

# The International Journal for Direct Support Professionals

## OUCH! How Understanding Pain can Lead to Gain when it Comes to Supporting Those with Developmental Disabilities

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### What is pain?

Just because someone you support can't tell you in words that they are in pain doesn't mean it doesn't hurt.

"Pain is an **unpleasant sensory and emotional experience** associated with **actual or potential tissue damage, or described in terms of such damage**"

*International Association for the Study of Pain*

Everyone experiences pain differently!  
Something that may not hurt you at all could be quite painful for someone else.

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Knowing this information about pain is very important for many reasons:

- (1) This definition of pain tells us that what we feel emotionally and physically are connected. This means that having nervous feelings can make a sore stomach worse and vice versa.
- (2) People used to think that anyone who could not tell someone they were in pain (e.g., babies, people with Developmental Disabilities (DD)) didn't experience pain. We know now that this is wrong.
- (3) Everyone experiences pain differently, so we need to remember to take an individualized approach to pain assessment and management.

Like everyone else, people with DD experience all types of pain. In the pain world, we talk about two kinds of pain: 1) short-term acute pain, like stubbing your toe or getting a needle, and 2) longer-term chronic pain, like ongoing muscle aches or headaches. Acute pain can be helpful as it helps us know when something is wrong and we have to take action; for example, if you put your hand on a hot stove element, the pain would tell your body to move it quickly. Chronic pain doesn't act in this protective way – in many cases it can be like a false alarm telling us that something is wrong when everything is fine. Chronic pain can get better or worse from day to day but generally sticks around for a long time. The pain we feel and how we show we are in pain will depend on many other factors that fall in three categories: biological (e.g., chemicals in our body like adrenaline), psychological (e.g., feelings and thoughts), and social (e.g., how other people respond to our pain).

### **How common is pain in people with DD?**

For many years, people have wondered if individuals with DD experience less pain, more pain, or experience it differently than those without DD. Some people even wondered if those who engage in self-injury didn't feel pain. Researchers have been trying to find out the answers to these questions, but still aren't totally sure. We do know that people with DD may respond more slowly to pain and express it differently than those without DD. We also know that even people who self-injure can feel pain. And most importantly, we know that true insensitivity to pain is extremely rare. So, as direct support professionals we should always assume that the people we support can feel pain.

It is hard to be sure exactly how common pain is for kids with DD, but we know that these children experience pain more than kids without disabilities. Further, pain seems to be most common in those who have more severe disabilities. This may also be the case with adults, although sadly we talk about it less, and just like kids with DD, there is limited research about it. Certain health problems put people at higher risk for specific pain problems. For example, taking lots of medications often means having side effects which can lead to pain (e.g., from muscle spasticity: constipation). Some people with DD may need more invasive medical procedures like needles which are typically painful. These procedures may also be quite frightening which can make the pain worse. People with DD who can move around but have gross motor difficulties may be more likely to accidentally hurt themselves (e.g., falling down). Sometimes, even the type of disability a person has means they are more or less likely to have a certain kind of pain. For example, many individuals with Autism Spectrum Disorder have painful gastrointestinal disorders, and individuals with Cerebral Palsy tend to have musculoskeletal pain.

#### **Did You Know??**

Needles actually can hurt more if someone is very scared or tense! There are lots of things we can do to help make needles hurt less, like distraction!

## Why should we care about pain in people with DD?

As direct support professionals, our job is to help people with DD become more integrated and meaningfully involved in their communities. Unfortunately, people with DD can't do all the activities they want to do when they are in pain. In our society, we often talk about pain as a badge of honour (e.g., "no pain, no gain") or something that simply has to be endured. Sadly, this second kind of belief may be especially applied to people with DD but is wrong. Appropriate pain management is a human right.

When pain is left untreated in anyone, it can lead to all sorts of short and long-term consequences. People with chronic pain are more likely to have low mood, anxiety, sleep problems, and have difficulty doing what they need to do, such as going to school or work. People who experience unmanaged procedural pain (e.g., from a needle) are more likely to have longer procedure times, more distress, negative memories of the event, and may even avoid healthcare in the future. For people with DD, the impact of pain on functioning may be even larger given their other limitations. People with DD who are in pain may be less able to learn and apply skills needed to be independent and handle the daily demands in life. This includes their ability to communicate and connect with others and take care of themselves. When in pain, people with disabilities may also sleep more or less, engage in behaviours that seem oppositional (e.g., refusing to do certain things), become clingy or withdrawn, harm themselves (e.g., head banging, biting), and act out (e.g., hitting others). Sometimes unrecognized pain can lead to misdiagnosis. For example, we might see someone acting out or frustrated and believe there's a psychiatric problem, when really it is an impacted tooth, constipation, or an ingrown toenail. This kind of misunderstanding leads to treatment that isn't helpful and the problem may get worse.

## How can we recognize when someone is in pain?

**Self-Report:** Since everyone's pain is different, one of the most common ways to find out if someone is experiencing pain is to ask them. This is called self-report. For example, we might ask someone to tell us where their pain is or how much pain they are in. For people with DD, this can be hard! For example, they may not be able to communicate with words, or understand how to use 0-10 rating scales, or how to tell the difference between different descriptors or "size" ratings (e.g., small versus medium versus large). They may also have trouble showing us where their pain is. For example, a person may point to their foot if their leg is hurting.

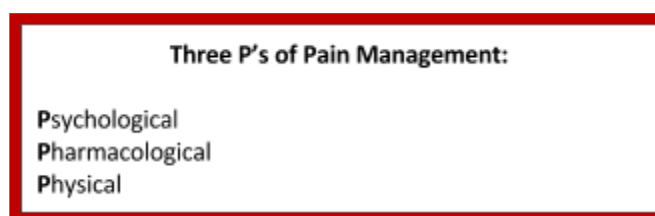
Even though self-report can be hard for people with DD, we may still be able to use it. We can make self-report easier by changing the questions we ask to match their abilities. For example, we can ask them yes/no questions instead of asking them to rate their pain on a 0-10 scale. We can also use pictures to communicate or concrete objects, like small, medium and large blocks, to help them differentiate between how much pain they are in. Sometimes, people with DD may have a special word that they use to talk about pain. For example, they may use the word "ouch" or "hurt" instead of "pain." When you ask them questions about pain, use their language (e.g., "Do you have any hurt?").

**Observations: Watching Behaviour:** Another way to tell if someone is in pain is to watch their behaviour. To do this, you will need to get to know the person you are supporting. You have to know what their “usual” behaviour looks like so you can tell when something has changed. Just like everyone’s pain experience is different, the way a person shows they are in pain will be different for each person, too. Watching facial expressions and emotions can help, but sometimes these are not reliable. You will want to look at a wide range of behaviours that you know may communicate that this individual is in pain. For example, does the person withdraw or become clingy? Have a unique sound they make such as a high-pitched squeal? Become aggressive? Engage in more sensory-seeking behaviours? You can informally observe the person you support, or, a number of assessment tools can also be used to help you with your observations (see resources section). Many of these measures are often used in medical settings, but could also be used or adapted for your work.

**Reports from Others:** It is often helpful to get information from other people who know the person that you support well. They will know a lot about the individual’s pain expression and common types of pain. For example, you can ask other professionals who know the individual well, their parents, or close friends/family members. It may help to write down the information they tell you so that you can review the information from time to time.

### How can pain be managed?

Getting rid of or reducing pain greatly improves the quality of life of those we care for - sometimes, we may even be able to prevent it altogether! There are lots of strategies that can be used to help with managing pain. Sometimes, people who know the person with a disability well will already know what helps them most when they are in pain. Other times, pain management may involve some trial and error. Just like pain assessment, pain management needs to be individualized. Different strategies may work better for different people. Pain should be re-assessed regularly to make sure that the management strategies being used are effective and safe. It is often a good idea to use more than one strategy at a time.



**Psychological:** Psychological strategies can be used to help individuals with DD cope with stress, relax muscles and distract from pain. Some people with DD may be able to use these strategies on their own, while others may need your help to stay focused on something other than their pain. Psychological techniques may allow those in pain to rely less on pain medication. Some examples of psychological strategies include:

- *Distraction:* You can distract a person and take their mind off of the pain with an activity that they like to do or find interesting. Listen to music, read a book/watch a movie, have a snack, tell jokes, play a game.
- *Deep breathing:* To use this strategy, you may first need to teach a person with DD how

to take deep breaths when they are not in pain. You can use lots of props to help the people you support learn the skill. For example, you could blow bubbles, party blowers, or pinwheels.

- *Guided imagery*: This is kind of like telling a story that involves all of your senses. You can find lots of guided imagery scripts online, or you can make up your own. The key is to make sure the story is one that the individual would like to hear and involves all the senses (e.g., you could hear ocean waves, feel the warm sun on your back, smell the ocean, see the different blues in the water, feel the sand).
- *Progressive muscle relaxation*: This is a fancy term that really means tensing and then relaxing different muscles groups through the entire body. One by one various muscle groups are tightened for about five seconds and then relaxed (e.g., hands, arms, shoulders...). You can find lots of scripts online, but you may need to adapt them to the needs of the person you support. For example, some people may not pay attention to the activity very long, or may need help understanding what to do (e.g., having them squeeze a stress ball and then let go of it instead of just telling them to make a tight fist).

**Pharmacological (Medications):** We know that there are lots of medications that can help make someone in pain feel better or make pain go away altogether. These medications can be found in many forms (e.g., liquid, pills, creams), and may be purchased over-the-counter (e.g., acetaminophen, ibuprofen, creams that soothe muscle and joint pain), or require a prescription (e.g., codeine, morphine, corticosteroids). All medication, whether it is prescribed or purchased ‘over-the-counter,’ should be approved by a physician or other prescriber and reviewed by a pharmacist. Together, these professionals make sure the right amount is prescribed and check that the drug is safe to take with other drugs. As direct support professionals, we should be consulting with the family members and health care providers of the people we support before providing any medication. As a direct support professional working with the individual, we should also make sure to communicate to others, like a new staff on shift or someone less familiar with the individual, what we know.

While medication may improve the wellbeing of people with DD who are experiencing pain, we want to be sure that the medications are helping them feel better and are not creating more problems due to side effects. Even when a medication has been approved by healthcare professionals and the primary caregivers of a person with DD, you still want to keep an eye out for any immediate or unusual side effects. For example, some medications may cause bleeding, dizziness, drowsiness, constipation and nausea. You may also wish to ask the individual with DD and/or their primary caregivers which side effects (if any) the person tends to experience so that you know what is normal for the person you support, and what may need to be documented. In some cases, people with DD may develop a tolerance to medication over time, meaning that the amount taken has to be increased for the drug to work. If you think that the medication is not helping, it may be important to tell the individual’s primary caregiver or primary health-care professional. Addiction to prescription pain medication, especially to opioids, is a serious medical problem and a complex issue. We want to make sure people get the pain relief they need and not experience negative outcomes like addiction. Any concerns related to addictions to painkillers should be addressed with a physician.

**Physical:** Various physical methods can be used to help make someone in pain feel better. Some examples include:

- Regular exercise, stretching
- Therapeutic massage
- Gentle rubbing of the area that hurts
- Warm baths
- Hug
- Applying heat/cold (not directly on bare skin)

Other professionals who work with the people you support may also be able to help. For example, physiotherapists can help with physical activity, stretching, and strengthening exercises. An occupational therapist can help suggest ways for the individual to complete activities of daily living and make adjustments for pain (e.g., pacing). Physicians can perform a nerve block which can help some people with their pain. Acupuncture may also be used for pain relief.

**Did you know??**

Sometimes things in our environment can make pain worse! For example, if you support someone who doesn't like crowds, their pain may be worse in a crowded mall than a quiet room. When managing pain we can also change the environment!

**Can pain be prevented?**

Depending on the type of pain, we may be able to prevent or lessen pain in people with DD. For example, chronic stomach pain could be the result of constipation, which a proper diet, plenty of liquids, daily exercise, and perhaps medication could prevent or treat (see our previous 'Scoop on Poop,' Volume 4 Issue 7, newsletter for more information about constipation). People who experience pain often fall into the "boom or bust" trap; when they feel great, they do too much and then their pain is much worse leading to doing nothing. Pacing allows the individual to be in control rather than the pain being in control of them. If we know that a certain activity can lead to pain later, we may want to help the person we support to pace themselves. While the activity may be fun, pacing may help prevent pain later on. Further, some accidental injuries (e.g., falls) may be preventable with changes to the environment or supervision (e.g., having railings installed, providing appropriate supports).

In some cases, pain may be a result of ill-fitting clothing, shoes, or poor hygiene. Catching these potential causes of pain early could prevent the individual from having to experience pain unnecessarily. Routine examinations by a physician and regularly checking to see if the client is having pain or other symptoms can also detect challenges early on.

## Special Circumstances: Pain during Needle Procedures

Sometimes, people with DD may need to have needles (e.g., for vaccinations, blood draws). If you as a direct support professional will be accompanying the individual to the procedure, it is important to consult with a primary caregiver or someone who knows the individual well to make a plan. Here are some important things to consider:

- Like any type of pain, worrying and fear can make the experience worse. A trusted caregiver or family member should stay with the individual with DD who is having the procedure to help with pain management, and in the communication between the client and the health professional.
- For some people, it may be helpful to know what to expect before the procedure day. If this is the case, you may wish to find out what happens before, during and after the procedure, and share this information with the individual in a way that they can understand.
- Anesthetic creams, gels or patches (e.g., EMLA, sold over-the-counter) can also be applied to the area where the needle will be inserted, 20 to 60 minutes before the injection. Vapo-coolants (cool, numbing sprays) can be applied right before the injection and may also help lessen pain. In some cases, prescriptions may be needed.
- Many of the distraction and breathing techniques discussed above may be used to help manage pain during these procedures!
- Try to have the person you support seated comfortably in an upright position, and be present in the room. If there is a history of fainting or dizziness, it may help to ask the individual to lie down. A technique called muscle tension is helpful to avoid fainting (see resources section).
- Avoid using a lot of reassurance (e.g., “It will be okay”) or telling the person that, “It will not hurt.” Point out that the vaccination is quick.
- For a vaccination, you can ask that the medical professional to avoid aspiration (pulling back on the syringe plunger after needle insertion, before the injection).
- If more than one vaccine is being given at a time, a support worker should ask the medical professional to give the most painful vaccine last.

### Final Remarks:

Appropriate pain management is a human right, and people with DD should be no exception! With care, patience, and persistence, learning how to better recognize and manage pain in the people you support is possible. It is hoped that this document and the resources below will be helpful in this way. Respecting and addressing pain experienced by people you support with DD will allow them to participate and contribute to their communities, and can also improve their overall quality of life.

## Resources:

- Pediatric Pain Profile - This is a behavioural rating scale designed to help parents and health care providers assess pain in children with DD.
  - <http://www.ppprofile.org.uk/>
- Chronic Pain Toolbox for Children with Disabilities - This is a research-based resource guide to help with chronic pain assessment for children with DD. It includes practice guidelines, assessment tools and implementation information specific to children with disabilities; however, some information may still be helpful even if you support adults with disabilities.
  - <http://hollandbloorview.ca/teachinglearning/evidencetocare/paintoolbox>
- Links to specific observational pain assessment tools - These tools are observational assessment measures designed to help caregivers assess pain in individuals with DD. Note that some of these measures are designed for children with DD while others are designed for adults with DD.
  - Non-Communicating Adult Pain Checklist:  
<https://www.painbc.ca/resources/links/non-communicating-adult-pain-checklist-ncap>
  - Non-Communicating Children's Pain Checklist-Revised: [http://pediatric-pain.ca/wp-content/uploads/2013/04/NCCPCR\\_200901.pdf](http://pediatric-pain.ca/wp-content/uploads/2013/04/NCCPCR_200901.pdf)
  - Non-Communicating Children's Pain Checklist – Postoperative Version:  
[http://pediatric-pain.ca/wp-content/uploads/2013/04/NCCPCPV\\_200901.pdf](http://pediatric-pain.ca/wp-content/uploads/2013/04/NCCPCPV_200901.pdf)
  - Grille d'Evaluation de la Douleur-Deficience Intellectuelle: [http://pediatric-pain.ca/wp-content/uploads/2013/04/GEDDI\\_2010\\_01.pdf](http://pediatric-pain.ca/wp-content/uploads/2013/04/GEDDI_2010_01.pdf)
  - Chronic Pain Scale for Non-Verbal Adults with Intellectual Disabilities:  
<http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf>
- Pain and Discomfort (Leaflets) - These resources are designed to help explain pain to those with developmental disabilities in an accessible way. For example, there is a resource to help them identify where their pain is, and another about pain in the hospital.
  - [http://www.easyhealth.org.uk/listing/pain-and-discomfort-\(leaflets\)](http://www.easyhealth.org.uk/listing/pain-and-discomfort-(leaflets))
- General resource about pain in people with intellectual and developmental disabilities.
  - <https://www.pchc.org/images/PDFs/Publications/Physical-Health/Management-of-Pain-Booklet.pdf>
- A video from Health Care Access Research and Developmental Disabilities (H-CARDD) with an example of getting blood work done:
  - Francie's Story: <https://www.youtube.com/watch?v=TqCu3hgRXm8>
- Oberlander, T. F. & Symons, F. J. (2006). Pain in Children and Adults with Developmental Disabilities. Baltimore: Paul H. Brooks.
  - This is a book focused on pain in individuals with DD and addresses a number of topics including what pain is, how it impacts quality of life, and pain management practices.



- Pediatric Pain, Health, and Communication (PPHC) Lab website:  
<http://pphc.psy.uoquelfh.ca/>
  - If fainting or feeling dizzy is a problem: under “Resources” there is a two pager on what muscle tension is and how to do it.
  - Check back to the PPHC Lab website for ongoing research about pain assessment and management training for secondary caregivers of those with DD. A Caregiver Pain Resource designed to facilitate communication about pain assessment and management between primary and secondary caregivers of children with DD is also under development and will be freely available on this website once the resource is complete.
  
- Help Eliminate Pain in Kids & Adults Team: although not specific to individuals with DD, this is a national group working on how to reduce pain and fear during vaccination across the lifespan. <http://phm.utoronto.ca/helpinkids/> The Resource tab is the best place to start. The Publication tab has links to the clinical practice guidelines which are written for healthcare professionals to know how to help.
  - Worked with Immunize Canada to give information on pain management during vaccination - found here <https://immunize.ca/pain-management-kids-and-adolescents>

### About the Authors:

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## Answers to FAQ's about the journal

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