

SEXUAL EXPRESSION POLICY DEVELOPMENT

A Guide for Long-Term Care Facilities & Assisted Living Programs

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introduction

Sexuality is a basic human need and the choice to be sexually expressive is one that belongs to the individual. The right to freedom of sexual expression among residents in long-term care facilities (LTCFs) and tenants of assisted living programs (ALPs) has proven to be a sensitive and sometimes controversial topic, particularly when cognitive capacity is in question.

By federal law, LTCF residents and ALP tenants are afforded multiple rights, many of which are relevant to sexuality. These rights include, but are not limited to, the right to privacy, confidentiality, dignity and respect; the right to make independent choices; and the right to choose visitors and meet them in a private location.

These rights must be preserved by promoting attitudes of awareness, acceptance and respect of sexual diversity. Through guidance and sexuality education to residents/tenants, family members, administrators, directors and staff, the Office of the State Long-Term Care Ombudsman (OSLTCO) and Disability Rights Iowa (DRI) support residents and tenants in developing

maximum self-reliance and independence regarding their sexual choices without restricting or regulating their behaviors.

Oftentimes, this involves providing assistance to long-term care facilities and assisted living programs as they work to develop policies that clarify acceptable/unacceptable forms of sexual expression and establish ethical response strategies so sexual expression can be facilitated in a safe manner.

Every resident's/tenant's health and level of capacity to consent varies, and there is no single or perfect answer to address every sexually related situation that may arise. Therefore, LTCFs/ALPs must take an individualized approach to each situation and focus on the needs and preferences of the resident/tenant.

This material was developed by the OSLTCO and DRI to help guide meaningful dialogue about sexuality in adulthood and among individuals with disabilities and contribute to effective policies and procedures for addressing sexual relationships between residents/tenants with diminished capacity.







step 1: assemble stakeholders

When your facility or program is ready to develop a sexual expression policy, it is important to identify and engage with stakeholders who can offer different perspectives on cultural norms and values.

Stakeholder involvement will not only enable you to create a more realistic and sustainable policy, but can also help your facility anticipate issues and concerns, reduce the risk of future litigation and develop a policy that is more eagerly and readily adopted.

 Identify key players to serve as the policy team and define each team member's role and the ways in which their input will contribute to policy development.

The team should always include a resident/tenant, but may also include others who have a role in residents'/tenants' lives (e.g., family members, physicians, ethicists, pastoral care workers, long-term care ombudsmen, nurses, therapists, social workers, dietitians, environmental services workers or board members).

 When selecting a stakeholder, identify why the potential stakeholder's input is valuable, necessary and useful to policy development, and describe how the individual in this role will contribute to the process.

Consider whether he/she will have a fundamental impact on the outcome of the policy and whether a fair policy can be written without the input of this individual. (Can a fair policy be written without the input of residents? Without the medical expertise of a physician?) Are there any potential conflicts of interest associated with the individual becoming a stakeholder?

 Inform staff who are not directly participating as stakeholders of the policy development process and request their feedback through surveys, focus groups, or interviews.

This information may be used to further inform policy decisions as deemed appropriate.

CASE EXAMPLE:

Residents' Right to Sexual Expression

Two residents in your long-term care facility wish to have a sexual relationship. Although the staff is aware of their mutual desire to be sexually expressive with one another, some employees are encouraging others to keep the residents apart due to concerns about facility liability or receiving a citation from the state regulatory agency.

As the administrator of the facility, what could you do?

Suggestions:

- Ask staff members if they have reason to believe the residents' safety is at risk.
 Remind them of the facility's sexual expression policy and their duty to respect residents' rights to be sexually expressive.
- Assure them that fear of receiving a citation from the state regulatory agency is not solely an acceptable reason for keeping residents apart, and advise them to stop encouraging other staff to do so.
- A thoughtful review of each resident's abilities and desires should be conducted to identify a solution that meets the needs and protects the rights of the individuals involved.

step 2: become subject-matter experts

After you have assembled your group of stakeholders, take some time to learn as much as possible about residents'/tenants' rights, adult sexuality and the issues associated with it (see the "Additional Information" section of this book for helpful resources).

 Gather relevant information and articles and learn about the issues that impact residents/tenants and may occur in your LTCF/ALP.

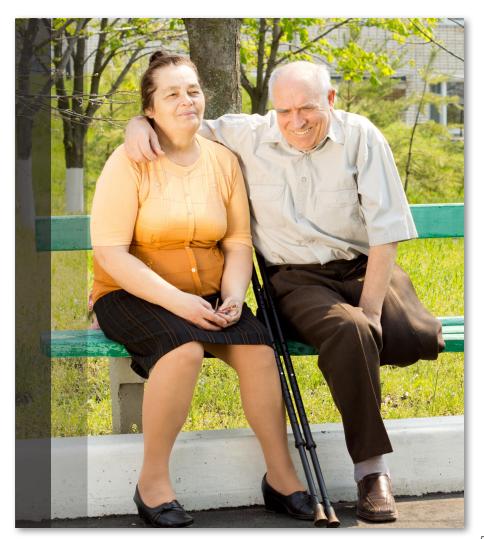
For example, learn more about how issues such as capacity to consent, dementia, the aging body, safety concerns, sexual health, sexual diversity and identifying as LGBT contribute to sexuality in adulthood.

 Look to media, legal cases, research and other resources for stories, studies and examples related to sexual expression and long-term care living environments.

How have other facilities structured their risk assessment policies? How have they responded to situations of sexual abuse/assault?

Educate team members on issues related to sexuality through webinars, films, speakers or topic experts.

The Office of the State Long-Term Care Ombudsman offers a variety of community outreach and education services throughout the year that can be specifically tailored to address resident/tenant sexuality. Call (866) 236-1430 for more information.



CASE EXAMPLE:

Resident with Cognitive Impairment

A staff member has come to you with concerns about a sexual relationship between Mr. Smith, a resident who moved into your facility a few weeks ago, and Ms. Jones, a resident with moderate dementia. The staff member walked in on them while they were kissing and holding each other, and believes Mr. Smith may be taking advantage of Ms. Jones.

As the administrator of the facility, what could you do?

Suggestions:

- Ask staff members to describe their concerns and explain why they believe Mr.
 Smith may be taking advantage of Ms.
 Jones. Ask both residents if they wish to be involved in an intimate relationship with one another.
- If there is any question regarding whether the act is consensual, a cognitive assessment should be conducted on each resident by their physician and members of their Interdisciplinary Care Teams should convene to assess the level of capacity to determine the benefits or potential harm associated with the expression.

step 3: build policy guidelines

Once your group is well-educated about issues relating to residents'/tenants' sexual rights, you are ready to start shaping a sexual expression policy that adheres to legal and organizational guidelines.

Consult state and federal legal standards.

Review the sexual expression policies of other LTCFs/ALPs, if possible, and consider reviewing policies developed for other segments of the population (e.g., mental health and disability communities). Be sure to comply with state laws when creating working definitions of key concepts (e.g., sexuality, intimacy, sexual orientation, consent, capacity, sexual abuse, etc.).

 Build policy guidelines that best match your organization's philosophy, values and mission statement.

Review existing organizational policies that may impede residents' sexual expression. Do certain existing rules prevent residents from exercising their right to be sexually expressive?

Be clear and consistent.

Make clear distinctions between what constitutes healthy sexual behaviors, sexual behaviors of concern/risk and signs/behaviors that require assessment or reassessment.

 Develop guidelines to meet the ongoing need for re-assessment.

Consider at what point residents should be reassessed (e.g., every two months, every six months, upon noticing a change in a resident's behavior or demeanor).

 Determine the formal systems involved in identifying, monitoring and addressing issues as they arise.

Identify the process for reporting incidents or concerns. Do certain situations need to be charted in a resident's care plan? Which agencies, interdisciplinary care team members, family members or other stakeholders need to be notified and when? How will situations be monitored on an ongoing basis and who will need to be made aware of outcomes?

step 4: assess facility environment

As you continue to draft your policy, assess your facility's environment to gain a better understanding of how residents/tenants and staff perceive sexuality and the ways the physical environment supports or prevents sexual expression.

 Consider the cultural or religious affiliations of your facility/program.

What are your organization's viewpoints on relationships between residents of the same sex, marital relationships, capacity to consent and confidentiality.

 Discuss the current cultural environment among residents/tenants.

Are residents/tenants aware of their rights to make choices related to sexuality? Are there residents/tenants who openly express their sexuality? Are residents'/tenants' personal, religious and political beliefs upheld by the facility? If so, how?

 Assess team members' attitudes related to residents' rights to be sexually expressive.

How might staff members' own preexisting opinions, beliefs, morals and biases related to sexuality in adulthood and among individuals with disabilities impact residents'/tenants' rights to be sexually expressive? Consider how a team member's moral code may conflict with his/her professional role. Could someone's religious, political or personal beliefs prevent them from honoring the sexual expression policy?

Determine whether staff are able to identify inappropriate or unsafe situations and carry out proper response strategies.

Have staff been educated on what constitutes healthy sexual behavior versus sexual behavior of concern/risk, signs and behaviors that require assessment or reassessment?

 Is the privacy of residents/tenants respected by staff members?

Do staff knock on doors before opening them or are they used to simply walking right in? Are doors left open to hallways or public areas? Can residents/tenants use "Do Not Disturb" signs? Consider if there are ways in which the physical building or environment of the LTCF/ALP prevents residents/tenants from being sexually expressive.

Are there shared rooms that offer little opportunity for privacy? Rooms that open directly to the nurses' station or common areas may dissuade residents from being sexually expressive.

 Does the LTCF/ALP offer privacy measures for residents?

Is there a room set aside for the purposes of offering residents/tenants privacy? Do residents have private places to take phone calls? Does the LTCF/ALP offer residents opportunities and spaces to socially and/or privately interact with other residents and visitors?

 Are residents' offered access to sexual content (magazines, movies, Internet, etc.)?

If so, are they aware? Is there a library of content? Is there a system or process for privately accommodating requests for material with sexual content?

step 5: policy development

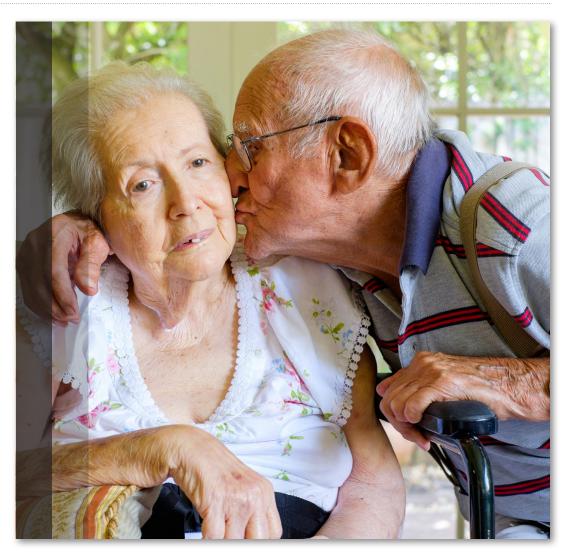
Now that your group is aware of current laws and regulations, better understands the benefits and risks of sexual expression among adults and individuals with disabilities and has taken into account the facility's cultural and physical environment, you are ready to develop a sexual expression policy.

 Determine appropriate responses and interventions for staff when addressing sexual expression among residents/tenants.

Consider the various types of sexual expression that may have already occurred in your facility and identify the organization's expectations regarding appropriate responses. Establish timelines and parameters for reassessing residents'/tenants' cognitive capacity to consent to sexual activities. Outline strategies and formal processes for identifying, monitoring and reporting sexually related situations.

 Determine appropriate actions to take when an intervention does not work as intended.

Anticipate specific issues and consider where they might fit into the policy. Focus on expectations for staff best practices.



CASE EXAMPLE:

Family Conflict

Your facility's social worker asks you to speak with a resident's son who is upset about his mother being in an intimate relationship with another resident. The son is the attorney-infact under a health care power of attorney and has said he will sue the facility if the relationship is allowed to continue.

As the administrator of the facility, what could you do?

Suggestions:

- Remind the son that it is not within the role of the attorney-in-fact to make sexual decisions on behalf of a resident.
- Share the facility's sexual expression policy with the family and attempt to educate them on residents' rights to be sexually expressive.
- Ensure the social worker and other staff members are aware of and fully understand the facility's sexual expression policy. Consider holding a workshop for staff that exposes them to common questions they may receive about the policy and equip them with answers.

step 6: policy implementation

When you have completed the first draft of your sexual expression policy, consider circulating it to staff, residents/tenants, family members and others who are stakeholders but were not part of the policy team. Ask for feedback, then finalize the policy.

 Distribute the policy to staff and residents/ tenants.

Consider hosting a Sexual Awareness Day/Week to familiarize staff and residents/tenants on the new policy. Invite guest speakers or use videos or presentations to promote discussion about sexual expression in your LTCF/ALP and how the policy will help determine appropriate responses to sexual expression. Repeat annually.

 Distribute the policy to family members/legal guardians/legal representatives of current residents/tenants.

Make sure you include contact information should someone have a question or concern.

 Distribute to prospective residents/tenants and family members prior to admission.

Include this policy as part of your information packet for prospective residents/tenants and be available for questions or clarifications.





step 7: policy evaluation

After your facility/program has implemented its sexual expression policy, you will want to evaluate it on a regular basis to ensure it is working and is a practical, useful and sustainable document.

- Develop feedback mechanisms for assistance in reviewing and revising the policy.

 Collect data, reports and outcomes associated with observed/reported sexual behaviors among residents/tenants and request staff input to assist in adjusting the policy, if needed.
- Periodically review relevant literature and practices to keep the policy up to date.

 Consider making policy revisions to reflect current understanding of sexual behavior in adulthood and among individuals with disabilities on a routine basis (e.g., every two years).
- Revise the policy based on feedback and circulate final policy.
 Update all parties about the policy and its implications for stakeholders.





CASE EXAMPLE:

Confidentiality

An aide has reported that a tenant in your assisted living program who is HIV positive has been seen in intimate situations with several other tenants. She feels it is her responsibility to notify the other tenants who may be at risk of infection and asks you for your opinion.

As the director of the program, what could you do?

Suggestions:

- Ask the staff member to describe what type of intimate situations were observed and where they were taking place. Remind her it is against the law for a health care professional like herself to share personal health information about tenants.
- If you determine that the tenant's behavior may have put other tenants at risk, report to the appropriate state regulatory agency.
- Consider modifications to the care plan which meet the tenant's needs and protect the other ALP tenants.
- Offer learning opportunities for sex education to tenants.

additional information

SAMPLE SEXUAL EXPRESSION POLICIES

• Office of the State Long-Term Care Ombudsman https://www.iowaaging.gov/long-term-care-ombudsman

STATUTORY REFERENCES

DISCLAIMER: This is not an exhaustive list of all relevant legal authority that may apply. The purpose of the following citations, information and resources is to provide a starting point for your facility's legal counsel or anyone else looking for additional legal and legislative information on this topic. Although the accuracy and timeliness of the information provided is current as of the date of this publication, laws and regulations change over time. It is always good practice to consult the official version of the information or consult with your facility's legal counsel.

FEDERAL LAWS AND REGULATIONS

Nursing Facilities:

• Residents' Rights (42 CFR 483.10)

IOWA CODE

- Dependent Adult Abuse Services (Iowa Code § 235B)
- Dependent Adult Abuse in Facilities / Programs (Iowa Code § 235E)
- Sexual Abuse (Iowa Code § 709)
- Health Care Facilities Rules (Iowa Code § 135C.14(8))
- Guardianships and Conservatorships –
 General Provisions (Iowa Code § 633.551)

IOWA ADMINISTRATIVE RULES

Assisted Living Programs:

- Iowa Administrative Code § 481.67.4(20)
- Iowa Administrative Code § 481.67.3

Residential Care Facilities:

Iowa Administrative Code § 481.57.26

Nursing Facilities:

• Iowa Administrative Code § 481.58.47



RESOURCES & TOOLS

 Office of the State Long-Term Care Ombudsman https://www.iowaaging.gov/long-term-care-ombudsman

 Disability Rights Iowa http://disabilityrightsiowa.org/

• lowa Department on Aging https://www.iowaaging.gov/

 Iowa Department of Inspections and Appeals https://dia-hfd.iowa.gov/DIA HFD/Home.do

• Long-Term Care Residents' Rights https://www.iowaaging.gov/long-term-care-ombudsman/residenttenant-rights

• Sexuality and Aging: Debunking the Myths
https://www.iowaaging.gov/sites/files/aging/documents/Sexuality%20%26%20
Aging fact%20sheet.pdf

Sexuality and Aging Brochure
 https://www.iowaaging.gov/sites/files/aging/documents/Sexuality%20and%20

 Aging Brochure.pdf

• Sexuality in Long-Term Care Webinar https://www.iowaaging.gov/long-term-care-ombudsman/resource-library/osltco-resources-presentations

 Centers for Disease Control and Prevention: Sexual Health http://www.cdc.gov/sexualhealth/Default.html

 American Psychological Association: Lesbian, Gay, Bisexual, and Transgender Aging http://www.apa.org/pi/lqbt/resources/aging.aspx National Resource Center on LGBT Aging: Inclusive Questions for Older Adults A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity

http://www.sageusa.org/files/InclusiveQuestionsOlder%20Adults Guidebook.pdf

Many Faces: Addressing Diversity in Health Care
 http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/
 ANAPeriodicals/OJIN/TableofContents/Volume82003/No1Jan2003/
 AddressingDiversityinHealthCare.html

Living with Dementia: Intimacy and Sexuality
 http://www.alzheimer.ca/en/Living-with-dementia/Understanding-behaviour/
 Intimacy-and-sexuality

 National Resource Center for Supported Decision Making http://supporteddecisionmaking.org/

- Sexuality and People with Disabilities: What Experts are Often Not Aware of http://www.independentliving.org/docs5/sexuality.html
- Through the Looking Glass http://lookingglass.org/home
- Sexuality and Disability Consortium, Institute on Disability and Human Development at UIC http://ahs.uic.edu/dhd/sdc/resources/

 A 5 is Against the Law! Social Boundaries: Straight Up! An Honest Guide for Teens and Young Adults

https://www.aapcpublishing.net/aapc-bookstore/product-viewer.aspx?slug=A-5-ls-Against-the-Law