Tanja Sappok
Sabine Zepperitz
Mark Hudson

Meeting Emotional Needs in Intellectual Disability

The Developmental Approach

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About the Authors

Tanja Sappok, MD, was born and grew up in Heidelberg and studied medicine at the RWTH Aachen, Germany, and at the Louisianna State University, Shreveport, LA, and the East Tennessee State University, Johnson City, TN, USA. As chief physician, she heads the Berlin Treatment Center for Mental Health in Developmental Disabilities at the Ev. Krankenhaus Königin Elisabeth Herzberge. Clinical and scientific fields of work include autism spectrum disorders, emotional development, behavioural disorders, and dementia. As president of the European Association for Mental Health in Intellectual Disability (EAMHID) and vice president of the German Society for Mental Health with Mental Disability (DGSGB), she is organising the EAMHID Congress 2021 in Berlin. She teaches psychiatry at the medical faculty of the Charité and with her work she aims to improve medical care for people with intellectual developmental disabilities.
Email: tanja.sappok@t-online.de

Sabine Zepperitz, Dipl.-päd., studied educational sciences at the Technical University of Berlin, Germany. She is a systemic therapist and trauma consultant and leads pedagogical staff at the Berlin Treatment Center for Mental Health in Developmental Disorders at the Ev. Krankenhaus Königin Elisabeth Herzberge. She works primarily with people with moderate to severe intellectual disabilities. Her task within the framework of psychiatric treatment is to conceive nondrug treatment methods and to implement them in the patients' living environments. Mrs Zepperitz trains facilitators for SED-S diagnostics and counselling in a series of workshops. She has been offering advanced training for caregivers and team consultations in the support for people with disabilities for several years.
Email: s.zepperitz@posteo.de

Dr Mark Hudson, DClinPsy, completed his undergraduate degree in psychology at the University of Leicester, UK, before studying clinical psychology at the University of Birmingham and University of Sheffield, UK. He is a practising clinical psychologist and assistant professor of clinical psychology at the University of Nottingham, UK, where he carries out teaching and research. After qualifying, he initially worked in an inpatient assessment unit for children with moderate-severe intellectual disabilities (ID), before moving to work in both a community child and adolescent mental health service and a specialist community team for children with ID. He has a particular interest in attachment and systemic family therapy, and has published on the use of these approaches in people with autism and ID. He currently co-leads the Elizabeth Newson Centre, providing specialist assessments to families where a child has developmental difficulties.
Email: mark.hudson@nottingham.ac.uk

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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

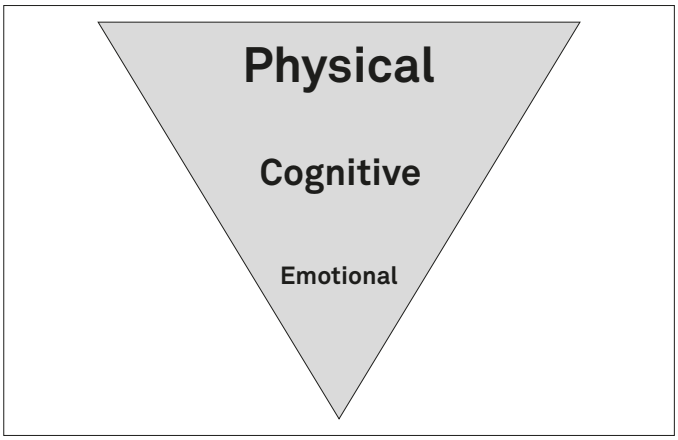

Figure 1: The encounter typically depends on the client's biological age, followed by their level of cognitive development; the emotional state of development is often the least considered. However, the emotional reference age may be lower, when compared to cognitive development.

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 lever 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).