What is pain?

Pain has been described as “a survival mechanism” — a warning signal letting us know something is wrong. The presence of pain can let us know when we are ill or seriously hurt. It motivates us to escape or avoid whatever caused it.

There are many different types of pain. Acute pain is short-term, typically following an illness or injury, and goes away when you heal. Chronic pain is experienced on an on-going basis for a long time (a minimum of 3-6 months) and is a result of damage to the body’s pain system itself. Subsequently, chronic pain works differently than acute pain in the Central Nervous System (CNS).

Pain can be experienced in many ways, including sensations that are: sharp / stabbing, cutting, burning, tingling, throbbing, or dull.

The source of localized pain is relatively easy to identify — the part of the body that is damaged is what hurts. Visceral pain (related to internal organs) is spread out, making it more difficult to locate the specific source.

We are made aware of pain via our CNS. Clifford J. Woolf identified three classes of pain: nociceptive, inflammatory, and pathological. Nociceptive pain results when certain peripheral nerve fibers, called nociceptors, are activated. These nerve fibers only respond to stimuli that is at or beyond an intensity that may cause harm to the body. Inflammatory pain occurs when tissues have been damaged. Pathological pain is a disease state caused by damage to the CNS.

The Pain / Behavior Relationship

People with I/DD sometimes have a hard time verbally describing internal experiences. Subsequently, the person’s behavior is our best (sometimes only) indicator that something is wrong. This is particularly true of people who have limited or no verbal communication, but even those who are able to communicate verbally may not communicate pain in traditional ways.

People may not realize the expectation that they report pain. For chronic pain sufferers, it may have been going on for so long, they don’t realize it is not part of the typical human experience.
Behavioral Manifestations of Pain

Since pain can manifest behaviorally in countless ways, anytime we observe behaviors that we find puzzling or challenging, we should consider the possibility of pain. Some things to keep in mind when assessing behavior:

- The same behavior can be driven by something different each time the person engages in it.
- People may react differently to chronic pain vs. acute pain, as they are processed differently by the Central Nervous System.
- Medications can mute (or amplify) the experience of pain.
- A history of Psychological Trauma may affect the neuronal response to (and the person’s perception of) pain.
- People may self-injure in an attempt to mask pain they cannot control with pain they can control.
- The person may induce pain (via self-injury) far from the site of the original pain as a distraction — a phenomenon known as counter stimulation.
- Although various forms of self-injury and aggression are the typical manifestations of pain, it can often present as agitation, pacing, running away, and sleep disturbances, and in other more subtle ways (such as loss of appetite, fatigue, facial grimacing, etc.).
- Itching can be as bad as pain.
- Anger can be a big problem — you can’t have pain and a long fuse.

Common Specific Pain Behaviors

The following are some common pain-related explanations for specific behaviors. It should be noted that these behaviors could be indicative of something other than pain. The absence of these behaviors does not necessarily indicate the absence of the pain / medical condition they may indicate.

**MOUTH** (biting, jamming fist): GERD; dental, sinus, or ear problems, etc. Biting the hand / fingers may indicate neuropathy.

**HEAD** (banging): migraine, dental problems, ear / eye problems, seizures, hallucinations, etc.

**SKIN** (scratching, gouging): rash, medication side effect, liver / kidney disorder, gastric problem, etc.

**MOVEMENT STIMULATION**: headache, chest / abdominal pain, vision problems, dental problems, etc.

**UNUSUAL GAIT**: muscle weakness, liver failure, arthritis, etc.

**POSITIONAL**: frequent changes: hip / back / genital / rectal pain; sudden sitting: cardiac problems, seizures, orthostasis, vertigo, ear infection, etc.

**GENITAL / ANAL**: Urinary Tract Infection, vaginitis, prostate problems, STD, pinworms, constipation, etc.

**BREATH-HOLDING**: gastro-intestinal problems, etc.
The long-term implications of pain

It is important for us to learn to recognize and respond appropriately to signs of pain shown by the people we support. Beyond the obvious alleviation of suffering, there are many additional effects of pain — particularly chronic pain — that can be avoided or alleviated with proper treatment.

Studies have shown that alleviation of long-term pain leads to decreases in anxiety and improved self-esteem.

Untreated (or under-treated) pain can lead to impairments in attention, working memory, problem-solving, and mental flexibility. It can also slow down the speed with which the person is able to process information. These effects are often reflected in a loss of daily functioning.

Pain can make it difficult to sleep, which adds to the fatigue and irritability that commonly co-occur with pain. Pain causes stress, which can cause physical tension, which causes more pain in a vicious cycle.

Social relationships often suffer, as pain makes everyday activities harder. It is difficult to motivate oneself when it hurts to move, no matter how enjoyable the activity might be.

Have we considered the “common culprits” — the most commonly occurring, often overlooked conditions in the I/D population?

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Did any major life events, illnesses, or medical procedures correlate with the onset of symptoms / behaviors?

Is there any evidence of abuse or neglect (currently or in the person’s history)?

Are there any known problems (currently or in the person’s history) that may account for the behavior (for example, head-banging in a person with a history of migraines)?

What can the person tell us about their pain? (There are several non-verbal pain assessment tools — you might try the Wong-Baker FACES available at www.wongbakerfaces.org)

One of the most important things we can do as supporters is to get to know the person so that we will be able to recognize when something is “off” for him / her. Beyond that, we need to recognize that behavior is a form of communication and people with an I/DD may challenge us via behavior to figure out something they are unable to communicate any other way.
PAIN AND BEHAVIOR TEST  

Name: ____________________  Role/Title: ____________________  Agency: ____________________  
Date: ____________________  

Please provide contact information (email address, fax number, or mailing address) where you would like your certificate to be sent: ________________________________________  
______________________________________________________________________________________  

You must submit your completed test, with at least a score of 80%, to receive 1/2 hour of training credit for this course.  

* To submit via fax, please fax the test and evaluation to 814-728-8887. Please fax only the test and evaluation, not the entire training packet.  

* To submit via email, please send an email to training@northwesthc.org. Please put “Pain & Behavior Test” in the subject line, and the numbers 1—5, along with your answers, in the body of the email, OR scan the test and evaluation pages and send them as an attachment.  

* To submit via mail, send the test and evaluation pages to NWHC, 247 Hospital Drive, Warren PA 16365.  

1. Pain is considered “chronic” when it occurs for at least 3-6 months. True False  
2. The source of visceral pain is usually easy to identify. True False  
3. Chronic pain and acute pain are processed differently by the Central Nervous System. True False  
4. The effects of pain often result in a loss of daily functioning. True False  
5. A history of abuse or neglect has no bearing on the person’s experience with pain. True False  

Think about a time in your life when you were in pain. How did it affect you?
**Training Title:** Pain & Behavior  
**Date:**

- [ ] Direct Support Professional
- [ ] Program Specialist
- [ ] Consumer/Self-Advocate
- [ ] Support Coordinator
- [ ] PCH Staff/Administrator
- [ ] FLP/LSP
- [ ] Provider Administrator/Supervisor
- [ ] Provider Clinical Staff
- [ ] Family Member
- [ ] Support Coordinator Supervisor
- [ ] County MH/MR/IDD
- [ ] Other (please list):

Please circle your PRIMARY reason for completing this home-study training:

- [ ] It’s mandatory
- [ ] interested in subject matter
- [ ] need training hours
- [ ] convenience

Please circle the best response to each question.

- 5 = Strongly Agree
- 4 = Agree
- 3 = Undecided
- 2 = Disagree
- 1 = Strongly Disagree

1. As a result of this training, I have increased my knowledge.

2. I learned something I can use in my own situation.

3. This training provided needed information.

4. The training material was helpful and effective.

5. Overall, I am satisfied with this training.

6. I am glad I completed this training.

Suggestions for improvement:

Additional information I feel should have been included in this training:

I would like to see these topics/conditions developed into home-study trainings: