



“Psychology Works” Fact Sheet: Pain in Children with Intellectual Disabilities who are Nonverbal

What is an intellectual disability?

According to the American Association on Intellectual and Developmental Disabilities, an intellectual disability:

1. begins before age 18
2. presents itself within different settings (e.g., at school, at home) through observable limitations in both
 - adaptive behaviour (e.g., personal hygiene, social skills), and
 - level of intellectual functioning (i.e., a child’s thinking ability).

These limitations cannot be explained by differences in one’s culture. Children may have these limitations but also have strengths in other areas. Children with intellectual disabilities are usually able to learn and improve in specific areas of functioning when their challenges are well-identified, and personalized supports are put into place.

There are a number of conditions and developmental periods in which a child is at risk for developing intellectual disabilities. First, chromosomal and genetic errors can lead to a number of syndromes associated with intellectual disabilities (e.g., Down Syndrome). Intellectual disabilities can also be caused by other factors during the pre, peri, and postnatal period (e.g., extremely low birth weight, infection, physical trauma). The degree of impairment can be determined, and classified into different categories:

- 1) Mild Intellectual Disability:
 - these children may experience difficulties in school, and can generally live independently
- 2) Moderate Intellectual Disability:
 - these children often remain at or below the level of a grade three student, and may be consistently dependent on others in some areas
- 3) Severe/Profound Intellectual Disability:
 - these children usually require support for the majority of daily activities, and many of these children do not have fully developed language skills.

What does it mean to be nonverbal?

In relation to this information sheet, *nonverbal* refers to children who have been diagnosed with an intellectual disability and do not communicate using spoken language. In other words, these children do not communicate with others using words or with a universally recognized form of sign language (e.g.,





American Sign Language). Children may occasionally be considered as *nonverbal* if they have a few words, but do not use them consistently or meaningfully.

What is pain?

The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage". Pain *experience* (how a person perceives what they are feeling) is different from pain *expression* (how a person shows that they are in pain). Pain is subjective: both pain experience and pain expression vary from person to person.

As individuals may experience pain differently, self-report is a very common method of pain measurement. However, many children who have intellectual disabilities and are nonverbal may not be capable of providing accurate self-reports about their pain. For this reason, caregivers are often asked to estimate the severity of pain a child is experiencing through observing their behaviour/pain expression. In this way, social factors may also come into play and be particularly important in a context where caregivers are relied on more heavily.

How does having an intellectual disability and being nonverbal impact pain experience and expression?

In the past, it was thought that children with intellectual disabilities did not experience pain in the same way that those without intellectual disabilities do. The belief that children with intellectual disabilities do not feel pain, are less sensitive to pain or are indifferent to pain still exists among some individuals. These beliefs are contrary to the findings of more recent research studies. The reason some individuals with intellectual disabilities, particularly those who are nonverbal, may appear to be insensitive to pain could be because they may express pain differently than other children. There are many potential explanations for this difference in expression, one being due to difficulty communicating effectively.

In what ways do children with intellectual disabilities communicate their pain to others?

As noted above, caregivers are often asked to report on these children's pain. In some instances, caregivers may be able to see the source of pain (e.g., an open wound), however, in other cases, this may not be possible. Lack of a visible source of pain should not be interpreted as an absence of pain. Despite this, assessing the presence and severity of pain may be difficult for caregivers because children who have intellectual disabilities and are nonverbal do not always express pain very clearly. In some cases, even those caregivers who know the children very well still have difficulty assessing pain severity and location. Research suggests that parents are capable of identifying common behaviours expressed by their children who have intellectual disabilities and are nonverbal when they are in pain (see section below).





Studies seeking to create a list of common ways to express pain in this population have identified some general behaviours that may indicate a child is in pain. For example, the *Non-Communicating Children's Pain Checklist*^{1 2} is a scale that has been used successfully by a variety of caregivers (e.g., health care providers, teachers, parents). A list of the behaviours on the NCCPC appears below. It is important to note that each individual may express pain differently and their baseline behaviour should be taken into consideration. Likewise, some of these behaviours may not always communicate pain; they may also express distress or frustration. Further, a child will not necessarily express all of these signals at once while in pain.

- **Vocal Behaviour:** moaning/whining/whimpering (fairly soft), screaming (very loud), crying (moderately loud)
- **Social Behaviour:** not cooperative/cranky/irritable/unhappy; less interaction with others/withdrawn, seeks comfort or physical closeness; difficult to distract/unable to satisfy
- **Facial Expression:** furrowed brow; changes in eyes; not smiling; lips pucker up/tighten/pout/quiver; clenches or grinds teeth/thrusts tongue out
- **Activity:** not moving/less active/quiet; jumping around/agitated/fidgety
- **Body and Limbs:** stiff/spastic/tense/rigid; gesturing or touching part of body that hurts; protects/favours/guards what is hurting; sensitive to touch
- **Physical Signs:** sweating; change in colour; tears; gasping

How can we ensure accurate pain assessment and management for children with intellectual disabilities who are nonverbal?

Effective pain assessment is critical for effective pain management. These processes are challenging, due to many factors including differences in pain expression and cognitive limitations. Research has demonstrated that primary and secondary caregivers have varying pain-related beliefs, some of which may not be accurate. These beliefs may also influence care decisions. First, training programs may be an effective way to improve pain-related knowledge of those who care for children with intellectual disabilities. Second, further development and implementation of effective pain assessment tools for these caregivers could help to improve pain management in this population. Some medical settings have adopted the use of 'tool kits' for managing pain in children with disabilities, such as Holland Bloorview's

¹ Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the non-communicating children's pain checklist—postoperative version. *Anesthesiology*, *96*(3), 528-535.

² Zabalía, M., Breau, L. M., Wood, C., Lévêque, C., Hennequin, M., Villeneuve, E., ... & Breau, G. (2011). Validation of the French version of the non-communicating children's pain checklist-postoperative version. *Canadian Journal of Anaesthesia*, *58*(11), 1016-1023.





Chronic Pain Assessment Toolbox³ for children with disabilities. Finally, ensuring that child-specific pain information is shared between a child’s various caregivers across settings is likely important. The Caregiver Pain Information Guide⁴ is one example of a resource under development which aims to serve this purpose.

Where can I get more information?

To Access the *Non-Communicating Children’s Pain Checklist*^{1,2}:

- <http://pediatric-pain.ca/our-measures/>
- <http://www.aboutkidshealth.ca/En/ResourceCentres/Pain/PainAssessment/MeasurementofPain/Pages/Tools-For-Measuring-Pain.aspx>

To Access the *Chronic Pain Toolbox*³:

- <https://hollandbloorview.ca/teachinglearning/evidencetocare/knowledgeproducts/paintoolbox>

To Access the *Caregiver Pain Information Guide*⁴ to be available at:

- <https://www.uoguelph.ca/pphc/resources/Caregiver-Pain-Information-Guide>

Additional Online Resources:

OUCH! How Understanding Pain can Lead to Gain when it Comes to Supporting Those with Developmental Disabilities *Not solely directed to children*:

<https://www.porticonetwork.ca/documents/38160/99698/sss%2520vol%25206%2520issue%25205%2520-%2520ENGLISH.pdf/bf828358-15c9-48f6-a7d7-70812c0df146>

Pain Assessment in the Nonverbal Patient: Position Statement with Clinical Practice Recommendations (MedScape) *Not solely directed to children with intellectual disabilities*:

<http://www.medscape.com/viewarticle/533939>

Understanding Pain in Patients with Intellectual Disabilities (MedScape) *Not solely directed to children*:

<http://www.medscape.com/viewarticle/752725>

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³ Orava, T., Provvidenza, C., Townley, A., & Kingsnorth, S. (2018). Screening and assessment of chronic pain among children with cerebral palsy: a process evaluation of a pain toolbox. *Disability and Rehabilitation*, 1-9.

⁴ Genik, L.M., Millett, G.E., & McMurtry, C.M. (under review). Facilitating respite: Preliminary evaluation of the Caregiver Pain Information Guide for children with disabilities.





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You can consult with a registered psychologist to find out if psychological interventions might be of help to you. Provincial, territorial and some municipal associations of psychology often maintain referral services.

For the names and coordinates of provincial and territorial associations of psychology go to:

<https://cpa.ca/public/whatisapsychologist/ptassociations/>





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Your opinion matters! Please contact us with any questions or comments about any of the *Psychology Works* Fact Sheets: factsheets@cpa.ca

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