



## 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*:

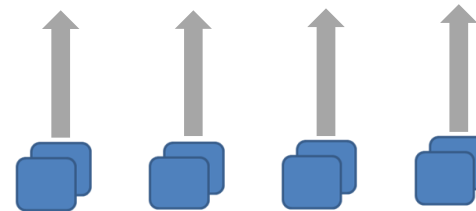
<b>Financing:</b>	EU-Project supported by the Horizon 2020 program
<b>Period:</b>	01/2018 – 12/2020
<b>Consortium:</b>	International & interdisciplinary
<b>Target group:</b>	People with profound intellectual and multiple disabilities
<b>Approach:</b>	<ul style="list-style-type: none"><li>• Development of a technology-supported responsive environment</li><li>• (Technical) analysis of behaviour signals</li><li>• Identification of needs for action</li><li>• Direct use of digital applications and services</li></ul>

## Creation of the INSENSION assessment tool



Feeding the  
Global Atlas

## Creation of a global database

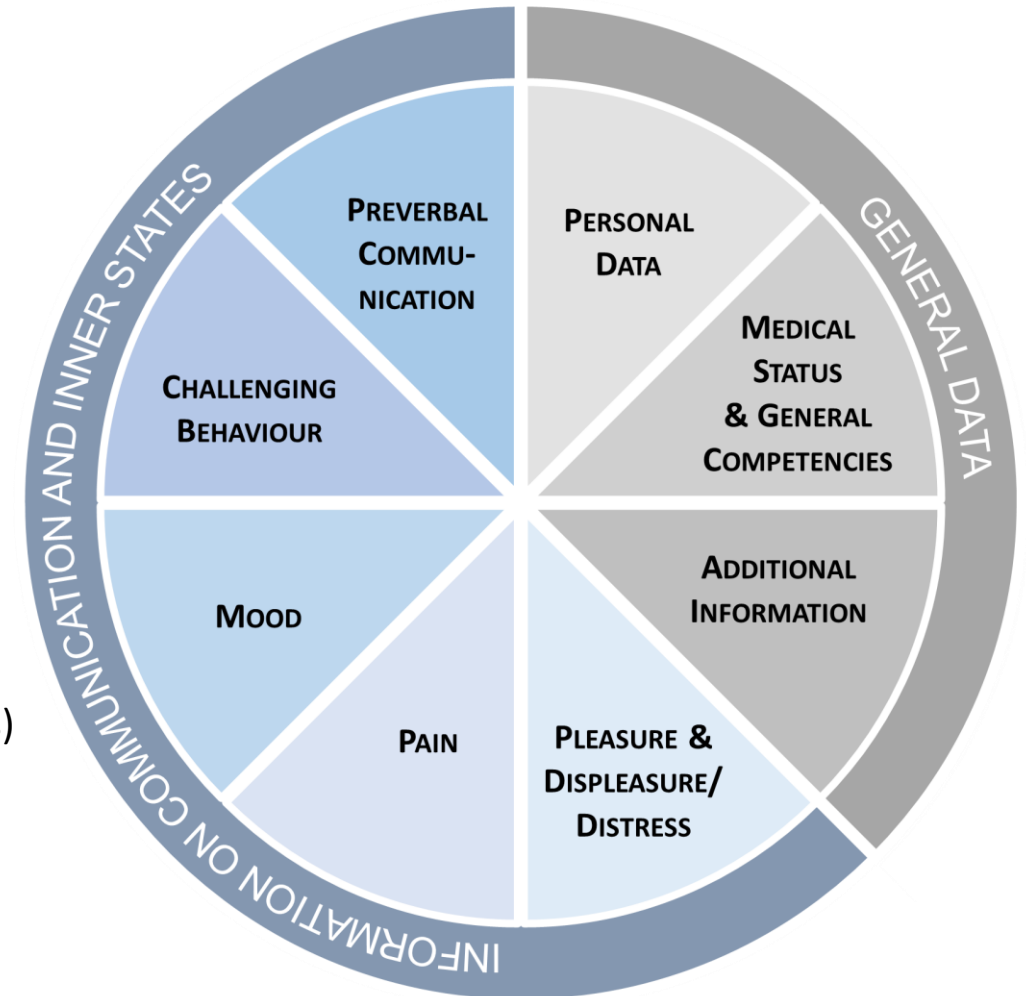


Intraindividual Analysis

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)



Based on:

## Preverbal Communication Schedule (PVCS)

by KIERNAN and REID

## Aberrant Behavior Checklist (ABC)

by AMAN & SINGH

## Mood & Anxiety Semi-structured Interview (MASS)

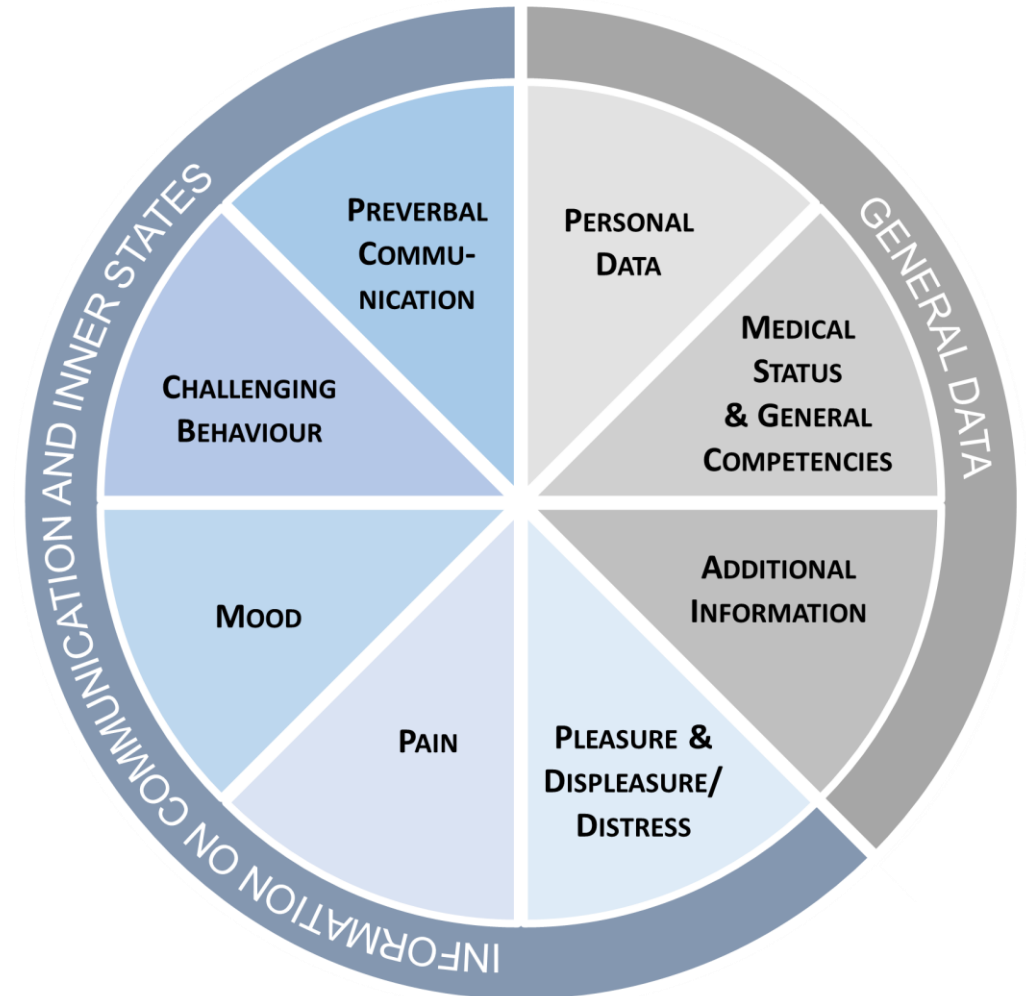
by CHARLOT et al.

## Non-communicating Adult Pain Scale (NCAPS)

by LOTAN et al.

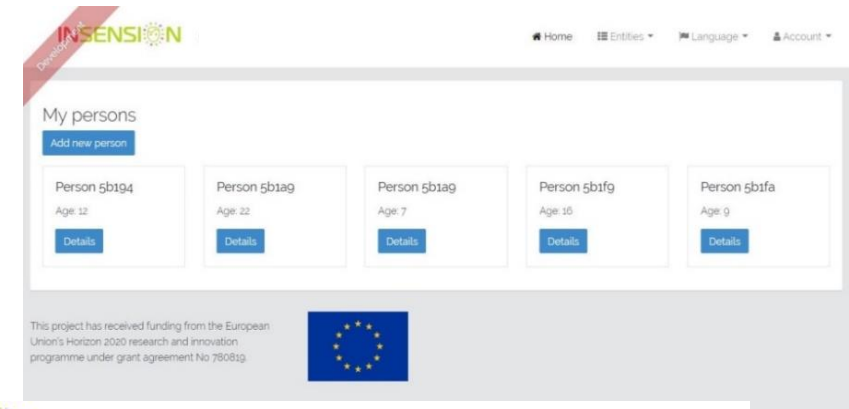
## Disability Distress Assessment Tool (DisDat)

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

A screenshot of the INSENSION web application showing the 'Information on Evaluator' form. The form includes a 'Type of Relationship' dropdown menu with 'personal caregiver' selected, a 'Center' text input field, and a 'Medical Status & General Competencies' section. This section contains four rows of information, each with a text input field and radio button options for 'yes (please specify)', 'no', and 'unclear':

- Diagnoses (e.g., syndromes like Rett-syndrome, autism, intellectual disability)
- Challenging Behaviour (e.g., stereotypes, self-injury, hitting)
- Perceivable Physiological Parameters (e.g., fast breathing, sweating, conspicuous muscle tone)
- Use of Vocalization (e.g., different sounds)

## How does it work?

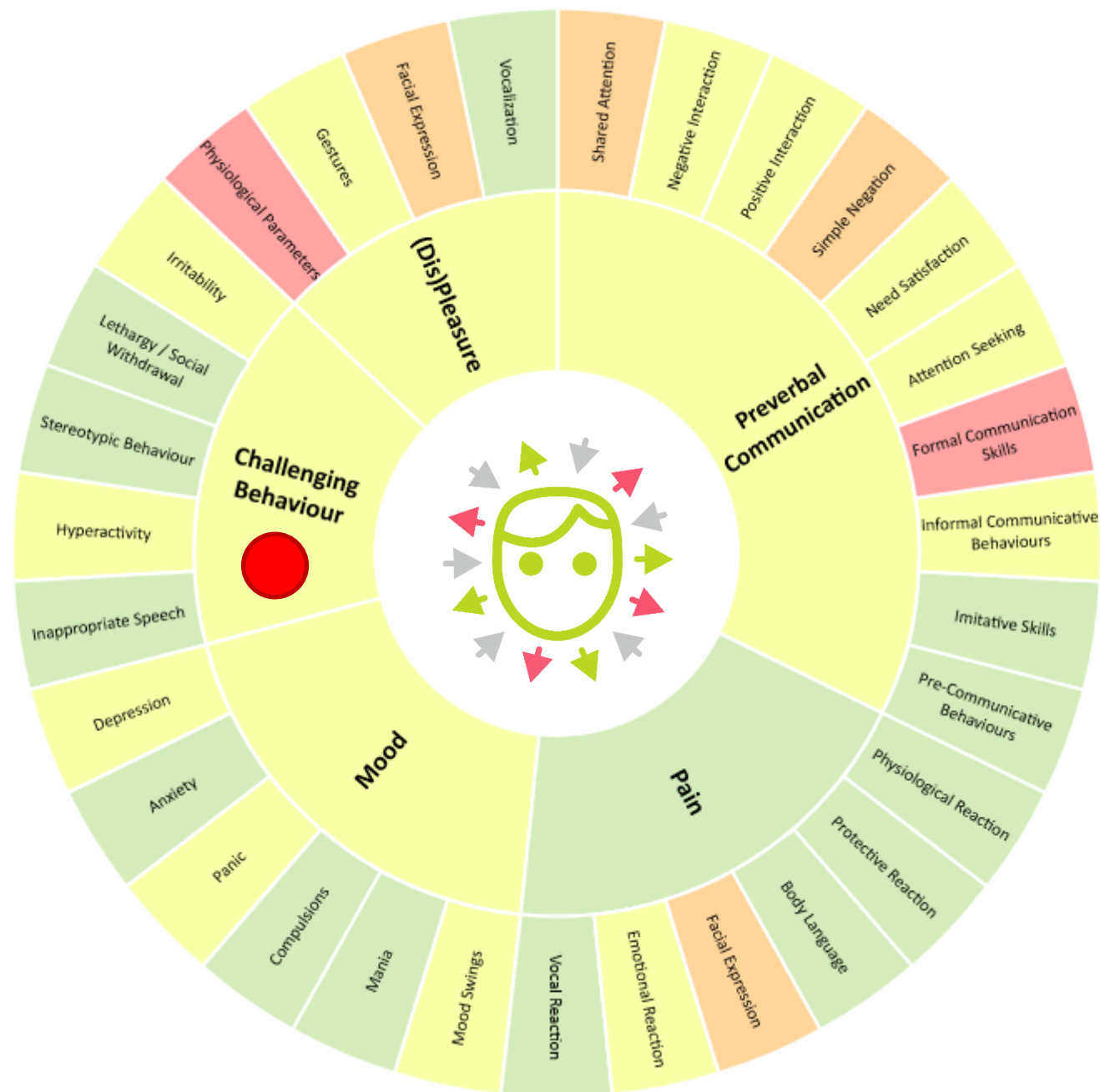
- Registered users can **add pseudonymized data** from people with PIMD using an online data form
- In exchange, they **get access to the whole of the collected database** for their own research studies
- Data should be entered steadily by registered users
  - (presumable 50 individuals in 2019)



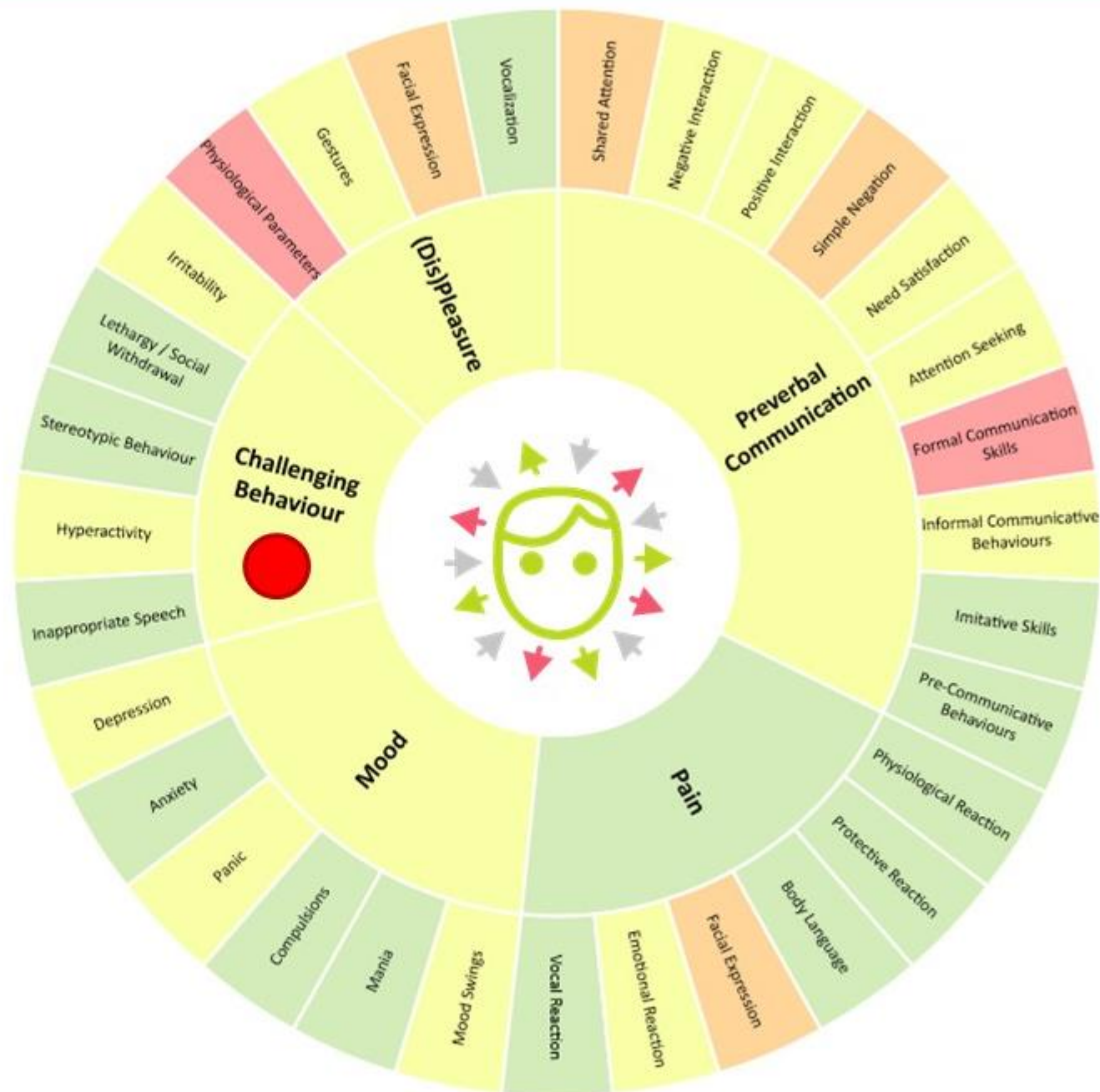
## What does it provide?

- 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
X	Perspectives of relatives
	Perspectives of professional caregivers



X

Both perspectives

Perspectives of  
relatives

Perspectives of  
professional caregivers



Both perspectives

Perspectives of relatives

X

Perspectives of professional caregivers

Problem is severe in degree

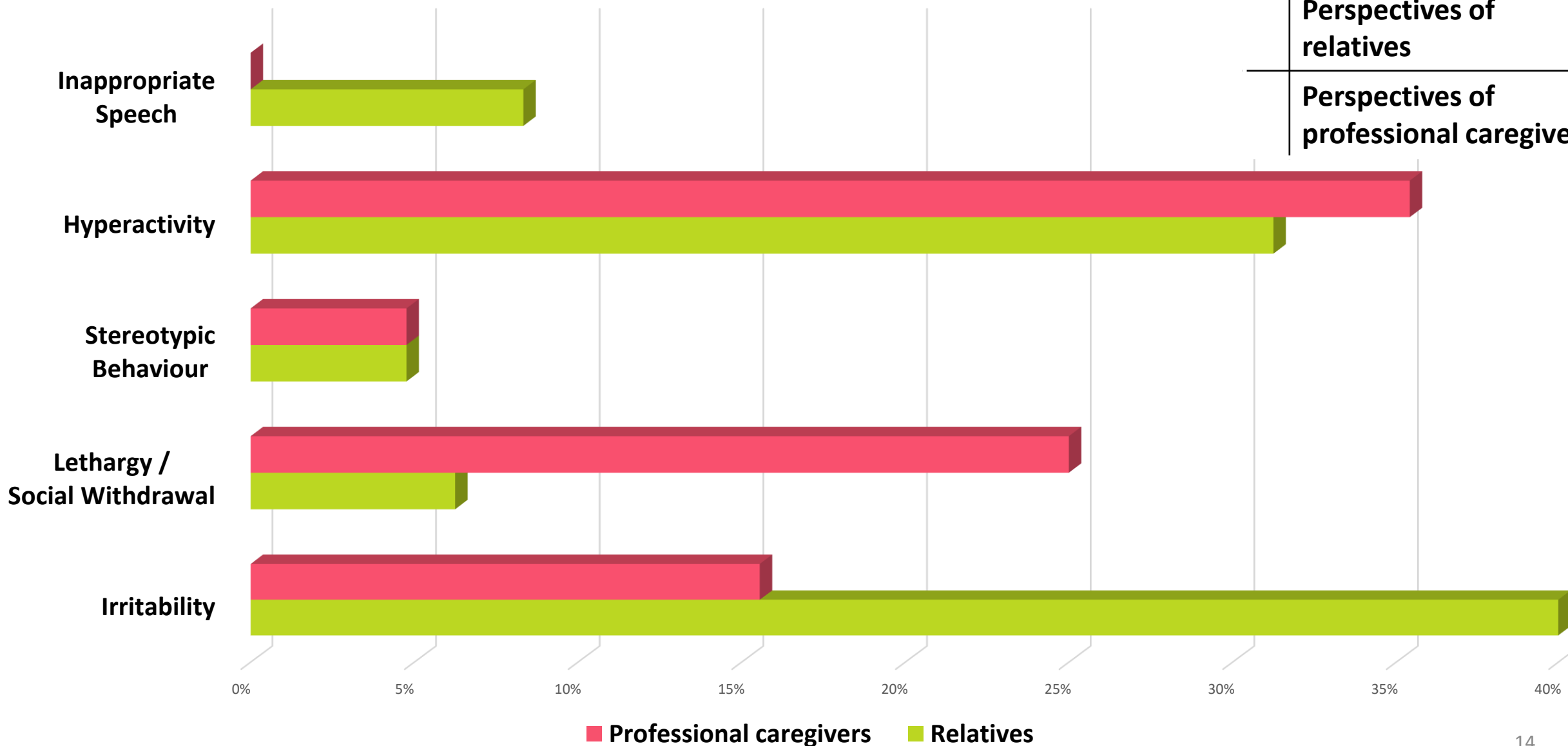
Problem is moderately serious

Problem, but slight in degree

No problem

# Challenging Behaviour – Different Evaluators

X	Both perspectives
	Perspectives of relatives
	Perspectives of professional caregivers



# 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...?

**www.insension.eu**

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