

Too Important to Ignore: Capacity, Consent and Decision- Maker Limitations

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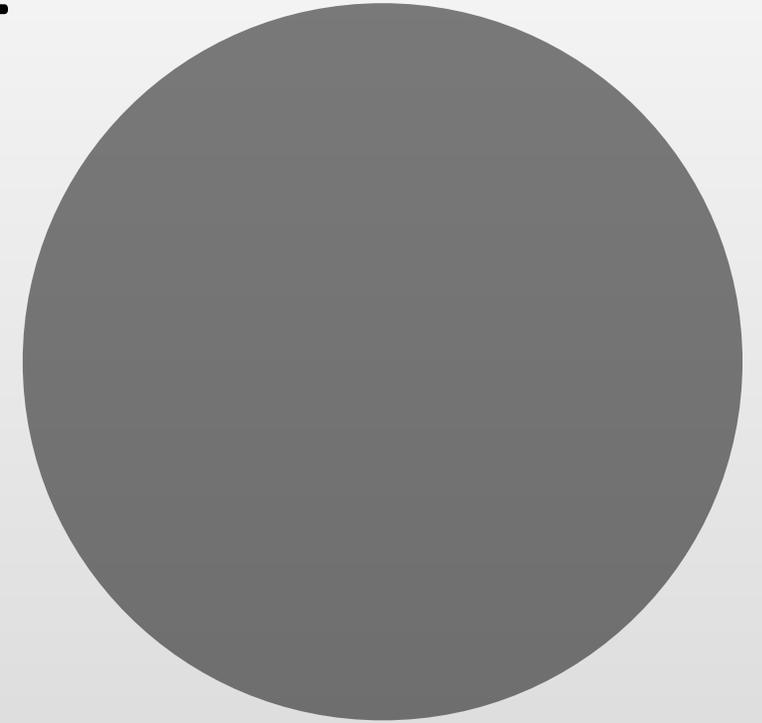
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State of Wisconsin

Board on Aging and Long Term Care

FOCUS 2019 Conference

November 20, 2019



Core concepts

- Once over 18, you are presumed competent to make your own decisions
- WI is not a next-of-kin or “family consent” state
- Need legal authority to act on another’s behalf
- Authority comes from the person or the court

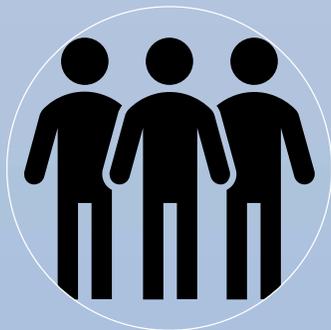


Current formal tools for people who need help with decisions



Release forms

- Person signs release forms authorizing a specific person(s) access to certain kinds of records (health, financial, etc.).
- Some release forms may allow a person to select certain records to be released while retaining privacy over others.
- Some release forms may provide one-time or time-limited access to records, others releases may remain in effect in perpetuity.



Supported Decision-Making agreements

- Person makes all their own decisions. Person identifies area in which they want support, identifies a Supporter(s) to help them gather information, compare options, and communicate their decisions to others.
- The Supported Decision-Making agreement outlines what types of decisions the Person wants support and the role of the Supporter.
- Agreement can be changed or stopped at any time by the Person or Supporter.



Representative payee

The Social Security Administration (SSA) appoints an individual/organization to receive SSI/SSDI benefits for a person who cannot manage or direct the management of their own benefits.

To change a Representative Payee, the Person must complete an application process with the SSA.



Power of Attorney

- Formal legal arrangements that permit others to act on the Person's behalf.
- Powers of Attorney (POA) designate another (agent) individual to make certain decisions (generally health care or financial) on the Person's behalf. POAs can be set up in different ways. Some POAs are activated only when a person is incapacitated.



Limited or Full Guardianship

- Transfers some or all decision-making authority from the Person to a court-appointed Guardian.
- Once guardianship is granted by the courts it is difficult (and costly) to modify or reverse the guardianship; any changes must be made through a formal court process.
- No least restrictive alternatives

Power of attorney



- Legal contract
- Gives chosen person(s)
- Authority to act on one's behalf

Power of Attorney for Health Care

- Adult of “sound mind”
 - Understand nature of the document, powers it conveys, rights and limitations
 - Low standard
 - Judgment call of the 2 witnesses
 - Only time presumed **not** to be of sound mind is if GP
 - Perfect memory not required, could be period of lucidity
- In writing, signed and dated by Principal and witnesses
- 2 disinterested witnesses
- Activated upon incapacity

Incapacity

- Two doctors or 1 doctor and 1 psychologist
- Unable to receive and evaluate information effectively
- or to communicate decisions
- to such an extent that they lack the capacity
- to manage **health care decisions**
- No court determination
- Mere old age, eccentricity or physical disability insufficient

What decisions can the POA-HC agent make?

- Agent can **only** make health care decisions.
- “**Health care**” means any care, treatment, service or procedure to maintain, diagnose or treat an individual's physical or mental condition.
- “**Health care decision**” means an informed decision in the exercise of the right to accept, maintain, discontinue or refuse health care.
- This does not include decisions like who can or can't visit.

Wis. Stat. §155.01, 155.60

Power of Attorney Health Care

- End of life care
- Decide between treatment options
- Consent to surgery
- Admission to nursing home or CBRF

ADMISSION TO NURSING HOMES OR COMMUNITY-BASED RESIDENTIAL FACILITIES

My health care agent may admit me to a nursing home or community-based residential facility for short-term stays for recuperative care or respite care.

If I have checked “Yes” to the following, my health care agent may admit me for a purpose other than recuperative care or respite care, but if I have checked “No” to the following, my health care agent may not so admit me:

1. A nursing home - - Yes No
2. A community-based residential facility - - Yes No

If I have not checked either “Yes” or “No” immediately above, my health care agent may admit me only for short-term stays for recuperative care or respite care.



Incapacity



loss of all rights

Standard for decisions

- Agent must follow expressed wishes of principal as expressed at any time
- If unknown, best interest standard
- Agent *cannot* supplant opinion in place of principal's
- If wishes are truly unknown, agent can make decision in their best interest



"Don't worry - the Power of Dad still trumps the Power of Attorney."

Revocation

- Can revoke at any time
- Signed and dated statement
- Tear it up, deface or burn document
- Express intent in front of 2 witnesses
- Execute new POA-HC

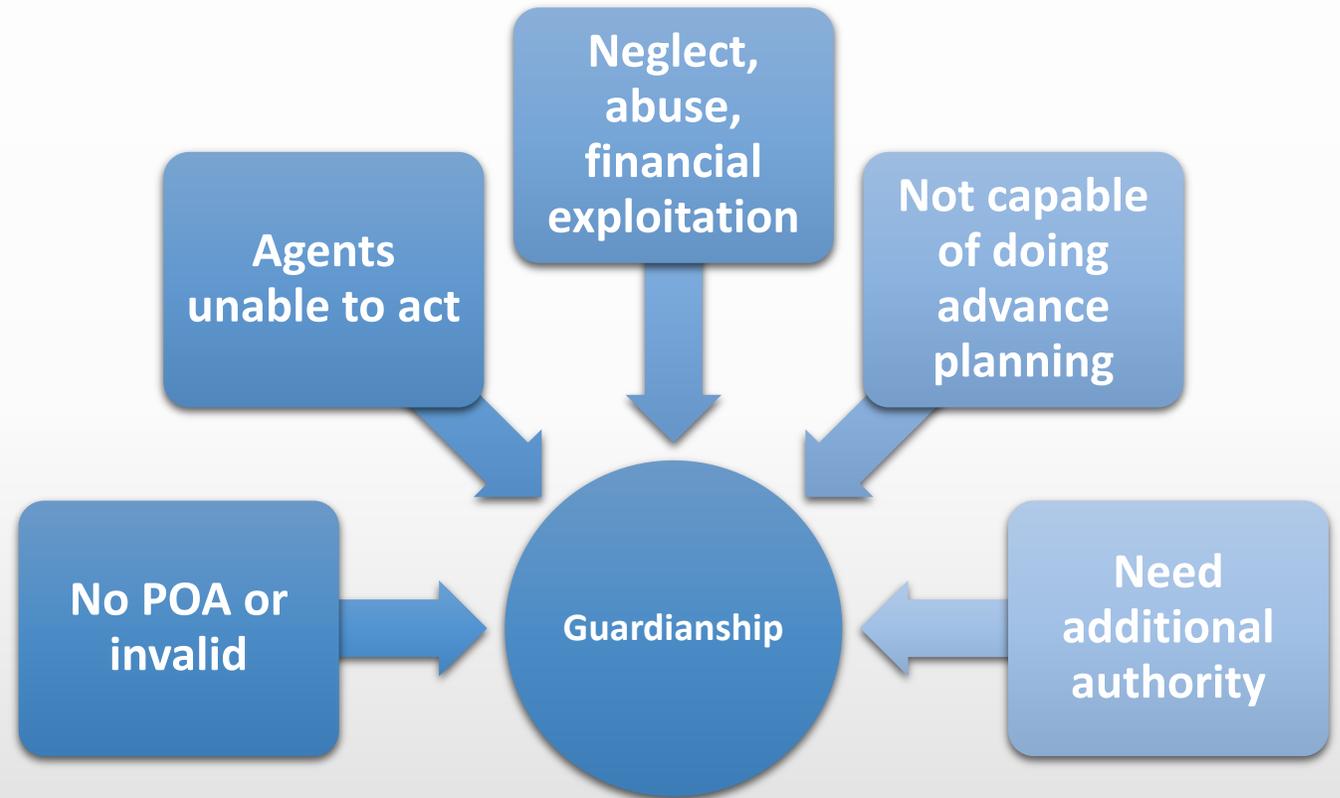
Deactivation

- Principal has regained capacity
- No formal process required
- Can have 2 physicians/physician and psychologist deactivate

Guardianship



Guardianship
is a legal
relationship
created by the
court



Incompetency

- Court determination
- Qualifying impairment
 - Degenerative brain disorder,
 - Developmental disability,
 - Serious persistent mental illness,
 - other like incapacities
- Because of impairment:
 - Unable effectively receive & evaluate information OR make or communicate decisions
 - Can't meet essential requirements of health or safety
AND
 - Can't be addressed by less restrictive measures

General Duties and Powers of Guardian

- Guardian only has authority that has been given to them, anything else is retained by ward
- Guardian can only be granted powers **necessary** to provide for needs that are **appropriate** and **least restrictive**
- Advocate for best interests
- Advocate for ward's rights, including resident rights and patient rights

Guardianship must be

“Least restrictive”

- Places the least possible restriction on personal liberty and the exercise of rights
- Promotes the greatest possible integration of an individual into the community
- Consistent with meeting essential requirements for health, safety, habilitation, treatment, recovery
- While protecting from abuse, exploitation, neglect
- *Wis. Stat. §54.01(18)*



Letters of Guardianship

- Indicate authority and duties of guardian
- Indicate if they are guardian, co-guardian, successor guardian or standby
- Indicate if POA-HC is revoked or limited
 - Note: POA will continue to make decisions if POA remains in effect and not the guardian
- Indicate how co-guardians act together
- Indicate other authority guardian might have that is not in the standard language

STATE OF WISCONSIN, CIRCUIT COURT, _____ COUNTY

IN THE MATTER OF _____ Amended

Name _____ **Letters of Guardianship of the Person Due to Incompetency**

Date of Birth _____ Case No. _____

To:
Address: _____

You are appointed guardian co-guardian successor guardian of the person of the above-named ward.

You are appointed standby guardian and your authority to act is limited to the following time period:
[Starting Date] _____ through [Ending Date] _____.

Power of Attorney for Health Care is revoked. limited as follows: _____

You are issued Letters of Guardianship of the Person with the following powers or limitations:

A. Co-guardians must agree with each other when making decisions on behalf of the ward.
 Co-guardians may act independently when making decisions on behalf of the ward.
 Co-guardians may act independently when making decisions on behalf of the ward only in these limited circumstances: _____.

B. The successor guardian is authorized to exercise powers as previously authorized or modified for this ward.
 See attached Letters dated _____.

C. The guardian of the person has all the duties specified under §54.25(1), Wis. Stats. The ward retains the right to exercise the following right(s) only with consent of the guardian of person to
 (1) consent to marriage.
 (2) apply for an operator's/driver's license.
 (3) apply for a fishing license.
 (4) apply for a license under Ch. 29, Wis. Stats., other than fishing.
 (5) apply for any other license or credential under §54.25(2)(c)1.d., Wis. Stats. Specifically: _____
 (6) consent to sterilization.
 (7) consent to organ, tissue, or bone marrow donation.

D. The guardian of the person is authorized to exercise the following specific powers in full or in part to
 1.A. give informed consent to the voluntary receipt by the ward of a medical examination, medication, including any appropriate psychotropic medication, and medical treatment that is in the ward's best interest, if the guardian has first made a good-faith attempt to discuss with the ward the voluntary receipt of the examination, medication, or treatment and if the ward does not protest.

GN-3200, 05/18 Letters of Guardianship of the Person Due to Incompetency §§54.18, 54.25, 54.46(5), 54.52 and Chapter 54, Wisconsin Statutes
This form shall not be modified. It may be supplemented with additional material.

All Wards Retain Rights!

- Access and communicate privately with the court and governmental representatives
- Provide input into support services
- File grievances including resident or patient rights
- Participate in court and administrative hearings
- Access and communicate with advocacy agencies
- Access, communicate and retain legal counsel

All Wards Retain Rights!

- Give or to withhold consent reserved to an individual under Wis. Stat. ch. 51.
- Exercise any other rights specifically reserved including free speech, freedom of association, and the free exercise of religion.
- Exercise any right not removed
- Petition for review of court orders

Honoring Preferences

- Diligent efforts to identify and honor preferences with respect to:
 - choice of place of living,
 - personal liberty and mobility,
 - choice of associates,
 - communication,
 - personal privacy,
 - choices related to sexual expression and procreation.
- In deciding to act contrary to what the ward wants, consider:
 - ward's understanding of the nature and consequences of the decision,
 - the level of risk,
 - the value of the opportunity to develop decision-making skills,
 - need for wider experience.

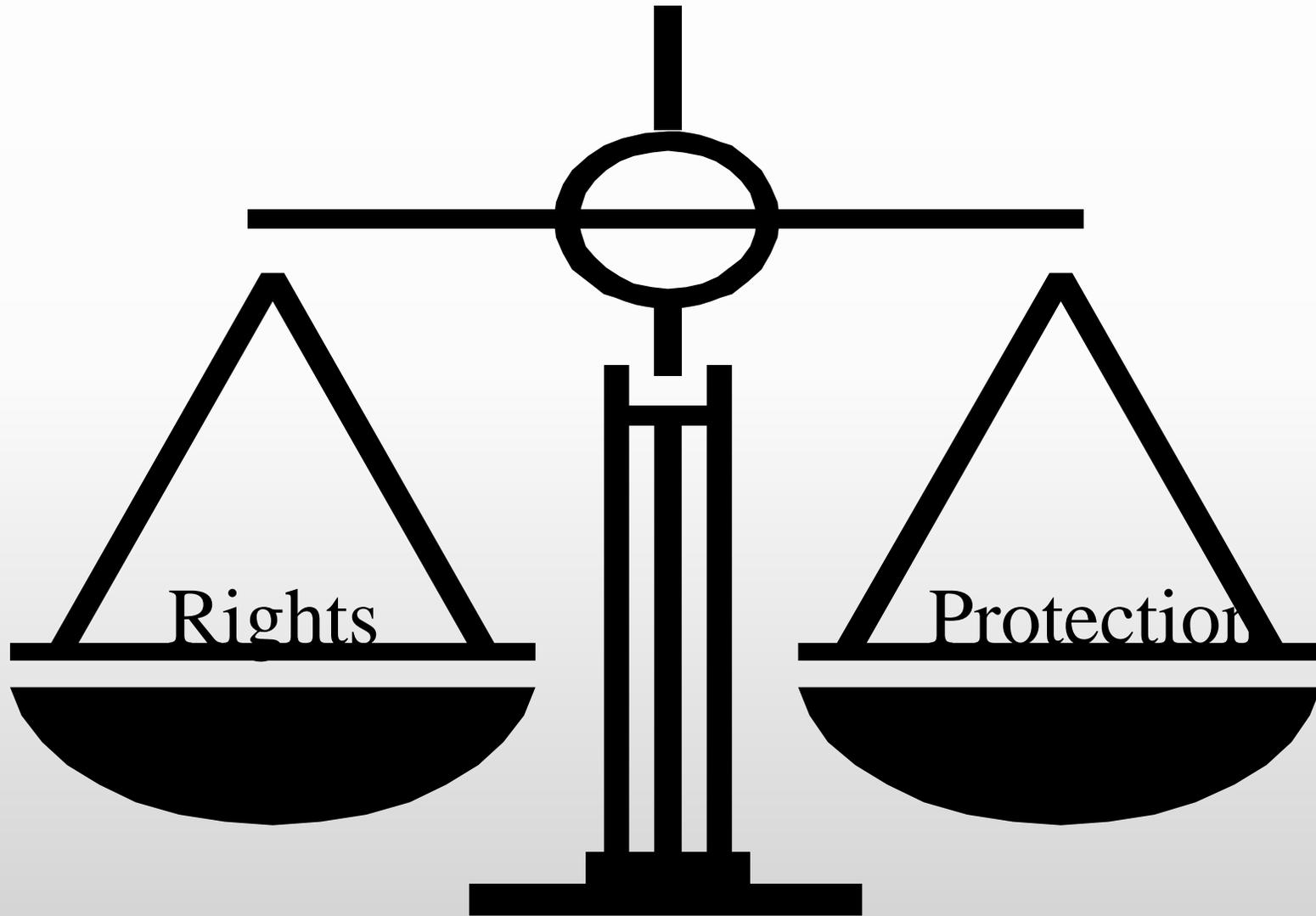
Wis. Stat. § 54.25

Capacity and Consent Recommendations for Addressing Resident Relationships & Other Important Decisions



State of Wisconsin Board on Aging & Long Term Care
Ombudsman Program

Balance



Capacity & Consent

- **Capacity** is the ability to both understand information relevant to a decision and to appreciate the consequences of a decision.

- **Consent** occurs when one person voluntarily agrees to the proposal or desires of another.

• *Source: "Assessment of decision-making capacity in adults;" Jason Karlawish, MD; September 2017.*

Capacity

- Capacity is **single decision-specific**, not a global finding based on cognitive screens or assessments such as MMSE, BIMS, SLUMS.
- Capacity is defined as the ability to both understand information relevant to a decision and to appreciate the consequences of a specific decision.
- Assessing for capacity represents that through conversation, observation, knowledge of medical and social history, staff and others, as appropriate, can attempt to discern what or how much the resident understands about the decision or choice being considered and her or his options regarding the decision or choice.

Components of Capacity Assessment

- **Understanding**: The ability to understand relevant information, the general facts of the decision under discussion;
- **Insight**: The ability to appreciate the situation and its consequences; to appreciate the personal implications of the decision;
- **Reasoning**: The ability to reason; the ability to communicate and express a choice.

- *Sources: Ganzini et al 2005, Lai & Karlawish 2007, Moye et al 2004, Qualls & Smyer 2007; Dr. Veronica Lofaso, excerpts from The IDA Tool 2019.*

Ability to *understand* relevant information:

Ask:

- What is your understanding of your decision about, choice to?
- What do you understand about your options?
- What do you understand about the benefits and risks?
- How do you think you will benefit from the decision?
- What do you think would happen if you decide against the decision to..., choice to...?

Ability to be *insightful* about the decision and its consequences:

Ask:

- Do you believe that it is possible that this decision (or choice, treatment) could benefit you?
- Do you believe that it is possible that this decision (or choice, treatment) could harm you?
- We have talked about other possible options. Can you tell me what they are?
- What do you believe would happen to you if you decided to make the decision or choice contrary to what others would like for you?

Ability to *reason*:

Ask:

- How might your decision affect your life?
- Thinking about your options, can you see how one might work better for you than another? Why or why not?
- Thinking about your decision, what things are important to you?

Ability to communicate and express a choice about the decision:

Ask:

- Have you ever found yourself in a similar situation, or a situation where other people didn't agree with your choice?
- Does this decision fit with your cultural or religious beliefs?
- You've been given a lot of information about your choice. Have you decided what you want to do?

Assessment notes:

- Assessment isn't just completing a checklist. Assessment is part of every interaction and observation.
- The greater the risk in the decision, or the more importance the person attaches to the decision, the more thorough the assessment needs to be AND the more clear the person needs to be in articulating the components of capacity.
- Remember that planning for necessary supports must be part of the assessment process.

Assessment notes:

- Cultural, religious and familial values are often well-preserved, even for persons with advanced dementia.
- A person's understanding of the information presented is influenced not only by values, but also by educational and experiential backgrounds, trauma.
- In addition to the above, the assessment process and the person's responses can often be influenced by many other factors: who is part of the conversation, biases of other participants, undue influence.

Assessment notes:

- Incapacity for many decisions is often reversible. Various illnesses and psychosocial circumstances can affect capacity temporarily. These might include severe physical or psychosocial trauma, illnesses such as UTI and pneumonia, unstable diabetes or cardiac condition, chronic pain.
- For persons who seem overwhelmed with the assessment process, try narrowing options and decisions by offering two at a time as opposed to the whole menu all at once.
- A determination of “incapacity,” such as that within the POA-HC activation process, does not mean an individual lacks capacity for ALL decisions.

Consent is...

- permission
- approval
- agreement
- acceptance
- voluntary
- understanding
- not forced



Random House Dictionary, © Random House, Inc. 2011

Merriam-Webster's Dictionary of Law, © 1996

Consent is NOT...

- Deferring to a Guardian, an Agent under an activated Health Care Power of Attorney and/or family member or friend
- Deferring to a physician or psychologist
- Deferring to caregivers and involved professionals
- Based on the person's actions or responses alone



WI Case Law provides Guidelines for determining a person's ability to consent to sex:

- The person understands the distinctively sexual nature of the conduct...the acts have a special status as “sexual.”
- The person understands that their body is private and that they have the right to refuse.
- The person understands there may be health risks associated with the sexual act.
- The person understands there may be negative societal response to the conduct.

Ability to consent is very complex and has basis in case law. This is a brief overview. A more detailed handout is available on the Ombudsman Program website at longtermcare.wi.gov.

Perspectives of older adults and people with disabilities who are LGBTQ+

- Potential to go back to living in secret
- Fear of not being accepted
- Fear of mistreatment
- Family ties may be severed
- LGBTQ+ elder may age alone
- SAGE and National LGBTQ+ Resource Aging Center are knowledgeable and sensitive resources
- *New: A national advisory council made up of ~50 entities, is building an LEI Assessment Tool (Long-term Care Equality Index) to develop inclusion in long-term care communities.*



“GEN SILENT”



What would you do to survive if you were old, disabled and ill – afraid of discrimination or abuse?

Gen Silent is a LGBTQ documentary from award-winning director and documentary filmmaker Stu Maddux that asks six LGBTQ seniors if they will hide their lives to survive.

They put a face on what experts in the film call an epidemic: gay, lesbian, bisexual or transgender seniors so afraid of discrimination, or worse, in long-term/health care that many go back into the closet.

And, their surprising decisions are captured through intimate access to their day-to-day lives over the course of a year in Boston, Massachusetts.



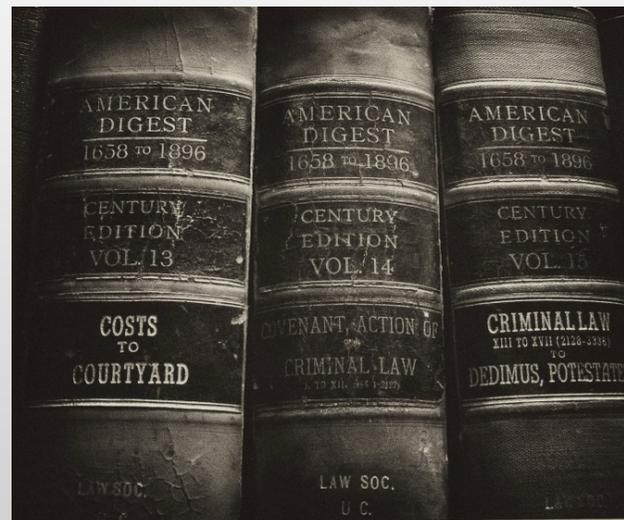
<https://www.youtube.com/watch?v=fV3O8qz6Y5g>

<http://stumaddux.com>

Sexual Contact:

Includes intentional touching of intimate body parts, either directly or through clothing by the use of any body part or object, for the purpose of sexual arousal, gratification, degradation or humiliation.

Paraphrased from 940.225(5)(b)



Allegations of sexual assault

People living in long-term care settings retain all civil rights, unless removed by a judge

- Rights related to access to Law Enforcement
- Rights related to protections afforded by Adult Protective Services
- Access to Victim Assistance or support
- Access to Sexual Assault medical assessment; SANE (Sexual Assault Nurse Examination)

Remember...

- No person can make the decision for another person to have sex.
- Not family, not legal guardian, not an agent under a Power of Attorney.
- Sexual contact is personal—every person must be capable of deciding this for themselves.

Consent must be based on individual assessment of both parties.

Through the assessment of capacity process, the person reveals their ability or inability to consent to sex.



Assessment is NOT:

- Thinking the relationship is OK because neither individual seems bothered, afraid or protesting;
- Thinking sexual relationships are OK as long as they are between two heterosexual, unmarried individuals;
- Thinking sexual relationships are never OK in a long-term care setting, regardless of the abilities or consent of individuals.

Common Questions...

WHAT IF...?

- The person is married or has a life partner?
- The person has dementia? Or has a disability?
- The family insists the person can have sex? Or cannot have sex?
- The person looks happy when with a partner?
- The doctor has determined the person can have sex? Or cannot have sex?
- The person has a guardian or agent under a Power of Attorney?

Assessment is STILL necessary. Consent cannot be deferred to any individual unless ordered by a judge.

Why is assessing for consent important?

- Healthy relationships are critical to quality of life.
- There is a lack of definitive guidance in matters of sex in long-term care.
- The stereotypes and myths that exist regarding older adult sexuality are damaging.
- LTC providers often fear regulatory implications.
- There can be criminal implications if assessment is lacking.
- Sexuality is an emotionally charged, value based, private matter that society often considers taboo when speaking of older or disabled adults.

Regulatory & Legal Safeguards

- Develop policies and procedures
 - Sexuality & Intimacy
 - Sexual harassment
 - Abuse
 - Investigation & Reporting
 - Rights to due process

- Educate ALL staff on Sexuality, Diversity, Unconscious Bias, Policies
 - Conduct periodic audits to assure compliance
 - Closely supervise staff and evaluate competence in policies and caregiving

- Respond appropriately to situations and complaints
 - Do not ignore words, touches, actions, hints, jokes
 - Notice if residents move in with orders for Viagra or other drugs intended to enhance a sexual experience
 - Consult with an ombudsman

Education for Residents

- Frequently inform residents of all rights.
- Discuss that rights must be the foundation for all decisions and actions.
- Clarify the importance of balancing all residents' rights, and note that each resident is responsible to respect the rights of all.
- Ensure that residents are aware of their right to participate in consensual relationships.

Education for Families, Health Care Agents, Guardians

- Resident Rights information must be provided to everyone, to ensure rights are respected, protected and promoted by all who interact with residents.
- Education works toward eliminating people's perceived control in directing resident relationships and in ignoring resident choice in other rights matters.

Education for All Staff

- Education provides staff with the knowledge and tools needed to address situations appropriately and from a person-centered focus.
- Education allows for open discussion about subjects that, for some people, are embarrassing or uncomfortable.
- Education builds team skills and promotes effective interdisciplinary approaches.
- Education leads to acceptance and appreciation.
- Education gives confidence.



Review - Assessing Capacity & Consent: The Process

- What does the resident understand about the situation or the decision she or he wants to make?
- What does the resident understand about her or his options?
- What does the resident understand about the risks and benefits of the situation or decision she or he wants to make?
- Over time and/or with different individuals, does the resident's understanding or choice seem to fluctuate or change?
- *Source: Toolkit for Primary Care: Capacity Assessment; Donna Scott, RN, BScN, CHRP*

Review - Assessing Capacity & Consent

- A determination of “incapacity,” such as that within the POA-HC activation process, does not mean an individual lacks capacity for ALL decisions. *Capacity is a single-decision process.*
- Staff in long-term care settings are really good at assessing for clinical concerns such as changes in blood pressure, cardiac status, skin integrity. Skills are sometimes less developed for assessing psychosocial changes in status, or for capacity to consent to decisions such as participating in sexual relationships.
- Assessing for capacity to consent for psychosocial decisions is a similar process as that for assessing other processes. It’s interactive between the resident and the staff, involves the need to have information about the issue or decision that is the focus, and occurs repeatedly over time to ensure the outcome is favorable.

Resources

❖ Wisconsin Board on Aging & Long Term Care Ombudsman Program:
800-815-0015.

❖ Wisconsin Board on Aging and Long Term Care webpage: longtermcare.wi.gov

The Ombudsman publications section includes:

1. “Resident Relationships Guidelines”
2. Appendix 1 “Intimacy Sexuality History”
3. Appendix 2 “Assessment for Consent”

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