BOARD ON

AGING & LONG TERM CARE

Balancing Rights and Protection: Inclusive Relationships, Sexuality and Consent

State of WI Board on Aging and Long Term Care

State of Wisconsin Board on Aging and Long Term Care

Long Term Care Ombudsman Program

1.800.815.0015

Medigap Helpline

1.800.242.1060

Medicare Part D Helpline

1.855.677.2783

http://longtermcare.wi.gov

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The Relationship of Person-Centeredness

- Emphasis is on supporting vs. fixing
- Builds on strengths vs. losses
- Understands and cares about the personal story of the resident; recognizes contributions: former, present and future
- Promotes a relationship of partnership vs. caregiver/caretaker
- Meaningful information about a resident's story is used when needed to build and support resilience to trauma
- Promotes choice, direction and control, especially in decisions that are impactful or during times of high stress
- Recognizes the balance of both paid and natural supports

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What does a person-centered culture look like?

- Language is inclusive vs. paternalistic; relationships are engaging vs. controlling
- Honors point of view: what is important to a resident from their POV, as well as what is important for a resident
- Listens to the choices residents want to make; accepts and respects the dignity of the whole person
- Incorporates both the internal and external community into resident life and supports
- Provides active support for quality of life vs. merely caring for physical health
- Staff education programs are dynamically centered around resident quality of life indicators, as told by residents

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Socialization, love & belonging are basic needs

FRIENDS

- Include the people we like to be with
- Enjoy a meal with
- Enjoy celebrations with
- Share our fears and heartbreaks with
- Share our stories with
- Spend quiet time with
- Just “be” with

RELATIONSHIPS

- Suggest purposes that go beyond friendship
- May include some aspects of touching, intimacy or sexuality
- May be more private in meaning and appearance
- May include supported decision-making
- May include other supports that are financial, business, legal, health-care-related

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Considerations for persons who are LGBTQIA+

Special considerations for relationships may arise when serving residents who are lesbian, gay, bisexual, transgender, queer or questioning, intersex or asexual or other gender identities and sexual orientations (LGBTQIA+).

- Some persons who are LGBTQIA+ have experienced bias and frank discrimination at some point in their lives and may worry that service providers and others will respond negatively to their identity.
- Your home must recognize and support with sensitivity the reluctance to reveal LGBTQIA+ identity for fear of abuse, mistreatment or disrespect.
- Family ties may be severed; a life partner or spouse may be introduced in a manner that does not reveal or honor the relationship.
- Your home must honor all resident rights, all relationships, and strive to make all residents comfortable regardless of sexual orientation or gender identity, so that all residents are treated with dignity and respect. This includes how intimate care is provided for bathing and toileting, respect for personal choice in dress, dignified responses to any requests for accommodation. Your home should be aware of how a person identifies and should not use certain terms unless the individual you are referring to explicitly identifies with it.

Source: SAGE & National Resource Center on LGBT Aging "Facts on LBGT Aging"

Cultural concerns for persons who are LGBTQIA+

Per SAGE:

- 82% of older adults who identify as LGBTQIA+ report having experienced discrimination and harassment, much of which has been condoned by societal norms, laws and policies. This same number reported at least one incidence of victimization.
- After decades of discrimination, LGBTQIA+ older adults are less likely to utilize community services such as meal sites, clinics and senior centers.
- *"Nearly 1 in 4 transgender people report having to teach their health care provider about transgender issues in order to receive appropriate care…"*
- *"88 percent of LGBT older people say they would feel more comfortable with long-term care services if they knew staff had been specifically trained about the needs of LGBT patients."*

Source: SAGE & National Resource Center on LGBT Aging "Facts on LBGT Aging"

Social isolation among persons who are LGBTQIA+

Per SAGE:

- Older persons who are LGBTQIA+ are more likely to live alone, have fewer circles for social and emotional supports and networks, circumstances that are often attributed to poor physical, mental and emotional health.
- *"59 percent of LGBT older people report feeling a lack of companionship and 53 percent report feeling isolated from others."* 39% of LGBTQIA+ older adults report having had suicidal thoughts.

Source: Source: SAGE & National Resource Center on LGBT Aging "Facts on LBGT Aging"

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Risks & challenges related to relationships

- Sexual relationships without consent or with questionable consent
- Visitors or others who interfere with care, resident wishes, choices, quality of life
- Visitors or others who seek to exploit or abuse
- Visitors who exert their own will over a resident's
- Staff who cross boundaries with residents or their families

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Sexuality & Intimacy

sexuality

[sek-shoo-**al**-i-tee *or, especially British*, seks-yoo-] SHOW IPA

See synonyms for *sexuality* on Thesaurus.com

noun

1. sexual character; possession of the structural and functional traits of sex.
2. recognition of or emphasis upon sexual matters.
3. involvement in sexual activity.
4. an organism's preparedness for engaging in sexual activity.

intimacy

[in-*tuh*-m*uh*-see] SHOW IPA

See synonyms for *intimacy* on Thesaurus.com

noun, plural **in·ti·ma·cies.**

1. the state of being intimate.
2. a close, familiar, and usually affectionate or loving personal relationship with another person or group.
3. a close association with or detailed knowledge or deep understanding of a place, subject, period of history, etc.:
   an intimacy with Japan.
4. an act or expression serving as a token of familiarity, affection, or the like:
   to allow the intimacy of using first names.
5. an amorously familiar act; liberty.
6. sexual intercourse.
7. the quality of being comfortable, warm, or familiar:
   the intimacy of the room.
8. privacy, especially as suitable to the telling of a secret:
   in the intimacy of his studio.

DICTIONARY.COM

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Let's talk about sex…

When?
- When moving in
- At resident council meetings
- One-to-one
- In care conferences, with consent*
- As needed regarding resident rights, including rights to intimate or sexual relationships

What?
- Rights to intimate or sexual relationships
- Ability to consent
- Relationship controls & authority of others
- Preferences & boundaries
- Relationship intent ("just friends," "not interested," "just looking" "No" and other words or gestures of importance

With who?
- Always with the resident(s)
- With consent*, with decision-makers, family, close others
- Staff

How?
- Build rapport
- Be prepared and comfortable with the topic
- Listen more than talk

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Sexuality is part of our humanity, regardless of age and ability

- Sex for some can be a way of belonging, avoiding isolation, feeling “human” physically and intimately connecting with others.
- It’s a stereotype to think that older adults lose interest and the ability to engage in sex once they reach late adulthood. Age does not necessarily change the need or desire to be sexually expressive or active.
- Older adults and persons with disabilities have the same basic human need to be in close relationships as do persons who are younger or those without a disability. For both, social networks of people can be small, or can diminish with aging.
- Attempts to disallow any type of relationship must be based on cause and facts, not on history that may no longer be relevant, or on the personal objections or opinions of others.
- Being sexual can be an important part of living a full and meaningful life.

“A good life depends on the strength of our relationships with family, friends, neighbors, colleagues and strangers.” David Lammy

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About Capacity

All persons are assumed to have capacity until, by process and assessment, they are found to lack capacity.

A particular diagnosis does not automatically indicate incapacity.

Capacity for decisions related to relationships is a different function from capacity related to decisions about health care decisions, financial decisions, legal decisions.

A low BIMS or MMSE score, even a finding of incapacity for health care decisions or having been deemed incompetent, do not automatically mean a person lacks consent for a particular relationship.

Assessing for the potential capacity to consent to sex*

- Assessing for capacity to consent is about conversation and observation, not based on a checklist.
- Conversations should start, less formally, at the time of moving in, and may occur periodically thereafter, based on need.
- While decisions about sex have a component of risk, conversations and decisions should be resident-driven vs. based on avoidance of conflict or regulatory vigilance.
- The goal of assessment is to allow the person to reveal their ability or inability to consent to sex, to determine how much risk is acceptable.
- If the ability to consent is unclear, the process of assessment continues. Such an important and complex personal decision requires a personalized, comprehensive, ongoing assessment.

**This does not constitute a legal or medical designation of consent, but serves only to help providers determine potential capacity for a specific situation related to a sexual relationship.*

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About Consent

The discussion in an opinion filed on November 6, 1997, Wisconsin Court of Appeals case State v. Smith, provides clear guidance to the meaning of the phrase, "capacity to appraise personal conduct."

In the document, "Guardianship of Adults" (DHS 2011) attorney Roy Froemming's analysis of State v. Smith was used to suggest four guidelines on which to base an assessment to determine a person's ability to consent to sexual contact:

1. The individual must understand the distinctively sexual nature of the conduct;

2. The individual recognizes their body is private and that s/he has the right to refuse to engage in sexual activity; the individual recognizes their partner's right to say no at any time;

3. The individual recognizes the sexual contact may create possible health risks and physical consequences;

4. The individual understands there may be negative social or societal response to the sexual behavior.

Ability to consent is very complex and has basis in case law. This is a brief overview, and not intended as legal advice. A more detailed handout is available from the Ombudsman Program at http://longtermcare.wi.gov

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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.

Stereotypes and myths that exist regarding older and disabled adult sexuality are damaging and disrespectful.

Long-term care providers may fear regulatory implications.

There can be criminal implications if assessment is absent or lacking.

Sexuality is an emotionally charged, value based, private matter that our society often considers taboo when speaking of older or disabled adults.

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Consent is Not:

Deferring the decision to have a sexual relationship to a Guardian, an Agent under an activated Health Care Power of Attorney and/or family member or friend

Deferring the decision about a sexual relationship to a physician or psychologist

Deferring the decision about a sexual relationship to caregivers and involved professionals

Based on the person's actions alone: no such thing as "It's OK if both partners seem happy"

Disallowing any sexual relationship, regardless of capacity to consent, in order to avoid regulatory or personal scrutiny

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Acts that are sexual assault regardless of "Consent"

***§940.225(2)(g)(j) Wis. Stats.**

Adult having sexual contact with a child.

Employee of a nursing home, CBRF, adult family home or a state treatment facility having sexual contact with a resident/patient.

Any person who performs or claims to perform therapy including social workers, physicians, nurses, counselors or psychologists, having sexual contact with a client.

Any person having sexual contact with someone whom they know is unconscious, who is physically unable to communicate a refusal, or who is under the influence of an intoxicant or is suffering from a mental illness or defect to the extent it impairs capacity to appraise personal conduct.

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The benefits of education for all: residents & staff

- Talk with residents at the time of admission, at resident council meetings, and individually as needed regarding resident rights, including rights and responsibilities related to different types of relationships.
- Education should be provided to all staff with onboarding and ongoing as needed regarding intimate and sexual relationships in the homes where your residents live.
- Education provides staff with the knowledge and skills needed to address situations appropriately and with sensitivity; it also allows for open discussion without judgment or bias.

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The benefits of education for all: families & decision-makers

- Education should be provided to families, health care agents and guardians in relation to their *perceived* power or control in directing resident relationships.
- Family members or legal decision makers do not have the authority to restrict sexual relationships when the resident is assessed to have the capacity to consent to the relationship.
- Agents under an activated Power of Attorney are responsible to make health care decisions based on the preferences of the principal. Guardian's powers and authorities are dependent upon the terms of the order provided by the court. This may or may not include authority related to intimacy and sexuality.

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Rights, Respect & Response

- **Recognize** (rights, expectations, point of view – residents and yours)
- **Request** (information about satisfaction and expectations, concerns large or small – don't wait for a concern to emerge before asking)
- **Respond** (listen more than talk, be objective, consider point of view)
- **Resolve** (collaborate on a resolution, consider dignity of risk, act when action is required)
- **Resource** (know who or what else may be available to achieve resolution, don't be afraid to reach out – call an ombudsman)
- **Reflect** (check back – more than once - to make sure the resolution is the right one)

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Ultimate Outcome

Successfully navigating the processes of determining the capacity to consent to sexual relationships can:

- make difficult conversations a bit easier;
- prevent concerns from becoming complaints, and complaints from becoming crises;
- offer respect for and balance to rights and protections.

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From the Field

She used to be my sister's best friend, so I kind of grew up with her. Couldn't believe it when I saw her at mom's group home and she kept throwing herself at me. At first everyone seemed cool with it, us being together, and then they accused me of sex abuse! They said she had Alzheimer's and I took advantage of her. Now I'm shamed, and the police have been all over my business, all because of a little hugging and kissing.

A visitor accused of sexual abuse of a resident.

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From the Field

He was the love of my life, my north star, the inspiration that started every day and blessed every night. We vowed to never be apart. MS deprived me of my physical self, but my daughter removed my heart when she forbade Louis to stay in my life after I had to move to Tall Oaks. Never did I think I would find myself where I am today, diminished, dismissed and disrespected in every way.

George, a resident of residential care who is openly LGBTQIA+.

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From the Field

When I told her daughter about her relationship with one of our male residents I had no idea it would go so far. The daughter, her 4 brothers and sisters and their spouses, all came in one night with a priest. They surrounded her bed and the priest actually did something like an exorcism, and said she should never “fornicate” again. Her kids threatened to move her if she didn’t stay away from him, and they forced me to move him to another wing. It seemed like only a few weeks before she stopped eating, socializing and then she just died, I think of shame and a broken heart.

A CBRF administrator, discussing a sexual relationship between two consenting residents.

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Assessing for the capacity to consent

Those who have good rapport with residents, staff and family alike, may have periodic conversations with participating residents as part of the formal and informal assessment process, so that decisions about whether the relationship is consensual are made over time and are resident-driven.

- The goal of assessment is to allow the person to reveal their ability or inability to consent to sex.
- If it isn't clear, assessment continues. Such an important and complex personal issue requires a comprehensive, ongoing assessment.
- Remember, sexual contact is personal — every person must be capable of deciding this for themselves. *It may be necessary to inform a decision-maker of sexual contact if consent has not been determined, but this is different from getting a decision-maker's permission for the sexual relationship when residents are able to consent.*

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Guideline #1:
The individual must understand the distinctively sexual nature of the conduct

Example Questions:

- Do you have any special friends that you are intimate or sexually involved with?
- What does sexual contact mean to you?
- How do you feel about touch? Do you have a special friend who touches you?
- Are you and your friend having sex together?
- What do you understand about your relationship with {name of partner}?

  Follow up, if needed: Are you just friends? Are you lovers? Are you having or are you planning to have sex?

  Break down follow up questions as needed to questions about being undressed together, intimate touch, use of condoms, etc.

Guideline #2:
The individual recognizes their body is private and that s/he has the right to refuse to engage in sexual activity.

Example Questions:

- Is there anyone around here who makes you feel unsafe or uncomfortable? In what ways?
- Has anyone ever touched you in a way you didn't like? Can you talk about it?
- If you don't like something your partner wants you to do, how do you say no?
- What do you do if your partner says stop or no when you're having sex?
- What does it mean to you when your partner pushes you away during sex, if you're kissing or holding hands?
- How would you feel if your partner told you she or he didn't want to have sex with you?

Guideline #3:

The individual recognizes the sexual contact may create possible health risks and physical consequences.

Example Questions:

- Can you describe any health issues connected to having sex? Do any of these worry you?
- Do you know what a Sexually Transmitted Disease or Infection is? How would you prevent an infection? What would you do if you had signs of an infection?
- What are some things you could do to avoid a sexually transmitted disease?
- What would you do if you wanted to use a condom but your partner didn't?
- Have you and your partner talked about your sexual histories? *{If one has an STI or is HIV positive: Have you told your partner you have xxx?}*

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Guideline #4:
The person understands there may be negative social or societal response to the sexual behavior.

Example Questions:

- Have you ever been afraid people would talk negatively about your relationship with xxx?
- Has anyone hurt your feelings about your relationship choices?
- Do you have concerns that your family or friends would treat you differently because of your relationship? How does that make you feel?
- Do you ever feel like you need to hide your relationship with xxx from others?

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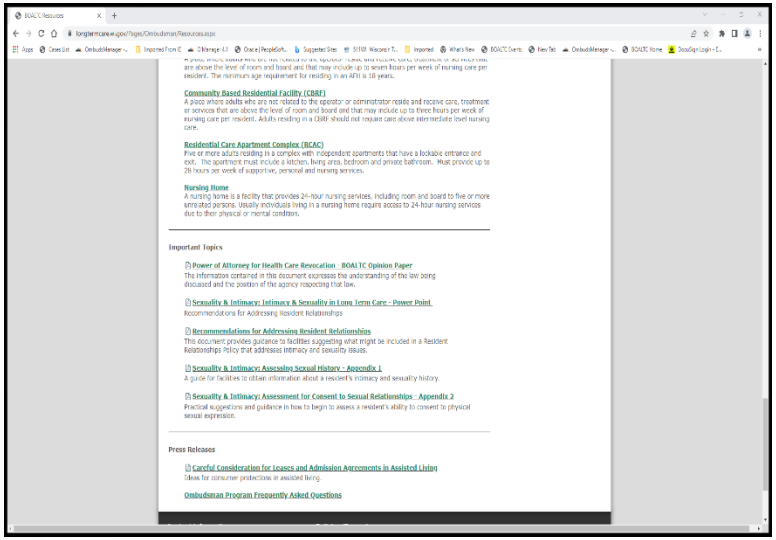
Ombudsman Program Resources*



https://longtermcare.wi.gov/Pages/Ombudsman/Resources.aspx

- Recommendations for Addressing Resident Relationships
- - Sexuality & Intimacy: Assessing Sexual History – Appendix 1
- Sexuality & Intimacy: Assessment for Consent to Sexual Relationships – appendix 2

*Currently undergoing revisions.

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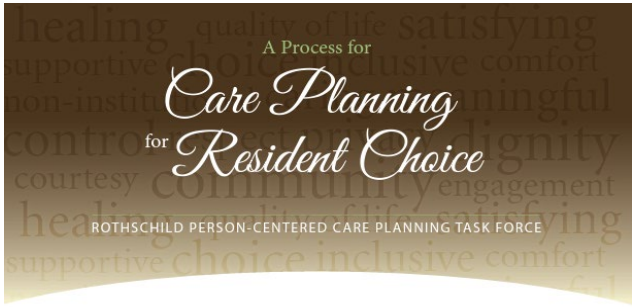
Decision-Making & Risk Resources



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Sample Scenario: Outside

DOCUMENTATION FORM FOR HONORING RESIDENT CHOICE AND MITIGATING RISK

Resident Name: Harry Eisenstadt

I. IDENTIFY AND CLARIFY THE RESIDENT'S CHOICE		Date	Date	Date	Initials
What is resident's preference that is of concern?	Mr. Eisenstadt desires to spend time daily outside in the fenced-in patio unsupervised, whenever he desires. He wants to be able to go for short walks as well as sit in the sun.	9/18			RB
Why is this important to the resident?	He says he likes to leisurely read the paper and enjoy the sights and sounds of being outdoors and the sunshine like he always did at his home, and doesn't want to be watched "like a small child."	9/18			RB
What is the safety/risk concern?	Mr. Eisenstadt walks with a walker subsequent to a mild stroke. He has had one fall in the dining room 6 months ago, with no serious injuries.	9/18			RB
Who representing the resident was involved?	Mr. Eisenstadt manages his own affairs.	9/18			RB
Who on care team was involved in these discussions?	Margie Statler, LSW, Renee Blankenhorn, RN	9/18			RB
II. DISCUSS THE CHOICE AND OPTIONS WITH THE RESIDENT		**Date**	**Date**	**Date**	**Initials**
What are the potential benefits to honoring the resident's choice?	Honoring the choice enhances dignity and autonomy; provides circadian rhythm adjustment from sunshine; and provides opportunity for exercise.	9/18			RB
What are the potential risks to honoring the resident's choice?	Potential fall and sunburn risk. Also staff need to know where all residents are, in case of a fire or other emergency. Staff were also concerned in case he had a fall or medical event how he would be able to notify staff if he is outside alone.	9/18			RB
What alternative options were discussed?	It was proposed that Mr. Eisenstadt be outside only when activity programs were occurring on patio. Rejected by Mr. Eisenstadt because he said that he wants to be in charge of when he uses patio.	9/18			RB
What education about the potential consequences of the choice alternative actions/ activities was provided?	Nurse educated Mr. Eisenstadt about residual weakness from stroke to both the left leg and hand, and how the outdoor sidewalks might prove difficult for him to propel his walker safely. Also his medications make him more susceptible to sunburn.	9/18			RB
Who was involved in these discussions?	Mr. Eisenstadt, Margie Statler, LSW, Renee Blankenhorn, RN	9/18			RB

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Summary

- Residents have the same rights that you and I have.
- Residents have the same types of relationships that you and I have, and may need some support in being in those relationships.
- Residents have the right to make choices about visits until or unless the visit seems harmful to the resident.
- Residents have the right to visit in private, to manage other aspects of relationships in private.
- Residents have the right to engage in a relationship with another if both parties are able to consent based on assessment.
- Rights are important in all decisions and actions in a resident's life.
- Consent for a sexual relationship is a personal decision, and cannot be deferred to a POA or guardian, or an MD, or any staff member. The judgments of others should not interfere with a resident's right for a particular friendship or relationship, without cause.

Top 10 reasons to call an ombudsman

- Residents and/or others remain dissatisfied, make repeated complaints
- Others disrupt resident care and/or well-being
- Question need for involuntary discharge
- You are contemplating closing*
- Residents wish to engage in sexual or risky relationships
- Substitute decision-makers “protect” beyond boundaries
- Other individuals attempt to deny rights, disrespect rights
- Resident wants to live somewhere else
- MCO wants to move resident due to care, rate dispute
- Resident “bullies” other residents

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The role of the ombudsman

- BOALTC Ombudsmen serve persons who are 60 years old and older, and who live in any LTC setting or who receive HCBS from Family Care, PACE, Partnership or IRIS
- Anyone may call an ombudsman, but the ombudsman's client is always only the resident
- All ombudsman contacts with residents are confidential, disclosed only with consent, free of charge
- Ombudsmen are specifically trained to assist with needs and education in areas including Rights, Dignity of Risk, Sexuality and Boundaries of Legal Decision-makers
- Ombudsmen also consult and educate about Resident Rights in relation to visitors, privacy and the need to balance rights and protection

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Ombudsman Program Authorization

- Congressional authorization through the Older Americans Act, providing for unrestricted access of Ombudsman Program services.

- Additionally, provides unrestricted access to Ombudsman by clients, and unrestricted access to clients by Ombudsmen “at any time and without notice.”

- Source: 45 CFR 1324 & §16.009(4)(a), Wis. Stats.

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Ombudsman Responsibilities

Discuss care options, refer to ADRC for options counseling

Resolve challenges according to client wishes and direction, only with permission

Consultation services to providers, MCOs, ICAs/FEAs, individuals

Provider and Community Education

Resident/Tenant & Family Councils

Systems Advocacy (local, state and federal)

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Ombudsman Certification

- Long-term care ombudsmen in Wisconsin are certified via a two-tiered process, comprising more than 500 hours of classroom and field-based education

- Orientation topics include but are not limited to Trauma-Informed Care, Equity & Inclusion, Legal Issues, Special Populations, Regulatory Processes, Boundaries, Collaborative Relationships, Appeals & Grievances and Ombudsman Code of Ethics

- Additionally, ombudsmen must meet continuing education requirements of a minimum of 40 contact hours annually

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Resources

- Board on Aging and Long Term Care Ombudsman Program

  800-815-0015 / http://longtermcare.wi.gov

- Disability Rights Wisconsin - www.disabilityrightswi.org
- Guardianship Support Center

  (855) 409-9410 / guardian@gwaar.org

- Fact Sheet - Residents' Rights and the LGBT Community: Know YOUR Rights as a Nursing Home Resident; The National Long-Term Care Ombudsman Resource Center, The National Resource Center on LGBT Aging, Lambda Legal. June 2022

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Resources

- A Process for Care Planning for Resident Choice; Rothschild Person-centered Care Planning Task Force; The Hulda B and Maurice L Rothschild Foundation; February 2015; updated 2018
- Consent: It's as Simple as Tea: https://www.youtube.com/watch?v=fGoWLWS4-kU
- Gen Silent: https://www.youtube.com/watch?v=fV3O8qz6Y5g
- The Door Does Not Lock: https://www.youtube.com/watch?v=IiIZvR7c8kg&t=32s
- Communicating about sexual expression in continuing care homes: https://www.youtube.com/watch?v=-GYnK6w7i5w
- Capacity for Sexual Consent in Dementia in Long-Term Care; The Society for Post-Acute and Long-Term Care Medicine; March 2016.
- National Resource Center on LGBTQ Aging - https://www.lgbtagingcenter.org/

Resources from SAGE

- "Facts on LGBTQIA+ Aging" – Downloadable PDF https://www.sageusa.org/resource-posts/facts-on-lgbt-aging/
- "Inclusive Services for LGBT Older Adults: A Practical guide to Creating Welcoming Agencies" – Downloadable PDF
- https://www.lgbtagingcenter.org/resources/pdfs/Sage_GuidebookFINAL1.pdf?_gl=1*u23jov*_ga*ODY4NTIzNDkuMTY1NzIzOTQ2Mg..*_ga_YKVT8DY5PC*MTY2MDMyMTQ2My4zLjEuMTY2MDMyMzEzOC4w
- "Advocacy & Services for LGBTQIA+ Elders" - https://www.sageusa.org/

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Use of This Presentation

- It is the philosophy of the Ombudsman Program of the Board on Aging and Long Term Care that all clients, including those with activated powers of attorney and/or guardians, have the right to participate, to whatever extent they may be capable, in all decisions impacting their choices, care, safety and well-being.
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