

Interdisciplinary pain care for people with intellectual disabilities

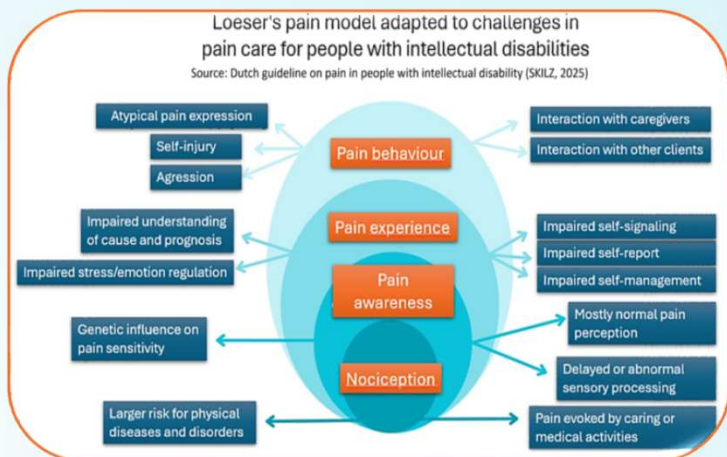
Creating networks within care centers, nations, and Europe

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Why is specialized pain care needed?



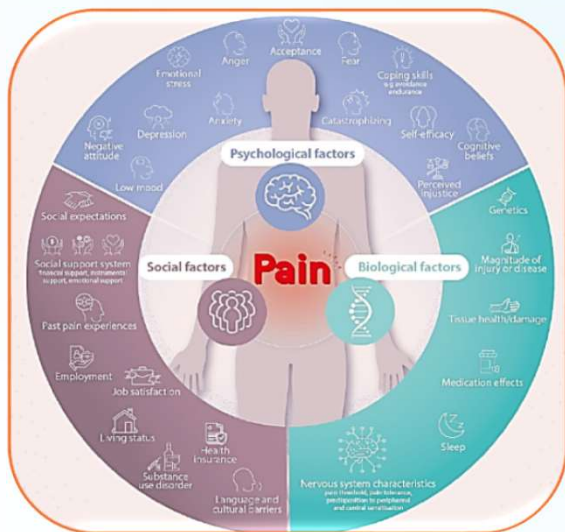
This requires methodical, interdisciplinary pain care:

- Clinical practice guideline(s)
- Implementation networks (collaboration and expertise)

What are recent guidelines on the topic?

Pain care in adults with intellectual disabilities (NL, 2025)

- Survey on the needs of care professionals
- Systematic literature search on pain diagnostics
- Methodic interdisciplinary flow charts for care centers
- Pain signaling, diagnostics, treatment, and management
- New: focus on personalized pain signaling and care
- New: biopsychosocial approach to chronic pain
- Care organization and implementation (with plan)
- Approved by professional and advocacy associations



Pain care in profound multiple and intellectual disabilities (EUR, in progress)

- Systematic literature search on pain diagnostics
- Expert opinion (methodical) based on Dutch guideline
- Patient (parents) perspective, external review of experts
- Recommended standardized and personalized tools

How can pain care be implemented?



2025-2028: 10 Dutch care centers implement the guideline with a tailor-made plan. *Pain Care (Un)limited* knowledge network (PZO) facilitates and evaluates national implementation.

What are the next steps?

European networks

- National contact persons could form a European network for research, implementation, and expertise
- ERN-Ithaca guideline will be implemented
- European working group (NL, BE, IRE) is creating a decision tree for the use of personalized pain care instruments



Worldwide exploration

- Invited submission of paper, outlining recent guideline developments on pain care (American Journal of Intellectual and Developmental Disabilities)
- Collaboration of European Pain Federation and International Association for the Study of Pain on clinical guidelines for intellectual disabilities

Interested? Contact/join us!

