GLOBAL ATLAS OF PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

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Target Group

- People with profound intellectual and multiple disabilities (PIMD)
  - Profound intellectual disability (IQ < 20) and significantly below average adaptive behaviours
- In addition:
  - Motor impairment
  - Medical problems (e.g. epilepsy)
  - Sensory impairment
- Communication:
  - Usually no verbal language
  - Often on a pre-symbolic level
  - Use of unconventional behavior signals

→ Extensive support needs
Background

EU-Project **INSENSION:**

**Financing:** EU-Project supported by the Horizon 2020 program

**Period:** 01/2018 – 12/2020

**Consortium:** International & interdisciplinary

**Target group:** People with profound intellectual and multiple disabilities

**Approach:**
- Development of a technology-supported responsive environment
- (Technical) analysis of behaviour signals
- Identification of needs for action
- Direct use of digital applications and services
Creation of the INSENSION assessment tool

Creation of a global database

Global Atlas

Feeding the Global Atlas

Intraindividual Analysis

Interindividual Analysis
Assessment

• **Purpose:**
  • Development of an appropriate assessment tool

• **Procedure:**
  • Collection of renowned assessment tools

• **Content:**
  • Six sub-questionnaires
    • General data
    • Communication development
    • Inner states (Mood, Pain, Pleasure & Displeasure/Distress)
Assessment

Based on:

- **Preverbal Communication Schedule (PVCS)**
  by Kiernan and Reid

- **Aberrant Behavior Checklist (ABC)**
  by Aman & Singh

- **Mood & Anxiety Semi-structured Interview (MASS)**
  by Charlot et al.

- **Non-communicating Adult Pain Scale (NCAPS)**
  by Lotan et al.

- **Disability Distress Assessment Tool (DisDat)**
  by Regnard et al.
What is the Global Atlas?

- Thought as a **knowledge repository** available to the community concerned with supporting individuals with PIMD

- Provides a user interface to a repository which contains a **comprehensive collection of information** on the target group
How does it work?

• Registered users can **add pseudonymized data** from people with PIMD using an online data form

• In exchange, they **get access to the whole of the collected database** for their own research studies

• Data should be entered steadily by registered users
  • (presumable 50 individuals in 2019)
What does it provide?

• Users may:
  • Gain **overview** about current communication/ways of behaviour etc. from individuals they have assessed
  • Track **progress** over time + document changes
  • **Compare data** of specific individuals they have assessed to other similar individuals (stored in the atlas) → comparison with random-sample
  • **Compare different ratings**, e.g. parents and professionals
  • Use the **report function** via email → collaboration between parents and professionals
INTRAINDIVIDUAL ANALYSIS
Both perspectives

Perspectives of relatives

Perspectives of professional caregivers
Challenging Behaviour

Perspectives of relatives

Perspectives of professional caregivers

Problem is severe

Problem is moderately serious

Problem, but slight in degree

No problem

Both perspectives
Challenging Behaviour

Problem is severe in degree
Problem is moderately serious
Problem, but slight in degree
No problem

Both perspectives
Perspectives of relatives
Perspectives of professional caregivers
Challenging Behaviour – Different Evaluators

- Inappropriate Speech
- Hyperactivity
- Stereotypic Behaviour
- Lethargy / Social Withdrawal
- Irritability

Professional caregivers vs. Relatives

- Perspectives of relatives
- Perspectives of professional caregivers

Both perspectives
INTERINDIVIDUAL ANALYSIS
Interindividual Analysis

• Mapping of **typical developmental trajectories** within one syndrome (typical benchmarks)
• Calculation of **correlations**, e.g.
  • between syndroms and communication
  • between challenging behavior and communication
  • between challenging behavior and mood
  • ...
  • ➔ Evaluation of research findings
Evaluation of research findings

• **Behavior and communication**
  • Communicative limitations are known to lead to challenging behavior
    (HOLDEN and GITLESEN 2006; LUNDQVIST 2013; POPPES et al. 2010)

• **Behavior and inner states (mood, pleasure & displeasure/distress)**
  • People with PIMD show clear signs of low mood. Low mood is associated with a higher frequency and greater severity of challenging behavior
    (ROSS and OLIVER 2002; HAYES, MCGUIRE, O’NEILL, OLIVER and MORRISON 2011)
  • People with lower subjective well-being more often express challenging behavior than people with higher subjective well-being
    (ADAMS and OLIVER 2011)
Thanks for your attention!

Question, comments, remarks...?

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