Respite Care Training Program

ifespan Caring Network

Topics Covered

- Disability Basics
- Client Care
- Medication Administration
- Abuse and Neglect
- Communication Techniques
- Coping with Challenging Moments
- Free Time Activites
- Meeting with Clients and Caregivers

*Adapted and used with permission from "Lifespan Respite Training Manual" published by the Respite Care Association of Wisconsin





The Illinois Respite Coalition

- In 2010, Wisconsin received a three-year federal grant to expand the availability and accessibility of respite services in Wisconsin, through a unique collaboration between the WI Department of Health Services/Division of Long Term Care, the Respite Care Association of Wisconsin, and Easter Seals Wisconsin. Together, they collaborated and created the Respite Care Training Program, a program designed to train respite workers for families across their state.
 - Thanks to their hard work and with their permission, the Illinois Respite Coalition is proud to offer their training to individuals in Illinois interested in becoming respite workers. As the public's knowledge of respite and its need grows across the country, the IRC seeks to bring as many resources for caregivers to Illinois.
- If you have any questions on this training or its materials, please contact the IRC at (630) 205-3627 or by email at thielenc@maryvilleacademy.org.



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What is Respite?

- Adapted from "Lifespan Respite Training Manual"
- published by Respite Care Association of Wisconsin

Topics Covered:

- What is Respite Care?
- Common Terms Related to Respite Care
- Assets of a Respite Care Provider

What is Respite Care?

When we take a breather from responsibilities or regular activities, we may envision a variety of options: a coffee break, a lunch break, a break from a particular project, or a break from the boss.

"I need a break "– what does this phrase mean to you? To most of us, "a break" is a chance to step away, to take a breath. Maybe you run errands on your lunch break, or perhaps walk around the block. Whatever you do, a break gives you time to refresh, and get some respite.

re•spite noun \'res-pət
Definition of RESPITE
1 an interval of rest or relief

Respite Care

- Caregivers often lack the opportunity to take a break. Tens of thousands of homes all around the country include a person with special needs from cerebral palsy to AIDS to autism to Alzheimer's. Caregivers are the backbone of our nation's long-term care system. Sometimes they find themselves in the position of caring for an individual in their home without adequate preparation or a support system.
- Often this responsibility takes a toll on the emotional and physical health of the caregiver.
- The simple act of "taking a break" can deliver much-needed relief to America's caregivers. Whether the respite is provided in the home or in the community setting, the benefit to the caregiver and client is tremendous.

Common Terms Related to Respite Care

- Primary Caregiver: shall mean an unpaid family member or other adult or foster parent who provides in-home monitoring, management, supervision or treatment of a child or adult with special needs; such caregiver may, but need not, reside in the same household as the care recipient
- Care Recipient: an adult with special needs or child with special needs who requires care or supervision to meet the person's basic needs; prevent physical self-injury or injury to others; or avoid placement in an institutional facility
- Provider: a non-profit, for-profit organization or an individual which provides respite care services, for example: home based and consumer-directed services, long term care facilities and hospitals, respite centered-based model, crisis nurseries and foster home settings, camps, and adult day care
- Emergency Respite Care: means the placement of an in-home respite care worker during an unplanned or planned event, or the temporary placement of the care recipient outside the home, to substitute for the caregiver; emergency respite care may be provided on one or more occasions
- **Lifespan**: A term used to indicate that respite care can be accessed regardless of age.

Assets of a Respite Care Provider Source: Lifespan Respite Network of Ashland and Bayfield Counties

Providing respite care is a demanding profession requiring specific knowledge, skills and patience. While every care situation is unique, it is these values that help make the experience for the caregiver, respite provider, and respite recipient worthwhile.

Experience goes a long way in establishing comfort and trust between the caregiver and respite provider. In the absence of caregiving or respite experience, it is up to the respite provider to be honest and open with the client.

Education in a higher education setting is desirable, although not a requirement. There are no requirements to become a respite provider.

Assets of a Respite Care Provider Source: Lifespan Respite Network of Ashland and Bayfield Counties

Appropriate values that are compatible with the profession are crucial. Respite providers must operate with compassion, integrity and accountability for those entrusted to their care.

Good communication skills are a must for any respite provider, as it is the transfer of information from caregiver to respite provider and back again that will help support the care relationship.

Independence is a highly valued asset for respite providers., Being able to successfully work with minimum supervision (as appropriate) helps to strengthen the relationships with family, friends, and caregivers.

Assets of a Respite Care Provider Source: Lifespan Respite Network of Ashland and Bayfield Counties

A good personal support system goes a long way to help maintain sanity, perspective, and emotional stability.

Confidentiality is important to anyone using a respite program, and families needing care may have concerns about revealing family information. In addition parents (or others) needing crisis care may be concerned about being identified as abusive or inadequate, or having their children removed from their home permanently.

Therefore, it is imperative that each respite program/service have a policy regarding confidentiality, and that each provider be versed in those responsibilities.



Disability Information

Adapted from Avenues to Understanding, Easter Seals Wisconsin

Topics Covered:

- The Language of Disability
- "Person First" Language
- Words to Avoid
- Etiquette
- Offering Assistance

Disability-Specific Information

This section will not cover specific diagnoses. There are a lot of disabilities and we would not be able to do a good job covering them here.

This information is general, and covers talking to a person with a disability, and basic etiquette when interacting with someone with a disability.

At the end of this section there is a list of websites for information about specific disabilities.

The thing to remember is that each person is different. Just because you know one person with autism, does not mean you know about another person with autism. It is important to ask questions of the individual with whom you will be working, and the caregivers.

The Language of Disability

"The difference between the almost right word and the right word is really a large matter— 'tis the difference between the lightning bug and the lightning."

-Mark Twain

The Language of Disability

Language is a fluid thing. It evolves as sensitivity to the impact that words can have on attitudes, increases. Terms that are thought to be perfectly acceptable one day, may be deemed unacceptable the next.

Like any group of people, people with disabilities often do not agree on what terminology is "correct" for their "group." But most agree that language can foster negative, positive, or neutral images and attitudes.

Because language does play an important role in shaping beliefs and behavior, the words used to describe people with disabilities, or the disabilities themselves, are important, and should be used with thought and care.

While not universally accepted by disability rights groups or people with disabilities, the following will give you some tips regarding currently preferred language.

Disabilities and Handicaps

- The words "disability" and "handicap" are NOT interchangeable.
- A disability is a condition caused by an accident, trauma, genetics, or disease which may limit a person's mobility, hearing, vision, speech, or mental function. Some people have more than one disability. According to the U.S. Census Bureau, one in every five Americans has a disability. It is estimated that 50% of all people will have some type of disability during their lifetime.
- A handicap is a physical or attitudinal constraint that is imposed upon a person, regardless of whether that person has a disability.

Disabilities and Handicaps, cont.

Many people with disabilities feel that their real disability involves problems with the environment, rather than problems with their bodies. Architectural barriers limit participation, productivity, and independence. For example, if a person who uses a wheelchair is offered a job that he/she cannot accept because it is located on the second floor of a building without an elevator, the real problem - the handicap - is that there is no elevator.

Attitudinal barriers can cause further limitations. If an employer passes on a qualified candidate with a disability because he believes the person will miss too much work because of their disability, the real problem - the handicap - is the attitudinal barrier in the mind of the prospective employer.

"PERSON FIRST" Language

When speaking about people with disabilities, perhaps the most important thing to remember is to always *put the person first*.

Referencing the person before their disability conveys respect and simple good manners. For example, say:

- "person with a disability" rather than "disabled person"
- "student who is deaf" rather than "deaf student"

People are NOT medical conditions, and prefer not to be referred to as such. Say:

- "people with spinal cord injuries" rather than "the spinal cord injured"
- "people who have epilepsy" rather than "epileptics"

Words to Avoid

Avoid: special, burden, burden to their families or to society, unfortunate, less fortunate, sick (a disability is not a sickness), fragile, abnormal, subnormal, deformed, deformity, pitiful, retarded, crippled, deaf and dumb, dependent, incompetent, patient (unless the person is in the hospital), poor.

Avoid: suggesting that people with physical, sensory, or cognitive disabilities are in any way menaces, deviants, dangers to society, outcasts, or that they are somehow biologically inferior, or less than fully human.

Avoid: suggesting that people with disabilities are in need of charity or welfare, or that they are "non-contributing" members of society.

Avoid: words like courageous, brave and inspirational. Adapting to a disability does not automatically mean acquiring those traits.

Disability Etiquette

Meeting someone with a disability can sometimes cause discomfort, particularly if it is a new situation, and if you're worried about saying or doing the "wrong" thing.

The most important thing to remember is that people with disabilities want to be treated just as you like to be treated. Be friendly, and show the same interest you would show when meeting anyone for the first time.

There is some etiquette involved when conversing with people with various disabilities, however, and we offer some guidelines to ease those first meetings. Don't let fear of violating a suggestion keep you from interacting with someone with a disability. Ignoring a person with a disability because you're worried you might say or do the wrong thing, is much worse than actually saying or doing the wrong thing.

Common Courtesies

- When talking with someone who has a disability, speak directly to him or her, rather than through a companion who may be along, including interpreters and personal aides. It is insulting to talk in the third person about a person who is present.
- Offer to shake hands when introduced. People with limited hand use or an artificial limb can usually shake hands. Offering the left hand is an acceptable greeting.
- Don't lean or hang on someone's wheelchair. Wheelchairs are an extension of personal space.
- If possible, when talking with a person in a wheelchair for more than a few minutes, place yourself at their eye level.

- Treat adults as adults. Call a person by his or her first name only when you extend this familiarity to everyone present.
- Don 't pet guide or companion dogs. They are working. However, it's more than appropriate to compliment the beauty and good behavior of the dog.
- Don 't discourage children from asking questions about a wheelchair or other assistive devices.
- Never start to push a wheelchair without *first asking* if you may do so.

- *Relax.* Don't be embarrassed if you happen to use common expressions such as, "See you later" or "I've got to run," that seem to relate to the person's disability.
- People with disabilities are entitled to the same courtesies you would extend to anyone, including personal privacy. However, it's fine to *talk about the disability* if it comes up naturally, and if you do so in a courteous and respectful way, without prying. Be guided by the wishes of the person with the disability.

- Give your whole, unhurried attention when you're talking to a person who has difficulty speaking. Don't talk for the person, but give help when needed. Keep your manner encouraging rather than correcting, and be patient rather than speak for the person.
- When necessary, ask questions that require short answers or a nod or shake of the head. *Never pretend to understand* if you are having difficulty doing so. Repeat what you understand. The person's reaction will guide you to understanding.

- To get the attention of a person who has a hearing disability, tap the person lightly on the shoulder or wave your hand.
- Look directly at the person and speak clearly and slowly to establish if the person can read your lips. Not everyone who is deaf or hard of hearing can lip-read. Those who do will rely on facial expressions and other body language to help them understand. Show consideration by facing a light source and keeping your hands and food away from your mouth when speaking.
- For people who use hearing aids, *speak in a normal tone*; hearing aids are set to standard voice levels. If they ask you to speak up, do so. Written notes may also help.

- When greeting a person with a severe loss of vision, always *identify yourself and others who may be with you*. When conversing in a group, remember to say the name of the person to whom you are speaking, to give a vocal cue.
- Some people with disabilities don't exhibit the same types of visual "I understand" cues you may be accustomed to. It might take some *time and experimentation* before you're certain that you're both on the same page.

When Offering Assistance

- If you would like to help someone with a disability, ask if he needs it before you act. Listen to any instructions he may give. Don't be offended if your help is refused, and don't assume anything. If you have a question about what to do and how to do it, ask.
- Before deciding whether or not to push a wheelchair up or down a step, curb, or other obstruction, *ask the person if and how she wants you to proceed*, and be aware of your own limitations.
- Be considerate of the extra time it might take someone with a disability to get things done. Let the person set the pace in walking, etc.

When Offering Assistance, cont.

- When giving directions to a person in a wheelchair, consider the distance involved, weather conditions, and any *physical obstacles* the person may encounter such as stairs, curbs, and steep hills.
- When directing a person with a visual impairment, use specifics such as "left a hundred feet" or "right two yards."
- When you offer to assist someone with a visual impairment, *allow the person to take your arm*. This will help you to guide, rather than propel or lead, the person.

To Keep In Mind...

People with disabilities are individuals. *Don't generalize about all people with disabilities from your knowledge of a few.*

Again, relax, be yourself, be natural, and don't force enthusiasm. If you concentrate on the person and not the disability, you'll be fine.





Communication

Individuals communicate in a variety of ways. This is a brief description of some common communication techniques.

As always, ask the family how the individual communicates, and to explain what you need to know.

Language

Two Types of Language

- Receptive Language: Listening and understanding what is bring communicated
- Expressive Language: Communicating a message to someone else

Some individuals have an imbalance in these two types of language. Thus, even if someone cannot communicate expressively, he/she may be able to understand what you are saying.

Verbal Communication

- Some individuals are able to communicate what they need verbally, in full sentences. Others may have limited verbal communication, e.g. may only say a few words.
- Other individuals seem to have great verbal capacity, but may only repeat phrases that they hear (echolalia) rather than using language to communicate.

When making a verbal request, *give processing time*. For some individuals, it can take up to 45-60 seconds to understand the question or request, and then to respond to it. Adding more words or repeating the request may add too much to process, and the information is lost.



Think of a clothes dryer - if you keep adding wet clothes throughout the cycle, the clothes will never dry.

Communicating With Someone Who Is Non-Verbal

- Expect non-verbal people to communicate.
- Ask the person to show you how they indicate "yes" and "no."
- Find out how the person "points" (with the finger, eyes, fist, etc.)
- If there are communication instructions visible, take a moment to read them.
- Make sure the person's communication system is within reach.
- Ask one question at a time and wait for a response. Don't be afraid to ask open-ended, rather than yes and no, questions.

Communication Boards

- Some individuals use communication boards, books or talk boxes. The boards are all different and each individual uses them in a different way.
- Always ask the family to show you how to use the communication board with the individual.
- Some of these are very expensive, so take care when using.
- Individuals use communication boards to type, or point to, words or phrases.





Picture Communication

- Some individuals respond better to pictures than to written or verbal words. Choices of food, activities, clothing, etc. can be given and the individual can choose the picture he wants. "First, then" statements can also be presented in pictures.
- Many families have a picture system set up for the individual, if this is how she communicates. Ask how to be shown how to use it, how many picture choices to give at one time, etc.
- Practice with the individual.

Sign Language/Gestures

- Some individuals use gestures or sign language to communicate what they need.
- Some individuals have their own signs that are closely related to the actual ASL (American Sign Language) sign; others might use gestures that are not related.
- Ask the family/caregiver to demonstrate the common signs that individual uses, and the ways to best communicate with him/her.