

International Perspectives on  
Early Childhood Education and Development 13

Louise Bøttcher  
Jesper Dammeyer

# Development and Learning of Young Children with Disabilities

A Vygotskian Perspective

 Springer

# International Perspectives on Early Childhood Education and Development

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Volume 13

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# Development and Learning of Young Children with Disabilities

A Vygotskian Perspective



Springer

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# Preface

Plenty of introductions to disability theory and research from a medical or a social/sociology perspective can be found on the market. The intention with this book is not to add another one to this list. Instead, the ambition is to use the theoretical framework of cultural-historical theory, drawing on the legacy of Vygotsky and developmental concepts developed from Vygotsky's work, to discuss early development of children with disabilities.

In our research with people with disabilities, we discovered that a cultural-historical psychological understanding of disabilities was absent. We decided to explore how a cultural-historical conceptual understanding would allow a more integrative biopsychosocial approach across the gulf between medical and social models of disabilities. For a decade, we have carried out both empirical and theoretical studies to explore this perspective and find new ways of modelling disability fruitfully. In this book, our intention is to collect and continue this work.

The subjects addressed are grounded in central issues within disability studies. Through the different chapters, we will provide an up-to-date presentation of some of the major psychological issues for children with disabilities, based on the latest international research reframed within the cultural-historical theoretical understanding. The content will include an introduction to theoretical models of disability, methods in special education, issues about specific groups of children with disabilities and different assessment issues with interest for professionals.

The authors of the book have both worked as clinical and counselling psychologists and researchers within the field of disability psychology and special education. These experiences are reflected in the book's intention to integrate research with a practical knowledge about children with disabilities.

This book is written for professionals, students and researchers who work with children with disabilities. Disciplines and professions of interest may be counsellors, psychologists, teachers, social workers, nurses and many more. The book can

be read by both beginners in the field of disability research and by people who know the field but seek to challenge prevalent perspectives.

We would like to thank colleagues and students with whom we have discussed the outline and the content of the book.

Copenhagen, Denmark

Louise Bøttcher  
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# Introduction

What is disability and why is it important? The practical relevance of the subject can be found in the fact that 10–20 % of the world’s population has one or more disabilities (World Health Organisation/World Bank, 2011). From a more theoretical point of view, the relevance of disability studies as a student or researcher arises from the understanding that disabilities mirror general approaches of biological, psychological, social and cultural issues. The cultural and historical nature of child development is at times more salient in children with disabilities, and thus, understanding the development of children with disabilities might also make us wiser in relation to child development in general. Children both with and without disabilities have a lot in common.

The aim of this book is to provide an alternative to prevalent biomedical approaches to childhood disabilities on one side and ‘pure’ social models of disability on the other. Overcoming the dichotomy of biology or society as two opposite perspectives on disability can be done with cultural-historical theories. With the cultural-historical alternative presented in this book, we want to incorporate cultural-historical theories of children’s learning and development from the legacy of Vygotsky’s work on *defectology* with current empirical knowledge and research about specific impairments. The theoretical framework of the book will be outlined in the first two chapters.

Disability studies are a cross-disciplinary field, combining psychological, medical, social, technical and philosophical sciences. This book will not be another general textbook introducing a number of current themes and issues about children with disabilities. Nor will it be yet another typical book focusing on political or ideological issues addressing social exclusion and social inequality from a disability rights perspective. Instead, the aim of this book is to frame a new model of disability based on developmental psychological themes and empirical studies of particular types of impairments.

The book is divided in three parts. In part 1, Chap. 1 begins with a short description of the two most current and competing approaches to disability (the biomedical and the social model) to set the scene for the proposal of an alternative cultural-historically grounded approach that constitutes the foundation of the book.

Vygotsky's work on developmental psychology has been influential and has inspired a great number of developmental psychologists, including Barbara Rogoff and Mariane Hedegaard, to mention just two. In contrast, Vygotsky's work on children with disabilities has received much less attention. In this book, we wish to restore central ideas from Vygotsky's work on children with disabilities (defectology) to the mind of practitioners and researchers working in the disability field. We find that the cultural-historical understanding of disability provides contributions to how children with disabilities can be supported – in ways that transcend the current divide between either biomedical approaches (with a focus on individual shortcomings) or social model approaches (with a main focus on social barriers). The cultural-historically grounded approach states that a disability arises from an incongruence between the child's development (constituted by the biological impairments) and the form of the social practices (schools, families, etc.) in which the child participates.

Chapter 2 elaborates on the concept of developmental incongruence introduced in the first chapter by considering how the incongruence emerges and develops from microprocesses within the child's everyday social settings and, further, how the activity of the child will sculpt the neural structure and thus create future developmental possibilities. A neuropsychological conceptual understanding within the cultural-historical framework will be outlined. This micro-level perspective will be related to macro-level developments through a walk through disability history and four specific examples: life and death of infants with disability, institutionalisation of children with disabilities, early intensive treatment programmes for children with disabilities and inclusion as a current (and global) value position. All four specific examples will be addressed through analyses of how societal value positions at macro-level are turned into practices and developmental opportunities in the daily activity settings of children with disabilities.

The cultural-historical approach outlined in the first two chapters will be elaborated in the second part of the book in relation to general developmental challenges for children with disabilities during early childhood. In three chapters – infancy, toddler and preschool age and early school age – it will be discussed how the development of children with impairments arises from feedforward cultural-historical developmental dynamics between the child, his/her primary caregivers, professionals and the institutional and societal conditions and contexts for families, preschools and schools. Together these three chapters will discuss the main aspects of child development from a chronological approach.

The chronological approach in part 2 is followed by thematic-oriented chapters in part 3, aimed at in-depth cultural-historical analyses of thematic issues related to childhood disability. The chapters will discuss a various number of themes related to communication, mental health, learning, use of aids and assessment to mention a few. Although many of the themes are particularly salient or pronounced in some types of disabilities or diagnostic categories, and examples within each chapter might draw on one or two types of disabilities in particular, the addressed themes are relevant for most disability categories. The chapters will incorporate empirical knowledge to the cultural-historical theoretical frame outlined in the first part.

The last and concluding part, 'Creating a future together', draws on the discussions in the first two parts to formulate a theoretically and empirically guided frame for supporting development and learning for children with disabilities. This final chapter focuses on developmental time and challenges in family life. Even though families with children with disabilities carry many similarities with other families, the developmental incongruence often brings additional responsibilities that parents need to take care of in most aspects of their child's life. Furthermore, the chapter will outline how the cooperation between the child's parents and the professionals in nursery, preschool and school is pivotal in negotiating the incongruence into a local congruence between the child's development and the practices in which the child participates.

# Part I

## The Theoretical Frame

For a book concerning disability in early childhood, an important start will be to outline a general model of what disability is. Basic understandings of disability have varied throughout history and across scientific approaches. The aim of the two chapters in Part 1 is to inspect current models of disability (Chap. 1), being the medical perspective on one side and the social model of disability on the other, and to outline the cultural-historical framework of this book and based upon this, build a new model of disability (Chap. 2). Readers not familiar with the cultural-historical perspective in psychology will get a general introduction in Chap. 1 through the lenses of disability theories.

# Chapter 1

## Beyond a Biomedical and Social Model of Disability: A Cultural-Historical Approach

The most influential definition of disability originates from The World Health Organisation (WHO) (2001, 2007). The WHO definition states disability as an umbrella term covering a complex phenomenon that reflects the interaction between the individual's body functions and the society around. An *impairment* is defined by the WHO as a problem in body function; an *activity limitation* as a mirror of the individual's difficulties in executing a task or action; and a *participation restriction* as the difficulties by an individual to participate in the society in which he or she lives. The current WHO definition (World Health Organisation 2001, 2007) incorporates ideas from two opposing models of disability: The *medical model*, focusing on disability as the result of one or more physical defects of the individual body; and the *social model*, focusing on how society is organised and how barriers in society construct disability by limiting the participation of particular groups of people, for example, wheelchair users. The medical model is not an explicitly described model, but a label attached to a large body of research with a focus mainly on individual and biomedical explanations. The label was established by an emerging group of disability activists dissatisfied with the lack of attention to the social aspects of disability. Thus, the other model, the social model, was developed in opposition to the medical approach, at first in the United Kingdom in the 1960s and 1970s, and since then disseminated globally. The central idea is that the main contributory factor to disability is not the physical impairment, but the failure of society to take individual differences into account. Since the initial introduction, the social model has inspired and developed into a diverse range of critical, cultural minority, political activist, social constructionist, poststructuralist, and many other perspectives.

However, the popularity of the social model has been increasingly criticised in the past number of years, mainly for ignoring that disabilities are grounded in biological impairments, and for overlooking individual psychological perspectives of people with disabilities (see, eg, Shakespeare 2006). This book will follow up on this critique by discussing how the cultural-historical perspective owing to



Vygotsky's defectology can overcome the dichotomy between the social and the medical model.

## **Impairment and Disability**

In this book, both *impairment* and *disability* will be used. *Impairments* will refer to the biological aberration causing individual inability to move one's muscles, hear sound, etc. *Disability* will refer to the consequences of the impairment. Thus, disability could involve not being able to play with other children as a consequence of the impairment of walking, or not being able to talk as a consequence of the impairment of not being able to hear. However, as will be outlined in the first two chapters – and throughout this book – the connection between impairment and disability is anything but straightforward. As such, a more precise definition of what the term *disability* means – from a cultural-historical perspective – will be explained throughout this chapter.

## **The Impact of the Biomedical Model**

The medical model considers disability as caused mainly by biological impairments. Research from the biomedical perspective most often divides the general area of disability according to the specific impairments such as physical, cognitive, mental, sensory, emotional or some combination of these. The aim of this type of research is to study and describe the associations between different impairments and particular types of problems, support and interventions. Acknowledgment is given to the variation among individuals with disability due to type and severity of the impairment. From the knowledge about a particular impairment, the idea is to develop individual healthcare, medical surgical procedures, physiotherapy, aids and special educational arrangements in order to ameliorate or manage the impairment. Researchers and professionals working within the medical model approach often hold specialised knowledge about particular conditions or diagnoses. Research and journals are organised according to diagnoses or types of impairment. The differences and the distinctiveness of particular impairments are foregrounded, rather than similarities between different types of impairment and disability as a shared category.

The value of the mount of empirical knowledge the biomedical research has contributed to most disability groups cannot and should not be ignored. The strength of the medical approach is that it offers a nuanced conceptual framework for understanding impairments, and the relation between specific impairments and how they might impact on individual functional skills. Situational aspects of life with a disability are also acknowledged, but are mainly included as extrinsic to individual functioning.

The medical approach dominates many aspects of current psychological, pedagogical and teaching practices. There are several reasons for this. The medical approach is given an early start in national screening programmes for pregnant women (eg, ultrasound scans) offered by many countries, in order to prevent the birth of children with particular impairments. Following birth, newborns and infants are often screened in order to identify congenital impairments and treatment needs (eg, hearing impairment). Sometimes it is possible to remedy the congenital impairment (eg, operate for a heart malformation); at other times the aim will be to prevent complications or further impairment, for example, addressing a congenital metabolic disorder with a particular type of diet. This addressing of medical and treatment needs underlines a medical approach and is, from society's perspective, experienced as beneficial for the children with congenital or early-acquired impairments and their families. The classifications enabled by diagnoses are needed for providing the best medical treatment and special educational needs service. Further, diagnoses are often actively sought because they function as the gateway to legal rights and financial support for the family, preschool institutions and school (Florian et al. 2006). However, diagnosis used as part of medical procedure often follows the child into pedagogical and educational practices, even though it might be less useful or, as some have argued, downright detrimental to the child (Mehan and et al. 1986; Tomlinson 1982) and the educational system (Skrtic 1999). The medically based diagnoses are often sought and treated as explanations of the way the child acts (McDermott 1993), the problems and challenges the family experience, and/or the differences the parents feel or see between their child and other children (Mehan et al. 1986). Thus, one major problem of the medical model approach is that it tends to reduce wider enquiry into why the child behaves in certain ways or experiences certain problems and developmental challenges. The medical model supports developmental and pedagogical perceptions of the child that focus mainly on specific, individual impairments and specific, fixed strategies and methods to treat and minimise the individual consequences of the particular impairment. Even though the medical impairment approach uses 'special educational needs' or similar terms instead of 'diagnosis' in educational settings in order to focus more on learning as a process embedded in a social context, the reality is that special educational needs are still treated as emerging from the impairment itself (Solity 1991). A central weakness of the medical model is its individualised approach that overlooks the impact of social conditions on the learning and development of children with impairments.

Children with disabilities share many similarities with children in general and the relations between the general and the special in our conceptual understanding of the development of children with disabilities need to be considered. It is necessary to understand that many of the differences that exist between children with and without disabilities arise from disability as a condition for living and are not caused by the biomedical impairment (Bøttcher and Dammeyer 2013). Thus another important flaw of a medically based approach to children with disabilities in early learning contexts is that problems with learning are most often attributed to the child, thereby overlooking the role of context, for example, lack of properly accommodated

support in educational practice (Norwich 2002). The attribution of learning problems to the individual child often rests on cognitive and neuropsychological conceptual understanding. For instance, explanation and design of intervention are organised based on neuropsychological assessment, even though children with disabilities are considered a difficult group to assess because their impairments make it difficult for them to participate in psychological assessment using standard administration. The impairments are thought to invalidate the neuropsychological assessment, because they diminish the reliability and validity of the assessment (Haywood and Lidz 2007). The methodological problems point to a more basic theoretical problem in the medical and individualised approach to children with disabilities in educational practice. The fluctuations often observed in cognitive abilities of children with disabilities need to be included both in the theoretical and the practical understanding of the potential of these children for learning and development. Fluctuations and impairments in, for example, attention or comprehension are not confounders of the evaluation of the cognitive abilities of the child; they are part of their cognitive functioning. Otherwise, the reduction of their cognitive functioning to one stable description may invalidate the description of the child and undermine its value in the process of organising support for him/her. Acknowledgment of the role of situational and environmental factors in the development of the brain can be found within the neuropsychological perspective, but the biosocial dynamics are far from explained.

The aim of this book – to understand cognition of children with disabilities as developed under cultural-historical conditions – calls for a shift in focus from cognitive abilities and impairments within a child-to-child activity, from child as object to child as active subject in concrete practices. This will be expanded upon further in the following sections.

## **The Social Model Alternative**

The social model is a cluster of different approaches mainly rooted in sociological and political theories. Proponents of the social model accentuate the central role of social factors and how they cause barriers to equal social participation for children and adults with disabilities. For example, a motor impairment will not be a disability if society offers adequate support, aids and legal rights to participate in society. The focus is on analysis of common challenges to participation associated with living a life with social barriers, while the impairment is mainly considered as part of a continuum of biological differences shared by all of us (Reindal 2008). Therefore, the particularity of different impairments is put aside as irrelevant.

The social model has been very influential in changing the disability agenda over the course of the last four decades. National legislation stressing disability rights such as accessibility, financial compensation and the right not to be discriminated against owes a great deal to the activists of the social model. At a global level, the influence is mirrored in the change of focus from the first to the second WHO

disability definition. The first definition, the ICIDH (International Classification of Impairments, Disability and Handicaps (World Health Organisation 1980)), separated between impairment, disability and handicap. The two first concepts, impairment and disability, referred to individual biological defect and subsequent loss of function or ability, while the third, handicap, denoted individual disadvantage arising from the impairment and/or disability. Not surprisingly, this first definition was criticised for its linear approach, which assumed a direct causality from impairment to disability to handicap. The individual approach underlying the first definition thus missed the role of social barriers (Bickenbach and et al. 1999). This type of critique, including the lack of social and cultural factors in the making of disability, led to a second, revised WHO definition, the ICF (International Classification of Functioning) (World Health Organisation 2001) defining disability from a biopsychosocial approach through descriptions of impairment of body structures, and functions, limitations or restrictions of activities and restrictions of participation, seen in relation to environmental factors. Disability is approached as an umbrella term denoting severity in restrictions of biopsychosocial function in a continual rather than categorical way. Besides being a definition of what disability *is*, the ICF has been developed as a taxonomy for coding an individual's functional limitations in order to decide what *type of support* is necessary to alleviate restrictions in function and participation. For instance, one code in ICF is "d6301 Preparing complex meals." This is defined as:

Planning, organizing, cooking and serving meals with a large number of ingredients that require complex methods of preparation and serving, such as planning a meal with several dishes, and transforming food ingredients by combined actions of peeling, slicing, mixing, kneading, stirring, presenting and serving food in a manner appropriate to the occasion and culture. Exclusion: using household appliances (d6403) (<http://apps.who.int/classifications/icfbrowser/>).

The code d6301 can be given if the person is unable to fulfil the function and society is obliged to plan proper support or compensation, whatever that may be. As such, ICF was meant for clinical use. The ICF has been followed up with a version encompassing developmental aspects of relevance for understanding disability in children and youth (The ICF-CY (World Health Organisation 2007)) and is therefore of particular relevance for this book. The child and youth version was developed from a need to incorporate elements relevant to the developing nature of the difficulties experienced by children and youth with impairments, and their families. The content and depth of the descriptions in the ICF-CY are increased to better capture the changing nature of functioning as the child grows and develops biologically: First, an important addition is the introduction of the concept of developmental delay. It is the idea that variations in the emergence of body functions, body structures and acquisitions of skills arise from individual differences in growth and development and may be caught up later rather than being a stable impairment. It is stressed that the emergence of developmental delays may be influenced by physical and psychological aspects of the environment. Second, participation of the child is dependent on the interaction with primary caregivers, especially in the early years. Even though the environment is included in the ICF, there is a greater need to

understand the participation of the child within the family context. Third, the environments of children are often different from those of adults, with more institutional transitions related to the age and developmental stage of the child (World Health Organisation 2007).

The basic approach in the ICF-CY considers the development of the child as a series of successive developmental systems. This approach is useful and it will throughout this book be elaborated with concepts that enable analyses of the impact of its different concepts; for example, the significance of child participation and different contexts on developmental delay over time. From a cultural-historical point of view, the ICF-CY's focus at child participation and significance of different contexts on developmental delay over time is relevant. However, these concepts – as well as the distinction between delay and impairment – need to be further elaborated upon within a dialectical developmental understanding. A dialectical elaboration means that the book will be focused on how the mismatch between children with disabilities and their environment creates tensions over time that can result in disabilities, but also contains developmental possibilities. The dialectical concepts bring to attention how developmental delays may turn into impairments/disabilities, which will be shown in Parts 2 and 3 of this book.

The social model has succeeded and the change from the ICDHI to the ICF/ICF-CY is one important example of the impact of the social model. Participation in social life as an aspect of disability along with the role of the impairment is now a part of many studies with otherwise biomedical approaches (eg, the SPARCLE study (Study of Participation of Children with Cerebral Palsy Living in Europe) <http://research.ncl.ac.uk/sparcle/>).

However, the social model has recently been criticised for being too focused on the social rights and oppression of people with disabilities, while overlooking the consequences of impairment itself, such as pain or fatigue. Furthermore, this model is criticised for simply detaching biology and mental elements from the person with disability (eg, Anastasiou and Kauffman 2013). Different writers have proposed ways to approach disability that seek to embrace the reduced function of the individual along with the social barriers to participation (eg, Shakespeare 2006; Thomas 2003). Shakespeare argues for a more nuanced and plural understanding of disability and avoids dichotomies in disability theory research by, for example, allowing individualistic concepts and biological realism to the social model (Shakespeare 2006). This book agrees with these writers about the need to transcend the dichotomy between the medical and the social model, and seeks to develop a more interactional understanding of disability by using the cultural-historical approach. Biological, psychological and social levels of disability all need to be incorporated in an understanding of childhood disability and the impact of disability on development.

## **Transcending the Dichotomy Between Medical and Social Models – A Dialectical Approach**

The medical and the social model of disability both hold important pieces to a bio-psychosocial understanding of disability that is necessary in order to fully support the needs of young children with disabilities. The aim of this book is to solve the challenge of combining central aspects of both models from the legacy of Vygotsky's defectology from the 1920s and 1930s – a cultural-historical framework of how the development of children with disabilities could be understood and supported (Vygotsky 1993). Vygotsky's work about the development and education of children with mental retardation, deafness or physical disability (the categories used at that time) are based on his general theoretical understanding and concepts about child development. An introduction to cultural-historical thinking about the development of young children with disabilities therefore includes concepts of child development as outlined in Vygotsky's work. Many of the developmental concepts have been used and developed further since then and the cultural-historical dialectical approach in this book will also incorporate concepts from newer elaborations of the *cultural-historical developmental* approach. In current cultural-historical traditions working within a Vygotskian approach, children's development is conceptualised as situated in concrete historical and cultural practices (Hedegaard 2002; Rogoff 2003). These perspectives have been part of a broad theoretical critique of the so-called traditional developmental psychology's universalistic concepts. The dialectical cultural-historical approach to understanding disability highlights that even though disability arises from one or more biological defects, it is at all times necessary to study disability as a phenomenon that has emerged within specific physical, social and cultural-historical contexts. The developmental trajectories towards specific cognitive dysfunctions and restricted social participation have previously been explored by some researchers in relation to specific aspects of participation (see, eg, Ferm (2006) on communication or Daniels and Hedegaard (2011) on special needs education). Still, studies from a cultural-historical perspective are few and do not offer a coherent theoretical and conceptual platform for how to understand the development of children with disabilities.

## **Incongruence – A Fundamental Concept**

Vygotsky outlines development as made up of two lines. The first is the *natural line of development*, which is the individual biological maturation. The second is the *cultural line of development*, understood as the socialisation process, whereby the child acquires knowledge of and the ability to use cultural tools through his/her participation in social practices. Under normal circumstances, the natural and the cultural line of child development support each other. They have developed and merged together. As an example, consider a child that is learning how to ride a bike.