



A Guide to Substituted Consent/ Decision-Making for DSPs

Department on Disability Services

Background



After 2005, law changed:

- ❑ DDS not allowed to provide substituted consent for invasive medical treatments for incapacitated individuals.
- ❑ Gave Habilitation (MR) Court power to appoint advocates that can provide substituted consent for health care decisions, if stated in court order.
- ❑ DDS maintains responsibility to ensure that individuals who need decision-making help have an available decision-maker, and that the type of decision-maker is the least restrictive option.

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Principles of Substituted Decision Making

Appointment of Guardian is the last resort

- Deprives person of **basic rights** to make personal and/or financial decisions. (*limited = specific types, general = all*)
- DDS must present clear and convincing evidence (second-highest standard) to the Court that appointment of a guardian or conservator is needed.
- There are a range of alternatives to guardianship, and DDS must use the least restrictive option.

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Capacity Means...

The mental ability to understand the nature and implication of a decision (that there is a choice to be made) and the information (alternatives) being presented AND the ability to communicate a decision clearly and consistently.

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Capacity vs. Competence

- Under the law, all DC residents are presumed to have capacity to give written informed consent.
- *Capacity* is a clinical term and *competence* is a legal determination, based on clinical evidence.
 - **Six areas of capacity**: (1) Granting, refusing and/or withdrawing consent to medical treatment, (2) Life Planning, (3) Habilitation, day programming and/or work, (4) Treatment other than medical (*i.e.* PT, OT, etc.), (5) Type and place of residence, (6) Finances.
- A court is the main place a person can be declared incompetent, and the judge will specify what decisions the person is incompetent to make. (ex: incompetent to stand trial, incompetent to accept services)

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Assessing Capacity



- Only a mental health professional can formally evaluate capacity via assessment (testing) tools and clinical observation.
- Psychological assessment is a way to clarify someone's capacity to provide consent for themselves, and to determine appropriate type of help.
- *REMEMBER:* *Members of team can and should make informal observations about capacity → should contribute observations to MH professional and should request new formal assessments when needed*

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Examples of Capacity Statement

Example I:

- Due to cognitive deficits consistent with severe mental retardation, Mr. Sample does not evidence the capacity to make decisions on his own behalf in treatment, habilitation, medical care, residential placement, financial matters, and life planning. However, with proper explanation, he does show the capacity to choose the person he desires to make those decisions for him, and could execute a durable power of attorney. Mr. Sample is able to verbally make known many of his wants and preferences. Once these matters are explained at a level appropriate to his understanding, full consideration should be given to any input he is able to give to such decisions.
- Elsewhere in the ISP you may find that Mr. Sample has a nephew who is willing to assist his uncle in any way possible.

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Examples of Capacity Statement

Example II:

- Ms. Exemplar shows the capacity to provide informed consent to decisions on her behalf in treatment, habilitation, residence, financial and life-planning decisions. She shows the capacity to grant, refuse, or withdraw consent to medical treatment. She further could execute a healthcare power of attorney. Care should be taken that matters are explained at a level appropriate to her understanding and that she fully understand the consequences of those decisions.

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MOST INDEPENDENT
(has capacity)

Capacity Scale

LEAST INDEPENDENT
("incapacitated")

Full capacity in **ALL six (6) areas**
Fully independent
May be legally admitted to the system or is receiving services from DDS
Individual capable of making own medical decisions
Advance Health-Care Directive
Durable Power of Attorney (for future)

Capacity in **ALL six (6) areas** with assistance
Individual capable of making decisions and who he/she wants to assist him/her
If capable, Advance Health-Care Directive or Durable Power of Attorney (for future)

Capacity in **MOST of the six (6) areas** with assistance
Individual may be capable of making decisions, choosing person to assist with or to make decisions
If capable, Advance Health-Care Directive or Durable Power of Attorney (for future)
If incapable, Family Consent Affidavit **OR** court appointed MR advocate with medical decision authority **OR** court appointed limited guardian

Does not have capacity in **MOST of the six (6) areas**
May be legally committed
Individual may be capable of making decisions, choosing person to assist with or to make decisions
If capable, Advance Health-Care Directive or Durable Power of Attorney
If incapable, Family Consent Affidavit **OR** court appointed MR advocate with medical decision authority **OR** court appointed limited guardian

Does **not** have capacity in **any of the six (6) areas**
May be legally committed
Decision-making for individual handled by Substituted Decision-Maker
Individual may be capable of choosing SDM
If capable, Advance Health-Care Directive or Durable Power of Attorney
If incapable, Family Consent Affidavit **OR** court appointed MR advocate with medical decision authority **OR** court appointed guardian

LEAST RESTRICTIVE

MODERATELY RESTRICTIVE

MOST RESTRICTIVE



Assess Capacity for Each Decision

- **Each individual & situation is unique, so it's important to:**
 - Match capabilities of individual with situation
 - *What opportunities has the person had to make decisions before?*
 - *Does the person have capacity, but consistently refuses treatment?*
 - *Will their decision be challenged by others? By hospitals or the legal system? How can you help support their decision-making daily?*
 - Identify available alternatives
 - *Any family members that might be able to provide support now or in future?*
 - *Would rephrasing or a less stressful environment help?*
 - Continue to build capacity!!!
 - *Use things the individual likes to build interest!*
 - *Start small, work up to bigger decisions.*
 - ***Remember, just because a person needs help with decision-making doesn't mean they can't contribute to the decisions being made!***

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Planning Ahead...

Planning ahead allows for involvement of the individual:

- Durable Power of Attorneys
- Living Wills or Advance Directives
- ISP discussions about wishes and needs



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Decision-making Options: Circle of Support

Substituted Decision Maker: Any person authorized to make decisions on behalf of another individual for medical treatment recommended by the individual's physician. If the individual's wishes are known, the Substituted Decision Maker should use substituted judgment. If unable to use substituted judgment, and should act in the individual's best interests.

- ❑ Family
- ❑ Friends
- ❑ Neighbors
- ❑ Advocates
- ❑ Host Home Providers (in some circumstances)



USE Substituted Decision Maker Form! (*Copies to DDA file, Healthcare Passport, selected decision maker, Legal file*)

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“Substituted Judgment” vs. “Best Interests”

SUBSTITUTED JUDGMENT – *always first!*

- Requires Substituted Decision Maker/guardian to learn as much as possible about the lifestyle and preferences of the person;
- Uses person’s values/beliefs as a guiding element;
- Substituted Decision Maker/guardian makes decisions that reflect what the person would have decided if he/she were capable of making the decision;
- Substituted Decision Maker/guardian should educate self about range of options and assist in making timely decisions that promote maximum health/well-being of person.

BEST INTERESTS – *only when Substituted Judgment is not possible!*

- Used ONLY when it’s not possible to determine what the person would have done in a given situation. (*i.e.* when Substituted Judgment is not possible)
- Based on what a reasonable person would do.

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Other Options

Government Benefit Programs

- Microboards: <http://www.tnmicroboards.org/index.htm>
- Representative Payee for SSI, SSDI
- Section 8 Housing Voucher

Volunteer Programs

- Church support systems
- Self advocate support groups
- ARC or other volunteer advocates

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Decision-Making Options: Legal Tools

Advance Health Care Directive: Clear and specific instructions prepared in advance by an individual with capacity. Identifies a substituted decision maker to act on their behalf or provides direction for medical care/ treatment in the event that the individual loses capacity in the future.

Court-Appointed Advocate: Appointed by the Habilitation Court and may have authority to provide substituted consent for medical decisions by a specific court order.

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Decision-Making Options: Legal Tools

Conservator: A person who is appointed by court order to manage the individual's money and other assets.

Durable Power of Attorney: A legally enforceable document that allows a person to designate someone else to make decisions. Can be all decisions or can be specific. Both people involved must have capacity and must freely agree to participate.

Guardian: An individual named by court order to make personal decisions for the individual – can include all decisions (general guardian) or specific decisions (limited). Often limited to health-care.

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Decision Making Options:

Health Care Decisions

- **Support** - friend, family member, or advocate to help individual give informed consent.
- **Limited Durable Power of Attorney (DPA) for Health Care:** a legally enforceable document where person states what type of care they would like in certain situations and/or appoints someone to make health care decisions on their behalf.
- **Substituted Decision-Maker:** If there is no DPA and person has been certified incapable of making a particular health care decision, then in most cases, a relative can make the decision for them.
- **Limited Health-care Guardian or Court-Appointed Advocate** if no other options available.

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Decision Making Options:

Financial Issues



- **Support** - friend, family member, or advocate to help individual manage finances.
- **Limited Durable Power of Attorney for Finances:** legally enforceable document authorizing someone to make person's financial decisions and transactions.
- **Trust:** legal arrangement by which one person gives property to another to hold for the benefit of a third person.
- **Representative Payee** agent appointed to receive gov't benefits on behalf of person
- **Conservator/Guardian** if no other options available

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Decision Making Options:

Habilitation or Therapeutic needs

- **Training** to help individual understand options
- **Support** from Family and Friends – informal supports to understand options/make decisions
- **Support** of IDT and ISP team
- **Independent Advocacy** –to support the individual in making decisions and obtaining support (i.e., court-appointed advocate, community advocate, peer advocates)
- **General Guardian**, if no other option

Note: For any restrictive procedures or psychotropic medications - *remember RCRC, HRC, and Psychotropic Med Panel*

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If a Guardian is Needed...

- DSP input can be critical in deciding whether to go forward with a guardianship – observations on daily decisions, about current decision-maker
- Guardianship request packages are submitted to OAG by DDA SC and provider staff → if you collect affidavits from MD/PhD, check for correct name, gender, checked boxes before leaving office.
- DDA submits annual reports to DC Council tracking total time it takes to obtain a guardian. Three stages: (1) from identified need to OAG, (2) from OAG to Court, (3) Court filing to final appointment of guardian. Periodic reports on similar information for Evans Court Monitor.

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Commonly Encountered People

(in the guardianship process)

- **Probate Attorney** – appointed by Probate Court to represent individual for purposes of the guardianship hearing (or any subsequent Probate-related hearing).
- **Guardian *ad litem*** – appointed by the Probate Court to assist the individual in expressing his/her wants and wishes, or when unable to determine individual’s wants, to express best interests of individual
- **Visitor** – social worker appointed to be “eyes and ears of the Court”; provides an independent look at overall situation by gathering information and interviewing involved parties.
 - **Student Visitor (Guardianship Assistance Program)** – social work students earning semester credit with the Court, assigned to review issues raised in guardianship reports, etc.
- **Examiner** – rarely appointed in our cases, but is a psychologist or psychiatrist who provides the Court with an independent evaluation of the individual’s capacity for decision making.

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Special Considerations...

- **If the emergency treatment cannot wait for temporary guardian process, remind treating physician about the “two-professional rule” (D.C. Official Code 21-2212 (c)):**
 - Emergency health care may be provided without consent to a patient who is certified incapacitated under 21-2204 if no authorized person is reasonably available or if, in the reasonable medical judgment of the attending physician, attempting to locate an authorized person would cause:
 1. a substantial risk of death;
 2. the health of the incapacitated individual to be placed in serious jeopardy;
 3. serious impairment to the incapacitated individual’s bodily functions; or
 4. serious dysfunction of any body organ or part.

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After guardians are appointed...

- **Guardians are required to:**
 - ❑ Visit monthly (unless court order says otherwise)
 - ❑ File 2 reports with the Court a year
 - ❑ Maintain consistent communication with provider and DDS – be available and responsive! Should have their orders (“Letters of Guardianship”) available to prove that they have access to individual and records.
 - ❑ Be involved with decision-making consistent with their appointed powers -- using substituted judgment wherever possible, or then best interest standard.
 - ❑ Seek permission of Court to expand powers, or to consent to removal of life support, experimental therapies.
- **If the guardian is not meeting requirements, (or if any other issues), DOCUMENT EVERYTHING and notify SC or OAG.**

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Any questions regarding the Substituted
Consent/Decision-Making procedures
should be directed to:

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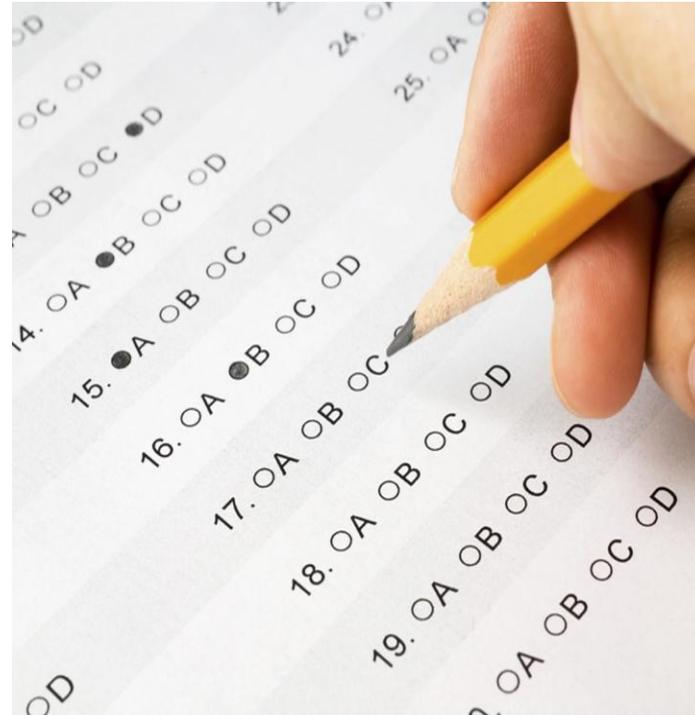
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Now, are you ready for the test?



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