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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*

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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

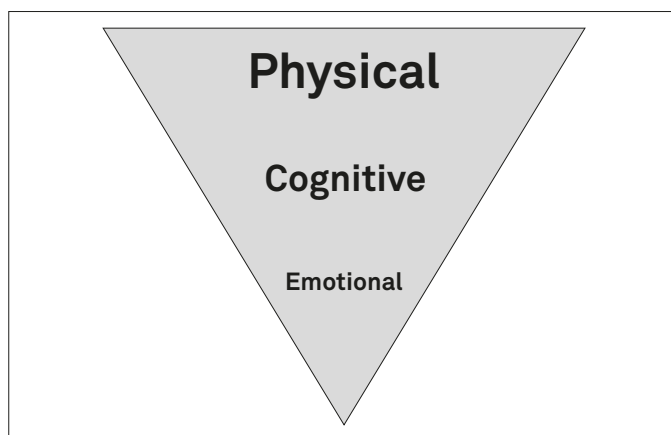


Figure 1: The encounter typically depends on the client's biological age, followed by their level of cognitive development; the emotional state of development is often the least considered. However, the emotional reference age may be lower, when compared to cognitive development.

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

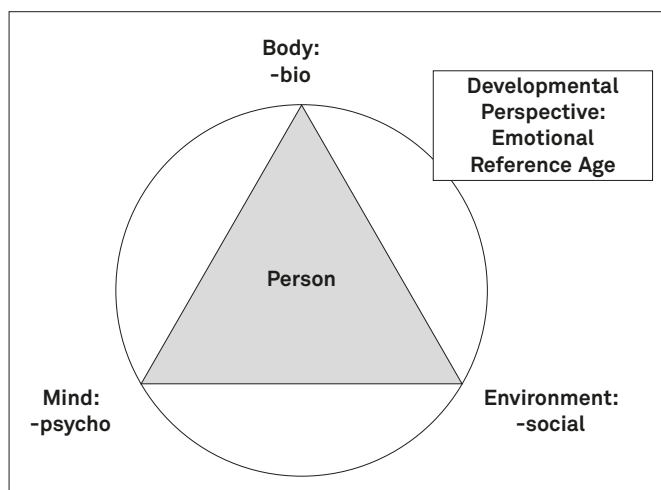
In Western culture, which has been shaped by philosophers such as Descartes and Kant, the concept of intelligence is predominantly related to mathematical, logical, and verbal abilities. This is contrasted with socio-emotional processes based on affective experiences and interpersonal relationships. 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).

**Figure 2:**

The bio-psycho-social disease model is extended to include the emotional development perspective.

In a nutshell

- Cognitive and emotional brain functions are located in different brain regions.
- In people with an intellectual impairment, social brain networks may also have delayed or incomplete development.
- The stage of emotional development may differ from the cognitive reference age.

1.2 Conceptualisation of Emotional Development

Emotional competencies develop over the course of childhood. Newborns are already emotionally competent beings who can express, perceive, and react to various basic emotions (Bowlby, 1969; Piaget, 1954; Stern, 1985). During the first year of life, the emotional reactions of the child become increasingly modulated by the behaviour of the caregiver (Bertin & Striano, 2006; Stern, 1985; Winberg, 2005). In the second year, the experience of divided attention with a close caregiver evokes joy in the child (Kasari, Sigman, Mundy, & Yirmiya, 1990; Trevarthen, 1980). The emotional responses and regulation possibilities gradually become more complex, e.g., children are able to influence the emotional states of others (Jackson & Tisak, 2001). Pre-school children can increasingly understand the causes and consequences of emotions and regulate their affective states themselves (Rieffe, Terwogt, & Cowan, 2005). At school age, further advances in empathy and increasingly pro-social behaviour become apparent (Rieffe et al., 2005). These age-appropriate changes in the emotional system are the basis for our self-concept and the formation of our personality structure (Došen, 1997).

We consider the concept of *emotional development* in the sense of the developmental approach described above, i.e., the acquisition of emotional competencies according to the typical maturational processes during childhood. Therefore, the concept of emotional development contains predominantly affective but also social, sensorimotor, and cognitive

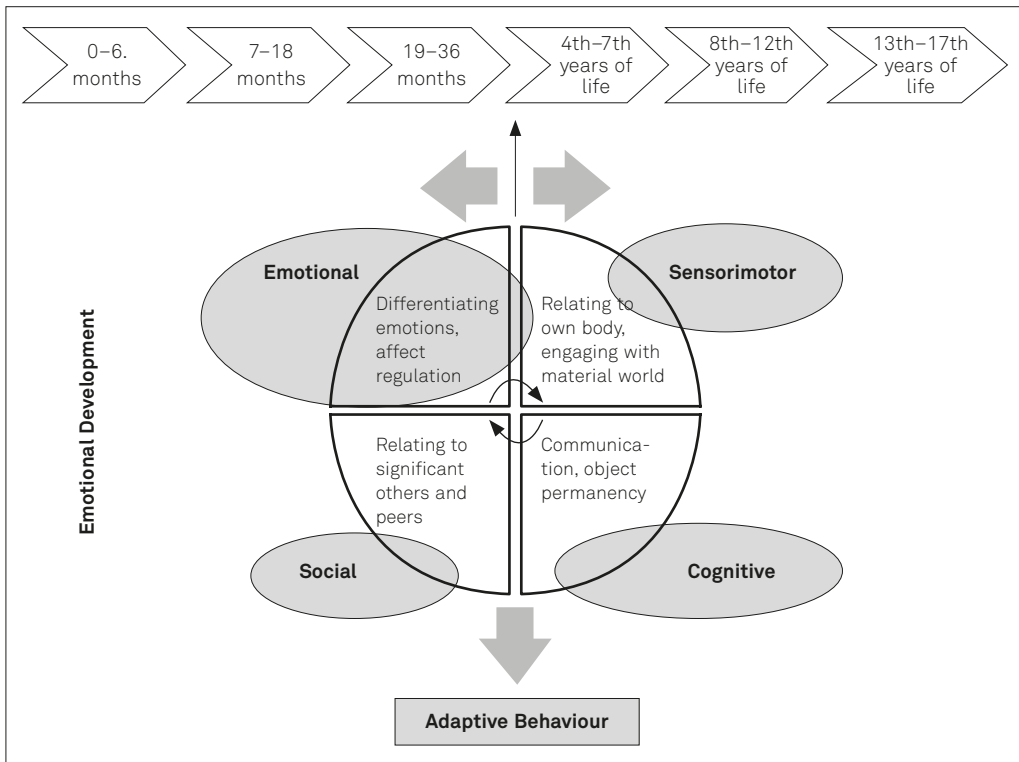


Figure 3: Conceptualisation of emotional development. Adapted from Sappok et al., 2013.

functions that are relevant to developmental psychology (see Figure 3; Došen, 2005a; Greenspan, 1985; Sappok, Schade, Kaiser, Došen, & Diefenbacher, 2011; Sroufe, 2009). These different components interact with and stimulate each other and thus lead to further maturation and adaptation of the young person to the environment (Izard et al., 2006; Mayer, Roberts, & Barsade, 2008). This ability to adapt to the demands of everyday life, i.e., adaptive behaviour, is crucial in order to use and live out one's own potential productively and to lead a fulfilled life. Therefore, the assessment of brain functions should be extended to include not only logical, mathematical, and verbal abilities, i.e., purely academic competences, but also socio-emotional brain functions, such as perceiving, recognising, and consciously influencing feelings, being able to regulate one's own emotions, or mentalisation abilities.

In a nutshell

- The typical development of emotional competencies in children and adolescents serves as a model for the emotional development approach.
- The emotional development approach includes affective, cognitive, sensorimotor, and social aspects relevant to development.

1.3 The Development of the Emotional Brain

So far, there are only a few studies on how social networks develop in the brain. It is currently assumed that this is an interplay between automated, genetically determined brain maturation processes on the one hand, and environmental adaptation processes on the other (Johnson et al., 2005; Johnson, 2011). Phylogenetically, old brain areas and networks (see. 1.4, the lower limbic level) develop partly due to a congenital predisposition, i.e., the aspects of the social brain are created at a very early stage (Happé & Frith, 2014). On the other hand, these automatic processes can be influenced by external factors, such as learning experiences, stress, deprivation, or maltreatment in early childhood (Hanson, Chung, Avants, Shirtcliff, Gee, Davidson et al., 2010; Karmiloff-Smith, 2010; McCrory & Viding, 2010). By pruning or sprouting synaptic connections between nerve cells, existing neural networks can be specified or reinforced (Workman, Charvet, Clancy, Darlington, & Finlay, 2013).

The development of emotional competencies is closely interwoven with cognitive maturation processes (Damasio, 2012; Martínez-Castilla, Burt, Borgatti, & Gagliardi, 2015). Object permanence, i.e., the inner, representational model of the external environment, is, for example, an important prerequisite for the development of a secure attachment style, since the child is then able to internalise a multi-modal representation of the mother's affective responses (Piaget, 1954; Schore, 2016). This promotes the development of autonomy and allows delayed gratification of the child's needs (i.e., during separation). Interaction processes characterised by sensitivity and empathy, in which caregivers mirror the inner emotional states of their infants, thereby also promote emotional development and secure attachment (Ainsworth, Bell, & Stayton, 1974; Bowlby, 1969; Choi-Kain & Gunderson, 2008; Kernberg, 2012). Finally, the situational context can also influence emotional regulation mechanisms and emotional reactivity (Aldao & Nolen-Hoeksema, 2012; Wieser & Brosch, 2012). For example, the father's increasing role in arousal modulation and stimulation in the middle of the second year influences the experience-dependent growth of cortical areas and helps to resolve the child's emotional ambivalence towards their mother during this period (Schore, 2016).

Disorders of brain development, such as genetic syndromes or other brain injuries, can affect the development of the emotional brain (Kok, Post, Tucha, de Bont, Kamps, & Kingma, 2014). For example, autism, a pervasive developmental disorder associated with a range of cognitive differences, appears to also affect the social brain network (Sappok, Budczies, Bölte, Dziobek, Došen, & Diefenbacher, 2013). Adults with intellectual disability but without autism have been shown to reach an emotional reference age of 3 to 7 years of age. By contrast, people with an additional autism spectrum disorder had an emotional developmental stage corresponding to a reference age of 1.5 to 3 years of age. This lower level of emotional development was independent of the severity of the intellectual disability (Sappok et al., 2013). Not only autism spectrum disorders but also other cerebral impairments, such as meningoencephalitis (Sappok et al., 2012), or genetic syndromes, such as Down's syndrome (Cicchetti & Ganiban, 1990; Kasari & Sigman, 1996), can delay emotional development or make it incomplete (Kok et al., 2014). In addition, environmental factors can also impair the formation of the social brain circuits, for example, traumatisation (Hanson et al., 2010; McCrory & Viding, 2010; Vela, 2014), insufficient emotional support in

institutionalised environments (Nelson, Bloom, Cameron, Amaral, Dahl, & Pine, 2002), emotional neglect (Hughes, Power, O'Connor, & Orlet Fisher, 2015), or crises, acute illness, and permanent stress. Different causes can thus lead to short- or long-term emotional developmental delays or regressions.

In a nutshell

- The emergence of the mind and the developmental periods of emotional brain functions are closely linked with the formation of the respective neural circuits within the limbic system.
- Hence, higher-level neural circuits that carry out sophisticated mental functions build on lower-level networks.
- Consequently, the basic needs, developmental tasks, and ways to perceive the world and to respond depend on the maturation of the different components of the limbic system.

1.4 The Neuroanatomy of the Emotional Brain

Neuroanatomically, the functions of the *emotional brain* are located in the limbic system (Roth & Strüber, 2018, LeDoux, 2000, 2002; Kennedy & Adolphs, 2012). Figure 4 graphically depicts the functions of the different levels and their origin.

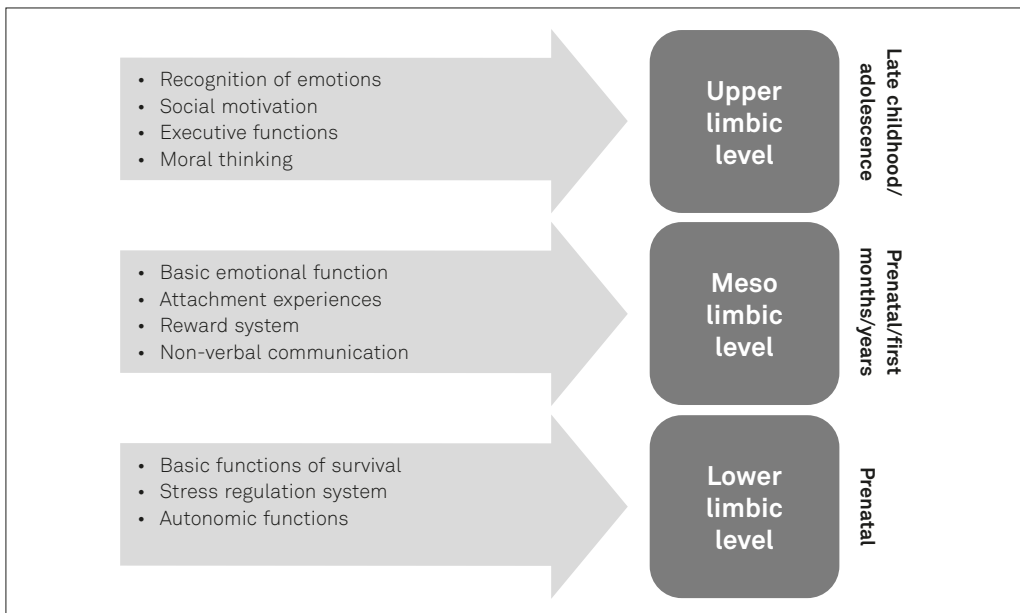


Figure 4: The neuroanatomy of the emotional brain: functions of the different levels of the limbic system (arrows on the left) and time of origin (right). Note: The functions of the lower and middle limbic levels operate unconsciously.

The *lower limbic level* consists of the diencephalon (hypothalamus, brain stem centres, and periventricular grey) and the central amygdala. Most of these structures develop before birth. Here, basic survival functions, such as eating, sex drive, and the flight-flight-freeze response, are controlled. The stress regulation system and mechanisms underpinning autonomous bodily functions, such as sweating or heart rate, are also located here. The processes localised in this part of the limbic system are predominantly unconscious and are genetically or epigenetically determined. Fundamental brain functions of the newborn phase are regulated in these brain structures. The functions of the emotional brain described here can be influenced only minimally by education or life events.

In the *mesolimbic system*, basic emotions, such as fear, sadness, disgust, joy, and anger, are determined. These emotions are conditioned by early childhood attachment experiences, i.e., the infant learns to perceive, differentiate, and understand their own emotions, as well as those of others, in interactive contact with caregivers (Kernberg, 2012). This part of the limbic system consists predominantly of subcortical brain regions, such as the basolateral amygdala, the ventral segmentum, and the nucleus accumbens or ventral striatum. These brain structures develop prenatally or during the first months and years of life. Here, the control circuits for non-verbal communication are localised, i.e., emotional-communicative signals are recognised and processed. In addition, the internal reward system (endogenous opioids and dopamine) forms the basis for behavioural motivation. These brain functions are predominantly unconscious. The milestones of emotional development observed in infants and toddlers are particularly regulated in these brain regions.

The *upper limbic level* is localised in the associative neocortex, especially in the orbitofrontal, ventromedial prefrontal, anterior cingulate and insular cortex. This is where conscious emotional perception and social motivation take place. Skills such as impulse control, delayed gratification, frustration tolerance, empathy, and weighing up the consequences of one's own actions are controlled in this area. In this way, risks can be realistically assessed and actions consciously controlled. Moral thinking is also anchored here. These competences are developed in contact with the broader social environment, i.e., friends, schoolmates, other family members, etc. Environmental factors and sensory perception of the environment influence emotional reactivity and the available emotion-regulation strategies (Aldao & Nolen-Hoeksema, 2012). The various basal, sensory, motor, and cognitive functions, in interaction with environmental factors, have an influence on the development of the so-called emotional brain and thus on an individual's instinctive survival reactions and temperament, their regulation and control of emotions, as well as their social adaptation. The upper limbic system develops in later childhood and adolescence.

In summary, various brain structures and their connections form the architectural components of the so-called *emotional brain*. This forms the neuroanatomical basis for observable social and emotional abilities that are biologically closely linked to cognitive competencies (Damasio, 2012; Pessoa, 2014; see Figure 5). The state of emotional development depends not only on various internal and external aspects, such as genetic factors or acquired brain damage, but also on learning and social interaction processes; cognitive, sensory, and abilities; and environmental and psychological stress factors. People with intellectual disabilities generally go through the same stages of development as people without disabilities, their development may be delayed and

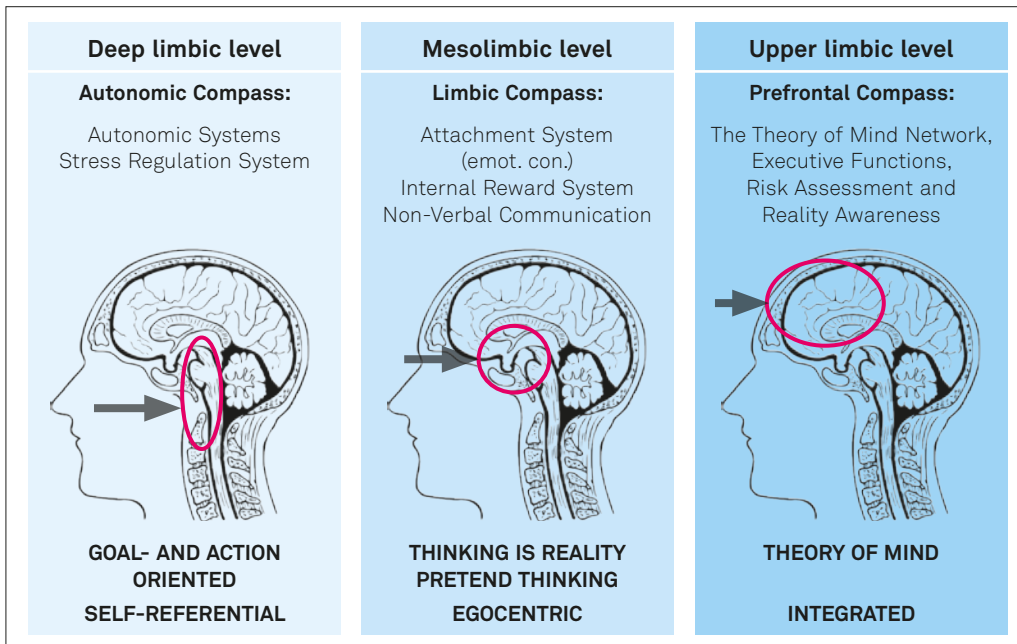


Figure 5: Relationship between neuroanatomical development of the brain, the associated neuropsychological control loops, and mentalisation ability (see also Figure 9). Depending on the maturation of the different networks, different parts of the limbic system are instrumental for the behaviours that can be observed. These active parts are a kind of compass for the expressed behaviour.

possibly incomplete (Cicchetti & Ganiban, 1990; Greenspan, 1997; Hodapp & Zigler, 1995; Martínez-Castilla et al., 2015; Webster, 1963).

The neuroanatomical knowledge of brain development presented here requires scientific methods, such as functional imaging, which have only been available for the last few decades. The first developmental psychological investigations and findings were therefore initially conducted on the basis of behaviour (Nelson et al., 2002). The following section summarises the related aspects of child development described by well-known developmental theorists.

In a nutshell

- The emotional brain initially develops prenatally and in the first few years after birth.
- Disturbances in brain development, e.g., as a result of a genetic condition or brain injury, can also impair the maturation of the emotional brain.
- People with intellectual disabilities go through the same stages of development as people without disabilities, but development is delayed or incomplete.