Pain Assessment of Adults With Intellectual and Developmental Disabilities

ABOUT PAIN ASSESSMENT AND IDD: Pain is often missed in people with Intellectual and Developmental Disabilities. Although self-report is often a recommended approach for assessing pain (eg, asking someone if they are in pain), it relies on expressive communication abilities and cognitive skills to understand and self-reflect – abilities that may be limited in a person with IDD.

It is important to also use observation tools developed for assessing pain in adults with IDD. These tools are designed to pay close attention to physiological indicators of potential pain (changes in breathing, skin colour, perspiration, tears), and behavioural changes that may indicate pain (facial grimacing, aggression, avoidance, posturing, verbal utterances).

When to use a pain assessment tool?

- 1. WHEN YOU THINK A PERSON MAY BE IN PAIN (eg, sustained an injury, if bowel movements are irregular, appetite seems less, sudden behavioural change, etc.).
- 2. TO CAPTURE A BASELINE WHEN THE PERSON IS DOING WELL. Because every person is unique, it is helpful to have a baseline on record, which you can then compare in the future to help assess for changes which may indicate a person is in pain. It is best for caregivers to proactively look for signs of pain, rather than waiting for a person to come and tell you they are in pain.

Recommended tools:

(Click on the underlined text below to access tools)

- Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID), available from the Centre for Pediatric Pain Research, Dalhousie University, Nova Scotia, Canada
- Non-Communicating Children's Pain Checklist-Revised (NCCPC-R), available from Centre for Pediatric Pain Research, Halifax, Canada
- Disability Distress Assessment Tool (DisDAT), by Northumberland Tyne & Wear NHS Trust and St. Oswald's Hospice, United Kingdom

Common self-report measures

To add to your observational assessment, use the following tools to ask the person how they are feeling and to report their response.

- Access the Wong-Baker FACES Pain Rating Scale at: http://wongbakerfaces.org/
- See page 2 for the Numeric Rating Scale



More information on pain and IDD

How do you assess pain if the patient can't communicate verbally? Slideshow by Lynn. B., Departments of Nursing, Pediatrics & Psychology, Dalhousie University. Available at: https://portal.sd47.bc.ca/public/3kj3ua7/Documents/BREAU-NonVerbalPatients.pdf

