

B.2 Informed Consent and Guardianship (Approved by CMS August 2010)

All transition coordinators, as well as their respective team members, will be responsible for providing information to demonstration participants, and to inpatient facility residents who are considering enrolling, and for providing the opportunity for demonstration participants to exercise informed decisions. No decision will be made about transition services without the participant's active involvement; even when there is an authorized agent or surrogate decision maker for health care decisions.

California Code of Regulations (CCR), Title 22, section 72527(b-c), Residents' Rights, requires that a nursing facility document in a resident's health record, a physician's or court's assessment when the resident lacks capacity to make some or all health care decisions. It will be up to the transition coordinator to work with inpatient facility staff to determine who has authorized decision makers and what decisions they are authorized to make.

The state will provide orientation to transition coordinators so that there is consistency in meeting the demonstration's requirements for participants' informed decision-making. Topics will include demonstration and waiver standards, DHCS standards, HIPAA, informed consent, and using the Preference Interview Tool. This orientation is discussed in section B.3.

Each inpatient facility resident is assumed to be legally able to make a decision unless there is a surrogate decision maker who meets the standards outlined in this section. Each individual situation will be treated as a private and unique set of circumstances, and therefore, care will be taken to:

- √ Communicate initially with the appropriate authorized decision makers.
- √ Avoid sensitive communications with those who do not have direct involvement with the resident and his or her health and welfare.
- √ Engage, when necessary, social workers and/or the Long-Term Care Ombudsman whose expertise is adult protection, if there are reasons to suspect abuse or exploitation.

The process for obtaining informed consent of inpatient facility residents must accommodate individual traits and disabilities to ensure that individuals receive and understand the information that is being provided orally or in writing. Considerations are:¹

- Location of the interview
- Time of day
- Primary culture and language of the resident
- Level of language and understanding of words (literacy)

¹ Stay Well and Healthy! Project for adults with traumatic brain injury and other acquired disabilities.

- Adequate time to engage in conversation and to ask to questions
- Clarity and sequence of questions and follow-up discussions
- Opportunity and desire to have (or not have) others present during the information and consent process

The following are principles that will guide the transition coordinator and team members in identifying who can provide informed consent for decisions involving relocation to community living from an inpatient facility.

State Criteria for Informed Consent²

Although this background is primarily focused on individuals residing in an ICF/DD facility, it will be used by the state to guide informed consent procedures for all population groups under this demonstration.³ This section will:

- Provide information about assessing the capacity of adults to give informed consent.
- Describe the California laws, which are applicable under the ICF/DD model, that allow for “legally authorized” representation for adults who lack capacity to give informed consent for health care. This includes the use of “closest available relative” as a consent option that has been reviewed by CMS.

Federal regulations for ICF/DD facilities state that providers must “allow and encourage individual clients to exercise their rights as individuals of the facility and as citizens of the United States...” [42 Code of Federal Regulations (CFR) 483.420(a)(3)]. These rights include the right to be informed of “...medical condition, developmental and behavioral status, attendant risks of treatment, and the right to refuse treatment...” [42 CFR 483.420 (a) (2)].

The “Interpretive Guidelines” under these regulations state that an individual is sufficiently informed when they are aware of the:

- Proposed treatment, procedures to follow, and who will perform the treatment.
- Intended outcomes or benefits.
- Possible risks.
- Ramifications of refusing treatment and the alternatives.
- Voluntary nature of his or her consent.

These principles will be applied to communications with all adult demonstration candidates or participants. California law (Probate Code 4657) states that an adult (18 years or older) is presumed to have the capacity to make health care decisions, give or

² From the Department of Health Services, Licensing & Certification program *Informed Consent Bulletin*, August 2003

³ California Code of Regulations, Title 22, §72528 (Nursing Facility) and/or §73524 (Intermediate Care Facility)

revoke an advance directive, and designate or disqualify a surrogate. Capacity is defined as a person's ability to:

- Understand the nature and consequences of a decision,
- Make and communicate a decision, and
- Understand the significant benefits, risks, and alternatives of a proposed treatment (Probate Code 4609).

It is the position of DHCS that individuals living in inpatient facilities are to be given the support, education, and opportunity to participate in their own health care and treatment decisions to the fullest possible extent. DHCS requires providers to protect the rights of adults to give or withhold informed consent for themselves. Ideally, all adults will be empowered to make their own treatment decisions when given the appropriate support and accommodations. However, it is recognized by DHCS that, even when given the appropriate support, education, and equipment, some individuals will still lack the capacity to make some or all of their treatment decisions. These individuals need to have a surrogate decision maker for all treatment decisions that require informed consent.

In California, the primary physician makes the determination that a patient lacks capacity to make a health care decision (Probate Code 4658 & 4732). The physician makes this determination based on a clinical assessment. This determination should be decision-specific rather than global, because some health care decisions are more complex than others. For example, an individual who has developmental disabilities may be able to understand the risks and benefits and give their own consent for the relatively simple decision to have a tooth removed. But the same individual may lack capacity to understand the risks and alternatives to a more complex decision involving psychotropic medication, and so would need the assistance of a representative in consenting to that treatment. For the consent process, decisions which involve a higher risk of harm require a greater understanding of the potential risks and benefits.

When there is any question of the individual's capacity to understand the implications of a treatment decision that involves a significant risk, it is appropriate to involve an authorized representative to ensure that the individual's wishes and best interests are protected. Each transition coordinator will work with primary care physicians, nursing facility staff, Long-Term Care Ombudsman and others, to identify the person who can legally make health care decisions in each individual situation, if the participant is unable to legally give his/her consent. Transitioning back to community living is a significant life change when the inpatient facility stay has been six months or more. Transition coordinators will research each individual's situation to identify who may provide informed consent.

California Laws Addressing Informed Consent and Authorized Representatives

A legally authorized representative may provide informed consent when an individual lacks the capacity to understand and communicate a health care decision. There are several ways under California law to fulfill the need for what is described in the CCR

Title 22 (76015, 76802) as the “authorized representative” for residents of inpatient facilities.

76015. "Authorized representative" means a person authorized to act on behalf of a client by law, by court order or by a written statement signed by the client, if competent, or signed by another authorized representative of the client. Except in state operated facilities, an authorized representative designated as such by a client or by another authorized representative of the client shall not be a facility owner, administrator, employee, representative or agent of the facility.

76802. Authorized Representative means a person authorized to act on behalf of the client by law, by court order or by a written statement which shall be signed by the client, unless the client has been judicially declared incompetent or gravely disabled. Except in state operated facilities, an authorized representative shall not be a facility owner, administrator, employee, representative or agent of the facility.

Inpatient facilities are charged with determining which arrangement is most appropriate for a specific person. Many factors should be explored during an assessment process. These considerations are:

- The individual’s wishes and needs for representation,
- Who is available to represent them,
- The complexity of the treatment decisions that are involved, and
- The presence of a previously appointed conservator or agent.

Medical records should indicate when an individual has been determined by a physician or court process to lack capacity to make some or all health care decisions. For some adults who have developmental disabilities, the Regional Center Service Coordinator is assigned the responsibility of implementing, overseeing, and monitoring informed consent for treatment decisions. For other adults, someone else may have that responsibility. Each situation will be different. DHCS requires the transition coordinator to work with primary care physicians and nursing facility staff to determine – in each situation – the person who can provide informed consent for transition planning.

It is the position of DHCS, that when an individual lacks the capacity to make a treatment decision for themselves, they should be provided with representation that affords him/her the greatest autonomy while, at the same time, protecting individual rights.

1. Appointment of a Surrogate (Probate Code section 4711 et seq.). An adult who has capacity may designate another adult (orally or in writing) as a surrogate to make health care decisions by personally informing the supervising health care provider. The designation must be promptly recorded in the medical record. Unless the individual specifies a shorter period, the surrogate designated is effective only during the course of treatment or illness or during the stay in inpatient facility when the surrogate designation is made, or for 60 days, whichever period is shorter.

2. Durable Power of Attorney for Health Care and Advance Health Care Directive (Probate Code 4600-4805). A Power of Attorney for Health Care can be completed by an adult who has the capacity to do so. This method could be utilized for individuals who can communicate their wishes, and have the capacity to understand the implications of allowing a designated agent to sign consents on their behalf when they can no longer do so. An advance health care directive is an individual's health care instruction that is written or oral and directs providers regarding a specific health care procedure or treatment option. These documents are executed in advance of lack of capacity.
3. Closest Available Relative [Cobbs v. Grant, 8 Cal.3d 229, 244 (1972) and Barber v. Superior Court, 147 Cal.App.3d 1006 (1983)]. In some circumstances, the "closest available relative" can give informed consent. This method is acceptable if the following conditions can be clearly established:
 - The "closest" available relative means a person who is close in terms of blood or marital ties, and has a caring relationship to the individual. It is a person who is aware of the individual's values and beliefs, and is available to make the needed decisions. It does not refer to physical proximity.
 - The closest available relative is clearly guided by the individual's expressed wishes, or if his or her wishes are unable to be determined, by their best interests.
 - It has been reasonably determined that the individual does not object to the representative arrangement.
 - It has been reasonably determined that no other close relative objects to the representative arrangement, or to the procedure or treatment decision in question.
 - There are no legal barriers to involving the proposed relative representative, such as a restraining order.

If the above conditions are met, the closest available relative may give treatment consents for an individual living in a health facility who cannot give his or her own consents. There is no established hierarchy for whom this relative must be (e.g., mother, brother, aunt).

4. Consent Authority of Regional Centers (Welfare and Institutions (W&I) Code section 4655). California law states that the Director of a Regional Center, or his designee, may give consent to medical, dental, and surgical treatment of a Regional Center client (person with a developmental disability) who is incapable of giving his or her own consent. This authority can be exercised when the individual has no legally authorized representative, or his or her representative does not respond within a reasonable time to a request for consent. An advisory letter from the Department of Developmental Services (DDS), dated January 2002, further clarified this authority to include consents "related to restrictive behavior modification techniques or treatments."

5. Consent Authority of the Medical Director of a State Hospital (Welfare and Institutions Code section 7518). For persons living in state developmental centers and state-operated community facilities (ICF/DD), the law authorizes the Medical Director of that facility to consent to medical, dental, and surgical treatments on the behalf of the individual under the following conditions:
 - The individual is mentally incapable of giving consent and,
 - Either the individual has no legally authorized representative, or
 - The individual has a legally authorized representative who does not respond in a reasonable amount of time to the request for the granting or denying consent for treatment.
6. Petition to the Court (Probate Code section 3200 et seq.). A petition may be filed to establish that an individual lacks capacity to make a specific health care decision, and to designate a person to make that specific decision.
7. Guardianship and Conservatorship (Probate Code section 1400 et seq.). This is a formally adjudicated process, which results in the court appointment of a person (guardian or conservator) who oversees the health care and/or financial matters of another person (ward or conservatee). The power to make health care decisions can be specified in the letters appointing the Guardian or Conservator. If the power is specified, the guardian or conservator has the power to make health care decisions on behalf of the ward or conservatee in good faith and based on medical advice. The Director of DDS can be appointed as a guardian or conservator under certain circumstances for people who have a developmental disability (Health & Safety Code sections 416 and 416.5).
8. Persons with Mental Illness and LPS Conservatorships

A Lanterman Petris Short (LPS) Conservatorship is a process by which the court appoints a person to make certain legal decisions for another person who is gravely ill due to mental illness or chronic alcoholism and unable to take care of him/herself. "Gravely ill" means that, because of the mental disorder or chronic alcoholism, the person cannot take care of his or her basic personal needs for food, clothing or shelter. An LPS conservatorship can last for a maximum of one year at a time and can be renewed in court at the end of the year. This conservatorship often begins when a person's symptoms become so severe that they interfere with self-care and safety, and the person is placed in a locked facility.

Once a Conservatorship is established, the court-appointed Conservator is required to place the Conservatee in the least restrictive alternative placement, as designated by the court. If the Conservatee is not to be placed in his or her own home or the home of a relative, first priority shall be given to placement in a suitable facility as close as possible to his or her home or the home of a relative. The court's order must also indicate those persons to be notified of a change of placement. The fact that a person for whom conservatorship is recommended is not an inpatient shall not

be construed by the court as an indication that the person does not meet the criteria of grave disability.

LPS conservatorships are governed by the Welfare and Institutions Code. Section 5358(d) makes it clear that the Conservator is the only party authorized by the court to make changes in the Conservatee's placement. If the conservator is notified by the person in charge of the facility serving the conservatee that the Conservatee no longer needs the care or treatment offered by that facility, then the Conservator is responsible for finding an alternative placement within seven days. Extensions of up to 30 days or more may be possible in unusual circumstances.

The Conservator may transfer his or her Conservatee to a less restrictive alternative placement without a further hearing and court approval. In any case in which a Conservator has reasonable cause to believe that his or her Conservatee is in need of immediate, more restrictive placement because the condition of the Conservatee has changed so that s/he poses an immediate and substantial danger to himself or herself or others, the Conservator has the right to place his or her Conservatee in a more restrictive facility or hospital. If the change of placement is to a placement more restrictive than the court-determined placement, the Conservator must provide written notice of the change and reason for placement to the court, the Conservatee's attorney, the county patients' rights advocate and any other persons designated by the court.

NOTE: While a formal guardianship or conservatorship may be necessary to safeguard the rights of some individuals due to the complexity of their circumstances, it is the position of the California Department of Public Health (CDPH)-Licensing and Certification (L&C) and DHCS that not all cases require this protection. By its design, this court process has the potential to strip a person of the very rights it seeks to protect by delegating those rights to another person. It is also expensive, cumbersome, and time-consuming, and may not be preferable given the other provisions for consent and decision making that exist in California.

- ✓ This protocol requires that the Long-Term Care Ombudsman be contacted in circumstances where the public (county, state, etc.) or private (court appointed lay person) guardian or conservator has been unavailable or uninvolved with the resident on a regular basis to review and make service planning decisions.

Limitations to Surrogate Decisions

There are situations where the consent of the individual's Conservator or the authority granted under a surrogate decision making arrangement is not adequate to ensure protection of an individual's rights. State law (Probate Code section 4652) prohibits consent by an agent or a surrogate for any of the following without a specific court order:

- Involuntary commitment to or placement in a mental health treatment facility
- Electroconvulsive treatment

- Psychosurgery
- Sterilization
- Abortion

Other situations where court intervention may be necessary concerning consents for adults who are not conserved are when:

- The individual is clearly resistive to the treatment in question.
- There is controversy between family members regarding a health care decision.
- The motives of the surrogate decision maker are questionable.
- The treatment is experimental, punitive, or aversive.

NOTE: Operators and employees of residential or health facilities, in which an individual resides and is receiving care, are prohibited from acting as a surrogate or health care agent for the individual (Probate Code 4659).

Protocol for Identifying Surrogate Decision Makers

Transition coordinators are responsible for identifying every individual's authorized decision maker and the scope of the decision-making authority. If there is a surrogate, the legal considerations above apply and should guide the transition coordinator in each situation. Transition coordinators must develop working partnerships with inpatient facility staff in order to identify surrogate decision makers. Because of privacy and other considerations, outreach to families and surrogate decision makers will be in writing and will include information about contacting the community transition team for follow-up action. Surrogate decision makers, including guardians and conservators, will be contacted using the following protocol:

- ✓ The transition coordinators and team members will furnish brochures and letters to the inpatient facility social worker.
- ✓ The inpatient facility social worker will send letters and brochures to the list of Medi-Cal eligible residents, families and surrogate decision makers.
- ✓ Surrogate decision makers will follow-up if they are interested in learning more about the demonstration.
- ✓ If contact is made, the surrogate decision maker must verify his or her authority with the transition coordinator to make informed consent decisions for a specific resident.
- ✓ If the surrogate is a public guardian or conservator, the transition coordinator must verify that there has been sufficient interaction with the resident to make informed decisions and sufficient protection of individual rights. The transition coordinator is required to involve the Long-Term Care Ombudsman in each situation where the resident has a public conservator for the purpose of making this determination. Consultation with the state project director is also recommended in these situations. Case details must be on file and available to the state and to CMS.
- ✓ If the surrogate decision maker is determined to have authority over placement decisions, the transition coordinator will make arrangements with the decision maker

The resident understands s/he can contact the transition coordinator at any time to arrange for and/or make changes to the services received under the demonstration.

The resident can report suspected elder and dependent abuse by calling the local Adult Protective Services program and/or by contacting the local police department or sheriff. The Resident has made note of these numbers and understands who to call in an emergency.

The resident understands s/he will promptly contact someone who s/he trusts if the resident feels any at risk of failing to get the needed supports and services to allow him or her to stay in the community.

If the resident's request for Medi-Cal services are denied or modified, s/he can appeal by filing a request for a state hearing.

The resident will provide feedback to the community transition team on any surveys or questionnaires about the quality of services under the demonstration and his or her general satisfaction with his or her return to community living.

A *Participant Information Form* documenting the items above is included as Appendix IV. A signed copy of this form documenting that these items were addressed will be kept with demonstration participants' records.

All changes and modifications to the comprehensive service plan will be made according to this informed consent protocol and documented with the participant's (or his/her authorized surrogate decision maker's) signature.