

PERSONAL CARE GUIDELINES

Family Support Options gratefully acknowledges the contributions of the following sources in the compilation of this document:

The Ethics of Touch, David Hingsburger and Mary Harber, Diverse City Press, Quebec, 1998

Essex County Association for Community Living, Essex, Ontario

Fanshawe College, Developmental Services Worker Program, London, Ontario

Making a Difference, Jacqueline Brown and Pat Mirenda, Ministry of Children and Families, British Columbia, 1997

Community Living North Halton, Milton, Ontario

THE ETHICS OF TOUCH, ESTABLISHING AND MAINTAINING APPROPRIATE BOUNDARIES IN SERVICE TO PEOPLE WITH DEVELOPMENTAL DISABILITIES

INTRODUCTION

All human beings need touch. We need to be held. We need to hold. At the same time we need boundaries. We need to know our body is our own. We need to be in control of what happens to us, who touches us and under what circumstances we choose to become vulnerable. The intersection between touch and boundaries is often so poorly marked that there are needless accidents causing unintended hurt.

Those who provide direct care to people with developmental disabilities are often asked to be in private places performing intimate services. From bathing, to toileting, to dressing, we are necessarily in close proximity to those we serve. Given this situation, it is imperative that staff be aware of how to provide these services while maintaining appropriate professional boundaries.

Even more confusing than establishing boundaries when providing physical assistance, is understanding your role in meeting the emotional and intimacy needs of people with disabilities. There are so many questions...

*Who are we to the people we serve? Are we friends? Are we a surrogate family? How do we appropriately express affection towards those we serve?
Should we let a person with a disability hug us even if it makes us uncomfortable?*

Because people with disabilities have often lived with loneliness and isolation, staff have seen the need for touch, for intimacy and for relationships. We need to find new and healthy ways of helping people with disabilities fulfill their deepest needs. Needing touch is one of the best things about being human. Building boundaries is one of the best things about being free.

Why are people with developmental disabilities so vulnerable?

- A.** Power Imbalances
- B.** Negative Attitudes
- C.** Learning to be Compliant
- D.** Isolation and Protection

A. Power Imbalances

- Abusive situations are always about power imbalances.
- A person in a position of power, trust or authority can use his/her power to control another person who has less or no power.
- People with developmental disabilities are at a greater risk since they usually depend on others or are taught to depend on others for the support they need.
- The chance of abuse increases with the degree of dependence that has been created.
- The person's mental or associated physical disabilities may make it more difficult for them to recognize, avoid or escape from risky situations. For example, if you are blind, you can't see your attacker coming. If you are deaf, you can't hear your attacker coming. If you can't physically defend yourself, you can't fight back. And, if you can't speak, you can't call for help or tell someone what happened afterwards.
- People with developmental disabilities look up to those who provide support as role models, mentors, friends and therefore, may not see themselves as being victims of abuse.

B. Negative Attitudes

- Attitudes are changing, however, people with developmental disabilities are still among the least valued and respected members of society.
- Risk is increased because offenders devalue and disrespect their victims.
- Negative attitudes are a result of myths and stereotypes that believe people with developmental disabilities are:
 - difficult to manage or are out of control
 - just like children
 - can't learn about or understand what's going on around them
 - are unable to feel pain or experience emotions such as sadness, loneliness, anger and love
 - are "oversexed" or have no sexual needs or desires at all
 - make up things and lie
 - are poor learners and need harsh consequences for certain behaviours in order to learn right from wrong
 - are dangerous to society
 - are less than human, and are better off dead
- Caregivers who believe that people are incapable, dangerous and unable to make their own decisions are not likely to encourage choice, community inclusion, or the development of communication skills. These skills give people power and without power the chance of abuse increases.
- Cultural beliefs and social attitudes may trivialize crimes committed against people with disabilities and rationalize them after they occur.
- It has been very difficult to bring an offender to justice. Police, lawyers and judges have been reluctant to proceed with criminal investigation or trial because they believed people with disabilities were not credible witnesses, distorted facts or made up stories. Although this is changing, often the reason abusers are not brought to justice is an agency's inability to deal properly with a disclosure.

C. Learning to be Compliant

- People with developmental disabilities are often encouraged or expected to follow the direction of their caregivers and follow established routines, instead of being encouraged to make their own decisions.

- Being a “people pleaser” increases the risk of abuse. Perpetrators look for people who are easy to manipulate and control.
- “No” is not readily accepted or encouraged.
- Teaching “no” and listening to the person when they say it is essential.
- Teaching assertiveness skills enabling the person to feel confident enough to say “no”.
- Understanding the word “no” and believing in the power it has is a very important part of the education you are providing.

D. Isolation and Protection

- Isolation increases the risk of abuse because it provides both opportunity and privacy for an offender.
- Segregation decreases the number of people who the person will feel safe going to for help if the abuse has occurred, as well as those who would recognize the warning signs.
- Over protection of the person supported will prevent them from experiencing the “dignity of risk.” With the dignity of risk comes new experiences, reasonable chances and trying new things. Without these opportunities, there is less access to information about different kinds of relationships, what abuse is and how to recognize dangerous situations, and what to do if abuse occurs.
- Learning through experiences provides the opportunity for risk taking in decision making. This builds confidence and people learn to rely on their own decision making abilities.
- In the past, we sheltered people (and to some extent we still do) making decisions for them, creating “learned helplessness”, which in turn increases vulnerability.
- With fewer opportunities to build a network of friends, the person is more likely to be dependent on family members, caregivers and service providers who might be abuse.

We can decrease vulnerability by teaching people boundaries, protection skills, appropriate social/sexual behaviour and how to say no, which in turn will enable them to be their own first line of defence against abuse.

POLICY REGARDING PERSONAL CARE FOR THE SPECIAL SERVICES AT HOME PROGRAM AT COMMUNITY MENTAL HEALTH CLINIC

Purpose

The purpose of this policy is to define in principle:

- i) The standard of behaviour expected of SSAH contract workers regarding their responsibilities when providing personal care to person(s);
- ii) What personal care is.

Introduction

David Hingsburger’s research has clearly identified that one of the main reasons that individuals with developmental disabilities are at higher risk of sexual victimization is due to the number of staff, volunteers and students who provide personal care. He argues individuals with developmental disabilities have difficulty discriminating between who can and cannot touch them. By staff providing personal care as soon as the contract starts, David argues that the message individual s with developmental disabilities receive is: **strangers can touch them.**

Personal care is defined as any physical touching which includes but is not limited to assistance with bathing, toileting, incontinent care and intimate hygiene.

Policy

1. Special Services at Home contract workers will not observe and/or provide personal care until after they have had a minimum of two weeks to develop a relationship of trust with the person(s). Someone who knows them well (e.g. parent/guardian) will need to provide the care over the two-week period. The maximum amount a new worker should be able to touch over the two weeks is on the person's arm and that is with his/her permission.
2. The two-week period begins from the first contact with the person(s). A SSAH worker who has worked with a person previously is required to complete this two-week period again if he/she returns to the contract.
3. Personal care should only be provided with the informed and explicit consent of the person(s) or appointed guardian(s).
4. In the case of an emergency where there is no parent/guardian available, the worker may intervene (e.g. seizure in the bathtub or if there is risk of injury).

The Ethics of Touch (*Diverse City Press, Quebec, 1998*)

Family Support Options has a training package entitled The Ethics of Touch. It consists of two videos (a 3 hour lecture in total) on "touch", "privacy" and "boundaries" by renowned trainer and consultant David Hingsburger. Along with the video lecture comes a training manual, co-authored by Mary Harber of the Sexual Health Resource Network at the Sunny Hill Health Centre for Children, British Columbia. SSAH contract workers can access the training package by contacting their Program Coordinator.

The following notes were taken from David Hingsburger's workshops and materials on The Ethics of Touch. They will provide guidelines in developing a respectful environment by establishing and maintaining appropriate boundaries in supporting people with disabilities.

Personal Boundaries

It is imperative that SSAH workers possess healthy, clearly defined personal boundaries, and respect for the personal boundaries of the person(s) they work with.

The fact that people with disabilities do not mind caregivers taking care of their personal needs without even knowing them is an issue. As a result of having so many workers they are used to having their privacy and personal space invaded regularly by "strangers." This can make them prime targets for abuse. Workers need to teach discrimination in terms of what the person(s) should say to them and what workers should be allowed to do with them. Workers must do all they can to teach people healthy personal boundaries and to model the same for them.

Drawing personal boundaries is healthy. Living without boundaries would be terrifying. Good boundaries make good relationships. Teaching people with disabilities to live behind healthy boundaries is a critical social skill. It also ensures that workers never even accidentally violate their trust. The invasion of privacy can be "subtle" and unintentional.

By understanding boundaries, workers can ensure that they are giving precisely the kind of respectful support that is needed. Workers need to remember that the clients they provide intimate/personal care to are at their mercy, dependent on their good will, good sense and good character. Many of the folks served can't speak up for themselves. Therefore, workers need to approach each situation as if they were on the other end of their own care.

The attitude, approaches and manner of workers needs to be respectful. They must always feel honoured to be allowed to provide intimate care. It's when workers forget to be honoured that they begin to treat people with dishonour.

Privacy is a Learned Skill

We have learned this skill without knowing we have. We learned the concept of privacy continually in our own home environments. It is important to provide opportunities for people with disabilities to learn this skill also. Privacy is a right, not a privilege. Workers must build in privacy for those they serve. People with disabilities have a right to physical and emotional boundaries. Workers must be careful not to invade people's personal boundaries without permission. As workers respect people's privacy every day, they will reinforce what they are teaching by modeling.

Privacy is a Mental Health Issue

We as individuals in society see the need for privacy for ourselves but not for people with disabilities. We enjoy moments of privacy at home, school or work. People with disabilities need the same freedom. Workers must work diligently at guarding their clients' need for privacy too.

We need to ask ourselves:

- a) Have we become desensitized to privacy issues?
- b) How can we maintain privacy, while doing intimate personal care?
- c) Do we respect individual's rights to privacy in their own homes or workplace?
- d) Do we have different standards for ourselves than we do for the people we support?
- e) Are we good role models?
- f) Are we teaching people that it's acceptable for strangers to touch their bodies?

Touch

Touch is a very important form of communication. It can convey comfort, caring, love, affection and reassurance. It can also convey degradation and abuse. The purpose of touch can be taken the wrong way due to culture, religion, personal values/beliefs and basic life experience. All procedures must be performed in a respectful competent and professional manner.

Standard Precautions

Standard precautions involve setting up barriers to prevent contact with blood, body fluids, or body substances. It is recommended that gloves be worn whenever there is possible contact with any of these. Disposable gloves act as a barrier to protect both worker and client from pathogens in the blood or other body fluids and from micro-organisms on the skin (cuts). Gloves are important to ensure that no contagious diseases are being transferred between worker and client.

Professional Use of Vinyl Gloves

Gloves should be worn during any and all personal care activities. Personal tasks include: assistance with toileting, diapering, dressing, tooth brushing, washing, bathing, and administering suppositories.

The use of gloves also acts as a visible barrier in the teaching around sexual abuse. Clients need to know that when a worker is completing personal tasks and is wearing gloves, that the task is being completed in a professional situation. Clients need to be aware that the touches are necessary to complete the personal hygiene routine. When possible, the worker should support the client to complete tasks hand-over-hand after asking permission to do so. The worker should always talk the client through the routine so the client is more comfortable with the process and understands the rationale for the task occurring. The worker should never force the client to let the worker touch him/her. Over time, clients will learn that a gloved hand is “professional” hand. This will also help clients to define that when gloves are not being worn, they should feel there may be some inappropriateness in the contact. A bare hand will hopefully signal a “red flag” for them.

PRIVACY AND CONSENT

A client’s right to privacy must be protected at all times. Exposure may be viewed as sexual abuse.

- **TEACH PRIVACY BY MODELLING PRIVACY**
- Make sure clients dress, bathe and use the toilet in private.
- Knock before entering a room.
- Close doors and blinds.
- Use proper draping procedures when assisting with personal routines where the client’s body may be exposed. Add barriers between the client and yourself (and any others in the vicinity). This can be accomplished by taking off and putting on one piece of clothing at a time, and covering parts of the client’s body with a towel or a sheet.
- **ASK PERMISSION TO DO OR ASSIST.** Always ask to see and always ask to touch. Do not proceed if the client declines assistance.
- **WAIT FOR CONSENT.** (Even if the person you are supporting is non-verbal, allow them time to indicate with body language if this touch is okay.)
- **EXPLAIN EACH STEP OF ANY PROCEDURE** – what you are doing and why. As you pair your words with your actions you will teach respectful touch.
- Remember to bring appropriate clothing when moving from location to location (e.g. bedroom to bathroom).
- Position yourself to give as much privacy as possible, if you must remain in private rooms (bedroom, bathroom).
- **KEEP PRIVATE SUBJECTS PRIVATE.** Do not discuss a person’s bodily functions, sexual habits or personal hygiene publicly; defer questions about private subjects to a private time and place; teach where and when certain subjects can be discussed, and follow those rules yourself. Even personal care skills like hair care and tooth brushing are personal routines which need to occur in private areas.

Bathing

Bathing is private and should be treated as such. When a SSAH worker must remain in the bathroom to provide assistance and for safety reasons, he/she will remember:

- The use of bubble bath (good quality to prevent genital irritation) can provide a privacy screen.

- Doors and blinds should be closed.
- To use a large sponge and gloves when hand-over-hand assistance is required.
- To give the client private time by standing away from the tub.
- To make sure all personal hygiene supplies are in the bathroom as well as towels, and clothes.
- That no company is allowed.
- To adapt the environment in any way possible (e.g. shower doors, shower curtains, half curtains) to provide as much privacy as possible.
- That conversation may increase the comfort level of the worker but may decrease the comfort level of the client in the tub. Use a gentle tone of voice and avoid eye contact when appropriate.

Wheelchairs

Workers should avoid leaning or touching a client's wheelchair without permission. The wheelchair is an extension of the person's body.

Hugging

People with disabilities often have a reduced sense of boundaries. You need to find respectful ways in which to clarify your role with those you serve so that they understand the boundaries in your relationship. This includes appropriate touch between worker and client.

Teach **APPROPRIATE TOUCH**. A frontal hug or kiss may be fine for the family members, but is not appropriate for the bus driver or the SSAH worker. If hugging and kissing are the only ways a client knows to express affection then boundaries can easily be crossed. Never initiate frontal hugs or kisses. Gradually wean clients off frontal hugs and slowly begin to introduce something else to show affection. Use side hugs during the weaning process. 20% of our affection skills use touch, 80% do not. Use and teach alternative ways of showing someone you like them: a handshake, a "high five", a wave, a touch on the upper arm or shoulder, a smile, a warm nod, a wink, a "thumbs up", or eye contact, verbal praise, listening, and spending time with the person.

When you engage in inappropriate hugging, you set the standard for the next staff member or anyone from the community. You teach the client it is acceptable for anyone to hug them. That next person may violate safe boundaries and abuse the client.

Statistics show that 80% of women and 60% of men with developmental disabilities have been sexually abused by the age of 18. 80-90% of the perpetrators of abuse are known to the victim; and people with disabilities are 83 times more likely to be a victim of violence by 50 years of age. (Ontario's Roeher Institute, 1995).

Create an **ADDICTION TO RESPECTFUL TOUCH**. A person who has learned to expect respectful touch will react to violation. Workers must not teach over-compliance. People with disabilities say "yes" even when they mean "no". **IT IS IMPORTANT** to give people with disabilities permission not to hug a person and to say "NO." By empowering clients to say "NO", workers create a hostile environment for the abuser and a safe place for people with disabilities to live.

A hug is a mutually agreed upon act. Without the agreement, it is assault. It is critical that clients understand this so they will recognize violation.

Rules of Touch for Children

Children generally start developing/learning:

- a) modesty around the age of 5;
- b) understanding of relationships around the age of 8; and
- c) social distance around pre-puberty.

Affectionate skills are emotional and greeting skills are social. Workers must help children differentiate between the two by making wise choices themselves. The hugging guidelines previously discussed should be applied for children as much as possible.

If contract workers are giving a child a quick hug, they must ensure they are not touching body parts other than the child's head or shoulders, and that the worker's hands are up high on the child's back/shoulder area.

Relationships

Sex education classes have taught people with disabilities there are private parts on the body that they cannot touch. By teaching them there are private parts versus public parts, we are still setting them up to be abusive or abused. We need to teach that all of the body is private, some parts are special, and only under certain conditions and circumstances can one person touch another person.

For most of us, we have a safe distance in which we find it acceptable to communicate with others. For people with disabilities, workers should teach them that a safe distance is four feet – not their skin. They are the world's perfect victims as they have little or no concept of personal space in relationships.

Workers must consciously assist clients with making the correlation between social distance and social relationships. Contract workers must always teach, demonstrate, and role model age-appropriate behaviour even though the social maturity level of the client may not match their chronological age. Despite developmental disabilities, all clients should be challenged to learn these social skills as they are essential in learning to protect oneself.

In this profession, most service providers are caring individuals. It is difficult not to become emotionally attached to the people who are being supported. However, contract workers must realize they are not family members. It is not their role to meet the emotional and friendship needs of their clients. While contract workers can be friendly in their approach, their role is to connect clients with real friends, not be their friends. This will ensure that clients do not become too emotionally attached to workers.