

Assessment of Communication Skills and Inner States within the Context of People with Profound Intellectual and Multiple Disabilities



Meike Engelhardt

Heidelberg University of Education, Department of Special Education
Email: engelhardt@ph-heidelberg.de



Background

People with profound intellectual and multiple disabilities (PIMD) often communicate on a **pre-symbolic** level and use **unconventional behavior signals** (e.g., specific body movements or vocalizations) to express their needs (Bellamy et al. 2010; Maes et al. 2007; Carnaby 2007). The number of interaction partners who are capable of accurately perceiving and interpreting these specific and **highly individual** behavior signals is very limited in most cases. The exact understanding of their needs is often not possible even for close direct support people (Petry, Maes 2006). This significantly **restricts the participation** of people with PIMD in all areas of life. The group of persons with PIMD is relatively small but very heterogeneous with a prevalence of approximately 1-2% of people with intellectual disabilities (Doukas et al. 2017). Hence, there is significantly less research in the field of diagnostic in comparison to the context of milder forms of intellectual disabilities. Unfortunately, this leads to a **lack of adequately sensitive and standardized as well as empirically based assessment tools** for people with PIMD (Brady et al. 2018).

Method & Research Question

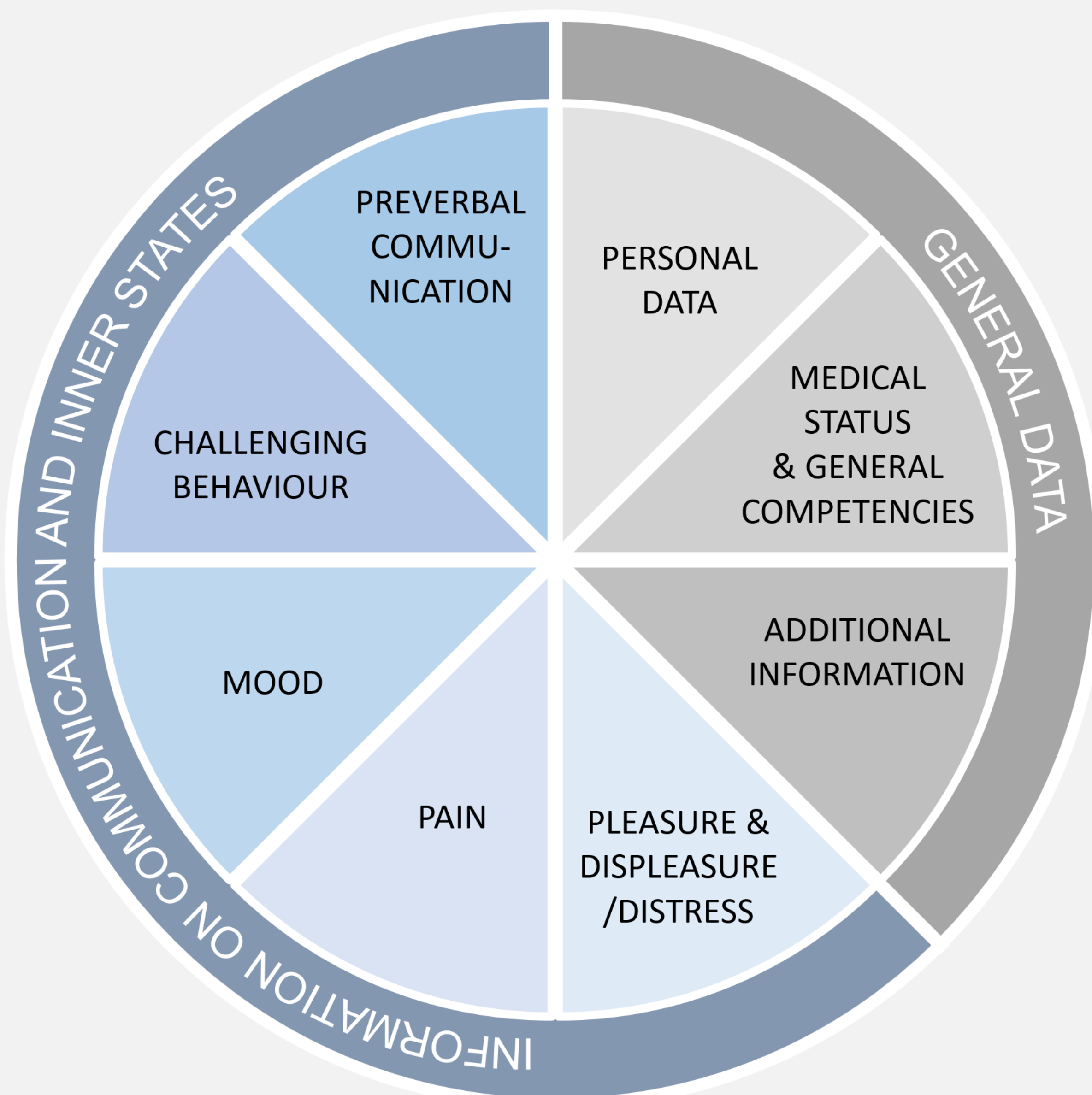
As direct questioning of the target group is impossible, observation procedures and **questionnaires for direct support persons** are the methods of choice (de Geus-Neelen et al. 2017). To satisfy the enormous heterogeneity a **highly individualized approach** is necessary. Therefore, this research focuses on the following question:

Which existing diagnostic instruments are applicable for people with PIMD and what kind of competence areas do they cover?

To gain an overview, an international **review of literature and assessment tools** for this target group has been performed. Based on this research, a comprehensive assessment tool has been developed and tested with 25 participants.

Results

The developed **INSENSIION questionnaire** includes 5 pre-existing questionnaires on **Communication Skills and Inner States**, which were chosen out of 38 analyzed diagnostic instruments. Within the **INSENSIION questionnaire**, they are complemented by several questions on **General Data** covering all in all 39 pages. It should be filled in by at least two **different raters** who know the particular person with PIMD for at least 6 months (e.g., relatives and teacher). The structure of this questionnaire allows a **completion in stages** and some items require direct testing with the particular person with PIMD. In order to increase usability a **web-based version** is envisaged.



Preverbal Communication Schedule (PVCS)

by KIERNAN and REID (1987)

Aberrant Behavior Checklist (ABC)

by AMAN & SINGH (1986)

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)

Conclusion

A detailed assessment of information on *Communication Skills and Inner States* gathered in a standardized way by means of the **INSENSIION questionnaire** can help **evaluating the specific needs** of a person with PIMD and **improving their understanding**. The assessment can also build the **base for pedagogical implications** like an Individual Education Plan. Furthermore, the **comparison** between the statements of the different raters allow interesting insights. Additionally, the **INSENSIION questionnaire** will serve as a starting point for the **Global PIMD Atlas**, a web-based knowledge repository on PIMD.

References:

- Bellamy, G.; Croot, L.; Bush, A.; Berry, H.; Smith, A. (2010). A study to define: Pro-found and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, 14(3), 221-235, DOI: 10.1177/1744629510386290
- Brady, N. C.; Fleming, K.; Romine, R. S.; Holbrook, A.; Muller, K.; Kasari, C. (2018). Concurrent validity and reliability for the communication complexity scale. *American Journal of Speech-Language Pathology*, 27(1), 237-246, DOI: 10.1044/2017_AJSLP-17-0106
- Carnaby, S. (2007): Developing good practice in the clinical assessment of people with profound intellectual disabilities and multiple impairment. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 88-96.
- Doukas, T.; Fergusson, A.; Fullerton, M.; Grace, J. (2017): Supporting people with profound and multiple learning disabilities. Core & essential service standards 1st edition. Retrieved from <http://www.pmlmlink.org.uk/wp-content/uploads/2017/11/Standards-PMLD-h-web.pdf> [31.05.2019].
- De Geus-Neelen, K.; van Oorsouw, W.; Hendriks, L.; Embregts, P. (2017): Perceptions of staff and family of the quality of life of people with severe to profound intellectual disability. *Journal of Intellectual & Developmental Disability*, DOI: 10.3109/13668250.2017.1310813
- Maes, B.; Lambrechts, G.; Hostyn, I.; Petry, K. (2007): Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. *Journal of Intellectual and Developmental Disability*, 32(3), 163-178, DOI: 10.1080/13668250701549427
- Petry, K.; Maes, B. (2006): Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. *Journal of Intellectual and Developmental Disability*, 31(1), 28-38, DOI: 10.1080/13668250500488678

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