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# Transition between home and school in children with severe disabilities — Parents' possibilities for influencing their children's learning environment

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A R T I C L E I N F O

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A B S T R A C T

The argument presented is that children's transitions between family and school have considerable developmental consequences for children with severe disabilities and that knowledge exchange between parents and school professionals is therefore of value. Children with such disabilities rarely fit with standardised conditions and demands in school practices. Parents' extensive knowledge about *their* children and how to support them is therefore often necessary in order to ensure that support and demands for participation in teaching/learning activities in these practices are appropriate.

Case data based on video-observations of teaching activities, observations at team meetings and interviews with mothers and staff, taken from a three-year long research project at a special school, are presented. The analysis shows a stark contrast between the successful tailoring of school practice for one boy, enabled by a sharing of knowledge about the child and ways of supporting him, and the continuation of ill-fitting school practices for another boy, despite his parents' efforts to share their knowledge about how to support him. The analysis of developmental processes begins with the motivated activity of each child and his parents, but it is the way the professionals interpret the child and their capabilities and support needs that leads to potentially different social situations of development for each child.

It is argued that knowledge exchange between home and school is important in order to create mutually supportive social situations of development so that a child's daily transitions between different contexts support his or her development rather than present a developmental hindrance.

## 1. Introduction

Like other children, children with severe disabilities live their life across different institutional practices, most often including their family. At a concrete level, they move between home and school and after-school centres. As they do this, they move between practices with different adults, rules, values and knowledge about a child. Within the cultural–historical approach to understand child development, the social situation of a child is central (Hedegaard, 2008). As Vygotsky (1998) describes the social situation of development, it is the system of relations between the child at a certain age and the child's social reality. Neither can change alone; if the child changes, his or her social situation of development will also change and vice versa. The social situation of a child is not only family, but also several institutional practices including school and different kinds of leisure activities. Child development needs to be understood as it emerges through a child's participation in these institutional practices across several institutions. As is the case for other children, the development of children with severe disabilities needs to be understood holistically and includes paying attention to their participation in activities within each potential social situation of development rather than seeing it as inherently arising from his or her impairment.

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For a child with severe neurobiological impairments, a longitudinal trajectory through institutional practices is often problematic, because the institutional practices and the age-graded demands are culturally–historically adapted to children with normal psycho-physical constitutions (Bøttcher & Dammeyer, 2012; Vygotsky, 1993). The alternative institutional pathways of children with severe disabilities are often based on the impairments of the child, but the way the trajectory is expressed and the way it affects the development of the child are not a direct result of biological defect in itself. The argument here is that these alternative developmental pathways can only be understood when looking at the child and his or her social situation of development together. In the present article the focus is children's transitions between family and school in order to highlight the value of this dual focus. It will be suggested that these transitions are of considerable developmental importance for children with severe disabilities and that knowledge exchange between parents and school professionals is therefore of value. The argument will be made through presentation of data gathered at a special school for children with motor and learning impairments.

## 2. Development and transitions

The study is focused on cultural–historical accounts of child development (Hedegaard, 2012; Kousholt, 2012). These accounts indicate that different institutional practices hold different conditions for children and their development. The conditions in part shape the development of a child. However, and this is central in cultural–historical dialectical thinking, children – and their caregivers – are co-creators of children's developmental conditions. Through their motives and through the demands the caregivers and the children place on others, they co-create their own developmental conditions in the different practices (Hedegaard, 2012). Parents are the main caregivers for their child, both at home and in other contexts, with responsibility for ensuring that other caregivers are offering their child acceptable developmental conditions (Kousholt, 2012). This responsibility is a central motive for parents and is expressed through how they support their children's participation in other practices, for example, getting them to school on time. It is also evident in the demands they place on other practices, such as discussing or negotiating short- and long-term learning goals with professionals or making requests on behalf of their child.

This parental task is often experienced as frustrating for parents of typically developing children (Kousholt, 2012), but for parents of children with severe disabilities it can contain additional challenges. The individual capabilities of a child with biologically-based impairments rarely fit with the conditions and demands in typical school practices and activity settings. Under normal circumstances the individual developmental level of the child and conditions and demands in the child's practices support each other. This fusion of individual and cultural development builds on cultural–historical dialectical processes that have shaped and still shape both children and cultural–historical institutions in which children and other people live their lives. For example, the activities in school are organised to fit with the age-graded socio-biological maturation of a child. Activities in first grade are based on play, reflecting agreed views on children's cognitive maturation within a Western society. This process of mutual adaptation between cultural–historical institutions and their individual participants is based on the most widespread ways of participating and therefore on individuals with psychophysical constitutions within the normal range (Vygotsky, 1993). The often problematic development of children with disabilities is the result of an incongruence between on the one hand, the biological and physical development of a child and on the other, the structure of cultural forms in which a child is living (Vygotsky, 1993). Often, a child with even a minor disability does not fit with how schools are organised and may find it difficult to participate in learning activities without support.

In the case of children with moderate or severe motor impairments, their inability to participate in learning activities at the same conditions as peers is salient and school conditions are modified, either in a mainstream school environment or by placing them at a special school. In the Danish context, children with severe cerebral palsy and multiple impairments, e.g. motor, learning and communicative impairments are considered too disabled for modified mainstream schooling and are usually placed in special schools. These schools offer a wide array of standard adaptations such as lower teacher–pupil ratios; specialised knowledge about teaching; aides to meet specific physical needs such as tube feeding; and physio-, occupational and speech therapists.

However, even when placed in such a specialised setting, the fit between the child's individual development and the setting might call for further adjustments. The particular child's constellation of impairments creates specific and idiosyncratic demands for further adaption of the environment and the pedagogical practice. Professionals at these schools frequently have a long experience in making adaptations. Still, parents of children with severe disabilities have the most extensive experience with *their* children and often feel that they hold knowledge that is relevant for the fine-tuning of their child's learning environment at school. Other researchers have highlighted how parents of children with severe disabilities and complex needs describe the necessary cooperation with school as a struggle (Dammeyer, 2010). The incongruence between each child and the practices when she or he enters in school needs to be addressed repeatedly. A cultural–historical argument for constant attention to maintaining congruence is the recognition of the basic person–practice dialectic in which both the child and the practice change. In addition, children change teachers, 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 a child's and his or her family's economic and social wellbeing; while laws about school placement or municipal interpretations of laws can impinge on opportunities for children.

Developmental incongruence is a theoretical concept not immediately apparent in daily life. Research needs to address how the activity of children, parents and professionals impacts on this developmental incongruence. How is the mismatch between the child and the practice experienced and acted upon by the child, the parents and the professionals and what are the possible developmental consequences over time of incongruence or congruence for children with severe disabilities?