



**A CLIENT CARE MODULE:
WORKING WITH CLIENTS
WHO HAVE INTELLECTUAL
DISABILITIES (ID)**



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We hope you enjoy this inservice, prepared by registered nurses especially for caregivers like you!

A Client Care Module:

WORKING WITH CLIENTS WHO HAVE INTELLECTUAL DISABILITIES (ID)

Instructions for the Learner

If you are studying the inservice on your own, please do the following:

- Read through **all** the material. You may find it useful to have a highlighting marker nearby as you read. Highlight any information that is new to you or that you feel is especially important.
- If you have questions about anything you read, please ask your supervisor.
- Take the quiz. Think about each statement and pick the best answer.
- Check with your supervisor for the right answers. You need **8 correct** to pass!
- Print your name, write in the date, and then sign your name.
- Email In the Know at feedback@knowingmore.com with your comments and/or suggestions for improving this inservice.

THANK YOU!

After finishing this inservice, you will be able to:

Define intellectual disability.



Discuss the common causes of intellectual disability.



Describe the four levels of intellectual disabilities.



Name at least two ways (for each area) to help clients who have intellectual disabilities meet their mental, physical, behavioral, and social challenges.



Describe how you can support the rights of clients with intellectual disabilities.



Inside This Inservice:

What Is ID?	2
What Causes it?	3
Levels of ID	4
Four Major Known Causes	5
Helping Clients with ID	6-9
Myths and Facts	10

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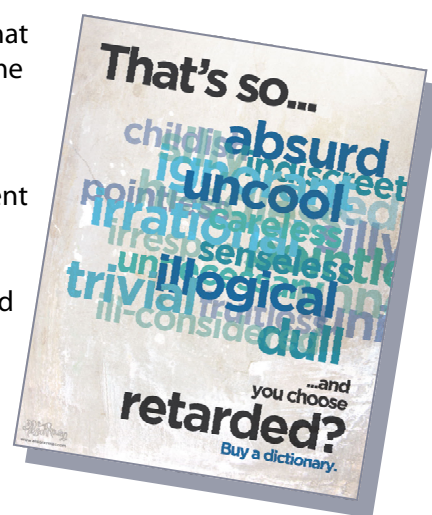
A Client Care Module: Working with Clients Who Have Intellectual Disabilities

WHY THE NAME CHANGED

Throughout history, we've seen certain words that start out as regular explanatory language become popular ways of *demeaning* people.

It's most noticeable in race-related terms. For example, the term Jew, (a person of Jewish decent and/or faith) has become a term many people associate with greed or being tight-fisted. "He tried to Jew me down," means that he attempted to rip me off, or he wouldn't pay a fair price.

You can probably think of plenty of other words that started out harmless but became popular ways to disrespect others.



⇒ **Mental retardation, retarded, and retard have all fallen into this category of words.** Mental retardation used to be a perfectly respectful clinical term used to describe people with below average intellectual functioning. But, today it's most often used as a slang term to describe anything or anyone who is stupid, slow, different, off, weird, or abnormal.

When "retard" and "retarded" are used as synonyms for "dumb" or "stupid," it only reinforces painful stereotypes of people with intellectual disabilities being less valued members of humanity.

⇒ **Respectful and inclusive language is essential to preserve the dignity and humanity of all people.** That's why in October 2010, congress passed Rosa's Law, which changed references of "mental retardation" to "intellectual disability," and references of "a mentally retarded individual" to "an individual with an intellectual disability."

The debate is not over and the term may change again soon to reflect an even more precise definition. But until then, everyone agrees that the term mentally retarded can no longer be used to medically diagnose another human.

Keep reading to learn all about intellectual disabilities (formerly mental retardation), and find out how you can help your clients with ID lead full and fulfilling lives.



WHAT IS AN INTELLECTUAL DISABILITY?

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as:

A disability characterized by significant limitations in both intellectual functioning and adaptive behavior which originates before the age of 18.

- **Intellectual functioning** (also called intelligence) refers to a person's ability to learn, apply reason, and solve problems. It's usually measured by an IQ test.
- **Adaptive behavior** refers to skills that are learned and performed by people in their everyday lives, such as communication, self-care, social skills, staying healthy, staying safe, enjoying leisure activities, and working at a job.



In general, this means that to be diagnosed with an intellectual disability, these three signs must be present:

1. An IQ less than 70.
2. Problems adjusting to everyday life.
3. Symptoms that show up during childhood—before age 18.

What's the difference between an intellectual disability and a developmental disability?

Sometimes intellectual disability is also referred to as developmental disability which is a **broader term** that includes autism, epilepsy, cerebral palsy, developmental delay, fetal alcohol syndrome, and other disorders that occur during the developmental period (birth to age 18).

The major differences are in the **severity of limitations** and the fact that a person with a developmental disability **may or may not have a low I.Q. score**.

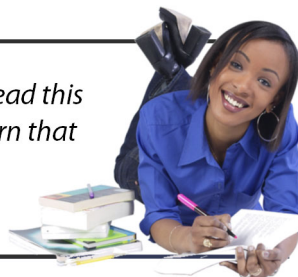
- ⇒ For example, one person with autism (a developmental disability) may have a low IQ, while another person with autism can have a high IQ. The autistic person with a low IQ can be said to have an intellectual *and* developmental disability while the other autistic person would be diagnosed with a developmental disability only.

The Facts

- In the U.S., roughly 6.5 million people are identified as having an intellectual disability.
- Every year, 125,000 children are born with an intellectual disability.
- Ten percent of Americans have a family member with some sort of intellectual disability.
- Intellectual disabilities are 25 times more common than blindness.
- The majority of individuals affected by these disabilities show only mild symptoms and may be slightly slower learners than their peers.
- People with intellectual disabilities create one of America's largest disability groups.

WHAT'S NEW?

Grab your favorite highlighter! As you read this inservice, **highlight five things** you learn that you didn't know before. Share this new information with your co-workers!





CONNECT IT!

CLIENTS' RIGHTS

People with intellectual disabilities have the same rights as everyone else.

- **Right to Liberty**—This is the right to make decisions for themselves.
- **Right to Habitation**—Intellectually disabled people want to be able to live where they choose.
- **Right to Be Free From Harm**—With the right support from the community, people with ID can live pretty much on their own and still remain safe.
- **Right to Education**—People with ID deserve to have the same opportunities for education as everyone else.

Help support your clients' rights by learning more at:

⇒ www.thearc.org

⇒ www.sabeusa.org

CAUSES OF INTELLECTUAL DISABILITIES

Intellectual disability can be caused by any condition that impairs development of the brain **before birth, during birth,** or in the **childhood years.**

More than 250 causes of intellectual disability have been discovered but, in about one-third of the people affected, the cause remains unknown.

PRENATAL CAUSES—Prenatal” means “before birth.” One third of all severe cases of intellectual disability develop before birth (during pregnancy).

Prenatal causes of intellectual disability include:

- Infections such as German measles and HIV.
 - Drugs & alcohol.
 - Health problems in the mother (such as hypertension and diabetes).
 - Trauma during pregnancy.
 - Abnormal chromosomes.
- Prenatal intellectual disability may be prevented if women:**
- Receive good medical care during their pregnancies.
 - Eat a balanced diet during pregnancy.
 - Avoid drugs and alcohol while pregnant.

PERINATAL CAUSES—“Perinatal” means “around the time of birth.”

Intellectual disability develops during childbirth about 11% of the time.

Perinatal causes of intellectual disability include:

- Premature birth.
 - A lack of oxygen at birth.
 - Trauma to the baby’s head at birth.
 - Infections picked up during birth.
- Perinatal intellectual disability may be prevented if:**
- Mothers receive good medical care during the birth process.

POSTNATAL CAUSES—“Postnatal” means “after birth.” Up to 12% of people who are mentally retarded develop the problem *after* birth. Postnatal causes of intellectual disability include:

- Reye’s Syndrome.
 - Infections (especially brain infections such as meningitis).
 - Lead poisoning.
 - Injuries, especially to the head.
 - Metabolic defects.
 - Malnutrition.
- Postnatal ID may be prevented if:**
- All newborns are screened for metabolic defects.
 - Families use child seats and seat belts to avoid head injuries.

LEVELS OF INTELLECTUAL DISABILITY

	PRESCHOOL (0—5 Years)	SCHOOL AGE (6—20 Years)	ADULT (21+ Years)
MILD IQ: 51 to 70	Young children with mild ID may not even show symptoms until they start school.	Able to complete academic and vocational programs with some special training.	Most can live and work in the community.
MODERATE IQ: 36 to 50	Can learn to talk and take care of their basic needs.	Able to learn skills to help them function in familiar surroundings.	Many often perform semi-skilled work in a sheltered environment.
SEVERE IQ: 21 to 35	These children usually develop slowly and may have physical disabilities. They have difficulty communicating.	Older children with severe ID can learn to communicate and may learn to help with their own personal care.	With supervision, adults severe ID can help take care of themselves.
PROFOUND IQ: 20 or less	Young children with profound ID often have physical disabilities, too. They have difficulty responding to their environment.	Older children with profound ID develop very slowly. They may learn some basic self-care skills.	Adults with profound ID may learn some communication skills and may be able to perform basic functions in a highly supervised environment.

- **85%** of people with ID are **mild**.
- **10%** of people with ID are **moderate**.
- **3.5%** of people with ID are **severe**.
- **1.5%** of people with ID are **profoundly** disabled.

But, remember...

People with intellectual disabilities are **individuals**—not just IQ's. They may not “fit” exactly into one of the above categories. Each person with ID learns at his or her own unique pace—just like the rest of us.



WHAT EXCITES YOU?

CAN A DOG HELP?

Just like a seeing eye dog can help someone who is blind, dogs can be specially trained to help clients with ID to:

- Remember to take medications.
- Reduce stress in certain environments, like an airplane or supermarket.
- Dial 911 in an emergency.
- Stay safe when walking.
- Calm down during a panic attack by nuzzling a distraught owner to soothe him.

Want to learn more about service dogs for your ID clients? Ask your supervisor or social worker for a local resource or go online to: www.caninesforservice.org to learn more!

MAJOR KNOWN CAUSES OF INTELLECTUAL DISABILITIES

The four major known causes of intellectual disability are Down syndrome, Fragile X syndrome, fetal alcohol syndrome (FAS) and autism. Here's a closer look at each:

DOWN SYNDROME

Down syndrome is a genetic disorder. People with this syndrome are born with an extra chromosome.

- No one really knows why Down syndrome happens, but it is linked to the age of the mother. The older a woman is when she gets pregnant, the greater her chance of giving birth to a baby with Down syndrome.
- Tests can be done during pregnancy to check for Down syndrome.
- Most people with Down syndrome have mild to moderate ID.
- People with Down syndrome often grow slowly and may have small heads, flat faces, small hands and feet, and upward slanting eyes.
- Many individuals with Down syndrome live full, productive lives.



FRAGILE X SYNDROME (FXS)

People with FXS have an X chromosome that is abnormally susceptible to damage.

- The effects of Fragile X syndrome are different for males and females. Generally, the condition is worse for males.
- It's common for children with Fragile X syndrome to have emotional and behavioral problems along with ID.

Some of the other symptoms of Fragile X Syndrome include:

- Hyperactivity and/or anxiety.
- Autistic-like behaviors.
- A long face and large ears.
- Flat feet and joints that bend the "wrong" way.

FETAL ALCOHOL SYNDROME

Fetal alcohol syndrome (FAS) is one of the leading causes of preventable intellectual disabilities.

- Alcohol passes directly from the blood stream of a pregnant woman, through the placenta, to the developing fetus' brain.
 - It is not clear how much alcohol it takes to damage the fetus' brain. That's why most doctors recommend pregnant women avoid alcohol completely.
 - The problems caused by fetal alcohol syndrome vary from person to person, but may include physical deformities, intellectual disabilities, learning disorders, vision difficulties, and behavioral problems.

AUTISM

Autism is defined by the presence of difficulties in three areas: social difficulties, communication problems, and repetitive behaviors, with an onset in at least one area by age three.

- Autism occurs on a spectrum. That means there are many variations and symptoms can range from mild to severe.
- Some people with mild forms of autism may have no language delays or intellectual disabilities at all.
- An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism.
- No single cause has been determined to lead to autism. Most researchers believe a combination of genetic and environmental factors are responsible for the disorder.
- Many adults with autism are able to lead independent lives. A small percentage have serious, lifelong limitations in functioning.

YOU CAN HELP CLIENTS WITH INTELLECTUAL DISABILITIES

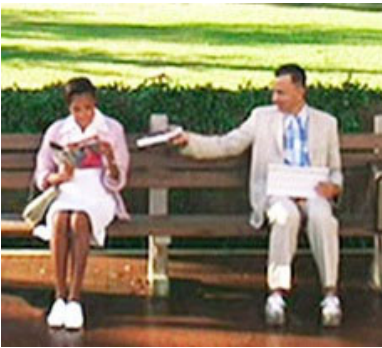
HELPING CLIENTS MEET MENTAL CHALLENGES

- Keep in mind that 85% of people with ID are only mildly disabled. That means they CAN and SHOULD attempt to learn new information and skills—it just might take a little longer.
- You may hear talk about your clients being a certain “mental” age. For example, Susan may be 24 years old, but you may hear someone say she has a mental age of 7 years. Please remember that this mental age refers to IQ only. It does not take into account all the experiences Susan has had in her 24 years of living. Susan is an adult, regardless of her IQ.
- It’s common for people with ID to have short attention spans. Be ready to change activities when you see their interest fading.
- Try to figure out when your clients are at their best. For example, if Mary is able to focus better in the mornings, then help her do any complicated tasks before lunch.
- Give instructions one step at a time. Review each step as often as necessary. (And praise them when they’ve finished each step!)
- Many people with intellectual disabilities are able to work in semi-skilled jobs. If your clients work, be sure to ask them how their jobs are going. Offer to help them “brush up” on any skills they need for work.
- If your client would like to work, talk to your supervisor or your client’s social worker about locating resources in your area that help people with ID find appropriate jobs.
- The sooner a person is diagnosed with intellectual disability, the sooner special training can begin. If you suspect a child you work with has ID, tell your supervisor.



HELP CLIENTS MEET COMMUNICATION CHALLENGES

- Some people with ID—especially if it’s caused by Down syndrome—are at risk for hearing loss. Often, they begin to lose their hearing at a young age. Watch for (and report) signs of hearing loss, including:
 - Turning up the TV or radio.
 - Becoming confused in noisy situations.
 - Speaking louder than usual.
 - Getting frustrated during conversations.
 - Rubbing their ears.
 - If your clients are already hearing impaired, be sure to:
 - ⇒ Speak slowly (not loudly).
 - ⇒ Face them when speaking to them.
 - ⇒ Write words down when necessary.
 - People with ID may have trouble following instructions. Try providing simple written instructions for each step of a task such as getting dressed or making a bed. You might also use pictures or drawings to get the idea across.
- When speaking with clients who have an intellectual disability, try to:
 - ⇒ Use simple, clear language.
 - ⇒ Keep your sentences short.
 - ⇒ Be patient! Repeat your statement or question once or twice, if necessary.
- As you help your clients with their personal care, try to work alongside them rather than “ordering” them to do things.
- Encourage your ID clients to participate in conversations. Help them learn to ask polite questions of others (like “How are you doing today?”) and then to wait for the answer!



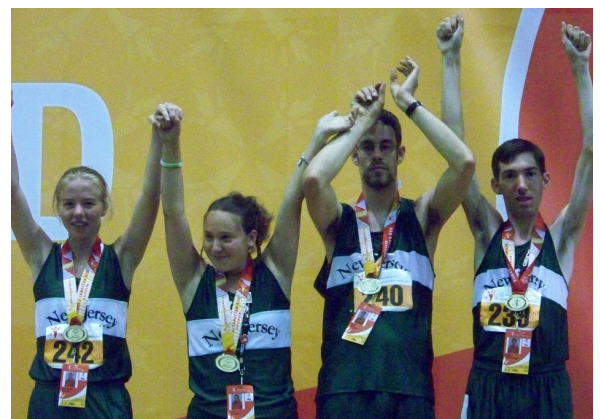
SEE IT!

To see some sensitive portrayals of intellectually disabled people, consider watching these movies:

- **Forrest Gump** (1994) with Tom Hanks and Robin Wright
- **What's Eating Gilbert Grape** (1993) with Johnny Depp and Leonardo DiCaprio
- **I am Sam** (2001) with Sean Penn and Dakota Fanning
- **The Other Sister** (1999) with Juliette Lewis
- **Of Mice and Men** (1992) with John Malkovich
- **Radio** (2003) with Cuba Gooding Jr.
- **Secret Life of Bees** (2008) with Dakota Fanning, Jennifer Hudson, and Queen Latifah

YOU CAN HELP! HELP CLIENTS MEET PHYSICAL CHALLENGES

- Ask your supervisor to tell you about any physical problems your clients may have, so you'll know what to look for day to day. For example, your supervisor tells you that Jim, who has Down syndrome, has a high risk of developing Alzheimer's disease. Now, you know that it's very important to watch for mental changes such as acting more forgetful or confused. You'll be able to report any problems right away.
- Your clients with ID may have certain physical characteristics like a small head, flattened nose, or large tongue. These characteristics are only "skin deep." Be careful not to judge your client's ability by how he or she looks.
- Watch your clients carefully to keep them safe. People with ID may not have a sense of possible danger. They may take physical risks without knowing it.
- Nearly one half of all intellectually disabled people are overweight. Help your client maintain a healthy weight by encouraging a balanced low-fat diet.
- People with ID tend to have problems with muscle strength and flexibility. Encourage your clients to improve their physical fitness by exercising at least three days a week. Everyday activities provide exercise, such as:
 - Climbing the stairs.
 - Getting up to change the TV station instead of using the remote.
 - Sweeping.
 - Folding laundry.
- Exercise can also be fun. Activities like basketball or playing catch are great. If possible, help your clients get involved in the Special Olympics. (This sports program is for anyone over age eight and is available in 25,000 communities across the U.S.)
- If your clients don't have a lot of energy, try taking them for short walks—five or ten minutes—several times a day. All that exercise time will add up!
- Help your clients take pride in their physical appearance by making sure they are neatly dressed and groomed. Praise them when they accomplish these tasks.



YOU CAN HELP!

HELP WITH BEHAVIORAL & EMOTIONAL CHALLENGES

- People with intellectual disabilities may have trouble figuring out the “best” way to behave in a certain situation. As a result, they may behave in a socially unacceptable manner at times. Remember that this behavior does not usually develop overnight...and it will probably take time to change it, too.
- Unacceptable behavior may be a way for people with ID to tell you what they need. For example, Sarah may be disruptive in a group because she is scared when she’s around a lot of people. Or, Sam may bang his head against the wall when he can’t find the words to tell you that he’s hungry.
- People with ID have the same need for affection as anyone else. You can help them learn when it’s okay to hug someone and when a handshake would be better.
- Give your clients as much control over their own lives as possible. For example, ask them: “Do you want to wear your red shirt or your green sweatshirt today?” Or, “Do you want to watch TV or play a game?”
- Remember, every day your clients are confronted with many things that they can’t do. Make sure that they also have the opportunity to shine. Help them use their unique strengths and talents every day so that they can feel successful.
- You may notice that your intellectually disabled clients try hard to please you. Your approval may be very important to them. So, offer praise—even when they complete the smallest task!
- If your clients behave in a way that is disruptive, try to change the activity. For example, Ben has been drawing quietly for several minutes when suddenly he begins to rip paper and throw it on the floor. Ben could be telling you that he needs to move around, so taking a walk may be a better activity for him at this time.
- Reward the behaviors that you want to see your clients continue. (And you may have to ignore the behaviors you’d like them to stop.)
- If you find yourself getting “stressed out” by a client’s inappropriate behavior, tell your supervisor. Don’t let yourself get to the point where your anger gets the better of you in front of a client.



THINK ABOUT IT!

A DELICATE BALANCE

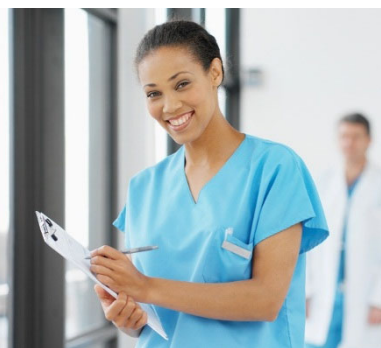
Think about a client you care for right now who has an intellectual disability.

Is there anything you think your client CAN do that others usually do for him?
(Example, make breakfast, get the mail, wash his own dishes after a meal.)

Is it safe for this client to do this job on his own? Can he do it with supervision?

What would you do if your client refused to do something you knew he could do—because someone else had always done it for him?

Share your answers with your co-workers to find out what they would do!



FIVE KEY POINTS!

REVIEW WHAT YOU LEARNED!

1. In October 2010, congress passed a law to change references of “mental retardation” to “intellectual disability.”
2. Intellectual disability is defined as having significant limitations in intellectual functioning and adaptive behavior which originates before the age of 18.
3. Intellectual disability can be caused by any condition that impairs development of the brain before birth, during birth, or in the childhood years.
4. People with ID can have many variations and symptoms can be mild, moderate, severe, or profound.
5. At least 85% of people with intellectual disabilities are considered to have “mild” symptoms. Less than two percent are considered “profound.”

YOU CAN HELP! HELP CLIENTS MEET SOCIAL CHALLENGES

- Think about it. Our society values intelligence, success, beauty, and talent. People with disabilities often feel that our society doesn't value them as much. Be sensitive to your clients—they want to “fit in,” just like everyone else does.
- People enjoy feeling like they belong. However, for people with ID, isolation is a very real problem. They may feel isolated because:
 - It's difficult for them to communicate with others.
 - They live in an environment that's separate from the general population.
 - They may be separated from their family and friends.
- Some people with ID can become dependent very easily. This means they might come to depend on you to do too much for them. Try hard to keep a balance between helping them and pushing them to do things for themselves.
- Your client may take medications that help them get along better in a group setting. (However, this is not usually the answer to inappropriate behavior.) If your client takes medications, be sure you know the possible side effects. Let your supervisor know if your client seems to be suffering from side effects.
- People with ID tend to be very trusting, too. They may not understand the potential danger in speaking to, or getting into a car with, a stranger. Because of this, they are at risk for being abused. Protect your clients at all times from situations in which they might become a victim of abuse.
- Everyday group activities help intellectually disabled people learn how to act in social settings—and give them a feeling of belonging. For example, birthday parties and holiday celebrations are great ways to boost group participation and self-esteem.
- Playing sports with a group helps to teach social skills as well as providing exercise!
- Check to see if there is a “Best Buddies” group in your area. This program creates friendships between adult volunteers and their peers with ID. (Visit their web site: www.bestbuddies.org for more information.)





A Client Care Module:
Working with Clients Who Have Intellectual Disabilities

EMPLOYEE NAME
(Please print):

DATE: _____

- ***I understand the information presented in this inservice.***
- ***I have completed this inservice and answered at least eight of the test questions correctly.***

EMPLOYEE SIGNATURE:

SUPERVISOR SIGNATURE:

Inservice Credit:

<input type="checkbox"/> Self Study	1 hour
<input type="checkbox"/> Group Study	1 hour

File completed test in employee's personnel file.

Are you "In the Know" about intellectual disabilities? Circle the best choice or fill in your answer. Then check your answers with your supervisor!

- To be diagnosed with ID, all these signs must be present, EXCEPT:**
 - A. An IQ less than 70.
 - B. Mental illness.
 - C. Problem adjusting to everyday life.
 - D. Symptoms present before age 18.
- Intellectual disability can be caused by any condition that impairs development of the brain:**
 - A. Before birth.
 - B. During birth.
 - C. After birth.
 - D. Any or all of these.
- Most adults with mild ID:**
 - A. Should be institutionalized.
 - B. Can be cured with medications.
 - C. Can live and work in the community.
 - D. Don't really know what's going on around them.
- Most people with ID have symptoms that are considered:**
 - A. Mild.
 - B. Moderate.
 - C. Severe.
 - D. Profound.
- True or False**
Nearly one half of all intellectually disabled people are overweight.
- True or False**
People with ID should not be allowed to have sexual relationships with others.
- True or False**
A person with an intellectual disability is unable to learn new skills once they become an adult.
- True or False**
People with ID tend to be suspicious of others and are not likely to talk to strangers.
- True or False**
Mental retardation is a perfectly respectful clinical term commonly used today.
- True or False**
Intellectually disabled people have the same rights as everyone else.

