



SELF-STUDY GUIDE: HUMAN INTIMACY

The information in this guide is to help staff with discussions about human intimacy and sexual health they may have with their customers. It is a resource to help guide them through those sensitive topics. InReach has Human Intimacy Liaison's (HIL) available to assist and support staff as they face dilemma's surrounding the complex topics associated with human intimacy. For further information about how to access an InReach HIL, please contact Jeanne Pritt at ext 411.

Unit I: Sexuality Education and Intellectual / Developmental Disabilities (I/DD)

Many people with disabilities can have and want to have relationships that include sexual expression. It is important to have education that is age appropriate, factual, and teaches people to manage and enjoy relationships, make responsible choices and distinguish right from wrong.

Sexuality education helps people with disabilities avoid making social mistakes that make them look careless or might be mistaken for criminal activity. Education also helps people understand the possible consequences of sexual activity, such as the risk of pregnancy and disease. It teaches people how to protect their health and safety.



Just like everybody else, people with disabilities have the right to be educated about sexual health, the right and responsibility to make choices and decisions about their bodies and the right to be sexually active if they choose to be.

A Credo for Meaningful Relationships:

Written by citizens with disabilities across North Carolina

People with disabilities are people just like YOU, but we are often disregarded in terms of our choices to live lives that are full and meaningful. Too many other people make our choices for us out of a desire to protect us, make their lives easier, keep us segregated, etc. Life without choices, love and friendship is not much of a life at all. Treat us with dignity and respect and we will respond the same. Support us, care about us, even if on a professional level, the way you would want to be. As self-advocates who matter as people first, we want to have meaningful connections with other people with and without disabilities, who share our beliefs, genders and orientations, or even who have different ones because being different is what makes us all the same. In terms of love, friendship and a full social way of life in the community:

1. We want to learn about safety and healthy relationships – including friendships and romantic relationships with people of all abilities, genders, values, preferences and orientations that we choose.
2. We want support and education about our bodies, how things work in a healthy way, how to stay healthy; how to choose intimate partners right for us, and how to protect ourselves against abuse, cancer, sexually transmitted diseases and other health risks.
3. We want to learn valuable safety tips for safer dating, connecting with new friends and maintaining contact with family – whether in person or online.
4. We want the federal marriage penalty to be adjusted. The marriage penalty cuts our benefits if we choose to get married.
5. We want parents and loved ones to talk openly with us when we ask about making friends, dating, sexual health and safety. If they can't talk to us, help us find someone who can talk in terms we understand.
6. We want to be recognized as adults, regardless of the challenges we face or others presume we deal with.
7. We want privacy to be alone with our thoughts in our homes and our rooms, and with friends and dates. Teach us how to ask staff and family to give us our space once we've learned safe and healthy habits.
8. We want to choose our own friends instead of paid staff becoming the only friends we have. We want to choose who we don't want to be with anymore, too.

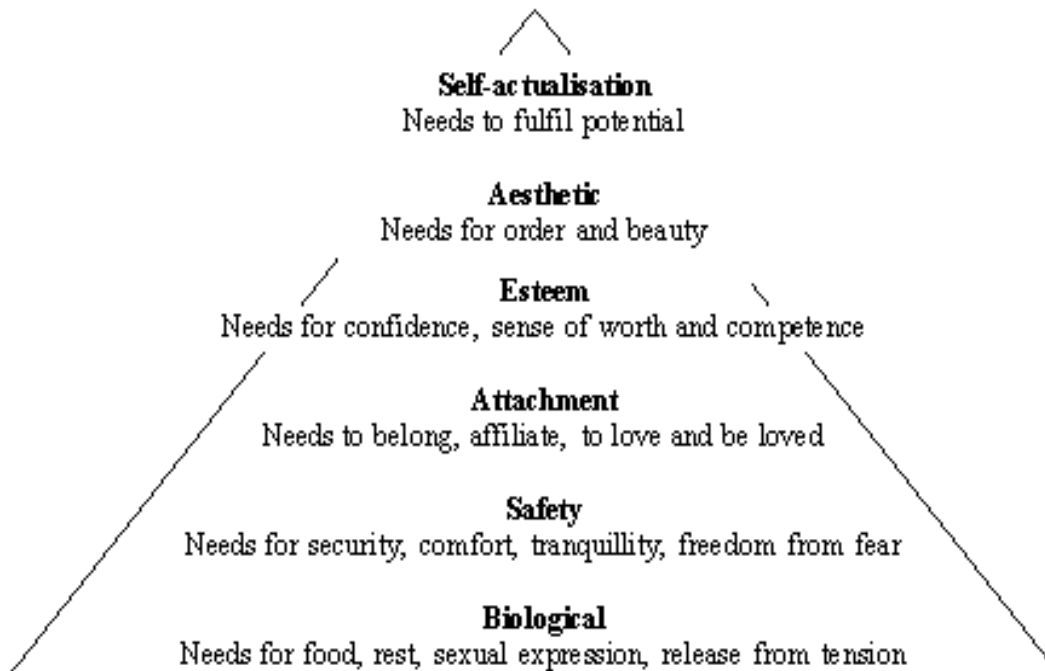
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9. We want to become “regulars” at places like the local coffee shop, church, the Laundromat, school, the library, and other places in the community, so that we can learn how to meet people. Maybe, people will begin to miss us and ask about our well being if we don’t show up on our regular day or time.
10. We want the community to notice us by who we are first. We aren’t solely defined by our disability labels. The staff supporting us doesn’t define us either.
11. We want you to befriend us and be sensitive to us, so we have more people to share our likes and dislikes with. That way, we’ll have more people to tell if something is wrong or we need help.
12. We want better, accessible transportation to see our friends and go out in the community.
13. We want to go to funerals, weddings, family and community functions that are important to us, regardless of inconvenience to staff that seem to have time to take us to the doctor, the store and other service provider appointments. We are part of important family and social circles, too.
14. We want to be able to make our own choices, as well as mistakes, and learn from them without being judged or having our mistakes thrown back at us every time we try to move forward.
15. We want to be heard and know our feelings and opinions matter.
16. We want you to share your good or bad news with us. Don’t assume we won’t understand or it will be too upsetting. We are allowed to have our feelings and express them the best we know how. We can handle it!
17. We want safe, affordable, accessible places to live where both we and our friends can have fun without worries of danger.

We are People first – adults – with wants and needs just like you. Remember that as you care for, support, advocate with, live among and work with us. We have feelings, desires, dreams and wishes for a life with love, friendship and respect. Put yourself in our place before you make decisions about our social and emotional experiences. Think about how you would feel if opportunities to connect to others on a deeper level were taken from *you*; or your need for companionship was denied. That wouldn’t be all right with you, would it? It’s not all right with us. We know what we are missing. We know we deserve these experiences in our lives like others do. Support us, teach us, guide us and help us to be a bigger part of yours and other people’s lives and encourage others to be a part of our lives. We have more to offer than you assume.

Citizens with Disabilities across North Carolina in collaboration with the NC Relationships Initiative, 2011

Basic Human Needs:



According to the World Health Organization,

“Sexuality is an integral part of the personality of everyone: man, woman and child. It is a basic need and aspect of being human that cannot be separated from other aspects of life”.

The Sexuality Information and Education Council of the United States (SIECUS) affirms,

“Sexuality is a fundamental part of being human, one that is worthy of dignity and respect”.

Sexuality is not just sexual activity. It also has to do with:

- Being female or male, and how females and males are alike and different in the way they look and behave
- How we view our bodies and our relationships with others
- How we grow and change over the years
- Who we are as girls and boys, women and men
- Intimacy
- How we reproduce

While not all people are sexually active, all people are sexual beings.

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Expressions of sexuality include, but are not limited to:

- Socialization
- Friendship
- Boundaries in relationships
- Body awareness
- Human connectedness
- Self-image
- Self-care
- Decision making
- Assertiveness

Knowing what sexual expressions are acceptable and safe is important. **Sex education is vital in preparing people with intellectual disabilities to partner with others in promoting their own safety.**



When discussing sexuality with customers:

- Use the correct names for body parts and their functions
- Describe the qualities of good relationships (friendship, mutual respect, communication, love, etc.)
- Talk about decision-making skills, and how all decisions have consequences
- Do NOT place your own personal beliefs, values and/or morals on the individual's we serve; we have no right to do that as support staff

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- Do NOT lecture; try to keep the discussion relaxed
- Look for “teachable moments” in daily life when you can take a situation from their job, their friends, a television show or from observing people in the community to discuss topics related to intimacy and sexuality
- Do NOT use slang words; only use appropriate terms when talking about sexuality

Unit II: InReach Human Rights Policy on Sexuality and Relationships

InReach acknowledges that all persons have the need to develop and maintain personal relationships that are meaningful to them. We acknowledge that the form a meaningful relationship takes may vary from individual to individual, based on the abilities and preferences of the individuals involved. InReach is committed to supporting the customers it serves as they establish personal relationships, and to fostering personal choice whenever possible. **InReach sees its role as one of teaching responsible behavior, consistent with the norms of the community in which the customer lives.** InReach acknowledges the role that legal guardians play in making choices of treatment services and medical care (and financial management when so designated). InReach notes that the North Carolina Guardianship Standards do not specifically give the guardian authority over the individual’s personal associations. We further note these standards do state that, *“To the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him.”* (GS 35A-1201.5)



When InReach staff become aware that a customer has formed or is forming a relationship that may be or may become sexual, they will use the following procedures:

Step 1: Discussion with Customer

1. Staff will meet privately with the customer and ask about the nature of relationship. If the relationship appears to be only social, staff may provide formal or informal instruction regarding social relationships and refer to counseling if appropriate.
2. If the relationship appears to be one that may result in a sexual activity of any type, staff will notify their supervisor of the situation. The staff member and the supervisor will review the customer's case history and may make referrals for or provide formal or informal counseling or instruction to address any potential customer needs.
 - a. Considerations for referral to outside agencies include:
 - ✓ Need for contraception
 - ✓ Possible abuse or exploitation of or by either party
 - ✓ Risk for sexually transmitted disease
 - ✓ Known mental health issues

The intent of InReach is to help teach people how to engage in healthy relationships in a way that is helpful and supportive.

In talking with the customer regarding a current or potential relationship, staff is encouraged to review the following topics:

- 1) How the customer met the individual.
- 2) How the relationship has developed to date, including how often they meet or talk, and where and when they typically see each other.
- 3) Where the customer sees the relationship going (i.e. casual friend, dating, marriage).
- 4) How the customer's roommates, if any, feel about the individual. How may this relationship affect the customer's relationships with his/her roommates? Staff should follow-up with roommates to get their feedback.
- 5) If the customer's family is aware of the relationship, and how they may react.

Staff must avoid giving their personal opinions or reactions. If there is concern regarding the customer's immediate health or safety, staff needs to contact their supervisor immediately.

Step 2: Meeting the Friend

1. If the relationship is more than a casual relationship between peers, staff should attempt to meet the customer's friend. For community customers, including those in Supervised Living, it is preferable to meet away from the person's home. For group home customers, staff may meet the friend at the group home or in the community.
2. Staff is encouraged to meet privately with the customer after meeting the friend to discuss their first impressions. If necessary, staff is encouraged to give their feedback in a therapeutic manner, using an approach that will not potentially damage the positive rapport they have established with the customer.

Step 3: Consultation with Supervisor

1. After talking with the customer and meeting the friend, when possible, staff will meet with their supervisor to discuss their findings, conversations with the customer and possible instructional or service needs. These recommendations will then be discussed with the customer.
2. The customer will have the choice to accept or reject any recommendations given, or to request other types of assistance. If the customer does not want relationship-related services reflected in his/her service plan, these can be documented in progress notes only. Informal monitoring and follow-along services will also not be reflected in service plans.
3. Staff will continue to follow-up with the customer regarding any significant relationship issues, including the ongoing monitoring of roommates and or family concerns. If a referral is made to an outside agency or professional, staff will follow-up to assure that the services are being received.



Unit III: Sensitive Issues

1. Modesty:

Some of the people we support are very innocent about their bodies. They may respond to discomfort, environmental triggers or boredom by removing their clothes in places that are considered not appropriate. They do not know that they should be embarrassed or feel shame about exposing specific body parts in public.

- a. Innocent behaviors may be perceived as strange or threatening. Though people with I/DD may be innocent in terms of modesty, they may be guilty in the eyes of the community. There are clear laws that allow people to be arrested for exposing themselves in public or for behaving in a way that is considered offensive.
- b. Support staff and loved ones do not always respect the person's modesty. Without trying to be disrespectful, they may leave the stall door open in the bathroom to supervise more than one person, or change people openly in a classroom due to being short-staffed.

General Tips for Managing Modesty Issues:

- **Model respect for modesty, and require others to respect modesty.**
Refrain from changing people in places other than restrooms and other designated areas. Do not allow others to let the person be exposed in front of others.
- **Be aware of environmental triggers.**
Many people with sensory impairments and developmental disabilities associate actions with specific things in their environment. For example, if a person showers they may associate anything that sprays water with bathing. When he passes a sprinkler in a neighbors yard he may think, "It's time for a shower". You may need to avoid the neighbor's yard during watering times as a way to prevent this from happening.
- **Think about comfort.**
Most of us want to take off uncomfortable clothing. However, some people with I/DD may not have the same self-discipline and will remove anything that is causing the discomfort. One way to avoid stripping is to know what the person likes and dislikes regarding fabrics, fit, etc. One person may like soft, fuzzy clothing while another may like light, silky fabrics. One may like tight-fitting clothes while another prefers loose clothes.
- **Complicated clothing may prevent problems.**
For a person who is known to remove clothing in public places, you may find it helpful to slow them down with buttons, zippers and belts. You will have time to notice and intervene if they are struggling to get the clothing off in the first place.

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➤ **Teach the concept of “wait”.**

First, let the person know that you acknowledge there is a problem, such as it is hot and you know he wants to take off his shirt. Second, let him know he will be able to take the shirt off, but he needs to wait. Lastly, provide some temporary comfort to redirect, such as fan him or put a cool water bottle on his neck for a few minutes.

He will learn he has to delay it, his need but it will be met.

➤ **Teach the concept of “private”.**

These basic concepts teach people that there are rules for their behavior. “Private” means that others can’t look or others can’t touch. If a person begins to take off her clothes in the mall, tell her, “No. Wait. Private”. At home, help her to know she is in a private place by closing her door before undressing. Expand the “private” concept to body parts and personal items that others can’t touch.



Specific Modesty Issues:

a. Stripping in Public Places:

❖ **Determine why the behavior is occurring.**

- Is the person uncomfortable?
- Is her behavior triggered by the environment?
- Is he using his clothing to self-stimulate?
- Is he tearing his clothes because he is upset?

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- ❖ Be calm and acknowledge the person's need to remove the clothing.
 - "I know you want to take off your shirt. I know that shirt is hot".
 - Redirect by saying, "Later" or "Wait". Fan the person or take her to the restroom where she can put a cool cloth on her face and neck. Provide something else for the person to do with her hands.
 - At appropriate time and place, allow person to remove her shirt. Give praise for waiting and removing clothing in private.



b. Scratching Private Areas in Public:

- ❖ Determine if there is a physical reason for the behavior.
 - Does the person have a rash?
 - Is the clothing scratchy?
 - Does the person have an infection, such as a yeast infection?

- ❖ Redirect the behavior.
 - Say, "Wait" and "Private".
 - Give the person something to do with their hands.
 - Seek medical attention if needed.

c. Obvious and Prolonged Adjusting of Undergarments in Public.

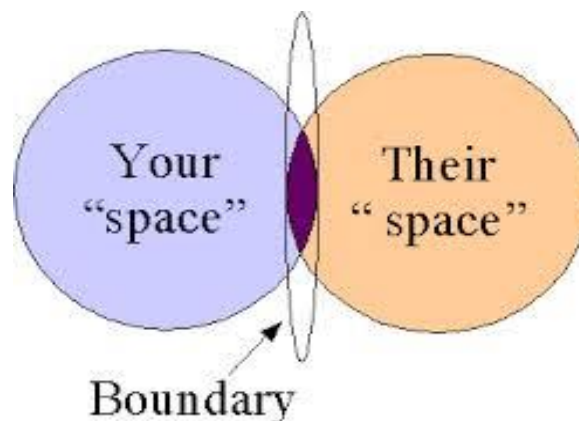
- ❖ Determine if there is a physical reason for the behavior.
 - Is clothing too tight or too loose?
 - Are tags or stitching irritating the person?
- ❖ Acknowledge the person's concern and redirect the behavior.
 - Say, "Wait" and "Private".
 - Move the person to a location that is private for adjusting problem clothing.



2. Appropriate Touch and Personal Boundaries:

As a general society, we have strict and often complex rules about touch and personal space. Every culture within our society has defined clear rules about touching. For example:

- If you bump into someone accidentally, you're expected to apologize.
- To get a person's attention, you're expected to speak to the person first. If that fails, you might touch the person on the shoulder or arm, but not on the face, etc.
- We typically avoid eye-contact with strangers in elevators, and don't stand too close if avoidable.



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a. Social Cues:

- ❖ Some customers need to learn ways to appropriately greet familiar and unfamiliar people. Just as importantly, others in the community need to learn how to introduce themselves to the individual. This is one area where modeling can and should be used.
- Create “rules” related to touch and personal space. The person can shake hands to greet teachers, church members, friends and new acquaintances. She can hug in the greeting routine for mom, dad, sister and brother.



b. Address Issues Related to Perseverative Touching:

- ❖ Some people with sensory issues and developmental disabilities will become fixated on or even obsessive about a particular object, person or activity. He may constantly talk about, seek out or try to acquire the object of his fixation or obsession. This is called **perseveration**.
- ❖ Sometimes perseverative behavior may cause the person to touch inappropriately or violate personal boundaries. Behavior like this is not about misunderstanding appropriate touch. It is about perseveration and needs to be addressed with professional support.

3. Masturbation:

Regardless of staff's personal beliefs and because standards do exist in society, it is in the best interest of customers to address masturbation as a part of sexuality education.

Masturbation is a normal, healthy behavior that is acceptable if done in private.

- *Masturbation is unacceptable in public places.*
- *Masturbating in public is a deviant behavior that violates certain laws.*
- *A person who masturbates in public invites advances from sexual predators.*

Effective Intervention Strategies for Masturbation Issues:

➤ **Increase supervision and activity levels.**

Ensuring that the person's day is well-structured, well-supervised and full of interesting activities and interactions is one of the best ways to reduce an interest in masturbating.

➤ **Dress the person in complicated clothing.**

Clothing that makes access to the body more difficult, such as pants that zip and have belts, shirts that have buttons, etc. can help decrease masturbation in public places. Sweat suits are comfortable, but also make it easier for the person to openly masturbate.

➤ **Avoid the triggers for masturbation.**

If the person associates sitting on a park bench with masturbation, then sit at the picnic table instead. Whatever triggers that behavior, have a plan to avoid that trigger if possible.

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- **Be clear with the person about when masturbation is appropriate.**

In some settings, the strategy may be to redirect the customer to a designated area where they can have privacy, such as his bedroom or bathroom with the door closed. Other times the person may have to wait a while before they will have access to a private area. For example, if the person has roommates, she may have to wait until the others leave the area for a period of time to give her the privacy she needs.

Customers need to be given a private and safe place to masturbate if they want to.



- **Staff must respect the customer's dignity and keep matters confidential.**

Masturbation, or any sexual health needs, should never be the source of humor or gossip for any InReach staff. Failure to maintain confidentiality may result in termination of employment. Professionalism is required at all times.



Unit IV: Sexual Abuse

Sexual abuse can be defined as: forcing, threatening, coercing, tricking or manipulating another person into unwanted sexual contact or into sexual contact to which the person does not have the capacity to give consent.

It involves power and control over another person without his or her consent.

Sexual abuse can involve a wide range of unwelcome sexual actions from others, ranging from inappropriate language and touch to violent force.

Statistics vary, but research shows that people with intellectual and developmental disabilities are at a greater risk for being sexually abused than people without disabilities.

People with disabilities are often targeted as victims of sexual abuse because of...

- ✓ Physical limitations
- ✓ Cognitive limitations
- ✓ Limited social experiences
- ✓ Lack of education about abuse
- ✓ Impulsivity, low self-esteem, and poor decision-making skills
- ✓ Lack of social opportunities that results in loneliness and vulnerability
- ✓ Frequently taught to be compliant to requests from caregivers or other authority figures



Sexually abused persons may demonstrate the following behaviors:

- Seem fearful of a particular person
- Resist physical exams
- Have extra difficulty in social situations
- Sleep disturbances or nightmares
- Depression
- Increased sexual “acting out” behavior
- New or increased interest in sexual issues
- Regression to childlike behaviors
- DO NOT DISMISS SUSPICIOUS EVENTS OR BEHAVIOR AS BEING PART OF THE DISABILITY.
Common symptoms of sexual abuse are often overlooked and attributed to the person’s disability, which is why so many cases of abuse go undetected for so long with the intellectually and developmentally disabled population.

To protect people from being abused, we must teach them about abuse. Before we teach people about abuse, they must first have an appropriate understanding of human sexuality and healthy sexual expression.

Basic Principles of Self-Protection for the People We Support:

- 1) People need to have a clear understanding of healthy sexual expression.**
It is critical for customers to know that sexual contact by a service provider, or any caregiver, is abuse.
- 2) People need to be aware that everyone has a right to privacy.**
A customer’s body and personal information should not be displayed or disclosed in a manner that is without dignity or may cause embarrassment.
- 3) People must know that they have the right to say “No” to personal care or behavior that makes them feel uncomfortable.**
Customer’s need to be informed that they have the right to say “No” if a service being provided doesn’t feel safe or comfortable.
- 4) People need to know their personal rights.**
Each person has a right to be safe in their home, at work and in the community. People need to know that nobody has the right to touch you if you don’t want them to.

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5) People need to inform somebody if there is a problem.

Customers need to understand that if someone is hurting them or bothering them, they need to seek help from a person they trust. If they are unsure about a situation, they need to reach out for assistance to help determine if it is okay or not okay.

6) People need to feel good about who they are.

Everybody needs to know that they are special, valued and cared for. They must understand that if another person ever tries to make them feel differently, they can stop or even report that person.



Unit V: Birth Control and Protection against Sexually Transmitted Diseases (STD's)

Information about birth control and family planning is critical for people with intellectual and developmental disabilities to make responsible decisions about sexual health and behavior. While there are disabilities that make it difficult or impossible for an individual to reproduce, most are physically capable of having children.

A person needs to understand the basics of human reproduction, along with how to prevent pregnancy. Abstaining from sexual intercourse, or choosing not to have sex, can certainly be a choice for some people. Others may choose to use condoms, birth control pills, etc. as a way to prevent unwanted pregnancy. It is advised that the customer, along with their guardian if applicable, meet with his or her family physician or nurse practitioner to make that personal decision.



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People with disabilities need to understand that many methods of birth control do not protect against sexually transmitted diseases (STD's). They also need to understand that the most effective way to avoid getting an STD is to abstain from having sexual contact.

It is important that people are informed about accurate, up-to-date information on:

- ✓ **The signs and symptoms of STD's**
- ✓ **How to prevent the transmission of STD's**
- ✓ **Health-promoting behaviors, such as regular check-ups, self-exams and identifying problems early**
- ✓ *NEVER USE SCARE TACTICS*
- ✓ *ALWAYS USE CONCRETE TERMS; BE FACTUAL*

Curable (mostly bacterial)	Incurable (viral)
Syphilis Chancroid Gonorrhea Chlamydial infection Trichomoniasis	HIV/AIDS HPV Hepatitis B Genital herpes

A good place for a person to get accurate information about sexually transmitted disease prevention is from their family physician or nurse practitioner.



Resources on Human Intimacy and Intellectual & Developmental Disabilities

Centers for Disease Control & Prevention

http://www.cdc.gov/std/default.htm?s_cid=bb-nchhstp-nr-sam-002

The North Carolina Relationships Initiative

<http://www.hsri.org/files/NCRI/NCRI%20Policy%20Recommendations.pdf>

U.S. Department of Health and Human Services:

Reproductive Health Information

<http://www.hhs.gov/opa/reproductive-health/>

Article: Relationships & Adults with an Intellectual Disability

http://donaldbasley.org.nz/publications/NHC_Relations.pdf