



## Office for People With Developmental Disabilities

### ADMINISTRATIVE DIRECTIVE

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<b>To:</b>	Executive Directors of Voluntary Provider Agencies Developmental Disabilities Regional Office Directors Developmental Disabilities State Operations Offices Directors Care Managers and Care Coordination Organizations (CCO) CEOs			
<b>Issuing OPWDD Office:</b>	Counsel's Office			
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<b>Subject:</b>	Right to Sexual Activity and the Role of Consent			
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<b>Attachments:</b>				
<b>Related ADMs</b>	<b>Releases Cancelled</b>	<b>Regulatory Authority</b>	<b>MHL &amp; Other Statutory Authority</b>	<b>Records Retention</b>
	July 30, 1993 Memorandum <i>Considerations for the Development of Agency Policies Concerning Sexual Contact and Consent</i>	14 NYCRR Parts 633.4; 633.12; 633.16	MHL §§ 13.01, 13.07, 16.19, 33.01, 33.02	18 NYCRR 504.3(a)

**Purpose:**

The purpose of this Administrative Memorandum (ADM) is to affirm that individuals with intellectual and developmental disabilities (“individuals”) have rights regarding sexual expression and sexual activity and to ensure that these rights are not unnecessarily denied. Additionally, this ADM outlines the procedures used for determining or assessing an individual’s *capacity* to make an informed choice regarding sexual activity if concerns are raised in this regard. Finally, this ADM offers guidance for providers regarding the development of training and supports for individuals who require additional education and supports on this topic.

The NYS Office for People With Developmental Disabilities (OPWDD) is committed to supporting individuals with developmental and intellectual disabilities in exercising the rights they share with all citizens to develop and enjoy social relationships, including rights related to sexuality and sexual activity. Further, individuals have the right to be free from discrimination on the basis of their sexual orientation and sexual identity.

At the same time, OPWDD recognizes that individuals with intellectual and developmental disabilities, especially women and LBGTQ individuals, are at increased risk for sexual abuse and trauma and that decisions and determinations affecting sexual activity must balance the rights of people to engage in sexual activity with the need to help protect them from sexual harm or exploitation.

For the purposes of this ADM, the following definitions are used:

- **Capacity to Consent:** This refers to a more general state or condition whereby the individual has adequate abilities and knowledge necessary to exercise informed consent in regard to sexual activity with another person. All adult individuals are assumed to be capable of consenting unless there are specific concerns raised in regard to their abilities to exercise informed consent for sexual activity.
- **Consent (i.e., individual providing consent at a particular moment):** This refers to a situation in which someone willingly agrees, knowingly gives permission, and indicates "yes" to a particular sexual activity with another person without coercion, undue influence, or deception. Consent must always be given voluntarily and all people in a sexual situation must feel that they are able to say "yes" or "no" or stop the sexual activity at any point.
- **Individuals:** Those who are eligible to receive services that are funded by OPWDD either through state operated programs or voluntary service providers.
- **Informed Choice:** When an individual decides based on an informed understanding of options available, the risks and benefits involved, and how that choice may affect his/her/their life or the life of others. Individuals can make informed choices on their own, or they can ask their family, friends, or others for support with making the choice. Capacity to consent is a necessary component of informed choice.
- **Sexuality:** The way people experience and express themselves sexually, including sexual feelings, sexual orientations and gender identity. An individual’s sexuality may be displayed through his/her/their sexual activity, expression, and affiliations.

- **Sexual Activity:** Activities that are sexually stimulating with or without involvement of another person(s) (e.g., masturbation, “sexting”) or physical contact between people for the purposes of sexual experience or sexual gratification (e.g., sexual intercourse/penetration/non-penetrative sex, oral sex, or any touching of the sexual or other intimate parts of a person whether directly or through clothing). Please note that other activities such as holding hands, hugging, kissing, or dating do not meet the definition of “sexual activity.”

This ADM affirms that adult individuals generally have the right to exercise choice and control about their social relationships and sexual activity. However, agencies must ensure that individuals are not subjected to undue harm, abuse, or exploitation. Additionally, there are situations in which individuals may be unable to make informed choices about sexual relationships and activities. OPWDD supports the rights of individuals to be free from unwanted sexual advances and safe from sexual exploitation, abuse, or assault. Providers have both a duty to protect individuals from harm and a duty to support mutually desired sexual and intimate relationships.

This ADM establishes OPWDD’s policy regarding the sexual rights of individuals and seeks to assist providers in the following:

- Protecting the rights of individuals to express their sexuality and engage in consensual sexual activity;
- Protecting individuals from harm by determining if, and when, an assessment of an individual’s capacity to provide consent for sexual activity is clinically indicated;
- Establishing agency policy, training, and intervention and supports related to sexuality and sexual activity; and

Limiting the rights of an individual only when necessary and with justification, receiving and responding to objections to restrictions on individual’s rights.

This ADM does not establish procedures for responding to situations or circumstances that may involve criminal acts, nor does this ADM establish procedures for responding to incidents involving abuse, neglect, or mistreatment. Agencies must report and respond to potential criminal acts or incidents per agency policies and procedures, OPWDD regulations including 14 NYCRR Part 624 or Part 625, and in accordance with applicable state law.

Further, this ADM does not establish requirements for the management of behavior, including challenging behavior that is sexual in nature and considered criminal and/or violates the rights of others. Providers should respond to such behavior in accordance with applicable regulations, including Part 633.16, which pertain to the use of interventions to manage, modify, or control challenging behavior.

#### **Background:**

All people have the right to have friends, engage in mutually desired social relationships, to feel emotionally connected to others, and to love and be loved. For people with intellectual and developmental disabilities, sexual activity may, or may not be, part of their social interactions or relationships. For some people, sexual interest or activity may be low or absent, or limited

primarily to activities that do not involve other people (e.g., private masturbation). The identified presence of a “boyfriend,” “girlfriend,” or “partner” does not necessarily imply a desire or intent for sexual activity with that person. Friendships or relationships that are not sexual, or likely to become sexual, are not subject to this ADM.

Consenting adults have the right to engage in intimate relationships and sexual activity and they have a right to begin and end a relationship as they choose. The presence of an intellectual or developmental disability, or other disability alone is insufficient justification to limit an individual from expressing their sexuality or choosing to engage in sexual activity.

There may, however, be circumstances when rights related to sexual activity may be limited for the protection of the individual or others due to an individual’s inability to make an informed choice and/or provide informed consent about such sexual activity. An individual’s inability to make an informed choice about sexual activity could be affected by a variety of factors, including limitations in functional abilities, social/emotional understanding, or a lack of basic knowledge. When any person in the individual’s program planning team raises concerns about an individual’s ability to make an informed choice about sexual activity, a formal determination of the individual’s capacity to consent may be initiated.

The consent determination process must be both individualized and person-centered. It is possible that an individual’s ability to consent to sexual activities may change over time. For individuals who are unable to consent (e.g., adults assessed as being unable to consent), access to and receipt of appropriate training, education and/or counseling must be offered to enhance their ability to consent to sexual activity. An individual’s ability to consent to sexual activity may develop over time and should be re-determined, as needed, if and when circumstances change. If rights limitations are put in place related to the lack of capacity to consent to sexual activity, the program planning team must review the appropriateness of these limitations and the accuracy of the determination of incapacity at minimum, on an annual basis.

Individuals have the right to access sound education on topics pertaining to sexuality and sexual activity, as well as any necessary supports that may assist them to make an independent informed choice pertaining to sexual activity or exercising their right to engage in sexual activity. They have the right to access appropriate medical care and to pursue birth control and other contraceptives. They may require support with learning basic self-care (i.e., hygiene) or obtaining, if desired, devices/items available to the general public for the purposes of achieving sexual satisfaction (e.g., sex “toys” or other intimate products).

### **Discussion:**

#### **I. Rights and Limitations of Rights**

##### The Right to Self-Initiate Sexual Relationships

Providers must protect the rights of individuals receiving services while supporting their right to engage in mutually desired sexual and intimate relationships. Providers must ensure that individuals are afforded the opportunity to:

- Receive visitors or visit others;
- Have privacy when visited;
- Communicate freely with others (including the right to engage in or abstain from sexual activity with a mutually consenting adult);
- Make decisions regarding conception and pregnancy; and
- Have access to education and counseling regarding the topic of sexuality, which includes, but is not limited to, information concerning sexual activity, sexual health, reproductive decision making, and family planning services.

Individuals have the right to self-initiate sexual relationships unless they are unable to make such an informed choice based on a formal determination as set forth herein. Limitations on an individual's rights must be considered, determined, and documented as described below.

#### Limitations on Sexual Activity

Individuals may freely express their choices in sexual activity when:

1. The individual and his/her/their partner can make an informed choice to engage in sexual contact; and
2. The type of sexual activity does not infringe on the rights of others.

An individual's rights must not be arbitrarily denied. An individual's right to self-initiate sexual activity may only be limited when:

- a) The decision to limit the individual's rights to engage in sexual activity is developed through person-centered planning;
- b) There is adequate, current clinical justification for limiting such right(s); and
- c) Any limitation(s) on the individual's rights to engage in sexual activity were determined by the program planning/treatment team.

The decision to limit an individual's self-initiated right to sexual activity based on a determination that they lack the capacity to consent should not be considered permanent and must be re-evaluated upon a change of circumstance (such as the completion of an educational or training program) and reviewed by the program planning team on no less than an annual basis. Any rights limitations must be documented in the individual's person-centered plan and developed in accordance with applicable 633.4 regulations involving rights limitation. The individual's program planning team must determine and provide needed supports and services to support the individual's choices to engage in sexual activity and to increase capacity if deficits are identified.

Facilities and programs must not limit an individual's rights to sexual activity as punishment or for the convenience of staff. Rights may not be limited due to failure to provide reasonable privacy (i.e., access to private locations when not contraindicated with safety) or because of discrimination against one's sexuality.

Providers may establish guidelines to ensure the safety, privacy, and comfort of all individuals

sharing the facility. For example, sexual activity may be limited to private areas of the facility, such as the individual's bedroom. Efforts should be made to accommodate an individual's preferences and wishes when reasonable to do so and when doing so will not create undue burden or discomfort of other individuals (i.e., scheduling private time in a private location if individuals share a bedroom).

### The Right to be Free from Sexual Abuse or Coercion

OPWDD affirms that all people have the right to be free from sexual abuse and harassment and have the right to protection from exploitation. These rights exist regardless of whether an individual can, or cannot, make an informed choice about sexual activity. This includes being free from unwanted sexual activity (i.e., sexual activity in the absence of consent), abuse, assault, or harassment.

Individuals can be safeguarded through education about their right to be free from sexual abuse or coercion, how to identify sexual abuse and coercion, and where/how to report such abuse. Individuals can also be protected through supports that assist them to navigate social relationships and maintain personal safety. Cultivating environments that are safe, supportive of sexual expression and tolerance for diversity, as well as educating staff on how to support individuals can also assist with safeguarding.

Sexual activity involving an individual who is deemed unable to give consent, or who does not provide consent, is sexual abuse. Lack of consent may take different forms, including but not limited to the following examples:

- *Refusal/absence of consent* – where the individual refuses, retracts, or declines to consent to engage in sexual activity, but that activity is forced upon them or otherwise coerced;
- *Age* – where the individual is incapable of consenting due to age (e.g., a minor under the age of 17);
- *“Physically helpless”* (as described and defined in NY Penal Law 130) – where a person is unconscious or for any other reason is physically unable to communicate willingness to an act. ;
- *“Mentally disabled”* (as described and defined in NY Penal Law 130) – where a person suffers from a mental disease or defect which renders him/her/them incapable of appraising the nature of his/her/their conduct; or
- *Unequal power dynamic in a relationship* – where the individual may be considered incapable of providing informed consent due to situational circumstances regarding the imbalance of power between the parties or perceived imbalance of power (e.g., caregiver relationship, provider relationship, health care professional relationship, direct support professional relationship, work supervisor relationship).

Any suspected incident of sexual abuse must be reported to the New York State Justice Center per 14 NYCRR § 624. Please refer to this regulation and the Part 624 Handbook for additional information on reporting requirements. Further, agencies must report any suspected criminal activity, or potential criminal activity, to law enforcement.

## **II. Assessment of an Individual's Ability to Provide Consent for Sexual Activity**

The decision to review or request an assessment of an individual's capacity to consent to sexual activity should only occur as described below. Many individuals with intellectual and developmental disabilities do not need to have a determination made or an assessment completed. For example, if the person is not expressing an interest or engaging in sexual activity, there would be no need for such a determination. Similarly, if the person is expressing an interest in sexual activity and there is no valid reason to question their decisional capacities, no formal determination or evaluation needs to be completed.

### When to Perform an Assessment

A review of an individual's ability to provide consent for sexual activity should only be completed when:

- a) the individual expresses an interest in engaging in sexual activity or is engaging in sexual activity; and
- b) a member of the program planning team finds there is reason to question an individual's ability to provide informed consent for such activity.

Sexual activity must be considered as part of the person-centered planning and service planning process. The individual's privacy should be respected, and personal dignity upheld to the fullest extent possible. The individual should have the opportunity to discuss this topic with appropriate staff or other sources of social support.

### Factors to Consider when Determining Capacity to Consent

The program planning team must consider several factors if and when determining whether an individual has the ability to consent to sexual activity. While level of cognitive functioning (i.e., Intellectual Functioning or IQ) may be considered as part of such assessment, an individual's IQ alone is not considered adequate justification to restrict or limit rights to engage in sexual activity with another person. Simply having one or more disabilities, including cognitive, developmental, or physical disability, may not prevent an individual from making informed choices.

Factors relevant to deciding whether an individual can consent to sexual activity are related to knowledge, rationality and voluntariness.

#### 1) Knowledge/Understanding

Knowledge refers to the person's awareness of the sexual acts, knowing the real or potential consequences of such acts (e.g., pregnancy, sexually transmitted diseases, social or legal consequences) and knowing potential benefits and risks associated with sexual activity and protection that can be used to minimize potential risk. Knowledge also refers to the person's basic understanding of the physiological nature of sexual activity and understanding basic information on the topic that will assist the individual in making an informed choice regarding a sexual act(s). This includes the individual

understanding the possible social consequences he/she/they could experience because of such choices involving sexual activity.

2) Rationality

Rationality refers to the person's ability to critically evaluate and weigh the benefits and risks when making a knowledgeable decision. Beyond simple knowledge of facts, rationality seeks to understand from the person's perspective, how they go about making decisions and to see that they have shown some ability to critically evaluate the information and situation in order to reach their decision.

3) Voluntariness

Voluntariness means that the person is aware that they have the choice to engage in (i.e., consensual) or refuse to engage in any sexual act at any time and that the individual can communicate (either verbally or non-verbally) such choice.

If legitimate questions have been raised about a person's ability to consent and the program planning team members cannot reach a consensus about whether the individual can make an informed choice regarding sexual activity based on the factors referenced above, the team should refer the individual to a licensed professional for a clinical opinion. The licensed professional should be a NYS licensed clinician such as a psychologist, clinical social worker, nurse, psychiatric nurse practitioner, psychiatrist, physician, etc., who has experience working with individuals with intellectual and developmental disabilities, and is familiar with factors relevant to sexual consent determinations.

The use of an assessment tool (such as the Tool for the Assessment of Levels of Knowledge-Sexuality and Consent (TALK-SC) or the Socio-Sexual Knowledge and Attitudes Test-Revised (SSKAAT-R)) to aid in the process of assessing an individual's level of knowledge regarding sexual activity may be helpful but is not required.

Please note that individuals receiving services may decline to participate in such an evaluation. Declining to participate in the evaluation may not be used to justify a determination of "not capable to consent." Other observations and evidence would be needed to support such a determination.

If a specific assessment has been requested, the program planning team must consider this clinical opinion when determining whether the individual can consent to sexual activity, but the program planning team maintains the final responsibility for determining the individual's sexual consent status.

The results of the assessment, including any professional guidance or recommendations offered, must be documented in writing in the individual's record if the assessment finds the individual to be unable to consent. The information in this assessment should be used to guide the development of interventions and supports for the individual.

### Documenting limitations Related to a Lack of Capacity to Consent to Sexual Activity

If the program planning team determines that specific limitations are necessary related to a person's lack of capacity to consent to sexual activity, then such limitations must be documented in the individual's person-centered plan and developed per rights limitation regulatory requirements (Part 633.4).

Documentation must include the following:

- a) A description of the ways the individual's rights must be limited, and the individual basis for the limitation(s);
- b) Identification of any person-centered interventions, supports, or services that will be made available to the individual (including education/training as indicated) so that he/she/they can exercise his/her/their rights to the degree possible if/when appropriate to minimize risk; and
- c) The schedule and plan for reviewing and/or removing any restriction(s)/limitation(s).

When specific limitations are necessary related to a person's lack of capacity to consent to sexual activity, the individual's ability to make an informed decision to engage in sexual activity must be reviewed as part of the person-centered planning process on an annual basis, or sooner if warranted. Any limitation(s) or restriction(s) on the individual's right(s) related to engaging in sexual activity should be communicated to the individual in a manner that the individual can understand. Such limitation or restriction should also be communicated to all staff to the degree necessary for them to perform their job duties and to ensure adequate protection(s) of the individual and others.

### **III. Agency Policy, Training, Intervention and Supports Related to Sexuality and Sexual Activity**

#### Agency Policy and Procedure

Agency policy and procedures must:

- 1) Affirm the rights of individuals to engage in sexual activity and sexual expression;
- 2) Identify the circumstance(s) under which an individual's ability to engage in sexual activity may be questioned and/or limited based on the policies outlined in the sections above;
- 3) Identify when, and the circumstances under which, an assessment to determine an individual's capacity to consent to sexual activity should be performed; and
- 4) Require that staff members who are part of the program planning team be trained on:
  - a) agency policies and procedures pertaining to an individual's ability to make informed choices about sexual activity;
  - b) interventions and approaches that should be utilized if an individual is currently deemed unable to make informed choices about sexual activity and would like to receive interventions and/or supports to build the ability to make informed choices in the future; and

c) interventions and supports to be used if an individual can make informed choices about sexual activity, and the individual desires to engage in sexual activity with support.

### Staff Instruction and Training

Agencies and programs must establish requirements for training staff on the topics of sexuality and sexual activity for individuals with intellectual and developmental disabilities (I/DD). Training should emphasize that individuals with I/DD have the same sexual feelings that individuals without I/DD experience, and they must be afforded their rights to sexual expression and sexual activity, unless there are limitations as described above. Instruction and training must inform staff so they:

- have the skills to address or respond to potential issues pertaining to sexuality;
- know who (e.g., therapist, counselor, supervisor) to refer individuals to when individuals have questions pertaining to sexuality or sexual activity;
- can assist the individual with accessing such resources or persons;
- can use appropriate professional boundaries pertaining to these topics;
- can assist with any person-centered plans or procedures established by the program planning team;
- are aware of the need to maintain confidentiality and respect of the privacy of the individual;
- understand how to protect the rights of individuals, including those individuals who have restrictions on their right to engage in sexual activity;
- prevent and/or immediately stop and respond to activity that constitutes sexual abuse; and
- engage in conduct that preserves the dignity of all individuals served.

### Interventions and Supports

An individual's ability to make an informed choice about engaging in sexual activity can vary over time. Whenever appropriate, individuals should be offered the necessary supports and services to make informed choices about sexual activity. These supports include:

#### 1. Access to Education and Information

Individuals have the right to access clinically sound instructions on the topic of sexuality and family planning services. This includes education on accessing medication/contraception or devices to regulate conception when clinically indicated and appropriate. Education should also include self-protective measures as well as education on identifying and reporting abuse and/or harassment.

An individual's inability to make an informed choice pertaining to sexual activity may be the result of lack of education or knowledge on the topic. If so, providers must identify specific areas for training and/or education so that the individual may be able to attain the ability to make an informed choice, if the individual wants it.

Individuals are entitled to education and counseling about sexuality and sexual activity throughout their lives, particularly as individuals develop new interests, have new experiences, or encounter new opportunities or risks. This education and counseling must be offered to all individuals who express a desire to engage in sexual activity.

2. Access to Counseling or Therapeutic Services

In some cases, the program planning/support team may recommend that the individual participate in counseling or therapy to address issues pertaining to sexual activity. For example, an individual's history of sexual abuse may impact his/her/their current decision-making pertaining to sexual activity. Counseling or therapy to address specific issues may be clinically indicated and therapeutic for the individual if the individual is agreeable.

3. Access to Healthcare Services

Individuals should be encouraged to discuss their sexual health and sexual history with their healthcare provider. In some cases, individuals may choose to discuss the use of contraception with their health care provider.

4. Practical Supports

In some cases, individuals may need support with identifying appropriate locations and times for engaging in sexual activity. They may need assistance with learning proper hygiene and safe practice, accessing needed items (e.g., birth control, condoms, etc.), and other guidance with navigating their personal relationships (i.e., discussing relationship issues with a clinician).

#### **IV. Objections to Restrictions on Individual's Rights**

##### Objections to Restrictions on Sexual Activity

If the individual, the individual's legal guardian, advocate, or circle of support member disagrees with a restriction or limitation on the individual's rights to engage in sexual activity, the program planning team should:

- (a) Offer the individual, his/her/their guardian, advocate, or circle of support member the opportunity to meet with the program planning team to discuss any concerns and the factors that were considered when the team made the determination;
- (b) Review the recommendations, supports, and services that could be offered so that the individual could later be able to make informed choices about sexual activity or be supported to engage in sexual activity as he/she/they desires; and/or
- (c) Arrange for the individual to receive a formal assessment performed by a licensed clinician to determine the individual's capacity to consent for sexual activity.

Should the individual and/or his/her/their guardian, advocate, or circle of support member be dissatisfied with the results of such efforts to remediate the issue, then any restrictions or limitations listed in the individual's Life Plan may be contested through the process outlined at 14 NYCRR 633.12.