

Identifying and responding to pain in people with severe or profound intellectual disability

People with severe or profound intellectual disability (ID) can experience multiple health problems related to pain, but often pain is not recognised or treated. Because of complex communication needs, people with severe or profound ID are unable to self-report pain. Instead, it has been suggested that support workers and others look for behavioural signs to help determine if someone is experiencing pain.

The aim of this research was to understand the experiences of pain in adults with severe or profound ID and explore the impact of an education session on support workers' beliefs, knowledge and confidence in identifying and responding to pain in this group of people. The education session also trialled two behavioural checklists to determine whether they could be used to identify pain. It is anticipated that the results of this research will help us to better identify and respond to pain in people with profound or severe ID.

Educating support workers



After completing the education session*, support workers showed improvements in 1) beliefs and knowledge about pain in people with severe or profound ID; 2) confidence in identifying pain; and 3) confidence in using strategies to reduce pain. Some, but not all, of these changes were still evident three months after the education session had been completed.

What are the most common causes of pain?



The most common causes of pain were constipation, dental issues, and contractures / muscle problems.

Where is the pain located?



The most common location of pain was the abdomen/ stomach followed by the legs and upper back/ shoulders.

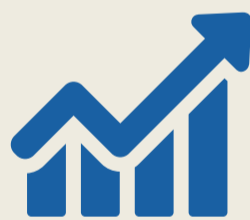
How often is pain experienced?



50%

of participants with ID experienced pain daily or several times a week.

How severe is the pain?



42.9%

of participants with ID experienced moderate pain.

How is pain detected?



Support workers relied on a combination of behavioural indicators to determine whether the person with ID was in pain, namely facial expressions and vocal signs.

Do pain checklists help?



It isn't clear whether pain checklists helped support workers identify pain but many said that were "very easy" or "easy" to use.

Is the pain treated?



78.5%

of participants with ID received some treatment to manage pain but support workers had mixed views about the effectiveness of treatment.

How is pain treated?



89.3%

of participants with ID visited a doctor/ general practitioner for treatment and the most common treatment was medication (71.4%) followed by massage (46.4%).

For more information, email Dr Stella Koritsas at research@scopeaust.org.au

* 28 people participated in the education session and completed a survey before and immediately after the session. 16 of these people also completed the survey at 3-month follow-up.