



Ethics of Touch 2019

Material adapted from The Ethics of Touch: Establishing and Maintaining Appropriate Boundaries
In Service to People with Developmental Disabilities
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(1 hour)



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Training

Ethics of Touch

Learning Objectives

1. Recognize the four principals of privacy.
2. Understand the relationships with people we serve.
3. Understand the rules of touch.
4. Recognize the boundaries regarding private parts of the body.
5. Understand the importance of boundaries.
6. Understand the boundaries of hugs.
7. Understand how cultural differences influence touch and boundaries.
8. Understand how to develop appropriate relationships with the people we serve.
9. Understand staff role in relationships, touch and affection.
10. Understand the provisions of providing intimate care.
11. Recognize the areas of discussion for practice guidelines.

Four Principals of Privacy

Privacy is learned

As we grew up, privacy was respected and encouraged by our families. Privacy was ingrained in us, usually informally. We learned at a fairly early age to knock on doors before entering, closing the bathroom door, and closing the door when changing clothes.

At around age 4 or 5 we developed body modesty. We did not want the parent of the opposite gender to see us undressed, we made sure the bathroom door was closed when using the facilities, etc. At around age 6 or 7 we had relationships down. We understood that mom and dad were not related other than by marriage; we understood about aunts and uncles and cousins. By pre-puberty we developed social distance. At this age, children no longer sit in a parent's lap, hold their hand and are uncomfortable with public affection from parents.

Recipients, especially those institutionalized, are used to getting dressed, undressed, using the toilet, getting personal care needs met, bathing and showering in front of other people. Because most recipients were never taught those privacy things that were ingrained in us they have inadvertently been taught that it is okay to be naked in front of other people, even strangers. As support staff, recipients must be taught about privacy.

Invasions of privacy can be subtle

Direct care staff as well as support staff can subtly invade recipient's privacy by:

- Discussing private things in public places
- Discussing issues at the person centered planning meeting that do not need to be shared with everyone on the support team
- Reading information in the person's record or gaining information about an individual that does not relate to their care or support plan

We tend to notice when people invade our privacy. Sometimes staff fail to notice when they have invaded recipient's privacy.

Privacy is a mental health issue

We build privacy into our lives to regroup and keep our sanity. At work, some people engage in "off task behavior" by closing their doors and doing nothing for a few minutes. Some people daydream. At home we may go into the bathroom and just take a break from others in the house. We may run a quick errand alone. Regardless of how we do it, we all do it. No one can concentrate on a task for an unlimited amount of time without taking a break for a few minutes.

When recipients engage in this behavior, we discourage it and make efforts to engage them back into meaningful activity. Sometimes recipients are even put on a behavior program to "fix" "off task behavior".

Privacy is needed and should be allowed and supported. We can support privacy by:

- Allowing recipients to go to their rooms when desired for reasonable amounts of time.
- Allowing recipients to engage in activities of their choice and not engage in activities they are not interested in.
- Knocking before entering bedrooms and asking permission to enter.
- Be sensitive to times when recipients may be tired or need to "wind down" for example after work or program.

Privacy is a social skill

Think about times when you need to get the point across to someone, especially a recipient. If something is very important and we need to make sure the person understands us we tend to:

- Get very close to the person's face
- Make eye contact
- Touch the person – usually on the arm or shoulder
- Talk loudly to the person

On the other side of the coin, think about what recipients do when they have something important or very exciting to tell staff. They get very close, hold on to staff and talk loudly. How can we teach social distance when as staff, we violate social distance all of the time? Start to notice when you violate recipient's privacy. We need teach social

distance by role modeling accessing someone's attention in more socially appropriate ways.

- Maintain the social distance of approximately 30"
- Talk to the person in a normal tone of voice
- Attempt to make eye contact but don't demand it
- Tell the person what you need them to know in simple, direct language using a neutrally pleasant tone of voice
- Ask the person if they understand – ask them to repeat in their own words the message you were giving them

Relationships with People We Serve

New staff are allowed to bathe, change briefs, assist with toilet activities, and provide intimate care the first day on the job. Over a one year period, at least 30 different people could be providing intimate care to a recipient. Some stay only a few days or weeks and then another stranger takes that staff's place.

What we are teaching is: Your body is absolutely public. A stranger is actually a staff that hasn't started working yet. Strangers walk into the home all of the time. Some support staff don't even have to knock. We teach "No one is allowed to touch your body without permission" when we should be teaching "No one is allowed to SEE your body without permission". Our casual attitude about the person's body:

- Makes the person more victimizable – an easy target
- Sets the person up to be an offender – if anyone can see my body, the other side of the coin must be I can see anyone else's.

As much as possible, new staff should be assigned duties that do not involve the provision of intimate care until

- The recipient gets to know the new staff
- All background checks including the ORR background check have been received and reviewed by the home administrative staff
- The new staff has been trained in the provision of providing intimate care

Rules About Touch

Think about a time when you were somewhere with a room full of strangers, maybe at a restaurant, or at a party. Someone touches you on the outside of your arm and asks you what time it is. You give the person the time then the incident is out of your mind. In a day or two you won't even recall the incident. Now image the stranger puts his/her hand on your shoulder blade and asks you the time. You give the person the time but the person's hand lingers on your back for a few more moments. Would you feel uncomfortable? Imagine the person then slid his/her hand across your back and left it there. How would you feel?

Once the hand crosses the spine, you have just been embraced or embraced someone. People will either feel embraced or an intrusion depending on how well you know the person and your own feelings about touch by strangers. When doing hand – over assistance, staff should never stand behind the individual and put their arms around the recipient to give hand guidance. Staff should sit or stand beside the person to give hand guidance. Most recipients are not resisting hand guidance; they are resisting the “embrace” from staff – just as you would pull away from someone giving you an unwanted embrace.

Get permission before touching a recipient. Ask the person if you can assist them with the task. If the person is not able to give consent for the assistance, let him/her know what you are going to do before you do it.

Private Parts

We teach children and some of the recipients we serve “there are three private zones on the body”. People are taught that breasts, buttocks and the genital area are private zones. Some people teach a private zone is anything covered by a bathing suit. This leaves a lot of private parts of the body public: upper thigh, stomach, lower back, inner arm, etc.

We need to teach ALL parts of the body are private but some can be public under certain circumstances:

- Hands are public when someone shakes your hand as a greeting; holding or rubbing your hand is private.
- The inside of the arm from the wrist to the armpit is private.
- The outside of the arm from the wrist to the elbow may be public if the touch is brief and intended to get someone’s attention.
- The outside of the arm from the elbow to the shoulder may be public if the touch is brief and intended to get someone’s attention.
- All other body parts are private.

Boundaries

A lot of the individuals we serve have a reduced sense of boundaries. For some people their boundaries are their skin. For years people receiving mental health services, especially those with developmental disabilities living in group homes or institutions have had many different people providing intimate care, body checks, treatments, etc. With high staff turnover, recipients may not understand staff’s touch versus a stranger or a predator’s touch. Staff touch recipients all the time and rarely ask permission. Recipients may have gotten used to being touched by strangers and see it as a normal part of the day.

Touch should always be:

- Contextual: let the recipient know why you are touching them before you touch them.

- **Public:** Unless providing intimate care, always touch a person on a public part of the body.
- **Appropriate:** Maintain appropriate physical space before and after the contextual touch.

Hugs

It is never appropriate to frontal (bear hug) a recipient. This does not mean that a recipient should never get a hug. Hugs should be:

- **Side by side:** stand beside the recipient, arm goes behind his/her back, pull them toward you, release and maintain socially appropriate distance.
- **Hand never goes under the arm:** if your arm does not reach across the person's back, do not put your hand under the person's arm.
- **Contextual:** Let the person know why you are hugging them. For example: "Thank you for helping with the laundry".
- **Brief:** Hug, then let go.

Some people with disabilities have a hard time reading social cues. Individuals may misinterpret hugs and other types of physical touch and may not understand the staff – recipient relationship. With high staff turnover, if a recipient is used to people they do not know well giving them physical affection, they may not recognize first intrusion. When touch is contextual and appropriate it teaches the person about boundaries and first intrusion.

We need to strictly follow affection rules because:

- It teaches circumstances for appropriate behavior
- Identifies what is happening
- Makes your motive understandable
- Protects staff from assumption

Staff should never kiss a recipient. The Office of Recipient Rights will consider kissing a recipient sexual abuse.

Cultural Differences

We need to recognize that there are cultural differences for touch and boundaries. Some families are used to giving hugs as a greeting. Some people communicate by physically touching and standing very close to the person with whom they are speaking. We need to be sensitive to individual's cultural background but at the same time, teach to the conservative norm. Different affection rules need to stay in the family home.

There is a public opinion about people with disabilities. There are a lot of people who view people with developmental disabilities as eternal children. Others view people with mental illness as dangerous and incompetent. Our job is to set an example with our language and our actions that promotes the dignity of all people with disabilities. As

professionals, when we give physical affection to adults with disabilities, we are reinforcing the idea that people with disabilities are different instead of reinforcing the idea that people with disabilities are capable, competent adults. IT IS NOT STAFF'S JOB TO PROVIDE PHYSICAL AFFECTION.

It is important to:

- Set boundaries with your language – call individuals by their name, not terms of endearment.
- Teach recipients that staff are not their family.
- Teach recipients “people who know me better can touch me more, people who know me less, touch me less”
- Teach recipients that affection does not have to mean physical touch.

Relationships

Who are you to the people you serve? You are:

- Not their best friend
- Not there to supply physical affection
- Not there to meet their emotional needs.
- Not their family.

How would you feel if your superiors were the only ones who supplied your emotional/affection needs?

If all of your friends were getting paid to be your friend?

Our job is to facilitate the person in getting their emotional needs met by natural supports. You have walked into the lives of people who did not invite you in. You care for the person, provide for their needs, ensure their safety and well being and the person grows dependent on you for all of their needs. If staff are also meeting all of the emotional needs of the recipients, what is going to happen to that person when you walk out of their life? An argument can be made that we all have people walk in and out of our lives and we all go through that grief at some point in our lives. The difference is we can choose who and how many people we want that intimacy with. We also have a circle of intimate family and friends that stays relatively stable. A recipient sometimes has no choice. In a three year period as many as 100 different people could have provided intimate care to that person. If we grieve when one person we care about very much leaves us, how would it feel when we are left over and over again?

Facilitating the person getting their emotional needs met by natural supports lessens the trauma of staff turnover and provides stability in the person's life.

Staff need to talk about:

- If not us then who?
- How do we facilitate this?

Relationships – Touch and Affection: Our Role

During emotional times when the person is most vulnerable, more boundaries are needed. Staff can give hugs and comfort during emotional situations while maintaining clear boundaries:

- Sit beside the person but do not allow them to lay on you.
- Provide the side by side hug and verbalize your support.
- Redefine boundaries as often as needed.

Never engage in behavior that could lead to abuse.

If a recipient says “I love you”, acknowledge the moment, clarify the context, and don’t diminish the content or challenge their behavior. Staff can say something like “I love working with you too” or “I love going for walks with you to”. Although we may love the people with whom we are working, we still need to maintain clear boundaries. Chances are good that the recipient doesn’t love staff as much as they love that particular moment they are having with staff.

Some individuals may engage in behavior challenges that come from wanting touch and affection. For many individuals, the more a person engages in behavior challenges, the less likely they are to get touch and affection appropriately. It is important to give appropriate touch, non-physical affection and closeness when the person is not acting out.

Staff should keep in mind:

- Living in a group home can lead to isolation and loneliness.
- Touch does not mean affection.
- Staff need to come up with ways to give affection without touch. Some examples could be: having inside jokes with the person, sharing a favorite activity one-on-one, sharing a special treat or cup of coffee, conversation, etc.

Providing Intimate Care

Staff who provide direct care to individuals are entrusted to care for our most precious commodity. One of the most important responsibilities staff have is to protect individuals who are at the mercy of others. Individuals with disabilities can be easily victimized and either cannot tell or don’t know that they should tell of the victimization.

Staff can protect individuals during the provision of intimate care by:

- Telling the person what is going to happen and why, before doing anything.
- Be sensitive to startle reflex – approach the person from the side and start talking to them before you get to them.
- Build in privacy.
- Be observant of new staff. Check on staff and recipients during shower/bathing, changing briefs, etc. If a staff is a victimizer, they will not get into a “comfort zone” of being alone with a vulnerable person.

Remember that staff will be charged with Criminal Neglect for failing to report the suspected or actual sexual abuse of a recipient.

Areas to Discuss for Practice Guidelines

- **Sexuality Education:** Ensure people have access to accurate information and able to make informed choices around healthy relationships.
- **Ongoing Training for Staff:** Remain current with issues that affect the quality of service staff are providing. It is important to ensure that staff are receiving the support they need in order to provide the best service. Training should be available to clarify roles and boundaries and establish practice guidelines.
- **Provision of Personal Intimate Care:** Guidelines and protocols should be set around personal care to allow respect and privacy. Family, guardians, support staff, and people with disabilities can work together to establish boundaries and protocols specific for each individual.
- **Sexual Expression:** Support the people we serve in expressing their sexuality in a safe manner. Reinforce positive messages about the expression of sexuality.
- **Respond to Disclosure of Abuse and Neglect:** Follow the ORR guidelines on reporting suspected or witnessed abuse and neglect. **You have a legal obligation to report.**