

Module 19. Working with an Independent Adult with Physical Disabilities

Goal

The goal of this module is to prepare participants to work within the consumer-directed model with adults living with physical disabilities,

Time

4 hours (includes 30 minutes for break and warm-up or closing)¹

Activities	Methods	Time
19.1 Introduction to Working with Consumers with Physical Disabilities	Interactive presentation, individual exercise, and discussion	1 hour
19.2 Working with Self-Directing Consumers	Interactive presentation, individual exercise, discussion	1 hour & 25 minutes
19.3 Responding to Sexual Behavior of the Consumer	Discussion, interactive presentation, small-group work, large-group role plays and discussion	1 hour & 5 minutes

Supplies

- Flip chart, markers, and tape
- Paper and pencils
- Index cards
- Blank writing paper
- Wheelchairs and/or crutches (enough for ¼ of participants)
- Cotton balls (enough for all participants)
- Eye patches (enough for ¼ of participants)
- Slings, neck ties, or rope to confine one arm (enough for ¼ of participants)

¹ Module 16 continues the focus on consumers with physical disabilities and is 3 hours long. Modules 15 and 16 are designed to be presented in the same day, which will still fit the 7-hour framework (with additional time for the lunch break).

Handouts

- Handout 19.1 Understanding Physical Disabilities
- Handout 19.2 Help Wanted: Personal Assistant
- Handout 19.3 Joe's Requests
- Handout 19.4 Responding to Appropriate Sexual Behavior
- Handout 19.5 Responding to Inappropriate Sexual Behavior

Advance Preparation

Review all the training instructions and materials for this module.

Copy all handouts for participants.

Consider inviting a self-directing consumer with a physical disability and/or their personal care worker to be guest speakers for this module. You can show them the learning outcomes and ask if there are any they would like to address. Or you can simply ask them to speak about their experiences, focusing on the tasks that are done with a personal care worker and how consumer-direction works for them. Some activities would have to be cut from the module for the sake of time, but it would be well worth it for participants to have a chance to hear from and ask questions of a self-directing consumer.

Warm-up/Introductory Activity

⇒ Teaching Tip

Each module of this curriculum leaves time for the instructor to include a warm-up or introductory activity in the first 15 minutes of the day. In this module, we suggest instructors build the following activity into that warm-up time to prepare for the rest of the module.

Explain that to build empathy for persons with physical disabilities, participants will experience a variety of limitations during this module. These limitations are meant to give them a sense of what a consumer with that disability might experience. However, it should be viewed only as an introduction to that experience. For example, wearing a blindfold for an hour cannot give an accurate sense of what it is like to live in our society as a person who is blind. Yet, it is a start.

The experiential “limitations” will be:

- Eye patches or a scarf over both eyes
- Cotton in the ears
- A sling or tie for their dominant arm
- A wheelchair or crutches, with the instruction that no weight can be put on their right leg.

Module 19. Working with an Independent Adult with Physical Disabilities

Ask participants to count off by 4's – 1-2-3-4, 1-2-3-4, and so on. All the “1's” will be assigned eye patches, all the “2's” will put cotton in their ears, etc. At the beginning of Activities 19.2 and 19.3, participants will be asked to report briefly on their experience of limitation and to switch to a different limitation. By the end of the module, they will have experienced three out of four limitations.

Activity 19.1: Introduction to Working with Consumers with Physical Disabilities

Prepare flip chart pages for “Learning Agenda” (step 1), “Disability” (step 3), “Goals of Working with Consumers with Physical Disabilities” (step 12), “The Role of the Direct-Care Worker in Assisting Consumers with Physical Disabilities” (step 13), and “Causes of Stress for Consumers with Acquired Physical Disabilities and Their Families” (step 15).

Activity 19.2: Working with Self-Directing Consumers

Prepare flip chart pages for “Self-Directing Consumers” (step 3), “What to do if the job involves tasks or services that make you uncomfortable” (step 12), “Assertiveness” (step 13), “Tips for Being Assertive” (step 16), and “Assertiveness Role Plays” (step 17).

Activity 19.3: Responding to Sexual Behavior of Consumers

No advanced prep.

Closing Activity

Remember in your closing activity to include some discussion of how participants felt experiencing the various physical limitations. Here are some suggested questions:

- *How did you feel during the day while experiencing physical limitations?*
- *What is the most important thing you learned today about having a physical disability?*
- *How has your thinking about people with physical disabilities changed, if at all?*
- *What questions would you now want to ask a person with a physical disability?*

ACTIVITY 19.1 Introduction to Working with Consumers with Physical Disabilities

1 hour

Learning Outcomes

By the end of this activity, participants will be able to:

- Define disability and describe the various types of physical disabilities that their consumers may have.
- Identify some of the general differences between this consumer group and those they have studied already and how those differences affect their role as a direct-care worker.
- Describe how the range of services may be different under consumer direction than in an agency-supervised work setting.
- Describe the goals and the role of the direct-care worker in working with consumers with disabilities and their families.

Key Content

- ❖ A disability is defined as a physical or mental impairment that substantially limits one or more major life activities. Disabilities:
 - May be temporary or permanent
 - May be caused by illness, injury, or other factors
 - May affect physical or mental functions or both
- ❖ Types of disability are:
 - Physical – resulting from illness or injury affecting one or more body systems
 - Emotional – resulting from mental illness or a physical condition
 - Developmental – resulting from illness or injury before, during, or after birth, or in early childhood
- ❖ A consumer with a physical disability directing his or her own care is likely to be a young or middle-aged adult, but elders may also use this model. The goals of working with consumers with physical disabilities are to promote self-care and independence and to maintain dignity and self-respect.
- ❖ The direct-care worker, often called a personal care aide or attendant in this context, achieves those goals by assisting the consumer with:
 - Personal care and other ADLs
 - Housekeeping
 - Shopping
 - Planning and preparing meals
 - Going with consumer to appointments and community or social engagements

Another important function of the direct-care worker is to provide relief for other caregivers, typically family.
- ❖ For people whose disability is the result of injury or illness (i.e., “acquired” as opposed to a developmental disability), the disability causes many changes in their lifestyle. The direct-care worker can assist the consumer and the consumer’s family in managing these changes, including:
 - Changes in routine
 - Changes in income
 - Disruption in plans
 - Role changes
 - Changes in self-image
- ❖ Acquired disabilities often are accompanied by a sense of loss, leading to anger,

depression, and denial. By being supportive and accepting, the direct-care worker can help the consumer to address this sense of loss.

- ❖ The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in the areas of employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. The direct-care worker can inform the consumer and the family about their rights and may be able to refer them to resources to help them exercise their rights.

⇒ **Teaching Tip**

During the 15-minute warm-up activity, assign one of four physical “disabilities” to each participant (see Advance Preparation for detailed instructions).

Activity Steps

Interactive presentation (10 minutes)

1. Introduce the module by posting the flip chart page with the topics to be covered. Note that many elder consumers have disabilities and what participants learn about disabilities in this module will apply to elders also. The reason why this module focuses on younger adults—from late teens up through middle age—is that most of the younger consumers that they will work with will have some kind of disability. Note that, as before, participants will review and build on what they have already learned from the previous modules and apply that to working with consumers who have a physical disability.



LEARNING AGENDA: **MODULE 15**

- Physical disabilities and the needs of consumers
- Working with a self-directing consumer
- Respecting sexuality of a consumer and responding to sexual situations

2. Ask participants: *What does the word “disability” mean to you? Or, what does it mean if we say someone is “disabled?”*
3. After a few responses, post and review the flip chart page on disability.



DISABILITY: a physical or mental condition that limits one or more major life activities.

TYPES OF DISABILITIES

- Physical
- Emotional
- Developmental

DISABILITIES MAY BE:

- Temporary or permanent
- Caused by brain injury around time of birth, illness, accident, or other injury

Individual exercise (10 minutes)

4. Explain that this module will focus on working with people with physical disabilities. (Emotional and developmental disabilities will be addressed in Module 18.) Ask participants to brainstorm all the different kinds of physical disabilities that they know of. List their responses on a flip chart page. (This list should include being blind, deaf, or mute, and morbidly obese as well as various types of paralysis—e.g., paralyzed from the waist down, from the neck down, etc.)



PHYSICAL DISABILITIES:
EXAMPLES

5. Ask participants to think about the disability they have been assigned for this exercise (vision, hearing, mobility). Distribute a blank sheet of paper to each participant and ask them to write that disability at the top of the paper.
6. Ask them to close their eyes and imagine that they have this disability permanently. Ask them to keep their eyes closed and think about the following questions:
 - *How would your life change as a result of having this disability?*
 - *What activities would you not be able to do on your own anymore, if any?*
 - *How would your relationships change, if at all?*
 - *Which change would be the most difficult for you to accept?*
 - *What kind of assistance would you need to keep doing the things that you currently do?*
7. Ask participants to open their eyes and immediately write on their sheet of paper what kind of assistance they would need to maintain their normal life with this disability.

Discussion (10 minutes)

8. After everyone has finished writing, ask participants to share some of their thoughts and feelings about having a physical disability. Briefly discuss each of the questions from step 6.

Interactive presentation (15 minutes)

9. Explain that by imagining themselves having a physical disability (and by experiencing some disabilities during this module), they should be better able to understand what a consumer feels and what he or she might need from a direct-care worker. Note that having a physical disability does not necessarily change how people feel about themselves and how they relate to others. Point out how they were able to imagine continuing their normal life with a little assistance.
10. Note that you have been talking about “people with physical disabilities,” rather than calling them “handicapped.” Ask participants:
 - *What does the word “handicapped” mean to you?*

After a few responses, note that many people with physical disabilities dislike the use of that word. This is at least partly because, in the past, people who were called “handicapped” were treated badly and not allowed to do many normal activities that they were actually capable of doing. Many people associate the word “handicapped” with people whose only means of support was from begging.

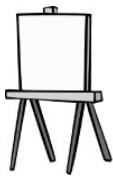
11. Summarize by noting the importance of looking at what a person with a physical disability *can* do (i.e., their ability), rather than what they *cannot* do. With some assistance, many consumers with physical disabilities are able to maintain a home, raise a family, hold a job, be active in their community, and pursue personal goals and dreams.
12. Post and discuss the prepared flip chart page on “Goals of Working with Consumers with Physical Disabilities.”



GOALS OF WORKING WITH
CONSUMERS
WITH PHYSICAL DISABILITIES

- Promote self-care and Independence
- Maintain dignity and self-respect

13. Post and review the prepared flip chart page on “The Role of the Direct-Care Worker in Assisting Consumers with Physical Disabilities.” Note how many of these tasks were mentioned by participants in the discussion of what assistance they would like if they had a physical disability.



THE ROLE OF
THE DIRECT-CARE WORKER
IN ASSISTING CONSUMERS
WITH PHYSICAL DISABILITIES

- Personal care
- Housekeeping
- Shopping
- Plan and prepare meals
- Provide relief to other caregivers
- Go with consumer to appointments and community or other social engagements

Discussion (15 minutes)

14. Note that in situations where a disability is “acquired” from injury or illness—as opposed to being something the consumer was born with—helping to decrease the stress for consumers and their families is one important role for a direct-care worker. Any kind of illness or injury

leading to disability will cause many changes for the consumer and their family, most of which are stressful. The direct-care worker can help them adapt to these changes.

15. Post and review the prepared flip chart page about the causes of stress for people living with an acquired disability and the role of the direct-care worker in helping to lessen that stress. For each type of change, ask participants to discuss these two questions:

- *How might the changes be stressful for a consumer with an acquired disability and/or the consumer's family?*
- *How can the direct-care worker help to reduce that stress?*



CAUSES OF STRESS
FOR CONSUMERS WITH
ACQUIRED PHYSICAL DISABILITIES
AND THEIR FAMILIES

- Changes in routine
- Changes in income
- Disruption in life plans
- Role changes within the family
- Changes in self-image

16. Note that many of these changes are experienced by the consumer and the family as a “loss.” This can lead to emotional responses similar to grief—e.g., denial, anger, or depression. Explain that by using the communication skills of listening and asking open-ended questions, the direct-care worker can show support for and acceptance of the consumer, which can help reduce some of the emotional stress from the sense of loss.

17. Note that some of the “losses” people with acquired disabilities experience are the result of discrimination—e.g., it may be more difficult to find a job or a place to live. Explain that the Americans with Disabilities Act is a law that makes it illegal to discriminate against a person because he or she is disabled. This applies to employment, public accommodations, commercial facilities (e.g., banks, restaurants, stores, and other businesses), transportation, and telecommunications. The direct-care worker can inform the consumer and the family about their rights and provide them with information about resources to help them exercise their rights, if needed.

18. Distribute Handout 19.1, “Understanding Physical Disabilities,” for participants to add to their resource binders.

Module 19. Working with an Independent Adult with Physical Disabilities

19. Explain that before the next activity, there will be a short break. While still experiencing their assigned physical limitation, everyone should take this opportunity to either go to the restroom or out to the street. When they return, groups will be given a new disability to experience.

ACTIVITY 19.2 Working with Self-Directing Consumers

1 hour & 25
minutes

Learning Outcomes

By the end of this activity, participants will be able to:

- Describe a self-directing consumer.
- Describe the role of the direct-care worker in the consumer-directed service delivery model and the relationship between the consumer and the direct-care worker.
- Demonstrate how to use good communication skills to clarify consumers' requests and to negotiate when a request makes the worker uncomfortable.
- Define assertiveness and describe when it is important for a direct-care worker to be assertive with a consumer.

Key Content

- ❖ Consumer direction refers to a model of service delivery for people with disabilities, both young and old, who are mentally capable of making their own decisions. In this model, the consumers are described as “self-directing,” which means they employ and supervise their own workers.
- ❖ Self-directing consumers are mentally alert and able to make choices, understand the consequences of their choices, and assume responsibility for the results of those choices. The role of the direct-care staff person is to support consumers in living their lives as fully as possible.
- ❖ In the consumer-directed model, because the consumer determines what goes into the service or care plan, there is more flexibility in the services and supports that the consumer can request. Whether services are paid for with government funds or by the consumer privately, there should be a care plan or some written agreement that states what services are expected.
- ❖ Under consumer direction, direct-care workers may be asked to do things they may not feel comfortable doing. (This can happen in any long-term care setting, but is more likely in the consumer-directed model.) Direct-care workers have the right to express their discomfort and to clarify which tasks they will and will not do. This is especially important to address during the interview and contracting phase. Whether during the interview phase or already employed, the direct-care worker needs to be mindful that the consumer has a right to ask for assistance and that refusing to do a particular task or perform a specific service for the consumer could mean that they will not get (or keep) the job.
- ❖ Using communication skills of active listening, paraphrasing, and asking open-ended questions will help the worker to better understand requests especially when those requests are initially confusing or unsettling.
- ❖ It is also important to be assertive and clear when communicating about a task or service request that the worker is not comfortable doing. Being assertive means being able to express oneself and one’s rights without disrespecting and/or violating the rights of others.

Activity Steps

Discussion (5 minutes)

1. Ask for one volunteer from each “disability” group to share how their functional limitation affected them in the previous activity. Then reassign the functional limitations so each group has a new experience, either with vision, hearing, or mobility.

Interactive presentation (15 minutes)

2. Ask participants what they remember about the definition of consumer direction (Module 2.1) and how it is different from other work settings. Emphasize the main points: 1) the consumer is the supervisor of the direct-care worker and is usually responsible for hiring and firing, and 2) the consumer determines what services and supports are to be provided by the worker. The consumer in this model can be described as “self-directing.”
3. Post the prepared flip chart page and discuss characteristics of a self-directing consumer.



SELF-DIRECTING CONSUMERS:

- Are mentally alert
- Are able to make choices
- Understand the impact of those choices
- Assume responsibility for the results of those choices
- Need assistance to physically perform some activities to carry out their choices

4. Distribute Handout 19.2, “Help Wanted: Personal Assistant.” Ask for a volunteer to read the ad aloud. Briefly discuss how advertising and interviewing are used in consumer direction.
5. Then read aloud the notes of the direct-care worker who answered the ad and was interviewed by Joe Capella. Ask participants:
 - *How is Joe Capella different from other consumers that we have “met” so far?*

Individual exercise (10 minutes)

6. Distribute and review Handout 19.3, “Joe’s Requests.” Emphasize that Joe has the right to state his needs as done in this activity. Joe wants to hire a direct-care worker who can help him maintain a lifestyle that is as close to normal (for him) as possible. Remind participants of the list they wrote in the previous activity, identifying what kind of assistance they would need if they were physically disabled. Each person will have a different set of needs and all are valid.
7. Review the instructions on the handout. Using the first request as an example, answer for yourself if you (the instructor) would put a ✓, ?, or X next to it, with a brief explanation of your reasons.

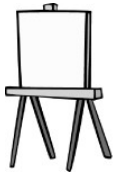
8. Give participants 5 to 10 minutes to complete the worksheet, working on their own.

Discussion (10 minutes)

9. After everyone is finished, ask participants:
 - *What were some tasks that you would do without question (the ones you placed a ✓ next to)? Why?*
 - *Does anyone feel differently about those same requests? Why?*
10. Ask the same questions about those requests that people would definitely not feel comfortable doing (those with an “X”) and those they were not sure about (“?”). Note that different people have different levels of comfort with particular tasks. This is normal, but they need to remember that the consumer has the right to make any requests.
11. Hand out three index cards to each participant. Ask participants to identify the three requests that they were the *least* comfortable with and write one request on each index card. They will keep their cards for the next exercise.

Interactive presentation (15 minutes)

12. Explain that it is common for workers to be asked to do things they don’t feel comfortable doing. This can happen in any long-term care setting not just in the consumer-directed model. In other settings, the tasks are set forth clearly in the care plan. With consumer direction, the tasks are set from the beginning by the consumer, starting with the job interview. The worker needs to be clear about what the consumer wants the worker to do. If the worker is not comfortable with the consumer’s requests, they have several options. Post the prepared flip chart page and discuss these four options:



WHAT TO DO IF THE JOB
INVOLVES TASKS OR SERVICES
THAT MAKE
YOU UNCOMFORTABLE:

Options

- Clarify the task and the need
- Negotiate
- Get a written contract or service plan that you agree with
- Don't take the job, or resign if a new agreement can't be reached!

⇒ **Teaching Tips**

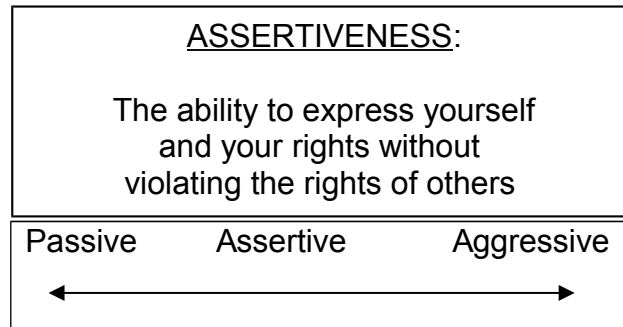
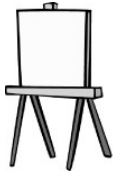
The presentation should touch on the following:

- 1) Clarify what the consumer is requesting and why *you* are needed to do this. Paraphrase and ask open-ended questions to make sure that you understand the request and the need.
- 2) Ask if the tasks or services can be negotiated. Say which ones you can do and which ones you can't or won't do and explain why. Discussing this during the interview is important to establish clear expectations and boundaries around your work. Be aware, though, that the consumer may not hire you if you cannot do the tasks and/or provide the services or supports requested.
- 3) If you take the job, make sure the tasks and services that you agreed to do are written in a work agreement/contract (which is like a service plan) as the basis for your job description. The work agreement can include an acknowledgement that the plan will be used for regular performance review and feedback and might change based on changes in the consumer's needs. Including this statement establishes the understanding that both the consumer and worker can expect future changes and that each new request should be negotiated.
- 4) Don't take the job, or resign if a new agreement can't be reached! Ask participants to think about where they would draw the line. How would they find out from the consumer if he or she might require assistance that crossed that line?

13. Note it is important to be clear and firm when communicating your discomfort to the consumer and negotiating which tasks or services you will and will not do. This is called being “assertive.” Ask participants:

- *What does the word “assertive” mean to you?*

After a few responses, post the prepared flip chart page and review the definition.



14. Note the continuum at the bottom of the page and ask participants:

- *What is the difference between “passive” and “aggressive”?*
- *How is being “assertive” different from being “passive” or “aggressive”?*

⇒ **Teaching Tip**

When you are being *aggressive*, you are expressing yourself and your rights, but violating the rights of others. Being *passive* is the inability to express either yourself or your rights, and in this position, people may take advantage of you or violate your rights.

15. State that it is important in direct-care work to be assertive in your communications with consumers while allowing the consumer to assert their own needs. This is true in all models of service delivery, but may feel more challenging when working with a self-directing consumer who is concerned about their loss of independence. Having a relationship where both people are comfortable being assertive opens the flow of communication and leads to more constructive interactions.
16. Note that being assertive is not always easy. Post the prepared flip chart page with the tips for being assertive while “negotiating” with the consumer.



TIPS FOR BEING ASSERTIVE WHEN
NEGOTIATING WITH THE
CONSUMER

- Be clear in your own mind about what you think and feel
- Use “I” statements to express your thoughts or feelings – “I think...”; “I feel...”; “I’m not comfortable with...”
- Be specific about what makes you uncomfortable or what you’re not willing to do

Demonstration role play (5 minutes)

17. Explain that you are going to demonstrate using these tips in negotiating with “Joe” about a task that he wants you to do, but you’re not comfortable doing. Note that participants will also practice this by role-playing in pairs. Post and review the flip chart page with the role-play steps.



ASSERTIVENESS ROLE PLAYS

- Paraphrase to clarify
- Ask open-ended questions to understand how this would be helpful
- Be assertive – use “I” statements and be specific about what makes you uncomfortable
- Respect the consumer’s need; be honest about your discomfort
- Ask if there is some way this could be done without you doing it

18. Ask for a participant to volunteer to help you demonstrate. Ask him or her to choose one of their index cards with the tasks they are *least* comfortable with. Explain that the participant will play Joe, and you will play the worker. The participant will ask you to do that task. Then you will demonstrate how to paraphrase, ask open-ended questions, be assertive, be respectful, and explore other ways of getting the job done.
19. After the role play, ask if there are questions about the steps.

Pairs work: Role plays (10 minutes)

20. Ask participants to form pairs. Have one participant give one of their “least comfortable” cards to their partner. The partner plays the role of Joe and asks the “worker” to do this task. The worker then role plays being assertive, communicating his or her discomfort, and negotiating another way to do this job.
21. Role players switch roles and repeat the process with a task that the other participant finds to be “least comfortable.”

Discussion (15 minutes)

22. Ask participants to return to the large group and briefly share how the role plays went—what was easy, what was difficult, what they learned.
23. Ask participants:
 - *What is the most important thing you have learned so far about working with self-directed consumers?*
24. Ask participants, with their current functional limitation, to use the break between activities to go to the restroom or to get some fresh air by leaving the building. Remind them that when they return, each group will experience a new limitation.

ACTIVITY 19.3 Responding to Sexual Behavior of the Consumer

1 hour & 5 minutes

Learning Outcomes

By the end of this activity, participants will be able to:

- Explain the importance of respecting the sexual needs of a consumer.
- Distinguish between appropriate consumer requests related to their sexual needs and inappropriate sexual behavior.
- Demonstrate respectful and assertive responses to potentially inappropriate sexual behavior (verbal or physical) of the consumer.

Key Content

- ❖ Sexuality is a basic part of everyone's life, consisting of all of our thoughts, feelings, and actions related to being male or female. It is shaped by our beliefs, cultures, and social norms.
- ❖ When someone has a disability or is aging, that person's sexuality and sexual desire does not disappear. The need for warmth, caring, and security may increase when an individual is suffering from chronic disability and loss. The ability to engage in sexual activity, such as intercourse or masturbation, can continue in spite of illness or disabling conditions. Thus, it is important to be aware of and respect the sexual needs of the individual consumer.
- ❖ This sexual need sometimes complicates the relationship between the direct-care worker and the consumer. Direct-care work is very intimate and, over time, the relationship formed between the worker and consumer usually strengthens. Drawing on that closeness, sometimes consumers (and possibly family members) make sexual advances towards the direct-care worker.
- ❖ For the direct-care worker, pulling back from an emotional response in such a situation is important. Paraphrasing is also essential to be clear about what was said. Using a clear "I" statement helps in being assertive, along with a firm statement of your boundaries. Being respectfully assertive in these kinds of situations can help to affirm the consumer's sexuality, at the same time as maintaining professional boundaries and the worker's rights.

Activity Steps

Discussion (5 minutes)

1. Ask a different volunteer from each group to share how their functional limitation affected them. Assign new functional limitations—either seeing, hearing, arm motion, or mobility.

Large-group exercise: Anonymous survey (5 minutes)

2. Note that this activity is about responding to sexual behavior of the consumer. Explain that before you begin, you want to take a quick “anonymous” survey.
3. Ask participants to close their eyes. Read the statement: “Consumers with physical disabilities should not have sex.” Ask participants to keep their eyes closed and raise their hands if they agree with the statement. Quickly count the number of hands raised, note the number, and then ask participants to put their hands down.
4. Ask participants to still keep their eyes closed and raise their hands if they *disagree* with the statement. Again, quickly count, make a note, and ask participants to put their hands down.
5. Tell participants they can open their eyes; thank them for their honesty. Explain that you’ll announce the “results” of the survey in a few minutes.

Interactive presentation (15 minutes)

6. Briefly present the information in the first two bullets of “Key Content.”
7. Now, share the results of the class survey. Note that, regardless of how they “voted,” it is important for them to know how they personally feel about consumers’ sexual behavior; one purpose of the survey was to start them thinking about that. For many people, this is an area of life that makes them uncomfortable. However, as a direct-care worker, they need to be able to work with people who definitely have sexual feelings and may be sexually active. So they may have to learn how to set their discomfort aside, in order to be able to deal with sexuality of consumers.

⇒ **Teaching Tips**

- One purpose of the survey is to give you, the instructor, a quick sense of the attitudes of participants toward sexual behavior for consumers with physical disabilities. This is a very crude “survey,” however; participants may find the question confusing and may want to change their “votes” after some discussion.
- The other purpose is to show participants that, on one hand, they have a range of opinions about the sexuality of consumers, and on the other hand, they are not alone in their opinions. The main point is that, regardless of the workers’ feelings, consumers have the right to be sexual. As workers, they have to find some way to deal with that.

8. At the same time, direct-care workers need to be able to tell the difference between sexual expression that is acceptable within the boundaries of direct-care work and sexual expression that is not acceptable. A quick *assertive* response can help to defuse situations that are not acceptable, before they become major issues or problems.
9. Note that Joe, the consumer profiled in this module, is a healthy 25-year-old male who enjoys sex. Distribute Handout 19.4, “Responding to Appropriate Sexual Behavior” and read the scenarios to the group. Note that each scenario is an *appropriate* expression of sexuality by Joe—in other words, he has the right to do each of these activities. Their task is to figure out what is an appropriate response as a direct-care worker.
10. Explain that, in fact, there are many ways to respond to these situations, and these could be drawn on a continuum, much like assertiveness. One end of the continuum, or one extreme, is being totally disrespectful to Joe and his sexual needs. The other extreme is being overly supportive, whether you feel comfortable or not. The most appropriate response is somewhere in between those two extremes—acknowledging the consumer’s need as well as your own feelings of comfort or discomfort.
11. Give an example. Using the first scenario—passionate kissing with a date—your disrespectful response might be to say, “Stop that right now! Joe, you know I have to work in this room today!” The too-supportive response might be, “Oh, hi, don’t mind me, I’ll just clean around you two ...” The in-between response would be, “Excuse me, Joe. I really need to clean in this room. Do you think you and your friend could go to another room until I’m done?”

Pairs work (10 minutes)

12. Put participants into pairs and assign one scenario to each pair. Ask them to think of three responses to their scenario—one disrespectful, one that is so supportive that it goes against their own feelings, and one that appropriately acknowledges both the consumer’s rights and their own feelings and professional boundaries.

⇒ **Teaching Tips**

- Sexuality is a taboo topic to discuss in such a frank way, so there is likely to be some comments, laughter, and giggles. A little laughter is a good release of nervousness, but you may need to remind participants that this is also a very serious assignment.
- By exploring both the extreme responses and the appropriate response, participants should be able to identify some of their own biases. However, it may be a challenge to find the “in-between” response. Monitor the groups and help them if needed.

Group reports and discussion (15 minutes)

13. Ask each group to report their three responses, beginning with the two extreme responses and ending with the appropriate response. Ask the rest of the group if they agree with the “appropriate” response or what else they would suggest.

Discussion (15 minutes)

14. Remind participants that, while it is important to accept sexuality as a normal part of the consumer’s life, it is not okay for anyone you are supporting to make inappropriate sexual remarks or advances toward you. Present the information in the last two bullets of “Key Content.”
15. Distribute Handout 19.5, “Responding to Inappropriate Sexual Behavior.”
16. Read each scenario one at a time, and ask participants to suggest responses that are both respectful and assertive. Remind participants about “pulling back” from their own emotional reaction. Remind them also about the power of: using the “I” statement in being assertive—e.g., “I am not comfortable with this behavior...”; and being clear about your boundaries—e.g., “If you need to masturbate now, I will leave the room and do other work until you are done.”
17. Ask participants what they learned from this activity. Remind them about the normal aspects of sexuality and sexual feelings—for workers as well as consumers—in all settings, not just with consumers with disabilities. Be sure to emphasize that, though unwanted sexual advances from a consumers in long-term care are not the norm, it is also not uncommon in any setting—not just with self-directed consumers. Being respectfully assertive in these kinds of situations can defuse the situation, by affirming the consumer’s sexuality, at the same time as maintaining professional boundaries.

Module 19 Handouts

Working with an Independent Adult with Physical Disabilities

Activity 19.1: Introduction to Working with Consumers with Physical Disabilities

Handout 19.1

Understanding Physical Disabilities

Activity 19.2: Working with Self-Directing Consumers

Handout 19.2

Help Wanted: Personal Assistant

Handout 19.3

Joe's Requests

Activity 19.3: Responding to Sexual Behavior of the Consumer

Handout 19.4

Responding to Appropriate Sexual Behavior

Handout 19.5

Responding to Inappropriate Sexual Behavior

Handout 19.1—Understanding Physical Disabilities

Page 1 of 2

A disability is a condition that limits the way we:

- Move
- See, hear, touch, taste, or smell
- Think
- Feel

Physical disability:

A physical disability means that a part of the body (or a system) does not work the way it is supposed to. This makes it harder to do daily activities.

A physical disability may last only for a while. Or it may last for the rest of your life.

Some people are born with a disability. Others become disabled when they get hurt or sick. Older people may also become disabled by the normal changes of aging.

Goals of working with consumers with physical disabilities:

- Assist the consumer to take care of themselves and to live as independently as possible
- Assist the consumer to maintain dignity and self-respect

Handout 19.1—Understanding Physical Disabilities

Page 2 of 2

You can assist consumers with physical disabilities by:

- Assisting with personal care
- Assisting with housekeeping
- Assisting with shopping
- Assisting to plan and prepare meals
- Providing relief to other care-givers
- Going with consumer to appointments and other activities outside the home

These changes can cause stress for consumers with acquired physical disabilities and their families:

- Changes in routine
- Changes in income
- Interrupted life plans
- Role changes within the family
- Changes in self-image

Handout 19.2—Help Wanted: Personal Assistant

Page 1 of 2

You are a direct-care worker, and you saw this ad in the local newspaper.

**Personal Assistant Needed
20 hours per week**

I am a physically disabled young man. I need help getting around. I am looking for someone who can help me shower, dress, and use a wheelchair. I need someone who has a car and is willing to run errands for me. I am friendly and easygoing. I can pay you \$8.00 per hour. Call and leave your name and telephone number at: 555-3833.

Handout 19.2—Help Wanted: Personal Assistant

Page 2 of 2

You called and set up a meeting with Joe. After the meeting, you made some notes. Here's what you wrote.

Joe is 25 years old. He lost use of his legs in a car accident 2 years ago, riding home with a friend after a night of drinking. The friend was driving and fell asleep and the car crashed. Joe was not wearing a seatbelt, and his spinal cord was hurt.

Joked about the crash but says he lost a lot more than the use of his legs. Used to live with his girlfriend who left him after the accident. He relies on friends to drive him places. Lives with mother and says he feels like a kid again.

Used to work as a store clerk and really like the job. Said he's "stuck in these 4 walls" and "chained to the wheelchair." Watches TV a lot and goes out with friends sometimes. Still goes to clubs once in a while. But gets him down for days because he drinks too much.

Used agency aides at first. Liked them but they fought a lot with his mother because she kept bossing them around. Mother's the caregiver now but she's tired and wants him to have his own personal assistant again. Says she'll "mind her own business" and let Joe be "the boss" this time. Joe will hire and be in charge.

Seems nice and easy to talk with. Has limited use of his arms, uses catheter and needs help emptying it and keeping it clean. Needs help getting in and out of the shower. in/out of bed and other daily tasks, like dressing, shopping, getting to appointments. Talked a lot about meeting girls.

Handout 19.3—Joe's Requests

Page 1 of 2

Imagine that, during your interview, Joe asks you to do these tasks. Think about how you would feel.

Write:

- √ If you **would** do the task
- ? If you are **not sure you should** do the task
- X If you **would not** do the task

_____ Buy beer for him.

_____ Buy his mother a birthday present.

_____ Change the cat's litter box.

_____ Clean his genital area before the rest of his body.

_____ Clean his room.

_____ Clean his wheelchair.

_____ Clip his toenails.

_____ Cook macaroni and cheese for dinner.

_____ Do the dishes.

_____ Do his grocery shopping.

_____ Dust the living room.

Handout 19.3—Joe’s Requests

Page 2 of 2

- _____ Go to church with him.
- _____ Go with him to a sports bar.
- _____ Ignore anything his mom tells you to do.
- _____ Iron his shirts.
- _____ Listen to music with him.
- _____ Make dinner for his new girlfriend.
- _____ Make his bed while he is still lying in it.
- _____ Make his mom’s bed.
- _____ Put lubricant on his penis just before his date arrives.
- _____ Scratch his back.
- _____ Shave his face.
- _____ Stop his mother from coming into his bedroom.
- _____ Take him down the street to the post office.
- _____ Walk his dog and clean up the feces.
- _____ Wear “street clothes” instead of a uniform.
- _____ Work Saturday instead of Monday.

Handout 19.4—Responding to Appropriate Sexual Behavior

Page 1 of 1

Responding to Appropriate Sexual Behavior

Joe Capella is a healthy 25-year old male who enjoys sex. These are appropriate behaviors for him. What might be an appropriate response by you, as a direct-care worker?

What if...

- Joe has a date at the house when you arrive and they are passionately kissing and fondling while you are working near them?
- Joe watches a pornographic movie while you are working in the same room?
- Joe asks you to accompany him to a local stripper bar?
- Joe explains what he'd like you to do around the house (normal tasks) and then asks for some privacy while he has sex with his girlfriend in the bedroom?
- Joe asks you to position him in his bed for a sexual encounter with a woman?
- Joe's sexual partner is a man?

Handout 19.5—Responding to Inappropriate Sexual Behavior

Page 1 of 1

Responding to Inappropriate Sexual Behavior

Respecting sexuality is important. But setting boundaries is equally important. Be respectful AND assertive when you respond to these situations.

What if...

- Joe rubs your breast as you bend over him?
- Joe asks you to wash his penis for him (when he is capable of doing it himself)?
- Joe is masturbating while you are working near him?
- Joe wants to be naked while you are in the house?
- Joe asks you to have sex with him?