Tanja Sappok
Sabine Zepperitz
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Meeting Emotional Needs in Intellectual Disability

The Developmental Approach

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Dedicated to our patients

Preface to the English Edition

In this book, *Meeting Emotional Needs in Intellectual Disability*, we introduce the emotional development approach and offer a variety of tools to help support the challenging behaviours associated with the different stages of development. This is the result of an interdisciplinary collaboration between a medical doctor (Tanja Sappok), a behavioural specialist (Sabine Zepperitz), and for the English edition, a clinical psychologist (Mark Hudson). It draws on the expertise and insights from family members, doctors, behavioural specialists, therapists, psychologists, nurses, and other healthcare professionals, as well as special needs educators and social workers who have lived or worked for years with people with an intellectual disability (ID) and mental health problems or severe challenging behaviours. This scientifically based textbook aims to reduce problem behaviours and to foster well-being and mental health in people with an intellectual disability. The first part of the book (Chapters 1–6) anchors the developmental approach within the theoretical frameworks of developmental neuroscience and developmental psychology. The second part (beginning with Chapter 7) increasingly focuses on the implications of the approach for clinical practice and people's daily lives. Therefore, if you as the reader are more interested in the practical aspects, then you may wish to start from part 2 or read the short "in a nutshell" summaries in part 1 first.

Even though we believe that developmental science can substantially improve the living conditions of people with disabilities in modern society, there are certain risks associated with this view. As a result of a decade-long emancipation process – and finally with the adoption of the UN Convention on the Rights of Persons With Disabilities – adults with an intellectual disability are also recognised and treated as adults. The result is a respectful but also distanced form of interaction. The application of developmental neuroscience expands our concept of adulthood in intellectual disability to encompass needs which are typically associated with earlier developmental stages. This, however, creates a new area of tension. We do not mean that adolescents and adults with intellectual disability are childlike, and we respect the fact that they will have had many experiences and gained skills which would not be expected of a young child. Rather, we would like to encourage you to acknowledge all aspects of their personality, including their physical, intellectual, and social–emotional competences and their personal and family goals, in order to help them fulfil their potential in a self-determined way.

Tanja Sappok, Sabine Zepperitz, and Mark Hudson,
Berlin and Nottingham in May 2021

Contents

1 Emotional Development: An Introduction

A 20-year-old woman with a severe intellectual disability scratches and bites herself and walks restlessly between rooms. The restlessness occurs mainly in situations where she must wait or when she is physically uncomfortable, e.g., because of hunger. She needs help to eat and to get dressed. She is often on her own; she rocks back and forth, snuggles in her bed during the day, twirls her hair, or chews on a sensory object. She lives in a residential home with seven other residents and works eight hours a day in a sheltered employment project. However, she is not interested in any of the other residents and only seeks contact with her caregivers.

A 25-year-old man with a moderate intellectual disability cannot stay alone, seems restless, and walks around a lot. He continuously seeks out caregivers and complains when they turn toward another service user. He persistently asserts his own will. Otherwise, he is a friendly, curious person who can understand consequences and has some abstract thinking skills. His restlessness and constant search for affection are so stressful for the carers that he was dismissed from his job. This makes the situation even worse because he is at home all day long.

These examples demonstrate that people with intellectual disabilities often behave in ways that challenge their relatives, caregivers, and healthcare professionals. In order to better understand and deal with these behaviours, emotional development should be considered alongside physical and cognitive development. When supporting people with intellectual disabilities, we often first ascertain their biological age and cognitive abilities, whereas their emotional developmental age is typically not known and is therefore given little consideration (see Figure 1). This can result in overwhelming situations, which can lead to serious behavioural problems or even to mental health difficulties, such as depression.

The young woman presented at the beginning shows an emotional reference age of about 6 months. Her great need for rest, desire for immediate satisfaction of her needs, predominant preoccupation with her own body, and lack of interest in peers are expressions of her emotional stage of development. At this stage, the primary need is for physical and emotional regulation; the development task is integrating sensory information. Therefore, caregivers should take on the role of reliable providers, offer body-oriented and sensory interventions, and ensure she has sufficient rest and recovery periods.

The emotional reference age of the young man is about 3 years; emotionally, he is in the so-called *phase of defiance*. His primary need is therefore to develop autonomy. The central developmental task is individuation, i.e., separating from his main caregivers and establishing his own sense of self. In this stage, establishing clear structures and rules and

external reality. What is happening in the mind at that moment is absolutely real for the child; there is no distinction between fantasy and reality. At the thought of a monster in the closet, the monster (from the person's point of view) is actually in the closet.

Step 3: Pretend mode of thinking (about 3–4 years) – Pseudo-mentalisation [Self-other differentiation]

The distinction between one's own thinking and reality now develops in the 3rd step with the ability to differentiate oneself from others. However, one's own thinking is uncoupled from reality. This creates a shelter in which new behaviours can be practised without having to function in reality, e.g., in father-mother-child or doctor games. In this way, one also learns to put oneself in the shoes of other people, e.g., knights, princesses etc. However, it is not yet possible to clearly distinguish one's own world of imagination from the external environment and to change perspective. The child's thinking and world view are therefore still egocentric. Now the child imagines being a monster, feels strong, and frightens others. However, the child is not aware of the fear that is triggered in the other person. In the safe world of fantasy, the child can try out new skills, behaviours, and roles without the associated dangers in the real world.

Step 4: Integration of one's own thinking and reality (> 4 years) – Mentalisation [Theory of mind]

From a cognitive developmental age of about 4 years, the child is able to put themself in the shoes of others and to distinguish between their own thoughts/imagination and the external environment. Other people's feelings and experiences can be integrated into one's own world of thoughts. A conscious awareness develops of the fact that the inner and outer worlds are not the same but are nevertheless related to each other. Now one knows that in reality there are no monsters, while at a carnival, they may consciously dress up as monsters with the aim of frightening others.

In a nutshell

- Theory of mind describes the ability to attribute opinions, thoughts, or beliefs to oneself or others.
- Connected with this is the ability to distinguish between one's own thoughts (fantasy) and the external environment (reality).
- Theory of mind is the prerequisite for empathy and pro-social behaviour.
- Theory of mind develops step by step (SOS-ToM):
  - Step 1: Sensory: Goal- and action-oriented way of thinking
  - Step 2: Object permanence: Thinking is reality
  - Step 3: Self-other differentiation: Pretend mode of thinking
  - Step 4: Theory of mind: Integration of one's own inner world of thought and outer reality.

1.5.5 Emotional Development

Emotions differentiate themselves more and more over the course of development. In infancy, predominantly undifferentiated positive or negative emotional states (distress) can be observed (Camras, Oster, Campos, & Bakemand, 2003; Messinger, Mattson, Mahoor,

2 Phases of Emotional Development

Our whole life involves development; we all develop individually from conception to death. The findings of developmental psychology have been thoroughly summarised in overview books (e.g., Berk, 2007; Smith, Cowie, & Blades, 2015). This chapter is intended to provide a brief introduction to developmental psychology; it does not replace an in-depth examination of the subject.

The Dutch child and adolescent psychiatrist Anton Došen created a phase model of emotional development on the basis of the above-mentioned psychosocial and neurobiological understandings of child development (Došen, 1997; Došen, Hennicke, & Seidel, 2018). Although development is best understood as a continuous process, in this model, five essential developmental steps from birth to the age of 12 were delineated. In Dutch, the phase model is called "Schema van Emotionele Ontwikkeling," or SEO for short. Since development does not end at the age of 12, and the description of the next phase is important for demarcation and classification, we extended the five-phase model of Anton Došen with a sixth developmental stage in this book:

- Phase 1: Adaptation (reference age 0–6 months): Sensory processing and integration
- Phase 2: Socialisation (reference age 7–18 months): First attachments, body schema, object permanence
- Phase 3: First individuation (reference age 19–36 months): Self-other differentiation, secure attachment
- Phase 4: Identification (4th–7th years of life; reference age 37–84 months): Ego-formation, theory of mind, learning from experience
- Phase 5: Reality awareness (8th–12th years of life; reference age 85–144 months): Self-differentiation, logical thinking
- Phase 6: Social individuation (13th–17th years of life; reference age 144–216 months): Identity development, abstract thinking.

The age ranges refer to the approximate age, i.e., the reference age, at which a typically developing individual would exhibit the prominent characteristics associated with each phase of emotional development. Please be aware that, for example, 4th–7th years of life includes those who are at a developmental stage of 3 years but who are in their fourth year of life.

Figure 12 summarises Anton Došen's phase model of emotional development.

Picture 3: SED-S-3. 42 years old, severe intellectual disability: Develops own will. Circular, loop-like scribbles stand for increasingly directed, stable environmental exploration at a reference age of approx. 2 years. Drawing is done from the wrist. The movement can be deliberately slowed down, interrupted, or resumed.

Picture 4: SED-S-3. 56 years, moderate intellectual disability: communication via signs. After a sequence of different scribbles and the ability to close a circle, different scribbles are assembled into geometric basic forms towards the end of this developmental period. These can also be named.

has an inside and an outside. Meaningful scribbling can be observed from a reference age of approx. 2.5 years onwards. Hereby, the scribble may be attributed to represent a certain object or person, and the attribution may change during the painting process. For example, when asked what they are drawing there, the person may answer: "It's a cat." When asked a little later the same question regarding the same drawing, the person may answer: "Oh, that's you." This is followed by an increasing variety of lines and other basic geometric forms that can be assembled and filled in (see Picture 4).

In group situations, the person now begins to develop an interest in their peers. A game played next to others (parallel play) or a game in which peers are dominated is possible. Due to the person's strong egocentrism and the resulting dominance towards others, conflicts or jealousy often arise, which have to be regulated by the carers. The person's world view is egocentric; they perceive themselves as the centre of the world. In this phase of development, there is no theory of mind (see Section 1.5.4), i.e., the ability to change perspective or to distinguish between fantasy and reality. Supposed untruths are therefore not told with the intention of lying, since one's own thinking is reality for people in this phase of

3 The Practical Application of the SED-S

3.1 The Scale of Emotional Development – Short: SED-S

The SED-S consists of 200 binary (yes/no) items that describe the emotional state of development according to the phase model described above in eight different developmental domains:

1. Relating to their own body
2. Relating to significant others (originally SEO domains 2 & 3)
3. Dealing with change – object permanence
4. Differentiating emotions (originally SEO domains 4 & 9)
5. Relating to peers
6. Engaging with the material world
7. Communication and
8. Regulating affect

In a sample of 160 typically developed children, the SED-S showed a precise agreement with the chronological age of 77% of the children and a relative agreement (squared weighted kappa) of $\kappa = 92\%$ (Sappok et al., 2019). Further psychometric assessments of the SED-S are currently taking place in the various study centres (Belgium, the Netherlands, Switzerland, Germany, and United Kingdom) of the NEED group.

In a nutshell

- The stage of emotional development can be determined with the help of the SED-S.
- The SED-S consists of eight different developmental domains.
- The result is a developmental profile and an overall assessment of the stage of emotional development.

4 SED-S: The Milestones of Emotional Development

Development is a continuous and unique process for every human being. However, it is always dependent on the genetic predisposition and the environmental conditions under which one develops. Of course, this process does not take place in domains or phases in reality! Nevertheless, such a heuristic can serve to better understand a person, since models in practice often facilitate the classification of behaviours. However, no model replaces a holistic view of the human being. Above all, the life experience of adults with intellectual disabilities and their advanced physical development influence the picture considerably and are important resources. These must not be neglected when cognitive and emotional abilities are compared with those of children.

Since development must always be seen in context, the environment in which people with intellectual disabilities are cared for and the conditions under which they live have a significant influence on their personality development. Thus, let us be aware that by accompanying people with intellectual disabilities, we make a significant contribution to their development. We have a responsibility to create developmental spaces that are beneficial and to create relationships in which a personality can develop. A comparative look at child development (cf. Lohaus and Vierhaus, 2015; Lohaus, 2018 ; Smith, Cowie, & Blades, 2015) should help us to recognise abilities and needs and to orient our support accordingly.

Chapter 2 has already introduced Anton Došen's five-phase model of emotional development with the addition of Phase 6 (Došen, 1997), while Chapter 3 has presented the scale for the assessment of emotional development (SED-S) in the eight different developmental domains (Sappok et al., 2018). The milestones of emotional development correspond to the phase model of Anton Došen and the developmental domains of the SED-S. They are summarised in Box 1. The developmental steps of Phase 6 (social individuation) which not (yet) depicted in SED-S are printed in italics.

Box 1: Milestones of emotional development in SED-S, supplemented by Phase 6

Domain 1: Relating to Their Own Body

The first domain is concerned with the development of sensory and motor functions, which can be observed in areas of daily life, such as personal hygiene and getting dressed.

Developmental Milestones in Domain 1

1. Explores their body haphazardly and is primarily occupied with processing physical sensations and environmental stimuli via the proximal senses (i.e., touch, smell, taste)
2. Gradually develops a vague mental image of their body and discovers that it can be used as an instrument (i.e., grasping, handling objects etc.); largely gross motor activity
3. Experiences their body as the centre of the world and deliberately uses it as an instrument to communicate and get what they want; develops fine motor skills
4. Forms a gender identity
5. Is able to assess their physical appearance and abilities realistically
6. *Discovers adolescent sexuality and the significance of physical appearance*

Domain 2: Relating to Significant Others

This domain looks at how individuals interact and form attachments with emotionally significant others, both on their own initiative and in response to that of others. Typical examples of significant others are parents and primary caregivers, but they may also include other members of an individual's family, residential group, sports team, or similar, as well neighbours or co-workers.

Developmental Milestones in Domain 2

1. Is largely self-absorbed; makes contact primarily via the proximal senses and is aroused/soothed (i.e., physical and emotional states are regulated) by contact with significant others
2. Is extremely fixated and dependent on significant others; makes contact via the proximal and distal senses
3. Asserts their will and independence; resents longer separation from significant others; makes contact through language, objects, and the distal senses
4. Increasingly obeys rules and identifies with authority figures; begins to show empathy and develop an internal moral compass/sense of right and wrong; uses language and play to establish contact and interact with others
5. Internalises social rules and norms as conscience formation proceeds; uses social and cognitive skills to establish contact
6. *Seeks independence from important others; searches for autonomy*

6 Mental Health Problems

6.1 The Importance of Emotional Development for the Development of Psychological Distress

From an emotional development perspective, a complete re-conceptualisation of the clinical-psychiatric approach to people with intellectual disability and mental health problems, often in the form of challenging behaviour, is necessary.

The stage of emotional development serves as a guide for individual normality (see Figure 27).

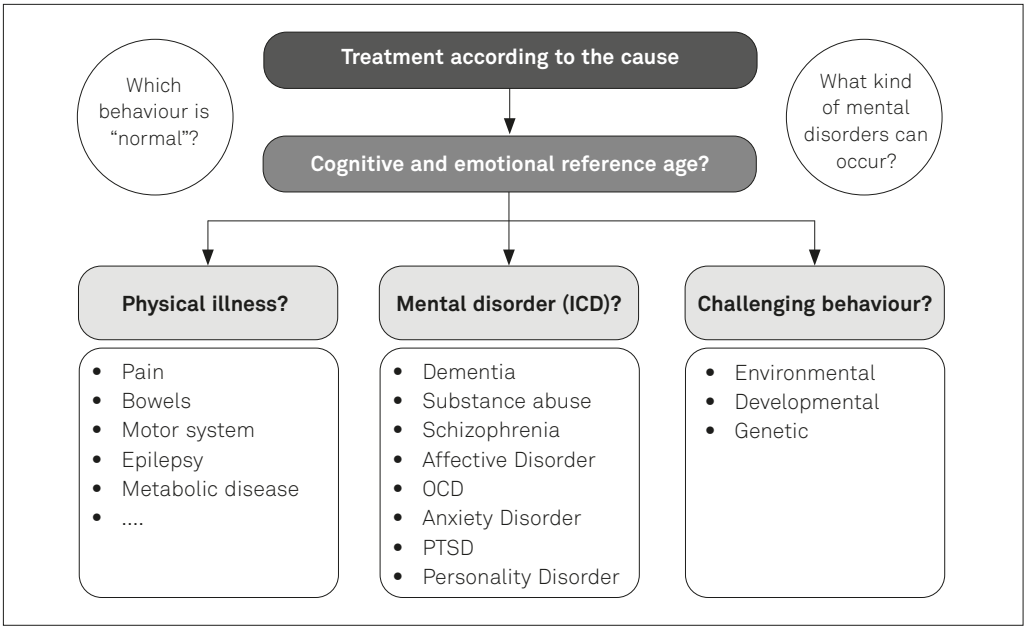

Figure 27: Diagnostic clarification of salient behaviour and expressed complaints: There are certain complaints or challenging behaviours that lead to a referral (upper bar). The symptom picture should first be observed and assessed, taking into account the individual's intellectual abilities and stage of emotional development (middle bar) What behaviour and what delineation of the symptom picture can be expected at this stage of development? Subsequently, physical or psychological disorders are to be systematically excluded (lower bars). Any further challenging behaviour that is not sufficiently explained as a result is now referred to as a maladaptive behaviour (far right). This can be caused by unfulfilled needs, social problems, or environmental factors (bottom right).

Table 4: Summary of important developmental steps and suggestions for everyday living

Developmental stage	Reference age	Developmental steps/educational approaches
Phase 1 (Adaptation)	0–6th months of life	Processing sensory stimuli: individuals live in the here and now and are busy processing all sensory stimuli that flow into them. Satisfying basic needs (eating, drinking, touch, pain, rest), ensuring well-being, Snoezelen, massages, music, smells (bath), swings, situations involving undivided attention … Client has no understanding of rules; care-giver ensures avoidance of anger.
Phase 2 (Socialisation)	7th–18th months of life	Attachment/body schema: Close attachment to the caregiver (provides security), client learns what they can do with their bodies, discovers the world, learns that what they do causes a reaction. Offer specific 1:1 relationships, stay in sight, short contacts; offer activities involving shredding, painting, Snoezelen, touches, weighted vest/blanket to feel their body; if possible, do not break off contact during aggression … Does not understand general rules but only specific rules given by a person in a certain situation.
Phase 3 (First Individuation)	19th–36th months of life	Conflict between dependence and autonomy: discovers own will and wants to enforce it; on the other hand, is insecure in the case of criticism. Attention and structure, clarity in the team, praise, simple responsibilities handed over, simple plans supported by pictures/symbols, simple reinforcement schedules, immediate reward, compromises – do not enter into a power struggle, enable to make one's own decisions. Understands simple rules but has not yet internalised them; tests them. The significant others need to be very clear about the rules and represent the rules in person.
Phase 4 (Identification)	4th–7th years of life	Development of Self: Search for a rough identity (man/woman, abilities, weaknesses …) Discussing rules, handing over tasks, supervised peer group, promoting empathy, specific conversation offers (perception of feelings, who am I, proximity-distance …), creative offers, creating body image, giving realistic feedback, working out rules for sexuality and physicality. Understands rules, benefits from visual representation, care-giver communicates rules in conversation.
Phase 5 (Reality awareness)	8th–12th years of life	Self-differentiation: Search for their own role in a group of peers. Promoting independence, independent living possible, more complex creative offers, co-determination, educational offers, sex and drug education, peer group. Can follow rules that have been internalised (has theory of mind), needs support in crises or major changes.
Phase 6 (Social individuation)	13th–17th years of life	Identity formation: Seeking one's own role in society, development of independent, planned, and responsible action. Support in career and family planning, training opportunities, independent living. Has internalised social rules (moral self), needs selective support in the big questions of life or in planning for the future.

10 Opportunities and Possibilities for Development-Based, Multi-Disciplinary Case Conferences

In clinical practice, the SED-S can be used as a guide for case discussions and support planning; having a specific discussion between people from different professions is particularly valuable.

The process of assessing a person's stage of emotional development holds therapeutic value in itself. For this reason, it is advisable to engage people from as many professions as possible. For the sake of efficiency, establishing the client's stage of emotional development prior to a multi-disciplinary meeting can be useful. At the beginning of such a meeting, it is necessary to introduce the person briefly. This may take place over video, and should include a summary of important background information, physical and psychiatric diagnoses, and if necessary, the client's medication history. It is also advisable to formulate specific questions at the beginning, which should be discussed together with the results obtained from the SED-S assessment. In the discussion between the different professional groups, a comprehensive picture is worked out. In practice, the assessment of the current stage of emotional development often provides an explanation for existing behaviour and provides approaches to problem solving for difficult clinical situations.

Through the joint discussion, all participants expand their knowledge. Carers from everyday life (living, working) provide important observations of behaviour and usually have a treasure trove of intuitive experience in supporting people. They know the limits of the care system and the requirements of service providers. Professionals trained in therapy or developmental psychology can make the shown behaviour understandable against this background. Doctors provide explanatory approaches resulting from physical and psychiatric diagnoses or an existing medication. The discussion leads to actions and coordinated interventions that can be implemented in daily life. This results in an increase in knowledge for all professional groups involved. Attitudes also change when the intention of a behaviour becomes clearer. For example, a person's constant search for contact can be perceived as less provocative if it becomes clear that the person is panic-stricken and afraid of being abandoned by their caregiver.

Particularly in the case of challenging behaviour, it is advisable to draw up a joint crisis plan that gives the carers confidence in dealing with the person and has a calming effect. Within the framework of the case conference, the professional groups involved (medical

Definitions and Abbreviations

ADHD: Attention deficit and hyperactivity disorder

Affect: Defined here as a generic term that encompasses mood and emotion. This includes an intensity of excitement, a quality of feeling, the physical and expressive dimensions as well as the motivation to act.

Affect representations: Inner image of the quality and meaning of affects, in which emotional expression and quality of experience are linked to certain situations and behavioural reactions. Basis for mentalisation.

Anterior attention system: Can be localised in the anterior cingulate gyrus and controls the intentional focus of attention as a reaction to cues as well as targeted strategy considerations. It partly overlaps with the executive functions.

Behavioural abnormalities, problem behaviour, challenging behaviour, behaviour that challenges: Synonyms for conspicuous, problematic, or challenging behaviour perceived by the affected individual or their environment. This often leads to a referral to doctors or counselling centres for the disabled. All possible physical, psychiatric, or behaviour-based disturbances may be hidden behind this term.

Behavioural disorder: The behavioural disorder is a psychiatric diagnosis and is coded as F7x.1 in the ICD-10. It describes culturally inappropriate behaviours of considerable intensity or duration that endanger physical health or social participation and cannot be explained by other mental disorders or physical illnesses.

Behavioural phenotype: Behavioural patterns typical of certain genetic syndromes or defined disorders.

Behavioural syndrome: A suite of behavioural traits which are related to one another.

Central coherence: the ability to perceive, to assemble parts into a whole and to grasp it as a whole.

Contingency: Link between different events, e.g., the baby's pedalling with the movement of a mobile.

Contingency maximisation: The infant's effort to establish appropriate relationships between its own behaviour/perception and its reaction to it. The successful connection, e.g., by mirroring one's own emotional expression by the mother or actively evoking a suitable reaction to one's own expression, is associated with positive arousal.

Coping strategies: Coping strategies in problem situations or constellations.

Subject Index