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How to cite this publication
Please cite the final published version:

Bøttcher, L. (2020). Creating relevant and supportive developmental conditions for children and youth with disabilities. Learning, Culture and Social Interaction, 26, [100228].
https://doi.org/10.1016/j.lcsi.2018.04.007

Publication metadata

| **Title:** | Creating relevant and supportive developmental conditions for children and youth with disabilities |
| **Author(s):** | Louise Bøttcher |
| **Journal:** | Learning, Culture and Social Interaction |
| **DOI/Link:** | https://doi.org/10.1016/j.lcsi.2018.04.007 |
| **Document version:** | Accepted manuscript (post-print) |
| **Document license:** | CC BY-NC-ND |

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Creating relevant and supportive developmental conditions for children and youth with disabilities

Louise Bøttcher

Aarhus University, Danish School of Education

Keywords: Disability, parental perspective, future possibilities, motives, cerebral palsy, moral imagination

Abstract

This article aims to conceptualize how young people with severe disabilities can be supported in their development as social participants. Hedegaard assigned a pivotal role to the concepts of value positions, demands and motives in her wholeness approach. This conceptual approach guides the analysis of a study of young people with severe disability and highlights how parents develop their motives from the societal value position of inclusion and the general aim ‘to give their child the opportunity to realise it’s potentials’. The concept of moral imagination is used to explore the interrelation between imagination – what ought to be - and development of motives that lead parents and professionals to envision possibilities in the other person and direct their activity. Moral imaginations were shaped by societal offers, trajectories and technologies in different activity settings, but at times breaking with them and creating wholly new opportunities, thus illustrating another point of Hedegaard: How persons can impact on and reshape their activity settings. Relevant and supportive developmental conditions for children and young people with severe disabilities require partners willing to engage in mutual imagining of how the future ought to be and role-modelling how they can make active and socially oriented demands in their social settings.
Creating relevant and supportive developmental conditions for children and youth with disabilities

Support of young people with disabilities are often either based in individualized assessments of their impairments (e.g. Anderson et al. 2001; Baron & Rey-Casserly, 2013) or a focus on social barriers for their participation (e.g. Case, 2000; Petriwskyj et al., 2016). However, departing in the general conceptualizations of development, an important point of the cultural-historical understanding is children’s ability to impact on and change their developmental conditions through their motivated activity (Hedegaard, 2012; 2014). Thus, an important preliminary point related to the title of this article is that the creators of relevant and supportive developmental conditions include the children and youth themselves. Drawing on Hedegaard’s wholeness approach, it is central to consider how the child with disabilities develops as a social participant who is able to negotiate demands and place demands on other persons through its motivated activity.

The main characters in this article will be a group of young people on the verge of adulthood and living in the Danish society in the 2010’s. What is particular about them – and what they all have in common – is that they are severely disabled. All have severe cerebral palsy, none of them have normal verbal language. Considered from a mainstream position, the limitations of these young people in shaping their own lives are very salient. Nevertheless, the aim of this article will be to explore how the young people become active social shapers in their own life, together with their parents, and to analytically draw out a cultural-historical conceptualisation of developmental support for children and youth with disabilities.

1.1 Societal value positions, motives and demands

Vygotsky made an analytical distinction between the individual and biologically based development of the child (the natural line of development) and the social and cultural development of the child that takes place in the institutional practices such as families and schools (the cultural line of development) (Vygotsky, 1993). Under normal circumstances, the natural and the cultural line of child development support each other. This idea of dialectic intertwining is central to the developmental thinking within cultural-historical theory and means that child development – with or without a disability – requires analyses of how the biological/individual and cultural lines of development condition each other and create future developmental possibilities by creating solutions to present conflicts and challenges.

1 AAC: Augmentative and Alternative Communication
The zone of proximal development is the central concept to capture the developmental potential of children’s engagement in activities with other children (older or more competent) and adults with more skill and knowledge of cultural ways. Through the child’s imitation of the activity based in it’s preliminary idea about the meaning of the activity, she or he becomes able to do what it would otherwise not be capable of (Vygotsky, 1998). The imitation process might work through explicit demonstration or instruction as is often the case in school or through unspoken expectations and on-going everyday demonstrations to the child (Rogoff, 2003).

To further analyse the developmental relation between person and environment, Hedegaard (2012; 2014) has assigned a pivotal role to the concepts of value positions, demands and motives in her wholeness approach. Beginning with value positions, different institutional practices endorse particular ideas about what constitutes a good life. The activity settings are organised according to the institutional goals about a good life for the participants under the conditions of the institution as set by the societal objective (Hedegaard, 2009). The institutional value positions are expressed in the dominating activity or activities associated with particular institutions. In school, the dominating activity is learning, although learning can be organised in many different ways in the actual activity settings. In the family, the dominating activity is the upbringing of children according to societal and parental ideas about what would be a good life (for their child), but again, different values about a good life exist and thus different motives and different ways of organising family life.

Within the institutional setting, the institutional motives are experienced by the individuals as demands (Hedegaard, 2014). Furthermore, institutional settings and their demands are not isolated from each other. Experiences of demands in school migrate into the family activity settings as activities (e.g. homework) or conflicts (e.g. about how to spend time, when to get up in the morning). Similarly, ideas and values from the family setting can also affect how the child experiences and participates in activity settings in school (Hedegaard, 2009).

Children and adults develop motive orientations from the wholeness of their social situation, the demands and their engagement in activities within the setting. Thus, engaged participation is prerequisite for development of personal motive orientations that corresponds with the institutional motives. However, as the child or adult develops his motives, he engages and participates differently in the activity settings and begins placing new demands on other children and adults. The developmental change is in the person as well as the environment.

1.2 Motives and imagination
Cultural-historical conceptualization of learning and development aim to capture the unity of the person and the environment. The concepts of value position, motives and demands drawn from Hedegaard’s
theories of child development have been a central inspiration in my explorations of development and learning of children and youth with disabilities in an approach that incorporates the unity of biologically based impairments and motivated social agency. In this article, the conceptual tools from Hedegaard will be further developed in order to understand the role of future imagination in the motivated social agency of persons. Vadeboncoeur & Vellos (2016), drawing on Green (2008), writes how imagination allows human beings to release a different state of things, to open the windows of consciousness to what might be and what ought to be. To further understand the role of imagination, take Vygotsky’s idea that parents impose meaning on infant’s actions, even before and beyond what the infant had possibly intended at first (Vygotsky 1987). However, by imagining what could be the meaning of the infant’s act, the possibility for the potential to become reality is increased. The movement of the arm is interpreted as reaching and the parent acts accordingly, giving the child the object the arm is moved towards. The imagination about the intentions and potentials of the other person directs the activity of the partner, directs the parents’ activity. In the analysis, I will explore how imagination and development of motives – what ought to be – is related in the activity of the participating parents and young persons.

2.1 Development with disability: Young people with severe cerebral palsy at the beginning of the 21st century

2.1.1 Disability and development

Across different types of impairment, the research focus is often to describe and understand the problem and challenges associated with special needs or impairments. From the cultural-historical tradition perspective, the often problematic development of children with disabilities arises and develops from an incongruence between the natural line and the cultural line of development (Vygotsky, 1993). Many age- and context-typical activities are less relevant and supportive for a child with disabilities. The developmental potential of activities with more competent others and the mediation with tools and procedures in mainstream activity settings implies particular motor, cognitive, perceptual and communicational capacities in the participating children. Thus, the primary biological defects (such as sensory, organic or neurological impairments) affect the ability of the child to participate in social activities, including learning activities. Typical activities might be beyond the child’s zone of proximal development. The cultural-historical institutionalized mediation in mainstream settings do not support and accommodate the development of children with atypical psychophysical constitutions the same way they do with children without impairments. The question of this article is therefore how to create relevant and supportive developmental conditions for children and youth with disabilities.
2.1.2 The study
Eight young people between 15 and 25 years of age participated in the study. The study design consisted of two waves of in-depth interviews with the young participants and their parents, separately. Jonathan, Emilia and Freya communicated by a gaze- or manually-controlled voice-output device. Susan and Frederick communicated with low-technological communication aid’s such as books or tables. Sarah, William and Magnus communicated with their dysarthric natural (verbal) language that was translated by their teacher or personal assistant. The interviews were individually tailored to accommodate the communicational preferences of each participant. Susan and Frederick found the interview situation too cognitively or emotionally demanding and interviews were substituted with discussions about their communication with their pedagogues and their pedagogue and language therapist instead. Susan participated actively in this discussion.

The first wave of interviews focused on current communication preferences and the life history of the young person and the family. The second set of interviews were shorter follow-up interviews a year later. The analysis presented in this chapter focuses on how parents and the young people themselves actively tried to shape their developmental conditions.

References in parentheses refers to statements numbers in the interview material.

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Insert table 1 about here
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All participants had severe cerebral palsy due to a brain lesion sustained at birth or the time around birth and were wheelchair users. Due to the severity of the brain insult, the parents became aware of their child’s disability early on, even though several of them only discovered the communication impairment when their child failed to develop verbal language at the time typically developing children start to talk. The study did not include a formal psychological assessment. Drawing from their life history and current social situation, the participants ranged from age-equivalent cognitive and emotional development to participants with a history of learning disabilities (e.g. difficulties learning to read) and delays in social-emotional development.

2.1.3 Institutional opportunities and trajectories
The study is set in a Danish context. Societal value positions are guided by the Salamanca declaration and societal value positions about inclusion (http://static.uvm.dk/Publikationer/1997/salamanca.pdf). Furthermore, the welfare system and the municipal service are guided by an obligation to ensure families
with children with disabilities and people with disabilities have equal opportunities for social participation (for example legalization on social service no. 369 from April 18th 2017 https://www.retsinformation.dk/Forms/R0710.aspx?id=191895). Schools as well as power wheelchairs, communication devices and other necessary aids along with professional support are provided free of cost as part of the welfare system, according to the child’s needs. However, it is an ongoing debate whether children actually receive what they need and are entitled to because municipal budgets for disability support are being cut. Participants came from different parts of Denmark and thus from different municipalities which offered different sets of kindergarten and schools at their local level. Furthermore, the Danish (and Nordic) welfare system offers a system of user-managed personal assistants. Families may apply for assistants at home that also accompanies the child in for example leisure activities. Adults with disabilities, who are able to plan and direct their own life, may apply for around-the-clock user-managed personal assistants.

Due to the severity of the participant’s disabilities, the incongruence between the children’s competences and demands in mainstream nursery and kindergarten activity settings had been salient in all cases from early on (Jonathan parents 12+36-41; Emilia parents, 10; Frederick parents, 4; Freya parents, 27; William parent, 103). The families had been offered accommodated or alternative settings, depending on the child’s particular impairments and level of competences, and the existing institutional possibilities in their municipal area. Some of the families found that the offer was in congruence with the needs their child had regarding accessibility, support of alternative communication, and relevant and supportive activities with peers (Emilia parent, 14+31; Freya parents, 29). The parents of Jonathan were quite satisfied with the kindergarten itself, but found the long hours for transportation had a negative impact on their son. However, as no local, suitable kindergarten were available, they saw no alternative but accept the long hours (Jonathan, parents, 50-64). The parents of Susan were not satisfied with the kindergarten offered at first and initiated their own search for what they considered to be a more suitable practice, by widening the search to neighbouring municipalities. Their own municipality accepted to cover the additional expense of the daily transportation in bus or taxi (Susan parents, 14-18).

When the children approached school age, once more it was evident that none of the children would be able to go to the local school, at least not without a set of adaptations. Often, the institutional choice was between the nearest special school and the nearest mainstream school assessable for students with motor impairments. Depending on the child’s geographical location, a third in-between opportunity could be a mainstream school with self-contained classes with special teachers and physiotherapy at the school. Susan, Sarah, William, Jonathan and Magnus had attended this type of school: The parents of Jonathan had
not been satisfied with the municipality’s offer of a special school and had found a mainstream school with self-contained classes in the neighbouring municipality on their own (Jonathan, parents, 68-90). William’s parents had sought out a school with self-contained classes by themselves, while he was still in kindergarten, bought a site in the area and built a house (William parent, 95-101).

Thus, the set of cases reveals that when mainstream developmental trajectories are unsuitable due to the incongruence, the Danish society has a set of alternative trajectories, parents are either offered or can demand. Societal value positions of inclusion and the obligation to provide tailored support to enable the child to participate in social settings are reified in sets of institutional opportunities and trajectories. The particular choice will depend on geographical availability and how the child’s developmental needs is evaluated by the parents and professionals.

2.1.4 Parent’s development of motives in relation to their children

Along with the usual demands of a child for food, care and contact, all parents in the study experienced an additional set of demands associated with their child with disability. Several of them had moved or refurbished their current home to accommodate their child’s need for more space for a wheelchair and aid’s in the bathroom (Jonathan parents, 20-22; Freya parents, 12; William parent, 95). In several of the families, at least one of the parents had worked part-time since the birth of the child with disability and attributed this choice to the child’s disability (Jonathan parents, 17; Susan parents, 215; Freya parents, 25).

Particular impairments had also functioned as demands for parents:

Emilia’s mother: When she was little, we thought or quickly realized that she would not be able to talk. And we realized, we agreed that we had to come up with some signs to enable her to communicate, because we could tell she had it [language] in her head and she wanted to express herself and give her opinion, also when she was quite small. And then we decided together with her that ‘yes’ would be like this and ‘no’ would be like this (Emilia parent, 19).

Furthermore, parents had experienced a demand to orient themselves in and choose a suitable kindergarten and school for their child as described in the previous section rather than just placing their child in the nearest local unit.

However, demands from the disability is not neutral, but are translated by parents into particular motive orientations. Across cases, the parent’s choices were based in their general motive: To do everything possible to support their child, to ensure that their child is given the opportunity to realise it’s potentials, despite the congenital impairments (Jonathan parents, 80; Frederick parents, 14-18; William parent, 233; Emilia parent, 83; Freya parent, 149-151). In their efforts to create the best possible developmental
opportunities for their child, the concrete expression of this dominating motive varied from family to family, depending on how the parents choose to negotiate the incongruence between their child with disability and possibilities within societal institutional developmental trajectories. For some of the parents, their main effort has been aimed at how to ensure their child’s ability to live a life as close to how children without disability in Denmark live their lives: For example, the mother of Emilia expresses that “our attitude towards youth education is that she should have a life as close to mainstream youth life as possible. Because that’s what she has been used to all along” (Emilia parent, 95). This motive has permeated all efforts and decisions of Emilia’s parents. The parents of Jonathan, Susan and Freya describe similar motives and subsequent efforts they have made to enable their child to participate in mainstream settings as much as possible (Jonathan parents, 80-87; Susan parents 347-348; Freya parents, 33-39).

Frederick’s parents translated the demands from their child’s impairments in a different way. They chose to exploit the legalisation that entitles parents to conduct intensive home training for their child including hiring paid helpers. From 4½ until Frederick was 12 years of age, his parents conducted intensive home training according to the Dohman method. This involved all of their son’s waking hours and all days of the week (Frederick parents, 4-9). The Dohmann method is based on behaviorist principles (Dohman, 1974) and offers a highly structured and demanding environment for the child as well as the parent’s and trainers who must adhere to the training program at all times. Thus, the life of Frederick from when he was 4 to 12 years was in many ways very different from the life of typical children at that age in Denmark and from the life of the other children in the study. However, when focusing on the motives rather than the activities, the differences diminish. The hope and imagined future of the parents was that the intensive training would improve the functional level of their son especially in regard of motor functioning and in the future enable him to participate in mainstream settings (Frederick parents, 14).

Taken together, parents develop motives from (a) societal ideas about life for children in general and life for children and youth with severe disabilities reified in socio-cultural opportunities and trajectories and (b) from how they perceive their child’s needs as demands. Early demands were also based in their particular impairments and interpreted in relation to their motives about a good life for their child: To give the child the opportunity to realise it’s potentials’ and inclusion as far as possible.

2.1.5 Negotiating incongruence
The choice of school was based on broad ideas about what type of learning environment would best accommodate the child, among the geographically possible opportunities. However, more adaptations and
tailored support was necessary to ensure the active participation of the children in the study due to their severe motor impairments and lack of or impaired natural language. The incongruence between the children’s capacities and the demands of their different activity setting called for further negotiations. A recurrent theme for all participants had been to develop an efficient communication system. All had tried different systems of AAC such as systematic communication books with symbol systems or manual or gaze-controlled voice output systems with varying success. And even when the AAC system was successful, further accommodation was necessary, as explained by Freya:

During class, I raise my hand, the teacher picks me and gives me time to write my answer, while the teacher let some of the others answer the question. Then I have enough time to write my answer and don’t get stressed out (Freya, 27).

This accommodation within the activity setting circumvents the challenge associated with most aided communication, included communication with the Tobii voice-output system, of the device being slower that natural speech. Emilia describes a similar practice at her high school (Emilia, 31).

Not all specialized settings were equally successful in overcoming the incongruence. Frederick had attended a special school. The school had the stated aim to support development of communication for its students. This was in line with the dominating motive of his parents who by that time had given up on improving his motor functioning. However, despite many different approaches, the professionals at the special school were never successful in finding an AAC solution for Frederick. The situation of not being able to communicate independently (being dependent on others to ask (the right) questions that only requires yes or no) maintained or even increased the incongruence for a young person as Frederick in relation to societal demands to develop independence from one’s parents. Moving away from his parents became extremely stressful for him because of his dependence on people who could guess his needs and take action accordingly (Frederick parents, 76-78).

Another aspect of negotiation of incongruence is that the established local congruence needs to be continually maintained by the parents:

Freya’s mother: Now, Monday, they are going on a trip and I had to ask; Have you checked that the bus is accommodated to a wheelchair? And nobody knew and they asked around, and it turned out it had been a free trip and they just didn’t know. And I just have to say; well it’s nice that the trip is free but you need to remember you have a student in a wheelchair. […] All the time, and all these years, I have had to follow up on everything, because otherwise, it is Freya who pays the price (Freya parents, 121-123).
Even within institutionalized trajectories for children with severe disabilities, the parents still experience a call for ongoing maintenance and re-negotiations of the actual activity settings, according to the parent’s motives. The persistent incongruence from the social developmental situation demands the parents to be ongoing demanding on behalf of their child towards the activity settings and the professionals.

2.1.6 Breaking new ground in the cultural-historical setting
In several instances, the parents had found the established set of opportunities inadequate. They had had to go beyond the current institutionalised possibilities in order to realise the motives and imagined futures they held for their child or young person. The first example is in regard to AAC technologies. The municipalities offer communication solutions and support, both directly to the families and for kindergartens and schools. However, the parents of William, Jonathan and Emilia all went beyond the standardised offers of their municipality and sought out new types of communication technologies by attending trade fairs for rehabilitation. At the trade fairs they encountered the (at that time) cutting-edge Tobii computer technology controlled by gaze and immediately imagined it as a great opportunity for children. However, the (expensive) Tobii technology was not part of the municipal offer and overall considered unsuitable for people with cerebral palsy:

Jonathan’s mother: They didn’t think it [the Tobii] was for him. […] We were in a meeting and I could almost hear where the conversation were headed. That they thought he should try out the whole lot of [communication] books first. The direction we suggested was wrong, he should try in a different direction. They were quite certain, this [the Tobii] was not for him. Then I said; We can let him try, that’s the least we can do.

[…]

Jonathan’s father: So, she came home to us and set up the equipment [the Tobii]. Then Jonathan came home from school and were introduced. And then he was supposed to try out a few things.

Jonathan’s mother: And he started with ‘memory’. Six pieces and he managed that one right away. Then we stood there and talked a bit and while we did that, he had chosen a bigger one, one with sixty pieces, by himself. After five minutes he had solved that one too.

Jonathan’s father: Then she said, how old are you, Jonathan? And he looked at her, 12 years! You should have such a computer, she said (Jonathan parents, 215-237).

Afterwards, the parents had struggled to get the municipality to fund a Tobii computer for their child, before finally succeeding. Thus the current communicational function of Jonathan was founded by his
parent’s exploration of technological opportunities, their ability to imagine how it would work with their son and their negotiations with the municipality, resulting in their active creation of a new developmental opportunity within the municipal service offer. The parents of Emilia and William relate similar experiences of struggling to expand the municipal service with the Tobii technology (Emilia parent, 39-43; William parent, 66-69). In contrast, the parents of Freya, the youngest participant with a Tobii in the study, had not had to struggle. In the few years since the parents of Emilia, Jonathan and Sebastian had their struggles breaking new ground, the Tobii had become part of the municipal service offer (across different municipalities) and Freya had her Tobii for communication and school work from school start (Freya parents, 67-75).

Another example of parents creating new trajectoral opportunities regards Emilia. The educational trajectory after mandatory school for young people with severe cerebral palsy in Denmark contains two main possibilities. In 2007, a new legalisation entitled youth with disabilities, who are unable to partake in mainstream high school education, to three years of specialised youth education. This educational trajectory was followed by William, Frederick, Sarah and Jonathan. The other possibility is mainstream high school. However, the typical mainstream trajectory for young people with moderate or severe cerebral palsy is to take their high school exam as single subjects at an adult education centre, due to learning problems or fatigue problems that makes mainstream three-year high school unfeasible. The solution with single subjects means the young person spends many years to finish and forego the experience of belonging to a regular classroom of peers. As described earlier, Emilia and her parents had the dominating motive that Emilia should have a life as similar to typically developing youth as possible. Both existing trajectories for youth education were incommensurable with this motive. Instead, the family imagined that Emilia should attend a local mainstream high school, but in an accommodated way with less subjects per year and five years to finish instead of three. This solution would enable her to participate in the social life of a typical high school student, while accommodating her in her need for extra time due to her more strenuous work processes. The negotiations associated with turning this idea into reality required work breaking new ground as this solution had no precedent in Denmark. First, the family had to apply to the ministry of education to get permission for Emilia to spend five years on her high school education. Next, the local education counsellor evaluated Emilia unsuitable for mainstream high school and recommended Emilia to apply at the adult education centre instead; the traditional, established solution. This made the head of the local high school reject Emilia’s application despite her having the required grades. Luckily, the town had two high schools and the head of the other high school accepted Emilia as a five-year student without further ado (Emilia parent, 85-93).
A third example of breaking new ground is William, who wished to attend a local specialised youth education unit specialized in teaching technical music production, but not in youth with severe motor impairments. Through his father’s negotiations, he was accepted at the education unit and thus able to follow his motive of becoming competent in technical music production, using the Tobii computer his parents had struggled for years earlier, for his school work (William parent, 219-223).

2.1.7 Crisis and moral imagination
What sets parents off in their struggles for one particular institutional setting and trajectory or in the creation of new opportunities? At times, institutional opportunities and demands are imagined as incommensurable with the type of opportunities, trajectory and future, parents imagine would be right for their children. Jonathan’s parents found that the local specialized youth education unit offered by the municipality in the first place was far from what they thought would accommodate Jonathan’s need for demands and support:

Jonathan’s father: I visited the place. It was an old school building they had converted to a specialized youth education unit. I was really negative, when I came home.

Interviewer: Why?

Jonathan’s mother: There were stairs everywhere.

Jonathan’s father: It was on the first floor. And there were stairs. The bathroom was downstairs and no guarding on the stairs. We could just image him in his wheelchair, going over the top...

Jonathan’s mother: There was no physiotherapy at the school, he would have to go by bus to somewhere else. [...] And the teachers, they had no knowledge about communication at all. (Jonathan parents, 301-316)

The parents used their past experiences and imagined projections of Jonathan at the proposed municipal specialized youth education unit in the assessments or interpretations of the institutional demands and opportunities. The parent imagined a situation of developmental crisis, in which Jonathan’s current competences and motives were challenged by new demands for how to be a social participant and at the same time his motive for communication would not be met with suitable professional support. In a cultural-historical perspective, crisis as interruptions between old and new forms of social relations may fuel development as the child is confronted with tasks that challenge his or her existing ways of thinking and acting and place new demands on the child’s way of participating and development of new motives (Vygotsky, 1998). However, given Jonathan’s current functional motor level, going on stairs or becoming
efficient with a power wheelchair was not within his zone of proximal development. The parents imagined a situation of increased incongruence and incommensurable with the future they envisaged for Jonathan: To become able to live independently with user-managed helpers (Jonathan parents, 417).

*Imagining* and *imagination* was stressed above. To understand the role of imagination in development, I referred in section 1.2 to Vygotsky’s idea that parents impose meaning on infant’s actions, even before and beyond what the infant had possibly intended at first (Vygotsky 1987). By imagining what could be the potential of the person’s act, the possibility for the potential to become reality is increased: The gaze of the young Emilia was interpreted by her mother as communicative intent and by suggesting a system of communication, the mother realised the imposed meaning. Negotiating, struggling and breaking new ground is based in moral imagination. The motives can depart from imagination of future crises as in the example above of Jonathan and the municipal specialized youth education unit or experiences of present crises and incongruence (Frederick parents, 63-69). The example of Emilia going to mainstream high school is a second example of moral imagination. The parent’s struggles with allocating Tobii computers for Emilia, William and Jonathan is a third example from the study of how the participating parents imagined what could be and how things ought to be and acted upon it.

### 2.1.8 The building of relevant developmental support and socially relevant demands

The dominating motive of the parents is to realize the potential of their children and moral imagination is the main tool. Moral imagination takes place in a relationship. How does the moral imagination of parents develop their children in the social relation?

Frederick is a very interesting example of how moral imagination develop the person’s way of relating to the world. As mentioned earlier, Frederick had no way of communicating beyond yes/no with eye blink or sounds at the time of leaving compulsory school. According to the father, Frederick “lets one know it when there’s something he is unhappy about” (Frederick parents, 96). Frederick made demands by making loud noises that his parents and professionals were left to guess the meaning of. Similar to Jonathan, Frederick was offered a municipal specialised youth education unit, but his parents negotiated with the municipality and succeeded in getting the municipality to fund a more expensive unit in another municipality, organised as a boarding school. At that school, Frederick was introduced to communication with a communication book with a symbol system and a particular conversational structure that needed to be learned (Pragmatic Organized Dynamic Display, Porter, 2007). This new set of demands was much harder than what Frederick
had encountered in previous communicational situations. However, the demands were supplemented with a special type of support:

Frederick’s pedagogue: So, in the first long period, the young person is not required to express himself with the [communication] book. He only needs to absorb what you can use the book to express. [...] We are the guides and the moment they [the young students] show initiative to express something, or – I might also begin by saying “I wonder whether we together might learn what’s on your mind right now? Let’s try it out! Let’s go fishing in the book.” And if we don’t succeed in the first attempt, then it’s just: “Oh, this wasn’t what’s on your mind, I see, let’s go back to categories. Is it something with a person? An activity? Or is it dut dut dut?” [Refers to her pointing in the book]. And then, suddenly we hit it. And this mutual experience; together we discovered what you had on your mind, with this tool, it endows them with the drive to try it out themselves... (Frederick pedagogue, 16).

Rather than demanding an answer, the staff regarded themselves and other students with similar disabilities but more experienced as communicators as role models. The support in the situation - the professionals as role models - was not only to demonstrate the categories of the book and the conversational structure, but also to demonstrate the motive of the activity with the book; to express and share what was on the young person’s mind. During the mutual, but heavily supported, communication she managed to share her moral imagination with Frederick about him as someone who had something to contribute with in social relations. During the next couple of months, Frederick began to use the book to express not only statements about his immediate condition (e.g. being in pain or thirsty), but to make demands and contributions to the social setting in wholly new ways, for example by expressing that he wanted to buy a present for his sister at her birthday (Frederick pedagogue, 51). He became active in a garbage collecting and sorting project, joined the ‘men’s club’ at the school and began growing a beard as part of this (Frederick & pedagogue, 188). Frederick was becoming an active, contributing social participant. He developed his ability to make and express socially relevant demands and understand how he could contribute to particular activity settings. The new kind of demands reflected his more mature understanding of the social situations, their opportunities for him, and how he could shape the activity settings. Thus he was beginning to imagine himself as a social participant and take a stand regarding what type of social participant he would like to be.

Emilia, now in high school, imagines a future for herself as a scientist:

Emilia [email interview]: “In the future I dream about going to the university. Actually, I think it is not just a dream, it seems more and more realistic. It is still four years ahead, but I am thinking about it. I
would like to study science, but I am not sure what particular subject yet. [...] I hope I will be allowed to take my university degree in a flexible way” (Emilia, 52).

Jonathan imagines a future living for himself in his own flat with user-managed personal assistants (Jonathan, 48-54) and William imagines himself as a technical music producer (William, 653-660). Susan, a young woman with delayed social and emotional development, imagines herself in a future that includes one of her preferred activities horseback riding (Susan parents, 249). Sarah writes articles for the cerebral palsy user organization about chiropractic treatment, thus imagining herself as someone with experiences of interest for a wider social group of adults with cerebral palsy (Sarah, 354). In all these imaginations about themselves in a desired future, the young participants have developed motives and new competences through relevant zones of proximal development created or negotiated earlier by their parents and professionals, but increasingly also shaped by themselves. Despite their severe disabilities, all of the young participants had learned to make active and socially oriented demands in their social settings. They are learning and becoming skilled in understanding and negotiating opportunities in relation to life with severe disability.

3.1 Concluding remarks
The aim of this article has been to conceptualize how young people with severe disabilities can be supported in their development as social participants, understood as persons that have the ability to understand their social opportunities and make socially relevant demands. Hedegaard’s conceptual framework and her continual insistence on the centrality of motives in understanding human activity has been my guideline all along.

Parents develop their motives from both societal ideas about life for children in general and life for children and youth with severe disabilities, and from how they perceive their child’s needs. Parental values for a good life for their child was guided by the societal value position of inclusion, and ‘to give their child the opportunity to realise it’s potentials’. Moral imagination about the potentials of the other person directs the activity of the parents. Creating relevant and supportive developmental conditions for children and youth with disabilities hinges on the ability of parents and professionals to negotiate current institutional opportunities, including the ability to imagine developmental potential and possible incongruence that threatens the child’s developmental opportunities (See also Bjarnason, 2002). Moral imagination and reflections about a possible future for one’s child might not be singular for parents of children with disabilities. But I will argue that having a child with disability calls for a particular kind of moral imagination. The transition from kindergarten to school was for many of the families a matter of finding and choosing between different existing schools. Choosing required the ability to imagine what kind of kindergarten and
school that would be suitable for their child. In doing this, parents’ imaginations were shaped by societal offers, trajectories and technologies. However, several of the parents in the study imagined wholly new opportunities, imagined futures for their children that transgressed the existing institutionalised trajectories. But, despite their struggle and work breaking new ground, parents cannot build zones of proximal development for their children by themselves. Zones of proximal development are socially mediated. Parents often work indirectly by negotiating placement of their child in particular practices and activity settings.

One question is left regarding the role of professionals in moral imagination. The main example through the article has been parents’ imaginations. However, the example about Frederick in the last section came from a professional setting and regarded a pedagogue who used her professional knowledge and skills in moral imagination about Frederick as a contributing social participant. Unfortunately, another type of situation dominated in the material:

Freya’s mother: You have to struggle for all this something extra, because [for them] an aid is an aid, then you are compensated, because you have received an aid. But really, you want to optimize, talk about how it can become even better, right? (Freya parents, 81).

From the study, the question is left whether professionals and their institutional settings have the willingness to engage in moral imagination when building support and futures for children and young people with disabilities?

Last, but not least, I would like to raise attention to how the young people themselves navigate by taking over and mix parental motives and societal motives, and develop them into their own particular motives and interests. Their dominating motives are coloured by their disability as a life condition but still developed from the wholeness of their social situation, which includes friends, schoolwork, youth education, and other mainstream activities.

This work received funding from Aarhus University Research Foundation [Grant number xxx]

4.1 References


<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Current communication and transportation means</th>
<th>Social situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan</td>
<td>26</td>
<td>Communication board, some words, body language. Walks in low manual wheelchair.</td>
<td>Temporary living unit</td>
</tr>
<tr>
<td>Sarah</td>
<td>22</td>
<td>Helper translates verbal language, letter sheet for spelling. Power wheelchair.</td>
<td>Own flat with 24/7 helpers</td>
</tr>
<tr>
<td>William</td>
<td>21</td>
<td>Helper translates verbal language, yes/no with eyes. Manual wheelchair.</td>
<td>Own end of parents’ house, with 24/7 helpers. Specialized youth education.</td>
</tr>
<tr>
<td>Frederick</td>
<td>20</td>
<td>Yes/no with eyes, communication book. Manual wheelchair.</td>
<td>Specialized youth education at boarding school.</td>
</tr>
<tr>
<td>Jonathan</td>
<td>19</td>
<td>Gaze controlled voice-output system (Tobii), yes/no with eyes. Manual wheelchair.</td>
<td>Specialized youth education at boarding school.</td>
</tr>
<tr>
<td>Emilia</td>
<td>16</td>
<td>Gaze controlled voice-output system (Tobii), helper talks/elaborates, yes/no with eyes. Power wheelchair.</td>
<td>At home. Attends local high school with practical helpers</td>
</tr>
<tr>
<td>Freya</td>
<td>15</td>
<td>Hand and gaze controlled voice-output system (Tobii), iPad with communication program, yes/no with words/mimic. Power wheelchair.</td>
<td>At home. Attends local school with practical helper</td>
</tr>
<tr>
<td>Magnus</td>
<td>15</td>
<td>Helper/teacher translates verbal language, iPad with communication program. Power wheelchair.</td>
<td>At home. Attends local school, self-constrained special class.</td>
</tr>
</tbody>
</table>