic’s; restrictive or adverse behavior support plans; and admissions, discharges and placements of persons receiving the services of the Department.~~

Health Care Provider: The Department is a “health care provider.” The definition includes a person, health care facility, organization, or corporation licensed, certified or otherwise authorized or permitted by the laws of this State to administer health care.

Health Care Professional: A physician or dentist employed by DDSN is a “health care professional.” This definition includes persons who are licensed, certified or otherwise permitted by the laws of this State to provide health care to members of the public. Nurses, nurse practitioners and other departmental personnel may be included as well. The key to the definition is that the person by virtue of a license, certification or permit be able to provide health care to the public, notwithstanding their employment with DDSN.

Minor: A person under the age of 18 is considered a “minor” in South Carolina, excluding a person who has been legally married or emancipated as decreed by the family court, S.C. Code Ann. § 63-1-40 (1) (Supp. 2010). A minor under the age of 16 is deemed unable to give consent for health care by virtue of the status of his/her age. A minor who has reached the age of 16 may consent to any health service except operations, unless the operation is essential to the health or life of the minor in the opinion of the attending physician and a consultant physician, if one is available, S.C. Code Ann. § 63-5-340 and § 63-5-350 (Supp. 2010).

Patient: An individual sixteen years of age or older who presents or is presented to a health care provider for treatment.

Power of Attorney (POA): A person (principal) may designate another (agent) to make health care decisions on their behalf. The agent is often called “attorney-in-fact.” Normally, when the principal becomes incapacitated to the extent that he/she cannot manage his estate, the Power of Attorney would automatically become ineffective. However, if the principal executed a “durable power of attorney” [S.C. Code Ann. § 62-5-501 (Supp. 2010)] with the special provisions that the power becomes effective only upon physical or mental incapacity, then the Power of Attorney would allow the attorney-in-fact to make health care decisions even though the principal might be incapacitated. These Powers of Attorney are also known as “health care power of attorney” or “durable power of attorney.” These documents are complex and should be reviewed by the Department’s legal counsel prior to implementing the provisions of the Power of Attorney.

Surrogate: This term is used to denote a person authorized to consent on behalf of another. Another term used in this context is “consent giver.” Within the meaning of the Adult Health Care Consent Act, a surrogate is a person that fits into one of the listed priorities and can legally make health care decisions for someone unable to consent. Normally, a surrogate provides substitute judgment; that is, be guided by what the person would have wanted when competent. However, when those wishes are unknown, then the surrogate must decide based on the person’s best interest.

Treatment: The broad range of emergency, outpatient, intermediate, and inpatient services and care that may be extended to a patient to diagnose and treat a human disease, ailment, defect, abnormality or complaint, whether of physical or mental origin. Treatment includes, but is not limited to - psychiatric, psychological, substance abuse, and counseling services.

Unable to Consent: This concept is at the heart of the Adult Health Care Consent Act. It means that the person is unable to appreciate the nature of his/her condition and the proposed health care, or to make a reasoned decision concerning the proposed health care, or to communicate his/her health care decision in an unambiguous manner. This definition does not include minors since their inability is based on their age status, irrespective of the fact that the minor may also be cognitively unable to consent.

Behavior support and restrictive program: These are defined in DDSN Directive 600-05-DD: Behavior Support Plans.

I. AUTHORIZATION TO DISCLOSE

Title 42 of the Code of Federal Regulations, relating to public health, and the privacy rule of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) require that the health care provider or agent of the provider offer the patient the opportunity to designate a family member or other individual with whom the provider may discuss the patient’s medical condition and treatment plan.

This opportunity must be provided upon determination of eligibility for DDSN services, admission to any service and/or change in service provider, on a patient information form or by

electronic means and must present the question in bold print and capitalized as follows: **“DO YOU WANT TO DESIGNATE A FAMILY MEMBER OR OTHER INDIVIDUAL WITH WHOM THE PROVIDER MAY DISCUSS YOUR MEDICAL CONDITION? IF YES, WHOM?”**

The authorization to disclose must be offered to all persons and the form will be signed by the patient, guardian or surrogate.

This authorization must specify that the patient may revoke or modify an authorization with regard to any family member or other individual designated by the patient and the revocation or modification must be in writing.

A health care provider may disclose information pursuant to an authorization unless the provider has actual knowledge that the authorization has been revoked or modified.

A health care provider who in good faith discloses information in accordance with an authorization signed by a patient is not subject to civil liability, criminal liability, or disciplinary sanctions because of this disclosure.

The requirement for authorization to disclose is **not** to be construed to:

1. Require a health care provider to disclose information that he otherwise may withhold or limit;
2. Limit or prevent a provider from disclosing information without written authorization from the patient if this disclosure is otherwise lawful or permissible;
3. Prohibit a provider from receiving and using information relevant to the safe and effective treatment of the patient from family members; and
4. Conflict with an individual’s health care power of attorney as provided for in the South Carolina Probate Code.

II. HEALTH CARE CONSENT

Essential Characteristics of Consent

Consent is a legal concept defined by law. It is composed of three elements - capacity, information, and voluntariness. **Capacity** refers to the ability to do something. It is defined with respect to a person’s age, a person’s competence, and the particular situation. Generally, a person below the age of 18 is deemed legally incompetent. Instead, parents, a legal guardian or persons standing in loco parentis (as a parent) are empowered by law to give or withhold consent on the minor’s behalf, S.C. Code Ann. § 44-26-60 (Supp. 2013). Even though a minor’s consent may be given by a substitute or surrogate consentor, the standards governing consent – capacity, information and voluntariness – still apply.

For Adults, those 18 or older, capacity is usually determined by cognitive processes and references to whether the person has the ability to manage his/her affairs with ordinary or reasonable prudence, has demonstrated rational understanding or intellectual comprehension, or has substantial ability to understand and appreciate the nature and consequences of a specific act. Capacity includes the ability to communicate one's choices. Without communication, cognitive processes cannot be determined and, thus, intellectual ability will be negated.

The particular situation where consent is required may dictate the degree of ability necessary to make a decision or consent to an act. A person's ability to consent, must take into account his/her adaptive behavior and measured intelligence. A person with an intellectual or related disability may not be wholly competent or wholly incompetent. These persons may have the capacity in some situations, but not in others. The "situational capacity" approach may frequently result in the same person being found competent, for example, to purchase a shirt, but not the sale of his/her real estate. The "all or nothing" concept should be rejected, thus, allowing the person to experience growth depending on his/her developmental level.

Consent is ineffective unless the person or surrogate consent giver has sufficient **information** upon which to make a rational and informed decision. Information as a prerequisite for consent consists of two elements: the substance of the information and the manner in which the information is communicated. Thus, the focus is on "what" information is given and "how" it is given.

Effective and informed consent requires disclosure of the nature of the proposed health care, its importance and its possible consequences. Facts concerning the care must be revealed, its risks and benefits, the duration of the care, possible discomforts or adverse side effects. Available alternate health care and its potential risks and benefits should also be made known.

This information must be received and understood. The explanation of the proposed health care should be at an appropriate comprehension level and in the language and terms that is likely to be understood. The person or surrogate consent giver must have an opportunity to digest the information or to consult with others.

Voluntariness is normally presumed unless it is shown that the person giving consent was unable to exercise freedom of choice. The person should have sufficient autonomy to make a choice without duress. There must be an absence of overbearing coercion, duress, threats, inducements or undue influence. For persons with an intellectual or related disability, the voluntariness of consent may be suspect because of his/her placement in a facility, his/her lack of experiences for independent action, his/her eagerness to please and be accepted and his/her susceptibility to authority figures. Voluntariness also incorporates the notion that the consent giver is aware that the requested consent may be withheld or if given, it may be withdrawn.

INITIAL PROCESS

Normally, the Service Coordinator, the interdisciplinary team or the attending physician will initially raise the question of a person's competence to give valid consent for health care. The issue would not arise in isolation, but in connection with a proposed or "triggering" health care

treatment or program. For the purpose of this directive, healthcare is grouped into four categories:

1. medical/diagnostic care, studies and procedures,
2. psychotropic medication,
3. restrictive programming/behavior support plan, and
4. admission/placement/discharge.

When health care is proposed for a person, consent must be obtained prior to implementation of the care. This directive sets forth procedures to obtain consent for health care for children and adults. The law designates who may give consent on behalf of children. For adults who are unable to consent, again the law designates who may consent for them, and how a surrogate consent giver is selected. This process is described herein for both emergency and non-emergency situations where consent is needed for health care. Once it is decided who will be the consent giver, whether it is the person himself/herself or his/her surrogate, then this directive describes the process required to obtain valid consent, highlighting the three essential characteristics of consent.

The Service Coordinator and attending physician are the key players in this process. They must take the lead and ensure that the requirements of this directive are met. If the health care is based in traditional medical activities, treatment/diagnostic procedures, or psychotropic medications, then the attending physician must be responsible for the consent process. However, if the required consent involves restrictive programming/behavior support plans or admission/placement/discharge to or from any departmental entity/program, then the Service Coordinator should ensure compliance with this directive. This is a team effort monitored by the interdisciplinary team or key staff. This does not negate a person's rights to privacy under the Health Insurance Portability and Accountability Act (HIPAA).

SURROGATE SELECTION

I. Children

Children (below the age of 18) have only a limited capacity to consent to health care. Unless there are exceptional circumstances, parents should always be involved with their child's health care. There are some special situations where the age of the "minor" is different than 18 years. However, these situations are not encountered with any frequency with persons receiving treatment or habilitation from DDSN. If a person is a minor, decisions concerning his/her health care must be made by the following persons in the following order of priority:

1. legal guardian with court order,
2. parent,

3. grandparent or adult sibling,
4. other relative by blood or marriage who reasonably is believed by the health care professional to have a close personal relationship with the child,
5. other person who reasonably is believed by the health care professional to have a close relationship with the child, or
6. authorized designee of DDSN (i.e., the Facility Administrator **of a DDDSN Regional Center**, Executive Director of a DSN Board, or Executive Director of one of the four DSN Board-like entities (i.e., Babcock Center, Charles Lea Center, Tri Development Center, and Berkeley Citizens)

The above list of priorities is found at S.C. Code Ann. § 44-26-60 (Supp. 2013). This law provides that if persons of equal priority disagree on whether certain health care should be provided, the health care provider or any person interested in the welfare of the person may petition the probate court for an order to determine what care should be provided or for the appointment of a temporary or permanent guardian.

Priority should not be given to a person who the health care provider determines is not reasonably available, unwilling or unable to make health care decisions for the person.

In an emergency, health care may be provided to a child without consent under the same emergency provision applicable to adults, even where the incapacity of the child is based solely on the child's minority.

II. Adults

The Adult Health Care Consent Act, S.C. Code Ann. § 44-66-10 (Supp. 2010), sets forth a process for obtaining consent when an adult is unable to consent. Usually, an adult is presumed competent to make decisions concerning his/her own health care. This presumption may fail, however, in light of the adult's intellectual or related disability in effect at the time consent is needed.

If there is a question concerning a person's competency or ability to make his/her own health care decisions, then the Adult Health Care Consent Act process must be followed to determine competency and to select a surrogate consent giver. A person is unable to consent to health care when he/she is unable to:

1. appreciate the nature and implication of his/her condition and proposed health care,
2. make a reasoned decision concerning the proposed health care, or
3. communicate a decision in an unambiguous manner.

When the question of inability to consent arises, two licensed physicians must examine the person and independently conclude that he/she is unable to give valid consent. The physicians

must certify the inability and give an opinion regarding the cause and nature of the inability, its extent and its probable duration. The opinion becomes part of the person's medical chart. The Adult Health Care Consent Act does not restrict a treating physician from being one of the two certifying physicians. However, **in an emergency** the person's inability to consent may be certified by a health care professional responsible for the care of the person if the health care professional states in writing in the person's medical record/chart that the delay occasioned by obtaining certification from two licensed physicians would be detrimental to the person's health. Once the person is certified as unable to give consent, a surrogate consent giver is selected and recognized. The Adult Health Care Consent Act sets forth a list of surrogates in the order of their priority of selection:

1. A guardian appointed by the court, if the decision is within the scope of guardianship;
2. An attorney-in-fact appointed by the person with power to make health decisions;
3. A person given priority to make health care decisions by another statutory provision, such as when the Department of Social Services (DSS) has taken custody of a vulnerable adult (see item #8);
4. The spouse of the person unless they are separated due to:
 - a) divorce proceeding,
 - b) a written separation agreement, or
 - c) an order of divorce or separate maintenance;
5. A parent or adult child of the person;
6. An adult sibling, grandparent or adult grandchild of the person;
7. Any other relative by blood or marriage who reasonably is believed by the health care professional to have a close personal relationship with the person, or
8. A person given authority to make health care decisions for the person by another statutory provision.

The last priority designation (#8) is designed to address situations of persons unable to consent for needed health care and who have no relatives or none who are willing or able to provide health care decisions. This provision allows DDSN's State Director, or her designee (i.e., the Facility Administrator, Executive Director of a DSN Board, or Executive Director of one of the four DSN Board-like entities (i.e., Babcock, Charles Lea Center, Tri Development Center and Berkeley Citizens) to make health care decisions when no one else stands in a higher level of priority, S.C. Code Ann. § 44-26-50 (Supp. 2013). Priority #8 should not be confused with priority #3. The only time a DDSN designee would make a health care decision would be in the capacity of priority #8.

ASSESSMENT OF ABILITY TO CONSENT

The process of obtaining consent involves a verbal dialogue that is usually reduced to a written consent form. With persons who have an intellectual or related disability, autism, head or spinal

cord injuries, or other similar disabilities, this dialogue must be tailored to the person's intellectual level. Normally, the discussion will focus on the following topics:

1. the person's current condition or problem,
2. the intended or proposed health care,
3. the anticipated benefits of the health care,
4. the potential risks, adverse outcomes or side effects,
5. possible alternative approaches and their risks and benefits, and
6. risks/benefits of not having the proposed health care.

The physician or health care professional must make a judgment about the person's ability to understand the information needed for valid consent. The Adult Health Care Consent Act gives very little guidance other than that specified in the definition of "unable to consent." Assessing the person's ability or inability will necessitate the physician or health care professional asking a series of questions and weighing the answers. Thus, the assessment occurs and is a part of the dialogue required to inform the person of the proposed treatment as stated above. Care must be given to determine if the person is unable to either appreciate the nature of his/her condition and the proposed health care, to make a reasoned decision concerning the proposed health care, or to communicate his/her health care decision in an unambiguous manner.

In traditional medical consent situations, the physician would inform the patient about the proposed treatment, its benefits and risks, then discuss the matter answering all the questions posed by the patient. With intellectual or related disabled persons it may be necessary for the physician or health care professional to be more pro-active and present questions that will elicit a dialogue. By allowing the person an opportunity to express himself/herself, a fair and accurate assessment can be made of the person's ability to consent. There is no formula to assist the physician or health care professional in determining the level of mental capacity needed to consent to specific procedures. **Generally, a high threshold is not necessary to demonstrate a person's understanding of his/her condition, the proposed treatment and its risks and benefits. However, as the proposed health care becomes more risky, intrusive or irreversible, the more scrutiny and inquiry of the person's understanding is required.**

EMERGENCY CONSENT

Health care for the relief of pain and suffering may be provided without consent at any time that an authorized person in the priority list is unavailable.

In emergency situations, health care may be provided without consent if no person on the priority list is immediately available, and in the reasonable medical judgment of the attending physician or other health care professional responsible for the care of the person, the delay occasioned by attempting to locate an authorized person to make the health care decision would present a substantial risk of death, permanent disfigurement, impairment of a bodily member/organ, or other serious threat to the health of the person.

Also, health care decisions on behalf of a person who is unable to consent may be made by a consent giver on the priority list if no consent giver having a higher priority is available immediately, and in the reasonable medical judgment of the attending physician or other health

care professional responsible for the care of the person, a delay occasioned by attempting to locate a consent giver having a higher priority presents a substantial risk or serious threat to the health of the person.

Health care may be provided without consent where there is no person on the list of priority who is reasonably available and willing to make the decision, and in the reasonable medical judgment of the attending physician or other health care professional responsible for the care of the person, the health care is necessary for the relief of suffering, restoration of bodily function or to preserve the life, health or bodily integrity of the person.

ADDITIONAL NOTES

The Adult Health Care Consent Act does not authorize the provision of health care where the attending physician or other responsible health care professional has actual knowledge that the health care is contrary to the religious beliefs of the person, unless the person while able to consent stated contrary intent to the physician or health care professional.

Nor does the Adult Health Care Consent Act authorize health care to a person unable to consent if the attending physician or responsible health care professional has actual knowledge that the proposed health care is contrary to the person's unambiguous and uncontradicted instructions expressed at the time when the person was able to consent.

A person who in good faith makes a health care decision as provided in the Adult Health Care Consent Act is not subject to civil or criminal liability on account of the substance of the decision. A person who consents on behalf of a person unable to consent does not by virtue of that consent become liable for the costs of the health care provided to the person.

The Adult Health Care Consent Act protects the health care provider, DDSN, DSN Boards and DSN Board-like entities (i.e., The Babcock Center, Charles Lea Center, Tri Development and Berkeley Citizens) who in good faith rely on a health care decision made by an authorized person from civil and criminal liability or disciplinary penalty on account of reliance on the decision. This protection also applies in emergency situations.

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To access the following attachments, please see the agency website page "Attachments to Directives" under this directive number.

Attachment 1	Health Care Consent Act Flow Chart
Attachment 2	Instruction Sheet for Health Care Consent Form
Attachment 3	Health Care Consent Form
Attachment 4	Instructions for Authorization to Disclose Protected Health Information
Attachment 5	Authorization to Disclose Protected Health Information Form