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# Personalized intelligent platform enabling interaction with digital services to individuals with profound and multiple learning disabilities



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 780819.

#### PARTNERS



Jožef Stefan Institute







### **Employing Advanced ICT for the Inclusion of People with Profound Intellectual and Multiple Disabilities**

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### IT IS ENTIRELY POSSIBLE THAT BEHIND THE PERCEPTION OF OUR SENSES, WORLDS ARE HIDDEN OF WHICH WE ARE UNAWARE

**Albert Einstein** 



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# The INSENSION project

- Financing: EU-Project supported by the Horizon 2020 program
  - Period: 01/2018 06/2021
- Consortium: International & interdisciplinary
- Objectives: Design and develop an ICT platform that enables persons with PIMD to use digital applications and services that:
  - can enhance the quality of their life
  - increase their ability to self-determination
  - enrich their life



## **Technological partners**





Future Internet, eInclusion technologies

**Artificial intelligence** 

**Computer vision** 



### **Domain partners**







Intellectual disability, special education Care provision to people with intellectual disability

**Creation and distribution** of assistive technologies



# **Different perspectives on the INSENSION project**





# **Different perspectives on the INSENSION project**



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### The goal

Design and develop an ICT platform that <u>enables</u> persons with profound intellectual and multiple disabilites to interact with their surroundings and, as a result, increase the ability to selfdetermination.



## **Target Group**

### People with profound intellectual and multiple disabilities (PIMD)\*:

- Profound intellectual disability
- Adaptive behavior clearly below average

### In addition:

- Motor impairment
- Sensory impairment
- Medical problems (e.g. epilepsy)

\* also referred to as PMLD – profound and multiple learning disabilities



### **Pre-verbal Communication Development**

#### **Communication:**

- Usually no verbal language
- Often on a pre-symbolic level
- Use of individual and unconventional behavior signals





# Assessment of Communication and Inner States in People with PIMD





### The INSENSION Questionnaire – Longform (InQL)

Hall et al. (2008) & Vos et al. (2012)

Preverbal Communication Schedule (PVCS) by KIERNAN and REID (1987)

Aberrant Behavior Checklist (ABC) by AMAN & SINGH (2017)

Mood & Anxiety Semi-structured Interview (MASS) by CHARLOT et al. (2007)

Non-communicating Adult Pain Scale (NCAPS) by LOTAN et al. (2009)

Disability Distress Assessment Tool (DisDat) by REGNARD et al. (2007) complemented by Roemer et al. (2017)





# **Evaluation of the InQL**

- Difficulties in implementation:
  - Assessment of pain and stress situations
  - Assessment of behavior during the night
- Advantages & benefits of the INSENSION questionnaire:
  - Attention also to the knowledge of the relatives
  - New perspectives
  - Impulse for reflection and conscious analysis



### **Further Information**



Engelhardt, M., Krämer, T., Marzini, M., Sansour, T. & Zentel, P. (2020). Communication assessment in people with PIMD. Evaluating the use of the INSENSION Questionnaire – Longform (InQL). Psychoeducational Assessment, Intervention and Rehabilitation, 2(1), 1–14. https://doi.org/10.30436/PAIR20-01

Kosiedowski, M., Engelhardt, M., Krämer, T. & Urbanski, J. (2019). Global Atlas of people with profound intellectual and multiple disabilities. Journal on Technology and Persons with Disabilities, 7, 106–119.



### The INSENSION Questionnaire – Shortform (InQS)

#### Hall et al. (2008) & Vos et al. (2012)

Preverbal Communication Schedule (PVCS) by KIERNAN and REID (1987)

Aberrant Behavior Checklist (ABC) by Aman & Singh (2017)

Mood & Anxiety Semi-structured Interview (MASS) by CHARLOT et al. (2007)

Non-communicating Adult Pain Scale (NCAPS) by LOTAN et al. (2009)

Disability Distress Assessment Tool (DisDat) by REGNARD et al. (2007) complemented by Roemer et al. (2017)





### **Meaningful Behavior Signals**





### **Annotation Process**

- Based on the individual annotation guideline
- Annotation of selected videos regarding
  - different behavioral signals and
  - different inner states
- Over 20 h of annotated recordings





### **Further Procedure**





# **Different perspectives on the INSENSION project**





### **Non-symbolic interaction (1)**













# AUGMENTATIVE AND ALTERNATIVE COMMUNICATION





# **Non-symbolic interaction (2)**

- Reactions to the happenings around through:
  - gestures
  - facial expressions
  - vocalizations
  - gaze
- These signals are highly individual!



### **Non-symbolic interaction (3)**





### The system



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### The goal

Design and develop an ICT platform that <u>enables</u> persons with profound intellectual and multiple disabilites to interact with their surroundings and, as a result, increase the ability to selfdetermination.





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### **Insension platform**









### The process of supporting user's interaction with surroundings



Recognition of the context of behaviors



### **1. Recognition of behavior signals**



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### **Recognizers of behavior signals**



Facial expression recognizer



#### Gesture recognizer



Vocalization recognizer



### 2. Recognition of the context



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# **Context recognizers**

Ambient sounds recognizer



Identity recognizer



**Ambient sensors** 

Feedback from assistive applications



**Object recognizer** 



### 3. Interaction decision support



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### **Interaction decision support**

- Objective: interpret the data collected by recognizers as *user intents* using machine learning techniques
- A user intent contains:
  - inner state of the user (PLEASURE/DISPLEASURE/NEUTRAL)

#### plus

potential causes of the behavior related to the current user intent



### 4. Selection of the assistive application to act



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### Selection of the application to act (1)

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nighttime					More	Set as default	Edit	Delete					
Available applications Run as first Media Player Run as last Communicator (Default	0												



### Selection of the application to act (2)

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### Application has to confirm it will take action





### 5. Action in the surroundings of the person with PIMD



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### **Assistive applications**

- Goal of the INSENSION platform: provide information on the current need of the end user to external applications which are capable of acting on behalf of the end user
- Example (pilot) applications:









### Applications must be configured to know what to do when



Rules

Actions



### **Further Information**



- Kosiedowski, M., Radziuk, A., Szymaniak, P., Kapsa, W., Rajtar, T., Stroinski, M., Campomanes-Alvarez, C., Campomanes-Alvarez, B., Lustrek, M., Cigale, M., Dovgan, E., Slapnicar, G. (2019). On Applying Ambient Intelligence to Assist People with Profound Intellectual and Multiple Disabilities. In: Bi Y., Bhatia R., Kapoor S. (eds) Intelligent Systems and Applications. IntelliSys 2019. Advances in Intelligent Systems and Computing, vol 1038, 895-914. Springer, Cham. https://doi.org/10.1007/978-3-030-29513-4\_66
- C. Campomanes-Álvarez, B. R. Campomanes-Álvarez and P. Quirós (2019). Person Identification System in a Platform for Enabling Interaction with Individuals Affected by Profound and Multiple Learning Disabilities. 2019 IEEE 18th International Conference on Cognitive Informatics & Cognitive Computing (ICCI\*CC), 2019, 166-173. https://doi.org/10.1109/ICCICC46617.2019.9146032



# **Different perspectives on the INSENSION project**









Permanent monitoring through artificial intelligence?

Taking pre-intentional behavior as a reference point for our communicative actions (Hennig 2011)

Acknowledging and respecting communicative downtime (Klauß 2002) functioning of the INSENSION system

balance between necessary caring, attentive accompaniment and paternalistic supervision



### **Concerns about technology in care?**

- ... related to the functioning of the INSENSION system
- **little concern** about cleaning robots or technical aids such as electric beds or wheelchairs that are able to avoid obstacles
- medium concerns about prostheses, the use of which will be made safer by sensors, service robots that can handle transport routes
- **major concerns** about so-called care robots, which interact directly with people in need of care, providing them with medication and food

(Butter et al. 2008)



... related to the functioning of the INSENSION system

### **Dehumanization through artificial intelligence?**

- Addressing technical aids in the care of vulnerable people goes to the heart of what it means to be human
- Increasing humanization of robots and artificial intelligence leading to dehumanization of care



# Dehumanization through artificial intelligence?

... related to the functioning of the INSENSION system

### Our approach:

- Increase the independency and self-efficacy of people with PIMD
- Support for the caregivers (assistance in decision-making)
- More quality-time for human interactions!



... related to involving people with PIMD in research

# Involving people with PIMD in research?

- Participation despite lack of consent of the persons with PIMD themselves
  - Permanent monitoring
  - Collection of personal data
  - Unclear long-term effects on participants with PIMD and caregivers



# Involving people with PIMD in research?



### Our approach:

Informed consent

- Informed consent at the beginning including close caregivers (professionals and relatives)
- Substitute 'consent' by legal guardians
- Focusing the benefits for the persons with PIMD

Ongoing consent

- Ongoing consent during the whole research process including all persons involved
- Monitoring the behavior of the persons with PIMD
- Permanent and transparent reflection with optional readjustment



### **Further Information**



Engelhardt, M., Kosiedowski, M., Krämer, T., & Tyrakowska, J. (2019). Should Artificial Intelligence be Used to Empower People with Profound Intellectual Disabilities? Proceedings of the STS Conference Graz 2019, 84–104. https://doi.org/10.3217/978-3-85125-668-0-06

Krämer, T., & Zentel, P. (2020). Expression of Emotions of People with Profound Intellectual and Multiple Disabilities. A Single-Case Design Including Physiological Data. Psychoeducational Assessment, Intervention and Rehabilitation, 2(1), 15–29. https://doi.org/10.30436/PAIR20-02



### **Additional study**



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Additional study: influence of monitoring physiological response on the platform accuracy

Literature has suggested that including information on physiological response of people with PIMD might help to interpret their behaviors:

- *"heart rate and skin temperature can give information about the emotions of persons with severe and profound ID"* [Vos et al. 2012]
- "frequent consistent physiological reactions" to stimuli [Lima et al. 2013]
- *"a shallow, fast breathing pattern, used less thoracic breathing, had a higher skin conductance and had less RSA when experiencing positive emotions then when experiencing negative emotions"* [Vos et al. 2010]



# **Physiological parameters monitoring**

• <u>Contact-free monitoring</u>:







rPPG



Heart rate (HR) + Heart rate variability (HRV) +

 $\rightarrow$  Mental state

•••

• <u>Contact monitoring</u>:







### **Summary**



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### **Summary**

- Providing technological means to (successfully) support people with PIMD in interacting with others and surroundings is challenging
- The research leading to creation of the prototype of such technology is complex and requires integration of expertise from several disciplines
- The system must be verified with the participation of the target end users people with PIMD (and their caregivers)
- While the system extensively uses AI, it does not aim to remove the human caregiver
- An AI-based system to support people with PIMD is a must: not applying Artificial Intelligence on people with PIMD due to their incapability of consenting to it would refuse them the possibility to benefit from the potential of achieving a (higher) level of independence



# Thank you for your attention!

Further information: Follow us on Facebook: www.insension.eu www.insension.eu/fb



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### References

- Aman, M. G., & Singh, N. N. (2017). Aberrant Behavior Checklist: Manual (2nd ed.). Slosson Educational Publications.
- Axelsson, A. K., Imms, C., & Wilder, J. (2014). Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: Parents' and personal assistants' experiences. Disability and Rehabilitation, 36(25), 2169–2177.
- Butter, M., Rensma, A., Boxsel, J., Kalisingh, S., Schoona, M., Leis, M., Gelder-blom, G. J., Cremers, G., Wilt, M., Kortekaas, W., Thielmann, A., Cuhls, K., Sachinopoulou, A., & Korhonen, I. (2008). Robotics for Healthcare: [Report]. European Commission, DG Information Society. Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. Nursing Ethics, 19(4), 558–567.
- Calveley, J. (2012). Including adults with intellectual disabilities who lack capacity to consent in research. Nursing Ethics, 19(4), 558 https://doi.org/10.1177/0969733011426818
- Charlot, L., Deutsch, C., Hunt, A., Fletcher, K., & McLlvane, W. (2007). Validation of the Mood and Anxiety Semi-structured (MASS) Interview for patients with intellectual disabilities. Journal of Intellectual Disability Research, 51(10), 821–834.
- Coons, K. D., & Watson, S. L. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and Practical Implications for Qualitative Research. Journal on Developmental Disabilities, 19(2), 14–24.
- Hall, S., Arron, K., Sloneem, J., & Oliver, C. (2008). Health and sleep problems in Cornelia de Lange Syndrome: A case control study: A case control study. Journal of Intellectual Disability Research, 52(5), 458–468. https://doi.org/10.1111/j.1365-2788.2008.01047.x
- Hennig, B. (2011). Interaktion und Kommunikation zwischen Menschen mit schwerster Behinderung und ihren Bezugspersonen: Aspekte des Gelingens. In A. Fröhlich, N. Heinen, T. Klauß, & W. Lamers (Eds.), Handbuch schwere und mehrfache Behinderung interdisziplinär (pp. 273–297). ATHENA-Verlag.



### References

- Hennig, B. (2011). Interaktion und Kommunikation zwischen Menschen mit schwerster Behinderung und ihren Bezugspersonen: Aspekte des Gelingens. In A. Fröhlich, N. Heinen, T. Klauß, & W. Lamers (Eds.), Handbuch schwere und mehrfache Behinderung interdisziplinär (pp. 273–297). ATHENA-Verlag.
- Kiernan, C., & Reid, B. (1987). Pre-verbal communication schedule (PVCS): Manual. NFER-Nelson.
- Klauß, T. (2002). Können Menschen wirklich nicht nicht kommunizieren? Anfragenzu einem an Watzlawick angelehnten sonderpädagogischen Glaubenssat. VHN, 71(3), 262–276.
- Lotan, M., Moe-Nilssen, R., Ljunggren, A. E., & Strand, L. I. (2009). Reliability of the Non-Communicating Adult Pain Checklist (NCAPC), assessed by different groups of health workers. Research in Developmental Disabilities, 30, 735–745.
- Mietola, R., Miettinen, S., & Vehmas, S. (2017). Voiceless subjects? Research ethics and persons with profound intellectual disabilities. International Journal of Social Research Methodology, 20(3), 263–274. https://doi.org/10.1080/13645579.2017.1287872
- Nakken, H., & Vlaskamp, C. (2007). A Need for a Taxonomy for Profound Intellectual and Multiple Disabilities. Journal of Policy and Practice in Intellectual Disabilities, 4(2), 83–87.
- Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). Journal of Intellectual Disability Research, 51(4), 277–292.
- Vos, P., Cock, P. de, Munde, V., Petry, K., & van den Noortgate, W. (2012). The tell-tale: What do heart rate; skin temperature and skin conductance reveal about emotions of people with severe and profound intellectual disabilities? Research in Developmental Disabilities, 33, 1117–1127.