CHAPTER

1

Introduction

Mijna Hadders-Algra

This book provides an overview of early detection and early intervention in developmental motor disorders. Developmental motor disorders are defined as disorders characterized by limitations in mobility due to an altered organization of the brain that had its origin in early life. This definition has two main components. The first component consists of the limitations in mobility. Mobility is the term of the International Classification of Functioning, Disability and Health, Children & Youth version (ICF-CY) to describe activities and participation with a motor component (World Health Organization 2007; Fig. 1.1). Examples are changing and maintaining body position; moving around and walking; and carrying, moving, and handling objects. The second component is the altered organization of the brain originating in early life. The altered organization may consist of a congenital malformation, a prenatal, perinatal, or neonatal lesion of the brain, or a more subtle disruption of the developmental processes occurring in the brain during the prenatal, perinatal, and neonatal period (Hadders-Algra 2018).

So far, so good. However, at an early age it is generally not easy to determine which infant will be diagnosed later with a developmental motor disorder. In clinical practice, the diagnostic trajectory often starts with a careful monitoring of infants who are at high risk for developmental disorders, for instance infants who had been critically ill in the newborn period, such as infants born preterm, or infants with intrauterine growth retardation, hypoxic-ischaemic encephalopathy, a complex congenital heart disease, or a lesion of the brain. It is well known that these infants are at high risk of developmental disorders, including motor disorders (Mercuri and Barnett 2003; De Kieviet et al. 2009; Miller et al. 2016; Van Iersel et al. 2016; Huisenga et al. 2020). But not all high risk infants have an impaired outcome (e.g. about half of the preterm infants have a favourable outcome). In addition, a substantial proportion of children with a developmental disorder has an uneventful prenatal, perinatal, and neonatal history. Part V of this book addresses how we best can detect the infants at high risk for developmental motor disorders.

In older children, two groups fulfil the criteria of developmental motor disorder. First, children with cerebral palsy (CP), who have limited mobility due to a congenital malformation or an early lesion of the brain (see Text Box 1.1). Second, children with developmental coordination disorder (DCD; see Text Box 1.2). Children with DCD also have a limited mobility, but mostly the limitations are less marked than those in children with CP. In the majority of children with DCD, no evident lesion of the brain can be demonstrated. However, neuroimaging studies suggest that the brains of these children exhibit minor alterations in organization (Peters et al. 2013; Wilson et al. 2017; Brown-Lum et al. 2020).

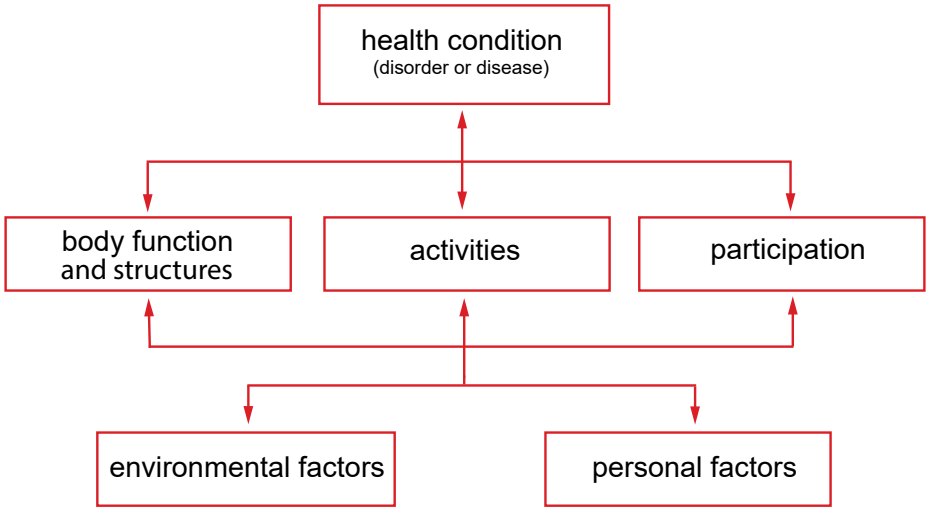

Figure 1.1 Diagram of the ICF-CY. The diagram illustrates the dynamic interactions between the various entities determining a child's health condition and his activities and participation.

Text Box 1.1 Cerebral Palsy

Cerebral palsy has been defined as 'a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy and by secondary musculoskeletal problems' (Rosenbaum et al. 2007, p. 9).

Rosenbaum (2014) highlighted that:

- The focus of the definition is on limitations in activities and participation and not on impairments in body structure and function.
- CP is a developmental disorder, implying that the permanent disorder originating in early life is characterized by changes in clinical manifestation over the lifetime.
- CP is characterized by heterogeneity in clinical manifestation (i.e. by variation in signs, severity, and co-morbidity).

To cope with the heterogeneity in the manifestation of CP, functional classification systems have been developed to characterize the individual's gross motor function (Gross Motor Function Classification System; GMFCS; Palisano et al. 1997), manual ability (Manual Ability Classification System, MACS; Eliasson et al. 2006), communication (Communication Function Classification System, CFCS; Hidecker et al. 2011), feeding and eating (Eating and Drinking Ability Classification System, EDACS; Sellers et al. 2014), and visual function (Visual Function Classification System, VFCS; Baranello et al. 2020). In addition, the clinical manifestation of CP can be described using the distribution of neurological impairments: spastic CP (unilateral or bilateral), ataxic CP, or dyskinetic CP (Rosenbaum 2014).

Text Box 1.2 Developmental Coordination Disorder

The diagnostic criteria of developmental coordination disorder (DCD) described in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5, American Psychiatric Association 2013) are:

A. The acquisition and execution of coordinated motor skills is substantially below that expected given the individual's chronological age and opportunity for skill learning and use. Difficulties are manifested as clumsiness (e.g. dropping or bumping into objects) as well as slowness and inaccuracy of performance of motor skills (e.g. catching an object, using scissors or cutlery, handwriting, riding a bike, or participating in sports).
B. The motor skills deficit in Criterion A significantly and persistently interferes with activities of daily living appropriate to chronological age (e.g. self-care and self-maintenance) and impacts academic/school productivity, prevocational and vocational activities, leisure, and play.
C. Onset of symptoms is in the early developmental period.
D. The motor skills deficits are not better explained by intellectual disability (intellectual development disorder) or visual impairment and are not attributable to a neurological condition affecting movement (e.g. CP, muscular dystrophy, degenerative disorder).

At an early age, children with CP and DCD do not fulfil the diagnostic criteria of their disorders. Due to the substantial developmental changes occurring in the brain during the first postnatal years (see Chapter 3), it takes developmental time before the disorders become fully expressed. Generally, CP is first diagnosed from about the end of the first postnatal year onwards, whereas in some children it may take several years before the clinical picture is established (Smithers-Sheedy et al. 2014; Granild-Jensen et al. 2015). DCD is typically not diagnosed before the age of 5 years (Blank et al. 2019). However, the last version of the *Diagnostic and Statistical Manual of Mental Disorders* (i.e. its fifth edition [DSM-5]) introduced for the diagnosis of DCD the new criterion that the symptoms start in the early developmental period (criterion C, Text Box 1.2). Yet, the evidence supporting this criterion is limited.

Developmental motor disorders are the main theme of the book. It should be realized, however, that developmental disorders usually are not restricted to limitations in one domain. For instance, limitations in mobility are often accompanied by limitations in learning and communication. Two major factors explain the high rate of limitations in multiple domains: (1) adversities that interfere with early brain development generally do not affect single functional systems; (2) the high degree of interrelation between development in the various domains. For instance, limited mobility hampers the infant's discovery of the world, which, in turn, negatively impacts cognitive development and, vice versa, limitations in learning (e.g. in exploratory drive) interfere with motor development.

The book zooms in on the prenatal period and the first 2 years post-term – the first 1000 days of life. It uses the ICF-CY as framework of reference. The ICF-CY emphasizes that activities and participation in daily life do not only depend on body function and structure, but also environmental and personal factors (Fig. 1.1). What the latter may imply is recounted in the reflections on disability presented in Text Box 1.3. The book starts with the clinical picture of early detection and early intervention. Next, in Part II, the neurodevelopmental mechanisms occurring in early life are discussed, including vulnerability and plasticity. Part III comprises chapters on typical development. It not only discusses motor development but also sensory and cognitive development. It is increasingly recognized that motor development is strongly interrelated with developmental changes in other brain functions (Diamond 2000). The strong interrelation explains why children with developmental motor disorders often have comorbid disorders, such as learning disorder, autism spectrum disorder, and attention deficit and hyperactivity disorder (Novak et al.

Text Box 1.3 Reflections About Disability – A Personal Point of View

- *Disability or different abilities?* Why do we characterize persons with a disability by their disability? Is it because the disability is frequently quite visible? Are we scared by this view as the disability confronts us with the vulnerability of human existence? What prevents us from being open to the idea that everybody has different abilities, everybody has strengths and weaknesses? Isn't being able to share a smile when the sun warms the skin and the wind strokes the hair equally valuable as being able to write a chapter?
- *Walking or wheeling?* Families and professionals often choose as a major goal of early intervention the achievement of the ability to walk (independently). Of course, I won't deny that it is convenient to be able to walk without help. However, when the walking costs an enormous effort, it is perhaps better to skip this activity and save the energy for communication, other forms of social interaction, learning and applying knowledge. I learnt this well from personal experience. I acquired a partial spinal cord lesion at the age of 16 years. The physicians doubted whether I would be able to walk again. However, being somewhat on the hyperactive side of the spectrum, I massively practised and regained the ability to walk. Over time, the walking deteriorated and I realized how much upright stance and walking interfered with communication and cognitive function. When I started to use the wheelchair, I 'regained my brain'.
- *Interdependency.* Disability is associated with dependency (i.e. a condition that is the opposite of autonomy and independency that are advocated as ultimate goals for individuals in Western industrialized societies). Actually, I think, that the Western societies can learn from other societies, such as the Asian and African societies that focus more on interdependency (Nisbett and Miyamoto, 2005). These societies acknowledge more than the Western that humans are social beings, with a brain that is totally tuned to interaction with others (Chen et al. 2018). The interdependency implies that all humans depend on other human beings. In general, we consider it as typical that we depend on the pilot of an aircraft when we fly, or on the employees of a supermarket when we go shopping, but we feel embarrassed by the idea that we might need assistance when visiting the bathroom. Again, from personal experience, dependency in this situation does not differ from that in the other ones. You just get confirmation that the large majority of fellow humans are friendly and respectful, and that humans indeed are social beings.
- *Assistive devices.* Families and professionals may have a negative view on assistive devices, as they underline that the infant has specific impairments or limitations. But we perhaps should try to root out this view, as assistive devices are meant to do what their name tells: to assist, to make life easier. It is interesting to consider the change over the last five decades in the perception of the visual assistive device 'glasses'. Fifty years ago, wearing glasses was regarded as negative; children with glasses were called names and bullied. However, nowadays glasses have an entirely positive aura; they are part of fashion and used to express a person's identity.

2012; Blank et al. 2019). Part IV discusses atypical motor development. After the preparatory chapters of Parts I to IV, the heart of the matter follows: Part V provides an overview of the methods available for early detection, and Part VI summarizes early intervention methods, including their evidence on effectiveness. Special attention is paid to the family (Chapter 12) and environmental adaptations (Chapter 15).

Finally, two practical remarks. First, the infant ages used in this manual always refer to ages corrected for preterm birth, unless otherwise indicated (e.g. foetal ages and gestational ages of preterm infants). This is not further indicated in the text. Second, writing about individuals who may be male or female gives an author the awkward choice of consistent referral to all gender typologies by using expressions such as he/she, or the selection of a specific gender. The latter results in a text that is easier to read, but this option has the disadvantage that an impression of 'neglect' of other gender identities occurs. We opted for a single gender option to facilitate readability, and choose the female gender when referring to the professional and the male gender when referring to the child. However, we would like to stress our gender-neutral intentions.

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SUGGESTIONS FOR FURTHER READING

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