

Diagnosis and treatment of chronic pain in people with intellectual disabilities

|  | <b>Explanation</b>  | <b>Disciplines involved</b>  |
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| <b>1. Inflow / registration</b>          | After subacute pain or in case of prolonged (> 3 months) unrecognized pain  | Client and client system (e.g., caregivers), relatives, other disciplines involved   |
| <b>2. Multidisciplinary consultation</b> | <p>a) Mapping biopsychosocial dimensions of pain (Somatic – Cognitive – Emotional – Behavioral – Social, (source: Dutch guideline on pain in ID, SKILZ, 2025 and Dutch guideline pain for GP, Dutch GP society, 2018), including characterization of pain and client resilience</p> <p>b) Mapping genetic causes, comorbidities and side effects of medication</p> <p>c) Formulating a working diagnosis</p> <p>d) Formulating a treatment plan</p> <p>e) Formulating evaluation criteria</p> | All disciplines involved or to be involved.<br>At least: family, caregiver, intellectual disability (ID) physician, behavioural expert, pediatrician   |
| <b>3. Additional diagnostics</b>         | For characterizing the pain and/or identifying causes (congenital or acquired).<br>Examples: research into neuropathic pain or genetic causes.  | ID physician, pediatrician, other qualified healthcare professionals   |
| <b>4. Additional diagnostics</b>         | Focused on load capacity.<br>Example: mapping daily activities in relation to physical and psychosocial load capacity.  | Occupational therapist, physical therapist, behavioural expert   |
| <b>5. Additional diagnostics</b>         | Focusing on psychosocial and emotional factors influencing pain (e.g., research on social-emotional development, trauma, pain coping, interaction of pain behaviour with caregivers)  | Behavioural expert   |
| <b>6. Evaluation criteria</b>            | Establishing evaluation criteria prior to any (trial) treatment. These can include self-report, behavioural observation, and physical examination.  | General practitioner, ID physician, pediatrician, behavioural expert, physiotherapist, occupational therapist, in consultation with caregiver and family                                     |
| <b>7. Pain education</b>                 | Explanation and education about the pain, its causes, influencing factors, and ways to deal with it by clients and/or relatives   | General practitioner, ID physician, pediatrician, (ID) nurse, behavioural expert, physiotherapist, occupational therapist. Preferably one practitioner depending on the treatment plan       |
| <b>8. Treatment</b>                      | Non-pharmacological or pharmacological.<br>Examples: exercise, balancing load and load capacity, advice on painful daily care situations, reducing stress, psychosocial interventions, or advices on sleep and diet. To avoid distress due to treatment, interventions must be prioritized and phased in.   | General practitioner, ID physician, pediatrician, behavioural expert, physiotherapist, occupational therapist, Depending on the treatment plan and in consultation with caregiver and family |
| <b>9. Evaluation</b>                     | In line with established evaluation criteria, periodic evaluation is often necessary in the treatment of chronic pain   | All disciplines involved.<br>At least: family, caregiver, intellectual disability (ID) physician, behavioural expert, pediatrician   |
| <b>10. Follow-up</b>                     | <p>a) Report in the digital client file</p> <p>b) In chronic pain, it often is necessary to repeat the process several times before the treatment is appropriate</p> <p>c) Formulate a pain profile (eg: PPP or RAPPID)</p> <p>d) Optional: seek advice (e.g., pain specialist)</p>   | All disciplines involved.<br>At least: family, caregiver, intellectual disability (ID) physician, behavioural expert, pediatrician   |