
Appendix B: Background Information for Funding Bodies

Determination of Needs for Individuals with Intellectual and Developmental Disorders Using the Developmental Approach

1. Emotional Development and Intellectual Disability

Intellectual disabilities rarely manifest themselves solely in cognitive functioning; in most cases, social-emotional development is affected as well. A person's behaviour and needs are decisively influenced by his or her level of emotional development (Sappok, Zepperitz & Hudson, 2022). Thus, it depends on the emotional development level whether and how a person can regulate aggression or how intensively they depend on caregivers in everyday life in order to feel safe. For adequate care it is essential to know the level of cognitive *and* emotional development. Therefore, the emotional reference age needs to be determined in addition to the severity of ID. The level of emotional development can be evaluated by using the SED-S (see 3. The SED-S: Scale of Emotional Development – Short by Sappok, Zepperitz, Morisse, Barrett & Došen, 2022).

Example: Ms K (31-years-old) has a mild intellectual disability. She is often very dominant towards her housemates in the outpatient group and gets angry quickly. She usually behaves egocentrically and does not see the needs of others. Her emotional reference age of three years is clearly lower than her cognitive reference age (9–12 years). This explains her behaviour and must be considered for her to be able to live in the community.

2. Emotional Development and Participation

Participation means “being included in a life situation” (ICF, 2005). Ensuring the participation of a person according to his or her expectations is the approach of UN Disability Rights Convention (2006). What individuals need and what kind of support they may require in order to participate in life in their

community is largely dependent on their level of functioning. The emotional reference age of an individual indicates, among other things, how strongly they are dependent on the security provided by caregivers. Depending on individuals' stage of emotional development, personal or structural security is necessary to participate in many situations, otherwise they would, for example, show behavioural problems such as aggression towards themselves or others. Behavioural problems can prevent participation and experience has shown that problem behaviours can often be avoided if care is better aligned to individuals' emotional needs. Moreover, we can better understand behaviour when we take a holistic approach. Behaviour typical for the respective level of emotional development should be considered as integral to the person in question.

Example: Mr Z (39-years-old) is a man with a moderate intellectual disability (cognitive reference age: 6–9 years) and a low level of emotional development (reference age: approx. 1-year-old). He needs constant visual contact with caregivers due to his insecure object permanence. If he does not see them, he becomes restless, hits himself and throws things around. This behaviour is “normal” for his individual stage of development and must be considered to enable him to live in a residential group home.

3. The SED-S: Scale of Emotional Development – Short

The SED-S is an instrument used to assess a person's level of emotional development. The SED-S can be used to identify an individual's emotional needs by analysing behaviours using a standardised observation questionnaire. The SED-S can be used to assess emotional development in eight developmental domains. The behaviour of a person is assigned to one of the five developmental stages through the assessment. The five developmental levels correspond to the respective reference ages in typically developing children.

Example: Ms O (53-years-old) often gets angry. If she cannot assert her will, she pinches others and screams. Her emotional development is classified as SED-S Level 3 in the domain of “Regulating Affect”. This corresponds to a reference age of 1.5 to 3-years-old. For children, this would be the “age of defiance”. Of course Ms O is an adult, but her behaviour reflects her emotional needs. Self-determination must be considered along with her emotional needs. The focus of care is on supporting her autonomy and on providing security through structure and a secure attachment with a caregiver.

4. Scientific Research on the SED-S

The SED-S is based on scientific research by experts in developmental psychology and the European research group NEED (Network Europeans on Emotional Development). The NEED group is a special interest group of EAHMID (European Association for Mental Health in Intellectual Disability). The SED-S and its application have been scientifically researched in various studies. An evaluation of typically developed children demonstrated a high level of agreement (81%) between the biological age of the children and the result of the SED-S. It shows a very good agreement between different raters (Cohen’s $\kappa = 1.0$) and high internal consistency (Cronbach’s $\alpha = .99$) (Sappok et al., 2020). An investigation of adults with intellectual disability showed applicability to individuals with and without autism (Sappok et al., 2020). Moreover, the applicability to children with intellectual disability is given (Sterkenburg et al., 2021).

A Selection of Scientific Studies on the SED-S

Scientific evidence that the SED-S is appropriate as an empirically based, practical tool to determine the level of emotional development in people with intellectual disability:

Sappok, T., Barrett, B. F., Vandavelde, S., Heinrich, M., Poppe, L., Sterkenburg, P. et al. (2016). Scale of Emotional Development-Short. *Res Dev Disabil*; 59:166–75.

Validation study of 160 typically developed children (0–12 years) provides evidence for criterion validity at the item, domain, and scale levels:

Sappok, T., Bohm, J., Birkner, J., Roth, G. & Heinrich, M. (2019). How is your mind-set? Proof of concept for the measurement of the level of emotional development. *PLoS One*;14(4): e0215474.

Standardisation of the application and evaluation of SED-S:

Sappok, T., Došen, A., Zepperitz, S., Barrett, B. F., Vonk, J., Schanze, C., Ilic, M., Bergmann, T., De Neve, L., Birkner, J., Zaal, S., Bertelli, M. O., Hudson, M., Morisse,

F. & Sterkenburg, P. (2020). Standardizing the assessment of emotional development in adults with intellectual and developmental disability. *Journal of Applied Research in Intellectual Disabilities*, 33(1): 542–551.

Applicability of SED-S to adults with intellectual disability with and without autism:

Sappok, T., Heinrich & M. & Böhm, J. (2020). Autism Spectrum Disorder, intellectual developmental disabilities, and emotional development: Relatedness and diagnostic impact. *Journal of Intellectual Disability Research*, 64(12): 946–955.

Validity and applicability of the SED-S in children with intellectual disability:

Sterkenburg, P. S., Kempelmann, G. E. M., Hentrich, J., Vonk, J., Zaal, S., Erlewein, R. & Hudson, M. (2021). Scale of emotional development-short: Reliability and validity in two samples of children with an intellectual disability. *Res Dev Disabil*; 108:103821.

Evaluation of the outcomes of continuing education courses on SED-S and their impact on everyday companionship for adult clients with intellectual disabilities:

Conty, M., Birkner, J. & Sappok, T. (2020). Emotionale Entwicklung besser verstehen: Evaluation eines Weiterbildungskurses in der Begleitung von Menschen mit Intelligenzminderung. *Psychiatrie und Neurologie*; 4: 22–24.

Comprehensive information about the emotional development approach:

Sappok, T., Zepperitz, S. & Hudson, M. (2022). *Meeting Emotional Needs in Intellectual Disability – The Developmental Approach*. Abingdon: Hogrefe Publishing.

Questionnaire for assessment of Emotional Development Level:

Sappok, T., Zepperitz, S., Morisse F., Barrett, B.-F. & Došen, A. (2022) *Scale of Emotional Development-Short*. Abingdon: Hogrefe Publishing.

Political information:

World Health Organisation (WHO) (2005). International Classification of Functioning, Disability and Health (ICF), c.f. <https://icd.who.int/dev11/l-icf/en> (accessed 11.4.2022).

United Nations (2006). 15. Convention on the Rights of Persons with Disabilities, c.f. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (accessed 11.4.2022).