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Parents' management of the development of their children with disabilities: Incongruence between psychological development and culture

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Abstract

Being the parent of a disabled child is not easy, it is experienced as a situation marked by stress, crises and grief. As Vygotsky described eighty years ago, the development of children with disabilities and the culture do not fit as they do for non-disabled children. The development of a child with disabilities is not determined by the child's physical defect alone, but constituted by the incongruence between the physical defect and the culture. In this study, the lives of four families with deafblind children were followed for two years. Interviews and observations were conducted in different settings. This study finds that because of the incongruence between the physical defect and the culture, it is difficult to reach and maintain the zone of proximal development for a child with disabilities. This study illustrates how the network of professionals and parents around the child can make a local congruence that creates a platform for the child's development.

Keywords

Disability; Vygotsky; culture; families; deafblindness

Introduction

L.S. Vygotsky has described the relation between culture and a child with disabilities. For a non-disabled child there is a fit between culture and psychological development. A child starts school when the law says it must, which occurs at about the same time as the child is biologically and psychologically mature enough to participate in culturally formed school activities. But the fit between school activities and psychological development is not always true for a child with disabilities.

> *"A normal child's socialization is usually fused with the processes of his maturation. Both lines of development – natural and cultural – coincide and merge one into the other. Both series of changes converge, mutually penetrating each other to form, in essence, a single series of formative socio-biological influences on the personality (…) Atypical development (conditioned by a defect) cannot be spontaneously and directly conditioned by culture, as in the case of a normal child." (Vygotsky 1929/1993, p. 42)*

In relation to families with disabled children, several different psychological theories have been put forth[1]. Most of them have had, in opposition to Vygotsky, an individualistic clinical perspective.

Several studies find a higher risk of stress and depression in families with disabled children (Hornby, 1997). Theories about crises (Fyhr, 1988) dominate the explanations for these findings. The "loss of the normal child" creates a situation of crisis in the family – and different stages must be lived through in order to heal the "loss". The stages are often named as: shock, denial, anger, grief, reorganisation and adjustment (Seligman, 1979; Hornby, 1997). These theories can be useful for parents and professionals in order to understand emotional reactions, but the problems are assumed to be located in the parents and the given culture is not taken into consideration. The risk is that the social worker in the municipality only understands the parents' anger as being a part of their crisis and not also as part of trying to create the best possibilities for their child in the given culture. Because of the individualistic perspective, these theories do not always promote a better cooperation or fit between the culture and the development of a disabled child.

Different theoretical perspectives in psychology do expand beyond understanding the disability as something biological within the child and the reactions as something psychological within the parents. These theories focus on relations between family members or on the institutions outside the family. As an introduction to a socio-cultural approach to disability and to argue for a Vygotskian perspective I will present systemic, narrative and ecological theories.

Systemic (Minuchin, 1981) and narrative (Mattingly, 1998) theories focus on processes and relations in the family. It is not only the child who has a disability, but the whole family; the narrative or "the system" contains the disability. Focus is placed upon the communication – and often limited to the family. It is not upon the relation between the child's development and culture, as in the case of Vygotsky.

Ecological theories (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 1998) provide another perspective that expands the contextual perspective on development. Ecological theories do focus upon how interactions between different contexts support and influence child development. Bronfenbrenner (1979) describes the development of children as

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[1] This article focuses upon psychological theories and perspectives about children and families with disabilities. The breadth of sociological theories (Barnes, Oliver, & Barton, 2002) is not taken into consideration.

influenced by different interacting systems: Activities and interaction patterns in the child's immediate surroundings (the Microsystems) are connected (the Mesosystem) and influenced by different social settings that do not contain the child (the Exosystem, for instance, the parents' workplace) and cultural traditions, norms etc. (the Macrosystem) which do not belong to any specific context. The different systems interact and influence each other in different ways as the child grows up.

Along this line, but with a more dialectical approach, Vygotsky can be introduced. In a Vygotskian perspective, called a sociocultural perspective, child development is understood as an intersubjective and socially mediated process taking place in culturally specific practices. Dialectical processes are taking place between the child's development and culture – the child is not just "placed into" a social context, a system or a fixed culture. In this perspective, sociocultural theory goes beyond ecological theories. In sociocultural theories, cultures exist in the form of social practices. Development is created in and promoted by the child's participation in cultural contexts and institutions. The child's development and cultural conditions interact.

This article seeks to analyse the interaction between the development of children with disabilities and culture from a sociocultural perspective. Vygotsky's statement that there is incongruence between culture and the development of a child with disabilities will be the starting point and the purpose of this study: How does the incongruence between culture and the development of a child with disabilities take form in Danish society in 2007? And how is it met by parents and professionals surrounding the child?

To make the analysis of the incongruence between the development of a disabled child and the culture more explicit, Vygotsky's concept of zone of proximal development (Vygotsky, 1978) is relevant to take into consideration. The zone of proximal development refers to that which the child cannot yet handle alone but can accomplish with the help of adults and more skilled peers. The zone of proximal development is a concept which emphasises that development is intersubjective and that socially mediated processes are taking place in culturally specific practices. It is through the intersubjective and socially mediated processes that the incongruence between culture and the development of a child with disabilities must be analysed. The purpose of this study can be characterised by the following question: How is the zone of proximal development constituted and how is it maintained for a child with disabilities?

Method

Participants

Four families, including five children with Usher syndrome[2], took part in this project from spring 2005 to spring 2007. All of the families live in Denmark. The five children with Usher syndrome were between 3 and 13 years of age at the beginning of the project. Three of the children were boys and two girls. One child attended a school for the deaf, two

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[2] People with Usher have a genetic condition which means they are born deaf or hard of hearing, and then gradually start to lose their sight. Usher syndrome is the major cause of deafblindness in adults, affecting 3-6% of the people in the UK who were born deaf or partially hearing. The early symptoms include difficulty seeing in the dark and in different lighting conditions. Over time vision gradually deteriorates until tunnel vision develops (Sense, 2007).

children attended main-stream school and two were in kindergarten. All children used cochlear implants, but with varying outcomes. One child used sign-language as the first language and the other four children used oral Danish more or less supported with signs. Socio-economically, all families were middle class. Due to their hearing and vision disabilities all children face difficulties concerning communication. They need to practice their oral speech, and language development takes time. The communicative difficulties affect the social and cognitive development of the children. It takes more time to learn to read and write, and in play situations with peers it can be difficult to hear everything.

Different professionals took part in the project: the author of this article as psychological researcher, two deafblind-consultants and one person from The Danish Information Centre for Acquired Deafblindness.

Methods

Inspired by participant observation methods (Hoyle, Harris, & Judd, 2002), we followed the lives of the children and the families throughout a period of two years. Methodologically this project was carried out along the lines of practice research (Nissen, 2000), meaning that practice was used and understood as a part of research. The research was, from start to finish, a joint venture among all participants. (See Dammeyer (2006) for a discussion of this methodological perspective in relation to this project.)

Different kinds of qualitative methods were relevant to this project for exploring different socio-cultural practices around the child.

Regularly scheduled meetings: The four professionals and the four families met for one full day every third month. At all the meetings, except for the first, second and last meeting, taped interviews were made with all parents together. The interviews were structured around the themes mentioned below – focusing on what the families had experienced since the last meeting. At the second meeting, the parents were interviewed individually and asked to tell the life-story of their deafblind child. The life-story interview was made as a way to know the child's history from the parents' perspective.

Observations in different settings: Between the meetings, the children were observed in different settings in and outside the home and institutions by the deafblind-consultant or the author. Observations were made at school picnics, family weekend holidays, visits to hospitals and clinics, etc. During the observations, the observer(s) acted as a professional guest (deafblind-consultant, psychological researcher), participating in the activities and speaking with both the children and adults. Observations were made 3-4 times for each child in a period of 3-4 hours. Observation-notes were made afterward. All the children were used to having different kinds of professionals "visit" them in school and at home. They all knew the aim of the observations and accepted having "visits" by researchers and professionals.

Collecting data beyond the children and families: During the project, some of the themes encountered in the interviews or the observations were explored further in different ways. A theme about "public service" was investigated by studying laws and procedures about the local municipality. Another theme about "diagnoses" was investigated by studying definitions of diagnosis and procedures in the clinical health service.

Procedure

Observation-notes and taped interviews were transcribed and analyzed by categorizing the content into different themes. The categorization was made by the author in cooperation with the professionals. After the first interview and observations, all the professionals and the author read the transcribed materials and made suggestions for relevant themes in accordance with the sociocultural perspective and the purpose of this study. During a meeting, the themes were discussed and agreement was reached regarding which were the most important. At the next meeting, the selected themes were discussed with the families. The parents had access to the transcribed interviews and observations of their child. The discussions with the parents about the themes were managed by the author. Agreements about the themes were not the goal of these discussions, but to elaborate and specify the content of the themes. The themes were used as guidelines in the process of investigation. This procedure was used at every meeting. Some of the themes, for example "parents' struggle against the system," were ongoing while others concluded or changed over the course of the two years. Observations, collected data and daily life experiences between the meetings were an important part of the specifications and explorations of the themes.

To manage the data, all materials about a theme, including interviews, observation notes etc., were gathered into a separate data-file.

In this article, only some of the themes analysed in the project will be presented and discussed. The themes will not be presented in any specific order, but will be discussed in relation to each other. Themes were selected and will be discussed in relation to the sociocultural perspective as presented in the introduction. Themes presented in this article are: cooperation with professionals and public services, struggling for children's development, emotions, being a "professional" parent and the use of networks for the child. Focus will be on the parents.

Findings

Struggling for cooperation and a good fit between child's development and culture

In Denmark, there is a long tradition of a high level of public welfare service for children with disabilities. The service for children and families with disabilities is managed and financed by the local municipality. All disability-related expenses, such as aids, different kinds of therapy, transportation etc., are paid by the municipality. The municipality also has the responsibility to arrange and offer relevant education and support, including medical treatment. In Denmark, there is a national team of consultants offering services for deafblind children. Private health insurance is not used.

The Danish government's law about social service for children with disabilities concerns the cooperation between parents and public institutions and the municipality.

> *"4(1) The municipalities offer and arrange the services for children, adolescents and their families. This will be done in cooperation with the parents and in a way that promotes the development, well-being and independence of children and young people." (Authors translation, Ministry of Social Affairs, 2006)*

But the parents in this study did not find this cooperation easy to establish. The parents experienced that they had to struggle to enter into a cooperative relationship with their respective municipality. They said that they needed to be well prepared, coming up with arguments and strategies to establish cooperation with public services and institutions. Sometimes they found that it became a struggle.

> *"Father: We need to "draw the line" in relation to the municipality. We need to say that we do not want to be manipulated and receive bad service. We listen and try to keep up on knowledge from organisations and societies in order to be ahead and in front in the discussions. You need to be up in front of the municipality. They need to know that we, the parents, but also professionals around these children, know about this. We decide, not them."*

Around this theme, we discussed what kind of role and competencies the parents needed to have. First of all, the parents described themselves as being "professional parents" to deafblind children. They needed to know more than other parents. Being professional and strategic was something these particular parents believed they needed to learn. Experience was needed in order to deal with the "system", and getting that experience was a hard job. They need to be prepared meeting public service systems.

> *"Father A: First we just met the system "as it was" – we did not fight. Only after someone told us that we needed to fight, we did.*
> *Father B: Right, in the beginning, you think that it must be right what they [different professionals at the social service] tell you.*
> *Father A: You learn not always to accept a "no"."*

"Fight" was, again and again, a central theme for all parents regarding the different tasks involved in raising their deafblind children. The parents felt that they had to fight for the best fit between the child's development, public service and institutions. They say they fought for better cooperation, explaining that they need to be prepared and give a lot of information before it was possible to get into a cooperation with public service and institutions.

An example can illustrate the parents' fight for cooperation. One of the parents visited the school once a week to be sure that their child received his speech-therapy. They informed and talked to the school many times.

> *"Mother: We press them (the school). We want them to assist with the therapy – not that much time, just ten minutes, fifteen minutes together with him [their child]. If we don't say anything, nothing happens. We tell her [the teacher] every time we see her. We also call her and talk to her about it.*
> *Father: I express my hope for it every time we meet. Only five minutes.*
> *Mother: At least once a week, I am with him in class. I don't work on Tuesdays, so I drive to the school and stay with him all day to see how it goes. And I talk with the teachers and so – try to make them do it with him."*

To explore these parents' stroggle for improved cooperation, we observed this 10-year-old boy in the school and made a short interview with one of the teachers. The teachers also talked about the speech-therapy. The teachers said that they did not have that much time for speech-therapy, and that when one teacher was ill, they could not take the time for it. The teachers were glad for the visit by the mother, because it made a better focus on speech practices at home. The boy was satisfied with both the speech-therapy and his mother's visits. Cooperation was established because of the mother's weekly visits.

Seen from the boy's perspective, it looked like a stroggle for being part of the cultural practices around him. Observing the 10-year-old deafblind child in the school with other hearing impaired children gave the impression of a child struggling against being visually impaired, working to communicate, doing his schoolwork, and being part of the peer-group. He wanted to fit in and be like the other hearing-impaired children around him. He always tried to do what the teachers told him. In the speech therapy lessons, he never lost the motivation – regardless that it was a very hard job for him to hear anything. In some ways it looked like the boy's fight corresponds to the parents fight with the public service system, professionals etc. The same incongruence was faced for all of them, but in different contexts and with different content.

Establishing cooperation seemed like a hard job for the parents. The lack of continuity among the professionals was another problem reported by the parents. Teachers and other professionals were often substituted, and the parents felt they had to start all over again with informing and building up a new cooperation. The parents needed to get acquainted with every new professional before any cooperation about the child's development was possible. It takes time to get to know the child. The parents met the same problem dealing with the municipality.

> *"Father: Now it's our third municipal caseworker being responsible for our child. The first one was "difficult" while number two was nice and much more stable. We could trust her, and were not surprised or afraid of her. When we were with the first one, we were almost afraid of her. Now we got a third and we do not know her yet."*

The incongruence between the child's development and the culture is experienced by the parents as a problematic and difficult facet of establishing cooperation with the "system". It is a hard job and sometimes it feels like a fight. For some children it seems to be a hard job, too. They struggle to fit into the social context into which they are placed. In the next section, I will continue to describe how the parents, and the children too, managed the incongruence between the deafblind children's development and culture.

Parents' promotion of developmental tasks

The parents told how they needed to remain several steps ahead of their child's needs and the situation in general. For example, the transition from kindergarten to school, or from one school to another, is not as easy as it is for a non-disabled child. It is a big job. During the project, one of the children moved to another school, because of peer-related problems and problems with reading and writing abilities.

> *"Mother: We did think at one period: Did he have more conflicts than other kids? How was the language development? Who did he play with? All these different things.*
> *Father: Again – listen to different people and then make your own decision.*
> *Mother: We had meetings where all professionals around him participated: a psychologist, a speech therapist, one from the kindergarten and one more. The next step needs to be discussed a long time in advance. What's the next? From child care to kindergarten, from kindergarten to school. Those are huge discussions."*

Compared to a non-disabled child, the possibilities for parents of deafblind children are limited. There is, maybe, only one school in the region. For a deafblind child, one school can make it possible to communicate while another school cannot, because the child uses tactile or visual communication. Differences between schools are bigger than they are for a non-disabled child. Often no school at all is able to deal with the child's special needs and something else needs to be done. The limited possibilities force the parents to be well prepared and engage different professionals to manage the child's development.

We spoke to different professionals working with the child, regarding the transitioning between schools to explore the parents' experiences. Once again, we heard and saw about a child who was struggling to make friends, learning to read and write – both in the school he moved from and the one he moved to. He told us that he wanted to "do practices with his eyes, so he could have better vision." He wanted to play soccer despite his bad vision. This child wanted to fit into the presented cultural practices. The teachers supported him in this effort, trying to help him fit into the peer-groups and teach him rules about how to behave in the school. But everybody stated that it was a hard job getting things to work. Everybody was worried about the next day and, in particular, the future.

The parents believed that they needed to prioritise among the developmental tasks facing their deafblind children. School placement and hearing devices like cochlear implants were important issues. They can not stop taking care of communication and social well-being. The parents do not think it is possible to solve all problems; there is not one easy solution to everything.

> *"Father: If you build a big tank with ten cannons, it will not end the war. If you have solved one problem, there are still other things. There are many things to focus on to improve the live of these children. Some of them need to stay in the background."*

The incongruence between the child's development and the culture cannot be solved using a magic trick. The interviews and the observation give the impression that the incongruence always will be there in every developmental task for the disabled child. It is a fundamental condition the parents need to learn to manage – and help the child to learn to manage, too.

In other words, it is difficult to be inside and maintain the zone of proximal development. The parents tell that it is difficult to support and guide a deafblind child in playing soccer in the local club. It is not enough to repeatedly explain to the child why the other children do not play ball with him and ask the other children to be tolerant. Visual aids do not help and besides soccer, there are no other sport activities in the village. Many cultural practices are limited, and cannot (as easily as they are for non-disabled children) be the mediators of socially significant activities which promote the child's development.

The emotional component

The parents think they need to be professional parents for their deafblind children. But still they dream about just being parents like everybody else – just being together with their children and not being professionals, to play with their children instead of writing letters to the public administration, etc. It is an emotional stressor to manage and deal with the incongruence between the child's development and the culture.

> *"Mother: It is emotional. You always feel that way when you go to these meetings [about the child]. It is very emotional, because you need to do it better for this child. Your heart beats and so on – you never learn to be cool.*
> *Father: You cannot take away the tough stuff. You know that you have to make it. The child doesn't wait."*

The parents feel and express emotions in front of professionals. The emotional expressions are constituted in the relation between cultural practices and the child's developmental. An example helps to illustrate how this takes place. During the project, one of the families found a doctor at a hospital to be very helpful and trustful. Another family found the same doctor very negative and the relation to him was full of conflicts. In the interviews, all parents together talked about this doctor and were able to understand the different positions the doctor was in and why he chose to do cochlear implantation for one of the children and not for the other. The hospital's economic limitations and the children's different language abilities provide some of the explanation. The parents' analysis in the interview of the doctor's different positions in relation to the children provided a better understanding of the situation and reduced the tense emotions. The next time the parents met the doctor, it was easier to cooperate with him. Through the project, we not only understood the analysis of the doctor's positions as a reflection of people's different attitudes, but also as a critique of the limitations and incongruence of cultural practices around these deafblind children. Parents' conflicts with professionals must be understood in relation to the professional's position in cultural institutions, e.g. medical doctor at a hospital.

Using the network around the child

The parents experience that the network of professionals around the child manage the incongruence between the child's development and culture. In the citations above, the parents report that they prepare developmental tasks, for example the transition from kindergarten to school, by talking to different professionals, e.g. teachers, doctors, professionals etc. Sometimes they ask professionals to meet with the municipality to talk about and plan the best solution. The parents are often the executive persons of this network of professionals trying to bring people and decisions together. Sometimes a professional, often the deafblind-consultant, takes the role of managing the network. The parents report that this is a big help.

Besides the professionals, the parents also turn to other parents of deafblind children for reflections and good advice. "New parents" learn from those with greater experience.

They keep up a network via e-mail and telephone, and meet up once a year for a family weekend.

Different professionals and parents are needed at different times in the child's development to find the best solution. To manage the development of a deafblind child is not necessarily about finding the right solution, but creating something that works.

Next section turns to and expands upon Vygotsky's perspective on children with disabilities. This will be an elaboration of some of the themes mentioned up to now.

Discussion

Speeds and directions of development

Vygotsky's formulation of the incongruence between psychological development and culture will be described by using a metaphor of speed and direction in relation to developmental trajectories. The developmental direction and speed of a disabled child change in a different way than those of a non-disabled child. The speed and direction of a non-disabled child's development is correctable by different kinds of support. Culture offers different kinds of supports which are relatively easy to obtain. But the development of a disabled child is fundamentally different and cannot be guided into a normal trajectory. There are no fixed milestones of psychological developmental, like walking by year one, speaking at two years, and so on. A child with disabilities reaches these milestones in development by different, often complicated, pathways or simply never reaches them. To walk is something different for a child with a motor disability and to speak is something different for a child with hearing impairment. The development of a disabled child is a race without lanes or rules given by the cultural forms. It is a vehicle without any well-working steering, the culturally formed "steering" fitting with non-disabled children's delevopment. The task is both to steer the development and to assign an individual lane in order to promote the best development. Language development of a deafblind child can exemplify this metaphor. Maybe it is possible with years of training to help a deafblind child speak or it is possible to have communication take place in different modalities or forms. Development of speech and communication are not predefined processes or described in any handbook of child development. This metaphor of speed and direction describes the difficulties in reaching and maintaining the zone of proximal development.

The development of a disabled child is, compared to a non-disabled child, in general slower, and some functions are more delayed than others. For a deafblind child, communication and social development is often delayed. Cultural forms and practices, such as governmental laws, social administration etc., is constituted in accord with normal development. A disabled child cannot just flow with the cultural forms and practices. Parents, together with a network of professionals, need to find a school which matches the physical, communicative and academic possibilities of the child, as we have seen. Teachers, the head of the school, and parents of the other children in the class need to cooperate. Several aids and appliances need to be found, tested and financial supported by the municipality. It is difficult to create and maintain the zone of proximal development, and is not self-sustaining once created. As the child develops, the disability takes other forms, and other aids and schools are needed.

The trajectory of a disabled child's development is shaped by culture and history in different ways than that of a non-disabled child. Attitudes towards people with disabilities change over time and create different conditions for the development of the child. A few generations ago, deaf people were seen as dumb and primitive because they could not hear the word of God (Ladd, 2003). For many years, there has been a discussion about how to teach deaf children: Is it best to teach deaf children to speak oral language (the oral method) or is it best to use sign language as the first language (the manual method) (Brill, 1984). This controversy has been going on for decades and remains pertinent as related to the introduction of cochlear implantation for congenitally deaf children (Li, Bain, & Steinberg, 2003; Lynas, 2005; Hintermair & Albertini, 2005). Controversies between professionals supporting the oral versus the manual method influence the possibilities available for deafblind children. The chosen method influences school placement, peer-relations, and social life in general. Will the child belong to the deaf society or to the hearing world? They are two very different trajectories. Ten years ago, congenitally deaf children in Denmark learned sign language at deaf schools and were socialised into the deaf society. Today, congenitally deaf children receive cochlear implants and a lot of them learn to speak and will not use sign language. Differences among the five deafblind children in this project illustrate this change. The two oldest children used sign language while the three youngest did not. Things have changed within a relatively short period of time and created differences even between siblings.

The example of the cochlear implant illustrates how the different trajectories of a disabled child's development have become constituted differently across a short time span in recent history. Elder (1998) describes how disaster, wars and periods of rapid economic and social change can profoundly affect people's lives. Historical times and events, like the Great Depression of the 1930's, make an impact on development. This is true for disabled people, too. But following the four families with deafblind children, the impact of changes in society seems to have increased and become much more distinct. Because of the incongruence between the child's development and culture, the children seem much more vulnerable in the face of changes in laws and the structure of public service. Small changes can have a huge impact. Fundamental things like communication can be destroyed if access to hearing-aids or courses in sign language is not offered to children, parents and professionals.

To have or not to have a hearing aid, such as a cochlear implant, can make the difference between communication and no communication for a deafblind child. The development of cochlear implant technology is proceeding very rapidly – so fast, in fact, that the cochlear implant creates differences between those siblings who received it in 1999 versus in 2005. Parents and children need to manage these technology-created differences. The effect of the cochlear implant depends upon the timing of the surgical procedure. Due to the decrease in brain plasticity over time, it is best to have the cochlear implant before the age of three years (Manrique et al., 1999; Holt, Svirsky, Neuburger, & Miyamoto, 2004). Ten years ago when cochlear implants were still new, it could take several years for the public administration and the health care system to make the decision and do the operation. Sometimes, as for one of the deafblind children in this project, and due to the parents' conflicts with the doctor, it was too late for the child to develop oral speech. Today, getting a cochlear implant is accepted and almost a routine in both the public service and the health care systems. The speed of technological development is faster and transforms the development of a deafblind child. Technologies such as cell phones and computers transform the development of non-disabled children. But technological aids for disabled children can make life complete different.

The zone of proximal development

Using the Vygotskian concept of zone of proximal development (Vygotsky, 1978), it can be said that establishing the zone is a difficult task and a struggle for the parents and professionals around the child. The zone around the child's development must be identified and created before it is possible to guide the child into it. To establish the zone of proximal development, a network of parents and professionals around the child is useful. As presented in this study, the network can be utilised during the transition from kindergarten into school or from one school to another. The network may be able to find the right school or maybe create a new school for this child. It could be a school in which socially significant forms of activity take place by using tactile sign-language or another appropriate mode of communication. This will bring the child into a local culture maybe together with other people who are deafblind. A "local congruence" between the child's development and culture can be created. The deafblind child does not have to fit into existing cultural practices. Rather, what is created, within the frames of the cultural practices, is a local practice that works specifically for that young deafblind person. This makes a platform for setting up the zone of proximal development. The incongruence between culture and the child's development can be transformed into a productive platform for development – for the disabled child, the parents, and the culture.

Turning back to Bronfenbrenner (1979), it can be said that the network of parents and professionals concern flexibility and resources of the different contextual systems. The network provides an ongoing analysis of how the different systems work and cooperate in supporting the development of the child. As seen in this study of the four families, linking different microsystems, like school and home, and the macrosystem is difficult. The system of parents and professionals is another important context around children with disabilities. It is a system beyond the mesosystem that links both micro- and macrosystems.

As stated by Vygotsky in the quotation below, deafblindness cannot just be biologically understood as loss of hearing and seeing, but is constituted in the intersubjective and socially-mediated processes taking place in culturally-specific practices. Deafblindness is a dialectical process taking place between the child's development and culture.

> *"If we subtract visual perception and all that relates to it from our psychology, the result of this subtraction will not be the psychology of a blind child. In the same way, the deaf child is not a normal child minus his hearing and speech. (…) Just as oxygen and hydrogen produce not a mixture of gases, but water, so too, (…) the personality of a retarded child is something qualitatively different than simply the sum of underdeveloped functions and properties." (Vygotsky, 1929/1993, p. 30)*

Conclusion

The development of a child with disabilities is a complicated process. It is not possible to find only one key to one door. Professionals need to be explicit about their part and position in the cultural practices and explain their limitations and possibilities for helping the parents to manage the development of the child with disabilities.

To reach and maintain the zone of proximal development is a difficult task because of the incongruence between the culture and the child's development. Sometimes it is possible to create a local culture that fits the child's development and provides a platform for the zone of proximal development. The network of professionals around the child can be the one that creates that culture for a disabled child.

It seems as though the incongruence between the culture and the development of a disabled child is a condition that needs to be taking into consideration - for parents, children, and professionals. Deafblindness is not only inside the eyes and ears of the child, but something that is constituted by the incongruence between culture and the development of a child.

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