

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

Louise Bøttcher  
Danish School of Education  
Aarhus University  
Copenhagen, Denmark

Jesper Dammeyer  
Department of Psychology  
University of Copenhagen  
Copenhagen, Denmark

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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  
Jesper Dammeyer

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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.

Even though riding a bicycle is an activity based on individually developed balance and motor skills, it is at the same time the mastering of a culturally developed tool and a skill that arises through the supported activity of the child within cultural practices. The child practices riding the bike supported by a parent or some other adult in areas suited for bike practice, later followed up by instructions about how to ride the bike safely in places with more traffic. The natural and the cultural part of the practice together support the learning progress and the setting up of the next level of training and competence. This *dialectic* intertwining is central to the developmental thinking within cultural-historical theory and means that child development – with or without a disability – requires more than adding together elements from the biological and the social line of development in the analyses. The dialectic nature of development requires analyses of how the biological and social lines of development condition each other and create future developmental possibilities by creating solutions to present conflicts and challenges. Furthermore, a central part of cultural-historical thinking is that the conflicts and tensions experienced in everyday practices need to be dialectically related to the wider social and cultural practices of which they are part. Childhood social institutions – for example family, day-care and early educational institutions – are endowed with a priori goals for child development, and with demands and expectations to the abilities of the participating children. Demands and expectations as cultural-historical phenomena will often be related to the age of the child, and activities in childhood institutions are organised to fit within these age-graded expectations. For example, when a child begins day-care in a nursery at around the age of one, as do many children in some western countries, the social practice in the nursery is organised around the expectation that many of the children cannot transport themselves from one place to another or eat on their own. Help and support from adults are needed and provided. When moving to kindergarten at around the age of three, this has changed. Now the practice is organised around a common expectation that each child is able to move around unaided and eat on his/her own. Throughout history, cultural practices and societal structures have merged closely with the natural line of children's development.

The cultural line of development actively shapes the natural line of development. Often the age-graded demands are a little beyond what the child is able to do by him- or herself. However, the presence of supportive adults and the way the activities are organised enable the child to participate and gradually acquire new skills and competences, thereby being able to participate in new and more advanced ways. As will be explained in Chap. 2, the development of the brain and body supports the gradual and sequential nature of social and cognitive development that feeds back into the biological base of development, strengthening operational neural pathways and connections while eliminating redundant ones.

The conceptual understanding of development expressed in the two developmental lines represents an elegant solution to the old controversy of nature versus nurture. The idea of development arising out of a mutual intertwining of the natural and the cultural line fits within the later model of *probabilistic epigenesis* (Gottlieb 2007). The point of both Gottlieb's meta-theoretical model and Vygotsky's conceptual understanding of two lines of development is that nature and nurture

cannot be separated as distinct elements. The development of the individual (natural/biological/genetic) and environmental/cultural-historical lines of development are enabled and enable each other. The question is not, “Is development of A determined by nature or nurture?” The question, “How much of A is determined by nature and how much is determined by nurture?” is still not to the point. The question to ask is: “How is gene expression and neural development enabled or inhibited by the child’s social situation of development; and how does the expression or inhibition of genes, or the particular sculpturing of the child’s neural system, enable the child to participate in new ways?”

A broad field of theories in developmental psychology stresses the complexity of biopsychosocial factors and their interaction. The perspective is often labelled *developmental psychopathology models* (Cicchetti and Cohen 2006; Rutter and Rutter 1992; Sameroff 2009). This wave of research began in the 1970s and 1980s as an alternative to monofactorial and causal models on child development. The aim was to develop a conceptual framework for understanding the emergence of individual differences in development, including the continuities and discontinuities between different aspects of development and across time. Both protective factors (eg, well educated parents) and risk factors (eg, mother’s drinking during pregnancy) affect development in complex chain reactions interacting with other factors, thereby creating multiple developmental pathways (multi-finality) for children with and without disabilities (Cicchetti and Cohen 2006; Rutter and Rutter 1992). Attention disorder in children is not caused by one factor but by several factors, which have different impact at different times and over time. This perspective incorporates a developmental complexity, in which biological and contextual factors are considered to shape development, and is therefore also a useful empirical approach to link to a cultural-historical and dialectical understanding of development for children with disabilities.

The fusion of natural and cultural development builds on cultural-historical dialectic processes that have shaped and still shape both children and the cultural-historical institutions in which children and other people live their lives. However – and this is a central point – this process of mutual adaptation between cultural-historical institutions and their individual participants is based on the most widespread ways of participating: individuals with psychophysical constitutions within the normal range (Vygotsky 1993). For typical children, their everyday environment often offers multiple activities that are experienced as relevant and support the development of the child. In contrast, the way a child with an impairment is able to participate often does not fit with how institutions and their activities are organised and thus the child may find it difficult to participate in learning activities without additional support. The dialectical understanding of disability departs in this fundamental thesis of Vygotsky that “[...] a child whose development is impeded by a defect is not simply a child less developed than his peers but a child who has developed *differently*” (Vygotsky 1993, p. 30, original italics).

The stance implies that whereas Vygotsky includes biological defects in his theoretical understanding of children with disabilities, such as deafness or motor impairment, his aim is to conceptualise the way a biological deviation from the

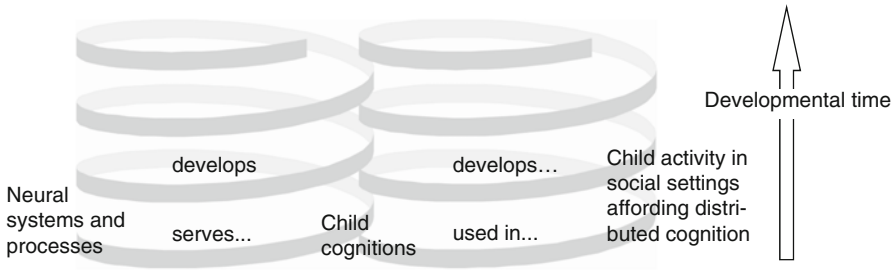


norm impacts on the developmental path of the child through his/her development in cultural-historical social practices, and how we can understand and make use of the open-ended nature of the developmental trajectory for remedial purposes. As Vygotsky phrases it:

A defect creates certain difficulties for physical development and completely *different* ones for cultural development. Therefore, the two lines of development will diverge substantially from one another. The degree and character of the divergence will be determined and measured in each case by the different qualitative and quantitative effects of the defect on each of the two lines. (Vygotsky 1993, p. 43, original italics)

The often problematic development of children with disabilities arises and develops from an *incongruence* between, on one hand, the biological development of the child (the natural line of development) and on the other, the structure of cultural practices (in institutions, families, etc.) in which the child is living (the cultural line of development) (Vygotsky 1993). Many age- and context-typical activities are less relevant and supportive for a child with disabilities. The cultural-historical institutions do not support and accommodate the development of children with atypical psychophysical constitutions the same way they do with children without impairments. Thus, the incongruence at one moment in time feeds forward on the developmental opportunities to come.

The non-linear nature of the relation between impairment and disability stressed by Vygotsky is also based in his distinction between *basal and higher mental functions* (Vygotsky 1993). Human cognition develops through shared activity in historically and culturally developed practices. The individual child is equipped with natural neurobiological-based cognitive functions, such as perception, attention and memory. Through time, human progress, inventions, and ideas become part of the cultural heritage that is passed on to the next generation, both as concrete tools, for example, a hammer or a computer, and symbolic tools such as language, writing and knowledge. As the child is introduced to and learns to use the concrete and symbolic tools through his/her own development, the gradual internalisation of cultural tools develops the child's cognition to new levels of higher mental functions. From relying on direct memory, the child becomes able to use logical and strategic memory; from direct perception, the child becomes able to reflect on the world using concepts and conceptual relations. The higher mental functions do not substitute the basal natural functions; nor are they a combination of natural functions. They function as a superstructure to the natural functions, which both enables more effective use of natural functions and opens up new lines of thinking about and acting in practice. To be able to use a cup (for drinking properly) the child both needs perceptual and motor abilities and cultural-based knowledge about how a cup can be used, where, when, with which liquids, etc. It is only through the child's active participation in cultural practices that he or she develops higher mental functions. At the same time, the development of higher mental functions furthers the child's competence as an active social agent as the child begins to understand new aspects of social life, and through this understanding becomes able to contribute in ways experienced as relevant by the other participants within the particular practice.



**Fig. 1.1** Development involving biopsychosocial dialectical processes

The primary biological defects (such as sensory, organic or neurological impairments) affect the ability of the child to participate in social activities and learn relevant social skills and cultural tools, and thus influence the development of higher mental functions. This means that the primary biological defects reorganise the development of the child as a whole, including social development and the learning of cultural tools, which often results in secondary defects (Vygotsky 1993). The impairments of the child have biological origins, but the disability evolves from the incongruence between the child and his/her social conditions for development. Thus, the incongruence can also be labelled *dis-ontogenesis*: disruption of the individual development.

## Development of Incongruence

As a fundamental concept, developmental incongruence is constructive in its reconciliation of the otherwise entrenched conflict between the medical and the social model of disability. Departing in the cultural-historical framework, the following figure (Fig. 1.1) was constructed to enable incorporation of more recent biomedical and neuropsychological conceptual understanding of the developmental processes between the natural and the cultural line of development. The idea is to enable a more fine-grained conceptual understanding of what Vygotsky coined ‘defects’ within the cultural-historical understanding, in order to allow analyses of learning in relation to knowledge about neural constraints and plasticity. Neural plasticity refers to a fundamental property of the neural system to change, generally in an adaptive way, in response to external demands experienced by the child. The changes are seen in both the structure and the functioning of the brain (Stiles 2000). During normal neural development, an abundance of neurons and connections are lost due to competition for resources. Some cells and connections are lost due to endogenous processes, but a major part of the elimination process in the system happens in response to the child’s activity in cultural and social activity settings, thereby sculpturing the cerebral system. This means that cognitive development and learning are active processes based on interaction between activities at different

levels: activity in neurochemical systems, activity in cell assemblies and connections, and the activity of the child at the social level. It is the active use of particular cognitive functions by the child in thinking and acting which in the end determines which neural potentials that are turned into actual neural pathways. The activity of the child feeds into the neural and cognitive development of the child through learning and plasticity, making participation within activity settings the engine of both learning and neural development:

In the figure (Fig. 1.1), *neural systems and processes* covers the neurobiological complexity of neurons, synapses, neurotransmitters and glia cells that support the neurons and the activation patterns of singular neurons and assemblies of neurons that characterise brain activity. The neurobiological layout of the child is present as biological constraints on neural and cognitive functioning and possibilities for neural plasticity that make out the biological processes structuring neural development (Stiles 2000). The neurobiological processes underlie and support all aspects of child cognition and child behaviour at all times, without the child's awareness. As such, they are an inherent part of the child. *Child cognition* denotes individual processes of perceiving, remembering, paying attention, reading, calculating, etc. Cognitive functions are enabled by functional neural networks sculptured by use (Karmiloff-Smith 1998). Individual children will have different levels of competence in each specific cognitive function, depending on his/her natural endowments *and* previous use and development of cognitive abilities. As depicted in the right side of the figure, *Child activity in settings affording distributed cognition* covers that the single child's cognition hinges not only on neurobiological conditions, but takes place within cultural activity settings in which the individual cognitive processes are supported, transformed, enabled, constrained etc. by shared activity including cultural artefacts and cognitive mediation. In the activity settings, cognition ceases to be an individual capacity and becomes distributed between participants and activities. The child develops higher mental functions through his/her active participation in the different activity settings. The social agency of the child is at one and the same time conditioned by social demands and expectations, while the child also functions as an active shaper of the social environment through his or her activity. Thus, it underlines the basic premise that learning and thinking are subjective activities, guided by personal motives and conditioned by both practice frameworks and by neurobiology.

The dynamic in the left spiral of the figure follows recent research in neural plasticity (Juenger et al. 2007; Stiles 2000; Stiles and et al. 2005) in which the biological base is considered to be changeable in response to the activity of the child. In order to incorporate the dynamic nature of the impairments, the impairments are considered as biological constraints of the child's development. The impairment impacts on the left spiral as biological constraints on the ability of the neural and bodily systems and processes to serve, for example, cognitive or sensory processes and, through the feedback process, the possibilities for further development that are dependent on input from the child's activity and use of body and mind.

Still, the development of cognitive and emotional functions and biological bodily processes is related to the right spiral of the figure. The child's participation in dif-

ferent activities affords and develops particular cognitive abilities and processes, which in turn furthers the development of the neural systems and processes in the left spiral. The relation between the children's cognitive functioning and the child's environment functions with a spiral-like dynamic: the child's cognition is furthered or constrained by his/her activity in the specific settings, while his/her activity at the same time will be enabled or constrained by cognitive and bodily abilities.

The incongruence, which arises when a child with a significant bodily defect has to participate in social practices cultivated for typically developing children (eg, in kindergarten and school), might constrain cognitive *and* neural development through its impact on the possibilities of the child to participate in activities. This approach means that biological impairments gain significance within social activity settings. Disability is a condition for living, in which impairments are neither caused by biology nor by social conditions alone, but arise in the interaction between two developmental spirals: one between neural structures and processes and cognition; and another between cognition and activities that afford different types of child activities. Because cognition figures in both spirals, they merge into one developmental dialectic. The two spirals represent one central developmental dialectical process, similar to Vygotsky's two lines of development: one natural/individual and the other social/cultural, that – in practice – are dialectically intertwined, constantly constraining and enabling each other.

## **Developmental Trajectories**

From the above descriptions of a cultural-historical understanding of disability, disability can be understood as the constantly evolving consequences of a twofold impact of the impairment on the development of the child. First, the direct effect of the impairment(s) on the child's ability to participate in activities, for example the ability to hear conversations or school instructions. Second, the impact of the impairment(s) on the child's participation in the activities where important cultural knowledge and skills are learned, internalised and developed by the participants, for example, participation in verbal conversations where concepts and knowledge are passed on. The dialectic nature of development means that both primary and secondary consequences feed forward into the developmental trajectory of the child, along with environmental support and challenges. Many aspects of impairment and social conditions for participation impact on the emergence and transformation of a disability, requiring specific analyses of developmental processes in the ontological time of the particular child. The incongruence and the difficulties associated with an impairment are never stable, but vary with patterns of interaction and the child's particular social conditions at any given time and within particular cultural frames.

Starting in school is a good example of how the child with impairment may come to follow a developmental trajectory different from his or her peers without impairments, due to both primary and secondary aberrations from his or her more typically developing peers. Most mainstream schools (understood as activities directed by

rules, time structure, furniture, buildings) are arranged to fit children functioning within an average range. Even in early school, children are expected to be able to sit down and pay attention to oral instructions or the reading of stories, for shorter spans of time at least. They are expected to be able to receive a simple instruction and solve simple, concrete exercises – and further follow the behavioural rules set by the schools, and flexibly play and interact with peers on their own. For a child with an impairment influencing, for example, attention or social difficulties, the activity settings in school may not accommodate that child's way of acting, resulting in barriers for the child's participation, learning and further development. On the other hand, the child's social network is an important factor in creating congruence and possibilities for the child to be able to participate in learning and social activities, and to develop social skills.

## **The Zone of Proximal Development**

The concept zone of proximal development (ZPD) (Vygotsky 1978, 1998) is Vygotsky's concept of how mental development takes place through supported activity. The concept stresses that development is a process, where skills at first are carried out or practiced with support (interpersonal – in the social context) before they become part of the child's own competence repertoire (intrapersonal). The concept of proximal development covers both formal and informal learning activities. The engine of development is the child's own activity of imitation of the activity, whether due to formal instruction in a typical learning situation or set in a supporting activity setting. Edwards and Middleton's (1988) analyses of how parents support their children's development of remembering (through mutual activity of looking at family photos) could be an example. By recording conversations between mothers and children oriented around family photos from holidays and other earlier mutual experiences, it became apparent how informal family conversations provide a rich environment for developing skills in remembering, for example, how contextual information can be used to enhance recall of past events. The ZPD concept foregrounds social participation as the engine of development. The role of providers of early learning and education is to organise activities that are within the zones of proximal development of the children in the group – ie focus at tasks and skills in which the child is able to participate with support from others.

The commonalities in both the biological and cultural line of development in typically developing children mean that their zones of proximal development have a lot in common. Activities organised at a group basis will often be able to address the ZPD of most children around the same age. However, for children with disabilities included in a mainstream setting, the group-based activities might not match their ZPD that easily, or in the same way. If the barriers to entering zones of proximal development are not addressed, their quality and quantity of participation in social activities where development is enabled are further restricted, thus creating further incongruence and delay in development.

With the concept ZPD, Vygotsky stresses the child's own activity as central to his/her development. Mere presence in a social setting will not lead to development of the child. The child must be provided with an opportunity to actively participate. This is an important point both in discussions of inclusion, which have to some extent been driven by an idea that 'placement within or proximity to peers without disabilities' would automatically develop the child with disabilities (Gresham 1982). Communication, being discussed in Chap. 8, is one ability where it is important to stress the necessity of active participation of the child to be able to develop actual communicational competence (see for example Pennington (2008)). However, even in cases where the child with disability participates in an adapted mainstream setting or specialised setting, the ZPD is often more difficult to identify. Parents and professional are often bewildered about the particular competences and challenges of children with disabilities. As will be elaborated upon later on, assessment practices are deeply rooted in cultural-historical assumptions about the functioning of our cognitive system, assumptions that are often violated in children with neurobiological impairments. Furthermore, the cultural-historical support of the social and cognitive activities of typically developing children is often difficult for the teacher to discover, because it is part of a tacit background of the practices. Thus, it becomes difficult for the teacher to uncover how to reorganise the activity setting in order to create a better match between the child's development and the social practices, so as to offer the child with disabilities activities within that child's zones of proximal development.

## Social Practices

Social practice is a central concept in cultural-historical theory. Central to the cultural-historical use of the concept is the way the activities and social relations in practices are organised from societal value positions. Thus, while being part of a social group or community is important, it is necessary to further understand how the activity of the community is not only focused on production and reproduction of itself, but is anchored in societal and cultural-historical values of that practice. The role of values in understanding social practices takes on importance in understanding differences between the activities of children with and without disabilities, who apparently participate in the same social practices. Many examples can and will be given throughout this book, including mainstreaming practices of the 1980s and 1990s. These have been criticised for applying different values in regard to children with and without disabilities. While children without disabilities participated in activities aimed at their learning of the curriculum, children with disabilities were met with a second demand of being able to adapt to the mainstream practice, along with the first aim (Avramidis and Norwich 2002).

The developmental dynamic depicted in the model (Fig. 1.1) takes place in different practices at all times. The social practice may be the day-care centre, family, etc. and it is through the child's participation in social practices that the child

develops and learns. Hedegaard (2012) has elaborated the practice concept by stressing how particular practices are made up of different activity settings. While the practice is an institutional organisation based in cultural-historical traditions and expressed through a set of demands and expectations, the activity setting is defined as recurrent events within the institutional practices. The aim of the elaboration is to enable more fine-grained analyses of the child's activity within the institutional setting. Different activity settings within the practice might offer the child different possibilities for participation. Vygotsky highlights that children with impairments have different and limited access to learn and develop within social practices compared to children without disabilities. Still, the incongruences might be more pronounced in some activity settings than others, depending on the particular impairments of the child. For example, a deaf child may very well be able to participate in a motor activity by mimicking the activities of the other children, while story-reading without adaptations offers very limited opportunities for social participation. For the child with moderate or severe motor impairments, the opposite might be the case. Thus looking at a social practice, for example a preschool, at large and considering whether it supports the participation of the child with impairment or not will often be too coarse. Analyses of the different activity settings will be more informative.

## **The Child as Social Agent in His/Her Social Situation of Development**

The social practices and the activity settings provide the conditions for the participation of each person in the setting. At the same time individuals create, recreate and modify the same social practice through their social agency. The concept of *participation* underlines that all behaviour and subjective agency are rooted in concrete cultural-historical practices (Dreier 1999). Psychological development as well as disability therefore needs to be studied through the children's participation in social practices and activity settings.

In current cultural-historical theories about child development, a central focus has been on the child's participation and social agency in the construction of their developmental trajectories in social practices (Dreier 1999, 2008; Rogoff 2003). One major point has been how children and adults participating in the same institutional practices become developmental conditions for each other (Højholt 2012). Possibilities for participation will most often be different for children with disabilities, no matter whether they are included in mainstream institutions or specialised institutions. The focus on participation allows analyses of inclusion/exclusion beyond mere placement in either mainstream or specialised settings.

The concept of participation has also generated an interest in the child's perspective, a *first-person perspective*, stressing that the child's development needs to be understood from the subjective viewpoint of the child (Dreier 2008). Even though

the first-person perspective is unconventional to study in relation to development of typical children, it is even more so in relation to children with disabilities. Most often, the learning and development of children with disabilities is understood from an outside view that represents an abstract and decontextualised perspective, ignoring how learning and development arise from children's motivated, subjective activity, disabled or not.

The first-person perspective underlines cultural-historical theory as a phenomenological grounded approach. Every study of children with disabilities needs to be grounded in the view from the subjective participation in social practices. The concept of *the child's social situation of development* holds the same approach but is a more complex concept than participation. The social situation of development is the system of relations between the child's dominating motives at a particular age and the social conditions for the child's development, arising from cultural-historical values and practices for demands and support of child development (Hedegaard 2012). The way the child chooses to participate arises from his/her social situation of development, rather than from conditions with the activity setting alone. The social situation of development functions analytically as an anchor for analysing individual participation and serves to explain why the participation of different individuals varies. The concept of the child's social situation of development will be used to anchor the incongruence concept in the subjective perspective of the child/infant and parents.

The concept of  *motive*, another central concept in the cultural-historical tradition (Hedegaard 2002, 2012), denotes the child's cultural-historically formed interests and intentions. Motives are related to the goals of children's activities in different practices over an extended period of time (Hedegaard 2002). Cultural values of what constitutes a good life and appropriate development are reflected in institutional practices, and, through the participation of the child in social institutions, the cultural values become conditions for the development of child motives. The leading motives of a child originate from central and important activities in dominant practices. All activities are multi-motivated. Each child develops a motive hierarchy, in which one or more of the mentioned leading motives figures along with other motives (Hedegaard 2002). The specific motives of a particular child are the result of former experiences, development in interests and ideas about what it would like to do in the near future. Motives develop and change as the cognitive and emotional abilities of the child grows, leading the child to new forms of acting and participation in new institutional settings; thereby providing the child with new cognitive and emotional challenges. As such, motives are an integrated part of development. The small child's leading motive may be playing, whereas the leading motive of the young schoolchild may be learning. Again, the child's present motive is formed by both natural development and the cultural-historical forms of the social practice.



## Age Periods and Demands

As already introduced, the activity of a community is not only focused on production and reproduction of itself, but is anchored in societal and cultural-historical values built into the practice. The values of the participants shape their activities and the demands they place on themselves and on each other. *Demands* are value-bound expectations by which the child is confronted in different activity settings. Demands are not confined to one particular setting. Demands from, for example, the school may very well travel home with the child (eg, the requirement to do homework) or demands from home may travel to leisure time (eg, the child still acts according to demands expressed by the parents at home).

A central aspect of the concept is that demands are not only something the child is confronted by, but also respond to. While being confronted by demands and expectations, the child itself places demands on parents and other adults, as well as through them, on the wider institutional setting. The role of demands – provided by parents, teachers and other children, institutional settings and activities and vice versa – is a central point in relation to understanding developmental incongruence. The concept of demands will be elaborated upon throughout this book.

*Age periods* are another central theoretical concept in the cultural-historical understanding of child development. Even though age periods are connected to the chronological age of the child, an age period arises from the child's social situation of development. The dynamic establishment of an age period arises from the relation between the individual characteristics of the child and the social environment (Vygotsky 1998). Again, there is an intertwining between, on one hand, the individual development of the child, and on the other hand, the development in cultural demands and developmental support. The transition from one age period to the next arises not from the passage in chronological age in itself, but from the dialectical dynamic between the interests, motives and competences of the child and the opportunities, demands and support from the child's present cultural practices. The developmental dynamic starts with a misfit between the interests, motives and competences of the child on one side and the opportunities, demands and support within the cultural practice on the other side. For instance, the school sets demands for the child to take part in formal learning activities, but the child's dominating motive is still to play. The passage from one age period to the next thus carries similarity to the developmental incongruence that gives rise to disability. The difference is that typical institutional transitions, from, for example, kindergarten to school, supports the shift from one age period to the next in typical children's development. Children at the end of the toddler period may feel bored in the small-scale setting of the nursery, looking for a wider range of playmates and more interesting play opportunities. What has so far counted as developmental support might now seem as a constraint on the type of activities in which the child would like to partake. Another example is the child in kindergarten who feels a growing interest in school-like activities (learning about letters and numbers). However, the pursuit of this interest is not supported with organisation of relevant learning activities within the activity settings of

the kindergarten (example from Hedegaard (2009)). Age periods are thus connected to institutional organisation and institutional shifts, not by nature, but by the same gradual adaptation that has created the merge of the two developmental lines: the natural and the cultural.

The mismatch between child motive and opportunities within the child's activity setting during typical development is a developmental conflict (Hedegaard 2009) (or by Vygotsky (1998), labelled 'crises'). The solution to developmental conflicts comes about by a new fit between the personal development of the children, and the support and demands from the social setting. For example, when the child moves from nursery to kindergarten, new play opportunities become available for the child to explore. However, the new situation may be too difficult if the child is not ready for the transition due to, for example, developmental delay (from biological as well as social reasons), and the demands of the new institutional setting exceed the child's zone of proximal development. Extra support for the child, or adaptation of the institutional practice, is needed to solve the developmental conflict/crisis and avoid the risk of emergence of a developmental incongruence. The role of developmental delay and developmental crisis is important in understanding differences between the development of children with and without disabilities.

Defined age periods and developmental time take on a central role in the creation of developmental incongruence. Even though it is a subject that will be elaborated upon throughout this book, one example is relevant here to further a basic understanding of the dialectic between age periods and disability. A central developmental theme in psychology during infancy is the establishment and further development of sustained relationship between the infant and his/her parents. The relationship builds on and elaborates a mutual recognition of each other's acts as intentional and contingent, and each partner thus responds appropriately and in a way that can maintain and further develop their interaction into communication (Trevarthen and Aitken 2001). However, many types of impairments affect the development of this early intersubjectivity, even though the child's mental potential for development of social interaction and communication is similar to that of children born without impairments. For example, both visual impairments and motor impairments have been shown to hold a risk of affecting the development of primary intersubjectivity and communication (see Chaps. 3 and 8). The development of primary intersubjectivity has to be developed and supported by different means, compared to that for children without impairment. If not, one consequence is that the development of primary intersubjectivity becomes delayed and maintains its importance as a developmental theme at a later chronological age, where children without impairment have developed into different themes of intersubjectivity and communication in their social situation of development. Developmental delays in infancy emerge and contribute to developmental incongruences later in childhood.

## Affordance

As has been explained, the child's activity takes place within cultural activity settings in which the individual cognitive processes are supported, transformed, enabled, constrained, etc. Perception and social agency are seen as active cognitive processes in which we interact selectively with the array of possibilities afforded to us by the environment. The *affordance* concept was first coined by J. J. Gibson (1979). One of his main aims was to capture the bottom-up processes in perception; how the meaning of objects is directly perceivable from their physical forms in relation to the perceptual-motor functions of the individual animal or human being. The affordance meaning of an object is a relational property that exists neither in the individual perceiver nor in the environment, but arises from the relation between them. Any given environmental feature have multiple affordances. According to Gibson, it is the psychological states of individuals that make them perceive particular affordances and not others.

Affordances are the properties of the person's relation with the environment, including objects and other human beings that offer the individual the potential to interact in a variety of ways. A classic example is the handle on a coffee mug that affords the action of grasping. How affordances are perceived is a function of experience and learning from participation in cultural-historical practices. The affordance concept has been proposed as a concept that can be used to interpret empirical material in terms of both the functionality and intentionality of recorded artefacts and practices (Bang 2009). Artefacts presented in the institutional practices constitute environmental properties, which may help to initiate activities through exploration and appropriation, or limit them as barriers to activities eg, indoor security fences. The affordance concept facilitates studies of the relation between the environment that includes both the historical and societal nature of artefacts and practices and the individual's intentions and perception of possibilities for actions. The cultural nature of the relation with the affordances of the environment is true for all children, but is exceedingly salient in children with moderate and severe disabilities, because they are dependent on specialised support, for example, remediating artefacts, to function. The aim of including the concept in this book is to capture resonances between the child and his/her environment, and how they affect the activities of the child, as an analytic way to include the perspective of young children with disabilities. Affordances also bring in the materiality of both development and learning in that the development of children with disability as intentional social agents hinges on both social and material conditions (eg, aids and environmental assessability in Chap. 8).

## **The Inclusion of Impairments as Central to Understand the Emergence of Disabilities**

The central contribution of the dialectical approach lies in the understanding of the role of biological differences within institutional practices. The social model approach mainly accepts impairments as part of a continuum of biological differences shared by all of us – but ignores the impact of these differences on individual development. Even if impairments are acknowledged, they are considered external to the development of disability. The dialectic approach assigns a more intrinsic role to biological defects in the emergence of disability. Still, the inclusion of impairments in the understanding of how disability emerges and evolves is different from the biomedical understanding. From the cultural-historical vantage point, the shortcoming of the biomedical understanding of disability is exactly that it fails to notice how a child with impairment has to act in social practices first and foremost adapted to children with typical psychophysical constitutions. The dialectical disability approach focuses on the relation between the biological defect/impairment and the disability. The child may have, for example, cognitive difficulties of biological origin, but the learning difficulties of that child need to be understood as developed from the incongruence between the abilities of that child and the way the school and the teaching are organised. From this perspective, disability is defined as the continuously evolving consequences of a twofold impact on the development of the child. First, the impairment often has a direct effect on the child's ability to participate in relevant cultural-historical activities. Because of a motor impairment, the child finds it difficult to participate in many play activities with peers requiring either ability to run and/or to manipulate toys. Secondly, because participation in these activities pass on important cultural knowledge and skills, which are developed by the participants, the consequences of the impairment are likely to escalate. The often-escalating impact of an impairment on a child's development is an important aspect of the cultural-historical model of disability. The child with motor impairments may come to lack knowledge and skills about important play themes and social rules due to more time alone or with adults, and less with peers. Both the primary and secondary consequences feed forward into the developmental trajectory of the child, along with environmental support and challenges. Many aspects of an impairment and social conditions for participation impact on the emergence and transformation of disability throughout childhood, requiring specific analyses of the dialectic processes. This book will be dedicated to this kind of analysis. The aim is twofold: both to understand how disabilities arise, but – just as important – how to amend the consequences of impairments.

## Chapter 2

# Unfolding Time in the Cultural-Historical Model of Disability

Chapter 1 discussed the shortcomings of the biomedical and the social model and introduced a cultural-historical dialectical model of disability. The model has been outset in Vygotsky's work on defectology and his statement that disability develops from an incongruence between the natural and cultural line of development. In this chapter, we will unfold the perspective and explain how the cultural line of development is constituted by both micro-level processes and societal and historical processes at a macro-level over time. Following Vygotsky's idea that social and cultural processes regulate the child's acquisition of higher mental functions in individual ontological time, we will analyse how the concepts *developmental time* and *developmental time windows* at an individual level are related to cultural and historical time changes.

### An Introduction to Developmental Time

In most mainstream theories in developmental psychology, time is first and foremost understood as the chronological time of a child, ie, the child's age measured in years and months. In the cultural-historical approach, interwoven levels of history and cultural development are included to understand development at an individual level.

In her text, "Vygotsky's uses of history" (Scribner 1997), Scribner unravels four scales of time and development in Vygotsky's developmental theory. First is phylogenesis, the development of species, including the human species. Cultural-historical theory rests on the central assumption that phylogenesis, as an evolutionary macro level of biological evolution, has been displaced by historical-cultural development during the emergence and development of human culture (Scribner 1997; Vygotsky and Luria 1994). Thus, phylogenesis takes us to a second scale: the historical development of societies (sociogenesis) expressed in development of

institutional practices, technological progress and changes of social structures that transform society over time and create new conditions and challenges for the human beings participating in them.

The third scale of time in Vygotsky's work, according to Scribner, is the micro-level of the mutual development of the natural and the cultural line of development described in the previous chapter. This individual-near scale of developmental time is dialectically related to development at the societal scale through the concept of *value positions* and the idea that the *signs and tools* of development of higher mental functions are anchored in concrete practices in cultural-historical time. A third concept connecting time at historical macro-level with ontogenetic micro-level processes is *demands*. During the child's chronological development, the child similarly moves from a biological to a social way of development. This process starts early on, as the child's activity within the environment is supported and mediated by parents and other caregivers. The movement towards a social way of development enables a 'freedom of action' for humans including children and families with disabilities. This freedom of action is grounded in each individual's development of higher mental functions, thus marking an intrinsic relation between the historical development of signs and tools, and an individual developmental of higher mental functions and ability to understand and use signs and tools. Despite the similarity in the description of sociogenesis and ontogenesis, ontogenesis does not recapitulate either phylo- or sociogenesis. The development of a child will always be grounded in his/her present sociocultural environment (Scribner 1997). Understanding of the child's psychological development needs to be informed by knowledge of conditions in the present culture.

The fourth scale of developmental time lies in understanding the development of particular developmental systems. Vygotsky himself describes the genesis of numerous psychological functions such as counting, general perception, memory, language and use of concepts just to mention a few (Vygotsky 1994; Vygotsky and Luria 1994). The analysis of psychological development of young children with disabilities and developmental changes needs to be informed by the larger sociogenetic background and, at the same time, be expounded from a participant perspective in concrete activity settings of the individual (Hedegaard 2012). As described in the previous chapter, the natural and cultural lines of development meet in the development of the individual person and constitute the ontogenesis. Even though sociogenesis has superimposed phylogenesis at the macro level perspective, biological development is still apparent at the ontogenetic micro level as individual developmental potentials.

For the purpose of understanding and describing development of young children with disabilities, two scales of developmental time therefore become especially interesting in the following: The first scale of developmental time is Scribner's second scale of individual societies' history and the development of individual psychological processes from the interrelation and variations in incongruence between the natural and the cultural line of development. The other one is Scribner's third scale, the micro-level of developmental time. An elaboration of the natural line of development is relevant based on recent neuropsychological theory. Some areas of

neuropsychology are of particular relevance for a cultural-historical perspective, one being the neuroconstructivist approach (Karmiloff-Smith 1998; Segalowitz and Hiscock 2002). In this approach, cortical development is understood as arising from dialectical processes between a biological system with sets of biological constraints and a structuring outer environment, that together sculpt individual neural development through the activity of the developing person (Karmiloff-Smith 1998). The development of particular psychological functions – for instance, visual-perceptual analysis and theory of mind – will be in focus to analyse how organisations of activity settings create particular conditions for individual participation and cognitive development that enables or constrains the social agency of children with different types of disability.

Scribner's second time scale will be investigated in relation to how incongruence at the practice level is embedded in larger cultural-historical movements in policies for disability understanding and disability support. This embeddedness takes place in every single practice in which the person participates. Furthermore, children and adults in institutional practice settings become developmental conditions for each other (Højholt 2012) and thus other children and adults become part of the developmental possibilities of the child. Time at the different levels begins to cross over and open and close developmental possibilities for young children with disabilities; thus, we need to become aware of the consequences of developmental time windows as they open and close on different ontological scales: biological, individual, social and cultural-historical. The concept of developmental time windows will be further elaborated upon as we unfold the analyses. Time and how the child's development builds on his/her social situation of development becomes further challenged by the interrelation of time at different levels and by asynchrony with typical cultural-historical timelines when the child has a disability. Furthermore, the concepts *delay* and *speed* become useful to describe the often not straightforward development of children with disabilities and will be introduced in this chapter.

## **Micro-Level Ontogenesis – Neurobiological Developmental Time**

The need for an all-encompassing understanding of developmental time for children with disabilities once again begins with the incongruence between the child's biological development and the cultural forms of demands and support necessary for the child's development of higher mental functions. Approached from the neuropsychological theoretical vantage point, the individual natural line of development consists of the child's employment of his or her own biological potentials through activity. Biological potentials cover different types of developmental mechanisms. In early childhood, neurobiological-sensitive periods arise as biological developmental windows during which a particular ability, for example visual development, needs to develop. During a relatively short period of time, a particular stimulation

must take place; if not, the neurobiological opportunity will be lost or partly lost and the individual will come to lack the full function of an essential cognitive capacity, or the cognitive capacity will be developed in an aberrant way.

Greenough et al. (1987) term this type of biological development ‘experience-expectant’ information storage. *Experience-expectant storage* is mainly a mechanism for primary sensory development, in which general analysis of sensory information is fine-tuned by non-individual-specific information. The mechanism is important in understanding early development of vision and hearing, where experience of general environmental qualities such as angles, contrast, colour and movement in basic vision, vocal pitch and other sound input in auditory perception are central. For a relatively short period, an abundance of synapses are available in the primary sensory areas as a genetically based biological opportunity situation. The synapses that are used remain, while the rest disappear again, thereby fine-tuning the system and enabling effective information processing that serves both basic and higher mental functions.

In Greenough’s description of the experience-expectant processes, they are described as general and independent of particular cultural and historical settings. Visual angles, contrast, colour, pitch and sound volume are present in all societies and in all cultures, although cultural differences exist in colour categories and which phonetic sound discriminations are important in different languages. However, these differences are not important for the foundation of a basic primary perceptual system. Then again, if a child is born with a sensory impairment, or acquires one very early on, even this very basic biological developmental process reveals itself as constituted by Vygotsky’s two lines of development. Processes at an individual, biological level become dependent on processes in the cultural line of development at the social and cultural-historical level. Knowledge of, and supportive practices surrounding, the biological developmental time windows in basic perceptual processes are crucial when supporting children with congenital visual or hearing impairment. In children with low vision or cortical visual impairment, early detection of problems and specialised visual stimulation will have profound importance for the children’s future possibilities of developing a useful visual function (Dutton et al. 1996). Similarly, for children with congenital hearing impairment, early (few months after birth) treatment with hearing aids and later cochlear implantation (around 1 year) followed by intensive training in listening is crucial for later language, social and cognitive development opportunities (Knoors and Marschark 2014). Processes at different levels, biological, individual, social and cultural-historical, are interdependent and shape development together over time. Changes at the societal level alter how the incongruence between the child’s individual development and the cultural-historical practices are formed at the practice level. Economic growth, recession or technological development may dramatically impact on the life course of children with disabilities.

A study by Dammeyer (2010b) involving four families with five children with congenital deafness provides an example of how cultural- and societal-level processes in technology and economics impacted on practice-level processes, not only changing the present incongruence, but creating different life courses for siblings



with similar impairments. Dammeyer's study took place in Denmark between 2005 and 2008, during the introduction of paediatric cochlear implant technology. The five children with congenital deafness were between 3 and 13 years of age and were followed for 3 years. The two oldest children received cochlear implantations at a time when they had learned to use sign language as their main mode of communication. Both were starting to be assimilated into the deaf community, going to deaf/sign language kindergartens and schools. Despite these two children gaining the ability to hear via the cochlear implants and being trained in oral language, they continued to use sign language as their main mode of communication.

The social situation of development for the three youngest children was different in several crucial ways. They were both infants when they had the implants and thus their main mode of communication became oral language. They did not join the deaf community. Both social situations gave rise to developmental incongruence, but of very different kind. The two older children faced challenges concerned with being a minority, learning and using sign language in a society where oral language is the norm. When starting school, they were enrolled in special schools for deaf and hard-of-hearing children. The younger children were met with the demands of learning oral speech and challenges associated with inclusion in mainstream schools. Following the local regular school programmes, they enjoyed a school life and relationships with friends with typical hearing – despite moderate difficulties with hearing, both in regard to teaching activities in the classroom and in peer-relations. Thus, the timing of the technological development in cochlear implants and the political decision to offer this type of advanced and expensive treatment to children with congenital deafness created different developmental trajectories for the children. Their similar congenital hearing impairment evolved different incongruences and two qualitatively different kinds of disabilities. The primary biology-driven challenges gave rise to developmental incongruence that impacted on the whole of the child's development. The process of development did not rest on biological potentials and biological maturation alone, but arose from the intersection between biological, psychological, social and cultural changes over time. Changes in societal values and recommendation of particular practice for treatment of congenital deafness changed how the incongruence between the child's individual development and the cultural-historical practices for supporting the child were formed. In the example, economic growth and technological development had a huge impact on the life course of children with congenital deafness. Similar dialectical developmental processes between individual developmental possibilities and changes in attitudes and practices associated with developmental support have been found in research with children with, for example, motor disabilities and intellectual disabilities, as we will return to in later chapters.

The attention to how historical changes contribute to developmental possibilities at an individual level owes a lot to the seminal work by Glen Elder (1999). In his study from 1974 (Elder 1999), Elder explores how historical events, for example the great depression in the 1930s, changed societal possibilities and through this impacted on the life course of different generations. Analogous to how the presence of different amounts of neurons and synapses during individual biological time are

open for the individual to put to use or not, social time involves the presence of different amounts of possibilities for participation, made up of institutional practices. Values about appropriate developmental skills are built-in in activity settings, along with cultural age-standards, as windows of social development. The opening of a social developmental window means that development towards a particular skill is supported. Thus a child's trajectory through institutional practices is also a trajectory through different social developmental windows, some of which may disappear or change radically as the child gets older.

Social developmental time windows become important in relation to the individual time scale and neurobiological opportunities, because most of our learning and development is based on another type of information storage than the one that characterises the basic primary perceptual systems. This second storage system has been coined 'experience-dependent' (Greenough et al. 1987) and depends on the active formation of new neurons in response to incoming information from activity that is distinctive to the individual. Thus, this process refers to the active shaping by the individual of their own neural system through goal-directed activity within particular cultural-historical and social activity settings. From this approach, most of the information storage utilises biological opportunity situations that build on previous neurobiological development, and which arise and evolve in accordance with the activity of the child in his/her environment. The active sculpting of the neurobiological system builds on the individual's experiences, which take place and evolve in social situations. In the example of children with hearing impairment, learning to listen utilises the child's participation in learning situations in the local oral language. Language learning is a complex process involving higher-order functions and social situations where language is used by participants to play, share their points of view, work together, etc. The activity and choices of stimuli are choices available within and shaped by a cultural-historical and social environment, even though they are perceived and stored by the person in specific activity settings.

The concept of sensitive periods of development and experience-dependent development becomes relevant in relation to the developmental incongruence of children with disabilities in two ways. Firstly, both types of information storage highlight that developmental potential unfolds in specific time windows. Developmental potential is brought to fruition from the interaction between biological possibilities and experience within an environment specific to the particular person through the activity of the child (the developmental spirals of Fig. 1.1 in Chap. 1). Secondly, but just as important, the 'environment' (as often called in the neuropsychological literature) is made up of the cultural line of development and thus constituted by institutional practices. The institutional practices are constituted by more than just the immediate environment of the child. Bronfenbrenner (1979) has been a central person in elaborating how proximal processes between an individual and the near environment are nested in other environmental contexts, some of which the person was directly involved in and some of which the person did not participate in, but nevertheless had an impact on the processes taking place around the developing person (Bronfenbrenner and Morris 1998). Focusing here on his concept of context, he proposed the developmental context to be conceptualised as a structured

societal system: first, a micro-system comprised of all the contexts where the developing child participates; and second, a mesosystem connecting the micro-systems of the child at a particular moment in time. Furthermore, the mesosystem is conceptualised as placed within a macro-system understood as overarching patterns of culture, economics, politics and legal systems, which impacts on the processes within the micro- and mesosystems. Bronfenbrenner's system of nested contexts has been criticised for placing too much weight on how the person's activity is the outcome of systems, at the expense of understanding the person's activities as processes (Hedegaard 2009). In our approach to child development, we adopt this critique in order to be able to elaborate upon the dialectical processes between the natural and the cultural line of development. The concepts offered by Vygotsky's cultural-historical defectology enable closer analyses of how the natural and the cultural line of development unfolds in activity processes and through the internalisation of concrete artefacts and symbolic signs that develop the child's way of thinking. Bronfenbrenner's concepts of person and context as two distinctive systems that meet and interact in proximal processes grasp the person-situation dynamic, but not the dialectical processes of same. In particular, the use of Vygotsky's concept of incongruence enables analyses of how the mismatch between the child and the cultural forms of developmental support affects the child's social situation of development in the present *and over time*.

Bronfenbrenner's structured and nested system of incorporated nearer and more distant contexts hold many similarities to cultural-historical analyses of how cultural and societal cultural values and institutional practices becomes important at the practice level for the child's learning of higher mental functions; and the further development of the child's social situation of development, including expansions or contractions of the mismatch between the child and developmentally supportive activities within practices. The cultural line of development can be further described as a social trajectory constituted by the several contexts the child moves through in chronological time (infancy, preschool age, early school age) and in their everyday life (for instance, home, bus, school, bus, leisure-time setting, bus, home). The organisation of the activity settings is enabled and constrained by values, policies and economic conditions at societal and global levels. Furthermore, it is bound in historic time, as will become apparent in the next section.

## **Elaborating the Dialectic Between Cultural-Historical Conditions of Disability and Developmental Opportunities of Young Children with Disabilities**

Current practices of supporting children's development – both typical children and children with disabilities – are developed through history. Previous cultural and historical practices have shaped current developmental conditions and demands for children with disabilities, the cultural and societal attitudes towards them and the way their development is thought about and supported. Thus, in a cultural-historical

psychological view, historical analyses of disability and developmental situations of children with disabilities through time become essential in order to understand the wider frames of current developmental conditions for children with disabilities. In addition, the attention to how historical values shaped past practice settings and created particular developmental conditions for the children participating in them will help us to highlight how present-day practices are rooted in particular cultural and societal values as well.

The following historical overview (based on the review of Thorleifsdottir (2013)) will present analytic reflections on the dialectical relations between historical values, attitudes and developmental conditions. Different early childhood practices for children with disabilities have created very different developmental conditions for children with disabilities through time. The aim of the following historical presentation is not to write a thorough historical analysis of disability, but to further elaborate upon the cultural-historical dialectical nature of the psychological developmental understanding of disability. Understanding the history of culture and society for children with disabilities is also to understand the practices alongside which children of today develop. Many of the treatments and remedies of times past may seem obscene or inhumane today. However, at the time they were planned and implemented, they made sense in relation to the contemporary societal attitudes and associated value positions about the aetiology and developmental possibilities of children with disabilities. The treatments and attitudes had an impact on the lives of children with impairments, creating and barring possibilities within biological and social developmental time. As we will show, a fit between child and practice does not reveal the true nature of the child's impairment or developmental possibilities, but rather needs to be related to societal and cultural values about that child, his/her impairments and the related aims of the practice setting.

## **Value Positions, Practices and Developmental Opportunities I: Euthanasia and Eugenics**

The history of disability is as old as the history of humankind and society. One of the first written references is in an Egyptian document from 1552 B.C. called the 'Therapeutic Papyrus of Thebes', where people with mental and physical disabilities were characterised as having brain damage (Scheerenberger 1983). Researchers agree that the ancient Egyptians showed some respect to people with physical disabilities, in particular to people with dwarfism and deafness (Ladd 2003). Deafness and sign language may have had high status and respect in some of these societies.

In contrast, the general attitude in ancient Greece toward people with disabilities was detrimental. The ancient Greeks associated human value with physical strength and the ability to reason, and their societal values contained little or no respect for

people with disabilities (Ladd 2003; Scheerenberger 1983). Plato (427–347 A.D.) recommended eugenics for the ‘flock to be maintained in first rate condition’ and he supported the killings of ‘unworthy infants’. In his *Politics*, Aristotle (384–322 B.C.) called for a law that no deformed child should live (Harris 2006; Scheerenberger 1983).

In ancient Rome, a negative attitude probably persisted. Deformed infants were often killed and those allowed to live were in some cases mutilated further to increase their value as beggars. The majority of people with disabilities seem to have been marginalised and excluded from societal activities (Harris 2006). In ancient Roman society, deformed people were often displayed for popular amusement, for example, slaves with intellectual disabilities, who were used for entertainment (Harris 2006; Trentin 2011). Despite this, early Roman law did protect property rights of people with disabilities and some were provided with guardians to help with their affairs (Harris 2006).

The contrast between ancient Egypt and ancient Greece and Rome provides an opening illustration of the impact of societal values on life conditions and developmental possibilities of children with disabilities. Attitudes to children with disabilities can change rapidly over time – and through history it has at times meant the difference between life and death. From the late nineteenth century to the Second World War, the fear of human degeneration and theories of race and social hygiene inspired from Darwinism increased the ideas of eugenics: the science and methods of improving hereditary qualities and thus contributing to a better society by breeding better people. These ideas lead to a large number of people with disabilities being forced into sterilisation and segregation in Europe and the United States. In 1923, Denmark passed eugenic legislation restricting marriages, and practiced placement of deviant people in homes on isolated islands. The aim was twofold: to protect society from degeneration; and to teach people with disabilities the moral and practical skills to be able to take care of a working life in society (Kirkebæk 1993). The eugenic thoughts came to their climax and end during the Nazi regime in Germany. The campaign was built on accepted scientific theories on eugenics and Social Darwinism of that time, and an ideology of a better society for all, reducing the financial burden for the society, having a healthier population and compassionately putting people with disability out of their misery (LaMonica 1998).

Today the standard practice in many countries of prenatal screening of early signs of Down syndrome and abortion of fetuses with disabilities may be seen as a replacement for earlier practices of eugenics and euthanasia on children with disabilities. Thus, societal values about what kind of children and children’s lives are worth supporting and which ones constitute ‘low quality of life’ are mirrored in medical practices that might actually end the life of a child with disabilities before it is born.

## **Value Positions, Practices and Developmental Opportunities II: Institutionalised Upbringing**

During the nineteenth century, two major ideas came to shape the lives and developmental conditions for children with disabilities and contributed to setting their developmental trajectories apart from the developmental trajectories of children without disabilities: categorisation and institutionalisation. Institutionalisation as a value and a practice has roots in earlier historic time. During the middle ages, Christian charities and the church established hospitals, hospices and orphanages (Biasini et al. 1999; Harris 2006; Scheerenberger 1983). In late Middle Ages and Renaissance, individuality, education and secularity came into focus. As the authority of the Church decreased, the Church's institutions for people with disabilities were either closed or were taken over by the state (Scheerenberger 1983). At the same time, the cities grew and alongside them grew problems with poverty. So called 'poor laws' which also included people with disabilities were adopted in several European countries, for example, England, where Queen Elizabeth I supported a number of relatively humane Poor Laws between 1563 and 1601. One of the most important laws required the state to care for the poor and ensured that alms-houses, poorhouses and workhouses for poor people were financed by taxes. The poor laws and poorhouses had both the aim of supporting people in need and to move them away from the streets and the public. Despite the humanity of the laws, the conditions in the poor- and alms-houses were often inadequate (Scheerenberger 1983).

As states become more organised during the nineteenth century, the first institutions for specific groups of children with disabilities, for example, 'Royal Deaf and Blind Institutes', were established around Europe early in the century (Knoors and Marschark 2014) and similar institutions for 'idiots' and epileptic children were later established (Kirkebæk 1993). The aim was still double: to put this group of people to work, train them morally and to control and protect society from them (Kirkebæk 1993). During the century, institutions grew in size and numbers as governments began to take on increased responsibility for people with disabilities as well as other 'deviants'.

The era after the Second World War marks a time in which hospitalisation and institutionalisation of children and adults with disabilities were replaced by daycare centres and small-scale residential homes. The 1948 United Nations Universal Declaration of Human Rights contributed to an increased focus on rights for people with disabilities. These new ideas were followed by critique in public media and in research of the conditions, institutionalisation, and treatment of people with disabilities. The approach in psychology also changed from a dominantly clinical focus to be more oriented towards humanistic, social and educational psychology issues. Medical and clinical research was supplemented with sociological and humanistic approaches. Normalisation became the key word for services and highlighted that their aim should be to provide school and life experiences for children with disabilities that were as close to normal living circumstances as possible (Owen

et al. 2009). The former dominant medical treatment practices of children with disabilities was partly replaced with practices with wider pedagogical and humanistic aims of supporting the development and quality of life of children with disabilities.

The history of disability thus reveals that placement of children with disability in institutions has been a widespread practice through time. Despite the huge body of research that has pointed to the detrimental effect of institutionalisation, the practice still exists in many parts of the world (Mulheir 2012; UNICEF 2013). An evaluation from 2005 estimated that in Central and Eastern Europe, 217,000 children with disabilities lived in institutions (UNICEF 2005). Children with disabilities growing up in institutions provides us with a specific example of how value positions about children with disabilities at the societal level has impacted on practice-level developmental processes in the dialectic between the natural and the cultural line of development. Thus this value position of containment and provision of basic vocational training has become expressed and developed as a specific social situation of development. An important factor in understanding the psychological development of children with intellectual disabilities as the consequence of institutionalisation, rather than the intellectual disability per se, was suggested by Zigler in the 1970s. Following a series of experiments, he was able to argue that children with intellectual disabilities and early experiences of institutionalisation showed more attention towards and dependence on adults, compared to children with intellectual disabilities who had not been placed in institutions (Zigler and Balla 1977). It was also shown that children placed in institutions developed more stereotyped and self-stimulating behaviour and less socially oriented behaviour (Kaufman 1967).

Later studies of mental growth in children with Down's syndrome pointed to advantages for children reared at home or placed in educationally oriented institutions compared to institutions without an educational orientation (Meindl et al. 1983). Shifting to the neurobiological level, studies from the 1960s were among the first to substantiate that an enriched and stimulating environment has positive consequences for brain development (in animal models) (Rosenzweig and Bennett 1996), a result that has been backed up since with several studies finding developmental differences in the neurobiological system between animals reared under conditions with impoverished sensory and activity stimulation and animals reared under conditions providing them with opportunities for social relations, exercise and novelty (Lewis 2004).

Further studies of neurobiological and cognitive development of children reared under deprived conditions in orphanages in Romania confirmed that early deprivation of basic needs (biological, sensory, cognitive, emotional and social) affects the development of particular brain structures and patterns of brain activation (Bauer et al. 2009). Thus, examples from research in institutionalisation of children both with and without disabilities substantiate that this particular social situation of development has, at times, created or increased the existing intellectual impairment. However, to understand the impact of institutionalisation on development, the institutional setting needs to be further specified, from a general characterisation to particular activity settings in relation to the type of activities, the group of children and

adults, the aim of the institutional placement, etc., all of which are parts of the child's social situation of development.

As became apparent in the historical account, the aim of the placement of children with disabilities in institutions was often threefold: to provide the best special education, to remove them from society and to provide orphanages for children whose parents could not or would not take care of them. One negative effect of institutionalisation is lack of social-emotional relationship with caregivers, which has been shown to have negative effects on the overall development of the child; for example, in arrested physical and psychological development (Crockenberg et al. 2008). The effect of changing the aim and the organisation of the activity setting towards better social-emotional relationships through education of the staff was explored in the "St. Petersburg study" (Crockenberg et al. 2008). In the post-Soviet Russian Federation, placement in orphanages was still a common practice for children without parents or whose parents were unable or unwilling to take care of them. Three orphanages participated in the study. The children placed in the orphanages were aged from newborns to 4 years of age. Around a fifth of the children in the orphanages had an obvious disability. In the study design, two orphanages were used as experimental groups and one as the control. In the first two orphanages, the staff received education in early childhood development and mental health needs from an attachment perspective, thus aimed at changing the dominating motive of the staff from basic physical caregiving to support of the children's social and emotional development. In addition to the training in attachment-supporting activity, structural changes were introduced. In order to accommodate a change towards more socially and emotionally close relationships between the children and the staff caregivers, children were assigned to smaller groups with more consistent caregivers and work schedules were reorganised to ensure more continuity for the children. For example, earlier on the practice was to move the children between different wards and caregivers as they got older. The intervention terminated this practice and supported more long-term relationships between children and caregivers. At the third orphanage, being the control, only the training part was carried out. The study ran for 5 years, and results showed substantial improvement in the development of children both with and without disabilities, most pronounced in the first two orphanages receiving both education and practice reorganisation, but also in the control orphanage in which only training was carried out. The St. Petersburg study shows the dialectic dynamic between societal values and aims, practices at an institutional level and the developmental conditions and developmental outcome for children placed in institutions. The change in values and institutional practices created a change in the developmental opportunities of the children towards building and sustaining social-emotional relations, an important part of early child development. It is not institutionalisation alone but how it is practiced that becomes important. The St. Petersburg study and the other studies referred to above also show that the developmental dynamic is similar in children with and without disabilities as they included children both without and with impairments.

However, negative attitudes towards children with disabilities still exist and a higher degree of institutionalisation and a lower level of expectation and/or support of their development is one of the consequences (UNICEF 2013). Better organisa-



tion of the institutional practice in institutions for children with disabilities still needs to be in focus, both because of cultural and societal devaluation of children with disabilities but also due to lack of knowledge about the developmental pathways and potentials these children have despite their impairments (Groark et al. 2013). In present-day institutions in low-resource countries, the professional staff often lacks knowledge about how to support the development of children with disabilities and basic equipment for taking care of special needs of, for example, children with physical impairments (Groark et al. 2013). A recent study (Groark et al. 2013) duplicating the St. Petersburg design in two Central American institutions for children with severe and multiple disabilities highlighted why it might be more challenging to change practices in institutions for children with disabilities compared to institutions for children with typical development. First of all, supporting development of children with severe and multiple disabilities often calls for more specialised knowledge. Secondly, a wide range of developmentally supportive practices is organised around specialised equipment and training in how to use it. Neither the equipment nor educated staff might be within reach in many low-resource countries. Still, the study was able to show effects of interventions aimed at emphasising social-emotional relationships similar to the St. Petersburg study, supplemented with elementary techniques for how to support the children physically.

The development of specialised technical and educational support in some types of impairments, being crucial for overcoming the risk of developmental incongruences, makes the debate about institutionalisation complicated. It has, for example, been argued that children with congenital deafblindness and deafness have very specialised needs for tactile and visual communication, respectively, and may benefit from placement in institutions with professional staff educated to provide the child with these means for communicational development (for deaf children see Knoors and Marschark (2014)). The argument is that the congenitally deaf child will develop from placement at boarding school where sign language is used, instead of living with his/her parents and joining a mainstream school where no one is able to communicate with the child in his/her first language. Empirical research evaluating the developmental outcome for deaf children in specialised deaf schools/institutions versus mainstream shows a mixed picture of local placement. A number of micro-level developmental issues (eg, early communicative experiences and additional disabilities) and more specific educational factors (eg, teacher qualifications, relations and teaching methods) seem to be more important than general placement (Knoors and Marschark 2014).

### **Value Positions, Practices and Developmental Opportunities III: Intensive Treatment Programmes**

Another influential idea arising in the nineteenth century was the concept of categorisation (Kirkebæk 1993). The practice of categorisation evolved from medical research with the aim of treatment. Precise categorisation was in focus in medical research because it was considered a prerequisite for treatment practices to function.

Categorisation did go hand in hand with the increasing focus at providing better education, health, and social care in the upcoming welfare states (Kirkebæk 1993). Since then, an increasing amount of technical and biomedical research knowledge has enabled still more fine-grained diagnosis and specialised treatment methods and technologies. Today it is possible to diagnose and treat (both technically and medically) many impairments to a degree that was not possible just a few years ago. Public administration in many western countries calls for more evidence-supported methods and best practices, including the ability to better manage increasing financial costs in the welfare systems.

A similar movement towards categorisation has taken place within the educational system and educational psychology. During the beginning of the last century, the upcoming educational and developmental psychology had the central aim of categorising children in order to identify those in need of special support in school (Goodey 2011) and children considered trainable rather than fit for conventional mainstream education. The practice of assessing general intellectual disabilities began when the French government requested a method for assessing schoolchildren in order to identify those who would need special support (Goodey 2011). In 1895, Alfred Binet published the first standardised intelligence test based on years of experience of working in the French school system. IQ quickly became the primary criterion for diagnosing intellectual disability (Detterman et al. 2000) and was widely used to identify intellectual impairments in a variety of groups, for example, prisoners, immigrants and prostitutes (Carlson 2010).

Educational psychology and psychological testing was solely dominated by an individualistic approach, aimed at the identification of individual special educational needs. Thus, categorisation was connected to societal management of resources. Although the original aim of testing was to identify those in need of specialised teaching, the practice of categorising has been criticised for attributing the source of learning problems to the individual alone and ignoring contributing factors of a cultural and social nature (Skrtic 1999). Special educational needs are an important theme in the development of young children with disabilities and will be elaborated upon in later chapters (Chaps. 5 and 7 in particular).

As mentioned, categorisation is not only a means for administration, but also for developing and choosing appropriate treatment. From the 1980s, several programmes for intensive treatment of general or specific impairments have become available. Often, the intensive treatment and training programmes are based in medical categorisation and diagnosis and the idea of curing disabilities. Many of the programmes are based in particular centres that offer instruction and supervision for parents and professionals involved in the implementation of the programmes in the child's community, either at home or in professional settings. Professional settings cover both specialised centres and more community-based settings, such as daycare institutions. Most of the programmes are highly intensive. The child or the family might be involved in one-to-one training for between 20 and 40 h per week, for a period lasting at least 1 year. From a developmental perspective, this means that many of the child's waking hours are taken up by training. In addition, many or

most of the activity settings within the family will be organised as training sessions for the duration of the program.

One such programme is the Applied Behavior Analysis (ABA) (Matson et al. 2012), which is an early and intensive behavioural intervention aimed at children with autism spectrum disorders. The programme is aimed at improving language, adaptive skills and decreasing maladaptive behaviours and autism symptoms. The Doman methods are used in rehabilitation programmes at the Institutes for the Achievement of Human Potential (IAHP) and the Family Hope Center (FHC) is an example of another system for intensive training, aimed at children with a wider range of impairments: cerebral palsy, epilepsy, spina bifida, sensory deficits, intellectual disability and autism spectrum disorders (von Tetzner et al. 2013).

At the societal level, the emergence of these programmes reflects current biomedical and neuropsychiatric ideas about the aetiology of autism spectrum disorders and other types of impairment and subsequent theories about neural and developmental plasticity of children. Research about neural plasticity and the neurobiological benefit of an enriched environment on brain development (eg, Lewis 2004) also fosters the development and dissemination of intensive training programmes. To some extent, this scientific background is mirrored in the recommended timing and intensity of the training. Follow-up studies of the efficacy of particular training programmes have generated mixed results in the scientific literature. Support for some positive effect of the ABA method has been found (Dawson and Burner 2011), but is not strong; more controlled studies and knowledge about the long-term effects are needed (Dawson and Burner 2011; Sham and Smith 2014). The Doman methods have received further criticism and studies have shown no overall positive effects (von Tetzner et al. 2013). The dissemination of intensive training programmes can also be seen as an outcome of current societal values placed on the agency of the parent for their child. Parents often express satisfaction in relation to the intensive training programmes despite small or modest improvements in their child's functioning, and part of this satisfaction has been attributed to the active involvement of the parents in their child's development (von Tetzner et al. 2013). A last point about the role of societal-level cultural movements is that policy changes in for example Denmark (Ministry of Social Affairs 2012) have created the opportunity for families to receive financial support to carry out an intensive training program, thus representing societal support for these highly intensive training methods.

At the practice level, and from the individual child and family's perspective level, the intensive training methods have a high impact on the way the child's life is organised. Due to the many hours required by the training sessions, the child's activity settings will diverge substantially from the typical developmental conditions of children within the same cultural setting. Of course, it can be argued that the developmental trajectory of the child would have diverged anyway due to the disability of the child. From the biomedical perspective, the aim of the intensive treatment programmes is to move the child's developmental trajectory closer to a normal developmental trajectory through the intensive training of particular impaired functions. In other terms: to cure the child. However, effect studies point to small or

medium improvements of early, intensive training of children with autism spectrum disorders in IQ scores, language scores and scores of questionnaire-based adaptive measures (see for example Dawson and Burner (2011)). The actual effectiveness in real-life settings and the impact on the developmental trajectory of the child is more difficult to substantiate. Many of the children having gone through training programmes still required specialised service afterwards (Fennell et al. 2011; Peters-Scheffer et al. 2011). From the dialectic perspective, the question would be whether these programmes address the disability proper. When the disability is seen as arising from cultural deprivation due to the mismatch between the child and cultural forms, rather than from the impairment alone, the benefit of an intensive treatment programme becomes a question of whether it excludes the child from important sociocultural activities, compared to how the child would have fared if not enrolled in the program. Other participants in the activity settings of the child and the family, for example peers, carry on with their lives, participating in cultural-historical social practices. While seeking to exploit biological developmental possibilities of neural and early behavioural plasticity, the children and their families might lose out on opportunities for social development. On the other hand, proponents of intensive treatment programmes would argue that the training of, for example, specific social skills would increase social participation possibilities of the child in the future. The purpose here is not to favour or disapprove of intensive treatment programmes; rather the aim is to highlight how the cultural-historical background has a profound impact on the developmental trajectory of particular children at the micro level, both in terms of biological and social developmental opportunities. From the cultural and social macro-level perspective, values and decisions about disability and recommended treatment practices will impact on the child's life, affecting his/her activity and choices of stimuli and through this affecting his/her neural architecture and behavioural repertoire.

## **Value Positions, Practices and Developmental Opportunities IV: Normalisation and Inclusion**

Societal conditions changed after the Second World War. An improved global economy and social reforms in the middle of the twentieth century extended societal commitment to support children with disabilities. From the 1950s and throughout the following decades, attitudes to people with disability began to change – human rights for people with disability were taking the scene and disability rights movements took place in the Western world. As already mentioned, the 1948 United Nations Universal Declaration of Human Rights led to an increased focus on a rights discourse for people with disabilities, accompanied by public and scientific critique of the general conditions of people with disabilities. In addition, parents' organisations/movements rose all over the Western world and many of them became influential in creating change. The key terms became normalisation, equality, equal

human rights for all people and mainstreaming (Kirkebak 2001). Today the focus is still on equal rights in legislation and a strong focus remains on inclusion (at least in some countries) (Booth 1999; Baviskar et al. 2013; Lindsay 2007). Inclusion has substituted concepts of normalisation and mainstreaming, a conceptual change towards greater emphasis on the social process instead of 'placement' (Devarakonda 2013) but funded in the same ideological ideas.

Inclusion as an agenda and a challenge began in the 1970s as the effort to deinstitutionalise people with disabilities gathered momentum (Koyanagi 2007). More normal accommodation facilities were built and the population gradually decreased in the larger institutions. However, moving people with disabilities out from the institutions to mix with the general population resulted in other problems. Many people who had a lifelong history of institutional care were now left to live on their own and subsequently poverty affected many of the formerly institutionalised people; increased mortality rates also became a concern (Craig and Lin 1981; Koyanagi 2007). Life in the large institutions had deprived the individuals of important aspects of cultural development and maintained or increased the initial incongruence, because these institutions were organised around the aim of containing the inhabitants rather than their inclusion in wider society. The higher mental skills and the mastering of common cultural forms of thinking and acting had not been developed, or had been developed in ways embedded in the activity settings in the institutions and were thus difficult for the individuals to use in their newly gained independence. Loneliness and isolation were reported among people with intellectual disabilities who moved out from the institutions (Tideman 2005). The newfound independence may for some have been stressful and difficult to handle and resulted in an increased incongruence despite the intent, which was the opposite.

The other side of the incongruence – the problem of the cultural demands – became increasingly addressed by disability activist organisations that emerged in the United Kingdom and United States in the 1970s (Oliver and Barton 2000). Their dissatisfaction with the social barriers to participation for individuals with disabilities began the dissemination of the new value position that has developed into a central influence on the lives and developmental possibilities of many children with disabilities in the present. The main message of the disability activists was that disability was caused by limitations and barriers in society, not by individual impairment. This was the emergence of the social model approach to disability described in Chap. 1. The inclusion agenda arose from the central value at the heart of the social model approach: to accept variation as part of humankind and accommodate society in accordance with the strengths and shortcomings of all types of individuals. Thus, the social model formulated and fought for by disability activists has had a huge impact on general attitudes and actual practices. For young children with disabilities, inclusive practices have moved – and still move – many of them towards lives in mainstream practices. Cultural-historical analysis of inclusion will be the focused of Chap. 7.

A related value position is mirrored in the emergence of deaf communities in the 1970s and 1980s (Ladd 2003), the founding argument behind which is that deafness is not a disability but a minority culture with its own communities, traditions and

language. Deaf people being part of deaf communities and cultures have no interest in being able to hear, but instead fight for cultural minority rights (see also Chap. 7). Deaf communities and the deaf cultural movement have been successful and become powerful in many countries; for instance, local sign languages have been approved as minority languages in many countries. The deaf minority culture movement illustrates how the incongruence between members of society with and without disabilities can be transcended. For some deaf people, the disparity no longer exists at an individual level. Similar to the stance of disability activists, social participation problems are considered to stem from society's lack of necessary support and accommodation of particular groups of people. The deaf minority culture movement challenges both the medical and social model of disability – and instead calls for the right to have a different culture and use their natural first languages: sign languages. The impairment neither has to be cured nor overcome by full participation – but instead celebrated as a powerful and rich minority culture (Ladd 2003).

## **Values, Institutional Practices and Developmental Opportunities in Current Disability Trends**

As pinpointed in the walk through the history of disability, different value positions and practices have dominated in different historical times and have contributed to practices of human life and society since ancient times:

- The person with disability being dangerous to for the community, society and the human race. This value position has been related to practices of keeping persons with disabilities in institutions and practices of eugenics.
- The person with disability as someone in need of treatment, care and education; a patient that needs to be diagnosed in order to be treated or cured. The patient perspective also identifies the person with disability as being a victim, a tragedy caused by an illness – and therefore in need of medical treatment and rehabilitation support, or euthanasia in different forms.
- The person with disability being part of a cultural minority group and being respected as having a different life and different values about what constitutes a good life.

Two other value positions are not touched upon above, one of which is the person with disability being a clown or jester that can be used as an object for amusement and entertainment. This value position has been related to practices in which persons with impairments are allowed a special position in society, for example as beggars (Schweik 2007). Another value position is the person with disability being seen as having special spiritual or cognitive gifts and abilities, for instance the child with blindness with superior hearing and the child with autism spectrum disorder having special cognitive abilities.

Despite their many similarities with typical children, children with disabilities are a group of people representing the extremes of human life. These extremes arise from the break between the child's development and cultural forms. Practices – at times rather extreme – organised for children with disabilities can be seen as different ways of addressing the incongruence: By positioning children with disabilities as sick, dangerous, clowns, etc., an attempt is made to make a niche for them in society. Today's inclusion and equal rights discourse is also an attempt to address the incongruence at an ideological level: We are all human beings with equal rights. This perspective easily misses the fundamental fact that disability emerges and develops from the conflict between the child's development and the cultural forms in institutions and practices organised not only from the value position of inclusion, but from many others. These might at times be counterproductive value positions, for example a school's value position in achieving a high level of curriculum learning among their students.

Even though developmental incongruence is affected by societal level value positions, disability issues are not similar to issues related to gender, sexuality and race. Developmental incongruence is affected by macro-level value positions, but still, the problems of incongruence in development cannot solely be eliminated on a macro-level. As stated in this book disability is formed by incongruences between biological, psychological and social developmental levels. Deaf activist movements (the Deaf Culture movement (Ladd 2003)) has strongly argued that the communicative, cognitive, and social difficulties many children with congenital deafness experience are solely caused by factors not related to the hearing impairment itself but to oppression of the Deaf Culture. This can manifest in a lack of access to sign language in institutions and schools, minority cultural rights; a general understanding in society that hearing people are superior to deaf people; and lack of acknowledgment of the different lifestyle, mind-set and abilities of deaf people (Ladd 2003). Recent (mainly psychological) research has questioned the empirical support for this assumption (Knoors and Marschark 2014). Empirical research on different aspects of congenitally deaf children's development indicate that they experience some fundamental developmental differences from early in life (no matter the degree of support) (Knoors and Marschark 2014), which leads to incongruence between natural and cultural development and further disability for many. Therefore, disability issues are only partly comparable to issues related to gender, sexuality or race, in which incongruences are based in social and cultural discourses (Anastasiou and Kauffman 2013). Individual and developmental consequences of living in a country with extreme oppression of one's sexuality or race can to a large extent disappear by moving to another country free of oppression (if such a country exists). It is less easy to wipe away all the developmental consequences of congenital hearing impairment by moving a deaf child from a hearing community into a deaf. In many cases, some of the developmental consequences of the congenital deafness can move with the child. Disability issues cannot be understood or solved within a sociological or cultural perspective alone – as we argue in this book, a biopsychosocial understanding is needed. The cultural-historical complexity and mixed

picture of congenitally deaf children's development and deaf cultures will be elaborated upon in later chapters, including Chap. 8.

## **Summing Up: Using the Dialectical Disability Model to Analyse Early Child Development**

The four examples above – euthanasia and eugenics, institutionalisation, early intensive treatment and inclusion – are examples of how changes in society alter cultural-historical practices for children with (and of course also without) disabilities; and through this, the incongruence that forms the developmental conditions of young children with disabilities. The increase of specific diagnoses and further assessment has allowed the creation of more tailored support in the shape of training and education programmes. In addition, practices of diagnosis have created a base for further research about specific disability groups and their particular difficulties. However, the danger may be that the knowledge gained will shift the weight towards individualistic medical understandings of disability that disregard the conditions of the dialectic of development. Societal ideals about normality as the desired state along with a mainly medical model approach support medical and individualised treatment of different types of disability, for example intensive training of children with physical impairments towards walking or autism spectrum symptoms towards age-normal behaviour. The increasingly specialised biomedical methods stand partly in contrast to the approach of political and educational inclusion. The dominance of the medical model especially becomes a developmental constraint when the negative consequences of a disability (such as acting out or inability to participate in social activities) are interpreted as integral symptoms of the impairment, rather than as arising from the cultural-historical framed incongruence and developmental conditions within the child's practices. The challenge is to retain the focus of specialised knowledge of specific impairments and rehabilitation methods together with a pedagogical focus on children's participation in social practices.

Analyses thus need to focus on the dialectic processes between biological, individual-psychological and social levels of functioning, not only in the situation but also in their history and the way the incongruence affects the developmental possibilities of the child and his/her social situation as a whole. The extent of and reasons for the disability will differ from one child to another as they stem from dialectical processes between the child's biological endowments and the social practice in which the child participates. Over time, the dialectic processes between intrinsic and extrinsic factors affect and develop each other, calling for analyses of how interaction at one point in time has the potential to impact on the developmental trajectory of the child within social practices.

Many types of childhood impairments have a direct impact on the developmental speed of the child on one or more aspects of their individual development. As became apparent in Chap. 1, the primary biology-driven challenges give rise to



developmental incongruence that impacts on the whole of the child's development, including his/her developmental speed. However, the important point of this chapter has been that the process of development does not rest on biological potentials and biological maturation alone. Neither does it rest on a static, surrounding society with unchanging participants. The lower developmental speed is related to the organisation of the child and family's activity settings and the social opportunity situations within each. As mentioned earlier, a child's development is also a trajectory though different social developmental time windows, some of which may disappear or change radically as the child gets older. In different historical times and in different cultural settings, the arrangement of these social developmental windows has changed. However, across different cultural practices, parents and professionals of children with disabilities need to work towards reducing the incongruence between the developmental speed of the child with disability and the child's movement through social developmental windows. In modern western societies, this is often reified in institutional trajectories organised to support the development and learning of children.

A local fit between the child's abilities and the cultural practice can be created. Family, early learning and school activities that allow for sensitivity towards atypical ways of acting by children with biological aberrations (in eg, attention or visual perceptual analysis) can be established. The incongruence is a fundamental condition that parents and caregivers need to learn to manage – and help the child learn to manage, too. How to make this possible will be the theme for the remaining chapters of the book.

## **Part II**

# **Development and Disability**

The developmental incongruence of a child with disabilities means that he/she often cannot follow typical developmental trajectories. Vygotsky outlined the fundamental task of research in the area of defectology as the study of the particular paths of development for children with different defects. His recommendation was to focus on processes of support of child development, which needed to be analysed through study of the child in interaction with his/her surrounding environment and by the data of natural educational experiments, preferably as prolonged studies of children with different types of biological impairments in the process of learning and education (Vygotsky 1993). In this second part of the book, we will investigate how disability arises and develops out of the dialectical connections between the natural line of development of children with different types of impairments and his or her capabilities of participation in cultural-historical activity settings. This will be done in three chapters covering three age periods in early childhood in which different developmental agendas become important.

## Chapter 3

# Development of the Infant with Disability

The infant period is a developmental time period during which the newborn and infant becomes acquainted with life together with his/her parents and caregivers. The infant is invited into and participates in social and emotional life and early communication. Many types of impairments impact on the relations between parents and the infant child. Some types of impairments are associated with difficulties in engaging in social-emotional relationships. Others affect early relationship-building through their impact on the ability of the child to participate interactively in the same way as other infants. Furthermore, the social situation of development will often be affected by the parents' experience of ongoing adjustment to the situation of incongruence, learning not only how to relate to their child (especially if it is their first child) but also how to create zones of proximal development for their child when ready-carved cultural-historical developmental trajectories do not fit. This set of early emerging developmental challenges together makes disabilities visible and significant from early infancy. The analysis of incongruence during infancy opens up for an understanding of how time and timing become a crucial cog in the developmental of disability both during infancy and later on.

### **The Social Situation of Development of Infants with Disabilities**

The immaturity of the human infant – relying on his/her caregivers to take care of all basic needs – means that the social situation of development of infants with (as well as without) impairment is closely bound up with a set of caregivers and their motives and practices of child management and support. The social situation of development of the infant was defined in Chap. 1 as the systems of relations between the child's dominating motives at a particular age and the social conditions for the

child's development, arising from cultural-historical values and practices for demands and support of development (Hedegaard 2012; Vygotsky 1998).

At the macro-level perspective, practices for infant caretaking and parents' ways of being together with their newborn and infant have been informed by cultural values and scientific ideas about needs and capabilities of the human infant, ideas and values that are very much bound up in cultural-historical time (Ariès 1960). The following quote, a 100-year-old statement from a Danish textbook about infant and childcare written by a professor in paediatrics, clearly illustrates how the scientific and cultural understanding of infant development and care has changed radically from then till now:

Another common mistake is to interact too much with the child, to play with them while they are newborn. On the contrary, one should spare the child's nervous system, especially its brain. The brain of a newborn child is one of the comparatively least developed organs; while the brain of the adult is relatively firm, the brain of the newborn is soft, fluid. In the first year of the child's life, this organ develops quickly; one must therefore take care not to disturb this development by asking too much of the child. As long as the child is only a few months old, it shall only be nursed, cleaned and let sleep. After the first three months one can probably without harm occupy oneself with the child; seek to evoke its attention but preferably as little as possible. In addition, how is this type of activity of benefit to the child? To be honest, we do it mainly for the sake of our own entertainment, or phrased differently, we use the child as a toy. If one accustoms the child to be engaged only rarely, it will not make demands in that respect, but lie still in its bed without demanding one to entertain it. (Translated from Meyer 1899)

Similar to the changes in practices for infants in general, practices for treatment of newborns and infants with disabilities have varied through time, influenced by new ideas about typical infant development and by development of new medical and psychological knowledge and treatment of specific types of impairments. The most fundamental value position concerns the issue of life or death of a child with impairment. Will the child be allowed to be born and if so, will the child survive the first, often critical, weeks and month of life? As reviewed in Chap. 2, euthanasia and exposure had been practiced on infants with disabilities since ancient times, until Christian ethical practices and later human rights ideology influenced western societies. Both economic and social resources may have been explanations for practicing euthanasia, but a true feeling of compassion and loss of societal reputation and status if a family had a child with disabilities may also have been a factor. As also introduced in Chap. 2, in many western countries, exposure has in recent history been practiced and supported by hereditary theories and during the 1930s by the idea of race and genetically healthy societies. Today, prenatal screening programmes for specific chromosomal abnormalities are an integrated practice in many western countries. Elimination of an embryo/foetus with abnormalities is still practiced and accepted, both at a societal macro-level mirrored in the medical screening programmes and at the micro-level seen in the compliance of parents to participate in the screening programmes and the number of subsequent abortions. When studying policy paper arguments and the public debate, the arguments hold similarities to earlier practices of euthanasia: protecting the unborn child from a life in pain and

low quality of life, and to avoid the economic and social burden on the parents (Thorleifsdottir 2013).

Another side of medical practices concerns the ability to treat children born before term and increase their chance of survival even in cases of extreme prematurity. Practices of intensive early treatment enable these children to survive, but a higher number of these children have or acquire impairments. For example, the rate of bilateral cerebral palsy have increased during the last decades, a rise associated with the increased survival rate of children born very or extremely premature (Sigurdardottir et al. 2009).

Seen from the perspective of the families of children with disabilities, their particular social situation of development means that many of them have begun life together under difficult conditions, facing dilemmas and decisions concerning life or death. Further, for children with, for instance, extreme low birth weight or a severe chromosomal/genetic syndrome, the first days and weeks after birth are a period of high mortality risk and/or successive surgeries, intensive treatment and constant surveillance of the child. Many of the cultural, emotional and economical dilemmas about the survival of a child with impairments on macro-level are thus moved into micro-level medical practices at hospitals and become part of the earliest developmental situations for the child. The early demands and support of the child's development – and survival – creates a situation where typical cultural-historical practices for infant care are considered inadequate and the child and his/her parents become part of a larger institutional treatment system in which diverse medical, societal and cultural motives of life quality, survival, and treatment are activated. Parents find themselves in situations where they become involved in practices and decisions of early medical treatment that may be critical for their child's chances of survival and may alter the developmental trajectory of their newborn child in lifelong, irreversible ways. Through the participation in the practices, parents may adopt treatment motives as a way to develop social agency as parent of their newborn in this particular social situation (van McCrary et al. 2014).

## **Parental Grief or Reaction to the Emerging Incongruence**

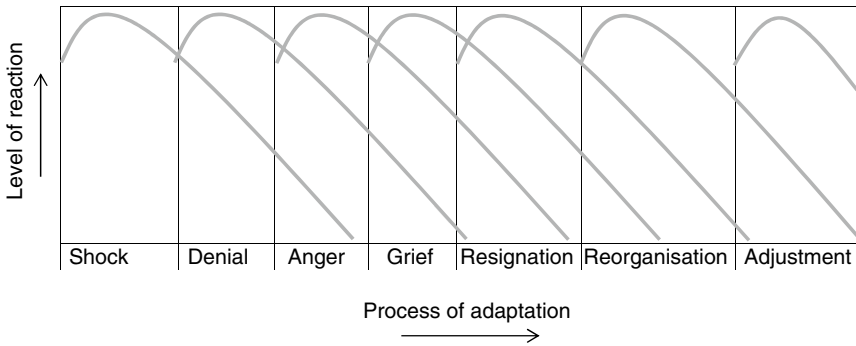
Depending on the type and degree of impairment, the first period of life for a child with disabilities may vary between parents' lack of awareness that anything is wrong, to chaotic situations in which typical cultural-historical practices for infant care are impossible and become substituted with participation in intensive medical treatment. The first days, weeks and months may already constitute a difficult social situation of development. It is the parents' first experience of developmental incongruence, either not knowing what is wrong or not knowing how to treat and support their child. Parents often report the time before, during and after the conclusion of the diagnosis to be severely challenging. In clinical psychology, the emotional situation of the parents is often described under the headings of psychological stress and crisis (Hornby 1997). Studies of parents of preterm infants at neonatal intensive

care unit or infants undergoing cardiac surgery have found a high level of stress and further a high risk of depression and other symptoms of mental health problems among the parents. At the same time, and interesting in this theoretical context, a high variability of symptoms is often reported. Some parents do not experience a higher level of psychological stress and mental health symptoms, while others experienced mild to severe symptoms of psychological stress (Sáenz et al. 2009).

Research into how parents experience and go through the whole process of recognising and accepting the impairment of their child has mostly been informed by theories and concepts of life crisis and grief, interpreted as reactions to the 'loss of the normal child' (Moses 1985; Moses and Van Hecke-Wulatin 1981). The traumatic event (discovering the impairment for the first time) marks the beginning of a shorter or longer process of grief, where the parents pass successive phases of shock, denial, anger, grief, reorganisation and adjustment (Hornby 1997; Seligman 1979). According to this approach, the first experience will often be of shock characterised by a feeling of chaos and maybe severe mental and physical stress symptoms in a short or longer period. During this first period, the parents often need support from the people around them. The shock phase passes into a phase characterised by denial. The parents may doubt that the child has any disabilities, may claim that the doctors are wrong or that the symptoms are caused by something else or that the child can be cured by a special treatment or diet. The next three phases are characterised by feelings of anger, grief and resignation. In the last two phases, the parents have accepted the disability and are reorganising and adjusting their life to the new situation with the child with disabilities. The phases are not fixed but vary in time and strength for each parent. The phases also overlap – the intensity of feelings within one phase will, in the transition to the next, be mixed with feelings from the next phase (see Fig. 3.1). Once through the succession of grief phases, the parents may experience a new and maybe existentially richer and deeper life (Hornby 1997).

Within a cultural-historical framework, it becomes significant to reinterpret crisis and stress as a social-emotional reaction that includes social conditions for becoming a parent and taking care of an infant. In a cultural-historical framework, crises (or critical periods (Vygotsky 1998)) emerge from situations of entering new practices that demand development of new motives and competences or developing new motives for competences, which cannot be fulfilled in current practices. Similar to the child preparing his/her self to become a schoolchild, parents also prepare themselves for the new situation of being parents. They acquire equipment considered necessary for childcare, they may read books about childcare, observe childcare practices and imagine and talk about how they will take care of their newborn. After the child is born, they continue the reconstruction of new competences, strategies and motives. As such, the birth of a child, especially the first-born, potentially presents the parents with a situation that can be characterised as a life crisis.

The feeling of stress, life crisis, or mental health problems associated with the birth of the first child, with or without impairment, is widely recognised in most



**Fig. 3.1** Stages of grief, from shock to adaptation, among parents of children with disabilities (Translation of the Figure labels: x-axis: Process of adaptation, y-axis: Level of reaction. Phases: Shock, Denial, Anger, Grief, Resignation, Reorganisation and Adjustment)

western cultures as well as in psychological research. So, what is the difference between the crisis of new parents of a typical infant and the parents of an infant with impairment? Parents of an infant with one or more impairments may indeed experience emotions of grief, anger, stress and anxiety, but these emotional reactions are not only individual reactions and need to be understood as reactions to the incongruence between the child’s development and the cultural forms. As explored above, the clinical grief approach to crisis defines the emotional reactions as individual reactions caused by the loss of the expected ‘normal child’; but this overlooks the wider cultural-historical dimension of parents as social actors in family practices of parenthood and societal values of childcare practices. The parents’ motives for taking care of their child, how to do it and ideas about desirable developmental aims arise from cultural-historical values about a good life, both as a family and regarding a desirable life trajectory of their child. These general societal values about the good life as a family and desirable life trajectories become challenged when the child is born with one or more impairments. The adjustment of the parents to the demands of the situation, for example the learning and carrying out of specialised treatment practices necessary for their child, requires them to accept and adopt values and/or practices that are different from the most dominating within their cultural-historical setting. The reactions mentioned in the crisis literature are not reactions in individual personalities, but reactions to one of the first experiences of developmental incongruence of the parents.

Another parental experience of developmental incongruence is that typical childcare practices might not fit with their child. One example mentioned previously is

the early intensive treatment of a premature infant, so very different from the child-care practices for typical term-born infants. During the first days and months, many parents of infants with impairments experience that normal cultural traditions and practices of feeding, sleeping or communicating with their child do not work. Even though the situation of receiving a diagnosis for their child can be followed with reactions of shock and grief, elements of relief might also be present. Previous experiences of incongruence are suddenly explained and the parents may sense a hope for help and support to decrease the mismatch between the child's individual development and the cultural support of the child in the time to come: "Now we know what is wrong and we can start plan the future". Parent's reactions will not be uniform but vary with regard to the complexity of the situation and the cultural-historical practices in which they participate, including available support systems (Dammeyer 2010b). This could partly explain the variability in feelings of stress and mental health reactions mentioned earlier.

Seeing the child and his/her parents as a unit, the social situation of development has the potential to become characterised by conflicts between the parents' motives of taking care of their child and his/her developmental needs, and their competences in regard to fulfilling the demands as parents of an infant. For example, the cultural traditions and practices for supporting the early development of motor functioning and language learning may not address the child's zone of proximal development, if the child is born with either cerebral palsy or hearing impairment. The stress reported in the literature of parents of infants with disabilities can both be related to specific situations such as surgery and medical treatment, and a daily struggle for taking care of and supporting their child's needs. In a study made by one of the authors (Dammeyer 2010b) parents of children with disabilities were interviewed about their experiences of being parents. They did not report any experience of grief and crisis but across all cases, parents expressed strong emotions related to experiences of having to 'fight' and 'solve conflicts' with the support system and institutions (local municipality, local school, daycare, etc.). Frustrations, anger and sadness were often experienced when the parents had worked hard over a long period in order to get what they found to be a correct, proper, and timely support. The stress and eventual tendency to place demands on and criticise professionals may also reflect a struggle to create the best opportunities for their child, arising from a new and unique motive in parents of children with disability to overcome the developmental incongruence between the child and the cultural forms. The whole complexity of cultural practices in which the infant, parents and professionals participate needs to be taken into consideration. "Grief" is intersubjective and socially mediated and emerges in concrete contexts of social practices. It is within the processes in the cultural-historical practices that the different emotional reactions need to be understood. Still, individual clinical grief models are often invoked by professionals to explain the behaviour and emotional reactions of the parents. The unresolved crisis and grief may increase the risk of conflicts ending with the decision that the parents are unable to take care of their child (Pianta et al. 1996). Milshtein et al. (2010) explored parental acceptance of 61 mothers and 60 fathers of children with an autism spectrum disorder diagnosis or epilepsy. About half of the mothers were



found to be “unresolved” in relation to the diagnosis and this was attributed to a negative perception of raising a child with disability. If parents are criticising and dissatisfied with the support they are offered from the professionals to the child, this can be interpreted as being parents with unresolved pathological grief caused by the loss of “having a normal child” (Hornby 1997). It is a societal value position that professional staff view parents of a child with disabilities as having more or less severe symptoms of psychological distress.

Summing up, the social situation of development for the infant with congenital or acquired impairments, seen from the perspective of the parents, is different compared to the social situation of development of typical children first and foremost because of difficulties in creating a zone of proximal development for their child. The social situation of development differs from the situation of parents of typically developing children because they contain conflicts arising between parental motives of creating a satisfying family life with their newborn and their culturally based knowledge about what a newborn’s needs are and how it will develop. In response to this difficult situation, many parents may experience difficult feelings of anger and frustration. However, these are not individually isolated reactions of parents due to the unexpected situation of having a child with impairments. Instead, we have argued that the experiences and reactions of parents needs to be re-addressed as conflicts arising from incongruences in practices of childcare and child development from (a) macro-level cultural-historical values and frames for developmental support (see also Chap. 2) and (b) micro-level practice settings where the parents experience problems and inconsistencies between how others describe life with an infant and their own experiences with their child with impairments. Both types of conflict – mismatch between culturally instituted practices for infant care and everyday challenges of taking care of a child – may contribute to creating difficulties in areas not caused by the initial impairment. The initial incongruence holds the potential to become a source of early delay in development, as we will explore in the following sections.

## **Development of Early Intersubjectivity and Communicational Skills**

The earliest motive to appear in the infant is to be in emotional contact with his/her caregivers (Elkonin 1999). Infants are from birth active participants in social practices; however, the way parents respond to and further enable the active participation of their infants is highly dependent on their values relating to infants and appropriate practices with infants. Processes of mutual engagement of minds work between persons and are formed by motivational, emotional and sensory systems (Panksepp 1998) and are adapted and come to function within cultural frameworks of meaning (Bruner 1983). The institutional practices facilitate and shape how social participation takes place in meaningful ways. Thus, the capacity of an infant

to be active in social interaction is culturally mediated by the way cultural practices for childcare and relational being with infants are organised. Much has happened since the Danish professor in paediatrics wrote about contemporary ideas on infant care in 1899 (the quote at the beginning of this chapter). During the last 30–40 years, psychological infant research has revolutionised the cultural-historical understandings of the infant's life and development. One of the most radical changes in infant development theory has been research showing that newborn infants are able to take part in complex social interaction and nonverbal communication when they are only a few days old (Trevarthen and Aitken 2001). The new theoretical understanding has emerged hand-in-hand with the development of new technologies, first of all video-recording technology that has allowed frame-by-frame analysis of mother-infant interaction. These studies have shown how newborn infants respond with synchronised behaviour to visual stimuli, sounds, and touch (Dammeyer and K ppe 2013). A new understanding arose that infants not only need to be fed and cared for physically, but are human subjects taking an active part in interactions with their caregivers. Theories built on this empirical research argued that early social interaction behaviours are the first steps in the developmental trajectory of positive interpersonal relationships, language development, emotional regulation, attachment, understanding of the minds of others and much more (Tomasello 1988; Trevarthen and Aitken 2001).

Colvin Trevarthen has been one of the central researchers studying early infant development. He used the concept *infant intersubjectivity* (Trevarthen and Aitken 2001) to describe how even newborn infants, with their very immature brain and body, are motivated beyond instinctive behaviours and biological needs to communicate with their caregivers. This natural sociability of infants serves as a motive for social interaction and participation and plays a leading role in the infant's development. The infant's communicative motivation and intuitive orientation to social interaction reflects the human mind's capacity for cultural learning as described by, among others, Vygotsky (Trevarthen and Aitken 2001). The infant's orientation towards communication and social interaction animates an initial self-other awareness, as well as reception of motives and emotions in social practices.

As already mentioned, one of the very early intersubjective behaviours between infant and caregiver which has been investigated is *synchronicity* – or with similar concepts reciprocity, attunement, mutuality, responsiveness, matching, and regulation. The ability to synchronise gaze, body movements, vocal sounds, emotions and other behaviours and mental states has been found by researchers to be a basic condition in the human organism, which works as the foundation for the establishment and maintenance of dyadic social interaction that in time provides the infant with capacities in intersubjectivity and sociocultural participation. The engagement in synchronised interaction organises the infant's cognitive and affective experiences and development (Trevarthen and Aitken 2001); thus, social interaction works as the building platform for further development of synchrony. Through the synchronicity in interaction, the partners become attuned to each other's states and changes of bodily and mental condition (tiredness, attention, and arousal) (Stern 1982; Trevarthen and Malloch 2000). The capacity to participate in synchronised

interaction provides the infant and the caregiver with the ability to be with another person in one structure of time and to allow this time to be shaped into mutually satisfying periods of interaction (Trevarthen and Malloch 2000).

Some researchers describe musical parameters as essential features in infant-caregiver interaction and studies have been undertaken on rhythm changes and temporal timing in body-movements and vocalisation (Stern 1982, 1985; Trevarthen and Malloch 2000). The interaction is established and develops similar to improvised dance or a piece of music. Communicative musicality describes the dynamic processes of how infant and parents are able to sustain a coordinated relationship over time and to share jointly constructed behaviour. Caregivers dynamically influence each other in activity settings of a cultural-historical nature.

At a basic level, impairments have been found to affect this development of primary intersubjectivity and early pre-verbal communication. Studies have reported that mothers of infants with motor impairments found it more difficult to identify their children's acts as intentional and contingent and thus respond appropriately, in a way that could maintain and further develop their mutual interaction into communication (Olswang et al. 2006). The motor impairment of the child makes his/her initiatives less clear for the caregiver to understand. For example, the child may display a lot of involuntary motor activity, making it difficult for the caregiver to detect intentional acts, especially if they are delayed in time vis-à-vis the acts of the caregiver. This in turn can affect the rhythmic attuning of the infant-caregiver dyad. The contingency of the mutual interactive initiatives becomes more difficult to establish and maintain, which hampers the early development of intersubjective relationship-building and causes delays in the communicative developmental trajectory (Olswang et al. 2006). However, the child's developmental delay in communication emerges from the social situation of development rather than from the motor impairment itself. Olswang et al. (2006) suggest addressing the communicative interaction between child and caregiver by teaching caregivers to wait for and recognise unconventional communicative initiatives from the child and respond to and support the child's early initiatives to allow further communicative development. This intervention approach places focus on overcoming the incongruence between the child's abilities and the cultural forms of typical infant-caregiver interaction.

Another example of how impairments may impact on the development of early intersubjectivity and call for different developmental means is children with congenital deafblindness. Because of the vision and hearing losses, the early social intersubjectivity and communication has to be established by other modalities. In supporting the child's development in cases of congenital deafblindness, the caregiver needs to increase the focus on the tactile modality to explore and support the social interaction with the child by responding bodily to the child's expressions of tempo, rhythm, intensity, and emotions (Hart 2006; Rødbroe and Souriau 1999). By being sensitive to the deafblind child's bodily and tactile expressions, it is possible to establish complex social interaction as a ground for further development (Janssen and Rødbroe 2007). The example of children with deafblindness is further elaborated later in this chapter.

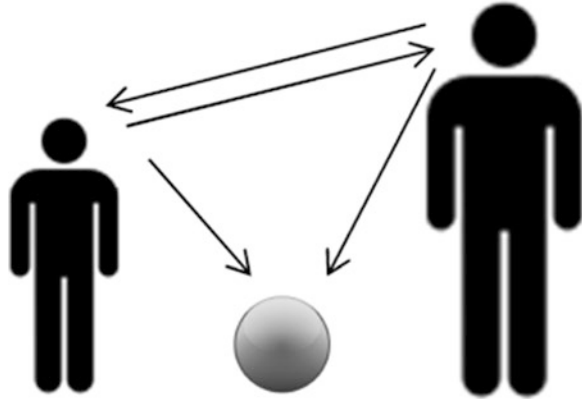
Both examples highlight that early building of primary intersubjectivity with children with impairments – even complex and severe impairments – is aimed at the same motive as in children with normal psychophysiological capacities: to build a relationship in which emotional states can be shared. However, the differences in the child's capacities call for changes in the way the caregiver acts and reacts with the child and a need to direct the caregiver's awareness to particular modalities or different types of responses in order to allow attention to the child's initiatives that might otherwise go unnoticed. The incongruence between cultural-historical expectations to the child – expressed in cultural traditions about how to act with an infant and what to demand from an infant and the child's ability to meet demands – makes it necessary to establish particular, adapted social situations of development for the child with impairments. If not, the child may seem unable to relate to the caregiver and the activity setting in a meaningful way and risk to be deemed intellectually deficient or otherwise impaired (Dammeyer 2014a). When his/her initiatives are not recognised or supported and the child is deprived of social opportunities for development, the resulting conflict between motive for social participation and support and demands from his/her activity settings has the potential to lead to delay *and* actual intellectual impairment of the child. This arises not from a congenital impairment in neurobiological functioning, but as a secondary effect. As stated in Chap. 1, development of neurobiological potential is an active process and deprived of opportunities for participation, the child will not be able to develop his/her neurobiological potential for intersubjectivity.

Summing up, as theories and methods of studies of infant-caregiver dyads have been adapted to children with disabilities, research has revealed that social interaction and communication between children with disabilities and their caregivers occur and develop during play activities and social routines, just as they do in children without disabilities (Olsson 2004). However, special attention to deviations in the early social situations of development may be needed and development of early intersubjectivity may be a dominating motive for a longer period when the child has a disability. Social interaction may need to be established and developed by different means if the child, for instance, has a sensory or motor impairment. Special support and training programmes has been developed and in the following sections, these will be reviewed with regard to the early steps in early development from a cultural-historical perspective.

## **Development of Triadic Joint Attention**

Joint attention, the ability to share and be aware of each other's attention, has been suggested to be a crucial next step in children's early development (Trevarthen and Hubley 1978). The ability to take part in shared attention is fully established for typical children at around 9 months of age. Researchers talk about three levels of joint attention: shared gaze, dyadic and triadic. Shared gaze occurs when two individuals are simply looking at an object, and dyadic joint attention is

**Fig. 3.2** Joint attention:  
To be aware of each other's  
attention to an object



conversation-like social interaction, which already starts when the infant is around 2 month of age. Triadic joint attention is the ability to pay attention to an object and be aware of each other's attention. Triadic joint attention is more than mutual attention. In joint attention, the partners have to be aware of each other's attention to the same object or activity (see Fig. 3.2). Triadic joint attention goes beyond the individual's capacities – the dyadic interaction – and needs to be understood as a complex social interaction involving both participants (Reddy 2005). Researchers have argued that joint attention is closely linked to the later development of theory of mind: The ability to attribute mental states – interest, desires, emotions, to others and to understand that others experience these mental states differently from one's own (Korkmaz 2011).

The ability to identify intention and direct the attention of others has been suggested to be important in a child's ability to develop communication and learn language (Tomasello 1988; Tomasello and Farrar 1986). For example, joint attention is necessary in word learning. In learning that a car is called a car, the child needs to be aware of and follow daddy's pointing to the car and combine the pointing, the car and the sounds of "car" together.

The change from dyadic (you-me) to triadic (you-me-it) interaction is an opening of the child's capacity to participate in activity settings. The possibilities broaden from interaction as child-partner to child-partner-object and later on to child-partner-word. The participation of the child is not limited to take place with one partner or one object at the time; different elements of the activity settings can be actively integrated. Thus, the emerging ability to triadic joint attention is a significant shift in the process of learning, and in cognitive and social development, that enables the child to participate in new ways in activity settings.

Different impairments often impact on the ability of the child to participate in activities of joint triadic attention. In the following section, we will discuss three groups of children with disabilities and their challenges with triadic joint attention: children with autism spectrum disorder, children with visual impairments and children with hearing impairments.

Several studies have documented that children with autism spectrum disorder experience difficulties with joint attention, both in quantity and in quality (Mundy et al. 1990; Rollins and Snow 1998; Warreyn et al. 2007). Impairment in the ability to take part in joint attention is one of the early key characteristics of autism spectrum disorder. It is debated whether joint attention, and other early social interaction and communication abilities, can be trained in children with autism spectrum disorder and if so, to what degree this type of intervention reduces or prevents the development of autism spectrum symptoms. Systematic reviews point to some effects but in general results are contradictory (Oono et al. 2013). Some training programmes are directed towards specific skills such as joint attention and other aspects of social interaction and communication by training the specific behaviour. Another group of broader interventions focuses on the child's activities in relation to developmental themes (Casenhiser et al. 2013). Taking eye contact is one example, because it is a significant precursor for later abilities to joint triadic attention. It is not the behaviour of looking into another person's eyes that is important; it is the child's motives in the specific activity – to check if the partner is paying attention, to find out if the partner would like to play – determining the mental state. Doing so, the adult has to be aware of the child's subtle and different initiatives (eg, body position) for joint attention, arrange a social setting where joint attention can take place and develop (eg, a quiet room and with some favourite activities), be attentive to and respond to communicative attempts as if they are purposeful, emphasise emotional expression and affect sharing. Focus has to be on the developmental capacities in the social activity of participation rather on the isolated behaviours (Casenhiser et al. 2013). Following this perspective, Casenhiser and colleagues (2013) found in a controlled trial positive effect on the development among 51 children with autism spectrum disorders, between 2 and 5 years of age. Parents were given two hours weekly coaching in social interaction and communication with their child. After 1 year, the children in the intervention group had significantly improved social interaction and communication skills in comparison to the control group. The parents' skills were found to be important for supporting the child's social interaction development. Focus on the specific incongruence in the specific social activities of development, and not an isolated behavioural impairment, seems to be important. Similar results, with similar types of intervention, have also been found in other groups of children with impairments, for instance, children with congenital deafblindness (see also Chaps. 6 and 7).

Another group is children with visual impairment or blindness. The visual modality tends to dominate the establishment of joint attention in many or most mainstream activity settings and thus joint attention becomes difficult to establish when this modality is impaired (Bigelow 2003). A third group is children who are deaf or hard-of-hearing. Many deaf children experience difficulties in development of joint attention, which are attributed to the hearing impairment (Harris and Mohay 1997). In both children with blindness and children with hearing impairment, the caregiver has to support and respond to joint attention behaviour in alternative sensory modalities. For children with blindness, the parents can be guided to establish joint attention with touch and vocalisation (Preisler 1996). Joint attention strategies

have been investigated among deaf parents of deaf children. It has been shown that parents who are deaf themselves are able to establish joint attention by visual and tactile strategies without delay in the child's developmental trajectory, qualitatively or quantitatively. They are flexible, attentive and able to guide and support their deaf child's attention using touch and visual gestures (Nowakowski et al. 2009; Spencer and Harris 2006). The deaf children with deaf parents often experience no delay in language, cognitive and social development later on compared to children with typical hearing (Mayberry 2003). This means that the sensory impairment can fully be substituted by using other modalities – in these cases, congenital impairments result in no incongruence of development in the micro-level activity setting of child and parents. The experience-bound support of joint attention by a different modality is part of the deaf parent's cultural repertoire.

The unidirectional view of impairments as a universal source of developmental delay in the development of joint attention can be challenged by a dialectical point of view. The presence of delays in development of joint attention can, as demonstrated, be a product of research methods biased on mainstream modalities for joint attention. However, research practices and childcare practices both stem from the same cultural-historical setting and thus caregivers of children with impairments in vision, motor functions or other types of impairment might show similar bias towards conventional communicative signals and patterns that are difficult or unachievable for their child. For example, the findings of a universal delay in the development of social interaction abilities in infants with visual impairment can be reinterpreted as an expression of a cultural bias towards considering vision as the primary mode of communication in activity settings, in theories and in research methods (Rattray and Zeedyk 2005).

Although vision can compensate for hearing, research has shown that it is difficult to overcome developmental incongruences from congenital hearing impairment. Only deaf parents with high competences in supporting their children are able to effectively avoid incongruence in early social interaction and communication, as well as the risk of further developmental delay (Knoors and Marschark 2014) (see also Chaps. 6 and 7). Similarly, mothers of infants with visual impairments find it more difficult to identify their children's acts as intentional and contingent and thus respond appropriately (Baird et al. 1997). Just as research theory and methodology need to attune themselves to a wider set of behaviours, some caregivers of children with impairments may need to be introduced and supported in the use of adapted and unconventional means for building early intersubjective relations with their infant. Otherwise, the difficulties and delays in development of joint attention might become real in the sense that they affect the child's ability to participate in everyday social practices now and in the time to come. The sharing of subjective states and later the sharing of focus of attention can be established by touch, by the mutual handling of an object or by vocalisation means in infants with visual impairment (Rattray and Zeedyk 2005; Janssen and Rødbroe 2007).

The reinterpretation of delays and impairments in development of joint attention as a secondary impairment arising from the child's social situation of development (rather than the primary biological defect) underlines the principle of the

cultural-historical model of disability. Parents of deaf children who are deaf themselves and native sign language users support the child's development and engagement in joint attention using visual and tactile strategies. Appropriate strategies are already part of the activity settings within their family practice. Thus, their demands and the activities available for imitation will more often be within their deaf child's zone of proximal development. Most deaf children are born with normal ability to take part in joint attention, but if the social and communicative partner does not build on the deaf child's visual abilities, the ability will not develop correctly. Because of difficulties with joint attention, there is a risk to the deaf child in relation to experiencing escalating developmental difficulties – among other language delays, further socio-cognitive difficulties such as delayed theory of mind (Dammeyer 2012; Knoors and Marschark 2014). Likewise, visual impairments have been found to affect not only the development of joint attention and preverbal communication (Fernell et al. 1998; Sapp 2001). Joint attention has further been associated with delay in theory of mind and language development later on (Pijnacher et al. 2012; Tomasello 1988; Wetherby et al. 1998). The disability, being the incongruence between the child's development and the cultural forms, often begins early in infancy in the social interaction where the child's need for tailored demands and developmental support in taking part in cultural-historical social activities is not met.

## **Parent's Part of the Incongruence**

Parents of infants with impairments have been found to feel insecure and less competent (Lappin 2006). The frustration and/or lack of confidence of the parents can be a sign of the conflict in the social situation of development described in the previous section, when normal practices for early infant care-giving and communication are not applicable. The conflict(s) in the social situation of development can be magnified by the negative reactions of others to the 'difference' of the child, a situation that has been found to contribute to parents' feelings of being socially inappropriate (Green 2003). Still, the picture is not unequivocal. Many parents find or work out adapted ways of relating to their children with disabilities. McKillop et al. (2006) (and Buchanan (2009) in the next chapter on toddlers) report how parents in their practice settings find or invent toys, objects and activities of interest for their children because conventional toys and activities do not fit with the interest or capacities of the child and the child's need of support in his or her development as an active participant in activities of, for instance, joint attention. Disability or not, parent and children have the same motive of sharing subjective states of mind and interesting aspects of the world.

However, the emotional turmoil of having to cope with the negative reactions of others, a reluctance to arouse further social attention (Green 2003), lack of knowledge about the child's precise impairments (Rowland 1984) and/or knowledge about how to support the child, may contribute to difficulties of the parents to



explore alternative ways of relating to their child. At times, the difficulty of finding the alternative means calls for interventions from professionals with special knowledge about how to enable and support the building of early intersubjective relations and later activities of joint attention by alternative means. Otherwise, as already shown, visual impairment (Rowland 1984), deafness (Meristo et al. 2012) and motor impairment (Pennington and McConachie 1999) give rise to secondary spill-out effects of developmental delay in the social line of development from the primary biological impairment.

## **Children with Congenital Deafblindness – Double Incongruence**

Education and support of children with congenital deafblindness exemplifies how knowledge developed within cultural-historical practices about early social interaction and communication has been important and completely changed the practices associated with developmental and educational support, at least in some countries (Dammeyer et al. 2015; Hart 2006). In most countries, education and support for individuals with deafblindness has throughout history been organised as a sub-discipline of deaf education and teaching. Practices have been organised from the same methods, only adapted to the tactile modality. The result has been that children with congenital deafblindness have been trained in the local spoken language or visual sign language (Dammeyer et al. 2015; Ask Larsen 2013). To reach this goal, different educational approaches have been pursued in deafblind education. Until 1980, the central developmental goal for teachers was to teach congenital deafblind individuals to use a symbolic linguistic system: signed or oral. Different behavioural training methods were often used, for instance sign-reference systems (Hart 2006). The child with deafblindness was for instance trained in using the conventional sign language sign for “eating” by linking it to the touch of a spoon. However, this approach was criticised for lack of success and at best leading only to conditional behaviour learning, not language in a communicative sense. The lack of success in the previous approach moved interest toward theories about pre-lingual communication development during the 1990s, inspired by theories surrounding how natural social interaction and nonverbal communication between infants and their caregivers can provide the foundation for later symbolic language and higher-order social and cognitive development (Dammeyer et al. 2015). It was recognised that the incongruence between the child’s development and participation in activity settings impacted profoundly on infant-caregiver interaction from birth in children with dual sensory impairment. To support the child’s development of social agency in communication in cases of congenital deafblindness, a shift was needed in order to focus on how to overcome the incongruence at the very early steps of social communication (Souriau and Rødbroe 1999). Caregivers and researchers started within the tactile modality to explore and support the social interaction with the child with

congenital deafblindness by responding sensitively to the child's bodily and tactile expressions (Hart 2006; Souriau and Rødbroe 1999), instead of communication at a symbolic level and in modalities the child was unable to reach. Play as well as eating and bathing routines were found to be useful pathways to establish the platform for developing early turn-taking and understanding of course and effect by using touch. Signals for turn-taking were found to include reaching out with a hand, whereas a signal for turn-giving may be a change of hand position (Janssen et al. 2004, 2002).

Joint attention using tactile strategies has been shown to be an important, but difficult, ability to support in children with congenital deafblindness. Attentional cues and signals may be given differently when the child is deaf and blind. It may for instance be by responding to the child's attention cues such as head turning (Bruce 2005) or pauses in movements. The focus on supporting early social interaction by using the tactile modality as a mean, being the foundation for later language, cognitive and social development among children with deafblindness, has been documented in research (Dammeyer 2014b) and has become the dominating rehabilitation approach in many countries.

Nevertheless, even with support, the development of joint attention and early communication is difficult and takes longer to establish when the activities have to be accomplished by the tactile modality only (Dammeyer et al. 2015). A developmental delay is unavoidable, thus creating a mismatch with typical cultural-historical developmental trajectories. In addition, even when the child with deafblindness has learned to participate in activities of joint attention, he or she will still be dependent on adapted activity settings to use the acquired capacities, given the double sensory impairment. The incongruence can be diminished, but never fully removed (Ask Larsen 2013).

## **Development Beyond the Age of Infancy**

Children with deafblindness are one example of a complex of multiple impairments making development much slower than in children without impairments. For children whose disability arises from complex matrixes of impairments, developmental themes from infancy can still be relevant beyond the typical age period of infancy. The slowness of development in cases of severe and complex disabilities is due to a double challenge. The impairment complex in itself deprives the child of many aspects of the physical and social environment, making it more difficult and slow for the child to interact and build affordances with the world. One example, given previously, is children with deafblindness. Understanding what a 'dog' is takes a longer time when the affordance has to be built on shared attention in the tactile modality only. Other examples are children with severe autism spectrum disorders, whose preference for sameness makes it difficult for them to participate in as many and as varied social practices as their peers. A third example is children with severe cerebral palsy, whose severe motor impairments are often accompanied by an inability

to imitate sounds and sometimes cerebral visual impairments, a complex of impairments that deprive them of many of the possibilities for social agency that are readily available to their peers (Sandberg and Dahlgren 2012). Exploring shared attention and object qualities is much more difficult to achieve if the child has severe cerebral palsy and lacks both the physical and verbal means to indicate his/her points of interest and explore them (Sandberg and Dahlgren 2012). For children with multiple and complex disabilities, their natural line of development is so constraining that they are mainly able to participate actively in specialised, adapted activity settings. Compared to children with normal psychophysical endowments, they participate less in developmentally relevant activity settings and may need longer time to learn the same as other children due to sensory, motor, emotional and/or cognitive constraints (Bøttcher 2012).

One consequence of the developmental delay may thus be a necessity to keep a focus on support of social interaction building beyond the chronological age of infancy. The demands and support of children – and adults – with severe communicative disabilities who are not yet able to use a symbolic language need to be based on themes from early social interaction. Awareness, attunement and response to movements, vocalisations and emotions will often be the communicative form in which the child has to be met. Parents and professionals need to establish primary intersubjectivity with means of behavioural, emotional and other non-verbal interaction to overcome the incongruence in the activity settings. One important tool for this aim is video observations. Similar to the researchers discovering typical infants' early social interaction by video observation, the atypically shaped non-verbal social interaction with individuals with severe disabilities is often best identified when analysing video-recorded interactions (Dammeyer and Køppe 2013). Careful observation is needed to be able to identify basic incongruence and inform developmental practices.

## **Summing Up: From Intersubjectivity to Social Agency as a Dominating Motive**

The last decades of research have discovered how infants are active social agents taking part in social-cultural practices from birth. Therefore, the incongruence between the child's development and the cultural forms becomes a developmental challenge that will be of consequence in the development of early intersubjectivity from birth and further into the child's development as an active social agent. Even though the motives of both the child with impairments and his or her parents are in many ways similar to typical children and their parents, the social situation of the child with impairments will often contain conflicts between typical practices for childcare and the capacities of the child to engage in social interactions and act in accordance with the parents' culturally based expectations. Thus, the lower ability of the child to engage in and develop social relations arises early on from the

incongruence between the capacities of the child and activities and demands to the child in different activity settings. If the barrier is not addressed, the incongruence will often increase as time goes by. What starts out as an incongruence in social interaction with a blind child due to an unmet need to synchronise in non-visual modalities may later result in difficulties in joint attention, attachment, theory of mind, and emotional regulation, making the child more and more out of synchronisation with typical cultural-historical institutionalised developmental trajectories.

The potential escalating effect of the early incongruence to a developmental delay vis-à-vis peers and institutionalised trajectories later on stresses the importance of early intervention, which has been empirically underlined repeatedly in developmental psychology research. In addition, to complicate it further, because the biological time windows (introduced in Chap. 1) for certain abilities (eg, language development) close down, timely and early intervention are crucial.

From a cultural-historical point of view, parents are central figures in an infant's life and thus become the key figures to overcome the developmental incongruence associated with impairment. The important role of parents is recognised in many types of intervention. Many different special support and training programmes involving the parents have been developed. However, it is important to be aware that programmes for support and treatment are not "objective solutions", but are grounded in particular cultural understandings of the nature of the child's difficulties. The current value position foregrounding parents as central agents is at the core of many contemporary training programmes. From a cultural-historical perspective, the parents' engagement in the early inclusion and training of children with disabilities makes sense. Parental involvement is neither isolated nor considered an extra resource to train the children, but rather seen as part of the parents' role as the ongoing, often life-long managers of the incongruence of their child with disabilities. (See also Chap. 9 for parents' management of incongruences.)

## Chapter 4

# The Toddler and Preschool Child with Disabilities: Becoming a Social Agent

The age from two to five, characterised as the toddler and preschool period, is an important developmental time period for all children. The subjects for this chapter by no means exhaust all the developmental themes during this childhood period when the child develops as an increasingly independent social agent. Rather, we have chosen first to focus on the impact of disability on the child's exploration of the cultural meanings of *objects* and use of them through participation in ongoing activity settings. The reason for this focus is the crucial role – seen from the cultural-historical theoretical perspective – of this important developmental aspect of the cognitive as well as the social development of the preschool child, with or without disabilities.

*Play* is a time-dominant activity during the toddler and preschool period. Analyses of the impact of disability on play motives and play activities is central to the theoretical unfolding of the developmental incongruence during the toddler/preschool years. A second theme in this chapter is therefore play as a social activity. Through exploration of objects and activities, first with parents and later with peers, the child begins to explore what it means to be a social agent. Developmental delays are common in toddlers with impairments. At times, developmental delay seem inherent to the impairment, for example in many children with cerebral palsy who reach motor milestones later than typical peers because of the underlying brain lesion and its direct effect on muscle tone and control. At other times, developmental delays of children with cerebral palsy during the toddler and preschool years emerge from the incongruence that impacts on the child's exploration and playful use of both concrete and symbolic cultural tools. The analyses of developmental delays opens up for an understanding of the nature of the incongruence associated with disability during the toddler and preschool time period.

## Cultural-Historical Understandings of Play

The infant's early play with the concrete properties of an object, explored through sucking, touching and manipulating, are central to the evolution of the practical intellect of the child (Piaget 1964). As became apparent in the previous chapter, the infant's early exploration of objects often involves his/her caregiver through activities of joint triadic attention. During this type of activity, the couple may share their mutual interest in the object through shared emotions. The shared activity with different objects in activities is also considered to be a foundation for later language development (Tomasello 1988).

Around the age of two and three, the child is still to a large extent bound by the concrete properties in his/her use of the object. But as the exploration of objects becomes associated with the child's learning of cultural signs (first and foremost words), the child's explorative activity transforms into imitation, imitative exploration and creative play with the cultural properties and use of the objects in his/her everyday activity settings. Sandbox play is a good example of a central activity setting in many parts of the western world for the infant and preschool child to explore textures and material qualities of their environment. Often, toddlers in the western part of the world are placed in the sandbox or encouraged to enter the sandbox and explore the material qualities of the sand by touching, scooping, digging, pouring, etc., and later on shaping "cakes" and "castles", often by imitating older children or adults, or probed by adults. In other parts of the world, infants and toddlers engage in similar activities without the particular frame of the sandbox. The introduction of playful experimental activity with material qualities enables the development of basic motor-perception coupling and establishes the affordance of the sand as a particular material in relation to the child, different from other types of materials in the environment that cannot be shaped in similar ways. The affordance of shaping-play is often supported by other objects, for example, sandbox tools, the frame of the sandbox, rules and organisation of the activity setting of the sandbox (e.g., young children are placed in or encouraged to enter the sandbox, prohibited to dig sand out of the sandbox or bring dirt into the sandbox). The exploration of the material qualities thus establishes the foundation for the latter activity of shaping sand into cultural objects such as cakes. The shaping of the sand also represents an exploration into the activity of connecting material objects with cultural signs: at first, from the likeness between the object and the sign, seeing the cake of sand and naming it a cake or hearing an older child or an adult saying "look, a cake". The confusion of playing "as if" the cake of sand is a cake and the sign "cake" to denote the object of a real, edible cake is mirrored in the mistake of young children who take a real bite of the cake of sand. For the child who makes this type of mistake, the meaning and the object are still fused (Vygotsky 1966). It is only later in development that the relation between the object and the sign is separated and gradually turned around. This change is usually marked with the child's engagements in pretend play, first by the naming of objects with meaning, for example in the naming of the shaped sand as a cake. Gradually, the child becomes able to use the sign to plan

his/her activity with the material object and imagine the cake first and produce it afterwards. The child utilising his/her (newly) acquired ability to use sand moulders and knowledge about the material qualities of the sand (e.g., that wet sand makes better cakes than dry sand). The toddler and preschool child's exploration of the cultural meaning of environment and objects through play activities hold an imaginative stance towards the environment, the objects and the play activities itself. During the play activities, the child tries out various elements of "what if" and thus explores both the physical qualities (such as sand by touching and pouring) and the cultural qualities of objects, their meaning and use (such as baking, selling and eating cakes). The playful exploration of the cultural qualities, use and meaning of objects is bound up with possibilities for active exploration and thus the process of connecting the natural line of development – individual motor, perceptual and language skills – with the cultural line of development, the appropriation of meaning and use of concrete and symbolic tools.

Whether or not the child has a disability, it is through his/her motivated activity that affordances emerge between the child and the environment. The central difference is that the child with disabilities often has more difficult conditions for this active process due to the incongruence. Children with disabilities both have a reduced range of action possibilities and may play differently compared to typical children in a sandbox. The difference may be so distinctive that they cannot be fitted within the cultural frames of how to play, for example, in a sandbox.

## The Emergence of Affordances

Affordances arise and evolve from the developing relation between the child and the environment, inviting the child to particular sets of activities in accordance with his/her abilities and motives and the natural and cultural properties of objects and materials. At first, in very young children, the affordances of objects are closely bound to the immediate physical and situational constraints (Vygotsky 1966). As the toddler becomes acquainted with and learns to use cultural signs, the affordances cease to be the material qualities only and become infused with the historical and cultural meanings *at the level known to the child*. The child gradually becomes acquainted with the natural and cultural properties through his/her own activities, framed by the activity setting. This process starts during the infant period with the development of shared triadic attention and continues as the child begins to use and explore objects in a more independent manner. Disability that hinders or delays development of shared triadic attention or independent exploration transforms into a lesser acquaintance with object properties. This happens because a central part of the object properties is the toddler's abilities and possibilities of impacting, changing, moulding, affecting and experience of using the objects towards his/her own motives and ends. Thus, a central element of development at the toddler age period is tightly bound up with the child's own interest, explorative initiatives and explorative capacities in relation to the different objects in his/her surroundings.

The activity of exploring the environment and objects arises from multi-perceptions of the environment that enable the toddler to explore the cultural meanings of objects and activities through play activity. Development of higher mental functions, in which thought/meaning is separated from the object, enables the child to act from culturally based ideas about objects, rather than the immediate perception of objects. Thus, affordances are *qualities that arise between the meanings as perceived by the child and the cultural meaning*. The child develops a basic sense of his/her own agency in relation to concrete objects and activities, and an understanding of their (cultural) meanings and action possibilities. The abilities and disabilities of toddlers with impairments to actively explore objects and the environment thus impact on the development of higher mental functions, even in children whose impairment does not seem related to this ability, for instance motor disorders, chronic somatic diseases, or visual impairment (see Smitsman and Schellingerhout (2000) “The landscape experiment” elaborated upon later in this chapter). Possibilities for activity with objects – or lack of possibilities for exploring and acting with objects – are subjectively built over time through the infant and toddler’s experiences with objects in his/her concrete activity settings. As became apparent in the previous chapter about infants, development of intersubjective interaction with young children with disabilities often requires use of different means. The call for different means continues into the toddler period in relation to play and development of social agency. As we will return to later in this chapter, play with children with different types of impairments often requires different ways of organising the activity, although the child’s aim of the play activity might be the same: to explore and act with objects and cultural-historical activities encountered during everyday living and in social interactions and communication.

## **To Play and Not to Play with and Without Disabilities**

Children with disabilities are involved in many activities with a wide array of objects: some of a more common kind, some specialised, such as aids and particular training objects. Thus it becomes important to delineate what marks out an activity as ‘play’, compared to for example ‘training’ or ‘treatment’, especially because many treatment and training programmes for children with disabilities are organised with play-like or game-like features. However, this does not necessarily turn them into play from the perspective of the child. For an activity to be play, the child’s explorative activity must entail a high degree of involvement of the child (van Oers 2013). The imaginative stance towards objects and the environment – the playful exploration of cultural qualities – is grounded in the child’s perception of what is important, impressive and interesting (Schousboe 2013a). Play cannot be imposed on the child and similarly, explorative activity must take its point of departure from the toddler’s own interest and perspective. Vygotsky (1998) explicitly stresses that development through imitative acts needs to be founded in the child’s own exploration of the meaning of the activity it imitates. Play activity must also be



based in a relatively high degree of freedom for the child in relation to the form and content of the activity (van Oers 2013). The delineation between treatment and play thus will often need to be made by considering the freedom of the child to explore motives and interests – not by superficial features of the activity. The demands placed on the child in treatment and training activity settings depart in motives usually set forth by someone other than the child, often a therapist, developmental psychologist or parent.

However, adults and specialised aids might come to hold a central role in the impaired child's play with objects. The child's playful exploration is based in his/her cognitive and physical abilities at the time, along with previous experiences in the particular activity setting. As a consequence, different types of impairments hold the potential to impact on the toddler's process of exploring the environment by play. The impairment may change or hinder the awareness of objects or aspects of objects. For example, severe physical impairments in the arms and hands hinder the infant and toddler in grasping objects, thus not developing a sense of some objects as 'graspable'. The young blind child will not be attracted to and explore the colourful patterns of an object. The impairment is transformed into different types of involvement or non-involvement with objects. The impairment may also have the effect of making specific aspects and qualities of objects and activities particularly salient to the child, for example the touch of the surface or the reflecting qualities of a shiny object for a child with visual impairment.

The inability of the young child with physical impairments to grasp objects or the blind child to explore mirrors and the attraction to particular aspects of objects must be understood in the cultural-historical practices, where tools and toys are built for use by children and adults with typical motor and perceptual abilities. The cultural-historical typical toddler's exploration of objects and his/her environment and emerging affordances is supported by cultural-historical practices for children's rediscovery of the use and cultural meanings of objects. Toys and cultural tools in the toddler's environment are developed to support an active stance towards the environment. They are designed to fit and support the perceptual and motor skills of the child and at times to constrain and shape the activity of the child in accordance with adult's motives and values about children's activity (Valsiner 1997), developed from societal values about desirable play activities and developmental goals (Schousboe 2013b). Thus, the natural line is not alone in enabling and constraining the development of environmental affordances. Different social, cultural and historical frames encourage or support particular practices for toddlers' explorations. Impairments impact not only on use of the object, but on the whole process of supporting the toddler's exploration of the cultural meaning of the objects through imitation and his/her own agency in building relations to objects relative to the child's own motives and acts. The impact of disability on possibilities for play activities during the toddler age is tightly connected to the child's development of an active stance towards the environment and his/her possibilities with it. Societal values about normality and how objects should be used and what kind of interests are acceptable or not are passed on and enacted by adults vis-à-vis the child.

The incongruence between the toddler with disabilities and the cultural objects become enhanced if the child follows atypical interests and/or atypical ways of engaging with objects and activities, ways that do not fit with conventional cultural practices of tool use, play and social conduct in general. One of the characteristics of children with autism spectrum disorders is described as atypical and stereotyped use of objects, for example, paying exclusive interest to turning one wheel of the toy car, having huge interests in dinosaur's skin structure instead of typical play themes with cars and interests in dinosaurs. The atypical and stereotyped use of objects is not the core essence of what autism spectrum disorders are, but one identifiable sign/symptom of incongruence, given cultural expectations about how this object should be used in play activities. Not surprisingly, children with autism spectrum disorders also show deviant symbolic play behaviour. Both object and play divergences are observed, which can be traced back to early social interaction and communication difficulties, among other difficulties with engaging in joint attention (Jarrold and Conn 2011). The way the other social actors (parents and professional adults) react vis-à-vis the unusual interests and play activities, with demands and organisation of constraints or possibilities in the activity setting, is a theme to which we will later return, when we consider how different practices of treatment create different ways of relating to the child.

## **How to Support?**

Delay in the child's development is common in case of impairments, both due to more limited access to the world and due to difficulties of participation and active independent exploration. The adult and/or one or more intervention methods might come to occupy an important role in providing objects and aspects of the environment and activities of interest to the child, thus enabling and guiding the child in his/her exploration of motives. The challenge might be for the adult to pin down exactly what type of objects and activities the child might be interested in. Often, the process will build upon joint attention; therefore, any delay in joint attention has the potential to impact on the availability of objects of interest to the child. In order to foster an active stance in the child, it is important for adults around the child to explore the interests of the child – and in the case of children without apparent interests and curiosity to raise an interest by all means. For children with impairments, this will often include stressing or exploring different means, using alternative sensory modalities such as the tactile or auditory, use of different light, different materials, or alternative toys and activities. This idea has been a founding idea in the building of “Snoezel houses” (Chitsey et al. 2002) and similar interventions. Snoezel houses have rooms specially designed to stimulate the senses with light, music, movement, scents etc. Activities and objects are introduced with the aim of awakening and stimulating one or more senses. Snoezel houses are commonly used with children and adults with multiple disabilities. However, to successfully awaken and stimulate the senses in a cultural-historical approach, sensation must be

connected to exploration of cultural objects, activities and artefacts in a cultural-historical practice. Due to the risk of overstimulation, Snoezel houses have to be more than "sensory stimulation": they have to be social and cultural mediated activities of development. After "awakening" a child with severe intellectual impairment with light, sound, and vibrations, these impressions have to be communicated and thus shared in a social and cultural setting. Another important requirement is that the child experience agency, for instance, by being supported in the ability to start and stop the stimuli. Thus activities, materials, lights, etc., can be used to introduce the child to the idea and strategies of exploration. The activity and the use of alternative means need to be based in the adult's hypotheses about the child's interest, interpreted from the way the child acts with objects. The specific motives develop and are developed by the object and activity affordances experienced by the particular toddler as the result of former experiences in specific practices. The toddler has to develop an interest in and ideas about what he/she would like to do with the object in the near future. The affordance of the same object will change as the child plays with it, becomes experienced with it and develop new motives for exploring and using it in his/her play activities. At the same time, motives and affordances develop and change as the cognitive and emotional abilities of the child grow, leading the child to new forms of acting and participating in new cultural-historical practices, thereby providing the child with new cognitive and emotional challenges.

The degree of freedom within the play activity is central to its developmental nature (Schousboe 2013b). The child with severe physical impairments is extremely dependent on others to make interesting objects available, to manipulate play objects for them, to place them in locations and positions where they will be able to explore materials, objects and play themes in accordance with their motives. It has been shown that teaching of triadic gaze in young children with physical impairments can improve this skill (Olswang et al. 2014). By teaching the child with physical impairments to use triadic gaze, the child's own capabilities and ability to act are improved in a central way, but the maintenance and further development requires continued interpretations by the adult about what the child finds interesting about particular objects and what types of questions it would like to probe on his/her own or assisted by the adult.

## **Supporting the Child's "What-If" Exploration of the Cultural-Historical Environment**

The development of affordances hinges on motives and affects intentionality of the child, as outlined above. The development of affordances also hinges on a degree of freedom for the child to pursue the qualities and queries it finds interesting. It is the toddler's own questions of "what if" explored through playful exploration of the objects.

For many children with disabilities, the degree of freedom in explorative activity becomes a challenge, not only due to their impairment and their greater dependence on support, but also from the cultural-historical values of particular intervention or treatment programmes. Treatment programmes for children with motor impairment can serve as examples of the dynamic relation between society's value positions and down to the demands met by the children in their everyday settings. Earlier, the dominant intervention for toddlers with physical disabilities was aimed at the remediation of locomotor skills based in a theoretical frame that conceptualised development in a stage-like manner. The main aim was to get the child to walk as much as possible and normalise movement patterns, while atypical movement patterns and use of aids that could ease the child's explorative activity were discouraged (Wiert and Darrah 2002). For typically developing infants and toddlers, development of locomotor skills take place along with explorative activities. Nevertheless, for toddlers with motor impairments, remediating support of locomotor skills often takes place within a framed activity organised by adults. Within this treatment practice, the support of the toddler's locomotor activity is organised towards specific goals set by the organising adult and might thus compete with remediation of more open-ended opportunities for physical-motor exploration (Henderson et al. 2008). The social values and practices for children with particular impairments thus impact on the demands made on the child, the particular organisation of the activity setting and the child's possibilities for development of motives and affordances in particular activity settings, as pointed out in Chap. 2.

Leontjev (1981) stresses how motives arise and develop from changes in the relation between the child and his/her activities. The motive to explore is both associated with the social practice of remediation and the child's previous experiences and motives associated with that practice. Starting with the first point (the affective intentionality of the explorative activity) it is seen that the incongruence between children with motor impairments and the cultural conditions for participation create a passive stance towards the environment, sometimes conceptualised as "learned helplessness" (Butler 1986). Reinterpreting the passivity in relation to the treatment approach introduced above, the passivity reflects the child's successive experiences of the environment and the objects as unavailable. It creates affordances of objects and activities that do not invite the child to explore. Without the toddler's questions of "what if" towards the environment, and the objects and tools within it, the affordance relations and the child's explorations of objects and tools do not develop. It is not that the toddler with disabilities is unable to understand or learn to manipulate objects and use tools, but due to the incongruence, he or she has not been able to participate to the same extent as toddlers without impairments in the activities where the cultural use of tools is mediated.

## The Landscape Experiment

Another group of children whose impairment impacts on their possibilities for exploring is young children with congenital blindness or severe visual impairment (Preisler 1996). Smitsman and Schellingerhout (2000) designed an intervention project aimed at the explorative activity of a group of children with congenital blindness or severe visual-perceptual impairments. The study is discussed here, because it illustrates some points of interest. First of all, the intervention departed in the general problem mentioned earlier: that many toddlers with different impairments display or develop, as part of their disability, a passive stance towards the environment. The hypothesis guiding the intervention was that the loss of the visual sense diminished the infant's and toddler's ability to explore the environment, because the information from the remaining senses did not support the child in developing a sense of relationship with surrounding surfaces and the environment at large. As stressed above, explorative curiosity does not arise from the child alone, but from the child's active interest in and possibilities of exploring his/her own questions of "what is" and "what if" and how the explorative activities are supported and either encouraged or discouraged by adults. In the study, an environment and an activity were created that supported the child's own explorative activity in an open-ended manner. Secondly, the study also illustrates why the incongruence between the toddler with impairments and the environment suited for children without impairment easily translates into developmental delay, even when support and treatment are provided. The intervention was built on a Gibsonian theoretical perspective (Gibson 1979), but the basic idea of the experiment was in accordance with the basic Vygotskian understanding of disability: that the problem of blindness is not the missing visual sense, but the reorganisation of the remaining system vis-à-vis a cultural-historical environment built to support exploration and activities of toddlers with typical visual functioning; and further, that the function or dysfunction of the senses integrates with cognition.

The participating children were placed in front of a specially designed surface, a small-scale landscape made of rubber with small bumps scattered over the surface as a pattern of texture gradients. Through activity of touching, rubbing and fingering, the children could experience patterns of differences in the surface and thus explore the landscape by touch, developing a sense of how particular sensations relate to direction and location of the hand vis-à-vis the environment (Smitsman and Schellingerhout 2000). Hence the atypical activity setting was aimed towards developing the relation between the child and his/her environment, through the support of the child in building a state of awareness about his/herself and the environment.

Of course, the small-scale landscape with rubber bumps did not represent the children's activity settings at large. However, over a prolonged period of time (five experimental sessions), the participating children developed more active reaching. Within the experiment, they became more efficient in searching for and finding a pin placed within the miniature landscape. In the family setting, the parent reported that their children showed more explorative activity, although this data was not gathered

systematically, but appeared from informal conversations. Increased reaching has been interpreted as the emergence of strategies for how to gather and use sensory information, building on an experiment by Ungar et al. (1995). In this experiment, the strategies and ability to mentally rotate were examined among partly sighted and blind children who had to explore and reproduce a layout of tactile symbols. Five different strategies for learning the layout of tactile symbols were identified and it was found that the use of a more efficient strategy predicted reproductive performance rather than degree of visual impairment.

Mental strategies for reaching and exploring are higher levels of perception; therefore, strategies for information-gathering will also enable the child to consider questions of “what if I do this” and subsequently seek answers to his/her own inquiries. Secondly, the higher level of perception supports development in the child’s sense of the use of touch and of a more active stance towards those affordances of surfaces, objects and materials in the environment, which can be explored by touch. The small-scale landscape intervention seemed to support the children’s ability to reorganise their sensory system and the way the senses were integrated to structure information from the environment and thus support the child’s active exploration of environmental affordances. Since exploration and imitation are both central to the genesis of symbolic activity and development of higher mental functions, the child’s exploration of objects and playful experimentation with tool-use develop both the natural and the cultural line of development and support the coupling between them. A biological impairment that affects the child’s ability to engage with the environment and the objects within it potentially affects the linkage of the two developmental lines and creates or enhances developmental delay in the child’s development of higher mental functions.

For children with different types of impairments, their freedom to explore often becomes intertwined with treatment goals or the framing of an aid. Treatment aims might risk being foregrounded at the expense of supporting the active stance of the child. Nevertheless, the developmental incongruence needs to be approached from a wholeness approach that addresses the child’s social situation of development rather than isolated impairments. To be able to do so, adaptations and tailored support of the child’s explorative activity, as illustrated in the study by Smitsman and Schellingerhout (2000), is needed. First, it is necessary to ensure the presence of objects that the child can explore actively with or without support. In order to be able to do thus, parents and other supporters of the child need to have specific knowledge about the nature of the child’s impairments: not just a diagnosis, but the child’s specific array of abilities/disabilities. Secondly, it is necessary to ensure the presence of objects of interests for the child. The parents and others therefore need to know the types of activities that typically arouse interest in that particular child, as well as the usability of different objects. It can be anything: post offices (as illustrated in Buchanan (2009)) or buses, bus drivers, routes of busses, mud, etc. Thirdly, more time will often be needed to explore objects and activities.

The cultural-historical approach represents a different way of thinking about intervention, assistants and assistive devices. Foregrounding and supporting the toddler’s building of an active affordance stance towards the environment feeds forward

into the toddler's future ability to explore his/her own queries about object properties and to explore cultural ways of handling objects, even though developmental delay may be inevitable. The impact of cultural-historical frames for support on the child's possibilities for developing his/her social agency will be further explored in the next section.

## **A Societal Level Perspective on the Child's Development as a Social Agent**

Object exploration and development as a social agent take place within cultural-historical settings, in the family and often in daycare institutions, at least in the western part of the world. For the toddler with a disability, the longitudinal trajectory through institutional practices is often problematic, because the institutional practices and age-graded demands are culturally-historically adapted to children with normal psychophysical constitutions (Bøttcher and Dammeyer 2012; Vygotsky 1993). Societal acknowledgment of the toddler's impairment and need for developmental support beyond what is offered to typical children and their families is expressed at the societal level in the financial support of treatment programmes, in the building of specialised support systems, education of professionals and access to different types of aids. The arranged establishments for support affect the developmental conditions the toddler will face in his/her particular social practices. In the toddler's specific activity settings, treatment programmes and intervention of the specific impairment often create alternative developmental pathways – both in mainstream and in specialised settings. Therefore, from a cultural-historical point of view, the development of the child is not formed by the impairment in itself, but can only be understood when looking at the child and his/her social situation of development together. Aids, specific interventions or more comprehensive treatment programmes enter the social situation of development as a smaller or larger part of the child's developmental conditions, as we will exemplify in the following section.

Children with autism spectrum disorders are suitable as a main example of how specialised adaptations impact activity settings and demands. The general acceptance, at least as a dominating value position within the western countries (i.e., that autism is a spectrum disorder with specific symptoms that must be treated) has resulted in the emergence of a wide range of treatment practices. One example, which will be discussed below, is the widely used Applied Behaviour Analysis (ABA) treatment programme (Peters-Scheffer et al. 2011) (see also Chap. 2). Looking across the variety of treatment offers, it is easy to notice the many similarities between them. The dominant approach across the programmes is "early intensive treatment". *Intensive* treatment is often built around comprehensive treatment practices, addressing behavioural, language and social interactional aspects of the child's activity during a substantial part of the child's waking hours. The general recommendation of these treatment programmes is that treatment needs to start

*early*, preferably before the age of five. Often, the treatment involves the *family* to a great extent by addressing problems in communication and social participation skills. A good family function gives an enriching environment, supporting the child's development and prevents development of secondary mental health problems such as anxiety, eating disorder, or challenging behaviour (Meng-Chuan et al. 2014). Despite the relevance of the interventions, the inherent value position of the treatment will lead the parents, pedagogues and therapists in creating demands differently than for typical children. They will interpret and act differently in relation to the activity of the child and consequently the support of the child as a social agent will be different.

ABA is a family of treatment practices based in the application of behavioural principles and the theoretical framework of operant conditioning (Peters-Scheffer et al. 2011). The actions of the child are analysed in relation to antecedent stimuli and the child's prior experiences of consequences. The basic method is that the child is presented with stimuli, reacts to the stimuli, and the child's act is then followed by the consequences that can be positive reinforcement if the act is among the preferred, or ignored or punished if the act is considered unwanted (Lovaas 2003). The aim of the programme is to shape the child's actions towards normal/typical ways of acting, preferably within an inclusive setting. The ABA treatment practices are often very intensive and time-consuming compared to typical treatment. The efficacy of ABA has been investigated in many studies. Results are unclear, both in regard to overall treatment gain and size of effect, possibly because of differences in treatment programmes and variations between children receiving the treatment (Dawson and Burner 2011; Eikeseth et al. 2012; Peters-Scheffer et al. 2011; Spreckley and Boyd 2009; Virués-Ortega 2010). Another problem is that many of the studies of the effect of early treatment use measures such as IQ to document treatment effect. Although a gain in IQ may be beneficial for the child, the increase in IQ does not necessarily translate into better everyday functioning. Another study measuring gain in adaptive functioning found that intensive (between 15 and 40 hours per week) and non-intensive targeted behavioural treatment (e.g., toilet training or speech training) did not differ significantly in outcome with regard to adaptive functioning. Both groups were in need of specialised support afterwards (Fennell et al. 2011). It is worth noticing that this study included children with epilepsy, learning disabilities and other additional problems together with autism spectrum disorder, children who are often excluded in other studies.

Another study also focused on gain in adaptive functioning did find a significant improvement following early and intensive treatment based in ABA compared to less intensive, targeted treatment (Eikeseth et al. 2012). Still, the remaining point stands that even though treatment gains may be seen, especially in children with normal cognitive level of functioning at the start, the treatment may diminish the incongruence, but does not eliminate it.

Another widespread treatment practice is the TEACCH programme (Erba 2000). The TEACCH approach recognises autism spectrum disorders as a lifelong condition and does not aim to cure but to respond to autism spectrum characteristics as a "culture" – that means the acceptance and respect of the unique behavioural,



communicative, cognitive and social characteristics shared among people with autism spectrum disorders. It focuses on children with autism spectrum disorders as visual learners and users of structure, schedules, and work systems. The programme aims to support difficulties with communication, organisation, generalisation, concepts, sensory processing, change and social relations (Mesibov et al. 2004). Next to behavioural therapy, the treatment approach draws on the Piagetian constructivist approach and stresses the necessity of the child as an active cognitive agent in his/her own learning. The basic understanding behind the programme is that the autistic symptoms arise from an organic aberration within the child that causes difficulties in the child's ability to create a coherent meaning from the incoming stimuli. In conceptual accordance with the Piagetian constructionist understanding, this central deficit constrains the child's ability to gather information and learn from his/her activity, either by assimilating the information with existing conceptual schemes or by accommodating his/her schemes to the situation at hand (Erba 2000). From the point of view of the TEACCH approach, the dysfunction in the basic biology/organic constitution of the child is considered impossible to cure. Rather, the aim is to address the fit between the child with autism spectrum disorder and the child's social practices and to support the child's ability to understand the ongoing activities and participate in them as an independent agent, despite his/her different preconditions. The unusual actions of the child are understood as arising from the child's cognitive deficits that make it difficult for him/her to understand the meaning of the activity within the practice, including what is expected of him/her. The solution is to provide an environmental structure that will assist the child to understand the meaning and demands of activities within his/her daily practices and to learn through active participation. Undesired actions can also be extinct by operant techniques if the child's acts are considered highly problematic and counterproductive to learning and developmental activities. The weight, however, is on accommodating the environment to better support the child's learning, especially learning of social and communicative capacities.

At a micro-perspective, the choice of treatment approach shapes how a child participates in concrete activity settings and *affords* a particular activity of the staff in response. Bøttcher (2014) analyses how different children within the same learning/treatment environment were met very differently by the adults present. All children participating in the study had severe cerebral palsy and depended on the support of adults for taking care of all basic needs. The support included moving them around in their wheel chairs and supporting their communication by supplying them with their communicative aids and interpreting their signs and communicative acts (e.g., pointing to a symbol on a communication board). One group of the children had very salient reactions when the adaptive fit between the child and the environment was weakened. They would react by becoming loud, violent or very distressed. Due to repeated experiences of these salient reactions, the staff had developed a practice of monitoring the current mood of these children continuously in order to prevent the situations. The children that required constant monitoring had an "urgency" attached to them, not as a physical sign or personal quality, but as agents in the learning practice and in the concrete activity settings. The urgency was

felt and acted upon by the parents and the professional adults. The afforded urgency opened up the necessity of tailoring the practice to accommodate the motives and activity of the child, thus creating conditions for the child to experience and develop her- or himself as a social agent. During his first year at the school, one “urgent” boy, “David”, participated in the standard, group-based teaching activities at the school. However, as time passed and the staff successively had to deal with David’s salient reactions when the organisation of the group-based activities did not fit with his particular needs, a new teaching situation was created especially for David: In the following years, he participated in a highly tailored school day. He was moved to a different department with his own room and solo learning activities with tailored content and speed. In addition – and contrary to the ordinary practice at the school – the teacher from his former department now worked across departments and taught David in his new department. In addition, a retired favourite pedagogue of David came in every Monday to secure a good start after the weekend (Bøttcher 2012). Other urgent children over time also ended up in different practices tailored especially to their particular way of participating.

Another group of children was less successful in their attempts at social agency. They acted, but their much less salient actions did not afford a response from the professional adults. Contrary to the group of urgent children, these children seemed “silent” in the particular activity settings. Again, “silent” is not a description of an individual quality in the child, but a description of the relation between the child and the adults, the affordance the child holds in particular activity settings. The afforded “silence” did not support further tailoring of the practice and thus maintained the present situation, including the current level of incongruence that lacked support of participation and development of social agency. Hence, the children’s conditions for exploring and developing their own agency also depended on the type of response from the environment; both the physical environment and the persons present within the different activity setting that together conditioned the child’s social situation of development. The affordances of “urgent” or “silent” were not related to the relation between the child and the professional adults alone, but emerged as functionally significant properties in environments with cultural-historical properties, including the values within the institutional setting (Bang 2009).

Whether it is ABA treatment, the TEACCH approach or yet a third treatment approach, the parents and the professional adults around the child are motivated by their goals, with the children emerging from the treatment as a cultural practice. Within the ABA approach, monitoring is related to decisions about the need to provide a positive reinforcement or opposite to negatively reinforce the activity initiated by the toddler. Within the TEACCH approach, monitoring is related to decisions about the need to make adaptations to the activity setting in order to support the toddler and counteract the child’s tendency to act out in a non-adaptive manner. The affordance of being silent within an ABA treatment setting could be an action by the toddler that is not noticed or granted importance within the behavioural analysis, for example because it was overshadowed by other behavioural aspects in the situation. Within a TEACCH setting, it could be a vague lack of fit between the toddler and the situation that does not result in undesired behaviour but on the other hand does

not support the toddler's agency. The child's success or failure in making an impact on his or her conditions for acting feed forward into future conditions for experiencing oneself as a social agent, pointing him/her in directions of an active versus a passive stance towards the environment. The active stance holds the greatest potential for the toddlers to further their own development through their shaping of activities towards activities and content of interest for them. However, the creation of the active stance also depends on a sensitive environment. The social agency of the toddler is shaped by the type of activities and exploration that are available and possible for the child and how the child's agency is met and acted upon.

The importance of the conditions for social agency provided by value positions, adult motives and adult demands is applicable to all toddlers. Two aspects are special in relation to children with impairments. First of all, they are often objects of intensive treatment, with the risk of leaving them with a lesser degree of freedom for their development of social agency. The degree of freedom to follow his/her own interests and intentions risks limitation within, for example, an ABA programme, due to its time-intensive nature with pre-planned training sessions built around adults prompting and reinforcement of preferred actions. Secondly, due to the incongruence, toddlers with impairments are often dependent on a tailored set of supports and demands in order to be able to participate. Accordingly, their early development of social agency is more constrained and more dependent on the active support from parents and other adults.

## **Parents as Supportive Systems: Play and Development of Social Agency from the Parents' Perspective**

Research in play activity of parents with toddlers with impairments reveals that many parents adapt their interactions during play to their child's developmental level and the responsiveness of the child. Several studies of parents (mothers) of children with autism spectrum disorders found that they applied a strategy of more attention-getting behaviours, more physical proximity and greater use of non-verbal prompts, compared to mother-child pairs with typically developing children. And more important, the alternative strategy of the mothers supported the mutual play activity (Doussard-Roosevelt et al. 2003). Similarly, a study of mothers playing with their toddlers with Down syndrome showed that the mother's participation in the play activity supported the engagement and active exploration of the children compared to when the child was playing by him- or herself (Childress 2011). Parents' adapted engagement in their toddler's play activity has been found to be important for their development of, for example, communication both in children with global developmental delays due to prenatal alcohol or drug exposure (McConnel et al. 2002) and in children with autism spectrum disorders (Siller and Sigman 2002). Parents of toddlers with disabilities hold an important role in

supporting their children's development as social agents in the time-dominating activity of that period: play.

As noted in the previous section, the disabled toddler's conditions for social agency are profoundly shaped by societal value positions and the motives of parents and other adults as they together set the scene for the interpretation of the child's own contributions in the daily activity settings. Although the toddler is never without means for making demands on his/her activity settings, the affordance of the child with disabilities in relation to the adults and their motives was shown to hold important future implications in relation to the child's development of an active versus passive stance towards the environment. Seeing that parents of toddlers with impairments act differently both when playing with their other children without disabilities and in comparison to parents of typically developing children (Doussard-Roosevelt et al. 2003), the question that comes to mind is what the children with disabilities afford to their parents? What are the motives that lay behind the activity revealed in the research recapitulated above? The following case study of three children with different types of impairment allows more insight into the motives and acts of parents of toddlers with disabilities.

## Case Studies of Play

The study described by Buchanan (2009) used a combination of observation of everyday activities in the home setting and interviews with the mothers that explored the daily routines at home prior to the observations; and maternal perspectives on the play activities following the observations. Three mother-child pairs participated: a girl at 30 months with Down syndrome, a girl also at 30 months with asthma and a metabolic disorder and a boy at 32 months with cerebral palsy. The naturalistic study design allowed insight into important knowledge about the role of play in the supportive activities of parents of toddlers with disabilities.

First of all, the study highlighted the competence of the mothers in supporting their children in the home setting, in unison with many other quantitative studies (Childress 2011). Often, the initiative of the mothers in shared play activities took their lead from the children's own play motives, even when these differed from conventional play motives and activities. The most striking example was the boy, Corey, with cerebral palsy. At the time of the observation, he was able to roll on the floor to get around and he used signs for communication because he was unable to speak. Corey's impairments made it difficult for him to engage in pretend play on his own. However, one of his favourite activities was to get his mother to make up songs at his request and about themes he enjoyed (e.g., songs about the post office). The mother saw pretend play as a valuable activity but was aware that her son could not play pretend games on his own as he was unable to act out or speak/sing the imaginative play situations. She considered the song activity as his kind of pretend play and spent a lot of time supporting it (a little more than a third of their play episodes during the observations) (Buchanan 2009). His mother's sensitive

observation of the fantasies that engaged him and her use of them in narrative songs in interaction with him made Corey able to participate actively in song/play activities with developmental qualities of pretend play. Given the importance of pretend play from a cultural-historical point of view, this observation highlights the need to analyse the directive and supportive activities of parents “as activity with cultural meanings” for both parents and the child. This particular local adaptation to the developmental incongruence created alternative opportunities for Corey to explore cultural meanings of different activities in play – in the example going shopping and going to the post office – and thus supported his development of higher mental functions.

Another finding was that the mothers’ play activities with their toddlers with disabilities were often mingled in with the daily care and treatment routines. It could be during time-consuming diapering and physical therapy exercises or asthma medicine treatment. This is of course also the case with toddlers without disabilities. However, the importance of this focus at play in daily care routines for toddlers with disabilities is heightened because the often very time-consuming care and treatment routines – long mealtimes due to difficulties with eating, laborious dressing routines or daily physical therapy exercises – could be a source of developmental delay, as they leave less time for other types of activities. The challenge of time-management becomes even more pronounced later in the child’s development, as we will explore in Chap. 7.

In the study by Buchanan (2009), the supportive nature of the three mothers’ play with their toddlers was found to be a balance between the child’s initiatives and the direction of the child, set within the constraints of the activity setting. The mother’s supportive activity could be interpreted as a balance between passing cultural values and norms on to their children versus allowing the child to explore themes and motives of importance to them, even though they seem odd or repetitive from the parents’ perspective. Children with autism spectrum disorders constitute a group of children, where one main characteristic is their atypical way of relating to the environment. The atypical way is described as “excessive interest in particular objects”, “restricted interest”, “restricted object use”, etc. Often, children with autism spectrum disorders show a preference for visual exploration, spinning objects and rotating objects (Ozonoff et al. 2008), that are pursued at the expense of other types of object explorations. Research in the development of toddlers with autism spectrum disorders proposes a negative feedback loop, where the occupation with particular aspects of objects and activities results in less attention to the general activities within the activity setting and less imitation of activities and object use. However, as the motives of the child in relation to objects and activities arise from both personal interests *and* experiences *and* the social institutional values that shape activity settings (Hedegaard 2002), play with objects as an activity holds an important role in the development of the preschool child with autism spectrum disorder as a means to move towards more varied perception, cultural affordances and higher mental thinking about the environment and objects. Playful exploration of object affordances, even arising from atypical preferences for spinning or rotating, may provide a gateway for encouraging the child to explore the cultural meanings of

objects and activities through the supportive play activities of parents balancing their child's particular engagements with initiatives for further development of the play activity. A sole preoccupation with the biological impairments will point to questions of whether exploration and development of the play activity is possible, given the biological barriers of the child. An equally important awareness is needed to the cultural line of development and societal values about normality and preferred development. How do the child's practice settings allow different types of exploration of the environment and of objects and tool use, thus providing a basis for the child's further development as a social agent? As outlined above, research has highlighted how many parents of toddlers with disabilities are adept at accommodating their initiatives to the types of expression their children prefer, to the abilities of their children and to the motives in which their children are engaged, thus creating positive opportunities for their children to explore active social agency within the family setting.

For a child with autism spectrum disorder having a special interest in, for instance, the surfaces of trees or the mechanics of a laundry machine, it is first of all important to recognise the interest and share it, rather than trying to alter the child's interest towards more typical culturally accepted interests, such as how to use a laundry machine or collecting leaves from different trees. By taking the child's perspective, it becomes possible to share attention, emotions, objects and minds (Lorentzen 1998). To understand, respect and follow the child's first-person perspective and motive is essential in order to provide the child with conditions for active exploration and possibilities for contributing actively to the activity setting, even if the child's way of contributing may seem different and odd from a 'typical' perspective.

## **The Challenge of Playing with Peers**

The toddler is in many ways dependent on his/her parents and the parents hold a central role in supporting the development of the child. But compared to an infant, a toddler is much more independent, in respect to type activities, motives and the structure and organisation of the environment. While the focus of the previous chapter on infancy was on the impact of impairment on the social interaction between the child and his/her primary caregivers – their basic establishment of communication and intersubjective relationship with each other – a new central track in this chapter on toddlers will be the child as becoming an agent within a wider range of socially organised activity settings. Participation in activity settings with peers becomes important. Of course the child has been a social agent before the age of two. However, the end of infancy marks a time when the natural development of the child and the child's social situation of development together open up for social agency to become a dominating and challenging motive. The child can walk and move around, talk and communicate with other people and often spend many hours every day outside the home in preschool childcare institutions.

During the toddler period, other children are increasingly becoming important developmental conditions for each other, first and foremost as playmates. As mentioned in the previous chapters, the challenge across all ages is also to be timely. The child has to master specific skills in order to be able to participate in his/her social settings. During the toddler period, the relation to peers arises as a new aspect of the developmental incongruence, now between the trajectory of the child with disability and the child's peers following typical developmental and institutional trajectories. As the child begins to participate in activity settings with peers, in kindergarten or other preschool settings, the exploration of cultural meaning expands into play in pairs and groups. Individual imagining becomes supplemented and further elaborated with collective imagining. The social participation of toddlers and preschool children with disabilities concerns not only the ability to carry out play activities as the play unfolds: participating in the play activity includes being able to contribute to all aspects of the play; setting up and developing the make-believe events or rules of the play, staging the play by negotiating roles, rules and proposition, while taking the conditions of reality into consideration. Play thus involves three different spheres: the sphere of *imagination* where the play unfolds and evolves, the sphere of *staging* where roles, rules and the content of the play or game are negotiated and the sphere of *reality* being the environment, the participants and other physical or social conditions that the children may use, or at least take into consideration, within their play (Schousboe 2013a). The different aspects – spheres – of play are intertwined and operate simultaneously, although they vary in importance throughout the play activity. This conceptualisation of play elaborates on the elements of play from Vygotsky (1966) who stresses the rules and the pretend elements of play. To understand the impact of particular impairments and disability as an incongruence that affects social agency, it is necessary to include the impact on all aspects of play, not only on the ability to carry out an operation within the play, but the way the disability affects the child's ability and possibilities for participating in the setting-up and negotiating the imaginative aspect of the play and carry out the role required to participate. The relation between all three aspects will impact on the child's ability to participate in the play activity.

The incongruence arising from both developmental delay and impairment will affect the child's ability and possibilities for participating in play activities with peers. Children participate in play from their individual abilities, motives and cultural-historical knowledge base. A cultural-historical object as a blanket may signify a cape that transforms the wearer into a (particular) superhero or supervillain, thus starting a fantasy play building on and expanding themes from a cartoon known by the children in the game. The same blanket could also signify a completely different creature 30 years previously, or among children with no cultural knowledge or interest in superheroes. It could also be that a stick with a ball on string signifies the ball-game "Tet" for children in Sierra Leone, but a fishing rod for children familiar with that tool. Through meta-communication and activities with each other, children enable a collective exchange of meaning and negotiations of new meaning (Fleer 2013). Even games as early as peek-a-boo and rough-and-tumble physical games contain rules and thus elements of social negotiation through

exploration of these rules (Schousboe 2013b). Through the individual and collective imaginations, the child or children at play explore, negotiate and develop roles and rules within their particular cultural-historical activity setting. The reality and possibilities of “as-if” imagination and use of objects present in the environment is bound in the cultural-historical context.

However, play also needs to be regarded from the micro-perspective of children in particular activity settings. The knowledge base of children will not be completely similar, although children growing up in a particular country are introduced to a broad repertoire of similar tools, artefacts, toys, stories and activities at use within the cultural-historical practices (Schousboe 2013b). By going to a *particular* kindergarten or preschool and by participating in a *particular* peer group, children are introduced to a local range of activities and build their own repertoires of known and preferred play themes and activities (Winther-Lindqvist 2013). During their everyday activities, they continue earlier activities and games building on a micro-structure repertoire between friends (Winther-Lindqvist 2013). The incongruence arising from both impairment and developmental delay affects the child’s ability and possibilities for participating in play activities. Many types of impairments hamper the child’s ability to carry out operations within a play or game. Physical play such as rough-and-tumble constitutes a considerable part of early preschool play and often continues to be important in later fantasy and sport play, especially among boys (Winther-Lindqvist 2013). In these types of games, initiatives and contribution may be mainly physical or a combination of verbal and physical negotiation and contributions. Sensory or physical impairments may hinder the child’s ability to perceive or express contributions in the mutual negotiation of ongoing play. Research has shown how toddlers with hearing impairment experience difficulties in free play situations with peers (Spencer and Meadow-Orlans 2004). For example Brown et al. (2001) compared play activities of ten 30-month-old deaf children in a mainstream programme with ten hearing children of the same age. The deaf children’s play was delayed compared to that of the hearing children across a number of parameters. The researchers further found, similar to other studies, that the level of pretend-play was significantly related to their expressive vocabulary and language abilities in general (see also Chap. 8, relating to language and communication development). Sensory and cognitive impairments may easily hamper the child’s ability to understand or process social information during all three spheres of play. On the other hand, skills in cognition and communication can enable the child to negotiate a role that decreases the impact of, for example, a physical impairment. As an example, consider Donna, a girl at 5 years of age with moderate cerebral palsy, who goes to a mainstream preschool. On one day, when one of the authors of this book was out doing observational studies, Donna and two other girls play a game where they pretend to be dogs. However, Donna is not able to crawl. During the initial staging, she incorporates the reality of her physical impairment and negotiates that she is a dog trainer, while the two other girls are dogs. Thus she has negotiated a role for herself where she is an active part of the play despite her physical impairment. After the initial staging process, the play unfolds with Donna as the trainer of the dogs.



## Sharing Activities and Minds

The point of the above example with Donna is to illustrate a point by Vygotsky (1993) that disability has a twofold impact on the development of a child: (a) It impacts as an ongoing impediment and obstacle and (b) because development is fuelled by obstacles and disruptions, the defect may become an ongoing source of development of roundabout ways. Donna's roundabout way of participating was the result of her social negotiations in play and her ability to create a valid role in relation to the emerging play activity and the possible roles of her playmates. This process, understanding the intentions and ideas of others – and understanding them as different from one's own – is often referred to as theory of mind, part of a child's higher mental level abilities (see also Chap. 8). The conceptual composite of theory of mind is important here as a prerequisite to share a pretend world, negotiate roles, rules and events within the play, and to navigate between the spheres of reality, imagination and staging. Theory of mind is a requisite for negotiating a common imaginary world in fantasy and role-play, though not sufficient in itself. Theory about theory of mind has identified it simultaneously as an individual capacity and a socially enacted ability that builds on and expands the child's previous exploration of the cultural meaning of objects and activities alone and with his/her parents (Dunn 1996). From a cultural-historical point of view this is not surprising, but rather reflects an ongoing dialectic developmental trajectory of the child's development of social agency and theory of mind. Play activities contribute to the development of theory of mind as the children negotiate and develop the imaginative sphere of their play together by feedback, conflicts, break-down of the process and reinforcement from successful, joyful, fun or exciting developments of the mutual play theme. The ability to understand and process social information builds on basic individual cognitive processes, but develops during social interaction. Social cognitive development is necessary for the child to develop as a social agent, while social participation is necessary for social development to take place, impairment or no impairment (Dunn 1996). In friendship, children provide each other with ongoing opportunities to explore the understanding of each other's emotions, ideas and perspectives as they play (Dunn et al. 2002). A word, a sentence, a movement might refer to a game or play activity from the day before, to a cartoon story or a character from a currently popular children's series, a computer or tablet game. A basic theory of mind ability will be necessary, but not sufficient, to participate in both staging and the play itself. To follow the suggestions made by the other children, the child needs to be acquainted with their cultural-historical and local repertoire of play themes and recurrent play activities. For toddlers with disabilities, their development of valid, meaningful participation in play activities draws on social cognitive capacities *and* at least a basic knowledge of what the activity is about. The child needs to know what type of act or suggestion would constitute a valid contribution to the play or game, based on previous participation.

The consequence of developmental delay or prior participation in for example a different, specialised activity setting becomes expressed in the child's lack of

relevant knowledge in the new mainstream setting. Research has pointed out deviations in the play of children with disabilities. This may be seen among children with autism spectrum disorders in preschool settings where Wong and Kasari (2012) found that, compared to children with other developmental delays, children with autism spectrum disorders spent less time engaged in symbolic play. The children and adults were observed in their classroom environment for two hours over three separate days and a coding system was used to identify play and joint attention behaviour. Even though this study does not explain why the children with autism spectrum disorders differed, it shows their participation is different; a difference that will leave them with less experience with symbolic play later on.

Many support programmes and interventions of the child arise from a biomedical and behavioural approach that addresses the difficulties of participation in play activities as an individual lack of ability in, for example, turn-taking. The individual and specific ability focus fails to include the important point that even when support is provided for the particular impairment, the child might still lack the right type of cultural knowledge to be able to come up with contributions that are judged as relevant by the other participants in the game or play activity. This child's knowledge base can only be built through participation in the peer group over time and as long as the adults who support the child continue to bear in mind the dialectic nature of the child's difficulties with participation. In the previous example (Wong and Kasari 2012), the researchers noticed that the preschool teachers rarely facilitated play situations or otherwise supported the children's abilities to play.

The example of theory of mind illustrates how children at the toddler age period and forward are beginning to function as developmental conditions for each other (Højholt 2012). From the perspective of the children, an important set of developmental conditions, opportunities and demands now arise from the peer group. Impairments and developmental delays potentially affect the child's trajectory vis-à-vis other children. Attitudes towards the child, how the child experiences his/her own capability as play partner and is experienced by others as a play partner becomes important. The motives of adults and other children participating with the child are not per se developmental. Social agency within the peer group is bound up on the child's ability to contribute socially, first and foremost in play activities. An impairment may result in different interests and cultural knowledge of a child. The child may show a preference for types of play or for stories, television programmes and computer or tablet games aimed at children younger than the child's chronological age. This can cause the child's initiatives to become regarded by other children as invalid and "childish" contributions, meaning not age-appropriate, thus increasing the incongruence. Atypical interests and/or a large amount of time spent on training programmes will also contribute to the child with disabilities as set apart from the knowledge base of more typical peers. The difference in developmental level becomes expressed in asymmetrical positions and different leverage in negotiating the play. Contrary to the play activity with parents, who have been shown to use their superior developmental level to support the initiatives of their child (Buchanan 2009), the child with a developmental level below the other children in a peer group will often find him- or herself in a subordinated position with limited

or no influence on the play interaction, as Nordström (2011) found in her study of children with intellectual disability in an inclusive setting.

Still, the dialectic approach clearly points to a need to include peers as part of the support of toddlers with disabilities. Several treatment approaches do invoke peers as “peer-therapists”, for example, in teaching children with autism spectrum disorders to participate in simple play activities like rolling a ball back and forth (Strain et al. 1977). However, this and similar intervention practices had limited success beyond the isolated activity setting and a behavioural measure level (Strain and Schwartz 2001). Seen from the cultural-historical perspective, the use of peer-therapists introduces a different motive to the shared activity compared to the situation where two children are developing a play activity together with each of them contributing and negotiating about the content and setting of the play. The child with impairment risks becoming the object of the activity rather than a social agent in his/her own right. Becoming and being able to participate in a social group hinges not on the social and cognitive skills of the child alone but also on the child being recognised as a social agent within the peer group. The child’s initiatives for negotiating the demands of a play or game need to be recognised and accepted by the other participants. Böttcher (2010) provides a case about a boy, Angus, with moderate cerebral palsy, who was included in a mainstream setting. It is autumn and most children from the class successively play a wild game of running and throwing leaves at each other. Angus joins the game and performs as well as he is able. He has developed a technique of bending down and slowly raking leaves together with his hands, then picking up the pile and walking as fast as he can to throw the leaves at some other child, preferably someone standing still. Both Angus’ gathering of leaves and the process of running and throwing leaves is slow and strenuous, compared to the quickness and agility displayed and acclaimed by the other participants. Still, Angus’ participation is recognised and leaves are thrown at him, thus appreciating him as part of the game despite his less ample performance. The example with Angus illustrates that the establishment of a child with disability as a social agent has two sides: the child’s ability to negotiate the demands of the activity setting where the play takes place and the peers’ acceptance of the child as a valid social agent.

Returning to the societal perspective, the life of the child takes place in cultural-historically based institutionalised opportunity situations, meaning that even though life in our present society is marked by a high level of free choice, there are limits to the range of available trajectories that arise along the developmental path (Hundeide 2005). In many current cultural-historical social practices, childhood is partitioned by participation in successive and parallel institutions. Delays can be difficult to make up if the child misses social developmental opportunities that disappear as the child moves on through his/her institutional trajectory. Within the social setting, the biological development of the child, seen in the bodily changes of the child and the fact that these are not reversible, also become of consequence. The child with a bodily appearance of 10 years of age and interests and preferences of play activities more typical of children aged three might find it difficult to find play-mates, at least in mainstream settings. At the same time, same-aged peers find the

child's initiatives invalid or not interesting. Supporting this child in the development of social skills thus calls for creative thinking in how to create opportunity situations for shared social activities with peers. The need for peers as developmental conditions for social skill development is not necessarily unattainable, but stresses a real need for addressing the wholeness of the child's disability in his/her social situation of development, rather than training of isolated impairments.

### **“The Integrating Background”**

The development of the toddler with disability as a social agent together with other children hinges on the ability of the child to contribute to the activity. This means a general sense of being able to contribute to, impact on and negotiate the shared social practice. The challenge is the fit between the wholeness of the child's social situation of development and the finding of common motives for all children within the activity setting. In cases of large incongruence, this might not be attainable by the children alone. Rather, it will require support from adults that helps to create the framework for development of a common motive for all participating children. The adults need to hold a motive of supporting the child with disability to contribute to the activity along with the other children in the activity setting. One example of such a cultural-historical framed inclusion is “The Integrating Background”, based in the idea that the professional adult creates common zones of development for all children through exploring the traces and engagements of all the present children (Cecchin 2013). “The Integrating Background” works with projects in which professional adults enter the negotiation sphere of play along with the children. Through the mutual participation in both the negotiation and imagination spheres, the adults observe the interests of the children and use this information to plan and organise pedagogical activities that includes the diversity of the children. The purpose of the activity is not to teach particular skills to all or to particular children, but to enable social interaction between the children through searching for significant elements in the interests of the present children and creating connections between them in narratives and activities (Cecchin 2013).

### **Summing Up: The Challenges of the Development of Social Agency**

The development of oneself as an independent agent is by no means a developmental theme that is finished by the end of the toddler period. Rather, development as a social agent continues throughout childhood and adolescence into young adulthood and can be seen as part of a lifelong development. The important point here is that during the toddler period, social agency is established as an important foundation

for further development. What the child affords from the environment affects how he/she acts towards the environment. For toddlers and preschoolers with impairments, one central agenda is a passive versus an active stance towards the environment. The development of an active and curious stance towards objects and the environment hinges on the child's conditions for developing as a social agent. The natural line is not alone in enabling and constraining the development of environmental affordances. At a societal value level, there exists awareness of the incongruence and several practices for treatment, bound in particular values about preferred development and remediation of children with particular impairments and diagnoses, have been developed. The particular practices for intervention or treatment reflect particular social, cultural and historical value positions and express specific sets of demands for children with particular impairments and further particular opportunities for activity and developmental possibilities.

The cultural-historical delineation of developmental challenges for the toddler or preschool child with disability includes feed-forward processes, in which the social situation of development at one point in time creates a new set of possibilities. Over time, both more open and more restricted developmental trajectories will be possible. A more restricted trajectory emerges, for example, from the growing passivity of child. Difficulties may start out because of the greater challenge of participating in games and play due to the developmental incongruence.

Support based in operational and behavioural approaches is often based in individual biomedical approaches to disabilities, with a focus on isolated impairments and lack support of the child's own motivated initiatives for contributing and transforming social activities. These types of approaches do not recognise and support the toddler as a valuable social agent. The passive stance of the child hinders the active participation necessary to develop recognised social skills, competence and influence in relation to popular play activities and may thus cause the incongruence to expand. As will be elaborated upon in subsequent chapters, larger incongruence may be associated with a higher risk of challenges in school and learning (Chaps. 5 and 7), mental health problems (Chap. 6) and communication difficulties (Chap. 8).

In order to create more open trajectories with regard to developmental possibilities for the child, it is important to pay attention to how different impairments impact on the development of the toddler's basic sense of agency and social identity. Often, it will be necessary to create a supportive system of the child's early development of active social participation, where the toddler with impairments is able to explore him- or herself as an agent who is uniquely contributing to social life. Focus has to be on how to support the child in exploring both physical and social properties of the world. It has to be experimenting through play and building and grasping him- or herself as a unique person with thoughts and emotions – with and without others. By supporting the child as a social agent on his/her own terms, the child is invoked as a change agent who creates better opportunities for his or her own participation in social practices of relevance.

## **Chapter 5**

# **Development in Primary School Age for Children with Disabilities**

School as an institution and teaching as an activity have a major impact on the life of the school-aged child and his/her family. Not only do activities in school consume a major part of the weekdays, but the school structures parts of life at home (Hedegaard 2012), constitutes a primary arena for social life, friend-making and further independent exploration of and reflection on one's capacities and personal identity.

For many children with disabilities, the beginning of school is a major challenge. Even before school starts, the challenge can be to find a school that match the child's particular needs and is able to support the child's learning and development in relevant ways. Sometimes parents have to make a crucial choice between mainstream schooling and special schooling; at other times, the choice has been made for them at an administrative level. Regardless of how the decision about school placement is made, schools are social settings of development that do not fit the child with one or more impairments as readily as it does for the child's peers without impairments. The beginning of school often prompts an increase in the incongruence between the child and the demands and expectations on the child in terms of social practices, which in turn calls for local adaptations in order for the child to be able to participate, learn and develop. This chapter will discuss some of these challenges, how they emerge from the incongruence and how intervention can take form within a cultural-historical understanding of disability.

### **Learning as the Central Value Position in School**

The overarching purpose of the school has been and still is to facilitate learning. Moving into the institutional setting of the school, childhood disability thus becomes closely associated with the question of whether the child has special educational needs and how to meet them. The question is by no means straightforward, as shifts

in political and theoretical positions have provided different answers. The twentieth century witnessed a dialectical development between different societal value positions regarding children with disabilities and educational psychology, now continuing into the twenty-first century (see Chap. 2).

One of the main aims of the emerging educational psychology at the beginning of the twentieth century was centred on separating children considered educable from those considered more fit for vocational training (Goodey 2011). The technology of psychometric assessment was developed and improved as a means to fulfil this aim throughout the century. Issues related to psychological testing are a subject to which we will return in Chap. 7. The division of children into those who should be taught in mainstream education and those with *special educational needs* who should be educated in special settings was grounded in the biomedical model. However, the idea that children with disabilities have different needs with regard to teaching and learning conditions is by no means alien to the cultural-historical approach. The main difference to the psychometric and biomedical approach lies in the dialectic conceptualisation of disability and special educational needs. According to Vygotsky, the education of children with disabilities calls for

...the necessity of creating special cultural tools suitable to the psychological make-up of such a child, or of mastering common cultural forms with the help of special pedagogical methods, because the most important and decisive condition of cultural development – precisely the ability to use psychological tools – is preserved in such children. (Vygotsky 1993, p. 47)

Later he stresses that children with disabilities need to achieve the same goals as normal children, only by different means. Thus, from the dialectical point of view, an impairment will almost always affect the child's ability to learn, either directly or through the impact on his/her ability to participate in activities where culture is mediated. Learning activities in school builds on the child's prior foundation of learning and development. The basic incongruence and the way it has been negotiated earlier will affect the child's level of development at the start of school and his/her ability to participate in school activities, even when the child has an impairment that does not directly give rise to cognitive impairments (eg, deafness, motor disabilities of a non-cerebral aetiology or speech difficulties). It is only through the child's active participation in cultural practices that he or she develops higher mental functions. Therefore, earlier incongruence or delay will have affected the child's development as a whole, including aspects of cognitive functioning, unless a thorough supportive practice has been established from early on.

The question of how deaf children learn literacy abilities can be an opening example. The hearing impairment is often a barrier when the child is beginning to learn to read and write and many deaf children experience a delay in the development of literacy skills. However, results do not paint a uniform picture. Some deaf students read and write at the same level as their hearing peers, while others experience severe delay (Dammeyer 2014c). Literacy is neither predicted by a degree of hearing impairment nor solely by phonological skills (the ability to decode and process phonological sounds). Instead, general abilities in language have been

found to be important for the development of literacy abilities, whether they be good abilities in oral language or sign language (Dammeyer 2014c). Early language acquisition is important (as in many other aspects of deaf children's development; see also Chap. 7), and deaf children with deaf parents are in general found to perform better in tests of literacy, although they might still experience some delays in development of language and difficulties with literacy learning compared to hearing children (Knors and Marschark 2014). From a cultural-historical understanding, this is not surprising, given that the general knowledge base of language – concepts and word meaning – is learned through interaction in different social settings throughout childhood and social participation in a varied range of settings will be more difficult for deaf children, including those with deaf parents. Deaf children of deaf parents will be able to engage in conversations at home similar to children with normal hearing. But with peers and adults at preschool and elsewhere, cultural learning and experiences with language will be reduced and this (minor) deprivation affects their ability to learn to read and write later on (Knors and Marschark 2014).

## **The Question of Special Educational Needs**

The need for different learning means of children with disabilities might sometimes translate into special learning goals. The threshold for when special educational needs emerges depends on both the organisation of the learning setting, the particular impairments of the child and the change in support and demands within the setting through time. Therefore, disability will never be interchangeable with special educational needs, as is also pointed out by Porter et al. (2008). The point of separating disability from special educational needs translates into a twofold question: (1) To what extent does the child have learning needs that are not met by the present organisation of the teaching/learning activity? (2) To what extent does the child have other needs for accommodation of his/her activity settings at the school due to the incongruence between the child and the cultural forms of the environment? For example, does the child with disabilities experience problems with peer interaction at school arising from his/her impairment? Special needs beside those strictly related to learning could arise during break time, lunch time or, as pointed out by Porter et al. (2008), from lower school attendance due to medical treatment or more fragile health.

This chapter will concentrate on themes in relation to the second question, while we in Chap. 7 will return to learning and learning needs of children with disabilities.



## The Transition to School

In the cultural-historical perspective, the transition to school is first and foremost about the transition to an institutional setting organised around a practice of teaching. Considering the child's social situation of development, the transition to school takes on importance, because (1) the school presents the child and the family with a whole new set of activity settings and related demands (Hedegaard 2014) and (2) the change is experienced by the child as a relocation that calls for new social and cognitive form of knowledge and skills (Zittoun 2008). Of course, learning will have figured as a motive in the child's earlier practices, but the transition to school marks a move to a practice with learning as the dominant motive (and for the teachers, teaching). Understanding the transition to school for children with disabilities thus involves their conditions for developing a motive for learning in a dynamic relationship with the institutional demands and structure and support expressed by their teachers, their parents and other important adults (and finally peers, as we will see later in this chapter). As children participate as social agents in the activities at school, they engage with societal expectations for their development (acquiring knowledge and skills considered necessary for children to participate in society later on) and the appropriate motive of the school: the motive for learning (Hedegaard 2008).

Cooperation surrounding how to support the child's learning and school participation rests on a mutual understanding of the activities at school, that is to say, what they are about and how the child is supposed to participate in them. In order to ensure the mutual cooperation, a flow of information is necessary. Parents need to be informed about the school: the content of the different learning subjects, expectations of them and to their child, how the school day is organised, etc. When parents are well-informed about the school, the transition has been found to function better (Margetts 2002). And vice versa, when teachers have information about their new pupils' prior development and experience, this has been found to help the transition to school (Margetts 2002).

Parents of children with disabilities often raise the issue of information as a major difficulty in the transition to school. They lack knowledge about how their child's impairment might impact on his/her ability to learn, as well as information about available supportive resources at the school (Hanson et al. 2001; Janus et al. 2008). On their side, schools and teachers report that they lack information about the children they are asked to include (Janus et al. 2008). The mutual complaints about lack of information mirror a concrete instance of the incongruence associated with development with impairments. For typically developing children, the organisation of the information flow between parents and school can rely on routines and well-established practices for information. It is easier for the school to provide information to mainstream parents where they can rely on already established material and routines. The same information will be valid for most parents. In their meeting with typical children, teachers can draw on a large and easy accessible cultural-historical knowledge base about typical development of children in the

current cultural-historical situation when they set up tasks and demands, even though minor support or adaptations might be needed to accommodate the practice to the actual children starting class. In contrast, their knowledge about the child with disabilities, his/her previous experiences and present developmental level will be more limited. The available cultural-historical knowledge base will only partly be useful and relevant for the child with disability. Thus, the teacher is often placed in a vacuum of knowledge about development, support and best practice.

Studies have reported that teachers with previous experience with inclusion of children with disabilities express more positive attitudes towards inclusion (Avramidis and Norwich 2002). Through the prior practice the teachers have built a knowledge base about how to teach particular children with disabilities and thus experience themselves as more capable in relating to and working to overcome the incongruence. If the school and the teacher held a dynamic view of the special educational needs of children with disabilities, experience with children with disabilities contributed to the development of their teaching methods (Avramidis and Norwich 2002). Whereas the opposite view, in which children's learning problems were understood as inherent to the individual child, was found to impede the necessary development of teaching methods and thus potentially counteract the circumvention of the incongruence, especially for children with disabilities included in a mainstream school environment.

The positive impact of teachers' previous experience with inclusion is supplemented by the experience of the child and the family with inclusion. Prior placement in inclusive settings has been found to facilitate the transition to a full-inclusion school setting (Hanson et al. 2001). Several mechanisms might act together to explain this trajectory. During the transition process, engagement as positive adjustment is promoted when the child has some familiarity with the situation (Margetts 2002). Carrying relevant skills and competences enables the child to participate in the new setting, even though the setting will contain new demands and tasks for the child. This is a basic condition for all children at the transition to school. Coming from a previous, inclusive setting will have provided both the parents and the child with knowledge and experience with mainstream supports and demands, knowledge that can be used to promote local adaptations aimed at the incongruence and thus provide the child with better conditions for engaging in school activities. Although parents often report that resources and support from the earlier practice are commenced, changed, or require reassessment (Dockett et al. 2011; Janus et al. 2008), the former experience of setting up a supportive network in an inclusive practice will still be of use. Moving from an inclusive preschool setting to inclusive school also enables the child to move together with his or her social network/friends, which has been shown to ease the transition to school for children at large (Margetts 2002). Because of the lack of cultural-historical knowledge and practice available, a platform for development for each child with disabilities has to be built, by establishing a set-up of cooperation and resources grounded in the local social settings.

Thus the transition presents with particular challenges when the child has a disability. Two reasons are in front from a cultural-historical approach: First, the transition experience of moving to a practice with new demands of the child and his/her

family is often more pronounced compared to children without disability due to the incongruence between the child and the demands met in school. Secondly, the cultural elements available in the setting (teachers' supportive practices, organisation of first days at school, organisation of teaching/learning activities in the first month and year of school) is fitted to typical children, while their fit with children with disabilities will be less good. Some or more of the demands and expectations will be beyond the zone of proximal development of the child with disabilities or the usual support for learning will not address the child's need for support. The need for building up platforms for educators and parents in cooperation to help the child to engage with the demands in school is obvious. It is both needed with regard to the creation of supportive practices and at times, through accommodation of the demands, to be within the child's proximal zone of development. (These perspectives on support are elaborated upon in Chaps. 7 and 9).

Last, but not least, the nature and severity of the disability have been found to impact on both the transition (Janus 2011) and the following trajectory in school, including social participation. We will follow this important lead throughout the rest of the chapter and discuss the role of impairments in relation to the demands associated with the life as a schoolchild with disabilities.

## **Motives for Learning**

A motive for learning: what does it really mean? The budding learning motive can be expressed in a readiness to engage in the activities at school, often identified by the child's interest in participation in learning activities – often related to letters, numbers and academic knowledge – offered at home and in school. The development of a motive for learning is thus not an isolated trait in the child but is mediated by the child's activity settings. This means that the basic developmental incongruence might impact on the child's conditions for developing a motive for learning. Similar to other developmental challenges, the development of a learning motive might be less optimally supported when the child has a disability.

The development of motives is part of the child's social situation of development, disability or no disability. The former dominant motive of play begins to be replaced by an orientation towards the activity of learning. That is when the child begins to understand the social difference between playing as-if and the actual activity (eg, between pretending to read and the actual activity of reading) and subsequently develops an interest in reading for real (Hedegaard 2002). For some children, the development of a learning motive begins before school entry. The child in pre-school is introduced to and begins to develop an interest for the activities associated with school and school learning and anticipates the transition to school. The child's cognitive, emotional and motivational preparation for the transition to school is often supplemented or promoted by parents and other adults, who talk about the transition to school, arrange visits to school or invite the child to participate in activities with school-like content. The child might experience a longing for the

prestigious social identity as a schoolchild rather than the former identity as a child-at-play (Winther-Lindqvist 2012). These feelings are often mixed with fears or anxiety about the transition to school, eg, the loss of time to play, best friends and the well-known preschool environment. Thus, either way, the development of a learning motive builds on the child's social situation of development, on earlier development of motives and participation in activities and the child's present cognitive and emotional level of development. Similarly in the case of a child with disabilities, the incongruence and developmental delays that have emerged in earlier age periods impact on the child's development of "school readiness" in several ways.

First of all, children build on their previous knowledge, experiences and interests when they try to understand the subjects and activities in school (Hedegaard 2002). Many children with disabilities come to school with a more limited knowledge about the world due to their barriers in exploring the environment and the cultural meaning of objects and activities. These barriers easily cause a delay in conceptual knowledge and development in higher mental functions. The subject matter presented in the school curriculum thus becomes more difficult and abstract to grasp and seem more distant from the interests of many children with disabilities.

The less developed motive for learning and school readiness at the time of school start might thus arise from both the impairment in itself (biological developmental delay) and experiences (or lack thereof) from their participation in previous social practices. Research has shown that many children with disabilities allocated to segregated classrooms or special schools participate in practices with a different set of aims than characterise inclusive practices (Jenks et al. 2009; Mike 1995). In more severe cases, the disability-related aims may be those of child safety, taking care of basic needs of nutrition and hygiene, basic living skills, social behaviour skills, and communication skills. The aims may function in addition to mainstream school aims or they may substitute aims for learning of academic skills and curriculum found in mainstream classrooms (Jenks et al. 2009). The substitution of academic aims with daily living skills is based in the value position that (1) the skills and curriculum of mainstream learning practices are beyond the cognitive developmental potential and the learning abilities of the child and (2) the child with disability has no real interest in learning basic academic skills as they will be of no use for the type of life trajectory open to the child. Both assumptions are based in an individual biomedical understanding of cognitive potential. Cognitive skills are assumed to be the unfolding of a biologically fixed potential: The constrained potential of the child with disability opens up for a much more limited set of life trajectories compared to children with typical biological possibilities. From a cultural-historical point of view, this approach lacks an understanding of the role of culture in the development of motives and higher mental skills and the feed-forward processes of cognitive abilities. The learning of academic conceptual thinking and skills such as counting, basic calculation and reading transforms the child's thinking processes even if the child only ever comes to master them at a basic level without further development into the skilled level necessary for using them in a vocation. The full curriculum of typical children may be beyond what is attainable for the (severely) disabled child.

However, holding back important subject matter is holding back what could develop the child and thus fulfil the second assumption that the child is moving towards a particular and constrained trajectory. Eliminating or minimising subject matter learning of central importance from an adapted curriculum is to ignore the right side of Figure 1 presented in Chap. 2: The child's participation in learning activities affords and develops his or her cognitive activities and processes, which in turn furthers the development of the neural systems and processes in the left spiral of the figure. The relation between the child's cognitive functioning and the child's environment functions with a spiral-like dynamic, in which the child's cognition is constrained by the practice framework of cognition and the learning activities in the child's activity settings. A focus only on the limited potential of the child and withdrawal of basic academic subject matter from the child contributes to a further constraint of the child's development of individual cognitive abilities – and the child's development of a learning motive similar to typically developing children. Only a practice aimed at academic subject matter learning, alone or together with other aims, will invite the child into activities that require it to explore academic subjects and then the possibilities for new academic competences. Both aims are of crucial importance in the organisation of activities that will further support the child's understanding of everyday matters and everyday problem-solving.

The central point is that the development of a motive for learning is not given at a certain age. Even though we expect children around the time of the transition to school to have a budding learning motive or the cognitive and social precedents, the age-appropriateness of children at the transition to school – “being mature for school” – is a socially mediated development. Developmental delay, either as a primary biological delay (slower biological development) or a secondary delay because of the impact of the biological defect on development as a whole, can impede the child's development of a motive for learning. Some children just need a little extra time and might benefit from an extra year in preschool before they begin school. In other cases, children have impairments that will continually impede their development and abilities to take part in traditional school activities. In this case, the solution is not to wait for a learning motive to emerge before providing the child with schooling and academic challenges. This would represent a passive maturation approach and not an understanding of learning and development as arising from the child's active participation in cultural-historical activities. No matter what motives dominate the child's hierarchy of motives, the child will learn from his/her activity at all times of their development. However, to get the child to engage and participate, their learning activities will need to be organised in accordance with their dominating motives and for some children with disabilities and delayed development, motives typical of earlier age-periods will still be dominant. It could be the close relation to a known adult, own exploration of the physical world or play. The consideration of the child's level of motivational development is part of a wholeness of adaptations of the learning material and learning activities to the child's present level of development. The child's motives function as the engine of his/her social agency in relation to all the different areas of development: motor, perceptual,

communicative, emotional and/or cognitive. The role of motives in learning will be elaborated upon in Chap. 8.

## **Affordances and Social Agency in School**

Development of social agency continues from preschool to school practice where the child seeks to participate based on his/her previous skills and understanding of the world. Purposeful transformation of the activities becomes increasingly tied with teaching/learning, the overall aim of the school. Participating in learning activities constitutes a substantial part of school-life, both in regard to how time is spent and in relation to what type of skills and characteristics are valued by the other participants. The development of a learning motive will be part of the social affordance, “ready for school”, as seen by others and will thus be a prerequisite for being able to participate in learning activities in ways considered valid by the teacher. The concept of social affordance is here used to cover an institutional position that describes the child’s experience of his/her own social agency in relation to social others within the social setting (Bang 2009). Thus, social affordance describes a kind of “social identity” within a social group. The social affordance of the child develops through the child’s agency and motives for agency that are related to particular social expectations and values within a social group. It is therefore significantly attached to the evaluation of the child’s contribution by others and by the child’s evaluation of his/her own contribution. The social affordance opens and closes possibilities for the members to contribute to and transform the group over time, and thus feed forward into the member’s development of social agency and possibilities for contributing to the aim and content of the group. Social agency and a social affordance of feeling and seeming capable in areas valued by teachers and peers are both central to the development of a sense of belonging in school. Social participation and development of a social agency, characterised by an active stance in school, hinges on the child’s experience of being a capable participant and by being recognised as a capable pupil by teachers and peers.

Even though the feelings of inadequacy created by the incongruence according to Vygotsky’s concept (1993) could be stimulating in their creation of a motive to overcome the disability, he also stresses the necessity of a teacher and a school environment that give the child opportunities to achieve common goals by alternative means if necessary. Otherwise, Vygotsky describes the social consequences of an impairment as the development of a personality characterised by feelings of inadequacy and inferiority in relation to the majority (Vygotsky 1993). This description fits with research findings of learned helplessness in different groups of children with disabilities, for example children with motor impairments (Butler 1986) and children with learning disabilities (Valås 2001). Vygotsky’s description is also substantiated by studies of self-perception in children with learning difficulties (Kelly and Norwich 2004), which repeatedly find negative self-perceptions in young schoolchildren with learning disabilities. Kelly and Norwich (2004) found that

children going to special school had a higher level of positive self-perceptions compared to children with learning impairments in mainstream schools. Similar results have been found with regard to deaf children in mainstream schools compared to hearing impaired units or deaf schools (Hindley et al. 1994). Reinterpreting these results within a cultural-historical understanding of disability, the children placed in special schools might experience a better fit with the demands and support in the learning activities and thus a smaller incongruence within the school setting and in relation to learning activities (Bøttcher 2011) (See also Chap. 6). Another reason for the more positive self-perception of children going to special schools was that their immediate reference group was also other children with similar learning needs (Kelly and Norwich 2004; Hindley et al. 1994), which contributed to their feeling of being socially adequate.

## Social Life

Making friends and participating in social life at school and within peer groups is of course beyond learning and learning motives. The learning motive, although important in the development of social agency, faces serious competition throughout school from another dominating motive: the motive to interact with and belong to a social group (Winther-Lindqvist 2012).

Turning to the research literature, it quickly becomes apparent that children with disabilities often are met with difficulties in participating in peer groups and making friends. A few empirical examples can be given: Children with intellectual disability, in inclusive settings, do have friends, but are found to hold below average social status (Vaughn et al. 2001). Children with autism spectrum disorders, but high functioning, are more often in the periphery of the social networks. While this might not be surprising, given that one of the diagnostic criteria for autism spectrum disorders consists of deficits in understanding, developing and maintaining relationships (Diagnosis and Statistical Manual of Mental Disorders (DSM-5)), the consequence is that many children with high-functioning autism spectrum disorders report feelings of loneliness and express a desire for companionship (Bauminger and Kasari 2000). Children with cerebral palsy in mainstream classes have fewer reciprocated friendships, are more isolated and more often victimised (Yude et al. 1998; Nadeau and Tessier 2006). While underlining a cultural-historical understanding of disability, these studies also report that the problems are not directly related to degree of physical impairment (Nadeau and Tessier 2006), IQ or behaviour problems (Yude et al. 1998). (For further discussion of this point see Chap. 6 on development of mental health problems.)

The general higher risk of social problems cloaks a mixed picture both across groups and within a group of children with the same type of disability. Some children experience massive problems while others enjoy friendships, social status and a position as a capable person at the same level as their peers without disability/ impairments. The impairment in itself or degree of impairment seems not to be able

to explain the variance found. Analysing possible sources of these problems is extremely important. The ability to participate in social activities, evolving around a social affordance as a capable person in relation to valued peer group activities, is central for many aspects of social agency, including the learning of social skills, cognitive development, emotional development, communicative development, becoming independent and thus the development of a positive trajectory in the early school years and beyond (Ladd 1990). Research using the sociometric approach unequivocally points to more problems in peer relations for children with disabilities compared to children without disabilities. And it has been argued that mainstreaming does not automatically solve this problem and create positive peer relations because children with disabilities often lack the necessary social skills (Gresham 1982). From this perspective, the origin of social problems across particular impairments or diagnoses is considered to be individual deficits in social skill or social cognition. One example is the study by McIntyre et al. (2006), where the development of a positive school trajectory was found to be associated with social skills development. During the first year of inclusion, dual cognitive and behavioural problems were found to have a negative effect on the child's adaptation to the school demands. The social skills deficit framework has been very influential in research on peer relations; however, the problem with this approach is that it views peer relations and social competences from a mainly individualistic approach while overlooking social factors (Farmer et al. 1996). From a cultural-historical perspective, this means that only one side of a dialectic relation is considered. Social skills in the early school years build on social cognition such as moral sensibility, ability to pretend play, ability to understand emotions, ability to share and develop a shared imaginative world and communicative skills. As outlined in the previous chapter, the child's skills as a social agent develop through activities and negotiations between friends and playmates in the preschool years (Dunn et al. 2002) and later on. The individual social cognitive abilities impact on the child's ability to act and be recognised as a valuable play partner and through this develop a positive social affordance in relation to peers. Differences in social standing are not dependent on the child's social cognitive skills alone. Social cognition is anchored in processes in the peer group and the ability of the child to impact on the social group culture, as well as influencing what type of identifications and activities that are considered important and popular within the peer group. The child's skills in social agency can be a help or a constraint in his/her participation in social activities. A passive stance or developmental delay in one or more areas of development impedes the child's capability for collaborative participation, as the child does not see him- or herself as able to contribute and be acknowledged as a contributor. It is a developmental dynamic, where influential children are able to impact on the types of activities that are popular, to participate in them, and thus reconfirm themselves as socially appropriate. Furthermore, the development of social agency relies on the child's continued development of higher mental functions through participation and appropriation of sociocultural skills, values and activities within his/her activity settings. Influential children are able to create better conditions for their participation and their own further development than less influential children.



## Supporting Peer Interaction

Popularity and high and low social standing are not specific to children with and without disabilities, but are distributed throughout the whole peer group. Thus the question becomes: do different types of impairment or developmental delay differentially impact on the child's opportunities for participation, development of social cognitive skills and establishment of social affordances associated with a positive social identity?

One aspect of building a social affordance of being a capable social agent is the accommodation of the school to the particular needs of the child in relation to his/her impairments, such as getting around, adapted lavatories and space for and general acceptance of necessary aids. Lack of practical adaptations – or lack of acceptance of the child's needs for adaptations and aids – creates social and environmental barriers to participation that makes the child with disability stand out as less able to meet school demands. A small incongruence at school starts, and if not handled, interferes with the child's ability to participate across different activity settings, for instance from school to leisure settings.

The accommodation of the school also regards how the school has chosen to (re)organise their practice to accommodate the child with disabilities. In a mainstream setting, this involves the schools' organisation of inclusion. Inclusion without any accommodation of the institutional setting will create incongruence as outlined in the first part of the book. Teachers' development of negative attitudes towards inclusion of children with disabilities is related to particular types of disability that are considered to demand extra teaching competences, such as mild intellectual disability, moderate hearing loss, visual disability, severe physical disability, hyperactivity or disabilities that together create complex needs (Avramidis and Norwich 2002). The different ways of organising inclusion within the institutional practice also impacts on the child's possibilities for developing social agency. One widespread way of organising inclusion is by providing the child with disability with an assistant that follows the child during the school day, either full-time or part-time (Egilson and Traustadottir 2009; Giangreco 2010). The inclusion practice with an assistant in the mainstream class is used in relation to children with different types of disabilities; for example, physical disability or learning impairments (Egilson and Traustadottir 2009). However, a general finding across the different types of disability is that the social agency of the child becomes tied up with the teacher assistant, making the child dependent on his or her personal "grown-up" and setting the child apart from the social group (Giangreco and Edelman 1997; Hemmingsson et al. 2003). The ability to develop independent agency will depend on the extent of the incongruence and the child's affordance within the setting as dependent/independent of the assistant. Some children are still able to act on their own when their assistant is not present and thus develop a sense of independent social agency in themselves and in relation to peers. The presence of the assistant has been found in some studies to counteract the teacher's need to accommodate the teaching to the children with disability included in the class (Giangreco and Edelman 1997), which

maintains the incongruence. The teacher might even address his or her teaching instructions to the assistant rather than to the children with disabilities (Hemmingsson et al. 2003) and thus reinforce the social affordance of the child with disability as only being able to participate when assisted by his or her helper. Some of the children participating in the study by Hemmingsson et al. (2003) actively refused to receive help because it made them stand out from their peers. Bøttcher (2011) found in her case study-based in interviews with the teacher assistant and the participating boy, Peter – that Peter became passive when his assistant was not around, both due to the development of a passive stance towards the environment and because the incongruence between his cognitive impairments and the demands in the class activity setting constrained his possibilities for active agency.

## Teachers' Role

Teachers' behaviour, attitudes towards and recognition of the child in school is an important theme. The teacher enacts feedback on how particular children perform as social agents in relation to institutional demands and possibilities (Winther-Lindqvist 2012). The size of incongruence between the child's impairments and the school's demands (natural and cultural line of development) plays a role. Often, teachers find children with, for example, severe physical impairments easier to include in their classroom than children with moderate attention and conduct disorders or intellectual disability (Avramidis and Norwich 2002). Some inabilities may be more at odds with the structure of the school activities than others. Teachers' attitudes contribute to the child's opportunities to develop a social affordance as an appropriate social agent in the school setting by the way they act in relation to children with disability included in their classrooms. This could take effect by not including the child with disability in the learning activities, by excluding the child with disability from the classroom, or by continuously placing the blame from conflicts within a group of children on the child with disability (Davies and Watson 2001). Each of these examples would contribute to the development of the child's affordance of not belonging in the school. On the contrary, a teacher who does include a child with disability in the activities contributes to the child's building of a social affordance as a relevant and contributing member of the activity setting, setting off a positive developmental pathway.

The teachers' support of potential friendships is another aspect. The child's developmental level of social cognition and ability to participate as age-appropriate in the peer group builds on his/her former experiences as a toddler and preschool child (Dunn et al. 2002). As outlined in the previous section, research with children with intellectual disability has shown that although they were able to participate in play and leisure activities with their typical peers, they often did so in a marginalised position; however, playtime together with age-mates with similar functional prerequisites opened up for equal and active contribution of both children (Nordström 2011), with a positive impact on the child's experience of him- or herself as a

competent, capable and valuable person. Another study (Raghavendra et al. 2012) found that while children with physical disability alone participated actively in social activities in school, children with physical *and* communicational disability had difficulties with the establishment of social relations in school. The more complex needs for support of the last group meant that the children had fewer opportunities for communication in school and came to rely on family members for social activities. An explanation could be that their communicational skills required support from the interlocutor to support expression and co-construct the message beyond what peers could offer. Inclusion of children with disabilities in mainstream school can render it more difficult for the child to find playmates with similar functional prerequisites of the kind relevant to the interests and pursuits of the child.

## **Developing Positive and Negative Social Affordances**

The central role of participation – from a cultural-historical perspective – in the wholeness of the development of the child places the question about social agency at the centre. For a child with disabilities the analytic question becomes: What will it take for this child to be recognised as socially appropriate, with relevant and unique contributions to the social setting? The concept of social stigma by Goffman (1963) introduced the idea that the social identity and participation of individuals who divert from the majority is heavily impacted by the attitudes of other social participants. This has led to a line of research looking into the attitudes of children without disabilities in relation to children with disabilities. In the present context, this research is interesting in relation to how it sheds light on how the societal-level value position of inclusion is associated with development in children's understanding and acceptance of their peers with disabilities. A study by Cairns and McClatchey (2013) compared children's attitudes towards peers with disabilities at two different primary schools: school A with an inclusive practice and a high number of students with disabilities (8%) and school B with only a few students with disabilities (<2%). The students with disabilities in the inclusive school covered a wide range of disabilities, including children with physical and medical needs and children with severe learning disability. Children from the two schools were shown various video clips of children with a range of disabilities and asked what they noticed about the child and if there were ways they could help this child. To take one example, they were presented with a video clip of Paul, who was deaf. Children at school A made more comments about his academic characteristic than expected while children from school B mostly noticed how his communication differed from communication in general. However, when asked about proposals for help for Paul, children from the inclusive school A suggested that they could help with communication, whereas children from the less inclusive school B in general suggested academic help only. Thus, children from school A, who had had more experience with peers with different types of disabilities, expressed more appropriate ideas about what types of needs children with different types of disability might have.

An objection against these studies of attitudes can be the non-linearity between attitudes and actual behaviour. The verbal expression of a positive attitude towards, for example, having a child with disability as a friend might not lead to actual friendship or social invitations to a classmate with disability. Despite this limitation, the study above indicates that prior experience with children with disabilities provides the typically developing peer with more relevant ideas about the challenges children with different types of disabilities experience and might need help with in order to participate.

When peers with disabilities are present in the school environment or classroom, it becomes interesting to consider the interaction between the attitude of peers towards their classmates with disability and the social behaviour of the children with disabilities. Often, research in these two interrelated aspects of development of social affordance has been done separately; either as research in attitude formation of peers without disability (eg, Cairns and McClatchey (2013) from a social model approach) or as research in social cognitive skills in children with disability (eg, Dodge et al. (1986) and Guralnick (1999), according to the medical model approach). Analysis of the being or becoming of social agency requires consideration of the idea that the child with disabilities might have specific impairments and developmental delays that impact on the way the child acts and is perceived as a social agent – by the teacher and by other children.

The concept of “perceived social acceptance” can be used as a proxy measurement for social affordance. Research has found that perceived social acceptance mediates the relation between skills in tests of theory of mind and social adjustment, both in children with intellectual disability and in children following typical developmental trajectories (Fiasse and Nader-Grosbois 2012). The main difference between children with intellectual disability and typically developing children was a developmental delay in both theory of mind and social adaptation in the group with intellectual disability (Fiasse and Nader-Grosbois 2012). Thus, delayed development of theory of mind is associated with lower perceived social acceptance.

The lower social adjustment of children with intellectual disability might both be expressed as externalising behaviour, characterised by a high level of aggression, impulsivity, agitation and/or opposition or internalising behaviour, such as social withdrawal (Guralnick 1999; Nader-Grosbois et al. 2013). For children with externalising problems and less adherence to social rules, a dialectic interpretation would be that the delay in development of social adjustment creates a negative bi-directed effect: The child with, for example, more impulsive behaviour or delayed ability to consider the perspective of others in social negotiations is perceived negatively by his/her peers and is less invited into social activities, play activities, games or other social areas for development of socially mediated skills such as cultural aspects of theory of mind and social regulation, again leading to further delay. Another negative bi-directional effect is children developing internalising behaviour or withdrawal, for example, due to lack of understanding of the demands and social rules due to developmental delay. Withdrawal from peers leads to less participation in the activity settings where the relevant knowledge and skills are learned (Nelson et al. 2003), once more contributing to further delay and incongruence.

Research in cognitive social skills can be used to shed light on why children with disabilities are more vulnerable to developing negative social affordances. Specific basic cognitive skills such as problems with attention, working memory and speed of information processing have been found to be associated with impairments in development of social skills (Guralnick 1999). Basic cognitive skills are important preconditions for the development of higher mental skills that further are a precondition for the development of a positive social affordance. Deficit or delay in executive self-regulation and/or theory of mind – alone or together with, for example, communicative dysfunctions or lower speed of information processing – is prevalent in many types of childhood disability (eg, congenital deafness (Knoors and Marschark 2014) and cerebral palsy (Sandberg and Dahlgren 2012)). Small delays in executive self-regulation and/or development of theory of mind in relation to peers create incongruence, especially with respect to peer expectations to social performance. This incongruence feeds forward through negative social affordances and increases the risk of further maladaptive behavioural development and withdrawal from peers or by peers.

The focus on the child with disability as being, becoming and developing as an appropriate social agent requires acceptance of the idea that the child with disabilities might have specific impairments and developmental delays that require individually tailored support. Repair of the incongruence at practice-level will often be necessary before it is possible for the child with disability to act and contribute as a person with positive social affordances. At the same time, the practice-level perspective needs to be supplemented with a broader societal value-position perspective, with a focus on the identification and possible removal of social barriers that mark the child as less appropriate in the school setting. Importantly, this perspective has to be both in the eyes of the other children and in the child's own experience.

### **Summing Up: Consequences of ‘Cultural Deprivation’ in the School Years to Come**

Similar to the preschool period, the feed-forward processes of development create possibilities for positive as well as negative developmental trajectories. In the previous chapter, the positive and negative developmental trajectories were associated with the development of active versus passive stances towards the environment. During the early school years, the social agency of the child becomes challenged by the transition to school that often marks a time when the disability becomes much more difficult to handle. Problems and challenges are often found to increase. One reason is that the school is an activity setting where the possibilities for valid social agency become narrower than in the preschool setting. New types of demands arise that some types of impairments make it difficult to meet, thus creating new instances of incongruence or increasing existing ones. Developmental delays from earlier periods (eg, in theory of mind, pretend play, own acquaintance with skills and

objects in the world) mean that the child with disability has less knowledge to build upon, knowledge that teachers tend to assume children bring to school. This delay in knowledge and skills increases the incongruence in relation to demands in school, thus creating further incongruence that is only indirectly related to the child's impairments. The child with disability will often seem and act less "ready for school". However, it is central to understand "school readiness" as dialectically developed. The child with disability might never become ready for school in the same sense as other children without disability. Children with disabilities have more difficult conditions for school participation due to biological *and* social reasons. Many types of impairments give rise to special learning needs, considered as an inability to learn the required curriculum the same way and at the same speed as peers. The additional problem is "cultural deprivation": a lack of development of higher mental skills leading to a general delay in skills that will contribute to a negative developmental pathway as the distance to peers grows and the incongruence increases. As the child begins to develop an awareness of the minds of others and social perception, the experience of his/her own social agency will include its own stance in relation to particular social expectations within a social group. Social affordances within the peer group opens and closes possibilities for the members to contribute and transform the group and thus feed forward to the member's further development of social agency and possibilities for contributing to the aim and content of the group and its activities. The contributions of the child with disability to the class and the peer group through his/her social agency will be mirrored in the social affordances of the child and hold the potential of negative as well as positive developmental trajectories. The danger of cultural deprivation requires us to take care of both sides of the problem: individual development/learning and social agency. Cultural deprivation due to the impairments of the child need be addressed by dialectic assessment of the child to ensure acknowledgment and support of the child's learning potential. Secondly, a passive social stance requires us to create opportunities for the child to feel and act as a valid contributor to the school practice – themes to be followed up in Parts 3 and 4 of this book.

## Part III

# Developmental and Educational Themes During Early Childhood

The chapters of Part 2 showed how the incongruence can develop into different disability outcomes during early childhood. A congenital inability to hear or develop control of muscles holds the potential to expand into communicative, social, and cognitive impairments due to the incongruence associated with the child's participation in cultural-historical social practices. If and how an impairment creates incongruences and whether the incongruences develop into a disability has to be analysed from the dialectical interplay between biological, psychological and social processes over time within the cultural-historical practices of participation.

From the chronological walk through some of the many developmental pathways in early childhood of children with different types of disabilities, the chapters of Part 3 will take thematic focuses. In Chap. 6, developmental outcomes of impairments on mental health will be discussed to further explore how impairment can lead to severe mental health problems for some children, while not for another child with similar impairment but a different social situation of development. Chapter 7 will continue the discussion of themes related to the child's life in school. Learning, inclusion and special needs education will be analysed from a cultural-historical model of disability to shed light on opportunities for schools and teachers of how to support the child with disabilities. Communication and language, being necessary brokers of higher-order social and mental functions, serves as in-depth examples in Chap. 8 of the dialectical cultural-historical development processes. Linked to this will be a look at communicative aids. As will be shown, aids are culturally developed tools that can interact in positive as well as negative developmental circles in the child's development.

## Chapter 6

# Mental Health and Children with Disabilities

The first two parts of this book have made it clear that children and families affected by disability will often follow developmental trajectories that differ from those of typically developing children and their families. Early relationships, situations of play and social participation may look and develop differently. The cultural-historical point of view is not to strive for children with disabilities to follow the same developmental trajectory as children without disabilities. The important point of our insistence on diminishing developmental incongruence is to ensure the child adequate developmental conditions, which may very well come along with the creation of alternative developmental trajectories within the given social contexts. Thus the social situation of development may look very different from those of typical children without necessarily being judged as abnormal in a pathological sense.

However, this leaves an important question that will be the subject of this chapter: If alternative developmental trajectories are to be expected, when are abnormal developmental trajectories supportive and when are they detrimental to the child's life now and in the time to come; and thus, when do they require intervention? The importance of this question is substantiated by plenty of research that has documented a higher prevalence of mental health problems in all groups of children with disabilities, thus indicating an underlining common risk dynamic. The difference is not given by the gap between the situation of a child with disability and "a typical child", but needs to be analysed from two time perspectives: firstly, from the current perspective of the child and his/her family and their subjective judgement of the situation here-and-now; secondly, from the perspective of how the current situation of development relates to a potential increase or decrease in incongruence in future developmental time. Are some developmental trajectories more problematic than others for the child's behavioural, social and emotional development? In short, how do mental health problems and disability reflect each other?

To link with current research in disability and psychopathology, we begin by exploring the question of whether specific types of impairments are associated with certain types of developmental aberrations. The cultural-historical model of



disabilities will be used to analyse the processes involved and how a higher risk of mental health problems among young children with disabilities can be avoided. Similar to the other thematic-based chapters in this book, empirical research among children with different types of disabilities is included and discussed, both with the aim to reach a deeper understanding of what psychopathology in early childhood is and to shed light on what parents, professionals and policy-makers can do to support psychological wellbeing for young children with disabilities.

The opening example of this chapter will be attachment. Attachment has been studied in psychology as one important factor that may explain the development of both positive mental health and mental health problems (Prior and Glaser 2006).

## **Attachment Behaviour and Problems of Attachment**

Even though attachment was defined initially as a mainly universal and biologically driven need (Bowlby 1951), attachment as a concept has also been developed within particular cultural-historical practices. The attachment concept denotes the dialectical relation arising between the infants demands on his/her parents' caregiving capacities and the dominating motive of parents to take care of their (small) child. Soon after birth, the infant also becomes able to distinguish known caregivers from unknown adults and later they begin to react with separation anxiety when left by their primary caregivers, or weariness or distress when left with or picked up by strangers (Prior and Glaser 2006). Research has shown that children with all types of disabilities are able to develop attachment to a caregiver. This has been shown for children with autism spectrum disorders (eg, Sigman and Ungerer 1984) and intellectual impairment (Cicchetti and Serafica 1981; Dissanayake and Crossley 1996; Thompson et al. 1985). Buitelaar (1995) found that children with autism spectrum disorders react to separation from the parent with attachment behaviour similarly to children without autism spectrum disorders. However, several other studies also show that the caregiver system and the infant's attachment system can be affected if the child has a disability. Children with disabilities are less likely to be classified as being securely attached compared to children without disabilities (Rutgers et al. 2007). From a cultural-historical developmental perspective, attachment behaviour develops hand-in-hand with the child's participation in different activity settings. An early impairment does not rule out the presence of risk factors associated with insecure and/or disorganised attachment found among children without disability. However, it is important to keep in mind that the developmental trajectories leading to insecure or disorganised attachment in children with impairments might be different from children without impairments. The child's particular impairment on one hand and the caregiver's ability to adapt culturally passed on norms of child-care to their particular child on the other hand can create situations of greater or smaller incongruence. Although the particular impairment feeds into the dynamic of attachment development, the development of attachment must be understood and addressed from a cultural-historical perspective. Early attachment develops from

situations where the child feels and expresses heightened physiological and emotional arousal and the caregiver reacts by helping the child to regulate and manage his/her bodily and emotional state. The need for proximity and security varies with the circumstances, for instance, if the child is sick or in an unfamiliar environment, the attachment system is more easily triggered and increases the child's desire for proximity to his/her caregiver (Cassidy 2008). The attachment behaviour also changes as the child develops more abilities. When the typical child begins to move around and explore the surroundings, the need for a secure base to return to often becomes more activated, especially in situations experienced as dangerous by the child. Thus, from an attachment perspective, the child can early on be considered as an active social participant in the development of the attachment system. The lower-order, biologically driven need for security is mediated in cultural and historical social situations into higher-order psychological (cognitive, personal, social) characteristics and abilities. In different social settings, formed by culture and history, the child's behaviour can be interpreted as more or less difficult, dangerous, independent, powerful or otherwise. At least three aspects of the social situation of development will be important to consider when trying to understand how disability and development of attachment are associated:

1. The child's arousal system and his or her perception of the environment as secure or threatening: From the parents' perspective, the child's active perception of his/her immediate surroundings and situation will, for instance, be encountered as the child's easiness of regulation, temperament and personality.
2. The parents' availability and capacity to be emotionally attuned to their child's state of mind/level of arousal: Availability and capacity will be formed by social and cultural norms and traditions on childcare and parenting. This will include how parents interpret the child's signals and what type of reactions they will consider as appropriate.
3. The environment experienced as new versus familiar by the child and how the environment is arranged and restricted by the parents following cultural norms and traditions.

In a cultural-historical understanding of development, these three aspects feed into one another. Children born with cerebral impairments have been found to show poorer attention, increased excitability, arousal, hypertonicity and stress, along with lower scores of self-regulation (Pineda et al. 2013). Recent research and reinterpretations of former research have found that reduced ability to regulate arousal is associated with disorganised attachment at 12 months (Spangler 2013). The child with congenital neurological impairments is a different social agent than children with normal neurological functioning and parents may find that the cultural patterns of child-soothing and regulation that work with typical children might not work or work less well with their infants with early neurological damage. To take autism spectrum disorders as an example, John et al. (2012) and Atkinson and colleagues (1999) have suggested that children with low-functioning autism spectrum disorders or intellectual impairment show less secure attachment behaviour because of their limited ability to participate in the social interaction and communication

necessary for intimacy and attachment relationships and not because of a behavioural inability to display attachment behaviours. In a study among children with autism spectrum disorders, a group of children with good verbal language skills was classified as having better attachment behaviour compared to those with low verbal language abilities (Dissanayake and Crossley 1997). These studies underline that attachment is built and develops around parents and their infant/child as mutual social agents; and the congenital dispositions the child brings into the mutual system impacts on the development of the attachment system.

Plenty of research has pointed to the interplay between child dispositions and parent sensitivity (see Spangler (2013)). A child of mid-range temperament may be regulated by parents with a wide range of sensitivity. Children who are easily aroused and difficult to regulate may require higher levels of caregiver sensitivity. And in the latter case, less sensitive parents may more easily find themselves in situations where the child's demands seem overwhelming or otherwise stressful. Starting at one point in time, the impairments of the child may lead to a situation where the parents find it difficult to interpret their child's signals and thus appear as less available to the child. For example, in parent-infant pairs with children with autism spectrum disorders, the child's barriers to participate in dyadic interactions have been found to affect the caregiver's sensitivity and finally the attachment quality (John et al. 2012). Although parents are sensitive and pay attention to their child, the child's lack of responsiveness and involvement affects the attachment development dynamic and has consequences for the attachment quality. Another example is children with congenital blindness. In dyads with children with congenital blindness, early social interaction (eg, co-regulation of contact and emotions) is often more difficult to establish and develop if the caregivers do not use alternative strategies (Preisler 1996). However, the important thing to hold in mind is that the child's disposition (blindness) is associated with a higher *risk* of a developmental pathway to disorganised attachment only. Sensitive care-giving and/or use of other means in the parent-child interaction can counteract the risk of developing disorganised attachment.

The wider social and cultural situation of the parent-child dyad also affects the conditions for their development of attachment to each other. Early hospitalisation can work as an example that illustrates this point. Many types of congenital impairments may require medical treatment such as successive operations or intensive medical treatment. Early hospitalisation can make the parents less available to the child due to intensive medical treatment and lead to more situations in which the child and the parents find themselves in an unfamiliar environment and in situations experienced as threatening or otherwise upsetting. Compared to parent-child dyads with typical children, the early life period of many children with congenital or early-acquired impairment offers less optimal conditions for the establishment of early relationship. Research in dyads with high-risk premature infants and longer periods of hospitalisation has found a higher number of children with anxious-resistant attachment behaviour compared to a control group of healthy premature infants with shorter hospitalisation periods (Plunkett et al. 1986). Finding a pattern of insecure and/or disorganised attachment patterns later in a child with a disability around

the age of 12 or 18 months thus calls for attention to developmental challenges in the previous life periods of the child and his/her parents.

## **Disability as a Risk Factor for Development of Mental Health Problems**

The previous section introduced a cultural-historical understanding of attachment, considered through the lens of incongruence or congruence between a child's development and the cultural forms of early parenting. The child's biological, neurological and medical situation was shown to impact, along with cultural procedures such as hospitalisation and parents' knowledge of alternative strategies for regulating their child. To understand how an impairment affects developmental trajectories and sometimes causes psychopathology, what is needed is a balanced understanding of the role of particular impairments and disability as a condition for living, not only in one moment in time, but as the child moves in a developmental trajectory constrained by a series of age-graded demands and tasks embedded in social institutions (Hedegaard 2009; Rogoff 2003).

Plenty of research across different disability categories has found that mental health problems are more common among children with disabilities compared to children without disabilities. For example a prevalence of all types of mental health problems of approximately 20–40% has been found among children with hearing impairment (Fellinger et al. 2012; Hindley 2000). The higher prevalence of mental health problems covers attention and behavioural disorders (Hindley 2000; Stevenson et al. 2010), and emotional disorders such as depression (Fellinger et al. 2009b). Despite the higher prevalence of most kinds of mental health problems in children with hearing loss, most studies have failed to find a direct relationship between the degree of hearing loss and mental health problems (Dammeyer 2010a; Fellinger et al. 2009b; Hintermair 2007; Sinkkonen 1994; Stevenson et al. 2010; van Eldik et al. 2004; van Gent et al. 2007). The biological defect (hearing impairment) does not seem to have direct causal link to a higher risk of mental health problems.

More or less the same picture of prevalence and associations between impairment and mental health problems can be found by investigating children with cerebral palsy. In general, research finds a high prevalence of mental health problems, with a documented prevalence between 25 and 61% (Breslau and Marshall 1985; Goodman and Graham 1996; Parkes et al. 2008). The most reported types of psychopathology were emotional problems – mainly anxiety (Goodman and Graham 1996; Parkes et al. 2008; Sigurdardottir et al. 2010) – and behaviour problems, for instance hyperactivity (Bjorgaas et al. 2012; Goodman and Graham 1996; McDermott et al. 1996; Parkes et al. 2008). In follow-up studies, all types of psychopathology were found to be persistent (Breslau and Marshall 1985; Goodman 1998). However, despite the high prevalence, a direct association between degree of

cerebral palsy and mental health problems is missing (Bøttcher and Dammeyer 2013).

Despite the obvious differences between congenital deafness and cerebral palsy, similar patterns seem to occur when examining the risk of mental health problems:

1. Both groups experience a higher level of mental health problems compared to children without disabilities
2. The types of mental health problems vary and cover all categories of mental health problems.
3. No direct association between degree of biological impairment and the risk of mental health problems has been found (Bøttcher and Dammeyer 2013).

To explain the risk of mental health problems among children (with or without disabilities), the developmental psychopathology perspective (Cicchetti and Cohen 2006; Rutter and Rutter 1992; Sameroff 2009) has become a widely used model in research and practice (see also introduction of this perspective in Chap. 2). Within the developmental psychopathology perspective, the “risk factors” concept plays a central analytical role. The risk concept arose from the research tradition that analyses predictors of later maladaptation, for example psychopathology, by statistical methods. Looking at these studies together, many different predictors are found and the predictors are further found to interact with each other. Thus, risk factors are thought to affect development in complex chain reactions interacting with other risk factors or counteracting promotive factors, thereby creating multiple developmental pathways (multi-finality) (Cicchetti and Cohen 2006; Rutter and Rutter 1992). As such, the developmental psychopathology perspective incorporates a developmental complexity compatible with the cultural-historical thinking, in which biological and social processes together are considered to shape development differently at different ages and from individual to individual. Within the developmental psychopathology perspective, psychopathology has been described as the result of a breakdown in the usual patterns of adaptation between the child and the context (Sameroff 2000), thereby highlighting the idea that individual qualities gain meaning from the way in which they interact with environmental demands that vary between social practices and over time. Patterns of adaptation between individual abilities and environmental demands are a matter of goodness-of-fit.

The concept of risk from the developmental psychopathological perspective is useful in the context of the cultural-historical model of disability to expand and explain some of the processes taking place when disability leads to mental health problems. The incongruence between the child and the environment creates a social situation of development for the child that often does not support his or her development in an optimal way. Impairment (eg, a hearing impairment or cerebral palsy) becomes a risk factor, and the extent of incongruence reflects how critical a risk factor the given impairment has become (Bøttcher and Dammeyer 2013). Likewise, considering how an intervention will affect a child’s wellbeing involves reflections on how it will affect the social situation of the child, and so the incongruence. The risk is mediated by the social situation of the child. For example, removing an emotionally distressed child from an overwhelming situation lessens the immediate

strain on the child. However, if the aim of the child was to engage in play with other children, repeated removal of the child potentially increases the incongruence as the other children build and expand their mutual capacities for play. The conflict between the child's motive for social participation and possibilities for social participation increases, thus heightening the risk for future emotional distress and removal unless another line of intervention is chosen.

In children with congenital hearing impairment, the higher risk of mental health problems can be attributed to early communication and language delay that arises as an often seen consequence of the hearing loss. Communication and language delay early in life affects development of a variety of higher-order cognitive functions later in childhood (Mayberry 2003). One of them found in research is delayed development of theory of mind (Meristo et al. 2007, 2012). Theory of mind is important for early social development. Thus, psychosocial difficulties commonly found in children with congenital hearing impairment (Dammeyer 2010a) are not caused by the biological impairment alone, but stem from derived delays in communication and social skills. The pattern of incongruence, which arises when a child with significant biological impairment is required to partake in practices cultivated for typically developing children, has the potential to constrain the adaptive skills of the child. Because of the impairment, the child's potential to participate in mainstream cultural activities is often more limited. However, research also highlights that if the deaf child is supported in his/her development of communication through tailored social practices that support the child in learning an oral or signed language from early on, difficulties in psychosocial wellbeing will be no higher than the prevalence found in children without hearing impairment (Dammeyer 2010a). Functional language abilities throughout childhood have also been found to be associated with age-appropriate development of theory of mind (Meristo et al. 2007, 2012). Psychopathology associated with different types of impairments is not straightforward, but develops over time in social situations of development with different demands on the child.

Some studies find that children with milder forms of cerebral palsy and children with moderate hearing loss have a higher risk of developing mental health problems than children with severe cerebral palsy (Parkes et al. 2008; Seidel et al. 1975) or profound hearing loss (Hindley et al. 1994). Children with a minor impairment may experience greater incongruence than children with moderate impairments because they are more likely to live in mainstream contexts, in which they are confronted with age-typical demands. A higher level of stress, difficulties with peers and isolation are reported among these children with minor disabilities in mainstream school practices (see for instance Hindley et al. (1994) for children with hearing impairment).

Many studies have found that having more than one type of disability is associated with a higher prevalence of mental health problems. In children with hearing loss, additional disabilities (eg, intellectual impairment) have been reported to increase the risk of mental health problems substantially (Dammeyer 2010a; Hintermair 2007; van Gent et al. 2007). Similarly, children with cerebral palsy and intellectual impairment are particularly at risk of developing psychopathology

(Bjorgaas et al. 2012; McDermott et al. 1996; Sigurdardottir et al. 2010). Early studies demonstrated that development of psychopathology was associated with the brain lesion responsible for cerebral palsy rather than the physical impairment in itself (Graham and Rutter 1968; Rutter et al. 1970; Seidel et al. 1975). This finding led to the assumption that the development of psychopathology has aetiological factors within the brain. The brain lesion is thought to impact on the development of psychopathology through its effect on the child's level of intellectual functioning (Goodman and Graham 1996). However, level of IQ alone does not explain the higher prevalence of psychiatric and psychological problems, because, even when matched for IQ, the group of children with cerebral palsy still had more symptoms of psychopathology (Goodman and Graham 1996). The brain lesion might function more indirectly as the cause of psychopathology through its relation to the child's development of adaptive skills and cognitive functions, which are essential for participation in social practices. One example is the finding that psychopathology is associated with communication problems (Bjorgaas et al. 2012). Another example is that the brain lesion, which gives rise to spastic cerebral palsy, has been reported to be associated with specific cognitive impairments in sustained and divided attention and the ability to perceive and/or integrate visual and auditory information (Bottcher et al. 2009). Each type of impairment creates incongruence, such as motor impairments in some activity settings and communicative difficulties in others. Each aspect of the incongruences call for different kinds of knowledge – and often the involvement of different types of professionals – about how to support the child and enable his/her social agency. Supporting motor impairment and communicative difficulties separately calls for two different practices, but if both are present in the same child, the needed support becomes much more complicated. In the case where severe cerebral palsy hinders oral language production, the motor impairment of the upper limbs also hinders the child's ability to use sign language and constrains use of communicational aids in general. Thus, multiple impairments create a much more complicated developmental challenge compared to each of the impairments alone – and a higher risk of mental health problems because of the greater incongruence.

## **Psychopathology in the Early Life of Children with Disability**

Being born with or acquiring an impairment early in life can thus be considered to be a risk factor for developing psychopathology as described in the above sections. However, situations exist where the delineation between disability and psychopathology becomes complicated in a different way.

Autism spectrum disorders are characterised by impaired social interaction, impaired or atypical communication, and restricted and repetitive behaviour. Often, autism spectrum disorders are co-morbid with other types of disorders, most commonly intellectual disability (Meng-Chuan et al. 2014). Other types of co-morbid disabilities are deafness (Jure et al. 1991), cerebral palsy (Goodman and Graham

1996; Kilincaslan and Mukaddes 2009), anxiety, ADHD and tic disorders (Meng-Chuan et al. 2014). From the biomedical model point of view, autism spectrum disorders is considered to be a congenital condition expressed as a range of behavioural signs even though some of the symptoms may not become apparent until later in development (eg, problems in understanding the minds of others) (Peterson et al. 2005). Leaning towards a biomedical model of autism spectrum disorder, the symptoms are thought to arise from biologically based impairments. The symptoms associated with autism spectrum disorders constitute a developmental trajectory of an aberrational kind. The biomedical model also lies at the base of different types of treatment programmes aimed at treating the primary impairments, whether through behavioural training or modifications of the environment (see Chap. 2). However, from a cultural-historical point of view, two different life-outcome situations may exist. In one, the impairments of the child are considered as a condition for living that need to be addressed throughout the child's life, but do not necessarily prevent the child from satisfactory quality of life. In the second situation, (particular) behavioural traits of autism spectrum disorders express the child's distress and/or lack of support for development related to the incongruence in his/her current social situation of development. This second situation is likely to involve low quality of life and mental health problems. From a strictly behavioural perspective, the two situations may seem very much alike. However, from the cultural-historical point of view, the behavioural approach is too simple. From the cultural-historical point of view, it is necessary to look behind autistic traits as in-built constitutions of the child and consider how development of the psychological constitution of autism spectrum disorders, for example deficits in social-emotional reciprocity, may emerge from the child's social situation of development rather than from intrinsic impairments of the child.

A model example of the cultural-historical view on autism spectrum disorder symptoms is found in studies of children with congenital blindness. Prevalence studies have found that autism spectrum disorders or autism-related symptoms or features among congenitally blind children are frequent (Mukaddes et al. 2007; Cass 1998; Rogers and Newhart-Larsen 1989; Fraiberg and Adelson 1977). In a study by Brown et al. (1997) of 24 children (aged 3–9 years) with congenital blindness, almost half of the sample met the formal diagnostic criteria for autism spectrum disorders. Another study by Mukaddes et al. (2007) found that 30 individuals among 257 blind children met the criteria for autism. Behavioural similarities have been reported among children with autism spectrum disorder and children with congenital blindness have been reported in regard of all symptoms. However, behind the shared atypical behavioural traits in children with autism spectrum disorders and blindness, the developmental origin of their behaviour is different. Congenital blindness affects early co-regulation of contact and emotions and the establishment of mutual and joint attention (Preisler 2005, 1995), unless the caregiver is aware of the child's impairment and how to use alternative strategies for early development of social interaction. In the latter case, the child does not develop autistic-like behavioural traits. Thus, even though behavioural traits may be similar, the case of children with congenital blindness represents a second and different situation to the



one found in children with autism spectrum disorders (Hobson and Lee 2010). The example does not leave out the possibility of co-morbidity between autism spectrum disorders and congenital blindness; however, several authors have asserted that, due to the behavioural similarities found in the two conditions, there may be an over-diagnosis of autism spectrum disorders in children with congenital blindness (Andrews and Wyver 2005; Cass 1998; Hobson et al. 1997). One of these studies is Hobson and Lee (2010), who followed a group of nine congenitally blind children. At the age of 5–8 years, all children in the study satisfied formal diagnostic criteria for autism spectrum disorders. However, 8 years later, in adolescence, only one of the nine children met the formal diagnostic criteria. Congenital sensory deprivation may result in quasi-autistic features as identified by Hobson and colleagues in blind children (Hobson and Bishop 2003). They argued that the autistic features seen in congenitally blind children must in many cases be understood as the consequence of congenital sensory deprivation and lack of adapted support of development. Without support, the visual impairment hinders the child's ability to participate in the common cultural forms of early social interaction and communication when the activities are based on or around visual objects and activities calling for visual orientation skills. This could be reading a picture book, partaking in physical play and games of running, jumping, etc. The decrease in symptoms of autism spectrum disorders in the studies mentioned above was attributed to compensation for the children's difficulties in social interaction (joint attention and social co-ordination, among others) (Hobson and Bishop 2003; Hobson and Lee 2010).

Differential diagnosis between autism spectrum disorders and sensory deprivation necessitates a balance between medical and social modes of explanation through a focus on the child's social situation of development. Autism spectrum disorders as a biological constitution – and thus belonging to the natural line of development – still emerge and develop as a disability through the interactions with the cultural line of development. Aspects of autistic behavioural traits may be unproblematic from the child's point of view, for example a preference for sameness in the everyday setting. Anxiety and distress when the everyday setting is not accommodated to the needs of the child represent a problematic social situation with potential negative impact on the social agency of the child. Autistic behavioural traits arising from, for example, sensory deprivation denotes another problematic social situation. Both types of situations require attention to the child's conditions for social agency in his/her everyday activity settings, but the supportive interventions for each of the two situations will be very different. Building supportive practice for each of them calls for analysis of how to understand the social situation of the child now and how the situation has developed from both the natural and the cultural line of development together, expressing conflicts between the two. Even in cases of what could be called primary autism spectrum disorder, the biological defect does not explain how a particular child has developed and still develops as a social agent. Analysis of developmental trajectories of autistic traits may open up for decisions about what the child's particular social agency denotes and how alternative developmental trajectories have emerged and still transform in accordance with what the child considers to be interesting and worth striving for.

Behaviour considered to be problematic (either for the child, for the environment or both) needs to be understood as the child's social agency in answer to conflicts between the natural and the cultural line of development; furthermore, it calls for intervention because the child's mental health is in danger now or will be in time to come. Although intervention will differ between children whose autistic behavioural trait arises from sensory deprivation and children born with a neurobiological constitution associated with or developing into autism spectrum disorder, both types of intervention begin with the question: How is this way of acting meaningful to the child? This central assumption will be elaborated upon next.

## **Development of Challenging Behaviour**

One mental health problem experienced among a variety of groups of children with disabilities is challenging behaviour or outer-reaction tendency. Challenging behaviour can be categorised in two types: behaviour the child inflicts on him- or herself, for instance a child beating his/her own arms, banging his/her own head against the wall, pulling hair out, cutting him- or herself, etc.; and behaviour directed against others, for instance beating, kicking or scratching other persons or destroying objects. Challenging behaviour also differs in the degree to which it affects the child and his/her relations to adults and other children, from being a problem to be handled almost around the clock to episodes arising from time to time or in particular situations. Challenging behaviour is more common among particular groups of children with disabilities; thus, challenging behaviour is often reported among children with autism spectrum disorders and children with intellectual impairment. Hattier et al. (2011) studied the prevalence of challenging behaviour among 2131 children, of which 633 had an autism spectrum disorders and 1498 had atypical development. Challenging behaviour was mostly found among the children with autism spectrum disorder. The risk of developing challenging behaviour has been found to be more frequent among boys compared to girls, to increase with degree of intellectual impairment and to be more common among children with sensory, motor or communicative impairment (McClintock and et al. 2003).

There are two dominant views about the mechanisms behind problematic behaviour. The first is the behavioural approach (with roots in behaviourism), in which challenging behaviour is understood as a response to environmental or social stressors. Behavioural intervention methods are linked to this perspective. The second view is that challenging behaviour is caused by underlying biological disturbances. Analyses of self-injurious behaviour by Iwata and colleagues (1994) found that in 65 % of the investigated cases, self-injurious appeared to be maintained by the social environment whilst in 25 % of the cases it was maintained by so-called "automatic reinforcement" associated with self-stimulating activities. Meta-analytic studies point to the fact that the most effective interventions are applied behaviour analysis, including child-environment analysis (Harvey et al. 2009; Kahng et al. 2002). In

contrast are psychopharmacological and other biological interventions, which prove less effective or without effect (Singh et al. 2005; Tyrer et al. 2009).

What is lacking in both the behavioural and the pharmacological approach is the link between the child and the environment. Even though challenging behaviour is associated with particular impairments and diagnoses, challenging behaviour needs to be understood as the individual child's social agency in relation to the incongruence between the child, his/her aims and capacities and the social practices in which the child participates. No matter how odd or demanding the behaviour appears from the outside, the way of acting is meaningful to the child within the situation, given his/her particular emotional and cognitive constitution and the way the practice is organised. Involuntary acts do exist, but as we will elaborate upon in this section, even involuntary behaviour is shaped and interpreted culturally and thus needs to be understood from a practice perspective rather than as automatic behaviour of an isolated machine-like child. The challenging behaviour is part of the social agency of the child, a way of acting that needs to be understood rather than extinguished. The cultural-historical approach to the behaviour as meaningful given the particular social situation of development does not rule out that the behaviour may still be problematic to the child and/or other agents within the child's activity setting. The way of acting may still need to be addressed as problematic.

As a start, the odd and/or problematic social agency of the child is met and interpreted by other social agents. Their assessment of a particular behaviour as odd or problematic is cultural and based in expectations of the child, built from the activity of typically developing children. Since the child behaving oddly is part of cultural practices, it is valid to relate the child's activities to typical cultural practices. However, we need to look beyond the surface and probe the aims of the child and how they are related to the wider practice. Acts and acting can be meaningful in many different ways. One example could be a child at 6 years of age who sits and bites down on his own arm. Even though the act may seem odd and challenge our sense of acceptable and meaningful ways of acting, the biting may arise from many different aims from the point of view of the child: It can be a reaction to pain, a communicative act, a reaction to a stressful situation in order to calm down or distract him- or herself from a situation, a response to an activity or a person experienced as threatening or joyful, the child's active self-stimulation, relaxation or entertainment. The point is, we do not know just from looking at the outside.

The typical, "unproblematic" way of acting is based in the capacity of the child to meet demands within activity settings. A simple act such as being in a classroom is based in the cognitive capacity to filter out part of the visual and auditory input generated by many children and the activities in which they are participating. Participating in the social activities within the classroom requires the child to gather relevant perceptual information and interpret it into a cultural configuration in relation to which it can act. Relevant information will both be explicit, for example instructions, or implicit, for instance non-verbal body language, facial expressions, and cultural knowledge about proper behaviour. The behaviour of the child, even when problematic, is a response of the child given the child's understanding of the situation, repertoire of social agency and his/her particular motives.

For many children with disabilities, their understanding of the demands within the social situation will be different. Children with cognitive impairments may have difficulties in gathering information at the same speed and amount as other children at their age; they may require more time or help in sorting relevant from irrelevant information and may need to have information broken down in smaller units. For children with sensory or perceptual impairments, their understanding of the situation will mirror both the extent to which they are able to perceive information about what is going on and from the extent of adaptations made to the environment and the activities in order to accommodate the child. Many groups of children with disabilities will also be more limited in their understanding of the activity setting, due to less experience with the particular social setting or with participating in social settings of various kinds. Finally, the child with disability may understand the social setting just as well as his/her peers, but react to the pressure from the demands and lack of right support.

A child's active response to a situation is based on his/her current repertoire of participation. The repertoire can be limited given the child's impairment for example an inability to make speech sounds. At other times, the repertoire may be limited or further limited from lack of environmental support, for example the non-verbal child in a situation where communicative aids are turned off or out of range and communicative signs are ignored or not understood by the recipients. In probing the possible meaning of a child's problematic behaviour as intrinsic to the social situation of development, it is necessary to consider both the capacity of the child to understand the situational social demands, the child's repertoire of social agency in relation to cultural demands and the availability of support within the specific setting.

As mentioned above, one of the dominant approaches to challenging behaviour is behavioural intervention. Behavioural intervention addresses the misfit between the child's way of acting and cultural expectations of child behaviour within the practice, but without consideration for the contextual, cultural or developmental aspects of the child's social situation of development. Intervening to extinguish or replace behaviour without consideration to how it is related to the aims and capacities of the child on one hand and cultural forms within the situation where the activity takes place on the other hand risks adding to the incongruence rather than reducing it. The root of the problematic social situation may remain untouched if it is not analysed in its social and cultural complexity.

## **Reducing Stress and Overcoming Difficult Behaviour**

Before intervening to reduce problematic behaviour, a relevant question to ask is whether the behaviour is actually problematic or dangerous to the child and/or the environment (Elvén 2010). A blind child's rocking behaviour is harmless and may serve as relaxing self-stimulation. Blind adults report that after a day at work, they enjoy half an hour of rocking at home. Knocking one's own head or pulling hair out

may also serve as harmless self-stimulation or relaxation similar to what people without disabilities do, although their self-stimulation is adjusted to cultural norms (for instance, picking one's nose when alone or swinging a leg hidden under the table during a meeting). The problem of the behaviour may mainly be its oddity compared to cultural norms. Several communal movements have arisen during the last decade with the aim of redefining "pathological" oddness into a different but valid way of being. At a time, developing oral language was considered the ultimate goal of deaf education. However, the deaf minority cultures around the world have been powerful in establishing acknowledgment of sign languages as their native language (Leigh 2009). Other disability groups are also trying to transcend the incongruence by establishing a minority culture approach. "Aspies For Freedom" is a solidarity and campaigning group that tries to raise public awareness of autism spectrum disorders as a different way of social functioning (Biklen 2009): *"We know that autism is not a disease, and we oppose any attempts to "cure" someone of an autism spectrum condition, or any attempts to make them 'normal' against their will. We are part of building the autism culture."* ([www.aspiesforfreedom.com](http://www.aspiesforfreedom.com)). "Hearing Voices Movement" (Longden et al. 2013) is yet another example of a disability rights movement that seeks to redefine "pathological behaviour" into atypical but valid ways of functioning.

At other times, the child's way of acting may serve the child well in his/her motivated activity at the moment, but be problematic in relation to the activity and the other participants within the practice. It could be a child yelling or hitting to get attention from other children or adults within the practice. The child yelling and hitting will render the situation unpleasant to the other participants and might result in for example the child being removed from the situation or other children withdrawing from the child with disabilities. Both types of consequences will be detrimental to the development of the child with disabilities in a future perspective, because they deprive the child of valuable possibilities for learning social and cognitive skills passed on through participation in the practice. In a developmental perspective, this type of situation is problematic to the child as well because it increases the present incongruence and constrains the development of the child in the time to come.

Yet a third type of social situation arises when a situation is experienced as confusing and too demanding by the child and the problematic behaviour is the best choice of the child, given the child's capacities to understand and act. By definition, disability seen as an incongruence denotes a situation of stress, because the tasks and demands mismatch the person's abilities. The child with disability has reduced or different cognitive, social and communicative resources to manage the particular situational demands. Stress thus serves as an analytic concept for probing the situation with problematic behaviour in order to consider whether the child is severely distressed by the incongruence between his/her own capacities and the environment (Elvén 2010). In an extremely stressful situation, the aim of the child will change from participation in the activity to avoidance or escape from the distress experienced within the situation. If the child is not able to avoid or escape the situation, more stress is generated. Within this analytic frame, problematic behaviour (eg,

yelling, hitting, scratching) is interpreted in relation to the complexity of the situation, the demands within the situation, the child's capacities to act within the situation and the aim of the child. The problematic behaviour of the child may actually serve it well if it succeeds in raising attention to the problem and the need to change it to better accommodate the child. What is needed in the situation is not to extinguish the problematic behaviour in itself, but to change the social situation of development towards better alignment between the capacities of the child and the demands within the situation.

Even though the above description outlined three different situations, a particular way of acting may in practice signify in all three situations at once. The analysis of developmental trajectories of autistic traits mentioned earlier in the chapter can serve as an example: Autism traits are a prime example of behaviour often considered pathological and undesirable and as arising from a particular impairment of the child and less related to the child's social situation of development. However, questioning the child's aim of his/her peculiar way of acting opens up for decisions about when the child's particular social agency is actually problematic and in need of intervention. Children with autism spectrum disorders often insist on "sameness" in regard to people, objects and activities. Insisting on sameness may seem odd or pathological from the outside, while the sameness from the child's perspective is related to an aim of making the world manageable. Current theories about autism spectrum disorders point to cognitive impairments, for example, in perceptual processing from elemental to global levels necessary to create coherent understanding of situations (Minshev et al. 2003). Given this particular impairment, the child's insistence on sameness is meaningful rather than pathological. Within the familiar situation, with recurring structure and content, the child knows what to do, what to expect and which preferred persons and activities with which to engage. On the other hand, despite being meaningful, the child's insistence on sameness may be a problem in a developmental perspective, if the insistence on sameness is not met with a proper social situation in which the child can develop. For young children, without the introduction of at least some new aspects, the situation becomes a situation of cultural deprivation. The arrest of learning has the potential to increase the incongruence over time. Also, if the child does not learn to manage a certain amount of variation, an insistence on sameness will constrain efforts towards inclusion, endangering social participation at large.

Challenging the problematic insistence of sameness of the child with autism spectrum disorder may at times be counter-productive, as it will raise the level of stress experienced by the child and result in even more problematic behaviour. For example, take a child with autism spectrum disorder asked to change seat in the bus by the preschool teacher. The situation in the bus might be experienced as stressful by the child from the start due to a high level of noise. When asked to do something difficult that adds to the stress, the child's reaction may be problematic behaviour, such as self-harm or kicking the preschool teacher. In this situation the preschool teacher has at least two options. The first is to maintain the demand with the argument that there are equal roles for all children or the child has to learn to be more flexible. The second option is to accept that changing seats is too stressful for the

child, let the child remain seated where he/she is and next time prepare the child to sit in a specific seat; the teacher could also consider ways to reduce the noise, as it will probably also suit children other than the child in question. In the latter situation, the incongruence between the child's abilities and the demands of the situation is reduced both in the current situation and probably also in the time to come.

In handling difficult behaviour, the caregivers first of all have to analyse the specific stressors and how these can be reduced by decreasing the incongruence in the specific social situation. To overcome the gap between the abilities of the child and the demands and complexities of the social practices, several lines of action are possible. Whatever action is taken, the central part of the intervention is to address the complexity of the social situation in which the difficult behaviour has emerged.

## **Approaching and Addressing the Risk of Developing Mental Health Problems**

Analysing mental health problems and difficult behaviour requires more than just taking in the perspective of the child. The understanding of mental health problems and problematic behaviour needs to be turned completely around, from considered as intrinsic to the child and his/her impairment to seeing how they are related to the social agency of the child within particular cultural-historical practices. In Chap. 4, the urgent child versus the silent child was discussed with regard to development of social agency during toddler age. This example also becomes relevant in relation to both development of mental health problems at large and difficult behaviour more specifically. In Chap. 4, we outlined a situation in which children with difficult behaviour afforded urgency in relation to the professional staff and, through this agency, opened up for the necessary tailoring of the practice to accommodate to their motives and abilities to develop as social agents. The silent children were less successful in their attempts at social agency. They acted but their much less salient actions did not afford an answer from the parents or professional adults. The afforded silence did not support further tailoring of the practice and thus maintained the present situation, including the current level of incongruence that lacked the support of participation and development of social agency. To understand a child's way of acting – including development of mental health problems and problematic behaviour – and decide whether to intervene (and which interventions are required) always requires analysis within the frame of the social situation and the child's development as a social agent. Only this type of analysis will allow us to penetrate the surface of the behaviour and address the aim of the problematic behaviour and alleviate it – when necessary. Taking up insistence on “sameness” as a kind of problematic behaviour thus requires the professionals to attend to the child's aim of keeping the world manageable rather than considering insistence on sameness as an aim in itself. It also requires us to consider how the social situation of development is related to the developmental trajectory to come. At times providing sameness

may be necessary to avoid situations of severe stress or feelings of inner/outer chaos that are counterproductive in relation to the development of social agency. At other times, the task for the professional will be to help the child to engage in new activities and situations of interest and learning by helping him/her to manage the situation, for example, by providing the child with strategies for sorting and handling the incoming information in order not to be overwhelmed.

The affordances of urgent or silent are not related to the relation between the child and the professional adults alone, but emerge as functionally significant properties in environments with cultural-historical properties including the values within the institutional setting (Bang 2009). Values about learning and development towards skills and capacities for an independent life as an adult are dominant in relation to typically developing children. In relation to children with disabilities, especially children with severe conditions, long-term goals may be less clear as an independent life can be improbable given the child's impairments. However, understanding mental health problems and difficult behaviour as social agency and analysing it within the child's social situation of development has the potential to lessen the incongruence that produces the problems.

## **Summing Up: The Developmental Complexity of Disability and Mental Health**

This chapter has outlined a dialectical understanding of the processes between biological impairment, individual experience of mental health symptoms, social practices and culture values about preferred ways of acting. Together with an analysis of the current situation, addressing the future risks is important in relation to many children with disabilities. Problematic behaviour and mental health problems hold the risk of more difficult conditions for development of social agency for the child with disabilities as both of them makes it more difficult for the child to partake in mainstream settings without support. The meaningfulness of the child's way of acting requires us to consider the child's perspective. However, we suggest that it is also necessary to transcend a mere consideration of the child's perspective and address how mental health problems and interventions will affect the child's possibility for developing and pursuing his/her aims within future social situations.



## Chapter 7

# Learning and Teaching When the Child Has Special Educational Needs

In the first part of the book, we outlined how primary biological defects, individual development and social participation are interconnected and influence the development of the child as a whole. In this chapter, the aim is to use the cultural-historical perspective to analyse school practices of children with disabilities and understand learning of children with so-called “Special Educational Needs”. We approach cognition and learning from the perspective that even though cognition and learning are carried out by individual children, both processes are always socially and culturally situated and distributed. Understanding the challenges and supporting children with disabilities in school revolves around the overall aim of the school: learning, and the learning motive of the child. Differences in school practices will be exemplified by drawing on cultural-historical educational literature as well as the existing body of empirical educational research that will be reinterpreted within a cultural-historical understanding.

### Cultural-Historical Practices of Inclusion

As mentioned in the second and fifth chapters, inclusion is foremost a political agenda developed from the ideas of human rights and equality of participation in society from the middle of the twentieth century. The inclusion agenda has been accentuated in the last decades and international organisations and national governments have committed themselves to the inclusive development of education (Booth 1999; Mitchell 2005). Its increased centrality in educational politics and practice has developed in parallel with the social model of disability. From the political and cultural-value perspective, the current situation builds on a consensus that inclusion is valuable for society at large and especially for individuals with disabilities and other groups that have experienced or still experience social exclusion. However, a number of issues arise when inclusion is translated from a political and human

rights perspective into inclusive practices. First of all, the effectiveness of inclusion in the creation of better opportunities for social participation and learning has been questioned. In a comprehensive review of the literature on the effectiveness of inclusive education/mainstreaming, Lindsay (2007) concludes that “*the review does not provide a clear endorsement for the positive effects of inclusion*”. Inclusion is typically described as the process of increasing participation and decreasing exclusion from the culture, community, and curricula of mainstream schools (Booth et al. 2000). However, concrete processes of inclusion still need to be spelled out (Florian and Black-Hawkins 2011). Florian and Black-Hawkins (2011) carried out observation and interview studies of teachers’ inclusive practice in schools in Scotland with the aim of finding examples of what types of practices work and how. The main finding was that it was difficult to carry out an inclusive pedagogy in practice, because the schools often lacked sufficient organisational support, for instance, by providing opportunities for teachers to use alternative grouping (see also in Norwich (2008)). From a cultural-historical perspective, the organisational barriers stem from the development of the school as a cultural-historical practice. The current organisation has developed to accommodate the educational needs of “typical” children, while the accommodation of alternative educational needs will vary depending on the type of tailored support needed by the child.

Ainscow et al. (2006) also notice that inclusion is on the global political agenda, but is difficult to bring into reality for schools and practitioners. They point to a number of organisational and structural misfits, but also to the fact that inclusion as a concept is inherently contradictory. Raising the inclusion agenda underlines that (some) children are different and the focus on individual difference removes focus from the social practice of development and participation. Graham and Slee (2006) stress this point by analysing how inclusion risks ending up in its negation: exclusion. Using poststructuralist theories (Foucault 1980) they argue that:

*First, talk of ‘including’ can only be made by those occupying a position of privilege at centre. Second, that talk seldom revolves around recognising and dismantling that vantage and the relations of power and domination sustaining it. Third, talk has constitutive and material effects that can function either as cultural work in a refusal of what is (Foucault 1980), or as strategic rhetoric that functions to obscure and (re)secure the existing order of things. (Graham and Slee 2006, p. 19).*

A political discourse of inclusion holds the risk of maintaining an inclusion-exclusion dichotomy at the schools and in the classrooms. A better approach might be to focus on general educational terms, for instance, participation. Poststructuralist critique is useful and underlines how misfits at a discursive and societal level affects institutions and individuals. However, teachers request specific knowledge about useful educational practices from professionals with special education and experiences with people with disabilities (Forling and Chambers 2011), though evaluations of the effect of this perspective in other studies are mixed (Lindsay 2007).

Mitchell (2008) has reviewed different practices for inclusive education. The majority of the teaching strategies in the review were based in cognitive or behavioural approaches to learning. However, one of the strategies addresses the interaction between the organisation of the school and the activity settings and the

individual differences between children. The strategy is called “Universal design for learning”. The concept is to organise a variety of ways of presenting information to the children and offering the children different ways of responding. Rather than calling for an education in which the teaching can be accommodated to each individual child, the idea is to create a didactic platform that is accommodated to all types of children. Mitchell (2008) states that the efficacy of Universal Design for Learning (UDL) is difficult to determine because it covers a matrix of interventions. Even though UDL is based in the idea of human diversity as a norm, research in the efficacy of UDL rather addresses particular special educational needs (e.g., reading disabilities (Coyné et al. 2012) and learning with visual impairments (Siu and Lam 2012)). Thus the focus on the match or mismatch between (diverse) learners and learning environments leads back to analyses of how individual impairments and organisation of learning practices are related, similar to the perspective of the cultural-historical model of disability. In addition, the cultural-historical model of disability includes the impact of developmental time and peers as important aspects of the learning environment.

## Special Educational Needs in a Cultural-Historical Understanding

Terms such as “mental retardation” and “learning difficulties” denote that the failure of the child to learn is considered as a lack of *ability* to learn in spite of participation in conventional education. Both labels are grounded in an understanding of learning ability as a mainly intrinsic quality of the child. However, groundbreaking studies from the 1970s into the tradition of disability studies (social model of disability) (see Chaps. 1 and 2) pointed out that universal labels such as mental retardation were linked with social, cultural and ethnic factors (Mercer 1973). Children from particular cultural and social backgrounds were much more liable to receive a diagnosis of mental retardation or learning disabled (the terms of that time), compared to children from white middle-class families. Even though this observation does not rule out biomedical reasons, it opened up for research in how categories of learning disabilities and intellectual disability arise in cultural and institutional settings organised in such a way that particular types of children attract diagnoses more readily than others.

The term “special educational needs” was introduced at the end of the 1970s and beginning of the 1980s in order to enable a move from individualistic understandings of learning difficulties to an approach based on the role of teaching and institutional practices (Department of Education and Science 1978; Visser 1993). Children could be different in degrees of learning abilities, but not in kind, and by stressing *need* in the term, the idea was to focus on the right type of intervention and support (Norwich 2002). In Britain, the term came in parallel with a change in law ensuring the right of education for children with disabilities, some of which had hitherto been

labelled “uneducable”. The change of terms to special educational needs represented the change to an understanding of learning as a process enabled by the school and by particular choices of teaching strategies and curriculum and mirrors the advent of the social model approach of the period.

However, it has been argued that the term special educational needs still contain notions of individual deficit (Norwich 1993). A dilemma in practice between a focus on the individual deficits of a child and a focus on the level of institutional accommodations to the needs of the child or groups of children easily occurs (Norwich 2002). Rather than seeing this as a problem to be solved by a further move towards a pure social model approach, the cultural-historical model of disability of this book (including the developmental perspective outlined in Chap. 2) seeks an alternative solution. The dilemma can only be solved through a common framework that incorporates both the individual and social elements that enable a child to learn. Here, we will not recapitulate the arguments from the first chapters, but instead move on to analyses of the emergence of special educational needs for the individual child – and point to how impairments, learning abilities and practices for teaching are related.

Special educational needs are of a dynamic nature similar to disability, but as the concept of special educational needs are related to the institutional setting of the school, special educational needs express the extent to which the child has learning support needs that are not met by the present organisation of the teaching activity in school. The threshold for when special educational needs emerge depends on three aspects: (1) The organisation of the learning setting, (2) the particular impairments of the child and (3) the change in support and demands within the setting through time.

Learning is, of course, not confined to the child’s participation in teaching activities in school. As pointed out in previous chapters, learning is the foundation of development and takes place from the birth of the child and in all of the activity settings in which the child participates. Special educational needs are related to the child’s participation in the institutional settings of the school. Disability will never be interchangeable with special educational needs (Porter et al. 2008); nevertheless, it is reasonable to expect overlap between children with disability and children with special educational needs, as the child’s disability will often affect both school readiness and social participation and thus call for accommodations of the activity settings at school. This basic point of the cultural-historical disability model is that the impact of an impairment on the child’s learning and development is not predictable due to differences in the dialectic interaction with the settings. Special educational needs, similar to the disability, emerge and develop in dialectical relation to the school’s aims and practices.

From a cultural-historical point of view, learning in school is based in activities of situated cognition (Cole and Engeström 1993). Situated cognition covers that learning is an activity at a biological, cognitive and social level, all of which are connected to each other and contribute to the development of the child through their mutual dynamic, as outlined in Part 1. The child’s learning, whether following typical or atypical developmental trajectories, is supported by functional neural

networks sculptured by use (Karmiloff-Smith 1998). The single child's learning takes place within cultural practices of participation (Lave 1988) in which the individual cognitive processes are supported, transformed, enabled, constrained, etc. by shared activity, including cultural artefacts and cognitive mediation. The child is part of the different activity settings as a participant, who is at one and the same time conditioned by social demands and expectations and an active shaper of the social environment through his/her own activity (Hedegaard 2012). Learning as development of both cognitive functions and neural processes is related to the child's participation in different activities and how they afford and develop particular cognitive activities and processes, which in turn furthers the development of the neural systems and processes. The incongruence, which arises when a child with an impairment has to learn in practices cultivated for typically developing children, has the potential to constrain cognitive and neural development through its impact on the possibilities of the child to participate in activities. "Intellectual disability" or "learning impairment" of a particular child becomes a condition for living, in which learning impairments are neither caused by biology nor by social conditions alone, but arise in the interaction between two developmental spiral-like processes as outlined and illustrated in Fig. 1.1, Chap. 1.

Brain lesions can work as an example. The idea of brain lesions as a constraint on the child's learning ability is readily accepted within the educational system. The opposite point of view – that schools create social barriers for children with brain lesions (often understood as socially constructed "labels") – has also been researched extensively (see for instance McDermott (1993) for a representative of this point of view). Research investigating the impact of learning conditions for children with brain lesions is scarcer. Jenks et al. (2007, 2009) investigated learning problems along with learning conditions of a group of children with cerebral palsy during their first year of schooling, either in mainstream schools ( $n=16$ ) or special schools ( $n=41$ ) in the Netherlands. The study focused on arithmetic learning difficulties that are more prevalent in children with cerebral palsy and have been found to be associated with cognitive impairments in working memory, visual-spatial analysis and visual memory (Geary et al. 2000), which are common in this group (Stiers et al. 2002; White et al. 1994). The study was designed to consider the role of cognitive impairments and social learning conditions together during the first year at school. Standard measures of IQ, working memory and early numeracy were supplemented with measures of the amount of arithmetic instruction per day, registered by the child's teacher. At the beginning of the first year at school, measures of early numeracy showed that children with cerebral palsy (CP) in mainstream school were behind their peers, but were still better than the group of children with CP placed in special schools. The groups also differed in a similar way with regard to measures of cognitive functioning (IQ and working memory). By the end of the first year, the CP mainstream group had caught up with the control group of typical first graders, whereas the group of children with CP in special schools still lagged behind. Although the groups did differ in cognitive functioning, analysis revealed a significant impact of instruction time on addition and subtraction accuracy. The children with CP in special schools received much less arithmetic instruction (about

60% compared to the mainstream CP group) and the difference in instruction time explained part of the variation in arithmetic competence, even when differences in cognitive ability were taken into consideration (Jenks et al. 2007). On the other hand, differences in instruction time did not explain all of the variation. General level of cognitive functioning, level of visual-spatial functioning and executive functioning (all of which are the base on which arithmetic instruction builds) still explained part of the variation in arithmetic skills.

Another study looking into the learning conditions of children with disabilities was undertaken by Bøttcher (2012). The study was a qualitative study at a special school for children with pervasive motor and learning impairments. The focus of the study was on the differences in the school practices of children with and without disabilities and how these differences affected the participation in learning activities of the children at the special school, compared to children in mainstream schools. Similar to the study by Jenks et al. (2007), this study found that the children in the special school received much less subject matter teaching due to a large amount of time taken up by basic care and physical therapy. This means that even though learning is harder for many children with severe disabilities due to cognitive impairments such as difficulties in sustained attention, slower information processing and fatigue, they often have less time for learning math, reading and other basic school subjects. Another finding of this study was that the conditions in mainstream schools often allow children to concentrate on one learning activity at a time, while the learning activities at the special school often were organised towards several agendas. One example from the study was a situation in which the children were playing a game practicing their skills with small numbers while standing in their standing frames in order to improve physical functioning. From the perspective of the professionals at the school (teachers and therapists), the aim of this organisation of the activity setting was to make the most of school-time. The problem was that the children had to use part of their limited energy and attention to hold their trunk in an upright position and/or lift their head, and thus were left with less energy and attention for the numeracy activity. Physical training during reading and math activities affects the ability of the child to engage in the activities. The slower learning of children with disabilities need not only be a consequence of their brain lesions and subsequent cognitive impairments, but seems also related to the time needed for basic care and the way activity settings are organised with multiple purposes. The different effects of an impairment escalated in the learning situation and enlarged the special educational needs of the child over time.

## **Identification and Measurement of Cognitive Impairments**

Special educational needs are often identified outside the teaching situation, by diagnostic checklists or assessments of cognitive ability by an educational psychologist. In this middle part of the chapter, we will outline some of the problems and

challenges associated with assessment of children with disabilities, considered from the cultural-historical perspective.

Knowledge about the strengths and weaknesses of the child is important. Both under- and overestimation of the child's cognitive abilities is a recurrent problem that is thought to impact negatively on the child's social situation of learning (Heywood and Litz 2007; Sabbadini et al. 2001). At the same time, the recipients of assessments – mostly professionals and parents - often express dissatisfaction with the conclusions and recommendations made in the reports. Shared elements in the critique are dissatisfaction with the negative outlook of reports and the poverty of recommendations (Lebeer et al. 2011). A deeper analysis of the assumptions and practices underlying standard psychological and neuropsychological assessment can help to reveal some of the reasons behind this dissatisfaction, grounded in a cultural-historical understanding of cognition and development. Furthermore, a clearer understanding of the problems with traditional assessment practice may also point to a solution to the dilemma that an objective evaluation of cognitive impairments are needed without losing the focus of the child's learning as developing in situated, socially shared activities. Thus, the focus of this part of the chapter will be on how to make assessments valid and useful.

Standard psychological assessment is based in the science of psychometrics. One of the basic assumptions of classical test theory is that each person has a true score in a measurement of general intelligence or specific cognitive functions (Lord and Novick 1968). The basic assumption of the psychometric paradigm is that a test score mirrors that the person has the same capacity in all places and at all times. Cognitive ability is a stable ability in each individual child. Doing the same test over with the same child might result in slightly different results, but this variation (called error of measurement) is supposed to be random error. Random errors are normally distributed and therefore it is possible to take random error into account by the use of statistics. The standard error of measurement allows the person summarising the test scores to estimate the degree to which a test provides inaccurate results. Many test manuals contain the test's standard error of measurement and provide confidence intervals for specific observed scores. An interpretation of a test result can convey the error of measurement by providing the result as a range rather than an exact number. It is therefore central to the validity of the score that the error is not systematic; it must not arise from the environment or the examiner in a systematic way.

The assumptions associated with “true score” are easily violated in relation to children with impairments. In clinical assessment practice, children with impairments often show more variability in their performance, for example, large performance differences depending on the stimulus material, the time of the day, or noise from the environment. Other types of problems in relation to assessment of children with impairments are fatigue, sensory problems (ability to hear or see), ability to pay attention (focused attention), ability to understand instruction, ability to keep instruction in mind (working memory), ability to keep working (sustained attention), etc. Thus, intellectual impairment or other types of impairments will often

introduce systematic error, as illustrated in the equation: true score + random error + systematic error = observed score.

Systematic error due to sensory impairments or specific cognitive dysfunctions presents a problem regarding both the reliability and the validity of the observed score. One example of how systematic error impacts on an observed score of general intelligence is the measurement of “performance IQ” in children with cerebral palsy. Repeated studies have found that children with cerebral palsy have lower performance IQ than verbal IQ. (In older studies, the revised or third version of the Wechsler Intelligence Scale for Children performance and verbal IQ is used; the newest, fourth version does not operate with performance IQ and verbal IQ). However, 6 out of 7 performance subtests of the Wechsler Intelligence Scale for Children that were used in the studies (WISC-R or WISC-III) are timed and required a motor output. In contrast, only one of the verbal subtests was timed and none of them required a motor output. The non-verbal subtests are based on the assumption that the child is able to convert non-verbal thinking into motor actions in an efficient way. Violations of this assumption contaminate the result and undermine the validity of the test score (Fennell and Dikel 2001). The low score in performance IQ might reflect motor impairment, specific visuoperceptual impairments, slow working speed or general intellectual impairment. In addition, the performance IQ will lower the general IQ score (which is the sum of performance and verbal IQ) and thus systematic error contaminates the final, compiled result.

Another systematic error occurs when using Wechsler’s Intelligence Scales with deaf children. In this case, the mayor validity problem is experienced in the verbal subtests (Maller 1997). Deaf children’s use of visual communication and frequent delay in language abilities undermines the validity of their response to many psychological tests (Edwards and Crocker 2008). Systematic violations of the underlying assumption of tests obscure the validity of the observed score and the extent to which it represents the true score of that child. As pointed out by Sabbadini et al. (2001), this methodological challenge is of real-world relevance because the lack of valid neuropsychological evaluations often results in over- or under-evaluation of the actual abilities of children with disabilities and subsequent problems with creating learning programmes in school at an appropriate level.

## **The Methodological Challenge of Psychometric Measurement in a Cultural-Historical Perspective**

Sabbadini et al. (2001) described a project of doing neuropsychological assessments of eight children or young people with severe cerebral palsy and accompanying neuromotor and verbal disabilities. Often, these children and youngsters are rendered unassessable, because the combination of motor and verbal disabilities hinders the use of standard administration procedures. Psychological tests are provided with standard instructions relating to how to present the task and the test



materials in order to measure the child's abilities as purely as possible by minimising the impact of the environment and the examiner. However, standard administration is often neither fair nor feasible with children with impairments. If we want to know the true score of the child, it will often be necessary to adapt the administration. The child who is deaf, hard-of-hearing, or has visual, communicational and/or motor impairment may have particular problems with receiving task instructions or producing the required answer. In that situation, not making adaptations to the test and the administration would be unfair to the child and of course undermine the validity of the test. If the child is deaf or hard-of-hearing or has communicational problems, the material would be presented visually, or the child would be allowed to use hearing aids and/or communicate by other means. The approach of adaptations is to compensate for the systematic error caused by the impairments, thus counter-balancing the systematic error from the impairment. Sometimes this appears straightforward: the child should wear prescribed glasses or hearing aids. At other times, adaptation becomes more complicated, in the case of, for instance, severe motor impairment, motor slowness, cortical visual impairment or more pervasive language or communicational impairment in which the child depends on environmental support in order to be able to communicate. The solution proposed by Sabbadini et al. (2001) is a classical testing approach with adaptations of the procedures for administration that enabled the participants to select their response without assistance from the examiner. Assistance from the examiner could be the examiner pointing to the different possible answers and asking each time if this is the correct answer. However, this method has the problem that the examiner might influence the test-taker's choice of answer. A better alternative suggested and used in the study was to provide the test-taker with tailored means to indicate which answer is correct, for example, use of a sensor for pointing independently among a set of possible answers. (See Sabbadini et al. (2001) for further descriptions of the procedure.)

The methodological approach of Sabbadini et al. (2001) enabled neuropsychological assessments of children otherwise often rendered too difficult to assess. However, the study still excluded children with extensive distractibility, weak communication skills, children unable to understand or adhere to the rules of the different tasks and children unable to make reliable visual discriminations. Other exclusion criteria could be mental rigidity, insistence on sameness and emotional distress in the case of deviations. All of the exclusion criteria are thought to diminish the reliability and validity of the assessment because they may produce low scores in a wide range of measures.

The methodological problems outlined here point to a more basic theoretical problem in the objective measurement approach to the learning problems of children with moderate and severe impairments. Which impairments should be counter-balanced and which impairments are parts of the abilities we are measuring? Impairments in attention or mental flexibility, for example, are not only confounders of the evaluation of the cognitive abilities of the child; they are at the same time an essential part of these children's cognitive functioning. The reduction of cognitive functioning to one stable exclusive ability makes the description of the child

with disabilities difficult to set up support for the child's special educational needs. From a cultural-historical point of view, the fluctuations in cognitive abilities in different social activities need to be included because different organisations and forms of learning activities affect the child's cognitive functioning. This poses a new challenge that is both theoretical and methodological: how are we to approach and capture fluctuations in cognitive functioning?

The methodology suggested by Sabbadini et al. (2001) is aimed at making knowledge of the abilities of the participating children available as objective descriptions. Nevertheless, in their interpretation of the cognitive performance of the participating children, they air considerations about the impact of both situational features and of cultural-historical practices on the cognitive functioning. As a first example, consider the following statement from Sabbadini et al. (2001): “[T]he methodology adopted by the present authors ensures that these patients are spared an excessive attention load in the execution of the procedures and can focus on the solution of the cognitive tasks” (p. 176). This means that problem-solving is always carried out in specific situations with particular means and tools for help or remediation. During a cognitive activity, cognitive functions and situational aspects are intrinsic to each other, not isolated elements. The result of the assessment using the methodology of Sabbadini et al. is not what the child is able to do by him- or herself, but is rather a measurement of what the child is able to do given the support of various remedies. This points out an important result of the study. The psychometric approach of Sabbadini et al. has enabled them to create a situation where the child is able to solve tasks independently of the experimenter, but is still given supportive remedies. It leads to a methodological shift in focus from cognitive abilities and impairments within a child to cognition in situated activity, from measuring the child as object to evaluating the child as a subjective agent within activity settings with different characteristics that can support or challenge the child's endeavours. Cognitive functioning as an innate stable ability needs, from a cultural-historical point of view, to be exchanged with the concept of cognitive potential focusing on how to employ the potential through learning and providence of the right means for the child to participate in the learning activities.

The proposed methodological shift is based in the situated cognition approach introduced earlier in this chapter (Cole and Engeström 1993). In the situated cognition approach, cognition is considered as a relation between an agent and a situation in which the agent is doing something or wants to do something (Greeno 1989, 1998). The situated approach to cognition is rooted in the cultural-historical assumption that learning and cognitive development is always situated in social contexts whether the child has a disability or not (Vygotsky 1998). Different activities – shared or individual – afford and support different types of cognitive activities. Moreover, through this employment of different individual cognitive processes, individual cognitive development is formed (Salomon 1993). As outlined in Chaps. 4 and 5, the forms of the practice may both initiate and restrict children's learning activities by stressing the use of different cognitive functions and affecting the ability of the child to function as a social agent in the learning activities, thereby becoming conditions for their further learning and development. In order to understand the

learning and cognitive development, and thus be able to assess and organise learning support, it will often be necessary to consider both the organisation of the activity setting and the individual cognitive processes of the child.

The perspective of situated cognition is aimed at understanding how situational factors are intrinsic to cognitive functioning. Consider the following excerpt from an interview with the teacher of a boy, Marcus, with moderate cerebral palsy including cerebrally caused visual perceptual impairment. (For further description of the study, see Bottcher (2010)):

Teacher: *“He always gets his reading up on the computer, where he sees it best, because we can enlarge the letters as much as necessary. And [that day] I chose the size I think we always use when reading, size 48 on his computer, and asked him; can you read this? Yes, I can, he said and started to read and he was able to see it. But he couldn’t see it well enough. He could see it because he had read the text at home. What he had seen then helped him in the situation, but then he arrived at a word, which challenged him, and then he couldn’t... then it became difficult for him to tell the letters apart. [...] Some days he sees things better than other days.”*

Interviewer: *“And it can be reflected in how big the letters must be on the screen?”*

Teacher: *“Yes. And of course in his ability to stay concentrated and keep concentrated when we talk about things all together in class.”*

When understanding the visual perceptual skills of the boy, Marcus, knowledge about the biological properties of the neural tissue supporting visual perceptual skills are relevant, along with considerations of how his particular lesions affect the capacity of his cognitive functioning. The location of his brain lesion has decreased his visual acuity. Still, Marcus’ visual perception, his ability *to see well enough*, is closely related to aspects of the particular activity he engages in. In addition, Marcus’ visual perception is described as related to events prior to the activity of reading at school (the reading at home) and to other cognitive functions such as memory and concentration. Higher-order cognitive skills such as semantic memory dynamically intertwine with lower order cognitive abilities, such as visual acuity. On top of this, Marcus’ own judgement of what he can see and cannot see well enough adds to the complexity of describing his visual perceptual functioning. Many facets of or around the particular cognitive function influence Marcus’ visual-perceptual functioning in a particular situation. These subjective and contextual aspects would not be revealed if the aim was to describe the perceptual and cognitive functioning of Marcus, free from particular practices and activities. Understanding cognition-in-practice requires not only a shift in theoretical approach, it requires a methodological shift that includes qualitative data about the activity in which the child participates, including the practices through which the information about the cognitive functioning is gained, whether from the classroom, from test sessions in the psychologist’s office or from observations in other activity settings (Lave 1988). Traditional normative assessment is organised to measure the child’s “current level of independent functioning”. From a cultural-historical learning approach, it is information about the child’s zone of proximal development that is useful in order to be able to plan teaching and learning activities. The methodological consequence is the necessity of simultaneously describing individual cognitive

processes and the activities of distributed cognition and their reciprocal dynamic in assessing the cognitive functions of children with disabilities. And furthermore, in understanding the developmental challenges and needs for support of children with special educational needs, it becomes central to investigate the dialectical connections between the child's different (biologically based) cognitive impairments and his or her capabilities and interactions in different types of environments. To further clarify the difference between an individual and a cultural-historical approach to cognitive functioning, we will present a case study done by both authors (Bøttcher and Dammeyer 2012).

### **A Case Study: Oliver with Cerebral Palsy and Cortical Visual Impairment**

The aim of the case study was to compare the competences of a boy as observed at his special school and in his home environment, in order to reveal how disabilities emerge and evolve within specific physical, social and cultural-historical contexts and in relation to the types of actions taken by the adults in order to meet the special needs that arise from the incongruence.

The case is an 11-year-old boy named Oliver with severe cerebral palsy (CP) and cortical visual impairment (CVI). Oliver was chosen for analysis because a huge disparity was expressed between the parents' and the professionals' notions of his present abilities and proximal possibilities for new learning and development. The parents felt the school underestimated Oliver's abilities and failed to offer him sufficiently challenging learning activities, whereas the professionals at school felt that Oliver's parents held unrealistic ideas about Oliver's capabilities, especially in relation to how well he could see and communicate. The question of under- or overestimation of the child's level of cognitive functioning raised by Sabbadini et al. (2001) was thus hovering in the cooperation between home and school.

Due to his motor impairments, Oliver was unable to move himself around and was mainly moved by others in a manual wheelchair. He could move around a little by himself when placed in a walker. Oliver communicated through sounds and word approximations, by pointing at symbols and using simple gestures to mean "yes". He also used a Rolltalk, a small portable computer with a touch screen that functions as a communication aid for people with speech impairments. The user of the Rolltalk selects fields with predefined images, which are read aloud in synthetic speech, e.g., "want to be alone" or "drink".

Videotaped observations of Oliver were made during his first year at the school during different kinds of school activities. Another three videotaped observations were made of home activities involving Oliver and his mother. The duration of the activities varied between 10 and 45 min. Two observations were chosen for the

study: one from school and one from home, both of which involved the use of the Rolltalk. (See Bøttcher and Dammeyer (2012) for coding procedure and analysis).

The analysis of the activity and the partner's response revealed several differences between the school and the home context with systematic impact on Oliver's visual and communicative functioning. Oliver's impairment in visual attention and his ability to make use of his limited visual ability depended heavily on how the adults responded to him and on the organisation and quality of the social interaction. In the school situation, the teacher was aware of Oliver's visual impairment and tried to establish greater congruence by focusing on Oliver's direction of gaze and by scaffolding his activity in accordance with the organisation of the activity at large. But often the teacher interpreted him as inattentive. Firstly, he directed his attention in an unusual way; for example, he looked *around* rather than *at* the objects of interest. The teacher seemed to interpret his direction of gaze as a sign of inattention and subsequently requested Oliver to look at the material while at the same time she tried to move the material around into what would constitute a typical centre of visual attention: right in front of the person. However, closer video analysis of Oliver's way of looking at objects revealed that this area did not seem to function as Oliver's centre of visual attention. Most likely, his cerebral visual impairment had affected his visual field. Secondly, Oliver needed time to focus and shift his attention, time that was not available in the school context. The teacher was focused at maintaining the typical class situation where all children had to respond to her instructions, for instance using the Rolltalk to reply to the question "what day of the week is it?". Given this organisation of the activity setting, the aim of the teacher was to pay attention to all the children in the group. This organisation placed a time constraint on her interactions with Oliver. The lack of continuous attention made it more difficult for her to discover what Oliver was focusing on, because the focus of his attention was not readily apparent the same way as it was for children without visual difficulties. When the teacher was not successful in her scaffolding activity, she attributed the failure to Oliver's perceptual impairments and general cognitive functioning. The situational aspect was not considered by the teacher, even though the teacher's scaffolding activity (flapping the exercise card, pointing at and moving the card or the Rolltalk around) amplified the incongruence in the school situation, because it increased the visual complexity of the situation. Given that visual processes are straining for persons with cortical visual impairment, Oliver seemed in the observations to react by reducing visual stimuli and look down, thereby further confirming the teacher's doubt about Oliver's ability to pay attention and participate in the activity. In the school situation, the incongruence between Oliver's visual abilities and the cultural practice was extensive. The organisational practice of the school and the organisation of the learning activity placed constraints on the teacher's interaction with Oliver that confirmed or even enhanced the incongruence.

At home, Oliver's gaze and visual attention behaviour was very similar to the situation at school. However, the visual array in the home situation was familiar and

stable, reducing the strain on Oliver's visual perception and visual attention. There was less need for Oliver to adjust and shift his focus of attention. His mother was used to his unusual use of visual attention and idiosyncratic communicational means and responded to all his acts as different communicational statements. Contrary to the teacher in the school situation, the mother focused on establishing shared attention to the interactional content rather than to a particular visual object. She accommodated her interaction with him in structure and timing, to allow him to take time off and to take advantage of his initiatives and abilities when he tuned in on the shared focus of attention once more. This was possible firstly because the situation allowed the mother to be responsive and flexible in timing and secondly, because her continuous attention to Oliver provided her with a context in which Oliver's different verbal and non-verbal statements and acts made sense, thereby straightening their mutual interaction and communication. The situation at home gave completely different options for Oliver to adapt his visual attention and motor abilities to the communication and social interaction compared to the more structured school setting, where the teacher aimed to give instruction and receive responses from all children in a limited space of time. The mother's confidence in Oliver's ability to pay attention enabled the establishment of shared attention that functioned as a prerequisite for communication and further development of the content of their shared activity.

The difference in attention capabilities between home and school was difficult to explain as long as the activity of the teacher and the mother and the situational constraints were left out of the analysis. When they were included, it became clear how Oliver's visual attention was functioning within situations and that both the school and the home descriptions of him held aspects of truth. However, this underlines the shortcoming of an individual, stable and objective approach to assessing abilities – because an individual approach misses the situated structures and processes that produce cognitive functioning and learning – and differences in cognitive functioning and learning. Some types of situated structures and processes enable the child to make better use of his or her abilities while others function as barriers. This type of information is often missed in the assessment and planning of how to support the cognitive functioning and development of the child with special educational needs (Lebeer et al. 2011).

The analysis of Oliver's disability in different situations also serves to highlight Vygotsky's central point that the fundamental problem in a child with an impairment is not the impairment in itself, but the incongruence between the child's individual psychological structure and the structure of the cultural forms. In the case example, it was seen in that the cortical visual impairment gave rise to visible ways of acting that differed from how people normally act when they "see" or "pay attention". The particular way of acting caused reactions from the environment, going from bewilderment as to whether the child was able to use his vision, to social affordances of inattention or unwillingness of Oliver to make an effort. The particular nature of the biologically based impairments became expressed through the

environment's interpretation and subsequent support of them. In the example, Oliver is profoundly dependent on others to organise activities for him because of his cerebral palsy. In addition, the way the activities are organised becomes crucial for his visual ability and his ability to experience and express himself as an active social agent. The visual perceptual functioning of Oliver (and many other children with cortical visual impairment) is highly variable and fluctuates not only due to environmental properties such as lighting, contrast and large print, but also as part of the content and structuring of activities with other children and adults. The observed differences in the two settings showed that Oliver's visual abilities depended on the social conditions. Seen as a natural experiment, the different constitution of congruence/incongruence in each of the two settings created different levels of abilities – and degrees of disability.

The situated nature of cognitive functioning is not confined to children with disabilities. Cognition and cognitive development are always situated and distributed. Artefacts present in the school constitute environmental properties, which may help initiate activities through exploration and appropriation. For children without disabilities, it is not so obvious, as their age-typical surroundings are adapted to them through cultural-historical processes and so their cognitive functioning appears more context-free than for children with learning disabilities. The difference is rather that children with learning disabilities, due to the incongruence, are dependent on local adaptations in school to be able to participate in the learning activities. As children's learning and development take place across different activity settings – and the quality and quantity of local adaptations between contexts often differs – the child might act in ways that appear confusing or unstable or – as in the case example – seem less capable in some activity settings than others. It is necessary to describe how a disability impedes or changes the ability of the child to participate in specific activities and how it impedes or changes the child's appropriation of cultural tools. As outlined in the analysis of Oliver, the individual cognitive processes need to be described along with the artefacts and the organisation of the activity.

## **A Cultural-Historical Dynamic Assessment Approach**

The challenge of assessment is therefore that children with learning impairments, due to developmental incongruence, are often dependent on local adaptations. Many children from the heterogeneous group of children with specific learning impairment or intellectual disabilities are more sensitive to changes across different activity settings and changes in demands (e.g., from teachers) across time. The slower learning of children with learning disabilities need not only be a consequence of their genetic layout or brain lesions and subsequent cognitive impairments, but are also related to their learning practices and the organisation of activities.

In order to improve understandings of the role of the environment in supporting the learning and cognitive development of children with learning impairments, the interpretational techniques from the *dynamic assessment* approach is useful. Dynamic assessment approach is a family of assessment techniques, where some of the techniques explicitly build on the legacy of Vygotsky (Lidz 1995). Despite differences in technical approach, they share a common aim: to measure the learning potential of the child through mediation of a more experienced person instead of measuring the child's present level of functioning by him- or herself alone (Haywood and Lidz 2007). Dynamic assessment often starts out with a session of traditional testing where the examiner merely presents the tasks and observes the child's performance, similar to classical standardised static testing. The dynamic aspect emerges in the following session or sessions, where the examiner adopts an active stance in the assessment through mediations such as help, questions and support, for example, the teaching of strategies for problem solving, all the while observing the subsequent changes in the child's performance. The result of the dynamic assessment is the description of the cognitive functioning *and* modifiability of the child's cognitive functioning, or zone of proximal development, in answer to particular ways of mediating the content or organising the learning activity. In the terminology of psychometrics from the beginning of this section, the examiner introduces 'mediation noise' rather than trying to reduce measurement noise in the assessment and observes and interprets the impact on the child's cognitive functioning. The introduction of active involvement of the examiner in the shape of mediation has been criticised for reducing the reliability of the assessment. Two assessors might not arrive at the same result with the same child (Haywood and Lidz 2007). However, the resulting reports from dynamic assessment which build around the inclusion of context, activity, teaching and support needs, have been perceived as more useful by teachers and parents, compared to descriptions derived from classical static testing (Lebeer 2005; Lebeer et al. 2011). The situated and dynamic analysis of cognitive functioning of children with learning impairments raises attention in relation to the opportunities for supporting the child's learning (Lebeer 2005) in line with the approach of this book. It is a shift in perspective of the child's teachers and other important adults to focus on the learning potential of the child and how to incorporate mediational means within the child's social situation of development, not only in school, but overall. Another gain will be an increase in the opportunities of the child to experience and develop his or herself as a competent social agent when important adults focus on the child's learning potential, rather than on biologically based shortcomings. However, creating opportunities for the active participation of children with severe disabilities is often more difficult not only because of their limited ability to act independently due to biological impairments, but because the fit between the child and the teaching practice needs to be repeatedly addressed throughout the child's school trajectory. Reassessment will be necessary from time to time.



## The Role of Motives in the Learning of Children with Special Educational Needs

Having a severe disability impacts on the person's conditions for learning and cognitive development through concrete instances of mismatch between the organisation of activities in the teaching practices and the child's motives and ability for participation. Following a cultural-historical understanding of disability, special educational needs do not necessarily imply a requirement for individualised instruction in a mainstream or specialised setting. Some types of special educational needs might be taken care of in mainstream teaching activities, while others will call for specialised organisation of the teaching activity. Whether mainstream or specialised setting, the child's active participation is a necessity for learning. As mentioned in Chap. 5, the development of the motive for learning in children with moderate or severe disabilities will often be delayed, compared with typical developmental trajectories. The role of child motives in supporting the child's active participation in learning activities was explored in a study by Bøttcher (2012). The overall aim of the study was to explore the relation between the social situation of development of children with severe motor, communicative and learning impairments and their participation in the learning activities at school. Three boys, all with cerebral palsy, were observed using video recordings in different school and leisure activities over the course of 3 years. As all children were non-verbal, information about child motives was gathered from a combination of interviews with their mothers and teachers and observations of what types of activities engaged the children. One of the boys was "Daniel". Despite his chronological age (7 years), his favourite activities were games of rough-and-tumble, to move around in his walker and play with mud – activities that mirror dominating motives of children around the age of two or three, exploring the physical world and their own bodily abilities. Daniel's favourite activities were not surprising considering his major motor, perceptual and communicative impairments. It took a lot longer for him to explore the environment and his own relation to it when he had to rely on others to provide him with the possibilities and interpret what he would like to touch or do. However, the social situation of Daniel was more similar to children of his chronological age without disabilities, as he began school at the age of six, the standard age of starting school in Denmark. Despite being a special school for children with pervasive motor and learning disabilities, many of the activities in the school practice were organised as typical teaching settings, although adapted to the particular children attending class. The general aim of the special school practice was to support the children's ability to participate actively in the teaching activities through the use of different artefacts and adapted activities. The adaptations included remediating artefacts such as supportive corsets, walkers and communicational aids. In addition, the organisation of activities encouraged the children to move as much as possible by themselves, learn to express themselves and use necessary remedies such as communication computers. The active participation of the children was necessary in most of the activities within the practice. However, not all types of participation were encouraged. As in

mainstream schools, only some types of participation were considered valid and supported. Daniel often acted in ways not considered as valid contributions. One example can be given. Originally, the idea was for the children to have their communication computers on their tables all through the lesson in order to use them for answering the teacher's questions. However, the teacher did start to remove them from the children as soon as the home news of each child had been played, because otherwise the children from time to time pressed on the machines and interrupted the other children's home news. This was the case for Daniel as well as for the other children. Just pressing buttons was not considered a valid contribution to the lessons by the teachers. This regulation was generally found to be grounded in the teacher's aim of setting up typical teaching activity, in which the teacher explained the subject matter while the class listened or one child at a time was answering while the rest of the children were supposed to wait for their turn. However, the daily removal of the communicators was in this study found to be counterproductive in relation to the aim of the communicators: that is, to enable the children to communicate about themselves and their experiences and actively participate in the learning activities. While "keep quiet" said to the mainstream pupil does not silence the pupil in the following activities, the opposite might be the case when the child has severe communicational impairments and part of the learning activities is to teach them to use augmented communication. Without a developed learning motive of the child, it becomes more difficult for the child to engage in classic, typical learning activities and participate in ways considered valid by the teacher and supporting the recognition of the child as socially appropriate by teachers and peers. In the observations, Daniel was not interested in the teaching activities associated with learning of concepts and numbers and had become more occupied with doing the opposite of what the teacher wanted him to do. The incongruence between Daniel's development and the institutional forms of cultural demands and expectations is not surprising given his severe impairments. Nevertheless, the solution is not to wait for a boy like Daniel to catch up by himself in his development of motives and competences, as he will continually lag behind typical chronologically based cultural expectations. Rather, the challenge is to make local matches through pedagogical remediation that enable children like him to develop despite the incongruence. Given that the overarching objective of school practice is the learning and cognitive development of the children attending the school, the challenge becomes how to accommodate the teaching activities in order to create greater alignment between the motives of the children participating in the practice and motives of the teachers with their different agendas. Even though Daniel often said no or refused to cooperate, there were other occasions and other activities during which he usually agreed to join and participated in with great pleasure and engagement. He liked to move around in his walker and according to the team of teachers and other professionals had made surprisingly good progress in his ability to do so. Daniel's motivation to move around on his own made him act in ways compatible with several professional agendas for Daniel about motor development and social development and lead to a possible alignment of his perspective and the professionals' perspectives. Creating opportunities for the active participation of children with severe disabilities might be more difficult not

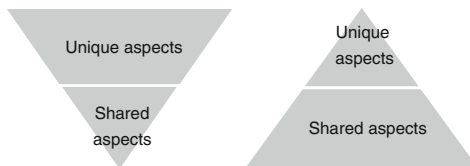
only because of their limited ability to act independently (due to multiple impairments), but rather because many children with severe disabilities come to school with motives typical of younger children, while they are expected to participate in teaching activities in a practice whose values and general organisation of activities are organised from implicit cultural expectations to the children's cognitive, motivational and emotional developmental level.

## **Special Educational Needs in Cultural-Historical Practices of Inclusion**

As mentioned in Chap. 5 and in the beginning of this chapter, inclusion as a value position predominates in current educational institutions in many countries. Inclusion is the practice of educating children with disabilities along with peers in the general education classroom. In everyday practices, inclusion translates into challenges for the teacher about everyday educational practices for the child with special educational needs vis-à-vis the class. Children with lesser impairments are often mainstreamed without prior adaptation of the teaching practice. However, all teaching activities build on assumptions about the cognitive functioning necessary to participate. These assumptions are based on the cognitive (and social and motor) functioning of children without impairments. Teaching practices in general have developed from the cultural traditions and value positions present in society. The activities that take place at the school relate to societal requirements and values about what cultural knowledge and skills children need to learn in school and how. One of the reasons for the difficulty in including children with cognitive and language impairments, pointed out in Avramidis and Norwich (2002), is the overarching aim of the school of teaching. If the child is not learning the curriculum, the school/teacher does not fulfil its objective. While children with social, emotional and/or physical impairments are easier to accommodate within the school activity setting, as long as their problems and challenges do not interfere with the teaching activities, children with cognitive and communicative impairments often require at least minor and often more substantial accommodation within the teaching practices in order to be able to participate. In considering how to support the learning and cognitive development of children with learning impairments, two central and related questions arise:

1. *What is it the child needs to learn; what is the learning goal?* Even though Vygotsky (1993) stresses that children with disabilities should work towards the same goals as children without disabilities, they might need to follow a different time schedule due to their atypical development. In practice, they might not be able to keep up with the curriculum, or all aspects of the curriculum, in accordance with their age or grade. Working towards the same goal needs to be understood in a more flexible and alternative way, rather than a fixed and specific

**Fig. 7.1** Distribution between unique and shared aspects for children with disabilities (*left*) and without (*right*), respectively



understanding in which the child with a disability should keep pace with peers without disabilities.

2. *How can the child learn; what are the learning means?* A situated and distributed learning approach calls for a focus on the shared characteristics of the group of learners. In a group of typical children, their cognitive, emotional and social abilities will share many aspects and their learning activities will be supported by the cultural forms of their everyday activity settings. Unique aspects such as particular interests, preferences for plays, cultural background, or family characteristics may call for minor adaptations of the teaching practice in ways that are compatible with the group or class as a whole. The adaptations do not challenge the wider organisation of the school practice either. The point is that a balance exists between unique and shared characteristics. This balance should not be seen from an individual point of view, but is created in relation to the organisation of the practice. For children with disabilities and special educational needs, the situation is somewhat different. The impairment or impairments create a situation where the unique aspects outweigh the shared aspects, still seen in relation to the organisation of the practice. This difference is illustrated with the opposite pyramids in Fig. 7.1.

The important conclusion is that the learning of typical children is more easily supported by the cultural forms of the school, while children with disabilities are less supported due to the basic incongruence pointed out by the cultural-historical disability model. One answer to the inclusion challenge is the adaptive instruction approach that focuses on an organisation of the learning practice aimed at accommodating the activities to all individual learners. The underlying idea is that all learners are individual in their learning and might benefit from adaptive ways of organising learning. Central aspects of adaptive learning consist of instruction based on assessed capabilities of each learner, where each learner is able to progress at his/her own pace and alternative learning activities are available (Wang 1990). The adaptive instruction approach is not aimed at particular types of learning impairment; rather it is a description of general strategies for a more adaptive way of organising learning activities of potential benefit for all children in the school activity setting. The characteristics of “adaptive instruction”, as pointed out by Wang (1990), is to be seen as a suggested recipe for how to overcome central aspects of the incongruence, namely those that fall under the label of special educational needs. At the same time, the implementation of an adaptive scheme such as the one listed by Wang (1990) will not be able to solve all aspects of the incongruence. It is not that simple. Even with an adaptive organisation, dilemmas arise between the

needs of different children or different needs of the same child. For example, many children with severe disabilities require more time to learn, for example, the alphabet because of easier fatigue, perceptual impairments, slower information processes and slower overall development. At the same time, their time for learning in school is much reduced each day, for example, because eating and going to the bathroom take up a lot of their time. Seen in relation to inclusion in mainstream schooling, a new dilemma is created between the needs of the group and the needs of the child in the way the day is organised. The rest of the group or class is able to work longer and at a higher pace and does not need the same extensive amount of time for eating and going to the bathroom. Over time, the dilemma between different needs translates into differences in developmental pace between the child with disability and the rest of the group. Inclusion may for a child be possible in regard to placement with the classroom – and the social environment of the class – but inclusion within curricular activities may no longer be feasible. Adaptive instruction will be able to address some types of incongruence, but not all.

The need for different learning means might sometimes translate into special learning goals. Aids are one main example of learning means that the child might need to learn to use, before they are able to exploit them towards the same learning goals as children without disabilities. For example, during the last decade, many computer programmes have been developed to help people with severe dyslexia. Still, the child or the adult will need to learn how to use the program before they can apply it in the mainstream learning activity. Other children with special educational needs are aided by sign remediation, for example, day schemes or work schemes. Nevertheless, similar to computer programmes or an electric wheelchair, the child must practice when and how to use it, either by him- or herself or supported by a teacher or helper. Aids always need to be implemented within the cultural-historical mediated practices, a matter to which we will return in Chap. 9. Even when working towards the same goals as their peers, children with impairments often have additional goals for their learning related to their aids.

Ideally, the teacher would be able to address both questions: the accommodation of learning goals and the adaptation of the child's learning means, within the classroom setting. However, the organisation of the teaching practice is conditioned by a wide array of structural limitations that become sources of incongruence in relation to children with learning disabilities, if inclusion is implemented through simple placement of the child in a mainstream setting without systematic adaptation of the practice. Systematic adaptation of the teaching practice could include organisation of resources for support, improving teacher's instructional skills and possibilities for organising their teaching to accommodate the class as a whole, including the children with special educational needs (Avramidis and Norwich 2002). However, depending on the nature of the child's learning impairment, particular adaptations of learning goals and learning might not be possible to negotiate through adaptations of the classroom or even the school setting, but are based in wider societal incongruences of structural, economic or political nature. Two main examples of this societal level of the cultural line of development in school are the use of cur-

riculum and the division of the school trajectory into grades and departments, for example, first and second grade and primary and secondary school. Together, the curriculum and the division into grades and departments create a paced trajectory through school. Children who for different reasons require more time to acquire the curriculum and thus fail to fit in with the mainstream-paced trajectory may find themselves at odds with the structural setting of the school. The teacher might be aware of this in addressing and adapting the teaching situation, but often it is beyond the individual teacher to resolve structural barriers. Institutions are slow to adapt to children with needs to which they have not previously adapted or that require decisions to be made at a higher organisational level outside the school. The institutional slowness arises from both material and structural sources, such as economic constraints and timing of decision processes (Janus et al. 2008).

### **Summing Up: The Challenge of Teaching**

The tangle of continuities and discontinuities between the learning of typical children and children with disabilities can be seen as a specific example of the developmental dysontogenesis Vygotsky describes as fundamental to the development of children with disabilities. To address the problems associated with developmental incongruence within the classroom setting, the professionals need to work with different teaching practices. At the beginning of school and throughout the school trajectory, the teaching activities are founded on a set of assumptions about the participating children's capabilities. Impairments in the areas of motor, perceptual, language, communication, cognitive, emotional and social functioning and many more need to be identified, as the incongruence between the impairments of the child and cultural-historical assumptions about the participating children's learning skills creates special educational needs.

Learning of connected conceptual knowledge is founded in the child's early development as a social agent at both infant and toddler stages (Hedegaard 2007). For some children, delays in development of social agency or language/communication will mean that the child is still preoccupied with preschool activities of experimentation with objects and imaginary representation through play activities. The child still builds personal conceptual knowledge and is thus not ready to participate in activities aimed at scholastic/scientific conceptual learning at a higher level. As pointed out earlier in this chapter, the transition to scholastic/scientific thinking includes alignment between the motives of children and adults within the teaching activity. Even though the alignment might be more difficult in the case of children with disabilities, the process of understanding how the child's way of acting is related to agents and activities in the setting is often hindered by the prevalent biomedical model that leads to individualised explanations of why this or that child is unable to participate in the teaching activities in a valid way. Separation of the child from the teaching activity risks creating a view of the child as an object, which puts

professionals at odds with how to get the children to participate in the organised learning activities. Including the perspective of the child is indispensable in understanding the child's motives for developing skills and how to organise activities that support the participation and development of that child. We will return to this important point in the final chapter of the book.

## Chapter 8

# Communication and Communicative Aids

Language acquisition is closely linked to the child's social and cognitive development. The social interactions in which language acquisition takes place are formed within cultural-historical social environments. It involves higher-order cognitive functions in social situations where language is used by participants to agree, disagree, share their points of view, play and work together, etc. One example of the influence of impairments in the development of language, social and cognitive abilities is children with hearing impairment. The inability to perceive sounds often impacts on the children's development of language and communication and their ability to participate in learning situations.

In this chapter, we will first look at different groups of children with disabilities and how the congenital or early acquired impairment in different ways affects the child's language and communicative development. To bring out both similarities and differences associated with particular types of impairments, the chapter will look at children with congenital deafness, congenital blindness, motor impairments and autism spectrum disorders and their development of communicative disabilities. Different communication theories, methods and practices will be included in the cultural-historical framework in order to discuss how different types of disabilities affect communication and language development. Two of these practices will be visual sign language and alternative augmentative communication.

In the case of language impairment or delay, support often involves communicative aids. Communicative aids are exemplary in demonstrating the need to understand the role and use of aids as situated in practices. Aids will be the second theme to be discussed in this chapter.



## **Cultural-Historical Understanding of Communication and Language Development and Impairment**

As stressed several times in this book, communication and language are central to the cultural-historical understanding of development. Language and communication are main cultural tools for participation in social practices and acquisition of higher mental functions. Research has shown how the infant and the parents are communicating using sounds, vision, and touch (see Chap. 3). If the child is born with a disability, the early communication between the infant and the caregiver can easily be affected in several ways – either as delay and/or by development along a different trajectory. Later in childhood, language and communicative skills continues to be central in many forms of social participation with adults as well as other children. The deficient or delayed language and communication often become a major source of incongruence between the child's individual development and the cultural forms because language delay and communication difficulties affect the child's ability to participate in practices where social and cognitive development takes place. Thus, language and communication development in many ways illustrates basic developmental elements of the cultural-historical model of development with a disability. Communication support often becomes crucial for many young children with disabilities to avoid negative escalating effects of the developmental incongruence.

One dominant approach to understand language development has been the perspective that language is an innate ability that mainly requires triggering from the environment to develop. This perspective was formulated by Chomsky (1957, 1968) and further developed by others, among them Pinker (1994). The nativist approach started from a critique of the behaviourist view on language learning. The behavioural theory of language acquisition depicted language learning in accordance with the general idea of learning as association between a stimulus and a response (Skinner 1957). According to the behavioural approach, a word was learned through the child's gradual building of associations between objects and their names, positively reinforced by praise from his/her parents when using the right word for the particular object. However, the nativist approach had several objections against the behavioural theory of language learning. For example, language acquisition follows cross-cultural patterns and takes place with a speed that cannot be explained from reinforcement of behaviour alone (see Chomsky's (1959) critique of Skinner's language learning model). From the nativist's point of view, the child will need and is born with innate abilities to decode and use different word classes and syntactical structures. Later, the idea of language as an innate capacity triggered by the environment was criticised by a group of theorists from the cultural-historical perspective (Bruner 1983) and social-pragmatist approach to linguistics (Tomasello 1992). This approach is often referred to as social interactionism – stressing that language is an ability that develops through intersubjective interactions. One of the best-known researchers representing a cultural-historical perspective on language learning is Jerome Bruner (1983). The basic idea is that language is part of the general social

activities from early childhood and the child learns language through participation in social activities. From early infancy the parents scaffold the child's language development through nonverbal "conversations", by means of turn-taking in simple games and routines. Early synchronicity of movements, sounds and emotions lead later in infancy to mutual attention and (at approximately around nine month of age) to joint attention. Joint attention can for example take place in the situation where the child points at a car and the parents say "a car". Because the child and the parent have engaged in joint attention prior to the exchange, the child is able to successfully combine the object (car) with the spoken word. The foundation of the child's development of language is made through such social interactions (Tomasello and Farrar 1986).

## **Deaf Children: The Complexity of Social Participation, Communication and Language Development**

From a cultural-historical perspective on disability, communication and language becomes central in order to understand how disability and development are connected during early childhood. Language functions as an important medium between the culture and the child's cognitive development. Learning culturally transferred skills rests on the mutual communication of child and caregiver. The use of language enables the child to reflect on the world using concepts and conceptual relations and thus language acquisition opens up for the child's higher-order mental functions. Consequently, impairments affecting a child's communication and language development can have far-reaching developmental consequences. In Vygotsky's writings about defectology, he often discusses development and support of children with hearing loss (Vygotsky 1993). In this chapter, children with hearing impairment will also be used as an illustrative case of cultural-historical developmental processes.

Vygotsky's access to empirical research reports about children with hearing loss was limited. Decades of psychological research in deaf children's development now allows us to include a greater level of detail about the cultural-historical aspects of social participation on one hand and the development of language and communication on the other.

Congenital deafness has the risk of interfering with social participation from early on in life and throughout childhood. As mentioned in Chap. 6, congenital deafness is associated with a number of mental health problems and developmental difficulties, among those psychosocial difficulties such as peer problems, emotional difficulties, and behavioural problems. Several studies have shown that it is the delay in deaf children's language development which constitutes a major risk factor for psychosocial difficulties (Dammeyer 2010a; Fellinger et al. 2009b; Meadow 2005; Stevenson et al. 2010). Dammeyer (2010a) found a prevalence of psychosocial problems almost four times larger than among hearing children. The same study

also found that the child's language skills, either oral or signed, determined whether or not the children experienced psychosocial difficulties. If the child's spoken or sign language abilities were sufficient (if the children were able to participate in a conversation by phone or take part in a sign language conversation without difficulties), no higher incidence of psychosocial problems was found. Similar results have been reported in other international studies (e.g., Stevenson and colleagues 2010).

## **Communication, Language and Theory of Mind Development**

Development of language has also been found to be important for development of theory of mind in deaf children (Peterson and Siegal 1999). Theory of mind is the ability to attribute mental states (beliefs, desires, etc.) to oneself and others and to understand that others have mental states that are different from one's own (see also Chap. 4). Most researchers agree that the ability to exercise theory of mind does not develop fully before the age of 3–4 years (Peterson 2004). As the child reaches a point in his/her development where activities with other children increase in importance, delay in the development of theory of mind development compared to the other children's development of the same skill may be associated with a higher risk of psychosocial problems, including interpersonal difficulties, among others. At the same time, development of theory of mind has been shown to hinge on social participation, as was elaborated on in Chap. 5's discussion of early school age. Communication functions as the means for development of theory of mind through conversations about different perspectives and emotions about ongoing activities. The child builds on his or her own ability to express his or her mind and learn about the mind of others (Nelson et al. 2003).

In line with the theory that development of theory of mind draws on communicational skills and social participation, theory of mind abilities are often developed later among deaf children. Studies of perspective-taking and theory of mind abilities among congenitally deaf children found associations between development of theory of mind and their level of communicational development (Mayberry 2003; Peterson 2004; Peterson and Siegal 1999). Furthermore, studies have shown that deaf children, who grow up in a sign language environment and use sign language as their first language, do not encounter delayed acquisition of theory of mind compared to their hearing peers. The sign language environment decreases the incongruence experienced by deaf children in oral language environments. However, deaf children who learn sign language at a later age often experience a delay in the development of theory of mind abilities (Meristo et al. 2007; Peterson and Siegal 1999). Therefore, it appears that the development of an efficient first language early in life is a necessary prerequisite for timely development of theory of mind abilities.

The effect of early cochlear implantation has been investigated regarding its influence on theory of mind development in congenitally deaf children. Peterson (2004) found that level of language development significantly predicted ability of

theory of mind, but deaf children with cochlear implants were just as delayed in theory of mind development as their deaf peers with hearing aids. This study also concluded that regardless of mode of communication or cochlear implantation, early communication abilities were the important factor. Children with cochlear implantation from early in life develop the ability to hear and speak, however, the delay in communication during the first 1–2 years of life seems to delay the child's later socio-cognitive development.

Research in deaf children's socio-cognitive development illustrates the importance of language and how language is the means for development of higher cognitive functions. Early language development is the strongest predictor for later development rather than degree of hearing impairment or type of hearing aid (Dammeyer 2010a; Mayberry 2003). Development of theory of mind is thus an example of the interplay between the two lines of development: the natural line and the cultural line. And for many children with disabilities, the incongruence between the natural and the cultural line of development constitutes a barrier to the development of theory of mind and explains why delays in development of theory of mind are so common among children with a wide range of disabilities. Children with severe visual impairment/blindness, severe motor impairment, and autism spectrum disorders also show delay and/or impairment in theory of mind development and similar to children with congenital disabilities, levels of social participation, language and communication development play a crucial part (Siegal and Surian 2012). Congenitally blind children experience delayed theory of mind development, which might be linked to these children's barriers in engaging in social interaction from early childhood (Pijnacker et al. 2012), for instance, difficulties with joint attention. Children with severe motor impairment (cerebral palsy) have also been found to be delayed in development of theory of mind (Sandberg and Dahlgren 2012), which was explained as associated with difficulties in participation in social interaction and communication. Finally, children with autism spectrum disorders are to a great extent characterised by theory of mind difficulties, either impairment or delay (Baron-Cohen et al. 1985; Peterson et al. 2005). The delay or impairment in social cognition can be shown already in infancy among children with autism spectrum disorders (and for children with deafness due to communication delay (Prezbindowski et al. 1998)) and may reflect a snowball effect similar to that found in deaf children (Surian 2012). Research has shown that difficulties in early social interaction (for instance, mutual attention and attunement) are precursors for later difficulties in joint attention (Scambler et al. 2007), later language development (Rollins and Snow 1998; Tomasello 1988; Tomasello and Farrar 1986) and finally theory of mind abilities (Tomasello et al. 2005). Later in childhood, difficulties or delayed theory of mind among deaf children may lead to difficulties in pragmatic language skills, peer problems and psychosocial difficulties (Dammeyer 2012). Similarly, delayed or impaired development of theory of mind in children with autism spectrum disorders are not isolated from other aspects of their difficulties, but develop in mutual interaction and need to be understood in relation to each other. In children with congenital difficulties in several of the areas associated with autism spectrum disorders, various impairments hold the potential to amplify each other. On the other hand,

better language development has been associated with a better overall developmental prognosis (e.g., Billstedt et al. 2005).

Development of theory of mind illustrates the principle of how developmental time becomes important in order to understand the impact of singular impairments on the wholeness of the child's development. The impairment itself may hinder the child in meeting the demands of a particular activity, for example play. In addition (and just as important to address) previous delays feed forward and thus the extra time required for the development of language, motor skills etc. follows the child into his/her next activity settings where he or she might find it difficult to participate in peer activities due to a developmental asynchrony that builds up over time.

## **Augmented and Alternative Communication**

Across specific disability groups there are children whose communication involves the learning of use of other means than the (verbal) language used by most people within their immediate cultural background. This group includes children with cerebral palsy, intellectual disabilities of various types and children with autism spectrum disorders. Because of cognitive and/or oral-motor impairments, some children are not able to develop verbal communication. To support these groups of children, a number of communication methods to supplement or replace speech or writing have been developed, all categorised under the umbrella term, Augmentative and Alternative Communication (AAC) (Beukelman and Mirenda 2013). One example is individual sign language signs used with children with dyspraxia or dysphasia (e.g., children with Down Syndrome) to support their oral language development. Another example is communication with symbols, for example cards with pictures of objects such as "a ball" being a sign used to communicate to a child with autism spectrum disorder when it is time for physical activities, or used by the child to communicate a preferred activity. AAC technologies are used with children with very different needs for communicative support, both children with intact cognitive potential for language learning but impaired speech abilities (e.g., some children with cerebral palsy) and children whose impairment is thought to include a reduced ability to develop linguistic language (e.g., children with autism spectrum disorders or intellectual impairment). The idea of augmented and alternative communication, and communicative aids in general, is to a large extent grounded in an individual impairment understanding of communicative difficulties. By providing the child with alternative means for communication, the missing ability or skill within the child is substituted with an external technological or alternative mean. However, in activity settings, the change from common to uncommon communicational means induces a need to accommodate the setting to new ways of communicating. The child is not only given an alternative means of communication; the implementation of alternative communication means moves the child into a different communicational micro-cultural setting that often functions as a language minority within the majority of typical language users. Rather than a neutral object that "repairs" the

impairment in a seamless fashion, communicational aids are complex cultural objects.

For children with disabilities affecting their development of communicational skills, aids for communication become important for their development at large. Hearing aids or cochlear implants often make the difference to being able to develop oral language or not and communication boards, computers or other types of technological aids may also be significant in becoming able to communicate in cases of severe anarthria (inability to make legible sounds). However, understanding how communication aids merge into the developmental trajectory of the child includes analyses of how very specialised cultural objects and activities enter the child's social situation of development. The case of Oliver with severe cerebral palsy and cognitive visual impairment (Bøttcher and Dammeyer 2012), introduced in the preceding chapter, will be referenced here to argue how communicative aids enter and become part of the child's social situation of development.

## **Oliver's Rolltalk – Communicative Aids**

Among other technological aids, Oliver, having cerebral palsy and cognitive visual impairment, used a Rolltalk for his communication. As already explained, the Rolltalk is a small portable computer with a touch screen that functions as a communication aid for people with speech disabilities. The user selects fields with pre-defined images, which are read aloud in synthetic speech, e.g., "drink". According to the producer, the idea of the Rolltalk is to "communicate your needs, maintain independence, take initiative, and to express one's feelings" ([www.rolltalk.com](http://www.rolltalk.com)). The producer thus tries to establish a cultural meaning attached to the aid as a neutral repairing object. The communicator is presented as a transparent object enabling the child to express his or her subjectivity. However, when put in use, the Rolltalk enters established activity settings made up of participants with motives and engaged in ongoing activities with other artefacts. The knowledge of different aids for communication and how to use them differs between different participants. For Oliver, the knowledge about him and how to support his activities with the Rolltalk also varied between the different activity settings during his day and during the week. Similar differences can also be experienced with young children without disabilities. Parents may understand the talk of their young child better than a stranger; being used to the child's developing pronunciation of words and being able to guess the child's meaning from their knowledge of the child's experiences. However, the child without disability will be better supported since participants across activity settings will share verbal language as a common means of communication. The child using uncommon communicational means will in each activity setting be dependent on interlocutors familiar with their particular mode of communication and often also some contextual knowledge, in order to be able to communicate successfully. The use of communicative aids is merged into the complex sociocultural

situations in which communication always takes place, even when we are not aware of it.

In the study, as introduced in Chap. 7, Oliver's use of the Rolltalk was observed both in school and at home. Oliver was clearly interested in his Rolltalk in both settings. His visual attention was often observed to circle around the Rolltalk and in one observation, he protested audibly when the teacher took his Rolltalk in order to show something on the screen to another child. In the following sections, we will compare Oliver's use of the Rolltalk in the two different settings.

In school, the intention of "the Rolltalk as the voice of the child" seemed to be taken literally. Oliver's movements and gaze were interpreted in relation to the Rolltalk, not as communicational means in themselves. However, as the teachers and other professionals worked to convey the Rolltalk as voice through school activities, for example by supporting Oliver to use it to answer the teacher's question during a lesson, the affordance of the Rolltalk transformed. The teacher began to have her main focus on Oliver's *inability* to answer promptly on the Rolltalk. She moved the Rolltalk back and forth in an attempt to place it in his visual field and moved his hand to make him press the correct response. However, the more the teacher pressed and prompted Oliver to use the Rolltalk as his voice to answer her questions, the less it seemed to work. The communicational aid – the Rolltalk – became a problematic object that did not work or was so difficult to get to work that it became an obstacle to communicational development. The affordance of the Rolltalk from the teacher's point of view became a disturbance to the teaching activity for Oliver. In the activity settings with group activities, the teacher often ended by giving up on Oliver and his use of the Rolltalk. From Oliver's point of view, the affordance of the Rolltalk in the school may also have been a problematic object that was very difficult to perceive and use at all.

At home, the situation with the Rolltalk was very different. The Rolltalk sat comfortably in a frame mounted on the wheelchair, held in the same place in front of Oliver all the time. The environment was familiar and stable, not stripped of other objects but with the familiar objects in familiar places and much less was going on around him. Oliver's mother focused on establishing shared attention to the interactional content rather than the working of the Rolltalk. The Rolltalk became part of a communicational configuration together with Oliver's other communicational means: sounds, movements and gaze. In providing this type of environmental support, Oliver's mother supported his perception and affordance of the Rolltalk as a device for "communicating matters on mind" in a social situation.

Thus, understanding communicational aids and how they can enable children's communication in different ways requires a focus on how uncommon communicational means acquire meaning and are used, not only by the children themselves, but also by the other participants and in different activity settings. The aid is constructed as a cultural object within each social situation. The use of a communicational device actually covers a complex situation in which all of the participants have accommodated their way of communicating to the specific activity setting. Because language development is socially bounded, learning how to use communicational aids will also be social. But contrary to communication with spoken words, the use

of uncommon communicational means requires accommodation of the social setting. For several reasons, the required accommodation is often more difficult to achieve. Parents and professionals will have to establish situations in which the uncommon communicational means are used, not only by the children, but also by themselves. This means they need to accommodate their own communication. Participants may have conflicting motives, which create barriers for adapting the activity setting to support the child's emerging communicational skills. In the example with Oliver above, the teacher's primary motive was to make her teaching run efficiently in a typical cultural-historical practice of teaching. Despite the fact that none of the children at this special school were expected to move into further education and jobs, the common cultural value position underlying "typical mainstream school practice" was still expressed. Time was organised in lessons and breaks in the first part of the day, with focus on teaching activities and less structured leisure time afterwards, with focus on creative, physical and social activities. Recurrent activity settings consisted of a group of children paying attention to a teacher, who had planned the structure and content of the lesson beforehand. During the lesson, it was the teacher who decided what kind of participation was required from the children, including how the children were supposed to communicate. The teacher asked questions like "What day of the week is it?" and all the children was expected to respond using their Rolltalks to answer, for example, "Monday". The teacher had based the activities in the lessons on the assumption that the children in the special school should be learning subject matters similar to curricula in mainstream schools. This mainstream-like organisational practice of the school and the learning activity constrained the teacher's communicative interaction with Oliver and enhanced the incongruence. The teacher had to pay attention to all the children in the group, which placed a time constraint on her communicative interaction with Oliver. Activity other than pressing the "Monday button" was considered as invalid and a disruption of the flow of the teaching activity. The correct use of the Rolltalk – to producing the required answer – became the purpose. Due to the way the activity setting was organised, the Rolltalk was not used as a communicative aid offering Oliver the communicational means to become able to participate and contribute in the social practice at a higher level. Amending a communicational disability thus requires paying attention to how language learning and language use is constituted in intersubjective and socially mediated processes that take place in cultural-historical practices.

## **Language and Culture and the Development of Disability Minority Cultures**

As shown, language development is socially bounded and thus learning how to use uncommon communicational means will also be social. The tight connection between language and communication on one hand and development of



participation in cultural-historical practices on the other is a major contribution to the developmental incongruence of children with disabilities who are non-verbal, or otherwise dependent on uncommon means such as alternative and augmented communication. Their access to cultural participation depends on specialised interlocutors and supportive ways of arranging conversations in order to participate. Furthermore, even when supportive communicational activity settings are established for the child, other activity settings will include participants and activities in which the local spoken language is used, which is not accessible for the child with disabilities. Possibilities for communicational imitation and experimentation with a wider array of communicational partners will therefore often be very limited for the child who depends on alternative or augmented communication.

However, one particular case stands apart from this general picture. For deaf children it is not always a matter of “alternative communicational means”. In their case, their uncommon communicational means are linked to a wider “Deaf Culture”, in which language, identity, and culture are linked to a particular disability: deafness. The deaf community claims sign language as a minority language and a cornerstone in Deaf Culture. The Deaf Culture movement is a radically different response and resolution to the cultural-historical incongruence following congenital disability (see also Chap. 2). That sign language plays a major role in this resolution illustrates, in the context of this chapter, how language and communication are part of cultural-historical processes of development. The scientific acknowledgment of sign languages as unique languages was, with use of the terms of Bateson (1972), learning at level III, a change of the context of learning. The transformation from viewing sign language as a means of communication, an aid for those with oral language impairments, to viewing it as the native language of a group of people, reframed the foundation for communication and language development of deaf children. Further, the value of sign language as a “real” language fuelled the emergence of the Deaf Culture approach and a new understanding of deafness. In the cultural-historical dialectical approach, the impairment (deafness) was re-contextualised into opportunities for development of a different language, culture, and identity. Research supports that sign languages are unique and independent languages – and not an advanced “alternative communicative system”. Stokoe was one of the first in (1960) to observe a sign language as a “real” language. He demonstrated that the sign language had its own linguistic structure. In the footsteps of Stokoe’s work, many linguistics and psychologists began to study the properties of sign languages, among others the use of sign language in the interactions between a deaf child and his/her deaf or hearing caregivers. Children’s acquisition of sign languages was studied in natural environments in interaction with parents and peers (Marschark et al. 2006). By the early 1980s, many studies had been conducted on sign languages, and subsequently they were recognised as “real” languages (Liddell 2003). After four decades of research, there is a rich, research-based understanding of the development of sign languages for deaf children and sign language studies continue to contribute important insights into human language (Schick et al. 2006). The psycholinguistic studies of sign languages led to a cultural change in deaf education with a shift into a bilingual/bicultural approach in the 1980s (Swanwick et al. 2014).

The bilingual approach means that the local sign language was used as deaf children's first language in school and the local oral language was learned as a second language. The bicultural approach supported the deaf children's membership of a deaf minority culture within a hearing majority culture. Today, deaf communities and cultures exist in most countries (Ladd 2003). Many deaf people are members of the deaf community and do not want to be "cured" of deafness but are instead fighting for minority rights with regard to sign language and Deaf Culture. The Deaf Culture emerged at the same time as the disability activist (see Chap. 2) and minority rights movements (for coloured people, homosexual people, women, Native Americans, etc.) to fight for equal rights and against oppression in the 1970s and 1980s (Ladd 2003; Leigh 2009). The Deaf Culture approach stands in strong contrast to both the medical and social model of disability – deaf people deny on one hand to be "cured" by modern hearing aid technologies and on the other hand to be supported into "cultural sameness" from the hearing majority culture. Instead, they want to be recognised and protected as a cultural minority which includes sign language-based primary schools, high schools and universities, sign language-based TV-programmes discussing Deaf Culture issues, deaf churches, World Games for the Deaf (Deaflympics), etc. As long as the deaf child grows up and participates within the Deaf Culture, development of language and communication will be supported in similar ways – and work as well – as for children learning mainstream oral language (Meadow 2005; Mayberry 2003).

The case of the Deaf Culture and sign language is interesting because it transcends, at a cultural level, the incongruence for the individual deaf child's development. By establishing a minority culture, the incongruence is moved from the individual level to the social level in which differences in values and ways of participating turn into an ongoing struggle for recognition and cultural minority rights. For a deaf child being born into a deaf society where everybody speaks sign language from preschool to university levels and participation in all kinds of deaf cultural activities (deaf sport clubs, magazines etc.) is possible, no incongruence exist. All of this underlines how cultural-historical processes link language development with culture and individual life. At the centre of this are the construction of disability and the developmental trajectories of the child. The next section will focus more closely on the cultural processes involved in deaf children's language development, in order to understand how individual language development and cultural-historical activity settings for supporting language development are intertwined.

## **Cultural Conflicts About Deaf Children's Language Development**

Acquisition of a sign language follows overall the same developmental milestones as hearing children's acquisition of an oral language with regard to babbling, use of gestures, first word development, etc. (Schick et al. 2006). Research has shown how

deaf parents (being native sign language users) are able to support their deaf children's language development. Deaf parents of deaf children use more visual cues and are better at guiding the child's visual attention (Spencer and Harris 2006). Research has also shown that deaf children of deaf parents in general show no language delays and – possibly as a consequence – no delay in social and cognitive development (Mayberry 2003).

However, during the last decade, technological advances have had huge effects on congenitally deaf children's opportunities for development. The advent of cochlear implantation to congenitally deaf children has challenged the former bilingual/bicultural approach (Knors and Marschark 2014). Oral language learning supported by cochlear implantation is much more than the substitution of one alternative way of learning to communicate for another; rather, it is a move away from the wholeness of the deaf minority culture and its former ways of being together and supporting language learning and social agency. Not surprisingly, the move is experienced as a threat by deaf communities. Protests against cochlear implantation have been massive and tense. Considered from the perspective of members of the Deaf Culture, cochlear implantation denotes an oppression of the minority culture. *"The cochlear implant is experienced, within the deaf community, as yet another attempt at socio-cultural genocide..."* (Sourdes en Colère, in Blume (1999)) and *"We deaf, what do we see in all the newspapers and on the television: "Extraordinary invention of doctor Chourard: 17,000 deaf mutes can hear and speak". We smile. Why not bleach the blacks and blacken the whites?"* (French Deaf, in Blume (1999)). They address the risk, from a minority cultural perspective, that a new generation of congenitally deaf children with cochlear implants will not learn sign language and not be able to participate in the Deaf Culture.

The efficacy of cochlear implantation compared to a bilingual/bicultural learning approach has been researched. Many children with early cochlear implantation develop language abilities at a level close to hearing children. However, for some, oral language development is more difficult and they develop significant language delays. With respect to social and cognitive development, delays are still reported (Knors and Marschark 2014). Nevertheless, in families with hearing parents, children with cochlear implants have better abilities in general than deaf children without cochlear implants (Knors and Marschark 2014).

Both types of approaches – a sign language and oral language approach with cochlear implantation – support deaf children's language development adequately, meaning they develop without a higher risk of social, mental and cognitive difficulties (Dammeyer 2010a). However, the case of cochlear implantation addresses the powerful influence particular communicational means (and technological developments) have on individual children's development at cognitive, social and cultural levels. The choice of a particular communicational means is not neutral, but takes place within cultural-historical value positions. Furthermore, the choice will lead the child toward particular future developmental trajectories while precluding others.

## **PECS – Picture Exchange Communication System**

The impact from different value-positions about communicational support and development is not unique for children with congenital deafness. Another example is the communicational method PECS (Picture Exchange Communication System) (Bondy and Frost 1994) which is often used with children with autism spectrum disorders. It is a system of pictograms in which the child does not have to master the social complexity of communication as a social interaction, but is supported in developing a functional communication system in which daily necessary messages can be passed from the child to his/her caregivers and vice versa (Bondy and Frost 1994). The PECS programme begins with teaching the child to exchange a picture of a desired item with a teacher/communicative partner, who honours the request. After the child has learned to spontaneously request a desired item, the system goes on to teach discrimination among symbols and then how to construct a simple sentence. In the most advanced phases, individuals are taught to respond to questions and to comment (Bondy and Frost 1994). Training in use of PECS has been shown to have a positive effect on the child's functional communication abilities (Preston and Carter 2009). On the other hand, the basic idea of this communicational system is to disconnect communication from the complexity of social interaction in the child's practices. Introducing the child to this particular communicational means implicates a move towards a particular and different way of communication. Reliance on the PECS communication system may enlarge the incongruence instead of being a means of decreasing it, by depriving the child of developmental possibilities based in more mainstream ways of communication. Contrary to sign language, no independent culture of PECS users exist and thus the child will become independent on others to provide him or her with situations in which PECS is accepted and functions as a communicational means. This challenge in learning/development is not singular to users of PECS but also holds for users of other types of alternative communicational means. Sign language users and their strong and independent language community constitute an exception. On the other hand, if the child would otherwise be without communicational means, this presents a social situation with a high risk of behavioural and social difficulties (Preston and Carter 2009). In this situation, introducing and training the child to use a communicational system such as the PECS system would hold an opportunity of a more positive developmental trajectory. The choice of a system such as PECS, and many others, therefore needs to be rooted in an understanding of the child's present social situation of development and his/her possible extensions into the future.

The PECS and other alternative and augmentative communication systems are helpful for many children for whom the social situation becomes too complex and needs to be reduced in complexity. All communicative support is about overcoming the incongruence between the child's development and the cultural forms in which it participates. Supporting communication with a symbolic communication system, similar to the PECS, is not the only way to support. From a cultural-historical understanding of language development, the social interaction and non-verbal

communication may be another, and for children with more severe communication impairments, a better basis for support. The following section will address this approach.

## **Pre-Symbolic Communication, Social Interaction, and Musicality**

As already introduced in Chap. 3, symbolic language development, whether with common or uncommon means, is based on skills in social interaction from early infancy (Bruner 1983). For some children with severe impairments, their development is so delayed that pre-symbolic communicational interaction constitutes their zone of proximal development even though their chronological age would suggest otherwise. Rules and practices of common cultural forms of communication – rules that are normally taken for granted – need to be reconsidered. In children with severe communicational delays, this requires a social situation which is not based on an alternative or symbolic system, but supports the child's agency in pre-symbolic social interaction. One approach is that supportive partners use and build on mutual responses of rhythm, tempo, pitch, etc. in order to build simple patterns of interaction, similar to a dance or musical improvisation of sounds and movements (Malloch and Trevarthen 2009; Stern 1982). The musical metaphor for interaction stresses the pre-symbolic nature of the communicative support. Another approach in pre-symbolic communicative support for children with severe communicative impairments may also focus on creative and aesthetic expressions as means for both communicational exchanges and social participation. It might be music, singing, dancing or manipulating with clay. Aesthetic forms of expression do not require that the child master the cultural symbols or other abstract forms of expression. However, aesthetic forms of expression and perception have to be supported in the social situation of social interaction as valid forms of participation rather than, for example, "occupation" while parents or other adults are engaged in other activities. The child with severe communication disabilities can express feelings and thoughts as a full and equal participant only if aesthetic forms are supported as forms for participation in social situations. The wholeness of the social situation thus needs to be reconfigured, including the motives of the adults and the activities in which the participants are engaged. The next section will provide one example of such a reconfiguration.

A music therapist presented a child with severe intellectual disabilities with a drum. He encouraged and supported the child in beating on the drum and answered by meeting the initiatives of the child with similar means. The intensity of the rhythm could vary from strong to weak and the tempo and rhythm similarly changed – as an exchange between the two as communicational partners. The rhythm and variation of the rhythm was used as an expression and sharing of feelings, thoughts and moods, and to establish a kind of communication and a social interaction, in which both partners were able to contribute. Thus, the child's

development of social agency was supported in the social situation through mutual expression and recognition of feelings such as joy, frustration and anger. From the social interactionist understanding of infant-caregiver interaction and intersubjectivity (Trevvarthen and Aitken 2001) (see Chap. 3), it is about paying attention to what the child expresses and responds to within the social situation. Different types of music therapy use this approach to establish a social relation functioning on pre-symbolic communication with the child with severe disabilities and through this support the child's social agency (Holck 2004).

## **Summing Up: The Mediation of Cultural-Historical Processes of Development**

Development of language and communication in many ways stresses the cultural-historical dynamics of disability. Language and communication are the means for children's development of higher cognitive functions and the medium for the dialectical processes between the individual child's development and the culture. Support of children's language development with a communicative aid or by intense training in alternative augmentative communication can be necessary but needs to be implemented with the wholeness of the child's social situation of development in mind. Both biology and culture need to be taken into consideration to understand the nature of a specific communication disorder. A pure social model, which states that disabilities are created by barriers to take part in society at large, is insufficient and does not provide any analytical tools for planning support to the individual child's communicative development. Aids are not isolated objects which "correct" a well-defined communication inability, but are constructed, as well as the disability, in the social situations where language is acquired. Communicative challenges need to be analysed in the specific activities and practices in which the communicational disabilities are created and evolve. As exemplified in the case study of Oliver, the specific impairments, motives and value positions of the communication partners and the organisation of the social setting as a communicational culture were all needed in the analysis to uncover how different incongruence/congruence emerged with regard to Oliver's possibilities for communicational development. Introducing the child to alternative communicational means requires a communicational-cultural development of the child's social settings where the child can imitate the communication that goes on and where the child's communicational efforts – no matter the level and type – are met as valid and valuable contributions.

## **Part IV**

# **Creating a Future Together**

In the last part of this book, we will change the focus and address how the incongruence is managed by parents. Doing this, we will take up concepts used throughout the book and bring them into a perspective of intervention. Parents and other professionals working with children with disabilities experience the incongruence and negotiate how to understand the conflicts and problems arising from the incongruence. One central focus of this section will be to outline why parents of a child with disabilities have to attend to their child's developmental time and future much more and in more difficult ways compared to parents of children without disabilities, in order to be able to create local and temporary congruences. The cultural-historical model of disability not only opens up for a more complex understanding of development of children with disabilities but also point to models of how development can be supported.

## Chapter 9

# Developmental Time and Parent's Future Imaginations: Overcoming the Incongruence

Throughout this book, we have worked from Vygotsky's central idea of ontogenetic development as a trajectory that is constituted of two lines of development: the natural line as the organic growth; and the cultural line as the ability to participate in social practices in which the cultural improvement of psychological functioning and the mastering of culturally formed behaviour becomes possible (Vygotsky 1994). This division of development has proved useful in order to untangle biological, psychological, social, and cultural-historical aspects of the young disabled child's developmental conditions that are otherwise difficult to differentiate and understand – or are simply overlooked, because the developmental conditions are attributed either to “disability as a biological impairment” (the biomedical model) or “disability created by social barriers” (the social model). Understanding the developmental conditions of the child with disabilities starts at the natural line of development that constitutes an upper, biologically defined, limit for functioning. It is not possible to exceed the biologically given possibilities and constraints. However, the development of natural potentialities into individual skills and competences rests on the active participation of the child in cultural activities. Development builds on relevant social opportunities. The cultural line of development hinges on social opportunities for participation and as we will elaborate throughout this final chapter, the cultural line of development may very well place limits on the development of the child with disabilities as much as the natural line of development. Nevertheless, understanding the biological-social mechanisms of the developmental trajectory also points to potentialities and how the development of a child with disabilities can be supported. A point to be elaborated upon in this chapter will be how parents and professionals are co-creators of the children's development through their active involvement in the child's developmental conditions. Through their motives and through the demands they place on the child and on each other, they co-create the child's developmental conditions at home and in the other practices in which the child's development also takes place (Hedegaard 2012). As will be argued in this chapter, parents and other adults are able to create local congruence for the child.



At the social level, developmental conditions are institutionalised as trajectories through already existing practices, based on the age of the child and societal values about children and child development. The institutional arrangements include not only adults, physical environments, time and organisational structures, but other children as well. Children are important social conditions for each other's development. As outlined in Chap. 4, the child's contributions to the peer group through his/her social agency will be mirrored in the social affordances of the child, which opens further or fewer opportunities to feel and act as a valid contributor in different social groups. The cultural line of development is thus complex, as each practice is constituted of different adults, rules, values and knowledge about the child. As we discussed in Chap. 2, shifts in cultural-historical values and social-political and economic changes also impact on the concrete social conditions for development for children and families. The value position about institutionalisation versus inclusion is one example. This shift in value position has replaced special schools using sign language with a mainstream approach, which focuses on oral language. The two types of schooling create very different institutional arrangements for children with hearing impairment and thus very different conditions for participation, learning and development through time. Physical factors (for instance, buildings and standards and innovations in technological aids), all formed in cultural-historical processes, also contribute to the child's social situation of development.

## **Typical and Alternative Developmental Trajectories**

Even though life in most western societies is marked by a high level of free choices, limits to available trajectories arise along the developmental path (Hundeide 2005). Childhood takes form via participation in successive and parallel institutions. Kindergarten is followed by school and school is partitioned into a succession of grades, each associated with the learning of particular curriculum and skills. The child's participation in and movement between them impacts on his/her social opportunity situations (Højholt 2012). Values about appropriate developmental skills are built-in to activity settings, along with cultural age-standards, as social developmental windows. During the opening of a social developmental window, development towards a particular developmental skill is supported through the institutional organisation. Similarly to the proliferation and subsequent reduction of redundant neurons during biological opportunity situations (see Chap. 2, relating to experience-expectant information storage and neural plasticity), specific age periods are associated with an abundance of social opportunities that are related to current cultural-historical ideas about age-appropriateness. Throughout this book, we have looked at developmental issues such as early attachment, development of shared attention, communication skills and social play skills as examples of child capacities that are typically expected and supported during specific age periods. The child and his/her family experience the values about appropriate developmental skills built-in to activity settings, along with cultural age-standards, as both demands

and opportunities. For example, the early school years are a period in which children in western societies participate in activities supporting learning of the alphabet and basic reading skills. Later in mainstream middle school, learning activities are organised from the presumption that the participating children master literacy. The child and the family develop their motives within these conditions from the opportunities and challenges they experience in their everyday life. When the age period ends, specific social opportunities disappear or are at least strongly reduced. As long as the child is able to develop along a typical developmental trajectory, the cultural-historical opening and closing of social developmental windows provides the child with relevant demands and opportunities. However, for the child following an alternative developmental trajectory, out of sync with social developmental windows, relevant peers and activities might not be as readily available.

One basic example could be learning to ride a bike. In many countries, riding a bike is a common type of transport for children and adults. Preschool children are supported by their parents in learning to ride a bike. The typical developmental trajectory is supported by cultural artefacts for bike training, such as training wheels and kids' balance bikes that are available in the proper size in most bike shops. The preschool non-biker does not stand out from peers. Later, from the beginning of school onward, most children have learned to ride a bike and from middle school onward, school excursions might involve transportation by bike. The schoolchild that is not able to ride a bike, for example due to a delay in motor development, will stand out from peers. A schoolchild with motor delay can still follow an alternative trajectory and learn to ride a bike, however training wheels in the right size may not be available in the local bike shop but need to be purchased from a specialised shop with remedies for children and adults with disabilities. The use of training wheels by the schoolchild will also be seen as associated with younger children and not considered age-appropriate. As a second example of social developmental windows in relation to typical and alternative developmental trajectories, we suggest considering the learning of social rules for being part of a social group. At first, it seems like a developmental skill with a lifelong developmental window. However, social rules evolve over a person's entire life, building on previous learned skills of social participation. Falling behind might mean that the child has difficulty acting age-appropriate, becomes less competent in his/her own age group, is given less opportunities to participate and then has less opportunities to learn social skills. As many aspects constitute social skills and social identity, a child might still be age-appropriate in certain areas that provide the child with opportunities to participate. Even though a child might be less adequate at bantering conversations, he might still be competent on the soccer field and so be an accepted part of the youth group. However, if a child falls too far behind peers in understanding and acting by social rules, it might become difficult to catch up, because the necessary condition for development – participating in social groups with peers – has disappeared, including participation in the soccer field. Alternative developmental trajectories of social skills learning will be needed if the child becomes excluded by peers as socially inappropriate.

It is by moving in congruence with institutionalised age-appropriateness that fusion between the natural and cultural lines of development becomes possible. The bounded indeterminate nature of these age-graded social opportunity situations are described by Valsiner (1997). He outlines how a range of possibilities exists within a socially and psychologically shaped situation, and how those becoming actualised (if any), is a matter of individual choice and mutual negotiation. Development is bound up with institutionalised trajectories and incongruence can be considered a state of persistent asynchrony with cultural norms of proper development for children. The asynchrony with normal age-graded expectations and support increases the risk of cultural deprivation: The development of the child is arrested or slowed down due to lack of possibilities for active participation in activities where the mastering of relevant cultural strategies of behaviour is learned.

A study will exemplify how social developmental windows and incongruence interacts and how parents and professionals can manage it. Ytterhus et al. (2008) explored social participation of children with learning difficulties and/or impairments in mobility through a longitudinal qualitative design using interviews and follow-up interviews of parents of children aged 3–12 years. One of their main findings was a how “social turning point” related to the age of the children. Turning points have been identified in earlier research, often in connection with institutional transitions (Guralnick et al. 2008; McIntyre et al. 2006). However, the turning points identified by Ytterhus et al. (2008) were not related to institutional shifts. For children with learning impairments or learning impairments and mobility impairments together, an age of the child of approximately 8 years marked a point in time where social participation became more difficult. For children with mobility impairments only, the change was described a little later, around 10 years of age. One reason for this change was that before the mentioned ages, parents of all children were often involved in the social activities of the children in term of inviting, arranging and supporting. The active involvement enabled the parents of children with disabilities to support their child's social participation by inviting children over and arranging suitable activities in accordance with their child's capabilities. Around the age of 8–10 years, the parents of children without disabilities stopped their involvement in the arrangement of play and social activities, leaving it to their children to make arrangements on their own and travel independently to play agreements instead of being transported by their parents. Another change related to the social turning point was a change in the motives and the types of activities in which the children were engaged. It changed from playing to trying on make-up and practicing life as a young person. The children in the study had not begun developing these motives yet and were increasingly excluded from activities. The parents' social window of arranging play dates had lapsed as it was associated with a no longer age-appropriate way of social participation, even if the children with learning disability still needed this type of support for their social participation and the children with mobility impairments still needed help with getting around and with physical care, for example, going to the bathroom. Thus, children with disabilities experienced increasingly social exclusion.

A similar finding is reported in Bøttcher (2011) in which the social participation of two children with cerebral palsy and learning impairments was analysed with respect to their motives and the organisation of social activities. The children were studied through separate interviews with the children with cerebral palsy and their teaching assistants, supplemented with neuropsychological testing of the children. One of the children in the study was Peter, a boy in seventh grade. Earlier, Peter had participated in activity settings during recess activities and in an after-school institutional setting, together with his peers. Now he experienced rising problems in his ability to participate in the social activities both during recess and in after school activities. The organised after-school activities had commenced and social activities had changed into ad hoc meetings of friends and a free choice between a wide range of leisure-time activities, such as soccer or dance classes. All children in the class had had to learn to negotiate this transformation from one type of after-school practice to another. They needed to develop new ways to participate in their friendship groups after school. Peter seemed to be motivated for social participation, including the new teenage life. He brought his basketball to school and he liked to watch the movie "High School Musical". However, due to his executive dysfunctions, the learning of how to navigate in the new social situation might have been a greater challenge for Peter compared to his peers. Therefore, instead of participating, he went home alone after school and watched television. During the recess activities at school, changes in Peter's participation were also seen. Often, he withdrew and watched his classmates from a distance. Peter's brain lesion and their impact on his cognitive functions had put him at a disadvantage with respect to social participation at the beginning of teenage life. Despite his interest in aspects of life as a young person, the lack of structure in the mainstream social setting made social participation too difficult. His social developmental window of participation had decreased and could be further decreasing as his peers continued to develop their abilities to "be and act as adolescents", while Peter lost developmental time in developing "adolescence skills". A trajectory of acting less and less age-appropriate and not developing social agency vis-à-vis his peers was started. Thus, incongruence in the present easily leads to more incongruence in the future as the difference to same-aged peers grows. The impossibility of rewinding chronological age time, made evident in the child growing and getting older, increases the incongruence and the challenge of making the necessary adaptations, because opportunities of social developmental windows in the institutional trajectories might be lost.

However, the asynchrony between chronological and developmental age might also set off negotiations about what type of activities and social settings could be appropriate for a particular child, given his/her age-atypical motives and skills. These negotiations include understandings of developmental delay, its source and possible consequences.

## Understanding Developmental Delay

The fusion or synchrony between the natural and the cultural development is the result of a long historical development. When the fusion between the natural and cultural lines of development functions suboptimally or breaks down due to incongruence, it often becomes expressed in developmental delay; meaning the child's developmental level is different from what is typically expected in relation to the chronological age of the child. Developmental landmarks are often reached later. Many types of disabilities are associated with developmental delay as we have illustrated throughout this book; some impairments slow down biological maturation, others mainly impact through the difficulties the child experience with participation, impacting on the child's possibilities for developing higher mental functions and relevant social skills. As became apparent in the first chapter, the primary biology-driven challenges give rise to developmental incongruence that has an impact on the whole of the child's development. Developmental delay of children with disabilities – compared to typical peers' development – creates asynchrony, contradictions and discordances between developmental dimensions. The impact of a defect becomes twofold: firstly, it lowers the biological potential of the child; secondly, it makes the child out of synchrony with normal age-graded expectations and support. From a cultural-historical theoretical point of view, smaller asynchronies are an in-built part of normal development, which fuel further development. Smaller asynchronies can, according to Vygotsky (1998), be called developmental "crises", emergent discordance between the motives of the child and institutional motives in one or more of the child's activity settings. The child's development of new motives and competences deconstructs the current relation between him or her and the social situation of development – a new relation becomes created and the child comes to master new competences in accordance with his/her new motives (Vygotsky 1998). In children with disabilities, this evolving mechanism of crises in development becomes impeded by the developmental incongruence (Vygotsky 1993). The fundamental incongruence keeps disturbing the dynamic of asynchronies between the natural and the cultural lines of development that support and fuel development. A developmental crisis and a developmental incongruence are different from each other. Delay due to incongruence arises from a deeper mismatch between the child and the social situation of development. Resolution of the incongruence often requires both analysis of the child's particular participations skills and adaptations of the social practices. Lack of adaptations might result in persistent asynchrony, or threats of asynchrony, between the biological and the cultural lines of development. Persistent asynchrony results in cultural deprivation, a situation in which the development of the child is arrested or slowed down due to lack of possibilities for active participation in activities where the mastering of relevant cultural methods of behaviour are learned. As we have elaborated on in this book, rather than being an inevitable part of the impairment, developmental delays are often created by the incongruence and at the same time developmental delays create or increase the incongruence.

The difference between “development” and “developmental time” differs in that developmental time highlights development as situated. Situated means bound in the particular institutional organisation of families, childcare practices, kindergartens and ways of organising teaching activities and schools – structured not only as activity settings but also in accordance with time. Developmental windows (see Chap. 2) emerge and evolve as critical periods in the interdependence between individual chronologically evolving developmental time and the social and cultural institutional limits and opportunities in the child’s social situation of development. Developmental progress is enabled by the dialectical interrelation between biological potentials and social opportunities through the participation in cultural institutions situated and distributed through time. Judgements about developmental delays and whether a child moves forward in his/her development (by typical as well as alternative developmental trajectories) require a focus to judge movement in relation to. One focus is to compare the child to him- or herself. At time T1 the child was able to do A, at time T2 the child is able to do A and B; that is, the child performs better, demonstrates more complex interaction, etc. Comparing the child with him- or herself is relevant when addressing the effects of chronological time or interventions such as mediations in dynamic assessment. However, the child’s development is situated in a social situation. Other social participants make formal or informal assessments of the child’s developmental level, developmental time becomes hinged to cultural-historical ideas about age-appropriateness, the synchrony between natural/chronological age and cultural/developmental age. In cases of synchrony, the child is judged and experiences him- or herself as being age-appropriate. In cases of asynchrony, the child stands out as odd, “childish” for his/her age, or as developmentally retarded. In order to understand the child’s social situation of development, his/her development also needs to be judged in accordance with age- or developmental-appropriate standards (the cultural line of development in Vygotsky’s conceptual understanding). Does the child keep up, fall behind, or follow peers? However, if the developmental delay is understood from the medical model, the delay will mainly be attributed to the child’s impairment. When considerations about appropriate expectations and demands for a child are based in the biomedical model of disability, two types of problems can arise. First, disagreements between, for example, parents and professionals become a matter of who is holding the truth. Cooperation can be stalled by disagreements about the developmental level of the child. Second, an additional and serious problem is the risk of downward adjustment of expectations and demands in response to lack of age-appropriate behaviour. A classic example is to interpret delayed development of higher mental functions due to previous incongruence as a sign of general (neurobiological-based) intellectual impairment. Another example could be interpreting the developmental delay in social behaviour skills of a blind child as symptoms of a congenital condition, for example, autism spectrum disorders (Hobson and Lee 2010). A small delay might appear inconsequential. However, if the developmental arrest and problems with social participation is due to lack of the right support and leads to a lowering of expectations about the developmental potential of the child and downscaling of demands, it is or becomes a situation of sociocultural

deprivation. Losing developmental time becomes especially critical when developmental delay is attributed mainly or solely to the child's biological impairments. After all, individual developmental time is conditioned by historical and political institutional time in all the practices in which the individual participates. Economic possibilities for compensation, political decisions about levels of economic resources for treatment, available aids and support have concrete impact on the everyday life of children and their families, for instance, what type of schools they attend and the type of life the family is able to live. Downward scaling of standards for demands and participation of the child holds the potential to change the child's future social situation of development, including what type of developmental possibilities are available and to change one developmental trajectory into another with fewer opportunities later on. It could, for example, be changing a trajectory aimed at finishing school with a diploma towards a trajectory of leaving mandatory school without a diploma and fewer opportunities for further education.

The asynchrony between the individual developmental trajectory of the child with a disability and the cultural institutionally shaped developmental trajectory may hold consequences for the child's future opportunities. Especially in cases where the compensation of developmental incongruence rests on synchrony between biological and social developmental time windows. Social opportunities for a remedy such as, for example, a cochlear implant, need to be present at the right biological time. After the implantation, the biologically created window for developing oral-verbal communication needs to be supported by social participation opportunities. If the child fails to develop age-appropriate verbal language skills within a few years, it risks additional delays in social and cognitive areas, for instance, mental health problems or delay in literacy (Knoors and Marschark 2014). In this example, social developmental windows and biological developmental windows interact in a mutually constraining way. In the case of children with severe disabilities, a change to a specialised setting with appropriate knowledge and support can change the developmental possibilities for essential skills, such as being able to read and/or communicate one's needs to one's helpers. Timely support of the child and establishment of congruence is needed to avoid often irreversible escalating effects.

## **Loss of Developmental Time**

Development is not only a matter of ongoing biological maturation, but also a matter of age-appropriate social opportunities bound in institutional trajectories. Even though development is increasingly considered a life-long process, developmental windows will not always be available. Transitions from one institutional setting to the next often need to take place at a specific time in the child's chronological developmental time: In many western societies, the end of the period as toddler and entry into compulsory school marks an important "transfer", or turning point, of developmental time in a social institutional sense. Decisions about the type of school need to be made at a specific time (in Scandinavian countries, at the age of five) for both

typically developing children as well as for children with developmental delay. Even though the child might be able to move school later on, the choice often carries lasting consequences for the child and his/her opportunities for learning and development. Research has shown that children with disabilities more often move from mainstream school to self-contained or other types of special education, while a move the other way is rarer. On the other hand, placement in a mainstream setting without knowledge about the child's special educational needs and how to support the child best might deprive the child of valuable learning situations and cause the child to miss development time windows.

Another important institutional transition arises around the end of adolescence, with the completion of compulsory school. Important decisions about the future adult life will be made around that time (16–25 years of age). For children with moderate disabilities, the question could be whether the child is moving towards a trajectory of education and possibly some kind of employment, or a trajectory of lifelong dependence on social benefits. This means that even though development is a lifelong process, institutional transitions mark important time points at which the child's capacities and developmental prognosis will be assessed by parents and/or professionals and important decisions about the child's future trajectory are made. A loss of time, either from biologically based delay or due to, for example, administrative slowness at the local municipality office for support, can be difficult to make up, as the social developmental window closes as the child moves past the transition point. Developmental delay may be transformed into particular developmental opportunity situations. For some children with disabilities, loss of developmental time threatens to switch the child from one social developmental trajectory to another. For other children, loss of developmental time might leave them with less time to develop essential skills before the end of social developmental windows. Developmental windows, for example institutional transitions, evolve as critical periods in the interdependence between individual, chronologically evolving developmental time and the social/cultural line of development expressed in the child's social situation of development. Thus, the consequences of attributing developmental delay to the child rather than previous developmental incongruence lie not only in how to understand the child in the present, but often continue as a projection of the present into the future.

As part of a research project looking into learning and development of children with severe cerebral palsy (Bøttcher 2014), interviews were conducted with mothers of children with severe cerebral palsy and accompanying impairments that included communicational impairments and complex needs for adaptation in most aspects of everyday functioning, including learning. The mothers' ideas about development as time that can be gained or lost, utilised or wasted was explored in relation to the ways they sought to provide developmental opportunities for their children through time and in different activity settings. Two interviews with each mother were conducted, with 1 year in between. The two boys, here named "John" and "Carl", were both in their first years of schooling. Both children were out of synchrony with the typical cultural line of development. Conversely, culturally based ideas about what is age-appropriate given the chronological age of the child



could not work as developmental standards for these children. Still, the mothers tried to judge the relative developmental speed of their child by comparisons with their child's social situation of development:

Interviewer: "In what areas of development is John making progress right now?"

John's mother (10 years of age): "It is difficult for me to judge here at home. Maybe because I see him every day. However, the teachers say he has changed in how he acts and what they work on."

However, a year later, she is more critical about the developmental speed of her son:

John's mother: "The teachers do have plans [for John's learning and development]. Nevertheless, the plans look like a continuation of the plans from last year; what they say is, "we just need more of the same". But John has progressed, so why does his current development plan hold the same developmental objectives? It makes it difficult to see the difference from last year."

In the first excerpt, she talks about John's development by looking at what he is able to do. In the second, she focuses on the institutional signs of development, the developmental plans that express the objectives of the learning trajectories organised in the school setting. John's individual development and the institutional trajectory are of course not the same, but the point stressed by the mother (and of relevance to the understanding of developmental time) is that John's social situation of development is constituted by his individual learning trajectory *and* the organisation of learning trajectories for the children at John's school. The mother expresses that the current constraint of his development lays in the unambitious development plans. She continues:

John's mother: "I cannot understand why we haven't received information about whether John is moving from primary to middle school, because his age would justify the move. He ought to move to middle school now. Moreover, I think his future teacher from middle school ought to get involved now, before the move. Otherwise, we will risk losing three months yet again. [...] At his age, he needs to be with peers at his own age. Before they move on. Otherwise, he risks being a step behind over and over again."

The quotation illustrates the mother's sense of developmental time as a resource that needs to be employed with care and thoughtfulness, because a loss now will affect John's future possibilities of moving together with peers. Her statement expresses the dread of possible closures of social developmental windows, how early losses of developmental time might place her child on a different developmental trajectory and how she will have to manage it. A loss of time can be difficult to make up, because if the child misses social developmental windows (within typical or alternative developmental trajectories), it could be difficult to catch up later as school trajectories and/or peers at the appropriate age may not be around anymore.

Management of time from the parents' subjective perspective is bound with their imaginations about the future and values of what constitutes a good life with a disability as an older child, an adolescent and an adult. When managing their child's development now and in the time to come, their activities are best understood from the values they attach to particular futures. This is, of course, not unique for parents

of children with disabilities. However, the creation and ensuring of developmental conditions for their child demand more ongoing work compared to the situation of parents of typically developing children, where many aspects of their child's development are automatically supported by the conditions already in place. The parents' concern with judging the development of their child is also about securing the developmental opportunities of their child, in order to ensure that their child does not get further behind. They would like to help their child to keep being in synchrony with established or adapted social developmental opportunities. Parents' sense of loss of developmental time could denote a situation of developmental arrest and loss of *expected developmental gains*. The future focus of a child's development leads to an orientation of developmental time covering the relative developmental speed of the child vis-à-vis relevant peers (not necessarily typically developing). A strategy of assessing one's child's development by looking at the social situation at school and comparing to atypical peers is expressed by Carl's mother:

Carl's mother (Carl nine years of age): "When you think about the extent of Carl's disability, I don't think many *with his difficulties* are learning at the speed Carl's teacher is going at." [Our italics]

The need of both mothers to assess their child's developmental progress and speed is based in their perception of developmental time as a resource that can be used or lost. Lack of progress becomes a source of concern or even alarm.

## **Creation of Alternative Developmental Trajectories: Time as a Developmental Resource**

Still, developmental trajectories are never inevitable but are actually actively created by children, parents and professionals. Social institutional arrangements and peers are crucial parts of the child's social situation of development and the child's conditions for developing motives and participating. Parents of children with disabilities often experience transitions, for example, from kindergarten to school, as a time where they have to work hard on creating institutional congruence for their child – finding and negotiating a good enough school setting (Dammeyer 2010b). Managing the development of a child with disabilities is more demanding compared to that of children without disabilities. Research shows that parents of children with disabilities experience more stress than parents of children without disabilities. For instance, parents of children with hearing impairment have been found to experience more stress (Quittner and Steck 1991). The experienced stress is associated with the child's degree of behavioural, communication and language difficulties (Quittner and Steck 1991; Zaidman-Zait and Most 2005) on one hand and socioeconomic status on the other (Topol et al. 2011). Another source of demands is that everyday life with a child with disabilities often contains more time-consuming or physically demanding situations. The child may react with greater sensitivity to unexpected situations or the non-verbal child may require more time and skilled

interlocutors to succeed in expressing a conversational subject. However, care of a typical infant is also time-consuming and requires sensitivity and ability to interpret basic needs from non-verbal communication. It is not the amount of time itself; it is the asynchrony with typical developmental time trajectories that makes development of children with disabilities more difficult for the parent to manage. While caregiving practices from infancy, for example, in communication or management of daily rhythms, may still be relevant for a child with severe intellectual disability at a later age, societal demands from preschool and school institutions often contain additional demands. Parents often work hard to overcome the incongruence by the creation of local adaptations. For children with minor or more invisible disabilities the incongruence can in most cases be overcome by supporting the child's participation within the mainstream settings and in the same conditions as his or her peers without disability. If the incongruence is more salient, overcoming the incongruence needs to be managed through the creation of alternative institutional pathways, as either individualised adaptations within a mainstream setting or by placement in specialised institutional settings. Creating alternative developmental trajectories most often requires a lot of work from parents and professionals.

When it becomes obvious that the child differs from his/her peers in terms of a need for developmental support, the challenge is to create alternative developmental trajectories. Part of the practices associated with creating alternative developmental trajectories will be to assess the child's level of development and what type of demands and support the child needs and will benefit from. In the case of children with impairments, the parents and the professionals cannot rely on cultural-historical presumptions about appropriate abilities and need for support anchored in the child's chronological age. While typically developing children are able to participate in and rise up to age-appropriate conditions and demands, the incongruence between chronological development and the impaired child's level of competence and social participation opens up for considerations and negotiations about what are appropriate behaviours, demands and expectations for that child. Due to the widespread use of the biomedical model of disability, lack of ability to participate and slowing down of developmental speed is often attributed to the child as an individual. The logic is that the child lacks age-appropriate skills due to his/her impairments. For example, decisions about institutional placement of children with disabilities are often based in arguments about the individual impairments of the child (Hjörne 2004; Røn Larsen 2012). However, as mentioned in Chap. 5, the assessment of the child, his/her abilities and potential for further development is by no means straightforward. The child's current developmental level has been created by biological and social conditions together. Furthermore, methodological and situational factors impact on both formal assessments, everyday impressions of the performance level of the child and the ideas about future developmental possibilities held by parents and professionals. As we have outlined throughout this book, the present developmental state and the developmental value of an alternative developmental pathway can only be understood by looking at the child and his/her social situation of development together – and has to be created individually in each social practice. From a cultural-historical perspective, the creation of alternative

developmental trajectories is interesting as a solution to crises in which development through a new synchrony is not attainable at the level of the child's activity. The analytic interest regards the way the alternative trajectory becomes expressed and the way in which it affects the development of the child. It will be the case whether the alternative developmental trajectory is organised within the immediate social setting or involving reorganisations of the practice at a higher organisational level. Higher-level reorganisations could be the organisation of special teaching at the school, the organisation of school placement at a municipal level or even educational acts at a national political level. The solution of developmental incongruences through reorganisation of the social practice plays a part in the dialectic understanding within the cultural-historical perspective, within which individuals can affect and change their own conditions for development (Dreier 1999). However, different structural levels in society are associated with different functional time scales (Bøttcher 2010). Solutions that require reorganisations of the activities in the learning practice through negotiations and reorganisations in other practices, such as a school board or municipal organ, often come about at a much slower pace than if the solution could be found directly by reorganisation of the teaching activity. The necessary but slower reorganisations may make the crisis situation appear immobile from the perspective of the child or the parents (Bøttcher 2010; Dammeyer 2010b).

## **Future Imaginations and Creation of Local Congruence: Children and Parents as Social Agents in Time**

Developmental time in a cultural-historical sense opens for the imagination and organisation of future developmental possibilities (Cole and Engeström 1993). The management of developmental time is a central task for parents of children with disabilities and holds the potential to impact on the child's developmental conditions now and in the future. Parents and professionals are social agents that create developmental trajectories for and with young children with disabilities. The children themselves are active participants too; however, the way their agency affects their developmental trajectory depends on how their acts are interpreted and acted upon by their caregivers, as discussed in Chap. 4. Our central point will be that by negotiating local congruences for the child, parents and professionals create the conditions for positive development – where the child can participate in and contribute to social practices in synchrony with social developmental time windows, whether in typical or alternative developmental trajectories.

A study of parents of children with disabilities exemplifies this point (Dammeyer 2010b). One couple in this study prepared the best daycare placement and support for their child with hearing impairment for more than a year by arranging meetings with counsellors, school principals and decision makers at the local municipality. They experienced it to be a hard job requiring long hours, because it was difficult to get the different professionals to work together, argue for the funding for the extra

support and ensure that each professional made decisions in a timely manner. To be able to manage the incongruence, the parents experienced that they had to be years ahead of the child's development, for instance, finding the best school needed in one case years of preparation. Finally, when they succeeded in the arrangement of the best possible school, the child's impairments had progressed and they had to start arranging a new school placement all over again.

Understanding the dialectical nature of child functioning and development turns attention to how practices of support are of considerable developmental importance for children with disabilities – and how parents and professionals manage to create local congruences for the child with disabilities. Parents' support and demands for their child and his/her present developmental conditions are held against past experiences about development and struggles for the necessary adaptations and short- and long-term future plans and visions. Parents are the main caregivers for their child, both at home and indirectly in other practices by actively ensuring that other caregivers are offering their child acceptable developmental conditions (Kousholt 2012). Through present interpretations of the child's abilities and future imaginings of the child's potential, parents organise developmental support in which ideas about potentials are tested, revised and actively turned into developmental trajectories. This developmental time concern is a central motive for parents in general and is expressed through how they support their children's participation in other practices, for example, getting them to school on time, supporting homework, finding financial resources for relevant school materials not provided by the school, etc. It is also evident in the demands they place on the other practices, such as discussing or negotiating short- and long-term learning goals with the professionals, making requests on behalf of their child, etc. The parental task of taking care of their children's development in other contexts is often also experienced as frustrating for parents of typically developing children (Kousholt 2012). For parents of children with disabilities, it will often contain additional challenges, because the individual capabilities of the child with biologically based impairments rarely fit with the conditions and demands in typical school practices and activity settings (Resch et al. 2010; Ytterhus et al. 2008). For example, the difficulties associated with arranging school for their child might in some cases include the planning of moving to a different part of the country in order to secure better developmental conditions for their child (Kluth et al. 2007). Parents of children with disabilities face a double challenge associated with the incongruence: they must simultaneously manage the present and the future with their child. Not even a specialised environment will fit all children with disabilities – individual arrangements and adaptations are almost always needed (Bøttcher 2014). The particular child's constellation of impairments creates specific and idiosyncratic demands for further adaptation of the environment and the pedagogical practice. Parents of children with disabilities have extensive experience with their own children and often feel they hold knowledge that is relevant for the fine-tuning of their child's environment in relation to learning and social participation. Based on the parents' experience with how the child can participate in different social practices, they express both hope and frustration in the on-going

work of creating developmental opportunities for their child, in order to make the best out of the present developmental time.

The creation of local congruence is often experienced as a struggle by parents of children with disabilities (Dammeyer 2010b; Palisano et al. 2009). In addition to financial pressure and time pressure, one underlying reason for this struggle is that the incongruence between the child and the practices needs to be addressed repeatedly. Children change teachers, they move to a different department or institution, develop new skills or needs, or get a new type of aid. Practices also change as a result of changes at a societal level, which have implications for the child and the family's economic and social wellbeing. It might be new legislation about school placement or municipal interpretations of legislation, which impinge on opportunities for the individual child. Parents are constantly working to create local congruences every time a change takes place. Previous solutions become outdated and need to be replaced by new. At a basic level, in order to maintain congruence, it is central to recognise the aetiology of new accomplishments and challenges in the basic person-practice dialectic in which both the child and the practice change. The fact that the cultural line of development is made up of several practices and activity settings with different adults and different goals means that the child's social situation of development becomes complex and that the support and demands may differ between settings. The complexity of the cultural line of development makes negotiations unavoidable. Negotiations can take place between the parents and adults from the different practices the child moves in and between different professionals involved with the child. Negotiations about what type of challenges, what type of possibilities the child ought to be met with, are always constrained by what is possible within the particular settings. As outlined earlier in the example with Oliver in Chaps. 7 and 8, the congruence in communication created at home could not be transferred to his school environment. The school as an activity setting was not organised around the kind of one-to-one continual attention to Oliver that supported his ability to communicate. One-to-one teaching could be a possibility, but would require a reorganisation of the current practice at a higher organisational level than the concrete activity settings where the incongruence was observed. For example, one solution could be that the principal at the school changed priority from motor function training to communication and social participation in learning activities.

The struggles associated with the negotiations of the future – which include difficulties with deciding what are appropriate developmental goals and getting the best or the most fitting adaptations – risk to slow down the developmental speed of the child. The necessary planned support of the child's participation needs to be put in place in order to secure the child's future opportunities of social participation and development of higher mental functions. Parents' frustration – or even desperation – about loss of developmental time seem to be justified, as loss of developmental time might hold real consequences for the skills and competences the child will be able to develop and the life opportunities available to the child now and in the future. Biological potentials risk being lost or left as unfulfilled potentials. An important point about developmental time is that developmental support is not only about the present, but also about imagining and organising future developmental

possibilities. Parents are concerned about a future when they are not around anymore:

Carl's mother: "What I fear most is ... who will spend six hours per week on updating his communicator, when Carl moves out of home? No one. [...] I want to make sure that when I let him go, I don't have to worry that he will be able to express himself."

Parents' imagination about the future also involves the concern that if their child misses developmental possibilities in the present or near present, the loss will affect the child's "end developmental state" and future quality of life. Parents express both hope and frustration in the ongoing work of creating and negotiating for developmental opportunities for their child, in order to make the best out of the present developmental time. Having a child with a disability only makes this task more salient – and often more complex. Parents hold a subjective sense of the developmental time made out of the perception of the relative developmental speed of their child vis-à-vis relevant peers (not necessarily typically developing), cultural-historical activity practices in which the child participates and their own and societal values of what constitutes a good life as an older child, an adolescent and an adult. In many present western societies, cultural-historical ideas about living independently from your parents are stressed and supported. Cultural-historical attention to the dialectic between person and practice highlights how children create the conditions of their own development and how important it is for responsible adults to enable their engagement as active agents. In so doing, this will be how they become independent in the future, whether their independence will look culturally typical or atypical (e.g., acting through a helper).

Negotiations between parents and professionals about how the child functions, ways of supporting the child and how to support the development of new accomplishments can become of value as platforms for developing knowledge about how the child is supported or hindered by particular activities, objects, persons, aids, etc. The negotiations about and arrangement of proper developmental support will always be present, because the child's development and the cultural forms never fully merge. Given the often complex needs of children with disabilities, the parents' ability to influence the child's potential social situation of development greatly impacts on the developmental opportunities available to the child.

Children whose parents are unsuccessful in influencing their child's immediate environment may be left with lesser conditions for participation compared to children whose parents are more influential social actors. Enabling their child to become independent holds real challenges when the child has impairments of a kind and/or severity that imply that he or she will always have to rely on support for basic daily functioning. Supporting children with disabilities is a constantly reflective and practical arrangement of cultural-historical social situations of development, working towards overcoming the incongruence.

## **Summing Up: Negotiation and Arrangement of Congruence**

Developmental time, being the focus of this last chapter of the book, reflects the complexity of development for children with disability. To understand and support the development of a child with disability requires more than a biomedical or social model understanding of disability. Throughout this book, we have analysed defects/impairment in the principal practices and activity settings of young children in relation to demands from activities and developmental support. Both cultural-typical support and specialised support for young children with disabilities has been analysed. Even though biological and social conditions are important elements in understanding the development of children with disabilities, biological and social conditions are only interesting as promoters and constraints of the development of the child as a social agent. Similarly, in terms of intervention, a mere focus on the child's individual biological shortcomings or rights for equal structural participation in society misses the role of developmental time and the dialectic interplay between cultural-historical processes on one side and individual development on the other. From a social model perspective, the child and his/her parents are left with a focus on structural opportunities of inclusion in mainstream institutional settings, often without taking into consideration how the inclusion process unfolds and transforms the child's developmental characteristics over time. Without a dialectical biopsychosocial model of disability, which takes development into consideration, parents are not given the analytical tools to properly understand or support their child with disability.

The first point is to understand the source of developmental delay. The development of the child with disability is arrested or slowed down due to lack of possibilities for active participation in activities where the mastering of relevant cultural strategies of behaviour is learned. Thus, the most important goal for negotiations between parents and professionals is to ensure adequate support of the child's social agency, whatever form it may take. This has been the second important point of this book. The children themselves are active participants too; however, the way their agency affects their developmental trajectory depends on how their acts are interpreted and acted upon by their caregivers. In addition, cooperation between parents and professionals (and the child as he/she moves beyond early childhood) must be encouraged in mutual negotiations of developmental values, now and in the future. Parents and professionals must cultivate ongoing openness to the child's perspective and align the child's motives for activity with their mature knowledge about what type of social agency will be valuable for the child in the future.

Thirdly, parents and professionals need to take developmental time seriously. The trajectory of the child must be managed in relation to age-graded demands and the trajectory of peers. If the child is unable to keep up a cultural-typical developmental speed, this needs to be addressed rather than waiting for the child to either develop or grow into difficulties. One short example can illustrate this: A child with intellectual disability was still attracted to games of rough-and-tumble by the time



he started school. His peers had developed other ways of social interaction and excluded him from their games when he tried to participate physically. Younger children were scared by his physical bulk. The social developmental window of physical social interactions seemed to have closed for him. However, an alternative developmental trajectory was arranged for him when the after-school practice arranged a weekly activity with wrestling. He participated together with peers and thus was able to continue his exploration of physical social negotiation.

A local fit between the child's abilities and the cultural practice can be created. Organisation of family life, early learning and school activities can be established that allow for sensitivity towards atypical ways of acting by children with biological aberrations. This will establish a local cultural fit, a "local congruence" between the development of children with impairments and their everyday practices for learning and development. Thus, the need for dialectical thinking of how cultural-historical processes merge with natural development of children becomes evident when these processes are challenged by impairments. The central task for parents of children with disabilities is to manage developmental time. Through this, the incongruence between cultural practices and the child's development can be transformed into a productive platform for development through the constitution of local practices that work specifically for that particular child.

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