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Meeting Emotional Needs in Intellectual Disability

The Developmental Approach

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and Mark Hudson**



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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 child-like, 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

About the Authors	ii
Preface to the English Edition	vii
1 Emotional Development: An Introduction	1
1.1 Emotion and Cognition in Dialogue	2
1.2 Conceptualisation of Emotional Development	4
1.3 The Development of the Emotional Brain	6
1.4 The Neuroanatomy of the Emotional Brain	7
1.5 Developmental Theories and Developmental Tasks	10
1.6 The Developmental Approach and Adulthood	27
2 Phases of Emotional Development	31
2.1 SED-S Phase 1: Adaptation (Reference Age: 0–6 Months) – SYMBIOSIS	34
2.2 SED-S Phase 2: Socialisation (Reference Age: 7–18 Months) – SAFETY	35
2.3 SED-S Phase 3: First Individuation (Reference Age: 19–36 Months) – AUTONOMY ..	39
2.4 SED-S Phase 4: Identification (Reference Age: 4th–7th Years of Life) – FORMING SELF	42
2.5 SED-S Phase 5: Reality Awareness (Reference Age: 8th–12th Years of Life) – SELF-DIFFERENTIATING	46
2.6 SED-S Phase 6: Social Individuation (Reference Age: 13th–17th Years of Life) – IDENTITY	49
3 The Practical Application of the SED-S	51
3.1 The Scale of Emotional Development – Short: SED-S	51
3.2 Assessing Emotional Development With the SED-S	52
3.3 Analysis of the SED-S	53
3.4 The SED-S Assessment and the Derivation of Therapeutic Interventions in the Case Study	54
3.5 Other Methods of Developmental Diagnostics	61
4 SED-S: The Milestones of Emotional Development	63
4.1 Domain 1: Relating to Their Own Body	68
4.2 Domain 2: Relating to Significant Others	70
4.3 Domain 3: Dealing With Change – Object Permanence	73
4.4 Domain 4: Differentiating Emotions	76

4.5	Domain 5: Relating to Peers	79
4.6	Domain 6: Engaging With the Material World	82
4.7	Domain 7: Communicating With Others	84
4.8	Domain 8: Regulating Affect	87
5	Challenging Behaviour	93
5.1	The Stage of Emotional Development as the Key to Understanding Challenging Behaviour	94
5.2	Emotional Development and Challenging Behaviour: A Case Study	98
5.3	Behavioural Syndromes According to the Level of ED	100
6	Mental Health Problems	107
6.1	The Importance of Emotional Development for the Development of Psychological Distress	107
6.2	Psychiatric Diagnoses as a Function of the Level of Emotional Development	108
6.3	Mental Disorders Influencing the Stage of Emotional Development	109
6.4	The Dilemma of Categorisation	112
7	The Implementation of the Emotional Development Approach in Clinical Practice	115
7.1	General Aspects	115
7.2	Special Features in Childhood and Adolescence	117
8	Characteristic Examples of Care and Treatment Approaches in the Individual SED-S Phases	123
8.1	Case Study for SED-S Phase 1	123
8.2	Case Study for SED-S Phase 2	125
8.3	Case Study for SED-S Phase 3	128
8.4	Case Study for SED-S Phase 4	130
8.5	Case Study for SED-S Phase 5	132
8.6	Case Study for SED-S Phase 6	133
9	Therapeutic Interventions	135
10	Opportunities and Possibilities for Development-Based, Multi-Disciplinary Case Conferences	153
	Summary	173
	Concluding Observation	174
	Acknowledgements	175
	Definitions and Abbreviations	177
	References	181
	Subject Index	191

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

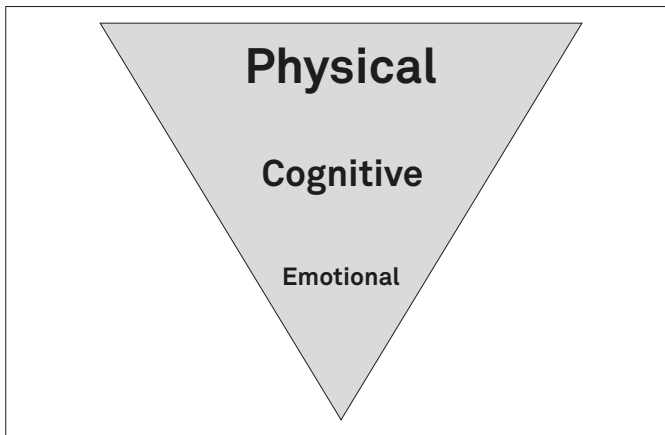


Figure 1: The encounter typically depends on the client's biological age, followed by their level of cognitive development; the emotional state of development is often the least considered. However, the emotional reference age may be lower, when compared to cognitive development.

identifying areas of life in which he can fulfil his growing need for independence in a gradual and manageable way may be helpful. Caregivers can ensure that they provide a clearly structured daily routine and ascribe responsibilities in certain areas, such as setting the table or sorting laundry. It is crucial that the team work together in a consistent manner and provide direct, immediate praise to reinforce desired behaviours. Through consistent positive regard – independent of behaviour – he will be confirmed in his person and will no longer need to demand attention. As a result, his restlessness is likely to decrease, and he will be able to separate from caregivers for longer periods.

By knowing the level of emotional development, caregivers can more easily change their perspective, understand a person's behaviour, and address their needs. Adapting interventions to the level of emotional development can precipitate the personality growth of clients, increase their opportunities for participation in social life, and lead to a better understanding of problem behaviours (Hart & Lindahl Jacobsen, 2018).

1.1 Emotion and Cognition in Dialogue

In Western culture, which has been shaped by philosophers such as Descartes and Kant, the concept of intelligence is predominantly related to mathematical, logical, and verbal abilities. This is contrasted with socio-emotional processes based on affective experiences and interpersonal relationships. In the 1980s, the importance of emotional competences for decision-making and social life was increasingly emphasised by researchers such as Damasio, which broadened the concept of intelligence (“Descartes’ error;” Damasio, 2012). *Emotion* and *cognition* are categorical terms that combine a multitude of different competences. The assignment of various abilities to being either cognitive or emotional is a social construct; the human brain itself does not assign its different functions to one or the other!

In people with an intellectual disability, emotional, social, and physical abilities can also be impaired in addition to pure cognitive skills (APA, 2013; ICD-11, 2018; Frankish, 2016; Lehmkuhl, Sinzig, Sappok, & Diefenbacher, 2011; World Health Organisation, 2001).

These abilities are displayed in various neural networks (Kandel, Schwartz, & Jessell, 2000; LeDoux, 2002; Pessoa, 2008; Yeates, Bigler, Dennis, Gerhardt, Rubin, Stancin et al., 2007). The cortical structures, which, for example, are mainly responsible for language, motor, and sensory skills etc., were first described in the 19th/20th century by Brodmann, Broca and Wernicke, among others (Brodmann, 2007; Dronkers, Plaisant, Iba-Zizen, & Cabanis, 2007; Wernicke, 1994). During the last century, it became possible to describe more complex cognitive functions, such as memory, in more detail, and to identify the neuronal centres involved (Kandel, 2001; Kandel, 2006), for which Eric Kandel, among others, was awarded the Nobel Prize for Physiology/Medicine in 2000 (Kandel, 2006). Concise case histories, such as Phineas Gage, who survived a severe head injury caused by an iron rod being driven through his forebrain after a construction accident, clearly demonstrated the importance of this brain region for action planning, impulse control, and the person's character (Damasio, Grabowski, Frank, Galaburda, & Damasio, 1994; Forbes & Grafman, 2010).

The foundation of the architecture of the social brain, which is located in various parts of the limbic system, develops at certain sensitive periods of prenatal and early life (Brothers, 1990; Byrne & Bates, 2010; Fox et al., 2010). The emergence of the mind and socio-emotional brain functions are linked to the formation of the respective neuronal networks (Roth & Strüber, 2018; Adolphs, 2003, 2010a, 2010b). The developmental changes in structural brain connectivity result from a sequence of (epi-)genetic mechanisms at key developmental stages (Fox et al., 2010). Environmental factors and early life experiences play a crucial role in the coordination and timing of the specific neuronal patterning. The brain architecture is scaffolded prenatally and early in life, followed by an extended period of differentiation of the cytoarchitecture by dendritic growth and formation, pruning and stabilisation of synapses. While short-range connectivity predominates in infancy, there is a shift towards long-range networks in adolescents and adults. Hence, higher order cognitive networks build on circuits that process lower level information.

In people with an intellectual disability, impairments of these areas/systems are associated with basically the same deficits as are observed in people without any intellectual impairment (Barnard, Muldoon, Hasan, O'Brien, & Stewart, 2008; Happé, 1994; Harris, Best, Moffat, Spencer, Philip, Power et al., 2008; Sappok, Bergmann, Kaiser, & Diefenbacher, 2010; van Lang, Bouma, Sytema, Kraijer, & Minderaa, 2006). Since various brain regions or systems are involved in different cognitive or emotional functions, these can also be disrupted or may function to different degrees (Baron-Cohen, Ring, Wheelwright, Bullmore, Brammer, Simmons et al., 1999; Kennedy & Adolphs, 2012; Izard, Youngstrom, Fine, Mostow, Trentacosta, 2006). Developmental delay in social cognition becomes more and more apparent during the course of development and as differences in physical development increase (Beck, Kumschick, Eid, & Klann-Delius, 2012; Rosenqvist, Lahti-Nuuttila, Laasonen, & Korkman, 2014). Depending on the cause and timing of the brain damage, brain development may be impaired differently in the various parts of the brain (Dennis, Barnes, Wilkinson, & Humphreys, 1998; Yeates et al., 2007). Therefore, it is not possible to deduce the level of emotional development from the intelligence quotient (Baurain, Nader-Grosbois, & Dionne, 2013). The cognitive, social, emotional, and physical aspects of development together form the personality (see Figure 2; Harris, 1998; Rutter, 1980).